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## Understanding The Experiences Of Saudi Arabian Mothers Of Children With Autism In The United States

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**UNDERSTANDING THE EXPERIENCES OF SAUDI ARABIAN MOTHERS OF  
CHILDREN WITH AUTISM IN THE UNITED STATES**

by

**BASMAH M. ALOTAIBI**

**DISSERTATION**

Submitted to the Graduate School

of Wayne State University,

Detroit, Michigan

in partial fulfillment of the requirements

for the degree of

**DOCTOR OF PHILOSOPHY**

2019

MAJOR: EDUCATION (Special Education)

Approved By:

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Advisor

Date

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## **DEDICATION**

I want to thank everyone who guided, encouraged, and supported me on this journey. I would not have achieved this goal without their help.

In particular, I am grateful to my father Maher Alotaibi, the person in my life who most strongly encouraged me to continue my studies. My siblings and I can easily recall many instances when he told us, “Without your degree, you are nothing.” My father patiently and consistently provided me with sound advice and a steady stream of encouragement. He also modeled for me what it is to be a learned person, as he has considerable knowledge on many topics. Without question, my father was and continues to be my best teacher.

To my lovely and great role model, my mom Noura Alhimyani. Throughout my life, I have learned from her to be patient in difficult situations. I am still learning so much from her especially now that I am rearing my own children. Without this firm foundation I would not be able to accomplish this work. I would also like to thank my siblings for their support and encouragement.

I am especially grateful to my husband Sultan. It was he who insisted that I earn my Ph.D. I remember him telling me, “Having a master’s degree is nothing without a Ph.D. A master’s degree is like a bridge between your bachelor’s degree and your Ph.D.” Because of his support and love, I was able to pursue this goal. To my lovely, friendly, and happy daughters Juman and Saja who are part of me. Every vein and bone in you are mine. You are my breath in this life. Even when you grow up, you will still be my children. You have made the experiences of mothering precious to me and an inspiration to me.

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## CHAPTER 1: INTRODUCTION

In 2007, I had a surprising experience that planted the seed for this research. At the time, I worked as an assistant teacher in a center for students with Down Syndrome. One day, I overheard one of our teachers talking with the mother of one of our students, who, like me, was from Saudi Arabia. The teacher focused her conversation on how the student was progressing in her learning and in developing her skills. The teacher urged the mother to continue to work with her daughter at home, as that would strengthen the lessons the little girl learned at the center. She said that learning could be best achieved if the mother worked in tandem with the school to help her child.

The mother's answer stunned me. She told the teacher that she felt that there was no point in working with her daughter at home. Her daughter had Down Syndrome, a disability for which there is no cure. She reasoned that the disability meant that her daughter was incapable of learning or improving. Of course, I did not agree with this position, nor did the teacher. No special education professional would. There are volumes of research that argue most convincingly that children with Down Syndrome can most definitely learn and improve. But it was striking to me that this mother was so hopeless about her daughter's learning.

I began to wonder why this mother felt as she did. Did she come to this conclusion about Down Syndrome from her own experiences trying to teach the child? Had she become perhaps hopeless because of what others had said to her – her husband, family, and friends? Might her cultural beliefs have shaped her attitudes, and if so, how? These are the nagging questions that have troubled me for these ten years since I overheard that conversation. Even though my particular interests are in working with children with Autism Spectrum Disorders, not Down Syndrome, you

will see in the pages that follow that overhearing this conversation foreshadowed and motivated my research.

### **The Researcher's Cultural Lens**

Each of us was born at a particular time, comes from a particular place, and has had a particular set of experiences that shape our values and beliefs. Combined, these create the cultural lens through which we enter the research field. My cultural lens sparked my interest in this topic, enabled me to ask my participants specific questions about their experiences, and shaped my understanding of the data.

I was raised in the city of Jeddah, located in Saudi Arabia's Red Sea coastal plain. Jeddah is the principal gateway to Mecca, Islam's holiest city, which able-bodied Muslims are required to visit at least once in their lifetime. It is also a gateway to Medina, the second holiest place in Islam. Because I am a practicing Muslim, I consider growing up where I did to be a great privilege. It made me feel that I was living in the heart of Islam.

Both of my parents are living and are married to one another. They continue to live in Jeddah. I have two sisters and three brothers, and I am the second eldest among them. I grew up around a large extended family. We would often gather with aunts, uncles, and cousins for celebrations and other events. I consider my childhood to have been a happy one because I was continually surrounded by the love of my parents, siblings, aunts, uncles, and cousins.

I have always been attracted to higher learning. I believe this is because my father is a great admirer of education. It was he who was most supportive of my decision to continue my education outside of Saudi Arabia. In 2008, I came to the United States for the first time to study English in State College, Pennsylvania, the home of Penn State University. In 2010, I moved to Muncie,

Indiana where I received a master's degree from Ball State University in 2011. After I graduated from Ball State, my husband and I were married in Saudi Arabia. Like me, my husband is also a Saudi Arabian. Together, we returned to the United States for his job. For seven years, we lived in Northern Virginia, in a suburban community near Washington, D.C. Together, we are raising four children – my two stepsons, who are teenagers, and our two daughters who are six and two. Currently, I am a Ph.D. candidate at Wayne State University, on a scholarship from my university in Saudi Arabia.

Living between the two cultures of Saudi Arabia and the United States has added a great deal to my experiences as a student, mother, and wife. I believe that coming to the United States has made me stronger and more independent than I was before. I am quite certain that if I had remained in Saudi Arabia, I would not be the woman I am today.

Both of my daughters were born in the United States. When we lived in Virginia, raising them without any help from extended family or nannies had its challenges, but I enjoyed my time with them immensely. I believe that if I had had help from others, as I would have in Saudi Arabia, I would not have enjoyed so many beautiful moments with them. I also suspect that I would have been less able to understand their needs and demands. Being responsible for my daughter's care so often by myself made me think about and even worry about them more than I would have otherwise. I also found that I missed them more whenever I was out of the house. I like to play, read, and talk with them whenever I can.

There is no doubt in my mind that my mothering framework changed when I came to live in the United States. Back in Saudi Arabia, I would have had more frequent in-person support available from my family. I suspect that I would have been willing to leave my children with my

mother and others to go out and do other things. Before I had children, I assumed that this would be my mothering experience. Because of our experience of living in the United States, I now want to be the one who cares for my daughters as much as possible. I believe that the intensity of my experience mothering my daughters has increased my capacity for loving them. It has also increased their attachment to me. They want me to be the one who cares for them. Today, I believe that as a mother, there is no substitute for spending time by yourself caring for your children.

Fortunately, I continue to remain close to my extended family. My extended family still provides support for my mothering, even when it is long distance. I speak to my mother and sisters every day or every other day. I feel their influence in my life every day. Without their support, I do not believe that I would have been able to continue my studies. It is a great feeling whenever I hear them say, “We are proud of you because you are a mother and student who sacrificed herself to achieve her dream.” I genuinely believe that my family admires what I am doing and all that I have achieved. Without their praise and encouragement, I would feel lost.

At times, I have felt that the stress of my studies and other responsibilities was too much for me to bear alone. When this has happened, my mother helped to lighten my load. She came to the United States for short visits to stay with me and to help with childcare. This meant so much to me because I trusted my mother more than I would have trusted anyone else. I knew that my mother would treat my children and take care of them as I would. This gave me the relief I needed along with great peace of mind. I have seen how much my mother loves both of my daughters. She continues to be a blessing to all of us, and especially to me as my mothering journey has included the ambitious goal of doctoral studies. Without this kind of support, I do not know how any mother of two such young children would be able to take on a gargantuan and daunting task such as this.

I am very grateful that my husband and I lived in a new culture when we were first married, where we could grow our relationship without the influence of our family and friends. I have some definite beliefs about gender roles. I firmly believe that men and women should share household responsibilities such as cleaning and cooking, as well as childcare responsibilities, which is common in the United States. Living so far away from my parents, siblings, and friends, I learned that whenever I must face any obstacle or challenge, I must face it and solve it by myself. I also believe that my husband and I have a stronger relationship because of our time in the United States. My spouse is my friend, my family, and the only person whom I felt I could trust 100% while living so far from home. Had we married and stayed in Saudi Arabia, our experience of and knowledge about marriage would be different. In all likelihood, we would not be as close as we are.

I also believe that living in the United States with my husband has influenced my mothering experience. When I needed to be away from our girls for a doctor's appointment or to study, my husband was most often the one who stayed with them. In Saudi Arabia, it would have been more likely that I would have had a nanny or that my mother or sisters would have watched them. Childcare in Saudi Arabia is more often the responsibility of women, not men. I also had to learn to trust my husband to be alone with our girls. This trust has deepened our marital relationship. I believe that my husband's relationship with each of our daughters is much closer than it might have been in Saudi Arabia. As I have found out, he, too, has learned that there is no substitute for spending time alone caring for your children. My husband and I share this bond, which has made me feel that I am co-parenting with my husband, not parenting alone, as I suspect many Saudi Arabian mothers do.

My expectations of myself are many. As a student, I expect to complete my degree and from there, to continue to improve myself by participating in ongoing training sessions and conferences. Ultimately, my educational goal is to gain the Applied Behavior Analysis (ABA) certification so that I am able to work directly with children with ASD. As a mother, my goal is to raise my children so that they can achieve their full potential. As a wife, my goal is to support my husband and to create a happy life with him. Someday, as a lecturer at a university, perhaps here in Saudi Arabia, my goal is to teach my students the lessons I learned in my years living in the United States.

Professionally, I am particularly interested in mothers of children with autism. My children do not have autism. However, my interest in this subject is based on my own experience as a mother. I know that mothers in Saudi Arabia are usually the primary caretakers for their children. I believe that if we offer mothers extensive programs and training about their children's disabilities, they will be in the best position possible to help their children to improve developmentally. Once I have completed my degree and certification, it is my dream to open my own center to help mothers of children with autism. In my center, I will provide training programs and other support for mothers. As you can see, I have a passion and dream to help mothers of children with autism.

Below, I provided some of the assumptions and beliefs that I hold. I know that I must own my assumptions and keep them in mind as I collected and interpreted my data.

1. Being a Mother and a Good Mother

- Being a mother is a great feeling that every mother may have.

- Mothers like to have their children near them at all stages of their lives. When the children become adults and have their own families, the grandparents want to have their children and grandchildren around them. These are happy moments.
- To me, a mother is the candle of the house; without her, there is no stability.
- She is the school of ethics, love, loyalty, and symbol of tenderness.
- She is the foundation of affection and love in the house. Without her, the house is nothing.
- She is the greatest homeland and the most honest human.
- She is self-sacrificing. She gives and offers true love, which is granted without charge and gives without limits.
- Mothers are responsible for taking care of their children. Their children must come first and should be their priority.
- I have seen many ideal mothers who are working hard with their children mentally, physically, and educationally to improve their skills, knowledge, and teach them good ethics. As a result, these children succeed, and they have great personal abilities. These children are competent, and they can deal with different matters in their lives.
- When a mother spends all of her time with her children, it is selfless, because she does not have time to do things on her own. It is also important for mothers to have their own time to relax without caring for their children.
- Mothers create different activities with their children to help them be creative.
- Mothers need to play with, read to and listen to children, especially in the early ages.
- Mothers can help their children to talk more instead of telling them to stop and be quiet.

- If mothers show appropriate behaviors in front of their children, their children will imitate that. For example, if a mother talks nicely and does not scream all the time, her kids will do the same.

## 2. All Mothers of Children with ASD

- Mothers have to advocate and improve themselves to find the best education for their children with ASD.
- Mothers have to work hard to improve the development of their children with ASD.
- Mothers have to accept their children with ASD and be patient as they wait for improvement. Children with ASD need time to improve.
- Mothers have to be strong.
- Mothers can have free time for themselves.
- Mothers can improve themselves by attending different sessions and training about autism.

## 3. Saudi Arabian Mothers in Saudi Arabia

- In middle-class families, mothers are the primary people who take care of their children. Few fathers are involved in parenting.
- Some Saudi Arabian mothers are employed in different professions in the morning, and in the afternoon, they are mothers who cook and teach their kids. In some cases, they might also do housework duties if they do not have nannies.
- Some Saudi mothers like their children to be the best and succeed.
- Some Saudi mothers depend on nannies to take care of their children.

- Some Saudi mothers prefer to spend their time away from home, rather than caring for their children.
- Some Saudi mothers worry a great deal about how people view their children, what people might say and how people might judge them. "What people say about us" is a phrase that is well-known among Saudi Arabian mothers.
- Some Saudi mothers provide their children with devices to play with because they do not want the children to make noise.

#### 4. Saudi Arabian Mothers in the United States

- Some can manage their lives without any help from others, and they are happy to do so.
- Some enjoy every moment with their kids because they have no family in the U.S that make them feel stress.
- Some of their relationships with their husbands become strong.
- Some fathers care for the children while mothers go doctor's appointments, run errands or socialize with their friends.

#### 5. Muslim Saudi Arabians

- As in any religion, being a Muslim in Saudi Arabia may or may not mean that a person has strong values and morals.
- Not all Muslim Saudi Arabians are religious. Some might not practice Islam. For instance, they might not do their prayers every day.
- Some Muslim Saudi Arabians are brave and have good morals. People can depend on them for help.

- Some Muslim Saudi Arabians might lie, and say things that are not real or true.
- Some prefer to be at home with their families and children. When they travel, they do so with their families. Others prefer to spend most of their time traveling and socializing with friends.

#### 6. Disability and Mothering

- Disability does not prevent mothers from practicing mothering. In fact, mothering is a weapon against disability.
- Having a healthy child is not a condition of feeling mothering.
- There are many examples of mothers who struggled with their disabled children. As a result, these ideal mothers achieved their meaning and collected gifts that God gave to them. They brought out a person who may have a disability but has a soul that is clear and honest. These children have more lessons to teach us than a thousand healthy people.
- Disability is not a punishment from Allah. It is a message from Allah that you have been chosen to be a mother of a child with a disability because you have the power, will, and determination,
- People with disabilities have the right to education, to health, and to live their lives as other typical people live.
- People have to focus on what people with disabilities can do instead of judging them on their impairments.

## 7. Marital Quality

- To ensure the quality of marriage, I believe that couples should come from similar education levels and socioeconomic class.
- Marriage quality is measured by the quality of individuals.
- I believe that in marriages, there are sometimes ups and downs in the relationship.
- Some people are happy with their marriages; others are not.
- Some have a conflict with their spouse most of the time. They are not satisfied. They are willing to live their lives with this conflict because of their children.
- One way to keep marital quality between couples is to find ways to renew the marital relationships
- It is essential to talk to each other after a big fight or conflict. It is the best way to get over feeling frustrated or exhausted.

## **Background**

**Overview of Autism Spectrum Disorders (ASD).** As of now, the cause of ASD is unknown. However, ASD may occur because of genetic factors or the environment (Luciano, 2016). Children with autism are usually diagnosed in the first three years, and the disorder is life-long (Hussein et al., 2011). Some diagnosed children have other developmental challenges such as intellectual disabilities, or they may suffer from seizures (Hussein et al., 2011). The most common manifestations of autism are a lack of socializing with others, a lack of communication and repetitive behaviors (Altiere & Von Kluge, 2009; Hussein et al., 2011; Luciano, 2016) For example, many children with ASD like to play with preferred objects, and they often like to move

objects and their bodies in a certain way. They can be resistant to change in their routines. Children with ASD are often more sensitive than typical children are to sound, touch, or food.

ASD is not so much a disability as a set of disabilities that fall under one umbrella. According to Hussein, Taha, and Almanasef (2011), ASD are “complex neurodevelopmental disorders” (p. 1). Luciano (2016) states that this set of disabilities includes different kinds of disorders such as “autistic disorder, Asperger disorder, childhood disintegrative disorder, and pervasive developmental disorder (not otherwise specified)” (p. 14). All of these developmental disorders are described in the *Diagnostic and Statistical Manual of Mental Disorders*, 5th edition (*DSM-V*) (Luciano, 2016).

**Incidence of ASD in Arab nations and other developed nations.** There are no clear data on the rate of autism in Arab nations (Hussein & Taha, 2013). Yazbak (2004) reports that autism has been increasing steadily in Saudi Arabia. In 2002, 42,500 Saudi Arabian children had been diagnosed with ASD, Yazbak says, an increase over previous years. According to Al-Salehi, Al-Hifthy, and Ghaziuddin (2009), that means that for every 10,000 children in Saudi Arabia, 18 children have been diagnosed with ASD. According to recent data, the incidence rate for autism among Saudi Arabian children is 1.8 per 1,000 — approximately the same as that of most European countries (Ness & Chia-ling, 2013). In contrast, the prevalence of ASD in the United States is much higher. According to Ness and Chia-ling, “Recent estimates show that one out of every 100 infants [in the United States] will show symptoms of autism.” (p. 34). Recent studies in other developed nations suggest that ASD occurs in only 13 cases per 10,000 children (Fombonne, 2005).

Diagnoses of children with ASD seem particularly on the rise when the parents are from a higher socioeconomic class and when they are more highly educated. It may be that such parents are more likely to seek early diagnosis, to use different means of evaluation, and to secure better resources and services for themselves and their children. As well, such parents may be more concerned about their children's atypical behaviors (Thomas, Zahorodny, Peng, Kim, Jani, Halperin, & Brimacombe, 2012). Conversely, parents who have lower incomes and who are less educated may have children diagnosed with ASD less often. This does not necessarily mean that the children do not have ASD nor does it mean that these parents are less concerned about the well-being of their children. Such parents may be less concerned about atypical behaviors in their children in comparison to other family factors. Such parents may be less likely to seek a diagnosis due to lack of resources or access to professional evaluation (Thomas et al., 2012).

**Saudi Arabia.** The kingdom of Saudi Arabia (SA) was established in 1932 by King Abdulaziz Al-Saud. The country is called *Saudi* because of the king's last name was Saud. Saudi Arabia occupies the largest part of the Arabian Peninsula. It is surrounded by other Arab countries such as Jordan, Kuwait, and Iraq in the north; the Persian Gulf, Qatar, and United Arab Emirate in the east; Yemen and Oman in the south; and the Red Sea in the west (Long, 2005). Saudi Arabia is the most important place on earth for Muslims because there are two holy mosques there, Mecca and Al-Medina (Long, 2005). Muslim people come from all over the world to visit Saudi Arabia and to go on pilgrimages. According to Saudi Arabian government statistics, the total population in Saudi Arabia is 31,742,308 people in 2016 (Stats.gov). The official language of Saudi Arabia is Arabic. Most Saudi Arabian citizens are ethnically Arab (Long, 2005).

**Religion in Saudi Arabia.** Saudi Arabia is an Islamic country. In Islamic doctrine, every Muslim must believe in and worship Allah. There are five pillars of the Islamic religion. The first pillar is comprised of two tenants: to believe and say that there is only one Allah (God) and to believe that the prophet Mohammad (peace be upon him, hereafter noted as pbuh) is the messenger of Allah. The second pillar is that every Muslim must pray in specific ways five times every day. The third pillar, regarding almsgiving, is “to pay 2.5% of the wealth annually for the benefit of the needy in the Muslim community” (Al-Shahri, 2002.p134). The fourth pillar, fasting, requires Muslims not to eat or drink after sunrise and after sunset during the month of Ramadan, which occurs annually in the ninth month in the Hijri calendar. The fifth pillar, pilgrimage (Hajj), requires Muslim people who are able to, to go to Mecca (the holy city) to perform a religious duty at least once in their lifetime (Al-Shahri, 2002).

Two primary texts guide Muslim people: Al-Quran Kareem, considered to be the holy book from Allah, and Al-Sunna, the supplication from the prophet Mohammed (pbuh) (Al-Shahri, 2002; Long, 2005). Al-Quran teaches every Muslim “moral and ethical guidance and values that human beings are supposed to apply in their personal and public lives, individually and communally” (Long, 2005, p. 19). Al-Sunna presents speeches by the prophet Mohammed (pbuh). It provides explanations and clarifications about specific Muslim sayings, deeds, worships, and practices (Al-Shahri, 2002).

A Muslim mother who lives her life according to the Al-Quran and the Al-Sunna would espouse to and teach to her children the moral and ethical values that the holy books teach. For instance, such a mother would not lie, cheat, or have a bad attitude, and would teach her children to behave the same way. There are many additional verses that discuss faith, belief, mercy, and

forgiveness, which she may also espouse and teach to her children. Mothers may choose to teach their children morals and ethics. For example, one of the morals is that mothers teach their children to eat with their right hand and not to use the left hand since Islam forbids it. Mothers of children with ASD may or may not want their children to follow the morals. In my study, it was important to know whether or not the mothers of children with ASD were focusing on teaching their children the morals.

The Islamic perspective greatly influences Saudi Arabian people in their daily lives (Al-Shahri, 2002). Saudi Arabian Muslims believe that Allah (God) wills everything that happens to them. They often say that everything that happens to them is their destiny from Allah. However, Allah is believed to be kind and fair. For example, when Muslim people have a disease, or when they have children with disabilities, they look at it as “a way of atonement for one’s sins,” not as punishment from Allah (Al-Shahri, 2002, p. 134). Saudi Arabian Muslims believe in fatalism or Allah's will. According to Long, “No matter in what context it is used, Allah's will must be taken literally. All things are subject to God's will, and unless God wills it, nothing can happen” (2005, p. 24). Saudi Arabian Muslim mothers of children with ASD may, therefore, believe that everything in their lives is Allah's will. They may willingly accept their child no matter what the challenge, without complaint. They may consider having a child with ASD as Allah's test of their own durability and strength, or a way for them to atone for their sins.

Saudi people also believe in using spiritual healing. They recite verses of the holy Quran and specific speeches of the prophet Mohammad (pbuh), which helps them to deal with problems such as Jinn and the evil eye (Khan, 1994). In my research, I studied Saudi Arabian mothers of

children with autism who are Muslim in order to learn more about their religious beliefs about predestination and spiritual healing.

Islam is more than just a religion. It is an all-encompassing culture and according to Long (2005), “cosmic in scope” (p. 18). Islam teaches that all things both animate and inanimate are Allah's creation and that everything is under Allah's dominion. As Long explains, “This belief is so central and so intensely ingrained in Saudi Arabia that it cannot be calculated by simply observing expressions of behavior, whether pious or profane” (p. 18). Muslims believe that all who submit to the will of Allah are at peace with themselves and with their neighbors, Long suggests (p. 18). Following this Islamic belief, it is likely that Muslim mothers will accept that everything in their lives is created by Allah, both their joys and their problems. Thus, Muslim mothers who have children with ASD may believe that the ASD was and is Allah's will.

Several verses in Al-Quran state that when people face difficult times and obstacles, they must believe that there is an end to their challenges and that they will again know relief and happiness. For example, the verse Surah Al-Inshirah states, “With every hardship, there is relief” (94:5). Most Muslim people believe that Allah gives every person an ability, strength, and potential. The verse Surah Al-Baqarah states, “Allah burdens not a person beyond his scope” (2:286). This verse is very relevant to my study. Mothers of children with ASD may feel that they have been given a great burden. Muslim mothers such as those in my study may find comfort in believing that having a child with ASD is not beyond their scope. As Muslims, they may believe that Allah knows them to be capable and able to care for their children. This may give them comfort and boost their confidence in their mothering.

**Cultural and social context in Saudi Arabia.** Saudi Arabia is a country with rich traditions and a strong culture. Banks (1997) defines culture as the “ideations, symbols, behaviors, values, and beliefs that are shared by a human group” (p. 8). Culture can have a significant influence on the way people live. For example, it can shape what people believe about themselves, their environment, disabilities, their children’s behaviors and abilities, and most everything in their lives. There is no doubt that the culture of Saudi Arabia is heavily influenced by Islam, as the overwhelming majority of its citizens are practicing Muslims (Al-Shahri, 2002).

In Saudi Arabia, Islam has shaped the culture and life, and it is evident in every aspect of Saudi life. As Al-Shahri (2002) suggests, the influence of Islam on Saudi Arabian culture starts from the flag of the country and the legal system and continues through “to the daily living activities of the people” (p. 133). Long (2005) argues that Saudi Arabian culture relies on the morals of people and Islamic social values that were started early in the seventh century and that continue today.

Saudi Arabians, as well, care a great deal about others and live predominantly within groups. This emphasis on groups is very likely to influence the mothering experience. Mothers living in Saudi Arabia are likely to mother their children alongside of and with the support of their mothers, sisters, cousins, and female friends. They may feel that they are mothering collaboratively with other women. They may revel in and rely upon the support they receive. They may enjoy deep social connections and bonds with other women with whom they may share their mothering stories, questions, and challenges. In my study, I wanted to know if the participants were connected with their families, and how that connection might have influenced their mothering experiences.

Saudi Arabian culture places a high value on the family. Abu-Hilal (1986) emphasizes the

importance of the role of family in Saudi culture. He says, “For the sake of the family, everything must be sacrificed” (p. 76). As El-Banyan (1974) explains, “The family in Saudi Arabia is the basic social unit. It is the center of all loyalty, obligations, and status of its members” (p. 46). Long (2005) also describes the importance of family in Saudi Arabian culture. According to Long, “Each family member shares a collective ancestry, a collective respect of elder, and a collective obligation and responsibility for the welfare of the other family member” (p. 35). Certainly, mothers in Saudi Arabian culture value their children, even when they must make great personal sacrifices to care for them. They will put their children's needs often before their own. Moreover, mothers in Saudi Arabia are unlikely to turn from their children because their challenges are unpleasant, time-consuming, socially or personally costly, unfamiliar, embarrassing, or expensive.

Today, many Saudi Arabian families are more open to interacting with other people than in the past, thanks to the rapid changes in the region, brought about by an influx of technology. Saudi Arabian families today more often socialize with others and do business not only with members of their own families but also with other people around the world (Long, 2005).

**Disabilities in Other Middle Eastern countries.** Muslims in Middle Eastern cultures hold varying attitudes toward and perspectives about children with disabilities. Each point of view is influenced by cultural concepts such as where the family lives, whether the family functions as an extended family or nuclear family, the education level of the family, and the family's socioeconomic class.

There is a social stigma associated with disabilities within the culture. For example, as Azar and Badr (2006) suggest, because of the stigma associated with a child's intellectual disability, Lebanese mothers of children with intellectual disabilities often isolate themselves and their

children from the world. As well, those mothers may not seek support or help from others. Often, this is due to their own illnesses and depression that result from their feelings of isolation. The mothers taking part in the Azar and Badr study were the primary daily caretakers of their children with intellectual disabilities. They also had full responsibility for household duties and reported that they did not interact with others because of the staggering responsibilities they had (Azar & Badr, 2006).

Having a child with a disability can affect the social structure of a family. In Crabtree's (2007b) study of 15 mothers in the UAE, two mothers of children with disabilities (autism and Down Syndrome) were repudiated by their husbands who had other wives. They felt that their relationships with their husbands were not stable because they had children with disabilities. These mothers reported that their husbands (the children's fathers) did not take responsibility for raising their children with disabilities. The mothers reported that these fathers were ashamed of their children with disabilities. However, the mothers also reported that these fathers were not taking responsibility for their typical children either.

**Disabilities in Saudi Arabia.** According to the Labor and Workman Law of Saudi Arabia, "person with a disability" is defined as "any person whose capacity to achieve and continue a suitable job has actually diminished as a result of a physical or mental infirmity" (Al-Jadid, 2014, p. 453). Some Saudi Arabian people hold rigid beliefs about people with disabilities. Their attitudes are based on the simple notion that a person with a disability is very limited. As Al-Gain and Abdulwahab (2002) suggest, some Saudi Arabian people's attitudes are based on the idea that a disability condemns an individual to "helplessness, continuing dependence, being home-bound, low quality of life, and lack of productivity" (p. 1). Furthermore, some Saudi Arabian people may

not be aware of how many people among them have disabilities. As Al-Jadid indicates, “It was thought that the number of persons with disabilities in KSA was quite low” (p. 455). This misconception is due perhaps to the practice of some families to keep disabled family members in the home, not permitting them to go out in public, visit other relatives, or participate in social activities. In some families, the only time when a person with a disability is “exposed to society” is when that individual must go to the hospital because of illness, or to see a doctor for a checkup (Al-Jadid, 2014).

It is possible, therefore, that Saudi mothers of children with disabilities may hold some of these rigid beliefs. For instance, they may feel that their children are helpless when they are not, and that they have more limitations than they do. They may assume that their children with disabilities are not capable of leading full lives, even when they are. They may also feel that they must limit the amount of time their children are out of the home to those times and venues that are essential. This may be especially true of women who have multiple daughters, one of whom has a disability, for fear that suitors will be dissuaded from courting and marrying their other daughters. As well, Saudi mothers of children with disabilities may experience mothering in greater isolation from other mothers, more so than mothers of typical children.

Islamic religion and culture present significant implications for mothers, particularly mothers of children with disabilities. In my research, I wanted to learn how my participants’ religion and culture influence their beliefs about disabilities. For example, I explored with my participants whether they believe that their children have ASD because it is Allah’s will. I also explored whether they saw ASD as Allah’s opportunity for them to atone for their sins, and/or if they believed that Allah believes them to be capable and able to handle the challenge of mothering

a child with ASD. I sought to understand whether my participants believe their children with ASD have limitations, and if so, what they believe those limitations to be. I explored whether my participants were mothering alongside of and with the support of other women, or more so in isolation. Finally, I wanted to know whether my participants took their children with ASD out of the home often or whether they did so only when it is essential.

**Cultural context in the United States.** The United States is a multicultural and diverse nation. Like me, the participants in my research were Saudi Arabian women who had been living in the United States. My research explored with them how, if at all, they believe that living in the United States has shaped their perspectives about and experiences of mothering, disabilities, their extended and nuclear families, and gender roles.

### **Research Problem and Questions**

Having a child with a disability can affect mothers' behaviors, thinking, and beliefs. Mothers of children with disabilities have differing views and experiences raising their children. Those views and experiences may be positive or negative and may be influenced by cultural and religious beliefs. Mothers' outlook on the future may also vary. The difficulties of caring for children with autism, starting from the onset of the diagnosis, can be especially stressful for mothers, who are often the primary caretakers of their children (McGraw & You, 2011). Mothers may experience stress and worries, and they may feel more socially isolated than fathers (Azar & Badr, 2006). Some mothers have great hopes for their children with developmental disabilities. As a result, they work hard to educate them and to find useful resources for them so they can reach for and achieve their potential (Azar & Badr, 2006).

The research problem for this study is: How do Saudi Arabian mothers of children with ASD living in the United States understand and experience mothering? I asked Saudi Arabian mothers in my study to share with me their experiences, beliefs, and thoughts about raising their children with autism. I used an interview guide and follow-up questions to gain clarification as they answered my questions and told me their stories. Some of the follow-up questions were:

1. How does Saudi Arabian culture influence the mothering of children with ASD?
2. How does a Saudi Arabian mother's particular religious beliefs, socioeconomic level, and educational level influence her mothering of a child with ASD?
3. How does living in the United States influence mothering among Saudi Arabian mothers of children with ASD?

### **Purpose of the Study**

The purpose of the study was to learn about the mothering experiences of Saudi Arabian women who live in the United States and who are mothers of children with ASD. Little research address the experiences of Saudi Arabian mothers using a qualitative research method. This is an important area to examine because there are many Saudi Arabian mothers of children with ASD, but only one study that has focused on parents of children with autism, their beliefs about its causes, and their decisions regarding their children's treatment (Alqahtani, 2012). There is no study of Saudi Arabian mothers of children with ASD, nor are there studies of Saudi Arabian mothers living in the United States. According to Dunn et al. (2001), parents of children with ASD may experience varying levels of stress and challenges in their marriages. I sought to learn more specifically about the mothering experiences of Saudi Arabian mothers of children with

ASD to see if my participants experience such stressors or if they have experienced conflicts about their mothering in their relationships with their spouses.

As a former and future educator, I want to know more about how to help children with ASD. That is why I proposed to study their mothers. In particular, I sought to learn more about the experiences and beliefs of Saudi Arabian mothers of children with ASD in the hopes that this knowledge will ultimately enable us to provide more and better services to children with ASD and their mothers.

### **Significance of the Study**

My study will contribute to the body of knowledge about mothers of children with ASD, particularly focusing on Saudi Arabian mothers living in the United States. It examines Saudi Arabian mothers' mothering experiences and their beliefs and attitudes about their children with ASD. The study aims to shed light on a population that has received little or no attention in the scholarly literature. It seeks to identify the least and most effective strategies that Saudi Arabian mothers with ASD are using to help them deal with their challenges. I hope that my study will be useful to educators, researchers, therapists, health care providers, mothers and fathers of children with ASD, and others.

### **Rationale for Choosing Qualitative Methodology**

Qualitative research is an appropriate methodology when researchers want to explore human experiences and how human beings make sense in their world (Savin-Baden & Major, 2012). As Savin-Baden and Major explain, "Many qualitative researchers are interested in exploring human experiences, and some of them seek to understand the nature of the experience itself" (p. 212). An underlying premise of qualitative research is that people can interpret their

experiences (Savin-Baden & Major, 2012). A qualitative method is different from a quantitative method because qualitative research focuses on the particular reality of people who live experiences. Also, researchers in qualitative research are themselves the primary tools for making research decisions and for collecting and analyzing data. Quantitative research, on the other hand, focuses on hypotheses and relationships among different variables and it tests cause and effect relationships (Savin-Baden & Major, 2012). In quantitative research, the researcher uses numerical instruments to yield results and findings, rather than personal observation.

My study sought to look at the particularity of the very human experience of mothering a child with ASD. Therefore, a qualitative method was an excellent fit for my research problem and questions.

### **Narrative Approach**

Narrative analysis was a tool that I could use to interpret my own experiences and to reflect on interpretations of those experiences. That's because narrative research helps researchers to interpret themselves when they interact with their participants.

### **Theoretical Framework**

A primary reason that I studied the mothering experiences of Saudi Arabian mothers of children with ASD is that I am a mother from Saudi Arabia, and I have experience working with children with disabilities. There are limited studies that focus on mothering children with disabilities (Brock, 2014,). Also, mothers of children with disabilities have not been studied sufficiently for us to know about their daily lives (Leiter, Krauss, Anderson, & Wells, 2004). I wish to contribute to a greatly-needed body of work about Saudi mothering and particularly, of children with autism.

**Summary**

There is a significant number of Saudi Arabian mothers who have children with ASD. Yet, there is little research to help us understand how these mothers experience mothering. We do not know how their culture, religion, and beliefs shape their mothering experiences. This study seeks to explore in particular the mothering experiences of Saudi Arabian mothers living in the United States who have children with ASD. I hope that this research brings a more significant understanding of the mothering experiences of Saudi Arabian mothers.

## CHAPTER 2: LITERATURE REVIEW

### Introduction

The number of children with autism has been increasing worldwide. There are a significant number of studies in Western culture that address mothering. However, there is a dearth of studies about mothering in Middle Eastern culture. This chapter discusses the structure of the Saudi Arabian family. It also examines the mothering experiences of mothers from different cultures, particularly while they are raising their children with ASD. Last but not least, this chapter explores the effects of raising a child with autism on both the mother and the family.

### The Structure of the Saudi Family

Family is an essential part of any person's life, and it is an extremely important value in Saudi Arabian culture (Al-Khateeb, 1998). Mothers most often play the essential role of primary caretaker of their children. In most families, mothers do their best every day to take the best care possible of their children. They also often do the majority of, or even all of, the housework in support of the family – cooking, cleaning, laundry, etc. In contrast, fathers in many cultures have little involvement in rearing their children or in caring for the house (Crabtree, 2007c). Most family members in Saudi Arabia are expected to support one another financially, even as adults. As Algahtani, Buraik, and Ad-Dab'bagh (2017) suggest, “Siblings [in Saudi Arabia] are expected to be supportive of each other” (p. 109). For example, when one member of the family has his own family and lives independently, he or she is expected to provide help to a brother and sister who is facing financial challenges. Financial help is also commonplace when a sibling wants to get married, buy a car, or pursue continuing education.

In Saudi culture, most husbands and wives have clearly defined roles. The male role is to

lead the family. He is a “breadwinner, protector, disciplinarian, spokesperson, and decision maker” (Al-Shahri, 2002, p. 136). In general, Saudi Arabian wives can only advise their husbands in an attempt to influence their decisions (Al-Shahri, 2002). However, in some areas, such as childrearing, they may have more decision-making capabilities. According to Al-Shanqiti (1993), Saudi women, whether married or not, feel secure in their families because a male relative is usually responsible for meeting their basic needs, such as feeding, clothing, healthcare, and housing. This is the case even when the woman possesses greater wealth than the man. Shanqiti suggests that females tend to delegate the task of signing consents to close male relatives even though they have the legal right to make completely independent decisions. Thus, most Saudi women grow up having a male relative to provide for, protect, and represent them. This dependence upon a male often continues when they marry, and their husbands assume these responsibilities (as cited in Al-Shahri, 2002).

Mothers of children with ASD have unique experiences rearing their children. They develop their own understandings of and expectations about the learning capabilities of their children and the disability. However, mothers can change those beliefs depending upon their cultural environments and their backgrounds. For example, their educational levels, incomes, and the cultures in which they were raised can help to shape their beliefs (Samadi & McConkey 2011).

Having a child with ASD or a child with any disability can have a significant impact on the family. According to Madi, (2014), citing Groce and Zola (1993) and McCubbin et al. (1993), “The cultural environment of the family fundamentally influences the processes of adaptation to the disability. These processes of family life are the way in which families give meaning to having a child with a disability, and they play a fundamental role in shaping the family's responses to

medical care” (Madi, 2014, p. 13). Thus, a great deal of what happens to a child with a disability – the services he receives or does not receive, and the place he occupies in the family – has to do with the cultural environment of the family.

According to Crabtree (2007c), based upon studies in the UAE, the Saudi family structure can be divided into three categories, the same categories as in the UAE. These are the extended family, the nuclear family, and the polygamous family.

**Extended family.** The extended family is a traditional form in Middle Eastern countries (Senturk, Abas, Berksun, & Stewart, 2011). The Saudi Arabian society depended upon the extended family for several generations (Long, 2005; Crabtree, 2007b). An all-for-one and one-for-all attitude prevail in Saudi family culture. As Long explains, extended family in Saudi culture offers “a collective ancestry, a collective respect for elders, and a collective obligation and responsibility for the welfare for other family” (Long, 2005, p. 35). The extended family in Middle Eastern culture more generally can be defined as family members who live in one place (Crabtree, 2007b). Many extended families still exist in the Middle East today, though not in the same numbers as in the past (Al-Khateeb, 1998).

Giddens suggests extended families are comprised of “close relatives other than a married couple and children who live either in the same household or in a close and continuous relationship” (2001, p. 173). For example, the grandparents, their adult children, and their grandchildren may live in one place (Crabtree, 2007c). As well, Senturk et al. (2011) defined the Saudi extended family as a husband and wife living in the same place as other family members. Lieberman (1979) defines the extended family as “those individuals bound by blood or marriage who, through their culture, make up a kinship” (p. 13). Thus, extended families in other parts of

the world, using this definition, may not necessarily live together in the same place as they do in Arab culture.

Very often, husbands and extended family members blame mothers for having children with disabilities (McGraw & You, 2011). As one Korean mother in the McGraw and You study put it simply, “My husband blamed me. He said it was my fault because I didn’t raise her right. My in-laws were saying the same” (p. 588). Korean mothers who have children with autism also face problems with their husbands and husbands’ families. They say that they are often blamed for their children’s atypical behaviors and problems (2011). Korean mothers of sons with disabilities in the McGraw and You study felt they were the object of extra blame because of the importance the culture places on the son carrying on the family name (2011).

In my research, I asked participants to describe their relationships with members of their extended families, especially their children's grandparents. How did the attitudes and behaviors of grandparents affect the mothering experiences of mothers of children with ASD? The research about grandparents' attitudes toward their grandchildren's disabilities is inconclusive. For example, Gray's 2002 study suggests that grandparents often accept their grandchildren with disabilities and are supportive of the children’s parents. However, Gray’s 1998 study found that grandparents of grandchildren with disabilities were prone to criticizing their own children about the way they parented their children.

Al-Khateeb suggests that the majority of Saudi families are not extended families, but nuclear families. The percentage of extended families living together decreased to only 15. 8% in 1998 (Al-Khateeb, 1998). This decrease in traditional Saudi extended families may be attributed to several factors. First, the discovery of oil has had a significant impact both on Saudi society and

on family structure. Young Saudis moved in large numbers to big cities to look for jobs, where they remained and started their own families. Finally, changes in Saudi property rights may explain the move away from the traditional extended family structure. In the past, homes were owned by the eldest male in the family. Now, homes may be individually owned (Al-Khateeb, 1998). Despite the decline in the traditional Saudi extended family, there is still loyalty to the clan and tribe (Al-Kandari, Alsalem, Abohaimed, Al-Orf, Al-Zoubi, Al-Sabah & Shah, 2017). Thus, while Saudi Arabian people may not live in extended families, their allegiance to the extended family remains strong.

**Nuclear family.** The nuclear family has become much more common in Saudi Arabia. According to Giddens (2001), the nuclear family is defined as “two adults living together in a household with their own or adopted children” (p. 173). Al-Kaabi (2004) studied family structure in Qatar and found that there, too, there has been a shift from extended to nuclear families. Al-Kaabi attributes this shift to several factors, including women moving into the workforce, shifts in the Qatar lifestyle, economic improvements, a shift toward more financial independence, and a more open social structure (2004). Al-Kaabi, describing the life of nuclear families in Qatar, suggest that the nuclear family and their relatives may still live together as they did traditionally, however not under one roof (2004). They may live nearby, in separate houses. The nuclear family today continues to act together as one unit at social events such as at dinnertime, maintaining strong social ties. The father of the household continues to have a considerable say in the nuclear family's issues. Al-Kaabi also suggests that the nuclear family is financially independent, but that members of the extended family may support one another in times of need both through job opportunities for men and women and through the open market policy (Al-Kaabi, 2004). Thus,

while Qatar extended families are still close-knit, they do not live under one roof in the same numbers as they did in the past. This is a finding that is consistent with the research previously referenced about Saudi Arabian family structure.

Nuclear families are prevalent in most modern societies (Senturk et al., 2011). In 1998, 83.2 % of Saudi families were nuclear families, Al-Khateeb says. Saudi Arabian adult children are more likely than their ancestors to make their own decisions, based upon their beliefs and preferences (Alghreeb, 2014). They are less likely to permit their parents and grandparents to make decisions for them or their children. For example, they typically decide what to study or major in higher education, and what kind of job they want to have when they graduate. They are also more likely to choose their own spouses. Grandparents in Saudi Arabia and other nations in the region are now more likely to live near, but not with, their adult children, and to offer their guidance and advice from this distance (Crabtree, 2007c).

The overwhelming majority of Saudi Arabians choose to live in nuclear, not extended families (Alghreeb, 2014). This is a huge difference from the extended family world of previous Saudi Arabian generations. The shift from extended to nuclear families has also occurred in Turkey. There, this shift brings with it both new and old ways of thinking. As well, while Al-Khateeb suggests that men in nuclear families in this region remain emotionally and even geographically close to their parents, nuclear families there, in general, tend to be closer to the woman's family (1998). Thus, while family structure evolves, families do not abandon their old beliefs and customs entirely. This is consistent with El-Haddad (2003), who says, "The Arab Gulf nuclear family is in a transitional stage that carries many features of both the Western model and the traditional extended family model" (p. 2).

My research considered whether the participants were living in extended or nuclear families and how those environments have impacted the mothering experiences.

**Polygamous family.** In Islamic culture, polygamy is much more common than in Western culture (Al-Shamsi & Fulcher 2005). In Al-Quran, explicit passages offer rules for men who seek multiple marriages. According to one verse,

And if you fear that you shall not be able to deal justly with the orphan-girls, then marry (other) women of your choice, two or three, or four but if you fear that you shall not be able to deal justly (with them), then only one or (the captives and the slaves) that your right hands possess. That is nearer to prevent you from doing injustice (Quran, 4:3).

The verse continues,

You will never be able to do perfect justice between wives even if it is your ardent desire, so do not incline too much to one of them (by giving her more of your time and provision) so as to leave the other hanging (i.e., neither divorced nor married). And if you do justice, and do all that is right and fear Allah by keeping away from all that is wrong, then Allah is Ever Oft-Forgiving, Most Merciful (Quran, 4:129).

Although Al-Quran allows polygamy, it tells polygamous men to marry fairly and justly, and that if they cannot, to marry monogamously (Al-Shamsi & Fulcher 2005). According to Al-Shamsi and Fulcher (2005), numerous studies reveal that polygamous marriages face many problems. These include financial hardship, a lack of fairness, and psychological problems. Polygamy may also impact children adversely, as they may end up having educational or psychological problems, Al-Shamsi and Fulcher say. It is important to note that polygamy affects not only children but their mothers as well (2005). According to Algahtani et al. many women in Saudi Arabia have many visits to therapists to deal with various issues that result from polygamy. These include “jealousy, poor self-esteem issues, interpersonal conflicts with in-laws or the new wife, sibling rivalry issues, and/or financial problems” (2017, p. 114). Having a child with disabilities in a polygamous culture

presents special challenges to mothers of children with disabilities. In the Crabtree study, one of the mothers pointed out that a man who has a child with a disability is free to blame his wife and regard her as damaged goods. He may not want to have any more children with her. If he is polygamous, he may choose to marry another woman, one whom he believes can give him a typical child or children (Crabtree, 2007b).

In Saudi Arabian culture, having another wife may not be as universally accepted as some think. Some families embrace polygamy and are supportive. Others find it difficult to accept. As Algahtani et al. (2017) suggest, polygamy can be met with a “hostile reception” within certain social circles, and polygamous individuals may at least temporarily be “shunned”. Mothers in polygamous marriages may also have additional concerns. According to Crabtree, “A graver consequence, however [of having a child with intellectual disabilities], was that this gave fuel to the other wife to put pressure on the husband to marginalize or even discard the rival family as tainted and therefore invalid” (p. 250). Some mothers in Crabtree's study described their polygamous husbands' unwillingness to accept their children with disabilities. Interestingly, some mothers said that they enjoyed a much higher acceptance for their children with disabilities elsewhere than they did in their families, with their husbands, and even throughout their community (Crabtree, 2007b). In my study, I sought to explore blame and polygamy in Saudi families as they related to mothers who have children with ASD.

**The U.S family.** The United States is comprised of people from many cultures. Many live in nuclear or extended families according to the traditions of their particular cultures. Sarkisian, Gerena, and Gerstel (2006) studied white, Mexican, and Puerto Rican Americans. Their data supports other studies that suggest that Latino Americans are more integrated than white people

into the daily lives of their extended families. They tend to have more siblings and children than white Americans. They are also more likely to contact their families by using different means of communication such as telephone, letter, and personal meetings.

Racial differences can explain some family contexts. For example, Sarkisian et al. (2006) report that white families do not typically live with or near their extended families. Instead, they live in nuclear families, especially if both spouses are highly educated and have high incomes. White Americans in the study also often had fewer children. Saudi Arabian families are more closely aligned with the Latino Americans in the Sarkisian et al. study. They tend to live more often in extended families and have more children.

The Sarkisian et al. study suggests several implications (2006). First, they may be likely to live near or with their extended families. They may have a relatively larger number of both siblings and children. As well, they may expect to live in extended family groups (2006). When this was the case with the participants in my study, it was important to find out how things changed for them when they immigrated to the United States. In some cases, they did not live near or with their extended families, much like my husband and me. In some cases, they found, as I did, that mothering alone with or without their husbands is quite different from the mothering they expected to experience in Saudi Arabia. Like me, some had to mother more independently than, their mothers and grandmothers did.

**Gender roles.** Gender ideologies and roles in the United States have changed a great deal in the last several decades (Milkie, Bianchi, Mattingly, & Robinson, 2002). According to Siordia (2016), gender roles influence both between- and within-gender interactions. What one believes about gender can explain female disadvantage, as those beliefs can relegate women to that Siordia

calls “undeserved inferiorization” (p. 230). Montgomery, Chaviano, Rayburn, and McWey, (2017) studied African American, Caucasian, and Hispanic fathers' roles in protecting the family and providing financially for the family. Some fathers mentioned how their parents were the ideal for them. For example, if their own parents provide love to their adult children, their adult children will, in turn, do the same and share love with their family. Montgomery et al. report that one father shared how his father was the exception to this gender norm and how he planned to be as well (2017). According to that father, “[I’m] similar in just showing her the love my father showed me...’Cause, regardless I know he loved me, you know, and he stepped up and he was a man ’cause a lot of guys don’t do that” (Montgomery et al., 2017, p. 1156). For this parent, his family of origin experiences influenced his decision to play an active role as a father. Fathers in the Montgomery et al. study noted their desire to differ from perceived gender stereotypes by playing a more active parenting role (2017).

This, however, may be challenging for fathers who may not have a role model from their family of origin or community to rely upon. As Montgomery et al. explain, “In such cases, they may feel ambiguity about their role as parents. This ambiguity, in turn, could be inadvertently reinforced systemically” (1166). Furthermore, Silverstein (1996) argues that while men may elect to take on a nurturing role as fathers, feminine gender roles now require mothers to be involved with their children as both nurturers and providers” (as cited in Montgomery et al., 2017).

The Saudi Arabian mothers of children with ASD who participated in my study held their own beliefs about their role as a woman and as a mother. In some cases, they had experienced a disparity in gender roles between their mothers and their fathers, and they had firm beliefs about whether they wish to perpetuate that disparity or do things differently. Some of these women held

strong feelings about what they should do for their children and what their children's fathers should do. As well, as women, some of my participants felt some expectation or even pressure to produce income, make decisions, or to take on other traditionally Saudi male roles in their households, especially the women who were married (this was true whether the married women were, or were not living with their husbands).

**Grandparents' roles.** In Saudi Arabian culture, most grandparents are involved in their adult children's lives. In fact, Saudi Arabian childcare centers are rare, especially for children under the age of two, because grandparents so often care for their grandchildren. Expanding on this idea, Aassve, Meroni, and Pronzato (2012) suggest that "public childcare is scarce" and "grandparents will play a stronger role in childrearing duties" in most Middle Eastern countries (p. 502).

Noriega, López, Domínguez, and Velasco (2017) found that grandparents can provide different kinds of support to their adult children including financial support, child rearing, and social support. Whether a grandmother is willing to take care of and watch her grandchildren will depend upon the grandmother's age and health (Aassve et al., 2012). As Bengston (2001) stated, the most common reason that grandparents provide childcare for their grandchildren is that the mother is working outside the home. As well, Bengston suggests that "higher divorce rates, high costs of formal care, and lack of public policies that support families" are reasons that grandparents care for their grandchildren (as cited in Noriega et al., 2017).

Grandparents can also play a significant role in a child's development. Interestingly, the grandparents' first concern may not be to teach the child. As Noriega et al. suggest, "In fact, value transmission, unconditional love, and caring are the three most important functions developed by

grandparents” (p. 1228). Some grandparents may have a significant impact on their adult children, especially in decisions about how to deal with financial problems or childrearing (Aassve et al., 2012, p. 501). For example, Hwang suggests that Korean grandparents can provide help to their adult children such as childcare, offering advice, and financial and social support (as cited in Lee, & Emmett Gardner, 2015).

Grandparents’ roles and perspectives may vary toward their grandchildren with disabilities. Their attitudes and beliefs may be dependent upon the nature and severity of the disability. Lee and Emmett Gardner (2015) suggested that some Korean mothers of children with disabilities feel that grandparents can be a burden to mothers. This is especially the case, the mothers say, when grandparents deny that their grandchildren have disabilities and when they speak negatively about their grandchildren and/or their disabilities. Also, mothers-in-law in the Lee and Emmett Gardner study were found at times to provide some support to their grandchildren with disabilities, but not to support their mothers, or to help them reduce their stress (Lee & Emmett Gardner 2015).

Grandparents' relationships with mothers will often depend upon which side of the family they are on. According to Lee et al., mothers considered maternal grandparents (i.e., their own parents) to be motivated to provide them with a personal source of support. They believed that their parents would help them by reducing the burden of childcare and more generally, by eliminating sources of stress. In contrast, mothers in the Lee et al. study described their mothers-in-law as supporting them only for the sake of positively impacting their grandchildren's education and development (2015). Lee et al. argue that this is a subtle yet potentially influential difference. Maternal grandparents are perceived to focus on meeting the needs of the mothers, Lee et al. report; paternal grandparents are perceived to focus on the needs of the grandchild (2015).

My study explored mothers' understanding and experiences of the roles that grandparents play for Saudi Arabian mothers of children with disabilities in the United States and how these roles impact these mothers while they are raising their children.

**Nannies' roles.** Saudi Arabian mothers are part of the workforce in larger numbers today than in the past. Modernization, changes in lifestyle, and a desire for higher economic levels has caused this shift to two-income households and has created a new, larger Saudi Arabian middle class (Hutter, 2013). Mothers in every culture and nation who are part of the workforce have relatively less time for their children and housekeeping than full-time mothers. That is why they often hire a nanny/housekeeper to take care of their children and their homes while they are working. According to Hutter, these nannies/housekeepers often originate from Third World countries (2013).

Most Saudi Arabian working mothers hire one or more individuals to serve as nanny and housekeeper. Some mothers engage a nanny to take care of their children and one or more housekeepers to handle domestic chores; others hire a nanny/housekeeper who handles both tasks. According to Sollund's 2010 study, "One Filipina [household employee] worked nine hours daily, had responsibility for a six-month-old baby, and did all the housework" (2010, p. 147). This is a very typical arrangement for Saudi Arabian families in which the mother is in the workforce.

Families enjoy certain benefits when domestic chores are outsourced to a housekeeper. According to Sollund, domestic workers decrease disputes between couples and parents report that they enjoy having more time to spend with their children (2010). One of the participants in Sollund's study described the employment of a housekeeper as a relief. According to this participant, "You come home, and everything is tidy and clean. Clothes are laundered and ironed,

and everything is in the closet. Dinner is on the table. I can concentrate on the children and really enjoy them. It is lovely, really lovely!” (2010, p. 148).

My study sought to learn more about participants’ experiences employing nannies and housekeepers, both in Saudi Arabia and in the United States. In addition, if the participants employed nannies, the study explored the roles of nannies in raising their children with ASD, and how employing a nanny affects the mothering experiences of mothers of children with ASD.

### **Mothering and Motherhood**

In the study of mothers of children with autism, the socio-cultural beliefs about disabilities in Saudi Arabia underscored every question I asked and everything the mothers told me about their experiences. As Lalvani (2011) explains:

If the meaning of motherhood is understood as fluid and relying on what motherhood is taken to be, then it can be argued that the meaning of mothering a child with a disability is further embedded in the contexts of socio-cultural beliefs about disability and valued children” (p. 277).

Thus, the researcher cannot consider the mothers’ experiences outside of the society and culture that have shaped their beliefs. As mothering is at the core of the research problem, it was essential to distinguish mothering from motherhood.

**Mothering.** Mothering is a shared experience of most mothers, and it is a complex one. According to Cowdery and Knudson-Marin (2005), “Mothering is linked with notions of femininity and gender” (p. 3345). It is a concept that describes taking care of children in their daily lives. Cowdery and Knudson-Marin suggest that as mothers interact with their children that they “create deep emotional bonds that influence maternal and connected ways of thinking” (2005, p.336). Mothering as a concept includes both the identity of the mother and the mother's emotional attachment to her children. Mothering is, therefore, a set of actions, an identity, and an emotional

attachment. For example, mothers who show fear for the wellbeing of their children are likely to be more anxious. The more anxious they become, the more they will want to protect their children from the world (Valle & Gabel, 2010). Thus, fear, anxiety, and a desire to protect can be ways in which we describe mothering. That alone, however, does not define the mothering experience for everyone. Each mother's mothering experience is uniquely her own.

**Motherhood.** Unlike mothering, motherhood is a construct or ideology. According to Muthukrishna and Ebrahim (2014), motherhood is also “a highly visible role (although the mother as a person can be invisible) and it involves certain socially constructed expectations” (p. 370). Motherhood frames mothering in terms of historical time and place, race and social status, and constructions of gender (Cowdery & Knudson-Marin, 2005). According to Cowdery and Knudson-Marin, “Changing notions of gender and equality are necessarily linked to the meaning and practice of motherhood” (2005, p. 335).

Many early studies focus on the concept of motherhood and provide different contexts. Some focus on “mothers as instrumental to the development of their children” (p. 335). Others focus on “mothers' experiences and examined motherhood as a set of social interactions that arise within a gendered set of relationships and social institutions at a particular time and place” (Cowdery & Knudson-Marin 2005, p.335).

Muthukrishna and Ebrahim (2014) suggest that there are debates about the concept of motherhood. They argue that motherhood is “culturally defined within social, cultural, economic and historical contexts” (p. 269). Notably, motherhood is defined beyond the role of the biological mother. Grandmothers, relatives and older siblings contribute to the care and education of children (Muthukrishna & Ebrahim, 2014). Thus, motherhood can refer to adults within the family who

play an important part in nurturing, socializing, educating, and caring for children (Harkness & Super, 1995). Many people in a child's life can, therefore, be considered to be part of the motherhood ideology, regardless of whether they are biological mothers.

**The ideology of the good mother.** Riddick (2001) argues that the image of a good mother remains as “a form of social regulation and influences the social and cultural positioning of mothers” (Muthurkrishna & Ebrahim, 2014, p.370). The concept of what constitutes a good mother seems to be part of every culture. According to Muthurkrishna and Ebrahim, in most cultures, mothers are held accountable for “the care, education and social and emotional development of their children” (p. 370). In other words, mothers, or specifically good mothers, are responsible for the way their children turn out. Muthurkrishna and Ebrahim argue that being considered a “good mother” is a critical identity issue for many women. The ideologies of the good mother suggest that it is up to mothers, more so than to others, to improve their children’s socializing skills and their emotional development.

Brock (2014) suggests that the ideology of the good mother is further complicated when the mother has a child with a disability. According to Brock (2014), “The way mothers of children with disabilities wrestle with the good mother concept is complex – they may go out of their way to conform to it, but at the same time fiercely resist it” (p. 20). There are expectations of the “good mother” of a child with disabilities that are not in place for mothers of children without disabilities. Specifically, Brock identifies five expectations for mothers of children with disabilities. Mothers of children with disabilities:

- Are the primary caregivers to their children and will remain so for the rest of their lives?

- Are assumed to be naturally gifted with qualities that make them capable of indefinitely being the primary caregiver for their children
- Are expected not to work outside the home in paid employment
- Embody qualities and skills that enable them to nurture their children optimally, and
- Maintain a façade of social “normality” in the sense that there is nothing particularly different about their mothering requirements compared to mothers of children without disabilities (Brock, 2014, p. 20).

Thus, following Brock, it seems that mothers of children with disabilities are expected to have nearly superhuman parenting skills. They have all of the expectations on them that any mother would have, as well as these additional expectations.

The concept of what constitutes good mothers includes what they and their children “should be doing to be considered successful” (Valle & Gabel, 2010, p. 191). Applying this argument, it follows that mothers should strive for perfection as a mother. In the scientific research, mothers are responsible for their children’s development (p. 191).

**Mothering across various mothering contexts.** The good mother ideology exists in every culture. For example, in Korean culture, mothers in the study of McGraw and You believed that when their children with autism succeeded, they succeeded too. They directed their time and energy toward helping their children with disabilities to succeed (McGraw & You, 2011). As in many other cultures, Korean mothers in the study took care of their children most of the time. They taught them extensively in academic subjects and in their social and communication skills (McGraw & You, 2011). In this regard, the Korean mothers in the McGraw and You study are much like many Saudi Arabian mothers, who are their children’s primary caretakers.

In Western culture, it is not unusual for a mother of a child with disabilities to shift career paths so she can advocate for her child and secure for him or her the best services possible (Brock, 2014). According to Brock, “The experiences of mothering, particularly the intensive and often never-ending experiences of mothering a child with disabilities, can shape the entirety of a women's life and sense of self -- thus reinforcing the power of the good mother ideology as a normative concept” (2014, p. 28).

**The good mother ideology in Saudi Arabia.** The good mother ideology exists in Saudi Arabia, but there is a dearth of research on this topic. In general, disabilities studied in Saudi Arabia have been in the medical field. According to Hussein and Taha (2013), most of the research and most of the services provided to children with special needs in Arab countries are in the medical field, not in the educational field.

Every mother has her own point of view and perceptions toward childbearing and good mothering (Porter, 2010). Mothers have different ways of thinking and acting when they deal with parenting and educating their children (Porter, 2010). My perspective about taking care of my daughters is going to be different from those of my mother and my sister. As a mother from Saudi Arabia who values education deeply, I am highly focused on providing the best education for children with and without disabilities, whether those children are taught by their mothers, teachers, or special tutors. Furthermore, I believe it is important to teach children good manners such as how to be polite, how to respect others, how to speak nicely and not loudly, and how and why to be honest.

Mothers in Saudi Arabia are their children’s primary caretakers. They stay with and spend most of their time with their children. They listen to them and talk with them on a broad range of

topics (Porter, 2010). As anyone who spends time with children knows, mothers must be patient with their children. Their responsibility, loving, and caring for their children does not end (Porter, 2010). Of course, mothers can enjoy their time outside of their homes and do what they like besides taking care of their children (Brock, 2014). In so doing, mothers can do something for themselves that helps to relieve their stress and gives them needed breaks from the burden of domestic work.

The concept of the good mother continues to evolve. According to Corman (2013), good mothers are responsible for helping their children to develop to the best of their abilities. They prepare their children to succeed in the future, and not to fail. Margolis (2001) discussed the discourse of good mothering in the context of the ideal of maternity. As Margolis suggests, “Mothers, and mothers alone, are responsible for their children’s character development and future success or failure” (p. 144; see also Green, 2004). Thus, it follows that if the child turns out to be unhealthy, unhappy, and ill-adjusted, the blame will be on the mother (Horwitz, 2004). According to Griffith and Smith (2005), if a child’s needs are not met or if the child is disabled and therefore not perfect, the mother will be blamed for “faulty mothering” (p. 38) and not being a “good mother” (Nelson & Robinson, 2002, p. 355). Connected to this concept of good mothering is what it means to be a good family (Arendell, 2000) and often, children are central to the definition of family (Fox & Luxton, 2001). According to Collier (2001) et al. good families foster an environment in which “everyone is happy, nurtured appropriately, and the needs of children are met” (p.1324).

Success and failure are concepts often tied to families. According to Coontz (2001), “If the family does not provide this type of nurturing and functional environment — the nuclear, happy, homogenous families... from the 1950s” (p. 205), families may be viewed as a failure. It is now

"normalized" that families of children with disabilities live together and provide care to their loved ones with disabilities (Cummins, 2001). If families are to care for their children with disabilities, and if mothers are primarily responsible for their children, then it follows that good mothers are the primary caregivers for their children with disabilities. A lot is expected of a mother of a child with disabilities. She must acquire specialized knowledge unique to her child's disability. She must meet with health care professionals at different stages of her child's development. She must also gain unique skills often associated with the work of health care professionals (Corman, 2013).

Saudi Arabian women's perceptions of mothering, focusing on how "gendered social structures affect their health" (Alyaemni, Theobald, Faragher, Jehan, & Tolhurst, 2013 p. 741). The Alyaemni study suggests that mothers may get sick and weak more often than fathers. This is because women are the primary caretakers of their children on a daily basis and concern themselves with everything from their children's physical care to their social development to their educational path, usually while they are also doing the housework. Other factors that contribute to women's sickness are stress, poverty, and marital conflict (Alyaemni et al., 2013).

Men in Saudi Arabia are usually tasked only with the job of providing financial support to the family. Women take care of the children and home and place their families first. One of the mothers in the Alyaemni study suggested that "women get sick more because everything is upon her, wiping, cleaning, and childbirth, which causes sickness" (p. 750). I believe that those mothers are taking too much upon themselves if they think only about their family, children, and housework. However, other mothers in the Alyaemni study believed that there is "honor in their role as homemakers because they viewed themselves as highly valued for their self-sacrificing role." One mother, describing her experience, said that "the woman is like a candle burning to give

light to others” (p. 750). Nonetheless, regardless of how the mothers in the Alyaemni study viewed their role, all of the participants reported that they worried about their children’s health more than their husbands did.

**Mothering in the context of Saudi Arabia and other Islamic cultures.** There is a dearth of scholarly literature about mothering in Saudi Arabia or other Islamic cultures, and even fewer studies that focus specifically on mothers of children with disabilities. Abu-Habib (1997, in Crabtree) suggests that there is also a significant research gap in the general area of disability and family support in the Middle East. However, there are a few studies that have been important in my research project. Among these is a qualitative study by Crabtree (2007, discussed below) that explores maternal perceptions of caregiving of children with developmental disabilities in the United Arab Emirates. Another study that has been important is one by Jegatheesan, Miller, and Fowler (2010, also discussed below) that explores autism from a religious perspective among South Asian Muslim immigrant families. Another work by Bywaters, Ali, Fazil, Wallace, & Singh (2003, also discussed below), suggests that Islamic parents of children with disabilities have low expectations of their children's abilities and their futures. Notably, a qualitative study by Alqahtani (2012, described below) places the issues for Islamic parents of children with autism in a cultural context and explores those parents' beliefs.

### **Mothering in the U.S. Culture**

People living in the United States place a high value on individualism. As Wang and Tamis-Lemonda (2003) explain, “Individualistic values reflect personal preferences, needs, and rights” (p. 629). Americans are typically independent [and] hard working (p. 629).” Each mother in the United States has her own values, beliefs, and expectations about rearing her children.

For example, Wang and Tamis-Lemonda (2003) compare U.S. and Taiwanese mothers by using a child-rearing instrument to identify and evaluate mothers' values. Their data suggests that U.S. culture has been portrayed as promoting values associated with individualism. These include "self-confidence, achievement, and independence," Wang and Tamis-Lemonda say (p. 629). Furthermore, most U.S. mothers teach their children to be more individualistic and independent than mothers in Taiwan. U.S. mothers also mention "connectedness" more often than Taiwanese mothers, perhaps expressing an emotional need that Taiwanese mothers take for granted. As Wang and Tamis-Lemonda explain, "U.S. mothers might also attempt to strike a balance between values linked to self-versus others, and connectedness may avert the risk of self-interest that is associated with an individualistic orientation" (p. 638). In comparison, Taiwanese mothers more often assign greater importance to politeness, humility, responsibility, getting along with others, not wasting time or resources, diligence, and following social rules. U.S. mothers, on the other hand, assigned greater importance to love/attachment to family, curiosity, self-esteem, and compassion/consideration (Wang and Tamis-Lemonda, 2003).

Among mothers in both cultures in the Wang and Tamis-Lemonda study, both Taiwanese and U.S. mothers most often mention values associated with "proper demeanor," and least often those associated with decency. Mothers of 3- to 4-year-olds from both cultures place much effort into socializing appropriate behavior and encouraging politeness, respect for others, and good manners/habits (2003).

There are, however, striking differences in mothers' views about obedience, humility, and following social rules to rear their children. According to Wang and Tamis-LeMonda, some U.S. mothers in their study defined these values positively (2003). For instance, one mother explained,

“Obedience means he can listen, which is especially important for safety.” (p.639) For other mothers in the study, these values implied passivity or submissiveness. As Wang and Tamis-LeMonda report, “One mother defined humility as ‘self-effacing, putting herself down, not taking credit,’ and another as ‘being passive.’” The value of obedience was of particular importance in the research. One mother said that obedience “sounds like conforming, thinking inside the box” (p. 640).

**U.S. mothers’ perspectives about disabilities.** People's perspectives about disabilities depend not only on their culture but also on their socioeconomic situations, educational levels, and religious beliefs (Zhang & Bennett, 2003; Ravindran & Myers, 2012). These factors can significantly influence what each of us believes about the causes of disabilities, diagnoses, and treatments (Danseco, 1997).

A number of studies of American mothers help us to understand the American mothers’ perspectives about their children’s disabilities. According to Landsman (2005), American mothers’ perspectives are often fragmented. That is because they find themselves at the intersection of competing and very strong discourses. As Landsman suggests, “They nurture their children in a society that devalues and medicalizes the lives of people with disabilities but is also the backdrop for a vocal and activist disability rights movement” (p. 121). In particular, some native Americans, Latinos, and Asians in the United States believe that family members are accountable for their children’s disabilities, Landsman suggests. He explains that the disability is thought to be “a form of punishment on the family for past sins” (p. 41).

A more positive attribution is found in some religious Latino and African-American families who believe that bearing children with a mental illness is a blessing from God (Rogers-

Dulan & Blacher, as cited in Welterlin, & LaRue, 2007). Navajo American tribes believe that a clan that has a member with a disability is fortunate because the disability can provide a special lesson for everyone. Some also believe that a person with a disability has a special gift or “sixth sense” (Medina et al., as cited in Ravindran & Myers, 2012, p. 312).

**Lived experiences of mothers of children with disabilities and children with ASD.** The goal of my study is to explore the mothering experiences of Saudi Arabian mothers living in the United States who have children with ASD. Therefore, it is appropriate to review the literature on the lived experiences of mothers of children with disabilities and children with ASD in order to understand different experiences mothers have. It is also worthwhile to explore ASD's effects on families and mothers of children with the disability.

Mothers can sometimes feel confused, sad, happy, and/or angry while raising children with disabilities. For example, mothers of children with disabilities in Turkish culture can feel more “fear, confusion, and loneliness” than other mothers (Koydemir-Özden & Tosun 2010, 56). Some Turkish mothers in the Koydemir-Özden and Tosun study reported that taking care of their children with special needs made them feel trapped and that it limited their “autonomy and independence” (p. 581). According to Koydemir-Özden and Tosun (2010), mothers of children with ASD have more stress and depression than mothers of typical children and other disabilities. They may feel that their personal lives are limited and that they do not have an opportunity for a social life with their friends (Koydemir-Özden & Tosun 2010).

Leiter et al. (2004) argue that when we compare mothers of children without disabilities with mothers of children with disabilities that maternal caregiving is less intense and complex among mothers of children without disabilities. This is because mothers of children with

disabilities need more time to take care of their children and to educate themselves about caring for their children with disabilities (Leiter et al., 2004). These mothers also need to work closely with professionals and health providers. In a sense, they must become experts about their children's disabilities. Green (2003) suggests that mothers with children who have special needs do not have time for their friends and family because of daily obligations such as medical treatments and other disability-related activities. A study conducted by Barnett and Boyce (1995) compared mothers of children with Down syndrome and typical children. Mothers who have children with Down syndrome decreased their time in paid work, increased their child care time, and decreased their social activity (as cited in Leiter et al., 2004). I was interested to see if the mothers taking part in my study reported similar experiences.

Mothering and taking care of children with disabilities can be difficult for mothers (McGraw & You, 2011). Mothers may have different feelings about raising their children with disabilities, and those feelings can have a significant impact on these mothers' lives (Brock, 2014). According to Brock, "Not only does it force women to recalibrate the fundamental practical concerns of everyday life, but having a child with a disability has a profound effect on women emotionally, and in many cases alters the way they see themselves as individuals" (p. 26). Mothers are the individuals who are most likely to be responsible for the decisions that are made for their children's health (Jackson & Mannix, 2013). This responsibility can take a lot of time and effort and can be stressful in its own right. As well, McGraw and You (2011) suggest that raising children with ASD can be stressful, emotional, and burdensome because mothers are responsible for teaching their children basic skills and improving their abilities. This can require a lot of patience

and time, putting a strain on the parents who may have other children to care for or demanding jobs.

Interestingly, Leiter et al. cite research that suggests that mothers of children with disabilities are as likely as mothers of children without disabilities to enter the labor force, “despite documented difficulties in obtaining appropriate child care for these children” (p. 383). It may be possible that some of these mothers have little choice but to work. It can be expensive to pay for services for a child with special needs. Certainly, single mothers must work to support their families.

Parents of children with autism also reported a feeling of being deserted by their family members because of their children's disability. Parents in the Altieri and Von Kluge study (2009) reported a lack of time for their friends because they spent most of their time taking care of their children. Parents who had typical children before or after having their children with autism reported additional challenges, as the typical children felt discriminated against as they watched their parents provide extra care to the child with the disability (Altieri & Von Kluge, 2009). The main reasons for stress during this period are the parents' feelings of sadness and anger and also because the diagnosis of autism is often ambiguous. Parents of children with ASD will often feel increased stress when they realize that there is no cure for this particular condition. Predictably, parents of children with autism reported more stress than parents of typical children (Altieri & Von Kluge, 2009).

Not everyone finds the experience of caring for a child with disabilities to be an extraordinary stressor. Taking care of children with disabilities may be pleasing and enjoyable for some mothers (McGraw & You, 2011). Some mothers feel happy and proud of their children with

disabilities and are positively focused on improving and maintaining their children's health. According to McGraw and You, some mothers of children with disabilities see themselves as advocates not only for their own children but for other children with special needs as well (McGraw & You, 2011). Altieri and Von Klug (2009) report that the parents in their study described the hope and joy they gained through their experiences raising their children with autism. Some parents said that they are able to get excited about minor improvements in development that would not have been noteworthy in typical children. Some said they learned greater patience through the experience. One mother described her son as a “happy child” and said she has high hopes for his future. As one father in the study put it, “I now realize that autism is not a death sentence” (p. 149).

Mothers in the Lalvani study (2011) had positive perceptions toward raising their children with Down syndrome. Mothers indicated that their experiences are as satisfying as those of other mothers who have typical children. They reject the idea of having difficult experiences, suffering from high stress, and falling prey to feelings of grief. According to Lalvani, “Their children have enriched them in ways that they had not previously imagined possible” (2011, p. 287).

Mothers of children with Down syndrome in the Lalvani study suggest that life changed for them when they had their children, as one might expect. However, they described their own lives and those of their families in much the same way as parents of typical children. They reveal that they have “a wide range of expectations, demands, and challenges” unique to their situations, but that they still feel that their experiences are the same as other mothers who raise typical children (Lalvani, 2011, p. 288).

### **ASD's Effects on Families and on Mothers**

In the following section, I reviewed what the literature suggests about ASD and religious expectations, cultural beliefs, gender relations, support or lack of support, shame and stigma, hope, social-economic class, and maternal education and their impact on the family. I needed to understand more about the particular backgrounds and situations of mothers taking part in my study. Of course, these factors must be considered within the context of their marriages and families. Hussein et al. (2011) suggest that even parents from the same cultural backgrounds may hold vastly different beliefs, based on their level of “acculturation, socioeconomic status, and education” (p. 12). For this reason, I asked the mothers in my study to tell me about their education and socioeconomic status.

**Religious expectations.** Religious expectations can affect parents’ acceptance and their choices when they are seeking treatment for their children with autism (Alqahtani, 2012). Several studies suggest that Islamic parents of children with disabilities may view their situations as the will of Allah (Crabtree, 2007a). In fact, a mother’s ability to accept the disability of her child, Crabtree says, can be “integral to their acceptance of Islam” (Crabtree 2007a, p. 56). Notably, one mother in Crabtree’s study suggested that acceptance of her child’s disabilities and her belief in Allah are one and the same. According to that mother, when recollecting her own early shock at her child’s diagnosis, others around her responded by asking her, “What, don’t you believe in Allah?” (Crabtree, 2007a, p. 56). Crabtree suggests that parents who accept the disability as Allah’s will brought “not merely compensations but actual blessings” upon the home (p. 56). Religious piety constructed in this positive way brought strength and resilience in such families, Crabtree suggests.

In Alqahtani's study, interviews with participants uncovered a religious belief that autism could be treated by reciting some verses of the Al-Quran. Alqahtani also found that at least one study participant had employed the services of a religious healer for reciting Al-Quran and for healing her son's "autistic features" (p. 19). Many parents in Alqahtani's study believed that spiritual intervention would benefit their children. Those parents chose to read passages from the Holy Qur'an to their children and to seek advice from religious healers.

Another study by Jegatheesan et al. (2010) suggests that Islamic beliefs frame parents' thinking about their children with ASD. Included in the parent's religious belief system are morals, loving attitudes, resilience as parents, being tasked as the protectors of Allah's gift (the child), fate, and a spiritual connection to the child. Some Islamic parents of children with autism believe that they have children with a disability because they (the parents) did something wrong in their past. They see the disability as a punishment from Allah. Other Islamic parents of children with disabilities participating in the Jegatheesan et al. study believed that because they have high morals and great love for their children, they are blessed with the strong challenge of a child with disabilities as a special gift from Allah. According to one parent in the Jegatheesan et al. study, "I think Allah found that we have the capability to handle it. We have the strength to deal with it. Not to be rude to him (their son). I mean not to blame the child, but love the child very much" (p. 102). According to Jegatheesan et al. these families had positive feelings toward their children; they did not feel any suffering or complain about having a child with ASD. In their view, to complain about having a child with disabilities would mean that they would be complaining about Allah's will and knowledge.

These parents sometimes faced cultural clashes with teachers and professionals during the assessment and therapy that was provided to their children. This is because these parents believed that the will of Allah and His ability to help their child should not be avoided. Interestingly, one family in the Jegatheesan et al. study suggested that fate and destiny caused them to have a child with disabilities. According to the mother in that family, “I never thought that having a son with autism is an unfortunate fate. I don’t think that way about having a special child. I believe that I am part of something that was decided for me before I was born” (p. 102).

The Crabtree study (2007a) also explored how mothers of children with disabilities positively or negatively accepted their children. It considered whether mothers believed that their children with special needs were from Allah as a punishment (Crabtree, 2007a). Crabtree suggested that parents in her study sometimes experienced guilt, thinking that their children were disabled because Allah wanted to punish or test them. Another feeling Crabtree described is one of shame for having children with disabilities, again, linking the disability to wrongdoing on their part and punishment. Because of their religious beliefs, some participants in Crabtree’s study did not seek better practices and health care for their children with disabilities.

Crabtree's study, along with the Jegatheesan et al. study mentioned above, suggests that Islamic parents of children with disabilities can have different attitudes based on religious beliefs. Some described difficulty in accepting their children's disabilities and had low expectations for them. Some did not look to others for help. At the root of these behaviors and beliefs was a lack of appropriate resources and/or an overarching belief that Allah handles all issues concerning their children (Bywaters, Ali, Fazil, Wallace, & Singh, 2003).

**Cultural beliefs.** Cultural issues often shape parents' views toward having children with special needs. Alqahtani (2012), who studied parents in Saudi Arabia, found that most parents in his study viewed autism through a cultural lens, which shaped their beliefs about the causes of autism. Parents in study cited a variety of causes for autism, including: the evil eye and black magic; trauma or loss in early childhood, and the resulting psychological effects; a lack of emotional attention from mothers; medical reasons, including misdiagnosis (and treatment) by doctors; breastfeeding; difficult pregnancies; the mother's vitamin B deficiency during her pregnancy; and vaccines such as the Measles-Mumps-Rubella vaccine (MMR). According to Alqahtani, parents' cultural beliefs also influenced the treatments they sought for their children with autism. For instance, some parents taking part in his study thought they could heal the condition with a diet that eliminated gluten and casein.

Many of these ideas are not unique to Muslim parents. According to Ravindran and Myers (2013), who studied Indian parents of children with autism living in Western culture, cultural factors can overlap with the parent's beliefs, thoughts, and faiths, and influence their treatment choices. Indian parents taking part in the Ravindran and Myers study considered disabilities as a punishment for some sin they had in the past, a "bad eye" received from another person, or other beliefs such as Karma. Most of them did not expect their children with autism to become successful, and many did not try to obtain appropriate services and rehabilitation. They focused on having to sacrifice and expected that their lives would have to be based around that sacrifice.

Ennis-Cole et al. (2013) also considered the cultural beliefs of parents of children with autism. Parents will choose treatment for their children that is consistent with their religious and cultural beliefs. For example, some parents in the Ennis-Cole et al. study believed that autism

could be caused by genetics, environmental factors, and problems during pregnancy and childbirth. Within American culture, different ethnic groups have their own understanding of faith and beliefs about the causes of autism. For example, some white Americans in the Ennis-Cole et al. study believed that physical elements contribute to the onset of ASD, including giving children too many immunizations at one time or too many immunizations at too young an age. Some black Americans in the study believed that the causes of autism might be related to issues with diet, particularly processed foods (p. 280). On the other hand, some Asian Americans in the Ennis-Cole et al. study said that they have children with disabilities or ASD because of sins they committed in their past life (2013).

The Bywaters et al. research in the UK studied Pakistani and Bangladeshi parents who have children with disabilities to learn about their attitudes, expectations, and beliefs about their children's abilities. Even though they believed that their child's life was in God's hand, these parents still did not want to seek assistance for their children and/or strive to provide the best care that they could. Parents did not want to share the care with others and were not willing to accept help (2003).

My study considers culture to be an important element in shaping a mother's perceptions relating to people with disabilities and how mothers perceive, experience, and manage health and illnesses. Just as ideas about disabilities vary among and within cultures, the concept of disability varies from one mother to another.

**Gender relation.** The relationship between a couple is the foundation of a strong family, as it is up to parents to ensure and provide security and peace for their children. When parents have children with disabilities, they may have marital conflict. In Middle Eastern culture, mothers are

the primary caretakers for their children, and there is little paternal involvement. Often, mothers are blamed for their children's disabilities. Azar and Badr suggest that mothers in that culture are more likely to express stress than fathers (2006). Conflict can lead to weakened relationships between a mother and a father, which can lead to divorce, or (in some cultures, including the Muslim culture) polygamy and repudiation.

According to Crabtree (2007a), "Childbearing issues on the wife's side are deemed sufficient reason for a Muslim husband to take a second wife under Islamic principles governing polygamy" (p. 55). Thus, when a first wife has an issue with her pregnancy or with childbearing, her husband has the option to marry another woman to ensure that he can have typical children. Another reason men in Islamic culture can marry another wife is if his first wife is sick (Alyaemni et al., 2013). One of the mothers in the Crabtree study indicated that "no one wants a woman with a disabled child because they are afraid that other children born afterward would also be disabled..." (2007a, p. 54). Some mothers in Crabtree's study mentioned that because they had children with disabilities, they feared that their marriages would end in divorce or there would be a chance of their husbands marrying other wives (Crabtree, 2007b). Koydemir-Özden and Tosun (2010) indicate that in their study a mother was divorced because her husband blamed her for having a child with ASD. Other mothers said that having a child with special needs led to much poorer relationships with their husbands.

In Saudi culture, when adult children have marital problems, their families may be moved to intervene to attempt to resolve the problems. Their roles are "reconciliation or arbitration" (Algahtani et al., 2017, p. 109). For example, one couple in the Algahtani et al. study had a child with ASD. The woman left her marital home and went to her parents' home because her husband

had hit her. Her father-in-law attempted to resolve the conflict by apologizing to the woman's father for what his son had done. Alyaemni et al. (2013) reported that Saudi Arabian mothers in their study were embroiled in marital conflict whenever they themselves got sick and were unable to care for their children. Raising a child with autism can be difficult and complicated for parents because "economic pressures increased, and the needs of family members are ignored to a great extent" (Koydemir-Özden & Tosun 2010, p. 64).

Interestingly, some parents in the Altieri and Von Kluge (2009) study reported positive effects from raising a child with autism. For example, couples said that they became more supportive of one another and that they refrained from using drugs so they would have more time for their families. In my study, I sought to learn how my participants resolved marital conflicts, whether by themselves or with the involvement of their own families or their in-laws.

**Support or lack of support.** Support or lack of support for parents was an important consideration in my study. Although parents of children with disabilities can get support from social workers, they still need less formal support from society (Altieri & Von Kluge, 2009). When parents of children with autism are unable to get the support they seek from their families, the lack of support can lead to estrangement (Altieri & Kluge, 2009). Other parents in the study reported greater success when they looked to other people for recommendations and support. They were able to seek advice to help them and their children (2009).

Some parents in the Altieri and Kluge study reported a similar lack of support from their religious communities. In contrast, one parent in the same study reported that she had constant support from her church, which provided the family with financial and emotional care (Altieri & Von Kluge, 2009). Similarly, in the Ennis-Cole et al. study (2013), some parents said that they

were able to find relief and support from their faith communities to help them emotionally and socially (Ennis-Cole et al., 2013).

Parents of children with autism are sometimes able to enjoy considerable support from friends who accept their children's disorders (Altiere & Von Kluge, 2009). Most of the parents in the Altieri and Von Kluge study came to value the friendships and support of others very highly. Because of that support, they reported that they were able to develop positive feelings of hope toward their children.

Interestingly, some mothers in the Azar and Badr study said that they preferred not to get social support; they preferred to stay away from their communities and isolate themselves (p. 379). They said that they chose to stay in their homes to avoid any stigma toward their children or even toward themselves. It is possible that mothers with such attitudes may feel that it is their responsibility alone to take care of their children (Azar & Badr, 2006). Azar and Badr suggest that families in their study may be so overburdened by the responsibilities of caring for their special needs children that they are not able to seek social support or to establish relationships with others. They suspect that depression may prevent some parents of children with disabilities from seeking such support.

McGraw and You indicate that most mothers in their study are reconciled with their children's disabilities and feel comfortable communicating with other mothers who have children with ASD. They can share the issues and pain they experience (2011). Another example of mothers getting support from others was described by Bywater et al., who said that older family members were the only support system for the mothers in their study. Parents looked for their family members to get more support because of a lack of appropriate services (2003).

In contrast to these results, one study of mothers of children with ASD in Kuwait found that the mothers' relationships with their husbands did not change. These mothers felt that they received support from their husbands, family, and friends and reported that they were able to enjoy their lives (Al-Kandari et al., 2017). This study was different from other studies because mothers were not looking for support from others such as medical staff, support groups, and professionals. In fact, when they did seek such support, they reported that their enjoyment of life decreased (Al-Kandari et al., 2017).

According to Alyaemni et al. (2013), Saudi Arabian mothers said that they lacked support and were embroiled in marital conflict whenever they themselves got sick and were unable to care for their children (p. 752). In my research, I explored the kinds of support my participants receive and how those supports affect their mothering experiences.

**Stigma and shame.** Stigma and shame are additional features that were important to consider in my study. From the Islamic perspective, people are expected to respect and provide extra help to those who have special needs (Crabtree, 2007a). Stigma and shame are still issues in any region in the world even if the area is highly developed and open-minded. For my study, shame and stigma focus on how people look upon disabilities and particularly, the mothers of children with disabilities.

According to Green (2003), "The issue of public perceptions of and reactions to individuals with disabilities has long been of interest to social scientists" (p. 1361). The Crabtree (2007a) study indicates that mothers had different experiences with discrimination in public. Crabtree (2007a) studied mothers of children with developmental disabilities in the UAE. Some of those mothers told Crabtree that they believed that their children with disabilities were objects of discrimination

within their cultures. One mother in the Crabtree study shared a story in which a religious leader told her that she should not take her son with special needs in public, but rather, keep him “locked up” at home (p. 37). On another occasion, another parent warned her daughter to stay away from a child with disabilities because he was “dangerous,” (p. 37).

Green (2003) states that the mothers in her study at first had negative attitudes about having children with disabilities, but that after their mothering experiences, their thoughts and outlooks changed. Mothers sometimes feel that they have to explain to others about their children’s disabilities and they may face internal turmoil because of having to give those explanations, especially when others blame them for their children’s disabilities (Green, 2003). In Green’s (2003) study, one mother reported that her mother-in-law blamed both parents for the disability and told them that they were responsible for having a child with special needs. Such experiences can cause emotional turmoil for the parents of children with disabilities. It can be extremely challenging to deal with such blame and criticism from close family members and from the public.

Mothers in the Green study felt upset and angry because of the outside stigmatization. Eventually, that led them to feel guilt and pain. Some mothers in the Green study reported that they used positive strategies to reduce the stigmatizations from others by ignoring the comments and using humor to make others laugh (2003). They also used humor to manage their own emotions and to educate others. Furthermore, Lalvani (2011) reported that some mothers said that their children with Down syndrome were “devalued in society” and faced “social isolation, exclusion, or a lack of acceptance in society” (p. 286). These mothers feared for their children’s futures, wondering if they would be “invisible, ignored, or excluded in their peer groups” (p. 286).

Azar and Badr (2006) studied mothers of children with intellectual disabilities in Lebanon and also reported a cultural belief that it is preferable to keep children with disabilities at home. Most mothers taking part in the Azar and Badr study said that they prefer to isolate themselves and keep their children at home “to avoid stigmatization and criticism” (p. 379). A high percentage of mothers (46.5%) in the Azar and Badr study reported depressive symptoms (2006). It is possible that raising a child with disabilities in a culture that may criticize and stigmatize the child contributes to this high level of depression.

Parents of children with ASD from Oman who took part in the Al-Farsi, Waly, Al-Sharbati, Al-Shafae, Al-Farsi, Al-Fahdi, Al-Adawi, (2013), study and who had low and middle-high incomes had the same view of “eyes of others” (p. 1219). They preferred for their children with ASD to stay at home instead of going to public places. They did not want their children's non-typical behaviors to attract attention to them (Al-Farsi, et al., 2013). As Al-Farsi et al. explain, “In the traditional Omani society, preserving external harmony in a communal society is paramount. Therefore, caregivers are likely to ground their disabled children at home so that they may not disturb ‘other’” (p. 1219).

**Hope.** Hope is another factor to consider in my context of studying Saudi Arabian mothers of children with autism. Crabtree (2007b) conducted a study in the UAE to learn more about mothers' hopefulness toward their children's abilities in the future. Some mothers were very hopeful. They believed that their children with ASD could have pleasant, productive lives. They wondered if their children could be trained to perform tasks that would make them employable. Some believed that their children would eventually live independently from them and even marry men or women with similar disabilities. In Gray's study, some of the participants had hopes that

their children with ASD would live a “near normal life” as typical people do (2015, p. 220). This is extremely important because mothers of children with ASD may be concerned about what will happen to their children when they themselves get old and die (Gray, 2002; Koydemir-Özden & Tosun 2010).

**Socio-Economic class.** In my research, it was interesting to see how participants' socio-economic and social class affected the likelihood that they would seek services for their children with autism. According to Ravindran and Myers (2013), parents' education levels, socioeconomic status, beliefs from a cultural viewpoint, and levels of awareness about disabilities may correlate to their actions to seek and appropriate interventions for their children with autism.

Azar and Badr (2006) indicate in their study that low-income mothers had relatively higher levels of stress, compared with mothers who had higher incomes. Wealthier families felt more empowered than families from lower incomes. The former can have “attitudes, knowledge, and behaviors which can be expressed at the family” (Koren et al., as cited in Casagrande & Ingersoll, 2017, p. 2387). Wealthier mothers in the study reported that they had more resources available to help them cope with stress (Azar & Badr, 2006). Furthermore, the wealthier parents could travel to other countries where the best services and solutions for their children are available (Al-Farsi, et al., 2013). Wealthier families are also able to employ different services such as “educational psychologists, occupational therapists, speech therapists and teachers for special needs” (Al-Farsi et al., 2013, p. 1219). When parents have high incomes, they may know more about how best handle their children's disabilities (Young & Roopnarine, as cited Koydemir-Özden & Tosun 2010).

Middle-class parents also reported having difficulties with finances because insurance companies do not always offer coverage for evaluation and treatment for children with ASD (Altiere, & von Kluge, 2009). Evaluations and treatments can be costly, causing parents to experience financial problems (2009). For example, some middle-class parents of children with ASD in the Altieri and von Kluge study reported having to take out a loan, sell land or a boat, and use retirement funds to pay for their children's care. One of the parents reported that the family used to donate to charities but could no longer afford to do so, given how much money was required to care for their child with ASD (Altiere & von Kluge, 2009).

Mothers may feel that they cannot or should not any longer work outside the home because of their children with ASD. For example, in the Altieri and von Kluge study, most of the mothers quit their jobs after they found out that their children have ASD, significantly lowering the family income (2009). In the Al-Farsi, et al. study, eight percent of mothers from middle-high income resigned from their jobs because they had to care for children with ASD (2013). This may be because middle-high income families are likely to spend more hours of their time each month taking care of their children with ASD (Al-Farsi et al., 2013).

One interesting finding is that Kuwaiti families of children with disabilities are living with higher incomes than similar families elsewhere. The Kuwaiti government provides those families with a monthly allowance because they have children with disabilities. This reduces their stress and eliminates or lessens the burden of looking for extra financial resources (Al-Kandari et al., 2017). In Saudi Arabia, every person with a disability receives both a monthly and an annual allowance, each determined by the disability. For children with ASD, the monthly payment is about \$213 or \$2,666 annually.

Low-income families must find another way to get more support from a welfare system (Al-Farsi et al., 2013). These families can be more likely to consume psychiatric services than higher-income families. Higher-income families may have the means to go to private centers, travel abroad for better services, or to provide in-home help for their children (Al-Farsi, et al. 2013). Moreover, a higher-income family may believe that it is a stigma to seek psychiatric services.

Leiter et al. (2004) suggested that having children with lifelong disabilities affects parents' financial wellbeing. Leiter et al. explained that children with special needs require outside help from professionals who specialize in their needs. Families that include a child with disabilities often require therapies in their homes and extra lessons to help their children improve (2004). Such resources can be quite costly. Furthermore, as already suggested, when mothers have children with disabilities, they may cut down their hours in their jobs or become full-time caretakers for their children. They may stop working because of the intensity of their children's needs (Leiter et al., 2004). Mothering a child with disabilities can most clearly affect employment, causing “either reduction of employment or cessation from employment” (p. 391). All of these factors take a toll on family finances. Socioeconomics can also be a factor in receiving early intervention, planning, education, and any technologies that are used to help children with ASD (Ennis-Cole et al., 2013).

**Maternal education.** There are two points of view on maternal education influences a mother's level of stress. Mothers with higher levels of education report lower stress and conversely, mothers with a lower level of education report a high level of stress (Azar & Badr, 2006). Furthermore, when mothers have less education, they are less likely to stop working. As Leiter et

al. (2004) aptly put it, “Family income is more dependent on the [financial] contributions” of the mother (p. 398).

More highly-educated mothers in the Leiter et al. study perceived themselves as having more choices to juggle their multiple roles. As well, a mother who is highly educated signals to others, including her children, that education is attainable (Leiter, 2004). Mothers with a higher level of education were more likely to try to make a better life for their children, and for themselves as well, than lower-educated mothers, who showed more tendencies to worry without being able to improve their lives (Azar & Badr, 2006).

Conversely, Al-Kandari et al. (2017) suggest that highly-educated mothers feel more stressed and are more often worried about their children's futures than are uneducated mothers. Those stresses and worries, in turn, make them less able to enjoy their lives.

These findings suggest important implications for my study. It was essential for me to determine the education level of my participants. I needed to see whether or not there is any correlation between the mother's level of education and her levels of stress and worry, as Al-Kandari et al. suggest. As well, I needed to explore whether there is a correlation between education level and the mothers' perception of having choices, as the Leiter et al. study suggests.

Crabtree (2007a) suggests that the level of mothers' education influences how likely they are to gain access to information. Mothers with higher levels of education in the Crabtree study were more likely to use the Internet, read articles, and look for community services for their children. In contrast, poorly-educated mothers found it difficult to use such resources (Crabtree 2007a). Though a mother's level of education and income will influence mothering in many ways, it does not seem to affect the chances that the child will receive intensive levels of in-home health

care (Leiter et al., 2004). Thus, while socioeconomics comes into play to some extent, there are some experiences and feelings that all mothers of children with disabilities will share, regardless of maternal education or income level. What stands out from the research, however, is that less-educated and poorer mothers of children with disabilities will have more negative attitudes and outlooks (Crabtree, 2007a).

As education for women in Saudi Arabia continues to improve, and most hold at least a diploma, I believe that mothers' awareness, thinking, and beliefs about disabilities are changing. In my study, I sought to explore my participants' education and to consider how, if at all, it influences their experiences and beliefs about raising a child with ASD.

### CHAPTER 3: METHODOLOGY

This research studied the mothering experiences of Saudi Arabian mothers who have children with Autism Spectrum Disorder (ASD) and are living in the United States. This chapter presents the research methodology and my reasons for choosing qualitative and narrative inquiry for my study. The chapter also discusses the four directions of narrative inquiry space, as well as the strengths of narrative methodology.

#### **Qualitative Research**

This section presents the definitions, the characteristics, and the purpose of using qualitative research in the current study.

**Definitions and characteristics of qualitative research.** Qualitative research helps us to understand the experiences of the human being (Bölte, 2014). The researchers are the main instruments of the research because they use multiple ways of collecting data such as interviewing, observing, and field notes in nature setting (Creswell, 2013; Savin-Baden & Major, 2012). Qualitative research depends on showing reality and the nature of the world as paradigms and has many philosophical stances (Savin-Baden & Major, 2012).

According to Ganong and Coleman (2014), “Qualitative interviews consisting primarily of open-ended questions allow individuals to explain in their own words what they think, feel, or believe about their family relationships” (p. 452). Ganong and Coleman also suggest that qualitative interviews help people to express their “lived experiences” and provide opportunities for them to express their feelings and thoughts with their family members (2014). Qualitative research helps us to capture how people believe they live their daily lives.

My research has enabled participants who have been marginalized to share their unique stories and to describe their experiences. The primary purpose of this study is to provide individuals on the fringes of society a venue to express their unique stories. As such, a qualitative methodology has been the best methodology to use for this research.

### **Narrative Inquiry**

My study further aims to identify common structures in experiences and to identify and name patterns in and among participants' stories. Narrative inquiry is appropriate because "it names the structured quality of experience to be studied, and it names the pattern of inquiry for its study" (Connelly & Clandinin, 1990, p.2).

**Definitions of narrative inquiry.** Narrative inquiry identifies and describes how people understand their own lives. According to Clandinin (2006), narrative inquiry is a way of thinking about experiences. Ayers and Miller (1997) suggest that the practice of narrative inquiry "considers the individual act of storytelling as well as how researchers select, shape, and present stories to stimulate engagement with a broader audience" (cited in Holley & Colyar, p. 680). As Moen (2008) states, "Narrative research is the study of how human beings experience the world, and narrative researchers collect these stories and write narratives of experience" (p. 56). Through narrative inquiry, I provided my participants with an opportunity to describe their experiences and identify the way that past events might influence their thinking and behaviors, both now and in the future.

Connelly and Clandinin (2000) further suggest that narrative is both a phenomenon and a method. This is significant for my study. Narratives as a phenomenon can capture participants'

feelings, thinking, faith, and beliefs. Narratives as a methodology provide a scholarly way to analyze participants' stories and experiences.

Across cultures, people present their lives as stories. They tell their stories to other people to share their joys, struggles, and triumphs. Although we can enjoy the telling and sharing of stories, narrative inquiry goes much deeper. The researcher's task is to collect stories, analyze them and write about them while applying the narrative methodology (Connelly & Clandinin, 1990). Thus, we say that "people by nature lead storied lives and tell stories of those lives, whereas narrative researchers describe such lives, collect and tell stories of them, and write narratives of experience" (Connelly & Clandinin, 1990, p. 2).

A narrative inquiry was undertaken as a lens into the complexities and lives of the mothers in this study. Central to narrative inquiry is the contention that stories give meaning to people's lives. Thus, stories are treated as data. Clandinin and Connelly (2000) assert that experience happens narratively, and that narrative inquiry is, in a sense, a kind of narrative experience. I was interested in what stories tell us about each mother's self and the nuanced way in which life is lived.

Riessman (1993) suggests that people can use their personal narratives to construct their past events, and in so doing, they can claim their identities and their lives. In my study, my participants shared stories from their own experiences. They were able to choose what they wanted to share about their lives, and what experiences they wanted to omit from their stories. They were able to bring their cultural and social frameworks into their narratives, which shaped their stories (Clandinin, 2006). I hypothesize that the obstacles shared in the narratives have shaped the

participants' perspectives and beliefs and that the mothers' narratives have influenced the ways in which they interact with others.

The narrative approach is used in different fields of inquiry such as medicine, health, and social science (Lai, 2010). Researchers in these fields focus on specific experiences and stories to help them understand their participants' lived experiences (Lai, 2010). Narrative methodology can also be used to seek out participants who fit the researchers' criteria. It can enable researchers to choose the appropriate data collection techniques that fit with their research questions. It can also help them transcribe and analyze the data and locate themes and patterns. Moreover, it can help researchers collaborate with their participants as they negotiate the relationship, purposes, transitions, and ways to be useful (Creswell, 2013).

People naturally tell stories. As a result, narrative and self are inseparable because we use narrative to understand ourselves and our experiences. Thus, narratives shape our relationships with others (Ochs & Capps, 1996). As a researcher, I am aware that the narratives I have collected reveal what Ochs and Capps refer to as the "apprehended partial self" (p. 22). The mothers would reveal only parts of themselves through their stories. There would be much more to them than I would be able to know within the context of my research study.

Ochs and Capps also suggest that even though the mothers may have been thorough in their storytelling, the tellings of personal experience are always "fragmented intimations of experience" (p. 21). Similarly, my knowledge of the mothers in my study is limited to the experiences and stories that they chose to share with me. As Bruner writes, "A life lived is what actually happened. A life experienced consists of the images, feelings, sentiments, desires, thoughts, and meanings known to the person whose life it is" (cited in Moen, 2008. p. 63).

**The four negotiations of being in the field.** Both researchers and participants who enter the inquiry field bring a lifetime of experiences with them and have lives that continue after leaving the field. When entering the field, they were therefore in the midst of their life stories. Their lives and their stories have continued even after my study concluded (Clandinin & Connelly 2002, p. 63).

It was important that when I asked questions in the field, I maintained flexibility in what would potentially be a continually evolving landscape. I also needed to remain aware that I brought into the field my personal narrative of experience, that I had done my own “living, telling, retelling, and reliving” (p. 70). Clandinin and Connelly (2002) explore four key negotiations that helped me maintain this flexibility. These are negotiating relationships, negotiating purposes, negotiating transitions, and negotiating a way to be useful. Clandinin and Connelly (2002) suggest further that from within the field that the initial arrangements between investigators and participants are “tenuous and always in the midst of being negotiated” (p. 72). Furthermore, all of these negotiations occurred during each encounter and interview that I conducted with my participants.

*Negotiating relationships.* As I negotiated relationships with my participants, I was aware that initially, our relationships might not be strong because we were strangers to each other (Clandinin & Connelly 2002). The participants might or might not have been willing to talk about their personal stories with me during our first meeting. It is possible that they were cautious and guarded because I asked them about private, personal, and sensitive information, such as their relationships with their husbands and their extended families. It was important for me to share with them that their experiences and stories would not only help me but also that they had the opportunity to be the first Saudi Arabian mothers of children with autism to share their experiences

in a research study on this topic. Knowing this, they felt that they could, at last, describe a problem that gets little recognition or attention and in so doing, they could help bring about needed change.

Furthermore, I believe that I had an advantage in entering this particular field of inquiry, as I am a woman and a mother from the participants' country, who spoke to them in their own language. Drawing from my own experiences, I was able to understand participants' feelings of hurt, frustration, or shame that stem from conflicts with spouses and extended families in this culture. I believe that I was able to gain participants' trust by reminding them that every house in the world has obstacles and complications within it. I was willing to share personal information about myself, such as my education and my experiences living in the United States, with the hope that doing so would strengthen my relationships with my participants and make them more comfortable opening up to me.

I used several tactics to avoid the obstacles and pitfalls that I knew I might encounter. First and foremost, I tried to respect my participants' experiences when they talked about their struggles, sadness, fears, and happiness. At times, I expressed empathy but was mindful not to register shock or disapproval. Because I am not the mother of a child with autism, I knew that I could not presume to know everything about their experiences and struggles. In some instances, participants grew silent at points in the interview. In other cases, the mother was shy or reluctant to speak, making it difficult to talk openly. In these situations, I had to act to get the participant to open up to me. This included asking questions or saying something that would motivate her to speak freely and without restriction. I also assured each participant that her stories would be shared with other mothers and that I would protect her identity.

As I tried to negotiate my relationships with participants, I found that there could be a significant gap between the participant's and my own “narratives of experience.” Simply put, a participant and I might not form a connection. Conversely, there could be a strong connection “born of the possibility of temporariness” that led to a “sad and wistful sense” (Clandinin and Connelly p. 72). The temporary nature of our relationship sometimes encouraged women to open up to me, but the bond we form would not last. As Clandinin and Connelly (2002) suggest, “We work in different places, have different purposes, and different ways to account for ourselves as researchers and participants” (p. 72).

*Negotiating purposes.* Negotiating purposes is heavily intertwined with negotiating relationships and provided evolving insight into my purpose as narratives were retold and my research progressed (Clandinin & Connelly, 2002). Just as I had my purposes for conducting the study and speaking with the participants, the mothers in the study had their own reasons for participating. The participants and I have much in common. We share the same culture, religion, and language. We are women, we are mothers of children in early childhood, and we are married to men from the same culture. All of this made me an insider. At the same time, there were differences between us beyond our purposes. I am an outsider because I do not have a child with autism. At the time, I had lived in the United States for nearly ten years. My experiences and my thinking could be both similar to and different from theirs. Knowing this, I had to remain flexible and aware of our similarities and differences as I negotiated my relationships with the participants.

*Negotiating transitions.* As the transition from the field and research was ongoing, I was in constant negotiations with the participants. Clandinin and Connelly (2002) state that the “most dramatic transitions are the beginnings and endings of narrative inquiries” (p. 74). When entering

the field of inquiry, I focused on transition strategies that established rapport. I started our interviews with easy questions to help participants feel at ease and worked up to the more difficult questions that asked participants to share sensitive stories and their feelings about them.

As I prepared to leave the field, I also made the transition as smooth as possible. I told participants what was going to happen next for me as I began analyzing the data and crafting my dissertation. I let them know that I will notify them when I have successfully defended my dissertation. I also promised to send them an abstract of my research study so they could learn about the themes and patterns that emerged from their experiences. In this way, my leaving seemed less abrupt to the participants, and I was able to leave the field less reluctantly.

*Negotiating ways to be useful.* My usefulness to participants also needed to be negotiated (Clandinin and Connelly, 2002). In the beginning, participants knew little of my experiences with and knowledge about children with autism. As our interviews developed, participants often determined that I could be useful to them as an expert source.

### **Strengths of Narrative Methodology**

When people tell their tales, they use different communicative modes to interact with others. They can use body language such as gestures and facial expressions to show whether they are angry or happy. This research focused on the spoken word. Because I lack training in art or artifact interpretation, I believe that oral storytelling has been the most comfortable and best way for me to understand mothers' experiences.

Narrative inquiry is, in a sense, a kind of narrative experience (Clandinin & Connelly, 2000). It is "the best way of representing and understanding experience" (Clandinin & Connelly, 2000, p. 18). According to Clandinin and Connelly (2002), narrative inquiries are collaborations

between researchers and participants “over time, in a place or series of places, and in social interaction with milieus” (p. 20). A strength of the methodology is that we experience and make sense of the world narratively (Clandinin & Connelly, 2000). Thus, it makes sense to study it narratively.

Another strength of narrative methodology is that it provided me an opportunity to interpret the data through the lens of my own experiences and stories. As Riessman suggests, “Nature and the world do not tell stories, *individuals* do. Interpretation is inevitable because narratives are representations” (p. 2). Riessman also suggests that narratives are relatively rare in qualitative interviews. She says, “Typically most of the talk is not narrative but question-and-answer exchanges, arguments, and other forms of discourse” (p. 3). Yet stories, though relatively rare, may provide participants with a way to talk about difficult experiences (Roth, 1993, in Riessman, p. 3).

### **The Researcher’s Relationship with Participants**

Narrative inquiry provides an opportunity for researchers to develop relationships with the participants in their studies. There are aspects of that relationship that the researcher must consider before, during, and after the interviews they conduct. Notably, they must consider positionality, reflexivity, identity, and power relationships.

**Positionality.** Positionality and reflexivity (below) are both important when researchers choose their philosophical stance (Savin-Baden & Major, 2012). Positionality refers to the position researchers take while choosing their research subject, participants, research context, and process (Creswell, 2013).

Certainly, my position in the research is unique. As an educator who has worked with children who have disabilities, I have a particular interest in the subject. I am a woman from Saudi Arabia and a mother. I am familiar with the culture and the context of my study. I entered the field of inquiry with my own experiences, perspective, and biases, and these must be taken into account when reviewing my data analysis and conclusions. With this in mind, I shared my position with research participants (to some extent). As Hampshire, Iqbal, Blell, and Simpson (2014) suggest, "... interviewers' positioning, in interaction with interviewees, can shape the process through which knowledge and understanding are arrived at and shared" (p. 218). As I negotiated my relationship with the mothers in my study, I believe that my positionality influenced the data I collected through interaction. As Hampshire et al. suggested, my appearance and experiences influenced the shape of the interview process (2014, p. 218).

Another aspect of positionality to consider in my research is the participants' position in the stories they shared with me. This includes "the narrator's positionings of self and others in the story told," and how they are "rooted in narrator-listener negotiation" (Quasthoff, 2013, pp. 132-133). As Quasthoff suggests, the narrative devices participants used helped them to "perform this function of managing the self as a certain type of actor "such as evaluator or victim or as a particular kind of person in the telling process" (p. 132). For example, participants may have told their stories to make themselves seem intelligent, kind, abused or misunderstood. With this in mind, I was careful to look for these devices and consider each participant's reasons for positioning herself in her stories as she did.

**Reflexivity.** Reflexivity is a way to demonstrate that the research has credibility (Dowling, 2006). It accounts for the fact that researchers reflect on and reveal their personal views during the

research process (Dowling, 2006,). Also, "personal reflexivity is described as self-awareness and mirrors reflection as a learning tool" (p. 8). Through reflexivity, I learned about both my participants and myself.

Furthermore, reflexivity is "an intersubjective process of vibrant tension between oneself as a subject and as an object" (p. 9). As the researcher, I was a subject in my study and also an object in my study, because I am a participant in the process. I told participants my purpose for studying this particular topic (Creswell, 2013).

According to Dowling (2006), reflexivity "involves being aware in the moment of what is influencing the researcher's internal and external responses while simultaneously being aware of the researcher's relationship to the research topic and the participants" (p. 8). Creswell (2013) mentions, "Researchers convey their background, how it informs their interpretation of the information in a study, and what they have to gain from the study" (p. 47). Though I have nothing to gain personally from the study other than my doctoral degree, reflexivity enabled me to have self-awareness toward my participants and the research environment. When I coded and interpreted the transcripts from my interviews with participants, it was important for me to be reflexive, and to consider how my own beliefs and experiences were shaping the process of my research.

**Identity.** When participants shared their stories and experiences, they revealed important elements of their lives (Spector-Mersel, 2011, p. 173). Every person has his or her own identity that shows that he or she is different from others. As Spector-Mersel suggests, "Self-narratives' direct object is ourselves. Thus, they relate to our life history: the collection of events and facts that constitute our lived life" (p. 173). No matter what role a participant may have played in the

story that she shared with me, she was always asserting her identity in that story. Even if the story were not, on the surface, about her, it would be about her lived life in one way or another. I considered the identity of the storyteller in every story. As Spector-Mersel suggests, “If a sense of identity is attained through the stories we tell ourselves and others, not only is identity *expressed* in narrative but also importantly, it is also *constructed* by it” (p. 173). Participants express and construct their identities through both their choice of stories and their storytelling devices. This remains true even when the stories are not accurate retellings of facts.

**Power relationships.** The relationship between participants and the researchers can influence the research study (Hollingsworth & Dybdahl, 2007). As Hollingsworth and Dybdahl suggest, “Power differences between researchers and the narrators they ‘study’ is an issue that appears in many narrative inquiries....” (p. 160). My participants may have perceived a disparity of power in our relationships. As the researcher, I knew more about my topic than my participants. As an educator who has worked with children with disabilities, I sometimes knew more than they did about autism. The very nature of our relationship as researcher and participant may suggest that I have more power in our relationship than they did. For instance: I shaped the research questions; I was the one asking the questions during the interviews; I did not share my personal stories with them the way that they shared their stories with me; and I would be analyzing and writing about their stories in my own words, considering what they tell me within the context of my study, not theirs.

While it may have seemed to participants that I had powers they did not, I believe that ultimately, they held a great deal of power, too. For one thing, I needed participants’ willing and full participation in my study. I needed them to complete all of our interviews, and I depended on

them to share their stories with me. Most of all, I was dependent on the quality of their stories, as these stories became the data for my analysis. Though different, my participants' power and my power have both come to play a role in my research.

### **Research Design**

**Purpose of the study.** My research was a study of how Saudi mothers who are living in the United States and have children with ASD experience and understand mothering. The research explored mothers' feelings and beliefs as they raised children with ASD. Through the research, I have sought to understand the participants' religious beliefs, thoughts and experiences, and how they influenced the meaning these women gave to their mothering as they raised children with ASD. Finally, the research study explored family responses to children with ASD and how those responses impact mothers' experiences of mothering.

**Theoretical framework.** The framework of my research study is the unique experience of mothering children with ASD within the specific cultural context of Saudi women living in the United States. I have considered many studies that focus on mothering and believe that my work can contribute new insights to this conversation. According to Jackson and Mannix (2004), there are limited studies focusing on mothering experiences.

At its best, I believe that mothering is a beautiful relationship between a mother and her children. The mother-child relationship is often challenging, as it includes difficult days and complications. I know from personal experience how difficult it is to understand a child's needs. Before I had my daughter, I did not pay close attention to mothering. While I had my own mother as an example and had seen relatives and friends care for children, it was not until I had my own child that I appreciated how difficult it was for my mother to care for her six children. When I

became a mother, I was shocked by the challenges. Suddenly, I had to be aware of everything in my daughter's environment and anticipate her needs. It took me more than six months to adjust to my new role as a mother.

I think that a mother often sacrifices herself for the welfare of her children. In that way, she loses some of herself and some of her identity as a woman. Brock (2014) describes the role of mother as one in which a woman "sacrifices herself and her desires for the sake of a child: a mother undergoes so many unexpected and unanticipated changes and feelings that she risks losing her sense of self" (p. 22).

According to Lalvani, most mothers in his study discussed how challenging, difficult, and frustrating it had been for them when they became new parents. Their daily lives changed depending on their children's needs (2011). The experience for mothers of children with disabilities is even more challenging and more stressful, because of their children's medical needs and medical appointments (Lalvani, 2011). Mothers in the Lalvani study acknowledged that their additional stress did not mean that mothers of typical children do not have stress as well. All mothers – whether their children do or do not have disabilities – are living a similar experience (2011).

Before getting married and having my daughter, studying was relatively easy and carefree. I was responsible only for myself. Once I became a wife and mother, everything changed. Guilt became part of my daily life. When I began my doctoral program, I felt a great pull to be at home with my daughter instead of studying. Sometimes, I blamed myself for not taking the best care possible of my child, my husband, and myself. I sometimes felt my mother took better care of her family than I took of my own. As a new mother who was immersed in my studies, I believed that

I was not enjoying the mothering experience in the same way that other mothers enjoyed their experiences. After thinking long and hard about my situation as a mother and as a student, I decided to change my thinking. Since then, and even today, I try to think more positively about being a mother who is a student. My guilt, though still there at times, has decreased, and my increased happiness spills into my family. I now believe that when I succeed in completing my doctoral program and in mothering, my success will be my family's success as well. "The women's narratives reveal that the burden of blame takes its toll on women and might be experienced as guilt, feelings of inadequacy, anger, and self-blame" (Jackson & Mannix, 2004).

Along with guilt (which I have felt), many mothers go through cycles of blame – being blamed, blaming themselves or blaming others. For instance, some mothers might blame themselves for having children with ASD. They might believe that they did something wrong during their pregnancies, or that the ASD is a result of their experiences with depression. In other cases, mothers might blame their husbands, believing that the child's ASD is a result of a conflict that they had during the pregnancy, or that the ASD was caused by the husbands' lack of attention to the mothers' mental health during pregnancy.

For mothers, parenting is described in (Lalvani, 2011), "as presenting a wide range of expectations, demands, and challenges, and articulated beliefs that difficulties and stressors are inherent in raising any child" (p.288). Jackson and Mannix (2004) also explore the role of blame in the mothering experience. In their account of one woman's experience, they write:

Her difficulties at the time of her daughter's pregnancy were related to the pressures of mothering another of her children. Yet she still judged herself as a neglectful mother. Evident through the narrative was the idea that women might collude in blaming themselves for things that realistically might be well outside their own control. This had devastating effects on the women's self-esteem, health and well-being." (Jackson & Mannix, 2004.p.154).

Looking across the subjects of their study, they identified “mother blaming” as:

A phenomenon that comes at women from all angles; from family, friends, and society at large, as well as from helping professionals and the women themselves. Mother blaming was clearly revealed as an issue of concern for the women as mothers, particularly when seeking professional assistance to help resolve health and other problems with their children” (Jackson & Mannix, 2004. p.155).

In my study, I was curious to see how others viewed my participants, and the role that blame might play in their experiences of mothering children with ASD. I wondered if, like the Jackson and Mannix study, my study would “reveal that the difficulties and stressors associated with mothering can be compounded by maternal self-blame, as well as the blame and negative judgment of others.” (Jackson & Mannix, 2004). According to Valle and Gabel (2010), “Nothing makes a mother try harder to be there more perfectly than the education of her child. After all, a child’s success in school that leads to success in life—the ultimate confirmation that one is indeed a ‘good mother’” (p. 192).

In a story about a woman named Alexandra, Valle and Gabel note that “There is more than one way to understand, nurture, and respond to children.” (p.198). Alexandra's story also suggests that her mothering experiences with her child with a disability are different from her experiences as the mother of her typical daughter (Valle & Gabel 2010). Valle and Gabel (2010) shared the story of a mother who believed that because she had a child with a disability, she did not pay close attention to her daughter, who was a typical child. Alexandra explained, “I am paying more attention to him [her son with a disability] and ignoring my daughter. Because they make me – I am always concerned about him [her son]” (p. 199).

Mothers often know how to care for their children instinctively. Their feelings about mothering do not come to them by formal learning: these instincts begin to form as early as

pregnancy. As the children grow older, the mothering instincts develop further. Accordingly, mothers often think that their way of nurturing and caring for their children (both typical and non-typical) is the best way to ensure that their children are developing well, often with little regard for specific theories or methods. At times, this can lead to conflict between spouses, for instance, when a mother wants to follow advice from a teacher, but the father resists. Mothers may also have conflict with their children's teachers or healthcare providers over what is best for their children, or they may find that teachers are reluctant to use particular strategies with their children with ASD. In my study, I wanted to learn where mothers faced challenges and difficulties with other caregivers (spouses, teachers, healthcare providers) as they raise their children with ASD.

As Kitty writes, "for many women, mothering begins in a fiercely passionate love that is not destroyed by the ambivalence and anger it includes" (as cited Valle & Gabel 2010). Most mothers love their children without any conditions. It does not matter if the children are healthy or not, or if the children have disabilities or not; mothers love their children. For all mothers, and especially mothers of children with disabilities, being a mother becomes a central part of her identity. When a mother's time is consumed with caring for a child with disabilities, she might begin to lose her identity as an individual. By maintaining their own interests, mothers are often better able to enjoy their lives. This might include socializing with their friends, spending time alone, continuing their studies, or taking on paid work, in order to have a life outside of their mothering experiences (Brock, 2014).

In one study, Brock discusses mothers "who felt as though their identity as a mother could be separated from who they were, each [of these women] disclosed the "thing" that kept their "private selves" active and alive (2014.p.31). I think it is good to keep a balance between the roles

of mothering and having a private identity. In my study, I wanted to know if my participants were thinking as the mothers in Brock's study "sense of self outside of their role as mothers" if they were students, employees, or mothers who were able to socialize with their friends (Brock, 2014, p. 31).

Cowdery and Knudson-Marin (2005), found two models of mothering young children. The first is mothering as a gendered talent. In this model, the mothering experience was focused solely on women, with no roles for fathers. In this model, mothers are responsible for all of their children's needs. As a result, these mothers are more connected to their children (Cowdery & Knudson-Marin, 2005). The second model is mothering as a conscious collaboration. In this model, mothers collaborate, allocate and share responsibilities between parents. When spouses were involved in parenting, the fathers would build strong emotional connections with their children. Fathers in this model were also more open to learning (Cowdery & Knudson-Marin, 2005). My study sought to see if fathers had roles in involvement and collaboration with their partners in households and caring for children with ASD or if they were hands-off in their roles.

Using mothering as a framework for my study has much more than scholarly interest for me. There are so many questions about the role that guilt and blame can play in a mother's attitudes about mothering, the conflict they may have with other caregivers, the tension between loving their children with ASD and feeling some ambivalence, and the parenting models that they adopt. Studying Saudi mothers who are living in the United States and have children with ASD is personally meaningful for me.

**The researcher's position.** I am an educator with experience working with children with disabilities. I am a student who concentrates on children with autism and their mothers. I am a

woman from Saudi Arabia and a mother of two daughters. My participants and I share the same culture and religion.

I chose this topic after a mother told me that “[her] daughter has the disabilities, there is no cure for her.” I questioned why she would say such a thing, and why she would behave that way. Those questions led me to focus on Saudi mothers’ experiences and stories. I believe that because of their culture, these mothers had unique perceptions and expectations of ASD.

**Research problem**I interviewed mothers in my study. I focused on this research problem and used interviews to learn about their mothering experiences, everyday lives, spousal and family responses, and religious beliefs and practices. My particular focus was on participants’ mothering experiences raising children with autism.

Examples of the follow-up questions I asked them included:

1. What does it mean to you to be the mother of a child with autism in Saudi Arabia and in the United States?
2. How does your experience raising a child with autism differ from your experience raising your typical child/children?
3. Please tell me one or more stories about your challenges mothering a child with autism. (Jackson & Mannix, 2004, p. 152).
4. Please describe your mothering experiences in your daily life with your husband and with other family members.
5. How does your family respond to your child with autism? What do they say to you about your child? How do their behaviors and words affect your mothering experiences?

6. Please describe the support you receive or do not receive from your own family regarding your child with autism. How about your husband's family?
7. If you lack support from your family or your husband's family, how does that affect you as a mother of a child with autism?

To prepare for each interview, I read the transcription of my previous interview with the participant. This helped me prepare the appropriate follow-up questions. Since each interview was customized to the participant and her stories, within each round of interviews, the questions would vary from one mother to the next. I repeated this process with each round of interviews so that I eventually covered all of the questions with each mother.

**Locating participants and sample size.** I attended the 2014 Special Education Convention (CEC) Conference in Philadelphia, Pennsylvania. There, I met with a Saudi mother of two children with disabilities, one with autism. In May 2017, I called her to see if she would be willing to participate in my study. When it came time to conduct my interviews, she was unable to participate because she had moved back to Saudi Arabia following her completion of a master's degree program. She was, however, able to refer me to her sister, a mother of one child with autism who lives in Boston, Massachusetts.

I found the rest of my participants through Twitter. Although there are many Twitter resources, I used only the "Saudi in USA" Twitter page. I contacted the page administrator to receive their permission to post my inclusion criteria on this page (see APPENDIX A), which included my email address so that potential candidates could contact me. Only seven mothers contacted me via email, and I chose only the four who met my criteria. Once I no longer needed

the post, I asked the administrator of “Saudi in USA” to delete it. For my research, the total number of mothers were five.

**Criteria for participation in the study.** To participate in the study, participants had to have been born and raised in Saudi Arabia. The participants must have lived in the United States for at least four years and must be living in the United States at the time of the interview. This was important to the research because I wanted to explore the mothering experience for participants who had lived in two different cultures. Throughout the interviews, participants compared and contrasted their mothering experiences in Saudi Arabia and the United States.

To qualify for participation, the participants must be married to or divorced from the father of their children with ASD. In addition, participants were required to meet the following demographic criteria: between the ages of 25 and 50, possess a minimum of a high school degree, and have a clinically-diagnosed child (non-gender specific) with autism between the ages of three to eighteen.

As I planned to talk with them about their spousal relationships and extended families, I interviewed some of them via FaceTime. I met with some of them in person. Interviews took place in situ, the actual setting “where the narrative work is undertaken” (Gubrium & Holstein 2009, p. 34).

The participants had the choice to leave the study at any time. Because of this, I maintained a list of individuals not selected for the study that I could call upon if one or more participants dropped out.

**Interviews.** The interview is one of many types of data collection techniques (Savin-Baden & Major, 2012). Interviews enable researchers to ask participants questions and to get more

detailed information. Questions allow researchers to go deeper into the context of the study and into broad experiences to make them more specific (Savin-Baden & Major, 2012; & Clandinin & Connelly, 2002). I believe that interviews were the appropriate method for collecting mothers' stories to reveal their feelings, beliefs, and attitudes (both positive and negative), as well as their faith, their values, and their hopes and dreams for their children with ASD (Savin-Baden & Major, 2012).

I used different strategies when conducting interviews with my participants. These strategies enhanced the clarity and trustworthiness in my research. First, I shared with them a little bit about myself, and my position in the study, including that I am a mother who is from Saudi Arabia and that I have worked with children who have disabilities. I also shared other information that I had in common with my participants. For instance, I married a man who has two boys and who is also from Saudi Arabia. I am a student who is also taking care of my daughters, housekeeping, cleaning, cooking, and doing many of the same things that they are. I am also as a Muslim, so we shared the same religion and have lived in both the Saudi Arabian culture and the United States culture. By sharing these things about myself, I hoped to encourage the mothers to speak more freely. I also motivated and encouraged mothers to speak more by reinforcing them when I could.

***Interview guides.*** Researchers have roles and responsibilities while conducting their interviews. They must listen and observe (Savin-Baden & Major, 2012). They must listen actively to encourage their participants to talk and be careful not to speak too much. They should not interrupt when participants were speaking and being willing to allow silences or pauses.

While I took good notes when necessary, I was careful not to take too many notes, as that could make participants feel inhibited. I paid close attention to participants' comments and stories so I could follow them and asked the right follow-up questions. There were also some questions I had to avoid when participants did not want to talk about certain subjects. I also avoided over-empathic questions, manipulative questions, leading questions, and why questions (Savin-Baden & Major, 2012).

***Interview procedures.*** I conducted different recorded interviews with each participant. I let the participants know that there would be at least three and up to six interviews. Each interview lasted approximately one hour. I needed to establish trust, and I hoped that my relationship with each participant would be collaborative and active. I knew that this would be more likely to happen if I conducted multiple interviews (Hollingsworth & Dybdahl, 2007).

I planned to explore the possibility of communicating with participants afterward using a variety of tools including phone interviews, texting, and apps such as WhatsApp and FaceTime Audio. I asked each participant to tell me the best ways to communicate with her for additional follow-up and questions. I protected the mothers' identities by assigning them a false name for the study. I assigned each mother the name of a flower, such as Rose, Lavender, Lotus, Camellia, and Jasmine.

***Recording and transcribing the interview.*** Each interview was digitally recorded to ensure accuracy in the transcription and data analysis. Before my data analysis, all interviews were in the Arabic language. I hired a professional bilingual translator proficient in translating and transcribing the data from Arabic to English. The translator had to sign a consent form to maintain

the privacy and confidentiality of my participants in Arabic (see APPENDIX B) The English transcripts that the translator provided helped me to analyze the data's accuracy and clarity.

When I received the Arabic copy from the translator, I read it while I was listening to each recording to check if the translator missed something or did not know the context of the Saudi accent and culture. Then, I sent her a copy. She started to translate to English. When I got the English copy, I compare it with an Arabic copy to make sure that the translation accurately reflected the mothers' stories.

***Interview data storage.*** After each interview was completed, I ensured that data were stored in a safe place to protect the privacy of my participants. I stored my research data on my personal laptop with password protection and stored the computer in a locked drawer for which I had the only key.

### **Analysis: Criteria for Interpreting the Findings**

Narrative analysis has many forms and researchers can choose what they want to analyze narratively within stories (Clandinin, as cited in Lai, 2010). There is no one way to collect people's stories (Riessman, 1993). When researchers use life stories as a method to examine their participants' experiences, they have a great deal of choice about what they focus on (Burck, 2005). As Burck suggests, "The type of narrative analysis chosen depends on what the researcher wants to examine, which in turn influences the way text is selected and analyzed" (p. 252). Thus, two researchers could produce very different analyses of the same data.

**Transcribing the narrative stories.** After each interview, the translator/transcriber provided me with an electronic copy of the transcript as written text. I made two copies of each

transcript in case I lost the data in my laptop via electronic viruses. The transcripts were kept in my office to guarantee the privacy of my participants.

**Coding data.** The purpose of analyzing narrative is not only to examine stories deeply (Riessman, 1993), but also to synthesize data rather than to separate it into its constituent parts (Lai, 2010). I looked for opportunities to code the data I collected to help me identify emerging themes. After each interview, I wrote down my thoughts and any comments. I analyzed the data to understand the mothers' experiences and to identify themes that describe a broader experience. I analyzed the data by following a six-step analysis (Creswell, 2009).

Then, I started reading all of the transcripts, interview by interview. For example, I first read all of the first interviews of all five mothers to gain more information about the data. I carefully read and analyzed each participant's transcripts to look for patterns within them. I also compared responses from the five participants and identified similarities and differences. In the second step, I coded the data by using different colors and writing my thoughts in the margins and identifying possible themes by asking myself "what is that about?" Then, I organized all of the data into categories to make a list of topics. In step four, I reviewed that data to see any surprising experiences and recognize themes. I created a chart that I used to analyze the data easily for each mother. This chart had all three themes written on it. After finding the themes, I discussed them using subthemes and quotations. Then, I compared and contrasted among these subthemes to find any similarities and differences among the mother's stories (see APPENDIX D). I read the mothers' transcripts four to five times to find subthemes. Last but not least, I asked myself "What lessons I have learned?" (Creswell, 2009, p. 198).

According to Lai (2010), “Through narrative, researchers come into contact with their participants as people engaged in the process of interpreting themselves” (p. 6). When it is time to analyze stories, researchers have to understand “what is said and what is not” in the frame of participants’ lives (Lai, 2010, p. 6). For instance, I needed to pay close attention to whether a participant described her child as *challenging* or *impossible*, or her husband as *harsh* or *unsupportive*. While conducting my research with participants, I wrote my impressions and any ideas that came to me when these mothers start talking about themselves. I compared the context of the storytelling in the field of inquiry with the context of the story as it occurred.

*A text-based approach to analysis.* After each interview with the mothers, I had the recordings translated into English and transcribed. I used a text-based approach to story analysis. My purpose was to look for patterns and themes and to understand how the mothers organized their stories. I considered similarities and differences among the mothers' stories and storytelling choices and identified moments that surprised me. New questions and topics emerged from my analysis that I incorporated into later interviews with the mothers. Then, I moved to the second and third interviews and transcription analyses. In these readings, I compared and contrasted the mothers’ stories to help me find common themes.

*Narrative analysis and ethnography.* Throughout and after my data collection and analysis, I considered the particularity of my data. According to Gubrium and Holstein (2009), “Stories are assembled and told to someone, somewhere, at some time, for different purposes and with a variety of consequences. These factors have a discernable impact on what is communicated and how that unfolds...” (p. 10). The participants may not have told me the same stories in the same way if I had been a different person or if I had asked them my questions at another time or

in another place. They might have made completely different choices about their story content and strategies if I had been a person from outside their culture, a relative or friend, an older woman, or a man. As an ethnographer of narrative practice, Gubrium and Holstein would suggest that I must listen to and take systematic note of the actual stories I collected and the possible stories that I could have collected had we been in various settings. As well, Gubrium and Holstein suggest, “Some people remember very little, while others appear to have photographic memories. Some seem eminently reasonable and straightforward in their accounts, detailing step-by-step what they have been through and what experience might mean to them. Others meander” (p. 22). In my analysis, I tried to take each participant’s storytelling skills into account.

The quality of my transcriptions was also very important, especially since they were translated from Arabic to English. To ensure accuracy, I listened to the recordings and compared them with the transcripts. The quality of my notes also came into play. As Gubrium and Holstein suggest, “If notes or transcriptions of talk and interaction are important for analyzing narrative work, detailed ethnographic field notes are required for capturing the richness of narrative environment” (Gubrium & Holstein 2009, p. 36).

### **Summary**

This chapter was designed to shed light on the framework of the research and narrative approach. Being in the field, I was required to use the four negotiations; negotiating relationships, negotiating purposes, negotiating transitions, and negotiating a way to be useful. This chapter also explained the researcher position, how participants were selected, data collection and data analysis. Finally, this chapter explores my relationship with the participants including positionality, identify, power relationships and reflexivity.

## CHAPTER 4: FINDINGS

The aim of this narrative inquiry was to explore the experiences of five mothers from Saudi Arabia who have children with Autism Spectrum Disorder (ASD). The participants are of Saudi descent and used to live in Saudi Arabia, but then moved to the United States. In most cases, they came to the United States to study and work. This chapter provides a brief description of each mother and details her experiences as the mother of a child diagnosed with ASD.

Each participant and her children were assigned pseudonyms at the outset of the study to protect the mother's identity. Each participant was interviewed between three and six times, as was needed to gain a complete understanding of her experiences as a mother of a child with ASD. Interviews that took place face-to-face did so in public places such as a library, a shopping mall or a café. Each interview lasted between 45 and 60 minutes. Three of the participants lived in Fairfax County, Virginia. Two of the mothers lived outside of Virginia. These mothers were interviewed via FaceTime audio. Pseudonyms, the number of interviews completed, where each child was diagnosed with ASD, where the child was born, and their residence are indicated below:

<b>Participant Pseudonyms, Interviews and Biographical Information</b>				
<b>Pseudonym</b>	<b>Number of Interviews</b>	<b>Child's Place of Birth</b>	<b>Country of Child's Diagnosis</b>	<b>Residence</b>
Lotus	3	United States	Saudi Arabia	Virginia
Jasmine	6	Saudi Arabia	Saudi Arabia	Virginia
Camellia	3	Saudi Arabia	Saudi Arabia	Massachusetts
Rose	6	United States	United States	Chicago
Lavender	4	United States	United States	Virginia

### **Description of the Participants**

The children of the mothers in my study were born and diagnosed according to one of three circumstances. Lotus gave birth to son child in the United States, who was diagnosed at the age of two years, seven months, during a visit to Saudi Arabia in 2013. Jasmine and Camellia were living in Saudi Arabia both when their children were born and when they were diagnosed. Jasmine's son was born in 2008 and diagnosed in 2011. Camellia's son was born in 2004 and diagnosed in 2007. Rose and Lavender gave birth to their children in the United States, where the children were later diagnosed. Rose's daughter was born in 2014 and diagnosed in 2016. Lavender's son was born in 2011 and diagnosed in 2014

**Lotus.** Lotus was 33 years old, and the mother of two boys age 9 and seven years old. Both boys were born in the United States. Her younger son was diagnosed with Autism Spectrum Disorder in Saudi Arabia, during a trip to visit Lotus' family in the summer of 2013. At the time of her son's diagnosis, Lotus was 27 years old. She had lived in the United States with her husband for ten years, and was pursuing her master's degree.

**Jasmine.** Jasmine was 40 years old, and the mother of a 10-year-old son with Autism Spectrum Disorder. He was born and diagnosed in Saudi Arabia. When Jasmine's son was diagnosed, she was 31 years old. She had come to the United States without her husband to pursue a master's degree. In her interviews, Jasmine reported that her relationship with her husband was not strong. She graduated with her master's degree in the summer or 2018, and then returned to Saudi Arabia where she became an educator at a Saudi university.

**Camellia.** Camellia was 32 years old, and the mother of two children with special needs. Camellia's older son had been diagnosed with Autism Spectrum Disorder. He was 13 years old and

transitioning to high school. He was diagnosed with ASD at the age of nine, shortly before Camellia and her children came to the United States for her graduate study. At the time, she was 28 years old. Camellia's second child was 11 years old and had been diagnosed with autism and other disabilities that included ADHD, intellectual disability, developmental delay, and Sjogren-Larsson Syndrome. Camellia and her husband divorced before she came to the United States in 2013. Camellia graduated in the summer of 2018 but chose to remain in the United States, which she could do legally because she was qualified for Optional Practice Training (OPT), a form of temporary employment related to her F-1 visa's area of study.

**Rose.** Rose was 40 years old, and the mother of two girls who had lived in the United States for almost seven years. Rose's older daughter was a typical 11-year-old and was in her last year of elementary school. Her younger daughter was four years old and was diagnosed with Autism Spectrum Disorder when Rose was 38 years old. Rose first traveled to the United States with her older daughter, and without her husband, to study for her master's degree. She returned to Saudi Arabia after the completion of her master's and became an educator at a Saudi university. When she came back to the United States to pursue her doctorate, she did so with her husband and older daughter. Her second child was born in the United States. Rose's husband returned to Saudi Arabia in October 2017, leaving Rose in the United States with their children. At the time of the study, Rose reported that she and her husband were separated and that they had decided to divorce.

**Lavender.** Lavender was 38 years old, and the mother of a daughter and a son, ages 10 and six years old. In the winter of 2014, Lavender came to the United States without her husband to earn her master's degree. In the summer of 2014, Lavender's son was diagnosed with Autism Spectrum Disorder. At the time, Lavender was 34 years old. Lavender graduated with her master's

degree in December of 2015. The following year, Lavender secured an OPT opportunity and sought out permanent employment. At the beginning of 2017, she found a job in the United States. Lavender reported that she wanted to stay in the United States as long as she could because she felt that was the best place to secure high-quality services for her son.

<b>Summary of Participants</b>					
<b>Participant</b>	<b>Lotus</b>	<b>Jasmine</b>	<b>Camellia</b>	<b>Rose</b>	<b>Lavender</b>
Age of mother	33	40	32	40	38
Age when mother learned child had ASD	28	31	28	38	34
Father's age	33	47-48	38	40	42
Child's age	7	9	13	4	6
Child's age at diagnosis	2.5	1.5 – 2	9	18 months unofficially; 3 years for an official diagnosis	3
Number of siblings	1	0	1	1	1
Birth order	Second child	Only child	First child	Second child	Second child
Gender	M	M	M	F	M
Where born	USA	SA	SA	USA	USA
Years living in USA	10	4	4	7	6
Country living in now	USA	SA	SA	USA	USA
Marital status	Married, living together	Married, living apart	Divorced	Separated	Married, living together

### **Interview Question Themes**

Three themes guided the interview questions used to ask the mothers about their experiences raising children diagnosed with Autism Spectrum Disorder. These were:

- (1) Comparisons of raising children in the United States and in Saudi Arabia.

(2) Beliefs about mothering.

(3) Diagnosis and experiences of being the mother of a child with ASD.

In addition to these themes, a striking sub-theme emerged during the course of the interviews which led to numerous follow-up questions.

### **Comparisons of Raising Children in the United States and in Saudi Arabia**

The mothers whose children were diagnosed with ASD in Saudi Arabia, and who had raised their children in both Saudi Arabia and the United States noticed that there were significant differences in the educational and medical services and systems available in the two countries. These differences are described in detail below.

**Medical services.** The mothers who took part in this study reported that they believed the medical services in the United States were far superior to those offered in Saudi Arabia. For example, Rose, whose daughter was born in the United States, described the medical services her daughter had received there as, "Perfect...The staff here supports me, while in Saudi Arabia, I would be lost and nobody would support me." Rose was particularly impressed that the American doctor who suspected that her daughter might have autism, first informed Rose of this possibility quietly and carefully. She was struck by the doctor's professionalism. As Rose admitted, "At first, I doubted [the possibility of this diagnosis] because my daughter is emotional, expressive, and social, and has good eye contact. She was interacting with me and my friends." The doctor carefully and thoughtfully persisted, and in time, Rose was able to understand autism as a spectrum. That made it easier for her to understand the diagnosis and eventually accept it.

In contrast, Rose's experiences with doctors in Saudi Arabia led her to believe that doctors there do not care about their patients' mental health. She said:

In Saudi Arabia, doctors did not give me the time to explain my daughter's case. I remember I was talking to them, and they were not replying. The Saudi doctors would write the prescription after informing you to leave. Saudi doctors do not care about the mental health of patients, and this is the difference between America and Saudi Arabia. Also, early intervention is important, too. My daughter's pediatrician was caring, too. She gave me the names of daycare. I mean, all the doctors have resources, and they are cooperative.

The other key difference that Rose saw between the United States and Saudi Arabia was the willingness of the health sector and the educational sector in the United States to work together, under one umbrella, which is not the case in Saudi Arabia. In the United States, she found that information was shared among clinics, schools, and parents. School districts in the United States were keenly aware of the children in their schools with special learning needs which did not happen in Saudi Arabia. As Rose put it, "I mean all the doctors [and educators in the United States] have resources, and they are cooperative, but in Saudi Arabia, the health sector is not cooperative with the education sector." Rose was also skeptical about the intentions of educators in Saudi Arabia. As she put it, "I am not positive about the services provided in Saudi Arabia regarding the schools or the centers. They just take money, and they do not provide services in return."

Jasmine, too, had experience raising her children in the United States and in Saudi Arabia. Her son was born and diagnosed with ASD in Saudi Arabia. There, Jasmine reported, the doctors did not respect her feelings. To explain this, Jasmine shared one troubling experience with a Saudi doctor when she went to a clinic to receive a diagnosis for her child. Jasmine said that she asked the doctor if her son would be all right. As Jasmine explained, "He opened the door and told me, 'There are other patients who are waiting for me. Do not waste my time.' Then he left the room." Jasmine disliked how the doctors in Saudi Arabia treated her when she asked questions and said that she felt that they did not provide her with the support and resources she needed. She said,

"They told me, 'Do not run away, and accept the fact that your son has autism.'" She insisted she was not running away. According to Jasmine, "I accepted the reality." She explained that what she needed but didn't receive was support and resources, not admonishments.

In contrast with this experience, Jasmine said that she wished the doctor had treated her and her son with more respect. Jasmine described what would have been her ideal scenario:

First, they would have intervened early and called me. Second, they would have treated my son professionally. As a result, I might have cried for a half an hour in the clinic, but that would have ended. The way things went, I had to go through several experiences to come to a place of acceptance.

Jasmine had similarly disappointing experiences when her family noticed that her child was different from other children in his age group. They started to compare his developmental milestones to those of other children in her family. At that time, Jasmine went to a clinic, and her son saw a doctor. The doctor gave her son a diagnosis other than ASD. As Jasmine explained, "The doctors were telling me that my son was normal, but that he has a problem in the enzymes of chemical secretions in the brain." Naturally, Jasmine asked what they could do to help her son, and the doctors prescribed medication. Nonetheless, Jasmine said that she felt "lost." She didn't know in which school she should enroll her son, and she had many other questions the doctors did not address.

In contrast, when Jasmine came to the United States, she felt that a wealth of resources were available to her. As Jasmine explained, "Here [in the United States], I did not have to search for information. If I went to the hospital, the doctors gave me information about it [ASD]. If I went to the clinic, they gave me websites to visit." For example, Jasmine said that she had recently visited a website with information on TIC disorder, an involuntary sound disorder that sometimes occurred in children with ASD. This increased her knowledge of her son's behavior significantly.

As Jasmine put it, "I did not know about it [TIC disorder] before. I thought kids with autism might suddenly have habits that would vanish." Though it was difficult for Jasmine to realize that her son's behavior was linked to a disorder, she was grateful to have the knowledge, and not to feel, as she put it, "lost," as she did in Saudi Arabia.

Camellia's child, too, was born and diagnosed in Saudi Arabia before coming to the United States. Like Jasmine, Camellia felt that Saudi doctors left much to be desired. As Camellia put it, "Many problems occurred between the doctors and me. I had more than one doctor asking me, 'Who is the doctor here?'" In contrast, Camellia found as Jasmine did, that her child's American doctors provided much better care, and that they had more experience working with children with non-typical behaviors. American doctors had also been more willing to take Camellia's input into their decisions when adjusting her son's medication. As Camellia explains:

When we first came to the United States, my son was taking Concerta. I told the doctor I did not like it, and why. He was impressed that I noticed small, subtle changes in my son and welcomed my input. He prescribed Ritalin, which worked out to be a much better medication for my son. Doctors here [in the United States] appreciate mothers' opinions because they know that mothers are in the best position to observe their children. In Saudi Arabia, the doctors did not value our input or communicate with us.

Lavender had an experience similar to Camellia's. She felt that doctors in the United States had more respect for mother's opinions, compared to doctors in Saudi Arabia. She also cited a marked difference in attitudes between American and Saudi doctors with regards to medications. In Saudi Arabia, Lavender found, doctors were quick to prescribe medication as soon as a child was diagnosed with ASD, and treatment plans were limited to medication only. In the United States, she found that doctors regarded medication as only one factor in a much broader and comprehensive treatment plan. As Lavender explained:

In Saudi Arabia, medicines are typically the full extent of the treatment plan. But here [in the United States], the doctor told me that we will use *all* of the available means [to help my son]. She [the American doctor] wanted to try a number of other things, and use medication only if they didn't work. I first asked her about medicine for my child in 2014, when he was diagnosed. Now, in 2018, after trying many other things, she has prescribed medication for him, which we will use in conjunction with other therapies.

Lotus was the only participant in this study who had what she believes was an excellent experience with the Saudi medical system. However, her circumstance was rare, as her Saudi doctor has a child of his own with autism. Lotus explained:

He [the Saudi doctor] was practical and personal. I liked that we had that in common, yeah. [Lotus began to cry while talking.] He did not just tell me what to do. He gave me some time to talk about my feelings. That was new to me because I generally prefer to hide my feelings. I liked the way he worked with me, because he was honest with me, even though that was hard. Sometimes, it felt like the room was spinning. But he helped me work through that.

**American schools vs. Saudi schools.** Some of the mothers had an opportunity to experience and compare both Saudi and American schools. All of them believed that the educational systems and their services were superior in the United States. Jasmine had a great deal to say on this topic. To begin, Jasmine remembered that in Saudi Arabia she had relatively little contact with school personnel. Jasmine stated, "While in Saudi Arabia, a report is sent at the beginning of the year, without asking to meet with you. They say that you are welcome to add your opinion, but that's all of the involvement or input they want. At the end of the year, a report is sent of your child's achievements. That's all."

In contrast, Jasmine described her very different experience with American educators:

When I go to the school's meetings, I find a special education teacher who is the supervisor of the school. There is another teacher who is a specialist in pronunciation, and there are two special education teachers in the classroom, a speech therapy team, and also a sports teacher. They all work and cooperate with each other as a team. They also encourage me to participate in the plan for my child.

I attend every meeting every year. I meet with them throughout the term, and sometimes even in the summer, and they welcome my input.

Jasmine said that American educators prepared a detailed plan for each child, whether the parent was involved or not, and that they sent numerous reports throughout the year to clarify the level of the child and the future goals.

She also noted that there are few places where special needs children can be helped in Saudi Arabia. She says, "The opportunities in Saudi Arabia were very limited. The centers [for special needs children] in Riyadh don't exceed the number of my fingers." In the United States, by contrast, Jasmine believed there was a priority for educating special needs children, and that there were many places for them, whether in public or private schools. Homeschooling, too, was an option in the United States. As Jasmine sums it up, "So, you have so many alternatives here in the United States, while in Saudi Arabia you have only one choice -- a private center that requires you to pay for social services. This is a huge problem if you can't afford it."

Jasmine also suggested that in addition to the disparity in the number and availability of centers between the American and Saudi educational systems, there was also a significant disparity in the quality of the education provided. She referred to this as a "huge gap" between the American and Saudi systems:

In Saudi Arabia, anyone can open a center in his/her house without getting a license from the government or a private institution. Center owners are therefore free to do whatever they want and to hire whoever they like. Personally, I would never put my son in a place without governmental responsibility. In the United States, you would never see that. They [educational centers] must have a license to be legitimate. And they must hire only qualified specialists to work with the children.

Jasmine pointed to the United States Constitution as the root of this difference. "It says that every human being has the right to an education." As a result, Jasmine believed that people with

special needs had the same right to an education as everyone else. This was not what she experienced in Saudi Arabia, where she felt that the education system was designed with only typical children in mind.

One instance left an indelible impression on Jasmine. In her words:

I witnessed a young girl [in the United States] with quadriplegia and an intellectual disability. She came to school in a bus designed specifically with everything she needs. That impressed me. Here in the United States, they work in a humane way.

Jasmine did not believe that such transportation would be available to a child with the same disabilities in Saudi Arabia. Moreover, she did not think that a child with a similar combination of disabilities would receive the same quality of education in Saudi Arabia as she did in the United States, even if her parents somehow managed to get her to a school or center each day. While she said that financial services were available to her in Saudi Arabia, she had no support for finding suitable transportation for her son. As Jasmine explains, "My son's bus [in Saudi Arabia] was not suitable for even normal kids. It was a minibus with no air conditioning, and it had bad seat belts." Transportation for both typical and special needs children was far superior in the United States, she reported.

Jasmine believed that the most striking difference in her American and Saudi school experiences was in the preparation and attitudes of the teachers. Jasmine described her son's American teachers as "loyal" and "faithful." They poured themselves into their work, she says, and their attitudes were extremely positive. In her words:

The teachers here [in the United States] work with the child's physical and mental disabilities, whatever they are. They move with them, teach them, and even play with them. That encourages me. They make me think, "That looks so easy!" Because of that, I find that I can go back home and continue to do the same kinds

of activities with my son at my house, too. They treat each child as much as possible like any other child.

Jasmine said that American teachers were sincere and that they expressed their regard for their students warmly and naturally. They reassured and hugged a child if they felt that it would be helpful. They talked with their students kindly, whether they were happy or sad. Jasmine appreciated that American teachers treated her son as much as possible like any other child. "They do not treat him as disabled," she says.

American teachers also treated her as they would any other mother, which she appreciated a great deal. In contrast, Jasmine said that Saudi teachers looked at the mothers of children with disabilities as "different." She said, "They looked at me pityingly. They said prayers for my son and me." Saudi Arabian teachers also held onto the notion that the situation was "hopeless," she says. In her words, "They believed that hope could come only from Allah. It was not important for them to give it to mothers." In the United States, however, Jasmine found the teachers to be much more encouraging and hopeful. She said, "They gave me realistic hope. It was like they are saying, 'We will work with your son, and he will improve.'"

Other disparities between American and Saudi teachers that Jasmine cited were their teacher training and their overall levels of professionalism. Jasmine recalled that one of her son's Saudi teachers had only a social science degree. Another had only a high school diploma. In the United States, all of her son's teachers had much higher levels of specialized education for the roles they played. As well, Jasmine felt that Saudi teachers did not behave as professionally as American teachers, because they allowed their biases to interfere with their abilities to do their jobs. Jasmine explains:

I had a [Saudi] teacher tell me that my son is lazy. I felt lost because I've never known my son to be that way. The teacher went on to say that my son is lazy with spelling, lazy with math, and lazy in following instructions. I don't think that's laziness. But she did.

In the United States, in contrast, Jasmine explained that teachers gave mothers much more unbiased and specific observations about their children. They were more likely than Saudi teachers to welcome suggestions from parents. In Jasmine's experience, the teachers in the United States established written goals to be achieved by the child, and planned goals for them to work toward.

Similarly, Camellia had the opportunity to compare Saudi and American schools. Like Jasmine, Camellia believed that the services for her son with ASD were superior in the United States. While she believed that Saudi schools were "good," they focused only on academics. Schools in the United States and the many services they offer, she says, were "excellent."

Financially, Camellia saw a significant difference between the transportation services for children with disabilities in the two countries. In Camellia's words, "In Saudi Arabia, we heard about inclusion for children with disabilities, but we did not see it. Here [in the United States], my sons were in public schools. A bus came and took them." Camellia was also impressed by the way American schools merged her son into games, the school cafeteria, and art. She said, "It was through that emerging that they teach him simple things. If we were in Saudi Arabia, it would not be like this." Camellia also spoke of a woman employed by the school who used to come to her home to treat her son. Summing up the resources available, Camellia said, "All of these services are free here. But in Saudi Arabia. I had to pay so much money, and we didn't get half of these services."

Camellia believed that the abundance of resources for her son in the United States stems from a basic difference in the Saudi and the American educational systems. She said that while

both systems provided academic services, the American schools also cared about, "The psychology of children, social needs, physical therapy – really, whatever your child needs." Saudi schools, in contrast, provided only academic services, Camellia says. Overall, Camellia said that the environment in the schools was "different" in the United States than in Saudi Arabia and that this difference could be seen in the teachers themselves. Camellia's take on this was that in the United States teachers received extensive training about working with children with special needs. As a result of this, she said, they did not regard special needs children as "inferior," just different. "But in Saudi Arabia," she said, "I guess the way teachers deal with them [children with special needs] would be different." This was a crucial point to Camellia, who wanted her children to be regarded as equal, not inferior, and who strongly valued the quality of her children's education.

Camellia was particularly pleased to go to her son's regular IEP (Individual Educational Plan) meetings where she could discuss her son's goals and achievements with his teacher. It was very gratifying to her to see how her son improved and to learn what she could do to help him. As she aptly put it, "My kids spend most of their day at school. The school and the environment around them affect the way they will be raised."

Lavender, too, saw a huge disparity between the Saudi and American educational services available for her son. She was so displeased with the Saudi schools that she did not want her son to go to them. One troubling difference she cited is that the schools in Saudi Arabia were segregated by gender. As she explained, "I can't imagine enrolling him in a school for just boys where I can't visit him... I wouldn't be able to enter the school or see his teacher or his class."

Lavender felt that the quality of educational services in Saudi Arabia was generally very poor. She said, "There are no services for kids with special needs, and if there are, they are bad."

Lavender reported that Saudi centers were not, “care centers” but are “residences,” and that this, too, was not something she wanted for her son. She relayed the story of a mother she knew who had enrolled her son in one of those residential centers. When she visited him, Lavender said, the manager of the center said her son had poor manners, and that she’d have to take him home with her. That was the extent of the help they provided. Lavender also described her own experience at the Prince Mohammad Salman Center, which was part of a military hospital. Her experience meeting with the doctors there left her feeling that they did not like her or her son. They also did not share her goals for her son. Lavender explained:

They told me that he's amazing, but I kept telling them that I don't like his current status. They were shocked because my son can speak. I told them that he took speech therapy in the United States and that I wanted him to continue to have that service. The doctor complained that no graduates in speech therapy had been hired, even though the schools must have speech therapists. They also don't have an occupational therapist. And they called this the best center!

In contrast, Lavender believed that “everything” was available for her son in the United States. She said, “As soon as they diagnose it [ASD], they give you the necessary support. It’s true that I’ve never been to a support group, but they [groups] are there if I ever want to be in one.” In Saudi Arabia, however, Lavender likens her experience to being put in a “maze.” She says, “We don’t have enough services in Saudi Arabia. I wouldn’t know where to start. So, I would be lost there.”

Lotus shared the same beliefs as Lavender. In the United States, Lotus could visit her son at school at any time, regardless of his age. In her words, "I go to my son's school even if he is nine years old."

Perhaps the bleakest and most troubling description of the difference between the United States and Saudi Arabia was offered by Rose, an educator at a Saudi university. Rose was familiar

with the education systems in both Saudi Arabia and the United States, and said, "I am not positive about the services provided in Saudi Arabia regarding the schools or the centers [for children with disabilities]. They just took money, and they did not provide services in return."

**Raising children in the United States and Saudi Arabia.** The mothers who took part in this study reported that raising their children in the United States and Saudi Arabia were very different experiences for them. Two of the most significant differences that Jasmine noticed were the presence of people with disabilities in public places, and the ways that people related to them. She explained:

In Saudi Arabia, it's hard to go to the supermarket with a disabled child. First, you find that the stores don't have parking spaces for people with disabilities. Second, security officers in Saudi Arabia won't help me if my child becomes separated from me in the store. They tell me to go to the store director. In the United States, the security officer will bring my son to me immediately. Another big challenge I face taking my son to the Saudi supermarket is that everyone stares at us when my son starts to vocalize, as he sometimes does. I've even had women tell me that they will pray for me and my son. I don't need or want their pity. All I want is for them to leave us alone. Here in the United States, nobody even looks at us when my son speaks out. It's normal to see disabled children in public places in the United States. People have normal conversations with my son and with me. When they see that I am not comfortable with my child's behaviors, they change the subject or try to lighten it up with a joke. Then, we laugh together.

In the United States, Jasmine shared, she felt that there were kindness and humanity in the way that people dealt with each other that was missing in Saudi Arabia. Jasmine also said that one of the considerable differences she noticed in her experiences raising her son in Saudi Arabia and the United States, is that she received significantly more unsolicited (and often unwanted) advice from her female relatives when she was living in Saudi Arabia. As Jasmine explained:

In Saudi Arabia, I used to take mothering advice from my mother, sisters, and aunt. They focused a great deal about what was not "right" about my son. I was nervous a great deal of the time because I wanted my son to meet their expectations. They would ask me, "Why is he like that? Why is he still doing that?"

Jasmine said that looking back at that time, it is most interesting to her that she listened to her relatives because she had a degree in education and had much more knowledge about her son's disability and needs than her relatives. Nonetheless, Jasmine said that she felt she had no choice but to listen to them. Her son was her first child, she explained, and she lived among people in a community that "interferes in your life, whether you want their input or not." In contrast, Jasmine found that being in the United States gave her the freedom and the opportunity to parent her son more autonomously, and to follow her own instincts. She said, "I started to understand how to deal with him and how to react to him, regardless of what family members advised me. Now, I just listen to what they [her relatives] tell me, but then I do what's best for my child."

Rose reported that she had a lot of free childcare available to her in Saudi Arabia, more than she did in the United States. She said it is commonplace for grandparents and aunts to be involved in raising grandchildren and nieces and nephews. The effect of the extended family was therefore much more significant than it was typically in the United States. In contrast, Rose, who was separated from her husband, and lived in the United States with her children, had to do much more by herself.

Lavender, too, said that there were more people involved in the day-to-day care of her daughter in Saudi Arabia than in the United States, particularly her daughter's grandmothers and aunts. However, Lavender didn't always enjoy the help they provided or their criticism. She explained, "When she [her daughter] wasn't in my sight, I panicked. I had to know where she was and who she was with all the time, so I could tell her what to do and what to say. I knew they would criticize everything she did that they didn't like." Lavender said that without the help of extended family, her influence on her daughter was

greater in the United States and that she was a more confident mother here. To illustrate this, she shared a story of the time her sister visited her in the United States and criticized her. In Lavender's words:

When my daughter got upset, my sister said that her behavior was not okay and that she is being spoiled. Then, I told her that "I am teaching my daughter that's it is okay to be mad, but it's not okay to be rude." If we were back in Saudi Arabia, I wouldn't have said that. My daughter would have been more under the influence of relatives and friends. Here, in the United States, *I* am her community. *I* am the only one who influences her. She does what *I* want her to do.

Lavender was careful to point out that she didn't want to raise her children the way her parents raised her. She said, "I want my daughter to be mentally healthy; I don't want to raise her like my parents raised me." Lavender said that she believed that her parents did their best they could in raising their children. At the time, she said, there weren't resources available that we have now. "I don't blame them. They did their best," adding nonetheless, "I will never raise her [my daughter] like my parents raised us."

A striking way that Lavender's parenting style differed from her parents' style was in the values she was trying to teach her daughter. One of these was that she wanted her daughter to strive for and achieve success, even though she had special challenges. Said Lavender:

I always tell my daughter that knowing what you want in life, and being happy is the most important thing. Success has many faces. It's not just about school. Yes, that is one of the faces, but if you don't get 100%, that doesn't mean that you are a failure.

Lavender also wanted to teach her daughter to become an independent woman, and not to rely on her parents or anyone else to help her. This is in contrast to Lavender's upbringing. She said:

When my daughter tells me that she wants to have a house or a car someday, I tell her that no one will buy her a house and a car. She has to believe that she can do that by herself, without her parents' help. I don't want her to depend on her parents the way my parents taught me to depend on them. I tell her that she has to

study and work hard so she can buy what she wants. Of course, I will help her if I can, but I don't want her to depend on me.

Lavender also said that a way that she differed from her parents was in her attitude about honesty. She felt that her parents often lied to her or misrepresented the truth. "Honesty," she said, "is very important to me." Interestingly, Lavender described raising a child with autism as "messier" in Saudi Arabia than in the United States. She explained:

Maybe because I like being in control of everything, but there [Saudi Arabia], I felt like I am in a mess. Yeah, there are problems managing the servants, problems with the driver, etc. Here [in the United States], I just hire a babysitter. I can go out for a dinner with my friends, go home, pay her, and *bye-bye*.

Lavender believed that she was sensitive to the intrusion of others in her parenting, not only because of her parents but also because of her interactions with her siblings. Says

Lavender:

I have six older sisters who used to choose everything for me: from clothes to friends, to where I could go on the weekend. Every one of them used to tell me something different than the others. I don't want my daughter to go through what I went through. So, I encourage her to make her own choices and to be responsible for them. Her father and I don't always agree on this. He tries to make her choices for her, but I encourage him to let her discover what is good and bad for herself. That's how I want her to learn in life. She must learn to depend on herself, especially when she goes to university.

Lavender felt that the longer school day in the United States was helping her son, who has autism, to improve. She said, "He comes home at 4:30 pm, which is a great thing. There [in Saudi Arabia], they had a shorter day, and all they had is a daycare center where kids stayed for a few hours." Lavender said that living in the United States was for her, like living in relative "isolation," where fewer people had an influence outside of school on her children. "It was easier for him to improve his behavior," she says.

Finally, Lavender said that there were different expectations for children with disabilities in Saudi Arabia than in the United States. For instance, in Saudi Arabia, family members would often tell her child that what he does was culturally wrong. "In America," Lavender said, "I kept telling [my daughter] that we are not from here and we don't do what people here do. She can understand that." As well, Lavender felt that it was easier in the United States to let go of Islamic customs and traditions that would be more expected in Saudi Arabia. Said Lavender, "For an autistic child, the customs and traditions aren't as important here as what he could do. I have priorities. So, I won't try to teach him to use his right hand while eating. What's important for him is just to eat." However, it was also important, she said, that her son follows essential American customs while he lived there. She explained:

He really made me tired when he was learning to use the bathroom at school. Here, he had to wash his hands when he was done. They didn't do that in Saudi schools. But, because it is their [Americans'] culture, I had to help him continue with the same routine, even though he has special needs.

Lotus shared how her father has a different point of view about raising children. He wanted her to be distant from her sons. Her father, "Criticized me once when my kids were two and five years old, for spending my entire time with my kids. He wanted me to give them space. He wanted me to be independent. He does not like me to show my emotions." Lotus did not like to leave her sons far away from her or follow her father's advice about being distant. She had a vision that once her children were going to school, then at that time she could enjoy her life, not during their early years. "When my sons get older and go to school, I would have time to live my life. My father wanted me to have this distance from the beginning.

Lotus also did not like when someone asked her if her son was verbal or non-verbal. She felt like her son was “a creature from somewhere else.” I really got affected and bothered by this question. I could not bear it if I see my son being mistreated. At that moment, I could not think about being a source of inspiration for all people. I could only think about going back to Saudi Arabia, and working with autistic kids, this is the change I was thinking about.”

Camellia shared how being in the United States helped her with her children, compared to when she lived in Saudi Arabia. Camellia stated that it, "Made us more attached and closer to each other. We used to be close in Saudi Arabia, but America made our relationship stronger. I miss them so much if I go out, and so do they, but mothering is the same here and there. It depends on the mother herself."

**How living in the United States challenged and changed the mothers’ thinking.** Almost all of the mothers who took part in the study said that living in the United States and raising their children with ASD here had both challenged and changed them. For example, Jasmine said that living apart from her husband and family ended up making her stronger and more mature. As she explained:

Despite all the difficulties I have faced in my life [in the United States], I cannot say that life is hard. I believe life is full of challenges, though, and it was those challenges that made me stronger. I am no longer worrying about anything; every problem has a solution. The boat I am in will deliver me to the shore when I face a problem, whether it is an easy or a difficult challenge.

Jasmine believed, too, that living in the United States had made her more open-minded, and that facing her challenges here had made her more mature. "Yeah," she said, "I appreciate my life more than ever now."

Jasmine contrasted her life in Saudi Arabia with her life in the United States:

I used to ask my mother and my husband for help back in Saudi Arabia. Here, I do everything by myself. I used to think that men were the ones who are supposed to take care of everything. But I think differently now. You know, if my husband were here [in the United States] with me, I think I wouldn't have changed so much. I would probably have done the same things I did in Saudi Arabia -- just depended on him like the other Saudi Arabian women who live here depend on their husbands. I used to stress myself a lot because I felt lost and didn't know where to go. But the alienation I have felt in the United States has made me stronger. Also, being solely responsible for my child and being away from my family – that's made me stronger too.

Rose, who was separated and who planned to divorce, also said that living in the United States had made her stronger and more independent. She said, “I would not have been strong and independent like this. I felt ready to go back to Saudi Arabia alone. I didn't need anyone to live with me. I was comfortable with living alone with my daughters.”

Camellia, however, focused more of her conversation on the challenges she faced living in the United States. She described how difficult it was for her to juggle her studies, child care, and household chores without the support of her family or servants. As Camellia said:

Thanks to God that I succeeded! I took the language certificate, took care of my kids, and finished my master's degree. It was so hard, especially in the beginning. I did not have a servant and a driver to bring me everything and to do everything for us. In Saudi Arabia, we have our own house, and my father even gave me a salary. Now, it is different. I have to manage money very carefully, and I have to buy absolutely everything I need for my house. I was stressed out especially in the beginning. There were also so many appointments for my kids, and I had so many responsibilities related to my degree at my university. Like I say, it was hard!

Lavender, too, was proud of the growth she had experienced by facing her challenges living in the United States. Interestingly, she said that she was now "more aware of life" and that she no longer lived "to please others, even my family." Living here, Lavender said that she learned that if she wanted to achieve something that she had to do it by herself because no one would do it for

her. Lavender added that while living in the United States, she started to think differently about people, especially women. She explains:

Maybe I am being extreme. I know I have to respect all kinds of people, and that I have to control my feelings. But when I see a woman with no work, no college, and she has kids and servants who do all the work, and then I see her going shopping and to restaurants and complaining all day, I look down on this kind of person.

Lavender admitted that she did not always think this way. In fact, she said that she was "spoiled" as a child and that she didn't think poorly of women who were "spoiled." Now, after living in the United States, she believed that women should be more independent. She said:

Thanks to Allah. I have proved myself to myself. I won't forget that I was a spoiled child who used to have everything she wanted. Now, I live alone without any help, even from my husband. That has made me strong and independent. Now, I am capable of doing things that I wouldn't have thought that I could have done in a million years.

Lavender also said that living in the United States with her children and without her husband had been good for her because of the time she had available for them. Said Lavender:

Some people would say the relationship between a husband and wife would be in danger of living apart as we do. For me, that was not my priority. All I wanted was to take care of myself and my kids; that's it. So, I wouldn't have had time for him if he were here anyway. The con of living alone is that it is very exhausting. But the difference is living in Saudi Arabia is *mentally* exhausting and here it is *physically* exhausting. Frankly, that's better. I'd rather live here. But one of the cons of living this way is that I don't have a social life here. I barely have enough time for my studies and my kids.

Lavender shared that her perspective about life had changed. Before marriage:

I thought all I want is a family and kids and to raise them with my husband; of course, my perspective of life was like that because I was brainwashed by my mother and my sisters. I thought that it was the right thing to do, then it felt that I was not fit to be a housewife. I like to take care of my kids, but I didn't want to sit in the house 24 hours a day. In the beginning, I didn't have a job, so it took me a while to change my mind.

Since marrying, Lavender's perspective has changed:

I don't know if you are asking about the previous Lavender or the current Lavender. You know now I am weird. Now all I want is to go along with life without problems. I don't care about anything else. Before I was perfect. Everything, even my husband was perfect until I corrupted him, and sometimes I ask myself was I really like that? I followed high standards and values. I was determined to do the right thing. Now I don't care.

Today, Lavender has reached a point in her life "which makes me believe that every adult is responsible for what he/she is doing."

Some of the mothers felt that living in the United States had made them more patient and that they had been able to enjoy their time with their children more than they did in Saudi Arabia. For instance, Rose said, "I spend more time with my daughter. Our relationship got much better when I came here to America."

Camellia, too, had enjoyed a better relationship with her children while living in the United States. Camellia explained:

In Saudi Arabia, I was always in a hurry. Dress them quickly! Hurry up! That makes them impatient, too. When I came here, I noticed that people here are much more patient. They are okay waiting in a line, and don't become angry and annoyed. So, I asked myself, "Why am I so nervous?" And I realized that if I were like that, my kids would be so, too. So, I became calmer. I dressed my kids more calmly. If I want to go out, I prepare myself early.

Camellia also said that as a result of living in the United States she talked to her children more, because she had more alone time with them. She felt she knew them better, because they talked more to her, too. She felt that she had learned to respect them more and more. "In Saudi Arabia," Camellia admitted, "I used to talk to my sisters more than to my children. Now, I think more about my children, what they want, what they want to say. Now, we stay with each other." Camellia also reported that she spent more time playing with her children now. She said, "We play

all the time with each other, and that makes us happy. It wasn't like that in Saudi Arabia. My sister and I talked to each other and left our kids to play together. But not anymore. And because of this, I noticed that they are much happier. They are happy when I pay attention to them.”

Jasmine, likewise, mentioned that her experiences with her son changed because they spent more time together:

Now, we are having a great time with each other. We hang out and play with each other. I am observing how foreign women are treating their kids, and try to learn from them. When foreign women decide to have a baby, they enjoy being a mother, not like us. We give birth at 17 years of age and have kids for no reason. The foreign women teach, learn, play, and laugh together. They are enjoying their lives together. Day by day, I am learning more and more.

Among the participants in this study, only Lotus said that living in the United States did not change her much. She stated, “I was always an independent and open-minded person, so America did not change me a lot. I am so connected to my family. I love to have adventures. So, living in the United States was not hard on me.” Lotus liked to be with her sons. That time was pleasant for her. In her words, "I do love hanging out with them; it is okay even going to the train station or airport." Lotus loved every moment that she spent with her kids, and she loved their childhood. "I love my kids. I love their childhood. I enjoy my time with them. I hope my kids love hanging out, too."

**Gender roles in caring for children with disabilities.** The mothers who took part in this study had definite ideas about gender roles, especially as they related to parenting a child with disabilities. For example, Jasmine said that the mothers in Saudi Arabia were the ones who were responsible for their children and that they had to take care of them. However, she's observed that this balance of responsibilities was different in the United States. Jasmine explained,

I was raised to believe that only mothers are responsible for their children and that a man's role in the family is to be the breadwinner and no more. But in the United States, I've never seen married couples work this way. Recently I attended a parents' meeting, and there were mother and fathers. I felt that they share the same responsibilities towards their disabled children. They believe that they both have to understand their child because he/she is part of the family. In Saudi Arabia, I never saw a man at this kind of meeting. There were only mothers.

Jasmine added that sharing parenting responsibilities would result in children living happier lives. "When the two partners are involved in parenting their child, and learn more about their child's case," Jasmine said, "it would definitely make the child feel comfortable and happy." She believed sharing parenting, and household responsibilities put less pressure on everybody in the family. As well, she imagined that having two parents actively involved in parenting would bring more strengths to the family. Jasmine explained, "The father's cooperation creates balance. No parent can be perfect in every area. But perhaps he can be perfect in managing the house, and the mother can be perfect in parenting."

Interestingly, Jasmine retained some doubt about fathers' ability to provide and nurture the heart and warmth of the family, at least at first. She said, "They [fathers] of course can't cover everything like the sentimental area. But they can work on it."

Lotus believed that parenting responsibilities fell more on mothers than on fathers, both in Saudi Arabia and in the United States. She said:

I see that in the American and Saudi society, the role of women is heavier. For example, in bringing up the kids, men do not commit themselves to the [daily household and childcare] routines. My husband loves his kids and is trying his best to help me in raising them, but until now, he does not know how to deal with them. He does not exert the effort to know. He does not want to learn. He is similar to my father-in-law. Neither of them likes it, nor do they want it.

Lotus added that while men could support their families financially and mentally, women in both cultures were more generous with their time and effort. "Yet," Lotus added, "I cannot deny that

men play a great role. The father's role is in searching for centers and delivering them [the children] to the centers." Lotus explained that her husband "could not do more" than that partly because of his job, and partly because of the Saudi culture. She explained:

My husband did many things for our son. He filled out all the paperwork [for school and doctors]. But I was sad for him because he did not know how to deal with our son. He used to hand him the mobile device to occupy him. And he'd shout at him. We used to share everything. But you know the culture in Saudi Arabia, which we lived in before coming here. There is an attitude of, "Why shall I work more than you do?"

Rose, who was separated from her husband, had a great deal to say about gender and parenting. As a Ph.D. student, Rose saw a huge disparity in the amount of free time she and her husband had available. She explained, "My husband was bothering me a lot during my second year in my Ph.D. program because he wanted me to hang out and take breaks from school work and the house, but I did not have time for breaks. I could not hang out with him or anyone else, because I had so much homework, and I was responsible for our daughters. I remember us arguing about this." Rose admits that she felt "stressed out" at that time. She wanted to see a psychiatrist to help her manage her stress. However, her husband refused. Rose felt that her husband could have helped her more than he did. Even though she admits that he was helping her in some ways, he did not take care of their daughters, though she needed and wanted him to, because he felt that childcare was not his responsibility. As Rose explained:

I had my most challenging semester in my program in the Fall of 2014. There was a lot of complicated material for me to study and I had a really tough professor. I remember feeling stressed out! So, I told my husband, "I need to see a psychiatrist; I need soothing pills." He was mad at me and told me, "Do not go on this path. Just wait and let us look for other choices." So, for a while, he agreed to help me more with household chores, and he assigned me two days each week when he agreed that he would take care of our daughters by himself. However, this didn't last long. After a short while, he told me to take my daughters with me again. I pointed out that most days that he is at home anyway, so taking care of our

daughters shouldn't have been such a burden for him. He reluctantly agreed to continue to take care of them, but I knew that he felt forced to accept the responsibility. Deep inside his heart, I think he believed that he didn't have any obligation to care for our daughters.

Rose shared a troubling story in which her mother-in-law called her to say that it was her responsibility, and not her husband's, to care for their daughters. This occurred after Rose left her daughters in her husband's care for three days while she was out of the state to work on her studies. As Rose explained, "He was one hundred percent okay with that [my leaving the girls with him]. I do not know what happened to him, but he always tries to get sympathy from his family." Rose believes that her mother-in-law feels that it is improper for a man to do the work that she believes is a woman's responsibility. As Rose puts it, "His mother refuses to see him sitting with the girls or doing household chores." Rose recalled that when she recently came to the United States, her husband was doing the dishes when her mother-in-law called. "She got angry with us," Rose said, "and she asked about me." Rose said that she heard her husband justify to his mother that "this is the culture here [in the United States]. We share the household chores." But clearly, Rose did not believe that her mother-in-law approved of this division of responsibilities. Rose added, "His mother has strange beliefs that the man should not help in raising the kids or doing anything at home."

Rose is grateful to her husband for the time he did spend alone with their daughters, given his family's way of thinking. "When he did [take care of them], things were getting better between us, at least for a while." But, she said, "The independent, strong woman was really a problem...He was unbelievably dependent on me when we were in Saudi Arabia. And when we came here? He ultimately became even more dependent!" This issue was a huge problem in Rose's marriage. She

said, "We were fighting a lot over responsibility." Friends in the United States, even strangers, noticed that Rose's husband was not helping her.

Ultimately, the lack of cooperation from her husband, the pressure of her doctoral studies, and the responsibilities of taking care of their daughter with ASD caused Rose to regress at her university, and for her marriage to fall apart. When he returned to Saudi Arabia, her supervisor told Rose that she was better off without her husband, because he had a "negative impact" on her. She shared a particularly hurtful conversation she had with her neighbors, who suggested that the rift in the marriage was Rose's fault. According to Rose, they told her that she was the one to blame because she had spoiled her husband. Rose did not feel that that was the case. She believed that her husband's reluctance and ultimate refusal to care for their daughters stemmed from his upbringing, not from the way she interacted with him. "But I became really tired of the problems between us," Rose said. "If I had a fight with him, he would directly abuse me. Now, I go alone to the supermarket, clinics, and hospitals. And I took our child with ASD because he has refused to take her." Rose did not see a chance for reconciliation and was planning to divorce her husband.

Lavender, like the other mothers, reported that caring for her son with ASD was her responsibility, not her husband's. However, her husband felt that it is his place, more so than hers, to make decisions about their son's medical care. To illustrate, Lavender shared a story in which she administered three different prescribed medications to their son, two of which did not help him, and may have even contributed to worsening his behavior. The third medication, however, suited him, Lavender said. Her husband, though, did not like the medication because her son was uncharacteristically calm and no longer willing to play with him. Disagreement about the medication ensued and put a strain on Lavender's relationship with her husband. She explained:

I told him [her husband] that the medicine has nothing to do with that change in our son. There are many factors [involved]. Perhaps our son just didn't want to play with him at that time. But my husband didn't believe me. He kept saying that we have to change the medicine so our son could play with him. I finally convinced him that we had to give the medicine a chance. But he *always* fights me about *everything*. It's like he wants to make all the decisions and is saying that I deserve whatever bad thing happens to me because I didn't listen to what he said.

Camellia was the only participant in this study who was divorced before she came to the United States. She cited the gender disparities in household chores and parenting responsibilities as a primary reason for the divorce. For instance, when either of their children had a doctor's appointment, she was the one who went to those appointments, without him. Simply put, she said that her ex-husband was not helping her. In her words:

The way he thinks is different from the way I think about this. Because of that, we got divorced. He was not helping, and I got really tired. I think that some of his attitude about taking care of our son was cultural. But looking back, I think too, that he was depressed before our divorce. He loves his children. He loves both of them. But our son's case affected him very badly.

Camellia also hypothesized that her husband was jealous of her academic success, as she had finished her degree and her husband had not. "I could not study in front of him," she said, or he would become upset. Ultimately, though, Camellia believed that her husband felt it was too challenging to spend time with his children, which caused the demise of the marriage. She explained simply, "I feel that it was just too difficult for him to have children with disabilities." To support this opinion, Camellia says, when she asked her husband for a divorce, she took her children with her, and he did not object. "He did not say a thing."

Interestingly, two other mothers in the study suggested that their husbands were jealous of them: Rose and Lavender. In Rose's case, she believed that the jealousy did not stem from their parenting. As Rose explained:

There was a sense of competition between us. In the last few years, he showed jealousy. He was especially jealous of my family. Mine cares more about education than his; his family cares more about money and trade. When I was accepted to graduate studies to pursue my master's degree in the United States, he became arrogant, and he underestimated me. He would also lord over me the challenges he faced to come to the United States, claiming that things, in general, were a lot easier for me than for him.

Rose admitted that having been born in the United States, her English was more fluent than her husband's. Quoting her husband, Rose said that he told her, "You have a supportive family, while I do not have a supportive family. If *my* mother was supporting me and bringing me gifts at the end of the year, and if *my* father had been taking me to America every year, *I* would be smarter and more fluent in English, too." Rose says that this "ugly face" was quite unlike the man she thought she knew when they were married.

Lavender, too, said her husband was jealous of her, but for a reason much more closely aligned to their parenting. He was jealous that her children love her more than they love him. In her words:

Once he said to me that he was jealous because the kids want me, not him. I told him that that's okay, that it happens in every house because the father usually doesn't spend that much time with his children. All the kids are like this. I don't know what he was thinking. So that's another gap between us.

Despite what Lavender told him, her husband has not chosen to spend more time caring for their children. She believes that if he did that the children would not prefer her over him as much.

Islam has defined the roles of men in their marriages. According to Prophet Mohammed (pbuh), the Prophet said: "The best of you is the one who is best to his wife, and I am the best of you to my wives." Every Muslim man is expected to be kind to his wife and treat her according to the highest morals. Likewise, when a husband supports his wife under any condition and situation, his wife is expected to stand beside him in his difficult times.

Based on the teachings of Islam, parents who have a child with ASD or any disability should share the responsibility for that child. However, the traditions in Saudi culture can make that difficult. For instance, in traditional Saudi culture, men are only expected to support their wives financially. These traditional expectations for men and women are beginning to change to a more contemporary set of expectations, especially among young men who like to have a perspective that is different from their parents'. In the younger generations, there is more likely to be an expectation that everything should be shared between couples, especially when women hold jobs outside their homes.

**Marriage experiences.** All five mothers who participated in this study were married or had been married to the father of their children. Each of them spoke about her marriage, and most of them highlighted areas of dissatisfaction, disagreement, and strife. Jasmine's description of her marriage particularly troubled her. She said, "My experience as a mother in Saudi Arabia was one of the worst experiences in my life, even when you consider all the difficulties that I have faced living in the United States. The psychological effect of living with my husband in Saudi Arabia – that was the worst of all, because of the gap between us and my feelings of loneliness."

Similarly, Rose suggested that her marriage was extremely disappointing to her. She described the serious problems she had with her husband:

In fact, I am having many problems. He crushed my dreams. I was betrayed in love and marriage. He was annoyed, and he told me repeatedly that what I was doing was not a big deal. He is stubborn also. He has hurt me a lot and caused trouble in my studies. I was mentally hurt.

Most troubling to Rose was a time when her husband decided to leave her when she was "in dire need to him." Rose explained:

I was about to have a comprehensive exam. Our daughter was not yet stable in a school, and I hadn't enrolled her in an ABA center. I needed him to help me so I could focus on the exam. But he refused to take care of our daughter. He showed me that "I can hurt you," and that was the straw that broke the camel's back. We broke up for five months.

Rose and her husband did not go through divorce procedures, though family members knew that they were separated. She and her husband have left things on good terms for now. Her husband has returned to Saudi Arabia. However, the future of their relationship is uncertain. Not surprisingly, Rose and her husband continued to have different viewpoints about their daughter with ASD. Rose described her husband as "supportive by words but not cooperative," a challenging combination. Often, he attributed their daughter's developmental delays to "just needing more time," not to autism. However, Rose was careful to recall one time when her husband's tenderness surprised her. She said that he once told her that when he saw their daughter that he did not see an autistic child. He simply saw their daughter. This stood out to Rose as uncharacteristic, as he was a businessman accustomed to working with numbers, not people. But his comment obviously pleased her a great deal. Nonetheless, Rose did not give credit to her husband for having this attitude. She believed that Allah was responsible for making him feel this way about their daughter.

Lavender, too, talked about disagreements she and her husband have had about their child with ASD. According to Lavender, her husband did not say aloud that their son was sick, except on one occasion and only to her. However, he treated their son as he was. He persisted in thinking of his son as sick, she says, even though Lavender has told him otherwise repeatedly. He also seems unwilling to follow their child's therapist's instructions. In Lavender's words:

Every time I told my husband to do something that the therapist wants us to do for our son, he does nothing about it. He just does what he feels is right. He

thinks being a father is about instinct. He stays with this even when he sees that there is no result from his method. He never gives up on his way of doing things. I think, frankly, that part of it is that he resists doing whatever *I* want him to do.

Lotus has had a very different marriage experience than Jasmine, Rose, or Lavender. She believed that having children with disabilities sometimes strengthens marriages, as was the case for Lotus and her husband. Lotus explained:

My husband is cooperative, and he has helped me a lot. He told me that I have options and that I am free to go wherever I want. Being free and having so many choices makes life easier. He asks me why I am stuck with the kids, while I have the opportunity to get a servant. But I always reply I am happy with my life. I feel that we have a strong relationship. We have supported and helped each other in difficult situations, and we have never left each other. He always supports me in tough times.

When Lotus and her husband first learned about their son's diagnosis, he took her to her parents' house, and spent a little time alone for himself, to process the news. "I was afraid about him so much," Lotus said, explaining that like her, he was shocked by the news they had received. She gave him the space and distance he needed and said she always did that whenever they are stressed. "My husband was under pressure," Lotus says, "but these days he is close to us." It's important to note that Lotus's husband had an autistic brother. He was concerned that their typical child not be neglected because of his sibling with ASD. According to Lotus, her husband told her, "I know that you are a great mother, but please pay attention to our second son. My mother neglected the rest of my brothers because of my autistic brother. That's all I want."

Interestingly, Lotus mentioned that her experience of marriage and of mothering was different in the United States than it would be if she lived in Saudi Arabia. Living here, she said, away from the extended families, "We solved our problems with each other. We had more positive experiences of one another." As well, Lotus believed that she would not enjoy the close

relationship she had with her children if she had remained in Saudi Arabia. She said, “In Saudi Arabia, I would bring in a nanny. That would put space between my kids and me. So, living in America has changed the way I relate both to my husband and my children, and in a good way.”

Camellia stated that her family had issues with marriages between her relatives. For instance, many of her family members have disabilities, because they encourage marriage between cousins. In her words:

That is why we have a lot of disabilities. I am against marriage between relatives because I do not want people to go through all the difficulties that I faced with my kids. For example, they did not see G6PD anemia as dangerous. They see it as a normal disorder to live with, but a disorder like my kids' they see as retardation.

**Saudi and American attitudes about disabilities.** Three mothers in this study (Lavender, Jasmine, and Lotus) had the opportunity to raise their children with ASD for a time both in Saudi Arabia and in the United States, and/or knew of Saudi attitudes about disabilities through their families. Those experiences put them in a good position to talk about how disabilities are viewed in the two countries. Because Rose and Camellia had less first-hand experience with Saudi attitudes about disabilities, they had fewer (if any) points of comparison to share.

Lavender stated, "I can't say it's a shift, here in the United States there are rules against discrimination towards disabled people, we don't have these rules in Saudi Arabia, sometimes it's hard to convince people or change their mind without rules."

Jasmine's son was born in Saudi Arabia and was now being raised in the United States. She described the challenging circumstances of bringing her son into a public place or a school in Saudi Arabia:

When we go out in Saudi Arabia, they look pityingly at him, and tell me some prayers! Even employees at the facilities that are available for autistic kids in

Saudi Arabia look pityingly and even terrifyingly at him. They seem to be fearful that he may attack them. In fact, in Saudi Arabia, they look at disabilities as catastrophes. They think parents should lock their disabled children in a room and bring in a servant, rather than taking them out in public. They are totally ignorant. Here in America, at least in some places, they do not consider autism to be a disability. There is an autistic child in many homes, so it is more normal and acceptable here. People here always look at my son with a big smile.

Jasmine believed that Saudi people, in general, are not provided with sufficient education about disabilities. This perpetuated the general assumption people had in Saudi Arabia that disabilities are shameful; it explains why so many Saudi people isolate and hide their children with disabilities, Jasmine said. She contrasted the reaction to her son's behavior in the two countries:

If my son tries to kiss a woman in the United States, I tell her that he is an autistic kid and that that's why he kissed you. Typically, she might reply, "Give me another kiss." If this happened in Saudi Arabia, a woman would be much more likely to fear that my son is making sexual advances. Here in America; they consider my son to be a valuable member of society; they think he's like the rest of us, not so very different. But in Saudi Arabia, they give your son gifts because we feel sorry for and pity him. In America, everything is easy and normal.

Jasmine admitted that she is at a loss for what to do to help her son in Saudi Arabia. She said that she fears that if she took him in a public place there, and if he shouted as he sometimes does, a crowd would gather around them. She asks, "Shall I lock the door on us and stay in all the time?" Jasmine admitted that she, herself, had undergone a significant change in attitude about autism because of her experiences in the United States. She explained:

Before I came here, I looked at an autistic child as a disabled one. I thought that if I ever had one, I would lock the door on him, as is typically done in Saudi society. Even when I first came here [to the United States], I met ignorant women from my culture who like me, held onto these outdated beliefs about autism...Eventually, though, I found my way to much better sources of information.

Jasmine also suggested that Saudi fathers may have a particularly difficult time accepting that they had children with ASD, because of the culture in which they were raised and lived. To illustrate this, Jasmine explained:

Some fathers don't have a strong effect. Some fathers even refused the idea that their child is sick, and are in denial. One of my friends has an autistic daughter but her husband keeps telling her that there are no problems with my daughter, it's just you exaggerate it. I don't want to generalize it. I just say this from my experience and most of my friends' experience.

While it was hard for any parent to accept that something may not be typical about a child, Jasmine believed that Saudi fathers might have found the challenge especially difficult. She thought this would be understandable if you considered the Saudi society's reaction to people with disabilities.

Lotus suggested that negative and incorrect attitudes about children with ASD prevailed in Saudi Arabia and sometimes, too, in the United States. One of the biggest mistakes that people in both countries tended to make, Lotus said, is that they assumed that all autistic children were the same. She explained:

People, including some Americans, think of autistic children as stupid people who have their own world. They may talk and play with them, but not know much about autism. I've had people act very surprised when I have told them that my son is autistic and the details of his case. His behavior does not always make this obvious. I feel that they do not see or understand. They do not know that all autistic children are not the same. They are, in fact, very different.

Lotus admitted, however, that such negative attitudes continued to flourish in Saudi Arabia, and that she had encountered them less frequently in the United States. Lotus shared her experiences when she went out with her son. The public reaction toward her son was:

When he was young, he used to hit a lot. So, I had to hold his hands. I used to hold his hand and sit at the corner of the mall. It was hard, because of people's reactions such as, "Your kid is spoiled." To when he was hitting strongly or when he was pulling my hair to the ground. Even when he was young! They would make comments. They would look strangely at us.

Over time, Lotus says she has come to believe that “When people look at me when he [my son] beats me; Allah is testing me!”

Lotus was afraid when she returned back to Saudi Arabia, how the society would look at and treat people with autism. She would listen to her mother-in-law's advice. Even if her mother-in-law "is positive" her advice is "not to tell people that my son is with autism, because the community "will deal with him as if he is insane." At the same time, Lotus felt that she did not want to hide the truth. "I could not do that. I feel that I am hiding the truth," because she is "ashamed of him. When I go back to Riyadh, I will not tell people about him. You know the community is different from here [in the United States]." Lotus wanted to inspire people who have children with ASD. She wanted to show her son was improving, but at the same time, she was "afraid that the society would label my son ‘the autistic kid.’ My mother-in-law was educated and positive, but she knew our society very well. I am sure that she went through tough experiences; that was why she told me so."

Although her child with ASD had never lived in Saudi Arabia, Rose shared the same point of view as Lotus. If they go back to Saudi Arabia, Rose said that they would not tell people in the community that her daughter had ASD:

I did not have good experiences in the Saudi community, and I did not tell my relatives about Noor. Not because I am ashamed, but I have my reasons. I want to give my daughter a chance to grow up, walk, and be raised in a society that deals with her as a normal kid. I know if they were aware of her situation, they would not treat her as normal. I want her to be merged in society without restrictions. The name of Allah, Bismallah, I am seeing her developing, and nobody is noticing that she has autism, except when she nods her head and pronounce strange voices. I do not know if people notice that, too. I expect that my family will notice it because they are trained in special education.

**Mothers' relationships with their parents and their husbands' families.** Four mothers in this study had varied relationships with their families. Only Camellia did not detail her relationship with her ex-husband's family.

Lotus was enthusiastic about the support she had enjoyed, especially from her mother and her mother-in-law. In fact, she spent a great deal of time speaking about the strong and positive relationship she had with her in-laws, for whom she is very grateful. Lotus believes that they were so supportive of her son, and so helpful with him because they, too, raised a son with autism. That gave her a common bond with them, and in her mind, explained what made them so understanding and supportive. In her words:

They [my in-laws] were very supportive...As soon as my son showed symptoms, my mother-in-law called a center and booked us an appointment. His family's support has been huge. They reassure me, and they have such a positive attitude about autism. My mother-in-law would say to me, "He is fine. He will be okay. Do not cry. Let us hang out and breathe some fresh air."

Lotus said that her mother-in-law had on occasion likened Lotus's son's symptoms with those she observed in her own son long ago, and that seeing her brother-in-law today as a high-functioning adult had been very encouraging. She also said that her father-in-law paid most of the expenses surrounding tests for her son, totaling more than \$30,000.

Lotus was especially grateful to her in-laws for helping her learn how to deal with her child as a "normal child." She said of her in-laws, "My in-laws are highly educated and intellectual, so they love him...They treat my family as if we are brought down to earth from heaven." In fact, Lotus looked to her mother-in-law as her mentor and guide. Lotus said that the single best piece of advice that her mother-in-law ever gave her was to, "Take the test paper [from the doctors] and put it in the drawer, and deal with him as a normal kid." However, she attributed many other good

ideas to her mother-in-law that help her with her son's day-to-day care. For instance, Lotus had learned to manage her anger and impatience when her son took too long in the shower, thanks to her mother-in-law. Lotus also felt that knowing that her mother-in-law is always "ready for anything" made her feel that she's not alone. She said of her mother-in-law, "She does anything I ask. And she always asks me if I need anything or her help." Lotus described her mother-in-law as "kind-hearted," and she especially appreciated her great communication skills.

Lotus was also grateful to her father-in-law who she said always says positive things about her son. For instance, she had heard her father-in-law say on more than one occasion, "My grandson is smart." Both he and her mother-in-law had, considered her son to be "the smartest boy ever" since the day he was born, she said, and this did not change when her son was diagnosed with ASD. Both of her in-laws always wanted to hear about her son, she says, and they did not judge him if he does something wrong. Lotus added that though her father-in-law is an "old man," he played with her son and paid attention to him all the time.

Interestingly, Lotus had observed that raising a son with ASD put a strain on her in-law's relationship. She said that her mother-in-law came to the United States to have their son diagnosed and that her husband gave her financial support, but not the emotional support she needed at that time. Even now, there are remnants of that strain. Lotus explained, "My father-in-law does not like it when my mother-in-law shows him how to deal with their son, even today. This has affected their relationship with each other." Lotus hoped to negotiate the difficulties of raising a son with ASD with her husband a little better than her in-laws did.

Lavender, unlike Lotus, had not enjoyed a positive relationship with her in-laws and had found herself often in opposition to them, especially with her mother-in-law. To explain this,

Lavender relayed the story of her visit to Saudi Arabia with her son. Lavender prepared her mother-in-law for the visit by explaining that her son would eat only very few foods, among these pizza and hamburgers. She asked her mother-in-law to have those foods in the house and available for him, to make meal times easier. However, her mother-in-law told her that fast food is not good for him, and cooked "all kinds of pumpkin dishes," including pumpkin soup and dessert. Lavender said, "I told her that he doesn't eat that, but she insisted. It turned out that her daughter's neighbor in Egypt had told her pumpkin is good for autistic kids, so that's what she made." Lavender's son would not eat any of the pumpkin-based food. Yet, her mother-in-law continued to cook and serve pumpkin on the second and third days of the visit. Lavender said, "I told them at least bring in some chicken nuggets, but she was convinced that pumpkin was good for him." On the last day of the visit, Lavender felt that her mother-in-law wanted to tell her something before she left. "Then, my mother-in-law asked me, 'Do you read? Do you educate yourself?'" Lavender sighed audibly and rolled her eyes after she relayed this part of the story, expressing her obvious exasperation.

Lavender said that her mother-in-law was ignorant. She believed that she hung onto an "old fashioned" view of people with disabilities and that she assumed that people with special needs are sick. Said Lavender, "She was afraid of him [my son]. She was afraid that he would hurt her." To illustrate this point, Lavender recalled the time when her mother-in-law was troubled because her grandson didn't want to eat. In Lavender's words:

I told her that if he won't eat to let him be. However, she wanted me to feed him. I refused but said that if she wanted to feed him so badly that she should feed him herself. She told me, "No, I am afraid that he would hurt me. If you don't want to do it, I won't either. I won't chase him around the house to force him to eat because he will start to scream and make loud noises." At that moment, I understood that she thought of my son as dangerous.

Lavender added that her mother-in-law looked at her and her family with sadness. Lavender said that she got the feeling from her in-laws that they had the mentality that, "We are perfect, but your son is not." Lavender found it difficult to spend time with her in-laws and felt that they made things harder for her.

Rose's circumstance was unusual among the participants in this study in that her father, mother, brother, and sister are all trained in special education. Because of this, her family's support had been unwavering. She said, "My daughter's case was not a big deal. I was speaking to my parents about my daughter and crying, and they were like, 'So what? You are educated, and you have tools for dealing with your daughter. Your daughter is lucky that *you* are her mother.'"

Rose said that her father reminded her that raising her daughter was her role in life. Quoting her father, she said he told her, "This is not the end of the world. Just do your part, and Allah will do the rest. Always pray for Allah and He will help."

Rose was especially grateful that as special education specialists, her parents designed and facilitated engaging activities for her daughter whenever they visited her in the United States. She said, "Last summer when they came over here, they exposed her to as many different experiences as they could...She really enjoys being their granddaughter."

Rose's parents were also a source of helpful information. They often told her about new information they had heard about a program or about interesting facts they had read. Rose said, "My father, for example, sends me studies related to my daughter's case." Rose also said that her parents followed her daughter's case closely, and frequently asked questions her about her development. She added that her parents always told her, "Be thankful that her autism is simple and not complicated."

Rose added that she especially liked that her siblings played with her daughter and that they helped her to be active. Rose's brother and sister, both younger than she, sometimes played a little too rough, she said, but she wanted that for her daughter. Rose explained:

My daughter has a phobia, and she is spoiled. I want her to come out of her shell. She is interacting with them, and they are awakening her senses. That's really important because I remember in the early intervention that they told me to look for what activates her sense. My siblings help me to do that for her.

Rose was grateful for the support she and her daughter had enjoyed from her family.

Jasmine preferred formal support over informal support. When other people offered her advice, it added to her stress, and she would rather have information from a doctor or specialist, which she considered to be more reliable. In her words, people:

Make me feel guilty because of their exaggeration of taking care of their kids. I go to a specialist and pediatrician, maybe because they are Americans they understand autism better than me. Other people don't give you accurate information, so I have to depend on my doctor and my basic resources. I went to the research center in Baltimore to ask them about the diet, they told me that the FDA didn't recognize it, but there are some families who liked it.

Sometimes Jasmine sat with mothers of children with ASD. They sat and chatted about different areas of autism. In her words, "I do chatting with mothers, but all they do is just add insult to injury, which makes me run and run without reaching any result. Life is simpler than we think, even with an autistic child."

Jasmine provided an example of a mother whose son is older than hers. She felt like she could meet with her and this mother could be useful. Jasmine did not like that meeting:

I can't keep up with her, I am not that intellectual, and sometimes I don't agree with her, for instance, she says that 'My son's school is really bad,' but I see it as very good. The other mothers always make me stressed out. At the group meeting, they asked me why I didn't do a diet for my son, why I didn't go to a doctor, and after that, I noticed that she didn't do anything of what they asked me about. I mean why do they do that?

Jasmine could sum up her experiences from meeting mothers of children with ASD in that, “I believe that people shouldn't be carried away by what they hear, they must focus on the information from the reliable source, and take your information from doctors or teachers.”

Jasmine discussed how her family supported her but in their own way. Sometimes, she said, she wanted to listen to her family or to doctors, but often, their points of view conflicted. For instance, Jasmine’s family believes that going to a sheikh would be beneficial to her son: “Based in wrong beliefs, it is like taking your kid to a sheikh, so that he [the sheikh] brings out the devil who lives inside his body, and that confuses me between medicine and my family.”

When Jasmine asked her husband to go the sheikh, he refused, saying, “She is a witch.” But, Jasmine says, “If his mother suggested the same woman I did, he would happily accept it.” Jasmine’s husband listened to his mother more than he listened to his wife.

**The role of servants.** Some of the mothers in this study had servants when they lived in Saudi Arabia, who assisted them with household chores and childcare. For example, Camellia had a servant in Saudi Arabia. When she came to the United States, she spent the first three years on her own without a servant. When she eventually brought a servant to the United States to help her, Camellia described the experience as a kind of rebirth. In her words:

I was dead! Now I am alive. It was really tiring [without a servant] because there was no help, only me and my children. I had to do everything. I kept telling myself that it wasn't so hard and that I could manage it. Even in Saudi Arabia, I remember thinking that I would like living without servants because I don't like relying on them. Even so, I thought that if I had only one that I would rely on her.

Camellia was grateful to have had her trusted and favorite servant in the United States, and found things much easier with her help.

Lotus had lived in the United States for ten years, and chose not to have a servant for eight of them. She saw this as an expression of her "free will," and explained her rationale:

I wanted to be responsible for everything without help. I organized everything, and this is what I like in America. I do not want a servant here in America, because I love to control my entire house. I want to know who is in my house. When a servant comes to help, I feel that I have lost this control.

At the beginning of her time in the United States, Lotus said that she refused any external help at all, even babysitters until she felt that it was absolutely essential. She wanted to do everything herself. As her son grew older, she became more willing to accept the idea of employing others to help her. Now, Lotus employs someone to do household chores to free her up, so she has more time for her responsibilities as a mother and wife. She saw this as an improvement for her and for her family.

Jasmine expressed the negativity of having a servant. She said that some mothers were giving all the caretaking to the servant, which was annoying to her because mothers were not taking care of their children. The result would be that the children's language skills would be weak:

I expected their kids to be well educated, and I was surprised that their kids could not speak because they are with the servants all the time. The mother does not want her kids! She leaves them to the servant. That really annoys me. No feelings! No education! No advice! You find her kids spoiled because they spend their whole time with the servants. Allah has given you graces such as money! You can use it by bringing a qualified specialist to properly educate your kids or bring a servant to be responsible for the household chores, and you bring them up.

Lavender mentioned that even though she had two servants when she was in Saudi Arabia, she did not like for her daughter to spend her time with servants. In her words:

Here, I am busy, but I know that she is at her school, and she won't be here until 4:30 p.m., but there in Saudi Arabia she would be at home at 2:00 p.m. In Saudi Arabia, she would be with the servant until I got home, then she will go to her grandmother's house to play with her cousins, and I don't know where else. I didn't care about these visits. When I come home, all I want is to spend time with

my daughter, so I didn't want the servant to put my daughter to sleep. I did that because I want to tell her the bedtime story. Sometimes I fell asleep with her. Then my husband came to wake me up. So that was very important to me.

Rose also said that she was able to afford a servant in Saudi Arabia, but not in the United States. The servant freed Rose from some of the housework and provided additional childcare support as needed.

### **Beliefs About Mothering**

Having children with disabilities resulted in mothering experiences that would be different from rearing typical children. Four mothers (all except for Rose) shared their beliefs about their mothering experiences

**Mothering experiences.** Jasmine focused on the ways that her attitudes toward mothering have changed over time, and how her feelings about mothering were often complicated. She indicated that she didn't feel qualified to talk about mothering, because of her son's case, in her words, "We do not have a warm relationship between us, maybe we started to have it nowadays because he is getting older."

Jasmine said that when her son was first born, she expected that mothering would include cleaning her son and feeding him. When she discovered he had special needs, her expectations changed:

After having my son, mothering was about simple duties, to feed and clean him. Later on, when I found about his illness, the responsibilities became heavier, and I must care more for him. It's not a problem. It's more about the perspective in differences in mothering towards kids with special needs. It was a shock to me you know! I wanted to go through mothering like any mother, but being a mother of a kid with special needs is different, with so many emotions, increased responsibilities and many other things that are different.

Over time, Jasmine's feelings have grown more complicated:

It includes conflicted feelings between depression about feeling hopelessness about his situation, and on the other hand, wanting to try to cure him. You look at your kid in a different way, because all your thoughts are about how to make him better how to improve his condition. .

The biggest challenge Jasmine saw is to get her community to accept her child. .Once she accepted and loved her child with a disability, Jasmine said her family did the same. This could be because she included him in the family gatherings and social visits and did not hide him away from society. In her words:

First, to make society accept my son, I showed them that I love him, and included him in the society, and then they accepted him. People started to play with him, and they were curious to know more about him because he has autism. I started to bring him to social gatherings and talk with others about his behaviors. So, in the end, they loved him.

Looking ahead, Jasmine worried that when and if she moves to a new community, there will be people who are more reluctant to accept her son.

Sometimes, she said she felt guilty about her mothering experiences toward her child, especially when she saw other children with autism who were better than her son. Jasmine reported that "When I see a child with autism who is better than my son, I feel guilty in some way. Why is her son better than mine? What did she do that I didn't?" At the same time, she feels that mothering is, "A great experience, and it makes you forget the hardships of life...Mothering is somewhat of a strange instinct. Mothers will always keep caring about their children and even forget about themselves."

Lotus shared her opinion about her experiences with her children. In her view, she is sacrificing herself in order to have what is best for her children. For instance, she wanted to live in another state, not in Virginia, and she wanted to take care of herself. In her words, "I want to care more about myself and my life as a woman. Nowadays, I care more about my sons and their

schools. I used to read books about the kids' growth to observe their growth. I cared about who are my sons' friends. I felt that I am caring too much about them in a way I forgot myself."

Lotus was constantly observing her son while he was at school or sometimes taking him to the doctor, which made her worry even more about him and kept her from enjoying her time with her kids. Most of the time, she compared her son to other children. She wanted him to be perfect, and one of the best. "I was observing him, and taking him to the doctor. It was not observed for the sake of enjoying our life and the kids' life, but it was more like constant worry. I did not like that at all. I wanted him to be the best, and I was comparing him to others. I wanted him to be perfect, but in fact; I was going about it in a very negative way."

Lotus shared that when her son did not interact with others, it made her feel upset and sad. "I used to go with my child in the daycare, and sit with him and with the teacher, to encourage my son to interact. That really upset me, because I got sad when I saw him regress."

Lotus said that she made sacrifices in her life for her son in different ways as well. One of these sacrifices was not having free time for herself. Another sacrifice is enduring the stress that she feels as his mother. For instance, she wanted her son to learn, so she taught him what she had learned from the specialist. "I want him to learn now. I cannot wait for the specialist to come and teach him. I can apply what I have learned from her. I think that is a sacrifice, because I am stressed out every day, and I cannot prevent myself from comparing my son to other boys in his age group."

The other sacrifice Lotus had made is her mental well-being. She had anxiety separation when she left her son in a center or daycare. She could not leave him and go about her day in a normal fashion. She did not like to be separated from her son, as she reported:

I enrolled my son in a center, where I am not allowed to enter the session with him, yet I used to enter with him, and not just wait for him out in the waiting

room. This is one of my sacrifices. I feel afraid whenever I go to a place where they separate us from each other. For example, I told the administration at the daycare, that my son has special needs, and I need to be with him. They asked me, 'Why do you want to stay with him?' The teachers laughed and said, 'He's doing well.' But I have anxiety separation. I just cannot leave him alone.

Lotus said being a mom is grace, and this was from Allah. It motivated mothers to behave and to be better. She said, "Maternity was a gift from Allah, it was a great grace, it motivated the women to be better, it changed us into a bigger-hearted, it changed many aspects of us. (The mother started to cry while talking) I deeply love being a mother, and I do appreciate the grace of maternity. Also, I hate people who deny this grace."

Camellia shared her mothering experiences, and how she sacrificed herself for her kids. "I always think about them more than myself. I was thinking about signing up in OPT here, to give them the chance to join the school, which is better for them. When I got a job offer, I always think if this job is suitable for both of us, me and my kids."

Camellia pointed out that mothers had to take time for themselves to help them to have more energy, "Mothers, of course, will sacrifice for the sake of their kids! But they must give themselves time, too, think of themselves. For me, the ideal mothers are those who create a balance between herself and her babies. The one who gives herself time to keep herself full of energy."

Lavender said that in the United States she could practice her mothering better than in Saudi Arabia, because in Saudi Arabia if there was a family commitment, she had to attend, even if she did not want to:

I have time here to practice mothering, in Saudi Arabia you do not have time to be a mother, because you are always busy visiting your relatives. Commitments with the family take up a lot of time. As you know our culture, you should visit this and that. And if you do not go to visit them, they will be angry with you. This kind of expectations consume a lot of your time, and I do not even like these visits.

Lavender mentioned that in the United States her problems are not family-oriented, and the lack of interference makes her happy:

Here the situation is different, the mainstream is not as [extended] family oriented, so they value their [nuclear] family time. When I go to a place with my kids, the people respect that, because they know I do not have a lot of time. In America, where we live like groups which live with each other, but here I can practice mothering without any interference, not needing help from anybody makes me happy.

Lavender thanked Allah all of the time because of the balance Allah gave to her. In her case of having a child with ASD, Allah knew that she would have difficulty with her son, and because of that Allah gave her a daughter who is well-behaved. "The mothering is different than anything, Subhan Allah, it takes something from you, and gives something else. My daughter is very well behaved and a calm girl. I tell myself that I did a good job with her, but she turned out to be way better than I expected...I don't have any explanation, but all I say is Alhamdulillah."

Lavender likened raising children to raising a seed. When this seed had the love and respect for Allah, her daughter would remember how her mother raised her. "Even so, our children are like a seed, and we have to raise them with love and respect to Allah, so when I die, I am sure my daughter would never forget what I told her about."

**Mothers are perfect but not to be perfect in all areas.** All mothers in this study shared different points of view about the definition of the perfect mother.

Jasmine reported that mothers could be perfect even if they were different in rearing their children. "There is not one characteristic of a perfect mother, because all mothers are perfect. There are differences, but it doesn't mean that she is not perfect, unless she has mental issues, and she doesn't know what her responsibilities are." Her definition of a perfect mother is:

In my perspective, the perfect mother is a simple, ordinary mother. The word perfect, beautiful or good are critique words, perfection is extensive. All mothers have a perfect, kind heart, but they can be perfect in one area. She can be perfect in teaching, educating or improving the behavior of her child. That's my perspective of the perfect mother. She can be perfect in one area, and neglect another area. I expect when she expands her knowledge by reading and become aware of her position, it doesn't need to be 100% about pedagogical techniques.

Jasmine provided an example of a criminal mother who was in jail and had children. Even if this mother made a mistake in her life that doesn't mean she was a bad mother. She loves her children, but because of a lack of education, she made a mistake in her life. As Jasmine said:

Flaws don't affect their mothering. For instance, there can be a criminal mother in prison who everybody thinks is a horrible human being, but that doesn't mean that she is a horrible mother. Loving your children is instinctive no matter who the mother is. In my perspective, all mothers are perfect. She might be a bad person, but also a loving mother. A mother might make mistakes due to lack of awareness and education.

Jasmine believed that mothering was not instinctive, but it was obtained. In her words, "I am confused about that, but I think it means that all girls wish to be mothers, we become excited when we get married, then we become extremely happy when we get pregnant. Here the instinct plays the role. It is obtained by learning from others how to raise our children."

Ethics were acquired from a role model in order to practice mothering. As Jasmine reported, "By practice, you will have these ethics. Your parents have taught you these ethics, but then you have to learn it by yourself. I think that ethics are acquired from a role model, for example, when you like someone's reaction in a situation." Jasmine also said, "My ethics as a mother, are to be responsible for my son. For sure there are faults in my personality, but it is important and makes me happy to be responsible for my son. This is not part of ethics, but rather a duty. The ethics that a mother should have are to educate her kids, raise them up, to be their role model." Jasmine stated, "My mother is a great person who made many sacrifices in her life for us. After my father died,

she could have married again, but she didn't for her kids. She gave up her happiness and time for us. So unconsciously, I took her as my model, because she lived alone without a husband, without anybody, and now I live in the U.S. without a husband, too."

A mother needs to have many qualities. Jasmine described herself as a mother: "sincere, patient, sacrificial, and selfless, in order to make life carry on." Jasmine said, "Every mother must act selflessly."

Camellia mentioned that her perspective on mothering and perfect mothers was that:

It is something nice. I think it is a great experience. And it varies from one person to another. Some mothers, for example, wanted to be mothers before getting married, while some others think of mothering as a big responsibility. As a result, they do not treat kids kindly. But all women love their babies. They have the maternal instinct, Subhan Allah, they love their kids, regardless of how tiresome they can be.

Camellia believed that every mother who wanted to become a mother must think carefully about it because mothering was a big responsibility and involved sacrificing things. As Camellia reported, "Mothers should think before having babies because having babies means heavy responsibilities and sacrifices. Some mothers bring babies for the sake of nothing! They receive beliefs from the society that 'you must bring kids!' Women must understand that babies are humans who need care, and then mothers will enjoy raising them up."

Camellia said that mothers should take care of their children, and she provided an example of her son. "Mothers must care about their kids. When my son was young, he used to dirty his clothes. I used to clean his clothes without telling him anything. I think that is wrong.". Camellia added that mothers must care for everything for their children. "Ideal mothers care about the basics, also to feed her son healthy food, let him sleep well, make her kid feel safe. She must give her kid

feeling and love. I give them everything because the attachment between a mother and child will affect the kid in the future.”

Sometimes Camellia felt guilt toward her children, and at the same time, Camellia was enjoying her time:

I always feel guilty. But my friends tell me, "You are doing your best, but you are thinking a lot about your kids." But I do not think that! I give myself time when they go to sleep! I enjoy my time. I watch a movie or explore the internet. I give myself some space. For example, I can clean everything, study, and go out in the morning with my friends. During the last Christmas [Break], I wanted to see my family in Saudi Arabia! So, my sister came and stayed with my children, and I traveled to Saudi Arabia for a week.

Camellia did not care about other people opinions or if they misjudged her on how she raised her kids:

If someone misjudges me, I do not care what they say! If they say I am not a good mom, really, I do not care. For example, I do not like to hug my kids in front of people. That is something private. When we are alone, I kiss and hug them, but I cannot do that in front of others, because I see people do that, and they are just pretending to love their kids in front of us. Some people think that I am careless because I travel alone sometimes, but I do not care! I trust myself and what I am doing with them.

Moreover, Camellia believed that "Raising kids up does not mean just to feed them! It is to care about their mental health, too. I always ask them how they feel if I traveled somewhere. For example, they might get sad! They always ask the servant, ‘Where is Mom? Where is Camellia?’ When I open the door, and they heard the lock, they call out ‘Mom! Mom!’"

Rose, on viewing herself as a good mother or a bad mother, stated that she once considered herself to be a bad mother and that it took her a long time to think of herself as a good mother. She experienced feelings of guilt because she did not spend more time with her daughter, Noha, and had frequently left her at home. She had to remind herself often not to blame herself because it

was easy to beat herself up about her kids. People would even tell her that she was an active and caring mother, and she still found it hard to believe it. Rose found mothering to be rewarding and tiring at the same time. Rose used to say, "Why do we call children a 'fraction of my liver,' and not 'a fraction of my heart?'" She explained that when Noha became ill, she subconsciously put her hands on her stomach and said, "Ouch!" And she explained, "That is why we call our children, 'Fraction of my liver.'"

Lotus provided the definition of an ideal mother: The ideal mother would have given care to her children, and this care would have had many layers underneath: loving actions, time spent talking, being close with, and making them her priority. According to Lotus care meant:

To give him love and care, to talk with him, to be close to him, not to underestimate him, not to laugh at him, not to shout at him in front of people, and to be patient with him. Make him her first priority. For example, to skip a meeting for the sake of your kid. Some mothers say to me, 'You are wasting your time.' I do not waste my time when I sit with my kids, because when they get older, I will wish to sit with them again. The ideal mother is the one who cares, especially Saudi mothers. I lost a lot of my friends, because of my beliefs.

Lotus felt that mothering includes a collection of characteristics such as "forgiving, patience, and belief in destiny."

Lotus believed that the first years of child development were very important because the child can learn and gain different knowledge. In her case, she was under pressure because she wanted her child to learn as fast as she could teach him. She wanted to do as much as she could in those early years:

Many other mothers and I think that the first years of the kids' lives are the years in which he learns the majority of knowledge. So, I am under the pressure of time, and I must teach him everything. But that pressure is getting less. I believe that the pressure is getting lower over time, but I never regret giving my sons my time, because they need it, and they will be independent in the future. I do not feel guilty, even though people used to criticize me since my children were young. I

told them, "They are only little for a short time. "I am more comfortable because my son is getting older and improving. For example; I accepted the idea of bringing a nanny, and I accepted her help. I am able to live my life because my son has improved. When my son joined kindergarten, I joined the university.

Lavender agreed with Jasmine that all mothers were perfect, but they were different. "Mothers are different." Lavender saw herself as a perfect mother who cared more about the mental health of her children. "The most important thing for me is my children. I do not care whether the house is clean or not, or whether my daughter is good at school or not, all that I care about is my daughter listens to what I say to her, the most important thing for the perfect mother is taking care of the mental health of her children."

**Educational and social levels affect upbringing kids and mothering.** Educational and social levels of the mothers could have an impact on children, and how mothers reared their children.

Jasmine's point of view is that "Educated mothers are better than uneducated." According to Jasmine, when a mother was rich she should be able to live her life with everything available to facilitate educating her children, but sometimes this mother didn't care about education, and only cared about superficial things. "She is rich, and her life is easy! She can facilitate her kids' education! Regarding their kids? They do not care! They care only about outfits. She cares about their food and outfits, but she neglects their education."

An illiterate mother according to Jasmine:

She might only know a little about parenting, but her affection towards her children is beautiful. It is really exhausting being an illiterate mother. She cannot provide everything for her children, and that might affect their mental health in the future. I was thinking about mothers who cannot read or write. There are illiterate mothers who can love their children very deeply and show that affection in their behavior; however, their children may show bad behavior like bad language.

On the other hand, there are illiterate mothers whose children grow up to be doctors, but they did not show their affection to their kids thinking that affection may undermine the mother's position with the kids. So, it's normal that her children will be rigid due to the lack of affection from their mother. In short, some illiterate mothers give love instead of guidance and education, and others do not give love, but they raise their children very well. None of these ways is complete.

Rose reported that if mothers had higher education, it could affect the care mothers gave their children. Education played an important role in rearing children because mothers could have different ethics and methods for raising children. Mothers were aware of how to solve problems that their children had:

Mothers who have a high income [in Saudi], most of the time depend on servants. It has a huge impact if the mother is educated because mothers who read about bringing up kids and caring about them are much better than those who do not. Of course, education has a big role. It has an impact, but not on all these levels. Many of those who have a high income rely on servants in everything regarding the children's upbringing. Education is so very important because education develops a mother's methods of dealing with children, the ethics she wants to teach them, and her awareness about the methods of solving the problems her children face.

Rose described herself as a mother who was patient and thought about what causes problems, and why the specific behaviors occurred. Rose felt that she is stressed out because she is separated from her husband:

I am patient, and I always think of the problem's causes and the behavior's causes. Yet currently, I am stressed out and feel tired from everything. I cannot stand seeing negative behavior. If I noticed it, I would feel it like a burden on my shoulders. Sometimes I get angry about the behavior and start to talk to my daughters. Sometimes talking works and sometimes it does not. I am trying now to ignore any negative behavior. I need a rest. You know I just broke up with him, so I need a year and a half to overcome the break-up, and be mentally stable.

Camellia wanted to add that it was important that these days for mothers to be educated because kids were sensitive. "If the mother was not educated, she would raise her children by old ways, which means everything was okay, but if she is educated, then she will know how to deal

with her children, especially these days while children are very sensitive. These days you feel children can be affected by the drama in the family, but before they would not be that affected."

Socio-economic background and education level could both play roles. When Camellia studied in two different schools, she saw how her friends came from different backgrounds. "When I was a child I studied in private school, and then in public school, so the environment of the two schools was different. I found it in my friends, and how they think because of their different backgrounds. At the same time, it is not very good, because we have to believe that we are different and everybody has something unique about him/her."

Camellia pointed out that the environment could have had an effect on her friends and their parents' thinking. "You know that the environment made an impact on my friends. Their parents were educated, and their thinking was different from other non-educated parents." Camellia stated that education was important for mothers who their children were friends with because they made activities for both kids. "Now, if my son's parents are educated, we think to do different activities and educational outings for them."

Lavender also stated that social and economic status had an effect on the mothering. When mothers had a higher education, they noticed and understood any changes in their children's behaviors. "It has a huge effect on the mother. I remember when my daughter was two years old, and I noticed changes in her behavior, so I took her to a children's psychiatrist. My friend told me she could not imagine what will happen to the children if their mother is not educated. So, the educational and social background of the mother has a tremendous effect on her children."

Lotus shared, "Health is more important. It is very important, and I cannot deny it. Money makes our lives easier. So, thanks God, because my financial status is good, if my two kids are

typical, I won't need a therapist. I won't spend most of my time in the waiting rooms, spending extra effort. So, money helps! But it is not everything."

**Religious beliefs that affect mothering.** Moral principles in the Quran were very important for mothers in this study because they could guide them while raising their children. As Lavender reported, when she read the Quran, "It guides me. When I become lost and hesitant in my life, I resort to the Quran. That's the difference between them and us, thank Allah we have Islam." All the time Lavender told her daughter, "I will not be by her side forever, there is someone who is bigger than me, your father and everyone, and that is Allah. You always have to be by His side."

Rose discussed what ethics and principles written in the Quran meant to her as a mother and a wife. "They mean the world to me, and it is important for me to clarify the meaning for my kids."

Rose stated what God's will, mercy, and tolerance mean to her. "These are very important ethics, and I try to teach them to my daughters. It saddens me when I notice that my older daughter is missing one of these ethics." She taught her daughters these ethics in their time together during the day. She tried to use every situation they faced to teach them to be kind-hearted people and to think of others.

By way of example, Rose shared a story about a day when she was out driving. She slowed down her car. Her daughter asked her why she was slowing down, and she told her because there were pigeons crossing the street. They were headed to Wal-Mart, and there was a man begging near the entrance, who said that he was hungry. She said her daughter was so touched that she wanted to give him money. Her mom told her no that they should go inside, and bring him food.

While her mom was inside buying what she needed, her daughter was telling her to hurry. When they brought out the food, her daughter wanted to give it to him by herself. So, she let her daughter give him the food. Rose said that even though she had financial problems of her own, she always tried to remind her girls about helping other people because she wants to generate feelings of sympathy for others.

Rose also believed that when it came to health and diseases if Allah loved a man, he tested him. She said she always looked at the glass as half full not half empty. She tried to be positive, and always tried to thank Allah for the blessings, despite what happened to her. She always used to ask the question, "Why me?" Then she realized that Allah chose her because she was an outstanding person. She believes that Allah knew her abilities, and what she had to give a child. He knew the information she had, and her child is a blessing. She felt this is her goal in life, to raise awareness about Autism Spectrum Disorder by talking to talk to people about it:

I am careful about keeping my daughters aware of religion. My family is religiously committed, and their house is spiritually beautiful. When I enter their home, I become more religious. My parents read the Quran daily, they pray on time, and my father always motivates my sisters and brothers to pray. He tells my sister, "Any of you who cannot pray because she is on her period, can motivate her sisters to pray." My father, as well, has religious reflections. For example, when we sit at the table to have dinner, he would say 'Look how blessed we are, we all sit around one table, we can find any kind of food that we desire.' There are poor people who do not have this food". I also remember, when I was young, my parents taking us to a poor neighborhood. There were countless poor families, and they were giving them charities. I remember that I cried when I saw those people.

Rose connected her studies and her child's disorder. She believed that her daughter was sent to her from Allah, that she is a message from Allah and the reason she studied. This gift was the reason for her to continue learning. She didn't feel any desperation or difficulty in her life from having her daughter. She admitted that she was afraid in the beginning, and she still has some fear

at times. She doesn't deny it. She recalled how she would see misery in the faces of parents who felt like their disabled children were a burden. And she saw success in the faces of the parents who loved and accepted their children with disabilities. She believed that the parents who viewed their children as a burden would fail in their lives, along with their children, but the parents who saw their children as a gift, would succeed, and their children, in turn, would also have success. She admitted that all parents of disabled children might get depressed from time to time. But she put her trust in God. She was thankful that her family had supported her. At times when she was depressed, they were there for her. They encouraged her by asking if she would throw a gift from Allah in the streets or would she thank Him for this gift?

Rose continued, "My friends are the same, do you believe it? I do not think my daughter's disability or this disorder or that disorder will stop her [from learning and practicing her daily life]. I have a feeling she will be superior at it. She is growing, she is developing, she is catching up, and it is fully a matter of time. Maybe I see this coming because I am stubborn. I want her to forcibly improve." Rose believed that being positive about faith is important. Some people had told her that her daughter is a test from Allah, but she did not think that way. She thought she would be miserable without her daughter. Her daughters were her world. She doesn't care about the autism, retardation or hearing impairment. She saw Noor as a person with a personality all of her own.

Rose was sure that religious beliefs could affect the mothering experience:

If we use them in a positive way, then it would help, while if we use them negatively, then it would not. Some people think negatively about it, and they tell me, "This is a test from Allah, you have to be patient." Others think positively about it and say, "This is a gift from Allah." Some people think of autism as a heavy burden, even if they accept it, thanks, God. Whatever comes from Allah is good. I think Noha, Noor, and even my divorce are blessings and there is goodness inside

them. If these things were not happening to me, I would not be strong and independent like this. I feel that I am ready now to go back to Saudi Arabia alone. I do not need any man to live with me. I am comfortable with living alone with my daughters. I am a positive person, whereby I always look at the positive side of things. I always try to overcome the tiredness and sadness that I get from the problems I face. Noor is a gift from Allah. Honestly, if I was given the chance to choose between a normal and an autistic kid, I would pick the normal baby. I consider her as a gift. First, because her personality and soul are obvious, the disability did not cover them. I should not say "disability" I should say "disorder," because autism does not disable her. We are working on skills, and she is improving. Her autism is not heavy compared to others. Another grace is that I am an educated woman, and I know a lot about my specialty. Another grace is my family; they are well-educated and support me. In Noor's case, we must look at the bigger picture. Allah has granted us many graces, so it is shameful to call this a test. We must thank Allah for the plenty of blessings we have. I think Noor is passing this difficult phase, but if she remained as she is now, so what! I accept her because she is cute. I will always take care of her.

When Lotus was asked about how having a child with ASD from a religious perspective could affect a mother her answer was:

Positively yes, but negatively I do not know! Maybe they think that they made a mistake, so Allah is punishing them, but I do not think in that way. Allah is not oppressive. The idea that Allah is punishing you by your kid is a wrong idea, Allah is not unjust. I totally refuse this idea. I myself think of it as an expiation for bad deeds, if I do not have my son I would be. Away from my kids and husband! God knows what I will be like! His autism makes our relationship closer.

Lotus stated that the ethics written in the Holy Quran have meaning for her, "We try our best to follow these ethics." As a mother and a wife, "Both of them, there is no perfect person in life! But we are trying our best to follow these ethics and to represent it as much as we can. So, I am trying to be a good wife and to give my husband all his rights. I always blame myself when I do wrong things. All of this is driven from my faith. And it is my duty to do it."

Lavender stated that having a child with autism:

Is a test from Allah, and when Allah loves somebody he tests him/her. Second, there is a goodness in it. If I was given the chance to choose my destiny, I would choose my son to be with autism, because for sure, there is a goodness in

that. If he would not be with autism, he will be disobedient. I always think in this way.

Lavender felt that Americans people did have the concept of destiny "do not have this culture, it is important in this issue, we must accept this." Lavender did not feel mercy and tolerance when her son was diagnosed with Autism Spectrum Disorder. "What changed me was not being a mother to an autistic child, but living here alone as a single mother, and doing everything by myself. But it did not make me merciful. It made me tough." Lavender reported that she had a hard time crying in the beginning, but now she can cry at the smallest things, because of holding her feelings in for so long. She didn't feel like she has sympathy for others, because she has so many of her own problems. She would rather other people keep their drama away from her.

Jasmine believed Allah was rewarding her, by giving her a child with a disability. She said she had become closer and more faithful to Allah than ever. "I believe it is a grace from Allah. It is a blessing of Allah. I was negligent and had no idea about people with special needs. This has made me closer to Allah, strengthened my faith in Allah."

Furthermore, Jasmine reported that because she helps and serves her son, she will enter Jannah (Heaven):

I believe that an autistic child facilitates many difficulties in my life. I face many difficulties and challenges in my life; I believe it is a kindness of Allah, that I have a kid with special need. Also, you know the Hadith of the messenger Mohammed (pbuh) "A believer does not undergo (the trouble) of running a thorn or more than that when Allah effaces his sins." So what do you think of a woman who is serving an autistic kid? I always feel sorry for him; I care about his little details.

Due to Jasmine being a mother of a child with autism, her relationships with Allah, and with other people were fragile.

Like I told you in the beginning, I was in denial. I wasn't understanding. My thoughts were in maze. I felt my mind going to the right and left. That time I was just following his doctor. All I did was enroll him in school, and give him one session of speech therapy as I was told. When I realized and understood him, I said, I was really stupid because I did not know what I was thinking by giving him just one session, even though I had insurance at that time. I blamed myself for listening to other people, and then I started to work on him, after no improvement on my son. I was depressed because I opened my mind to what is really happening. Sadly, my connection with Allah became weaker, and also my relationship with other people became fragile. I couldn't listen to anybody, even my husband. I am faithful in [my relationship with] Allah, but sometimes I feel that I want to run away from everything. I afraid of being alone. I have no one with me, and I trust no one.

Jasmine's connection with Allah become stronger. "I even start to ponder all of Allah's creatures." She started to meditate more, "Yeah, how every creature's sustenance came to him, and how everything is subjected in this life." Jasmine's viewpoint towards illness was that it was a grace or a test. "Health is a grace from Allah, and you won't feel how important it is until you have lost it. If your nail was broken, you won't sleep. While the illness depends on the sick people themselves, you will find some people have cancer and are living in peace, because they are positive and taking it easy, while for some other people, they will live like it is the end of the world."

Jasmine said that the culture mothers live in could have an influence on their religious beliefs. If mothers were well educated and have a strong faith in God, their influences will be greater on the people around them:

Religious beliefs rely on one's culture, and on the influence of the people around us. I will talk about myself. I believe that the religious beliefs depend on the culture, whereby there are mothers who think their sick kids have autism, because of envy! They also might close the doors on their kids, and bring them a servant. They do not allow their kids to go out. So religious beliefs depend on your level of education, how much you believe in Allah, and on people around you.

All five of the mothers shared their opinions about Surah Baqarah Versa 286 [a verse from the Quran], "Allah does not place a burden on a soul more than it can handle."

Jasmine stated, "I always remember this verse when I am extremely stressed out. I tell myself that Allah tested me because I can afford it. If I could it bear it at some point, then Allah will fix it. I trust Allah, and I believe everyone can handle the burden placed on them." Jasmine also said, "Allah knows your capacity, and he gives the burden according to your abilities."

Camellia agreed that "Sometimes I know that I am not doing my best with them, but I know that I am tired, so I always tell myself, 'Allah does not place a burden more than it could handle.'" Camellia went on, "I feel that I am doing my best and not tiring myself!" She replied, "No! You *are* tiring yourself" Camellia continued, her friends always tell her, "You did what you can do! You do not have to do everything. Camellia, you did what you can do, you do not have to be Superwoman."

Lotus put her thoughts this way:

I strongly believe in it, that Allah will not place a burden on you, more than you could handle. He knows your capacity, and he gives the burden according to it. When you heard about a problem that happened to someone, you ask yourself, "How does s/he afford it?" But when you are in his/her shoes, you will find out that Allah placed a mercy and patience with the burden so you can afford it. Allah said in the Holy Quran, 'Surely with difficulty is ease.

Rose stated, "I am trying to use this quote recently. I always beat myself up. I always have pangs of conscience, and I consider myself as a bad mother. It took me a long time to think of myself as a good mother."

Lavender agreed, "It means Allah wouldn't test me with my son if I couldn't handle him." All of the mothers in this study agreed that Allah knew their ability to handle the autism, and because of that, they had given birth to children with autism.

**Mothers were aware of their children's behaviors, development, and wanted to teach them specific morals.** Jasmine was the only mother who was not aware of the stages of her child's development. When her son was delayed and didn't improve, she thought it was normal in his age because he was her first son. The remaining four mothers shared their experiences about how they were aware of their children's behavior, development, and how they desired to teach them specific morals.

Rose mentioned how she loved the way her brother and sister played with her daughter. That made Rose understand how her daughter's brain works. They made up different activities to activate her daughter's sense. Her mind would become active when she saw water, so they started filling the bathtub up with water in the morning so that she could play in it. Rose would take her to the playground so she could play outside. She would stay there for an hour and a half. Rose would notice that outside she was less idle, became more responsive and active, and began to understand more about her surroundings.

Rose insisted that whoever is working with the child, must know her abilities. Her daughter's abilities and needs are different. She still doesn't know if Noor is social or not. She can perform her self-care needs, so she has achieved that independence. The next focus is on lingual communication since her physical abilities are satisfactory. Rose works with her daughter very well. She takes her daughter wherever she goes and allows her to interact with different people. She tries to have friends as much as possible. According to Rose:

I depended on the center for several things. When I took her from school, we went to a supermarket, and we met friends in a café. For me, I had to spend time with Noor, unconsciously I exposed her to new experiences. I unconsciously trained her. Last time, we were in downtown Chicago. We took our coffee and went out of the café to sit. Usually, we sat inside, but that time I wanted to expose her to a new experience. She was clever, and she could handle it. There was a subway above of

us, and whenever it passed she was smiled at me, she did not fear its sound. The train and car sounds used to scare her, but not anymore. She loved the outdoors. When we ate all the donuts, she did not leave her chair as usual. She just waited.

From the beginning, Camellia was aware of the stages of development for her children. When Camellia went to the doctor in Saudi Arabia, he told her, "Your son is brilliant." Camellia did not pay attention to what he said, because she, "Knew that my son has a problem. Then I told my ex-husband to notice if our son tumbles at four months of age, which is the normal age to tumble. I already knew the stages of development with children his age. He did not tumble like my nephews. He was late for five months." Camellia knew that her son must go to special education. "He has to go to special school, not to just any school."

Lotus focused on behaviors in order to improve her children. For example, when she promised something to her children, she wanted to teach them that mother was not lying. She is trying to teach them discipline. Another example, "I tell them not to play with this thing, and I put it in front of them, so they learn discipline. That teaches them trust and privacy." Lotus wanted to teach them morals so that her children learned how to be kind and honest. "I hate hiding things. I say 'no,' and I leave it in front of them. I am trying my best to teach my kids honesty, by fulfilling my promises, and apologizing when I make mistakes."

Camellia was trying her best to be consistent in teaching her son certain things. She reported that she was worn out from trying to teach him things that could take years to teach. One thing that caused an enormous amount of stress was the iPad. It took years for her to convince him to finally give up on it. At this point, he thinks the iPad is gone. She recalled one instance when she was on a train with both of her children. The battery for the iPad died, and he got mad and started hitting his brother. She was stuck because she was on a train, there was nothing she could

do. When she got home, she yelled at the older brother to throw the iPad in the trash outside of the house. She said it becomes really tiring, and she asks Allah to give her strength. Recently, a new problem developed. Her son asked for the iPhone when they went to a restaurant. She decided to threaten him. She told him that if he asked for the iPhone, she would take him back home! She said she has decided to become strict, and insist that he obey.

Lavender was aware of her daughter's behavior. "I was consulting the psychiatrist about her jealousy. She started to pee on herself once her brother was born, and when she was four years old, she used to go to the bathroom by herself. She returned to pee on herself and biting her nails. It made me sad seeing her like this, even before I gave birth to her brother. I wondered how to solve that." Eventually, she says she:

Went to a psychiatrist twice in Saudi Arabia, once here, and now with ABA, and one of the things the doctor told me about is to use the golden time. When I come home. I hug and kiss her. The shower time would be a great time to start a conversation with her. [Ask her] 'What is the most thing that you like about me?' or 'what is the most thing that you hate about me?' and things like that. Also, she told me to use stories about values, values that I want to teach her. I brought some stories from Jareer [a library in Saudi Arabia]. So, long story short the doctor advised me to use the golden time like shower and bedtime.

Lavender described her role as a mother is, "to offer them guidance. I am like a shadow to them following them in every step." Lavender wanted to concentrate on specific targets so her child could be successful. "The first thing we do is work on his attention. If he can focus, then he can benefit from his study and his therapy. It is the last thing that I could think about because nobody will judge him. All I want for him is to be independent so that he could live alone. I will not be with him forever. I focus on independence. I teach him to be independent to succeed in life."

**Mothers worry for the futures of their children.** Only four mothers in the study shared their worries about their children future. Camellia did not submit an answer.

Jasmine explained, “[I worry about how] To make him independent, and rely on himself. And I was the reason behind this; I used to feed him by myself.” She continued, “He won’t eat by himself, even if I left the dish for several hours. Yes, these are my priorities; to depend on himself; I do not care if he talks or not! I want him to go to the bathroom by himself. Majed is clever, yet he entirely depends on me.”

Lavender’s feelings about the future towards her children were:

Love, fear, and anxiety. Always, she is my only daughter, and we have no one here. Sometimes I feel sorry for her. When I used to tell my mother about her, she was telling me my daughter is better than others. I should thank Allah. Lavender continued, When I think about her future it makes me worried, but I thank Allah she is a clever girl, from now she thinks about getting a job and saving money for the future.

Lavender said that she is always worried about her son "I trust nobody to be with him. I always think that when I pass away, he will not miss me because of his case, but Jana will be devastated. She has nobody besides me. Sometimes I think that I have to go back to Saudi Arabia for her sake, but I have to stay here for her brother. I don't know what to do."

Rose worried about the future of her daughter. “I am overthinking Noor’s future. I am really tired of thinking. I think about everything; what are the potential experiences available in Saudi Arabia?” Rose hid the disorder from other people in Saudi Arabia. “People who do not know about her being autistic, when they see her on my Snapchat, they tell me, ‘Your daughter is arrogant and sedate.’”

Lotus shared different views from Lavender and Rose. Lotus stated that:

I hear many mothers asking, ‘What will his/her future be like?’ I feel that I am focusing more on developing him, not on worrying about his future. Yes, even the Americans do not say that your son has autism. They look at your son as a kid, not as a case. I am afraid that people would treat him as a case. That is why I won't say ‘autism.’ People also think about my son's future, like how he will marry? But

I do not like to think about it. I am relying on Allah. And I have great hope! When he is a teenager, he will be almost normal. Because he is improving. He might be unsuccessful at school, but I won't stress him out. I am afraid about his future. He has all the stuff that makes him learn, and we are facilitating the process for him. I will give him the opportunity to study in America. We might find the cure for him when he gets older.

### **Diagnosis and Being the Mother of a Child with ASD**

This section shares the details of mothers' feelings during the diagnosis period and about being a mother of children with ASD.

**Mothers' feelings about having a child with ASD.** Rose had a misunderstanding about the disorder. "Based on my knowledge; I knew that autistic kids do not have feelings, and they do not express them." "I went back to my house crushed and started to cry." Then Rose started to compare her daughter's abilities before and after the disorder. Rose stated, "Not only comparing her, but I started to notice her doing things she has never done before. There was a connection between us. Then I felt that there is a tension between us."

As a mother of a child with ASD, she started to teach herself about the disorder:

I started to read and read about autism. Every time I read I saw things about her. I started to read different studies, and most of the research proved the positive relationship between autism and cramps. I read that imitation skills of autistic girls are better than autistic boys. I read more and more about it, and I was optimistic about her. They have not diagnosed it until that moment of autism. Also, I have a brother who is specialized in autism.

Rose said that one thing that helped her accept the diagnosis is her belief that differences between people are normal, and her willingness to understand people as individuals:

Noor is totally different from Noha, even in the way of teaching. But I believe that she is going to grow. We just need time, different strategies, and to be more patient. I always understand what she goes through. If she is overacting, I hold my patience. She is sensitive, that is why she overreacts in some situations. Because I understand the individual differences, I accept Noor more. If you look at my friends, I have librarian friends, religious friends, normal friends, Saudi friends,

and foreign friends. I believe in friendship between both sexes, so I have male friends, and most of them are foreign. Arab males do not know how to make friendship [with females], [I] just understand every personality, and accept it as it is. So individual differences affect everything.

At first, Jasmine denied the disability in her child: "I escaped. Because I had a tough experience. I was married for four years, before getting pregnant. I could not accept the fact that my kid is autistic. I was shocked and did not accept that fact. I was isolated from the world, in order to understand what is wrong with Majed. But when I accepted it, I trusted myself and went out to face the world."

Jasmine described her initial feelings about her child's diagnosis:

I collapsed because I knew nothing about the disease. None of my family members have any kind of disability. I felt that my life is over. Unfortunately, that's because there was no awareness in my community about people with special needs. We didn't use to see them at schools or anywhere in my community. So, it [the diagnosis] was like a monster.

Before I knew about his illness, I treated him normally. I took him to restaurants. He played, slept, and ate normally. But when I knew about it, I treated him like an alien from space, because "he's autistic." I can't do this and that, my life turned 180 degrees. For almost a year I stayed that way. Then, I told myself, before I knew about the diagnosis everything was fine. We were doing everything together like any normal kid. I started to open my eyes, and become more aware about him, and convince myself that's nothing changed. Why am I being so sensitive about it?

I confronted myself. Then I confronted my community: "Feeling like my son is an alien. All we know about aliens is that they are scary creatures, and we don't know how to communicate and deal with them." Like autism, I know nothing about it, and it makes me feel afraid. I was sick, tired and frustrated.

He is my first child. I waited for him for four years, and after all that, I find out that my child is disabled. I isolated myself from others. I felt like I am a deficient human being. I felt I pitied myself because there was no awareness in my community. Do you remember when I told you that we look at disabled people in a demeaning way? So, I became that person who is poor and has nobody. I become a stranger in my own community. That's a true thing that there are no good schools, no good diagnoses or even a decent resource in our country. I used to replay it. I am between the aggressive personality, and the broken, sad one. I even criticize

things which had nothing to do with me. I felt like I am drowning in the sea, who is trying to save his life and his child's life. I was in a mental crisis. Now, I blame myself for thinking of that crazy idea. After all, Allah, he is the one who created us, and he won't let my son be alone when I die, Allah will take care of my son.

Jasmine blamed her husband as the reason for having a child with ASD:

In fact, my relationship with my husband got weaker, and I also feel that he is the reason for my son being autistic.... During the pregnancy period, I was not happy; he was putting pressure on me, and saddening me a lot. I was sad all the time during my pregnancy.

Even after giving birth, many problems happened. I feel that he is the reason behind having an autistic child. You know as a pregnant woman, I desired to eat something; so, I asked him to bring it; he refused, saying "I am afraid to bring it and it won't be delicious." For God's sake! I want to try it, not you!! Or he might say, "I do not know the shops that provide it." He did not care about my mental health.

Camellia discovered the autism diagnosis very late for her son:

I told her when my son takes his medicine he becomes like autistic. She replied if this kind of medicine shows up the symptoms of autism, he might have autism. I went to 10 doctors, and none of them diagnosed him as autistic, they diagnosed him as hyperactive. I knew by myself that my son is autistic, when I came here [United States], doctors diagnosed him as autistic. I was sad because no doctor gave me the right diagnosis, the doctors were always saying the diagnosis in an indirect way, and that bothered me. I went to many doctors, every one of them told me that my son has nothing to worry about. I was very excited when I had my first baby Noah, and I tried to read everything for him to make him better

Lotus faced difficult feelings when her son was diagnosed as being autistic:

When I was at university studying psychology; they told me that my son might have autism spectrum. I remembered the woman I read about in one of the psychology materials; she described her feelings when she was told that her son has autism. She said, "I do not want him to be healed. I just want to enter his world." I remember that I cried. I felt the pain of autism. Can you imagine that a little thing changes the mother's life completely? We went through a tough experience because he was not a classic autistic.

Lotus blamed her for not noticing her autism:

I thought because we speak in both Arabic and English; he was just a late talker. That happened to his brother, too. When my brother-in-law told us to check on his ears, that was in Saudi Arabia. Here in America, there are doctor appointments where parents are asked these questions. I missed it because at that time I was in Saudi Arabia. When I went to the doctor, he requested that Adam give him a tissue, but he did not understand. I told him, 'Speak with him in English. He does not understand Arabic.' He did, and my son came to play around me. The doctor said that he suspected that my son is autistic, especially after he noticed hand flapping. "(the mother started to cry while talking) Just tell me what to do, and do not take time to talk about my feelings. I prefer to hide my feelings. I liked what he had done because he was honest with me. I felt that the room is spinning.

Lotus did not deny what her child has, but she blamed herself for not paying attention to his developments. Lotus pointed out that "I might be the reason...I cannot point to what my mistake was, but I am afraid that I did not do things for him. I greatly blame myself. For a long time; till now, whenever I talk about it, I cry! I am trying to be stronger, but it badly affected me."

Lavender had suspicions about her son's development, but she was denying it:

I noticed the symptoms when he was three, but actually, I noticed some earlier when he was two, but like any mother, I was in denial. I didn't want to go to doctors. I convinced myself that he would be fine by the time he goes to school. Then when he was three, I said it is time to do something.

Lavender sighed,

For example, when he was two years old at a birthday party, I noticed that his eyes would stray like his mind is somewhere else. He wasn't even aware that he is at a party. He wasn't feeling pain. He fell down the stairs many times, but he didn't cry once. When I call for him, he never responds. He is babbling, and I rarely understand him. I only understand just three words, mama, milk, and let's go.

Lavender diagnosed her son very late, and the early intervention is very important:

My sister who has a Ph.D. in special education told me that I need professional help because my son is not normal. I took her advice, and we went to a specialist doctor, and she confirmed our suspicions about my son. The early diagnosis and the early intervention were the most important things.

Lavender stated how when she was in the diagnostic phase and in the early intervention, both were difficult times for her. As Lavender stated, "Because this time was important to have early intervention, but the time passes by quickly, and he missed out."

Lotus stated that as a mother of a child with autism:

It makes me appreciate God's graces. When I see women with non-disabled sons talking and walking, and she does not appreciate that. While we study and exert effort to make them speak or do this or that. So, I appreciate this grace. I am appreciating every skill Adam has gained. And I always say Alhamdulillah. I enjoy reaching this step because we gained it through hard work.

Lotus describes how her child diagnosed and the time of reaching his goals "was like a journey, but its end is great." that made her appreciate the graces she had. In Saudi society, as she reported people:

Caring the most about materialistic life, we care about silly things. That is why they told me to travel to America, because I love simplicity, and I do not care about silly things. So, I started to appreciate everything I have, not like the rest of the people who do not appreciate what they have and feel sorry for the things that do not have. When you have two kids...this is the most important thing, that prevents me from looking at things from a materialistic aspect.

**Mothers' self-centeredness, self-esteem, and becoming mature.** Four mothers described themselves as self-centered, having high self-esteem and becoming more mature due to having children with Autism Spectrum Disorder. Lotus did not respond. Jasmine reported that:

I am still self-centered. Maybe because I live alone just with my son. Maybe it creates some kind of balance in my personality. Maybe I lack something in my life, and that thing makes a balance. I feel like it summarizes my life, and it helped me to know what it is wrong and right in my personality. I love myself and talk about myself a lot. I have a high level of self-esteem, and I feel bad that he does not respect and appreciate me.

Rose reported having a great ego, self-esteem, and self-importance of herself:

I realized that Allah chose me because I am an outstanding person. Allah knows my abilities, and my ability to give. I used to say, "Why me?" but now I say

because I am special and outstanding. I do. But from time to time, I regress and ask myself, 'Why me?'

Lavender stated that having children, especially her son with autism, changed her to become more mature:

My current life has a purpose, especially with Saad. I feel like I have long term goals: how will I manage to make him live without me after I pass away? What would happen to him? We have created man into toil and struggle. Sometimes I wish to be single again. Then I regret wishing that. If I were still single, I wouldn't reach half my way now. I can't imagine that I would be that mature.

Camellia was proud of herself and her achievements. She recalled:

My brother's wife told me once that I will not bear it. Also, my friend told me the same. So, what will happen to you with two kids with special needs? And you will study! She could not bear one baby, and she has no husband! I know my capacity, thanks, God! I am happy with my big achievements, not just a master's degree, I also treated my kids! I am Subhan Allah. I got married when I was in high school! And I finished high school after three years, and I did not join university! My ex-husband refused that. Alhamdulillah!

**Perspective of disability and illness.** Four mothers reported how they see disabilities and illness. Only Camellia did not share her stories.

Jasmine's perspective of disability was that:

It breaks us! I wish I did not say that, but it strongly breaks us! It means literally disability! You are too disabled to do anything. I experienced it, and I can see it around. I am still believing in the old definition of disability! Of course, I do not mean underestimating this group of people! But I think that disabled people are not merged into the society. That is why I think it breaks us. Disability is really painful, and what adds insult to injury. In the beginning, I thought I have to live in isolation, and I have huge responsibilities on my shoulder. Then I found out that my life and my son are normal. We can hang out easily because my son has the right to be in the public places as long as we do not hurt anybody. Of course, we have some obstacles, but that is okay.

Jasmine said her perspective about disability now was different than how she used to see it five years ago:

The idea of disability was like an alien being. I've never imagined I would have a disabled child. The idea of seeing a disabled person in my family is very sad. It was very sad. It was like death. Now, I have an autistic child, and my brother has a son with Down Syndrome, and we love them very much. When I see them in public places, I kiss them. They are very cute. I can't make people change their perspective about disabled kids. What's important to me is that I changed my own perspective.

Because of the change in her own attitudes toward disabilities, Jasmine said that her role now is to encourage and give hope to her sister-in-law who has a child with Down Syndrome:

She lives in agony and ignores the rest of her kids. She is responsible for taking him to centers. I encourage her, but I never give her fake hope that her son will be healed one day, like what people used to tell me. I told her that you will be happy with your kid, especially when you discover things about him. Do not just focus on him being disabled. Accept the reality that your son is with Down Syndrome. This is his face, and he won't change. It is something genetic. Instead of stressing yourself out, start looking for schools for him.

As Rose mentioned, disability was not something she had imagined in her own life. She was working with the disabled, and she did not expect to have a disabled child, even though her entire family is trained in special education. In her words:

We were raised up in an environment full of disabled people, but I had never imagined that I will have a disabled child. I have never been afraid of disabilities; my friends were worrying too much when they got pregnant. I was different from them. I was relying on my Allah a lot. I do not know if I can explain it to you.

According to Rose, the viewpoint of disability differs from one mother to another:

I see it in the upset parents' faces, those who carry a burden of their disabled children. I notice that the parents who love and accept their kids, they succeed in life, even though their kids have special needs, while the upset parents fail in their lives along with their kids. Rose provided an example of traditional beliefs. In the last year, when Noor was having early intervention, I was talking to the physical therapist. They were taking my daughter to the public library, in which there are many disabled people. I was surprised about that and told her, "But I do not see many disabled in the public places," so she said, many families are ashamed of showing up with their kids, not all of the parents can stand the idea of having a disabled kid. I personally do not care what other people think. I was raised in a

family who would go to a restaurant, and enjoy our time without even paying attention to those who are around us.

Rose believed the best way was to understand the autism disorder and deal with it in a positive way. Rose explained when the doctor came to tell her that her child was diagnosed with ASD:

I felt that in some ways I am kind of proud of my daughter, so she told me ‘you know, whatever I tell you, who advertise you daughter has autism or anything, parents know their children very well. I said, Yes, that’s sure, I see a lot of potential. My daughter, she is very smart. I know she has the skills and the ability, it is just a matter of training.

The doctor praised Rose for her attitude, and explained that having a positive attitude can help a child’s development, “because she feels her parents with her.:

Lavender believed:

Disability is a very bad word. With awareness, development, and reconciliation, about them now. I see these people as normal people just different than us. We already respect these values. We are not the kind of people who would say something bad when they have a disabled child. It’s true that I didn’t accept it from the beginning, but I was in shock. I didn’t want to hear any judgments, especially my husband’s family, because all they would say would be, let him eat this and that, and bring him to the Sheikh.

Lavender disused how people have a different point of view about disabilities. Some see their disabled children as vegetables, with no need to improve. As a result, they make no efforts to help their child improve. Others see the disabled child as not up to standard. Because he is not a “normal” kid, the parents do not want him to go outside. However, even with this misunderstanding of disabilities, Lavender believes that people can change their perceptions of disabilities. “That’s why [people who are interested in educating community] are trying to increase the awareness among people with autism and Down syndrome.” Lavender think that with social media people really have changed their way of thinking.

As Lavender reported, in the United States, there are laws for people with disabilities to help them and protect against discrimination. She compared that to Saudi Arabia, where there are no rules. In Lavender's view, it is hard to convince people to change their mind without any rules.

Lotus believed having a disabled/special needs child, "Means that s/he does not have the mental or physical skills that ordinary people have. I did not change after having a kid with special needs. But I became more caring for them. I was against people. I hate the way they look at them."

Since Lotus was young, she wished to adopt a child with special needs. Lotus studied Psychology because she loved to help people. She said, "I never hated disabled people." She remembered when she had her Adam, "I told myself, Subhan Allah, life brings you the things that you wish for."

**Mothers' roles when a child has ASD.** The mothers had different roles, and they shared their points of view. One mother wanted to become a significant influencer for people with Autism Spectrum Disorder. According to Rose, "The majority think that the autistic child does not speak and does not have feelings. I always talk about autism."

Rose wants to raise awareness about autism, and she always talks about it with others. She believes that "Every one of us has an autistic side to his/her personality. It is a blessing. I felt this is my goal in life, to raise awareness about it, talk to people about it. People's ideas about autism are wrong. I have been raising awareness about it, and I changed my friend's mind."

Jasmine discussed how people did not understand disability, and they had little awareness of Autism Spectrum Disorder. As mothers of children with ASD:

[We] are supposed to have an understanding and an awareness. We understand religion well, but we have not applied it to our social life. We do not accept the differences in our society. We must go through a disaster in our lives in order to understand this matter. People with special needs have to live naturally in

our society. We don't accept them. Just because my relative is disabled, we have to accept them.

Jasmine believes in being a good model to influence people so that they can learn from her. In her situation, she did know anything about disabilities due to the lack of education in our society. Jasmine reported "All I knew about it was a disabled person in a wheelchair, and I just heard of people with mental disabilities. After I became a mother of a disabled child, I started to know about their community. I used to look at them with pity. Now, I love and care for them."

Lotus had a perspective about how other mothers of children with autism advocated their entire lives to autism, and she did not do that. "I do not like mothers of autistic kids who advocate their entire lives to autism, this is unfair, on the other hand, I hate mothers who live independently from her kid, this is selfishness. I consider advocating one's life to autism is unfair."

Lotus likes to enjoy her time with her friends:

I want to enjoy my life, when I hang out with my friends, I do not think of autism or talking about my son's case. I talk about weather and fashion, like a normal person. I do not want to stress myself out, like mothers. They are under pressure because they do not accept her son's case. That is why she talks all the time about him.

Camellia's perspective changed about having a career:

From the beginning, I have dreamed of studying and having a career, but it is not about money, because now I have responsibilities. I was thinking in my last years with him, that I must have a career, in case anything happened between us. She studied psychology, Mostly because of my son Noah. First, I studied administration and economy at university. Then I changed it to psychology at Abdul-Aziz University. There was not a major called special education. I changed the major because of my son's case, and then I liked psychology. I intended to dig more into special education along with psychology. I liked psychology because I want to work with adults. I won't spend my entire life with kids! Anyways, may Allah bring me what is good for me.

Lavender wanted to improve herself and asked for help. She wanted to learn more about autism, and she felt she under pressure if she did not reach a high level of education herself. She also felt worried because she did not know much about her son's case. Once he was diagnosed, she began reading many books in special education to improve herself:

I need to be more educated. So far, I am still learning. That's why I needed a master's degree because I feel it will help me. I am optimistic that it will put everything in the right frame, it will give me a solid base. A while ago I was thinking of alternative ways of treatment, besides speech therapy and OT, and then I received an email about different ways of treatments. I contacted them [Son-Rise Admins] about the Son-Rise program, and they sent me a DVD. They asked me to visit them, but I couldn't, because they are in another state. Then they told me to attend a course, an online course. It helps you to go deep in the world of autism so that you can pull your kid out of it.

In addition to the Son-Rise program, Lavender ordered a book named Special Aid Law, to help her understand the school systems in the United States. As a mother of a child with ASD, Lavender believes she needs to work with her son and work with the school. That includes knowing her son's goals, as well as knowing the federal law in order to have an insight about what should be available to her child, and can recognize when and if the school falls short.

**Sibling roles.** Lotus and Lavender shared their experiences about the roles of siblings. Some siblings felt helpful towards their disabled sibling/s, but others experienced feelings of jealousy. One mother did not share her experiences, because she had only one child with ASD. Rose and Camellia did not share their children's sibling roles.

Lotus said that she wanted to create a balance between both of her children:

I did not give him [Ahmed] the attention I gave to his autistic brother. Most of my photos are with my younger child. I was forced to be with him for 24 hours a day because I had to teach him language instead of communicating using his hands. Then, I tried to make time for the elder one. He saw the change. When he was young, he used to tell me that he had a dream of his brother being by the toilet, and I flushed him down. So, I felt that there is something wrong. At some points,

he rejected his brother. When I was encouraging my son to speak, for example, 'I want iPad,' we would take it from my older son, so he got upset. Later on, I took him once to a camp; in which I explained everything related to his brother's case. He cried and understood.

Lotus said that there are benefits to having an older child who can be a helper to his young brother with ASD:

We taught him that Adam must learn from his older brother, Ahmed. I feel that Adam learns a lot from Ahmed, especially the way he plays, and his interests! Many skills, he would not learn from other boys! He loves when he sees his brother defeat and understands him. When he was a little kid, Ahmed has a great role in his brother. He is imitating Ahmed. As I said before, in the beginning, Ahmed was jealous of his brother, but later on, he understood that his brother has special needs.

Lavender feels guilty because she spends most of the time with her son, and not with her daughter as well as a sister feels toward her brother jealous. "It is a terrible feeling. I can see that his sister is aware of what is happening; sometimes she says she doesn't want him to go out with us, but she really loves her brother. She understands his situation, but she is still a kid. I knew I made a mistake by neglecting her. Lavender recounted the benefits of ABA to the mother and her daughter:

Sure, I've learned a lot from ABA. The ABA tried to talk to her and to make her understand that her brother has the right to go out, and what she did is wrong. I tell her to teach Jana things in indirect ways, like let's go to the back yard and look at what Saad does. So, I have to tell him this and that. That's the way she teaches her. My daughter is proud of herself. She believes that she understands Saad by herself, and that's why she teaches her father.

**Fathers' roles with a child with ASD.** The mothers in this study said that they cared more about their children than their husbands. According to Rose,:

I am too accurate. I care about everything related to her: the way she eats, the way she turns on the television, her day to day routine. When I used to go out of the house, he used to get annoyed. He does not like to care for her. He feels that I am controlling him by the rules I established. I used to ask him, 'Why wouldn't you come to the teacher conference?' His reply was, 'This is your major, you know

more about it.' He wants me to do everything, and that was hurtful for my daughter. This caused a real problem between us." Even though my ex-husband is accepting the disability of his daughter, he does not know how to treat her well.

According to Rose:

I only know that he loves her so much, and he accepts her. He has never been ashamed or embarrassed by her or talking about her. He has never complained about having an autistic kid. He always thanks Allah for giving him Noor. He always says, "When I look at Noor, I see my daughter Noor, not an autistic kid.

Rose mentioned that her ex-husband was learning from her.

He is learning from me how to treat her, but if she suddenly bites him, he cannot handle that. He wants to beat her, and I told him, "You cannot fix the behavior with the same behavior." That bothered him a lot. He used to say that it didn't make sense. Whenever I talked to him regarding Noha or Noor, he saw it as meaningless.

In addition, Lavender felt that she sacrificed more than her husband for her family. "Also, all I did was go to work, and then come home and take care of my daughter. She stated that when she was in Saudi Arabia, she did not like to send her daughter with the servant and the driver. "I was the only one who took care of my daughter. I didn't let the servant and the driver take care of her." There was a problem between her and her husband about who will drop her off at her school:

I asked my husband to take her, but he refused. Saudi men don't like to do multitasking. Going to his job is all he will do, he won't do anything else. I went to my job, and I visited my father in the hospital. He has been there for the last ten years, so we were taking shifts to care for him. At 2:30 p.m. my husband came home, then he slept until 4:00 or 5:00 p.m. and that is all he does during the day. When we came to the United States, I realized he's too lazy. He doesn't help me at all. Even his daughter complains about him. Then I told her to consider that you have a teenage brother. He thinks doing what they want makes them spoiled, but no!

Lavender pointed out that a father's role was to take care of all responsibilities:

We are used to the idea that our fathers take care of the house's expenses, and the mothers take care of raising the kids. Now this generation wants to share the responsibilities and the expenses. I have no problem with that. Back in Saudi

Arabia, I used to have a good salary, and I took care of all my expenses. I never asked him for one Rial. Now, I take care of the kids' expenses, but this is too much. I have to take care of them, to him, everything is not needed, anyway I give effort and money, and he only gives money. So, I feel that I sacrifice way more than he does. He really believes that he's cooking and cleaning the house while I am at work. I promised myself that I wouldn't argue with him. I already lived four years without him. I don't need more trouble. He doesn't see or understand that I give more than him to our family.

Lavender stated that her husband is not taking care of his whole family. She said, "When we first came here I lived in Virginia, and he lived in Texas. He lived a year in Texas. He only visited us twice. He told us that he would visit us every weekend, but he didn't." Lavender went on, "he likes to hang out with his friends, playing PlayStation, the typical Saudi guy. I believe that our standards are different, so I appreciate anything he does, but he's like a kid, he becomes very happy when he does anything."

Lavender reported that she does not feel her femininity, because she carries all of the responsibility that the husband should be handling. According to Lavender, "I feel like I am a man. I am responsible for everything: I am the father, the mother, the wife, the husband, the babysitter, and the driver. I lost my femininity, and I don't have time to take it back. I feel that someone switched off something inside me."

Lavender noticed that her husband changed when he learned about his son's situation:

His behavior toward me has changed after Saad. There were no big problems. Just I was annoyed about his silly behavior. He would get upset when I criticized him, then he started to avoid me, and I did the same. The two of us lived his life without interfering with the other. Even financially, he used to tell me that I shouldn't ask him for money, because I had a job. After Saad was diagnosed, he saw that I gave up my career to take care of Saad, so he was always giving me money without saying anything. He is proud of me in front of his family, but the problem with his family is that they love to show off.

Lavender argued a lot with her husband about her son, and she felt that his presence in her life had been annoying and making issues:

When I started applying the ABA with Saad, my husband took a vacation and went to the United States. He was trying to dress up Saad to go to the school bus. He usually doesn't want to wear his clothes in the morning. There is a specific way that I get him to wear his clothes. He screams to test you, to see will you give up, so I corner him and force him to wear the clothes, but my husband was not used to do this, and his face was pale. He got dramatic and started shouting about how I could be so calm when my son is so sick. When Saad went to school, I told my husband I did whatever the program said. That's how they teach us in the ABA. If you don't like it, then where were you four years ago? Then he said nothing.

Another issue her husband raise was about medication. He did not like the medication her child takes because his son was not playing with him anymore. Her husband also interfered in other ways that Lavender cared for her son, including what she fed him. Lavender responded:

Sorry, but it's none of your business. I ask him "what exactly do you want from him?" He said nothing. Just he is upset because he used to play with Saad, and now he's not. I told him do you want me to go to the doctor, and ask him to change the medicine so that you can play with him? Then, he said that's not what I mean. There are many factors which can affect Saad beside the medicine. He was playing with his father like he was a guest, but now he gets used to him, that's why he stopped playing.

Different levels of education and different parenting styles between Lavender and her husband created obstacles for negotiation between them:

Even before our child was born we had issues, and now the gap between us has gotten bigger, but he has tried to shrink that gap. He works as an officer. That's who he is now, but he had chances to improve himself, like now that he in the United States. But these mentalities won't evolve themselves. It used to bother me, but now I don't care. I don't want to keep nagging. If he doesn't want to improve himself, it's his business. I feel that he's jealous of me. When I took my master's degree, he told me not to be ego about it. I excuse him because I understand him. Deep inside my heart, I feel sorry for him. Now he tries to oppose me in everything just to show Lavender it is not right. Even in axiomatic situations, he has to oppose me. For example, when my daughter had a fever, he wasn't convinced that I didn't cover her with a blanket, so it's obvious that he is jealous. When we married, I was spoiled. Now, I proved myself, and he is still in the same place.

Lavender felt that she changed from being spoiled, but her husband did not improve himself and stayed in the same place.

Jasmine had run into many obstacles in her marriage with her husband, such as ignoring her role as a mother and dealing with financial issues. All the time her husband reminded her of that, "When he said, 'You are doing nothing!' At first, he was saying, 'Do not think that you are doing great things! You have done nothing! Do not consider yourself a heroine.' It is worth mentioning that I have never boasted about what I am doing for my son."

Initially, Jasmine was hurt by her husband's words, but nowadays, she does not pay attention to him, because she now has a job, earning her own salary:

It was hurting at first. Nowadays, he does not bother me at all, because he knows that it will not affect me! We only have a problem regarding financial issues. He is too stingy, despite [the fact] that he is earning good money. He is an old officer and earns good money, yet I am responsible for the house's spending. He sends me little money, but he is pretending that he is responsible for us. Most of the issues happened five or six years ago, so I decided not to talk about them. I am employed, and I can pay all of the expenses. I consider him dead. He has never offered me money. When I ask him to buy something, he looks for the cheapest thing, or he might delay purchasing it, so his family can bring it.

Jasmine continued described her experience with her husband was tough because he was a stingy person: with money, with feelings, with gratitude and with respect for others. Her husband was "living alone, eating for free, hanging out whenever he wants and having no engagements or responsibilities. I guess my son and I are part of his engagements."

Jasmine was thinking about getting divorced:

I think about getting divorced; if I did, who would marry a divorced woman with an autistic kid? Who would bear him! Allah will reward me if I was divorced or not. Sometimes I think deeply about it, but I said I do not want to get another man! If I got divorced; who will marry me? Of course, he will be worse than him! He will be divorced, too, and have kids. I am thinking about it all the time. First, he does not support me financially; he is not supporting me as a man! He is only

supporting me in continuing university here in America. Honestly; I cannot assume if it is for the sake of my education or for his son, or to feel free of our responsibilities. I guess he is keeping us just not to be blamed for not having a family. We are away from him so that he won't spend money.

In the end, Jasmine lost every argument with her husband:

I do not want him to push on my nerves. I have been always fighting with him, and I always lose in front of him. Every time I lose, I am crying, weeping, and feeling depressed. My husband does not engage himself in discussions. He even avoids discussions regarding Majed or anything else. He takes Majed to the hospital, and brings him medicine, and that it is. In addition to that, I am the one who cares about my son. I attend lectures, read books, and take him to centers. He does not do anything for his son. I paid for the last school my son was in. He refused to pay!

Jasmine's relationship with her husband was not stable. She reported that it was normal for them to go out together, but that they were quiet most of the time. Their conversations were formal, like an employer and employee. Their discussions were usually limited and uncomfortable. She discovered that their ways of thinking were very different from each other. It may not have been necessarily that one was right, and the other was wrong, just that they were different. They tried to be respectful to each other, but the disagreements left a wall of silence between them. Most of their conversations were limited to discussing Majed and his school.

Jasmine didn't feel as if there were any way to improve their relationship. She shared that even before they came to the United States, they slept separately. Even though she had tried to bridge the gap, there had been no intimacy between her and her husband. She had decided to request a divorce when she goes back to Saudi Arabia because she was tired of the situation. Her thinking before was that she wouldn't be able to make it alone if she got divorced, because of having a sick child. But since she lived alone in the United States, she found out that she can live alone. Her husband is not providing the basic things in life: financial assistance, help with the

children and care for his wife, so she doesn't see the point in living with him. As Jasmine stated, "There is no intimacy, no communication, no love, and no mercy. I feel this man has no mercy on me. He does not care about my feelings. He just cares about paperwork to do. Our relationship is dried up now."

Camellia's ex-husband had a hard time accepting his first child with a disability. He loved his son very much, and he was taking him to the hospital. He was very upset and tried to help. Even though Camellia accepted the diagnosis, he had a hard time accepting something was wrong with his son and refused to go to the first few psychiatrist appointments. He would give Camelia money to take their son to the doctor, but he would not go with her. In spite of not attending appointments, Camellia believed that the father cared about his son, and appreciated the effort she did make.

## CHAPTER 5: DISCUSSION

The purpose of this study was to explore the experiences of five Saudi Arabian mothers of children with ASD who are living in the United States, using mothering as the theoretical framework. Initially, I asked all mothers the same question, so that they would share their stories and reveal their beliefs, thoughts, and feelings about their experiences. That is, how do Saudi Arabian mothers of children with ASD living in the United States understand and experience mothering? Sub-questions that emerged with the main research question were: (a) How does Saudi Arabian culture influence the mothering of children with ASD? (b) How does a Saudi Arabian mother's particular religious beliefs, socioeconomic level, and educational level influence her mothering of a child with ASD? (c) How, if at all, does being in the United States challenge you as a mother? (d) How do you feel that children with ASD are regarded in the United States? How about in Saudi Arabia? (e) How does your family respond to your child with autism? What do they say to you about your child? How do their behaviors and words affect your mothering experiences? (f) What does it mean to you to be the mother of a child with autism who lives between two cultures in Saudi Arabia and the United States? (g) Have there been changes in your thinking and perspective toward disabilities and family values? (h) Being in the United States, have you shifted your career path? Are you planning to advocate for your child? (i) Are traditional beliefs about disabilities different from contemporary beliefs about disabilities?

Three themes came up in the research. These were:

1. Comparisons of raising children in the United States and Saudi Arabia.
2. Beliefs about mothering.
3. Diagnosis and experiences of being the mother of a child with ASD.

Through the lens of mothering as a theoretical framework, my study revealed that mothers have different feelings, thoughts, and perspectives about raising their children with ASD. Some of the mothers blamed themselves for having children with ASD. One mother blamed her husband for their child's ASD because she said that her husband did not care about her (the mother's) mental health. Mothers might also face many obstacles with their spouses because of the responsibilities on the mothers' shoulders.

I learned how these mothers deal with society and their families, and how they convinced others that their children with autism have a right to be educated and not held back because of their disabilities. I learned how these mothers handle conflicts with their husbands, ex-husbands, and others, and how they demonstrate strength when facing obstacles. Their stories have provided new ways for me to reflect on my own experiences as a wife, a mother, a stepmother, and an educator. Most of all, these mothers taught me a great deal about patience, resilience, self-motivation, self-judgment, confidence, positivity, willingness, and love.

Even of the difficulty mothers faced, I learned to be more self-motivated and positive in seeing things. My experience in mothering was different from them even if we were from the same culture and living aboard. To be patient meant to be patient in every task I did with my girls, or even with people who had different view than me. I had to understand their actions and reactions when they react and say that. I will make accept to them because everyone had their worries, concerns, troubles, and obstacles.

I used narrative inquiry in this study. Mothers shared their stories of their experiences, stories that help them to remember and make sense of their lives (Muthurkrishna & Ebrahim, 2014). Some mothers were more descriptive and talkative in their stories. When I asked them

questions, they told different stories about past events. Others only answered the questions I asked them, without going into detail or elaborating. Some remembered every detail of their stories. The mothers also chose different starting points for their stories. Some mothers began their stories by talking about their child's diagnosis through to the present. Other mothers told their stories by starting with the present day and reflecting on past events, sharing their greatest moments of worry, the conflicts they'd had with others, and the obstacles they had faced with their children.

The findings of this study were not generalized for all Saudi Arabian mothers of children with ASD. The result only for the five Saudi Arabian mothers of children with ASD, who lived in the United States and participated in my study.

### **Medical Sector and Educational Systems**

The study revealed that for some mothers, the experiences in the medical sector and educational systems were different in the United States and Saudi Arabia. Some mothers shared a perspective that the medical and educational services in the United States were superior to the services in Saudi Arabia for children with ASD. They believed that this was because, in the United States, there is greater collaboration between the educational and medical fields. This perspective was common among mothers whose children had been born and diagnosed in Saudi Arabia, as well as those whose children had been born and diagnosed in the United States.

Mothers said that in the United States, they did not need to search for information. They said that information about ASD comes to them through different people, including doctors, teachers in their children's schools, and anyone they might visit in a clinic or other medical setting. Based on these mothers' experiences, doctors in Saudi Arabia are not well trained to deal with children with ASD. Two of the mothers, whose children were diagnosed with ASD in Saudi

Arabia, said that the doctors there prescribed medication immediately following their children's diagnosis. Both mothers said that they did not like the doctors' approach, because it limited their children's treatment plans to medication only. In contrast, the mothers said that in the U.S., doctors prescribe medication only after using all other available treatments.

In this study, mothers talked about the differences between the educational systems in the United States and Saudi Arabia. For instance, in the U.S., a child with disabilities receives an individualized education plan that states their goals and objectives. Additionally, in public schools, there are team members who can assist children with disabilities. This might include speech therapists, special education teachers, general education teachers, Physical Education teachers, and physical therapists. These team members collaborate on the best ways to help the children and can provide the mothers with reports on their children's progress, as well as discuss the results with the mothers monthly and annually. In contrast, in Saudi Arabian schools, teachers send only one report on the child's progress at the end of the year. Although the teachers may tell the mothers that they are welcome in the school at any time, no formal meetings are scheduled with the mothers. In the United States, services are available in private and public centers. In Saudi Arabia, there are only a few places for children with disabilities to go.

Furthermore, the mothers in this study reported that teachers in Saudi Arabia and the United States tend to have different perceptions and attitudes toward disabilities. Saudi Arabian teachers look at mothers of children with disabilities as "different." The teachers express pity for the mothers of children with disabilities and offer prayers for the children and their mothers. Saudi Arabian teachers often feel the situation is hopeless for children with disabilities. In contrast, the mothers said that in the United States, teachers are willing to help, no matter what kind of disability

a child might have. These teachers gave the mothers hope that their children could be improving. In general, the mothers felt that the biases held by Saudi Arabian teachers led them to behave less professionally than teachers in the United States.

### **Raising Children with ASD or Other Disabilities in Two Countries**

Different cultures have differing points of view about people with disabilities. According to Al-Gain and Al-Abdulwahab (2002), the Saudi Arabian view of disabilities “is based on a simple notion of disability, and comprises helplessness, continuing dependence, being home-bound, low quality of life and lack of productivity” (p.2). In the United States, it is normal to see disabled children in public places. In general, people in the United States do not stare at children with disabilities as if they (the children) do not fit into society. This is because most people in the United States believe that people with disabilities have the right to go out and do not need to be kept in their homes.

In contrast, people in Saudi Arabia are not willing to have people with disabilities around them, believing that children with disabilities are scary and terrifying to their typical children. Communities in Saudi Arabia must improve their awareness about disabilities. This does not mean isolating children with disabilities from practicing their daily lives in society. These children have their right to go to public places with their families.

Saudi Arabian and American attitudes about disabilities are different. I believe that attitudes in Saudi Arabia exist because there is little attention given to disabilities. Al-Gain and Al-Abdulwahab stated that in Saudi Arabia there is little attention to educating the community through Saudi TV and radio (2002). The little awareness and insufficient education in Saudi society leads to a culture where children and adults with disabilities are not welcome in society.

With more inclusion of people with disabilities, there will be more acceptance within their communities.

Two of the mothers I spoke to said that while they wanted to return to Saudi Arabia forever, they did not want to tell people about their kids with ASD. They wanted to hide the truth of having ASD. This was not because they were ashamed of their children, but because they did not want to stigmatize themselves and their children with ASD. They wanted to live their lives as normal within the Saudi community. They did not want people to call them mothers of child with ASD. They believed that in one day their children would be better and live normally as other typical children. They wanted to give their children opportunities to practice and explore the environment. They wanted to talk and raise awareness about the disorder but without calling attention to their children. They did not to include their children as an example to the community.

Others said that they did not want to hide their children's disabilities and that they wanted to integrate their children into their communities. This their roles as mothers of children with ASD.

When mothers of children with ASD have the ability to speak and their economic status is higher, they can raise awareness by providing different sessions to help other mothers of children with ASD. There are different places where mothers can hold their sessions. For example, mothers can give speeches in Saudi Arabian universities or visit different schools for girls (education in Saudi Arabia is segregated by gender). To raise awareness, the universities and schools should collaborate with the mothers to help them do something for children with ASD and change Saudi community.

When young people have awareness about ASD, it's likely to improve acceptance. Social media is another tool to raise awareness of disabilities. With awareness, college students are likely

change their prospective about the disabilities. This is one example of their ability to raise awareness and acceptance of ASD.

The educators' role in building awareness is bigger because educators deal with different students who come from different backgrounds. To raise awareness, it would be good to use any chance to teach their students about disabilities in general.

The mothers in my study said that there is little understanding about ASD. People think that all children with ASD are the same and that they have the same characteristics. they think that having autism means that a person is non-verbal and has no feelings. One of the roles of a mother who has a child with ASD is to raise awareness and change people's thinking about autism.

Raising children in the United States made mothers think deeply about the role of grandparents and aunts in raising children in Saudi Arabia. Three of the women in my study lived in nuclear families in the United States, with only their husbands and children (Giddens, 2001). One of these women, will stay with her husband's family in their home when she returns to Saudi Arabia. Her father and mother-in-law are very supportive of her. The remaining two women (one married but is thinking to get divorce, one separated was going to divorce) as soon as they planned to return to Saudi Arabia, where they planned to live among their extended family. For these mothers, their families played a significant role, offering encouragement and support to their daughters. Their divorces were not due to having children with ASD. It was about other factors, primarily that mothers felt that they are more responsible for everything, both financially and child-rearing.

In Saudi Arabia, aunts and grandparents are typically involved in the day-to-day care of children. The mothers in my study said that, after living in the United States, they realized that

they did not like the involvement of the grandparents and aunts, feeling that it led to problems in the household. I think Saudi Arabian mothers shifted their values and roles from those that were traditional to those that are more contemporary and western. Saudi Arabian women today are more often working outside the home than their mothers did. The cultural perspectives shifted from communal to individualism.

They also said that their family commitments in Saudi Arabia created additional stress for them. Instead, the mothers in the study said that they preferred parenting in the United States, where they spent more time with their children, both due to a lack of family involvement on a daily basis and fewer (if any) family commitments. As a result of the additional time with their children, these mothers felt that they became more attached and closer to their children.

Fathers' roles were not obvious to the mothers in the study. As a Saudi Arabian mother, I think that when fathers help their wives in raising their children who are typical and non-typical, their families are happier because the couple's relationship is stronger, due to the different kinds of support. In these cases, the fathers' roles are deeper than providing financial support. Most wives prefer to get psychological and emotional support from their husbands. Wives want to feel that their spouses are caring about them and their children as their first priority. When women feel that there is no help or care from their husbands, they will be more likely to divorce.

### **Formal and Informal Support that Mothers Receive**

The mothers in this study said that they received more informal support than formal support, especially from their families. Informal supports meant mothers get support from their husbands, husbands' families, their families, friends. Formal supports are supports from educators

who specialize in special education, psychologists, doctors, and everyone who works with children with disabilities.

The mothers in my study said that they did not want support from other mothers who have children ASD, because they felt that other mothers tend to exaggerate when they talked about their children's ASD. Mothers in my study preferred to have friendships based on their own interests because they want to live their lives as normal mothers, without always focusing on autism. Unlike the mothers in the McGraw and You study (2011), which suggested that when mothers of children with ASD share their experiences with each other and form friendships, they can support each other, the mothers in my study did not support the idea of friendship between mothers of children with ASD. They preferred to have friendships with women who did not have children with ASD.

The women in my study did not share much about their relationships with their husbands' families. Because they lived far from their in-laws (specifically, their mothers-in-law), their relationships with their husbands' families were not strong. Additionally, their in-laws did not play a significant role in raising their children.

The mothers in my study who brought servants to the United States or who had nannies said that they enjoyed their lives more because they had help. Because of this, they had fewer responsibilities. They still had control over their children's care, but they did not have everything depending on them. Having servants or nannies gave the mothers free time for themselves and additional time to take care of their other children. They did not have to do the household work and their time was only for their children. When they had nannies, the mothers focused on their children who are typical or with ASD. Children with ASD needed to have more time and attention to help them develop, improve, and behave well. Without nannies, mothers would do everything,

which is time consuming. As a result, mothers would feel tired and have little energy, because they were raising their children and were responsible for the households.

None of the mothers were a first wife or second wife in my study. There was no finding to show how blame and polygamy in Saudi families impact mothers who have children with ASD.

### **Family Roles and Marriage Experiences**

Some mothers said that their typical children sometimes feel jealous or want to help because they spend all of their time caring for their children with ASD. Altieri and Kluge (2009) also found that siblings who do not have autism sometimes feel jealous of their sibling who has ASD and that they may also want to help the sibling with ASD.

Some fathers struggled to accept that their children had ASD. One father described his son as being “sick.” Another father had positive views about his child with ASD. He accepts her as she is. He believes that she was born this way and that ASD is part of her personality. In some families, the fathers were not patient as the mother. Traditionally, Saudi Arabian culture is based on the idea that men are not responsible for children raising even if they have children with ASD. Some fathers are raised not to be responsible. The relationship between the father and his child depends on the father’s personality. Distance between a father and his children may also be the result of a poor relationship between the parents. Mothers never leave their children. If the father and mother do not get along, that can cause the father to be distant from both his wife and his children. When parents have strong relationship between them, they are more likely to share the responsibility.

Mothers complained about their husbands not supporting them financially, which created obstacles between them in the beginning. The mothers in the study shared that having a different

level of education than their partner made their relationships more difficult. All of the mothers in this study have at least a master degree. In three of the families, the father has a high school degree, and in two of the families the father has a master's degree.

One mother got divorced before coming to the United States. Another decided to get divorced because she felt that she was more caring and sacrificing than her husband. A third is planning to divorce once she returns to Saudi Arabia. All three women said that they did not want the strain of marriage any longer.

Gender roles and beliefs come into play in parenting as mothers and fathers negotiated childcare tasks and household responsibilities. Mothers are often the primary people who are responsible for the care of their children and households (Koydemir-Özden & Tosun 2010). Among the mothers in my study, it was understood that mothers are the primary person to care for the children, whether they are typical children or children with disabilities. Often, there are no roles for fathers because mothers are responsible for their children's needs.

Mothers in this study shared their beliefs about the way that gender roles affect the relationships with their spouses, such as caring for the children and doing housework. Traditionally, the entire responsibility for the children and the home is on the mothers' shoulders, which can lead her to feel anxiety, stress, and depression. According to Alyaemni et al. (2013), gender roles in Saudi Arabia are obvious. Men in Saudi Arabia are usually tasked only with the job of providing financial support to the family. Women take care of the children and home and place their families first. In this study, mothers of children with ASD reported that they decreased their activities with their families and friends because they wanted to take care of their children.

That is, all mothers in the study said that they had many conflicts and disagreements with their spouses, though the specific conflicts were different from one mother to another.

When they were living in the United States, the mothers in my study noticed that fathers in the U.S. culture were more likely to play a larger role in the lives of their children with disabilities. In the U.S., it is common for couples to attend meetings about their children, as well as any other appointments or events where their children are involved.

### **Mothering Experiences and Perfect Mothers**

Mothers were very open in sharing their Mothering experiences. Mothering is at the same time a huge responsibility, a great experience, and a lot of sacrifice. Mothers knew how to care for their children instinctively. They cared for their children, worried about their children, and enjoyed pleasant moments with their children. When the mothers integrated their children with ASD into their own social lives, they said that the children were loved and accepted by the mothers' community.

The mothers in the study also shared the feelings they had when they learned that their children had been diagnosed with ASD. Some said they were in shock. Some said they isolated themselves from other people. Some started to read as much information as they could so that they could understand more about ASD. Some felt depression, hopelessness, and stress. Even with the difficulties of raising children with ASD, the mothers in this study said that they enjoyed their experiences with their children, especially once they began to understand and accept their children's disabilities.

These mothers listened to their families a great deal and were influenced by them, which had an impact on their mothering experiences. Some worried that they might not practice the

concept of mothering as well as other mothers within their family. Others were more accepting of the reality of their children's condition and loved working toward their child's improvement.

Mothers pointed out that all mothers are perfect but should not try to be perfect in all areas. All of the mothers agreed that the definition of a perfect mother varies from mother to mother. Perfect mothers give their children love and kindness, care for their feelings and make sure that the children eat and sleep well. It is also very important to care for the mental health of their children. It is not enough to only dress and feed them. When mothers feel guilty or blame themselves, even though they care so much for their children, it is good way to reflect on their mothering by guilt and blame.

### **Maternal Education, Awareness of their Children's Development and Worries**

The mothers in the study, almost all held a college degree, most held a master's degree, and one was studying for her Ph.D. They shared their worries about their children's futures. Because they knew the differences in the services available in the United States and Saudi Arabia, the mothers were especially worried if they planned to return to Saudi Arabia.

The finding of this study agreed with the study by Al-Kandari et al. (2017), which showed that when mothers are more educated, they have more stress and worry more about the development of and improvements in their children with ASD. In part, this is because it is easier for mothers who have an education to search for information that helps them understand their children's needs and demands. The finding of Crabtree study suggested that when mothers were more educated, it was easier for them to gain information (2007a). Nearly all of the mothers in my study held a master's degree. They were educating themselves about ASD by reading about their children's development. They were aware of their children's behaviors, their development, and

they wanted to teach their typical children specific morals. They wanted to teach their children to be honest, to respect promises and to be independent.

### **Mothers Change their Thinking and Perspectives**

In the study, the mothers said that being in the U.S. had changed their thinking and that it was challenging for them at the same time. They became more mature, independent, strong, and patient. This is because, in Saudi Arabia, mothers depend on their families, nannies, drivers, and husbands to help them.

Being in the U.S., mothers were able to present themselves as the individuals that they are. Being in the United States helped the mothers to appreciate and understand life more and become more open-minded. Most of the mothers in the study were studying while taking care of their children (both typical children and children with ASD). Even with the difficulty of raising their children without help, they were successful in school, with some having graduated already.

The mothers felt that their perspective on life had changed because they learned that they are capable of doing everything by themselves. They appreciated that their new lives taught them to do things on their own. As a result of living in the United States, some mothers described themselves as having become self-centered, having greater self-esteem, and becoming more mature after caring for their children with ASD.

### **Religion, Disabilities, and Illness**

Mothers shared their mothering perspectives about disabilities and illness. Some had a positive view, and others had a negative view. Some see disabilities as a grace and a gift from Allah. Others see it as Allah's punishment for the sins of their past deeds. A more positive attitude is found among some Latino mothers in Skinner's (1999) study. Within this study, a group of

mothers believed that they received children with disabilities as a gift from God because they are such good and capable mothers. When mothers view ASD as grace and a gift from Allah, it is easier for them to accept ASD as a disability. They have a positive outlook on ASD and they are more likely to enjoy their mothering experiences. On the other hand, when mothers see ASD as a punishment from Allah, it becomes harder for them to accept the disability, and their experiences are more likely to be difficult. Most Muslim mothers pray for their children, whether they have disabilities or not. They want for their children to be the best, to succeed and to have healthy lives. In Muslim families, the mother is the person who knows her children best, and who controls the children's behavior and actions. Every mother has passion, courage and hopes for the success of her children.

The mothers in my study shared their points of view about the perception of disabilities and illness, and how those perceptions had changed over time. Some mothers said that their perceptions of disabilities were the same as they had been before they had children with disabilities. One mother said that before having a child with disabilities, she had seen disabled people as alien. As she grew to know and accept her child over time, her perspective changed to love people with disabilities. Some mothers said that they had become more religious because of their children with ASD. They said that their relationships with Allah became stronger and that they began to think differently about all of Allah's creatures.

Some of the parents in Alqahtani's study (2012) believed that spiritual intervention could benefit their children. These parents chose to read passages from the Holy Qur'an to their children and to seek advice from religious healers. In my study, one mother went to the Sheikh because her

son was diagnosed in Saudi Arabia. Another mother was asked repeatedly by her mother-in-law to go the Sheikh when she visits in Saudi Arabia in the Charisms time.

### **Recommendations for Future Research**

This research focuses on the experience of mothers raising their children with ASD in the United States. Future research is needed to examine the experiences of Saudi Arabian mothers of children with ASD who are living in Saudi Arabia. These mothers might have different experiences to share because they are living in their native country with their families. Future research is needed to study how the roles of Saudi Arabian fathers of children with ASD vary in Saudi Arabia and the United States. More also research needs to be conducted for different disabilities to learn more about the experiences of mothers and fathers in the United States and Saudi Arabia or different countries.

Future studies might examine the impact of family structure on a mother's experience. For instance, research might look at the role of Saudi Arabian grandparents (both maternal and paternal) and how that might impact mothers' experiences. Further research is needed to learn more about the attitudes of grandparents and the impact of those attitudes on both parents and grandchildren with disabilities, as well as the role of grandparents in raising children with ASD. Future research is also needed to study how polygamy might impact mothers of children with ASD, whether positively or negatively. As it was noted in my research, when the mothers are married to the father of their children with ASD, there can be many conflicts around taking care of the children, financial support, and home responsibilities.

The roles of religious community, I hope to be effective in improving the Saudi community and life for families whose children have ASD. It could do this by providing

information and workshops about the disabilities, and letting people know that Islam does not stigmatize people with disabilities. These awareness raising events could take place on masjids, in public places, or using TV and social media to raise awareness. The Saudi communities have to accept people with disabilities.

### **Implications for Educators and Health Providers**

As for this particular research, readers should know that the United States provides more and better services and treatments for people with disabilities than Saudi Arabia. The findings of this study showed that there are many implications for educators who are working with children with ASD in Saudi Arabia. To be effective, educators must have a degree with a special education major, not a high school diploma or a different college major. Educators should only be qualified specialists who can understand and are aware of the needs of their students with disabilities. Because of their cultural context in Saudi Arabia, educators there tended to show pity to the mothers in this study. When educators are well trained to deal with children with ASD, the results will be better. Every school in Saudi Arabia should have a speech therapist who works with special education teachers to help their students with disabilities and also their typical students.

I have many hopes that anyone can act to change the educational and medical systems. I hope that when all Saudi Arabian students return to Saudi Arabia from the United States, they will apply what they have learned, especially in the education sector. I hope to contribute scholarship about Saudi Arabian mothers of children with ASD and with change people's perspectives about disabilities. I hope that the school system in Saudi Arabia will change to help children with disabilities.

I also hope that educators and medical providers contribute to changing the country, not

only for people with disabilities but also for their families, most especially for mothers, who are primarily responsible for taking care of their children. For example, in the United States, the educational and medical sectors work together to collaborate, starting with the diagnosis of a child with ASD. Both the educators and medical providers share information and resources to mothers to help them understand the disabilities and where to find help for their children. They provide mothers with access to mental health specialists and support groups, to help mothers find relief from the shock they experience when their children are diagnosed. I hope that doctors in Saudi Arabia will begin to attend sessions and workshops where they can learn how to deal with their patients, and begin to understand their patients' mental health.

### **Implications for Communities**

There is, unfortunately, still a lot of misinformation and stigma associated with disabilities in Saudi Arabia. When the Saudi community provides sufficient education about disabilities, so that people begin to know about and understand disabilities, there will be more acceptance of people with disabilities, due to greater awareness. I hope people with disabilities will be integrated into their communities, and that everyone will see that people with disabilities have the right to be in the Saudi community. My hope is that Saudi Arabian people with disabilities will ultimately have access to more and better services, that Saudi Arabian people will become more knowledgeable about disabilities, and that the stigmatization toward Saudi Arabian people with disabilities will decrease. It is very important to study more in-depth in order to understand mothers of children with other disabilities and to know more about their experiences.

### **The Limitations of the Research**

Each mother shared different stories of their children with ASD. Their experiences in raising their children with ASD might be difficult or easy, depending on their children's condition. The children in this study ranged from mild to severe forms of ASD, ranging from verbal contrasting to non-verbal. As a result, their mothers' experiences were very different from one another. For mothers whose children had severe autism, the experience of raising their child might be hard. Other mothers, whose children's autism was mild, might say that raising their children was not very difficult. Lastly, because the mothers were living far from their husbands' families, there were few findings in this area.

Another limitation of the research is that some mothers have no experience living in Saudi Arabia with their children. As a result, they have no basis for comparison between the two countries. Their perceptions of Saudi Arabia are from hearing stories from other mothers, or through stories that came to them through their communities.

The final limitation was the socioeconomic status. All of the mothers in my study were in the middle class. Each received their money from different sources. Their sources of financial support included a monthly salary for the mothers and their children from the Saudi Arabia Cultural Mission (SACM), which four of the mothers received, as well as salaries from university jobs in Saudi Arabia (where two women were employed), support from parents, from husbands, from in-laws and from jobs that the mothers had taken in the United States. If these mothers were in poverty and not lived in urban areas, they would not have the opportunity to study abroad. People who live in rural areas would find it difficult to afford to send their girls or wives to study abroad.

**Conclusion**

The narrative approach was used to study the experiences of five Saudi mothers of children with ASD in the United States. In the study, different interviews were conducted with the mothers. Some of the interviews were via phone or meeting them in public places. Mothers compared their experiences of raising their children with ASD between two countries, the United States and Saudi Arabia. The United States provides a better atmosphere in the educational and medical sectors for children with ASD and with disabilities. Mothers shared their perspectives about perfect mothers and about their mothering experiences. Diagnosis and being the mother of a child with ASD, in this phase mothers faced the disability, denied it, accept it, and lived happily with their kids.

The findings of this study are limited to the five participants who were Saudi Arabian mothers of children with ASD who were living in the United States. Due to the limited size of this study, these findings are not generalized for all Saudi Arabian mothers of children with ASD.

I would like to thank the mothers of children with autism in the study and every mother, you are great in your offering, in your mothering, in your patience, in your perseverance is great in all things.

**APPENDIX A: APPROVAL LETTER FOR POSTING MY CRITERIA ON SAUDI IN THE U.S.**



Date: February 9, 2018

To who it may concern,

The letter is in support of Basmah Alotaibi.

We are a Saudis in USA Twitter page. Our page is under supervision of Saudi Arabia Cultural Mission (SACM). We help Saudi student who need supports and assistants. We are welcomed and happy to help Basmah Alotaibi, a PhD candidate at Wayne State University to post her inclusion criteria in our page in Arabic language. Her inclusion criteria are:

- Must currently live in the United States.
- Must be biological mothers between the ages of 25-50.
- The mothers' children must be between the ages of 3-18.

Sincerely,

Ahmad Fallatah Public Relations Director

## APPENDIX B: RESEARCH INFORMED CONSENT

### الموافقة على المشاركة في البحث [السلوكي]

عنوان الدراسة: فهم تجارب الأمهات السعوديات للأطفال المصابين بالتوحد في الولايات المتحدة الأمريكية

الباحث الرئيسي: بسمة بنت ماهر العتيبي  
كلية التربية  
202-469-2524

عند استعمال ضمير المخاطب في نموذج الموافقة هذا، فنحنى به الفرد المشارك في الدراسة البحثية.

### الغرض

يطلب منك أن تكوني في دراسة بحثية للأمهات السعوديات لأطفال التوحد؛ لأنك كأم للطفل التوحد من المملكة العربية السعودية مؤهلة للمشاركة في هذه الدراسة. ويجرى هذا البحث في جامعة واين ستيت وفي ولايات مختلفة في الولايات المتحدة. ويقدر عدد المشاركات في الدراسة الذين سيتم تسجيلهم في جامعة واين ستيت وفي مواقع البحوث المقترحة أربع أو خمس مشاركات.

يرجى قراءة هذا النموذج وطرح أي أسئلة قد تكون لديك قبل الموافقة على أن تكوني مشاركة في الدراسة

في هذه الدراسة البحثية، تخطط الباحثة الرئيسية للكشف عن تجربة السعوديين- الأمهات على وجه الخصوص- في تربية أطفالهم المصابين بالتوحد. هناك أبحاث محدودة تصف تصورات الأمهات وتجارب أطفالهن المصابين بالتوحد. وتتناول قليل من البحوث التي تستخدم المقابلات الفردية تجارب الأمهات السعوديات.

### إجراءات الدراسة

إذا وافقت على المشاركة في هذه الدراسة البحثية، سوف يطلب منك المشاركة في أربع مقابلات فردية مع الباحث الرئيسي، كل مقابلة تدوم ساعة واحدة. كذلك، قد يطلب منك المحقق الرئيسي المشاركة في مقابلة أو مقابلتين مدة كل واحدة منهما ساعة واحدة إذا وجدت أنها مفيدة لتوضيح إجاباتك أو للتعمق أكثر في تجاربك. وستجرى جميع المقابلات خلال فترة ثلاثة أشهر أو أقل.

### الفائدة من الدراسة

كمشاركة في هذه الدراسة البحثية، قد تكون أو لا تكون هناك فائدة مباشرة بالنسبة لك. ومع ذلك، فإن المعلومات من هذه الدراسة قد تفيد أشخاص آخرين الآن أو في المستقبل. ويأمل الباحث الرئيسي أن يساعد هذا البحث الناس على فهم أفضل تجارب الأمهات السعوديات لأطفال مصابين بالتوحد حتى تتلقى الأمهات وأطفالهن دعماً وخدمات أكبر.

الفائدة المحتملة لك في المشاركة في هذه الدراسة البحثية هو أنه سيكون لديك فرصة المشاركة بتجربتك بحيث يمكن سماعها. فمن الممكن أن تجدين أن التكلم على تجربتك مفيداً لك شخصياً. كما سوف يكون المشاركون قادرين على معرفة المزيد عن

تجارب الأمهات الأخرى عندما تكمل الباحثة الرئيسية بحثها. وعلاوة على ذلك، يمكن للمشاركين أن يفتخروا بالمساهمة في استكشاف هذا البحث عن المرأة والأمومة والثقافة السعودية.

### المخاطر

من خلال المشاركة في هذه الدراسة، قد يكون هناك بعض المخاطر العاطفية. من الممكن أن تشعرى بعدم الراحة وأن تشعرى بالحزن عندما تتذكرين التجارب والأيام الصعبة. سوف تكون الباحثة الرئيسية حساسة وستتخذ العديد من الاحتياطات لتقليل عدم الراحة. يمكنك إيقاف المقابلة في أي وقت. وإذا شعرت أنه من الأفضل، يمكنك رفض الإجابة على أي سؤال أو حتى، إذا لزم الأمر، ترك الدراسة.

لن يتم استخدام اسمك وهويتك في هذا البحث. وسوف تتخذ الباحثة الرئيسية عددا من الاحتياطات للحفاظ على خصوصية وأمن البحث وحماية هويتك. ولن تذكر اسمك بالاسم أو تصفك أو تصف الظروف الخاصة بك حتى لا يسهل على أي شخص تخمين هويتك.

وهناك أيضا مخاطر تنطوي على المشاركة في هذه الدراسة التي لا يعرفها الباحثون في هذا الوقت.

### تكاليف الدراسة

المشاركة في هذه الدراسة سوف تكون دون أي تكلفة بالنسبة لك.

### السرية

جميع المعلومات التي تم جمعها عنك خلال هذه الدراسة سوف تبقى سرية إلى الحد الذي يسمح به القانون. سيتم تحديدك في سجلات البحوث من خلال اسم رمز أو رقم. لن يتم الإفراج عن المعلومات التي تحددك بدون إذنك. ومع ذلك، يجوز لمجلس المراجعة المؤسسي (Institutional Review Board) بجامعة واين ستيت، أو الوكالات الفدرالية ذات الإشراف المناسب، مثل مكتب حماية البحوث البشرية (Office for Human Research Protections) ومكتب الحقوق المدنية (Office of Civil Rights)، مراجعة سجلاتك.

عندما يتم نشر نتائج هذا البحث أو مناقشتها، لن يتم تضمين أي معلومات من شأنها أن تكشف عن هويتك.

سيتم حماية هويتك أو حجبها عند استخدام التسجيلات الصوتية الرقمية لمقابلاتك مع الباحثة الرئيسية. وسيبقى المحقق الرئيسي الملفات الرقمية على جهاز الكمبيوتر المحمول الشخصي الخاص باستخدام كلمة سر، وعندما لا تكون قيد الاستعمال، سيتم وضع الملفات في خزانة مغلقة. كما أنها سوف تنسخ الملفات والنصوص على ذاكرة بيانات (Flash drive) والتي سيبقى عليها في خزانة مغلقة. سيتم تخزين البيانات لمدة خمس سنوات. بعد هذا الوقت، سيتم تدمير جميع البيانات الإلكترونية والنسخ المطبوعة. سيتم تدمير التسجيلات بعد ترجمتها كتابتها من العربية إلى الإنجليزية.

سيطلع على المعلومات والتسجيلات مترجم يتقن ترجمة ونقل البيانات من العربية إلى الإنجليزية. سيقوم المترجم بتوقيع استمارة موافقة للحفاظ على خصوصية وسرية المشاركين في الدراسة. وسوف يكون بإمكان مستشار الباحثة الرئيسية في جامعة واين ستيت الاطلاع على البيانات. سيتم حماية الهويات الشخصية للمشاركين أو حجبها من خلال تعيين أسماء مزيفة لهم. سيقوم المحقق الرئيسي بتعيين كل مشارك باسم زهرة مثل روز، ليلك، لوتس، كاميليا، وياسمين.

### المشاركة التطوعية / الانسحاب

المشاركة في هذه الدراسة طوعية. لديك الحق في اختيار عدم المشاركة في هذه الدراسة. إذا قررت أن تشارك في الدراسة، يمكنك الانسحاب منها لاحقا، إذا قررت ذلك. أنت حرة في الإجابة فقط على الأسئلة التي ترغبين في الإجابة عليها. أنت حرة

في الانسحاب من المشاركة في هذه الدراسة في أي وقت. لن تغير قراراتك أي علاقة حالية أو مستقبلية قد تكون لديك مع جامعة واين ستيت أو الشركات التابعة لها أو غيرها من الخدمات التي يحق لك الحصول عليها.

قد توقف الباحثة الرئيسية مشاركتك في هذه الدراسة دون موافقتك. سوف تحبرك في حالة أنه لن يكون بإمكانك الاستمرار في البحث. ويمكن اتخاذ مثل هذا القرار لحماية صحتك وسلامتك، أو إذا كنت لا تتبعين التعليمات للمشاركة في الدراسة.

### الأسئلة

إذا كان لديك أي أسئلة حول هذه الدراسة الآن أو في المستقبل، فإنه يمكنك الاتصال بالباحث الرئيس: بسمة العتيبي، على رقم الهاتف التالي: ٢٠٢-٤٦٩-٢٥٢٤. إذا كان لديك أي أسئلة أو قلق بشأن حقوقك كمشاركة في البحث، فإنه يمكنك الاتصال برئيس لمجلس المراجعة المؤسسي على الرقم ١٦٢٨-٥٧٧(٣١٣). إذا كنت غير قادرة على الاتصال بموظفي البحث، أو إذا كنت ترغبين في التحدث إلى شخص آخر غير عضو في فريق البحث، فيمكنك -أيضاً- الاتصال بمحامي البحوث التابع لجامعة واين ستيت على الرقم ١٦٢٨-٥٧٧(٣١٣) لمناقشة المشاكل، والحصول على المعلومات، أو تقديم المساهمات.

### موافقة المشاركة في الدراسة البحثية

للموافقة طواعية في المشاركة في هذه الدراسة، يجب عليك التوقيع في السطر التالي. إذا اخترت المشاركة في هذه الدراسة، فإنه يمكنك الانسحاب في أي وقت تشائين. أنت لا تتنازلين عن أي من حقوقك القانونية عن طريق توقيع هذا النموذج. يشير توقيعك أدناه إلى أنك قد قرأت، أو قرأت لك نموذج الموافقة بالكامل، بما في ذلك المخاطر والمنافع، وقد تمت الإجابة على جميع أسئلتك. ستحصلين على نسخة من نموذج الموافقة هذا.

التاريخ	توقيع المشاركة / الممثل المفوض قانونياً
الوقت	اسم المشاركة / الممثل المفوض قانونياً
التاريخ	توقيع الشهود
الوقت	اسم الشهود **
التاريخ	توقيع الشخص الذي يحصل على الموافقة
الوقت	اسم الشخص الذي يحصل على موافقة
التاريخ	توقيع المترجم
الوقت	اسم المترجم

**[Behavioral] Research Informed Consent**

Title of Study: Understanding the Experiences of Saudi Arabian Mothers of Children with Autism in the United States

Principal Investigator (PI): *Basmah Maher Alotaibi*

College of Education

202-469-2524

When we say “you” in this consent form, we mean you as in individual participating in the research study.

**Purpose**

You are being asked to be in a research study of Saudi Arabian mothers of children with autism because you, as a mother of a child with autism from Saudi Arabia, qualify for participation in this study. This research is being conducted at Wayne State University and in various states in the United States. The estimated number of study participants to be enrolled at Wayne State University and in proposed research sites is four or five.

**Please read this form and ask any questions you may have before agreeing to be in the study.**

In this research study, the principal investigator plans to uncover how Saudi Arabian, mothers most particularly, experience raising their children with autism. There is limited research describing mothers’ perceptions and experiences of their children with autism. Very little of the research addresses the experiences of Saudi Arabian mothers using a one-on-one, interview method.

**Study Procedures**

If you agree to take part in this research study, you will be asked to participate in four one-on-one interviews with the principal investigator, each one lasting one hour. As well, the principal investigator may ask you to participate in one or two additional one-hour interviews should she find them helpful to clarify your responses or to go deeper into your experiences. All interviews will be conducted within a three month time period or less.

**Benefits**

As a participant in this research study, there may or may not be a direct benefit for you; however, information from this study may benefit other people now or in the future. It is the principal investigator's hope that this research helps people better understand the experiences of Saudi Arabian mothers of children with autism so that both mothers and their children receive greater support and services.

The possible benefit to you for taking part in this research study is that you will have an opportunity to share your stories so that they can be heard. It is possible that you will find sharing your stories to be personally helpful. Participants will be able to learn about other mothers' experiences when the principal investigator completes her research, and may find that to be helpful as well. Moreover, participants can be proud to contribute to exploring a little of this research on women, motherhood and Saudi Arabian culture

**Risks**

By taking part in this study, there may be some emotional risk. It is possible that you may experience discomfort and feel sadness when you remember difficult experiences and hard days. The principal investigator will be sensitive to your feelings and take several precautions to minimize your discomfort. You may stop the interview at any time. And, should you feel that it is best, you can decline to answer any question or even, if necessary, leave the study.

Your name and your identity will not be used in this research. The principal investigator will take a number of precautions to keep the research secure and to protect your identity. She will not mention you by name and she will not describe you or your circumstances in such detail that it would be easy for anyone to guess your identity.

There may also be risks involved from taking part in this study that are not known to researchers at this time.

**Study Costs**

Participation in this study will be of no cost to you.

**Confidentiality**

All information collected about you during the course of this study will be kept confidential to the extent permitted by law. You will be identified in the research records by a code name or number. Information that identifies you personally will not be released without your written permission. However, the Institutional Review Board (IRB) at Wayne State University, or federal agencies with appropriate regulatory oversight, such as the Office for Human Research Protections (OHRP) and the Office of Civil Rights (OCR), may review your records.

When the results of this research are published or discussed in conferences, no information will be included that would reveal your identity.

Digital audio recordings of your interviews with the principal investigator will be used for this research and your identity will be protected or disguised. The principal investigator will keep digital files on her personal laptop using password protection and when not in use, in a locked cabinet. She will also back up files and transcripts on a flashdrive, which will also be kept in the a locked cabinet. The data will be stored for five years. After this time, all electronic data and hard copies will be destroyed. Recordings will be destroyed after they are translated and transcribed from Arabic to English.

A professional bilingual translator proficient in translating and transcribing data from Arabic to English will have access to the recordings. The translator will sign a consent form to maintain the privacy and confidentiality of the study's participants. The principal investigator's advisor at Wayne State University will have access to the data. Personal identities will be shielded or disguised by protecting the participants' identities by assigning them a false name for the study. The principal investigator will assign each participant the name of a flower such as *Rose*, *Lavender*, *Lotus*, *Camellia*, and *Jasmine*.

### **Voluntary Participation/Withdrawal**

Taking part in this study is voluntary. You have the right to choose not to take part in this study. If you decide to take part in the study, you can later change your mind and withdraw from the study. You are free to answer only those questions that you want to answer. You are free to withdraw from participation in this study at any time. Your decisions will not change any present

or future relationship that you may have with Wayne State University or its affiliates, or other services that you are entitled to receive.

The principal investigator may stop your participation in this study without your consent. She will notify you now if it is not possible for you to continue. Such a decision may be made to protect your health and safety, or if you do not follow the instructions to take part in the study.

### **Questions**

If you have any questions about this study now or in the future, you may contact the principal investigator, *Basmah Alotaibi*, at the following phone number *202-469-2524*. If you have questions or concerns about your rights as a research participant, the Chair of the Institutional Review Board can be contacted at (313) 577-1628. If you are unable to contact the research staff, or if you want to talk to someone other than a member of the research staff, you may also call the Wayne State Research Subject Advocate at (313) 577-1628 to discuss problems, obtain information, or offer input.

### Consent to Participate in a Research Study

To agree voluntarily to take part in this study, you must sign on the line below. If you choose to take part in this study, you may withdraw at any time. You are not giving up any of your legal rights by signing this form. Your signature below indicates that you have read, or had read to you, this entire consent form, including the risks and benefits, and have had all of your questions answered. You will be given a copy of this consent form.

_____	_____
Signature of participant /Legally authorized representative	Date
_____	_____
Printed name of participant/Legally authorized representative	Time
_____	_____
Signature of witness	Date
_____	_____
Printed name of witness**	Time
_____	_____
Signature of person obtaining consent	Date
_____	_____
Printed name of person obtaining consent	Time
_____	_____
Signature of translator	Date
_____	_____
Printed name of translator	Time

**APPENDIX C: CHART FOR FINDING SUBTHEMES**

Participants	Theme 1: raising children in US compared to SA	Theme 2: Beliefs about mothering	Theme 3: diagnosis and being mother of child with ASD
P 1			
P 2			
P 3			
P 4			
P 5			

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**ABSTRACT****UNDERSTANDING THE EXPERIENCES OF SAUDI ARABIAN MOTHERS OF CHILDREN WITH AUTISM IN THE UNITED STATES**

by

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This narrative research examines the experiences of five Saudi Arabian mothers of children with ASD who are living in the United States. Multiple interviews were used in qualitative research to learn more about the different experiences of these mothers. The purpose of the study was to learn about the participants' experiences, including their stressors, beliefs, and thoughts about raising their children with ASD in a culture that is different from the one where they were raised.

Culture can shape mothers' attitudes and beliefs about raising children with disabilities. Saudi Arabian mothers living abroad are likely to observe different ways of mothering, and they may be exposed to new ways of thinking about mothering. When a Saudi Arabian mother of a child with ASD lives in a developed country like the United States, she may enjoy opportunities to live her experiences far from her extended family, with whom she may or may not have conflicts. She may also learn about resources that can foster her child's development. Living abroad means exposure to other people and other ways of thinking, which can lead to personal growth and change.

The most significant finding from these mothers was the comparison between the

educational and the medical sectors in the United States and Saudi Arabia. All of the mothers hope that the services in both sectors will improve to help people with disabilities. This study has implications for educators, doctors, and communities. Future research is needed to study the experiences of Saudi Arabian mothers of children with ASD who are living in Saudi Arabia.

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