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Experiences of Saudi Arabian Mothers of Young Children with Disabilities: An Exploratory
Study

by

Samirah Bahkali

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy in Curriculum and Instruction
with a concentration in Special Education
Department of Exceptional Education
College of Education
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Keywords: Special education, Social Life, Family, Saudi Culture, , Early childhood

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DEDICATION

This dissertation is dedicated to my parents, my husband, and my kids for their ongoing support and encouragement. Many thanks to my lovely husband, Dr. Ramzi, and my beautiful kids, Albaraa and Danah, for their patience and ongoing support to finish this journey.

Also, many thanks to my parents for continuous encouragement and support and for whispering words of wisdom. I dedicate this dissertation to all mothers of children with disabilities. My special dedication to my homeland, the Kingdom of Saudi Arabia, for giving scholarship and opportunity to study abroad, and for all the support throughout my ten-year journey, far from home. To the United States of America, for welcoming me and providing me educational experiences.

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In the name of Allah (God), most gracious, most merciful, “O' my lord increase me in knowledge” (The Holy Quran, chapter 12, verse 114).

“If anyone pursues a path in search of knowledge, Allah will thereby make easy for him a path to paradise” (Prophet Mohammed, صلى الله عليه وسلم).

First and foremost, I would like to thank Allah; with his help everything becomes possible.

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ABSTRACT

Saudi Arabia is one of the countries that seeks to provide and develop services for children with disabilities and their families. As times have progressed, regulations and laws have placed an emphasis on providing suitable and better services for children with disabilities and their families. However, a gap exists in the literature regarding the overall experiences of Saudi Arabian mothers of children with disabilities in the early childhood years from birth to age ten (Al Otaibi & Al Sartawi, 2009; Alazemi, 2010). This study explored the experiences of Saudi Arabian mothers of children with disabilities. A qualitative interview approach, utilizing in-depth interviews, was used in order to explore the experiences of five Saudi Arabian mothers of children with disability with the provided services, the social support systems for their children with disabilities, the effect of religion on their understandings of disability, and the effects of their child's disability on their lives in Jazan city. Five themes emerged from the interview data, which offered insights into Saudi mothers' experiences including : (1) Discovery and Diagnosis (2) Education Enrollment Challenges, (3) Un-met Needs, (4) Culture and Religion (5) Isolation and Psychological Impact. Findings of the study and aspects related to Saudi cultural beliefs of children's disability and diagnosis are discussed in detail.

CHAPTER ONE:

INTRODUCTION

Early childhood is defined as the period from birth through age eight. For children with disabilities, appropriate intervention during this stage is critical. Early childhood services contribute to improving a child's development and meeting their needs at an early age. This intervention should be based on a comprehensive plan providing effective early support to children with disabilities and providing their parents with resources and support to improve their communication skills with their children (Eaton, 2012).

Many childhood services have been established in the past decades to serve and improve the living circumstances of children with disabilities. For instance, the Education for All Handicapped Children Act (EAHCA), which was established in 1975, paved the way for children with disabilities and their families to receive their rights beginning at the child's birth. Among several provisions, this law ensures that children with disabilities receive early childhood services. In 2004, the Individual with Disabilities Education Act (IDEA) included a focus on early childhood and formal support to early education programs for children under the age of eight. Additionally, there were amendments that provided plans to implement and develop early childhood for special education services for children with disabilities from birth to age eight (Eaton, 2012). Under the IDEA 2004, part B and C seeks to provides services and enhance the development of infants and toddlers with disabilities from birth.

As aforementioned, intervention during the early childhood years is necessary to promote children's growth and development as well as to support and assist their families during the critical early years. It is the first building block in the formation of the child's communication

and development skills. In fact, interventions for some disabilities may begin during pregnancy based on some indicators such as the history of genetic disorders in the family (Ramey & Ramey, 1998). Such early interventions allow these parents to be prepared and to seek appropriate help and expertise starting at the earliest stages of their child's life.

Young children with disabilities require special services that help them and their families meet their unique needs and enable them to acquire needed knowledge, abilities, and social skills. As stated above, some signs of disability are evident during pregnancy; others may only show upon the child's birth or after birth. These disabilities have an effect on children and their parents as these disabilities may lead to learning difficulties or difficulties in acquiring special skills. In some cases, children with disabilities face difficulties in practicing normal daily activities. Therefore, young children with disabilities need to receive special services that meet their unique needs as soon as their disabilities are identified.

The birth of a child with a disability, physical or cognitive, is a challenge that affects the whole family as everyone is concerned about that child's life. Disability is a complex concept and a multidimensional challenge as it may limit an individual's opportunities in many areas of life. For instance, some children with disabilities may have limited abilities in carrying out daily tasks like changing their clothes or feeding themselves. The disability influence is not limited to the individual with the disability, rather, its influence extends on to the family and society. For instance, parents who have children with disabilities face many challenges in their life within the Saudi community. In other words, Saudi Arabian mothers face challenges that in many ways shape their life with their children as the services for disabled individuals are still in the developmental phase in Saudi Arabia (Alrubiyea, 2010). Saudi individuals with disabilities and their families face many challenges including misconceptions, mistreatment, and disparagement

from the society. In addition, these families face challenges about their children's learning and development disabilities, as well as facing challenges related to preventative and supportive services and interventions (Alrubiyea, 2010).

The birth of the child with special needs generates different psychological and social stress on the family, resulting in the parents reacting in differing ways to their child's disability. There are many factors that affect the parent's reactions such as the type of disability, its degree, the parents' culture, their level of education, their age, their economic condition, and their social outlook (Alsayyari, 2017). The nature of the parents' response may be affected by the way they learned of their child's disability and how aware they are of disabilities in their community. Usually, parents are shocked when their child is born with a disability as they know that child will require special care. Parental reaction to such news ranges from trauma to receptivity (Barbosa, Chaud, & Gomes, 2008). What's more, mothers of children with disabilities may feel social shyness that negatively affects their personality and psychological status, and in return, it reduces their interaction with others (Halhan & Cofman, 2008). Without doubt, parents need the help of individuals who have adequate knowledge about their situation in order to guide them to the proper ways to deal with the new family event. They need experts who can explain to them the needs of their child, how they can coexist with the newborn child, how to integrate him/her into the family, and how to meet the psychological needs of children with disabilities (Zhang & Bennett, 2003).

Furthermore, the family of the child with disability faces problems that lead to psychological pressures on their social relations. They suffer from psychological problems, self-reproach, and anxiety when thinking of their child's future (Abdulaziz, 2012). Sadly, some of the parents of children with a disability often feel ashamed. They often get disapproval and criticism

from those who live around them, especially when they are unable to control their child's behavior (Mak & Kwok, 2010). Therefore, some individuals blame the parents for using ineffective methods when raising the child with a disability (Fernandez & Arcia, 2004), which may cause pressure on mothers, and result in those mothers blaming themselves for being unable to help their children develop proper skills to survive in their current circumstances (Kuhn & Carter, 2006). Consequently, mothers feel shame and guilt which causes depression and anxiety in many cases (Mak & Kwok, 2010). On the other hand, some parents have negative thoughts and assume inaccurate truths such as the assumption that most of individuals in their communities disapprove of their child or view the child as a burden. Consequently, these parents prefer to be socially isolated in order to not feel embarrassed by others. Unfortunately, this increases the burden and psychological and social pressure on the parents and the child as well (Abdulaziz, 2012).

The discovery of a child's disability at an early stage of his/her life can be a severe shock for all families. Therefore, early childhood services are necessary to reduce the challenges accompanying disability as such services can help by instructing family members and training them on the ways of caring for children with disabilities or by directing the families to specialists in family counseling (Michael, 1998). In order for interventions to be effective for the child, the family should start early because the child is at the beginning of his/her preparedness for life. These young children's abilities to grow, change, and develop is still in progress, and so are their linguistic, social, and mental abilities. Therefore, these children's overall abilities and skills may still be easily influenced with early intervention.

Relatedly, a delay in early intervention leads to more deterioration and severe issues for the child and family. According to Hebbeler et al. (2007), early interventions that occur for a

preschool child are more effective and more useful in the development of a child with a disability. Nonetheless, the appropriate services help families to accept their children's disabilities and adapt (Mansell, 2010). Therefore, the lack of these services for families in Saudi Arabia contributes to the challenges faced by the mothers when caring for children with disabilities; such a lack in services is considered one of the most influencing challenges for Saudi Arabian mothers with children with disabilities.

According to Trigonaki (2002), the families of children with disabilities still need educational, financial, and social support. In fact, social support is one of the most important aspects positively influencing the psychological distresses in Saudi Arabian mothers. In the case of such mothers, social support helps them overcome some stressors (Cohen, Underwood, & Gottlieb, 2000). According to Duvdevany and Abboud (2003), the mothers of children with disabilities who received social support have a greater feeling of well-being than those who did not receive social support. Formal and informal social support are important factors in Arab families as they help these families to cope with the challenges of raising a child with a disability.

Furthermore, there are many needs that a family of a child with a disability require such as the need for information about a child's case, communicating with other people in their society who know about the child's disability, the need for support and financial assistance, and the need for community services (Bailey & Simeonsson, 1988). Parents who have a child with a disability need financial support as some types of disability require a significant amount of money to acquire special devices, medicines, therapy sessions, and much more for the child with disability. In addition, parents who have a child with a disability often need to reduce their

working hours and need to obtain paid or non-paid leave, which affects their income level in general.

Children with disabilities differ in terms of ability, personality, interests, and family background (Kyzar, Turnbull, Summers, & Gomez, 2012). It is necessary for those who work with children with disabilities and their families, such as social workers and service providers, to know about their population's different disabilities and their characteristics, as well as to have the knowledge of several issues that may negatively affect the children. The lack of awareness about the children's and the family's needs lead to not meeting the child's or the family's needs. In other words, those who work with children with disabilities and their families, such as social workers and service providers, should understand the different disabilities in their community and should know how to deal with them. For example, social workers and service providers should know that children with autism may display atypical behaviors like preferring to play alone or that children with sensory problems may put their hands on their ears if there is noise around them. To emphasize, if social workers and service providers lack the understanding of disability, types of disability, and the needs of children and their families, these social workers and service providers will face problems when attempting to choose or provide appropriate services matching these children's unique characteristics, strengths, weaknesses, as well as facing problems in meeting the needs of these children and their families.

Special Education in Saudi Arabia

Special education in Saudi Arabia began through individual efforts in 1958 (Aldabas, 2015) and Early Intervention from birth-to-eight years in 1960 (AlMousa, 2007). From 1960 to 1989, early intervention services were provided in hospitals funded by the government where children only received medical services. In addition, parents were responsible for providing any

additional early intervention services for their child with special needs (Alharbi & AL-Dar, 2013). Moreover, the Ministry of Health had a significant role in providing Early Intervention Services in Saudi Arabia; due to that, the rates of infant mortality and the deaths of children under five years old have declined significantly in the last few years. On the other hand, Aldabas (2015) pointed out that there was a lack of coordination or collaboration between the Ministry of Education and the Ministry of Health with regard to children with disabilities and information about them and the services that they need.

Currently, Early Intervention Services in Saudi Arabia provide services for young children with special needs from birth to eight years old (Merza, 2012). In fact, Early Intervention centers in Saudi Arabia are not public, but are operated through the private sector which charges the families to receive any of the available services. In Jazan, a city that is considered one of the smallest cities in the Saudi Arabia, there are no special centers that provide Early Intervention services for young children with disabilities from birth, but there are some centers that provide services for children with disabilities. Some of the parents who seek to provide services for their children with disabilities from birth tend move to one of the bigger cities in Saudi Arabia (Alharbi & AL-Dar, 2013).

What's more, there is a lack of research related to the prevalence and incidence of disability in Saudi Arabia. According to the report of the General Authority for Statistics in Saudi Arabia for the year 2017, the number of individuals with disabilities reached 632,078 and the highest percentage of the Saudi population with disabilities was reported in the Riyadh region at 24.69%. A national survey was completed by the parents of 60,630 children; the survey results revealed that 3,838 of the children were reported as having a disability. The surveys reported that the highest ratio of disabled children was in Jazan region with 9.9%.

Statement of the Problem

There is no doubt that parents feel anxiety when they know that their child has a disability. The family may feel overwhelmed and anxious about their child's future. Raising a child with a disability is not an easy task, especially if the parents are not experienced with how to deal with their child or how help the child discover his or her own abilities. Raising a child with special needs may place families under severe pressure, which may in return put pressure on the child without knowing. So social and psychological support for the families of children with disabilities is important to help them in raising their child, meet their needs, and help them provide appropriate care for their disabled children (Alrubiyea, 2010).

Given the fact that the number of disabilities is increasing (Visser, Bitsko, Danielson, Perou, & Blumberg, 2010), and based on available research, there are studies that discuss disability and its types; however, there are not many opportunities to discuss services for children with disabilities from birth to eight years old and their families in Saudi Arabia (Al Otaibi & Al Sartawi, 2009). According to Al-Mutair, Plummer, Clerehan, and O'Brien (2014), there is a need for comprehensive research to fill this gap. No studies have focused on recognizing the families' needs and concerns toward their young children with disabilities. Furthermore, Alazemi (2010) indicated that there is a need for effective programs and support services for children with disabilities and their families to improve their lives.

An early learning program would have the greatest impact on children with special needs and their families. Such a program can play an effective role in the development and improvement of children's skills and abilities during the early childhood period. In addition, an early learning program can help the children in developing their abilities, verbal skills, walking, running, and balance as well (Workman & Ullrich 2017). Intervention during the early childhood

stage has paramount importance in supporting children to adapt to the environment in addition to developing their mental abilities, linguistic abilities, and social abilities. Additionally, these programs provide various services for children with disabilities and their families which in return helps the families mitigate the burden for raising their child and meeting their needs. The prevalence of children with disabilities, regardless of the type and degree of disability, makes the provision of services for them one of the most challenging tasks that faces Saudi Arabian mothers. Therefore, many families suffer from social and economic problems that affect their ability to meet their needs and those of their children (Al-Krenawi & Graham, 2000).

In the light of that, there is a need for a study to explore the Saudi Arabian mothers' perspectives about services provided for their children with disabilities during the early childhood years and to explore these mothers' needs. This study can help service providers recognize any barriers that reduce the ability of these families to meet their needs and those of their children. Furthermore, the findings of this study may be used to increase knowledge, awareness, and an understanding of the needs of Saudi families who raise children with disabilities in the Saudi Arabian society.

Purpose of the Study

As discussed above, some mothers feel ashamed, guilty, and embarrassed about their child's disability while some mothers feel that disability reduces their value in the community (Green, 2003). However, there is a gap in literature examining the needs and concerns of Saudi Arabian mothers regarding their children with disabilities. Therefore, there is a need for research that offers insights into Saudi Arabian children with disabilities and their families. Specifically, this study aims to:

- 1- Explore Saudi Arabian mothers' experiences of having a child with disabilities, to explore the impact of disability on the family.
- 2- Identify challenges encountered by children with disabilities and their families in accessing special education services in Saudi Arabia.
- 3- Determine the needs and concerns of children with disabilities and their families in order to provide enough information for special education and related service providers to increase their knowledge of the necessary skills for working with these families and their children.
- 4- Inform KSA special education and related service providers about strategies for improving the delivery of services and any other suggestions for development.

A qualitative interview approach utilizing in-depth interviews was used in this study in order to investigate the experiences of Saudi Arabian mothers of young children with disabilities.

The interviews aimed to address the following research questions:

1. How do Saudi Arabian Mothers of young children with disabilities describe their experiences with their children during the early childhood years?
2. What are the experiences of Saudi Arabian Mothers of young children with disabilities with regard to support services and resources for their children and their families?
3. How do Saudi Arabian Mothers of young children with disabilities make meaning of the effects of their child's disability on their lives?

Theoretical Framework

Howell (2013) stated that "theories entail different understandings of knowledge and truth, knowledge development as well as acquisition, application evaluation and critique" (p. 24).

Theories are a hypothesis, principle, or a system of ideas aimed to explain phenomena and some aspect of the natural world. Howell (2013) has also stated that “theory is concerned with building substantive understanding, normativism and ideational simplification” (p. 24).

Furthermore, the theoretical frameworks also serve as a guide in a research study. In light of that, Eisner (2002) stated that “theoretical frameworks serve as a means for identifying aspects of the reality to which they address themselves” (p. 156). A theoretical framework is essential in the research study because through it, the researcher can introduce and describe the theory that explains why the research problem exists. It plays a critical role in guiding the whole process of the research study and allows the reader to conceptualize the study in a broader context. The purpose of the theoretical framework is to help the researcher see the variables of the study. It is the lens through which the reader evaluates the research problem and research questions.

The theoretical framework for this study is interpretivism. Interpretivism is considered an approach to social science that opposes the positivism of natural science. Interpretivism depends on the trained researcher and the human subject as the means to measure some phenomena. Interpretivism typically involves both observation and interviews. Furthermore, interpretivism lends itself to using qualitative methods for data collection. The interpretive paradigm is concerned with understanding and knowing the world as it is from the subjective experiences of individuals. Within interpretivism, the mind plays an active role in the construction of reality. It focuses on understanding and interpretation. Epistemology in interpretivism is "knowledge and the knower are inextricably linked; events are placed in intelligible frames by a mind that actively engages the world, attaching significance to those events" (Paul, 2005, p. 47). Research focuses on seeking to understand the specific context. The inquiry is value-centered rather than value neutral (Paul, 2005).

From an interpretivist standpoint, the researcher learned about the mothers' perspective on the services provided for them and their children. Interpretivism theory focuses on understanding and explaining human and social reality for the study. For an interpretive researcher, it is important to understand motives, meanings, reasons, and subjective experiences (Hudson & Ozanne, 1988; Neuman, 2000). Furthermore, in interpretivism theory, the researcher depends on participants' perspectives and their experiences to understand the research topic being studied. Under the interpretivism theory, the participants are allowed to freely express their opinions on the interview questions (Hudson, & Ozanne, 1988).

The mothers' beliefs about their ability to care for their children with disabilities strongly influences motivational, behavioral, and emotional processes. According to Kuhn and Carter (2006), there is a relation between mothers' sense of their own inability to exert a positive influence toward their children's development and low level of maternal self-efficacy. On the other hand, Kandari's (2005) study in Kuwait shows that a high level of caregiving and self-efficacy has an important role in decreasing the level of stressors related to the characteristics of the child. Other studies conducted in the United States and Europe show that mothers who have a high level of self-efficacy are more optimistic, authoritative, and compatible in their interactions with their children than are mothers with lower self-efficacy (Ardelt & Eccles 2001; Bandura, Barbaranelli, Caprara, & Pastorelli, 1996; Williams & Williams 1998).

After synthesizing the literature regarding disability, children, and family needs, the researcher collected a number of linked concepts that influence families' perspectives of having a child with a disability, their needs, their concerns, and their decisions regarding their children's care. The collected concepts represent factors that explain the differences in how parents raise their children, view disability, involvement in their children's care, and access social support; in

fact, research emphasizes how important it is for the parents to receive positive social support, whether formal or informal, when raising children with disabilities (Boyd, 2002; Lindblad, Holritz-Rasmussen, & Sandman, 2007). These concepts include religious beliefs, education level, and socioeconomic status. Therefore, there are many factors that affect families' perspectives of having a child with a disability and their decisions about their children's care. The researcher will discuss the influence of each of these concepts and factors in Chapter Two.

Delimitations

Participation in this study is delimited to Saudi Arabian mothers who (a) have at least one child with a disability; (b) have children with a disability under eight years of age; (c) have children living in Saudi Arabia; and (d) reside in Jazan, Saudi Arabia. Since I, as the researcher, could not find ample research about the needs of families of children with disabilities in Saudi Arabia, the researcher collected many pieces of literature from Western sources.

In order to inform the social officials and services providers to provide appropriate services to these families and their children, this study will identify and understand the mother's experiences with special education. To achieve the study's goals, the researcher used a qualitative interview approach with in-depth interviews in order to investigate the mothers' experiences. This type of qualitative design provided the data I need to answer the abovementioned research questions.

Definition of Terms

Child with disability. A child with a disability is a child evaluated as having autism, deaf-blindness, deafness, developmental delay, emotional disturbance, hearing impairment, intellectual disability, multiple disabilities, orthopedic impairment, other health impairment, specific learning disability, speech or language impairment, traumatic brain injury, visual

impairment including blindness, and who needs special education and related services (IDEA Sec. 300.8).

Early childhood. Childhood is one of the most important periods of a person's life, as it is characterized by continuous growth and remarkable development physically, mentally, socially, and emotionally. Childhood is the period from birth to eight years old where children are highly sensitive and affected by those around them (Allen & Schwartz, 2001).

Family. Family refers to a social unit comprised of a father, a mother, and children (Nour, 2005). The term family in this study includes birth parents who care for their child with a disability.

Special needs. Special needs are defined as any types difficulties that hinder individuals from practicing their life normally or that causes an individual to require additional or specialized services (Sahay, Prakash, Khaique, Kumar, Meenakshi, Ravichandran, & Singh, 2013).

Hearing disability. A person who suffers from hearing disability is a person who experiences some type of auditory impairment. Hearing disability ranges in intensity from the simple and medium degrees that results in auditory impairment to the severe degree that results in deafness that leads to hardship in understanding speech (Halhan & Cofman, 2008).

Visual disability. This disability refers to the loss of ability to use the sense of sight effectively, which negatively affects a person's performance and growth (Elkhateeb, 2013).

Autism. Autism is a disorder whose symptoms often appear in children before the age of three and this disorder affects many aspects of the child's growth, development, and social interaction (Elzarea, 2012).

Down syndrome. The initial diagnosis of Down syndrome for newborns is mostly dependent on the external appearance of the child. It is a type of mental disability and one of the most common types of disability identified at birth (Halhan & Cofman, 2008).

Saudi Arabia. The Kingdom of Saudi Arabia is a large developing country; it was established in 1932, and is located in the southwestern region of Asia. The Arabian Peninsula is bordered on the north by Jordan, Iraq, and Kuwait and on the east by Bahrain, United Arab Emirates, Qatar, and the Arabian Gulf Sea. On the south, Saudi is bordered by Oman and Yemen, and is bordered by the Red Sea on the west. The population of Saudi Arabia is about 25 million (Alquraini, 2011).

CHAPTER TWO:

LITERATURE REVIEW

This literature review involves a discussion of many concepts that represent factors influencing the families' perspectives of having a child with a disability, care and health services, social support, families' decisions making, and involvement in their children's care and intervention. These factors include educational level and socio-economic status (SES). Thus, these factors showcase the range of differences between families and cultures and how each factor is influenced by other factors. These factors have been identified as possible risk factors for families as they strive to achieve quality of life.

In addition, this literature review addresses the parents' experiences about raising children with disabilities including their perceptions and expectations of special care. Furthermore, this literature review provides an overview of Saudi Arabian families including origin, population, religions, classification, education, and occupations as well as Saudi cultural characteristics which are reflected in the family structure, in the relationships in the community, in the child-rearing approaches, and in the conceptualization of disabilities. The purpose of the discussion of these topics is to highlight the importance of considering the family's needs and concerns when discussing disabilities and providing services for families and children with disability.

The databases that the researcher used to locate literature are EBSCO, ProQuest, Google Scholar, PsycINFO, ERIC, JSTOR, and SAGE. The keywords used to locate literature and search the databases are the following: Saudi Arabian Mothers, Disability, Special Education, Early Childhood, Young Children, Religion and Disability, Young Children with Disabilities,

Saudi Arabian parents perspectives and disability, Saudi Arabian parents perspectives and culture and disability, educational level and disability, socioeconomic status (SES) and disability, acculturation, and disability, Saudi Arabian culture, Saudi Arabian, Saudi Mothers and disabilities, Saudi Arabian and disabilities, Saudi Arabian Mothers and disabilities, Saudi Arabian and Young Children with Disabilities, Disability in Islam, Disability in Saudi Arabia.

Mothers' Experiences of Disability

The mothers' experiences of their children's disabilities vary according to culture. Every culture, including Americans, Arabs, Asians, and Chinese, has perceptions and interpretations about the nature of disability that may be different from one culture to another or within cultural groups (Masasa, Irwin-Carruthers, & Faure, 2005; García, Pérez, & Ortiz, 2000). Furthermore, these experiences are formed through different resources, including needs of parents to provide treatment for their children, the ways to get their children an education, and parental expectations about their children's future (Daudji, Eby, Foo, Ladak, Sinclair, Landry, & Gibson, 2011). According to Diken, (2006b), there are many mothers who do not recognize the importance of biomedical interventions for their children. They think that their child's condition is not permanent (Danseco, 1997). So, cultural understandings of disability are essential, especially for parents and service providers.

Disabilities may have different meanings for parents and service providers from different cultural backgrounds (Santos & Mccollum, 2007). Saudi Arabia is an Arabic Islamic country. Islam is the primary religion of Saudi Arabia. Islam is the main part of Saudi culture that forms economic status, education, and environmental factors (Buckman, 2011).

Conceptual Framework

In this chapter, the researcher discuss education level and socioeconomic status (SES) for mothers and their relation to this study. This chapter is important in two ways: (a) to provide the audience (specifically service providers) with information about factors that have influenced mothers to provide services for their children, and (b) information presented in this chapter is an essential part for the collection of data in this study.

Education level. The educational level of parents plays an essential role in understanding disability and accepting it. In addition, it has an important role in determining the methods and techniques the parents use in raising their children with disabilities, their awareness of the causes that lead to disability, and ways of preventing it. Studies have shown that higher education levels of parents help them to build positive attitudes towards their children with disability. Higher education levels of parents provide them with the ability to find information and appropriate methods for dealing with their disabled child (Garland, Brookman-Frazee, & Gray, 2013; Hidalgo, McIntyre, & McWhirter, 2015). Nonetheless, Bandura (1996) states that there is a relationship between parents' education and family interaction patterns during childhood. Moreover, academic success and achievements for children can be linked by the social environment and cognitive framework. Bandura (1996) confirmed that socialization has an effective role in how children learn.

By comparing parents with low education levels to parents with higher education levels, Chen, Kong, Gao, and Mo (2018) found that parents with high education levels are more able to provide further help and support for their children. In addition, they have positive expectations toward their children's education because they have knowledge of approaches for addressing

difficulties that face their children and they have knowledge of proper parenting styles to build their children's personality.

The education level of parents is important to enhance the acceptance of special education programs. The study by Al-Shammari and Yawkey (2008) gives extensive research about accepting parents for special education programs and participating in it. Al-Shammari and Yawkey (2008) have defined students with a disability as those with special needs. Al-Shammari and Yawkey (2008) described them as students with one or more difficulty in the special development areas. The types of special needs evaluated in the study were hearing, visual, mental retardation, physical, autism, and learning disability. This research was carried out in Kuwait and the sample size was 350. The sample was specific in selecting parents who had children with disabilities. The researchers asked questions to collect information on the demography of the parents such as age, level of education, and their experience with other people. Findings indicate that the majority of parents with disabled children were in the age bracket of between thirty and fifty years and their educational level ranged from high or intermediate to low. These parents were also characterized by a lack of permanent jobs or lack of time for jobs due to the time spent in caring for their children. In addition, the finding revealed an important truth. Most parents do not understand special needs programs in schools for their children. Therefore, less participation of the parents in these programs has been observed. Parents should be taught the importance of these programs first before they involve themselves in the special education needs of their children. The level of education of these parents is also responsible for the level of understanding. If a parent is not formally educated, there will be difficulty in making them understand the programs that their children need (Al-Shammari & Yawkey, 2008).

On the contrary, Masoud's (2005) study showed that parents who have an intermediate educational level have positive trends towards disability more than parents of high education levels. Furthermore, this study showed that these parents have strong beliefs about disability and do not seek to hide them from others in society. Also, they believe that children with disabilities are a gift from Allah (God) and is not permissible to object to it.

Socioeconomic status (SES). This section aims to discuss the family's income and social position. Family's income and the social position of any family determine the ability of the parents' access to health care. This in return affects how these parents provide or cater to their children's needs in many areas of life such as access to early diagnosis, planning of an intervention, provide food, shelter, and clothing, as well as education requirements. Children with disabilities in low socioeconomic status (SES) families may be less likely to receive early intervention services. This is due to a lack of access early to early intervention services and lack of resources in the identification stage of their child's disability (McManus, McCormick, Acevedo-Garcia, Ganz, & Hauser-Cram, 2009). Furthermore, the family's low-income increases the possibility that these families will not possess adequate health insurance for their children to access adequate medical services (Rondero Hernandez, Montana, & Clarke, 2010).

Bailey, Hebbeler, Spiker, Scarborough, and Mallik, (2005) found that minority families faced more difficulty accessing early intervention services than white families. In their study, Bailey et al. (2005) conducted an interview with a large sample of parents who have children receiving early intervention services. They found that minority families faced difficulty in knowing about early intervention services when compared to their non-minority counterparts. Therefore, there is relationship between socioeconomic status (SES) and disability. According to Hanvey (2002), poverty status increases the financial strain on families to meet their child's

needs. Additionally, Oppenheim and Harker (1996) stated that children with disabilities have special needs to be able adapt to their life, some of which may be expensive to acquire such as modes of transportation, health care, adaptive equipment, and special diets.

Notably, a meta-analysis study of almost 200 studies conducted by White showed a positive correlation between socioeconomic status and academic achievement in children. However, another meta-analysis study including more than 70 studies conducted by Sirin (2005) showed that there was no high correlation between socioeconomic status and academic achievement in children.

Chen, Kong, Gao, and Mo (2018) confirmed that there is a relationship between occupation and income and the children's academic performance; in other words, parents with low socioeconomic status (SES) may have negative emotions toward raising their child because of financial pressure and unhappiness; as a result, the children's academic performance is negatively affected. Since each factor is influenced by the others, these factors work together in influencing the families' perception of having a child with a disability and their decision regarding their child's intervention.

The social-economic background has an effect on the performance of students. The social-economic background of the parents affects the children's academic performance. In more details, the parents' social-economic background affects the parents' ability in meeting children's school needs such as paying school fees, textbooks, uniforms, all of which may contribute to their children's academic performance and achievement (Considine & Zappalà, 2002).

In addition, home plays are an important role in students' psychological, emotional, and social state. The home is the first place in a child's life and the family is the bedrock of any society. So, home status and family background have an effect on the individual, whether on a

psychological, emotional, or social levels (Considine, & Zappalà, 2002). For instance, Uwaifo (2008) confirmed that parents' relations, such as successful marital stability, affect the child's academic performance. Furthermore, Fraser (2001) confirms that home conditions, divorce, adoption, or parental deprivation may be detrimental to the school performance of the child.

Similarly, Considine and Zappalà, (2002) conducted a study to explore the relationship between family socioeconomic status and the academic performance of children on over 3000 students from financially disadvantaged backgrounds. Findings from the study indicate that socioeconomic status has obvious influences on the students' educational outcomes.

Summary. In summary, mothers of children with disabilities learning experiences are affected by religious beliefs, education levels, and socioeconomic status. Religious beliefs have an important role in helping and supporting parents to understand disability and raising a child with a disability. In addition, education levels play an essential role in understanding disability and accepting it. Lastly, socioeconomic status, the family's income and social position determine the ability of the parents' access to health care and cater to their children's needs in many areas of life. The recognition for these important aspects can provide insights into the understanding of the study.

Saudi Arabia

Before discussing disability in Saudi Arabia and perceptions of Saudi Arabian mothers of children with disabilities, it is important for western researchers to understand the customs and morals of Saudi Arabian society in order to understand the need for additional literature and social work research. So, this section will explain the traits characterizing this demographic and its relationship with disabilities by providing an overview of Saudi Arabian people, their origins, their religions, social life norms, education, and occupations.

Origins. The Kingdom of Saudi Arabia (KSA) was established in 1932 when Abdel Aziz Ibn Saud conquered the majority of the Arabian Peninsula after a war that lasted three decades. The Arabian Peninsula is bordered on the north by Jordan, Iraq, and Kuwait and bordered on the east by Bahrain, United Arab Emirates, Qatar, and the Arabian Gulf Sea. On the south side, Saudi Arabia is bordered by Oman and Yemen, and on the west is the Red Sea (Alquraini, 2011). The land in Saudi Arabia is generally arid and its climate is a desert climate, which is very similar to the climate of the southwestern states of the United States. Also, its temperature reaches 90 Fahrenheit degrees in summer and 15 degrees Fahrenheit in the winter in most of the regions of the Kingdom. Saudi Arabia is characterized by the presence of oil which is considered one of most important resources. Furthermore, it is considered the biggest Islamic interface in the world. The population is estimated to be 30,770,375 Saudi citizens and non-citizens. The Saudi people speak Arabic, which is a Semitic language that originated in the Arabian Peninsula (Alotaibi & Almalki, 2016).

Religions. Saudi Arabia is considered the main home for Islam where it has two main Muslim holy cities—Mecca and Medina. Islam is the main religion of Saudi Arabia. It has an important role in all facets of Saudi life such as law, education, marriage, family life, and dress codes. The first thing that the infant hears after birth is the Athan, the “call to prayer,” which is believed to confirm that the infant is Muslim. Furthermore, it is not allowed for any people from different religions to exercise their faith publicly. As these non-Muslim live in Saudi, they are required to follow Islam and Sharia law. Nonetheless, religion has an important role in education and the curriculum at all levels of education. In fact, education in Saudi used to be separated by gender, but education currently has both genders studying side by side up to the third grade (North & Tripp, 2006).

Sharia law respects human rights and protects those with disabilities and prohibits discrimination whether based on ability, race, gender, or color (Hemdi, 2010; Al-Gain & Al-Abdulwahab, 2002). Furthermore, families of children with disabilities may be influenced by religious practices and various beliefs about disability. Sharia law confirms the necessity of the family to care for their child and encourages other people to help and support families and their children with disabilities.

Social Life. This section aims to introduce social relationships in Saudi society and social changes that happens in life in Saudi. Social relationships are between families or family and friends. These social relationships allow anyone in the family or friends to express their opinions in raising children. This means that members of the family or friends have a chance of sharing family issues such as caring for a child with disabilities. Friendship in Saudi Arabia is very important. Generally, Saudi families see friends as trustworthy persons and these families believe in long lasting friendships. Notably, Saudi women are friends with women folk, while men are only friends with men folk.

Recently, new laws now allow Saudi women to drive. This in return allows Saudi women to travel outside the country without the permission nor the approval of their legal guardians (typically their fathers or their husbands). In addition, child custody laws have changed as well. Nowadays, Saudi mothers have the right to raise their children whether boys or girls when divorced. As a result, these changes in law and society are expected to impact families of children with disabilities.

Education. Education is a key factor in Saudi society. According to the Royal Embassy of Saudi Arabia (2010), education started when King Abdulaziz Al Saud founded the Kingdom of Saudi Arabia. Education was limited to learning the religion and the Arabic language due to

the encouragement and support from King Abdulaziz Al Saud. Before the unification of the Kingdom of Saudi Arabia, education was limited to a few schools. Access to services and affordability was a matter of concern and the development of education had been slow. Over the years, there has been evident growth in Saudi education system, combined with an increase in the number of schools, students, and teachers. Education in Saudi Arabia officially began in 1925 and over the first few years, there were about 300 schools serving several thousand students mainly in urban areas.

Education is provided to all tiers of society, and all students can get a free education that is funded by the government. The Ministry of Education in Saudi Arabia is responsible for giving free and appropriate education for all students. It also is responsible for developing curricula as well as being responsible for special education services for students with disabilities (Al-Mousa, Al-Sartawi, Al-Abduljbar, Al-Btal, & Al-Husain, 2006). Most Saudi people are highly educated. They value education and seek to educate their children as well (Al-Ajmi, 2006).

Saudi Culture. It is important for western researchers to understand the Saudi culture and its role in child-rearing practices. This section briefly introduces the characteristics of Saudi culture, including family structure and child-rearing.

Family structure. Understanding the family structure helps researchers in determining the best means to gather data. The Saudi culture is characterized by families' interdependence. Family in Saudi is the central pillar of society as the culture lives collectively. A Saudi family is typically comprised of a husband, wife, children, and often in some families, the grandparents from the father's side live in the same house. It is normal for two or three generations to live in the same house. National statistics (2010) refer to that 82.6% of the families in Saudi Arabia

were nuclear families, which include the husband, wife, single children, and grandparents from the husband's side (Alhammedi, 2000). The parents are responsible for the care of the children and the grandparents. The grandparents are highly respected by families and society. Taking care of the elderly is a debt placed on their children (Elsaman & Arafa, 2012). The idea of social services for the elderly is perceived as disobedience from these elderly's children and may harm a family's reputation. So, most families do not accept the idea of senior homes or senior services (Soliman, 2013). All children live in their families' house until they marry, and the parents are responsible for all their children's needs until they find jobs (Long, 2005). The Saudi family relationships are very strong. For example, it is common for families to take responsibility for their divorced, widowed, or relatives with disabilities (Alhammedi, 2000).

According to Dubis (1987), the generational family relations and responsibilities toward children and the elderly in-home make it difficult for the family to care for a child with disabilities, which sometimes increases the pressure on the family. These pressures also increase depending on circumstances surrounding the disabled child, the type of disability, and the severity of the disability. Parents with children with disabilities face more challenges and need more help and support based on their situation whether it is financial, social, moral assistance (Swadi & Eapen, 2000).

In fact, men tend to have more responsibility than women in the Saudi society. They are responsible for all the basic income for the family and they are seen as the source of security and safety at the home. Women often depend on men in most home affairs. Nowadays, Saudi women work and help their men with the income of the family. Most families with high and middle income have domestic workers (maids and chauffeurs) who help the family in daily domestic

duties such as cleaning, cooking, grocery shopping, and taking the children back and forth to school.

Marriage is greatly valued in the Saudi culture and is considered as the main goal of life for any young adult. Consequently, having many children is highly encouraged and is usually welcomed by all family and their relatives. Moreover, not having children, or not having enough children, provokes an individual's family and their relatives to ask about the reasons for the delay in having children, which causes sadness and distress for the parents (Ajrouch, Hakim-Larson, & Fakih, 2016). Saudi families are keen on the idea of having children to strengthen the relationship between families. Families view marriages as an agreement between two families (Al-Kandari, & Al-Qashan, 2010). Therefore, families are still involved in the spouses' life after marriage and they provide guidance and financial support (Ahmad & Reid, 2008). Some families have rules and principles when getting married. For example, in some families, women are only allowed to accept a marriage proposal from relatives, such as cousins or the cousins' relatives, or only marry from within the family tribe (aka anyone holding the same last name). But men have the freedom to choose any woman for marriage whether these women are relatives or not. In fact, most men depend on their mothers or sisters to choose a wife for them.

Research shows that there is a relationship with the family structure and academic achievement. The research by Allen (2005) is very specific on the family's structural effect on academic achievement. The structure of the family determines the level of involvement of a parent in the school activities of the child. In cases of single parents or divorced parents, the child may not have the advantage of both parents involved in their school activities (Allen, 2005). Allen's (2005) research is a follow-up on an initial study which was set to evaluate the nature of the structure of the family on the performance of adolescents. The initial study findings

were that different types of parental involvement were responsible for different development outcomes in the child's academic work. Nonetheless, the main source of information in Allen's study was the National Educational Longitudinal Study of the 1998 to 2000 (Allen, 2005). The research findings show that parental involvement and intact families have a positive effect on the ability of students to comprehend and perform well. Students with consistent results were found to have both biological parents living with them. The performance was better than in cases where the parents were never married or never checked on the academic achievements of the students (Allen, 2005). The parental elements scored included checking on the academic performance of the students, discussing school with the children, checking on what was learned, and the challenges faced by their children. The above activities coupled with attending school activities by the parents positively impacted the performance of the students. This study concludes by attributing academic achievement to the socioeconomic status of the student.

On the other hand, research by Azumah, Samuel, and Onzaberigu (2018) investigated the effects of family structure on the academic performance of children. The researchers discussed the difference in the relationship between the academic performance of children from single-parent families and two parent families. In addition, this study discussed the difference in parental involvement in children's academic performance and its effect on students. The findings from this study indicated that there was no significant relationship between family structure and academic performance for students and more specifically, there is no significant difference in academic performance between children from single-parent families and those from two parent families. The study concluded that family structure was not related to the academic performance of students.

Child rearing. In the Saudi culture, having children is highly valued as previously discussed. The family, especially mothers, hold the primary responsibility for children's care which may cause pressure and tension for the mother. Children build their identity from the parent-child relationship. So, interactions between members of the family have an effect on children's identities. Children acquire values and customs from their parents. In Saudi culture, there are some aspects of identity that women live by which are different from men's identities. In other words, Saudi families are keen on teaching males and females their identities and roles in the society from an early age (Beitin & Aprahamian, 2014). There are different rights for males and females based on their genders in the Saudi culture and law. In the past, the family focused on their boys completing schooling getting a job, getting married and carrying on the family line. As for women, some families seek to teach their girls a sense of responsibility toward the home and that all her actions affect the reputation of the family. So, women always need protection (Ajrouch et al., 2016). Furthermore, Saudi families practice an authoritarian style of parenting while raising their children. Parents determine what is appropriate or not in their children's lives, and they require their children to listen to their words of wisdom and guidance (Kayyali, 2006). Parents tend to give commanding lectures to their children and expect their children to follow their orders (Dwairy et al., 2006).

Conceptualization of disabilities. The discussion of disability in Saudi culture is challenging and the reason is due to limited literature and research that discusses this topic (Gharaibeh, 2009). There are challenges that face children with disabilities in Saudi Arabia, such as the lack of awareness of the rights of people with disabilities, lack of knowledge about services that may help parents to provide it to their children, and the lack of knowledge about legislation to protect those rights. Furthermore, Saudi people believe that there are factors that

contribute to the presence of disabilities such as parents' age, marriage between relatives, and taking some medications during pregnancy (Gharaibeh, 2009).

The interpretations of disabilities often depend on Islamic philosophy that has a positive attitude towards disabilities. The Qur'an (the holy book) and the Hadith (record of the traditions or sayings of the Prophet Muhammad) provide principles and practical suggestions for caring for individuals with a disability. There is much evidence in Qur'an and the Hadith against discrimination on race, gender, color, or ability. Messenger of Allah (ﷺ) said, "Allah does not look at your figures, nor at your attire, but He looks at your hearts and accomplishments." In Qur'an, specifically in Surah Al-Fath (48/17), God said: "There is no blame upon the blind, nor is there blame upon the lame, nor is there blame upon the sick"

In Saudi societies, stigma and shyness from disability depend on the kind and severity of the disability whereas mental disabilities are more stigmatizing on families, and lead to families' isolation from society (Ahmead, Rahhal, & Baker, 2010), while visual impairments and deafness are less stigmatizing and lead to the empathy from society (Bazna & Hatab, 2005).

Consequently, families who have children with disabilities are negatively affected resulting in lower psychological status which makes them less interactive socially, lacking in self-confidence, and prone to depression, confusion, and feelings of guilt. Some families prevent an individual with a disability from attending social gatherings and meetings, and they believe that disability is a stigma for the whole family. Moreover, some families tend to hide their girls with disabilities so there are not reasons to prevent their sisters from getting married.

Disability Research on Saudi Arabia. Research on Saudi Arabian individuals with disabilities is limited. There are difficulties and hurdles in conducting research about disability in KSA (Al-Turaiki, 2000). Some people avoid participating in research because they feel ashamed

about disability or about telling people about the difficulties their family faces (Al-Hazmy, Al Sweilan, & Al-Moussa, 2004). An important barrier is the lack of a standard outcome measures used to assess or identify the degree of disability. In addition, there is a problem in data collection in research that discusses disability in Saudi Arabia in rural areas which then results in a lack of providing services and medical assistance as well as health education programs (Alsekait, 1993).

According to the World Health Organization, 15% of the population suffers a physical, sensory, intellectual, or mental disability in 2012, of which is 4,070,546 people in Saudi Arabia who need rehabilitation services (Al-Jadid, 2013). Furthermore, there are gaps in research regarding cases of disability in Saudi Arabia. In KSA, a study from Qaseem stated that the incidence of physical disability is about 1.7%, while children with intellectual disability is 1.4%, which means that the prevalence of intellectual disability is lower in comparison to physical disabilities (Al-Shehri, Farahat, Hassan, & Abdel-Fattah, 2008). A national survey in KSA reported that there are 3,838 children who have a disability and the highest percentage of these children are in Jazan region with 9.9%, followed by Riyadh with 4.36%. Physical disability is the most prevalent at 3%, followed by learning disability at 1.8% (Al Salloum, El Mouzan, Al Omar, Al Herbish, & Qurashi, 2011). Research indicate that the reasons behind these numbers is because some parents have a disability, later pregnancy, and mothers do not receive medical care and take the vaccination during pregnancy. Notably, neurological disorders in Saudi children were 45,682 (Al-Shehri, Farahat, Hassan, & Abdel-Fattah, 2008). More specifically, approximately 313 children have a chronic neurologic disorder. The prevalence rate of intellectual disability is 26.3/10,000 which makes it the most common type of disability, while cerebral palsy is 23.4/10,000. In addition, quadriplegia happens to the individual because of

traumatic accidents. Currently, about 72.8% of instances of quadriplegia in Saudi Arabia is caused by traumatic accidents (Al Salloum, El Mouzan, Al Omar, Al Herbish, & Qurashi, 2011; Al-Jadid, 2013).

Before the unification of the Kingdom of Saudi Arabia, access to services and affordability was a matter of concern and the development of education was slow. Education in Saudi Arabia officially began in 1925, and there were about 300 schools serving several thousand students mainly in urban areas. People with disabilities in Saudi Arabia did not obtain any type of special education services prior to 1958. Back then, the parents of students with disabilities were responsible for providing any assistance to their children (Al-Ajmi, 2006). Today, there is an evident growth in education and an increase in the number of special needs schools, students, and teachers. There are about 47325 schools providing education to nearly five million students; moreover, k-12 schools are now found in both rural and urban areas. During this great development and growth in education, the services of special education have emerged in Saudi Arabia. Also, the services of special education have moved from segregated schools to mainstreamed schools. These schools have developed and have changed over time in order to support learning for students with disabilities.

CHAPTER THREE:

METHOD

The purpose of this study was threefold: 1) to explore and understand Saudi Arabian mothers' experiences and perspectives of raising a young child with a disability, 2) to reveal their needs and concerns, and 3) to identify challenges encountered by children with disability and their families in accessing special education services in Saudi Arabia. This study also aimed to offer sufficient information about the mothers' needs with regard to special education and the service providers in Saudi Arabia. The findings of this study can be used to inform and spread awareness of the mothers' needs to institutions, organizations, and service providers who work with the mothers and their children. By doing so, these institutions, service providers, and organizations' knowledge of the necessary skills for working with these mothers and their children will increase.

Qualitative interviews were used in this study to examine and investigate the experiences of Saudi Arabian mothers of children with disabilities. The following research questions guided the study:

1. How do Saudi Arabian mothers of young children with disabilities describe their experiences with their children during the early childhood years?
2. What are the experiences of Saudi Arabian mothers of young children with disabilities with regard to support services and resources for their children and their families?
3. How do Saudi Arabian mothers of young children with disabilities make meaning of the effects of their child's disability on their lives?

This study was guided by an interpretive paradigm. The interpretive paradigm focuses on understanding and explaining human and social reality for the study at the level of subjective experiences of individuals. “Interpretivism” is considered an approach to social science that opposes the positivism of natural science (Paul, 2005). In fact, interpretivism depends on the trained researcher and the human subject as the means to measure some phenomena. Interpretivism typically involves both observation and interviews (Paul, 2005). Furthermore, interpretivism lends itself to using qualitative methods for data collection. The interpretive paradigm is concerned with understanding and knowing the world as it is from the subjective experiences of individuals (Paul, 2005). Analysis of “interpretivism” usually refers to the mind playing an active role in the construction of reality. It focuses on understanding and interpretation (Bevir, 2007). As for epistemology in interpretivism, it refers to the “knowledge and the knower are inextricably linked; events are placed in intelligible frames by a mind that actively engages the world, attaching significance to those events” (Paul, 2005, p. 47). In the light of that, research focuses on specific and concrete data and seeks to understand the specific context, while inquiry is value-centered rather than value-free (Paul, 2005).

For an interpretive researcher, it is important to understand motives, meanings, reasons, and subjective experiences (Hudson & Ozanne, 1988; Neuman, 2000). Through interpretive theory and based on their interview responses, the mothers’ experiences of having a child with a disability and the children’s disabilities needs were interpreted based on an understanding of the impact of families' social interactions, personal beliefs, and institutional practices on their lives. In this study, social reality had been explained through the subjective viewpoints of the mothers about their experiences with their children during the early childhood years. In addition, their

experiences about support services and resources for their children and the effects of their children's disability on their lives were explained.

Research Design

A qualitative interview study was used to investigate the experiences of Saudi Arabian mothers of young children with disabilities. Qualitative research is proper when attempting to deeply understand human beings and when studying social phenomena. Additionally, the qualitative approach is suitable for investigating subjects related to individual differences, and for knowing the subjects and their social status and several issues that cannot be measured through statistical measures (Creswell, 2013).

Hence, the qualitative approach was chosen for this study because it allows for an understanding of the experiences and opinions of these Saudi Arabian mothers through an interpretive lens. The use of qualitative research allowed for learning about the mothers' experiences in different aspects of their lives, how these mothers lived with their children since birth, and how their relationships shaped their life. In other words, the qualitative interviews examined and tested the experiences of the Saudi mothers of young children with disabilities and their perspectives on raising children with disabilities in Saudi Arabia. Also, the qualitative approach provided insights into the understanding of the topic which in return allowed for discovery of details about the topic. Thus, this method is suitable and ideal for this type of study.

In this study, a qualitative interview approach, utilizing in-depth interviews, was used in order to investigate and explore Saudi Arabia mothers' perspectives on their children's disabilities. This method was chosen as "the interview reports can contribute substantial new knowledge to a field" (Brinkman & Kvale, 2015, p. 19). As a result, the conducted interviews allowed for the collection of detailed information about the mothers' experiences that I needed to

answer the study's research questions. In addition, these in-depth interviews helped in understanding the mothers' beliefs, attitudes, and feelings.

As stated above, the interviews of this study allowed for an exploration of the mothers' perceptions of their child's diagnosis and the services provided to them since the birth of their children. The interview questions were designed to closely explore the participant's perspectives and thoughts on their experiences with disability and disability services in Saudi Arabia. Three interviews were conducted with each participant and each interview session lasted about 30 minutes. Three interviews were conducted with each participating mother in order to gather a dense description of their experiences and build an authentic report, which in return increase the validity of the research. There was a one-week period between the interview sessions.

Through in-depth interviews, comprehensive information was obtained on the subject. For participants, interviews are considered as a chance to share information and their experiences in their own words (Lichtman, 2013). There are many benefits for doing interviews with participants such as: (a) participants can express their opinions about the subject in great detail; (b) the researcher can fully understand the subject; (c) participants are allowed to speak for themselves, and through that, the researcher can improve the validity of the data (Wolgemuth, Erdil-Moody, Opsal, Cross, Kaanta, Dickmann, & Colomer, 2015).

Individual interviews with each mother were used to obtain detailed information on the subject. This is tied to the purpose of this study of knowing the participants' different stories about the child's disability and the types of services provided since birth. In addition, individual interviews were chosen as they were suitable for discussing sensitive topics or private matters. For instance, some Saudi families consider disability as a sensitive subject. What's more, participating mothers would feel more willing to share or talk about some private aspects of their

experiences of living with disability individually and privately; hence, the researcher opted for individual interviews rather than group interviews.

Sampling and Recruitment Procedure

In qualitative research, sampling depends on choosing participants whose responses can help develop a deeper understanding of the phenomena and provide information that serves the phenomenon being studied (Gall, & Borg, 2007). Participants who fit the focus of my study and who could provide valuable and rich information related to my inquiry were selected. Objective sampling was used because it can "help in understanding the research problem and the central phenomenon of the study" (Creswell, 2013, p. 156).

There are different types of strategies for purposeful sampling, and each type of strategy serves a specific purpose. The convenience sampling strategy is one of the purest and most straightforward sampling strategies. It is a non-probability sampling method. Convenience sampling relies on data collection from community members who are available to participate in the study. It is considered one of most common of sampling strategies used by researchers. Researchers utilize this strategy in situations where participants have points of similarity with the focus of the study (Etikan, Musa, & Alkassim, 2016). In this study, a convenience sample strategy was used. This type of strategy was useful for my study type because it allowed me to easily contact potential individual candidates and to reach a group of people who met the target demographic for the study.

In this study, the researcher contacted the Children with Disabilities Association in Jazan city and spoke with the principal of the association about my interest in the study. Recruitment flyers were printed and distributed around their association to help me recruit mothers who would like to participate in the study. Recruitment flyers were emailed to the association's

principal and she asked her staff to share the flyers with the mothers via email or on their social media platforms. The email and the recruitment flyers explained (a) the purpose of the study, study criteria, my contact information, (b) study procedures, (c) the potential (possible) risks and benefits of participating in a study, and (d) privacy and confidentiality of the data. Additionally, the contact and inquiry number (i.e., the study's IRB number) were shared so that interested mothers could contact me and get more detailed information if they so desire. Five of the original participants withdrew from the study before data collection and had to be replaced. Two of the participants withdrew from the study because they had coronavirus. The other three participants had some misunderstandings about how interviews would be conducted and about the use of the audio recorder. Upon their withdraw, these mothers were replaced by other mothers with the help of the principal. The principal reached out to the rest of the mothers via WhatsApp and directed the interested mothers to reach out to me. The principal explained to mothers the purpose of the study in detail. New mothers reached out and began their participation in this study.

Sample size. In qualitative research, the sample size is usually relatively smaller than in quantitative research (Gall, Gall, & Borg, 2007). According to Vasileiou, Barnett, Thorpe, and Young (2018), there are many factors that affect determining the number of participants in the qualitative study such as the study scope, study design, study topic, data quality, and the number of interviews per participant.

As described in Chapter Two, the social stigma of having a child with a disability in Saudi communities may be a discouraging factor for some Saudi Arabia mothers. This factor could affect their ability to participate, to allow their children to be evaluated for special education and related services, or to share their true experiences of having children with disabilities. Thus, recruiting participants is expected to be hard as it embodies recruiting from a

stigmatized group. In this study, five Saudi mothers of young children with disabilities were recruited.

Participants

Five Saudi mothers of young children with disabilities were selected from one city in Saudi Arabia. All participants are mothers from a Muslim religious background. All participants meet the inclusion criteria of this study and all data in this study were collected through in-depth semi-structured interviews. The inclusion criteria for selecting participants were as follows:

- Mothers from Saudi Arabia
- Mothers living in Jazan city, Saudi Arabia.
- Mothers who have at least one child with disability
- A mother of a child with a disability who is under 10 years old.

Respecting the participants’ rights to confidentiality and protecting their privacy was crucial for the success of this research. Therefore, pseudonyms for the participants and their children were used instead of using their real names. Moreover, information that was mentioned in this study was not linked the participants’ identities, the names of therapists, therapy places, or the names of schools and hospitals. Information related to the participant's identity has been deleted. In the table below, the important characteristics of the five mothers who participated in this study are summarized, which is then followed by a description paragraph of each mother and her child.

Table 1. Participants Characteristics

Characteristics		Number of participants
Participants age	30-35	1
	36-40	3
	41-45	1
Marital Status	Single	0

	Married	5
Educational Level	No School	1
	Elementary Certification	1
	College Degree	3
Employment Status	Employed	2
	Unemployed	3

Amal. Amal is a mother of Amar, a 7-year-old son.

Nora. Nora is the mother of Sara, a 6-year-old daughter.

Tala. Tala is the mother of Salma, a 6-year-old daughter.

Suha. Suha is the mother of Reem, an 8-year-old daughter.

Fatima. Fatima is the mother of Bader, a 5-year-old son.

Summary of Participants

All five participating mothers are from Saudi Arabia. They are all Muslims, and married. All mothers have at least one child with disability. Children were diagnosed with one of following disabilities: autism, tightness in the upper and lower extremities, quadriplegia, retinal atrophy, atrophy in the legs and hands and imbalance issues, and Hydrocephalus. The mothers' ages range from 30 to 45 years old. Most mothers had education that ranged from elementary to graduate degrees. One of them did not receive an education at all. Two of these mothers were employed, and the other three were unemployed. These mothers shared their individual experiences with their children and their lives with disabilities, diagnosis of different disabilities, the provided services to them, their understanding of their children's disability, their needs, and the special education process.

Data Collection

The data collection process is one of the most important steps in research. In this study, interviewing was the only and the main source of data collection. One-on-one semi-structured interviews were used to collect participant responses which provided useful data for my inquiry. The one-on-one interview is one of the most commonly used types of interviews in qualitative research. This type of interview consists of a meeting between the interviewer(s) and the interviewees. This type of interviews gave the interviewees a chance to share their thoughts and experiences (Marshall & Rossman, 2011).

During an interview, the interviewer extracts information from the interviewee by asking questions and follow-up questions to co-create knowledge (Merriam, 1998). The interviewer prepares a list of questions or topics that the participant needs to respond/reflect on (Brinkman & Kvale, 2015). Three interviews were conducted with each participant to create a genuine report that includes dense and rich information, which in return increased the credibility of the research. Interview questions were used to "encourage people to talk about their experiences, perceptions, and understanding rather than giving a standard answer, company line answer or textbook type" (Rubin, & Rubin, 2011, p. 135).

Semi structured interviews are a common form of interviewing in qualitative research (Brinkman & Kvale, 2015). In more detail, semi-structured interviews mainly involve preparing a list of questions or topics to be covered. The interviewer usually stays open to the change in the direction of the interview discussion, form, and/or the order of the interview questions based on the participants' responses (Brinkman & Kvale, 2015; Rubin & Rubin, 2011). Semi structured interviews also involve asking follow-up questions based on the participants' answers to obtain further insights (Gall et al., 2007).

As for the interview plan, the researcher followed the eight interview procedure steps presented by Brinkman and Kvale (2015). In their interview procedure, they emphasized the researcher's knowledge in the interview topic. Second, they emphasized the interviewer's ability to explain the interview purpose and length. Third, they highlighted that the interviewer should choose interview questions that are short and easy to understand by participants. Fourth, they highlighted that the interviewer should listen intently while allowing the interviewees to respond and elaborate on each question. Fifth, they emphasized the need for the interviewer to be vigilant to any emotional connotations behind any of the interviewees' responses. The interviewer should also determine the reason behind any emotional connotations by asking follow-up questions. Sixth, they highlighted the need for the interviewer's ability to manage and maintain the interview flow in order to obtain specific information, such a need arises especially in cases where participants go off topic; in such a case, the interviewer has to remind the participant of the study purpose and topic. Seventh, to see if the participants respond to the questions in the same way, the interviewer should ask further questions. Eight, they pointed out that the interviewer should ask the participants to explain their responses if they happen to provide responses that are unclear or require further explanation. Lastly, Brinkman and Kvale (2015) emphasized that the interviewer should decipher the meaning of participants' responses and ask the participants what they actually meant when there is a need for further clarification.

The confidentiality of participants is important in this study, which means that there was no disclosure of the identity or any information about the participants in the presentation of the study findings. Additionally, participants were informed that they could withdraw from the study at any time for any circumstance. Furthermore, the researcher's relationship with the participants has been maintained, and materials and resources were compiled for those who need assistance.

As for the interview questions, the researcher used open-ended interviews questions in this study. As the researcher begin the interview, the researcher first went over the informed consent and the researcher then moved to specific warm up questions. These questions aimed to build rapport with the interviewees to allow them to feel relaxed and comfortable while being interviewed. Participants were given a general idea about the research interest and the rationale for choosing the topic. Following that, some general questions related to mothers' backgrounds were asked by using questions such as “Tell me about you”; the researcher then gradually moved to the main topic of the interview “discovery and diagnosis of disability and education in childhood” by asking more topic-specific questions. For the second interview, participants were asked interview questions that focused on the mothers' perceptions and interpretations of special education services, the needs of Saudi Arabian mothers of children with disabilities, etc. During the third interview, follow-up and clarifications questions were crafted based on the participants' responses in the previous interviews. Verbiage such as explain the 'extent' or 'description' were used in order to further clarify the information previously provided. The interview questions were prepared in two languages: Arabic and English. However, all interviews were conducted in Arabic, and then transcribed and translated in English by the researcher. Each participant was interviewed three times. Interviews took place in a private room in the Children with Disabilities Association location in Saudi Arabia. The room was private and quiet and was the perfect place to conduct the interviews.

In the first interview, the researcher brought holiday candy because the interview was after the holidays (Eid al-Fitr). The researcher began the interview session by spending a few minutes establishing rapport with the interviewee. The researcher accomplished that by engaging the interviewee in an open conversation to allow both of them to get to know each other. By

establishing a rapport between interviewer and interviewee, the quality of the interaction and the credibility of the research is enhanced because “people will talk more willingly about personal or sensitive issues once they know you” (Glesne, 2011, p. 144). Next, the researcher showed the interviewee the informed consent form, which had been previously described in the recruitment email. The researcher started by reading the consent form to walk the interviewee through each section to ensure full comprehension. The researcher also asked if the interviewee had any questions, concerns, or if she needed more time before signing the consent form. Noteworthy, all five participants were interested in participating, and all of them had agreed to sign the informed consent immediately. Each mother signed two copies of the form, as one copy was for the mother to keep and one was for used for research records.

Before beginning the actual first round of interviews, the researcher asked each mother some demographic questions, which allowed the researcher to gather background information about the mother’s family status, socioeconomic status, and education level (see Appendix E). These demographic background questions were asked in a conversational style, not in an interview approach. Then, the researcher reminded the interviewee of the interview recording and showed her the recorder that the researcher will be using to record the interviews. When the researcher confirmed with each mother that she was comfortable being recorded, the researcher started the actual interview. The researcher started with pre-created open-ended questions to be able to add or reform them during the interview (see Appendix C). This question format allowed the researcher to have flexibility to ask any follow up question based on conversation flow, and to incorporate new insights on the topic or to respond to the stories told by the interviewee (Brinkman & Kvale, 2015). Using open-ended semi-structured interview questions is a flexible and a responsive method that allowed the researcher to note individual differences and allowed

the researcher to create some personalized follow-up questions to deepen communication and interaction with the interviewee (Patton, 2015).

After completing each interview, the researcher immediately listened to the recordings and transcribed the interview. To confirm the accuracy of the transcription, the researcher listened to the recordings twice while reading the transcription. Afterwards, the researcher changed any and all identifiable information to pseudonyms to protect the interviewees identity and privacy. As part of the validity criteria and to ensure credibility, the researcher emailed each mother her interview's transcripts after the researcher finished transcribing all interviews. The researcher asked each mother to feel free to add or share more information, and/or omit any information that she may decide to take out of the interview transcript. All the mothers confirmed the accuracy of the transcriptions and all of them did not omit any information.

In addition, during the interviews, two of the mothers asked about local parent support groups and wished for help in finding the contact information of such support groups. Therefore, when the researcher emailed each mother her interview transcripts, the researcher provided each mother with the information she asked for. After completing all the interviews, transcriptions, and confirming the accuracy of the transcriptions with each mother, the researcher began the process of organizing and managing the data, followed by starting the data analysis.

Data Management

With the participants' permission, all interviews were audio-recorded and then transcribed and analyzed. Data and files from interviews were organized (audio recording, consent forms, interview transcript files) and stored separately. All files were kept in a secure place so that access was restricted to members of the study only. Also, all data and files were saved on the

researcher's personal laptop in encrypted and protected files by a password so that access is restricted to the researcher only.

Data Analysis

After all the data in this study were collected through in-depth semi-structured interview questions, and after transcribing all the interviews data, the data were analyzed thematically. Thematic analysis was used because it is a method that fits the data collected in this study. All fifteen interviews were recorded via a mobile device after obtaining the participants' permission. These recordings were saved and secured by a password in a designated folder on the researcher's laptop. Then, the interviews were transcribed in a Microsoft Word document after each interview. In this study, pseudonyms were used instead of the participants' and school's actual names.

In order to analyze data, reviewed literature suggests starting the data interpretation right after the interview process ends (Erlandson, Harris, Skipper, & Allen, 1993; Brinkman & Kvale, 2015). As mentioned earlier, the Brinkman and Kvale (2015) eight interview procedure steps were followed in this study. In order to follow them, the researcher paid close attention to the meanings delivered by the interviewees. The interviewees were asked to reflect on their previous statements and thus confirming or disconfirming them during their review of the emailed interview transcriptions. To validate the interview statements, the researcher asked the participants to certify/agree to their previously submitted data. The researcher used the interpretation of the participants' statements and asked them to further explain their original thoughts (Brinkman & Kvale, 2015). Employing this mental process had engaged the researcher early in identifying any patterns or themes in the participants' statements.

Thematic analysis was used because it allows the participants' meanings and experiences to emerge (Braun & Clark, 2006). The coding process is based on using inductive approach to identify the emerging themes (Krahtwohl, 1998). Strauss and Corbin (1990) defined inductive analysis as codes that emerge from raw data. Strauss and Corbin (1990) have also stated that inductive codes have been used in qualitative research for a long time. Nonetheless, Thomas (2003) shared that the purpose of inductive codes is to allow the researcher to reveal the meanings of data by categorizing the data into themes.

In order to conduct the thematic analysis for the study, the suggestions of Brown and Clarks (2006) were followed. In the beginning, the researcher transcribed all the interviews. According to Ives (1995), the interviewer is the ideal person to transcribe interviews. After transcribing all the interviews, the researcher has familiarized herself with the interview data by reading the data transcription multiple times. While reading, the researcher took notes of main ideas emerging from the raw data (Braun & Clarks, 2006). The researcher read the data transcripts several times and took notes in an attempt to begin looking for the emerging themes related to the study. The researcher has transcribed all interviews verbatim without omitting any words.

In the second phase, the researcher started to identify initial codes. The coding process involved "aggregation of the text or visual data into small categories of information, seeking evidence for the code from" the data, and then labeling the codes (Creswell, 2013, p. 184). The researcher used Vivo Coding. Miles, Huberman, and Saldana (2014) indicate "Vivo codes" can help qualitative researchers to begin coding, and it gives honor to the participant's voice.

In the third phase, the researcher coded individual excerpts of data into several different themes. In addition, the researcher identified several processing techniques include themes that

were common between participants, repetitions, similarities, and differences. At the end of this phase, the researcher identified themes, sub-themes, and all data excerpts that coded in relation to them. In the fourth phase, the researcher had a clearer idea about the theme. The researcher reviewed and refined themes. This involved creating new themes, combining two themes, division of themes into more than one theme.

In the fifth phase, the researcher determined clear names for each theme and wrote about the core of the story, and the aspects of the data. Furthermore, the researcher determined the salient themes and its related to each other and how they related to the research question. In the final phase, the researcher wrote the final analysis and report after getting the final and satisfactory set of themes. The researcher then provided a detailed analysis for each theme, supported by excerpts from the data.

Validity Criteria

All researchers seek to show their research in an ethical manner in order to ensure research validity (Merriam, 1998). Maxwell (2013) described validity as “the correctness or credibility of a description, conclusion, explanation, interpretation, or other sorts of account” (p. 122). In this study, criteria for research included validity, reliability, portability, and confirmability; all of which were established to ensure the accuracy of this research (Lincoln & Guba, 1985).

Credibility refers to the extent of confidence in findings of a study, and that the data “accurately represented what the participants think, feel, and do and the process that influences their thoughts, feelings, and actions” (Lodico, Spaulding, & Voegtler, 2010, p.169). Credibility refers to the researcher’s confidence in the truth of the research findings. Through it, the researcher knows if the findings of the research are true and accurate or not. The credibility helps

in confirming that the results of the research are believable. Credibility requires the researcher to connect the research finding with reality, which confirms the truth of the research's findings. Credibility in qualitative research is done via several techniques such as triangulation, member checking, researcher reflexivity, member checks, and collaborative work (Miles, Huberman, & Saldaña, 2014; Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005; Lincoln & Guba, 1985).

In the study, rich descriptions are provided to make the tacit knowledge explicit through the thick descriptions of the interview process. By using the in-depth approach, many aspects, such as who was going to speak and what they were going to talk about, was monitored. The interview conversations were controlled, so the interviewees would stay on topic.

In qualitative research, member checking assists with credibility. Park and Lee (2010) stated that member checking enhances the validity of the research findings. Member checking is achieved by having each participant review and revise the transcript of each interview if necessary. The member checking process also allows the participants to correct any mistakes. So, after each individual interview, the recording was transcribed and sent directly via e-mail to the mothers for revision. All participants confirmed the accuracy of transcriptions without any changes.

Furthermore, a peer debriefing method was used to ensure the credibility of the study. In this study, two PhD students who demonstrate knowledge in the field reviewed the study and the qualitative research approach to ensure consistency in emerging topics and subtopics. Their comments were considered as these comments would enhance credibility and ensure the validity of the study. In addition, one of them was knowledgeable about speaking Arabic and English language fluently. She made sure that all excerpts were translated correctly.

As for the researcher's reflexivity, the researcher has self-disclosed her biases, assumptions, and values that influenced the research process. The researcher has kept a researcher reflective journal throughout conducting this study. This journal includes the researcher's expectations, beliefs, and experiences.

The purpose of qualitative research is to develop a deep understanding of the phenomena being studied rather than to generalize the study findings to different contexts. In fact, transferability is one of the common validity criteria in qualitative research (Lincoln & Guba, 1985). In this study, the researcher provided a thorough and detailed description of this study to grant readers and other researchers to understand, evaluate, and compare the phenomena at hand with the phenomena they are investigating in their research. To ensure transferability, the researcher have provided a thorough and detailed description of field experience, of the study's phenomenon, and of the study's implications by reporting appropriate quotes.

Ethical Considerations

Ethical consideration in the research is important to promote the value of the research. There are many ethical considerations involved in conducting the research including the researcher's relations with participants, collection of data, use and interpretation of research data, ways to write reports or record information, and review of the research plans or results (Merriam, 1998).

Before conducting the study, the researcher read the IRB guide of her university and its requirements. The researcher sought university approval by submitting a research proposal for an IRB approval. After obtaining the IRB approval, the researcher started conducting the study. At the beginning of the study, the researcher obtained an informed consent form from each participant to preserve the rights of both parties. Participation in this study was voluntary. The

informed consent form included sufficient information about the research process to ensure the participants' full understanding of the topic and what they were going to be involved in. This included providing information on the purpose of the study, how the data would be used, the procedures used to ensure the participants' privacy and protect their anonymity, and that participation was voluntary which meant that they had the right to withdraw from the study at any time (Locke et al., 2014).

CHAPTER FOUR:

FINDINGS

The purposes of this study were to: 1) Explore Saudi Arabian mothers' experiences of having a child with disabilities, to explore the impact of disability on the family; 2) Identify challenges encountered by children with disabilities and their families in accessing special education services in Saudi Arabia; and 3) Determine the needs and concerns of children with disabilities and their families to provide information for special education and related service providers to increase their knowledge of the necessary skills for working with these families and their children. Therefore, the study was guided by three research questions:

Q1: How do Saudi Arabian mothers of young children with disabilities describe their experiences with their children during the early childhood years?

Q2: What are the experiences of Saudi Arabian mothers of young children with disabilities with regard to support services and resources for their children and their families?

Q3: How do Saudi Arabian mothers of young children with disabilities make meaning of the effects of their child's disability on their lives?

The researcher contacted the Children with Disabilities Association at Jazan city by sending them an email explaining the purpose of the study, the study criteria, and the consent form in both Arabic and English. Five mothers of children with disabilities agreed to participate in this study. All of these mothers have at least one child who receives services through the

Children with Disability Association. Through in-depth semi-structured interviews, these mothers were able to share their individual experiences with their children with disabilities during the early childhood years.

The first mother is Amal and she is a teacher. She has a child who is 7 years old. The second mother is Nora and she holds a bachelor's degree. She has a child who is 6 years old. The third mother is Tala and she has an elementary level education. She has a child who is 6-year old. The fourth mother is Suha and she never received an education. She has a child who is 8 years old. The fifth mother is Fatima and she holds a bachelor's degree. She has a child who is 5 years old.

The findings of this qualitative interview study are discussed after the analysis of the interview data. The initial data and its analysis were conducted in Arabic before they were translated to English. The researcher made sure that meanings of the mother's responses were not changed when translating. The researcher translated the quotes and asked a native Arabic speaker graduate student from USF who is fluent in both Arabic and English to ensure the translation was accurate. In this study, the original Arabic quotes and the English translations are included to support the core of each theme. These themes were based on common responses that mothers gave in response to the interview questions and in connection to the research questions.

After finalizing the coding process and after finishing the peer-revisions of the identified themes, five major themes, some with sub-themes, emerged from the data. These themes and their connected sub-themes are outlined and discussed in this chapter. These themes are also supported by quotes from the interview transcripts in both Arabic and English.

Research Question 1: How do Saudi Arabian mothers of young children with disabilities describe their experiences with their children during the early childhood years?

The aim of the question was to learn of the experiences of mothers of children with disabilities with their children during the early childhood years. The differences in experiences allowed for a deeper understanding of the mothers' situations and their personal and social relationships, along with a deeper understanding of the difficulties that these mothers faced during the early years of their children's lives.

Theme #1: Discovery and Diagnosis

An essential part of this study was to explore the experiences of the mothers of children with disabilities and learn when and how they discovered their children's disabilities. In addition, an understanding of how the five Saudi mothers of children with disabilities understand their children's diagnosis of disabilities, and how their understanding affected their reactions in asking for help from their doctors was sought. All five mothers of children with disabilities expressed that they discovered that their child had a disability without intervention from doctors. However, some said they noticed their children's disabilities in the early months after birth while the doctors did not agree with them and only noticed the disability after six months. However, some mothers insisted on getting early discovery and diagnosis of their children outside Jazan city. In the following section, I arranged the discussion of the mothers' experiences into the sub-themes discovery of disability and diagnosis of disability.

Discovery of Disability. The mothers shared their love for childbearing and how much having children strengthens the relationship between the two parents (spouses). The mothers mentioned that one of the greatest afflictions was seeing one of their children sick or in pain, suffering from any physical or psychological distress, or feeling that the child may have a

disability. The mothers mentioned that discovering children's disabilities brought grief to the family; some of them shared that the discovery can become easier on the family especially if there is an early discovery of the child's disability, preferably since the child's birth. All mothers described their experiences at the beginning of their children's life using phrases like: "I wish knew when I was pregnant," "I wish I had discovered the disability in the first months," or "I didn't know." Some mothers were certainly aware of changes and differences in their child's development. Some mothers did not know about disability and they did not know that their child had a disability.

One of the mothers was unaware of autism, and she never heard that there is a type of disability called autism.

أمل: "في السنة الثانية من عمر طفلي اكتشفت أن عنده تأخر في الكلام، لم ألاحظ عليه أي اعاقه أو سلوك غير طبيعي. عندما تأخر عن الكلام بدأت أشعر أن طفلي عنده مشكلة. بعد ذلك سافرت به إلى مدينة داخل السعودية وهي جدة لأن عندهم عيادات أفضل من العيادات اللي موجودة في منطقة جازان لكي أعرف سبب تأخره عن النطق. لما كشف عليه الدكتور قال لي الدكتور فقط أن عنده تأخر لغوي وفي السنوات القادمة سوف يتحسن في اللغة. لما صار عمره ٤ سنوات بدأ ينطق بعض الكلمات البسيطة. وبدأت ألاحظ أن فهمه بطيء واستيعابه بطيء جدا. أيضا لاحظت أنه يسوي حركات لا ارادية وغير طبيعية. تقريبا في عمر ٤ سنوات لاحظت ان طفلي غير طبيعي وأني لا بد أذهب به إلى عيادة متخصصة لكشف الأطفال".

Amal: "In the second year of my child's life, I discovered that he had a speech delay. I did not notice any disability or abnormal behavior in him. When he experienced delays in his speaking abilities, I began to feel that my child had a problem. After that, I traveled with him to a city inside Saudi Arabia, which is Jeddah, because they have clinics that are better than the clinics in the Jazan region to know the reason for his speech delay. When the doctor examined him,

the doctor only told me that he has a language delay and in the coming years he will improve in language. When he was 4 years old, he started uttering some simple words. I began to notice that his understanding was slow and his comprehension was very slow. I also noticed that he makes involuntary and abnormal movements. At about the age of 4 years, I noticed that my child is abnormal and that I must take him to a clinic that is specialized in examining children”.

The lack of mothers’ knowledge about disability contributed to late discovery and diagnosis of disability. Mothers described feelings of guilt and self-blame about misunderstanding their children's behaviors before the diagnosis.

نورة "أنا ولدت طبيعي وكنت أشعر أنها طبيعية لا تعاني من مشاكل في أول سنة من حياة طفلي. بعد سنة من ولادتها بدأت أشعر أن لديها مشكله جسدية. وقت الحبي ما كانت تحبي مثل الأطفال وأيضا في الجلوس ما كانت تجلس مثل الأطفال العاديين يعني كل ما جلست تطيح على أحد جنبها. بعد سنة من عمرها وديتها المستشفى وكشفوا عليها وقالو ان لديها مشكله بالأطراف مثل الشد وتحتاج إلى علاج طبيعي“

Noura: "I gave birth naturally, and I felt that she was normal and she did not suffer from problems in the first year of her life. A year after her birth, I began to feel that she had a physical problem. At the age of crawling, she did not crawl like other children and also in sitting, she did not sit like ordinary children, which means every time she sat, she falls down on one of her sides. After a year of her age, I took her to the hospital, and they examined her and said that she had a problem with her limbs, such as stretching and straining, and that she needed physical therapy”.

تالا " بعد الولادة جلست بنتي في الحضانة أربعة أيام بس أدخل عليها أرضعها وأطلع فما لاحظت شيء عليها ولا حتى الدكاترة قالوا فيها شيء. بعد أربعة أيام طلعت من الحضانة وأول شيء لاحظته إنني وقت أحملها من عند رأسها تطيح يديها وما صارت تبكي كثير وإذا بكت كان ما تحرك جسمها مثل باقي الرضع. لما رجعتها للمستشفى وقلت لهم إنني ملاحظه عليها إنها ما تحرك أطرافها وشافوها الأطباء وقالو ما نقدر نحكم عليها وهي باقي أقل من شهر، قلت لهم بس أنا ملاحظه ان فيها شيء. قالو الأطباء خلاص تعالي بعد أربع شهور نشوفها. بعد أربع أشهر رجعتها المستشفى ولما شافوها الأطباء سولها تحاليل وفحوصات وأرسلوا بها خارج جازان ولما جات النتائج قالو ان البنيت عندها مشكله نقص اكسجين وما اعطوني أي علاج ولا أي شيء حتى كبرت وصار عندها شلل رباعي".

Tala, " After giving birth, my daughter stayed in the hospital nursery for four days. I used to visit her to breastfeed her and leave, and I did not notice anything wrong with her; the doctors did not even say anything about her. After four days, she came out of the nursery and the first thing I noticed was that when I carried her and placed my hand behind her head, her hands fell off freely. She did not cry a lot, and if she cried, she did not move her body like the rest of the infants. When I took her back to the hospital and told them that I noticed that she did not move her limbs, the doctors saw her and said, "We cannot judge her while she is less than a month old" I told them, but I noticed that there was something wrong with her. The doctors to come back after four months for us to see her. Four months later, I took her back to the hospital, and when the doctors saw her, they asked for tests and her tests were sent outside of Jizan, and when the results came, they said that the girl had a problem with lack of oxygen and they did not give me any treatment or anything until she grew up and had quadriplegia."

سهى " من الولادة بنتي البالغة الان عمر ١٠ سنوات كان عندها اهتزاز في بؤبؤ العين. وشعرت ان فيها شيء. طبعا كل ما تكبر بنتي كل ما يزيد الاهتزاز وبصير واضح شكل الاهتزاز بس كانت تشوف. لما صار عمرها خمسة سنوات صارت تطيح وتقوم وحركاتها ضعيفة على الرغم أنها من الولادة حتى خمس سنوات كانت تمشي طبيعي وحركاتها طبيعية. أنا أتوقع أن بعد ٥ سنوات حسيت انها فقدت البصر معد صارت تشوف. بعد ذلك ذهبت بها المستشفى قالو عندها ضمور في الشبكيات. بعد ذلك شعرت أن قدراتها العقلية بدأت تضعف وتقل وحركاتها صار لازم أحد حولها يساعدها لان حركاتها تنقل يوم بعد يوم".

Suha: "Since birth, my daughter, who is now 10 years old, had a tremor in the pupil of the eye. I felt that there was something wrong with it. Of course, the older my daughter grew, the more the vibration became clear, but she was still able to see. When she was five years old, she began to fall down and stand up more often, and her movements were weak. Although from birth until five years old, she was walking normally, and her movements were normal. I expect that after 5 years she lost her sight and started not to see. After that, she was taken to the hospital, they said she had retinal atrophy. After that, I felt that her mental abilities and movements began to weaken and decrease, and having someone help her became necessary because her movements have become heavier day after day".

فاطمة " من حملي في التاسع سويت سونار وقالو لي الدكاترة أن الطفل راسه كبير ولازم عملية. بعد الولادة شفت الطفل رأسه كبير جدا وغير طبيعي. فكلمت الدكاترة يأخذون الطفل ويوضعونه بالحضانة فرفضوا يستقبلون الطفل لأن المستشفى كان غير مهياً لاستقبال مثل هذه الحالات وليس لديهم علم بمثل هذه الحالات. بعد الولادة أخبرني الدكتور أن الطفل سوف يكون معي أو أذهب به أي مستشفى ليتم الكشف عليه ويتلقى العلاج. اليوم التالي طلعتنا من المستشفى وسافرت فيه لمدينة الرياض بأحد المستشفيات وتم استقبال الطفل

بالحضانه وجلست شهر تقريبا و عملوا له عملية بالرأس بعدها رأسه رجع لوضعه الطبيعي. حاليا طفلي يتلقى كل العلاج بنفس المستشفى بمدينة الرياض إلا التعليم في منطقة جازان".

Fatima: "In the 9th month of my pregnancy, I had an ultrasound and the doctors told me that the baby had a big head and needed an operation. After the birth I saw the baby and he had a very large and abnormal head. I talked to the doctors and asked them to take the baby and put him in the nursery, but they refused to receive the baby because the hospital was not prepared to receive such cases and they had no knowledge of such cases. After the birth, the doctor told me that the child would be with me or go to any hospital to be examined and receive treatment. The next day we got out of the hospital and I traveled to the city of Riyadh in one of the hospitals and the child was received in the nursery and stayed there for about a month and they performed a head operation for him after which his head returned to its normal size. Currently, my child receives all treatment in the same hospital in Riyadh, except for education in the Jazan region."

Diagnosis of Disability. Disability diagnosis whether educational or medical is the first step in treatment and rehabilitation. In addition, it is the first step in appropriately dealing with the disability or difficulty that the child suffers from. Diagnosis of any disability is an important event in a child's life. Through it, mothers know the child's needs, based on which they seek to initiate intervention services and support. Each of the five Saudi mothers of children with disabilities underwent a unique experience with the diagnosis of their child. Some mothers were completely unaware of disability and the importance of the diagnosis. They believed that the discovery of the disability by doctors is enough.

One mother described herself when she got information about her child's diagnosis. She said that “the ambiguity surrounding autism made her seek the right diagnosis in different clinics in Saudi Arabia.”

أمل " بعدما قالو لي الدكتور ان ابني عنده توحد كنت مره قلقان لأنني ما كنت أعرف ماذا يعني توحد فلما كلمت صديقاتي قالو لي أذهب به إلى المستشفى ليتم تشخيص حالته رسميا وأتطمأن على وضعه، تشخيص الإعاقة ليس سهلا. ذهبت به داخل وخارج المنطقة حتى أتعرف على حالته بالضبط".

Amal, "After the doctor told me that my son has autism, I was worried because I did not know what autism meant. When I spoke to my friends, they told me to take him to the hospital to be officially diagnosed and to check on his condition, the diagnosis of disability is not easy. I took him to hospitals within and outside my region to learn of his exact condition."

One mother did not know the importance of diagnosis of disability in early years of child's life.

نورة " بالبداية تم تشخيص حالته من الدكاترة بطريقة غير رسمية بس قال لي الدكتور أن نموه العقلي طبيعي ولكن يحتاج إلى علاج طبيعي مكثف وسوف يكون عنده تأخر في النمو. اعتمدت على كلام الدكتور. بعد 6 سنوات لما بدأ سن المدرسة قالو لازم تشخيص رسمي ما كنت أعرف أن فيه شيء اسمه تشخيص".

Noura, "In the beginning, he was diagnosed by the doctors in an informal way, but the doctor told me that his mental development is normal, but he needs intensive physiotherapy and he will have a delay in growth. I relied on the words of the doctor. After 6 years, when he reached school age, they said that an official diagnosis was needed. I was not aware that there is such a thing as an official diagnosis."

Some mothers credited the Association for Handicapped children with giving them useful information about their children's needs.

تالا " في الحقيقة ما كنت أعرف أنه هناك مركز يسوي تشخيص لذوي الاحتياجات الخاصة. لما دخل ولدي جمعية الأطفال المعوقين هم اللي قالوا لي انهم عملوا لها تشخيص وقدراتها العقلية أقل من الطبيعي."
Tala, "Actually, I did not know that there was a center that diagnoses individuals with special needs. When my son enrolled in the Association for Handicapped Children, they were the ones who told me that they had conducted a diagnosis for her and that her mental abilities were less than normal."

سهى " أنا كأُم اعتبر قدراتهم العقلية متوسطة. في عمر المدرسة طلبوا مني تشخيص رسمي ووجهوني لمستشفى معين. لما تم تشخيصهم قالوا إن قدراتها العقلية ضعيفة."
Suha "As a mother, I consider their mental abilities as average. At school age, they asked me for an official diagnosis and directed me to a specific hospital. When they were diagnosed, they said that her mental abilities are weak."

فاطمة " نعم سويت له تشخيص رسمي لحالته في بداية عمره وكل فترة أسافر فيه لمدينة الرياض يشوفون حالته والتطورات في المراحل العمرية."
Fatima, "Yes, I had his condition officially diagnosed at the beginning of his life, and every once in a while, I travel to the city of Riyadh for the doctors to see his condition and his age developments."

Theme #2: Education Enrollment Challenges

Part of this study aimed to identify the difficulties faced by the Saudi mothers when their child started their education before school and started school later. Mothers were asked several

questions related to the difficulties they faced regarding their children with disabilities in early childhood (4 to 6 years) and when their children started school after 6 years old. The mothers' responses focused on their experiences with kindergarten age schooling in the Jazan city, and they shared that schools are not adapting for kindergarten children with special needs. Some mothers of children with disabilities expressed a desire to obtain more information about their child's education from 4 to 6 years old. Two sub-themes emerged from this main theme: difficulties in early childhood education and difficulties in education when starting school.

Early childhood education. All five Saudi mothers expressed the importance of this stage of a child's life for acquiring life skills. According to the mothers, the child's awareness of independence grows, the child develops many skills, and the child asks a lot of questions as he/she wants to explore the world around him/her. Some mothers expressed that schools did not accept the condition of their children due to the lack of special education teachers in these school. Some mothers claimed that their children needed a lot of time and attention from the teachers compared to other children, so the enrollment of a child with disability into regular schools is a source of concern for ordinary teachers.

The mothers felt that there is a lack of teachers who can deal with students with disabilities in regular classes with ordinary students. Unfortunately, the mothers have received complaints from the school's teachers towards their children with disabilities, which had made these mothers pull their children out of school.

أمل" دخل ولدي روضة حكومية بس ما استمر، يعني تقريبا ثلاث شهور فقط وما كان كل يوم يروح الدوام. كان الأيام اللي يداوم فيها الروضة كان بيكي ما بيعي يجلس في المدرسة وأحسه كان عنده خوف مره من المجتمع. تواصلت مع المعلمات اللي الروضة يصبرون عليه بس قالولي أنه إذا جاء يشتت أذهان باقي الأطفال فما خابته يكمل في الروضة.

Amal, "my son was enrolled in a public kindergarten, but he did not continue; he was mainly enrolled for about three months, and he did not go every day. The days when he attended kindergarten, he cried, and he did not want to stay in the school, and I felt that he had a fear of the community (crowds). I contacted the teachers and asked them to be more patient with him. They told me that when he comes to school, he distracts the rest of the children, so I decided not to let him continue with the kindergarten."

One mother stated that she was dedicated towards her daughter's education and all of its needs and challenges. So, she reached out to the school and shared her willingness to participate in her daughter's educational needs and willingness to buy all tool/items necessary to make her daughter's education experience as convenient and smooth as possible.

نورة "أنا معلمة في مجمع يحتوي على روضه وابتدائي فكلمت مديرة الروضة أنني بسجل بنتي لأن ما عندي أحد يمسكها بالبيت وشرحت لها حالة ابنتي وأني مستعدة أتحمّل كل احتياجاتها بالمدرسة فوافقت المديرية".
Noura, "I am a teacher in a school complex that contains a kindergarten and an elementary school. I spoke to the kindergarten director and told her that I want to enroll my daughter because I had no one to watch her at home. I explained to her my daughter's condition and that I was ready to meet all her needs in the school, and the principal agreed".

The most important obstacle that prevents children with disabilities from getting access to educational opportunities at all levels is the distance between the schools that offer education for children with disabilities and their homes.

تالا "كل الروضات اللي حولي رفضت تقبلها لأنها على عريية ويديها ورجلها ما تحركها. فاضطرت أشوف الروضات الحكومية ثانية بالمحافظة اللي جنبنا تقريبا تبعد ٥٤ دقيقة. فروضة وحده فقط قبلتها بشرط أكون وياها طول اليوم. طبعاً وافقت عشان تتعلم وتحتك بالأطفال الأخرين."

Tala, "All the kindergarten schools around me refused to accept her because she is on a stroller and because she can't move her hands and feet. So, I had to explore the government kindergartens in nearby region, approximately 45 minutes away. Only one kindergarten accepted her under the condition that I stay with her all day. Of course, I agreed because I wanted her to learn and have contact with other children."

سهى "ما دخلت ابنتي أي روضة ولا تلقى أي شكل من أشكال التعليم قبل سن المدرسة. كل الروضات اللي بنفس المحافظة رفضت لأن عندها مشكله بالعين وبالحرركات."

Suha "My daughter did not attend any kindergarten and did not receive any form of education before school age. All the kindergartens in our region refused her enrollment because she had a problem with her eye and movement."

فاطمة "كنت أبحث كثير وهم باقي صغير عن مدارس تقبل ذوي الاحتياجات الخاصة عشان ولدي يتعلم مثل باقي الأطفال ولما صار عمره ثلاث سنوات وديته جمعية الأطفال المعاقين وبدأ عندهم حتى الآن."

Fatima, " while they were still young, I looked a lot for schools that would accept individuals with special needs as I wanted my son to learn like the other children, and when he was three years old, he was sponsored by the Association of Handicapped Children and started with them until now."

Elementary education. Education is one of the rights of children with special needs.

Mothers seek to educate their children in schools with other children. The mothers expressed that there are many difficulties in educating their children in regular schools such as the lack of preparedness of schools for children with special needs, the school's lack of special education teachers, along with difficulties communicating with teachers.

Teachers are one of the most important people that help build the future of children with disabilities. Also, they have a great role in influencing children with disabilities positively or negatively. So, communication between mothers-teacher throughout the school year is key to the children's success in school. One of the mothers expressed the difficulties of communicating with her child's teachers was due to gender differences.

أمل " اه وجهتني صعوبات كثير وإلى الان مستمرة في هذا الصعوبات . بالبداية كنت مسجلته في مدرستين وحده مركز خاص بالتوحد يداوم ثلاث أيام والثانية مدرسة عادية يداوم يومين. بعد سنة قالولي المدرسة أختار يكون في المدرسة أو يكون في مركز التوحد . فاخترت المدرسة لأنه ولد والمركز فقط لسن ١٠ سنوات ويطلع منه لأن نساء فقط. ولدي عنده فرط حركة وحركات كثير لا إرادية وصعوبة في الفهم والاستيعاب □ والمدرسة العادية تعاونت معي وقبلته عندهم ولكن ما عندهم معلمين لذوي الاحتياجات الخاصة. أيضا من ضمن الصعوبات أن ولدي في مدرسة أولاد وأواجه صعوبة التواصل مع المعلمين حتى أعرف وضعه في المدرسة أو أسأل عن شيء في دراسته إذا □ أو شيء."

Amal, "Uh, I faced many difficulties and until now I continue to face these difficulties. At first, I enrolled him in two schools, an autism center where he goes three days a week, and the second school was a regular school where he goes two days a week. After a year, the school told me to choose whether to keep my son in a regular school or in an autism center. So, I chose the school because he was a boy, and the center only allows boys to be enrolled to the age of 10 years old and

that is when he has leave the school because it is a female campus. My son suffers from hyperactivity, many involuntary movements, difficulties in comprehension and assimilation. The regular school cooperated with me and accepted his enrollment, but they do not have teachers for individuals with special needs. Also, one of the difficulties is that my son is in a male school and I face difficulties communicating with teachers to know of his status in school or to ask about something in his studies, especially he was absent or something."

Some mothers expressed that environmental conditions (school building layout) and school preparedness for children with disabilities to receive education were the two most common difficulties faced by mothers of children with disabilities in schools.

نورة " أكثر صعوبة واجهتني وقت بدأت ابنتي الابتدائي هو أن الفصول حق الابتدائي الدور الثاني والروضة كانت الدور الأول ولا يوجد الأسانسير في المدرسة. فصررت أعطي عاملة من المدرسة تحمل بنتي لدور العلوي وأيضاً تحملها عند النزول. أيضاً بالمدرسة اضطررت أوفر لها مقعد وكروسي خاص فيها ومناسب لحالتها لكي تتعلم في الفصل مع العاديين. أيضاً خلال التعليم تحتاج أحد يساعدها في الكتابة عشان الشد اللي معها."

Noura, "The most difficult thing I faced when my daughter started primary school is that the elementary classes are held on the second floor, and the kindergarten classes were held on the first floor, and there is no elevator in the school. So, I paid one of the school staff to carry my daughter up and down from the second floor. I have also bought my daughter a special chair and desk to accommodate her condition and to allow her to learn in class with the ordinary children. Also, during her education, she needs someone to help her in writing because of the tension that she has with her arms."

Across all interviews, the mothers expressed that finding a suitable education for children with disabilities is one of the most common problems that face the children and their families. There is a lack of specialized centers for educating children with disabilities. There are difficulties in getting to the schools that have teachers who are trained and qualified to deal with children with disabilities.

تالا " عانيت كثير عشان تدخل المدرسة العادية. كل المدراس العادية رفضت أنها تدرس عندهم لأنها جالسة في عريية والمدارس غير مهية لمثل حالتها. ولا يوجد في نفس المحافظة مدارس فكرية عشان أسجل بنتي فيها. اضطررت أسجلها في محافظة ثانية مدرسة أهليه ووافقوا أنها تدرس عندهم. بنتي درست بس سنة وحدة الصف الأول وكان صعب بعد المسافة فخليتها توقف تتعلم. بعد ذلك حولتها لجمعية الأطفال المعاقين والاختصاصيات اللي بالمركز هم سجلوها بمدرسة عادية في نفس المحافظة اللي ساكنة فيها وعندهم دمج ومتوفر عندهم معلمات ذوي الاحتياجات الخاصة. تواصل المركز مع المدرسة وتعاونوا معي الاختصاصيات راحوا شافوا المدرسة أنها مناسبة لبنتي أم لا. وطلبوا من المدرسة أنهم يجعلون فصلها بالدور الأول. أيضا قمت بتفصيل طاولة دراسية تناسب بنتي."

Tala, "I struggled a lot to enroll her on the regular schools. All the regular schools refused to her to study with them because she sits in a stroller and the schools are not prepared for her needs. There are no intellectual schools in the same region to enroll my daughter in. I had to register her in another region, in a private school, and they agreed that she can study there. My daughter studied for only one year, the first grade; and the distance between our home and the school was difficult, so I had her stop going to school. After that I transferred her to the Association of Disabled Children and the specialists in the center registered her in a regular school in the same region in which we live as they have integrated education and have available special needs teachers. The center communicated

with the school and the specialists cooperated with me and they went and checked if the school was suitable for my daughter or not. They asked the school to mover my daughter's classes to the first floor. I have also custom made a school desk to suit my daughter."

سهى " أعاني كثير في التعليم. كثير مدراس رفضوا يستقبلون بنتي لأنها كفيفة وقدراتها العقلية ضعيفة فتحتاج تعليم خاص. أضرت أوديتها مدارس خاصة بالإعاقاة الفكرية تبعد ساعة عن بيتي. فكان هناك صعوبة في التوصيل للمدرسة. أيضا صعوبة وقت يدخلون المدرسة لأنها فاقدة البصر فتحتاج مرافقات مخصصات في المدرسة تنتبه لها لازم أكون انا مرافقة لها. بعد سنة كلمت المديرية وكلمت لي عاملة من القرية تكون مرافقة لبنتي في المدرسة كل يومها وهي تعطيهها مبلغ مالي وأنا أيضا أزيدها مبلغ مالي لكي تنتبه لبنتي وتقوم باحتياجاتها في المدرسة. أيضا من ضمن الصعوبات هو تأخيرها عن الدوام أو جلوسها الطويل في المدرسة لأن الأ□ هو الشخص الذي يوديهها الدوام ويأخذها من الدوام ومرتبطة مع دوام بمسافه يعيده عن المدرسة وغالبا المعلمات يشنكون من التأخير."

Suha, "I struggled a lot with education. Many schools refused to accept my daughter because she is blind and her mental abilities are weak, so she needs special education. I had to enroll her into schools of intellectual disabilities, which was an hour away from my house. It was difficult to get to the school. There were also difficulties when she enters the school as she was blind and she needed specialists to accompany her around the school and that I must accompany her. A year later, I spoke to the principal and she spoke to a female worker from the village who would accompany my daughter to school every day, and she would give her money and I would also add some money to increase her pay so that she would pay attention to my daughter and meet her needs at school.

Also, some of the other difficulties entailed my daughter's tardiness to school or having to sit long hours at school because the father is the person who takes her back and forth to school while he has to go to his work at a distance far from school, and the teachers have often complained about him being late when picking her up after school."

فاطمة " ما واجهتني صعوبة لحد الان. هو يتلقى تعليم بالمركز وأحس أنه في تحسن ملحوظ."

Fatima, "I have not encountered any difficulties so far. He is receiving an education at the center and I feel that he is improving significantly."

Research Question 2: What are the experiences of Saudi Arabian mothers of young children with disabilities with regard to support services and resources for their children and their families?

The aim of the second question was to explore Saudi mothers' experiences with regard to support services and resources for their children and their families. The mothers' responses indicated a desire to obtain more information about services to assist their children with improving their abilities and skills. Some mothers expressed their lack of knowledge about services that were provided by Jazan city for children with special needs and their families. Some mothers also expressed a desire to receive early support and services for their children.

Theme #1: Un-met Needs

An important part of the study was aimed at finding out the needs of Saudi mothers of children with disabilities to better provide them with services for themselves and their children.

Two sub-themes emerged: the need for more information and the need for improvement in services for people with special needs.

The need for more information. All mothers expressed the need for more information about disability. In addition, they expressed the need for more information about services that Jazan provided for children with disabilities since birth.

One of the mothers shared the importance of getting more information about centers that provide services for children with disabilities.

أمل " بعد ما كشفت وشخصت حالة طفلي كنت معتمدة كثير على كلام الأطباء والفيديوهات. أول شيء جاء في بالي كيف سوف يتعلم ابني. لما جاء سن المدرسة كان أبحث عن مراكز تقبل الاطفال ذوي التوحد. كنت أحاول أسأل صديقاتي والناس اللي حولي عندهم أطفال نفس حالة ولدي. أسألهم عن المراكز اللي تخدم الاطفال ذوي التوحد."

Amal, "After I discovered and diagnosed my child's condition, I relied a lot on doctors' words and videos. The first thing that came to my mind was how will my son learn. When he reached school age, I looked for centers that accept children with autism. I tried to ask my friends and people around me who have children with the same condition as mine. I asked them about centers that serve children with autism."

Doctors are the ones who are able to diagnose diseases and human conditions from the beginning of their occurrence. Some mothers shared the importance of getting information from doctors about their children's status. Most of these mothers relied on the doctor's (obstetrician and pediatricians) diagnosis and knowledge of the child's special needs before they sought more specialized help and diagnosis from developmental doctors (pediatricians with experience in

children with disabilities). Some of these mothers have also relied on reading (online or in books) about their children's disabilities.

نورة " في الحقيقة أنا في أول سنوات عمرها توجهت إلى المستشفيات وسألتهم عن حالة ابنتي وكنت أراجع باستمرار المستشفيات وأسأل الدكاترة عن حالتها. أعتد على كلامهم كثير. أيضا أخذ المعلومات من قوقل بس بعض الأحيان لست متأكدة الكلام ينطبق على وضع طفلي أو لا."

Noura, "In fact, in the first years of her life, I went to hospitals and asked them about my daughter's condition. I was constantly visiting hospitals and asking doctors about her condition. I rely on their words a lot. I also took information from Google, but sometimes I am not sure if the information apply to my child's condition or not."

تالا " ما عندي معلومات كافية حول إعاقة بنتي وأغلب المعلومات أنا أسأل عنها الأخصائيات والأطباء وأيضا أسأل الأمهات اللي عندهم أطفال مثل حالة طفلي."

Tala, "I do not have enough information about my daughter's disability. I ask about the specialists and doctors about most of the information, and I also I ask mothers who have children with a condition like my child's."

سهى " ما أعرف ولا أي شيء عن حالة بنتي وكل مستشفى يقول فيها شيء أو سببها شيء وأنا أسمعهم. وفي البحث نت ما أعرف أقرأ ولا أكتب فما أستعين فيه أبدا."

Suha "I don't know anything about my daughter's condition and every hospital says something about her case and its causes, and I hear them. In the internet search, I don't know how to read or write, so I never use it."

فاطمة "أتوقع ما عندي معلومات كافية عن حالة ولدي. غالبا المعلومات أخذها من النت والأطباء."

Fatima, "I feel that I don't have enough information about my son's condition. I get most of the information from the internet and the doctors."

The need for improvement in services. All mothers in this study expressed their satisfaction with the financial services that the government provides monthly to their children with disabilities. In addition, they have shared their thoughts about their experiences with services provided by the Children with Disability Association such as (physical therapy, occupational therapy, and special education). Generally, the mothers who used these services from the Children with Disability Association had positive experiences and were satisfied with their children's improvement. Nonetheless, some of the mothers expressed a need for further services such as speech therapists. Some of the mothers desired more specialized services fitting for their children and more time spent in services to ensure the effectiveness of the services. Also, they expressed their need for more centers in all the country's regions that provides services to children with disability.

For instance, all five mothers expressed a need for professionals who have expertise about disabilities in schools and their education and deal with them.

أمل "يحصل ولدي على معونة شهرية. الحكومة تكفلت بدفع الرسوم الدراسية لمركز التوحد اللي يخدم إلى عمر ١٠ سنوات. أيضا أحد المستشفيات بالمنطقة قدمت جلسات التخاطب على شكل أسبوعيا. الشي الذي نفتقره هو وجود مدارس خاصة للأطفال التوحد في سن المدرسة بنفس المنطقة ويكون هناك مدرسين خاصين لتدريس للأطفال التوحد وعندهم مهارات التعامل مع الأطفال بشكل مبسط."

Amal, "my son gets a monthly financial aid. The government has paid for the tuition fees for the autism center that serves children to the age of 10 years old. Also, one of the hospitals in the area provided conversational sessions on a

weekly basis. What we lack is the presence of special schools for autistic children of school age in the same area. We lack the presence of special needs teachers to teach children with autism, teachers who have the skills to deal with children in a simple way. "

Some of the mothers shared that schools were not prepared to receive children with disabilities.

نورة " حصلت على كل الخدمات اللي بنتي تحتاجها مثل جبائر للأطراف وتتغير كل سنة. أيضا علاج طبيعي متوفر كثير على الرغم أن فيه أجهزة تناسب بنتي غير موجودة في أي مركز من المراكز اللي موجودة. الشيء اللي أفتقده في المدرسة ما في خدمات مناسبة لطفلي مثل ابسط شيء دورات المياه غير مهياة لبنتي، لدرج في صعودها وطلوعها غير مهياة لبنتي. أيضا المدارس ليس كلها موجود فيها معلمات ذوي احتياجات خاصة. المدرسة اللي فيها ما فيها معلمات ذوي احتياجات خاصة وكمان ما فيها فصول خاصة يروحون فيها الطلاب □ يأخذون تقويه في المهارات!"

Noura, "I got all the services that my daughter needs, such as casts for her limbs and they change every year. There is also a lot of physical therapy available, although there are devices that suit my daughter that are not found in any of the centers that exist. The thing I miss at school is that there are no suitable services for my child such as the simplest services: the toilets are not equipped for my daughter, and the stairs are not suitable for my daughter to go up and down. Also, not all schools have female teachers with special needs experience. The school she is in now does not have female teachers with special needs experience, and also, there are no special classes in which the students can go to improve their skills."

Providing necessary services for children with disabilities is the community's responsibility. The mothers expressed that services are lacking for their children with disabilities from birth. The mothers believe that the lack of early diagnosis and access to services will negatively affect their children's future lives.

تالا " بنتي حصلت على خدمات مالية وأيضاً بطاقة الأولوية لها بأي مكان. لكن بنتي كان لازم تحصل على الخدمات من أول شهر في الولادة ولكن للأسف الدكاترة ليس فاهمين حالتها وما في خدمات في المستشفى مهياً لبنتي. بنتي تحتاج إلى علاج طبيعي مكثف وما حصلت عليه إلا في المركز أو بعض العيادات اللي أروح لها. تحتاج بنتي كل يوم تقريبا العلاج الطبيعي ومتابعها وهذا متعب علينا فبعض الأحيان أقول أتمنى في خدمات منزليه للعلاج الطبيعي."

Tala, "My daughter received financial services and also a priority card for her anywhere she goes. But my daughter needed to receive services from the first month after birth, but unfortunately, the doctors did not understand her condition and there are no services in the hospital that are suitable for my daughter. My daughter needs intensive physiotherapy and I only found it for her at the center or some of the clinics I go to. My daughter needs daily physiotherapy and follow-up, and this is tiring for us, and sometimes I say I wish for home services for physiotherapy."

سهى " أنا ما أبحث وري الخدمات ولا أعرف كل وقتي مع أطفالي وما عندي أحد يوديني كل مكان. زوجي مشغول في دوامه وأنا في البيت مع عيالي. الخدمات فقط اللي من جمعية الأطفال المعاقين. بالجمعية في خدمات العلاج الطبيعي ولكن ما تناسب بنتي. بنتي تحتاج أجهزة عشان تقدر تحرك رجليها وملفي بالمركز هذه الأجهزة. أيضاً أحتاج إلى كرسي متحرك لبنتي ولا أعرف كيف أحصل عليه."

Suha "I do not search for services and I do not know of them because all my time is spent with my children, and I have no one to take me everywhere. My husband

is with his work and I am at home with my children. The services received are only those from the Association for Handicapped Children. The Association has physiotherapy services, but it is not what suits my daughter. My daughter needs devices so that she can move her leg , and my daughter's file is at the center where these devices are. I also need a wheelchair for my daughter, and I don't know how to get it."

Based on her experiences, one mother shared that services for children with disabilities beginning at birth are better provided outside Jazan city. She believes that pediatricians in Jazan city are not well informed about children's' disabilities and early intervention for disabilities.

فاطمة "ولدي حصل على كل الخدمات خارج مدينة جازان. بعدما شفت أن الخدمات الطبية لولدي غير متوفرة في المستشفى اللي ولدت فيه سافرت على طول لرياض وتلقى ولدي كل الخدمات في مستشفى بالرياض. الأجهزة اللي يحتاجها ولدي والكرسي المتحرك وفروها لنا المستشفى في الرياض. ولدي يحصل على كل الخدمات الطبية بالرياض وجازان بس في جمعية الأطفال المعاقين يتلقى ولدي خدمات العلاج الطبيعي والتعليمي."

Fatima, "My son got all the services outside the of Jazan city. After I realized that the medical services for my son were not available in the hospital where he was born, I traveled all the way to Riyadh and my son received all the services in a hospital in Riyadh. The equipment that my son needs and the wheelchair was provided to us from the hospital in Riyadh. My son receives all of his medical services in Riyadh. My son receives physical and educational services in Jazan in the Association of Handicapped Children."

Research Question 3: How do Saudi Arabian mothers of young children with disabilities make meaning of the effects of their child’s disability on their lives?

The third research question addressed the effects of disability on the children and their families’ lives. In this regard, the mothers expressed that religious beliefs and cultural norms were major factors helping them accept their children's disabilities. In addition, they expressed the positive and negative effects of children's disabilities on their lives through their experiences with their children. The most positive effect was that disability helped them to change their overall perspective on life. On the contrary, the most negative effect was that disability made some of the mothers experience a state of fear, depression, anxiety, isolation from people, and constant thinking about their children’s futures.

Theme #1: Culture and Religion

Religious beliefs and culture play a major role in the Saudi mothers’ understanding and acceptance of their children's disabilities. The mothers expressed that all things that happen in their life, whether good or bad, were tests from the God. Some mothers expressed that the disabilities of their children reflected their faith and eventually their place in the life hereafter.

أمل " أنا أو من بأن كل ما يصيب الإنسان خير حتى لو ما نعرفه . إعاقة طفلي أقول لعلها خير لي وأتمنى

أنه يشفى ويصبح طفل طبيعي تماما ."

Amal "I believe that everything that happens to a person is good, even if we do not know it. I say to myself that my child's disability may be good for me, and I hope that he recovers and becomes a completely normal child."

All five mothers believe in God's decree and destiny. The mothers stated that they have turned to prayers and supplication to deal with the challenges and difficulties in meeting their children's needs.

نورة " أنا مؤمنة بقضاء الله وقدره. وأقول كما قال الله " عسى أن تكرهوا شيئا وهو خير لكم".
فيمكن أن إعاقة بنتي خيره لها ولكل العائلة. متأكدة تماما أن ربي أعطانا بنت معاقة عارف أننا نقدر
لرعايتها."

Noura "I believe in God's decree and destiny. I say as God said, "Perhaps you hate something, and it is good for you." It is possible that my daughter's disability is a good thing for her and all her family. I am absolutely sure that God has given us a handicapped girl because he knows that we can take care of her."

تالا " الا عاقه هي اختبار من الله لعبده المؤمن. فنقول الحمد لله على ما حصل لنا. وهذا شيء
حصل لا نستطيع الاعتراض عليه."

Tala "Disability is a test from God to his faithful servant. We praise God for what happened to us. This is something we cannot object to."

فاطمة " أقول الحمد لله على كل شيء. يمكن هذا لي اختبار من الله أن أصبر أم لا.

Fatima, "I say, praise God for everything. May be this a test for me from God, to see if I can have patience."

Evil eye cause. One of the mothers expressed that her child's disability was caused by an evil eye (i.e., Arabs believe in the harms and misfortune of an envious eye of an envious person). The mother explained that her child just had visual problems and she was moving everywhere

and suddenly her child cannot move. She thinks that all that happened to her child is because of the evil eye.

سهى "تقريباً حول الأربع سنوات من عمرها صارت كثير تطيح وتقوم وحركاتها صارت قليلة، حسيت أنه أصابها عين أو حسد. ذهبت بها إلى وحده من النساء لتعطيها الأعشاب التي تذهب العين ولكن لم تحصل بنتي على أي فائدة. حالياً أقول الله يرزقني الصبر على تربيتها والحمد لله على كل حال."
Suha "When she was four years of age, she began to fall a lot and get up, and her movements became decreased. I felt that she was affected by an eye or envy. I took her to women to give her herbs that helps in making the evil effects go away, but my daughter did not get any benefit. Currently, I say God granted me patience to raise her, thank God for all situations."

Theme #2: Isolation and Psychological Impact.

Impact of disability on the child's life. Every child with a disability is affected according to his or her disability. Some mothers expressed that the type and extent of the child's disability has great role on the child's acceptance of herself/himself. Some mothers expressed that the family and the community perception of the child's disability also affects the child's self-acceptance. In other words, the presence of a feeling of acceptance from the family and society plays a major role in building the child's self-confidence and helping him/her view disability positively and adapt to it.

أمل " الإعاقة ما اثرت على نموه الجسدي ولكن لها تأثير كبير على نموه العقلي. أيضاً، أثرت الإعاقة سلبياً على نفسيته وخصوصاً إذا كان مع أطفال الآخرين. بعض الأحيان يجي بيكي يقول أصحابه ضربه وهو ما يقدر يدافع عن نفسه. بعض الأحيان يقول أصحابي يضحكون علياً أو ليه ما أعرف استخدم الجهاز هذا. أنا أحاول بقدر المستطاع أشجعه وأكون إياه بس أنت عارفة في المدرسة ما أكون وإياه وما أعرف ماذا يصيروا إياه هناك."

Amal "Disability did not affect his physical development, but it has a significant impact on his mental development. Also, the disability negatively affected his psyche, especially if he was with other children. Sometimes he would cry and say his friends beat him, and he could not defend himself. Sometimes he says "my friends laugh at me" or say "why I don't know how to use this device." I try as much as possible to encourage him and be with him, but as you know, I cannot be with him at school and I don't know what happens there".

نورة " أثرت الإعاقة عليها كثير في المشي وفي حركتها. أيضا أثرت الإعاقة على نفسيتها غالبا تبكي تبغي تمشي تلعب مثل اخوانها او أي طفل يلعب ويمشي ويجري تبغي تصير مثله. أحاول أواسيها وإنها راح تمشي بس لازم تأخذ العلاج الطبيعي دائما. بعض الأحيان أحس نفسيتها هي اللي تجعل الشد يزيد عليها."

Noura "The disability affected her a lot in walking and her movement. The disability also affected her psyche. She often cries, she wants to walk and play like her brothers, or any child that plays and walks and runs, she wants to be like that child. I try to console her and tell her that she will walk, but she must always take physical therapy. Sometimes I feel her psychology is what makes her muscle tension increase."

تالا " أثرت الاعاقة على أطرافها وحركاتها وكلامها وصحتها. صارت تمرض بسرعه والمرض يؤثر عليها أكثر. بعد سنتين من عمرها دائما تبكي. كانت دائما تحاول تطلع من العربية مثل الأطفال العاديين تبغي تمشي على رجلها وهذا الشيء يتعب نفسيتي أكثر."

Tala "The disability affected her limbs, her movements, her speech and her health. She gets sick quickly and therefore the disease affects her more. After two

years of her age, she always cried. She always tried to get out of the stroller like normal children, she wanted to walk on her legs, and this affected my psyche more."

Two of the mothers expressed that their children experienced a period of regression in development which had affected the child mentally and emotionally.

سهى " اه الإعاقة أثرت على بنتي كثير وخصوصا بعدما صارت تطيح وتقوم وتثقل حركاتها حتى معد مشت. حاليا صارت ما تقدر تسوي شيء إلا أحد يساعدها. تقريبا أنها ما تعتمد على نفسها بشي. كل شيء حتى أبسط الأشياء لازم أحد مرافقها مثل تنقلهم من مكان إلى مكان وهكذا."

Suha, "Uh, the disability affected my daughter a lot, especially after she started to fall and get up and her movements became heavy until she was unable to walk. Now she can do nothing without the help of others. In almost everything, even the simplest things, she must be accompanied by someone, especially when moving from place to other place and so on."

فاطمة " أثرت الإعاقة عليه في مشيته وأيضاً كلامه غير واضح وغير مفهوم. أيضاً عنده ضمور في المخ أثر على قدراته العقلية."

Fatima, "the disability affected him his walking and his speech was unclear and incomprehensible. He also has brain atrophy that affected his mental abilities."

Impact of disability on family life. Disability has a significant impact on the family and the child. In fact, mothers are the most affected by their children's disabilities. Mothers often get frustrated if a child with special needs is born to them. The family may feel disappointed as this may place additional burdens and responsibilities on them. Some feel despair about what to do with their child. Some mothers expressed that disability did make their families feel additional

burdens and responsibilities. In some cases, some of the fathers accused the mothers of being the cause of the problem. Moreover, some mothers mentioned that the birth of a disabled child in the family resulted in many emotional, behavioral, economic, and social problems that affected the course of the family's life.

أمل " بالبداية ما توقعت أني سوف أنجب طفل من ذوي الاحتياجات الخاصة. بعدما ولدت فيه وبدأت ألاحظ انه غير طبيعي صار أقضي كل وقتي معاه. في الحقيقة أنا خفت بعده أنجب طفلا آخر عشان لا يصير مثل حالته. بعدما ولدت فيه تغيرت حياة عائلتي وصارت أكثر قلق. نذهب به كل مكان نسمع أنهم شاطرين في التوحد عشان يتعالج وبصير طفل طبيعي. أفكر كثير بمستقبله وحياته إذا كبر كيف بيكون. أشعر أني أصبحت أم متشائمة وكثير الشكوى."

Amal "At first, I didn't expect that I would have a child with special needs. After I gave him birth and I started noticing that he was not normal, I spend all my time with him. In fact, I was afraid to have another child so that he/she wouldn't be like his brother's condition. After he was born, my family's life changed and there is more anxiety now. We go with him everywhere we hear that they are good at treating children with autism in order for him to be treated and become a normal child. I think a lot about his future and his life when he grows up, and how he will be. I feel that I have become a pessimistic mother that complains a lot."

Some mothers noted that the disabilities of their children made them reduce social interactions and contact with other people.

نورة " أنا وكل الأسرة تأثرنا كثير. في البداية كان الوضع جدا صعب. كنت أقضي يومي معاه ولا أطلع من البيت. وكثير تحصل بيني وبين زوجي مشاكل بس بعد مرور السنوات تكيفنا وتقبلنا حالتها. أيضا كان من الأسرة مثل أهلي أو أهل زوجي كثير ينظرون لنا نظرات الشفقة ودائما يسألون لماذا ما تمشي وما هو

مشكاتها ومين السبب وبالطبع هذا كان مزعج لنا. وإلى حد اليوم كثير من الالهل يتدخلون في حياة بنتي مثل
دايما يقولون ودوها مستشفيات او مراكز لكي تحصل على علاج."

Noura, "the whole family and I were affected a lot. In the beginning, the situation was very difficult. I used to spend my days with her and did not go out of the house. Many problems occurred between me and my husband, but after the years passed, we adapted and accepted her condition. Also, many of the family members, like my family or my husband's family, look at us with glances of pity and they always ask why she does not walk, what is her problem, and who is the reason behind it, and of course this was annoying to us. To this day, many of our family members interfere in my daughter's life; for example, they always say things like take her to hospitals or centers in order to get treatment."

تالا " بكيت كثير وقت شفقتها واعتبرها حرقه في القلب. مررت أنا والاسرة بحالة نفسية واكتنا □ بعد ولادتها. في البداية أثرت كثير وكان متعب علينا التنقل من مكان لمكان أو السفر وخصوصا لأن عندي أطفال كثير يحتاجون إلى اهتمام أيضا. الحين تكيفنا على الوضع وبعدما كبروا أخواتها صاروا يساعدوني فيها. فهمت خواتها أنه هي لها احتياجات خاصة ليست مثل العاديين نحتاج نراعي حالتها النفسية والجسدية!"

Tala, "I cried a lot when I saw her and considered it heartburn. The family and I went through a rough psychological state and depression after her birth. At first, it affected us a lot and it was tiring for us to move from place to place or travel, especially because I have many children who need attention as well. Then we adapted to the situation and after her sisters grew up, they started helping me with her. I explained to her sisters that she has special needs that are not like

ordinary people and that we need to take into account her psychological and physical condition.”

Two of the mothers felt that the disability of their children has caused a lot of psychological troubles for the family, and the mother/child specifically.

سهى " اعاقه بنتي أثرت عليا وعلى الأسرة كثير. أصابني مثل الخوف والقلق النفسي حول تدهور حالتها حول عمر ٤ سنوات. توجهت عند نساء يعالجون في منازلهم وكانوا يسون لهم مثل المساج. تعبت. الصحية نفسيتي والى الآن بسبب اعاقتها واعتمادها عليا كليا حتى في أبسط الأشياء. ما أقدر أطلع ولا أي مكان لأنها تتعب نفسيا. الطفل المعاق له احتياجات خاصة تؤثر في حياة الأسرة اجتماعيا مثل المشاكل العائلية أكثرها تفكر في حالته، واقتصاديا يحتاج الطفل دخل خاص له زيادة على الدخل من الدولة حتى نتطمأن على مستقبله، وعاطفيا نظرات الشفقة وتدخلات من الناس في أكثر الأوقات تزيدنا كابه."

Suha "My daughter's disability affected me and the family a lot. I was afraid and worried about the deterioration of her health around the age of 4 years old. I went to women who treated patients in their home and they used to give them massages. I can't go out anywhere because she gets psychologically upset. A disabled child has special needs that affects the family socially as we always think of the child's situation. Financially, the disabled child needs extra funds on top the government financial aid so that we can feel at ease about the child's future. What makes us more depressed is the pity glances from others”.

فاطمة " أثرت اعاقه ابني في حياة الأسرة. بكيت كثير على وضعه وخصوصا هو أول طفل لي. كلام الدكاترة اللي ولدوني كان يجرح. يعني بعد الولادة ما حصلت على كلام يواسيني أنا أو زوجي كل كلام كان

يزيد فينا القهر على حالة طفلنا. أما الآن بعدما قرينا حول الإعاقة وتثقفنا شعرنا أن المشكلة تقلصت وزاد الوعي عندنا. حالياً أشعر أن الإعاقة زادت الترابط الداخلي لدى أفراد الأسرة وعززت التماسك الأسري".

Fatima, "My son's disability affected the family's life. I cried a lot about his condition, especially as he was my first child. The words of the doctors who gave birth to me hurt. I mean, after the birth, I didn't get any words to comfort me or my husband rather their words made us feel bad about our child's situation. Now that we have read a lot and got educated, we feel like the issue is smaller. Now I feel that the disability has brought the family together and created a strong bond".

Summary

The purpose of this study was to explore Saudi Arabian mothers' experiences of having a child with disabilities, and to explore the impact of disability on the family. Five mothers of children with disabilities were interviewed in this study. A qualitative interview approach was used to explore Saudi Arabian mothers' experiences of identifying challenges encountered by children with disabilities and their families in accessing special education services in Saudi Arabia. After analyzing the data obtained from the interviews, five major themes emerged: (1) Discovery and Diagnosis (2) Education Enrollment Challenges, (3) Un-met Needs, (4) Culture and Religion (5) Isolation and Psychological Impact.

In this chapter, the findings of these qualitative interviews' and the findings on the exploration of the experiences of Saudi Arabian mothers of children with disabilities were detailed. In the next chapter, these findings will be reviewed in relation to the current study research questions, will be situated within the current relevant literature, and will be discussed in relation to the conceptual framework explained earlier in Chapter Two. Additionally, the

researcher reflexivity, implications of the findings for the field of special education, and recommendations for future research are discussed in the next chapter.

CHAPTER FIVE:

DISCUSSION

In this chapter, the findings of this study are reviewed in relation to the research questions, situated within the current relevant literature, and discussed in relation to the conceptual framework that was discussed in Chapter Two. In addition, the researcher reflexivity, implications of the findings for the field of special education, and recommendations for future research are also provided.

Study Findings in Relation to the Research Questions

This qualitative interview study explored the experiences of Saudi Arabian mothers of children with disabilities. The intent of this study was to understand Saudi Arabian mothers' experiences of having a child with disabilities, and to explore the impact of disability on the family. As detailed in Chapter Four, five major themes regarding the experiences of Saudi Arabian mothers of children with disability emerged from the data analysis: (1) Discovery and Diagnosis (2) Education Enrollment Challenges, (3) Un-met Needs, (4) Culture and Religion (5) Isolation and Psychological Impact.

In this section, findings are presented in relation to the study's three research questions. The intent of this section is to connect the findings to the research questions in order to showcase how the research questions were satisfactorily addressed. Further, later in this chapter, detailed discussions of these findings are presented.

RQ1: How do Saudi Arabian mothers of young children with disabilities describe their experiences with their children during the early childhood years?

The first research question, in all of its parts, aimed to explore the experiences of mothers of children with disabilities with their children during the early childhood years. It focused on how their understanding of their children's disability affects their desire to search for early

services for their children. Moreover, the mothers specifically discussed that early childhood services play a great role in influencing the course of their child's disability through the discovery and diagnosis of their disability at an early age. In addition, the mothers faced some difficulties when their children started early childhood education.

During interviews, the mothers were asked to describe their initial experiences in discovery and diagnosis of their children's disabilities. The mothers' responses clearly revealed that this experience was painful, but the late discovery of disability made things more difficult as some children with disabilities may have benefited from early intervention and early discovery of disability. Early discovery of disability greatly helps in the speed of diagnosis and rehabilitation, and thus general stability for the family and the child (El Hazmi, 1997).

Moreover, the mothers' responses revealed the difficulties that Saudi mothers face when their children started early childhood education and school. The mothers discussed the importance of early childhood education for their children with disabilities in the development of the children's skills and abilities. In addition, they discussed the benefits of education for their children with disabilities in improving many behavioral and psychological problems for children with special needs.

These findings clearly revealed mothers' experiences with their children during the early childhood years in terms of discovery and diagnosis of children's disabilities, and the difficulties they faced when looking for suitable education for their children's in Jazan City. These findings were detailed and supported by quotes from the participants' interview transcripts in Chapter Four. Further discussion of these findings is presented later in this chapter.

RQ2: What are the experiences of Saudi Arabian mothers of young children with disabilities with regard to support services and resources for their children and their families?

One of the critical purposes of this study was to explore Saudi mothers' experiences with regard to support services and resources for their children and their families. The mothers were asked several questions related to the support services and resources that their children and their families received thus far. Additionally, the mothers were asked questions in order to understand their need for services that allows the mothers to better provide for themselves and their children with special needs. The mothers' responses revealed that there is a need for more information about services and a need for improvement in services provided for children with disabilities in Jazan city.

These findings addressed the second research question with regard to support services and resources for children with disabilities and their families. A detailed description of these findings, supported by quotes from the participants' interview transcripts, was provided in Chapter Four. Further discussion of these findings is discussed later in this chapter.

RQ3: How do Saudi Arabian mothers of young children with disabilities make meaning of the effects of their child's disability on their lives?

The last research question aimed to explore the effects of disability in the lives of the children and their families. In addition, this question addressed the role of culture and religion in the mothers' reactions towards their children's disabilities. The mothers shared the positive and negative effects of their children's disabilities on their lives and family life. The mothers

described how having a close-knit family helps the whole family provide assistance and care for the child with a disability.

These findings addressed the third research question by showing the effects of disability in children and family lives and the role of culture and religion. These findings were detailed and supported by quotes from the participants' interview transcripts in Chapter Four. Further discussion of these findings is presented later in this chapter.

Synthesis of Current Study Findings and Previous Research on Related Topics

As discussed in Chapter Two, research including cases of Saudi Arabian Mothers of Young Children with Disabilities is limited. Saudi Arabia is the largest country in the Middle East. It is considered one of the countries that seeks to develop its services in many fields. One of these fields is education for children with disabilities. Disability is one of the human conditions that affects people's lives and results in issues affecting the social, economic, and medical fields in the Kingdom of Saudi Arabia.

Research on Saudi Arabian individuals with disabilities is limited as well. The research that addresses disability in Saudi Arabia focuses on disability in Saudi Arabia generally. No previous research has been published on the experiences of Saudi Arabian Mothers of Young Children with Disabilities, in particular. The current study is the first of its kind in Saudi Arabia. Therefore, it is challenging to situate the current study and its findings within the existing literature. Yet, it is critical to link the study and its findings to the existing published research on disability.

This section synthesizes the current study findings that were described in Chapter Four with the existing relevant research. The discussion centered on the following two topics: 1) the challenges that the mother and family face regarding having a child with special needs, 2) the

effects of disability on children and their families' lives, and the role of culture and religion.

Discussion related to these topics helps in clarifying how the current study findings contribute to the current body of published research. This study and its findings significantly contribute to the literature on disabilities and research on the experiences of Saudi mothers of children with disabilities.

Topic 1: The challenges that the mother and family face regarding having a child with special needs

Every mother of a child with a disability will face many challenges in their life (Resch, Mireles, Benz, Grenwelge, Peterson, & Zhang, 2010). Most challenges start at the beginning of a child's life (Yantzi, Rosenberg, & McKeever, 2007). The five mothers' journeys with disability started when they felt that there is something different about their children's development. No mother wants one of their children to be disabled. It is a hard experience that changes the course of a mother's life. However, the five mothers were exposed to these experiences shared that their children's needs and disability have changed the pattern of their journey in life.

The challenges started with mothers in the discovery and diagnosis of disability. The mothers believed that early discovery and diagnosis of disability could have helped their children with disabilities or at risk for disability to achieve the maximum improvement and progress in their life. In addition, the mothers could search for ways to help their children and provide them with the appropriate information, guidance, and training in the upbringing and care of children (Trute, Benzies, Worthington, Reddon & Moore, 2010). Findings of this study indicated that the mothers reported their initial concerns when they began to observe that something was not normal in their children's development. They started the search for answers with their children's pediatrician. The pediatrician is first person who the mothers spoke to about their concerns

regarding their children's development (Rhoades, Scarpa, & Salley, 2007). Some mothers in this study turned to many pediatricians in different cities in Saudi Arabia to acquire an early diagnosis and knowledge of their children's health. Continuously, the mothers heard reassuring phrases from pediatricians about their children's development. Most often, they did not get any detailed information or satisfactory answers to their questions. According to Dillenburger, McKerr, Jordan, and Keenan (2016), there are similar studies and findings stating that pediatricians ignored the mothers' concerns and they did not provide proper assessment of children with disability.

The problem of discovery and diagnosing disabilities is one of the most common difficulties that the mothers faced. For instance, the mothers described the discovery and diagnosis of disability as not an easy process. Additionally, the mothers faced a lack of specialized centers in diagnosing disabilities, their measures, and treatments, especially ambiguous disabilities. Therefore, the mothers spent a long time and effort visiting doctors in their various specialties in order to diagnose their children. These doctors' visits were in and out of Jazan city. In addition, mothers in this study described the initial discovery and early diagnosis of a disability as important in knowing about their children's disability. Knowledge about the children's status helped the mothers deal with their child's disability, better understand how to care for them, and learn how to teach their children to become capable of adapting to life (Trute et al., 2010). Early diagnosis for children with disability led to improved outcomes (Stadnick et al., 2017).

When some mothers get enough information about their children and diagnosis of their disability, they can better provide assistance to their children. In addition, the mothers' understanding of the importance of diagnosis leads to provision of better services for their

children (Hess, Molina, & Kozleski, 2006). However, in this study, some mothers faced challenges in providing services for their children in Jazan city. They had to travel to another nearby city to receive early services for their children. Some mothers also traveled to developed cities in Saudi Arabia in order to get a proper diagnosis for their children. They reported that they had positive experiences with services, especially the medical services outside of Jazan city. They were satisfied with their children's progress and improved growth.

Mothers in this study voiced that some aspects of special education services in Jazan city are lacking. These mothers expressed a desire for improved and more specialized services for their children. These mothers specifically shared a need for physical therapy devices and speech and language therapists in Jazan city. In addition, these mothers expressed a desire for suitable services to develop their child's abilities and skills along with a desire for more time spent in the provided services to observe more effectiveness and positive change in their children's development. Consistent with findings from Amitush, Moses, and Sky (2019), and Barak and Saliha (2007), the participants in this study expressed a feeling of satisfaction with the provided services. Their satisfaction was a result of the services meeting the needs of their children with disabilities and was a result of the presence of programs and services that helped develop the abilities and skills of their children with disability since birth. This is similar to the findings from Al-Otaibi and Al-Sartawi (2009) and Al-Wabli (1996) who reported that services to meet the needs of children with disabilities, particularly children residing in rural regions or small cities are lacking. In Saudi Arabia, some services for children with disabilities have yet to develop; the need for development stems from the absence of rich specialized cadres. In addition, children with disabilities need the support of some of these services from birth and these services may help them reduce the gap between them and the ordinary peers of the same age.

Furthermore, the mothers were asked several questions related to the available services that supported them in raising their children with disabilities. The mothers explicitly described the financial support services and the aid that children receive every month by the Saudi Arabian government as having a major role in raising their children with disabilities. The mothers expressed that the monetary support services helped them in overcoming most financial challenges they faced. Financial support helped mothers to live better with the difficulties associated with raising a child with disability. In agreement with this study's findings, Al-Maghlouth, (2002) found that the family becomes more able to adapt to the challenges involved with raising a child with a disability when the family has stable financial support.

The findings of this study indicate that mothers have a negative view of education due to several factors including a lack of awareness about children with disability and strategies to address their needs, failure to prepare schools for people with special needs, and as cited in the literature (Al-Ahmadi, 2009), the fact that there are no teachers with training in special needs in all schools. Moreover, the mothers expressed their concern about the absence of key factors for successful education for children with disabilities in school. These mothers voiced that providing education for their children with disabilities at an early age is important as education plays a role in improving the children's lifestyle and developing their communication skills. Research showed that mothers of children with disabilities face challenges in their children's education. However, education of children with disabilities in integrated schools with typical children helps children with disabilities in several areas (Al-Saud, 2010). Educating children with disabilities at an early age gives the child a sense of self-confidence, makes them feel their worth in life, helps them accept their disability and realize their abilities and potential at an early age, and gives

them a feeling of belonging to the members of the community in which they live (Cambra, & Silvestre, 2003).

Topic 2: The effects of disability on the lives of children and their families and the role of culture and religion

The findings of this study suggest that mothers' reactions towards their children's disability were influenced by their religion and their culture. The religious aspect has played a significant role in the Saudi mothers' acceptance of their children's disabilities. Religion has aided these mothers in all aspects of their life, whether good or bad. The mothers shared their belief that everything that happened from God is good for them and their family. Some mothers expressed that disability is a test from the God, and that they should believe in God's decree and destiny.

Noteworthy, one mother believed that the child's disability was due to the evil eye (an envious eye from an envious person). She explained that all that happened to her child was sudden and that the evil eye was responsible for all of it. Along these lines, in the Saudi culture and many Islamic cultures, there are beliefs that have a cultural and religious basis; one of which is the power of an evil (envious) eye has on someone's life, health, wealth, success, and luck. For example, the Saudi people believe in the evil eye's ability to cause harm and misfortune. The evil eye concept refers to the idea of a person who saw something he/she liked and commented on (or complimented) without saying the phrase "Masha'a Allah" which means (may God protect you from envy). Because this person did not mention the name of God (or the phrase Masha'allah) when he/she saw something they envied, then this person has allowed (invited) harm and evil to destroy what they envy in someone else. This belief of the evil eye (envious stare/look) is both cultural and religious in nature. In agreement with this study's findings Croot, Grant, Cooper,

and Mathers (2008) found the Pakistani and Turkish cultures confirm that the evil eye is the most common cultural source of disability and misfortune (bad luck).

In this study, all of the participants discussed that disability has played a major role in affecting many areas of the child's life including the emotional, behavioral, social, psychological, and developmental aspects. The mothers explained the negative effect of disability on their lives and their children's lives. They shared that the impact of disability depends on the kind of disability, its degree, and the child's behavioral problems. In agreement with this study's findings, Nachshen and Minnes (2005) found that mothers of children with disabilities suffer more stress and anxiety as a result of the increase in their children's behavioral problems. In addition, Rashid's (1996) study pointed that the family faces problems due to the disability and suffers from high levels of psychological stress compared to families whose members do not have a disability. The family is negatively affected, and marital relations are disrupted due to having children with disabilities, and the rates of divorce increase among the parents of children with disabilities (Rashid, 1996).

Having a child with a disability may increase mothers' stress and their self-blame (Reichman, Corman, & Noonan, 2008). The mothers in this study expressed the psychological pressures and the increase of anxiety, depression, and stress when they had a child with a disability. Some of the mothers in this study felt that disability is the main reason for every problem in their family life. In a study by Dyson (1996), the psychological stress of mothers of children with disabilities and the degree of both anxiety and depression was more when compared to mothers who do not have children with disabilities. In addition, Aidarous's (2012) study revealed that the level of psychological stress for mothers of children with disabilities increased.

Some of the mothers in the study expressed that spending more time with their children caused psychological pressure, especially when the child is completely dependent on the mother. In addition, the mothers expressed that the disability of their children made them feel isolated from the community. This finding is similar to Brinchmann (1999) who found that mothers of children with disability experienced extreme stress when it came to their decisions regarding their children. They resorted to isolating themselves and their children from the community. In addition, they had different feelings toward their children. The greatest problems with their children they reported were related to sleep and rest, especially since their children are completely dependent on them. Some of these mothers felt that home is like a prison for them. In addition, a study conducted by Olsson and Hwang (2003) confirmed that many mothers of children with disability suffer from psychological, marital, social, pressures, and many psychological problems that outweigh any psychological issues experienced by other mothers of children who do not have disability.

Recommendations from the Mothers of Children with Disabilities

An important aspect of the study was the Mothers' perspectives on how to improve services for children with disabilities. Two major recommendations emerged from these data. The mothers believed that they needed more information about diagnosis and services beginning with the birth of their children and a need for more information about disabilities both for themselves and for increased community awareness about children with disabilities. Atun-Einy and Ben-Sasson (2018) as well as Stadnick et al. (2017) noted that when early diagnosis is provided for children with disabilities, they showed better development of self-esteem and fewer behavior problems. As previously suggested, prior research indicates that early diagnosis for

children with disabilities is crucial and is associated with improved outcomes (Dillenburger et al., 2016).

As noted above, the second primary recommendation from mothers of children with disabilities is that there is a need to spread awareness about the educational needs of children with disabilities. This lack of awareness has resulted in a community that does not know the rights of the individuals with disabilities. All mothers expressed that there are deficits in educational provisions for children with disabilities such as a lack of accessible learning environments, scarce availability of various learning resources, and a lack of follow-up and evaluation sessions with special needs teachers. Therefore, this study highlights the importance of spreading awareness about the needs of children with disabilities in education as such awareness will aid in providing the children with individualized and effective support that achieves social and academic growth. Bekink and Bekink (2005) concluded that awareness of the needs of children with disabilities in education results in positive attitudes toward providing environments suitable for children with disabilities in education.

Conclusion

As the first study in Saudi Arabia to explore this topic, the findings offer insights into the Saudi Arabian mothers' unique experiences of caring for children with disabilities and provide a detailed discussion of the effect of disability on mothers in Saudi Arabia. It also provided information about services and social support systems available from the mothers' perspectives. In addition, this study confirms the fact that religion plays a great role in mothers' understanding of their children's conditions and their ability to cope with the demands of disabilities. Lastly, future studies should continue the exploration of the experiences of Saudi mothers of children with disabilities in different areas of Saudi Arabia.

The Implications of Saudi Culture on Families' Experiences

The Saudi people are citizens of Saudi Arabia. To a great extent, they all share the same culture and customs that include religion and Arabic dialects. They have differences in education levels and social classes. Islam is the dominant religion in the country (Al-Mutairi, Mushawah, Basardah, & Al-Shaer, 2018). The explanation of the Saudi culture helps the reader to understand differences in child-rearing practices and care. Understanding cultural concepts and religious beliefs about disability in the Saudi Arabian cultural context is essential to planning and providing mother-centered services for families of children with disabilities. However, there is little research that addresses the perceptions of disability in Middle Eastern countries, specifically the perceptions and experiences of Saudi mothers of young children with disabilities in the early childhood years. In Saudi Arabia, the mothers play a critical role in providing the care and upbringing of children. So, it is necessary to understand mothers' perceptions and beliefs about their children with disabilities. Despite the cultural similarity between Saudi mothers, every mother has a different perspective on their involvement in their child's care and their conceptualization of disability.

Saudi culture is characterized by interrelated relationships between the family members. Most Saudi families consist of the husband, wife, children, and their married children with their spouses and grandchildren. In some families, the grandparents from the husband's side are an essential element in the family (Al-Saif, 1991). Saudi culture is characterized by interrelated relationships between the families. The family has a great role in the upbringing of the individual, the formulation of his/her personality, and the development of his/her skills. Family members in Saudi Arabia are keen to provide respect, appreciation, and loyalty to each other (Al-Saif, 1991). Therefore, it is expected that children with disabilities get care and attention from

their families. Notably, providing adequate or appropriate care for children with disabilities is considered part of Islamic culture. The marginalization of children with disability in Saudi society is due to different reasons such as the lack of awareness about disabilities and shame (Al-Jadid, 2014).

Saudi culture plays a great role in children's rearing. The mothers have a major responsibility in all aspects of household management, such as cooking, cleaning, and children's care, which includes supporting the children psychologically and emotionally. As for the father, his role is limited to providing the family with all of their other needs and supporting the mother economically (Ajami, Rasmi, & Abudabbeh, 2016). The mothers were more responsible than the fathers for providing daily care for their children as well as their education. This responsibility makes the mothers more vulnerable to stress and tension. In this study, the mothers expressed the difficulties that faced them in providing care for more than one child, especially a child with a disability who needs more time and care.

Limitations

This study was the first to explore the Saudi mothers' experience of having a child with disabilities and to explore the impact of disability on the family in Saudi Arabia, especially in Jazan city. There are several limitations of this study. First, due to the current situation with the Coronavirus, the interviewer and interviewees wore masks, which resulted in difficulties in understanding body language and facial expressions. So, there were communication challenges while wearing a mask and conducting the interview. The interviews are more likely to be successful when the people can communicate clearly and understand the feelings of others through facial expressions. Non-verbal cues carry up to 55% of the content for communication (Ganguly, 2017).

Moreover, 5 different participants withdrew from this study before any data or interviews were conducted. Two of the participants withdrew from the study because they had coronavirus. They apologized and wished to continue the interviews online. Unfortunately, one of them did not know how to use technology or the internet, and another mother did not have enough time to do the interview because all her family members had coronavirus and she was responsible for providing care for all of them. The use of technology is considered new in Jazan city. Some rural areas around Jazan city have weak internet services. Therefore, some mothers, especially uneducated mothers or mothers who live in rural areas, do not have sufficient skill and knowledge of using online communication technology such as Zoom, Microsoft Teams.

Upon their withdraw, these mothers were replaced by another two mothers with the help of the principal. I reached out to the principal and informed her that two mothers withdrew, and that I needed her help in recruiting another two mothers. She reached out to the rest of the mothers via WhatsApp and directed the interested mothers to reach out to me. Two new mothers reached out and started their participation immediately.

The other 3 participants had some misunderstanding about how interviews were conducted and about the use of the audio recorder. The three mothers withdrew from participating in the study once they realized that their interviews have to be recorded for data transcription and analysis. Those three mothers did not have a problem participating in the study per se, but they had the stipulation that their voices were not going to be recorded in the interview and preserved. Their hesitance to being recorded may stem from their comfort level, cultural background, or personal preferences. Due to this limitation, future researchers need to be clear and precise about their interview procedure and share a description of the interview nature

with participants before scheduling or starting the interview with the interviewees (Rowley, 2012).

The family consists of more than one person, but this study focused on the experiences of mothers even though the disability had an effect on all the family members (Reichman, Corman, & Noonan, 2008). Future research should focus on other family members to explore the other family members perceptions of disability in the Saudi culture. In addition, it will be beneficial to study the experiences of other people, such as teachers and service providers, who have worked with children with disability and their mothers.

Implications

This study provides a detailed account of a small number of Saudi mothers' experiences with their children with disabilities through individual interviews. It demonstrates how the mothers' experiences with support services and their children's disabilities affected their daily lives and the lives of their children. The findings of this study present implications for the needs of Saudi mothers of young children with disabilities, particularly regarding service providers from the time of their children's birth; the findings also provide implications for the mothers' interactions with special education. These recommendations are essential to understanding mothers' needs, especially when service providers seek to improve planning, and to provide services for young children with disabilities. These recommendations can help special education and related service providers increase their knowledge regarding the needs of mothers of children with a disability during the early childhood years, provide more appropriate educational plans and services for the child and their family, and enhance the collaboration process between service providers and mothers of children with disabilities. The recommendations from the

findings of this study are related to the areas of interactions with Saudi mothers, knowledge of mothers' perspectives about disability, and support services.

Interactions with Saudi Mothers

In the Saudi community, there are many people from different nationalities who work in different public and private sectors. As many of them work in hospitals and private schools, it is highly possible that these people will interact with Saudi mothers. Moreover, Saudi mothers need different services beginning with the birth of their children with disabilities. Hence, it is essential to discuss communication and interaction features that distinguish the Saudi culture from other cultures. This clarification will provide information about the needed skills to increase awareness during the interaction with Saudi mothers and their children with disabilities.

Communication in Saudi culture. Communication is of great importance in Saudi culture. There are several forms and styles of communication. In Saudi culture, people tend to use informal and in-person forms of communication, especially when the purpose of communication is to get to know the person at the beginning of the conversation. Therefore, the first communication with Saudi mothers should be in the form of an informal conversation. In addition, most Saudi mothers do not feel comfortable expressing or sharing information about their life to anyone. They often depend on body language or use some phrases such as "Thank God or With God all is Good" when they do not want to talk in detail or answer questions (Al Khatib, 2017). On the other hand, Saudi women prefer to talk with other women about private subjects related to them such as their problems during pregnancy or childbirth. Therefore, service providers and special educators should know about the differences in communication styles in Saudi culture. The knowledge of communication styles will facilitate the communication process, make it more effective, and will aid in avoiding any misunderstandings that may occur.

Moreover, some Saudi mothers often move from one subject to another subject during the conversation. They might need more time to get their point about answering questions. So, the best way to reach an answer is to ask an open-ended question that allows to reach an answer and giving agreeable response as they talk. In addition, Saudi Mothers of children with disabilities consider that disability is a sensitive subject. So, it is important for those who communicate with mothers of children with disabilities to have knowledge and skill when dealing with them.

Through physical communication, Saudi mothers are usually comfortable with others when the conversation starts with handshakes of the same gender and welcoming. This makes them feel comfortable before starting the conversation. Appreciating and respecting mothers is an important factor to make mothers comfortable during conversation.

Social distancing. In Saudi culture, the distance between two people is important during the conversation, especially when there is no acquaintance between the two people. Thus, the close distance between mothers and service providers makes the mothers feel uncomfortable and stressed. Moreover, the conversation between women with strange men is uncomfortable for both. Wherefore, most women depend on their men in all aspects of their lives. In addition, the handshake and laughter between women and strange men is unacceptable by both genders.

Eye contact. In Saudi culture, eye contact between people is important. The lack of eye contact during conversation between people is considered as a sign of disinterest. On the other hand, eye contact between women and strange men is uncomfortable and uncommon. So, the service providers who work with Saudi mothers should know about the preferred level of eye contact.

Knowledge of Mothers' Perspectives about Disability

Saudi mothers have various cultural and religious perspectives of their children's disabilities. So, it is important to understand Saudi mothers' culture and their perspectives about disability. It helps special education and service providers from different nationalities, who work with Saudi mothers, in their planning and in providing these mothers with more adequate services. Saudi culture and Islamic values are important and have a significant influence on Saudi mothers who participated in this study. So, understanding the effect of these elements on disability is essential. Moreover, the awareness and understanding of the mothers' culture and beliefs are significant to access quality communication between mothers and professionals.

Mothers' reactions. Most Saudi mothers avoid the feeling that their children have a problem, especially if the disability such as autism is not apparent. The discovery and diagnosis of disability leads to an emotional response from the mothers. These mothers suffered from confusion and shock about their children's status. Therefore, the mothers may search for many places to diagnose their children's health and disability. These mothers start to focus on their children's behavior in order to compare the difference with other children. Some mothers refused the diagnosis, or any discussions related to disabilities, and tend to feel uncomfortable about having discussions with a therapist. They may direct their anger outward such as criticizing the hospital equipment, doctors' skills, or quality of services provided (Muhammad, & Mohamed, 2018). Therefore, professionals and service providers need to be aware of that and work with the mothers from the initial stages, aim towards ways of treating their children with disabilities, and place their focus on the child's strengths and their unique learning needs.

Islam is the primary religion in the Saudi Arabia, and the majority of the Saudi people are Muslims. Religion plays a significant role in mothers' reactions to disability. Religion is a key

factor in accepting and adapting to disability. The mothers in this study have turned to prayers and supplication in order to for their children's recovery and they may depend on it more than depending on interventions and therapy. Therefore, professionals should be aware that mothers' reactions are greatly influenced by their religion. They must respect mothers' religious reactions to disability because that will affect their acceptance of advice, guidance, interventions, therapy, and gaining the mothers' trust.

Support Services. In this study, the mothers expressed the greatest need for more information about services than Jazan city provides for children with disabilities and their mothers. They expressed the need to understand the disability and its causes, and how the disability will affect their child. Therefore, service providers should provide detailed information about services that support children with disabilities and their mothers. Moreover, some mothers did not have the proper awareness of the importance of the diagnosis of a disability and did not understand what the diagnosis entails. Therefore, it is important for professionals to provide mothers of children with disabilities detailed and important information about the diagnosis. This is will help to reduce stress and anxiety for mothers and will help them to better prepare for meeting their children's special needs and requirements.

Implications of special education policy and teacher education

Saudi Arabia had many policies and practices to serve children with special needs, improve the infrastructure of special education, and ensure the right of children with disabilities to have access to special education programs. These policies and practices seek to ensure that all children with disabilities receive appropriate and free special education and associated services, early intervention programs, and individual educational programs (Aldabas, 2015). They also focus on providing children with disabilities an appropriate life in a way that meets their needs.

In this study, the mothers expressed that they need access to appropriate services and high-quality, free, and appropriate public education for their children with disabilities. Some cities in Saudi Arabia do not implement effective policies for special education. For example, they do not provide some services for children with disabilities such as speech and language pathologists and occupational therapists. The proper implementation of policies will make special education more effective and useful for children with disabilities. Understanding policies and practices of special education will help parents to better understand and meet their child's needs.

According to Saudi Arabi Vision 2030, there are many objectives that the National Transformation Program seeks to achieve in order to develop special education services such as providing education services to all students, improving curricula and teaching methods, improving learning environments, and improving recruitment, training, and development of teachers (Mohammed, 2018). In addition, the King Salman center for disability research seeks to enhance the lives of individuals with disabilities and their families through funding research in all areas of disability.

For teacher education, it is important that all teachers should have general information about special needs. Children with disabilities have different needs that should be met and taken into account during teaching. The knowledge of special education will help to identify children with disabilities and adapt a teaching method that will be effective for those with disabilities. Also, the knowledge about special needs will help teachers to practice inclusive education. Teachers can merge methods of teaching in the classroom to make all children get the benefit. Moreover, in rural areas in Saudi Arabia, there are no special needs schools for children with disabilities. Children with disabilities are integrated into the general school. So, when teachers

have knowledge about special needs, they can provide an appropriate education for all children. Furthermore, knowledge and understanding of the special needs of children with disabilities helps teachers advocate for children with disabilities so they are not neglected and marginalized in the community or in the school. Understanding the processes of special education will help teachers to provide appropriate education and services for children with disabilities.

Recommendations for Future Research

This study aimed to explore Saudi Arabian mothers' experiences of having a child with disabilities, and to explore the impact of disability on the family. This study is the first qualitative research that focused on experiences of Saudi Arabia mothers of young children with disabilities. There are limited resources in Saudi Arabia that address special education and related services for children with disabilities beginning at birth. Thus, this study is considered the beginning of the exploration of this significant topic and there is a need for more research on the topic. Future explorations would allow service providers to be more aware of the disabilities from the mothers' perspectives and improve their services accordingly.

This research focused on mothers from one city (Jazan) in Saudi Arabia. So, the mothers' experiences from other cities in Saudi Arabia may be different. They will share the same culture and values, but they may have different experiences with the provided services in their cities. Thus, future studies are recommended to explore a wider array of Saudi mothers in different cities in Saudi Arabia. This may help in accessing different perspectives or make the findings comparatively stable.

Future studies could foster our understanding of the experiences of Saudi Arabian mothers of children with disabilities and allow us to explore the differences between mothers of children with disabilities and mothers of typical children. Future studies could use other

methodologies to examine this study's topic in more depth by using longitudinal research methods utilizing both qualitative and quantitative research designs. For example, future studies could use mixed methods design rather than just using in-depth semi-structured interviews.

Moreover, the disability affects all the family members. There are no studies that address the effects of disability on Saudi fathers. Thus, it is important to conduct more studies that focus on the perspectives and experiences of Saudi fathers and siblings of children with disabilities. Future research could involve recruitment of several Saudi fathers of children with disabilities to gain their perspective. Furthermore, siblings of individuals with a disability play a great role in the family and their disabled sibling development. In this study, some mothers expressed that their typical children contribute greatly by helping the parents provide care for their siblings with a disability. Therefore, it is also important to explore the perspectives of these siblings regarding how disability affected their lives in Saudi Arabia.

Reflexivity

Reflexivity is an important part of qualitative research. Roulston (2010) defined reflexivity in research as “the researcher’s ability to be able to self-consciously refer to him or herself in relation to the production of knowledge about research topics” (p. 116). In addition, it refers to the ability of the researcher to be aware during the research process (Dowling, 2006). In qualitative inquiry, researchers are considered the human instrument and the credibility, and the quality of the research findings depend on the researcher’s skills (Patton, 2002).

Litchman (2013) states “the main idea of reflexivity is the reflection of practice and process of research on the system and the system of research” (p. 165). The researchers occupy the main role of collecting, analyzing, and interpreting data. Moreover, the researcher’s beliefs, judgments, biases, practices, and perspectives could influence the research process. So, openness

and transparency is considered a part of the research and as a way to acknowledge the impact of the researcher's assumptions and experiences on the research process (Holloway & Biley, 2011).

Moreover, Mauthner and Doucet (2003) demonstrated that reflexivity occurs through the data analysis process and encourages the researcher to interpret and analyze their data. Further, it is important to develop a reflective journal during the research process to help the researchers to begin acknowledging themselves and their assumptions, values, and perspectives (Amankwaa, 2016). In this study, reflexivity was applied in all stages of the research process to address any biases. I kept reflective journals throughout the research process which includes information about my personal thoughts, the interview settings, and communication style.

My interest in this area is longstanding. After graduating from high school, I read about available majors in universities in all of Saudi Arabia. The special education major at King Saud University in Riyadh city attracted my attention. In Jazan city, no one knows anything about this major. I read more before registering in this major. As I was going through the process of applications to universities, I remembered when I was a child and my aunt, who has Down Syndrome, loved the idea of going to school. At that time, children with a disability stayed at home, and no school received any children with disability, nor provided any services for them. Because of that experience, I decided that I should register for this major and learn about special education in order to provide education to children with special needs in Jazan city. I traveled to Riyadh and I did the interview to register for the special education major. I was admitted and successfully completed a bachelor's degree in the mental disability field because it was most prevalent in the Jizan region. During my studies at the university, I took a course about early childhood; this course increased my interest in knowing more about children with disabilities in the early years of their life and in knowing about their needs and how to discover disabilities

from birth. Since I came to the U.S in 2012, this interest started to grow over time, and I kept finding myself searching and reading about early childhood special education. So, I decided to pursue a master's degree in early childhood special education to learn more about their needs in the early years and how providing services can positively affect children psychologically, socially, and educationally. In addition, these services have a great effect on the family especially mothers. Knowing their children's needs, and providing them with the information and skills necessary to educate and provide their children with the required skills is key to the success of the development of child with a disability. My deep understanding in this field has been critical as I conducted this important research and explored the mothers' experiences with their children in the early years.

My search for my study's literature review about special education in Saudi Arabia, and being a Saudi myself, who grew up in Saudi culture, all played a role in shaping my expectations going into this study. During the interviews, I was anticipating some of the responses to the questions. This included the parents' initial reactions to discovering their children's disability, the influence of religion on mothers, receiving services, parents' concerns, the importance of the role of family in supporting the mothers, and the effects of disability on the family. These expectations were confirmed in the mothers' interviews.

Furthermore, in this study, I expected the process of recruitment to be difficult. But the opposite happened; when I contacted the principal of the Children with Disabilities Association in Jazan about the participants' recruitment, she was very cooperative and involved as she asked mothers to participate in my study and provided me a private room to do the interviews. Lastly, I deeply appreciate the mothers and their willingness to share their experiences with me and the

future readers of my research in order to increase awareness. I also appreciate their adherence to the day and the time to do interviews despite the current circumstances with the Coronavirus.

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APPENDIX A:

INSTITUTIONAL REVIEW BOARD APPROVAL FOR STUDY



EXEMPT DETERMINATION

May 21, 2021

Samirah Bahkali
4121 E Busch Blvd 1506
Tampa, FL 33617

Dear Ms. Samirah Bahkali:

On 5/21/2021, the IRB reviewed and approved the following protocol:

Application Type:	Initial Study
IRB ID:	STUDY002573
Review Type:	Exempt 2
Title:	Experiences of Saudi Arabian Mothers of Young Children with Disabilities: An Exploratory Study
Funding:	None
Protocol:	• Protocol_cleaned version

The IRB determined that this protocol meets the criteria for exemption from IRB review.

In conducting this protocol, you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).

Please note, as per USF policy, once the exempt determination is made, the application is closed in BullsIRB. This does not limit your ability to conduct the research. Any proposed or anticipated change to the study design that was previously declared exempt from IRB oversight must be submitted to the IRB as a new study prior to initiation of the change. However, administrative changes, including changes in research personnel, do not warrant a modification or new application.

Ongoing IRB review and approval by this organization is not required. This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these activities impact the exempt determination, please submit a new request to the IRB for a determination.

As a reminder, please contact USF IT at secops-help@usf.edu to set up your Box.com study folder before storing data on the cloud. You will need to include the name of the Principal Investigator (folder owner), study title, data to be stored, and a list of IRB-

Institutional Review Boards / Research Integrity & Compliance
FWA No. 00001689
University of South Florida / 3702 Spectrum Blvd., Suite 165 / Tampa, FL 33612 / 813-974-5638



approved study team members in your email to USF IT. For additional information, please see Question 38 of HRP-103 - Investigator Manual.

Sincerely,

Katrina Johnson
IRB Research Compliance Administrator

Institutional Review Boards / Research Integrity & Compliance
FWA No. 00001669
University of South Florida / 3702 Spectrum Blvd., Suite 165 / Tampa, FL 33612 / 813-974-5638

Page 2 of 2

RECRUITMENT FLYER



SAUDI ARABIAN MOTHERS Participants Needed for Research

Do You Have Child with Special Need?

If you are Saudi Arabia Mothers of a child who has a special need
I invite you to participate in this study to share your experience in relation to your child's special need

The research seeks to understand your experiences of having a child with special needs and to explore the impact of disability on the family.

To participate in this study, you should be:

- Mothers from Saudi Arabia.
- Mothers living in Saudi Arabia.
- Mothers who have child with disability
- Children with a disability are under 10 years old.
- Mothers and children reside in Jazan, Saudi Arabia

Your voluntary participation would involve up to 3 interviews lasting 30-60 minutes each

Interviews will be at a place and time convenient to you

Transportation will be provided if needed

Your personal information will be treated in complete confidence

For more information, or to volunteer for this study, please contact:

Samirah Bahkali

Ph.D. Candidate at USF

813-203-5089

sbahkali@usf.edu

The IRB study number# STUDY002573



اعلان

البحث عن أمهات سعوديات للمشاركة في الدراسة

هل لديك طفل من ذوي الاحتياجات الخاصة؟

إذا كنت أم من المملكة العربية السعودية ولديك طفل من ذوي الاحتياجات الخاصة
أدعوك للمشاركة في هذه الدراسة لمشاركة تجربتك فيما يتعلق باحتياجات طفلك الخاصة

يسعى البحث إلى فهم تجاربك في إنجاب طفل ذي احتياجات خاصة واستكشاف تأثير الإعاقة على الأسرة

للمشاركة في هذه الدراسة، يجب أن تكون:

- الأمهات من المملكة العربية السعودية.
- الأمهات المقيمات في المملكة العربية السعودية.
- الأمهات اللواتي لديهن أطفال معاق.
- الأطفال ذوي الإعاقة أقل من 10 سنوات.
- الأمهات والأطفال مقيمون في منطقة جازان بالمملكة العربية السعودية.

ستشمل مشاركتك التطوعية ما يصل إلى 3 مقابلات مدة كل منها 30-60 دقيقة

ستكون المقابلات في مكان ووقت مناسبين لك

سيتم توفير النقل إذا لزم الأمر

سيتم التعامل مع معلوماتك الشخصية بسرية تامة

لمزيد من المعلومات، أو للتطوع في هذه الدراسة، يرجى الاتصال بـ

سميرة بهكلي

USF دكتوراه مرشح في

813-203-5089

sbahkali@usf.edu

The IRB study number# STUDY002573

APPENDIX C:

INTERVIEW PROTOCOL

First English Interview Protocol

- 1-How old is your child?
- 2-What kind of disability has your child been identified as having?
- 3-When did you discover that your child had a disability?
- 4- Who were the people you talked to about your concerns regarding your child's situation?
- 5- Was there a formal diagnostic process and if so, how and when did this occur?
- 6- When did your child first receive some form of early childhood education?
- 7- Did you face any difficulties when your child started his/her school and education?
- 8- What were the concerns you initially had about your child's future?
- 9- Describe your experience with your child during the early childhood years?
- 10- What are challenges that the mother and family face regarding having a child with special needs?
- 11- Do you have any additional information that was not included in the interview?

Second English Interview Protocol

- 1- What are the social services that your child and family are receiving right now?
- 2- What are the social support systems and services that helped the family in raising your child in early childhood?

- 3- What services did you and your child receive in the past?
- 4- Do you have sufficient information about the services provided by the community for children with disabilities?
- 5- What are your sources of information about special needs and early childhood?
- 6- How did you receive early childhood services?
- 7- What were some useful techniques you used with your child during the early childhood years?
- 8- What were some useful techniques you used to help your family dealing with your child?
- 9- What are the services that you and your child continue to receive? Tell me about your experience with these services?
- 10- What services do you think your child and you need and should receive?
- 11- Are you fully satisfied with the services that your child receives?
- 12- In your opinion, are the services provided sufficient or is there a need for services to be developed and improved, and how can they be developed from your point of view?
- 13- Do you have any additional information that was not included in the interview?

Third English Interview Protocol

- 1- What was your reaction when you heard about your child's situation?
- 2- How did society deal with your child?
- 3- How did your child's disability impact your social life?
- 4- How did the disability affect your child's development?
- 5- What is the impact of disability on your child's life and the family?

- 6- How does your child spend his/her day?
- 7- What are challenges that the mother and family face regarding having a child with special needs?
- 8- What crises and difficulties have you faced as a parent of a child with a disability?
- 9- Based on your experiences with early childhood education for your child, what suggestions do you have for the field?
- 10- What are your thoughts about your child's future life? Explain
- 11- From your experience, what recommendations do you have about raising a child with a disability during early childhood?
- 12- Do you have any additional information that was not included in the interview?

APPENDIX D:

ARABIC INTERVIEW PROTOCOL

بروتوكول المقابلة الأولى

- ١- كم عمر طفلك؟
- ٢- ما نوع الإعاقة التي يعاني منها طفلك؟
- ٣- متى اكتشفت أن طفلك يعاني من إعاقة؟

- ٤- من هم الأشخاص الذين تحدثت معهم بشأن مخاوفك بشأن حالة طفلك؟
- ٥- هل كانت هناك عملية تشخيص رسمية، وإذا كان الأمر كذلك، كيف ومتى حدث ذلك؟
- ٦- متى تلقى طفلك لأول مرة شكلاً من أشكال التعليم في مرحلة الطفولة المبكرة؟
- ٧- هل واجهت أي صعوبات عندما بدأ طفلك المدرسة وتعليمه؟
- ٨- ما هي مخاوفك في البداية بشأن مستقبل طفلك؟
- ٩- صف تجربتك مع طفلك خلال سنوات الطفولة المبكرة؟
- ١٠- ما هي التحديات التي تواجهها الأم والأسرة في إنجاب طفل من ذوي الاحتياجات الخاصة؟
- ١١- هل لديك أي معلومات إضافية لم يتم تضمينها في المقابلة؟ ممكن اخليه اخر سوال اذا تمت المقابلة بيوم واحد

بروتوكول المقابلة الثانية

- ١- ما هي الخدمات الاجتماعية التي يتلقاها طفلك وعائلتك الآن؟
- ٢- ما هي أنظمة وخدمات الدعم الاجتماعي التي ساعدت الأسرة في تربية طفلك في مرحلة الطفولة المبكرة؟
- ٣- ما هي الخدمات التي تلقيتها أنت وطفلك في الماضي؟
- ٤- هل لديك معلومات كافية عن الخدمات التي يقدمها المجتمع للأطفال المعوقين؟
- ٥- ما هي مصادر المعلومات الخاصة بك حول الاحتياجات الخاصة والطفولة المبكرة؟
- ٦- كيف تلقيت خدمات الطفولة المبكرة؟
- ٧- ما هي بعض التقنيات المفيدة التي استخدمتها مع طفلك خلال سنوات الطفولة المبكرة؟

- ٨- ما هي بعض الأساليب المفيدة التي استخدمتها لمساعدة أسرتك في التعامل مع طفلك؟
- ٩- ما هي الخدمات التي تستمر أنت وطفلك في تلقيها؟ أخبرني عن تجربتك مع هذه الخدمات؟
- ١٠- ما هي الخدمات التي تعتقد أن طفلك تحتاجها ويجب أن تحصل عليها؟
- ١١- هل أنت راضٍ تمامًا عن الخدمات التي يتلقاها طفلك؟
- ١٢- برأيك، هل الخدمات المقدمة كافية أم أن هناك حاجة إلى تطوير وتحسين الخدمات، وكيف يمكن تطويرها من وجهة نظرك؟
- ١٣- هل لديك أي معلومات إضافية لم يتم تضمينها في المقابلة؟

بروتوكول المقابلة الثالثة

- ١- ماذا كان رد فعلك عندما سمعت عن حالة طفلك؟
- ٢- كيف تعامل المجتمع مع طفلك؟
- ٣- كيف أثرت إعاقة طفلك على حياتك الاجتماعية؟
- ٤- كيف أثرت الإعاقة على نمو طفلك؟
- ٥- ما هو تأثير الإعاقة على حياة طفلك والأسرة؟
- ٦- كيف يقضي طفلك يومه؟
- ٧- ما هي التحديات التي تواجهها الأم والأسرة في إنجاب طفل من ذوي الاحتياجات الخاصة؟
- ٨- ما هي الأزمات والصعوبات التي واجهتها كوالدة لطفل معاق؟

٩- بناءً على خبراتك مع تعليم الطفولة المبكرة لطفلك، ما هي الاقتراحات التي لديك في هذا المجال؟

١٠- ما هي أفكارك حول حياة طفلك المستقبلية؟ يشرح

١١- من واقع تجربتك، ما هي التوصيات التي لديك بخصوص تربية طفل معاق خلال مرحلة الطفولة المبكرة؟

١٢- هل لديك أي معلومات إضافية لم يتم تضمينها في المقابلة؟

APPENDIX E:

DEMOGRAPHIC QUESTIONS

- 1) Where did you born?
- 2) Where did your child born?
- 3) How old are you?
- 4) What educational degree do you hold? Where did you earn it? which university?
- 5) What educational degree does your husband hold?
- 6) What is marital status?
- 7) Do you work? What type of work?

- 8) Does your husband work? What type of work?
- 9) How many children do you have?
- 10) Is there other child with disability in the family?
- 11) How many members of your family live with you in the same house?
- 12) What is the monthly household income? 1000-10 thousand / 10 thousand - 20 thousand / above 20 thousand

E الملحق

أسئلة ديموغرافية

- ١- اين ولدت؟
- ٢- اين ولد طفلك؟
- ٣- كم عمرك؟
- ٤- ما هي الدرجة العلمية التي تحملها؟ من أين كسبتها؟ أي جامعة؟
- ٥- ما هي الدرجة العلمية التي يحملها زوجك؟
- ٦- ماهي الحالة الاجتماعية؟
- ٧- هل تعمل؟ ما نوع العمل؟
- ٨- هل يعمل زوجك؟ ما نوع العمل؟
- ٩- كم عدد الأطفال لديك؟

١٠- هل يوجد طفل آخر معاق في الأسرة؟

١١- كم عدد أفراد عائلتك الذين يعيشون معك في نفس المنزل؟

١٢- ما هو الدخل الشهري للأسرة؟ ١٠٠٠ - ١٠ الف / ١٠ الف - ٢٠ الف / أعلى من ٢٠ الف

APPENDIX F:

ENGLISH INFORMED CONSENT FORM

Informed Consent to Participate in Research Involving Minimal Risk

Information to Consider Before Taking Part in this Research Study

Title: Experiences of Saudi Arabian Mothers of Young Children with Disabilities: An Exploratory Study

Study # STUDY002573

Overview: You are being asked to take part in a research study. Research studies include only people who choose to take part. This document is called an informed consent form. Please read this information carefully and take your time making your decision. Ask the researcher or study staff to discuss this consent form with you, please ask her to explain any words or information you do not clearly understand. The nature of the study, risks, inconveniences, discomforts, and other important information about the study are listed below. The information in this document should help you to decide if you would like to participate. The sections in this Overview provide the basic information about the study. More detailed information is provided in the remainder of the document.

Study Staff: This study is being led by *Samirah Bahkali* who is a *doctoral student at USF*. This person is called the Principal Investigator. She is being guided in this research by Dr. Ann Cranston-Gingras, USF, professor. Other approved research staff may act on behalf of the Principal Investigator.

Study Details: This study is being conducted at *Jazan, Saudi Arabia* and is supported/sponsored by University of South Florida. The purpose of the study is to explore Saudi Arabian Mothers' experiences of having a child with disabilities, and explore the impact of disability on the family.

If you take part in the study, you will be interviewed three times, and each time might take up to 60 minutes. The interview will be face to face or online. The interview will be audio recorded and you will be notified and your approval for recording will be taken before the interview. Recordings will remain in electronic format and will be deleted after the final report is presented to the IRB or 5 years later. After 5 years, images, recordings and transcripts will be deleted.

Subjects: You are being asked to take part because you have a child with special needs.

Voluntary Participation: Your participation is voluntary. You do not have to participate and may stop your participation at any time. There will be no penalties or loss of benefits or opportunities if you do not participate or decide to stop once you start.

Benefits, Compensation, and Risk: We do not know if you will receive any benefit from your participation. There is no cost to participate. You *will not* be compensated for your participation. This research is considered minimal risk. Minimal risk means that study risks are the same as the risks you face in daily life. There is a risk of transmission of the novel coronavirus from these procedures, and that while precautions will be taken, you cannot guarantee that the participant will not be exposed to the virus.

Confidentiality: Even if we publish the findings from this study, we will keep your study

information private and confidential. Anyone with the authority to look at your records must keep them confidential.

Why are you being asked to take part?

The purpose of the study is to explore Saudi Arabian Mothers' experiences of having a child with disabilities and explore the impact of disability on the family. You are being asked to take part because you have a child with special needs.

Study Procedures:

First a research team will explain the topic of the study to you in general. Then, you will be asked to answer interview questions. The interview will be conducted three times. Each interview might take up to 60 minutes. There will be two weeks between each interview. The interview will be audio-recorded. Before the interview, you will be notified about audio-recording.

At each visit, you will be asked to:

- Answer interview questions about (Mothers' experiences with their children, experiences regard to support services and resources, and the effects of their child's disability on their lives.)

Total Number of Subjects

About 4-6 *individuals* will take part in this study at USF.

Alternatives / Voluntary Participation / Withdrawal

You have the right to not take a part in this study and to withdraw from the study at any time.

You should only take part in this study if you want to volunteer. You should not feel that there is any pressure to take part in the study. You are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study.

Benefits

You will receive no benefit(s) by participating in this research study.

Risks or Discomfort

This research is considered to be minimal risk. That means that the risks associated with this study are the same as what you face every day. There are no known additional risks to those who take part in this study.

There is a risk of transmission of the novel coronavirus from these procedures if interview takes place face to face, and that while precautions will be taken such as social distancing and wearing masks, we cannot guarantee that the participant will not be exposed to the virus.

Compensation

You will receive no payment or other compensation for taking part in this study.

Costs

It will not cost anything to be in this study.

Privacy and Confidentiality

We will do our best to keep your records private and confidential. We cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law. Certain people may need to see your study records. These individuals include:

- The research team, including the Principal Investigator, study coordinator, research nurses, and all other research staff.
- Certain government and university people who need to know more about the study. For example, individuals who provide oversight on this study may need to look at your records. This is done to make sure that we are doing the study in the right way. They also need to make sure that we are protecting your rights and your safety.
- Any agency of the federal, state, or local government that regulates this research. This includes the Department of Health and Human Services (DHHS) and the Office for Human Research Protection (OHRP).
- The USF Institutional Review Board (IRB) and its related staff who have oversight responsibilities for this study, and staff in USF Research Integrity and Compliance.

Your information or samples collected as part of the research, even if identifiers are removed, will NOT be used or distributed for future research studies.

We may publish what we learn from this study. If we do, we will not include your name. We will not publish anything that would let people know who you are.

You can get the answers to your questions, concerns, or complaints.

If you have any questions, concerns or complaints about this study, call *Samirah abakkali* at 813-335-4042. If you have questions about your rights, complaints, or issues as a person taking part in this study, call the USF IRB at (813) 974-5638 or contact by email at RSCH-IRB@usf.edu.

Consent to Take Part in Research

I freely give my consent to take part in this study: and authorize that my health information as agreed above, be collected/disclosed in this study]. I understand that by signing this form I am agreeing to take part in research. I have received a copy of this form to take with me.

Signature of Person Taking Part in Study

Date

Printed Name of Person Taking Part in Study

Statement of Person Obtaining Informed Consent and Research Authorization

I have carefully explained to the person taking part in the study what he or she can expect from their participation. I confirm that this research subject speaks the language that was used to explain this research and is receiving an informed consent form in their primary language. This research subject has provided legally effective informed consent.

Signature of Person Obtaining Informed Consent

Date

Printed Name of Person Obtaining Informed Consent

APPENDIX G:

ARABIC INFORMED CONSENT FORM



الموافقة المستنيرة للمشاركة في البحوث التي تنطوي على الحد الأدنى من المخاطر معلومات

مطلب منك المشاركة تجارب امهات السعودية للأطفال الصغار ذوي الإعاقة: دراسة استكشافية

الدراسة

STUDY002573

نظرة عامة: يُطلب منك المشاركة في دراسة بحثية. تشمل الدراسات البحثية فقط الأشخاص الذين يختارون المشاركة. تسمى هذه الوثيقة نموذج الموافقة المسبقة. يرجى قراءة هذه المعلومات بعناية وخذ وقتك في اتخاذ قرارك. المطلب من الباحث أو ملقم الدراسة مناقشة نموذج الموافقة هذا معك، يرجى مطالبتهم بشرح أي كلمات أو معلومات لا تفهمها بوضوح. يتم سرد طبيعة الدراسة والمخاطر والمضايقات وغيرها من المعلومات الهامة حول الدراسة أدناه. يجب أن تساعدك المعلومات الواردة في هذا المستند على تحديد ما إذا كنت ترغب في المشاركة. توفر الأقسام الموجودة في هذه النظرة العامة المعلومات الأساسية حول الدراسة. يتم توفير معلومات أكثر تفصيلاً في الجزء المتبقي من المستند.

ملقم الدراسة: تقوم هذه الدراسة سميرة بهيكل وهي طالبة دكتوراه في جامعة جنوب فلوريدا. يسمى هذا الشخص الباحث الرئيسي. يتم توجيهها في هذا البحث من قبل الدكتورة أن كورنيلين **بجيتري**، أستاذة جامعية في جامعة جنوب فلوريدا. يجوز لموظفي البحث المعتمدين الآخرين التصرف نيابة عن الباحث الرئيسي.

تفاصيل الدراسة: يتم إجراء هذه الدراسة في منطقة جازان بالمملكة العربية السعودية بدعم / رعاية جامعة جنوب فلوريدا. الغرض من الدراسة هو استكشاف تجارب الأمهات السعوديات في إنجاب طفل معاق، واستكشاف تأثير الإعاقة على الأسرة.

إذا شاركت في الدراسة، فستتم مقابلتك ثلاث مرات، وقد تستغرق كل مرة ما يصل إلى 60 دقيقة. ستكون المقابلة وجهاً لوجه أو عبر الإنترنت. سيتم تسجيل المقابلة صوتياً وسيتم إخطارك وسيتم أخذ موافقتك على التسجيل قبل المقابلة. ستبقى التسجيلات بتسويق إلكتروني وسيتم حذفها بعد تقديم التقرير النهائي إلى مجلس الهجرة واللجوء أو بعد 5 سنوات. بعد 5 سنوات، سيتم حذف الصور والتسجيلات والنصوص.

الموضوعات: يُطلب منك المشاركة لأن لديك مفعلاً من ذوي الاحتياجات الخاصة.

المشاركة الطوعية: مشاركتك طوعية. لا يتعين عليك المشاركة ويمكنك إيقاف مشاركتك في أي وقت. لن تكون هناك عقوبات أو خسائر في المزايا أو الفرص إذا لم تشارك أو قررت التوقف بمجرد أن تبدأ.

القوائد والتعويضات والمخاطر: لا تعرف ما إذا كنت ستحصل على أي فائدة من مشاركتك. لا يوجد أي تكلفة للمشاركة. لن يتم تعويضك عن مشاركتك. يعتبر هذا البحث الحد الأدنى من المخاطر. يعني الحد الأدنى من المخاطر أن مخاطر الدراسة هي نفس المخاطر التي تواجهها في الحياة اليومية. هناك خطر انتقال الفيروس التاجي الجديد من هذه الإجراءات، وأنه أثناء اتخاذ الاحتياطات، لا يمكنك ضمان عدم تعرض المشارك للفيروس.

السرية: حتى إذا نشرنا نتائج هذه الدراسة، فسنحافظ على خصوصية وسرية معلومات دراستك. يجب على أي شخص لديه سلطة الاطلاع على سجلاتك الحفاظ على سريتها.

لماذا يُطلب منك المشاركة؟

الغرض من الدراسة هو استكشاف تجارب الأمهات السعوديات في إنجاب طفل معاق واستكشاف تأثير الإعاقة على الأسرة. يُطلب منك المشاركة لأن لديك طفلاً من ذوي الاحتياجات الخاصة

إجراءات الدراسة

يبدأ فريق البحث بشرح موضوع الدراسة لك بشكل عام. بعد ذلك، يُطلب منك الإجابة على أسئلة المقابلة. سيتم إجراء المقابلة ثلاث مرات. قد تستغرق كل مقابلة ما يصل إلى 60 دقيقة. سيكون هناك أسبوعان بين كل مقابلة. سيتم تسجيل المقابلة بالصوت. قبل المقابلة، سيتم إخطارك بالتسجيل الصوتي

سيُطلب منك في كل زيارة

- أجب عن أسئلة المقابلة حول (تجارب الأمهات مع أطفالهن ، والخبرات المتعلقة بخدمات الدعم والموارد ، وتأثيرات إعاقة أطفالهم .) على حياتهم

يُطلب منك أن تكون جزءاً من الدراسة لأنك أم لطفل من ذوي الاحتياجات الخاصة

إجراءات الدراسة

إذا أخذت جزءاً من الدراسة. سيتم مقابلتك ثلاث مرات، وقد تستغرق كل مرة ٦٠ دقيقة

المقابلة ستكون عن طريق وجه لوجه

سيتم تسجيل المقابلة صوتياً وسيتم إعلامك وسيتم اتخاذ الإجراءات اللازمة قبل فترة التدخل

إجمالي عدد المواضيع

ستبقى التسجيلات في شكل إلكتروني وسيتم حذفها بعد تقديم التقرير النهائي إليها

أو بعد 5 سنوات. بعد 5 سنوات، سيتم حذف الصور والتسجيلات والنصوص. IRB

[مشارك ما مجموعه خمسة أفراد في الدراسة في جميع المواقع]. USF سيشارك حوالي خمسة أفراد في هذه الدراسة في

البيئات / المشاركة الطوعية / الانسحاب

تتضمن بدائل المشاركة في الدراسة ما يلي: إذا لم يرغب المشاركون في المشاركة، لديك الحق الكامل بالرفض إن تكون جزء من هذه الدراسة. أيضا لديك الحق الكامل بالانسحاب من الدراسة قبل أو أثناء أو بعد الدراسة

يجب أن تشارك في هذه الدراسة فقط إذا كنت ترغب في التطوع. لا يجب أن تشعر بوجود أي ضغط للمشاركة في الدراسة. لك مطلق الحرية في المشاركة في هذا البحث أو الانسحاب في أي وقت. إن تكون هناك عقوبة أو خسارة للمزايا التي يحق لك الحصول عليها إذا توقفت عن المشاركة في هذه الدراسة

فوائد

لن تحصل على أي مزايا من خلال المشاركة في هذه الدراسة البحثية

المخاطر أو الانزعاج

يعتبر هذا البحث الحد الأدنى من المخاطر. وهذا يعني أن المخاطر المرتبطة بهذه الدراسة هي نفسها التي تواجهها كل يوم. لا توجد مخاطر إضافية معروفة لأولئك الذين يشاركون في هذه الدراسة

هناك خطر انتقال الفيروسات الجديدة من هذه الإجراءات، وأنه أثناء اتخاذ الاحتياطات، لا يمكنك ضمان عدم تعرض المشارك للفيروس

تعويضات

لا يوجد مدفوعات للمشاركين نطلب منك المشاركة في دراسة تجارب أمهات السعودية للأطفال الصغار ذوي الإعاقة: دراسة استكشافية

يسمى هذا الشخص باحث رئيسي. يتم توجيهه في هذا البحث من **USF** / تقود هذه الدراسة سميرة يهكي، وهي طالبة دكتوراه في **USE** قبل الدكتوراة أن كرايبتون غينفرايب

معلومات يجب مراعاتها قبل المشاركة في دراسة البحث هذه

التكاليف

لن يكلف أي شيء

الخصوصية والسرية

سنبذل قصارى جهننا للحفاظ على سرية وسرية سجلاتك. لا يمكننا ضمان السرية المطلقة. قد يتم الكشف عن معلوماتك الشخصية إذا كان ذلك مطلوبًا بموجب القانون. قد يحتاج بعض الأشخاص إلى الإطلاع على سجلات الدراسة الخاصة بك. يشمل هؤلاء الأفراد

- فريق البحث ، بما في ذلك الباحث الرئيسي ومنسق الدراسة والممرضات البحثية وجميع موظفي البحث الآخرين
- بعض أفراد الحكومة والجامعات الذين يحتاجون إلى معرفة المزيد عن الدراسة. على سبيل المثال، قد يحتاج الأفراد الذين يقومون بالإشراف على هذه الدراسة إلى النظر في سجلاتك. يتم ذلك للتأكد من أننا نقوم بالدراسة بالطريقة الصحيحة. كما أنهم بحاجة للتأكد من أننا نحمي حقوقك وسلامتك
- أي وكالة تابعة للحكومة الفدرالية أو الولاية أو المحلية تنظم هذا البحث. وهذا يشمل: وزارة الصحة والخدمات الإنسانية • **(OHRP)** ومكتب حماية البحوث البشرية **(DHHS)**
- والموظفين المرتبطين بها الذين لديهم مسؤوليات الإشراف على هذه الدراسة ، **USF (IRB)** مجلس المراجعة المؤسسية

النزاهة والامتثال البحوث USF والموظفين في

قد تتم إزالة معرفتك من سجلاتك الخاصة أو عيناتك. يمكن استخدام و / أو توزيع معلوماتك أو عيناتك على محقق آخر لإجراء دراسات بحثية مستقبلية دون موافقة إضافية منك أو من ممتلك القانوني أو

لن يتم استخدام أو توزيع معلوماتك أو عيناتك التي تم جمعها كجزء من البحث، حتى إذا تمت إزالة المعرفات، للدراسات البحثية المستقبلية

قد ننشر ما نتعلمه من هذه الدراسة. إذا فعلنا ذلك، فلن نقوم بتضمين اسمك. لن ننشر أي شيء يسمح للناس بمعرفة هويتك

يمكنك الحصول على إجابات لأسئلتك أو مخاوفك أو شكاواك

إذا كانت لديك أية أسئلة أو مخاوف أو شكاوى حول هذه الدراسة، فاتصل على سميرة يهكلي رقم 813-974-5638 [813].

جامعة جنوب إذا كانت لديك أسئلة حول حقوقك أو شكاويك أو مشكلاتك كشخص يشارك في هذه الدراسة، فاتصل بـ [يجب أن تُدرج] RSCH-IRB@usf.edu على الرقم (813) 5638-974 أو اتصل عبر البريد الإلكتروني على قوريدا [الأبحاث التي تُجرى فيها معلومات الاتصال التابعة لها

الموافقة على المشاركة في البحث

والتفويض بجمع المعلومات الصحية واستخدامها والكشف عنها

أمنح موافقتي بحرية للمشاركة في هذه الدراسة [: وأصرح بجمع / الكشف عن معلوماتي الصحية كما هو متفق عليه أعلاه في هذه الدراسة]. أنا أفهم أنه من خلال التوقيع على هذا النموذج، أوافق على ذلك

التوقيع

التاريخ

الاسم

بيان بالحصول على الموافقة المستنيرة وتفويض البحث

لقد شرحت بعناية للشخص المشارك في الدراسة ما يمكن أن يتوقعه من مشاركته. أؤكد أن موضوع البحث هذا يتحدث اللغة المستخدمة لتفسير هذا البحث ويتلقى نموذج الموافقة المستنيرة في لغتهم الأساسية. قدم موضوع البحث هذا موافقة مستنيرة فعالة من الناحية القانونية.

التوقيع

التاريخ

الاسم