

EMOTIONAL BURDENS AND SENSE OF SUPPORT OF KUWAITI  
MOTHERS OF CHILDREN WITH DISABILITIES

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## DEDICATION

To the loving memory of my mother, Shikah, who passed away before I could kiss her  
goodbye.

To the soul of my father, Jassem, who raised me with a strong belief in my ability to be a  
successful mother.

To the loving husband Sami, and gorgeous children Abdullah, Munirah, Sarah, and  
Madaui for surrounding me with love and support during the time of my graduate studies.  
To woman in the world specifically mothers in Kuwait who raise a child with a disability,  
you are a great mother.

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*“ And We have enjoined upon man concerning his parents - His mother beareth him in weakness upon weakness, and his weaning is in two years - Give thanks unto Me and unto thy parents. Unto Me is the journeying.– The Holy Qur'an; 31:14)*

It has been long journey since I first started this project. It started with searching for an answer for my question “How can I support my daughter (child with a disability)?” and it ended up with the completion of a Ph.D.

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## ABSTRACT

TAHANI ALASABAH

### EMOTIONAL BURDENS AND SENSE OF SUPPORT OF KUWAITI MOTHERS OF CHILDREN WITH DISABILITIES

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Raising children with disabilities (CDs) is particularly difficult in Kuwait, where mothers and children alike are often cut off and isolated from traditional support systems (Al-Kandari & Al-Qashan, 2010). This isolation makes it difficult to obtain information and resources and may critically affect both maternal and child emotional well-being. The purpose of this study was to examine the attitudes of Kuwaiti mothers towards their children, as well as the interaction between the mother, her family, her community, and the government. This study frames the boundaries of its research within the theoretical concepts of Bowlby's Attachment Theory and Bronfenbrenner's Ecological Systems Theory.

Multiple linear regression and simple qualitative analyses were used to address the two research questions and four hypotheses. A total of 85 mothers of a CD completed their respective surveys. Findings revealed that emotional burdens and sense of support were not independently associated with mother-child attachment relationship. However, emotional burdens significantly predicted social isolation, which in turn significantly predicted attachment relationship. In addition, emotional burdens significantly predicted

self-efficacy, which in turn predicted attachment relationship. Via open-ended answers, mothers reported that they receive some support from family, community, and government, but that they also desire more support from these sources. Implications, limitations, and directions for future research are also discussed.

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## CHAPTER I

### INTRODUCTION

Coping with childhood disabilities is a difficult task faced by millions of families around the world. Caregivers for children with disabilities (CDs) must find a way to provide for their children's unique needs in societies that are sometimes ill-equipped to handle them. Raising CDs is particularly difficult in Kuwait, where mothers and children alike are often cut off and isolated from traditional support systems (Al-Kandari & Al-Qashan, 2010). This isolation makes it difficult to obtain information and resources and may critically affect their emotional well-being.

The Individuals with Disabilities Education Act (IDEA) in the United States defines a "child with a disability" as any child who has:

Mental retardation, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance [...], orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities; and who, by reason thereof, needs special education and related services (Brault, 2011, p.3).

In the United States, there are approximately 6.4 million people between the ages of 3 and 21 years old receiving services under IDEA (U.S. Department of Education, 2013). The number of families affected by disabilities in the United States has greatly increased, with research indicating that disabilities of non-institutionalized children have doubled

since 1960 (Reichman & Corman, 2008). In fact, of the 53.9 million school-aged children (aged 5 to 17) in the U.S. civilian non-institutionalized population in 2010, about 2.8 million (5.2%) were reported to have a disability (Brault, 2011).

Whereas the dramatic increase in reported childhood disabilities is well-documented in the United States, the situation is less clear in Kuwait. The Kuwait Central Statistical Bureau, (2013) stated that in 2011, the Kuwaiti government reported 33,966 disabled individuals in the country, less than 1% of the total population. However, it is impossible to say whether this number has changed because 2011 was the first time any official tally of disabilities was recorded. It is difficult to obtain reliable statistics on the number of disabled individuals in Kuwait and many neighboring nations (Brown, 2005). Individuals, particularly children, with disabilities remain an overlooked and underrepresented segment of the Kuwaiti population, making research into their situation all the more vital.

Kuwait is one of the Arabian Gulf countries situated northeast of Saudi Arabia at the northern end of the Persian Gulf and south of Iraq. Kuwait's total area is 6,880 sq. mi (17,818 sq. km) with a population of 4,004,735 that is growing at a rate of 1.7% (Central Intelligence Agency, 2014; Public Authority for Civil Information, 2013). The population is 63% male and 37% female. Of this population, only 31% (1,251,532) are Kuwaiti nationals, whereas foreign nationals represent the remaining 69% (2,753,253) (Public Authority for Civil Information, 2013). Kuwait is one of the world's most prolific oil producers, owning 6% of the world's oil reserves, and ranks 10th in the world for oil

production. Oil constitutes 95% of Kuwaiti government income, making it one of the wealthiest oil nations of the Gulf. The supreme law of the land in Kuwait is Islam, which also serves as the primary religious institution governing the attitudes and development of the nation and people (Central Intelligence Agency, 2014).

In Kuwait, people with disabilities face overwhelming hardships that can affect not only their mental well-being, but also their emotional, social, and personal lives. One cultural paradigm in the State of Kuwait is the segregation of individuals with disabilities from social interactions, especially children who exhibit physical disabilities or deformities. This has escalated to the extent that many families purposely keep family members with disabilities hidden from society (Al-Hilawani, Koch, & Braaten, 2008). In Kuwait there is a strong social stigma against individuals with disabilities. These individuals are largely believed to be incapable of contributing to the community, thus burdening mothers of CDs with a disproportionate sense of shame and reinforcing their tendencies to keep those children hidden (Al-Kandari & Al-Qashan, 2010).

Fortunately, Kuwait has begun to develop and increase available services for children with disabilities. A 1996 disability law (NO 13/96) gave Kuwaitis with disabilities some legal protection, mandating that they be included in social settings, such as school and the workplace, and providing them with more social services (Al-Hilawani, et al., 2008; Salih & Al-Kandari, 2007). While this law is a useful starting place for protecting the rights of the disabled, it has not been strictly enforced and has thus far failed to take the wide-reaching changes needed to improve the lives of individuals with

disabilities (Al-Hilawani, et al., 2008). Legal mandates are just one of the many factors that affect the lives of individuals with disabilities and their caregivers.

Focusing on the relationship between mother and CD is important to understanding the depth of reliance between the two. Caring for a child with a disability is a unique task. Many CDs require direct assistance with daily activities, so a mother's responsibilities often go beyond the usual childcare duties (Bourke-Taylor, Law, Howie, & Pallant, 2010). The mother becomes the CD's main support, and the child is likely to completely rely on her for his/her entire life (Koydemir-Özden & Tosun, 2010). Within this dynamic relationship between mother and child, components of proximity, dependency, and emotional attachment are amplified and may be experienced in either a positive or negative way. Because of the connection that forms between the two, mothers develop an unconditional love that allows them to handle the stresses inherent in raising a CD (Sari & Altiparmak, 2012).

This study explored the significance of the reciprocal interactions that occur between mother and CD, mother and family, mother and community, and mother and government. These four relationships are inversely related and have an indirect impact on the mother's emotional burden and sense of support as a caregiver. These, in turn, directly affect the mother's self-efficacy, isolation from society, and attachment relationship with her child. Further examination of this area of study is essential, as these impacts have been identified as leading contributors to exhaustion and burnout for Kuwaiti mothers.

Although there has been some research into the study of children with disabilities, the relationship between the CD's mother and Kuwaiti society has been largely overlooked. The minimal research conducted about mother–society dynamics has resulted in findings that have been contradictory, leading to ineffective and inefficient child development policies. Furthermore, a strong negative stigma against CDs in Kuwait creates a societal disconnect between their mothers and the community (Al-Hilawani, et al., 2008; Al-Kandari & Al-Qashan, 2010; Alazemi, 2010). This research highlights the personal and emotional challenges of raising a CD and how that is reflected by the perception of disabilities in Kuwaiti culture and society.

### **Statement of the Problem**

The lack of resources and support available to parents and caregivers of CDs is a major problem in Kuwait. Research into special education and disabilities in Kuwait has been sparse (Almuhareb, 2007). Furthermore, of the studies conducted, few have focused on the parental or caregiver perspective (Alazemi, 2010). The current study addresses some of these inadequacies. In addition, the research looked at the mother's emotional burdens and sense of support and how they affect her self-efficacy, isolation from society, and the mother–child attachment relationship. Also, this current study investigated the impact that cultural paradigms have upon mothers' perspectives towards disabilities and their personal abilities to raise a CD, thus shedding some light on the disconnect between mother and society. It is hoped that this research will open a dialogue about maternal involvement in order to promote individual success, emotional well-

being, and increased understanding for disabled children, their mothers, and the Kuwaiti society as a whole.

### **Statement of Purpose**

In order to address the question of how social support systems and emotional burdens affect mothers, it is crucial to look at several aspects of disability in Kuwait. The purpose of this study was to examine the attitudes of Kuwaiti mothers towards their children, as well as the interaction between the mother, her family, her community, and the government. Through careful analysis, this quantitative study will hopefully raise awareness about the current social paradigm in Kuwait to bring childhood disabilities out of hiding so that mothers and CDs can live healthy and productive lives.

### **Theoretical Frameworks**

Although many lenses can be used to study the relationships associated with mothers and CDs, the primary focus of this research was on the mother's emotional burdens and sense of support while raising a CD. This study frames the boundaries of its research within the theoretical concepts of Bowlby's Attachment Theory and Bronfenbrenner's Ecological Systems Theory. The following is a discussion of these two theoretical frameworks and how these theories support this dissertation.

#### **Bowlby's Attachment Theory**

Drawing on concepts from ethology, information processing, developmental psychology, and psychoanalysis, John Bowlby formulated the basic tenets of his attachment theory. Bowlby's theory is a way of conceptualizing the ways in which

individuals construct strong emotional bonds to others, particularly caregivers. This theory revolutionized our way of thinking about a child's tie to his or her mother and how that tie is disrupted by separation, deprivation, and bereavement (Biringen, 1994; Slater, 2007).

According to attachment theory, the closeness between an infant and primary caregiver sets the foundation for all future relationships (Bowlby, 1958). These attachment figures can be either primary, which are the people with whom the child develops his or her main lifelong emotional bonds (usually mother and father), or secondary, which are the figures with whom the child develops special relationships (such as siblings, grandparents, etc.). As an individual grows up and becomes more involved with groups outside the home, secondary attachment figures become more prominent. Older children and adults can form attachments to schools, political groups, social groups, and so forth.

Drawing on the ethological theory, Bowlby (1958) postulated that attachment behaviors, such as crying and searching, are adaptive responses to separation from a primary attachment figure. Bowlby characterized *secure attachment* as a predictable, loving, and safe bond between a child and either a primary or secondary attachment figure. In contrast, an *insecure attachment* means that the child has a less predictable and loving bond with an attachment figure. Fostering an insecure attachment to parents during a child's infancy has been linked to increased aggression and poor emotional

control and social skills throughout childhood (Shmueli-Goetz, Target, Fonagy, Datta, 2008; Slater, 2007).

Research on adult attachment is guided by the assumption that the same motivational system that gives rise to the close emotional bond between parents and their children is responsible for the bond that develops between adults in emotionally intimate relationships with their families or community. The mothers in this study felt the role of primary attachment figure for their children, and their husbands do the same for them. Likewise, just as a child's positive attachment leads to feelings of self-worth, the same is true for mothers (Platt, Nalbone, Casanova, & Wetchler, 2008). This assumption provided a framework for the current study's exploration of how a mother's attachment to her family and community influences her relationship with her child and develops her self-efficacy.

The attachment theory reveals some interesting and insightful ways of understanding the inherent connection between attachment relationships and the parent-child relationship (Harris, Marshall, & Schvaneveldt, 2008). It can also help frame the different structures of emotional disturbance, which occurs as a consequence of disrupting attachment bonds (Biringen, 1994). Thus, this study utilized the attachment theory to examine how these emotional disturbances or burdens can cause a breakdown in the healthy parenting style of a parent with a CD.

## **Bronfenbrenner's Ecological Systems Theory**

Bronfenbrenner's (1979) Ecological Theory presents a model for human development in terms of a person's reactions and adjustments to contextual pressures. This theory is based on the premise that development does not take place in a vacuum; rather, people constantly adjust to ever-changing social and cultural environments including family life, community relations, and economic and political structures. This basic assumption was used as a starting point to explore the ways in which the mother's personal development as a parent is affected by her relationships with her child, family, community, and government.

The human ecology model is based on layers or systems of social interactions that affect a person's development. Within each system, a person's development or behavior is influenced by their activities, roles, and personal relationships. Roles are the societal expectations for how an individual is expected to act within a system, and personal relationships are the ways people treat others and interact (Zukoski & Luluquisen, 2006).

There are five systems in Bronfenbrenner's (1979) model: the microsystem, mesosystem, exosystem, macrosystem, and chronosystem. The *microsystem* is the innermost layer and includes interactions with the child, family, peers, and neighborhood. These bi-directional relationships have the most immediate effect on a person's behavior. The interactions between mothers and CDs are also at this level. A mother's family interactions and support systems are included in this level. The next layer is the *mesosystem*, which involves connections between microsystems, such as family-peer,

child–school, child–neighborhood, and so forth. Several aspects of a mother’s sense of support are affected by the mesosystem. Next is the *exosystem*, which consists of the social structures that indirectly influence a person’s development; for example, parent workplace schedules or community based family resources. A parent’s sense of support from the government will largely fall within the exosystem. The *macrosystem* refers to the larger cultural context that affects personal development, including political culture, socioeconomic status, and the media. Finally, the *chronosystem* involves the effects of events over time. Non-normative environmental changes, such as divorce, death of a family member, or diagnosis of a disability, would fall into this category.

Bronfenbrenner’s theory has played a significant role in studying contextual influences on child development around the world. In this study, it provided the framework for analysis of the many intertwining and multi-layered relationships that affect Kuwaiti mothers as they raise their CDs (Zukoski & Luluquisen, 2006).

### **Research Question**

The primary research question, which situates the current study in previous research, was:

How do emotional burdens and a sense of support affect Kuwaiti mothers as far as their self-efficacy, isolation from society, and mother-child attachment relationships?

Independent Variable 1: Emotional burdens

Independent Variable 2: Sense of support

Dependent Variable 1: Effects on mothers as far as her self-efficacy, isolation from society, and mother-child attachment relationships

This research further explored two key questions, which were at the forefront as the primary research is conducted. These two questions were as follows:

### **Research Question One**

How do the emotional burdens of a mother of a CD contribute to the feeling of isolation from society?

This question seeks to explore the stereotypes that have become a hindrance upon the functionality of the mother to fully and confidently perform her role. This question is critical in addressing those external forces that prohibit her performance.

### **Research Question Two**

How does a healthy sense of support contribute to increasing self-efficacy in a mother of a CD?

This question seeks to examine the factors that contribute to the well-being of the mother. By exploring both support and burdens, this study sought to gain an understanding of the balance that is essential for mothers in performing their roles.

### **Hypotheses**

The following hypotheses guided this study:

H 1. Mothers who perceive a higher sense of support will have an improved sense of self-efficacy regarding themselves and their parenting abilities. Conversely, those who perceive higher emotional burdens will have a lower sense of self-efficacy.

H 2. Lack of sense of support associated with mothers of CDs causes them to feel a disproportionate sense of social isolation. This, in turn, adversely affects the mother–child relationship. If the mother perceives her emotional burdens associated with raising a CD as higher, her sense of social isolation will also increase.

H 3. When mothers have higher emotional burdens and feel less supported, their attachment relationships with their CDs are negatively affected.

H 4. Many Kuwaiti mothers of CDs will perceive current support systems for mothers of CDs in Kuwait as inadequate. These mothers are expected to desire increased support from their families, their communities, and the government.

### **Delimitations**

1. The research sample was limited to Kuwaiti mothers who (a) are between the ages of 19 and 50 years old, (b) live in Kuwait, and (c) have at least one CD between the ages of 1 and 14 years old with a visible disability.
2. The study was limited to mothers of CDs with a visible disability.
3. Due to the lack of open access in supporting mothers with CDs, convenience sampling strategies were used.

### **Assumptions**

1. It was assumed that it would be difficult to recruit participants for this study due to societal stigmas against sharing personal information. The social tendency to hide CDs from public view will make this particularly challenging.

2. It was assumed that participating mothers would answer questions honestly and accurately to the best of their abilities.
3. Finally, it was assumed that mothers of CDs who chose to participate would be interested in seeking further assistance based on the results of this research.

### **Definition of Terms**

The following terms were defined for the purpose of this study:

1. Attachment: The emotional bond created between a child and the primary caregiver (Bowlby, 1958).
  - a) Secure attachment: means the child has a predictable, loving, and safe bond with either a primary or secondary attachment figure. (Shmueli-Goetz, et al., 2008).
  - b) Insecure attachment: means the child has a less predictable and loving bond with an attachment figure (Bowlby, 2007).
2. Bronfenbrenner's Ecological Theory: A model for human development in terms of people's responses to contextual pressures. This model includes five levels of social interactions that influence individuals (Bronfenbrenner, 1979).
  - a) Microsystem: The innermost layer that includes the mother's interactions with the child, family, peers, and neighborhood (Bronfenbrenner, 1979).
  - b) Mesosystem: Connections between microsystems, such as family-peer, child-school, child-neighborhood (Bronfenbrenner, 1979).

- c) Exosystem: The social structures that indirectly influence a person's development, such as the political system, educational system, and government (Bronfenbrenner, 1979).
  - d) Macrosystem: The greater cultural context, including national economy, media, and political culture, that affects the relationship between a mother and her CD (Bronfenbrenner, 1979).
  - e) Chronosystem: The effect of events over time, particularly non-normative environmental changes that influence development (Bronfenbrenner, 1979).
3. Self-efficacy: In the context of parenting, self-efficacy is the mother's perceived capabilities in meeting her child's needs and exercising control over events that affect their lives (Bandura & Wood, 1989).

### **Summary**

Disability theorists argue that the "inferior social status given to individuals with disabilities does not result from bodily defects, but rather to myths, fears, and misunderstandings that society attaches to them" (You & McGraw, 2011, p. 5). This is particularly true in Kuwait, where exclusionary practices exist at all levels of society, from family to community to government. This cultural paradigm has a profound impact not only on the CD, but also on his or her mother and family. Using a primarily quantitative design, this study focused on the maternal perspective of raising a child with a disability in Kuwait. This study examined the ways in which mothers make sense of

themselves and their children in terms of the sociocultural ideas about disability and maternal roles. It explored the impact of social context on the mother's sense of support and ability to perform her role and deal with emotional burdens, and how these factors influence her self-efficacy, isolation from society, and mother-child attachment relationship.

The mother's impact on a CD's life is critical to helping such a child navigate the challenges of life in Kuwaiti society. An open examination of the stresses mothers of CDs face in Kuwait will have the potential to open a dialogue about parental and societal involvement in a CD's life. Bringing these issues to light will create the opportunity to promote individual success, enhanced physiological and psychological well-being, and an improved quality of life for CDs and their families.

## CHAPTER II

### LITERATURE REVIEW

Raising a child with disabilities (CD) is a profoundly stressful task for any parent. Koydemir-Özden and Tosun (2010) reported that there are significant universal stressors for parents and CDs as they learn to cope with the everyday challenges of growing up with disabilities. Such stressors include balancing intensive childcare responsibilities with financial and time constraints, negative social attitudes, and lack of information, all while battling exhaustion and burnout. In Kuwait, where disabilities carry an extreme social stigma and CDs are generally isolated from their communities, the associated emotional burdens and poor support systems can be particularly overwhelming for mothers (Al-Kandari & Al-Qashan, 2010).

In traditional Kuwaiti society, mothers are the primary caregivers of their children. On the other hand, fathers play a less direct role in childcare (Al-Kandari, 2005). Unsurprisingly, in Alazemi's (2010) examination of stress in Kuwaiti parents of children with specific learning disabilities, he found that mothers had higher stress levels than fathers. Moreover, despite research into the adaptation process and coping strategies for parents dealing with initial diagnosis, Koydemir-Özden and Tosun (2010) stated that many researchers have found that mothers of children with disabilities consistently reported higher levels of stress, depression, and health problems than mothers of children without disabilities. Specifically, mothers of CDs tend to have higher stress levels

associated with the parenting relationship. This may disrupt the mother–child attachment and put the growth and development of both individuals at risk (Alazemi, 2010).

Two main contributors to maternal stress are the emotional burdens of raising a CD and a mother’s sense of support. Emotional burdens include the stress of dealing with initial diagnosis and the child’s future prospects, changes to family lifestyle, social stigmas against disabilities, and a general lack of resources. The way a mother copes with these burdens is affected by her sense of support from the family, community, and government. Together, all of these stressors affect the mother’s sense of self-efficacy, isolation from society, and overall emotional relationship with the CD.

### **Kuwaiti Families**

Before looking at the current literature focusing on the CD’s mother and society, it is important to begin the conversation with a discussion of the role of the family in Kuwait. Traditional familial roles have changed significantly over the years, contributing to the isolation and stress mothers may feel when dealing with CDs without a large, supportive family network. This study referenced Al-Thakeb’s (1985) research pertaining to Kuwaiti family structure and change. Although the study is 30 years old, it is the only such study available and the historical information it presents remains accurate and relevant to this day.

The word “family” has always had a special meaning to Kuwaitis (Al-Thakeb, 1985). The Kuwaiti people’s lineage is based upon an extended family structure. Family is the main source of support within the community. In the past, the Kuwaiti family was

very connected and known to help each member with emotional, financial, and social necessities.

The woman's role in Kuwaiti society has changed over the decades (Al-Thakeb, 1985). Formerly, the children were cared for inside the home by the women of that house. In addition, a newlywed woman was surrounded by other experienced women ready to help ensure the preservation of her marriage. This supportive network provided a useful source of parental advice. Outside of the house, neighbors and members of the mosque also saw it as their responsibility to stay involved with the actions and well-being of the children. Therefore, in many ways, the people outside of the home had an equally strong influence on a child's welfare and character development. This closely connected community promoted a child's attachment to his or her parents, extended family members, and neighbors.

In recent decades, Kuwaiti parenting styles have shifted away from their historical roles. As a result of the changing times, the family - which is the basic social unit in Kuwait - has been disrupted by the many transformations taking place in the country. The nuclear family has emerged to usurp the traditional role of the extended family, and poor communication between children and parents has led to numerous parenting problems (Al-Thakeb, 1985). For families with a CD, the reduced role of the extended family means the loss of a much-needed support network for both mother and child. Childcare duties that once would have been spread out among family members now rest solely on the mother, who may also have increased career responsibilities outside the home. Thus,

these cultural changes that isolate mothers from the extended family contribute to her emotional burdens and fundamentally change her sense of support while dealing with the challenges of raising a CD.

### **Emotional Burdens**

Research has shown that parents of children with disabilities have consistently higher levels of stress than parents of children without disabilities and that this stress is chronic and persistent (Koydemir-Özden & Tosun, 2010). Some of the biggest sources of stress are the emotional burdens associated with raising a CD. The mother, in particular, faces several unique emotional burdens as a direct result of her role as primary caregiver to the CD. The discovery that her child is disabled requires a radical shift in perspective and changes many family plans. Thus, one of the first challenges mothers must deal with is learning to handle their own emotional reactions to their child's diagnosis and how it affects their child and family's future prospects (Chang & McConkey, 2008; Kay, 2011; Koydemir-Özden & Tosun, 2010). In addition, caregiving for a CD is time-consuming and requires changes to the family lifestyle, which often becomes a source of family and marital discord. These burdens are compounded by social stigmas that isolate mothers from the rest of society, as well as a frustrating lack of resources for mothers seeking information and help with their child's disability (Chang & McConkey, 2008; Kay, 2011; Koydemir-Özden & Tosun, 2010).

## **Reactions to Diagnosis and Future Prospects**

The emotional toll associated with having a CD begins in the earliest stages of diagnostic discovery. Common parental feelings associated with the initial stages of coping with a CD include the initial shock of discovering their child has a disability, frustration, self-blame, and grief over their child's diagnosis (Koydemir-Özden & Tosun, 2010; Reichman & Corman, 2008). Since most parents hope for a happy and healthy child, the realization that their child is disabled inspires long-term unhappiness (Hasnat & Graves, 2000; Luterman, 2004).

Heightened parental stress lasts far beyond the child's initial diagnosis, stretching into the CD's childhood and adult years (Roll-Pettersson, 2001). CDs often have significant behavioral and psychological problems that act as a constant source of stress for mothers. Furthermore, it is well-documented that mothers tend to react with sadness and frustration when their children repeatedly struggle with basic developmental tasks (Al-Kandari, 2005). When Kay (2011) conducted a qualitative study of 40 Arab mothers of CDs, he identified that one of a mother's clearest points of grief is the sense of lost opportunity for her child. A constant source of worry is the CD's disappointing future prospects, particularly once the parents are dead or otherwise unavailable. Such common concerns include the CD's future prospects for education, employment, marriage, housing, recreation, and social life (Chang & McConkey, 2008; Kay, 2011).

Parents not only worry about the CD's future, but also about the possible impact on other members of the family. Could the same affliction strike one of them,

too? Leyser and Kirk (2004) found that these anxieties are rooted in a lack of knowledge about certain diseases and disabilities. This stems from social isolation, poor quality of instructors, and negative attitudes. For example, researchers found that one of the biggest worries for families of patients with Multiple Sclerosis (MS) in Kuwait was the fear that MS might surface in other family members. Such fears were found to have a negative impact on the quality of life of both the mothers and the individuals with the disability (Alshubaili, Awadalla, Ohaeri, & Mabrouk, 2007).

### **Changes to Family Lifestyle**

Research has demonstrated that adding a CD into the family significantly changes the family's lifestyle. Children with special needs demand an increased level of support from their parents (Gaad, 2004). Acting as the primary caregiver for a CD is a profoundly time-consuming task that often necessitates lifestyle changes for both mothers and families. In a survey of caregivers in the United States, 72% of those interviewed reported significant lifestyle changes to accommodate the needs of the individual with disabilities (National Survey of Caregivers, 1988). These changes included giving less time and attention to other family members, taking fewer vacations, and focusing less on the caregiver's own health. In addition, having a CD often increases the chance of divorce, forces mothers to quit working outside the home, and discourages couples from having larger families (Olsson & Hwang, 2003).

In a survey of Taiwanese parents, Chang and McConke (2008) explored the positive and negative lifestyle impacts of raising a child with a disability. Some of the

positive impacts reported included increased family closeness, since the entire family felt an obligation to help the CD, and “personal growth” and the self-pride parents gained from helping and supporting their child. Conversely, many parents experienced negative effects from their roles as caretakers, often feeling like their personal lives were abandoned in order to care for the CD. As a result, the majority of parents of children with disabilities found themselves in a situation where there is very little time to relax and take care of their own personal needs. Another common problem was poor communication between parents, who often had trouble expressing their feelings and emotions. Instead, these parents tended to internalize stress, which negatively affected their own health.

The everyday challenge of meeting a CD’s needs may consume a family and severely limit their social and recreational lives (Chang and McConkey, 2008; Olsson & Hwang, 2003). For instance, research has shown that couples with CDs have lower rates of social participation than those with children without disabilities (Olsson & Hwang, 2003). Furthermore, a mother’s time and attention can become so consumed by caring for her CD that the rest of the family feels that their needs are being neglected. Consequently, her husband and other children may feel rejected and resentful of the attention given to the CD, and the mother may feel stress and guilt because she has less time and energy remaining for other family members. Couples often hope to improve their lifestyles, and the failure to fulfill this desire can cause parents and families to lose

self-confidence (Alazemi, 2010; Olsson & Hwang, 2003; Reichman & Corman, 2008; Russell, 2003).

Furthermore, parents of CDs spend limited time together and are less satisfied with levels of mutual support. This leads to an increased sense of isolation and strain on their relationships. Unsurprisingly, research indicated that parents of CDs are more likely to have marital problems (Ferguson, 2002; Kucuker, 2006; Redmond, Bowen, & Richardson, 2000).

### **Social Stigma Against Disabilities**

An unfortunate cultural paradigm in Kuwait is the segregation of individuals with disabilities from social interactions. This includes children who exhibit visible physical disabilities or deformities. To this end, many families purposely keep family members with disabilities hidden from society (Al-Hilawani, et al., 2008; Al-Kandari & Al-Qashan, 2010). The idea that the CD reflects negatively on the family, specifically the mother, heightens this prejudice and creates a barrier between the mother and society. There is a common notion in Kuwait that the CD is not “right.” This attitude makes it difficult for the mother to find information, resources, and emotional support from the community. Salih and Al-Kandari (2007) pointed out that the lack of public knowledge about disabilities causes many people to rely on negative stereotypes of CDs. The exclusion of people with disabilities from positive public roles means many people are never exposed to positive examples of individuals with disabilities. This isolation contributes to the negative assumption that people with disabilities are a social burden.

Furthermore, misrepresentation of disabilities in the media compounds the problem, and researchers have observed much more explicitly negative attitudes towards disabled individuals in Kuwait than in Western countries (Awad & Sarkhoo, 2008).

Kay (2011) conducted a study in Qatar examining the perceptions mothers of CDs had toward community members' interactions with their children. The study included 40 mothers who had a CD between the ages of 3 and 21 years old. In this study, Kay found prejudices against individuals with disabilities similar to those observed in Kuwait and theorized that these stigmas-and consequently, maternal sense of shame - were rooted in Middle Eastern ideas of succession and heritage. For example, community members might view the disability as evidence that God is punishing the family for wrongdoings, or it might make it impossible for the CD to someday marry. Therefore, such stigmas may have wide-ranging impacts on the family.

### **Lack of Available Resources**

While there are many reasons that parents feel overburdened, one of the most common stressors for parents and families of a CD is the added responsibility of identifying and choosing services and programs for the child (Chang & McConkey, 2008; Olsson & Hwang, 2003). Due to the complex educational and social needs of CDs, parents may need to find early intervention programs for emotional, developmental, and physical rehabilitation (Reichman & Corman, 2008). This task becomes all the more stressful for parents who feel that they are uninformed about their child's disability and do not have access to necessary services or treatments. Since research has demonstrated

that parents who have better support for their CDs are less stressed, making these services and programs readily available to families of CDs is an important avenue to decrease stress and lead to more positive parental attitudes (Hastings, 2002; Hastings & Brown, 2002; Kucuker, 2006).

Unfortunately, research has found that services offered to CDs and their parents around the world are generally “uncoordinated, insufficient, unreliable, and difficult to access” (Alazemi, 2010, p. 39). For example, educators are often poorly trained with regard to dealing with childhood disabilities (Studer & Quigney, 2005). In addition, parents have trouble finding high-quality and affordable childcare, both because of a lack of appropriately trained professionals and the negative stigma that discourages friends and relatives from getting involved with the child (Al-Kandari & Al-Qashan, 2010; Reichman & Corman, 2008). Thus, parents of CDs spend a significant amount of time seeking the support and resources needed. Coupled with the challenges of processing the information and dealing with uncoordinated professionals, this greatly increases the burden on the parents (Chang & McConkey, 2008; Hasnat & Graves, 2000; Kucuker, 2006; Olsson & Hwang, 2003; Russell, 2003).

In summary, the aforementioned stressors-reactions to the diagnosis, changes to family lifestyle, social stigmas, and lack of helpful resources-overlap and combine to create emotional burdens on mothers of CDs that may often seem overwhelming. The ways in which these burdens and the mother’s sense of support affect her abilities as a parent were further explored in this study.

## **Sense of Support**

Mothers of CDs require support on many levels to cope with the stresses and challenges associated with raising children with special needs. In fact, support is recognized as the most important external coping strategy by parents with CDs, and lack of support is correlated with increased parental stress. Support may take the form of emotional support, information and education, medical services, and financial assistance (Chang & McConkey, 2008; Hastings, 2002; Kucuker, 2006). Unfortunately, many Kuwaiti mothers are unable to find the support they need to deal with the challenges presented by their children's disabilities (Al-Kandari & Al-Qashan, 2010; Huseen, Al-Saleh, & Al-Khalid, 2002; Kay, 2011).

Cutrona and Russell (1987) conducted a study researching the outcomes of supportive interpersonal behaviors and found that individuals receiving high levels of emotional and social support reported the highest levels of perceived coping mechanisms in stressful and depressive situations. Further highlighting the benefits of emotional support, Burleson (2003) discussed the positive effects of support networks on individuals battling multiple ailments. Burleson stated that previous research has even found that in severe situations-such as having a serious heart disease, a debilitating injury, or cancer-individuals with a strong support network have an increased ability to cope and attain a greater chance of recovery. For parents of CDs, social support from family and friends in the community can play a significant role in decreasing parental stress (Kucuker, 2006).

Notably, most parents of CDs tend to seek support mainly from professionals. For example, in a 1992 study of parents of children with disabilities in Jordan, the vast majority of parents surveyed (76.7%) stated that they preferred to speak to professionals when seeking support for their child, while 23.3% expressed a need to talk to friends, and 22% to family (Al-Kandari, 2005). Because of stresses on time, diminished recreation, difficulties in daily activities, and financial burdens, professional help and appropriate resources can be a valuable lifeline for a mother who is struggling to cope with raising a CD. Unfortunately, reserving support only for professionals promotes the idea that caregiving and building emotional ties with the CD is something difficult, unfamiliar, and specialized. This mindset makes it difficult for Kuwaiti mothers to form support networks because the care and support offered by family, friends, and other resources may fail to meet the standards set by professionals. Ultimately, this attitude can make it difficult for mothers to develop other supportive interpersonal relationships.

Although current conventional wisdom seems to put the emphasis on professional support, there are several potential groups and institutions Kuwaiti mothers may utilize when building support networks. As they learn to cope with the stresses of everyday life and parenthood, mothers of CDs look to their family, community, and government for help.

### **Support from Family**

One of the most immediate sources of support for a mother of a CD is her family. As discussed previously, the Kuwaiti family includes not only immediate family

members, but also the extended family network. Families can be sources of both practical assistance with day-to-day tasks and emotional support.

Familial support varies greatly for different mothers. Some parents rely heavily on their spouses and family members for support when dealing with their child's disability. However, many mothers find this support lacking, fostering a sense of isolation and loneliness in their relationships with others. For example, husbands usually have many issues to think of, so oftentimes the wife is unable to talk about her child with her husband. In addition, Chang & McConkey (2008) stated that some mothers mentioned that their relatives have their own problems and they do not want to listen to her complain or discuss her child's situation. Finally, many of the mother's relatives felt scared or uncomfortable being around a CD.

Although mothers often report a lack of family support, those that have strong family support networks are greatly benefited. Lindblad, Holritz-Rasmussen, and Sandman (2007) discussed the benefits of informal support. They asserted that, while medical professionals can assist with the physiological well-being of a child with a disability, informal support, such as a network of families with similar family composition, can be just as important. The extended family network can support the mother by sharing an understanding about the challenges, sorrows, and joys associated with having a family member with a disability. Lindblad et al. (2007) demonstrated that this informal family support network imparts a sense of security to the family and parents of the CD by including the CD in social relations with others. Such experiences foster a

sense of satisfaction and unity in the family. In fact, Chang and McConke (2008) stated that the encouragement and support of friends and relatives is not only crucial to keep parents going, but is in some ways even more important than help from professionals.

### **Support from Community**

Lack of community support and acceptance is a constant frustration for mothers of CDs. The deeply ingrained social stigmas against people with disabilities in Kuwait means community members are less likely to offer support and understanding to mothers of CDs. Al-Kandari and Al-Qashan (2010) reported that mothers of a CD in Kuwait are at an increased risk of facing negativity and rejection due to concerns that they are a burden to potential social supporters. Because these mothers feel that their emotional concerns and needs are so different from those of their peers, they express anxiety associated with finding the “right” group of people to share their difficulties, establishing emotional bonds, and finding an audience to adequately listen and support them without backlash and negative reactions towards their CD. These factors all lead to instability in maternal health and negatively affect a mother’s self-efficacy.

In order to provide the community support mothers of CDs require, a general change in public attitudes towards disabilities is necessary. Kay (2011) reported that Qatari mothers hold parents of children without disabilities responsible for failing to teach their children acceptance. As a result of children not learning to accept people with disabilities, CDs are often excluded in school by their peers, a fact that weighs heavily on their mothers. Research has indicated that the attitudes of community leaders and a CDs’

peers, such as other students, are critical in helping to change broader community perceptions toward CDs (Salih & Al-Kandari, 2007). Thus, it seems likely that small-scale changes, like public actions by leaders that include individuals with disabilities, or positive attitudes of students towards inclusive special education, could be the catalyst for larger-scale adjustments in the way members of the community treat CDs and their families.

### **Support from the Government**

Kuwait's government has the potential to become a major source of professional support for mothers of CDs. Since the government is largely responsible for healthcare and public special education, it could offer much needed special services to parents. In fact, under the Care for the Handicapped Law of 1996, the Kuwaiti government does provide services, such as rehabilitation centers, housing specifications, and monthly allowances for mothers and wives of individuals with disabilities (Al-Jazzaf, 2012). Unfortunately, although financial help is available, the Kuwaiti government has fallen short in providing the necessary supportive services needed by mothers who seek help dealing with parenting problems and the stress associated with childhood disabilities. Al-Kandari and Al-Qashan (2010) reported a distinct lack of referral services and professional help for parents seeking informational or psychological assistance specifically oriented towards parenting CDs. Parents require help identifying and coping with specific stressors and information about daycare, transportation, medical options, and other helpful community programs.

Another key form of government support for mothers and their CDs is special education programs. Special education for children with disabilities has improved significantly over the last 70 years, but still remains woefully inadequate to serve Kuwait's disabled population (Huseen, et al., 2002). Over the last 20 years, the Kuwaiti government has begun to offer some support for disabled students. The Ministry of Education established the Higher Council for the Disabled (HCD) providing oversight over government services including healthcare and rehabilitation, special education, social welfare, and advocacy for the disabled (Almuhareb, 2007). The HCD was also in charge of integrating special education classrooms for students with mild intellectual and developmental disabilities into public schools, although progress on this front was slow. Today, there are 38 special education schools in Kuwait: 15 public and 23 private. They serve 3678 students with disabilities including intellectual and developmental delays, blindness, deafness, physical disabilities, and autism (Ministry of Education, 2008, 2009).

As noted previously, a mother's sense of self-efficacy and happiness is closely tied to her child's successes and failures. Academic success and social acceptance are significant hurdles faced by CDs and, by extension, their parents. Studies have indicated that 70% of Kuwaiti parents of CDs are actively involved in their children's special education programs (Al-Shammari & Yawkey, 2008). Thus, government policies that advocate inclusion of CDs in public schools are essential to a mother's emotional well-being. Inclusion in schools is thought to be a first crucial step towards inclusion in society; it not only provides CDs with the tools to become productive and independent

members of society, but also conditions their peers to accept and include them in everyday life (Al-Jazzaf, 2012).

The 2010 Rights of Individuals with Disabilities Act called for inclusion of disabilities in public schools, marking the first official move towards widespread acceptance of student CDs (Al-Hilawani, 2011). The full-inclusion model of special education has yet to be implemented, partially because of resistance from some parents of children without disabilities-many believe that segregation is better for both abled and disabled child as far as education level-as well as the lack of qualified teachers. However, the Ministry of Education of Kuwait has declared inclusive education as a future goal to improve the quality of life for CDs. Some officials have suggested instituting separate special-needs classrooms within traditional schools as a possible alternative to complete inclusion (Al-Jazzaf, 2012).

Thus far, individuals with physical disabilities are more readily accepted in traditional schools than their peers with intellectual (ID) or developmental disorders (DD) (Al-Jazzaf, 2012). The ID and DD groups are generally still segregated into separate schools, a symptom of the larger social problem of excluding individuals with certain disabilities. However, advocates of the full-inclusion model hope that raising awareness will ease the transition into acceptance of these children in traditional public schools. As Kuwaiti schools use partial inclusion as a stepping-stone toward full inclusion, public education officials need to establish new, stricter standards for work ethics, teacher training, collaboration, and material support. Shifting towards a special education system

that empowers CDs and focuses on developing their strengths is one of the most promising avenues towards social acceptance and improved quality of life (Al-Jazzaf, 2012).

Although Kuwait has certainly made progress in its special education offerings, there are still not enough programs and services to meet the needs of the disabled population. Special education only accounts for 3,678 of the nation's students, compared to 525,759 non-disabled students in general education schools, and very few public schools have made any attempt to include children with disabilities in combined classrooms (Almutawa, 2006; Ministry of Education, 2008).

Compounding these problems is a lack of resources to train future special education teachers. No university in Kuwait, public or private, sponsors training or research in the special education field. This contributes to an overall lack of awareness in the country and makes it difficult for researchers to publish studies and disseminate information in order to bring about reforms (Almutawa, 2009).

On the whole, previous research indicates that the various support systems mothers might rely upon are often inadequate to satisfy the practical and emotional needs of mothers of CDs in Kuwait. This diminished sense of support combines with the aforementioned emotional burdens to add stress to an already difficult parenting dynamic.

### **Effects on Mothers**

For mothers of CDs in Kuwait, these emotional burdens and inadequate support systems take a significant toll on their mental well-being and parenting abilities. With so

many stressors, mothers experience adverse effects not only on their own psyches, but also on the mother–CD relationship. Compared to mothers of children without disabilities, mothers of CDs in Kuwait have lower self-efficacy, greater isolation from society, and a less secure parenting attachment relationship (Al-Kandari, 2005; Al-Kandari & Al-Qashan, 2010; Kay, 2011; Sari & Altiparmak, 2012).

### **Self-Efficacy**

Perhaps one of the most adversely-affected elements of a mother’s well-being is her sense of self-efficacy (Al-Kandari, 2005). In the context of parenting, self-efficacy is the mother’s perceived capabilities in meeting her child’s needs and exercising control over events that affect their lives (Bandura & Wood, 1989). A mother’s self-efficacy depends on her beliefs in her own childcare abilities and how well her child seems to be doing. She derives self-efficacy and self-confidence from her own perceptions of how well she is able to provide for her child’s emotional and basic needs, manage her child’s behavioral problems, advocate for her child, and maintain awareness of her child’s educational needs (Al Kandari, 2005).

The importance of self-efficacy cannot be overstated. Research has demonstrated that mothers with high self-efficacy experience less stress in raising their CDs (Al-Kandari & Al-Qashan, 2010). Improved maternal self-efficacy in mothers of CDs is linked to decreased guilt, less anxiety and depression, more secure attachment relationships with the CDs, greater consistency in mother–child interactions, and increased parental involvement in treatment and intervention programs. Such mothers are

generally more optimistic and more satisfied with life (Al-Kandari & Al-Qashan, 2010). Thus, a strong sense of self-efficacy is one of the greatest factors attributed to a healthy parenting style.

Parenting a child with special needs is a uniquely difficult task, and many Kuwaiti mothers of CDs report feelings of frustration and hopelessness due to their perceived shortcomings as parents (Boothroyd, 1997). This poor self-efficacy stems from the belief that they are unable to control their child's behavior, cope with frustration, manage their anger towards their child, understand their child's problems and educational needs, communicate with their family about the child, and ask others for help. Research has shown that many mothers facing such stressors tend to doubt their parenting abilities, a further source of stress and sadness (Al-Kandari & Al-Qashan, 2010).

Although poor self-efficacy can be a problem for mothers of CDs anywhere, mothers in Kuwait seem to be particularly self-critical. Al-Kandari and Al-Qashan (2010) theorized that the perceived insufficiencies of Kuwaiti mothers, when compared to those of mothers of CDs in Western countries, may be related to a dominant perception that their caregiving abilities cannot measure up to those of professionals and special education programs. Therefore, the lack of available professional help is an added source of anxiety for mothers. These researchers suggested the government and professionals in Kuwait ought to put an increased emphasis on family education in order to encourage and strengthen a mother's perception of self-efficacy in daily encounters with her child.

### **Isolation from Society**

Mothers often experience feelings of guilt and shame as a direct consequence of Kuwaiti society's stigma against individuals with disabilities. Childhood disabilities are generally characterized as God's way of punishing or testing a parent, so mothers are often overwhelmed by guilt and depression about their role in their child's struggles (Kay, 2011). This pervasive feeling of shame may lead them to further isolate themselves and their child from friends and relatives in the community. Adding to the burden of social stigma, a mother's failure to meet her own expectations compounds her sense of shame leading to feeling socially isolated. Raising a CD often bears little resemblance to the parenting experience a mother once imagined. Sari and Altiparmak (2012) described a mother's disappointment and shame surrounding the unexpected parenting experience and the perception of her "imperfect child" as a "narcissistic injury".

Closely linked to the burden of shame, mothers also find themselves increasingly isolated from society. The gradual withdrawal of family support because of the social stigma encourages feelings of isolation and makes it difficult to establish relationships outside of the immediate family. Staring, pity, and ill treatment by members of the community are markers of exclusion. Children without disabilities observe and mimic these behaviors, thus passing the exclusionary tactics down from generation to generation (Kay, 2011). These negative reactions from society cause the family to become more closed-off (Sari & Altiparmak, 2012).

Insufficient exposure to individuals outside of the family also has adverse effects on the mother and child's behavior towards society and overall well-being. Mothers often report a reluctance to take their children out in public (Kay, 2011). The overwhelming sense of exclusion from the community makes it difficult for mothers to form and maintain friendships. They may feel lonely and unsupported and be less satisfied talking to friends because of a lack of common ground (Al-Kandari & Al-Qashan, 2010). Mothers often feel cut-off from social activities and friendships after having their CD. According to Chang and McConkey (2008), this isolation stems from the prevailing social stigmas. For instance, one mother in the researchers' qualitative study reported that "they said you and your son suffer from disability because you have sinned" (p. 66). These factors all lead to instability in maternal health, ultimately making it more difficult for mothers to be productive caregivers to their CDs.

### **Mother-Child Attachment Relationship**

Lastly, the overwhelming stressors of emotional burdens and poor support networks put a great deal of pressure on the mother's attachment relationship with her CD. This study explored the ways in which the two aforementioned effects of that pressure—poor self-efficacy and social isolation—tend to mediate the mother-child attachment relationship.

According to Slater (2007), relationships form the key experiences that connect children's personal and social worlds. Slater stated that Bowlby's early work affirmed that unbroken early attachment to their mothers is essential to infant development. In

addition to the social implications regarding a child's development, attachment has also been recognized as being a key element in the foundation of healthy individual development. In fact, further research conducted by Shmueli-Goetz et al. (2008) has shown that the nature of relationships between parents and infants or young children greatly affect the child's later personality and relationship development. For instance, abused and neglected children or those who were exposed to parents with violent or poor quality marriages tend to have more anxious and avoidant attachment styles as adults (Platt, et al., 2008).

The high levels of stress mothers of CDs experience can put the mother-child relationship in jeopardy of future problems (Kazak & Marvin, 1984). Sari and Altiparmak (2012) discussed the complicated mother-child relationship, explaining that, although mothers of CDs consistently point to their deep love for their children as the motivation to deal with the stresses of childhood disabilities, the mother-CD relationship can have a darker side. One aspect of this is the rapid burnout experienced by mothers of CDs who report that they feel the need to supervise their children much more than they would a child without a disability. Another, perhaps more serious, problem is that mothers may make the inevitable comparison of their CD to non-disabled children. A common result of this comparison is anger towards the disability and the things that it prevents their child from being able to do. This anger, while originally targeted at the disability itself, can become misdirected toward the child, which then makes the mother mad at herself.

Consequently, parents of CDs are considered to be at a higher risk for anger than other parent groups.

### **Summary**

Much of current research has examined the importance of the mother's role in the CD's development. Conversely, research has also implied that the Kuwaiti mother's mental health and emotional stability is connected with societal factors and personal perception. The dominant finding among the articles reviewed on Kuwait was the need to create a societal support system geared towards acceptance and lack of exclusionary factors.

Kuwait needs to expand the framework used on the topic of disability as a child's development is not solely based upon his or her own capabilities, but rather are shaped by the mother (primary caretaker), family, and social norms. This will also help mothers understand how to assist their children and avoid the social and personal consequences that exist. It is common knowledge that Kuwaiti mothers generally want to support their children, but may not know the proper way. Therefore, it is important to utilize previous research done on maternal health to help them identify any linkage associated to a proper development patterns relating to their child's needs.

## CHAPTER III

### METHODOLOGY

The current study examined the mother–child with disability (CD) attachment relationship in the context of societal influences in Kuwait. Through quantitative method, this study also explored the significance of the interactions that occur between the mother and her CD, her family, her community, and the Kuwaiti government. The study investigated the way these relationships help shape the mother’s emotional burdens and sense of support, how these stressors affect her sense of self-efficacy, isolation from society, and how do these factors, in turn, mediate the effects on the mother–CD attachment relationship. Online surveys were hosted by psychdata.com and used to gather data from participants.

This chapter describes the methodology used in this study by detailing the guiding hypotheses, participant selection and sample size, procedures for protection of human subjects, and instrumentation. Finally, the procedures for data collection and analysis are outlined. The following research questions and hypotheses guided the study.

Research Question 1: How do the emotional burdens and sense of support of a mother of a CD contribute to the feeling of isolation from society and mother-child attachment?

Hypothesis 1: Lack of support causes mothers of CDs to feel a disproportionate sense of social isolation. This, in turn, adversely affects the mother–child relationship. If

the mother perceives her emotional burdens associated with raising a CD as higher, her sense of social isolation will also increase.

Hypothesis 2: When mothers have higher emotional burdens and feel less supported, their attachment relationships with their CDs are negatively affected.

Research Question 2: How does a healthy sense of support and low emotional burdens contribute to increasing self-efficacy in a mother of a CD and improved mother-child attachment?

Hypothesis 3: Mothers who perceive a higher sense of support will have an improved sense of self-efficacy regarding themselves and their parenting abilities. Conversely, those who perceive higher emotional burdens will have a lower sense of self-efficacy.

Hypothesis 4: Many Kuwaiti mothers of CDs will perceive current support systems for mothers of CDs in Kuwait as inadequate. These mothers are expected to desire increased support from their families, their communities, and the government.

### **Research Design**

This study followed a quantitative approach with a descriptive design. Data was collected through online questionnaires.

### **Participants**

The sample consisted of 85 mothers who each had a child between the ages of 1 and 14 with a visible disability. These mothers were recruited online by advertising via the researcher's Instagram account (Q8yaok), which currently has approximately 64,000

followers. The main purpose of the account is to educate women about issues related to the family. The sample size was determined based on a power analysis conducted with G\*Power 3 for a multiple regression analysis. The parameters for the power analysis were as follows: 3 predictors, a medium effect size of .15, alpha level of .05, and power of .80. That resulted in a sample requirement of 77 for the omnibus test and 55 to assess the individual predictors, for a total of 132 participants.

The following criteria were used to identify potential participants:

1. Each mother must currently reside in Kuwait and must have lived there for a minimum of the past 5 consecutive years.
2. Each mother must have a child with a visible disability.
3. Each mother must be between the ages of 19-50 years.
4. Each child with a disability must be between the ages of 1-14 years.

These criteria were selected because of certain aspects of Kuwaiti culture. For instance, the visibility of the disability is a critical component of this study because people with identifiable incapacities or deformities are often hidden from society in Kuwait (Al-Hilawani, et al., 2008). This plays a crucial role in the mother's perception of herself, her child, and how she functions as a mother. These visible disabilities, such as blindness or physical deformities, are included in Kuwaiti special education, unlike the less visible disabilities such as ADHD, dyslexia, or other neurological deficiencies that are not obvious to the general public. Therefore, mothers of children with invisible disabilities were excluded from this study.

Likewise, the age of mothers was based in part upon the consideration of Kuwaiti cultural norms. For example, as a result of 20<sup>th</sup> century Muslim laws, women commonly enter marriage at 18 years of age or older (Al-Kandari, 2005; Alqashan, 2008). Assuming that parameter to be correct, the age of 19 was considered to be the minimum age when the mothers might give birth to their first babies. Therefore, the exclusion of participants who fall outside of the age range of 19-50 years old allowed this study to have a defined scope for the populace being observed.

### **Protection of Human Subjects**

An application to conduct a research study was submitted to the Texas Woman's University Institutional Review Board (IRB). This was to protect the integrity of the study and the participants. The approval was granted by the IRB prior to any collection of data. The survey was uploaded to psychdata.com and posted in an advertisement linking to the survey on Instagram.

Psychdata.com is a professional online survey company that was used to host the surveys. Access to the results of the surveys was available only to the researcher and faculty supervisor via a secure username and password. There was no identifying information such as the participant names, addresses, or e-mail address, to identify the participants. All IP addresses were deleted so that they could not be traced back to the computers and potentially the participants. Every effort was made to ensure the protection and confidentiality of the participants' identities.

Participants were informed of confidentiality by an online consent form that they filled out before accessing the survey. Once the consent form was submitted, the participant was given a link to the survey. At no point were names or identifying data collected or attached to any surveys or forms. The confidentiality of all participants was maintained to the fullest possible extent. Issues of possible harm, confidentiality, and consent forms were addressed in the IRB application.

### **Demographic Information**

Table 1 presents the demographic information for the sample. There were 23 (27.1%) mothers between 19-30 years, 38 (44.7%) mothers between 31-40 years, and 24 (28.2%) mothers whose age ranged between 41-50 years old.

All mothers were married, and one was separated. The mode response for education was “4-year college degree” (45.9%) followed by participants who had some college (23.5%), a high school diploma (12.9%), a graduate or professional degree (10.6%), and less than a high school diploma (7.1%).

The number of children each participant had ranged from 1 to 7 ( $M= 3.76, SD= 1.78$ ). The number of children with a disability ranged from 1 to 4 ( $M= 1.30, SD= .62$ ). Fifty-six mothers (56%) had a male child with a disability, and 29 (34%) had a female child. Children’s ages ranged from 1 to 14 ( $M=7.62, SD=3.88$ ).

Table 1

*Demographic Information*

	<i>n</i>	<i>%</i>	<i>M</i>	<i>SD</i>	<i>Range</i>
<b>Mother's age</b>					
19-30 years old	23	27			
31-40 years old	38	45			
41-50 years old	24	28			
<b>Marital status</b>					
Married	84	99			
Separated	1	1			
<b>Education</b>					
Less than high school	6	7			
High school	11	13			
Some college	20	24			
4-year college degree	39	46			
Graduate or professional degree	9	11			
<b>Occupation Status</b>					
Working Full –Time	26	31			
Working Part –Time	21	25			
Stay Home	34	40			
Other	4	5			
<b>Number of children</b>			3.76	1.78	1- 7
<b>Number of children with a disability</b>			1.30	.62	1- 4
<b>Child's Age</b>			7.62	3.88	1-14
<b>Child Gender</b>					
Male	56	66			
Female	29	34			

## **Instruments**

One survey and several scales were used in this study: A demographic questionnaire, the Parenting Stress Index (PSI-4), the Parental Stress Scale (PSS), and the Sense of Support scale, which was developed specifically for this study.

**Demographic information questionnaire.** To assess the demographic characteristics of the sample, a 10-item questionnaire was used (see Appendix D). This questionnaire gathered information about participant age, education level, number of children with and without a disability, household income, focal child's age, education level, and gender.

**Parenting Stress Index.** Abidin's (2012) Parenting Stress Index (PSI-4) was used to measure sources and magnitudes of stress among caregivers of children with and without disabilities (see Appendix E). PSI-4 includes a 120-statement self-report questionnaire for use with parents of children up to 14 years of age. It is both a screening and diagnostic tool and a means of self-report. Participants were asked to consider several statements and rank them based on their own life experience using a 5-point Likert scale from 1 (strongly disagree) to 5 (strongly agree).

**Attachment subscale.** Mother-child attachment relationship was measured with the PSI Attachment subscale, which consists of PSI items number 61 through 67 (see Appendix E). These items were reverse scored to aid interpretation. Possible scores range from 7 to 35, with higher scores indicating less emotional closeness between parent and child. Reliability for the PSI used in this study was calculated using Cronbach's

alpha. For this sample, the internal consistency of the attachment subscale was below the acceptable level,  $\alpha = .63$

**Isolation subscale.** Social isolation was measured with the PSI Isolation subscale, which consists of PSI items number 91 through 96 (see Appendix E). Possible scores range from 6 to 30, with higher scores indicating greater social isolation. For this sample, the internal consistency of the isolation subscale was below the acceptable level,  $\alpha = .61$

**Competence subscale.** Self-efficacy was measured with the PSI Competence subscale, which consists of PSI items number 28 through 30 and 51 through 60 (see Appendix E). These items were reverse scored to aid interpretation. Possible scores range from 13 to 65, with higher scores indicating lower levels of self-efficacy. For this sample, the internal consistency of the competence subscale was acceptable,  $\alpha = .76$

**Parental stress.** Emotional burdens were measured with the Parental Stress Scale (PSS; Berry & Jones, 1995). The scale consists of 18 items on a 5-point scale (1 = *strongly disagree*, 2 = *disagree*, 3 = *undecided*, 4 = *agree*, 5 = *strongly agree*). The scale consists of PSS items number 1, 2, 5, 6, 7, 8, 17, and 18. These items were reverse scored to aid interpretation (see Appendix F). Possible scores range from 18 to 90, with higher scores indicating higher levels of parental stress. For this sample, the internal consistency of the scale was good,  $\alpha = .84$ .

**Sense of support.** In order to assess mothers' sense of support, they were asked to rate their perception of support received from each of three entities: family, community, and government (see Appendix G). Each was rated on a 5-point scale, and the three items

were be summed, yielding a possible score range of 3 to 15, with higher numbers indicating stronger sense of support. The internal consistency of the scale was below the acceptable level,  $\alpha = .62$

In addition, mothers were asked to indicate via open-ended questions what types of support they receive and what types of support they wish to receive from each of these entities. This open-ended format allowed mothers freedom in answering and provided the opportunity to gather in-depth feedback.

### **Procedures**

Upon receiving permission from the Texas Woman's University Institutional Review Board (IRB) to conduct research, the surveys (see Appendix A) were uploaded to a secure host via psychdata.com. Once permission was granted, participants were recruited via an educational Instagram account managed by the author. This account currently has approximately 64,000 followers, most of whom are women from the Arabian Gulf countries (Kuwait, Saudi Arabia, Qatar, Bahrain, Oman, and United Arab Emirates). The account is used as a tool to educate mothers about how to advocate for their children and to support the mothers emotionally. An advertisement containing information about the study, along with a link to the online survey, was posted at regular intervals.

The advertisement contained information about the study, eligibility criteria, contact information for the principal researcher and the research advisor, and a link to the survey (see Appendix B).

Although this recruitment strategy may not have allowed for a truly representative sample, data collection from this population was more feasible using convenience sampling than random or strategic sampling.

Once a mother agreed to participate and clicked on the link to the survey, she was informed via an online consent form that her participation was voluntary, that she was free to withdraw from the study at any time, and that her answers would be kept confidential (See Appendix C). Those who chose to participate would then click on a link to continue to the actual survey. The consent form and survey were available in both English and Arabic, and participants had the option to choose the desired language before beginning the survey.

### **Summary**

This primarily quantitative study focused on the maternal perspective towards raising a child with disabilities in Kuwait. Of particular interest are the ways in which various emotional burdens and sources of support act as stressors and how they affect a mother's self-efficacy, sense of shame, isolation from society, and mother-CD attachment relationship. A carefully selected pool of 85 mothers of children with visible disabilities in Kuwait was surveyed via anonymous online questionnaires. These questionnaires included the Demographic Information Questionnaire, Parental Stress Scale (PSS), the Parenting Stress Index (PSI), and the Sense of Support scale.

## CHAPTER IV

### RESULTS

The current study examined the mother–CD attachment relationship in the context of societal influences in Kuwait. Through quantitative research, this study was designed to explore the significance of the interactions that occur between the mother and her CD, her family, her community, and the Kuwaiti government. This study also investigated the way these relationships help shape the mother’s emotional burdens and sense of support, how these stressors affect her sense of self-efficacy, isolation from society, and how these factors, in turn, mediate the effects on the mother–CD attachment relationship.

#### **Preliminary Analyses**

Preliminary analyses were conducted to compute descriptive statistics and assess simple relationships between the main variables.

#### **Descriptive Statistics**

**Attachment:** Mother-child attachment relationship was measured with the PSI Attachment subscale, which consists of PSI items number 61 through 67 (see Appendix E). These items were reverse scored to aid interpretation. Possible scores range from 7 to 35, with higher scores indicating less emotional closeness between parent and child. Participants’ scores ranged from 11 to 34 ( $M = 18.92$ ,  $SD = 4.90$ ). See Table 2.

**Social isolation:** Isolation was measured with the PSI Isolation subscale, which consists of PSI items number 91 through 96 (see Appendix E). Possible scores range

from 6 to 30, with higher scores indicating greater social isolation. Participants' scores ranged from 9 to 28 ( $M = 17.42$ ,  $SD = 4.50$ ). See Table 2.

**Self-efficacy:** Self-efficacy was measured with the PSI Competence subscale, which consists of PSI items number 28 through 30 and 51 through 60 (see Appendix E). These items were reverse scored to aid interpretation. Possible scores range from 13 to 65, with higher scores indicating lower levels of self-efficacy. Participants' scores ranged from 24 to 58 ( $M = 39.23$ ,  $SD = 7.96$ ). See Table 2.

**Emotional burden:** Emotional burdens were measured with the Parental Stress Scale (PSS; Berry & Jones, 1995) (see Appendix F). The scale consists of 18 items on a 5-point scale. Possible scores range from 18 to 90, with higher scores indicating higher levels of parental stress. Participants' scores ranged from 22 to 75 ( $M = 43.93$ ,  $SD = 10.29$ ). See Table 2.

**Sense of support:** For the purpose of this study, the sense of support provided by the mother is referenced to outside support from the family, community, and government. In order to assess mothers' sense of support, they were asked to rate their perception of support received from each of three entities: family, community, and government. Each was rated on a 5-point scale, and the three items were summed, yielding a possible score range of 3 to 15, with higher numbers indicating stronger sense of support (see Appendix G). Participants' scores ranged from 3 to 15 ( $M = 8.76$ ,  $SD = 3.07$ ). See Table 2.

Table 2

*Descriptive Statistics*

	<i>n</i>	Min	Max	<i>M</i>	<i>SD</i>
Attachment	83	11	34	18.92	4.90
Social Isolation	83	9	28	17.42	4.51
Competence	81	24	58	39.23	7.96
Emotional Burdens	80	22	75	43.93	10.30
Sense of Support	54	3	15	8.76	3.07

**Relationship Between Main Variables**

To test the simple relationships between the main variables, Pearson correlations were computed. Table 3 shows that all variables are related and there is no multicollinearity present. Therefore, they were analyzed together.

Table 3

*Correlations for all Variables*

	SS	EB	SE	SI	Attachment
Sense of Support	-				
Emotional burden	-.45***	-			
Self-Efficacy	-.39***	.70***	-		
Social Isolation	-.37***	.49***	.54***	-	
Attachment	-.21***	.49***	.58***	.41***	-

Note. \*\*\*  $p < .001$

## **Main Analyses**

Data was analyzed using SPSS Version 21. This section presents the findings for this study. The study addressed two questions and tested four hypotheses, and the results of the analyses were as follows:

### **Research Question One**

Research question one: How do the emotional burdens and sense of support of a mother of a CD contribute to the feeling of isolation from society and mother-child attachment?

Hypothesis one: Lack of support causes mothers of CDs to feel a disproportionate sense of social isolation. This, in turn, adversely affects the mother-child relationship. If the mother perceives her emotional burdens associated with raising a CD as higher, her sense of social isolation will also increase

Hypothesis two: When mothers have higher emotional burdens and feel less supported, their attachment relationships with their CDs are negatively affected.

To analyze the first research question, linear regression was conducted to examine the predictive relationships among sense of support, emotional burdens, social isolation, and attachment. To assess the relationship between sense of support, emotional burdens, and social isolation on attachment scores, a multiple linear regression was conducted using sense support, emotional burdens, and social isolation as predictors and attachment as the dependent variable. The overall model was significant,  $F(3, 45) = 4.16, p = .011, R^2 = .217, \text{adj } R^2 = .165$ . Social isolation was not significant predictor in the model.  $\beta = .298 (SE = .167), t(48) = 1.84, p = .072$ . See Table 4.

Table 4

*Coefficients for Attachment*

Model	B	$\beta$	<i>t</i>	Sig
Sense of Support	.054	.034	.229	.820
Emotional Burden	.112	.245	1.459	.152
Social Isolation	.309	.298	1.844	.072

Follow-up analyses were conducted to test the possibility of mediating relationships and indirect effects. To assess the relationship between sense of support and emotional burdens on social isolation, a multiple linear regression was conducted using sense support and emotional burdens as predictors in the model and social isolation as the dependent variable. The overall model was significant,  $F(2, 46) = 11.62, p < .001, R^2 = .336, \text{adj. } R^2 = .307$ . Emotional burdens was a significant predictor in the model,  $\beta = .493$  ( $SE = .059$ ),  $t(48) = 3.66, p < .001$ . Sense of support did not significantly predict social isolation,  $p = .256$ . See Table 5.

Table 5

*Coefficients for Social Isolation*

Model	B	$\beta$	<i>t</i>	Sig
Sense of Support	-.236	-.155	-1.149	.256
Emotional Burden	.218	.493	3.660	.001

To assess the relationship between social isolation and attachment scores, a simple linear regression was conducted using social isolation as the predictor and attachment scores as the dependent measure. The analysis revealed that social isolation scores significantly predicted attachment scores,  $\beta = .41$  ( $SE = .111$ ),  $t(81) = 4.02$ ,  $p < .001$ ,  $R^2 = .168$ ,  $\text{adj. } R^2 = .158$ .

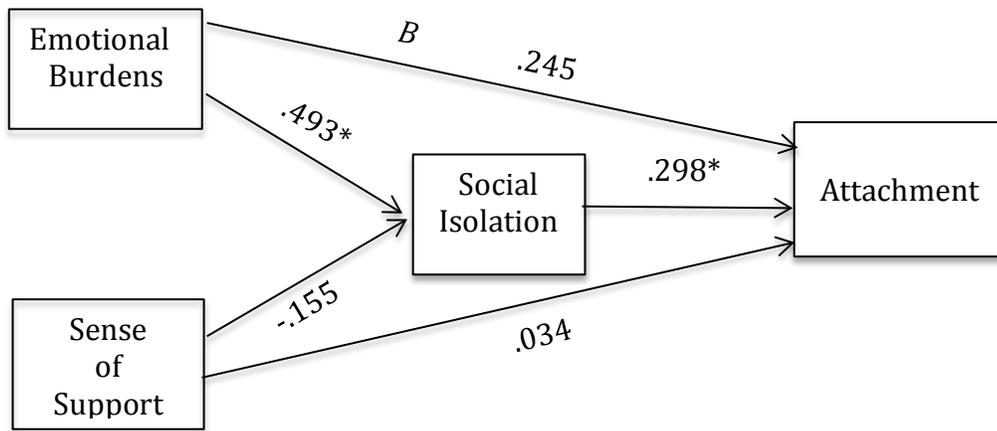


Figure 1. Model for research question one. \*  $p < .05$

### Research Question Two

Research question two: How does a healthy sense of support and low emotional burdens contribute to increasing self-efficacy in a mother of a CD and improved mother-child attachment?

Hypothesis three: Mothers who perceive a higher sense of support will have an improved sense of self-efficacy regarding themselves and their parenting abilities.

Conversely, those who perceive higher emotional burdens will have a lower sense of self-efficacy.

Hypothesis four: Many Kuwaiti mothers of CDs will perceive current support systems for mothers of CDs in Kuwait as inadequate. These mothers are expected to desire increased support from their families, their communities, and the government.

To analyze the second research question, linear regression was conducted to examine the predictive relationships among sense of support, self-efficacy, and attachment. To assess the relationship between sense of support, emotional burdens, and self-efficacy on attachment scores, a multiple linear regression was conducted using sense support, emotional burdens, and self-efficacy as predictors and attachment as the dependent variable. The overall model was significant,  $F(3, 42) = 6.91, p < .001, R^2 = .575, \text{adj. } R^2 = .283$ . Self-efficacy was the only significant predictor in the model,  $\beta = .591 (SE = .100), t(45) = 3.31, p < .001$ . See Table 6.

Table 6

*Coefficients for Attachment*

Model	B	$\beta$	<i>t</i>	Sig
Sense of Support	.129	.082	.527	.601
Emotional Burdens	.009	.021	.108	.915
Self-Efficacy	.330	.591	3.309	.002

Follow-up analyses were conducted to test the possibility of mediating relationships and indirect effects. To assess the relationship between sense of support and

emotional burdens on self-efficacy, a multiple linear regression was conducted using sense support and emotional burdens as predictors in the model and self-efficacy as the dependent variable. The overall model was not significant,  $F(2, 43) = 21.59, p < .001, R^2 = .501, \text{adj. } R^2 = .478$ . Emotional burdens was the only significant predictor in the model,  $\beta = .684(\text{SE} = .102), t(45) = 5.17, p < .001$ . See Table 7.

Table 7

*Coefficients for Self-Efficacy*

Model	B	$\beta$	$t$	Sig
Emotional Burdens	.529	.684	5.173	.000
Sense of Support	-.113	-.040	-.304	.763

A simple linear regression was conducted using self-efficacy scores to predict attachment scores. Self-efficacy scores significantly predicted attachment scores,  $\beta = .575(\text{SE} = .055), t(78) = 6.18, p < .001, R^2 = .331, \text{adj. } R^2 = .322$ .

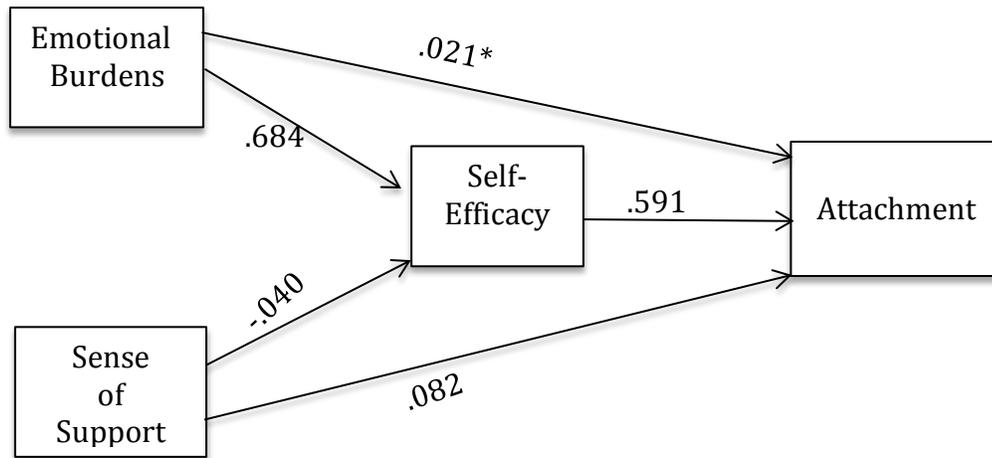


Figure 2. Model for research question two. \* $p < .05$

### Qualitative Analysis

Hypothesis 4 stated that many Kuwaiti mothers of children with disability (CD) perceive current support systems for mothers of CDs in Kuwait as inadequate. This was explored via simple qualitative analysis. In order to preserve the integrity of the data, the coding process used open coding, specifically in Excel and Word document format. Chunks of text were coded line by line and then placed into categories based upon corresponding patterns and themes (Bernard & Ryan 2010).

There were total of 51 mothers who responded to the qualitative questions. The answers were coded by finding the repeated words from the mothers' answers and then placing them in themed categories. Through coding of transcripts of the mothers' responses for the three qualitative questions of this study, 10 major themes emerged which were categorized under their respective question. Table 8 presents the emerging themes as well as how many times each mother stated the theme in her responses.

Table 8

*Current and Needed Support*

Source of Support	Theme	<i>n</i>	Current Support	Needed Support
Family	Child's physical care	21	<i>My parents support my child and me when we have a doctor's appointment or if we are staying at the hospital or if my son is sick</i>	<i>I need more help from my family to take care of my son, he needs someone to carry him to bed and bathroom</i>
	Psychological and moral support	43	<i>Helping me with teaching him taking care of him, playing with him, feeding him</i>	<i>I want my husband to understand that our son is a special needs child which means we want his time to be with us more and we need him to take care of our child and be at his side take him out spend some time know what he likes or dislikes.</i>
	Nothing	10	<i>Nothing, I am taking care of my child by</i>	<i>NOTHING, no one cares</i>

			<i>myself</i>	
Community	Emotional support	11	<i>There are several woman support groups that I visit very often to get information regarding taking care of my child</i>	<i>I wish that there were a center where we as parents can go to get emotional support, such as counseling and get some stress relief. Many times I feel exhausted and I can't do anything just because I feel over stressed</i>
	Programs	21	<i>My child doesn't have any places that he can go to learn or have fun, in fact it is very rare to find places for disabled children to learn.</i>	<i>Develop programs that help my child to learn and be included in the society</i>
	Social inclusion	44	<i>People always look sympathetically upon my child, when will people accept my child as a human being that has some differences. When will they include him in their social activities?</i>	<i>I think if my relative, friends, and the community start to invite my child to social events and include him as a guest or as an individual volunteer then he will feel more confidence.</i>
Government	Financial support	42	<i>Government pays a monthly allowance that barely covers my child expenses.</i>	<i>Increase the monthly allowance. What we get now it is not enough for private school fees and other expenses and provide us with special care for disabled children</i>
	Medical support	42	<i>They provide basic medical help to my child for free.</i>	<i>We need professional medical centers that provide services for children with disabilities. When I needed a dentist</i>

				<i>for my daughter, I couldn't find one who was a specialist I found only at a private hospital and it cost a lot of money</i>
	Educational support	32	<i>It is difficult to find a school for my daughter for high school, the school system segregates disabled children. I wish to allow my daughter to be in regular school.</i>	<i>Parents have a hard time finding a hospital that accept their child, we don't have professional hospitals that can take care of our disabled children</i>
	Social activities	6	<i>I wish that they provided more places for special needs children where they can have social activities.</i>	<i>When the government decided to have some activities for disabled children they always do it separately from other children. I think if they did more social events that include both children with and without disabilities then it would be beneficial for both.</i>

### **Family Support**

Table 8 represents the three major themes that emerged regarding family support derived from the mothers responses to the qualitative questions: Child's physical care ( $n=21$ ), Psychological and moral support ( $n=43$ ), and Nothing ( $n=10$ )

### **Community Support**

There were three major themes regarding community support: Emotional support ( $n=11$ ), Programs ( $n=21$ ), and Social inclusion ( $n=44$ ). See Table 8.

## **Government Support**

Three major themes emerged regarding government support: Financial support ( $n= 42$ ), Medical support ( $n= 42$ ), Social activities ( $n=6$ ), and Educational support ( $n=32$ ). See Table 8.

### **Summary**

This chapter presents the statistical analyses strategies and the results of a quantitative research study, including a description of the sample, and analyses of items on the questionnaires that were collected from 85 mothers.

Multiple linear regression and simple qualitative analysis were used to address the two research questions and four hypotheses. Emotional burdens and sense of support were not independently associated with mother-child attachment relationship. However, emotional burdens significantly predicted social isolation, which in turn significantly predicted attachment relationship. In addition, emotional burdens significantly predicted self-efficacy, which in turn predicted attachment relationship. Via open-ended answers, mothers reported that they receive some support from family, community, and government, but that they also desire more support from these sources.

## CHAPTER V

### DISCUSSION

This study focused on the significance of the reciprocal interactions that occur between mother and child with a disability (CD), mother and family, mother and community, and mother and government. These four relationships have an indirect impact on the mother's emotional burden and sense of support as a caregiver. These, in turn, directly affect the mother's self-efficacy, isolation from society, and attachment relationship with her child.

This study contains a total of five chapters. The first four chapters focus on the rationale of the study, the literature review, research methodology, statistical analysis, and the findings of the research questions and hypothesis. This final chapter discusses findings, recommendations, limitations, implications, as well as recommendations for future research.

#### **Social Isolation and Sense of Support**

Negative reactions from society in regards to the inclusion of children with disabilities cause the family to become more closed-off (Sari & Altiparmak, 2012). One of these negative reactions is social isolation, which is caused by several things, such as the lack of a sense of support from family, community, and government. Another negative reaction is the emotional burden that mothers feel because of having a child with a disability. For this study, research question one asked how the emotional burdens and

sense of support of a mother of a CD contribute to the feeling of isolation from society and mother-child attachment. Hypothesis one stated that a lack of support causes mothers of CDs to feel a disproportionate sense of social isolation. This, in turn, adversely affects the mother-child relationship. If the mother perceives her emotional burdens associated with raising a CD as higher, her sense of social isolation will also increase. While the results of this study did find a negative relationship between sense of support and social isolation (i.e., as sense of support increases, feelings of social isolation decrease), the results were not significant.

A potential explanation for the non-significant results may be that, while some mothers receive support and others do not receive the desired levels, all essentially receive the basic financial support from government and family. The factors above are supported by the Ecological Systems Theory (Bronfenbrenner, 1979), which indicates that humans need to establish a relationship with their surrounding environment. The human ecology model is based on layers or systems of social interactions that affect a person's development. Within each system, a person's development or behavior is influenced by his or her activities, roles, and personal relationships. Roles are the societal expectations for how an individual is expected to act within a system, and personal relationships are the ways people treat others and interact (Zukoski & Luluquisen, 2006).

One implication of this finding would be for mothers of CDs to ask for support rather than assuming that the family is aware of the support that is needed by the mother. Sometimes family members may not be aware of the mother's need for support and

would be agreeable to help the mother if they knew or were asked for support. Therefore, a second implication would be for communities to work together to provide support groups for mothers of CDs, which would help increase the awareness about the mother's need for support. A third implication is the need to provide resources to empower mothers to become proactive in informing the larger society of their children's challenges and qualities. This information would support them in their understanding of their child but also empower them to educate those without CDs as well as become advocates for the child's needs in society.

### **Social Isolation and Emotional Burden**

The gradual withdrawal of family support because of the social stigma surrounding children with disabilities encourages feelings of isolation and makes it difficult to establish relationships outside of the immediate family. In part two of research question one. It was also hypothesized that if a mother perceives her emotional burdens associated with raising a CD as higher, her sense of social isolation will increase. This hypothesis was supported by the findings that when emotional burdens increase then so does the sense of social isolation. Social isolation was found to be a significant predictor. When mothers feel a higher level of stress, they will then isolate themselves from society, as several mothers responded, "Nothing, no one cares", which indicated their lack of desire to even discuss their needs. This is consistent with previous research, which found that the everyday challenge of meeting a CD's needs may consume a family and severely limit their social and recreational lives (Chang & McConkey, 2008; Olsson & Hwang,

2003). For instance, research has found that couples with CDs have lower rates of social participation than those with children without disabilities (Olsson & Hwang, 2003).

The mothers' responses clearly reflect the cultural stereotypes that exist which are imposed upon the mother and her CD. One mother responded, "Most of the people talk about my child in a hurtful way and hurts me deeply. Also, when they see my son is so active they complain." As a result of this type of reaction, many families purposely keep family members with disabilities hidden from society (Al-Hilawani, et al., 2008; Al-Kandari & Al-Qashan, 2010). The exclusion of people with disabilities from positive public roles means many people are never exposed to positive examples of individuals with disabilities. This isolation contributes to the negative assumption that people with disabilities are a social burden. The majority of mothers in the survey agreed on the need for inclusion in society.

The findings supported Bronfenbrenner's Ecological Theory, which presents a model for human development in terms of a person's reactions and adjustments to contextual pressures. This theory is based on the premise that development does not take place in a vacuum; rather, people constantly adjust to ever-changing social and cultural environments including family life, community relations, and economic and political structures (Bronfenbrenner, 1979).

An implication of this finding is that mothers need to understand the underlying triggers of their stress, and the reason behind the increased emotional burden. Also, mothers need to engage themselves in social activities that are stress relievers for them.

Examples of activities where mothers can relieve stresses while bonding may include finding volunteer or learning opportunities where the mother and her child can participate. This bonding time would help mothers learn more about their CD while bonding. It would also be a mechanism to relieve stress while bonding with other families facing the same or simply exposing others to the wonders and joys of their CD. This will help her emotional burden to decrease. In addition it would be beneficial if mothers could be empowered to reach out to their families and communities in order to relieve certain stressors. Lastly, self-empowerment through education of the CD's ailments would help decrease the lack of knowledge of the CDs struggles.

### **Self-efficacy and Sense of Support**

In the context of parenting, self-efficacy is the mother's perceived capabilities in meeting her child's needs and exercising control over events that affect their lives (Bandura & Wood, 1989). Question two asks how a healthy sense of support and low emotional burdens contribute to increasing self-efficacy in a mother of a CD and improved mother-child attachment. Hypothesis three part one stated that mothers who perceive a higher sense of support will have an improved sense of self-efficacy regarding themselves and their parenting abilities. However, for this sample, there was not a significant relationship between sense of support and self-efficacy.

The idea that support is a critical component to self-efficacy is highlighted within the research of Koydemir-Özden and Tosun (2010), who stated that mothers of children with disabilities consistently reported higher levels of stress, depression, and health

problems than mothers of children without disabilities. Chang and McConke (2008) stated that the encouragement and support of friends and relatives is not only crucial to keep parents going, but is in some ways even more important than help from professionals.

Although poor self-efficacy can be a problem for mothers of CDs anywhere, mothers in Kuwait seem to be particularly self-critical. Al-Kandari and Al-Qashan (2010) theorized that the perceived insufficiencies of Kuwaiti mothers, when compared to those of mothers of CDs in Western countries, may be related to a dominant perception that their caregiving abilities cannot measure up to those of professionals and special education programs. Therefore, the lack of available professional help is an added source of anxiety for mothers. These researchers suggested the government and professionals in Kuwait ought to put an increased emphasis on family education in order to encourage and strengthen a mother's perception of self-efficacy in daily encounters with her child. A major implication of this finding would be for government to provide additional support in the form of resources and education. For example, providing educational programs for mothers to learn about common disabilities as well as a hotline for mothers to get connected to additional resources such as advocacy groups, mothers' networks, classes on CDs, etc. would be beneficial to mothers in addition to the financial currently provided. This additional support provided by the government would speak volumes to the community as well as to the mother, thereby reducing her burdens and improving her sense of support thus empowering her self- efficacy.

An additional implication for the government could be to institute policies in education reform that can remove isolationist barriers preventing non-disabled children from attending school with CDs. Currently, disabled and non-disabled children are regulated to their category specific schools which blocks any joint learning between the two children groups. By improving the relationships from an early age, the government would be instrumental in dispelling stereotypes early on. Many of the Western countries, especially the U.S. have an integrated school system where all students attend the same schools and CDs also attend special education programs geared at their needs; the daily interaction between non-disabled and disabled children has normalized the differences and created a culture where disability is not discriminated against nor ignored in the American culture.

### **Self-efficacy and Emotional Burden**

In hypothesis three part two, I stated that those who perceive higher emotional burdens will have a lower sense of self-efficacy. The findings showed that lower emotional burdens were associated with higher self-efficacy scores. The study concluded that self-efficacy is determined by emotional burdens placed upon the mother. Thus, if she feels that she has fewer burdens, she can positively care for her CD, while less support and more burdens cause her to negatively attach to her CD. Hypothesis three part two was significantly supported by the findings that when emotional burdens increase then self-efficacy decreases.

These results also support previous research, which has shown that many mothers facing such stressors tend to doubt their parenting abilities, a further source of stress and sadness (Al-Kandari & Al-Qashan, 2010). In most instances, if a mother with a CD or without a CD is stressed and tired, her ability to care for her children will ultimately be lowered and she will not be able to fully meet her child's need let alone her own. Improved maternal self-efficacy in mothers of CDs is linked to decreased guilt, less anxiety and depression, more secure attachment relationships with the CDs, greater consistency in mother-child interactions, and increased parental involvement in treatment and intervention programs. Such mothers are generally more optimistic and more satisfied with life (Al-Kandari & Al-Qashan, 2010). Thus, a strong sense of self-efficacy is one of the greatest factors attributed to a healthy parenting style. Therefore, mothers need to make sure that they themselves are healthy and cared for so that they in return can be fully present and available to meet the needs of their CDs.

### **Mother-Child Attachment Relationships and Social Isolation**

The impact on the mother-child relationship was investigated with research question one. Hypothesis one related to the impact of social isolation. It was predicted that hypothesis one, it stated that lack of support causes mothers of CDs to feel unreasonable sense of social isolation. This, in turn, adversely affects the mother-child relationship. If the mother perceives her emotional burdens associated with raising a CD as higher, her sense of social isolation will also increase. Similarly, hypothesis two stated

that when mothers have higher emotional burdens and feel less supported, their attachment relationships with their CDs are negatively affected.

The results of this study show that the relationship between the mother and her CD is significantly impacted by the mother's feelings of social isolation. Coupled with the finding that emotional burdens significantly impact social isolation, it can be concluded that emotional burdens indirectly affect the mother-child relationship through the impact on social isolation. If mothers become isolated or isolate themselves from family and society, then their relationship and attachment to their CD will be greatly affected. Thus, there is a strong need for mothers to be active in pursuing assistance and becoming engaged so that isolation is removed. This can be done by joining social groups, building healthy relationships with other mothers, and building a support system of people with whom they can talk out their issues. Doing this alone will help them find their voice and become an advocate for their CD, thus boosting their attachment to their CD as well.

The overwhelming sense of exclusion from the community makes it difficult for mothers to form and maintain friendships. They may feel lonely and unsupported and be less satisfied talking to friends because of a lack of common ground (Al-Kandari & Al-Qashan, 2010). In some cases, it can be easy for mothers to feel so inundated by daily stressors and child care burden that they can subconsciously choose to self-isolate out of fear, which would lead mothers to avoid family, hide their CD, and avoid social gatherings. This festering of negative thoughts and associations may ultimately causing a

detachment to their CD, and in some cases may lead to them to blame the CD for this existence.

### **Mother-Child Attachment Relationships and Self-efficacy**

According to Bowlby's (1958) attachment theory, the closeness between an infant and primary caregiver sets the foundation for all future relationships. According to Bowlby, the attachment relationship has long-term effects on the child.

The impact on the mother-child relationship was investigated with research question two which asked how a healthy sense of support and low emotional burdens contribute to increasing self-efficacy in a mother of a CD and improved mother-child attachment. Hypothesis three stated that mothers who perceive a higher sense of support will have an improved sense of self-efficacy regarding themselves and their parenting abilities. Conversely, those who perceive higher emotional burdens will have a lower sense of self-efficacy. The finding in this study indicates that self-efficacy is a significant factor in the attachment between the mother and her CD.

The high levels of stress mothers of CDs experience can put the mother-child relationship in jeopardy of future problems (Kazak & Marvin, 1984). Emotional burdens affect self-efficacy and thereby indirectly affect the mother-child relationship. Sari and Altıparmak (2012) discussed the complicated mother-child relationship, explaining that, although mothers of CDs consistently point to their deep love for their children as the motivation to deal with the stresses of childhood disabilities, the mother-CD relationship can have a darker side. Therefore, the mother and child attachment is greatly affected by

the mother feeling emotionally burdened which, in turn, affects her ability to provide and nurture her CD. More recent research has also confirmed that quality time between a mother and her CD is related to the child's well-being (Greenberg, Seltzer, Krauss, Chou, & Hong, 2004).

This research implies the influence of self-efficacy on the mother-child relationship. It is a critical need for mothers with children who have disabilities, thus there is a lacking overall cultural context around the relevance or need to build dialogue regarding this topic. Results of this study show that self-efficacy is affected by the mother's emotional burdens and this in turn affects the relationship with her child. In other words, a mother who experiences higher emotional burdens feels less capable as a parent, and those feelings have a negative impact on the mother-child relationship.

### **Qualitative Findings**

Hypothesis four stated that many Kuwaiti mothers of CDs will perceive current support systems for mothers of CDs in Kuwait as inadequate. These mothers are expected to desire increased support from their families, their communities, and the government. Today, the individual life and responsibility takes priority over supporting others in the family unit. Thus, a majority of mothers indicated that they receive a reasonable amount of support from the family, which is limited to financial support. When mothers were asked "*What kind of support are you getting from your family?*" the answers varied. Some stated that they receive "Nothing, no one cares" and thus felt isolated and lonely, whereas others expressed support, such as the mother who stated "*My parents support my*

*child and me when we have a doctor's appointment or if we are staying in the hospital or if my son is sick."* Another mother mentioned that her parents participated in *"Helping me with teaching him, taking care of him, playing with him, feeding him."*

Most of the women surveyed stated that on some level they did receive familial support in caring for their CD. However, this does not negate the fact that there are many other mothers who indicated that they still are in need of more support from the community and government. In general, the mothers may feel more supported if they can reach out to others and share their experiences, as well as their disabled children's experiences. This, in turn, may also help improve the acceptance of their children by society. When asked, *"What additional support do you wish to get from your family?"* one mother remarked, *"I want my husband to understand that our son is a special need child which means we want his time to be with us more and we need him to take care of him be in his side take him out spend some time know what he love or hate"* while another commented that she would *"like my husband to provide more support more often."* These comments reference a very large gap in the support provided by mothers and fathers, where oftentimes the mother is the primary caretaker for the CD and the father in some instances limits his time to other matters rather than providing equal or more support to the mother.

Regarding community support, the responses clearly reflect the cultural stereotypes that exist and are inflicted upon the mother and her CD. One mother responded *"Most of the people talk about my child in a hurtful way and hurts me deeply."*

*Also, the when they see my son is so active they complain,”* while another mother simply mentioned she received *“Nothing”* from the community. This was reaffirmed by the comments from the mothers about their perceived needs from the community. Most mothers responded with *“Respect him, give my child space, learn about his needs and become more active on behalf of his rights.”* Many mothers mentioned respect for their child, space for their child, and providing more information about the needs of CDs. There seems to be an emotional burden imposed upon the mother by the community’s lack of respect and positive treatment of their child. The mothers have a strong desire for the community to respect and acknowledge the life and livelihood of their CD. Another mother stated, *“My child doesn’t have any places that he can go to learn or have fun, in fact it is very rare to find places for disabled children to learn.”* These comments from the mothers point to a strong desire for the community as a whole to play a role in lessening their emotional burden through the transfer of equal treatment or by being tolerant and accepting of their CD and acknowledging the already stressful role of a mother of a CD. One mother responded, *“It is very hard for me to see people stare at my child or ask me what is wrong with his leg.”* These constant stares and judgments may cause this mother and others to feel burdened by the need to explain and force them to stay within their comfort zone so as to avoid answering people’s questions or enduring the stares and judgments that such questions can elude to.

Lastly, mothers were asked what kind of support they get from the government.

One mother responded, “*My boy is non-Kuwaiti while I am Kuwaiti; therefore, he only receives support for his school fees*” and many others clearly indicated that the only support they received from the government comes in the form of “*financial support.*” This indicates that they would like more support outside of financial support and are clearly aware that the needs of their CD are not among the highest of priorities of government advocacy issues. Another mother responded, “*Parents have a hard time finding a hospital that accepts their child, we don’t have a professional hospital that can take care of our disabled children.*” Another mother stated, “*I wish that they [the government] provided more places for the special needs children.*” These mothers point to the fact that the education system, ideally the Ministry of Education and government overall, continue to focus on financial costs rather than creating support systems and resources as well as helping shift the cultural stereotypes that exist around CDs and mothers of CDs.

There were several mothers who stated that they would like additional resources from the government. For example, one mother said “*I wish that there was a center where we as parents can go to get emotional support, such as counseling and get some stress relief. Many times I feel exhausted and I can’t do anything just because I feel overwhelmed.*” Mothers agreed on the need for programs and centers where they can get more educated on their child’s disability.

## **Recommendations**

While there are many recommendations that this research points out, I believe that three foundational recommendations should take place based upon the results of this study they are as follows:

First, in order to create a greater sense of support from society and community as a whole, it is recommended that the government should take an active role in helping diffuse negative stigmas about CDs and the mothers associated to them. By creating a campaign that educates the general public with regards to the diseases and genetic issues rather than perpetuating negative cultural beliefs, this will lessen the emotional burdens and sense of support for the mothers. This campaign should also include educating young students about how to engage and interact with CDs. For example, the government can host public seminars at public schools and universities to educate the public in regard to the child with disability's rights. This would help create a cultural shift that is more inclusive rather than exclusive of CDs and their mothers.

Second, while the government already provides medical and financial support to families, it should also provide support groups for mothers who have CDs. These groups' role should be to focus on education, and emotional and psychological assistance, as well as empowerment and a sense of community for mothers. Financial assistance alone provided by the government will not be sufficient enough to address the daily emotional burdens, lack of support, or stresses endured by mothers of CDs.

Finally, the government should include a more mixed platform for schools that includes inclusion of CDs in the regular curriculum. In other words, CDs and non-CD school children should be in the same schools so that they can grow and learn from each other rather than being isolated and taught to feel different or separate from each other. Isolating CDs could set a negative context for young people to perceive them as different or even fear CDs at a young age.

### **Limitations**

There were four major limitations to this study:

First, the initial sample group was 280 women, but the final sample was limited to 85 women who completed the entire survey and classified as Kuwaiti residents or citizens. This was in part due to the fact that some participants indicated the survey was too long, so they did not complete it. In addition, the Instagram account from which participants were recruited is accessible to all nationalities and several followers are from other countries in the Middle East. Although the eligibility criteria were clearly stated, some non-Kuwaitis still completed the survey.

Given that the G\*Power analysis indicated a minimum sample of 132 mothers, it is possible that some of the analyses lack adequate statistical power due to the smaller final sample.

The second limitation is a cultural barrier. Kuwaiti mothers are not comfortable talking about the disabilities of their child openly. This may be due to a denial in mothers

whose CDs have a non-visible disability and the feeling of shame for those who have visibly disabled children.

A third limitation is the barrier faced due to the online nature of this research. Many of the mothers were not comfortable doing the surveys online, but preferred face-to-face interaction with the researcher. It may be due to a cultural difference. The desire for face-to-face interaction is imbedded into a feeling of safety that their information and secrets are protected.

Finally, there were several of the scales that did not have good internal consistency for this sample. The PSI subscales usually have good internal consistency (Abidin, 2012); however, it may not be readily transferrable to a sample of mothers with disabled children. It is also possible that cultural differences and the reluctance of Kuwaiti mothers to share personal information online caused the scales to be less reliable with this sample.

### **Recommendations for Future Research**

While much research still needs to be done on this topic, it is recommended that there are two specific perspectives that future research should target: the CDs and the father's role. It is recommended that studies include the role of the father of CDs in order to understand the extent of their roles in the development of the CDs as well as the emotional burdens they may experience and the support they perceive they provide to the mother they provide to the mother. Secondly, more qualitative studies (interviews, focus group, etc.) are needed to include the perspective of the CD and the mother. This would

help to better understand how the CD views his mother, society, and his own personal development and growth. Finally, there is a great need for further research on this topic, specifically relating to Kuwait. Although there has been relevant research in the US and other western nations, there are only a limited amount of current articles on this topic in reference to Kuwaiti mothers, society, and CDs.

### **Conclusion**

In conclusion, this research is a critical component to the understanding of how cultural perspectives in Kuwait influence the perceptions of mothers and attachment to their CDs. It also points to a number of factors, such as sense of support, isolation, and emotional burdens and how these factors affect the mother-CD relationship and development. There is a need for a greater understanding of the community's perspectives and views towards families with CDs as well as the government's limited views on this topic. This research is ideally a starting guide for both the mothers' and the government's understanding on where the pitfalls of the current cultural views in Kuwait exist. It is the hope that this research further places this issue as a hot topic for discussion, as currently it is still closeted.

Findings in this research also lead to implications that the CDs themselves are left behind as incapable of actively participating in their lives. All CDs, regardless of disability, can somehow contribute to society's cultural shift as well as lessening the mother's emotional burdens if the mother has further knowledge about her CD's needs. Inclusion in schools is thought to be a first crucial step towards inclusion in society; it not

only provides CDs with the tools to become productive and independent members of society, but also conditions their peers to accept and include them in everyday life (Al-Jazzaf, 2012).

### **Summary**

Coping with childhood disabilities is a difficult task faced by millions of families around the world and a much more difficult task in Kuwait provided the negative and limited perspective on the topic by the government and society. Caregivers (usually the mother) for children with disabilities (CDs) must find a way to provide for their children's unique needs in society. Specifically, raising CDs is particularly difficult in Kuwait, where mothers and children alike are often cut off and isolated from traditional support systems (Al-Kandari & Al-Qashan, 2010). This makes it difficult to obtain information and resources and critically affects their emotional well-being. This study explored the significance of the reciprocal interactions that occur between mother and CD, mother and family, mother and community, and mother and government. These four relationships are inversely related and have an indirect impact on the mother's emotional burden and sense of support as a caregiver. These, in turn, directly affect the mother's self-efficacy, isolation from society, and attachment relationship with her child. Further examination of this area of study is essential, as these impacts have been identified as leading contributors to exhaustion and burnout for Kuwaiti mothers. Much work and research is still needed on this topic as well as a more holistic view of the problem and

solutions in Kuwait. It is the hope of this author that this research helps propel further dialogue on the issue at hand.

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Appendix A

Approval of Research Proposal



Institutional Review Board  
Office of Research and Sponsored Programs  
P.O. Box 425619, Denton, TX 76204-5619  
940-898-3378  
email: IRB@twu.edu  
<http://www.twu.edu/irb.html>

DATE: March 31, 2015  
TO: Ms. Tahani Alsabab  
Family Sciences  
FROM: Institutional Review Board - Denton

Re: *Approval for Emotional Burdens and Sense of Support of Kuwaiti Mothers of Children with Disabilities (Protocol #: 18031)*

The above referenced study has been reviewed and approved by the Denton Institutional Review Board (IRB) on 3/25/2015 using an expedited review procedure. This approval is valid for one year and expires on 3/24/2016. The IRB will send an email notification 45 days prior to the expiration date with instructions to extend or close the study. It is your responsibility to request an extension for the study if it is not yet complete, to close the protocol file when the study is complete, and to make certain that the study is not conducted beyond the expiration date.

If applicable, agency approval letters must be submitted to the IRB upon receipt prior to any data collection at that agency. A copy of the approved consent form with the IRB approval stamp is enclosed. Please use the consent form with the most recent approval date stamp when obtaining consent from your participants. A copy of the signed consent forms must be submitted with the request to close the study file at the completion of the study.

Any modifications to this study must be submitted for review to the IRB using the Modification Request Form. Additionally, the IRB must be notified immediately of any adverse events or unanticipated problems. All forms are located on the IRB website. If you have any questions, please contact the TWU IRB.

cc. Dr. Karen Petty, Family Sciences  
Dr. Brigitte Vittrup, Family Sciences  
Graduate School

Appendix B  
Advertisement

## Advertisement

Dear respected followers,

This ad is regarding the participation in a survey for Tahani Alsabah's dissertation. The purpose of the study is to provide an understanding of the relationship between mothers' emotional burdens and sense of support and how they affect her self-efficacy, social isolation, and mother-child attachment relationship.

Requirements:

1. The mother must currently reside in Kuwait, and must have lived there for a minimum of the past 5 consecutive years.
2. The mother must have a child with a visible disability.
3. The mother must be 19 years or older.
4. Each child with a disability must be between the ages of 0 -14 years.

The consent form and survey will be available in both English and Arabic. Participants will have the option to choose the desired language before beginning the survey. There will be no obligation to continue the survey, feel free to stop at any time. Name and personal information is not required. It is estimated that it will take approximately 30 minutes to complete the survey. There is a potential risk of loss of confidentiality in all downloading, or internet transactions. However, surveys will be downloaded onto a secure computer which is only accessible to the Principal Investigator.

If you have any questions regarding this study, please contact the Principal Investigator, Tahani Alsabah, [talsabah@twu.edu](mailto:talsabah@twu.edu).

Click the link below and start the survey:

Thank you very much for your support

## ملحق (ب) الإعلان

أعزائي المتابعين المحترمين،  
هذا الإعلان بخصوص المشاركة في دراسة استقصائية من أجل الرسالة العلمية الخاصة بتهاني الصباح.  
الغرض من الدراسة هو توفير فهم للعلاقة بين الأعباء العاطفية للأمهات والشعور بالدعم وكيف يؤثران في كفاءتها الذاتية والعزلة الاجتماعية وعلاقة الترابط بين الأمهات والأطفال.  
المتطلبات:

1. يجب أن تكون الأم مقيمة في الوقت الحالي في الكويت، ويجب أن تكون قد عاشت هناك على الأقل لمدة الخمس سنوات الماضية بشكل متتالي.
2. يجب أن يكون لدى الأم طفل مصاب بإعاقة مرئية.
3. يجب أن يكون كل طفل المصاب بالإعاقة بين سن 0 إلى 14 عام.

ستتوفر نموذج الموافقة والدراسة الاستقصائية بكلا من اللغة العربية والإنجليزية. سيكون لدى المشاركين الخيار في اختيار اللغة المرغوب بها قبل بدء الدراسة الاستقصائية. لن يكون هناك أي التزام لاستكمال الدراسة الاستقصائية، لا تتردد في التوقف في أي وقت. لا تتطلب المعلومات الشخصية والاسم. تشير التقديرات إلى أن الأمر لن يأخذ أكثر من 30 دقيقة لاستكمال الدراسة الاستقصائية.  
انقر على الرابط أدناه وابدأ الدراسة الاستقصائية:  
شكرا جزيلا لدعمكم.

Appendix C  
Consent Form

**TEXAS WOMAN’S UNIVERSITY  
CONSENT TO PARTICIPATE IN RESEARCH**

**Title: Emotional burdens and sense of support of Kuwaiti mothers of children with disabilities**

Investigator: Tahani Alsabab, M.S.....talsabah@twu.edu 940-898-2645  
Advisor: Brigitte Vittrup, Ph.D.....BVittrup@twu.edu 940-898-2624

Explanation and Purpose of the Research

The purpose of the study is to provide an understanding of the relationships between mothers’ emotional burdens and sense of support and how they affect their perception of themselves as parents and their relationship with their children. Another purpose of the study is to examine how mothers of a child with a disability are affected by emotional burdens and sense of support. This study is a dissertation as partial fulfillment of a doctoral degree at Texas Woman’s University (TWU).

By completing this survey, you agree to participate in this study and to allow the Principal Investigator to use the results in conference presentations and/or research publications. However, information is collected anonymously; therefore, the information you provide cannot be linked to your name or personal information. Participation is voluntary.

Description of Procedures

You will be asked to spend approximately 30-40 minutes of your time to answer questions about your parenting style, child characteristics, and relationship with your child. In order to participate in the study, you must be a Kuwaiti mother who is 19 years of age or older and have a child with a disability who is between the ages of 0 and 14 years.

Potential Risks

There are potential risks associated with this study, including emotional discomfort, loss of confidentiality, loss of time, and perception of coercion. Please note that you are free to not answer any questions with which you feel uncomfortable, and you may discontinue participation at any time. You are not asked to give any personally identifying information, and all answers will be kept confidential. Your decision to participate or not will not in any way affect your existing or future relationship with Texas Woman’s University or the Principal Investigator.

If you feel any emotional discomfort during or after the conclusion of the study, feel free to contact The Social Development Office in Kuwait (Phone: 22402409; 22402407 and Email: [contact@sdo.gov.kw](mailto:contact@sdo.gov.kw)).

There is a potential risk of loss of confidentiality in all email, downloading, and internet transactions. However, surveys will be downloaded onto a secure computer which is only accessible to the Principal Investigator.

#### Participation and Benefits

Your involvement in this study is completely voluntary and you may withdraw from the study at any time. There are no benefits or compensation for participating in this research.

#### Questions Regarding the Study

Thank you in advance for completing this survey. Should you have any questions about this project, or the results of the survey, please contact the Principal Investigator: Tahani Alsabah, 940-898-2645, [talsabah@twu.edu](mailto:talsabah@twu.edu), or the faculty advisor: Dr. Brigitte Vittrup, 940-898-2624, [BVittrup@twu.edu](mailto:BVittrup@twu.edu). If you have questions about your rights as a participant in this research or the way this study has been conducted, you may contact the Texas Woman's University Office of Research and Sponsored Programs at 940-898-3378 or via email at [IRB@twu.edu](mailto:IRB@twu.edu). If you would like a copy of this consent form, please print this page for your own records.

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

If you wish to participate in this study and are ready to proceed, please click the button below to begin the survey.

ملحق (ج)  
نموذج الموافقة

الأعباء العاطفية والشعور بالدعم للأمهات الكويتيات الذين لديهم أطفال مصابين من ذوي الإعاقات

الغرض من الدراسة هو توفير فهم للعلاقة بين الأعباء العاطفية للأمهات والشعور بالدعم وكيف يؤثران في كفاءتها الذاتية والعزلة الاجتماعية وعلاقة الترابط بين الأمهات والأطفال.

عند اكتمال هذه الدراسة الاستقصائية، فإنك موافق على المشاركة في هذه الدراسة وتسمح للمحققين الرئيسيين في استخدام النتائج في العروض التقديمية للمؤتمر و / أو المنشورات البحثية. ومن هنا، تجمع المعلومات بشكل مجهول؛ لذلك، المعلومات التي تقدمها لا يمكن أن يتم ربطها باسمك أو معلومات الشخصية.

تكون المشاركة بشكل تطوعي. لن يؤثر قرار عدم المشاركة على علاقتك الحالية أو المستقبلية مع مدرسة طفلكم. سيتم سؤالكم عن التجربة الشخصية المتعلقة بالمعلومات. فأنت حر في رفض أي سؤال لا تشعر بالرد عليه بطريقة مريحة.

هناك مخاطر محتملة بفقدان السرية في كافة البريد الإلكتروني والتنزيلات والمعاملات عن طريق الإنترنت. ومع ذلك، سيتم تنزيل الدراسات الاستقصائية على حاسوب آمن الذي يمكن الوصول عليه فقط عن طريق المحققين الرئيسيين.

من المتوقع أن تستغرق تقريبا 30 دقيقة في استكمال هذه الدراسة الاستقصائية.

شكرا لكم مقدما لاستكمال هذه الدراسة الاستقصائية. في حالة أنكم لديكم أية أسئلة بشأن هذا المشروع، أو نتائج الدراسة الاستقصائية، يرجى الاتصال بأحد المحققين الرئيسيين: بريجيتي فيتراب، 940-898-2624، [BVittrup@twu.edu](mailto:BVittrup@twu.edu)، أو الشبخة تهاني الصباح، 940-898-2645، [talsabah@twu.edu](mailto:talsabah@twu.edu). عندما تكون جاهزا لإجراء الدراسة الاستقصائية، من فضلك انقر فوق الزر أدناه لبدء الدراسة الاستقصائية.

Appendix D

Demographic Information Questionnaire

## Demographic Information Questionnaire

### Child Information:

- 1- Age \_\_\_\_\_
- 2- Gender \_\_\_\_\_ Female \_\_\_\_\_ Male

### Mother's Information:

- 1- Age \_\_\_\_\_
- 2- Marital Status  
\_\_\_\_\_ Married  
\_\_\_\_\_ Divorced  
\_\_\_\_\_ Separated  
\_\_\_\_\_ Widowed
- 3- Education  
\_\_\_\_\_ Less than high school  
\_\_\_\_\_ High school diploma  
\_\_\_\_\_ Some college,  
\_\_\_\_\_ 4-year college degree  
\_\_\_\_\_ Graduate or professional degree.
- 4- How many children do you have?  
\_\_\_\_\_ With a visible disability (e.g., physical disability),  
\_\_\_\_\_ With a non-visible disability (e.g., mental disability),  
\_\_\_\_\_ With no disability
- 5- Occupation status  
\_\_\_\_\_ Working Full- time  
\_\_\_\_\_ Working Part-Time  
\_\_\_\_\_ Stay Home
- 6- District  
\_\_\_\_\_ Al-Asimah  
\_\_\_\_\_ Al-Farwaniyah  
\_\_\_\_\_ Al-Jahra  
\_\_\_\_\_ Al-Ahmadi  
\_\_\_\_\_ Mubarak Al-Kabeer  
\_\_\_\_\_ Hawalli

## ملحق (أ)

### استبيان معلومات الديمغرافية

#### معلومات الطفل:

- 1- العمر \_\_\_\_\_  
2- الجنس \_\_\_\_\_ أنثى \_\_\_\_\_ ذكر

#### معلومات الأم:

1- العمر \_\_\_\_\_

#### 2- الحالة الاجتماعية

- \_\_\_\_\_ متزوجة  
\_\_\_\_\_ مطلقة  
\_\_\_\_\_ منفصلة  
\_\_\_\_\_ أرملة

#### 3- التعليم

- \_\_\_\_\_ أقل من المدرسة الثانوية  
\_\_\_\_\_ الشهادة الثانوية  
\_\_\_\_\_ حاصلة على كلية ما،  
\_\_\_\_\_ درجة جامعية لمدة 4 سنوات  
\_\_\_\_\_ درجة مهنية أو دراسات عليا

#### 4- كم عدد الأطفال لديك؟

- \_\_\_\_\_ المصابين بعجز ملحوظ (على سبيل المثال. عجز جسدي)،  
\_\_\_\_\_ المصابين بعجز غير ملحوظ (على سبيل المثال. عجز عقلي)،  
\_\_\_\_\_ بدون عجز

#### 5- وضع الوظيفة

- \_\_\_\_\_ العمل بدوام كامل  
\_\_\_\_\_ العمل بدوام جزئي  
\_\_\_\_\_ البقاء في المنزل

#### 6- المقاطعة

- \_\_\_\_\_ العاصمة  
\_\_\_\_\_ الفروانية  
\_\_\_\_\_ الجهاء  
\_\_\_\_\_ الأحمدية  
\_\_\_\_\_ مبارك الكبير  
\_\_\_\_\_ حولي

Appendix E  
Parenting Stress Index

## Parenting Stress Index

### PSI – 4: Item Booklet

#### Instructions:

Read each statement carefully. For each statement, please focus on the child you are most concerned about and circle the response that best represents your opinion. Answer all questions about the same child

Circle SA if you strongly agree with the statement.

Circle A if you agree with the statement.

Circle NS if you are not sure

Circle D if you disagree with the statement.

Circle SD if you strongly disagree with the statement.

1. When my child wants something my child usually keeps trying to get it.

SA   A   NS   D   SD

2. My child is so active that it exhausts me.

SA   A   NS   D   SD

3. My child appears disorganized and is easily distracted.

SA   A   NS   D   SD

4. Compared to most, my child has more difficulty concentrating and paying attention.

SA   A   NS   D   SD

\* Due to copyright, only a sample of this measure is included in this appendix

## مؤشر القلق الوالدي

اذكر تعليمات:

قراءة كل عبارة بعناية، الرجاء التركيز علي الأطفال الأكثر أهمية بالنسبة لك ثم ضع دائره حول الإجابة المناسبة

ضع دائرة حول SA إذا كنت توافق بشدة مع الجملة

ضع دائرة حول A إذا كنت توافق مع الجملة

ضع دائرة حول NS إذا كنت غير متأكد

ضع دائرة حول D إذا كنت توافق مع الجملة

ضع دائرة حول DS إذا كنت لا توافق بشدة مع الجملة

1. عندما يريد طفلي شيئاً ما، دائماً ما يستمر طفلي في محاولة الحصول عليها.

SA A NS D SD

2. طفلي نشيط جداً الشيء الذي ينفذ طاقتي.

SA A NS D SD

3. يبدو طفلي غير منظم ويتشتت ذهنه بسهولة.

SA A NS D SD

4. بالمقارنة مع معظم الأطفال، يعاني طفلي من صعوبة كبيرة في التركيز وإيلاء الاهتمام.

SA A NS D SD

\* نظرا لحقوق الطبع والنشر، سيتم عرض جزء من الأستبيان في هذا الملحق.

Appendix F

Parental Stress Scale

### Parental Stress Scale

The following statements describe feelings and perceptions about the experience of being a parent. Think of each of the items in terms of how your relationship with your child or children typically is. Please indicate the degree to which you agree or disagree with the following items by placing the appropriate number in the space provided.

1 = Strongly disagree 2 = Disagree 3 = Undecided 4 = Agree 5 = Strongly agree

- \_\_\_\_ 1. I am happy in my role as a parent
- \_\_\_\_ 2. There is little or nothing I wouldn't do for my child(ren) if it was necessary.
- \_\_\_\_ 3. Caring for my child(ren) sometimes takes more time and energy than I have to give.
- \_\_\_\_ 4. I sometimes worry whether I am doing enough for my child(ren).
- \_\_\_\_ 5. I feel close to my child(ren).
- \_\_\_\_ 6. I enjoy spending time with my child(ren).
- \_\_\_\_ 7. My child(ren) is an important source of affection for me.
- \_\_\_\_ 8. Having child(ren) gives me a more certain and optimistic view for the future.
- \_\_\_\_ 9. The major source of stress in my life is my child(ren).
- \_\_\_\_ 10. Having child(ren) leaves little time and flexibility in my life.
- \_\_\_\_ 11. Having child(ren) has been a financial burden.

- \_\_\_\_\_ 12. It is difficult to balance different responsibilities because of my child(ren).
- \_\_\_\_\_ 13. The behaviour of my child(ren) is often embarrassing or stressful to me.
- \_\_\_\_\_ 14. If I had it to do over again, I might decide not to have child(ren).
- \_\_\_\_\_ 15. I feel overwhelmed by the responsibility of being a parent.
- \_\_\_\_\_ 16. Having child(ren) has meant having too few choices and too little control over my life.
- \_\_\_\_\_ 17. I am satisfied as a parent
- \_\_\_\_\_ 18. I find my child(ren) enjoyable

## مقياس الضغط الأبوي

تصف البيانات التالية المشاعر والتصورات حول تجربة كونك أحد الوالدين. فكر في كل بند من البنود في كيفية علاقتك بطفلك أو الأطفال عادة. يرجى ملاحظة الدرجة إما أنك توافق أو لا توافق مع البنود التالية بوضع الرقم المناسب في المساحة المخصصة لذلك.

1= لا أوافق بشدة 2= لا أوافق 3= غير محدد 4= موافق 5= موافق بشدة

1. أنا سعيد في دوري كوني أحد الوالدين.
2. هناك القليل أو لا شيء لا أود القيام به لطفلي (أطفالي) إذا كان من الضروري.
3. الاعتناء بطفلي (أطفالي) في بعض الأحيان يأخذ وقتنا وطاقة أكثر مما ينبغي أن أعطيه.
4. أحيانا أشعر بالقلق سواء قمت بالكافي لطفلي (أطفالي) أم لا.
5. أشعر بالقرب من طفلي (أطفالي).
6. أنا أستمتع بقضاء الوقت مع طفلي (أطفالي).
7. يعد طفلي (أطفالي) مصدرا هاما للتأثير على حياتي.
8. وجود الطفل (الأطفال) يعطيني نظرة أكثر تحديدا أو تفاؤلا للمستقبل.
9. المصدر الرئيسي للضغط في حياتي هو طفلي (أطفالي).
10. وجود الطفل (الأطفال) يترك القليل من الوقت والمرونة في حياتي.
11. وجود الطفل (الأطفال) كان يشكل عبئا ماليا.
12. من الصعب موازنة المسؤوليات المختلفة بسبب طفلي (أطفالي).
13. يعد سلوك طفلي (أطفالي) دائما محرجا أو مرهقا بالنسبة لي.
14. إذا كان على القيام بذلك مرة أخرى، أود أن أقرر عدم إنجاب الطفل (الأطفال).
15. أشعر بأنني غارقة بمسئولية كوني أحد الأبوين.
16. قد يعني وجود الطفل (الأطفال) وجود القليل من الفرص والقليل من السيطرة على حياتي.
17. أنا أشعر بالرضا كوني أحد الأبوين.
18. أرى طفلي (أطفالي) ممتعين.

Appendix G

Sense of Support Questionnaire

### Sense of Support Questionnaire

1. On a scale of 1-5 (1 meaning very little support and 5 meaning a lot of support), how much support do you feel you get from your family to help care of your child?

1      2      3      4      5

2. What kind of support are you getting from your family?

3. What additional support you wish to get from your family?

4. On a scale of 1-5 (1 meaning very little support and 5 meaning a lot of support), how much support do you feel you get from your community to help care of your child?

1      2      3      4      5

5. What kind of support are you getting from your community?

6. What additional support you wish to get from your community?

7. On a scale of 1-5 (1 meaning very little support and 5 meaning a lot of support), how much support do you feel you get from your government to help care of your child?

1      2      3      4      5

8. What kind of support are you getting from the government?

9. What additional support you wish to get from the government?

### إستبيان مستوى الدعم

1- بناء على المقياس من 1 إلى 5 (1 يعني دعم قليل جدا و5 يعني الكثير من الدعم)، ما مقدار الدعم الذي تشعر أنك تحصل عليه من عائلتك للمساعدة في الرعاية بطفلك؟

1 2 3 4 5

2- ما هو نوع الدعم الذي تحصل عليه من عائلتك؟

3- ما هو الدعم الإضافي الذي ترغب في أن تحصل عليه من عائلتك؟

4- بناء على المقياس من 1 إلى 5 (1 يعني دعم قليل جدا و5 يعني الكثير من الدعم)، ما مقدار الدعم الذي تشعر أنك تحصل عليه من مجتمعك للمساعدة في الرعاية بطفلك؟

1 2 3 4 5

5- ما هو نوع الدعم الذي تحصل عليه من مجتمعك؟

6- ما هو الدعم الإضافي الذي ترغب في أن تحصل عليه من عائلتك؟

7- بناء على المقياس من 1 إلى 5 (1 يعني دعم قليل جدا و5 يعني الكثير من الدعم)، ما مقدار الدعم الذي تشعر أنك تحصل عليه من حكومتك للمساعدة في الرعاية بطفلك؟

1 2 3 4 5

8- ما هو نوع الدعم الذي تحصل عليه من حكومتك؟

9- ما هو الدعم الإضافي الذي ترغب في أن تحصل عليه من حكومتك؟