

MOTHERS' PERCEPTIONS OF COMMUNITY INTEGRATION OPPORTUNITIES
FOR THEIR CHILDREN WITH DISABILITIES IN QATAR

A Dissertation

by

ALYN KRISTIN ABBS

Submitted to the Office of Graduate Studies of
Texas A&M University
in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

December 2009

Major Subject: Educational Psychology

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Approved by:

Co-Chairs of Committee,	Patricia Lynch Laura Stough
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ABSTRACT

Mothers' Perceptions of Community Integration Opportunities for Their Children with
Disabilities in Qatar. (December 2009)

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This study analyzed the perceptions of mothers of children with disabilities in Qatar. This interpretive work included components of the methodology of both cultural study and translation study. Mothers' responses in Arabic and Farsi, were translated, separated, and analyzed through inductive analysis of data from translated interviews according to 22 thematic categories. Translators were questioned after each interview, and the personal interactions with mothers, both verbally and non-verbally, provided added substance to the delicate process of naturalistic inquiry.

Forty mothers of one or more children with moderate to severe disabilities from age four to 19 participated in the interviews. Their children attended the same education center for children with disabilities in Doha, Qatar. Mothers shared about their daily routines with their children, activities within the home, activities in the community, and needs they saw within the community to remove social and physical barriers that hindered access to the community for those with disabilities.

Due to a high prevalence rate of disability and social issues that limited access to service provisions, many individuals with disabilities had not received services in Qatar. The pervasive need for community resources, such as genetic counseling, appropriate medical facilities and care, and appropriate and inclusive schooling opportunities were reported. At the most basic levels of the education system, children with disabilities need to be present to foster greater awareness and acceptance of persons with disabilities. The education reform in Qatar has instituted change on a small scale level for a few children with mild disabilities, but this effort must be further expanded.

The data showed various impacts of disability on families. Results indicated that disability changed the way daily life was carried out and the activities that families participated in together within the home. Disability also readjusted the way families participated in the community. Community integration or lack thereof, affected the family life of those with children with disabilities in Qatar. These data reflected a lack of resources in a community where mothers expressed a desire for a more inclusive atmosphere for individuals with disabilities.

DEDICATION

I dedicate this dissertation to my family, especially Mom and Dad, whose encouragement got me this far; The Abbs Bunch: Tiffany, Annalisa, T.J., Marissa, Michaela, Alexis, and Christopher, with whom I have grown and love very much; The Kays, my loved ones in England; and Matthew and Elsie. You have become such a special part of my life during this time, and I am ever thankful that you are mine. Thank you all for being with me on this journey. Lastly, and most importantly, I give all of my thanks and honor to my Lord and Savior as I dedicate this work.

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I recognize that I have come this far because of an important thing called divine intervention. Whether it is about whom I have met, what has been accomplished, or what fell into place just as it was needed, it was about that special little gift.

I am very grateful for Noura Shafiei and Sana Esmaeli, who served as my faithful translators in this long process. I do not know what I would have done without you! I would like to thank the social workers of the Shafallah Center and the mothers who so willingly opened up to share their hearts through their stories.

My committee has given me a great deal of support and guidance, and I would like to thank each of them. Dr. Patricia Lynch was the one who lived the experience with me and continuously encouraged me from start to finish not to give up! Dr. Laura Stough was the one who taught me that it IS okay to contextualize as a non-native researcher. Dr. Jennifer Ganz was the one who stepped in when she was needed most and served as that extraordinary *Simon James Alexander Ragsdale the Third!* Dr. Yvonna Lincoln opened my eyes to the world of naturalistic inquiry in class just before I left for Qatar. It was life changing! I also thank the other faculty and staff at Texas A&M University who have worked with me along the way. I am deeply indebted to each and every one of you in Aggieland.

God has given me much more than I deserve in this lifetime and I thank Him for it. My husband is one example of this with his patient and kind heart. Thank you Matthew, for all of the love and support. During this time my little girl, Elsie, came into

this world early, under extreme pressure and insurmountable odds, and has inspired me in that she is a true ‘miracle kid’. Thank you, Elsie, for the reminder that miracles happen. Mom and Dad, thank you for those prayers and words of wisdom throughout the years that have kept me at it. To my family and friends, who have prayed so many times for me, just know that they were answered and will not be forgotten.

Through this process I have learned to trust in the Lord with all of my heart and not to lean on my own understanding. I must acknowledge Him because He has helped me to continue to walk on this path set before me.

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CHAPTER I

INTRODUCTION

Dembo, Leviton, and Wright (1975) defined *disability spread* as a society's perception of individuals with disabilities as primarily or exclusively focused on the disability, where assumptions, inferences, and generalizations are made about who a person is and what he or she can do according to the disability rather than their abilities. Since individuals with disabilities require certain supports at home, in school, or in the community, the way they are perceived and the way others interact with them can be changed (Giangreco, 2006). The social construct of *community*, or a gathering together of people, those with and without disabilities, is affected by unnatural social barriers built without understanding that affect interaction and true integration of those with disabilities (Bogdan & Taylor, 1989). Relationships between people with disabilities and those without might be passed up because of these barriers.

The issue of inclusion of children with disabilities into the Qatari community is pivotal and aligns well with recent moves in the State to recognize the rights of individuals with disabilities ("Sheikha Hessa Hails Efforts", March 20, 2006). The number of children diagnosed and living with disabilities is on the rise world-wide, much of which can be attributed to medical advances that rescue infants who are premature or who are in medical distress and also by the provision of better outcomes for children who become disabled ("Governments", April 26, 2007). Medical developments

This dissertation follows the format of *Exceptional Children*.

and laws protecting human rights for those with disabilities are furthering the cause of community inclusion for those with disabilities.

The United Nations adopted the Convention on the Rights of Persons with Disabilities, which includes articles that mandate moves by member nations to improve public awareness of disability issues and to maintain human rights for those with disabilities (United Nations, December 5, 2006; “Shafallah”, April 26, 2007). The State of Qatar has one of the highest rates in the world of infants born with disabilities, some 73 out of 1,000 live births; this is primarily due to a close gene pool and the traditions of intra tribal marriage, predominantly with first cousins (Mishra, 2007). This newly published news on disability is greatly needed information to raise the public awareness that disability is more common than what has been relayed to the public in the past. The stigma of disability in Qatar has brought shame upon some families who have a member with a disability and has most recently been thought to be far less common for Qataris, as shown by the current data that are available on disability in Qatar. This study reflects the input of individuals in the field of disability education and services because there is little published literature on disability in Qatar and the Middle East at large.

Qatar is an Arab-Islamic Emirate ruled by the Al-Thani family, the tribe which inherits the ruling power of the State through male succession and instills full executive power to the Emir (“Country Reports”, March 11, 2008). Qatar has morphed from a poor protectorate of Great Britain that subsisted on the pearl diving industry into a sovereign state with one of the highest levels of per capita income worldwide from oil and gas reserves (CIA, The World Fact Book, 2008). The current population is believed to be

approximately 900,000, with 200,000 of those persons being Qatari citizens (“Country Reports”, March 11, 2008).

In Qatar families have commonly declined services for their children with disabilities, because to some the acceptance of services is a sign that “disability” has been accepted (personal communication, F. Darwish, March 7, 2007). The social factor of shame affects whether or not a family would allow their child with a disability to attend a school like the Shafallah Center, a school option for Qatari children with more involved disabilities, or a public school where the answer to the question of whether or not the child has a disability would not be immediately known according to the name of the school attended (personal communication, F. A. Taher, February 15, 2007). For example, there were 35-45 children in pre-kindergarten through second grade who were included in general education classes in the State of Qatar in 2006-2007 (personal communication, F. Al Maadadi, February 5, 2007; personal communication, M. Al Rwaili, February 14, 2007). This number of students is very low considering the number of children at this age that might have disabilities. At this time children in Qatar who have serious health issues or a need for physical, occupational, and speech therapy are not included in the general education setting, but this is the goal for the future (personal communication, M. Al Rwaili, April 5, 2007). Prior to the establishment of laws to promote inclusion, it was not common to see individuals with disabilities in public or being taught in general classrooms with peers (personal communication, E. Al Obeidly, April 3, 2006).

Qatar is attempting a progressive, social change in the area of community inclusion for children with disabilities and this change is beginning in schools. Since 2004, inclusion of children with mild disabilities has occurred in general education classrooms across Qatar, but there is a severe shortage of trained teachers to work with children with disabilities and some parents still resist the thought of their child receiving special services because of the social implications (personal communication, M. Al Rwaii, April 5, 2007).

Fiza Darwish, the director of the Children's Rehabilitation Services at Rumeila Hospital does not have a waiting list for her program, which serves 90-95 children with multiple disabilities. Children must be referred to the program by a doctor. After more than 20 years Fiza has seen many highly educated parents refuse services for their children with disabilities. According to Fiza, to accept services can be shameful because everyone will know there is a child with a disability in a family. On the other hand, there are rural families, who live in regions of Qatar where there are few to no services, who may not realize that there is anything available elsewhere. Furthermore, mothers may birth their children at home, so there is no hospital diagnosis of disability or agency contact for services (personal communication, M. Al Rwaii, April 5, 2007). The prevalence rate of this is not known. Since Sheikha Moza has addressed the issue of disability awareness more parents are likely to accept services. Sometimes parents accept services once they understand the implications for their child (personal communication, F. Darwish, March 7, 2007).

Purpose of the Study

Qatar has made many changes in the areas of recognition of and provision for those with disabilities to have equal access to their community. Parents of children with disabilities are the closest source to a child who can recognize what works and what does not work to further the cause of community inclusion. This research was intended to help others understand the sharp awareness and knowledge and the keen perceptions of needs that a mother has of her child with a disability as a community member. Uncovering mothers' perceptions of interactions within the community, including what is and what is not available for their children, was the primary focus of this inductive analysis of data from translated interviews. The purpose of this study of perceptions was intended to impact the availability of opportunities within the community for persons with disabilities, according to the culture, as interpretations were made from qualitative interviews by a non-native researcher.

Research Questions

This qualitative study analyzed mothers' perceptions (awareness, knowledge, and attitudes) of their children's integration in the Qatari community in order to answer the following questions:

1. What has been the impact of disability on the family?
2. How does the child participate in family activities?
3. How does the child participate in community activities?
4. What do mothers suggest to improve opportunities for their children in Qatar?

Definition of Terms

In this study the key words are defined in the following manner:

1. **Integration** is used in the context of acceptance into a community; becoming an accepted member of a group or community where one's presence is not devalued.
2. **Inclusion** is primarily defined as instruction of an individual with a disability in the general education setting rather than in a segregated setting. The word *inclusion* means "presence in a group" ("Inclusion," 2007), but the hope is that the practice within the community at large would be closer to the definition of *integration*.
3. **Culture** is a word with many definitions. In this study two are employed:
 - a. Shared beliefs and values of a group and people who share those beliefs and practices as identification of place, class, or time ("Culture," 2007).
 - b. Shared attitudes about how a particular group of people characterizes others, for example, those with disabilities in a culture of inclusion or exclusion.
4. **Culture study** is an analysis of the phenomena of the lived experiences of mothers of children with disabilities in Qatar and the way in which these mothers have dealt with those experiences within their own community and cultural context.
5. **Hermeneutics** is the science and art of interpreting meaning.

6. **Phenomenology** is the study of phenomena; a philosophical investigation of lived experience and all of its quirks without questioning an individual's sense of objective reality (Lincoln & Guba, 1985).
7. **Perceptions** are acquired attitudes or understanding that comes from observations made about one's environment and thoughts that are processed about these observations. A *perceptive* person can be described as one who "notices or discerns things that escape the notice of most people" ("Perception," 2007). Knowledge and awareness can be gleaned from analysis of perceptions, especially when those perceptions are shared by exceptionally perceptive persons.

Assumptions

1. Inclusion of those with disabilities into the community in Qatar is a fairly novel practice.
2. Local schools are the initial place where individuals with disabilities will experience integration into a community of peers.
3. Mothers of children with disabilities who are most likely to obtain services for their children are at the Shafallah Center. Although this population is a small sample of the total number of mothers with children with disabilities in Qatar, it is representative of mothers willing to accept services.
4. Generalizations are not easily made between unique perceptions in naturalistic research. (Holsti, 1969, as cited in Lincoln & Guba, 1985).

Significance of the Study

This study comes at a time when many policy changes are being made that challenge social norms and perceptions about disability in Qatar in ways that will improve public awareness. Policy makers, administrators, and individuals with disabilities and their family members are collaborating to determine the best application of the law and to educate community members on the best possible way to address current problems or barriers that are faced by those with disabilities (Salhab, 2006). Some mothers are not aware of the importance of inclusion and integration into the community (personal communication, F. Darwish, March 7, 2007).

This study examined mothers' perceptions of the accessibility to resources within the community for their children and was used to obtain mothers' ideas about how improvements could be made to remove social and physical barriers that hinder access to the community by their children. The current body of knowledge about perceptions of disability in Qatar is minimal. This study attempted to add to the available body of information on community inclusion and integration according to the perceptions and evocative and knowledgeable descriptions of those working closest to children with disabilities: their mothers. These perceptions were captured, analyzed, and recorded to bring forth understanding that will impact change of viable practices in education and service provision for those with disabilities in Qatar.

Design of the Dissertation

Translated information, which answered the research questions, was separated and analyzed. Analyses regarded working hypotheses (Lincoln & Guba, 1985), which

were formulated and shaped by the senses and feelings expressed in words by interviewers in the process of translation. Questioning translators after each interview and personal interactions with mothers verbally and nonverbally provided added substance to the delicate process of inquiry based on translation study. The knowledge that translators relayed in English provided invaluable data from the well of relevancy from which real-life stories sprung forth before them.

The research is described in detail throughout five chapters. Chapter I introduces the study and offers an overview of the purpose of the study, research questions, definition of terms, assumptions, and significance of the study. In Chapter II the reader will review literature on integration of persons with disabilities in Qatar, including their rights, current laws, and prevalence of disability; education of those with disabilities, including current reforms, special education, the Shafallah Center, and inclusion; benefits and challenges of inclusion and integration according to an inclusion project and administrative follow-up on inclusion; cultural beliefs about disability in Qatar; and the methodology of hermeneutical phenomenological research, interviews of mothers with children with disabilities, culture study, translation, and second order data. The methodology of this interpretive research is presented in Chapter III. Chapter IV provides an analysis of 40 interviews with mothers of children with disabilities. Finally, Chapter V summarizes the outcomes of the study and their implications for the community and for further research.

CHAPTER II

REVIEW OF THE LITERATURE

Introduction

In order to gather and analyze information about the perceptions of Qatari mothers of children with disabilities on community integration opportunities for their children relevant literature was reviewed. The review focused on the Qatar educational reform initiative, the idea of disability in a Middle Eastern context, and beliefs about disability in developing countries, such as Qatar. Qatar is attempting to acquire a culture of inclusion. Due to the nature of the research, which was conducted by an American researcher in a Middle Eastern setting, other cross-cultural research was pertinent to the review. Interviews were completed in the native language of the interviewees, except for two interviews where the mothers requested they be interviewed and respond in English. Therefore, the majority of interviews were translated. Second-hand ethnographies and translation studies were reviewed to further explore how handling of information by multiple vested individuals might affect the data or its analysis. Finally, the appropriate methodologies necessary to support this research were reviewed.

Integration of Persons with Disabilities in Qatar

Rights for Persons with Disabilities in Qatar

In a socio-political context, the State of Qatar has been part of the conglomeration of the United Nations aiming to create an international convention focused on the promotion and protection of human rights for individuals with disabilities, which includes the availability of an appropriate education. In a Press

Release by the U.S. Department of State (Qatar Country Report on Human Rights Practices, 2001) reported that The Special Rapporteur on Disability for the United Nations (U.N.), Her Excellency Sheikha Hissa bint Khalifa Al-Thani of Qatar, has worked with a global team since 2001 to advocate for full participation of and equal treatment for individuals with disabilities in all areas of daily life, especially in her own nation (“Rapporteur’s Role,” October 30, 2004). Al Thani was selected by the U.N. Secretary-General Kofi Annan to head the U.N. Commission for Social Development from 2003-2005 (U.N. Press Release, June 6, 2003). During a strategic planning meeting to further advance Qatar and to end discrimination against those with disabilities, Al Thani pinpointed the main goal of her agency to become a force to remove social barriers allowing persons with disabilities full access to resources and to make known within the community the contributions of persons with disabilities (“Plan Drafted,” October 3, 2004). These efforts led to an Arab League decision at the 2005 meeting of the U.N. Convention about the Rights of People with Disabilities to deem 2004-2013 as the “Arab Decade for Disability” (“Shuriah Delegation,” 2005).

The problem with access to resources for those with disabilities in Qatar is not due to inadequate legislative action, but to an incomplete application of the laws that have been set in place (“More NGO Efforts,” 2006). In a National Human Rights Committee seminar in November 2006 Qatari adults with disabilities and parents of children with disabilities expressed the laws created to meet the requirements of Arab reform have been positive, but there is still a lack of awareness about disability, a lack of easily accessible facilities in the community, a limited number of educational programs

for children with disabilities, and few post-school options for children who complete the available programs at the secondary level (Salhab, 2006). According to the Special Rapporteur on Disability, the lack of resources for those with disabilities in the Qatari community is due to culture and tradition, as these have slowed the process of initial recognition of the issues affecting those with disabilities (“More NGO Efforts,” 2006). A lack of awareness of disability has been due in part to a sympathy-focused mentality rather than advocacy-based thinking about individual rights for those with disabilities (“More NGO Efforts,” 2006).

Laws to Impede Discrimination Towards Persons with Disabilities

Prior to 2004 there was no law that prohibited discrimination of those with disabilities; in fact, there was no form of governmental office in charge of investigating human rights violations until May 2004 in Qatar (“Country Reports,” February 28, 2005). Before the anti-discrimination law was established the government did not permit human rights groups to operate, realizing that societal discrimination was occurring regularly, but after began to form the National Human Rights Committee. In addition to human rights, accessibility to community resources for those with disabilities was mandated; free health care and educational services, although not inclusionary, were provided for citizens and non-citizens with disabilities (“Country Reports,” February 25, 2004).

Legal provisions to protect the rights of individuals with disabilities have just been established since 2001, and primarily after 2006 when the United Nations Commission for Human Rights furthered efforts for global inclusion, promotion, and

protection of the rights of those with disabilities by adopting the International Convention on the Rights of Persons with Disabilities (United Nations, December 2006). This law is pivotal to the acceptance of those with disabilities, especially in developing countries (personal communication, D. Mitchell, April 26, 2007).

Effective implementation of these laws takes time as communities under them digest and plan for the concept and practice. Qatari officials providing momentum to the inclusion movement expect that the Shafallah Center, an educational facility to serve individuals with disabilities, will be important to integration efforts (Newsweek, May 8, 2006), although it is a center-based program. Typically inclusion in general education classrooms is a primary focus of community inclusion to allow children with disabilities the right to participate as community members ("Centre," May 10, 2006). Current changes in the law not only affect the accessibility to education for individuals with disabilities, but also promote integration of individuals with disabilities in daily living activities within the community.

Prevalence of Disability

In 1997 the Planning Council (Supreme Council for Family Affairs and the Secretariat General of the Planning Council, 2003) of Qatar first began collecting aggregated data about disability. This information about disability included type, etiology, age, education status, and gender. Sources of the data were the population and household census data from 1986 and 1997, as well as disability data collected in 2001. Data from the Supreme Council for Family Affairs and the Secretariat General of the Planning Council (2003) revealed a rate of four individuals with disabilities per 1,000.

Further analysis by nationality found two persons per 1,000 non-Qataris with a disability and 9.9 persons per 1,000 Qataris with a disability (Supreme Council for Family Affairs and the Secretariat General of the Planning Council, 2003). These figures seem very low for a country which had 2,207 persons with disabilities in 2001, of which documents state 67% were Qatari and 33% were Non-Qatari (Supreme Council for Family Affairs and the Secretariat General of the Planning Council, 2003). There is an evident problem with accuracy and consistency of disseminated information.

Using the numbers given and the population statistics in 2001 of 170,000 Qataris and 650,000 expatriates (“Country Reports,” March 4, 2002) it is possible to see that “disability”, whatever specific characteristics that term may be used to describe, is either exceptionally low or the statistics are not accurate. When those statistics are tabulated with the census population data both groups appear to have a rate of disability that is less than one percent when using the numbers of 9.9 Qataris out of 1,000, two expatriates out of 1,000, and four out of every 1,000 members of the population with a disability (Qataris: 0.009%; Non-Qataris: 0.002%; and the general populace: 0.04%). The final figure of 3,280 people with a disability for the general population does not coincide with the previously mentioned figure of 2,207 people with disabilities, as reported by the Planning Council (Supreme Council for Family Affairs and the Secretariat General of the Planning Council, 2003). All pieces of information have been derived from national agencies. For all groups the calculation is less than 1% of the population with a disability when disability in the United States, arguably a different culture with different characteristics and perhaps a different definition of “disability,” has prevalence rates of

10-12% of the population with disabilities, although fewer than 1% of the population has a severe disability (Giangreco, 2006). Mishra (2007) reported that worldwide 6% of births involve serious birth defects.

In a 2001 report by the Supreme Council for Family Affairs of Qatar (Supreme Council for Family Affairs Committee on the Rights of the Child, 2001) the translator made note that the government supplied statistics given in the document were incorrect and did not tally properly. The source citation was “General census, March 1997” and the total number for the population of Qataris in the nation was listed as being approximately 13,000 more people than most documents suggest for the 1997 general census (Supreme Council for Family Affairs Committee on the Rights of the Child, 2001).

The Planning Council (2005), which carries out the Qatar census, provided 2004 statistics on disability in the Qatari population in the categories of congenital, pathological, accidental and other disabilities, as 941 infant, pre-school and school-aged children (birth-19 years). In infancy 14 congenital birth defects were reported in 2004. The number of Qatari nationals according to the 2004 census was 200,000 (“Country Reports,” February 28, 2005; Planning Council, 2005). The number of Qataris (all ages) with disabilities (congenital-1307, accident-205, pathological-776, and others-111) was reported as a total of 2,399 persons in 2004 (Planning Council, 2005; Appendix A), which was approximately 1.2% of the population. According to the Planning Council record there were 5,000 individuals with disabilities in need of community inclusion in 1997 (SCFA and the Secretariat General of the Planning Council, 2003). The Ministry of

Education reported 1084 children of school age with disabilities for the same year (Al Hail, 2005). Disabilities are prevalent, according to anecdotal evidence, but there have not been hard statistics (personal communication, A. Baker, April 26, 2007).

Obtaining Data about Prevalence of Disability

With the increase in population and as evidenced by reported waiting lists at schools that serve children with disabilities, the numbers of those with disabilities may be much higher (personal communication, S. Hannibal, March 3, 2007). The government of Qatar attempted to obtain correct data by carrying out a disability census, which began in January 2007 with a second phase commencing in March 2007. It is unknown when the information obtained will be disseminated and whether or not individuals are more likely to respond to survey questions about disability in their homes. This marked void of accurate and complete data on disability may also be due to an unstable definition of what “disability” means in the Middle East region.

According to a report “Disability Measurement for the Economic and Social Commission for Western Asia (ESCWA) Countries” produced by the United Nations Statistics Division (2002) that served as a training session for census evaluators in Cairo, Egypt in 2002, census questions were to be designed in a way that would avoid the use of the word “disability” in questions to individual household members in the Middle East. This adjustment took place two years prior to Qatar’s 2004 census. Further, the 2002 report called for census workers to avoid use of the term “disability” in conversations with household members. Instead the question design module recommended use of the word “difficulty”, such as “difficulty that lasted or is expected

to last 6 months and more in performing usual activities” with the different modalities of the senses (hearing, seeing, speaking, learning, ambulation, and self-care).

It is likely that those responding to past census questions where the term “disability” was not employed in Qatar, may not have revealed or responded accurately about any known disabilities, whether diagnosed or undiagnosed. It is possible that this vague descriptor “difficulty” may have brought to mind only those incapacitating effects that are more temporary in nature than long-term disability. The Planning Council’s 2007 attempts to determine the number of individuals with disabilities in Qatar did specify that the request was only for information on *permanent* disability.

In January 2007 the Planning Council publicized and commenced a disability survey to determine the accurate number of people residing in Qatar who have a disability. The intent of the survey was to collect information about members of each household in Qatar, no matter their nationality, in order to locate those eligible to receive services and to better guarantee the rights of those with disabilities (Al Sawaidi, 2007). The absence of accurate and reliable data about disability has long been a barrier in Qatar to informed decision-making in the development of quality programs, and this problem is exacerbated when searching for information in English (“Centre,” May 10, 2006).

The perception of disability in the region is a barrier to reliable data on disability and for this reason many families have refrained from providing information about their relatives with disabilities in past national surveys that were conducted (“Awareness Must for Social Acceptance of Physically Challenged,” 2007). It was noted that the 2007

survey would provide information about the number of people with disabilities, their age, their residential area, the cause of disability, medical treatment received, perceived social barriers, and family income and expenses (“Qatar’s ‘Special’ Step,” 2007). As those with disabilities are identified and provisions are made for their education, the country’s intention of change to consider a more inclusive educational and social setting for those with disabilities will be possible; although, there is still considerable concern as to whether or not those with disabilities will be located so that resources can be allocated to them.

It is recognized that even after a widespread effort such as the 2007 Disability Survey data may be inaccurate. Surveyors did not go door to door in all circumstances to ask about whether or not there was a person with a disability present in each residence. In some cases a letter (Appendix B) was sent to an apartment complex to be mass distributed on behalf of the Planning Council. The letter requested recipients to facilitate the completion of the Disability Survey by the Director of the Statistics Department in the office of the Secretariat General of the Planning Council. Five days later another letter (Appendix C), which served as a form, was distributed by the apartment complex. This required the recipient to claim if there were any persons with a permanent disability present in their residence and turn the completed circular into the front desk of their apartment, with information that included the apartment number, name, nationality, and physical disability and its nature within 3 days of having the flier placed under their door. The recipient was instructed to write “Confidential” on the envelope in which the information was contained so that it could be forwarded by the apartment to the State

Planning Council. Follow-up with those who did not complete the survey did not appear to take place. In survey research person to person contact and follow-up are essential elements to a high response rate (Patten, 2000).

When accurate census data is obtained, it might be compared with that of neighboring communities that have similar characteristics, where work is being done to increase disability awareness as part of the Arab Decade for Disability. In a survey by Taylor & Francis (2001), to discover the prevalence of childhood disability from birth to 15 years of age in neighboring Saudi Arabia, children were screened in 875 homes. Twenty-one percent of the children who were screened were diagnosed with a disability for the first time. Thirty-four percent of all children screened were a second or third child in a single family to have a disability. Of the children in the study 3.67 in every group of 100 children were diagnosed with a disability. Further research is needed about the existence of multiple incidents of disabilities within the same family and the definition of what “disability” means.

Consanguineous Marriage in the Middle East

For regions of the East that were part of the Arab-Islamic Khalifate there is a strong functional pattern between Islam and consanguineous marriage for which the region has the highest prevalence rate in the world (Korotayev, 2001). Conversely, when Islamization is not a factor in a region there is a noticeable absence of consanguineous marriage or parallel cousin marriage. For example, as part of the original eighth century Arab-Islamic Khalifate, the only region that does not have a high level of consanguineous marriage is that of the Iberian Peninsula of Spain (Korotayev, 2001).

Muslims of the Middle East have very strong social ties amongst themselves or a high level of “sociability”: al-‘alaqat’aawiyah, especially within their families where closeness ascribes value (Clarke, 2007).

Korotayev (2001) illustrated that in Islamic law (Al-Sharia’a) daughters are given an inheritance from their families half the size of that of a son (The Quranic verses of inheritance: 4:7). Beginning with agricultural families who would have a large plot of land that would be inherited by their children, it would only take several generations before land would be broken into small plots maintained by different households (families) if daughters were to be given land, most likely cared for by their husbands, and married outside of their own tribe. Their husbands would not be part of their family (or tribe) and would, therefore, manage the land of the woman, which now had been inherited and assimilated by marriage into the land of another family living within the region. For this reason consanguineous marriage, not deemed necessary in Islam, nor prohibited, aligns well with the property rights given to daughters according to Al-Sharia’a Law (Rosenfeld, 1957, as cited in Korotayev, 2001). Bittles, Sullivan, and Zhivotovsky (2004) noted a high rate of deaf-mutism in the Muslim population of Punjab because of the high prevalence rate of consanguineous marriage.

Consanguineous marriage is a common practice in the region where this study has taken place. Birth defects are present in approximately 6% of infants around the world, but the rate for Middle Eastern and African countries is 7-8% (Schuler, 2006), although the case has been made that data have not been accurate in the past and are

most likely an underestimate of true figures. Relevant to the relationship between consanguineous marriage and disability, it is a factor in this research.

Consanguineous Marriage in Qatar

In a study that took place from January to May 2004 1,515 Qatari women over the age of 15 were interviewed (“Marriages among kin,” November 12, 2006; Bener & Alali, 2004). Results of the study were that 54% of the women were in a consanguineous marriage; 35% were marriages between first cousins and 3% were between double first cousins where both spouses had parents who were also first cousins (Bener & Alali, 2004). Bener & Alali (2004) noted that asthma, mental retardation, epilepsy and diabetes were drastically more common in children born to parents who were related. Qatar has a higher rate of consanguinity in marriage than other Middle Eastern countries and in one generation the percentage of consanguineous marriage has increased from 42% to 54% of all marriages (Bener & Alali, 2004).

The likelihood of disability with such high numbers of consanguineous marriages is evidence that the rate of disability is probably much higher than what is publicly noted. While nationals of Qatar favor mandatory pre-marital medical exams that could lessen congenital birth defects, the center that provides checks has only served 30 couples from 2003 to 2006 (“Premarital Medical Health,” June 18, 2005; Nationals Call for Tests,” February 18, 2006). The rate of children born with birth defects and genetic disorders is high (personal communication, F. Darwish, March 7, 2007), but actual prevalence rates have not been determined. Disability is coming to the forefront as a topic of which the community must be aware, so that children with disabilities are

provided services and families have the information needed to search for provisions. Parents have a natural sense for development of ideas and understanding of needs about what will help their children. When a mother articulates her ideas of what it is like to raise a child with a disability her social, cultural and historical realities are inextricably a part of her story bound to be shared (Ferguson, 2002).

Cultural Beliefs about Disability in Qatar

Governmental hospitals in Qatar make the initial diagnosis that there is a disability, except in cases where a disability is not recognized until a family member, most likely a mother, brings it to the attention of her doctor. The child is diagnosed; services are then offered to the family (personal communication, F.A. Taher, February 15, 2007). No child can enroll in school without a health card which says whether or he or she has a disability (personal communication, M. Al Ruwaili, April 5, 2007). However, if schools do not have services available to children with more severe disabilities, the schools will turn students with disabilities away. For this reason parents choose not to disclose that their child has a disability or that they suspect their child might have a disability (personal communication, M. Al Rwaili, February 12, 2007).

From the hospital screening and this process of diagnosis of disability parents receive monthly income and daycare assistance. Mothers from rural areas do not have their babies in hospitals in the city of Doha, which means they may not know about services, they may not receive services, or they travel a substantial distance to receive services (personal communication, M. Al Rwaili, April 5, 2007). After diagnosis many

families choose not to receive services because of the social stigma and perception of shame attached to disability (personal communication, F. Darwish, March 7, 2007).

Due to the social pressures that are present, a family with a child with a disability may feel socially isolated, shameful, and embarrassed. The State of Qatar has been offering a larger variety of resources to individuals with developmental disabilities in order to encourage an awareness of their rights and the provision for what were once invisible needs in Qatari society. According to the U.N. Special Rapporteur Al Thani, efforts taking place in Qatar are intended to exemplify the goal of community integration for those with disabilities in the Arab world (“Sheikha Hessa Hails Efforts,” March 20, 2006). Progress toward this goal has been stifled at times because of deeply imbedded cultural stigmas attached to difference and a tradition of sheltering those with disability from society as was done in the past (personal communication, Y. Al Abdullah, 2007). It is essential that committees that act on behalf of or establish programs for families of children with disabilities prepare to see more individuals with disabilities in the community in the coming years.

Disability in Arab Culture

United Arab Emirates

According to Eapen, Zoubeidi, Yunis, Gururaj, Sabri, and Ghubash (2006) as part of a study of developmental delay in three year old children, the United Arab Emirates (UAE) is making headway in efforts to diagnose disability early. There has also been a move to encourage inclusion of children with disabilities in elementary schools with their peers in general education classrooms (Alghazo & Gaad, 2004), just

as Qatar is attempting to do. In this study, researchers employed clinical interviews to check for global developmental delays (GDD) in young children. The research team found that in developing countries like UAE it was more likely for children to be born with developmental disorders, but there have not been prior studies in the Gulf Region on the characteristics and prevalence of developmental disabilities in preschool children.

It was noted that UAE, like Qatar, is a developing country that does not have the risk factor of poverty because the per-capita income is high due to the oil industry. This makes it a challenge to make any sort of comparison with most other developing countries due to the extreme difference in economic factors. Risk factors that the authors noted from their prior research that are important to mention were a family history of a specific disability and also the presence of a consanguineous marriage between the birth parents of the child (Eapen, Al-Gazali, Bin Othman, & Abou-Saleh, 1998, as cited in Eapen, Zoubeidi, Yunis, Gururaj, Sabri, and Ghubash, 2006). However, in the current study the authors did not find that consanguinity was linked to global developmental delay. One factor that may have been influential was that the Ministry of Planning identified 726 households with three year old children to be screened. Of those candidates 694 entered the screening process. The possibility that the households that declined did so because of knowledge of a disability would be a likely possibility in the region. Of all children who were screened 8.4% had a developmental delay, which is relatively similar to the percentages common in developed countries.

There are a variety of reasons why an individual with a disability or his or her family may reject a label of disability or struggle to accept that disability. Finlay and

Lyons (2005) noted that from a social constructionist point of view label rejection might be expressed as denial in order to protect self-esteem, which can lead to a distancing from group membership. From a historical context of Greek thought, common in the West, Stainton (2001) conveyed the idea that the concept of cognitive disabilities from the view of Aristotle and Plato were linked to a belief that the attributes of human beings were encapsulated by their ability to reason and that the inability to reason was a serious defect of the soul that naturally led to social hierarchy (Aristotle). This explanation would explain why those with intellectual disabilities are not always embraced in the West, but why not in the Middle East?

Dinero (2002) presented a call for the need to have more information about disability in the Arab world in response to the position by author Lina Abu-Habib that women with disabilities in Arab culture are especially isolated to the social exterior of a community, as members who do not have value because of their disability or they are rejected and are not allowed the same prospects typical to other able-bodied community members. Dinero (2002) pondered the fact that, perhaps for reasons of posterity in a traditional, patriarchal, communal society, those with disabilities are discouraged and restricted from marriage as are their siblings once other families in the community are aware that a marriageable prospect for their son or daughter has a sibling with a disability (Reynolds, 2006; personal communication, F. Al Maadadi, June 20, 2007). Marriage and family are of utmost importance in Arab culture.

Egypt

In the first English study of disability in Egypt Reynolds (2006) notes that reforming Egyptian society to accept individuals with disabilities remains an intangible task because the thought is that to rehabilitate an individual with a disability means to make them more “normal” so that they can fit into society, rather than to focus on changing the perceptions within the society so that those with disabilities are accepted by their families and their communities. The premise of denial to avoid disgrace and to preserve individual or familial dignity is not the only factor involved (Finlay & Lyons, 2005; personal communication, F.A. Taher, February 15, 2007), but there are also more deeply imbedded reasons for shame and rejection due to a label of disability that are culturally imbedded and unique to Arab society and culture.

Succession by a child with a disability is not easily accepted in Arab culture (Khouzam, Chenouda & Naguib, 2003). Often there is a sense of resentment or ambivalence toward a child born with a disability in Arab culture due to the importance of heritage, especially in reference to male children (Khouzam, Chenouda & Naguib, 2003). Al-Fuhail, Al-Hamdan, & Suyyagh (1993) noted that there are many superstitious beliefs in regard to pregnancy and events that might cause disability in an unborn child in Arab society.

Lebanon

There are a limited number of studies on disability in the Middle East, but findings from those that are available are relevant to the study of disability in Qatar. In a study in Lebanon about the adaptations to disability by mothers, Azar and Badr (2006)

noted that the isolation families dealt with due to social stigma when they had a child with a disability was extreme. In their study of 127 mothers of children with disabilities they found an exceptionally high level of depression (60%) in mothers who were most often the primary caregivers of their children due in part to the lack of paternal engagement common in Middle Eastern communities (Zahr & Hattar-Pollara, 1998, as cited in Azar & Badr, 2006). Azar & Badr (2006) report that twenty-five percent of the children with special needs in Lebanon have cognitive impairments, but there is little data published about how families cope and function upon the birth of a child with a disability. The authors suggested more studies to understand how families have successfully adapted to a child in their family who has a disability.

In a study on mental disability in Lebanon, Karam, et al. (2006) considered the limitations of their research in the Middle East were due in part to the fact that public opinion research is not common and although researchers declare anonymity and confidentiality, the persuasive quality of this declaration to individuals in developing countries is less influential. In a study by Eleweke and Rodda (2002) regarding the challenges of the inclusion of those with disabilities in developing countries it was noted that the majority of those with disabilities are living in developing countries in Asia, Africa, the Caribbean, Latin America, and the Middle East and approximately 2% receive services that are tailored to meet their special needs (UNESCO, 1997, as cited in Eleweke & Rodda, 2002). The study also noted that there is a clear lack of services, materials, and staff to carry out service implementation in developing countries, as well as a lack of legislation that empowers those with disabilities to participate within their

communities. One thing that sets Qatar apart in recent efforts to engage those with disabilities in the community has been the strong anti-discriminatory legislation that has been passed.

Disability Spread

Disability in the Arab world has not been accepted as a characteristic valued in community membership. Those with disabilities in Qatar, and other Middle Eastern countries, have not received adequate services to include them within their communities. Dembo, Leviton, and Wright (1975) investigated the social-emotional relationships between injured and non-injured persons. Individuals between the ages of 19 and 58 years who had a visible injury, such as orthopedic impairments or amputations and other visible reminders left from surgery, were included in the study. Most were hospitalized servicemen and veterans. Non-injured persons included wives, other relatives, professionals who assisted the injured individuals, and other friends and acquaintances. Injured participants were interviewed about their perceptions of how their life changed after the onset of a disability and the reactions to their disability that they noticed from others. The objective of the study was to find out “how people act” and “how they should act” toward a person with a disability. The changes that occurred with an unexpected disability were analyzed according to the topics of misfortune, suffering, value loss, mourning, and the potential for devaluation of a person due to a permanent disability. Perceptions of those with injuries were compared to perceptions about disability according to persons in their lives who were non-injured.

Interestingly, the study described the concepts of aversion and spread as related to disability. These two phenomena were described as emotional means of avoidance by non-injured persons toward injured persons. Aversion was described as the voluntary reaction of non-injured persons to avoid injured persons with the belief that to do so was beyond the non-injured person's own control. Spread was described as the concept of exaggerated, negative effects of an injury which lead to avoidance or exclusion of injured persons for their own benefit. For example, a person with a disability may not be invited to a party because a person without a disability recognizes the potential challenge for the person with a disability to secure transportation to the party and to socialize with strangers. Since the person with a disability might feel uncomfortable at the party and even decline the invitation due to these factors, it is decidedly ethical to not extend an invitation. The sympathy mentality towards individuals with disabilities is then perpetuated. Dembo, Leviton, and Wright (1975) noted that jobs and group membership (valuable placements within a community) are often determined by those without disabilities, so it is of vital interest to those with disabilities that those without disabilities adjust to disability. In Qatar, and the Middle East, disability is viewed with sympathy and the stigma attached lessens the opportunities for true community membership. At the most basic level of provision, opportunities for children with disabilities to be included in educational settings are minimal.

Education of Those with Disabilities in Qatar

Education and Reform in Qatar

Ambitious plans for an overhaul of the primary and secondary education system in the small, resource abundant country of Qatar were initiated in 2001 by His Highness Sheikh Hamad Bin Khalifa Al Thani, Emir of the State of Qatar, and his wife, Her Highness Sheikha Mozah Bint Nasser Al Missned (RAND Education, 2006). Plans were put into action by 2002, as independent schools led by operators other than the former Ministry of Education (MOE) began to open doors (Al Hail, 2005). Reform efforts included the development of a standards based curriculum in four subjects: Arabic, English, mathematics and science. One major goal of reform was to create a bilingual society, beginning in the primary schools where instruction in mathematics and science was to be in English (RAND Education, 2006). Standardized assessments of all students in the independent schools were to be completed according to benchmarked standards of curriculum (RAND Education, 2006). The reform process also included provisions to better meet the needs of children with disabilities.

According to a draft document (Al Hail, 2005), as part of the reform process the MOE began to organize inclusion in educational settings by decision No. 6 in April 2004; this decision called for the formation of a supervisory board. In May 2004 administrative orders were given that involved strategic planning for how inclusion might occur and prescribed the formation of a committee to evaluate inclusion in the local schools. In November 2004 the MOE formed a committee that would employ strategies to encourage inclusion in general in Qatar. A committee for evaluation and

diagnosis of students with disabilities was created in February 2006. In a move that would provide special education for many children who had never before received those services, the MOE mandated that the Shafallah Center would accept all Qatari children with disabilities (personal communication, A. Sherawi, May 2, 2006).

Several local governmental schools do not accept children with disabilities and the national university, Qatar University, does not allow those with hearing impairments to take classes, which the National Human Rights Committee has recommended to be changed (“NHRC Report,” May 4, 2006). The fact that the National Human Rights Committee has pinpointed problem areas that are an expression of denial to the right of inclusion for individuals with disabilities in Qatar is a sign that the status of community inclusion is expected to change. This is an example of Qatar’s progress and development in education and integration for those with disabilities.

Special Education in Qatar

Al Sawaidi (2005) has classified the history of special education in Qatar to include initial provisions in the 1970s for segregated special education classrooms at specific schools. In 1975 there was one child with a hearing disability in a general education classroom. The MOE established the Department of Special Education in 1980. Institutions were no longer called “institutions,” but “schools” and there were two for boys with disabilities and two for girls with disabilities. In the 1990s the MOE opened two buildings for boys with hearing impairments and cognitive disabilities (Al Hail, 2005). More resources were available to those with disabilities as awareness of needs increased. The Emir of Qatar has continued to place focused efforts on passing

legislation to provide rights to those with disabilities, such as the May 2004 establishment of the Human Rights Committee and the efforts by U.N. Special Rapporteur Al Thani to promote the removal of community barriers to those with disabilities (“Plan Drafted”, October 3, 2004).

In the history of special education in Qatar, according to Sawaidi (2005), the greatest attention that the issue of inclusion received was when the Emir passed Law No. 2 during a special session held on the topic of provision of services for people with disabilities. This 2004 mandate acknowledged a commitment to the care and provision of all persons with disabilities in Qatar (Sawaidi, 2005; Al Sawaidi, 2007). A committee was formed to supervise the task of educational inclusion for persons with disabilities in April 2004 (Suwaidi, 2005), which led to the expansion of the Shafallah Center for Children with Disabilities.

The Shafallah Center

The Shafallah Center, a local center that serves children with disabilities opened a state of the art facility in Doha in May 2006. The old center, which is still in use for pre-school and female adolescent students, had the capacity in the year 2000 to provide instruction for 200 students (personal communication, A. Al Madadi, March 16, 2006). Special educators may complete a Special Education Diploma program through Qatar University, which is the only university to provide a special education training program. Concurrent with employment, the Shafallah Center provides training for those who wish to be special educators. The demand for special educators is high in Qatar, but a minimal

number of persons have sought training to meet the needs of the children in the nation who have disabilities (personal communication, H. Sadiq, January 16, 2007).

The Shafallah Center is currently the largest and most endowed community resource for those with disabilities in Qatar. Efforts of this center are supported by the Emir and plans for further development to provide progressive education for all Qataris are in the development process. Serving children with disabilities and their families is the primary focus of this center (personal communication, A. Sherawi, May 2, 2006). The Shafallah Center provides the only services that some parents have ever received for their children with disabilities (personal communication, G. Mohammed, May 23, 2006). Although offerings may be altered or completely changed in a way that may be more appropriate for any individual child, it may not be easily determined because of the array of responses about what “good” services are.

In planning for the new the Shafallah Center there was foresight to plan for the enrollment of 500-1,000 students in the coming years as waiting lists for educational services have been extremely long. With a new facility and more children receiving services, primarily those who are Qatari, per the guidelines of admission, the center continues to have a waiting list. Many expatriate children with disabilities are in need of services, but have a more difficult time finding a program that is able to accommodate them (personal communication, A. Sherawi, May 2, 2006). Although the exact numbers are unknown, many children remained at home and did not receive services prior to the expansion of the Shafallah Center. It is believed that this is still common, as the waiting lists for the center continue to exist (personal communication, S. Hannibal, February 6,

2006). As of fall 2006, the Shafallah Center was not able to accept all students who needed educational services and had applied. “The waiting list has 400-500 names of children who are in need of services, but there are not enough trained, Arabic-speaking special educators to instruct them” (personal communication, S. Hannibal, March 2, 2007). The problem does not only exist in schools established solely to serve those with disabilities, but it is also problematic in public schools in a country that is attempting to establish a climate of inclusion. The time is pivotal in the Gulf Region as the sense for advocacy pairs with a broadened understanding of rights by inclusion and integration of those with disabilities.

The Inclusion Movement in Qatar

Compulsory education was established in 2001 as free to all children registered with the State of Qatar to the age of 18 by the issuance of Law No. 25 (Convention of the Rights of the Child, 2006). Compulsory education for every child might be the mandate that led to further recognition of the importance of inclusion and integration for those with disabilities within the Qatari community. Where social inclusion and integration of those with disabilities may not occur naturally without the efforts of community members committed to the cause, the recognition of the need for education for each child creates the right of access to schools for all, including those with disabilities. Qatar, as part of recent reforms and social developments, has prepared foundational legislation and acted to create more suitable learning opportunities for children with disabilities in an inclusive society (Attiyah & Lazarus, 2006). For many

children with disabilities, the first time that they might be included in the activities within their community is when they first begin school (Odom, 2000).

Giangreco, Cloninger, & Iverson (1998, as cited in Snell & Brown, 2006) identify seven characteristics of an inclusive educational program: 1) A student is placed and welcomed into a class in a school where he or she would normally attend if living without a disability and would do so with necessary supports, without consideration of type or severity of disability (DeFosset, 1999); 2) the number of students with disabilities in the general education classroom would be proportional to the number of persons with disabilities in the local population; 3) education would take place in a setting that is with children of the same age; 4) children with and without disabilities would participate in like activities while meeting individualized goals with support and/or accommodations; 5) the most common setting for activities that those with disabilities participate in is also commonly frequented by persons who do not have disabilities (general classes in a local school, employment sites, or recreational programs for the community); 6) there is a balance between academic and social instruction in schooling; and 7) these characteristics are evident in the setting of the child with a disability daily.

The history of the inclusion movement in Qatar is not lengthy. The Supreme Education Council (SEC) drafted the history of inclusion, which provided a timeline of recent initiatives that have allowed for greater inclusion in the general education setting (Al Attiyah, Alabud, Lazarus, Albelsha, & Al Haddad, 2006). There were 11 primary independent (charter) schools that included children with disabilities in classrooms with

their peers without disabilities during 2006-2007 (personal communication, M. Armstrong, February 19, 2007). In 2002 Qatar adopted a greater commitment to the principle of inclusion in general education classrooms with the inception of the initial phase of a full inclusion project.

The SEC (Al Attiyah, Alabud, Lazarus, Albelsha, & Al Haddad, 2006) reported in a translated document from Arabic that the initial structuring of inclusion began in 1993 when children with minor physical disabilities were placed in general classes, resource rooms, or they received services from a consultant or specialist who traveled between classrooms to provide services. During the 1990s and a decade thereafter, children with disabilities primarily received education services from Rumeila Hospital and several small, private institutions for those with disabilities (personal communication, F. Darwish, March 7, 2007). After completion of fourth grade, children were then sent to general education classrooms in the governmental schools. It was not a common practice for children to be included in governmental schools prior to fourth grade (as reported by the SEC, 2001 in Al Attiyah, Alabud, Lazarus, Albelsha, and Al Haddad, 2006). In 2001 there was a committee established between the MOE and the National Committee for Disabled Children to study the best practices to begin a phase for full inclusion. The programming for children with disabilities was adapted to better meet the individual needs of each child.

During the first phase of planning between the MOE and the SEC, in collaboration with the National Committee for Disabled Children, two schools were appointed for a pilot study of the national inclusion project. The SEC (Al Attiyah,

Alabud, Lazarus, Albelsha, & Al Haddad, 2006) described the phases of the inclusion process. The second phase (2003-2004) required the drafting of an action plan that allotted support facilities (resource rooms and therapy rooms) and other resources for children with physical and learning disabilities in the schools appointed to the project. In the third phase (2003-2004) inclusion was implemented in a middle school for boys and a primary school for girls. In the fourth phase (2004-2005) two more schools were selected and more inclusion classes were added at the middle school for boys. In the fifth phase (2005-2006) five schools were added to the existing inclusion programs at both the middle school and primary school levels. During the final phase (2006-2007) five more schools were added to the group of existing schools and the committee evaluated 60 students who were applying to receive services in an inclusive setting. The SEC recommended 34 students to receive inclusive services for the following school year.

According to the SEC (Al Attiyah, Alabud, Lazarus, Albelsha, & Al Haddad, 2006), at the end of the first semester of the final year of the inclusion project, the committee determined that there were nine schools with inclusion programs; there were 124 children in these programs who had physical disabilities, learning disabilities, mild mental impairments or hearing impairments and used assistive technology. The number of students receiving services in an inclusive setting was minimal at the end of the 2006-2007 school year. The Shafallah Center was opened simultaneously to meet the serious and immediate need for special education services by provision of education in a segregated setting. The recent possibility for inclusion in the general education setting brought slight relief to an education system overwhelmed by excessive numbers of

children, many of whom were not receiving services, when there were, and still are, inadequate educational placements for children with disabilities. However, those placements did not offer appropriate personnel support. For other students who were eligible for services their families may not have known what was available to them or the children may have been on a waiting list to receive services in a non-inclusive setting for which they were eligible (personal communication, A. Sherawi, March 14, 2006).

Benefits and Challenges of Inclusion and Integration in Qatar

The research on inclusion has highlighted some of the potential benefits of inclusion: 1) modeling and imitation of social and developmental skills that can be practiced with peers (Turnbull, 1982; Diamond & Hestenes, 1996), 2) promotion of acceptance and greater opportunities for same-age peer playmates without disabilities (Turnbull, 1982; Nabors, 1997, Costenbader, 2000), 3) provision of the educational opportunity to be in a like-setting with peers (Turnbull, 1982; Odom, 2000, Erwin & Guintini, 2000), and 4) opportunity for those without disabilities to become familiar with individual differences and to be sensitive to and accepting of them (Turnbull, 1982; Diamond & Hestenes, 1996). Challenges or barriers that are faced when obtaining inclusive services for a child might be perceptions by vested parties (i.e. principals, teachers, other parents) that a child with a disability does not belong (Purdue, Ballard, & MacArthur, 2001), a lack of resources for the inclusive setting (Cross, Taub, Hutter-Pishgahi, & Shelton, 2004), harassment by peers (Petrie & Poland, 1998), or the need for better training for staff who work with children with disabilities (Schepis, Reid,

Ownbey, & Clary, 2003). These challenges have potential to create momentum for parents to learn to be advocates for their children with disabilities (Appendix H).

Follow-up to the Inclusion Project by Those in Higher Education

In a study describing the effects of the recent inclusion movement in Qatar by Attiyah and Lazarus (2006) 54 eight to ten-year old, male and female children with and without disabilities were randomly selected to be interviewed about their personal experiences. Eighty-five percent of the children with disabilities described their experience as being highly positive in their classrooms with peers without disabilities. However, this study also concluded that 55% of all the students without disabilities who were interviewed believed that harassment of children with disabilities was a problem of inclusion in their school. According to the interviews by Attiyah and Lazarus (2006), students with disabilities experienced aggression, laughter, curses, lies, stolen personal items and physical attacks. Negative comments and actions by children without disabilities can be perpetuated when children without disabilities have not been exposed to disability or are not familiar with the ways in which someone with a disability is like themselves (Pivik, McComas, & Laflamme, 2002).

In a study by Pivik, McComas, & Laflamme (2002) 15 children (9-15 years) with mobility limitations, a level of cognition necessary to participate in a focus group, and enrollment in an inclusive school and 12 of their parents listed barriers to accessibility of an inclusive education during 1.5 hour focus group sessions. Participants were asked to brainstorm and list the barriers that are common in inclusive schools and then they chose their top issues in need of a remedy. They were asked to provide suggestions for how

those barriers could be removed to make educational experiences for those with disabilities more accessible. Responses were audio taped and transcribed. They were then analyzed using qualitative thematic sorting software.

The results described four categories of barriers that were present in schools: physical (inaccessibility within a building), intentional attitudinal (bullying, name-calling, loneliness), unintentional attitudinal (lack of understanding about disability by others), and personal physical limitations for commuting within the school (difficulty getting from place to place due to the individual's disability). Parents were more concerned about the attitudes that teachers expressed toward their children with disabilities rather than how other children interacted with them. The primary implications of this research that are relevant in Qatar were that the authors recommended that civil rights laws be enforced within the school setting and that resources be made available to follow through on this. Principals should take a lead role in making sure that a school is fully inclusive for students with disabilities. The authors mentioned the importance of listening to children with disabilities and their parents in order to understand their experiences and to make change as needed.

Attiyah and Lazarus (2006) described the research as descriptive in nature based upon Arabic interviews of students using reflective questions. All the children in an inclusion classroom were interviewed and a random sample of children was chosen from general education classrooms by social workers. The boy's school had inclusion for six months and the girls' school had inclusion for three months when the data were gathered. Responses were written in Arabic, translated into English by the authors,

coded, grouped, and processed to obtain frequency data for the boys' and girls' schools together. Similar responses that consisted of one-third of the total number of children were used for reporting purposes. Limitations were not described.

Supreme Education Council and Ministry of Education Follow-up

A questionnaire created by the SEC (Al Attiyah, Alabud, Lazarus, Albelsha, & Al Haddad, 2006) was given to 379 special and general educators, students with and without disabilities, parents of children with and without disabilities, and specialists to determine the effectiveness of the Qatar inclusion project. Parents of children without disabilities had a positive attitude toward inclusion, while parents of children with disabilities recommended a better adapted curriculum for their children, as well as adapted evaluation forms specific to the needs of their children. Parents of children with disabilities also wanted more facilities, support services in the schools, and greater involvement in the schools with their children to educate people about disabilities, as well as better training for those who work with individuals with disabilities in both the schools and the community.

Educators had specific ideas about what they believed were the benefits and challenges during the extent of the Qatar SEC inclusion project. Of special and general education teachers, 85% agreed that the inclusion project was successful and this success was attributed to an evident change in the negative attitudes that were previously present toward children with special needs. Eighty-three percent of special educators supported the inclusion project because it helped to change the attitudes of society and created an awareness of the needs of children with disabilities. However, teachers struggled with

ways to convey information to children with disabilities in a general classroom so they could understand (24%); there was a lack of an adapted curriculum for children with special needs (21%); and there was minimal availability of materials or assistive technology (18%). It was not only lack of tangible resources that was listed as a challenge; it was noted by various participants in the interview that it was difficult to include children when the teachers were not knowledgeable about the needs of children with disabilities or how to best advocate for the children's needs within the school community (Al Attiyah, Alabud, Lazarus, Albelsha, & Al Haddad, 2006).

Special educators who were interviewed in the SEC study (Al Attiyah, Alabud, Lazarus, Albelsha, & Al Haddad, 2006) expressed that they had limited training (86%) and did not believe there was enough consultation for this project for follow-up and evaluation (81%); the impact of staff skills on the academic performance of children with disabilities has long been recognized (Peck, Killen, & Baumgart, 1989). Teachers felt they did not receive adequate training to design and implement individualized education plans for their students (16%). For those who had a teaching assistant, they believed it was a difficulty to direct them to work with children with disabilities (16%). General and special education teachers both expressed that they felt it was very stressful to include children with disabilities in a general education classroom because communication with the students with disabilities was difficult during activities (48%). Fifty-two percent of special educators, serving as facilitators of inclusion, expressed that they felt their position was negatively viewed by other teachers and the community. They believed their role as a teacher in the general classroom was looked down upon and

that this reflected poorly on their students with disabilities. It has not been uncommon for initial efforts to include children with disabilities to be sated with challenges (Giangreco, 2006). Even in the United States where inclusion has a much longer history those with disabilities still face challenges such as unreliable access to inclusive settings, curriculum lacking in quality, special educators who may not have needed resources, and a lack of educational and work options after secondary schooling (Giangreco, Cloninger, & Iverson (1998) as cited in Snell & Brown, 2006).

It is relevant to point out that without the foundation of inclusion being established in the school setting, further moves towards a society that integrates those with disabilities in meaningful ways, are less likely to occur in the future (Sahab, 2006). The provision of greater opportunities, such as employment and access to typical daily living activities outside of the home, will develop as the community continues to build the definition and practice of what early integration means for those with disabilities (Erwin & Guintini, 2000) in Qatar. Development of the structure of the system that supports integration and revisions to that system which make integration more viable for Qataris with disabilities are now being considered in ways that did not occur in the past (“Disability Major Issue,” 2006). Currently, those who are included in the general education setting are those with mild impairments; those with more severe disabilities are more likely to be isolated or to be educated in a segregated setting (personal communication, F.A. Taher, February 16, 2007).

The goal of this research is to serve as a tool to steer the implementation of further programs and the distribution of resources, as well as to dismantle community

barriers that restrain those with disabilities. This can be done by use of the suggestions and views of mothers of children with disabilities, based on their experiences in special education at the Shafallah Center in Qatar. This type of information is essential to a knowledgeable and balanced approach to providing academic and social support to those with disabilities in the school setting and in the community as community integration is encouraged for those with disabilities.

Methodology

Hermeneutical Phenomenology

The essence of qualitative research is hermeneutics, or the art and science of interpretation, with the purpose of “making sense of what has been observed in a way that communicates understanding” (Kincheloe & McLaren, 2005). When mothers are asked what they perceive to be barriers or opportunities in their community to the inclusion and integration of their children, their stories are their own lived experience. Analysis of this type of social phenomena, where the plan evolves while mothers reveal a gamut of complexities common to their lives in their own setting, can be described in rich form through naturalistic, multi-method inquiry (Slavin, 2007). Through interpretation of response, considering the impact of culture and the challenges proposed by relayed and interpreted second-order data, this research will document that which has not been conveyed in Arabic or Farsi and previously has not been accessible in the English language.

In a study by Lindseth and Norberg (2004), nurses were interviewed regarding their thinking or internalized ideas to discern principles or ethical promptings that are

evident in their daily work with patients. The authors described the difficulty of accessing the true internalized perceptions of nurses who may have never talked about the good and the bad of their own ethical decisions and actions surrounding past happenings in their field. The researchers noted that interviewees reached a point where they uncovered and processed emotions that revealed the meaning structures of decisions that had been made while working with patients in their profession, which can be challenging to comprehensively understand and clarify. The researchers took the position of narrators in a posture that carefully managed both their own personal judgments and conclusions, leaving the reader responsible to interpret and integrate intentions of the nurses into his or her own thinking. The goal of this example of research was to impact the quality of care in nursing through alternative means discovered through qualitative study. The lived realities of interviewees cannot be analyzed outside of the framework in which they live or work.

Interviews of Mothers of Children with Disabilities

As anthropologists have always known, the stories and myths that we adopt to explain our origins-whether as part of a family or part of a culture-always tell as much about our current situation as our past (Ferguson, 2002).

The majority of qualitative research is done by means of interviews which make accessible the perceptions and subjective experiences that occur in the lives of participants in ethnographic field studies (Peräkylä, 2005). The prevalence of interviews in areas where research is relatively scarce forms the beginnings of a method of inquiry in those areas. In this research, the presence of the identity of a non-native researcher impacts the dynamics of the interview (Lincoln & Denzin, 2005, pp. 1118-1119). The

meaning of “disability” to a family with a child with a disability is impacted by the prevalent social attitudes and historical context of the society in which the child is born; the professional interpretation of family interpretations of disability and acceptance is further imbedded in the socio-historical context of time and place (Ferguson, 2002) that emerges through interviews. There are many intricacies innate in qualitative research through data obtained from interviews.

In a study by Todd and Jones (2005) mothers were interviewed about parenting their children with disabilities. They expressed difficulty in discussing their lives beyond motherhood, but were very open when talking about their children’s lives. The researchers pointed out both the interviewer and interviewee trust factors are essential in interviews where concerns may not be accessible if a mother feels uncomfortable or lacks a trusting relationship with the researcher. Todd and Jones (2005) described how mothers’ identities were almost inextricably linked to being the mother of a child with a disability, yet they considered themselves “ordinary mothers.” Some expressed a belief that showing signs of self-interest, self-centeredness, or otherwise was reason to be socially ostracized. Todd and Jones (2003) explained that there is moral risk involved in sharing matters of the home with the professional world, and for this reason the voices of parents of children with disabilities have not often been heard in research.

Blaska (1998) carried out a naturalistic study which focused on the cyclical grieving process that parents lived while raising a child with a disability. Mothers and fathers recalled how different life events triggered grief from an overload of responsibilities to care for their child, health or behavior issues that were linked to the

child's disability, lack of understanding expressed by other parents who were peers, and the thought of caring for elderly parents. Parents expressed that they clearly recalled the emotions they experienced when they were told that their child had a disability. Blaska (1998) noted that many parents with a child with a disability struggled to accept the circumstances. For those who did come to a place of acceptance support systems within the community might have been a factor. Lessenberry and Rehfeldt (2004) reported that parents profoundly influence the progress that a child with a disability makes in school programs, but for many parents the stress that they experience from raising a child with a disability is extremely high.

Green (2003), a mother of a child with a disability herself, interviewed mothers with children with severe disabilities. She explained that qualitative research in the form of interviews may serve as a sort of "narrative therapy" as one's story is shared with a stranger. The retelling prompts the interviewee to participate in exchange which leads to personal growth and fosters the initiative to take more action in her own community in the process of change (Green, 2003). Wickham-Searl (1992) interviewed 14 mothers of children with disabilities who employed personal advocacy skills gained from working to access educational and vocational opportunities for their own children to serve in their communities as regional and state leaders. These mothers turned their own personal challenges and expertise into answers for themselves and others in the areas of service provision, advocacy, and creation of policy. No matter the culture in which a child is born, interviews with mothers of children with disabilities provide insight into daily living, triumphs, and obstacles faced by families of children with disabilities.

Cultural Study

Culture is an abstract and complex concept with many definitions making the activation of a clear definition of the word or concept the challenge (Yeganeh, Su, & Chrysostome, 2004). In hermeneutical research interpretation not only concerns words of the participant alone, but must consider the function of the participants' culture in the expressed dialogue of words that have deeper resonance. For example when a mother explains her child's morning routine there is an innate implication of the affect of that child's routine on the mother's daily life as she cares for her child, perhaps altogether different from the daily routine of a mother of a child with a disability from the researcher's framework.

For competent qualitative cross-cultural studies to be carried out, researchers have noted the importance of considerations of differences in language, beliefs, and values, as well as vastly different cultural characteristics in general between researchers and research participants (Tsai, et al. 2004). Walters, Warzywoda-Kruszynska, & Gurko (2002) list appropriate management and analysis of discovered constructs, honest reporting of the issues, and understanding of diversity within a culture as factors which should be carefully considered by a non-native researcher. Mains (2004) described the ways conversations between the interviewer and participant create movement and from that movement understanding is brought forth or stopped in the discovery of the cultural landscape. Interpretation by a non-native researcher requires extra safeguards in the description of knowledge, scene, and perception, so that the researcher's own thoughts and biases do not taint the results.

Constructs are not typically readily transferable from one culture to another and should not be assumed as universal (Walters, Warzywoda-Kruszynska, & Gurko, 2002). Saukko (2005) relayed potential problems that might underlie the premise of cultural studies as being interpretation and evaluation of constructs based upon social power; ideals that have been founded over time and girded in the realities of other cultural frameworks, for instance those of the West. These cultural frameworks may not mesh with the given cultural context of the research. There has been a more extensive focus and longstanding promotion of research in the West (Mains, 2004). Any research carried out in developing nations requires forethought as to the potential sense of invasiveness of the practice and whether or not the purpose of the research merits its introduction to the culture. Globalization has changed the way in which difference and culture are perceived and current research in other cultures must reflect this (Mains, 2004). Accountability to convey the worldview of the participants instead of the underlying problem of indiscriminately relaying the cultural worldview of the researcher is of high priority in culture studies (Bishop, 2005). There are obvious complexities involved with cultural studies. The methods and tools of the Middle Eastern field researcher must be adapted to respect issues such as gender in Islam and cultural individuality (Clark, 2006). In his indigenous research, Bishop (2005) listed age, class, gender, education, and color as a range of characteristics that impact the research relationship and add to the complexity of cultural studies.

Brislin (1983) described some of the many challenges faced by those carrying out cultural research: rival hypotheses (Schultz & Cobb-Stevens, 2004), desire to

interpret or to write in a judgmental tone, ethical concerns (Richardson, 2000; Christians, 2005), comparisons made between cultures (Walters, Warzywoda-Kruszynska, & Gurko, 2002), equivalent measures (Tsai, et al., 2004), and interpretation of the meaning expressed (Pillay, 2002). Rival hypotheses and comparison of cultures are not such grand issues in this research, however, accurate judgment of interpretation and other ethical concerns are at the forefront of concerns. Furthermore, in developing countries a researcher may be required either to start with nothing, or adapt concepts to meet the research needs of the country (Brislin, 1983). Both apply in this study.

The community of individuals employing qualitative research methodologies to interpret cultural trends is scattered globally in a world where research is linked to development and may be considered a reflection of colonial power to those less interested in research (Denzin & Lincoln, 2005, pp.1-32). Transnational research between developed and developing countries is essential to communication between cultures during a time when most research is published solely in one language and usually done so in wealthier countries (Maine, 2004). Cultural studies must be carried out in a manner respectful of innately different cultural attributes and forms of communication, which can be a challenge faced by lack of resources and available people qualified to act in the process of translation and interpretation (Van Widenfelt, Treffers, De Beurs, Siebelink, & Koudijs, 2005).

In research of a culture by a researcher from a different cultural background, the question arises as to whether or not the researcher has the cultural knowledge to carry out such research in a competent, valid, and reliable manner. Best (2003) proposed that

the researcher and participants might be matched with the same racial and ethnic identity. Realizing this may be a practice with some benefits, it may not always be plausible. Furthermore, Merriam, et al. (2001, as cited in Bishop, 2005) expressed concern that researchers who were “insiders” were found to be naturally biased or did not ask critical questions as they were too close to the interviewees. Swisher (1998, as cited in Bishop, 2005) charged that those best able to convey information, without the attached problem of viewpoint of an outsider looking in, are those who naturally give the story its voice. Vaara (2000), a social constructivist, went so far as to say that cultural difference and views of a specific culture are not an issue until humans allow awareness of them to arise in interactions with those from other cultures. Collaborative work with those knowledgeable about a specific culture who can extensively discuss relevant cultural issues in the development of a questionnaire has been a long-standing benefit in cultural studies (Brislin, 1976).

The scripted conversation that forms in dialogic methodology is action oriented and not confined to a single element of truth, but is colorful in form and expression of precept (Denzin & Lincoln, 2005, pp.183-190). Therefore, the interpretation of the conversation must do justice to the expression of the interviewee and make fair cultural considerations in the process of that interpretation. Cultural studies focus on the community and individual issues of identity, action, and change within that community (Grossberg and Pollock, 1998). Godamer (1989, as cited in Kincheloe & McLaren, 2005) cautioned that the hermeneutical researcher must realize the serious consequences of his or her interpretation of “what is” and how that interpretation defines “what ought

to be” in the researcher’s plight for social justice. Pillay (2002), recognizing that reflection through language leaves such great depth of knowledge as mystery, reiterated the age old question initiated by Descartes, “How do we establish that the ‘ideas’ in the mind are congruent to the objects that gave rise to them?” The duty of just interpretation of those characteristics falls on the researcher and the team of assistants who have some knowledge of the culture.

The productivity of cultural study relies on its focus of the reality which has been lived, the discourse about that reality, and interpretation in the context of history, society, and political structures and their workings, (Saukko, 2005). There must be an understanding of these dynamics through investigation for the non-native researcher to succeed in the interpretation of findings. Saukko (2005) defines the three dimensions related to methodology in cultural studies: contextual, dialogic, or self-reflexive (Richardson, 2000). Respectively, these make valid analyses of historical and social reality, portray the local person’s perception of his or her own world, or scrutinize a collection of texts or social dialogue on a topic, all in forms that create a multi-dimensional framework of analysis (Saukko, 2005). The researcher then places the participants’ stories in the real setting in time and space with shifting boundaries within which the story has been organized (Denzin & Lincoln, 2005, pp.183-190). Validity rests in accurate representation of the social reality of participants (Bishop, 2005). A primary area where validity can be destroyed is in the process of translation of meaning into another language (Torop, 2002).

Translation

Of all the parts that make up the substance of culture, language is the most complicated of all the habits with which a culture expresses itself (Schäffner, 1994). Whorf (1956, as cited in Page & DePuga, 1992) described individual perceptions of behavior and reality as being directly linked to language and how it is constructed to convey specific meaning. Language is important in the case of any story that must be subjected to the translation process to convert the constructed meanings from the first language to a second language (English in this case). There is danger of loss in this process where full transference of intent is not fully possible between two languages (Lorscher, 1989).

Brislin (1976) dialogued about the difference between the *emic* (from the word *phonemic*) and the *etic* (from the word *phonetic*) approaches to cultural study involving translation. Brislin (1976) distinguished the importance of these in the interpretation of meaning of qualitative data and the necessity of collaboration with local researchers to develop research instruments. The emic-etic principles of relationship to culture can be defined as the following: Research that is *emic* in approach applies the investigation of understanding a construct in the same way as it is grasped by those within the culture; the *etic* form involves understanding of constructs as they are juxtaposed and compared in relationship with similar constructs from other cultures (Yeganeh, Su, & Chrysostome, 2004). In this research every attempt has been made to understand intent according to the *emic* principle.

Studies are often translated for the purpose of cross-cultural comparison or to make available and validate a questionnaire in another language. The nature of this research in Qatar is intra-cultural, with no intention to compare by accessibility of translated information of the perceptions of Qatari mothers with mothers from other cultures. However, much of the available research literature on people groups, which involves translation, is cross-cultural and comparative in nature. In this study emic investigations will take place in the context of life in Qatar for mothers and their children with disabilities. Meanwhile, etic principles will be applied to capture the understanding of the concept of community integration or inclusion based upon foundational knowledge prevalent in other cultures that is available in the English language. Of the limited number of cross-cultural translation studies about disability in the Arab world, few have been translated to English as the research available on disability is not comprehensive (personal communication, A. Baker, April 26, 2007).

The literature on translation study is most common with validation of achievement tests (Hambleton, 1993) or in the medical arena where medical professionals must maintain a high standard of reliability in cross-language questionnaires and must be able to produce health information that is culturally accurate (Tsai, et al., 2004). Hambleton (1993) deemed improper translation as one of the most problematic issues when translating achievement tests for use in cross-cultural domains. A product must be brought forth that is in alignment with the original test in its original language, but which also is equivalent to commonly recognized question formats and procedures for testing in the culture of administration (Hambleton, 1993).

Researchers who work with persons in countries where a language other than English is the predominant form of communication and where the culture is different than the culture for which a questionnaire has been developed previously, must consider viable options for development and validation through back-translation. An efficient means of developing questionnaires in regions where instruments have not been developed is to translate and adapt questionnaire instruments to meet the needs of the culture of study (Van Widenfelt, Treffers, De Beurs, Siebelink, & Koudijs, 2005).

For example, Lips & Leplège (2000) designed a 48 question quality of life questionnaire for patients with osteoporosis which was developed in English and translated into twelve other languages. Back-translation, or translation from the language of the interviewee back to the language of presentation by an outside evaluator (Brislin, 1976), was completed by official, trained translators and then the questionnaire was taken through a correction and review process by the translation and research team and through validation in a pre-study at seven centers with patients with osteoporosis.

Thabet, Stretch, and Vostanis (2000) completed child mental health surveys of 322 Arab children living in the Gaza strip. The pre-validated Strengths and Difficulties Questionnaire (Goodman, 1997) was translated to Arabic by a panel of Arab-speaking doctors. Two different translations were compared to come to consensus on an agreed upon format and then these were back-translated to English before being discussed with a bilingual journalist and a bilingual psychologist. Any questions that arose regarding meaning were referred to the author (Goodman) of the original English questionnaire. Efforts were made by researchers to be systematic in their procedures. Thabet, Stretch,

and Vostanis noted that the way questions are viewed in the process of translation differs according to the culture of those who are examining the questions.

Feldman (1975) addressed the problematic issue of the influence of interviewers of an ethnicity other than that of the interviewee and the potential for the attitudes of the interviewee to be dependent on and change according to the ethnicity of the researcher. Although it will not remove all potential barriers of culture and translation study, it is beneficial for translators and interviewers to be highly familiar with the culture in which the study takes place and to be able to fluidly communicate with interviewees because of the researcher's cultural knowledge base.

Chang (1994), a bilingual researcher, implemented a translated survey to acquire information about language, culture, and ethnicity to examine how these were maintained according to school personnel, parents, and students in five Chinese language schools in California. The author recorded problems with writing questions that could be translated from Chinese to English, maintenance of the original meaning of questions through the translation process, cultural differences that affected responses, and notable differences and similarities that were prevalent in English and Chinese responses that were difficult to rectify. To ensure congruent questions in the two languages, Chang (1994) employed translation of the questionnaire, back-translation, and examination of the back-translation by knowledgeable, bilingual colleagues.

The application of decentering and back-translation to any documents from the participants' language to the language in which the data will be presented has long been recognized as a reputable process for validating a research instrument (Werner and

Campbell, 1970; Brislin, 1970, as cited in Brislin, 1976). Decentering is described as a procedure to confirm that the meaning of the translation is in alignment with the original, but has been modified to best fit the conveyance of the meaning in the native language of the interviewees (Van Widenfelt, Treffers, De Beurs, Siebelink, & Koudijs, 2005). Back-translation involves the following process: (1) preparation of a questionnaire in the language of the researcher, (2) translation by a bilingual person into the language of the interviewees, and (3) translation by a second bilingual person of the interview back to the language of the researcher so that the researcher is able to make a judgment on quality (Brislin, 1976) and to consider adapting a questionnaire for cultural nuance (Van Widenfelt, Treffers, De Beurs, Siebelink, & Koudijs, 2005).

More recently it has been observed that few published research articles adequately describe the process of translation and adaptation of a translated questionnaire instrument. Most frequently, simple back translation, common to cross-cultural research (Werner & Campbell, 1970, as cited in Brislin, 1976), is the only method recorded as a form of assessing the quality of a translated instrument in multiple translation studies. Back translation is insufficient to prove a good translation according to some researchers (Van Widenfelt, Treffers, De Beurs, Siebelink, & Koudijs, 2005). A well-designed and translated interview protocol in collaboration with local individuals helps to establish the trustworthiness necessary in translation studies, especially when the researcher is non-native.

Lee (2005) criticized the method used to create quality of life surveys that were completed in Korea with cancer patients, especially those which involved translation of

questions. Lee analyzed 31 studies and found that most authors did not prove the validity or reliability of their instruments. Furthermore, Lee (2005) discovered that none of the translation studies were back-translated, but rather solely relied on the translation of a bilingual individual without a cross-check of the correlation of the two languages or the cultural appropriateness of the translated questions. The translation efforts were completed by un-trained, bi-lingual translators without any checks of the quality of the translations. The presence of a trained translator does help to defend the validity of a translation when there are few guidelines that have been established and there is little empirical data about quality assurance of translations used in research studies (Van Widenfelt, Treffers, De Beurs, Siebelink, & Koudijs, 2005).

Second Order Data in Translation

Translators are not only responsible for the translation of text, but also for revealing “functionally optimal target texts in target cultures” as active “cultural mediators” in cross-cultural dialogue in research (Bedecker & Feinauer, 2006, pp. 133, 139). For centuries translators have been vital in the process of converting language to transmit it within and across cultures (Schäffner, 1994). The notion of culture cannot be separated in the process of the translation of language, because culture is linked to language in a complex manner (Torop, 2002). It is highly desirable to obtain knowledge and understanding through culture studies and translations studies, but the logistics of conveyance and analysis are a challenge (Tsai, et al., 2004). When translators convey the meaning of second-hand data to a researcher, intentions of the interviewee can be lost in the transmission (Temple, 1997). The research on cultural studies has predominantly

focused on the translated data and the effect translators have on that data as has been discussed (Tsai, et al., 2004), realizing that with translators who are untrained and culturally unaware of those being interviewed, data can be inadvertently altered (Temple, 1997).

There is the question of how a researcher knows that the perceptions relayed by a translator on behalf of an interviewee are accurate. Temple (1997) credits translators with the burden of decision-making in research as to details, punctuation, and tone of any given comment made by interviewees. After an interview the researcher should make notes about the dynamics of the interview in the field journal. Although, not specific to culture or translation studies, the importance of closeness to data and the validity that is cultivated from this state when carrying out naturalistic studies is worth sharing.

According to Frazier (1976) in the use of life histories, validity can be evaluated according to the number of steps away from the data the observer is at the time of the study. First order, or first hand, data is data obtained as the researcher observes the social actor (or participant). Second order data, according to Frazier, is obtained by listening to the participants' own recollections of his or her individual perceptions. In order to improve the validity and reliability of this type of data, the researcher can check it according to other sources of knowledge, such as through interviews of others and by using other referential materials, about the same topic (Denzin, 1970, as cited in Frazier, 1976), but should be careful so as not to allow for reinterpretation or exchange of the

participants ideas and perceptions with that of others who are interviewed (Frazier, 1976).

Individuals who have graduated with degrees in translation are a minority among those serving as translators, and empirical research consisting of translation and interpretation should not be done without the assistance of professional translators in genuine settings (Shlesinger, 1989). The capabilities of translators are only the first hurdle. The next is to ensure that interpretation follows the focus of the established research. Marilyn Porter, in one of very few discussions of second-hand ethnography, explained the difficulty of entrusting researched data to others when the researcher is not able to carry out the research alone due to cultural boundaries or language issues. The researcher ends up studying those carrying out the interviews in order to understand how the interviewers interpret 'their' data (Porter, 1994, as cited in Temple, 1997). In research involving translation, when the researcher is not fluent in the native language of the population being interviewed, careful dialogue, questioning, and communication of the focus and direction of the research is essential to complete with translators after every interview. Literature on the issues that surround data analysis of cross-cultural qualitative research that involves translation is limited (Tsai, et al., 2004). In an interpretivist study in another land, the naturalistic paradigm and its foundational postulates (Lincoln & Guba, 1985) support the design of analysis of responses to open-ended questions about personal and individualistic perceptions.

CHAPTER III

PHILOSOPHICAL CONTEXT

Introduction

The intent of this research was to explore the perceptions held by Arab mothers with children with disabilities of the community integration opportunities available to their children in Qatar through qualitative data analysis. The focus of this research was to determine what resources mothers believed were available to their child or children with disabilities and how their children accessed these resources. Realizing the difficulties in preserving an unalterable focus, it was expected that multiple realities would surface when processing the responses of 40 mothers with various circumstances and experiences. The existential focus of mothers' perceptions was analyzed based on a qualitative design measure that includes data in the form of translated interviews of mothers, field notes, and interviews of other key community figures involved in providing resources for individuals with disabilities in Qatar.

Hermeneutic Phenomenology

As an interpretive work based on the textual meaning of the dialogue of mothers, the method of hermeneutic phenomenology was employed in this research and included components of the methodology prevalent in research of both cultural study and translation study. A qualitative design was befitting to this study because of the role of language to convey perceptions (Pillay, 2002) and the need for *a systematic approach to understanding qualities, or the essential nature, of a phenomenon within a particular context* (Branlinger, Jimenez, Klingner, Pugach, & Richardson, 2005), specifically the

meaning derived from and mediated by culture, religion, and language as noted by Ricoeur (Lindseth & Norberg, 2004). Description of perceptions of mothers was used to produce purposeful scientific evidence (Branlinger, Jimenez, Klingner, Pugach, & Richardson, 2005) and its implications within the cultural context. Holding true to the precepts of naturalistic inquiry the design was shaped by the changing boundaries developed with each bit of new information that was processed and analyzed (Lincoln & Guba, 1985).

Husserl, a mathematician and the first phenomenologist, realized that the explanation of objects and events may neglect to draw on the aspects of the natural environment, lived experience, and the realization of the meaning of less objective, but powerful phenomena (Lindseth & Norberg, 2004). The analysis of the spoken word and its intent conveyed in the voices of mothers of children with disabilities in Qatar is a new path of exploration and proves a viable candidate for hermeneutical phenomenological analysis. This comes at a time of development in a country and in a culture where the issue of acceptance of differences is emerging as a relevant social issue.

Participants

The Shafallah Center, currently serving 335 children with disabilities and expected to grow by 40 students every month (“Forum”, April 24, 2007), offers services to the largest number of children with disabilities in Qatar. There are six other schools that serve smaller populations of children with disabilities (personal communication, F. Darwish, March 8, 2006). Children with mild to severe disabilities, ages 3 to 21, who are admitted into the Shafallah Center must be Qatari, except in special cases. Of all mothers

who were interviewed who represented non-Qatari families who received services, one father had diplomatic links to Qatar and others were allowed to enroll their children due to relationships with those in administrative positions at the Shafallah Center. Children ranged in age from four to 19 years-old with an average age of 11.2 years-old. In interviews mothers referred to 46 children, 30% who were females, 65% who were males and 5% who were siblings with disabilities whose genders and ages were unknown. Mothers had an average of 5.3 children. The types of disabilities that children had in this study were: Down syndrome, autism, cerebral palsy, rare genetic disorders, cognitive impairments, multiple disabilities, and other health impairments.

Participants in this study were 40 Arab mothers of children with disabilities who were students at the Shafallah Center in Doha, Qatar. Participants were selected by a team of seven social workers based upon a convenient and willing sample of mothers of children at the Shafallah Center. Based on willingness to be interviewed, social workers identified 55 of approximately 200 mothers who had children at the the Shafallah Center. Fifty mothers agreed to be interviewed for this project. Scheduling conflicts, which could not be re-planned, were present for four mothers. One mother sent her daughter to be interviewed because the mother could only speak Farsi and did not know that the translators were fluent in the language. The interview was dropped from the study. An initial group, consisting of 10 mothers who were interviewed to pilot and refine the interview protocol, was not included in the data analysis. The 50 mothers who were interviewed in total represented more than one fourth of the population of children receiving services at the Shafallah Center at the time.

Of the 40 mothers whose interviews were analyzed, there were 34 Qatari mothers, 1 Iranian mother, 1 Bahraini mother, 1 Kuwaiti mother, 1 Yemeni mother, and 2 Lebanese mothers. Five mothers who responded that they were Qatari also stated that they were raised in other countries, but had taken on Qatari citizenship by marriage. Of the fathers, whose descent determines the heritage of the child according to Islam, all were Qatari except for one Iranian father, one Yemeni father, and two Lebanese fathers. It is the exception, not the rule, to find that non-Qatari children have been admitted to the Shafallah Center; therefore, willing mothers were interviewed and their heritage was not known until they were asked demographic questions at the end of the interview. The 40 mothers, whose interviews were included as part of the data analysis, had a total of at least 46 children with disabilities. The group of 10 mothers who piloted the interview protocol had at least 14 children with disabilities.

Protection of Human Participants

There was contact with interviewees after approval by the Institutional Review Board of Texas A&M University. There were no major risks expected during this study. Each interviewee was made aware that they could refrain from answering any questions. It was documented when mothers chose not to respond to a question. The interviewees were able to request that the interview be terminated at their will. This did not occur in any of the interviews; however, one mother returned by request of her husband to ask that her information not be used as she did not want it to be published with her name in the local paper. She was assured by her social worker in Arabic that this would not

happen. The mother allowed her information to remain in the study. The interview format was of minimal risk to the interviewees.

Confidentiality

With the assistance of an Arabic book of baby names all persons involved in each interview, as well as the family members about whom they spoke, have been given pseudonyms to insure confidentiality. Those pseudonyms replace the names of family members in written documents. Children's ages in this study ranged from three to 19 years-old. The ages were labeled according to the range in which they fit. For example, four to five year-olds were listed as "young child", six to 12 year-olds were listed as "school-age child", and 13 to 19 year-olds were listed as "adolescent child". Only the researcher, the Shafallah Center social workers, and two Arabic speaking translators, would have knowledge or access to the actual names of those who have been interviewed for this study and the ages of their children. Those documents will remain secure with the researcher.

Interviewees received a thank you note for their participation in the study and did not receive any monetary compensation or coercion to join the study. Many interviewees were willing to participate out of respect for their family social workers and to discuss the topic of "disability", which is not usually an open topic. Mothers may have gained some therapeutic benefit from sharing their stories and they will contribute to the existing information available (Frank, 1997) about the benefits and barriers to community inclusion for those with disabilities in Qatar. Individual and societal benefits outweigh any associated risks from the interviews.

Instrumentation

The base information for the questionnaire used in the study of mothers in Qatar originated from an unpublished manuscript of a similar study by the researcher of 13 mothers in the United States (Abbs, 2005) and was culturally adapted with the assistance of a team of local colleagues and professional translators. After a bilingual Egyptian assistant translated English documents to Arabic for the Institutional Review Board process and for review by the Shafallah Center, in December 2005, approval was given to proceed with the research by both entities. In January 2006, the initial versions of the questionnaire were reviewed and revised to read in the Arabic of the Arabian Gulf region by bilingual Qatari mothers who were not interviewed as part of the study. Mothers checked the accuracy of the wording and the appropriateness of the questions in both the Arabic and English versions to prepare for interviews.

A group of approximately ten interviewers, some of whom served as interview protocol reviewers, were trained in methods of naturalistic inquiry and interviewing procedures (Appendix D). Their individual characteristics included motherhood, those who offered direct care to those with disabilities, those who were special education professors, and those who wished to teach students with disabilities. These individuals offered much feedback that helped with the revision process for the interview protocol to insure that the Arabic version was accurate. These women spoke Arabic and were Qatari; however, they did not participate in the data collection for the 40 interviews that were analyzed. All records have been kept of suggested and often accepted changes to the interview protocol. Input about additional questions and deletions was considered

and often accepted, although at times one question might go through several revisions before gaining consensus.

A refined version of the interview protocol for this research was developed with the assistance of a focus group of five Qatari women who were primary educators. These same women also worked through the revision process of the informed consent documents in Arabic and in English. The English versions of the interview protocol and informed consent were reviewed by a non-native peer debriefer. A final comparison and check was completed by the five individuals who had been part of the focus group. The interview protocol went through further revisions during the first 10 pilot interviews.

After initial development of the questionnaire, 10 interviews were conducted with mothers of children with disabilities in Qatar. These mothers spoke of their experiences based on raising 14 or more total children with disabilities. Those interviews helped to establish future questions for the interviews, as well as to cue into necessary probing questions that the translators should ask of the interviewees in the final set of completed interviews. Questions that did not appear to be clear to mothers were revised and probing questions were considered for future interviews with the assistance of the same review team. During that time revisions were made to assure that the translation conveyed like meaning in Arabic, but in an appropriate cultural context. The final version was revised and back-translated after the 10th interview with the assistance of a Qatari professor in the Special Education Diploma Program of Qatar University (Appendix G).

Translators and Their Qualifications

The two translators who participated in this research held master's degrees in Arabic-English / English-Arabic translation from the University of Durham in England. Both translators were of Iranian descent and had been raised in Qatar. Both were fluent in Arabic, English, and Farsi/Persian and spoke Arabic with a Qatari accent. The translators asked the participants questions using the interview protocol in the most appropriate language for the interview.

Relationships: Inquirer, Interviewer (Translator), and Respondent

Since the relationship between interviewer and respondent cannot be separated, according to axiom number three (Lincoln & Guba, 1985), the interviewers were trained so as to lessen validity challenges or any impact that the interviewer might make that could create a forced or oddly formulated response and to allow for the most natural sequence of dialogue between the interviewer and respondent (Appendix G). Translators also signed a Statement of Confidentiality to protect the rights of the interviewees (Appendix E). The researcher was only involved minimally in conducting interviews in English, and trained interviewers in safeguards for interviews conducted with the respondents in Arabic or Farsi. Interviewers were trained to flex with the reality of human response and its unpredictability to understand and evaluate when interactions should be extended by probing for further responses.

Procedures

Working Hypotheses

Lincoln and Guba (1985) explained the effect of “fittingness” between contexts and how this comparison is made when searching for similarities in contexts; an evaluation can follow as to the level of congruency between contexts. In this research evaluations were made about interview location (interviewee’s home, the Shafallah Center, or the local university). The introduction made by the researcher and translator affected the general atmosphere and comfort that each interviewee might express. On most occasions coffee or tea was served by the Shafallah Center staff to those involved in the interview, thereby distinguishing an informal setting from a clinical setting. Some of the factors that were hypothesized and clarified during the interviews were a mother’s willingness to be interviewed or her family’s permission that she be allowed to do so; individual choice about access to community resources other than the Shafallah Center; level of severity of the medical condition of an interviewee’s child; involvement in a social network for the family; and the mother’s personal perception of the stigma attached to disability. These are discussed further in Chapter V. These factors may change the dynamic of the feedback that would come from interviews from different sources. The common ground for mothers was that their children all attended the Shafallah Center. Tentative circumstances are difficult to generalize. Working hypotheses have been tracked in the field journal and involve the process of understanding how unique factors effect the direction of dialogue (Lincoln & Guba, 1985).

Commencement of an Interview

Before each interview the researcher and translator would prepare the room where the interview would take place, making sure there were comfortable chairs, writing instruments, and correct copies of documents with the interview number recorded on each one. Before the commencement of the next interview there was often a dialogue about what should be considered for the coming interview(s): application of lessons learned, probing questions, and any documentation in the field journal that still needed to be recorded. Once the mother arrived the translator introduced herself, as did the researcher in English with an apology for not being able to communicate in Arabic. The translator would explain this to the mother in her native language. If the mother was able to speak English she would express this at that point in time.

The translator would explain that the researcher would be taking notes, which would be about a previous interview or about any questions that arose during the current interview. If there were any questions, they could be asked of the researcher during the interview. The interview would begin and the researcher would record the start time in the field notes, as well as the time of completion. The translator would have the mother read or read to the mother the informed consent form and have the mother sign both copies. The mother would keep one and the other would be passed to the researcher to file with documentation about the interview. It was common for the translator to direct questions or comments that the mother had during the interview to the researcher.

Field Journal

A field journal was maintained diligently during this research. It is vital to keep a field journal as its notes augment the information that may be drawn from each interview transcription (Kahn, 1999). After debriefing with the translator the researcher recorded information from each interview directly upon completion. Recorded information included highlights of data, the specific disability of the child, and the translator's perceptions of the comprehensiveness of the interview (if the mother had much to say; if the mother had an appointment to get to directly after and was rushed to finish, or if the mother was emotionally affected by the interview). During the current interview, information would be written in the field journal about relevant characteristics of the interview: whether the mother became emotional (such as crying) and the translator offered her the choice to stop or skip a question with a note to later record which question had created the emotions, any pauses in the interview where the mother had a question or comment for the researcher, and any interruptions during the interview if someone entered the interview room unexpectedly. After the interview more details were recorded with the help of the translator during post-interview debriefing.

The field journal was also used to keep a record of personal communication with community members vested in advocating for and working with those with disabilities. Individual interviews with social workers, teachers, professors, and agency personnel provided information that could not be obtained in written documents. The field journal became an added source of documentation and information per the guidelines of conducting trustworthy qualitative research (Lincoln & Guba, 1985).

Safeguards

After an initial translation of the interview protocol by a translator from the Qatar Support Office at Texas A&M University was completed, it was revised in Qatar and piloted and refined during 10 interviews. The informed consent documents were reviewed by a Qatari professor in the Special Education Diploma Program of Qatar University (Appendix F) and the translation of the interview protocol was back-translated (Brislin, 1983) to ensure consistency with between the Arabic and English versions (Appendix G). Safeguards to the interview site (Shafallah Center) included: weekly contact with social workers, prolonged engagement (Lincoln & Guba, 1985) with staff and family members, which led to several unsolicited requests initiated by mothers to be interviewed toward the end of the data collection process. The researcher was present for all interviews with knowledge of the research, as well as the liability to explain the research and answer all of the questions of the interviewees with the assistance of the translator. This liability was not transferred to translators who were present for the sole purpose of translation. To maintain the integrity of translation, close monitoring of responses and careful translation was completed with the researcher by the translator who completed the interview as soon after the interview as possible. During this process the researcher would ask the interview question and the translator would state it as the mother had responded. Translators were asked many probing questions during translation in order to pin down the most accurate literal translation. The only case where functional translation was employed was in the case of the use of Arabic maxims or figures of speech. Some translations were the same in English and Arabic,

while others were not. In that situation a maxim with like meaning was used, or the literal translation was documented in Arabic. If a mother without an education responded using incorrect grammatical structures in Arabic, it was recorded in the translation in English. If a sentence was not whole, but partial, the partial form was recorded. Translation procedures were carried out carefully and thoroughly.

Translation took place as soon after the interview as possible. The majority of interviews were translated within minutes after the interview up to 6 hours after the interview when the researcher and translator reconvened in the evening to complete translations, especially when there were multiple interviews on the same day. For the translation process the researcher asked the questions in order and the translator responded in the same form as the mother. The time allotted for translation took approximately two times the amount of time as the interview.

Two mothers requested that they complete their interviews in English with the researcher. Although these two requests were honored, the research team felt that the richest interviews came from mothers who completed them in their native language. The translators were more fluent in English than were the mothers who could speak in English. The two mothers were very fluent in English, but it was evident that they were unable to convey deep concepts in their second language. The translators were also fluent in Farsi. One mother and the sister (whose interview was dropped as the research is based upon perceptions of mothers) completed interviews in the Farsi language. The remaining interviews were completed in Arabic.

Translators spoke in the native tongue and also shared the culture. They also had a very warm, yet professional demeanor during the interview and knew to refrain from suggestions that would create bias, but also immediately reacted to any upsets (tears) by the mother by asking if they would like to stop the interview or skip the question. The translators also encouraged responses that were honest perceptions rather than those to please the researcher/interviewer team.

Data Organization

Reflection on field notes came after each interview and during translation, including the addition of the interviewer's comments. Language usage in Arabic and English was analyzed and selected by the translator in order to deduce the nearest "natural language" translation to English (Lincoln & Guba, 1985). The translator was responsible for observing tone, style, and emotion of the interviewee. No audiotapes were produced as it was not culturally acceptable, hence the research was reliant on careful note-taking. Files for each interview were numbered 1-40. Each file contained informed consent signed by the mother, the Arabic interview documents, and the English transcriptions of the interviews.

Data Analysis

The first step in hermeneutical phenomenological analysis is to keep record of verbal and non-verbal communication in written form (Koch, 1994). That text is then interpreted according to the construction of meaning to comprehend that which can be analyzed in a logical manner beyond semantics (Lincoln & Guba, 1985). In this study the interpretation of the text had to be considered in terms of Qatari culture for mothers

of children with disabilities and not that of the translators and researcher (Mains, 2004; Walters, Warzywoda-Kruszynska, & Gurko, 2002).

During data collection the researcher kept a record of personal notes on the idea of perceptions of disability, thoughts about inclusion, and the idea of community integration as a novel occurrence in the community with a field journal. The first stage of analysis included a critical reflection about the researcher's own preconceived notions about the topic of study from reflections contained in field notes. The researcher prepared to reconstruct the themes that naturally formed according to culture and behavior when interviewees told about their experiences (Goetz and LeCompte, 1981, as cited in Lincoln & Guba, 1985).

The field notes that were collected from the inception of this research were analyzed as they contain interpretations made throughout the process of data collection. Field notes and data from translated interviews were analyzed to create initial interpretations as part of the process of analysis, which were then added to the field journal to create a system of cyclical interpretations of the unique experiences of interviewees (Lincoln & Guba, 1985). The field journal contains interpretations of pieces of data from the beginning to the end of the research, therefore, its preeminence as a data file in the research is essential.

Values

Value-bound inquiry consists of the researcher's values, the interviewers' values, and the respondents' values (Lincoln & Guba, 1985). Although many perspectives and, therefore, values were included and are of critical importance, some perspectives might

be emphasized more and included as part of the relevant, meaningful data chosen as part of the story. The final analysis of contextual information was organized and juxtaposed with separate resources that were linked to the data and had been collected from other key individuals in personal interviews (social workers, special educators, Qatari family members of those with a disability, etc.). Other resources were used to show where independent perceptions of mothers were either linked or not linked to perceptions of other mothers or community members. Contextual information and its interpretations were reviewed in English by the researcher, debriefers, and translators, as well as community members who worked in the field of special education to insure that the perceptions of mothers of children with disabilities were relayed to the reader in a trustworthy manner.

As for social and cultural norms, there was the dynamic of the feelings, thoughts, and decisions made by the American researcher, the Iranian translators (who have lived in Qatar all of their lives), and the Qatari mothers. Not only were there self-imposed guidelines that the research team followed in their dialogue, but there was the potential for the encroachment of each individual translator or researcher's cultural value sets. It was possible for mothers to perceive and respond to questions in a certain manner according to the real or perceived values of the translators and the researcher. It is possible that these perceptions impacted the meaning that was relayed during the interview.

Thematic Analysis and Interpretation

Axiom number four (Lincoln & Guba, 1985) questions the interpretation of causally linked bits of information. In an attempt to analyze the effects of observation in the Shafallah Center setting not with a presupposed conclusion, but with adaptability to revelations of the moment, pieces of information were sorted into themes using printed cards. Responses from questions in alignment with the research questions were printed according to each piece of information of each mother's dialogue with the translator. Themes were determined and information became interwoven among each of the 40 interviews as information was sorted according to the themes that emerged during analysis. Analysis by inductive reasoning was the shaping force of the study (location, individual differences, happenings of the day, culture), as multiple and intertwined experiences of the time were conveyed from the data sort. The steps of this process followed the naturalistic paradigm (Lincoln & Guba, 1985).

Since the researcher had to employ judgment to carry out this interpretive, but systematic process, which included the influence of her own values and beliefs, a reliability check was carried out to see that another researcher came to the same results with a portion of the data cards. With the assistance of an advisor the first three interviews were divided into units of information and were sorted. Six categories emerged: impact of disability, daily life, learning, activities in the community, goals, and needs. From this practice sort, category construction began. Categories from all 40 interviews fit into these initial, relevant categories from the practice sort. With the assistance of a peer debriefer, 40 interviews were broken into 1296 units of information

and were sorted into thematic categories that emerged into seven head categories: Impact of Disability, Daily Life and Participation in Family Activities, Community Activities, Community Needs for Improved Opportunities, Goals, Learning at the Shafallah Center and Miscellaneous. The final category was utilized sparingly. Goals and Learning at the Shafallah Center were later imbedded within the other categories. Twenty-two sub-categories emerged from these head categories; these were outlined and many are the section titles found in Chapter IV. The data that produced a response to the research questions presented in Chapter I were analyzed accordingly. It should be noted that the data set of 1296 is not large due to some brief interviews and some mothers who were more reticent than others. Another reason for the small data set could be due to mothers who were not accustomed to taking part in the interview process.

Each response was separated into individual units of information denoted by (/) marks for each response to be analyzed. These units (from as small as a phrase to as long as a paragraph) were printed on individual 4x6 cards. The cards for each interview were given a code that denoted the interview number, date of interview, child's alias, gender of child, age of child, mother's alias, mother's nationality, father's nationality, and the child's disability. The data were transformed into theoretical categories with relational properties. Thematic categories build upon themselves. An outline was created with a natural story-telling flow.

The reasoning or "universal explanation" for the placement of bits of information in each category was recorded in the field journal and labels were made for categories to facilitate the card sort based upon evident properties of each category. Bits of

information were sorted and recombined with like information from separate interviews to make visible the interconnected content that constructs themes or the “manifest content” (Holsti, 1969, as cited in Lincoln & Guba, 1985, pg. 337). With the assistance of a peer debriefer the rules of incorporation were formulated for a card to be placed within each of the categories and the sub-categories that emerged from the data (Lincoln & Guba, 1985, pg. 337). Memos were added by constant comparison and the peer debriefer served as a discussant who also took notes (Lincoln & Guba, 1985, pg. 342).

Rules of inclusion into each category were written at the top of the head cards. There was also a working “Needs a Name” pile for cards where a decision had to be made about inclusion into a category. The reason for inclusion was written directly on the card once it was decided. Cards that followed the rules of inclusion were placed respectively; cards were placed in a “Miscellaneous” pile if they were off topic; and cards were placed in a “Not Relevant” pile if the content was not informative. Cards that contained information for several categories were divided onto two or more cards, so they could be properly sorted.

In the case that there was a problem with categorization of cards the researcher stopped to take notes in the field journal. Data sort problems were reviewed with the peer debriefer. Categories were delimited by explicit description, until no further points needed to be added, and they were team categorized by the researcher and peer debriefer (Lincoln & Guba, 1985, pg. 342). Modifications were made to categories based on new information that was added with new pieces of data until a point of data saturation occurred.

The most paradigmatic of all pieces of information within a theme were chosen to convey the story of mothers' perceptions as the information was woven back together from all 40 interviews in order to be shared and to build knowledge of the subject. A point worth noting is that the mothers of children with disabilities are an "elite and unimpeachable" resource for information (Lincoln & Guba, 1985).

Reliability Check for Accuracy of Interpreted Links

Several community experts on disability and research, such as the second peer debriefer, translators, a university professor in education, the Shafallah Center Teacher Training Director, and the Shafallah Center Head of the Research Department were contacted to review the data analyses as part of a reliability check. Also, the two translators and a university advisor, serving as inquiry auditors, were involved in the check of the written interpretive analysis. The process of checking reliability is complex, but helps to bring about more meaningful interpretation of information in family research that is personal, unique, and multi-faceted (Perlesz & Lindsay, 2003).

Referential Adequacy Materials

Recent brochures and documents from the Shafallah Center were collected. The mother appointed by the State to advocate for those with disabilities; a professor who has written on disability, children and Shariah Law; and representatives from the Supreme Education Council and Qatar University have been interviewed to discuss current Qatari policy on inclusion of those with disabilities as included in this text.

Debriefing

A peer debriefer who is a doctoral student in Archeology/Anthropology offered guidance during this study from the United States, both in person and by e-mail. He evaluated feedback from five randomly selected interviews without names so that he could offer his advice on the questions that seem to offer the most relevant data according to the research questions. The peer debriefer has been involved in the development of this research from the beginning, including his input on the initial interview protocol. A second peer debriefer who works in the area of marketing offered guidance during data analysis and assisted with the categorical card sort.

Audit Trail

Dr. Patricia Lynch and my two translators (Noura Shafiei and Sana Esmaeli) served as inquiry auditors. The audit trail that can be followed for this research per the recommendations of Lincoln & Guba (1985) includes all interview records in Arabic and English and observational records, public documents beyond the newspaper articles collected about disability in Qatar, all survey results in Arabic and English, and data preserved in spreadsheet form and saved in Excel and NCSS. As part of data reduction and analysis, write ups in field notes were preserved about conferences with translators, events, behaviors, dates and times when mothers did not show up, reluctance by mothers to respond, a request to take interview data back, big ideas, working hypotheses, hunches about work a maid does for a child rather than the child's mother, money received from the government, notes about mother's accent, interesting issues about heritage, questions, responses, and anything extraordinary.

Field notes were maintained during data reconstruction and synthesis. Credibility was reinforced through field notes and prolonged engagement. Details of this are strengthened by the following: 50 mothers were interviewed, which was over one fourth of the student population at the Shafallah Center at the time; visits took place over several months from February to June; an initial informational meeting was conducted with the Shafallah Center social workers who had rapport with families and arranged interviews; translators and the researcher were given a tour of the Shafallah Center and introduced to the people who would be working with them during visits; rapport was established and trust was gained; and each interview was concluded by writing a thank you note for the mother with an Arabic translation.

Observations at the Shafallah Center were persistent. The researcher was present at every interview to take field notes and to speak to the mother about her rights according to informed consent to participate in the interview. Statements were translated in Arabic. After every interview the researcher had a discussion with translators about key points and atypical happenings. The team was careful to be professional, yet not prematurely close any interview. Most interviews included the local custom of tea or coffee to welcome another person. This was provided by the Shafallah Center. All mothers finished the interview completely. Several mothers, one quite seriously, considered withdrawing because of pressure from family members, but later reconsidered and allowed their interviews to be used.

Per the factors of conducting a rigorous study (Lincoln & Guba, 1985) the final product of this research is an overall display of coherence and interdependence of

multiple realities of mothers of children with disabilities and has been checked for reliability with evidence by other vested persons. The life's narrative has been presented in a way that faithfully captures the intended knowledge as conveyed by the respondents. In consideration of the characteristics that make this study rigorous, data has been carefully collected. The audit files are in order to establish trustworthiness and transparency.

CHAPTER IV

RESULTS

The practice of interpretation provided additional data as well as support for the trustworthiness of this study. Hermeneutic interpretation emphasizes record keeping of both verbal and non-verbal communication and information in written form (Koch, 1994), in this case, in both Arabic and English. Prior to the completion of data collection and analysis, field notes included reflections about preconceived ideas held by the researcher as suggested by Lincoln & Guba (1985). Additional data were recorded in field notes. These field notes were a collaborative effort between the researcher and translators and completed after each interview. Field notes also included notes by the researcher relevant to each interview obtained before the commencement of the study up until the stage of data analysis.

Informed consent and Institutional Review Board approval were used as safeguards when interviewing mothers, although mothers, social workers, and other staff found these procedures unfamiliar and at times intimidating. In addition, social workers and other staff members from the Shafallah Center approved all documents used in the interviews. Although some mothers were reluctant to sign in order to give consent to be interviewed, offering to be interviewed without providing signatures, all required signatures were collected. It was believed that mothers would be willing to participate, yet there was often reluctance on the part of mothers, and social workers had to convince them that the interviews were confidential. Mothers said that they were personally motivated to interview in hopes that their interviews might improve services at the

Shafallah Center. There were numerous missed or cancelled interviews that had to be rescheduled. It was difficult to complete 40 interviews: Cultural nuances such as lax timekeeping, shared family drivers who were not free to drive a mother to the Shafallah Center, and the belief that if an interviewee chose not to keep an appointment it was God's will, made it difficult to complete all of the scheduled interviews.

Fifty mothers of children at the Shafallah Center were selected by social workers at the Shafallah Center. There were unexpected challenges as the interview technique was unfamiliar to social workers, school staff and mothers. Social workers and other staff members were the gatekeepers to each interview. They prepared a place for the mother, the interviewer, and the researcher to carry out each interview. Social workers scheduled appointments with mothers and relayed this information to the researcher each week. Some mothers were happy to be interviewed, while others were more skeptical. Interviewee responses were collected over a four month period.

An Arabic interview protocol consisting of 13 open-ended questions, 13 demographic questions, 3 informative response questions, and 1 Likert-type scale item was employed. The protocol went through numerous revisions to check its appropriateness with Qatari women, many of whom were either mothers or had worked with individuals with disabilities. It was back-translated (Werner & Campbell, 1970, as cited in Brislin, 1976) to ensure consistency with the English version, and then was refined during a field test of 10 interviews (Appendix G). The final 40 interviews produced data which were analyzed with a card sort procedure common in naturalistic inquiry. This procedure consisted of coding units of information, categorizing units,

summarizing data based upon properties for each category, building upon emerging themes, and then creating a storyline (Lincoln & Guba, 1985).

Of the 10 Qatari women who expressed interest in being interviewers, only two were able to complete several interviews for the study, and none were trained in translation. Availability to interview was highly limited for these women as they needed family approval to go to the Shafallah Center in the afternoons and evenings. This first group of 10 Qatari interviewers who were trained by the researcher was not available to interview at the Shafallah Center consistently. Finally, the researcher trained two additional interviewers in the methods of the study. These two interviewers were lifelong, non-Qatari residents of Qatar who were trained as Arabic/English translators. Both translators spoke Arabic in the Qatari dialect and were also fluent in Farsi.

Data categories, after initial categorization by the researcher and an advisor, were delimited and team categorized by the researcher and a peer debriefer, as described by Lincoln & Guba (1985) four to five times a week for four weeks. Forty interviews were broken into 1,296 units of information and were sorted into thematic categories. After considering a system of inclusion and exclusion for categories, the data that emerged in the end were divided into four head categories: 1) Impact of Disability, 2) Daily Life and Participation in Family Activities, 3) Community Activities, and 4) Community Needs for Improved Opportunities. Initially, these categories included two more categories, Goals and Learning at the Shafallah Center, but it became evident during the card sort that mothers expressed the topic of goals for their children throughout multiple themes of discussion with the interviewer. Likewise, learning was a broad subject that was

difficult to categorize as it was imbedded within much of the data, and it included learning at the Shafallah Center, in the home, or at other places in the community. In most cases data about goals and learning better supported another thematic category, such as learning from a tutor in the home or learning from mother about safety in the kitchen.

Throughout the process of analysis a Miscellaneous grouping was used as a holding place for other data but was not a category in and of itself. The main themes and the subcategories that emerged from the data can be viewed according to the graphic in Figure 1 at the end of Chapter IV.

Construction of Thematic Categories

Data fell into 22 categories all of which were then divided further into sub-themes. Mothers' stories revealed the impact that disability had on their lives. Disability changed the way daily life was carried out and the activities that families participated in together within the home. Disability also readjusted the way families participated in the community when they had children with disabilities. Community integration or lack thereof, affected the family life of those with children with disabilities. Goals and learning opportunities were a vital part of the expectations that mothers had for their children at home and in the community. These themes will be presented with supporting details in this chapter.

Impact of Disability

“Most parents have a fear of the future for their child. They don’t know what the future will bring.”

*General Coordinator of Inclusion Programs
Qatar Ministry of Education
(F. A. Taher, personal communication, February 15, 2007)*

When mothers described the impact of their children’s disabilities many of the mothers began by describing when they first learned of their child’s disability and any medical diagnoses or interventions they felt were in error. They also described their own maternal fears and how these were multiplied due to the lack of information they received from medical personnel.

Learning of the Disability

The most commonly diagnosed disabilities of the children of these Qatari women were autism, cognitive impairments, Down syndrome, rare genetic disorders, multiple disabilities, health impairments, and cerebral palsy. However, a common theme that resulted from the analysis was that diagnosis of disability was inaccurate or at times delayed. Mothers often sought a diagnosis after recognizing that their children had different needs, usually when their child did not reach developmental milestones. This was when, mothers reported, that the diagnoses given by medical professionals often were in error. Mothers also reported that the birth of their child with a disability was not celebrated in the same way that was the birth of a child without a disability.

Al-Fuhail, Al-Hamdan, & Suyyagh (1993) studied birth customs in Qatar and discovered the first day or the seventh day of a child’s life in Qatar was significant as it was the period in which a father named a child. The family slew an animal to celebrate

the birth of the child on the seventh, fourteenth, or twenty-first days after an infant was born, as part of their Holy Prophet's tradition. Two sheep were slain for a boy and one for a girl. This sacrifice was representative of the economic status of the family and if the family could not immediately afford the sacrifice it could be done on the fortieth day. The days after birth were very important to families as the days when a child's name was bestowed and his or her birth was celebrated with family and friends. No mothers in the study referred to these common Qatari traditions, although the researcher had been told stories of these celebrations for children born without disabilities. These celebrations were typically considered and planned while children were *in utero*.

Although Fairouz was the only mother to specifically describe the fortieth day after her son's birth it is worth noting the cultural traditions surrounding this period. First of all, it was the last day that she was considered unclean from birthing a baby. Fairouz, mother of Zain Elabedeen, her adolescent son, described her emotions when hearing about Down syndrome for the first time, "Forty days after his birth they told me that he had Down syndrome, but I didn't know what was wrong with him. I started crying and got back home stressed and tired physically" (Interview 11, card 1). This usually would have been the period for Fairouz's family members to celebrate the birth of Zain Elabedeen.

Each interview began with responses to the statement: "Please explain how or when you first realized that your child might have a disability." Mothers' responses stemmed from their personal observations of their children's behaviors, physical

responses, or learning characteristics and were often supplemented by reports of the child's medical diagnosis.

When Ashgan, mother of two children with disabilities, was asked when she knew that her daughter had a disability she replied, "Since she came out of my womb," referring to the diagnosis of Samia, her school-age daughter with Down syndrome (Interview 5, card 1). Other mothers similarly reported that they were aware of their child's disability as soon as a child was born. For example, Widad, mother of Wafaa, her adolescent daughter with multiple disabilities, recognized the effects of hydrocephalus upon her daughter. "First she wasn't doing what she was supposed to do. She couldn't hold her head and neck up. Her head seemed bigger than my other kids'. She couldn't move her body because of the heaviness of her head" (Interview 10, card 1).

Similarly, Zaynab, mother of Daham, her school-age son, described her early perceptions of her child at birth:

From the first day of birth, I knew there was a problem from his appearance. When his siblings saw him they said he looked like a Filipino (description of child's eyes). Then, I noticed that his movement was not normal, especially in his neck. My husband called the doctor and he told him that we felt he was not normal. The doctor examined him and he noticed from the lines on his palms that he had Down syndrome (Interview 15, card 1).

Mothers typically recognized the occurrence of a disability by comparing their children's movements or physical characteristics with those of other children without disabilities. While mothers knew something was wrong, they frequently reported a lack of competence by doctors in confirming a diagnosis of disability. It was also possible that in a culture where there was a stigma attached to disability doctors were unwilling and did not wish to be the ones to give parents a diagnosis. Most doctors were not natives to Qatar and could potentially provoke problems for themselves by giving Qatari parents an undesired report about their children.

Medical Errors

“When a baby is born they wrap him in a blanket. When the blanket is taken off the baby stretches. He did not do that. He was just limp” (Interview 38, card 2). Sohaila, mother of Shawghy, her adolescent son, went on to explain, “Since he was born I had other children and I can tell the difference. His eye movement and his limp body were not like other children's. His was body was different from them” (Interview 38, card 1). Sohaila's experience was that each time she took Shawghy to the hospital she was told that nothing was wrong with him. As he grew she noticed more characteristics of his disability; for example, he could not hold his neck up (Interview 38, cards 3 and 4). Sohaila was told that she needed to be patient and he would change (Interview 38, card 4). Several different doctors did not determine that he had a disability.

In another case, Shahd shared about giving birth to her son Sajed without assistance:

When I was giving birth I was left in a room without all the nurses and the doctor. They left me and the child just came out. Because nobody was around me he didn't get enough oxygen. That was the cause of his disability (Interview 19, card 1).

Sajed remained in the hospital for six months. He weighed 840 grams at birth (Interview 19, card 2). Shahd reported that she believed her son's disability was due to her lack of medical care during labor. Sajed may have had a disability prior to his birth. If so, this was not determined expediently by doctors.

It had been only four years since Muna, mother of Nadeem, her adolescent son, first learned that Nadeem had autism and not mental retardation. Muna knew something was different when she took her son to kindergarten. By the end of the year he was hyperactive and he did not talk much, but she thought he was fine (Interview 29, card 1). The school that Nadeem was attending made the request that the parents have him checked for a disability. It took Muna a long time to figure out Nadeem's diagnosis (Interview 29, card 2).

They were telling me that he has retardation. I was sure that something else was wrong with him because he wasn't retarded. I visited all the sections of the hospital, like a neurologist and a children's surgeon to see what was wrong with him. We went to the neurologist and we had a CAT scan done. The doctor told me that he is hyperactive. We went to the audiologist, but he could talk and he was different than autistic children (Interview 29, card 3).

The neurologist was the first one to tell Muna that her son had autism (Interview 29, card 5). Since children with moderate to severe disabilities were not included in general education in Qatar, Nadeem was not able to attend school any longer once the school was aware of his disability and he was transferred to the Shafallah Center.

Another diagnosis error was reported by Ibtisam, mother of Asmaa, her school-age daughter with a rare, degenerative, genetic disorder, and mother of Ashwak, her young daughter with epilepsy and signs of the same genetic disorder:

My daughter is a rare coin. She was born naturally. She seemed normal until she reached four years of age....The doctors didn't understand her problem. They said it was because she was the only girl born in a family of boys. I ignored my [other] little girl after Asmaa. I had a CAT scan done for her brain. They said there was nothing wrong with her. I took her to a psychologist and he gave her pain relievers to make her calm. That affected her. After a year they did another test. They discovered that she has epilepsy and a lesion on her cerebellum. Her brain is degenerating. It's getting worse.

May God forgive [the] hospital. We got tired of them. They sent us to London and there they told us that she has [a rare, degenerative genetic disorder]. She doesn't move now. She doesn't talk. She doesn't walk. She does nothing. And, now there are some of the same symptoms in my younger daughter [Ashwak].

Ibtisam began to cry as she continued the interview (Interview 6, card 1; Field notes, May 3, 2006). It is likely that the local hospital was not aware of the characteristics of typical disabilities, such as autism and Down syndrome, per the descriptions of mothers. When a child was born with a rare genetic disorder it was even less likely that the diagnosis would be accurate or that medical personnel would be able to provide adequate support according to the child's specific needs.

Khadija, mother of Nijma, was in the seventh month of pregnancy when she felt that her child *in utero* did not seem normal compared to her three previous pregnancies, so she asked the doctor to check. "But, afterward they said everything was okay when they looked at the ultrasound. Maybe they didn't want to tell me the truth" (Interview 1, card 1 and 2). Ultrasound was used as part of the diagnosis to check for fetal distress and differences. It is possible that Khadija was not told because doctors did not recognize that her daughter had Down syndrome. Mothers reported fear about learning of a disability, and doctors had the challenge of reporting disabilities to mothers in Middle Eastern culture, which was not accepting of disability. In many cases mothers reported that the first doctors they visited did not diagnose their children's disabilities. The mothers felt that doctors did not report disability either due to negligence or ignorance. Perhaps this was also due to the stigma attached to disability and the unwillingness to diagnose it.

Maternal Fears

Mothers expressed their difficulties with confirming their children's disabilities, but they also reported that they feared hearing the truth. There was a sense that mothers sought knowledge of what was different about their children, but at the same time, they feared to learn that their children had disabilities. Zaynab explained, "We have the basic idea about children with Down syndrome. They took blood from him to do the test and they said the test would come back after one month. I wished he didn't have Down syndrome....I was shocked" (Interview 15, card 2). Learning of a disability was a possibility that invoked fear about what the future might hold.

Maryam, mother of Ghazi, her school-age son, told her story of learning of her son's disability and the fears she had about revealing it to her family:

He was seven months when I recognized that he had a disability. And he has Down syndrome. He didn't have any health problems, but only mental problems. I was surprised when I recognized that he was different than my other children, but he walked at the same age as (them) and crawled at the same time. I took him to the doctor in the health center and I told him that he was different than other children. He told me, "Your child has Down syndrome," and he said, "Didn't they tell you that in the hospital when he was born?" No....I accepted that, but I didn't tell anyone for four months (Interview 23, cards 1-3).

My [older] daughter studied science at school and she told me that (Ghazi) was different from the others. I asked her why. She said, "I

studied science and I know that something is wrong with him.” And, then I changed the subject but told her later what was wrong with him (Interview 23, card 4).

Ghazi was a year and a half old when he got really tired. I took him to the hospital with my eldest son Sultan. The doctor said that he was not normal. My oldest son was surprised and asked, “Why?” I told him that I would tell him later at home. I talked to Sultan and he asked why I didn’t tell (my family) [Interview 23, card 5].

This idea that family would not be accepting of a disability was prominent throughout stories in the study, and mothers reported that sharing about their children’s disabilities with others created fear in them. It was not uncommon for mothers to reflect on the challenges they faced by admitting a child’s disability to their families or, in some cases, in taking their child to visit family members.

Mashaël, mother of Muhannad, her adolescent son, noticed that her son’s walking was delayed, but she did not realize he had autism (Interview 34, card 1). When he was five years old, his mother noticed that she could not leave him alone for fear that he would hurt himself by self abuse. She had more tests done. “They told me that he has a bad situation. He has to go to a hospital for crazy people with mental problems. I got scared and kept him at home until he was seven,” (Interview 34, card 3). Mashaël’s fears caused her to decrease her son’s interactions with others, which in turn decreased his opportunities to play and to learn.

Mothers' fears included fear of future outcomes possible for their children with disabilities and fear of sharing about that disability with others, including family members. Upon learning of a disability, some mothers expressed that they wished that it did not exist in their lives.

Lack of Communication at Birth

Mothers relied on their knowledge of other birth stories, as well as their experiences with other infant children, to evaluate their own children and labor experiences. Difficulties experienced were a vivid part of the recollection of when mothers learned of their children's disabilities. Omniya, mother of Khamees, her adolescent son with cerebral palsy, recounted the story of her pregnancy:

In the name of God, the merciful, the compassionate. I was pregnant. I used to use birth control. But, I got pregnant and I had a test done. They told me I might be pregnant. Fifteen days later my husband died. He had a heart attack while we were driving in the car. I was 25 years old and I had high blood pressure after that. I was deeply affected by this. They gave me pills for my blood pressure. I would be in the hospital for 10 days and then I would be at home and then go back to the hospital, until I was six months into my pregnancy.

The baby was moving very well. Then, I felt that he didn't move like before. I told the doctor that he wasn't moving. I was also telling him that I had another child before him who died in my womb of asphyxiation. Then, they did the ultrasound and they told me that he

doesn't move much and he is disabled. They asked me if I wanted to take him out or leave him there. I told them, "You're the doctors. You decide!" Then, they told me that I needed to have a Caesarean section delivery because if I left him in my stomach he might die. That day they did the Caesarean and got the child out while he was six months and a week. I got better 10 weeks after delivery. They told me I had a son and that he was in special care. His weight was one kilo.

I gave them milk to give to him, but my milk gave him diarrhea, so they gave him formula. I saw him in the bed with these wires all over him. They were for food. They got me out of the hospital, but they kept him for a month. I saw his eyes and they were just a thread of a line wide. He was premature and they gave him an injection, but they didn't tell me anything about him (Interview 31, cards 1-4).

Omniya's story reflects not only difficulty with the birth of her son, but also the concerns that stem from the lack of doctor-to-parent communication and the stress associated with hospital visits for families with children with disabilities.

Amera, mother of Amal, her school-age daughter, observed Amal in the hospital nursery for over two months before she was able to take her home, knowing there was a problem but without clear communication from the doctor.

As soon as she was born her face was open. They wanted to take a sample of her brain tissue, but I did not agree. She had a lack of oxygen. She was slow when breast feeding and they did a surgery to create an anus hole.

She was losing weight. Her hand is not like ours. Her palm is too big.

They even told me that she doesn't have eyes. She had a deformed head and eyes" (Interview 16, card 1).

Amera's story reflects the lack of information that mothers had when they had a child with significant disabilities. Mothers reported in several stories that doctors told them their children had disabilities based on the fact that the children had large palms. There were few other details given in these stories about any other medical tests that confirmed this initial observation. This appears to be a lack of sophistication in diagnosis of disability by some doctors. These doctors need additional training in the West where disabilities have been studied more thoroughly.

Because of the delay of an early medical diagnosis, interventions did not commence early in the child's life. Mothers learned of their children's disabilities after multiple visits to professionals and at different stages of their children's development. Muna learned that her son, Nadeem, had autism at the age of 13. Prior to that he was believed to have mental retardation, hence he never received therapy tailored to the needs of individuals with autism (Interview 29). Late diagnosis had other negative consequences, such as inadequate preparation for school, delayed treatment, and lack of opportunity to enroll a child as soon as possible for services. It was necessary to register early for support, because the Shafallah Center was one of the few places providing services and the waiting list was long. Mothers expressed frustration with the medical field and had a sense of regret that interventions did not occur sooner.

The initial diagnosis, often received only after persistence of mothers who noticed something wrong, fraught with misinformation, greatly impacted Qatari mothers. Blaska (1998) studied the emotions experienced by parents when they first realized their child had a disability and the cyclical grief process that commonly followed. In Blaska's study mothers recalled memories of their children's lives that revealed grief. Mothers in Qatar similarly recalled the negative impact of their child's or children's disabilities on their family, such as fear about struggles with medical and health issues, especially at birth; safety concerns; and the impact of lacking educational and recreational stimulation for their children. Similar to these findings, Zaynab expressed the initial shock she experienced when she learned that her son had Down syndrome (Interview 15), while Ibtisam cried when sharing about the challenges she faced raising two daughters with severe degenerative disorders and talking about the poor expected outcomes for them (Interview 6).

Family Perceptions of Impact

Families were impacted in various ways by disability, whether they pragmatically adapted to it, considered it a blessing, or considered it a challenge. The way that family members personally perceived a disability affected the way in which that family interacted with that child.

Pragmatic Adaptation by the Family

“If it was in my hands I would do everything for them. You wish the same for them that you wish for your normal children.”

*Nuha, mother of Waseem, her adolescent son with Down syndrome
(Interview 30, card 24)*

*One of multiple wives in the same household;
multiple children with disabilities in the same household
(Field notes, June 5, 2006)*

One group of mothers were pragmatic about their children’s disability did what they could adjust to it. These mothers reported a desire for their children to be what they considered more normal, while knowing that adaptations and potentially long-term care would be necessary. Many mothers reported a belief that their children were born with disabilities because it was the will of God, which also seemed to lead to a practical approach to dealing with the child and his or her disability.

Normalization. Mothers frequently noted that they had different emotional responses to living with their children with disabilities as compared to their children without disabilities. One approach by more pragmatic-stance mothers was to do things that would make their children seem more “normal”; such as by reiterating that their child appeared normal to other people and, in the case of some mothers, treating the child like their children without disabilities.

Mothers expressed a personal goal toward their children’s *normalization*, and either hoped for normalcy or actively sought to promote what they believed to be normal. In some cases disability itself was considered normal for these mothers. When mothers were asked, “In what ways has your family had to change routines to meet the needs of your child?” seven responded that nothing had changed. Most mothers had

more to say about how their lives had changed. Haiba said, “Our life is normal and we treat him like his other siblings,” referring to her son Muftah, 11 years old, who had Down syndrome (Interview 13, card 2a). Six other mothers answered in a similar fashion, simply conveying, “It’s ‘normal’.” (Interviews and cards: 3/2; 15/14; 22/35; 33/23; 25/14; 24/11).

Other mothers commented in more detail: Widad said of Wafaa, “We try to be normal—to live normally. It took us a long time at first—her attention and focus—to find a treatment, to go to hospitals. Now we just continue life normally” (Interview 10, card 7). Thikra said of Raja, “We didn’t make any changes. She’s normal physically, but her mind is not developed for her age” (Interview 21, card 11). Khadija said of Nijma, “She does everything because I treat her as a normal child. She is normal, just not smart” (Interview 8, card 1). Konouz said of Layth, “Every mom hopes that her son is normal and that he plays with his siblings because he learns from them and copies them” (Interview 27, card 21). Mothers reported different opinions of what they considered normal for their children and whether or not they believed their children to be normal. Mothers reported that when they saw their children with disabilities copying the behaviors of children without disabilities they felt their children were more normal.

Ashgan, the mother of two children with disabilities, said, “We stopped having children. Everything else is the same” (Interview 5, card 17). Aliya said of Shoayab, “Thank God. God has given him to me. I was satisfied and I raised him as a normal child. I didn’t differentiate between him and my other kids” (Interview 14, card 4). A child’s disability was spoken of as if it were something that just happened one day. It

brought changes to families and was dealt with as it had to be. For example, in a culture where large families are expected to carry on tribal heritage it was no small decision for Ashgan and her husband to decide not to have more children.

Zaynab shared that she treats her son Daham as a normal child, and even her neighbors have said to her, “Mashallah”. This means, “Whatever God wants for you,” because her friends admired that she took her son everywhere, which they told her was unlike the behavior of many mothers of children with disabilities. “I treat him like a normal child and his disability does not exhaust me at all” (Interview 15, card 5). Similar to other cultures, religious beliefs may help individuals to find peace with circumstances. Religious beliefs help with acceptance because there is hope that circumstances will work out for the best.

Will of God. Many mothers’ comments reflected their belief that children’s disabilities were simply God’s will and one’s lot in life. Hind considered her daughter, Nawal, a normal person and from God, but because of Nawal’s disability her mother had to help her with eating and using the bathroom (Interview 39, card 3). Muna believed that her faith in God and her patience had both grown because of her son, Nadeem. She added her opinion, “This is something that you might not find in the Westerners here” (Interview 29, card 9). At first Shahd was upset that her son Sajed, the youngest of her six children, was born with a disability, but then she said, “We accepted him because this is what God had written for us” (Interview 19, card 6). Amera had been told by others, “I will go to heaven because of her,” referring to her daughter Amal (Interview

16, card 3). When mothers expressed acceptance they also reported a more positive outlook for their children's future opportunities.

Adaptations made for the child. Some mothers told how their children's disabilities had brought on a great deal of changes to the household, but these were practically dealt with by the pragmatic mothers. Adaptations to the routine and physical space often had to be made. Suheir told that her daughter Samah, who had multiple disabilities, brought so many changes to her household and its routine that she did not notice change any more and simply adapted to it (Interview 37, card 26). Masha'el made sure that if any changes were made to the room of her son Muhannad who had autism, she got his opinion first. "I have to provide him with anything he wants" (Interview 34, card 24). When Shaymaa and her husband had their house built, they had to make sure to prepare a special place to store Ziyad's wheelchair and to make sure that it would fit through the doorways (Interview 9, card 22). In the case that these sorts of adaptations were not made, it would be difficult for Ziyad's family to transport him from place to place within the home.

Acceptance of long-term care. The pragmatic mothers had come to a place of acceptance about having a child with a disability and having the responsibility to care for the child for years to come. Salah's mother simply stated, "My future is with him." The implication was that Samah would be caring for her son for the rest of her life, and she accepted that responsibility. Shaymaa had accepted the fact that she was primarily responsible for Ziyad. "His father doesn't help much in the home, but he is there in spirit and love and caring. He calls me during the work day to check on us" (Interview 9, card

13). Stories of children's interactions with their fathers were limited. Nojood said, "Fathers are shy to show that they have a child with a disability" (Interview 8, card 5).

Lama, the mother of adolescent twins with autism, said, "It was really difficult at the beginning. I learned that I have to accept [their disability] first, so the children develop. I give them love and kindness" (Interview 36, card 7). Ashgan, also the mother of two children with disabilities, said it took her two years to accept that Othman, then 18, had a disability. "And I learned [how to deal with him] and when my baby daughter [with disabilities] was born it was easier for me to accept her. The situation was easier and I thank my God for this." Samia was born nine years after Othman (Interview 5, card 3, Field notes, April 25, 2006). For a mother with two children with disabilities, the level of necessary adaptations in a community that was not always welcoming was multiplied. Practical mothers seemed to recognize their maternal responsibilities would not end once their children with disabilities reached adulthood.

A "Blessing" to the Family

"I believe in God and my son."

*Dana, mother of Jameel, her school-age son with autism
(Interview 26, card 13)*

"And, I have a key from heaven's keys. I'm special because of my son—because of his existence."

*Shaymaa, mother of Ziyad, her school-age son with
cancer in remission and multiple disabilities
(Interview 9, card 4)*

Another theme that emerged was that mothers saw their children with disabilities as a positive addition to their lives and as a "blessing", or gift from God, to their families. Mothers most often mentioned personal growth factors, such as patience,

understanding, and greater faith. Mothers reported a desire to see the best from the adverse situations in their lives.

Best aspects. Some mothers shared that the best aspects of raising their children were related to their own personal growth. “He is a gift. I learned lots of things. I don’t know how to describe it. I learned to be patient. My faith in God increased. And maybe He wants to test my patience,” offered Maryam (Interview 23, card 6). Manal shared that before her son Marzouk was born 12 years previously she was not as patient and that she would give up and crack under pressure. She believed that her growth in patience had been the best aspect of raising her child (Interview 22, card 10).

Najat remembered being anxious before the birth of her school-age daughter, Hayfaa, who had Down syndrome (Interview 25, card 3). “Now, after the difficulties and the shock [of having a child with disabilities], I am invincible.” She believed that she had learned patience through her many visits to the local hospital (Interview 25, cards 2 and 4). Similarly, Wodouh, who was educated with a Master’s degree, laughed, “I know that God will count all the good things that I do for [Masood] and the patience that I have for him because he makes me tired!” (Interview 32, card 3, Field notes, June 5, 2006). Mothers seemed to recognize their own personal growth through difficult circumstances, such as patience.

Nabeela believed she had been given “God’s wealth. God has given us everything” (Interview 28, card 10). Nojood analyzed, “Maybe it’s mercy for us and it’s a blessing. God will count this for me. It’s a big responsibility. When I’m with [Salah] all my senses work—my eyes, my hands, my mind and we are all responsible for this

human being” (Interview 2, card 4). “Because everyone can think, but [Salah] cannot, I am like his spare body and brain” (Samah, Interview 2, card 17a). Fawzya, mother of her adolescent son with multiple disabilities stated:

Every human being has problems and must learn from them. The mother is like the child. As she grows she learns more about her child. I’ve learned a lot from life. Whenever I see any child like Mubarak my faith increases and I get closer to God. He is a blessing! (Fawzya, Interview 17, card 3).

The belief that raising a child with a disability was the will of God helped mothers to see the positive aspects of caring for that child. For example, Ibtisam said, “I got closer to God and that’s something from God. ‘Do not ever despise something that might be good for you.’” (Interview 6, card 3; Field notes, May 3, 2006; Holy Qu’ran quotation).

Another type of positive aspect perceived by some mothers was related to improved opportunities to relate with other adults. Shaymaa said that she chose to leave her job at a hospital to work with other children like her school-age son, Ziyad. She believed that she had found direction in her life in educating children with disabilities at the Shafallah Center who struggled with severe health issues similar to those of her son. The Shafallah Center was a blessing to her because it changed her life to come to know so many people through working there whom she otherwise would not have known (Interview 9, card 3). Shaymaa believed that relating to people gave her strength to be the mother of her child and she felt content (Interview 9, card 6). Salma similarly commented on the benefits she had gleaned from her relationship with social workers

and doctors obtained through her experiences in obtaining services for her school-age son, Soulayman. Salma learned a lot of beneficial techniques for working with him (Interview 24, card 2). This made her feel more confident to care for a child with severe needs.

Blessings expressed by several mothers were that they related better with their husbands after the birth of their children with disabilities. When Ibtisam, mother of six children, had a son (which is preferred as more favorable to having a daughter in Qatar) it made her husband happy; however, she still wanted a girl. “When I had Asmaa I was emotionally touched because she came after four years and she filled our lives” (Interview 6, card 10). Ibtisam’s husband desired a son to follow him in the family line of succession. Asmaa was followed by the birth of Ashwak, who also had a disability. These two children required that Ibtisam and her husband communicated and worked well together to meet the needs of their children with disabilities.

Manal described the positive impact that the birth of her child with a disability had upon her relationship with her husband:

We really believe in God and we know that we were tested by God. We have hope that he would work in the future and my relationship with his father grew stronger. Our love increased and cooperation also increased between us. We do not depend on the maid because she will never be like the father and the mother (Interview 22, card 14).

Gaydaa remarked on a similar dynamic with her husband:

The most important thing was that I got closer to my husband. Our relationship was normal before, but we got to get closer and to connect with one another. And all gifts that we got were because of [my son's birth]. He's the blessing of the house and I hope that God would count that in the end (Interview 12, card 3).

While some mothers of the study recognized that they had lost relationships with others because of their children's disabilities, the mothers who shared the preceding stories of the best aspects of their children's disabilities perceived that their relationships with God, family members, other individuals with children with disabilities, and professionals had grown.

Omniya's blessing was in the form of motherhood; she shared how she had registered to go to college. Her mother told her at that time, "You are the eldest. Who is going to do the housework if you go to school?" After Omniya got married and still wanted to study, her father then asked her, "What are you going to do with your children?" Omniya did not go to school and when she had children she gave herself completely to motherhood (Interview 31, card 48). For Omniya, the best aspect of her child's disability was that she was honored with an award by Sheikha Moza, the wife of the Emir of Qatar, for her parenting as the mother of Khamees who had Down syndrome (Interview 31, card 49; Field notes, June 5, 2006).

Mothers' reported blessings included connections made with professionals in the medical field and special education field, as well as deepened relationships with their husbands as they raised children with many support needs. In the cases where mothers

noted improved marital relationships, there may still have been a limited paternal relationship with the child with a disability; however, the mother might have felt better supported in raising a child with a disability because her interactions with her husband were more positive. Those mothers who were content and kept a positive outlook, readily identified the “best aspects” about the circumstances of disability. Mothers deemed the best aspects to be blessings, such as patience, faith, and perseverance.

Desire to be needed. Another form of blessing perceived by some mothers was coming to a place of acceptance. “Best aspects? That I am the mother of a baby girl. That is what I was looking forward to when I got married. My relatives used to say, ‘God help her.’ But, she is my little girl,” reflected Sameera about her school-age daughter, Noora (Interview 4, card 3). Sameera’s reply hinted at the beliefs and pressures that mothers faced because disability was viewed by others in Qatar as a great challenge.

After asking the interviewer to reiterate her question about the best aspects of raising her child, Thikra said that she read a lot about disabilities and how to work with children like her daughter Raja. “She is considered a blessing and God will count that. It’s the first time we’ve had this situation in the family. Thank God for everything!” (Interview 21, card 3, Field notes, May 28, 2006). Widad also struggled in identifying a positive aspect of mothering a child with a disability, but finally replied:

It’s a great experience. She needs me. The purpose of my being is to be there for her. Even though she is disabled I feel I am blessed to save her.

At the beginning it was hard and it was because there were so many

problems. Now I think on the contrary—it was a blessing! (Interview 10, card 2).

Some mothers noted differences in the ways that they related with their children with and without disabilities. Mashael believed that she took better care of all her other children after Muhannad was born. She closely observed her other children to see if they had characteristics of autism. She learned everything about autism and the behaviors that were common to it (Interview 34, card 9).

Makboula, separated from her husband and a bit resentful that her other adult children were not as much a part of her life, was very thankful for the presence of her school-age daughter, Fajer:

The best thing in my life is Fajer. I would like for all my other children to be like her....When you ask them to do something for their benefit they will turn against you. My other children don't do anything for me, but my girl, Fajer, she is a bird of heaven. My other children—one of them got married, and my daughters are busy with their lives and I am always with Fajer and the maid. There are some people who don't like this experience, but it is God's will (Interview 18, card 4, Field notes, May 24, 2006).

Nojood described how she believed contentment and a positive attitude were important as she assisted her daughter with severe physical disabilities:

If the child is normal the mother would feel love for him, but imagine if the child is not normal. Her heart would feel more than the average mother. Thank God we are satisfied with the situation because they

(children with disabilities) are the birds of heaven. They need special care and help and when we see them we remember the mercy of God

(Interview 8, card 3).

This group of mothers accepted their children's disabilities encouraged by the fact that they knew their children needed their assistance.

Positive outcomes from stressful life events. Other mothers reported positive outcomes as a type of blessing from having a child with a disability. Manal compared difficult life circumstances. "All of my other problems have become easier. For example, my mother passed away several months ago and I was able to cope with it better because of what I had gone through with my son" (Interview 22, card 11). Mothers in interviews 37, 38, and 39 all expressed similar mixed emotions about the best aspects as well as the challenges of raising their children. While these three mothers agreed that having a child with a disability was a blessing, it was evident that it could be very difficult as well. If mothers had had difficulty becoming pregnant, the accompanying personal growth experience tended to be a welcomed surprise.

Suheir's eyes filled with tears. "Samah is a test tube baby. She was born after eight years of waiting to have a child. She looks normal, but her understanding is delayed" (Interview 37, card 5). Though Samah was born with severe physical disabilities (Field notes, June 7, 2006) Suheir said, "Samah is the blessing of the house" (Interview 37, card 6). After the interview Suheir explained that it was difficult for her to take Samah out in public in the Gulf Region as people stared. Despite these challenges these mothers found strength through their ability to cope with the unexpected births of

children with disabilities and the public responses to their children with disabilities in the Gulf Region.

Mothers reflected on how their children with disabilities caused them to grow in character qualities, such as patience, understanding, and perseverance. Najat considered herself “invincible” after the birth of her daughter Hayfaa (Interview 25). The daily complexities of raising children with disabilities seemed to have the power to create mothers who could overcome adverse situations, due to the intensity of pressures they had experienced with their children. Besides personal growth, mothers felt they were recipients of God’s mercy and were thankful that they had been chosen for a challenging task. They reported that this learning opportunity through stressful life events had increased their faith in God and also had helped them build stronger relationships with others.

Facing Family Challenges

“The most challenging thing is raising him.”

*Saiba, mother of Rashoud, her adolescent son with Down syndrome
(Interview 20, card 3)*

While some mothers appeared to adjust very well to having a child with a disability, other mothers considered it very challenging and, at times, unpleasant. Mothers experienced sadness about their children’s disabilities; and expressed that they had experienced a total life change after the birth of their children. Sohaila began, “The disabled child is a blessing for every family” (Interview 38, card 6). Yet, Sohaila, with her perfect makeup and in her beautiful, ornate jalabeya housedress, tried to hold back tears in her eyes (Field notes, June 7, 2006). Although Sohaila said that her child was “a

blessing,” her difficulties became clear in the interview. Although Sohaila’s comments seemed to reflect acceptance of a disability and the ‘good’ that it had brought to the family, her tears suggested that there was an underlying grief about her daughter.

Another category that emerged from the mothers’ perspectives was related to the challenges they faced in having a child with a disability. Some mothers had a difficult time recognizing any positive aspects. Mothers were inundated by the many challenges confronting them and their families. These challenges included a lack of interventions, medical needs of their children, lack of social interactions, negative social interactions, negative attitudes by family members, or lack of home support while raising their children. Time constraints, limited assistance by fathers, and the children’s difficulties with daily living skills, like eating and communicating, were explained as the greatest pressures upon mothers.

Lack of early interventions. Mothers who had not received an early diagnosis of their children’s disabilities regretted that interventions had not come sooner. “We started with him very late—when he was six years old and his personality had already been formed” (Interview 33, card 28). Nafela was convinced that her son Ameen’s progress would have been better if interventions had been made sooner; his training at the Shafallah Center did not begin until he was 16 years old. Muna also regretted that she did not seek interventions for her child sooner. “I started blaming myself when he was younger because I didn’t take him to Cairo and because it is easier to change things when a person is younger.” Muna’s son Nadeem was 17 years old at the time that interventions first began with him (Interview 29, card 39).

Sending children with disabilities to school was a difficult choice for some mothers to make. Mashaël wanted to take Muhannad to school early, but did not feel that she should do so. “Everyone was blaming me because I kept him at home, but I am scared to take him to a normal school because they might hit him and he doesn’t like shouting” (Interview 34, card 10). Muhannad was 18 and would not attend a general education campus before he finished school. Khadija deemed educating her daughter, Nijma, as her most difficult task. “She grows up physically, but I still have to treat her as a child” (Interview 1, card 4). Some mothers delayed the education of their children because of their fears about their disabilities. Occasionally mothers kept children from opportunities for community integration as in the case of Mashaël with her son Muhannad (Interview 34). In general, however, mothers realized the importance of early interventions for their children (Nafela, Interview 33), that there were better services outside of Qatar (Muna, Interview 29), and the challenges inherent in an inclusive setting in Qatar where disability was not widely accepted.

Fewer social interactions. Another challenge was that social interactions were limited for these children because mothers feared for their child’s safety if someone other than themselves watched their children when they went out. Sometimes a child’s behaviors made mothers reluctant to go out in public. If a mother felt that her child did not behave appropriately in social situations, she usually also expressed how this impacted her own social experiences. Wodouh was most annoyed by the fact that it was not easy to take her son out in public. “I cannot take him out like normal children...In

the house I don't have a problem and I accept him as he is, [but] what wears me out is that I cannot take him out" (Interview 32, card 5).

Makboula told that had she reduced her outings to those in which she was invited somewhere. She admitted, "I am afraid that she (her daughter Fajer) will get something sharp and hurt herself. I don't depend on anyone" (Interview 18, card 12). Makboula did not believe it was good to take Fajer with her nor to leave her at home alone. Muna explained that public displays of behavior reflect on her because it looks as if her son, Nadeem, was not raised well (Interview 29, card 14). Muna, referring to her adolescent son with autism, explained, "Their problem is that they look normal so they don't always give you warning that they are about to do something that is not so normal." (Muna, Interview 29, card 6).

Mothers were concerned for their children and feared displays of poor behavior in public. This same theme was even a concern in interactions with extended family. Children who expressed poor behaviors in public were less likely to be taken out; whereas, children who displayed socially appropriate behaviors were more likely to be taken out in public or to the homes of extended family members. Mothers did not feel that they had as many personal relationships and sometimes felt their children's disability was the reason they had few friends. Many voiced the opinion that they did not feel comfortable leaving their child with anyone, yet their choices for child care were limited because of few close friendships which would serve as support. It was clear to the researcher that most of these mothers needed respite. It would have been beneficial for mothers to have some resource within the community where their children could be

cared for for several hours on occasion. Mothers expressed extreme burdens in their lives, but very few had the resources to find time for reprieve from caring for the needs of their children.

Negative attitudes by family members. It was not uncommon for mothers to describe the negative attitudes that they had experienced from their other immediate family members, such as husbands or other children, extended family members, parents, siblings, as well as nieces and nephews of mothers or their husbands. Sometimes mothers expressed negative attitudes of resentment or shame towards their child with a disability. Amera vented,

The problem is with her father. He used to come with me to the parent trainings at Shafallah, but he doesn't come now. He used to come to these trainings and discuss the topic and talk with me, but now I come by myself and I do not pay attention to what they say because I am thinking about my problems (Interview 16, card 23).

Manar said of her young son, Majed, with autism, "Even my nephews and nieces get an attitude from him and they don't deal well with him" when she tried to encourage interaction between cousins (Interview 40, card 29). Omniya shared that her extended family did not accept that her son Khamees was normal (Interview 31, card 5).

A primary location for families to visit in Qatari society was at the homes of other relatives. Women reported stories of rejection of their child by their extended family, which in turn made visiting uncomfortable. Fawzya's relatives had trouble tolerating her son, Mubarak (Interview 17). Fawzya referred to her

adolescent son with multiple disabilities and concluded, “It’s difficult for me to take him to the homes of relatives or friends because it is hard for them to bear him” (Interview 17, card 12a). Social interactions, with relatives or otherwise, were desired, but required understanding visitors or those being visited since the behaviors of children with disabilities or the perceptions and responses of those around them created a barrier to typical visits.

Some mothers found it difficult to maintain friendships as a result of limited outings. Muna found visits to the homes of relatives to be her primary social activity:

Although I studied at Qatar University I do not have many friends.

Because of this I dedicated myself to raising my son and being with the family. On Thursdays I visit my mom and I get back home and visit his other grandfather (Interview 29, card 26).

There was an expression of shame about having children with disabilities and the way that they would be perceived in the community. Mashael told how Muhannad used to stay right by her side. She was really ashamed and afraid that others would see that he was different because of his characteristics of autism. She did not have the knowledge of what to expect with autism. “He’s the first disabled child in both families. I suffered a lot and my family, as well” (Interview 34, card 12). In a tribal system where individuals are interconnected as part of the group it is possible that extended family members feel that the disability reflects shamefully upon them as well as upon the immediate family.

Manar was questioned by Majed’s older brother. “Even his brother who is older than him asks, ‘Why is my brother like that?’” (Interview 40, card 28). Ashgan

witnessed sibling rivalry between her children. “Her other brother who is close in age gets jealous and hits her because she gets a lot of attention. His father takes him off and hits him” (Interview 5, card 15). Buthaina described her own, little family conflict, “Fatma has this attitude. She wants to play with video tapes a lot and this is something I couldn’t change, so I deprived the whole family of watching video tapes” (Interview 7, card 13). This was most likely much to the chagrin of other children in Buthaina’s family. Siblings were a considerable source of the negative attitudes towards their brothers and sisters with disabilities.

Maternal pressures. Maternal pressures, such as personal care, time for care needs, shame about child’s behaviors, and fear about the future were another challenge expressed as mothers described the daily task of meeting their children’s needs. Ibtisam, speaking of one of her two children with disabilities, Asmaa: “Her eating is difficult. She doesn’t talk. If she could do any simple thing it would make me feel like she is normal” (Interview 6, card 4). Ashgan, speaking of both of her children with disabilities, said:

Her brother has Down syndrome and she does as well. When I had my son they told me that he’s sick. I got [emotionally overwhelmed] and I didn’t believe it because all of my other children were normal. I’d like them to be normal” (Interview 5, card 2).¹

Nojood told how drastically her life changed after Anisa was born. Nojood described the time she spent working with her child with exasperation:

¹ As a note, there was a discrepancy with this report because the older child was reported as having an unidentified, moderate disability to the interviewer, but within text the mother said he had Down syndrome. This was the first time Down syndrome appeared in text for Othman, as well as Samia.

I give her all my time. There are some things that they (children with disabilities) really need. It's true that they are called children with special needs because they really need special care....I feel like my entire life belongs to my daughter. I waste all of my time on her (Interview 8, card 17).

Saiba also noted that the birth of her child, Rashoud, with Down syndrome totally changed her life. "It was an abnormal situation. He was like a piece of meat in my hands. I had to change a lot of things in my life because of him" (Interview20, card 2). Samah said of Salah, "He does things that make me sad. I think a lot about it and I cry about this situation" (Interview 2, card 18). She went on later in the interview:

And now I think how I'll be with him when he grows up and how can I control his thinking and behaviors. I think about his behavior now, but tomorrow I don't know because I can control him now. It's a big responsibility and it will get more difficult when he grows up (Interview 2, card 5).

Most of the burden of care for their children with disabilities fell upon mothers who were to carry out duties alone or perhaps with the assistance of their other children. Although most all mothers in the study were fortunate to have the assistance of one or more maids, the children were still their own responsibility. The constant care needs expressed, along with sadness and fear of the future put a great deal of pressure on the mothers.

Lack of home support. A majority of the mothers who were interviewed had home support with the assistance of a maid. Although several interviewees did not have this privilege, the few mothers without a maid felt a need for greater assistance. The reason for needing support was expressed as having a husband or other children who did not participate in helping with a child with a disability. All mothers were asked about help within their home; of the 40 mothers who were interviewed, 36 reported that they had from one to four live-in maids who assisted them and their family members. This level of home assistance was a characteristic typical of life in Qatar. Shaymaa, one of the four mothers who did not have a maid said, “I do not have a nanny or maid. Yes. That’s why my back is broken!” Her child Ziyad had multiple disabilities (Interview 9, card 14). On the other hand, Mufliha reported her challenges when caring for Nosym, “I got [Nosym] a special maid who washes his clothes and takes care of him” (Interview 35, card 9).

Some mothers had support in some form from other family members. “[Marzouk’s] father doesn’t help with feeding, bathing, and dressing, but he is cooperative. I have taught Marzouk to be independent. If he wants to eat food, I will ask him to go and get it in the kitchen by himself” (Manal, Interview 22, card 26). Samah explained when things became difficult she prepared her other four children to take part in helping with Salah who had autism:

We all became responsible for Salah. I gathered my children together and I told them that I’m not the only one who is responsible for him, but his siblings, too. We all have to be responsible for this human being. Because

he's not only my son, we watch him and think about his situation and are responsible for this child in this house. And whoever sits with him shouldn't only watch him, but needs to be with him—[using their] mind and thoughts and all [their] senses because [Salah] cannot be alone. He changes in a second (Interview 2, card 15).

Mothers expressed a lack of support from those who they expected to be of the most assistance, such as fathers, brothers, and sisters. Omniya also found it extremely challenging to offer educational support to her son, Khamees:

I am not educated and [Khamees's] brothers don't help me by studying with him. His brothers do not help me. I always take him out with the driver to the beach. Everyone is busy with his own work. I cannot leave him by himself with the driver. I can't. I don't know what he would do to him (Interview 31, card 19).

Nafela used to be an Arabic teacher, but had to retire due to the pressures of life at home and the responsibilities of caring for a son with a disability. "I really got tired from correcting student work and I used to bring the papers home. That annoyed my husband because I couldn't separate work from my family time" (Interview 33, card 22). Nafela's husband felt that the pressure of her job took her away from her family. Nafela finished "The challenge for me is to reach my goals with the absence of support and help in my home" (Interview 33, card 11).

Overall, governmental financial assistance to families with children with disabilities was very minimal in terms of financial support. Nojood added that

“everything” was a challenge with a child with a disability, but she said, “Thank God that the Emir gives them a salary!” At the time of writing that was 600 Qatar Riyals or approximately \$164.38 per month (Interview 8, card 4, Field notes, May 10, 2006). One mother described that this amount was enough to pay the monthly salary to hire a maid. The average salary for maids was \$100 - \$200 per month, plus room and board.

Whether from a lack of maids or little help and/or support from family members, mothers felt that the burden of care for their children with disabilities was their responsibility. The need for greater support in some form was a common theme.

Medical Impact

“One time there was a doctor who shocked me. He told me, ‘Why did you bring him here?’”

*Zaynab, mother of Daham, her school-age son
with Down Syndrome and a hearing impairment
(Interview 15, card 7)*

Another area in which families were impacted by having a child with a disability was in medical issues. Mothers mentioned these issues that concerned them at home, at school, or in the medical offices in the community. One mother told that because of her child’s medical issues the child was in need of supervision 24 hours per day. A common theme was the amount of time it took to meet with a doctor, especially with other individuals cutting in line in doctors’ offices. Mothers told how they traveled abroad for medical care that they considered more comprehensive and accurate in Canada, England, Germany, Kuwait, Lebanon, and the United States. Negative reactions to hospital visits in Qatar included comments about other people staring, no priority for individuals with disabilities, general anesthesia necessary for visits to the dentist or doctor, a child’s fear

when recognizant of a trip to the doctor, and the child being strapped down by doctors or nurses in order to check or test their prognosis.

Medical Concerns at Home

Monitoring health concerns was at the forefront of issues that mothers addressed on a daily basis: diabetic shock, falls, or any remedy that might improve the well-being of their children. Dana said she was constantly aware of Jameel's state 24 hours of the day. She had to measure his blood sugar and give him his injections three to four times each day (Interview 26, cards 11 and 8). "When I was delivering my next child in the hospital I was thinking of Jameel. My biggest worry with him is diabetes, not autism," (Interview 26, card 12). Mashael directed Muhannad that he must come and tell her if his hand was shaking because he also had diabetes. Muhannad was faithful to do that. "If you teach him anything he does it very fast" (Interview 34, card 21). It was necessary for Mashael to continuously monitor her son.

Manal's home remedy for Marzouk, who had mental retardation and multiple health impairments, was to give him lots of sunlight and massage him with olive oil. The doctors also gave him a special medicine which Manal believed made him better (Interview 22, card 6). Medical issues came to the forefront of concerns for mothers with children with severe disabilities. Mothers such as Manal were willing to try anything to help their children. There was constant concern for children who had disabilities.

Traveling Abroad for Care

Mothers expressed concern with the quality of care in Doha and some chose to take their children abroad for care. It was not uncommon to hear that a family travelled

outside of the country for medical care for their children with disabilities, especially due to the lack of medical knowledge about disability in local facilities. Dana recalled that she once took her son to a local doctor. She told him that Jameel had autism. She was surprised to learn that the doctor did not know what autism was (Interview 26, card 36). After Amera gave birth to Amal she took her home from the hospital and Amal began to lose a lot of weight very fast (Interview 16, card 2). Amera took Amal to the local hospital to have her checked since she had been born with multiple disabilities. Amera was left with no hope. The doctor said, “If you have money, you better save it for your normal children.” Amera burst into tears as she recalled this situation, “I just wanted a report from them and was not asking to have our expenses paid!” Amal stayed at the hospital for a month and a half (Interview 16, card 4). After a year and a half Amera took Amal to Germany (Interview 16, card 2). “After Germany, she got better, and so did I. The doctors really brought me down [in Qatar]. They told me that she is going to die, but in Germany they told me she is delayed and growing.”

Ibtisam took Asmaa and Ashwak to both the U.S. and Canada for testing since both girls have the same rare, degenerative genetic disorder, and there were a larger number of diagnosed cases in North America (Interview 6, card 2). Ibtisam also took the girls to a doctor in Lebanon who was very focused when she met with him. He did testing on her daughters and sent it to London for the results (Interview 6, card 12).

Even if travel was intended for a vacation, some families took the opportunity to seek medical advice. Widad said that her family took the opportunity to seek medical advice when her family traveled abroad (Interview 10, card 8). When Zaynab’s son

Daham was born he had jaundice and the doctors put him under warm lighting. As a complication of his Down syndrome, Daham had a hole in his heart. His family made their way to London for the surgery (Interview 15, card 3).

Mashaal picked up a magazine from her doctor in Kuwait about what foods children with autism should and should not eat (Interview 34, card 25). Dana also went to a hospital in Kuwait with Jameel. She said that Qatar does not have special medical care and individuals waited for months if there was a specialist who could work with children like her child. “I went to a hospital in Kuwait and it was written there that priority is given to people with special needs.” Dana thought a similar system would be beneficial to Qatar (Interview 26, card 40). Nafela dreamed of taking Ameen, now 16 years old, for tests abroad, but life in Qatar became too busy. “When he was four years old we went to the U.S. and they wanted to do testing with him, but we never got the chance to go. I got really upset because we got busy with other things and we couldn’t do this.”

Another complicating factor for traveling for medical care was the fact that most women were not to travel unaccompanied outside of Qatar without a male relative (Translator’s explanation of *mahram* or chaperone, Field notes, Interview 34). Mothers had to have finances and an open schedule for travels abroad for medical care because it was usually a very time consuming and expensive activity. The lower quality of medical care in Qatar, although free for residents, created an anxiety in mothers about accessing better services for their children. Just as mothers described the difficulties they had

obtaining diagnoses for their children, they continued to experience difficulties obtaining care across the disability spectrum.

Many Hospital Visits

Another subtheme of medical concerns that emerged surrounded frequent local hospital visits. Mothers reported that others cut in line before them, their children feared visits to them, and the staff members did not know how to work with children with disabilities. Lama, who had lived in several Middle Eastern countries with her two sons with autism due to her husband's work commented, "I like them to be cared for when I take them to the hospital and usually they are not nice to them there. It is like that in all the Arab world. And, [the staff] use their strength on them" (Interview 36, card 33, Field notes, June 6, 2006). Lama described a situation where one of her adolescent sons had to be tested at the hospital:

We couldn't make him calm. We took him to the lab and he still wasn't calm. [The staff] said that we should tie him down for the testing, but I didn't agree. If there was someone with patience they could do this test for him, but these people are not prepared or experienced to do these tests on these children (Interview 36, card 35).

Gaydaa explained what a typical visit to the dentist might look like for her adolescent son, Khalid, who had Down syndrome:

In the hospital they should have the priority to go first before anyone else. For example, when you go to the dentist you take a number and you wait for your turn. People don't understand. He knows that he's going to the

dentist, so he screams and he cannot sit in one place. People look at him in different ways. Some with loving looks, some with surprise, and some feel sorry for him.

Several other mothers had similar negative occurrences with their children at the hospital due to a lack of understanding about disability. Dana stated, “He doesn’t like Hamad Hospital and he doesn’t let them give him injections. As soon as we reach the roundabout that leads to the hospital he knows we are going there. He starts crying” (Interview 26, card 37). She continued, “I take him to Al Saad Hospital and his father, the maid, and I hold him so they can give him the injection. I cry when he gets sick” (Interview 26, card 39). Mashaal took Muhannad to the Al Mansoura Center, but the doctor referred her to Rumeila Hospital which had a special trainer for children with autism. Muhannad’s therapy sessions did not continue for long. “She was a foreigner and he didn’t understand her” (Interview 34, card 4).

Nafela, because of her curiosity about the reason her adolescent son, Ameen, was born with mental retardation, took him to the hospital frequently on her own accord. Nafela wished to have many tests done on him. “A CAT scan, genetic testing—nothing was wrong with him. Then, I did this specific genetic test to see if his sister had the same problem and if it was in our blood” (Interview 33, card 8). However, Nafela did not choose to divulge the outcome of the test or whether or not her other child had a disability (Field notes, June 6, 2006).

Frequent hospital visits related to required surgeries were reported to invoke fear in mothers. Aliya’s son Shoayab was born with a small hole in his heart (Interview 14,

card 3), a congenital heart defect, which is common for children with Down syndrome. Although Shoayab did not need to have heart surgery, he did have to have surgery to open his anus due to recurrent constipation as an infant. The doctor advised his mother not to breast feed and to give Shoayab formula instead. “I wish I could have given him my milk. I only had milk for two months” (Interview 14, card 2). For four years Aliya had to take Shoayab to the hospital frequently. “Four years of interviews, tests, X-rays, and an MRI. He has the hole in his heart and he has thyroid problems. He takes pills for that” (Interview 14, card 3). Salma said that when her son, Soulayman, who had Down syndrome, had to have a heart operation, it was her most challenging moment as a mother because hospital visits became so frequent throughout Soulayman’s life (Interview 24, card 3).

In terms of medical care in Qatar, mothers reported a sense of walking in darkness. They did not always know if medical results were accurate or if the final word was one that should be credited. State run medical facilities were the primary option available and mothers reported that staff members usually were not familiar with serving children with disabilities. These misunderstandings were further exacerbated by the behaviors and limited communication skills of children with disabilities (Interview 14).

Most mothers reported more medical and safety concerns for their children with disabilities because of the fact that the medical field had few immediate answers about interventions for disability and limited service provision for children with disabilities (Predominantly reported in interviews 6, 10, 15, 16, 26, and 34). Mothers said they wished for more information about specific disabilities. Families had a tendency to opt

for more adequate medical care outside of Qatar and found better outcomes when doing so, as reported by Amera, Ibtisam, Widad, Zaynab, Mashael, and Dana. Mothers reported little faith in medical professionals when they spoke about initially learning of the disabilities of their children (Interview 6). This concern persisted and was prevalent with children ages four to 19 who were still in need of medical care.

Limited Communication

“But, I think of the future. What is he going to do when I die? He is very smart. He knows everything, but he cannot communicate with others.”

*Dana, mother of Jameel, her school-age son with autism
(Interview 26, card 7)*

A significant impact of the disability was related to the children’s limited communication skills. Mothers noted that there were challenges for them when they took their children with limited communication skills into public places, especially when their children did not get their own way. Mothers commonly mentioned: crying, self-abuse and stubbornness, as well as safety concerns. Children had difficulties in general in communicating their needs in a way that those around them could understand. Mothers reported a sense of frustration regarding these limitations. Mothers reported that communication issues created barriers for children in social interactions with family and others. Widad shared how adolescent-age Wafaa’s needs were communicated to her daily by Wafaa’s sister because Widad could not understand Wafaa’s speech:

It is very difficult. Crying is the only way she can tell us she needs something. Sometimes at home she hits herself—pokes her eyes, pulls her hair, bites her hands. I do not like to see her hurt herself (Interview 10, card 4a).

Shahd shared that she and the family driver were the only ones who could understand adolescent-age Sajed (Interview 19, card 4). “He’s friendly. No one’s his enemy” (Interview 19, card 12a). Even his father, who had recently passed away, could not understand him (Interview 19, card 4).

The most challenging thing is that he doesn’t understand everything around him. The problem is with his speech. Sometimes we don’t understand what he wants, but I got used to it and as he gets older he becomes better and better (Interview 19, card 8).

Shad observed that Sajed could differentiate between different car keys. He knew which ones belonged to whom and the different car models that the keys matched if he were to point to the cars parked along the street. “He can understand what is going on; it’s just that he has a speech impairment” (Interview 19, card 5).

“When someone is an autistic person all you want him to do is to communicate” (Interview 40, card 17). Manar described her communication with her young son. “Majed doesn’t talk and he doesn’t express himself and he doesn’t say ‘Mama’ or ‘Baba’” (Interview 40, card 12). Manar noticed early on that her son not only did not express himself in words, but he could not use baby language (Interview 40, card 15).

Safety Issues with Limited Communication

It was difficult for mothers and children to communicate an understanding of safety issues and to instruct their children how to seek assistance. Gaydaa’s worst fear was that her son would be in danger if he could not communicate. “If he talks he can tell me what’s happening to him. When he cries he cannot tell me who hit him and if he’s

alone with his siblings or the maid I do not know what's wrong with him when he cries. I cannot blame anyone" (Interview 12, card 8). Zaynab expressed similar sentiments about her fear for Daham's safety and the need for extra help with supervision:

And, what I've done is that I've gotten a new maid who watches him because I don't like to leave him by himself. Once we left him in the yard and he went to the neighbor's house. He went up the stairs without anyone else. We were looking for him. Another time we were looking for him and we found him in the street. We asked him, 'Where are you going?' He said, 'I'm going to the desert.' He likes the desert a lot. We have to watch him. That's why I hired the maid. (Interview 15, card 15).

Daham did not entrust anyone with her son easily because she feared that he might be endangered since he was not easily able to communicate.

Widad also worried about Wafaa's safety in relation to her inability to communicate her needs.

I would like her to be able to express herself. Sometimes she wants something and it takes a long time to express herself. It is frustrating to us because we can't understand what she needs. I feel sorry for her. When she is hungry or hurt she can't tell us. This is hard for us. I do not like to see her suffering (Interview 10, card 4).

Salah found a way to communicate his wants and needs to his mother, Samah, whether or not he could say it in words. "I don't think that he can take any responsibility because

he doesn't talk or concentrate and there is not any means of communication. But, he gets what he wants" (Interview 2, card 30).

Hearing Impairment

In several cases limited communication was due to a hearing impairment. Gaydaa wished Khalid would be able to talk, but he cannot hear. "Even the hearing aid doesn't help. The cells are dead. We did a hearing test for him. He can hear things, but in different tones. Some sensory cells are dead" (Interview 12, card 6).

Zaynab mentioned that Daham's communication difficulties were her biggest challenge. She persevered in hopes that her son could talk and be able to communicate his needs. She chose to take him to visit a hearing specialist at the hospital, but experienced the same lack of understanding that other mothers have pinpointed in the medical field:

One time there was a doctor who shocked me. He told me, 'Why did you bring him here?' I said, 'I want to make sure that he hears well.' He said, 'No, that's for normal children only.' I couldn't talk when he said that. Even my husband asked me for his name and I told him, 'Just forget it; God forgives him.' I took [Daham] to another doctor and he hears better now. They fitted him for hearing aids in London and he can hear and talk now (Interview 15, card 7).

For children with speech and hearing impairments, as well as physical impairments that hindered both verbal and non-verbal communication there were limitations on the ability to communicate their most vital needs, such as their hunger,

pain, or distress (Interviews 12 and 15). Mothers reported concern for the immediate safety of these children in a community with both limited understanding of the needs of children with disabilities and medical facilities that were not well trusted by mothers in case their children did have an accident. Verbal and non-verbal skills are the most basic and essential communication components necessary for human interactions. The inability for children with disabilities to communicate was reported by mothers as a frustration for themselves and their children. Limited communication skills created a barrier to community integration in Qatari culture where there was limited acceptance of those with disabilities deeply rooted within the culture (Interview 37).

Treatment of Children with Disabilities in the Community

“In the past families were scared to show their children in public.”

*Aliya, mother of Shoayab, her adolescent son with Down syndrome
(Interview 14, card 35)*

“We never hide him from anyone. We take him everywhere. He’s so lovely and everyone loves him.”

*Shahd, mother of Sajed, her adolescent son with mental retardation
(Interview 19)*

Interactions in the Community

After an evaluation by mothers of relationships within the home and between family members, a significant theme related to having a child with a disability centered on the way the child, the family, or community members interacted and responded within the community. Mothers expressed this treatment in terms of interactions, reactions, public behavior and community response. They also discussed models of advocacy and inspiration from examples outside of Qatar. When mothers spoke about the community’s reaction to their child with a disability there was a general perception

of lack of understanding. Mothers discussed their children's interactions in the community according to how they or their children reacted to others, reactions to their children's behaviors or disability in general, and the initiative taken by mothers to advocate according to the responses of others to their children with disabilities. Manal perceived:

The most challenging thing is to take your child into the community, keeping in mind that the community understands him, but the parents should encourage his strength and acceptance into the community to prove his worth. Even our neighbors have become better with him (Interview 22, card 17).

Some mothers were reluctant to take their children into the community because of previous negative interactions. Ibtisam alleged, "The community does not accept them and the families don't make the children aware (about disabilities)" from her experiences with Asmaa and Ashwak (Interview 6, card 14). Ibtisam imparted that she feared children would not be kind to her daughters and she did not often take her younger daughter out in public because "the kids don't understand her situation" (Interview 6, card 13). Ibtisam shared her perception about how Ashwak's limited communication skills impacted her social life:

When Ashwak plays with kids they run away so she cannot see them. That's why I don't take her. The other kids Ashwak's age can talk, but she can't. That's why they make fun of her. There is no one like the mother and the father of the child (Interview 6, card 15).

Dana described what she saw when Jameel played with children without disabilities. “Normal children will play and run around, but our children just sit. And, the normal children will even hit them” (Interview 26, card 46). Dana commented, “Children with special needs will not harm each other” (Interview 26, card 47).

Staring and other impolite reactions by individuals in the community were irritating to mothers. Widad reported that she found it most challenging to take Wafaa in public because some people would stare (Interview 10, card 3). Suheir expressed, “The awful community that we live in. The community looks at them as if they don’t have feelings” (Interview 37, card 7). Haiba continued with her idea of the “biggest challenge”:

[There are] many challenges. The look in people’s eyes—in the hospital people ask how old [Muftah] is and what’s wrong with him. Also, the look in other children’s eyes towards him. I think this is another challenge. Dealing with him in general...his reaction to people (Interview 13, card 3).

Samah recounted a story of an infringement of Salah’s dignity which also serves as an example of the negative experiences of some children with disabilities out in the community:

I watch how people act towards him. I don’t like them to make fun of him or act inappropriately. I don’t like anyone to take a picture of him. There was a maid—my neighbor’s maid—who took his picture with her mobile.

Because I don't know what she might do with the picture I really just felt that I wanted to cry (Interview 2, card 17).

Suheir related that it hurt her when she felt that everyone was staring at her daughter Samah and that they did not have an understanding of who Samah was as a person (Interview 37, card 9). "She's a social person" (Interview 37, card 32).

The Community Response to Disability

Mothers were very concerned about the community response to children with disabilities and their families. Several mothers reported that they believed the Royal Family of Qatar was attempting to change the general negative community perception to disability. Nojood interpreted what she believed about her community:

The Emir and Sheikha Moza pushed forward and they said [children with disabilities] are normal, like us. They hear, but they cannot talk and they don't have a mind to think. We try to be just and fair toward them (Interview 8, card 5).

Haiba offered her idea, "The perspective of the mothers of normal kids towards those with disabilities is one of pity" Interview 13, card 18). Treatment of individuals with disabilities in Qatar caused mothers to avoid efforts, in some respects, to include their children in the community. Mothers reported that community members commonly had uncertainties about how to interact with individuals with disabilities because disability had been hidden for so long. Mothers reported that they found it difficult to take their children into the community for recreation and leisure activities, just as they had found it difficult to take their children to local hospitals and find individuals who would

understand the needs of their children. Challenges with community integration were not isolated, but widespread.

Impact of Community Response on Family

Mothers noticed a difference in the interactions their children had from place to place. Mothers had different perceptions about how well their children were received by the community. Nojood articulated her desire to protect Anisa who was medically fragile. “I am always with her and try to help her without the company of other kids because they would push her” (Interview 8, card 11). Nojood added, “Whoever sees my daughter thinks she is normal and I try my best so she can be like normal kids. But, she needs time” (Interview 8, card 8). On the other hand, Nafela indicated, “It was difficult for [community members] to understand me and it is still difficult” (Interview 33, card 12).

Wodouh used to take Masood to the beach. “To me he is very cute, but some people don’t think so” (Interview 32, card 4). “We cannot take him. The people will look at him funny and get surprised. This is very embarrassing” (Interview 32, card 11). Omniya felt bad about taking Khamees to the *Corniche* (promenade by the sea) because people stared at her family and said unkind things to them. “[Khamees] likes to run, so he runs ahead of me and I hear people say, ‘Did he come here by himself?’ Where’s his family?’ I get upset because they have to check up on that” (Interview 31, card 28).

Some mothers received more positive community responses. Manal revealed, “Any friend who accepts my child’s situation becomes someone I love and accept. And,

those who don't accept him—it's normal. It's their choice." Dana had a different opinion:

To prove that he is normal like his siblings I don't let anyone tell him anything—that he is not normal. Someone once told me in the hospital that my child is disabled. I got really upset and told them that my child is normal. There are many healthy people walking around. They look normal, but they don't think right! My child is normal and I get really tired of people pointing it out that he's disabled. I don't want anyone to tell him that (Interview 26, card 9).

Suheir had a more gentle approach for dealing with children who did not understand the multiple disabilities of Samah than she did for adults:

I don't know how to deal with the people here. If a small child stares at her, I talk to him and kiss him, but if it's a grown up, I stare back at him so he will go away because he is wrong and there is nothing wrong with her (Interview 37, card 11).

Public Behaviors

In discussing the way children with disabilities were treated in the community, mothers expressed concerns about dealing with problem behaviors in public. Shaymaa, a special education teacher who did not have the assistance of a maid in her house and disciplined her own children when necessary, described the scene when she needed to reprimand her school-age son, Ziyad, in public for misbehavior:

When we go out and he cries I tell him to cry more. And, I let him cry.

Some people come and say, ‘Don’t you have mercy?’ If people come and stare I will ask them, ‘Do you have a problem?’ Children are so clever (Interview 9, card 8; Field notes, May 10, 2006).

Lama found it irritating if one of her children had an outburst in public and it was misconstrued. “[People] think that they are spoiled when they do something. If we take them out and the child screams in public, people think that they are spoiled” (Interview 36, card 10).

Buthaina noted her belief that children with disabilities are patient and strong. She said she knew how to deal with her daughter Budour’s behaviors and needs as a child with autism, and she learned how to deal with children without disabilities who may not understand Budour and her behaviors (Interview 7, card 2). Buthaina reported how therapy helped her to include her daughter in the community more:

When I take her out into the community to play areas it is evident that the community doesn’t accept kids with special needs. At the beginning I didn’t take her out, but after her exercises (therapy) we became stronger and we challenged the people and the community (Interview 7, card 3).

Amera observed that her school-age daughter, Amal, who had multiple disabilities, did not go and mix with other children. Amera said she desired Amal to do this. “She comes to sit in my lap. The children and even some adult ladies are scared of her because she screams and she puts her hands on her ears” (Interview 16, card 11).

Mothers had a variety of ways to handle the interactions that their children had in the community. Some mothers appeared to handle negative responses by community members, while other mothers expressed offense. Taking a more positive approach, some mothers initiated relationship building between their children and others. Those mothers who took their children into public places tended to have a certain confidence about their own abilities to handle inappropriate behaviors.

Models of Advocacy

As a result of the way their children were treated, some mothers became advocates. Mothers recounted a few stories of their opportunities to advocate for their children with disabilities in the community. Muna took the opportunity to serve as an advocate for her child when she saw that he was not being treated as he should:

Here the simple people like barbers, bakers—treat him better, but doctors and nurses treat him like a mentally retarded child. I took him to the hospital and they strapped him in to control him so they could examine him. That was wrong! I told them to remove that and all he would need is more space. I talked to the people who were responsible for that, so they have more awareness and enlightenment! (Interview 29, card 13).

Fairouz found herself in a position to advocate for Zain Elabedeen when she desired to include him in the general education school setting:

The director of kindergarten refused to accept him at a regular school. I took him and I begged her. He was six years old. One of the teachers volunteered to teach him and he got accepted into kindergarten. He

studied there for a year and then he spent three months in Rumeila Hospital (for education services). Then, he got accepted at Shafallah. The situation was hard because he's not a normal child with eating and drinking (Interview 11, card 4).

It is worth noting that Zain Elabedeen's situation of acceptance into a local school was a rarity. Muna and Fairouz both spoke with those in places of leadership in order to change the situation for their children.

Inspiration from Visits to Places Outside of Qatar

Although many interactions in the community in Qatar were negative, some mothers were encouraged by how they saw people with disabilities being treated in other countries. Suheir decided, "If I were living in Europe it would be very easy there, but it's not here" (Interview 37, card 10). "[This] community's philosophy is that they (children with disabilities) should have a center, but in Belgium they are trained to be independent," compared Muna, who had done some traveling throughout the years to obtain services for her adolescent son (Interview 29, card 55). Muna had also taken Nadeem for vacations in other countries:

The community in the U.S. gives you the right to do what you want. No one stares at you there. I took him everywhere—Disneyland, for example, and no one gave him a look of pity. Even in the airplane they knew how to deal with him (Interview 29, card 12).

Mothers who had observed treatment of individuals with disabilities in other areas of the world where those persons were given equitable rights had been encouraged to hope for more in their own community.

Children with disabilities were not treated well in the community. It was common for their presence in the community to be considered inappropriate. Mothers reported that they either chose to refrain from community interactions or become advocates for their children in their community (Interviews 11 and 29). The community, much like the extended family unit of some children, tended to have difficulty accepting disability and differences as in the cases of Ibtisam and Dana. There were a variety of responses to inquisitive community members who lacked understanding about disability as in the cases of Nojood and Widad.

This section began with a quote by a mother who believed that, “In the past families were afraid to show their children in public,” yet, the same was reported by interviewees of their current experiences in Qatar (Interviews 6, 8, and 26; multiple interviews). Mothers reported that it was not safe or welcoming to present their children in public (Interviews 7, 36, and 37; multiple interviews). In earlier discussions about family life with children with disabilities there was a greater sense of security described at home, although in some cases, family members were not accepting of disability. In the case of community interactions there was a sense of reluctance, of fear, and one of defensiveness, which brought on the instinct of overprotection.

Some mothers reported that their sense of protectiveness was to save their children from the shame they might cause themselves due to their behaviors as in the

cases of Lama and Amera. In the broader context that was protection from a community that was reported to have poor perceptions and understanding of disabilities (Interviews 7, 10, and 37; multiple interviews). Mothers reported that they did not wish to encourage this perception if they were not able to explain their children to others in the community (Interviews 2, 10, and 13; multiple interviews). Mothers were often put in positions within the community to answer for their children's disabilities, a responsibility that they did not ask for, but it came to them and was then their own. It was a blessing to some and a curse to others. It moved some to advocacy, while it made others want to hide.

Daily Life and Participation in Family Activities

Interactions at Home

“If we have guests he will welcome them and tell them, ‘We’ll make you kebabs! Come!’”

*Nuha, mother of Waseem, her adolescent son with Down Syndrome
(Interview 30, card 6)*

Many mothers reported that daily life was filled with opportunities to interact with individuals sharing the same household or nearby households that also housed relatives. Daily life also included interactions with family drivers and maids as well as family members. In terms of social learning at home, there are two main types of interactions: those with siblings and cousins and those with drivers and maids.

Social Learning

In Qatar it was common for children to spend a great deal of time together with cousins as close playmates at a young age. Social learning not only came through school or in the community, but through these interactions in the home. After puberty children

were only allowed to continue to play with cousins of the same gender, but opportunities for interactions and social learning still occurred on a regular (typically weekly) basis.

Buthaina claimed cousins as Budour's primary source of interaction besides siblings. "I get really happy when I see her playing with normal kids" (Interview 7, card 16a). Khadija stated, "She is always with normal children. She plays with her cousins and they are normal" (Interview 1, card 14). Mashaal added, "[Muhannad] learns from them. Many times I used to get worried about him but he is fine with his relatives and they are really kind to him" (Interview 34, card 26). Shahd reported that Sajed learns a lot from his cousins. "They all love him. His family loves him" (Interview 19, card 18). Since they ride bicycles, adolescent-age Shahd is most likely to learn to ride a bike from them (Interview 19, card 18).

Children had opportunities not only for interacting with and learning from cousins without disabilities, but also with cousins with disabilities. Nojood shared how Anisa played with the kids in their big house. It was her grandmother's home where they lived. "It is a place where everyone comes. Then, she has dinner and gets ready to sleep. Sometimes we go out. We have many children in the house with disabilities" (Interview 8, card 15).

"The most important thing is that you don't differentiate between your kids with and without disabilities, keeping in mind the capabilities of each one," (Shaymaa, Interview 9, card 12). Aliya encouraged her other children to interact with their teenage brother, Shoayab:

I like [Shoayab] to play with them to understand them because he only listens to them and he answers them in a very loud voice. He plays with them and he likes to participate. The children ask me why he doesn't talk. I tell them, 'You should talk to him.' He likes to sit in the kitchen to eat and to be with everyone

(Interview 14, card 32).

Mothers perceived these interactions with cousins and siblings as positive contributions to their children's social learning. Buthaina commented that Budour, who had autism, was affected by her siblings because she learned natural responses when she played with them. "I feel that she feels better physically when she plays with her siblings, which is better than being isolated" (Interview 7, card 16). Konouz discovered that Layth would go out to the street to play with his siblings. "The aim of going out and playing is to mix with them, but, he doesn't [mix]" (Interview 27, card 12). Suheir found that Samah's behaviors were better when she was with her brother and sister who were really proud of her (Interview 37, card 29). Samah's brother and sister like to buy her toys and bring them home to her since she does not go out of the house very much (Interview 37, card 44). Ashgan shared that one of her older daughters would come home from work each day. "[Samia] sits with her and when she is on the internet *Al Samia* (the one and only Samia of the household) pesters her. Her sister loves her so much she would die for her" (Interview 5, card 13).

Ibtisam smiled:

Ashwak brings her sister sweets from kindergarten. She refuses to give any to her brothers. She is very kind to Asmaa. When I want to change Asmaa's clothes,

Ashwak will help me to do that—like bringing her clothes and listening to me (Interview 6, card 8).

It was evident that mothers believed the closest relationships that their children with disabilities had were with other people in the immediate home environment, such as with siblings and opposite-sex cousins. The cultural nuance of a closed community may be the reason that most social learning experiences were described to be with cousins or siblings, rather than other children outside of the family, such as those in the neighborhood or friends at school. It might also be that mothers were not aware of the close friendships their children had at school, as children were often taken to school by drivers and maids who worked in the home.

Drivers and Maids

Second to family members, individuals who most frequently assisted and interacted with children with disabilities were the family drivers and maids. Mothers reported that many of the daily tasks with children, such as feeding, bathing and dressing were the responsibility of the maid. To assist mothers with their child with a disability or all of their children in general, maids worked closely with their children. In some interviews it was mentioned that the mother had hired a maid who was only responsible for the child with a disability, as some children had significant support needs due to their physical disabilities. Children also had interactions with family drivers who lived with the family and were responsible for driving women and children from place to place as it was uncommon for women to drive in the Qatari culture.

We have two maids—a guy and a lady. The lady will help [Mubarak] in our home to feed, bathe, and dress him and the guy will help him outside the house. He takes him out and puts him in the car. Sometimes the guy takes him out to Landmark (mall) or he takes him for a walk (Fawzya, Interview 17, card 8).

The interviewer noted emotional distance between the mother and her child because of the severity of Mubarak's disabilities and the assistance of two maids and a driver in the home who interacted with him most often (Field notes, May 24, 2006).

Children may also have increased interactions with drivers if they served as a chaperone for another family member. Shahd shared that her son went with the family to visit friends and households of other family members:

Sometimes he goes with the driver to take his sister to work. It's not proper for her to be alone with the driver, so he will be the *mahram* (familial male chaperone who is an uncle, father, or brother). [Sajed] is treated as a person without a disability (Interview 19, card 14).

Behaviors and the Assistance of Maids

Hired help in the home was a predominant form of assistance, and often including disciplining the children in the family. Amera found that her maid worked better with her child than she did:

[Amal's] father only plays with her. If she is with me she doesn't listen to me. She only listens to the maid because I have spoiled her. When we give her a bath the maid and I should be with her or she will run away (Interview 16, card 12).

“When I bring a maid he tests her. He tries to see if the maid will be firm with him like his mother. If not, he takes advantage of that” said Shaymaa (Interview 9, card 9). Muna explained that due to Nadeem’s aggressive behaviors the nanny, who worked with her other children, did not usually work with him (Interview 29). Nojood commented that she lets her maid work with young Anisa. “My maid helps her, but I have to be there all the time because she hits the maid” (Interview 8, card 13).

I don’t let the maid do anything for him because I get scared. When we go to the Corniche, I take the maid—not to care for Zain Elabedeen, but so the maid can go out and do something different (Fairouz, Interview 11, card 16).

Fairouz implied that her son could be endangered because of lack of patience on the part of her maid (Field notes, May 17, 2006). Omniya said that since Khamees was 16 years old she would not leave him by himself or leave him alone with her maid (Interview 31, card 12).

Suheir went to the length of recording her maid. “When I leave [Samah] with the maid, I turn on a hidden video camera so I can see what the maid is doing with her or if she is treating her well because my daughter doesn’t talk” (Interview 37, card 22).

Ultimately, parents were not completely at ease with giving over the control of their children to their maids, but they stated that they did so due to the convenience of having live-in assistance or due to the imminent challenges of raising children with disabilities.

In summary, daily life and participation in family activities included social learning opportunities at home, not only with siblings, but also with cousins. Besides siblings and cousins, children with disabilities also interacted daily with the drivers and

maids who helped them with their personal care and took them where they needed to go. It was not typical for siblings and cousins to assist children with disabilities with personal care or to take them where they needed to go.

Daily Living Routines

“When she was younger I did all the feeding, bathing and dressing, but it seemed endless. I couldn’t do it all the time. I know she could never be independent.”

*Widad, mother of Wafaa, her adolescent daughter with multiple disabilities
(Interview 4, card 10)*

In this study the inherent importance of describing the home life of children with disabilities is to provide description of how predominant life at home was compared to integration into the community. Community integration was impacted by the level of support children needed in their daily lives. This could be seen by mother’s reports of their daily routines with their children.

Mothers reported daily household routines, which commonly included activities such as waking up, dressing, transportation, food, bathroom, behaving, and bedtime. Mothers reported that their children with disabilities had more problems adjusting to routine change. Mothers also described the physical changes in the household that they made, for example where to place the child’s bed. Mothers described different levels of discipline for their children as they integrated their children into family routines. Some children adapted well into family routines and others disrupted them. Safety precautions were frequently considered by mothers. Routines were not only a part of the daily interactions within the home, but also a part of the family activities.

Routines

A medley of routines was present in homes of interviewees, such as prayers, mealtimes, and visiting others. Some mothers reported that children with disabilities fit easily into their routines. Nafela responded that each afternoon she visited relatives with Ameen. “All of them live in the same area. We are neighbors and our houses are connected by a door” (Interview 33, card 18). Omniya explained that Khamees did not like to have too much activity in the house during their typical afternoon routine. “When we come back, if his sisters are here, and their children make noises he doesn’t like to sit with them” (Interview 31, card 23).

Saiba discussed her adolescent son, Rashoud. “We have changed everything like the way we treat him. He is different because he is mentally disabled, but in regard to the house [routines] we didn’t change anything” (Interview 20, card 9). Five daily prayer times included the child with a disability. “When I pray, she sits beside me. She mimics me. When I say, ‘Oh, God, heal Amal,’ and I put my hands together to pray, she does it, too” (Amera, Interview 16, card 6). Maryam explained that her son, Ghazi, received special treatment at home, but the routines did not change. “We didn’t do anything special for him. We love him and we are kind to him. Everyone in the house treats him differently.” Each person did special things to show Ghazi that he was cared for by his family (Interview 23, card 15).

Mothers most commonly reported changes to the household routine that were linked to visits with relatives, who typically lived in homes that were grouped together.

Mothers of children with autism reported the strictest adherence to routines throughout the interviews.

Othman is like a normal kid. Prays. Goes to school. Comes back. Takes off his clothes. Washes himself. Eats. Sleeps. Wakes up. Does his homework. Sits with his siblings and his father and he sits with all of us and then sleeps.

On the weekends he goes out with his brothers to City Center (mall), to the beach or to the sea, his grandfather's house and our relatives. He is like a normal human being and he is normal (Ashgan, Interview 5, card 11).

Sajed typically woke up at 6:00 in the morning. He went to the toilet and brushed his teeth independently. If he wanted to take a bath his mother had to help him. It was important to him to wear cologne and to dress up. He put his socks and shoes on independently. The thing he loved the most was *leban* (a yogurt drink) for breakfast and he liked salad for lunch (Shahd, Interview 19, card 11). His level of independence as described by his mother was at a high level that most children of interviewees did not attempt.

At the other end of the support spectrum were children like Fajer. Makboula said, "We have to do everything for [Fajer] in life. We dress her, feed her, comb her hair, and wax her body. She's not so difficult, but I want her to do everything by herself" (Interview 18, card 5). The level of support needed by children in daily routines varied from minimal support to total support.

Waking Up

Mothers' interactions with children with disabilities began as the children woke up and needed care and assistance in getting ready for the day. When Buthaina was available she helped Budour wake up in the morning, bathe, and have breakfast. If Buthaina was not there the maid helped her with these things (Interview 7, card 7). Manar described Majed's sleep as being very broken. "He wakes up early in the morning, even if he goes to bed late" (Interview 40, card 18). Muhannad woke up at 5:00 a.m. and had something to eat so he could stabilize his blood sugar, due to diabetes (Interview 34, card 16). "We sleep in one bed. I ask him to wake up and he goes out of the room and watches TV. He puts it on a Koran Channel. Then, I wake up and help him to wash up," declared Omniya, mother of adolescent-age Khamees (Interview 31, card 20).

Nabeela stated that Naseem went to look for her each morning after he woke up. His routine was to have breakfast and then to sit in front of the air conditioning before he left for school. "He puts his back up against it and sleeps for some time" (Interview 28, card 17). Manal added that Marzouk rode his bike before he went to school. "We like him to come to the center in good spirits, so we give him a bath and make sure he's full" (Interview 22, card 21). Since Nawal was just starting at Shafallah the week her mom was interviewed her mom told that she usually slept until noon. "She doesn't wake up early because she doesn't go to school or kindergarten. She is almost seven years old" (Interview 39, card 8).

Dressing

Dressing also required considerable effort on the part of the mothers. Few mothers mentioned allowing their children to choose their own clothes. However, Manal suggested that it was best for children to make choices, including what they wore. “When Marzouk needs clothes we let him choose what clothes he likes” (Interview 22, card 14a). Aliya said that adolescent-age Shoayab’s favorite clothes consist of a white *fanella* and *sewal* (typical Arabic house attire). It was important to these mothers that their children were dressed in socially acceptable ways when going out in the community.

Transport

Much like the ability to communicate, being able to traverse was also a factor that had the potential to help or hinder community integration. Several parents commented on difficulties in transporting their children. When Salah was younger he had a stroller that his mother would push him around in due to his physical disabilities, but when he got bigger she got him a grocery cart in which she would push him, but he came to not like the cart. (Interview 2, card 9b). Omniya recounted how Khamees was late walking. He walked when he was seven years old (Interview 31, card 10a). At eight years old, Samah’s father helped her mother by carrying Samah because she was getting heavier (Interview 37, card 20). Omniya explained about Khamees, “We are having more difficulties as he grows older. I thought he would never walk, but he did. He cannot walk straight. He has an awkward gait and wobbles when he walks. I want someone to work with him” (Interview 31, card 16). In Qatar, where accessibility is

often problematic, the ability to transport their children made going into the community more complicated.

Food

Specific issues related to eating, feeding, and preferences also impact the level of community integration in terms of needing to eat on a certain schedule, needing assistance, and behaviors while feeding.

Ziyad could not eat bread by himself, so his mother gave it to him. He also could not hold a spoon (Interview 9, card 15). Sohaila informed, “[Shawghy] can eat sandwiches and fruits by himself, but he cannot eat rice with a spoon because his hand shakes a lot” (Interview 38, card 16). “If he refuses to eat, he will not change his mind no matter what you do. He is very demanding” (Interview 38, card 7). When Amal returned from Shafallah in the mornings she ate from a bottle. Amera insisted:

She can't eat food that is thick. In my home I only have one maid and she can't do everything, so it is difficult for me to feed [Amal]. So, I give her the bottle because it takes her too long to eat with the spoon (Interview 16, card 9).

“I usually give him natural things, but not sweets, to not make him too full for lunch,” declared Manal about Marzouk's return from school daily (Interview 22, card 23).

Eating habits sometimes impacted those of other family members, as well. Hind indicated that she felt other family members had to sacrifice during meal time because of Nawal, “We deprived ourselves from eating fruit and drinking juice because when her sister comes back from work, [Nawal] eats with her. Also, when her brother comes back from school, [Nawal] eats again. And, again when her father comes from work”

(Interview 39, card 11). Hind was concerned about Nawal's weight from overeating. Buthaina planned for Budour. "I had a diet that I did with Budour where she doesn't eat sweets or sugar, so I did the same with the other kids. But, sometimes I send my kids to the grocery store to get sweets for themselves, eat it there, and come back home" (Interview 7, card 15).

Mufliha disclosed "[Nosym] doesn't like to eat from anyone else. If his father offers him food from his plate he will not eat it" (Interview 35, card 3). Manal reported, "[Marzouk] has to watch TV while eating" (Interview 22, card 24). Ghazi eats his lunch at 2:30. "He eats snacks or sandwiches or French fries by himself, but he cannot eat *machbous* (a rice and lamb dish typically eaten with the hands, customary of the Bedouin lifestyle), so I feed him" (Interview 23, card 10). Aliya commented, "[Shoayab] eats with a spoon, not with his hands. He likes yogurt and juice" (Interview 14, card 9). Aliya then added, "We used to eat on the floor, but now we've got a table" (Interview 14, card 30). This practice was common in a *majless* (low seat, floor-level sitting room, customary of the Bedouin lifestyle).

Families ate together, but in mixed male and female company men were in one section of the house and women were stationed in another. Maids were responsible for much of the meal preparation and serving of the food. Except for Thursday or Friday evenings that commonly included extended family, mealtimes were primarily only with immediate family. Mealtimes provided the opportunity for social interactions between family members, and the time was often impacted by including the child with disabilities.

The Bathroom

“I want him to take care of himself—go to the toilet by himself and do normal things that any child can do.”

*Wodouh, mother of Masood, her school-age son with autism
(Interview 32, card 6)*

Bathroom assistance was commonly given by family members or maids and was a great concern of mothers relative to community integration given the difficulty of toileting their children when in public. Nabeela listed bathroom time as one of the biggest challenges during her day with school-age Naseem. “He doesn’t go to the bathroom by himself and it’s getting more difficult as he grows older. He doesn’t understand very well and it’s difficult to deal with him” (Interview 28, card 11).

Gaydaa, indicated that diapering adolescent-age Khalid was a concern, especially for community outings. “He can control going to the bathroom for some time and then he can’t hold it any more” (Interview 12, card 7). Gaydaa hoped Khalid would gain more control in this area. “He used a diaper for some time, but he’s not using it now. For the long trips he has to wear it” (Interview 12, card 9). Aliya struggled with adolescent-age Shoayab. “I have difficulties changing him because he moves a lot. When the car (and driver) comes he wants his father to take him to the car” (Interview 14, card 13). For children to be immersed in the community the ability to independently go to the bathroom, or to do so with little assistance, was essential in a culture with strict boundaries between males and females. At times the only direct care-giver for a male child was a female maid who, depending upon his age, could not assist him in the bathroom while out in the community.

Bathing and bodily cleanliness were other issues that families had to address in order for community integration. “[Nadeem] wakes up, takes a shower, takes his medicine. He can take a bath by himself, but he does need a little supervision because if I leave him by himself he will use an entire shampoo bottle at once” (Interview 29, card 19). Hind said that Nawal’s sister helped her to bathe. “She doesn’t like maids” (Interview 39, card 7). Nabeela painted the picture of school-age Naseem’s bathroom activities. “He cannot put his clothes on by himself and he cannot take them off by himself. I want him to depend on himself and brush his teeth by himself and take a bath by himself!” (Interview 28, card 15).

Mashaal recounted her experiences training adolescent-age, Muhannad, for things he needed to take care of when he was in the bathroom:

I taught him since he was 12 to shave his face and his underarms and how to use deodorant. He takes care of himself and his clean linens more than his siblings do. Like, if his clothes get dirty he has to change them and I have to keep telling my other children that they need to shave, but they don’t listen to me like he does (Interview 34, card 22).

Nuha relayed that adolescent-age Waseem does everything in the bathroom, but “His father shaves for him” (Interview 30, card 5). Mother’s believed that bodily cleanliness was an important factor to community integration, especially in order to be clean before the five daily prayers.

Behaviors and Discipline

“Usually, she gets up in a great mood when it is in her time. When I get her up she gets up in a bad mood.”

Sameera, mother of Noora, her school-age daughter with Moderate Disabilities

Perhaps one of the biggest hindrances to community integration seemed to be behavioral problems. Mothers faced many behavioral challenges at home with their children with disabilities. “When [Noora] doesn’t get what she wants for breakfast, she cries and throws herself on the floor” (Sameera, Interview 4, card 10). Sameera explained:

She can’t be put in a certain category. She can’t think well; she’s not in our world. You talk to her, but she keeps singing songs. But, there are certain things she likes exactly. For example, her prayer rug cannot have any wrinkle. She comes and prays with me, but sometimes she wants to trade prayer rugs. She is very particular (Interview 4, card 15).

“I want [Shawghy] to know the difference between right and wrong and do it” (Sohaila, Interview 38, card 14). Nabeela, while describing that Naseem did not eat well and that he threw food on the floor, mentioned, “He really improved in his ability to eat. He used to steal food without my permission. He used to go and take food from the kitchen when he saw me leaving” (Interview 28, card 12). Sameera called her daughter, Noora, stubborn. “Noora is used to being fed, but I put her in a situation where she must feed herself” (Interview 4, card 8).

Nabeela discovered that Naseem was motivated by any trips out of the house. “He doesn’t like to sit at home. He doesn’t fear me, but he does fear his father. He sits

when his father asks him to do that—very quietly” (Interview 28, card 20). Manal said that before she was scared about letting Marzouk touch anything in the kitchen:

And sometimes he used to throw things and I used to get upset with him and tell him that. He knew he did something wrong. I don't like to hit him because that will make him angry. The biggest punishment for him is if he makes me upset (Interview 22, card 36). Sometimes he cries and doesn't accept anything, but when he goes out his mood gets better (Interview 22, card 45).

Muna shared that she could not take her adolescent son, Nadeem to buy clothes. “He will scream. His brother, Islam, took him with him once to try on some clothes and he was quiet” (Interview 29, card 33). Samah stopped taking Salah out as much because he would throw himself on the floor in public places (Interview 2, card 9a).

Muna conveyed that she feared to let Nadeem go places by himself in public, including to the bathroom, although his brother kept watch:

He knows that the key is to know another's weakness. For example, he knows that if he screams I will be ashamed. He has gotten used to me when I took him to his sessions [at Shafallah Center]. If I say anything I can't control him. He's used to me (Interview 29, card 34).

Andalieb realized that she had to lock the bathroom doors. “[Bader] goes in and plays with water and soap. If we are all busy and he wants to take a bath, then he goes inside the bathroom” (Interview 3, card 9). Aliya confirmed that Shoayab makes a mess in the bathroom. “He wets himself with water. He likes to play” (Interview 8, card 14).

One concern for mothers was that their children might hurt someone or damage things on outings. Makboula described Fajer as “a bit aggressive with other children”. Fajer became jealous if Makboula held any other children and Fajer hit them (Interview 18, card 5a). Nabeela noted that when Naseem became angry he would not speak in words, but, “He hits the wall and the cupboards. He doesn’t sit. He throws everything” (Interview 28, card 17a). Wodouh witnessed, “Sometimes he plays the entire day and other days he breaks and damages everything!” (Interview 32, card 9).

Many behavior problems were common and not always met with firm boundaries. While some mothers took children out to avoid behavior problems at home, many limited outings because of concerns about inappropriate behaviors in public places.

Different children lived under different expectations and levels of discipline in their homes. “I don’t consider [Ziyad] disabled. He is like his siblings. I punish him if he makes mistakes. I praise him when he does well” (Shaymaa, Interview 9, card 23). “[Waseem’s] situation is good so—and we don’t refuse anything that he asks to get. I got him a TV so he doesn’t act naughty and he listens to the Koran on tape” (Nuha, Interview 30, card 19).

“[Shawghy] likes musical toys” (Interview 38, card 11). Sohaila remarked, “He is very persistent with me. He asks and I have to do it for him. Sometimes I don’t. He asks for toys, but when I get them for him he breaks them” (Interview 38, card 9). “He wants everything. *Mashallah* (What God wants). He wants cars, bicycles, and today he told me, ‘Mom, take me in the new car to the play center’” (Interview 38, card 4).

Manal imparted her discipline method is dependent on Marzouk's day at school: He rides the bus and he's happy. He accepts that with high spirits. And, when he comes back I make lunch for him. If he was a good child that day, I give him juice and French fries. I wait for him and when he comes I give him the juice and French fries. If [he hasn't been good], I will not give him these.

Samah explained some of the strategies she had used in the past month to counter some of the negative behaviors of her son, Salah. Working to solve his problems helped him to get more sleep and to lessen his crying.

I need to take him for a ride in the car until he stops crying and he is quiet. It's better now and we don't know what he wants when he cries. He hits the floor. As we talked to the doctors and made arrangements, I learned to start ignoring [Salah]. By ignoring him he got better. The doctor made a plan for me to ignore him when he cries or touches the floor. With the passing of time I understood [Salah's] problem. I know his behavior (Interview 2, card 6).

Mothers reported differences in their levels of consistency that they provided for their children. Some mothers reported more behaviors because their children did not experience consistent follow-through on the boundaries set before them.

Bedtime and Sleep

Mothers mentioned different sleep patterns for their children. These patterns impacted family life and community integration opportunities in different ways for different families. Some children were more disciplined in their routines than others. It was evident that some families had routines while others did not. For example, some

children stayed up very late on school nights. “At nighttime he waits for them. If they sleep, he will sleep.” Nabeela referred to Naseem’s siblings (Interview 28, card 26). Maryam reported that Ghazi does not go to bed until all of his siblings have done so, also (Interview 23, card 12). Ziyad’s mother described the nightly ritual. “You have to sing a song for him before going to bed. He sleeps with the sound of music” (Interview 9, card 17).

Aliya described:

[Shoayab] sleeps very late. He sleeps in our room. He gets tired because sometimes he doesn’t sleep until 3:00 or 4:00 a.m. I take him to his bed and I close his eyes for him to show him it’s time to sleep” (Interview 14, card 31).

Manal reported a different schedule for Marzouk:

After dinner he has to sleep. This is his journey at the end of the day and he has to sleep on time. He wakes up between 4:30 and 5:00 a.m. His sleeping is scheduled. We train him on discipline and it works with him (Interview 22, card 27).

It is important to note that dinner was usually later in the evening, around 9:00 p.m. Bed times in Qatar were usually later for many children as dinner was served so late in the evening, but a several hour nap time in the afternoon also was observed by many families. If children went to bed early there was less opportunity in the evening to go out into the community. If children stayed up late and had difficulty getting ready to go to school, it lessened the opportunity for their primary interactions in the community.

Safety Precautions

Safety considerations, both around the home and in social interactions with others, were a concern to mothers and also impacted socialization and integration. Nabeela feared for the safety of Naseem in her household, so her family made changes to accommodate him:

He destroys everything! We took all the dangerous stuff out of the house. The TV is high so he cannot get to it. He has broken many televisions. He likes to hit them, but he can't reach them now. We took all the glass and tables out of the house—so we don't lose him! When he sees himself in the mirror he hits it. Once in my room he was looking at himself, he hit the mirror, and it fell back on him, but nothing happened to him. I took everything [out of his reach], even the sharp knives. Even the toothpicks because he thinks they are sweet and edible (Interview 28, card 16 and 24).

Another mother, Aliya, similarly modified her family environment, “We furnished the house in a way that suits him. We took all the sharp stuff and decorations out. The doors are always locked with a big lock because he always goes out of the house.” Sameera also remarked how much work it was to safety-proof her home for Noora:

We had to make sure that furniture was safe so she wouldn't get hurt. She would go on, over, under anything. She would get under a table and flip it or on top of something and go out the window or up on something to reach things she shouldn't have. So many safety precautions! She is unaware of things that may

harm her. Really, I mean she can get up on the TV table and fall, so we have to take care of these things (Interview 4, card 14).

As for changes in the routine, Konouz answered, “We changed some stuff at home. We changed the doors so he could not open them very fast. We lock all of the doors so he doesn’t go out” (Interview 27, card 16). She described, “His room is empty. It’s only the bed and the cupboard. There isn’t any glass in his room” (Interview 27, card 20).

Konouz informed, “The windows are covered in lattice work so no one can come in and he can’t go out” (Interview 27, card 19).

Sohaila indicated that she had trained her son about dangerous things so that he would not hurt himself at home:

He doesn’t play with dangerous things. We buy him toys, and school has helped him a lot. He knows that a knife is dangerous and electricity, too. If he sees matches he knows that they are dangerous. He has learned a lot (Interview 38, card 28).

Saiba imparted, “We don’t let him go to the mosque, but sometimes he goes because it is near to our house. There is a street in between the mosque and our house and I don’t like him to cross it!” (Interview 20, card 8). Lama revealed fear for the safety of Fares and Fadi. “Our house here is a villa, but our house in Beirut is on the 10th floor. I get scared” (Interview 36, card 22).

The challenges of keeping children with disabilities safe from harm were many. The fact the challenge of providing a safe environment existed in a community with limited supervised opportunities suitable for children with disabilities, further lessened

community integration and the understanding of disability. With so few children with disabilities being seen in public, community fears made children with disabilities less safe. For example, a stranger might be less likely to help a lost child with a disability unable to communicate well or a child having a seizure might not be assisted immediately. Overall, safety issues thus caused parents to be more reluctant to take their children out into the community.

In summary, daily living routines were very diverse in the homes of the mothers who were interviewed. They shared their stories of providing their children not only the basics of life, such as food, clothing, and shelter, but also the discipline their children would need to be accepted into the community. Mothers shared methods they used to train their children not to steal food, tantrum, or to treat others with respect. Some mothers reported that handling their children's behaviors was one of their greatest challenges. Safety concerns were a predominant factor throughout the research and impacted the potential for community integration.

As several mothers discussed daily living routines, they reported recognition that choice and independence were valuable options to give to their children; however, it was considerably rarer to hear mothers speak about choice and independence in a culture where disability was reported to be looked upon with pity. Aliya and Manal were two mothers who reported that they allowed their children to select their own clothes. These were the only two mothers who reported this out of 40. Food was a big incentive for children during daily living routines. However, it was not common for mothers to describe food incentives and choice linked to community integration activities.

Samah described how as part of the daily living routine she followed through on the intervention that had been discussed with her doctor. She ignored her son Salah when he had a tantrum. It was interesting to note this mother's story because of the way disability tended to be viewed as worthy of pity. Samah learned to react to her child's behavior by ignoring him when his behavior was not socially acceptable. It seemed that this technique of discipline was counterintuitive to Samah in a society where those with disabilities were reported to be viewed as outsiders. Within the community there was pity, but the community, including some mothers of children with disabilities, leaned toward a preference for exclusion rather than community integration during daily routines.

Working with the Child at Home

“To educate myself again about disabled children. To find books and resources that will help me to deal with Noora. That was the first challenge.”

Sameera, mother of Noora, her school-age daughter with moderate disabilities

Helping with Skills

One of the ways mothers sought to involve their children in family life was to work with them in the home. Specific goals included improving schoolwork, either by helping children themselves or by hiring a tutor, and involving their children in household chores. The intent of the assistance was so that children would be more successful at school and in the community. Nafela, regarding her adolescent son with mental retardation, stated “My goal is to teach him how to read and write” (Interview 33, card 13). Mothers were often the first instructors of their children with disabilities. “I taught [Muhannad] writing and math. He has autism. He knows all the numbers, to more

than 100. He memorized all of the alphabet and he knows it better than his siblings. He doesn't forget what you teach him" (Masha'el, Interview 34, card 6). "I want [Rashoud] to be able to write everything and to at least be able to read the Koran" (Saiba, Interview 20, card 4). Masha'el tried to get Muhannad into the training program for children with disabilities at Rumeila Hospital, but ended up teaching him herself. "I worked with him a lot at home when I didn't get him into the hospital" (Interview 34, card 7).

Although Muna claimed that she treated Nadeem just as if he did not have a disability, she modified to suit his level. "If a normal child needs to change something by practicing five times, my son needs to do it 100 times. I feel sorry for him, but that was my way to raise him up" (Interview 29, card 16).

Nojood's mother's early teaching involved physiotherapy. "I took her papers with diagrams of exercises and I did physiotherapy with her at home." Nojood reported that Anisa "is walking like normal kids do" (Interview 8, card 2a). Suheir's teaching involved adding her own interventions for Samah. "While she was on the waiting list for Shafallah Center I worked with her in the house a lot" (Interview 37, card 1).

On the other hand, some mothers found they could not help their children learn at home. "When [Noora] knows something or learns something that I want to measure—numbers, shapes, so on—she won't tell me, but when she wants to tell me she will." Sameera found that Noora's teachers had certain goals and objectives, but sometimes Noora will not show them what she knows (Interview 4, card 7). Fairouz articulated her dream, "I want [Zain Elabedeem] to learn how to read and write. He doesn't listen to me, but he does what the teacher asks him. If I give him homework he doesn't do it"

(Interview 11, card 5). Aliya remarked, “If I give him a paper to color he doesn’t do it. I bought him building blocks, but he doesn’t play with them. He does many things in Shafallah, but he doesn’t at home” (Interview 14, card 14).

Several mothers reported that they attempted to practice academic goals at home to compensate for the services that their children did not receive from local hospitals or because they could not receive full services at the Shafallah Center. However, in some cases mothers found that they were not able to provide services that were as effective as the Shafallah Center. One option for some families was to hire tutors to help their children with skills they were learning.

Hired Educational Assistance

“We engage her with her trainer three times a week. That is her time so we don’t do anything with the other kids.”

*Buthaina, mother of Budour, her school-age daughter with autism
(Interview 7, card 14)*

Some mothers sought in-home assistance from hired tutors to improve the academic skills of their children. Buthaina explained that Budour had attended the Qatar Center for Speech and Hearing, until she started a program for Budour at home (Interview 7, card 18). The teacher came to work with Buthaina for an hour at the house. “After that we sit together with her siblings, get ready for dinner, and sleep. If the teacher doesn’t come we take [Buthaina] to the swimming pool or to the play areas” (Interview 7, card 9). Buthaina’s family faithfully reserved time for her. Manar, another mother, mentioned she brought a trainer in for two hours per week for Majed (Interview 40, card 7). The only thing young Majed did outside of school was to work with his teacher, who had a special education degree, at the house. Nafela was a teacher herself,

but she reported she did not have the energy to work with Ameen. “I got a special teacher for him and she used to come two to three times each week because he couldn’t go to a normal school” (Interview 33, card 7). Following that Nafela added, “I took him to two special teachers and I paid for the expenses” (Interview 33, card 9a).

Amera recounted the progress she saw when a teacher came to her house. “I got a teacher to come to my home to work with [Amal]. She helped her to use the toilet. [Amal] got used to it, but she didn’t do it when the teacher left.” Mashael answered regarding the biggest change in her family’s routine, “Teaching. The teacher that I got for him taught him everything. I taught him all the phone numbers” (Interview 34, card 23).

Mothers recognized the need for focused and intensive training for their children and either provided it themselves or hired someone else to do it in many cases. Intensive training beyond the school day allowed for more opportunities to build skills so that children could more easily be integrated into the community.

Independence with School Work

“I hope that he improves. I hope that his skills develop.”

*Fairouz, mother of Zain Elabedeen, her adolescent son with Down Syndrome
(Interview 11, card 7a)*

Some children were self-starters who enjoyed working independently on academic skills at home, and their mothers simply encouraged them without providing direct support. “She likes to play, to draw, to write anything for herself, and she always tells me, ‘Mom, ask me to go and study.’ I usually tell the others, ‘Go and study,’ so she wants me to say the same to her,” Khadija shared about Nijma (Interview 1, card 6). She

added, “She brings out her papers and starts writing. At this age she sees her brothers and sisters go to school so she wants to go, too” (Interview 1, card 10). Konouz observed Layth in his after school routine. “He takes a pencil and notebook and writes his numbers” (Interview 27, card 10).

Mothers reflected on the self-starting capabilities of their children at home and the interest mothers had in assisting their children. There was a desire within mothers to educate their children with disabilities, but it was not necessarily a desire that included fully releasing their children to the public education system where their children’s treatment would be left to the hands of others. Mothers revealed that they had a mixed sense of protection, a hint of fear, and a desire for more than what was offered by the system.

Chores

Academic work was not all that was required of students from the Shafallah Center once they went home. A few mothers expected children to assist with chores. “I clean the table and I ask [Ziyad] to help me. When he does, I ask him to do it stronger and encourage him” (Shaymaa, Interview 9, card 21). Shahd maintained that Sajed was very clean. “He takes all of his things and puts them back. He cleans up the house and he helps everybody” (Interview 19, card 13). She shared that he also helps his older brothers. “For example, if they need the phone and it is upstairs, he will go and get it for them” (Interview 19, card 15). Muhannad helps to fold the clothes that belong to his brothers and sisters. “He knows what belongs to each one. They love him a lot. This is

his third year at Shafallah” (Mashaël, Interview 34, card 8). Mashaël implied that Muhannad learned how to fold clothes at Shafallah.

One mother, Manal, suggested allotting responsibilities:

I think he does many activities. He plays football, rides his bike—I let him take the trash out. I feel that he needs responsibilities and he gets really happy when you give him some. You shouldn’t give him activities only in playing, but he has to help with housework” (Interview 22, card 19).

Although noticeable in a few interviews, there was not a strong expectation for children with disabilities to participate in work within the home. This was also true of children in the general population. It was probable that this was due to mothers’ reports of the employment of maids to carry out most household tasks.

In summary, whether as early teachers, hiring tutors, or helping with chores, mothers described their eagerness to provide added supports for their children at home. Nafela, who was a teacher herself, hired a teacher to work with Ameen at home. The mothers who were most likely to hire teachers for their children were also the mothers who were not currently able to receive full services from the Shafallah Center. This coincided with the fact that the most serious issue facing the center and impacting families in the community was due to the lack of trained special educators who could also speak Arabic. Mothers shared stories of their children coming home to work on their homework like their siblings once they had experienced the school environment at the Shafallah Center.

Leisure at Home

“We try to keep everything quiet. He doesn’t like anyone to disturb him.”

*Omniya, mother of Khamees, her adolescent son with Down Syndrome
(Interview 31, card 27)*

Mothers reported leisure activities that focused on TVs and computers, toys, and in several cases gardening activities, besides daydreaming and tea drinking. The options for leisure activities were not very broad, but usually centered around playing with siblings. These recreation and leisure opportunities did not include many opportunities for community integration. “He sits alone at home. He sits and thinks as if he’s in another world. He daydreams. And, sometimes he listens to me if I ask him to bring something for me,” reported Aliya, mother of Shoayab (Interview 14, card 15).

Television was the prime choice for in-home leisure. Khadija commented that Nijma actually does not watch a lot of TV, but Khadija would like her to do so more for her leisure time. “I want her to busy herself with something else. I want her to focus more on TV” (Interview 1, card 5). Gaydaa noticed that in the summer Khalid responded like his siblings when he was around them a lot. “When [Khalid] watches a video and it turns off he knows how to start it again. He knows there is something he must turn on again” (Interview 12, card 17). “I wish [Bader] could understand things on TV and how to use the TV because right now he doesn’t know how to use the TV, so he damaged the old one that we had” (Andalieb, Interview 3, card 5).

Lama mentioned a special TV room for her children with disabilities, Fares and Fadi, in her home. “I made a special living room for them here with a special TV for them to watch the Cartoon Network. So, we have two TVs at home” (Interview 36, card

23). Lama added that she and her husband want their sons to have choice in their TV viewing. “Maybe it is wrong, but I don’t want them to watch a program with us that they don’t like. I want them to be comfortable” (Interview 36, card 25).

Playing with siblings and playing with toys were other favorite pastimes. Sameera imparted playing together was most important to her for each of her sons and daughters. “When I teach them I like to challenge them. So, for Noora, when she sees what real play is she can learn it like other children. It is very good to do these things for a child” (Interview 4, card 17).

Thikra determined, “[Raja] likes small cards with pictures and she plays with those for hours and sometimes she plays with her two younger sisters” (Interview 21, card 7). Buthaina observed that Budour played games with which she was familiar. “She is getting used to playing with girls’ toys like dolls. I want her to be active, to use her energy and to pass the time and have fun” (Interview 7, card 5). Maryam told about Ghazi’s simple favorites. “He plays with his bike and a ball. Even at lunch—he doesn’t come to eat quickly because he wants to play” (Interview 23, card 9a).

Interacting with others was an important component of leisure activities. Manal said she felt “that if [Marzouk] plays by himself he doesn’t benefit in any way, especially when it comes to talking” (Interview 22, card 38). “His father plays with him for hours” (Interview 22, card 37). Manal described some of Marzouk’s favorite pastimes:

He does all the activities now like a normal child does. He listens to Islamic songs and he plays on the computer. We like to have many activities for him. His father taught him how to turn the car on.

Four mothers specifically mentioned that their children enjoy working on the family computer as a leisure activity. Jameel's family made him a special room. "It has a computer and a PlayStation and other games that he likes" (Interview 26, card 32). Manal said, "In the afternoon we let [Marzouk] play with computer games so he doesn't disturb his siblings who study. When they finish studying they will watch TV together" (Interview 22, card 25). Besides cartoons, Lama remarked, "Fares likes to play with computers and there is this game that he has that gives him tests" (Interview 36, card 29). Mashael expressed her disbelief. "He loves computers. I get surprised because he does everything" (Interview 34, card 14).

Several children enjoyed being in the yard and assisting with gardening. Dana told, "We made a special garden for [Jameel] in the house" (Interview 26, card 30). She added, "In the garden we have sand because he likes to play with it" (Interview 26, card 32). Nabeela encouraged play in the garden from an early age. "I took him to the garden to play, but he would go into the street. He was one-year-old" (Interview 28, card 2). Now school-age Naseem enjoys the garden. "He swings in the garden. He feels really good when he's outside. We live in a flat and he doesn't feel comfortable there" (Interview 28, card 19). Zain Elabedeen simply enjoyed watching the gardener as he worked in the yard. Zain Elabedeen sat with him while he was working and watched him intently (Interview 11, card 10).

For some children, leisure activities were very limited. Asmaa had a degenerative disease, so her mother revealed how things have changed as her skills have decreased over time. “She doesn’t do anything. When she was younger she would play all the games, like shape games, but now she cannot do anything” (Interview 6, card 16, Field notes, May 3, 2006). For some, the ability to play with toys was fleeting; while for others, it created sensory overload. “[Amal] doesn’t like toys. If you give her toys she will not play with them. When I take her to play areas she doesn’t like to play and she covers her ears. She sucks on the toys” (Amera, Interview 16, card 7). Suheir acknowledged that it was difficult to find activities Samah enjoyed. “Her siblings bring her toys and make sure that they don’t disturb her” (Interview 37, card 21).

Summary

Besides playing with siblings and cousins, children with disabilities were content to just relax at home for their leisure time, especially if there was a TV nearby them. The primary leisure activity that mothers noted was watching TV. Mothers’ explanations of family participation in the community revealed a bit more about the lack of or access to community integration opportunities. When mothers were asked about activities that families participated in together, including their children with disabilities, the activities were mostly mundane activities within the home, as opposed to activities out in the community.

Interestingly, mothers desired for their children to watch more TV in the case of Khadija, Lama, and Andalieb. Perhaps mothers believed this leisure activity would serve to occupy their children and educate them. The leisure activities that were mentioned

tended to be solitary activities, except for playing with siblings. It was also interesting that a few mothers reported that their children enjoyed gardening in a culture where that was typically left to a gardener. However, it was an opportunity for interaction with another person who could watch the child. Beyond activities that children participated in at home, the bigger question was what they participated in within the community.

Community Activities

Recreation and Leisure with Family

“Our outings are less and when he says he doesn’t want to go out we stay with him in the house.”

*Haiba, mother of Muftah, her school-age son with Down Syndrome
(Interview 13, card 12)*

Mothers expressed a sense of being bound to their own homes because of the rarity of going out in public due to their children’s needs. Dependence on assistance provided by drivers and maids was essential. Mothers reported visiting extended family, the desert, other countries, and an array of popular places in the community, such as play centers, supermarkets, the Corniche, or the zoo.

Going Out in Public

Outings in the community were limited in variety and frequency for many of the families whose children attended the Shafallah Center. Muna relayed that the primary activity for her son, Nadeem, was to go to the supermarket. “Usually in the afternoons we don’t have any special activities because of the situation here. There are not a lot of places to go and there is no variety of activities” (Interview 29, card 22). Suheir reflected, “Before having her we used to decide to go out in a minute, but now we have to see about [Samah’s] situation. We have reduced our social visits” (Interview 37, card

27). “The normal kids and the one with disabilities—none of us go out much,” remarked Sohaila (Interview 38, card 26). Konouz concurred, “Our outings are not much. Sometimes we go to the beach or visit relatives, but we don’t have many activities because we live in a village (outside of Doha)” (Interview 27, card 15).

Nabeela said that her school-age son does not usually participate with the family when they go out. “We don’t let him participate in our activities because he gets tired very fast. He just does everything for five minutes and then he likes to come back and sit” (Interview 28, card 21). Wodouh mentioned, “We don’t have any activities outside of the house, but we take him for a ride in the car” (Interview 32, card 10). Aliya exclaimed, “We cannot take him on normal outings. In the supermarket, for example, he will take [a] cart and he runs with it and puts one copy of everything that we get in his own cart!” (Interview 14, card 29). Wodouh expressed her frustration. “We have to do something about these things. It’s difficult to take him out and that’s why he cannot participate in anything!” (Interview 32, card 7).

Family outings were often dictated by the behaviors and wishes of the children with disabilities. “[Khamees] doesn’t like shopping centers. He chooses the place to go” (Interview 31, card 26). “He doesn’t like screaming and noises” (Omniya, Interview 31, card 14). Thikra complained, “Even when I take [Raja] to the *souq* (typical market) or a small shop she doesn’t like to walk, so she keeps asking to go home” (Interview 21, card 10). “Her problem is that she’s stubborn and it’s difficult to change her mind” (Interview 21, card 4). Haiba was proud to say she took her son along. “I take [Muftah] out if we go

to the supermarket or City Center or a relative's house. Our 'going out' is rare, but we travel with him" (Interview 13, card 11).

The most common activities within the community were for mothers to take their children to the homes of relatives or grocery shopping. The relatively mundane local establishments were the places mothers most frequently took their children in the community. The lack of acceptance of children with disabilities in the community, as well as few options and behavior of children limited activities substantially.

Going to public places was not a simple task, but required time to prepare; preparation was made more important since there was a lack of acceptance for individuals with disabilities in public places. Several mothers noted the preparations that took place so that their children could make a public appearance. "One of [Muftah's] sisters helps him get dressed so that he looks nice if we go out in the evening. It's not to make him feel better. It's to show the people that he's tidy and can look nice" (Haiba, Interview 13, card 8). On Thursdays [Ziyad] knows that we have to go out and he grabs his clothes to show that he wants to be changed to go out. He knows" (Shaymaa, Interview 9, card 18). "We go to [Muhannad's] grandfather's house and he goes with his father to get food. He has to be well-dressed when he goes out" (Mashaal, Interview 34, card 19). These mothers took responsibility to help their children to make a good impression on the community. A few mothers expressed this was of special importance since the community lacked a spirit of acceptance for those with disabilities.

It was common to hear that taking children with disabilities out into the community was difficult and required added supervision and assistance. Lama referred

to the difficulties of traveling with both Fares and Fadi on outings. “If we want to travel, someone has to be with me to help me with these two children!” (Interview 36, card 21).

Suheir described:

Every weekend we go to the sports center and Samah is there before everyone.

We go to a club every week and they didn’t allow me to take my maid, so I got an exception to take her with me to keep her eye on my daughter. And I even asked them to make special parking for disabled people (Interview 37, card 24).

We go to restaurants twice a week and we take the nanny (maid) with us (Interview 37, card 25).

Ashgan expressed the strict household rules that she and her husband had for both of their children with disabilities about going out into the community:

We don’t let [Samia] go out, even with the maids. We don’t count on them. We have lots of servants in our house. We have four. Samia doesn’t go out unless we give her permission. We also go with her. She doesn’t go with a maid alone. But, [Othman] is okay” (Interview 5, card 18).

Ashgan meant it was okay if her son went outside to play by himself. Her daughter could not go outside of the house to play without an attendant. Ashgan’s maids were not allowed to go out into the community with Samia alone, but could go with the family; therefore, Samia’s opportunities to go out in the community were lessened.

Public outings were often limited due to children being present. Adolescent-age Zain Elabedeen does not go to the homes of relatives. “When I take [my children] to their house he would sit outside and tell me to take him back home” (Fairouz, Interview

11, card 15). “We don’t go to the homes of my female friends because he is older and they would have to cover their heads in his presence,” explained Nuha, mother of adolescent-age Waseem (Interview 30, card 14). “Traveling is less now because [Muftah] gets tired of traveling. We cannot have long outings because we need to get back so he can use the bathroom” (Haiba, Interview 13, card 13).

Mothers shared that an extra sets of eyes were needed for their outings with their children with disabilities. It was expressed that the perception of disability held by people in the community worked against the process of community integration for children with disabilities. Successful visits to the community required the utmost effort on the part of mothers. They were highly dependent upon the assistance of their drivers and maids to be able to take their children into the community.

Popular Places

“Some people who have a disabled child do not go out with him or her. I take him everywhere...to make him like other kids.”

Shaymaa, mother of Ziyad, her school-age son with cancer in remission and multiple disabilities

Although outings with children with disabilities required preparation and were very limited, some mothers described popular places where they took their children in the community. On Fridays, families typically spent time together out in the community in Qatar. On occasion this was also true of families with children with disabilities.

One option for leisure in the community was special play areas for children. Marzouk went out to play centers or parks with his siblings. “He started accepting other children” (Manal, Interview 22, card 28). Marzouk likes to go to Aladdin’s Kingdom theme park, [a clothing store called] Sana, and a play center that is in the City Center.

“Outside the house we bring a ball so he can play with his siblings. We go to places which are not crowded” (Manal, Interview 22, card 29).

Thikra took Raja to play centers. Thikra observed, “It takes her a long time to find the ride she wants and to come out when she finishes” (Interview 21, card 16). Before therapy, Budour could not go to play centers. “But, now she has gotten used to this stuff” (Interview 7, card 11).

Manal told, “We take him to a restaurant after work. He enjoys being in a restaurant a lot. He enjoys eating French fries and drinking juice. He feels that this is a treat for him because he has been quiet” (Interview 22, card 30). Shoayab loved restaurants, too. Aliya reported, “When we go out he points to any restaurant—like McDonald’s. He wants to go even when he is full” (Interview 14, card 26).

Lama said she took her two teenagers with disabilities to grocery shop once a week. “My sons go with me and they help me pick things out. One will push the cart. If they don’t want to go out we don’t go out” (Interview 36, card 17).

Khadija indicated that her family primarily went out if there was something special happening in the community. “If there are festivals in our town, for example, if we have a party on Al Khor’s Corniche, we take [Nijma] there” (Interview 1, card 15).

“We go to the Corniche and we ask [Soulayman] to help us take bags or stuff to the [there] for a picnic” (Salma, Interview 24, card 6). Salma continued, “We go for picnics and he enjoys this time like his other siblings” (Interview 24, card 9).

Jameel enjoys the zoo, too. “He doesn’t like crowded places and play centers” (Interview 26, card 25). “At the zoo [Hayfaa] knows each area and all the names of the animals” (Najat, Interview 25, card 12).

Najat shared, “When we go to the beach or the zoo or the *souq*, [Hayfaa] comes with us. I let her buy what she wants. At the beach she goes swimming and she likes watching the fish” (Interview 25, card 11).

Ashgan remarked about her two children with disabilities, “We go to the sea and we swim together. We go to the Corniche and parks and shopping centers. We take them out to eat. We don’t stay at home so they don’t get depressed” (Interview 5, card 16).

Nojood expressed that she had a close relationship with her sister-in-law, likely her cousin; Nojood was estranged from her husband, who was no longer involved in her life (Field notes, May 10, 2006):

My sister-in-law has three children with disabilities. We take them to Jungle Zone on the weekends. We go to the desert, to the sea—[Anisa] gets scared of some things and I treat her like normal kids. We (my sister-in-law and I) get worried about [our children with disabilities]. That’s why we don’t leave them by themselves [with a maid] (Interview 8, card 16).

Public outings were often limited due to children’s inappropriate behaviors and the stigma attached to disability, which made it difficult for community members to ignore behaviors. Amera commented on Amal’s behavior in public and the places Amal favored for her outings:

We only go to malls and shopping centers. She's stubborn. She doesn't like to go to play centers. She likes to go to Carrefour (grocery store) and if we don't take her she will scream and people will think we've kidnapped her! (Interview 16, card 15).

Samah mentioned her concern for Salah when he was in public:

If we go to the Corniche he plays with his brothers and sisters and I need to watch him carefully because with Salah things happen in a second. His maid should stick right with him (Interview 2, card 11).

"Sometimes I take [all of my children] to the Corniche or a park. [Raja] doesn't like to walk or to pray. She only likes to sit" (Thikra, Interview 21, card 9). Thikra mentioned that Raja became angry if she had to walk.

"All my friends call me and ask me to go and visit them because it's really difficult. Once I took [Majed and his brother with a disability] to my friend's house and [the boys] troubled me a lot" (Interview 40, card 27).

The last mother's comment exemplifies the thought that when other people were involved mothers were not only working to gain the acceptance of their friends for their children, but they were also working against deeply imbedded cultural perceptions of disability that were stratified across the community. This comment juxtaposed with the previous comments about the popularity of play centers, malls, restaurants, the Corniche, etc. which were activities allowing children with disabilities the opportunity to be out in the community, did not necessarily require interactions with individuals other than

family members within the community. The assumption that interactions occurred and relationships were made could not be inferred from the data.

Visiting Extended Family

It is a tradition in Qatar for many families to meet together with relatives, especially on Thursday evenings. For some families it was common to include children with disabilities. “We visit [Muhannad’s] grandfather’s house. He plays with his cousins. They make two teams and they play soccer and have bicycle races. The children love him and they cooperate with him” (Mashaal, Interview 34, card 20). Nuha explained, “We go out to my relatives’ house. He likes his aunties and he even likes to sit with the maids and talk to them” (Interview 30, card 13). “On vacations we go to visit relatives. [Jameel] plays with them” (Interview 26, card 24).

For other families the option to include children was sometimes limited due to disability during visits with extended family. “We visit our families. [Wafaa] comes with us to visit our families, but usually, it is rarely done.” (Widad, Interview 10, card 6). Khadija only included her daughter in some momentous family events if the circumstances were appropriate. “We take [Nijma] to weddings if they are close relatives only” (Interview 1, card 17). Weddings were an occasion where mothers made marriage arrangements for their children. Some families did not want others to know about their children with disabilities because it might have negatively impacted the prospects of a marriage partner for other children (Reynolds, 2006; personal communication, F. Al Maadadi, June 20, 2007). Khadija was the only mother to speak of taking her child with a disability to a wedding.

Challenges appeared when socializing a child amongst extended family. Most mothers spoke of visits to the homes of family; but many mothers also shared that the lack of support they received from their family members because of their children with disabilities was disheartening. Mothers were concerned with acceptance of their children, their children's behaviors, the stigma attached to disability, and their children's health when visiting the community. A more socially innocuous recreational activity than visiting family was to travel alone to the desert with immediate family.

Traveling to the Outskirts of Doha

A common recreation destination for families in the city of Doha is to go to the desert or a beach on the weekends, and this happened for many families who had children with disabilities. Mothers described activities that revealed an affinity toward less social pressure as they spent time alone with their immediate family members.

Fridays are a special day for Daham and his little sister. His father and I go with them. He likes the desert a lot. We have a farm there. He likes camels, goats—he waits for Friday to come so we can go there. Sometimes we go to the beach house, but he likes the desert mostly (Zaynab, Interview 15, card 12).

Although these outings were common for families, they also brought concerns related to the children with disabilities. Samah's family took Salah to the beach that they enjoyed traveling to on the weekends, but Salah required a great deal of supervision:

We have a house outside of Doha near the beach, but he eats sand, so we like to take him out, but he gets stubborn and cries a lot because he likes to eat sand and grass. That's why we take him out for a short time.

Dana said, “He likes swimming. He likes the beach.” Through the interviewer’s questioning it became clear that Jameel cannot swim. “I haven’t tested him on this. I do get scared about him swimming because he likes water a lot” (Interview 26, card 27). Shahd mentioned, “I’d like [Sajed] to learn to swim because he’s afraid of something called ‘water’” (Interview 19, card 10). These trips, while producing less concern related to the reactions of others, had their own particular stressors in the form of worry and safety for their children.

Traveling Abroad

Several mothers shared that their families enjoyed traveling outside of the country when possible, which is another typical family activity in Qatar. However, travel was often impacted by the presence of a child with a disability. “We used to travel every year, but now it is difficult to travel with [Samah] in the wheelchair. We cancelled the long distance trip because it is not easy for her” (Suheir, Interview 37, card 30). “We have yearly trips to France, the U.S.—on the first of July, I am going with [Nadeem] only to the U.S. because my sons are taking summer courses” (Muna, Interview 29, card 28). “We want to take [Marzouk] on *Omrah* (Hajj, the path of pilgrimage to Mecca in Saudi Arabia for Muslims)” (Manal, Interview 22, card 33).

It was interesting to note that it was neither common for Qatari women to travel alone, nor was it common for them to travel abroad without a chaperone. Mothers had reported this same issue when they desired to take their children to other countries in order to receive quality medical care. For mothers who could travel abroad, stories were

shared of perceptions that children with disabilities were accepted more in other regions of the world (Interviews 29 and 37).

In summary, children's visits to popular places tended to be with family or drivers and maids. These stories of outings highlighted the perceptions mothers held of the community. It was apparent that even if the community was to be more open to the possibility of the inclusion of children with disabilities, these children would not necessarily become individuals who truly were integrated into the community because they were not spending time with community members in the places they visited. Children were more likely to remain outside the realm of community membership, which reflected group value. Considering that most activities mothers described were predominantly in the home or in the community with other family members, community integration as part of recreation and leisure activities was not common.

Community Programs

When mothers were asked to tell the interviewer about programs that their children attend in the community, the responses were mixed, but they predominantly indicated a lack of community activities suitable for individuals with disabilities. Mothers had a difficult time describing their knowledge of programs for children with disabilities in the community. A majority of the mothers said that there were no programs available for children with disabilities. Twelve mothers responded that there was nothing except Shafallah (Interviews and cards respectively: (6/16; 16/18; 18/14; 21/13; 23/19; 25/16; 27/22; 32/14; 34/27; 36/31; 37/33; 39/13). Ten mothers simply answered, "Only Shafallah" (Interviews and cards respectively: 7/17; 8/21; 10/10; 11/17;

12/20a; 14/33a; 17/14; 30/21a; 31/30; 35/18). Seven mothers said, “Only Shafallah,” but they included commentaries. They continued by listing activities that they considered “programs for children with disabilities” within the community in addition to Shafallah. Twenty-nine mothers out of 40 referred to the Shafallah Center as being their primary option for education and their main community program or activity for their children with disabilities. Some of the commentaries follow.

When asked about programs for children with disabilities, Dana retorted, “Like what? Tell me what we have in Qatar? It’s only Shafallah. They just started thinking of children with special needs recently” (Interview 26, card 35). “There is nothing else except Shafallah here in Qatar. We wanted to do something for these children before Shafallah was started” (Interview 29, card 41). Shaymaa questioned, “What do you mean? Which programs? What other programs are here besides Shafallah? Shafallah and physiotherapy in Rumeila Hospital in the summer. The entertainment programs [for children] in the malls” (Interview 9, card 25). “Now? Nothing” (Manar, Interview 40, card 31a). These responses were similar to those mothers reported about the lack of medical services in the community.

Two mothers’ comments reflected no need for special community programs: “Here we have enough. We don’t need anything more” (Mufliha, Interview 35, card 20). “Everything is available. There are parks, playgrounds—they get the spiritual and financial support that they need” (Shahd, Interview 19, card 21). However, these perceptions did not conclude that there were existing opportunities for community integration for children with disabilities.

Mothers answered that they participated in existing programs at Shafallah or in the community in general. Nafela responded that she went to many workshops offered by Shafallah to train parents of children with disabilities rather than activities for the children themselves. “We do have special programs for these children. I come to every lecture or session that they offer us and I apply what I have learned on him. I haven’t heard of any program except for the ones here” (Interview 33, card 26). Maryam responded that sports clubs were all that she could think of, but she doesn’t take her son, Ghazi (Interview 23, card 14). Ashgan reported what she considered to be programs in the community:

We take [Othman and Samia] to the activities in the City Center if they have any in the summer. He is like a normal kid. I don’t let [Samia] feel that she is different from [other kids] and so she gets along with them and doesn’t get scared if she is with them (Interview 5, card 21).

“I took [Marzouk] to a lecture in Al Bidda park by Wajdy Ghaneem, and he is an Islamic teacher. They sang Islamic songs. I took him with me” (Manal, Interview 22, card 43).

Manal also mentioned:

If there are any children’s plays, I take him and if there are any other occasions and we have to go to these, we take him. We take him and we noticed that he becomes very happy when he experiences something new. We don’t like him to have too much routine in his life (Interview 22, card 44).

“[Soulayman] used to register to go swimming with his father, but he is too young to register him in summer programs. He goes to Shafallah on school days and that is about it” (Interview 24, card 13).

A few mothers described specific activities or programs for children with disabilities. Khadija commented that these seemed to come only once or twice a year (Interview 1, card 16). “If Shafallah arranged for special activities outside of the school day I would take [Daham]. Sometimes they do activities in the sports club and once in the Heritage Village” (Zaynab, Interview 15, card 17).

Sameera mentioned a planned community program or activity for children with disabilities:

In fact, society and the community can make an activity for these children. *Q-tel* (Qatar Telephone, the local telecommunications service provider) has done an activity for these children where they go and have fun in another place. Other companies or organizations should do this. It would be good. Art, picnics— Sports clubs should take Shafallah students to do things. They have done this in the past. For some activities they (the staff from the Shafallah Center) invite the whole family (Interview 4, card 20).

One issue that impacted mothers’ perceptions of community programs was transportation to and from programs and activities for children with disabilities. Konouz explained the difficulties with transportation issues, such as traffic and distance, a concern to the population in general regardless of having a family member with a disability. “There is horse riding, but it is difficult for us to take him there” (Interview

27, card 23). Lama planned, “I would like to register [Fares and Fadi] at Shaghab Horse Center” (Interview 36, card 13). However, the center was not yet open to the public at the time of the interviews.

Jameel likes horses. He was in the horse riding club. There was a horse that no one could control. No one could calm him down, but my son touched his face and the horse immediately was calm. My house is far and my situation is difficult or I would still take him there (Dana, Interview 26, card 15).

The majority of mothers responded simply and without much commentary, while referencing the Shafallah Center. Most mothers stated: “There is nothing except Shafallah,” or “Only Shafallah,” which provided evidence that most children with disabilities only accessed the Shafallah Center for programs and activities for children with disabilities in the community.

Mothers expressed their desires and future goals for community programs. Mothers requested programs and activities designed to meet the needs of their children with disabilities who only were recently being considered for programs and activities. The Shafallah Center was the primary and most predominant source for activities and mothers desired that there be more options for their children. Mothers took their children to community activities tailored to the general population, but these activities were not intended to provide an accessible option for community integration. Programs that were held at the Shafallah Center were the main opportunities that mothers referred to within the community. Transportation sometimes made it difficult for children with disabilities to participate in programs and activities in places other than the Shafallah Center. Due to

its ease of access for those who had been accepted to the center, the Shafallah Center was the primary source for community programs providing opportunities for community integration for children with disabilities.

A Coveted Placement

It was impressed upon the interview team that the Shafallah Center was the most coveted placement for children with disabilities and the only placement of its kind within the community. The center was a government-supported entity for which some mothers expressed gratefulness, while others made it known that they believed the government should provide more for children with disabilities. The center served approximately 200 children and had a waiting list for entrance into its programs that had 300-400 names in 2006 and 400-500 names in 2007. Children could not be accepted at the Shafallah Center until teachers who were trained in special education and could speak Arabic were located. There was a severe shortage of personnel with this skill set. According to the numbers on the waiting list, there were many children with disabilities in the community who were not receiving any educational instruction that met their individual needs. Mothers commented on the availability of a spot for their child.

I went to Mecca and I prayed to God to make a way or to open a door for him so he can learn. When we returned they called us telling us that they accepted Khalid in Shafallah, but only for the afternoon sessions (Gaydaa, Interview 12, card 30).

Samah remembered, “They registered him at Shafallah. They started with him when he was three years old. They didn’t want to let him come into Shafallah. We had to argue

for it and argue for it until they accepted him” (Interview 2, card 3). Salah was seven years old.

When Ashgan told about the wait she had experienced, in order to receive services for her children at Shafallah, she seemed angry (Field notes, April 25, 2006).

Ashgan expressed her concerns and her desire for more services for her daughter, Samia:

Inshallah. We don't need their help. We can teach them more than Shafallah can teach them. My daughter is nine years old and she only comes here for two hours in the evening. We waited a lot. We complained, but no one heard our complaints (Interview 5, card 25).

Since mothers were very reliant on the Shafallah Center it was evident that the waiting list for placements caused a great deal of concern. Those who had obtained placements for their children recognized the fact that there were many others who had not been able to acquire the same for their children. Mothers pointed out that they had few other options in the community.

Social Interactions through the Shafallah Center

From the data that were analyzed regarding children's experiences at the Shafallah Center, that which was most relevant to this study was about social interactions. Mothers deemed the Shafallah Center their primary community program and resource for their children with disabilities besides interactions with siblings. In some cases mothers considered the center the place where their children were integrated into the community. This was an interesting perception since the center was segregated, and children did not interact with peers without disabilities. Mothers discussed the social

interactions of their children at the Shafallah Center, especially as their children attended a school that was solely for children with disabilities. Mothers were asked how important they believed it was for their children to interact with children without disabilities. Nojood conveyed her belief. “Very important. If she sees children she will mix with them so she will feel that there is no difference between her and them. This is her right to live a normal life. We feel that she tries her best” (Interview 11, card 18). Other responses were varied. “I don’t know if it’s important. Because Ziyad is with his siblings who are normal at home and he plays with them. Except at school because he is only with kids with disabilities” (Shaymaa, Interview 9, card 24). Some mothers interpreted their child’s time at Shafallah as inclusion with children without disabilities or counted time with siblings as inclusion with those without disabilities. “So he gets used to them and copies them. He loves his siblings very much and he has gotten used to them and even here in Shafallah, he likes the children and he likes to play with them” (Interview 28, card 25).

Other mothers expressed concern for their children’s interactions with other children at the center. “If my son didn’t have a severe disability I would have a teacher come to our home because he learns bad habits at Shafallah from other kids” (Gaydaa, Interview 12, card 16). Most mothers considered social interactions at the Shafallah Center to be beneficial for their children. As before, there were some concerns about children picking up poor behaviors from others, as Gaydaa mentioned. Mothers expressed similar sentiments when they discussed the limited communication of their children and the effect it had upon their socialization and learning. Shaymaa recognized

the fact that most interactions for her son, Ziyad, were only with children with disabilities.

Benefits of Socialization

Mothers who believed there was a benefit to interactions with other children without disabilities shared their perceptions. “You know just when [Wafaa] is around kids she is enjoying herself and laughing and participating. You can see the difference. I think it is good for her to be around other kids” (Widad, Interview 10, card 9).

“[Nijma’s] the type who likes to imitate normal children. She will learn from them and imitate them” (Khadija, Interview 1, card 13).

Makboula responded:

If you see her you will say that she’s normal. If she mixes with normal kids she will get better. If she stays with disabled children she will be like them. She was with a boy who hits himself all the time and she started to act like him. You put her with normal children and she will be like them (Interview 18, card 13).

Zaynab, referred to her son’s response to social interactions with his father:

Being with normal children helps him to acquire their behaviors. His father takes him with him to the *majless* (parlor where men meet to socialize). He learned how to serve coffee and to give nose kisses to friends (an Arabian greeting).

Since he has gone to these majlesses he has become more like the men there and he has learned the traditions of the people of our country (Interview 33, card 25).

“I feel [Soulayman] learns some skills from them and some habits and he tries to behave or copy their behavior” (Salma, Interview 24, card 12; Nuha, Interview 30, card 20; Dana, Interview 26, card 34; Salma, Interview 24, card 12).

Maryam replied that she wanted her son to learn language skills from children without disabilities. “I want him to learn how to speak from the other children. I get really happy when I see him playing with the neighbor’s children and his siblings and he does learn to speak from them. The experience and everything else is learned from them—even when he plays football” (Interview 23, card 18; Ashgan, Interview 5, card 19). Nuha evaluated, “[Waseem] changed a lot since he got to this school. If someone says a bad word he tells them that it’s not nice to say that” (Interview 30, card 18).

Mothers addressed the challenges involved with social interactions with children without disabilities. Lama felt that children without disabilities needed to accept and understand the situation for children with disabilities:

For me, I would love to see him playing with them. And, because he doesn’t talk very much, that is difficult. By playing with them, he might change his ways and learn to play the game, but if he is with a child with the same disability, he learns inappropriate behaviors (Interview 36, card 25).

Wodouh expressed, “I want [Masood] to play with [children without disabilities], but they don’t accept him when he shouts” (Interview 32, card 13). Hind added, “[Nawal] takes on their behavior and skills, but they don’t want her sometimes” (Interview 39, card 12). “[Rashoud] learns from them when he is with them. They hit him and he hits them back” (Interview 20, card 10).

Gaydaa felt Shafallah was not the place for some mothers to seek services. She said her son learns from children without disabilities. “Whoever has a child with a disability should bring him here if he really needs it, but if he has some abilities it is better not to bring him here. He shouldn’t come here” (Interview 12, card 15). Gaydaa was referring to children with mild disabilities. Muna described, “The problem is that it is like [children with disabilities] are in a glass bowl. If you leave them with themselves they will not come out of this hole. You have to do something so they can get outside of this bowl” (Muna, Interview 29, card 38).

Some mothers expressed their belief that segregation was the best option. Najat suggested:

It’s better if they separate children with autism from the children with Down’s Syndrome. Children with Down’s Syndrome do copy everything all the time, while children with autism have bizarre movements. My daughter copies them. She screams all the time. It’s better to separate them so they can benefit more, especially the ones with mild disabilities (Interview 25, card 19).

Suheir commented, “It’s better for [Samah] to play with her normal siblings and friends with the same problem” (Interview 37, card 31). Manar said, “It is important, but it is not very important because they will not provide him with an environment where he can get better and interact” (Interview 40, card 30). Manar believed that children with disabilities improved their skills and interacted more when they received special education services in a segregated environment.

The Shafallah Center was the primary option and resource for services to children with disabilities in Qatar, provided by the government. It was intended for children with moderate to severe disabilities, but due to the lack of inclusionary programs in independent schools the center also served some children with milder disabilities. If the necessary supports were provided these children most likely would have been able to benefit from an inclusion program in a local school. While mothers appreciated that the Shafallah Center was their only option for their children with moderate to severe disabilities, their views on socialization of their children varied. Some mothers were concerned with bad habits and behaviors that their children would learn from other children with disabilities or they feared their children would not be accepted by children without disabilities. Several mothers expressed their belief that segregation of children with disabilities was best.

Government Provisions

Services at the Shafallah Center were provided by the Qatari government; while this was recognized by the mothers, specific thoughts about this support varied. “The Qatar community doesn’t like to pay for private projects. They depend on the government to pay for them” (Muna, Interview 29, card 45). “I don’t know these things,” said Aliya. “The education is provided [by the government] and it’s better developed than before. In the past children with disabilities were left eating and drinking and they were left by themselves, but now it has improved a lot” (Interview 14, card 34).

Ashgan described her perception of the climate:

The government gives [children with disabilities] salaries. Having connections [to get what you need] is big here. The only resource is Shafallah. I want [my kids] to work honestly in all that they do. There are many kids who were not accepted at Shafallah. Everything depends on if you have connections. There is no integrity (Interview 5, card 24).

Lama observed, “They cannot do everything in the coming year. They’ve just opened so they can’t fulfill all of our requests” (Interview 36, card 32). Lama referred to the opening of the new Shafallah Center, which occurred in the middle of the interview process.

“Shafallah is a gift,” said Gaydaa. “It’s enough for Sheikha Moza that she opened this and that will take her to heaven. There are many more disabled children in houses across Doha” (Interview 12, card 32). “Everything is provided by Shafallah. It’s a job well done and I pray that God gives them wealth for doing this for our children!” (Nabeela, Interview 28, card 27). Samah finished, “Shafallah is providing our needs, but there are many kids. The center is not enough. There are some private centers, but it is different if it is supported by the government, like Shafallah” (Interview 2, card 22).

Suheir felt fortunate that Samah had been accepted at Shafallah, although she had only attended for two weeks. “The other centers that we used to take her to were really commercial and wanted money, but this center is supported by the government and they want the best for the children. But, they need support” (Suheir, Interview 37, card 36). “I wanted her to come to Shafallah. Sheikha Moza did her best. Shafallah is the biggest center in the Middle East or Gulf countries” (Samah, the mother, Interview 37, card 38).

Community programs were difficult for mothers to describe because it was reported that there was little available in this regard except for the Shafallah Center. Of all community interactions that children participated in, mothers recognized those at the Shafallah Center to be most consistent, most interactive, and most intensive. It was interesting to note that children went to a variety of places in the community as part of family recreation activities, but few had interactions with others, which was also true of the community programs that mothers could describe in the community, such as concerts, family activities, or summer programs. These activities did not require integrated participation of children with disabilities. Mothers believed that more could be provided by the government for their children with disabilities.

Qatar was a country that provided much financial support and other incentives to its inhabitants with citizenship, although limited financial assistance was provided to families with children with disabilities. The country's leadership was lauded for their beneficent rule. Most mothers reported a high level of praise for the Shafallah Center even though they believed their community was missing a spectrum of services for children with disabilities. There was an expectation that welfare be increased by the government.

Community Needs for Improved Opportunities

“Shafallah is not enough. People are waiting.”

*Samah, mother of Salah, her school-age son with autism
(Interview 2, card 20)*

“I think the Qatar community is starting to provide most of the resources for disabled kids.”

*Widad, mother of Wafaa, her adolescent daughter with multiple disabilities
(Interview 10, card 11)*

One of the themes that emerged was a need for greater community services.

Mothers had many opinions about resources that were needed for their children in the community. Needs that were described were both tangible and non-tangible and tailored to suit either the characteristics of the individual child or the needs of children with disabilities throughout the community. These varied in focus and scope from categories as diverse as buildings and personnel for medical or recreational services to improved community awareness. Most mothers recognized that action was being taken to provide services to children with disabilities, even though more and better resources were desired by mothers.

Genetic Testing

One issue that was suggested by several mothers was a need for genetic testing or counseling due to their cognizance of the cultural issue of consanguineous marriage.

Manar felt testing and counseling would prepare mothers. “This is a matter that all the mothers fear will happen to them (their child will be born with a disability) again or it’s in the family heredity and will be passed on again” (Interview 40, card 35). Nojood started by saying, “There is something I wish for in my mind.” She continued, “That they would do a pre-test for children. To do the test they would check couples for

genetic compatibility. We need to have these tests for the couples so the children are normal” (Interview 8, card 22).

The need for genetic testing and counseling was validated by the fact that the 40 mothers interviewed represented at least 47 children with moderate to severe disabilities. Some mothers directly referred to both children with disabilities, while others only referred to the second child with a disability in the family during response to the open-ended questions. In the field test of 10 interviews, at least 13 children with disabilities were represented by mothers. This means that approximately 20% of respondents had multiple births of children with moderate to severe disabilities. This profound example was similar to what Taylor and Francis (2001) reported in Saudi Arabia. In a study of 875 households 34% of children screened were the second or third child in their family with a disability. This rate of multiple births of children with disabilities in the same family within this area of the Gulf Region provided further support of the conclusion that the statistics on disability in Qatar were most likely inaccurate.

Although there has been reference in local media to the issue of consanguineous marriage and the high level of disability that it perpetuated (Bener and Alali, 2004), mothers did not specifically address that aspect in regard to the need for genetic counseling. Instead, matters of culture and tradition were first to be upheld; however, these two mothers believed that knowledge of potential for disability or early diagnosis of disability would be beneficial to prepare families to better care for their children born with disabilities.

Special Schooling

There was a desire for more and more diverse academic support among several mothers, including the expansion of existing programs as well as the creation of other educational opportunities. “From the educational side they need a specialized curriculum for kids with special needs so [Budour] can learn academically. This curriculum should be accredited. She could complete this curriculum at different levels” (Buthaina, Interview 7, card 21). Dana pled, “I wish they wouldn’t close Shafallah in the summer, because he feels better when he goes to Shafallah” (Interview 26, card 16). Fairouz described:

We need capable and good teachers. He had a teacher for four months. He developed skills very fast. She was concentrating on him. He learned everything from her in four months. Then, she traveled. It was a loss for Zain Elabedeen (Interview 11, card 19).

Manar added that the most challenging thing for her was that she could not find enough services in order to train Majed each day. She said that it made her feel helpless to not be able to provide for her son in this way (Interview 40, card 10).

Mothers desired educational services that were available for more hours of the day. Some mothers were referring to more than the full services they were receiving at the Shafallah Center from 7:00 a.m. to 12:00 p.m., while others who were actually only receiving several hours of services for their children each week because there were not enough staff to support the efforts of the Shafallah Center, were hoping perhaps for full

services. Mothers recognized that the Shafallah Center was really the only program available and that it was not sufficient to meet the needs of all children with disabilities.

Special Medical Services

Medical services were another expressed need, and mothers articulated their wishes for a special hospital, special dental services, priority care, special labs for routine check-ups, and pharmacies that supplied wheelchairs and other orthopedic devices. At the time of interviews it was part of the Shafallah Center's master plan to have an on-campus medical facility to meet the needs of students at the school (personal communication, S. Hannibal, March 24, 2006). Several mothers were annoyed by the rough care which doctors in the community had used on their children (Interview 15, card 7), including trying to force them by strapping them to a hospital bed (Interview 29, card 13). Mothers desired more knowledgeable medical staff members who had been trained to work with individuals with disabilities (Interview 16, card 2).

Mothers expressed a desire for specialized and individualized medical care. "They should build a special hospital for them [and] have a special section for them (children with disabilities) in the hospital, especially for dentistry. The dentist says, 'I don't know how to deal with him.' Nafela continued with her belief that children with disabilities should receive priority care: "They shouldn't have to wait for more time and more care" (Interview 33, card 29).

Dana also mentioned that a special hospital with special care would be helpful. "Some families don't understand [Jameel's] situation and they stare at him ... We don't have anything like that now and they don't give them priority in the hospital" (Interview

26, card 39). Dana continued, “They should have a special center and a special hospital of dentistry. I visited [Kuwait] and the children with special needs have their own houses, salary, and special care” (Interview 26, card 41).

Buthaina added that there was a need for special labs where testing and routine check-ups could be done (Interview 7, card 19). “There should be a special therapist to take blood or do other tests without using force on them.” Lama gave an example of how she took her first child to the hospital for blood tests. “They couldn’t do it for him, but they could with the other child” (Interview 36, card 34). Widad thought it would be helpful to have more pharmacies that carry wheelchairs and orthopedic devices. “We need a place where we can go to easily get these things” (Interview 10, card 12).

Inadequate services, long wait times and/or rough treatment by hospital staff were complaints that were most common. Mothers of children with disabilities experienced greater challenges because of the exceptional needs of their children and the lesser awareness of those needs by medical staff. Similar to the expressed need for appropriate and quality school placements, mothers desired appropriate and quality medical care for their children with disabilities.

Parent Training

It was evident that mothers desired parent training so that they could go with their spouses or other community members to learn more about the needs of their children with disabilities. The themes that emerged regarding parent training were as follows: community workshops on acceptance of children with disabilities, workshops on how to encourage daily living skills, family training programs, summer workshops on

specific disabilities, such as autism, and a parent support group. Not only did mothers desire more knowledge about disability themselves, but they also wanted training to better advocate for improved services for their children.

Haiba answered what she felt was needed. “Training mothers so they don’t get shy and they will take their children out [into the community]” (Interview 13, card 18a). She added, “Do workshops for mothers of disabled children, so they come to know how to deal with these children when it comes to dressing and feeding them” (Interview 13, card 21). “They should help the parents by having special programs from the beginning so that they don’t get lost. So they will know what to do with their children” (Interview 33, card 27). In a society where disability has been a stigma, parents perceived education as important so that they could better care for their children with disabilities.

Another expressed need for training was for the community at large. Nafela felt it was important to have training programs for families and for people in the community. She said she thought this would help people to become more accepting of persons with disabilities. Haiba believed that this type of training was needed for all mothers with children with and without disabilities in the community (Interview 13, card 17). Dana also expressed that a wider audience for trainings might be beneficial:

I hope that they will do some workshops in the summer for the parents, for the community—so they could know about this situation. There are some families who do not know about autism. They should have summer activities and they should let the moms attend the classes with the kids (Interview 26, card 18).

Mothers recognized the challenges of raising children with disabilities in Qatar and believed that parent training could help them meet those challenges. Mothers might have received the social support that they needed so that they would be able to handle negative attitudes or the recognized lack of support from their families.

In interview field notes it was noted that Manar, mother of Majed and another son with a disability, was the only mother to request a parent support group for the community, especially for parents of children with autism (Field notes, June 7, 2006). This unique request would have linked nicely with parent training to meet the need for education and socialization of mothers of children with disabilities who lived in the same community and shared similar challenges.

Special Community Places

A majority of mothers expressed that Qatar was lacking in recreational and leisure activities or entertainment (Dana, Interview 26, card 44), as well as open access to these types of resources. Haiba expressed her desire for change: “Enlightening the community, in general, is to provide special places for [children with disabilities] alone” (Interview 13, card 19). These mothers wanted more options in terms of places where they could take their children with special needs in the community.

Special Family Centers

Mothers not only wished for more education for themselves, but also for accessibility to special centers for them and their families so they could participate in typical community activities. Manar suggested, “To have special community centers where parents can go” (Interview 40, card 36). “We need special programs to know how

to deal with these children at home and how to teach them. I want him to learn in a natural setting. I want him to learn” (Interview 40, card 38). Manar noted that her ideas came from Kuwait where a special center was built for children with autism and all the parents of children with autism raised the money to have it built (Interview 40, card 37). This comment was made in reference to the educative function of a center for parents (Interview 40). The request was for a segregated facility that was safe and allowed children and families the opportunity for leisure in a setting that was accepting of disability.

It was interesting how a common thread through the many desires of mothers of children with disabilities was the request for safer and more secure segregated facilities or activities. This aligned with the fact that there was a high level of satisfaction and thankfulness for the Shafallah Center, a segregated facility that provided variety of services, but was unable to provide for the needs of the entire community.

Special Clubs for Sports and Activities

“Sports. I would love to see her walk because she is always in a wheelchair. I would love to see her swimming, running, playing—”

*Suheir, mother of Samah, her school-age daughter with multiple disabilities
(Interview 37, card 12)*

More physical activity for their children was a common theme for mothers, and this was expressed through a desire for more places in the community that could be accessed by individuals with disabilities. A particular type of community place mentioned was a sports club or places for physical activity. “I wish [Khalid] could participate in sports activities...according to his disabilities and social activities, as well” (Gaydaa, Interview 12, card 22). Muna said that she would like to see adolescent-age

Nadeem participate in sports because he does not do that now and it would help him to expend his energy (Interview 29, card 18). “The teenager period is very difficult” (Interview 29, card 15). Nafela articulated that sports activities would be the answer for Ameen:

Our houses are not the right places for these activities, but he loves sports and here (at Shafallah) they don’t use their afternoon time for anything active. In the house he cannot do these activities and I cannot leave him by himself to go with the driver to go to the sports club (Interview 33, card 16).

Some mothers were concerned about their children’s health due to a sedentary lifestyle. Hind shared her concerns about her daughter’s weight. “I want [Nawal] to do some sports because she’s chubby and she likes to sit all the time” (Interview 39, card 4). Thikra described Raja’s situation:

I want her to do sports more often. She is overweight and she does sports here in Shafallah, but she doesn’t do that at home. She likes to do it in a group; she likes teamwork. I tried to find her a sports club for girls so she can participate, but I didn’t find any that would accept her (Interview 21, card 5).

Nuha revealed, “[Waseem] has gotten bigger now and it’s all because of soft drinks. He needs sports. I cannot take him to a sports club (Interview 30, card 22).

Nuha added, “I wish there was some place I could take him to learn to swim” (Interview 30, card 21). Wodouh thought a multi-purpose facility would be helpful. “I would like them to have sports centers for swimming, entertaining, and with parks with special teachers or trainers” (Interview 32, card 15).

Omniya recounted a story of a time in the past when an attempt was made to have a sports club for children with disabilities:

There were some clubs. There was one club where the building was 50 years old—an old building. It was really old. Their activity was to let them all sit in a room with a TV and they kept an Indian man in the room with them. They should build a new club for them and not some old house that has been turned into a club and is not comfortable.

My word to Sheikha Moza is to build a very huge club for them here—even here at Shafallah and not some old room. Because my son always tells me that he wants to go to a club. We don't have a sports club for their entertainment. He always says he wants to go to the club because he likes to ride the bus to get there [with Shafallah]" (Interview 31, card 32).

Omniya finished her interview with similar sentiment, "I hope in my lifetime they will build them clubs so they don't sit at home" (Interview 31, card 34).

It was a challenge for parents to find viable options for activities and programs for their children who were often left in the care of family maids. "Qatari parents need these options, too, because not everyone can leave their children and maids are not enough. The kids need to do other activities, too. Not just sit with the maid" (Muna, Interview 29, card 49).

Thikra suggested, "Try to build or have sports clubs for them. In the summer they do activities, but there isn't any center or sports club, so they can play, which suits them." She added, "Some specialists who could help the children in playing because

their mentality doesn't allow them to understand that they have to do things fast so they need someone to deal with them and be patient with them" (Interview 21, card 15).

Konouz felt that sports clubs were also needed, but she requested that they be specially prepared for children with autism, give them priority, and be made to be secure (Interview 27, cards 24 and 26).

Several mothers suggested a special club, not specifically for sports, but for activities other than sports, especially in the afternoons after the Shafallah Center closed.

"I wish they could have more activities where we could participate. Even an hour in the afternoon with all the children with special needs" (Manal, Interview 22, card 46).

Nafela said she sees a need for activities in the afternoon two or three times a week under the supervision of Shafallah staff. "It is better than places that we don't trust, especially during vacation and even normal days" (Interview 33, card 30). Nabeela felt summer activities were needed. "They sit at home all the time in the summer" (Interview 28, card 28). Manal offered that if there were a special center, not only for entertainment purposes, but also for educational activities, she said she believes parents would help to operate it (Interview 22, card 48). Fawzya said she thinks the most pertinent time period for a special club would be from 3:00 to 8:00 p.m.

Mothers recognized a lack of accessibility to sports clubs and a lack of availability to any other sorts of activities or programming after school or during summer vacation for children with disabilities. Mothers relayed concern about safety and supervision if there were to be an after-school club for their children. Several mothers recognized that their children were not living a very healthy lifestyle and were in need of

more physical activity, as well as activity beyond the school day. Special sports clubs or activity clubs seemed to be a popular solution to this issue.

Special Play Centers

“I wish she could play with others. She can hold a ball, but she doesn’t throw it.”

Amera, mother of Amal, her school-age daughter with multiple disabilities

(Interview 16, card 8)

Many families in Qatar took their children to play centers in malls. These centers were much like an indoor amusement park, due to the desert heat, and they included carnival rides and games. There were requests by mothers for special play centers in the community designed with children with disabilities in mind. Buthaina said that she would like to see Budour ride a bicycle and play normal games with her siblings (Interview 7, card 4). “I wish [Anisa] could play ball like normal kids and ride a bicycle and talk like them because she watches them, but she cannot do it” (Nojood, Interview 8, card 10). “I wish I could see [Amal] playing...I do not want her to feel different because others do play and she cannot [play] very easily” (Interview 16, card 17).

Amera thought for a few seconds. “They have many things here [at Shafallah]. I wish they had a special playroom, so she can play with other children and get used to it. They should get used to doing these activities” (Interview 16, card 19). “The play centers here do not suit them” remarked Dana (Interview 26, card 50). “There are other children who cannot walk. They should have special play centers. Some of them are in wheelchairs. Some of them are slow moving” (Interview 26, card 45). “Kids with disabilities need to have specific places for playing and to create competitive games for them. Something like Shafallah” (Interview 1, card 18). Mothers expressed several

desires for activities for their children. Some mothers expressed that they wanted their children to be involved in more activities either similar to daily activities at the Shafallah Center or more recreational in nature. Other mothers felt that more family-centered activities would be beneficial to their children and to their families as a whole. Mothers expressed a sense of desperation for something for their children to do outside of the school day. Nabela gave the example of sitting at home all day long as the plight of many children with disabilities.

Financial Assistance

Several mothers suggested special financial assistance for mothers of children with disabilities, as opposed to additional places or training within the community. There were suggestions for special funding from the government that would provide sustainable resources for children with disabilities into the future. Makboula and Muna clarified a situation that had been a curiosity to the interviewers as mothers had mentioned the salary they received from the government for each child with a disability (Field notes, June 4, 2006). Makboula suggested:

For a mother in my situation, whose husband is dead, the salary is not enough—600 riyals for a child with a disability each month. [The government] should provide a driver and a maid for them. In Kuwait they are providing that for them. Sometimes I don't have anyone to take us to the hospital and today I didn't have anyone to pick me up. I don't think that everyone should get a driver and a maid, but in special situations like mine. I'm a widow (Interview 18, card 15).

Muna revealed her concern for the future:

Let's be realistic. When we die our children will not have anyone to be with. We have to think about this matter from now on. [The government] should provide a place for them and they can start taking money from us now for that matter. They can ask parents to help fund this now for the future. Today we can take care of them, but tomorrow you will not be with them. That's why we need a fund to collect every month in a year (Interview 29, card 50).

Some places like Kuwait started to take initiative and have a fund. In Egypt they already did that. That's something that will not harm people, but will benefit them. Some people get 600 riyals for the help [to hire a maid] and 600 riyals for the children's health (Interview 29, card 53). I suggested to the social workers once that they stop giving families the extra 600 riyals and put this into the fund for the future instead (Interview 29, card 57).

Muna went on to explain that some people received 600 riyals each month if they had a child with a disability and they were part of a higher tribe in the hierarchical system. Some high tribe Qataris received more than 600 riyals from the government each month and some did not receive any money if they only had a document for citizenship, but not a Qatari passport (Interview 29).

Muna had described how hard it was for her to be with Nadeem all the time. "I know a lady who got a specialist for her son from Egypt who stays with them all the time, like a nurse, but not everyone can afford that. We should have these services" (Interview 29, card 47). Omniya lamented, "They don't give [Khamees] a salary because

he is not a first class Qatari. I didn't ask them to give me the salary because his older brothers help me with that" (Interview 31, card 33).

The tribal ethos in Qatar created a hierarchical system for those who received financial incentives for their livelihood from the government and those who did not. Qataris in higher tribes received greater benefits from the government. Qataris of the lowest tribes were, in some cases, financially deprived. This system of special monetary privilege was not accessible to all families with a child with a disability. Some mothers perceived that the generosity extended by the government, maintaining the welfare of the people of Qatar, should have led to provision in many other aspects of daily life for families of children with disabilities. Requests for financial incentives for children with disabilities seemed reasonable to mothers.

Special Privileges

Discounts and identification cards were another request mothers expressed as a means of supporting their children's opportunities for community integration. Shaymaa conveyed what she thought would help:

We get discounts for tickets for flights—no! That's not true! There are no discounts at all. If they want to give us a discount they put us on a waiting list or on standby. I travel a lot because of my son's disability (Interview 9, card 5).

In Splash (clothing store) and Shoe Mart they give me a discount because I'm the mother of a disabled child, but in other places like Next and Marks and Spencer they do not give discounts. They should do this. I feel special when I go to places like Splash (Interview 9, card 27).

“You don’t find there is much for these children in the community. You have to wait and wait for your turn and you get tired. They should have special identification cards so they can get in first” (Gaydaa, Interview 12, card 27). “They should have priority when they go to play centers because they don’t like to wait for their turn and they don’t like to sit” (Interview 27, card 25). Besides the desire for monetary discounts, mothers requested first position in lines. This request had also come up when mothers discussed medical and dental care for their children. It was common to hear the complaint that others did not wait their turn in line, so the task of taking a child for care was more daunting because of the extended wait in lines.

Public Service Announcements on TV

Finally, it was suggested that public service announcements on TV would benefit the community. Buthaina shared her novel idea. “We need programs on TV that will encourage public awareness about kids with disabilities and their needs because there are many people who see them differently and special programs would make people aware of these kids” (Interview 7, card 22). Suheir did not think lectures and lessons were the way to enlighten the community about issues affecting those with disabilities. “People would not listen to lectures and lessons. They need someone like Nancy Ajaram, Hayfa Wahabi, and Elissa (popular singers)! These people need to sing about people with special needs and people would listen to them!” (Interview 37, card 41).

*Non-tangible Needs**Acceptance by Families*

It was mentioned that some families with children with disabilities did not accept the disabilities of their children and, therefore, did not seek resources for them. This led to a perceived need for greater acceptance of children with disabilities.

There are many children with disabilities but we don't know about them. They have to look for them and get together with the families and don't let them come to school with the maids or drivers. I feel sad when I see children who only come with their maid (Samah, Interview 2, card 23).

"I know some families who have disabled children. They sit at home all the time and they don't think of even having another child. Instead, they should choose to be an example for everyone" (Manal, Interview 22, card 18). Nojood, who was no longer with her husband, said, "We need the love of relatives and they need to be hand in hand with [us] in the community to help" (Interview 8, card 23a). "I learned from [the United States] that the mother should be the advocate for her child in the community" (Lama, Interview 36, card 11).

There are some children whose parents are ignoring them and not taking good care of them. They say [their children] are not worthy. I want someone to discover these kids and go to them in their houses because there are a lot of them just staying at home.

I know this family that really believes in God, but they refuse to admit that their child is disabled (Interview 2, card 21).

The total numbers of children with disabilities who did not receive any services or simply were not known to others in their community were unknown and most likely had not been discovered by the January 2007 disability survey sponsored by the Planning Council. It was evident that the concern that was raised by mothers about children who remained at home and did not receive any medical, educational, or therapy services was a vital point for the community to address.

Acceptance in the Community

There was acknowledgment of change over time regarding community-wide acceptance of children with disabilities in Qatar. However, there was also cognizance that there was still room for growth.

Twelve years ago in Doha there wasn't this awareness about these children, but because I was a teacher the other teachers helped me. I used to tell them about my son and they told me about this social and special care that was available here (Nafela, Interview 33, card 2).

"The challenge is how to get the community to accept him. In the U.S. they understand us, but here they don't" (Lama, Interview 36, card 9). "We have to enlighten the community because the child changes by receiving love and kindness" (Mashaal, Interview 34, card 30).

We have to support [kids with disabilities] and make them feel comfortable because if they are made to feel comfortable the community will feel comfortable. We need to solve this problem and not find a temporary solution (Muna, Interview 29, card 56).

“The government and the people [of Qatar] should know that these people [with disabilities] are part of the community” (Muna, Interview 29, card 50a). “It is the clever person who understands the importance of including them in the community. That is the best example to offer” (Nojood, Interview 8, card 7).

Shaymaa noted acceptance of her child in the community as one of her biggest challenges, next to Ziyad’s stubbornness. “When we go out everyone stares at him and they will say, ‘Oh, you poor child!’” (Interview 9, card 7). Shaymaa, when asked what resources Qatar needed, responded, “More awareness. Not to have this sad look on peoples’ faces when they see my son. Because he can do things that normal people could not do. He comes up with things that others do not see or do” (Interview 9, card 26).

“We should prepare the child for the work they will do in the future. Income is not important, but for [Khalid] to feel his value in the community is” (Gaydaa, Interview 12, card 23). I wish they had special places for them to work when they say we have to mix them with the community (Gaydaa, Interview 12, card 23). “As much as we say that the community is open, the children aren’t really comfortable when they are in public” (Manal, Interview 22, card 47).

The lack of community-wide acceptance and understanding of disability and the predominant idea that it was not okay when someone had a disability were the greatest barriers to community participation for both children with disabilities and their families. These attitudes promoted exclusion and perpetuated a spirit of rejection toward individuals with disabilities. Mothers wished to see a community that made way so that

individuals with disabilities could comfortably accept the role of “community member” and the benefits of inclusion that went with that role.

Inclusive Schooling

Qatar initiated minimal inclusion of children with mild disabilities into the local independent schools in 2003-2004. At the time of this study, children with moderate to severe disabilities, the majority of the student body at the Shafallah Center, could not be admitted into local independent schools. “I don’t have any important thing, but my wish is that they could mix with public schools so they don’t feel they are isolated” (Maryam, Interview 23, card 20). “Thank God! The building (Shafallah Center) is beautiful—but the productivity of the center and change needs to be different” (Gaydaa, Interview 12, card 21).

Saiba shared the one resource she thinks Qatar needs for children with disabilities:

That they mix them with children without disabilities. For example, they should mix the schools. They should offer them whatever they need. They should value kids with disabilities more so they are not treated like they don’t have a mind (Interview 20, card 12).

Maryam and Saiba were the only mothers of the study who specifically suggested that community integration take place in the school setting. They believed that children with disabilities should have the opportunity to attend local independent schools other than the Shafallah Center. In inclusive communities it is a common practice to initially

integrate children with disabilities into their community by placing them in the school setting with their same-age peers without disabilities (Odom, 2000).

Widad had a simple request highly dependent on the resources available in the community. “I want [Wafaa] to be happy and to see all of her needs being met. I want to see her develop to her full potential,” (Interview 10, card 13). Not only did mothers have many opinions about people and tangible places and resources that were needed for their children with disabilities, but they also shared ideas of non-tangibles that they believed were essential to further the cause of community integration for their children.

Mothers reported a desire for the provision for themes that have been imbedded throughout this study. Genetic testing reflected a desire for mothers to know of disability sooner and for their children to receive interventions earlier as was reported by mothers when they first learned of their children’s disabilities. Special schools, medical facilities, and doctors reflected the desire for individuals within the community who were trained to work with children with disabilities and mothers even reported a desire to be better trained themselves about topics concerning disability. Many mothers reported teaching their own children without any special training, often due to the perception that their children were not receiving enough training and/or education. Furthermore, there was a desire for special family centers, clubs, and play centers that were exclusive to families of children with disabilities. This reflected the negative attitudes that mothers reported from others when visiting these places within their community. Finally, to make way for their children with disabilities, mothers requested more financial assistance, privileges, and awareness campaigns on TV for the community that would help to change the

perception of disabilities. Mothers reported a reliance on governmental intervention to solve the difficulties associated with community integration. Furthermore, mothers voiced their requests that government leadership steer the community towards positive perceptions of disability, which mothers did not believe they could attain themselves.

Summary

Results from the data showed various impacts of disability on families. These data reflected a lack of resources in a community where mothers expressed a desire for a more inclusive atmosphere for individuals with disabilities. Insufficient services were perpetuated by consistent misdiagnosis or failure to recognize a disability by medical facilities, which led to a delay for families to receive necessary medical and academic supports. The need for frequent medical visits by families typically led to fear in children with disabilities of medical facilities, staff, and procedures. The lack of understanding of disability that was consistently reported by mothers further exacerbated those fears. The pervasive need for community resources, such as genetic counseling, appropriate medical facilities and care, as well as appropriate and inclusive schooling opportunities was reported. Evident in responses was a thread of fear about the future due to poorer academic and medical services, especially those available to those in rural areas.

Academic services and leisure opportunities provided by the Shafallah Center were the primary service within the community for children with disabilities. Mothers often noted that a ramification of disability was not only fewer opportunities for community integration for their children with disabilities, but the entire family usually became less involved in the community. A common reason for this was the level of

support necessary to take children into the community. It was believed that the community had a limited sense of how to accommodate and accept those with disabilities. The negative treatment families commonly experienced by community members led to social isolation of families because of their children's disabilities.

Since mothers had few places to take their children besides the Shafallah Center, where specialized support was available, they were deterred from taking their children into the community. Mothers expressed that they considered the community less than understanding and welcoming. The exception was in the case of mothers who had a more positive outlook about their children with disabilities and advocated for them to have a place in the community. Furthermore, some mothers with fewer coping skills did not feel comfortable taking their children out or did not find it valuable to do so.

The limited communication skills of children created challenges for community integration. This occurred either by hindering interactions when in the community or by causing others to believe that because communication was limited, there would be no benefit from community integration. Daily life most frequently solely included interactions with immediate family or other students at the Shafallah Center. Community programs were both limited and desired. Mothers expressed a desire for a deeper sense of community awareness of the abilities and needs of those with disabilities.

Besides activities at the Shafallah Center, leisure included common activities like shopping or watching TV. This was due in part to the fact that not all leisure activities, such as attending sports clubs or after school programs in local general education schools, were open to those with disabilities. Mothers noticed that social learning

occurred at school, whether or not they viewed it to have a positive or adverse effect on their children and their behaviors. Leisure activities for which children participated were either with their families or through the Shafallah Center. The center served as the primary resource for services and access to experts in the area of disability in a community necessitating an abundance of added disability services and community integration opportunities for children with disabilities. These topics will be discussed further in Chapter V.

Chapter Summary

A clear definition of *community integration* needed to be clarified to mothers prior to interviews. The question might be what mothers' perceptions are of where their children are accepted members of a group or community and where their presence is not devalued because of their disability (Chapter I). It is important to note that prior to data analysis the thought was that mothers would discuss more about places where their children were integrated with children without disabilities, but it was rare to find many interactions beyond those with siblings and cousins without disabilities or other students with disabilities at the Shafallah Center. While the area should be further studied, it was difficult to find true examples of community integration in Qatar.

Figure 1 contains a graphic representation of the themes that emerged from data analysis. This diagram exemplifies how categories emerged and how the thematic categories were constructed. The graphic display was created to show the final themes and subthemes represented in Chapter IV of this study and how they are related. It should not be considered a theoretical model.

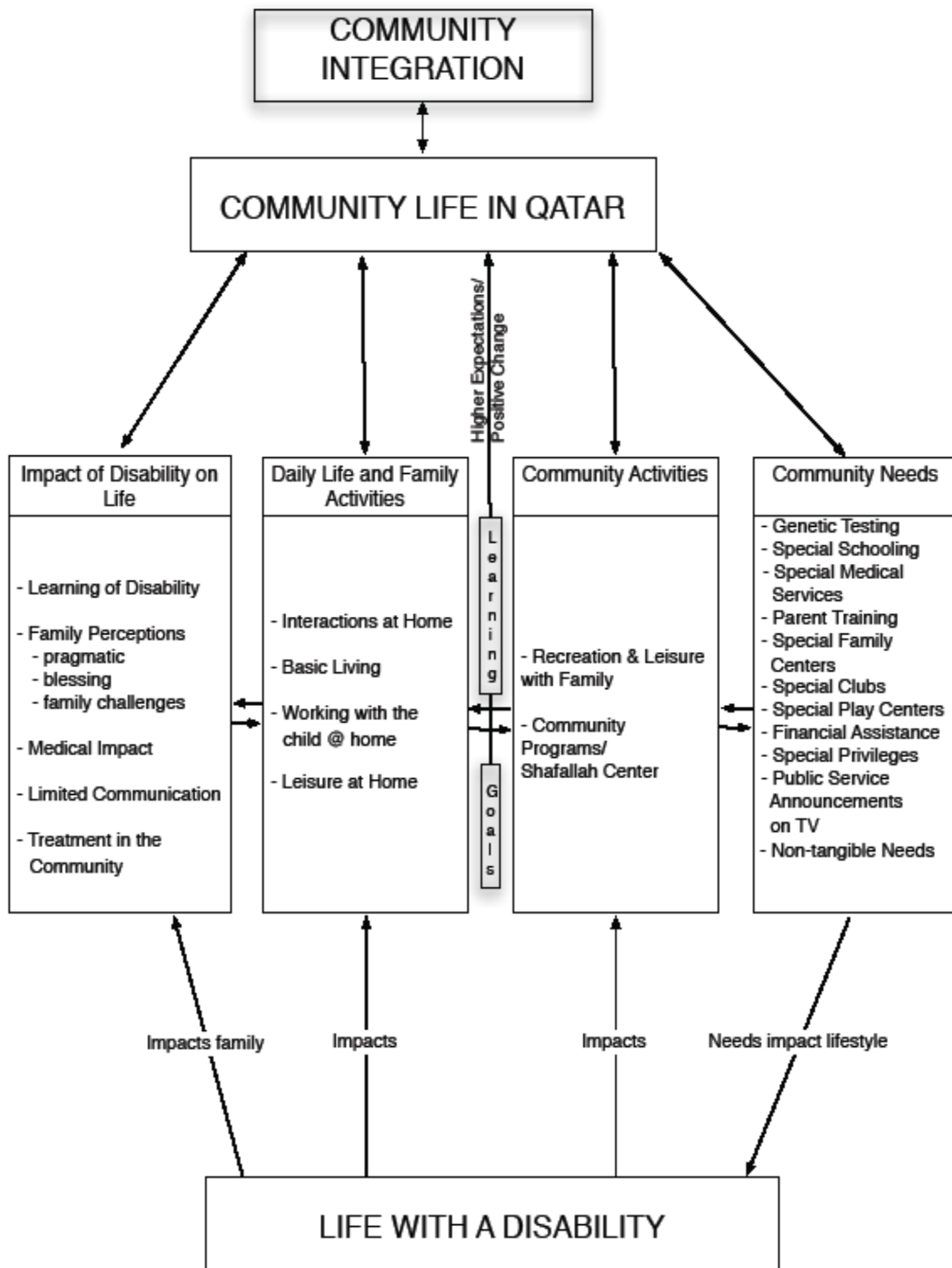


Figure 1. Relevant themes.

CHAPTER V

DISCUSSION

This chapter contains a discussion of the analyzed responses of Qatari mothers regarding community integration for their children with disabilities. Conclusions drawn from the data set presented in Chapter IV will be presented and discussed in terms of how they answer the research questions posed as well as their contributions to existing related literature. In addition, implications for future research on disability issues in Qatar will be suggested.

The purpose of this research was to further the understanding of the awareness and knowledge that mothers had of their children with disabilities in Qatar and of how their child's disability impacted the family. The study was designed to answer the following questions:

1. What has been the impact of disability on the family?
2. How does the child participate in family activities?
3. How does the child participate in community activities?
4. What do mothers suggest to improve opportunities for their children in Qatar?

Reported family interactions within the home and the community as they pertained to the disability of the child were analyzed. Mothers reported on the opportunities they believed were most needed in their community for children with disabilities.

Within Qatari culture, as in all culture, there are differences amongst individual experiences. It is important to recognize that this study represents the views of 40

mothers whose children with disabilities who were all receiving services at the Shafallah Center. These views are likely to be different from those of mothers whose children with disabilities were not receiving any services; therefore, it cannot be assumed that the views that were expressed represent the perceptions of all mothers of children with disabilities in Qatar.

Answers to Research Questions

The following are the results from the analysis in Chapter IV discussed according to each of these research questions.

Research Question 1: What Has Been the Impact of Disability on the Family?

Disability impacted how involved families would or would not be included in the community. Turnbull, Beegle, and Stowe (2001) recognized the impact on lifestyle of each member of a family due to disability. The disabilities of children in this study affected a gamut of changes necessary for family members; brought unique perspectives on positive and challenging aspects of having a child with a disability; and brought to the attention of mothers a slew of other concerns, such as education issues, medical issues, communication issues, treatment options, recreational and leisure possibilities, and adjustment to treatment by community members of the family because there was a child with a disability in the family.

Learning of a Disability

Mothers commented that close familial marriages were preferred in their culture and that one of the ramifications of that custom was that the birth of a child with a disability was a more common occurrence in Qatar, as it was in other Middle Eastern

countries with similar social practices (Alghazo and Gaad, 2004). Epilepsy, asthma, diabetes, and mental retardation were the most common of all health issues related to interfamilial marriages (Bener & Alali, 2004). Nevertheless, mothers expressed shock when they learned that their child was born with a disability. Some mothers were reluctant to admit that their children had disabilities (Interview 29) or shared how they could not tell their family members (Interview 23). Mothers described how they had received incorrect or insufficient medical information (Interview 6). There was a belief that the stigma attached to disability made it difficult to integrate their children with disabilities into the community (Interview 9).

Medical Challenges

As mothers discussed how they first learned of and accepted their children's disabilities, medical issues were made evident. First, the diagnosis of a child's disability was usually delayed and prompted by mothers' own observations, rather than by a referral by medical personnel. It was not uncommon for mothers to seek several medical opinions before they discovered what their children's needs were, often due to the fact that medical professionals frequently misdiagnosed or neglected to diagnose disability. Most mothers believed doctors in Qatar were not aware of how to treat children with disabilities.

In Qatar services were offered to families only once there was a medical diagnosis of disability (personal communication, F.A. Taher, February 15, 2007); however, some families chose not to receive services due to the social stigma and perception of shame attached to disability (personal communication, F. Darwish, March

7, 2007). If doctors were not able to diagnose the existence of disabilities, children were unable to receive services. In general, these birth stories brought to light the problem of delayed or inadequate diagnosis by doctors.

Pragmatic Adaptation

When asked about changes brought on by disability, 13 mothers claimed there were no changes in their family interactions following the births of their children. Some of these mothers said that they considered their children's disabilities to be normal and any changes brought little to no impact to the family. This tendency to use "normal" as a descriptor for a child with a disability seemed to be a function of the pressures of living in a society where disability was not widely accepted. It appeared as a function of denial of disability (Lessenberry and Rehfeldt, 2004; Finlay and Lyons, 2005). Dybwad (1968) stated that the most basic step of integration is community-wide normalization of disability; however, Salhab (2006) noted a general lack of awareness about disability in the Qatari community.

As mothers comprehensively described their circumstances, the overall impact of disability and the changes that had occurred in their lives and the lives of other family members became more evident. Mothers gave examples of their difficulties finding treatment for their children with disabilities and their difficult experiences with hospitals (Interview 10), their desire to normalize their children with disabilities (Interview 13), their decision to stop having children after having multiple children with disabilities (Interview 5), their changes to the routine and physical space in the home (Interview 37), and their life-long responsibility to care for their children with disabilities (Interview 2).

Positive Impact

Some mothers expressed how their lives were impacted positively by disability while raising their children. These included: increased faith in God, increased patience, newfound relationships with other individuals who were familiar with disability, and greater growth and knowledge as they experienced raising their children with disabilities.

Increased faith. Some mothers perceived positive impact in the form of spiritual or character growth. Religion was a strong factor in the coping abilities of mothers. The ability of these mothers to cope in an otherwise unwelcoming environment seemed to rely greatly on their belief in God. They perceived both their spiritual lives and their character to have been strengthened by disability. Their reaction could be viewed as a coping mechanism necessary to accept disability in a culture where disability was not easily accepted.

Increased relationships. Many stories about life after a child was born with a disability cited reduced maternal socialization with family or friends. A few mothers reflected on their relationships with school personnel, perhaps due to the personal support that these individuals offered. Encounters with other mothers with children with disabilities, doctors, or teachers were described by mothers as being helpful support. In a study by Todd and Jones (2005) the authors related how mothers of children with disabilities received considerable support from service professionals while facing the seemingly insurmountable changes and challenges associated with raising a child with a disability. This social network was an important factor in the ability of mothers to

advocate for their children. This was a defining difference between mothers whose children were receiving services and those mothers whose children were not receiving services.

Wickham-Searl (1992) recognized that mothers who had the necessary social supports were those most likely to advocate for their children with disabilities, for example, much like the mothers of children with disabilities in the United States who achieved the passing of legislation to provide free, public education for everyone. Those mothers who had better supports also seemed to have a more positive outlook toward their child. The mothers of children at the Shafallah Center had a platform from which to advocate for their children with disabilities, while the mothers of those children who were at home and had not been accepted from the waiting list at the center did not. Perhaps those mothers who still kept their children at home would have a different perception. Some mothers in the study reported that they had limited interactions with those outside of their families because of their children with disabilities.

Having a child with a disability also was found to impact the relationship some mothers in this study had with their children's fathers. Contentment was expressed by some mothers due to the growth in family cooperation or due to better relationships with their husbands after the birth of a child with a disability. However, Azar and Badr (2006) noted a lack of engagement by fathers in Middle Eastern communities and several mothers in this study confirmed this view. The findings of this study provide further support for the lack of engagement of fathers in the Middle East as the study conducted on family dynamics by Azar and Badr (2006).

Personal growth and knowledge. Mothers mentioned several additional positive points about their children's disabilities. For example some mothers reported that they gained more knowledge about disability, they were better able to cope with problems, and they believed raising a child with a disability was their lives' purpose. Green (2003) similarly discovered in interviews with other mothers of children with severe disabilities that the sharing of their children's stories led to personal growth of the mothers and fostered their will to advocate for their children.

Challenges

Mothers also noted challenges in dealing with their children. Some of the biggest challenges for mothers were the lack of interventions, delayed interventions, and perseverating medical issues. Delayed interventions, along with statements of self-blame for not noticing the need for an intervention, were mentioned by most of the mothers. Many mothers expressed the deleteriously high pressures that they faced on a daily basis. These findings were similar to those of other studies. Challenges included negative social interactions, negative societal attitudes towards disabilities (Blaska, 1998), extremely high maternal and family pressures (Lessenberry and Rehfeldt, 2004), and lack of support from a family's closest social network of immediate and extended family (Azar and Badr, 2006). These issues reinforced the fact that the community needed an outlet for respite care for those who were raising children with disabilities.

Difficulties achieving community integration. For the 27 mothers who did feel there were many changes brought to their families by their children's disabilities, they primarily reported that it was very challenging to take their children out into public.

Most of the 13 mothers who said there were not many changes also felt that it was challenging to take their children into public. The most common reasons that mothers felt being in public was a challenge were negative interactions with community members, feeling pressure to defend children in public, embarrassment by children's inappropriate behaviors, and the response to these behaviors by community members. Other mothers described how they sent their children on outings with drivers, maids, or siblings or they simply rarely went out in public with their children with disabilities. Therefore, this study revealed that nearly all of the mothers in Qatar who were interviewed perceived being in public with their children to be a difficult challenge. Under those circumstances it was difficult to assume that true acts of integration took place within the community for children with disabilities.

An overarching theme expressed by mothers was that children with disabilities were not understood by the community and this impeded the integration of their children into the community. Mothers believed that families of children without disabilities did not teach their children to accept those with disabilities. Mothers also believed that children without disabilities often excluded those with disabilities. Different mothers commented about negative reactions in the community to children with disabilities, such as staring, pity, and otherwise ill-treatment in places that were common for mothers from the general population to visit with their children, such as the Corniche, play centers, or the grocery store. The impact of societal rejection because of disability was painfully tolerated by most mothers of the study. Most of the families did decrease visits out into

the community rather than face reactions that were difficult for mothers and their children to bear.

Not only did most of the mothers report little integration into the community for their children with disabilities, but reported that their families as a whole also became more isolated after the child's birth. Similarly, Azar and Badr (2006) noted the extreme social isolation experienced by families with children with disabilities in Lebanon due to the social stigma of disability. Similar to Lebanon, this general perception of disability impacted how the family was perceived and treated when in the community in Qatar. Furthermore, mothers in Qatar expressed that the impact of the stigma attached to disability made its impression on each family member of a child with a disability and affected their children with disabilities emotionally, mentally, socially and academically. This loss of opportunity for children in their family seemed one of the most pertinent points of grief for mothers.

In general, mothers believed they could not take their children out in public due to the negative societal attitudes that they experienced. This perception of mothers in Qatar aligns with Dembo, Leviton, and Wright's (1975) conception of "disability spread" in which the community's focus is on disability rather than ability. Perhaps mothers who were not able to take their children with disabilities to the Shafallah Center felt even less able to take them out into the community. The belief that children were not accepted and numerous other challenges of making community outings possible led to a reduction in family outings. Mothers reported difficulties with limited involvement from other family members, transportation issues, supervision issues, and the social stigma

present in the community. Limited outings with those with disabilities were explained by mothers as primarily due to cultural stigmas, such as the disability being labeled as punishment from God for wrongdoing by parents and issues of heritage and succession that could impact family circumstances in marriage. These issues perpetuated a tradition of sheltering disability within the Qatari community.

Mothers' inability to accept disability. Mothers in Qatar expressed their desire for normalization in ways that were sometimes contradictory: They questioned whether or not they perceived disability to be normal and whether or not disability was dignified. Reynolds (2006) studied disability in Egypt and concluded that reforming society to accept individuals with disabilities was an elusive goal because, much like Qatar, the focus was on normalizing the person with a disability rather than changing community perceptions to accommodate those with disabilities. "Silent" barriers like negative attitudes and negative facial expressions from community members were the most powerful barriers to community integration. True integration was seemingly so difficult that mothers questioned the thought of involving their children with disabilities in the community.

Isolation of the family. Blaska (1998) noted the importance of a circle of friends to provide support to mothers because of the pressure prevalent in raising a child with a disability. This support system was highly lacking in the Qatari community for mothers of children with disabilities. Some mothers found difficulties in maintaining friendships while raising children with disabilities either due to the specifics of their children's disabilities, such as inappropriate behaviors or health issues, or other cultural issues. For

example, it would be culturally inappropriate for adolescent boys and girls, who would be considered marriageable, to mix. Mothers typically could not take a teenage son to the home of a female friend or cousins of marriageable age because it was considered culturally inappropriate. Therefore, if a mother of an adolescent with a disability wished to visit a home where there was an adolescent of the opposite sex then it would be inappropriate for the mother to visit unless she left her child at home. Mothers described that this was difficult to do because of concern for their child's health and safety.

Visiting was a less complicated issue for mothers who were able to leave their children at home, typical of mothers of children who did not have disabilities. Qatar maintained a segregated community with cultural age and gender barriers which seemed the most prominent factor in determining community integration or segregation of teenage children with disabilities in Qatar. Limited social visiting was a barrier to relationships and community integration in an Arab society where socialization, especially amongst family members, was highly regarded (Clarke, 2007).

The challenge of change. Most mothers expressed that changes in their lives had come due to their child's hospital treatment, limited cognitive development, and/or worsening health. After the child's birth, household routines or the environment usually changed, for example, schedules accommodated the care needs of the child with a disability or a house was modified so that it became wheelchair accessible. The diverse experiences that mothers had, related to their change and their children's needs, were valuable to support future advocacy with the potential to lead to positive change in Qatar, similar to that exemplified in the study by Wickham-Searl (1992).

Fathers' inability to accept disability. Some mothers expressed how their husbands had reacted differently to the births of children with disabilities. The extant literature explained the negative reaction of some fathers to disability in Middle Eastern societies. In Egypt the thought was that an individual must change to be more "normal" in order to fit into society (Reynolds, 2006). Others have observed that culturally imbedded shame and rejection are a unique part of Arab society and these feelings encourage the denial of disgrace and the protection of dignity in order to benefit the family unit (Finlay & Lyons, 2005; personal communication, F.A. Taher, February 15, 2007). Finlay and Lyons (2005) might have explained the rejection of labels by mothers in Qatar as a denial process that helped mothers to protect their self-esteem in a community that was unrelentingly harsh to those with disabilities.

Some mothers commented that fathers did not attend parent training about disability with their wives at the Shafallah Center, and suggested that this behavior reflected a paternal lack of acceptance of and responsibility for the child's disability. Extremely low participation was reported of fathers in daily living tasks such as feeding, bathing, and dressing of children with disabilities. This lack of involvement by Middle Eastern fathers of children with disabilities (Zahr & Hattar-Pollara, 1998, as cited in Azar & Badr, 2006) impacted the entire family system. When mothers were asked about family activities, few shared stories of interactions between their husbands and children with disabilities.

Lifelong needs. Mothers described the lifelong care needs for children for which they expected to be responsible. Mothers' expressed how their families were impacted

by the fact that someone would always need to be there to care for a child with a disability, including siblings when parents were no longer around. The current situation was counter to culture, since typical families may rely on a child to care for parents in later years. Blaska (1998) noted the difficulty parents had to accept the circumstances when they had a child with a disability, which included considerations for long-term care in Qatar.

With the expectation that care of children would extend beyond adulthood there was a strong desire for more community-wide acceptance and support, so there would be other willing individuals or community resources that would provide care for individuals with disabilities once the parents were no longer able to do so.

Impact on siblings. Mothers expressed that other children in the home were negatively impacted by changes in the routine that were required for children with disabilities, such as scheduling or what family members could and could not do or could not eat in order to accommodate a family member with a disability. Although siblings in some families were given the responsibility of helping with a child with a disability, in other situations it was implied that in some cases siblings did not understand or accept the disability of their own sibling.

A sibling might eventually be responsible for a child's care. Also, a sibling could have trouble marrying if others knew of a family member's disability (Reynolds, 2006). Negative attitudes by close family members toward disabilities added to maternal pressures in a society where the family usually provided the strongest social support system to its extended members. Azar and Badr (2006) noted that there was little data

published in the Arab world about how families dealt with the occurrence of disability in their families, although the highest rate of disability was in developing countries (Karam, et al., 2006), like Qatar.

Segregation by choice. A provocative implication that stemmed from the hierarchical system was a philosophy that segregation was best. Some mothers perceived segregation was safer. Mothers made comparisons to other countries where independence for those with disabilities was encouraged and freedom to traverse without stares from onlookers was observed. Mothers reported the challenges they faced to overcome a deeply rooted sympathy-focused mentality toward those with disabilities in Qatar (“More NGO Efforts”, 2006). This mentality was far reaching because it was imbedded in mothers’ comments about the response received from others when on family walks along the Corniche or in malls, in the doctor’s office, or at school. Perhaps mothers chose segregation as an easier path than to purposefully include their children in the community.

Research Question 2: How Does the Child Participate in Family Activities?

Daily Life and Family Activities

Mothers remarked about a variety of different activities that their children enjoyed participating in at home with family. Stories of daily life included descriptions of interactions with children with disabilities at home; basic living activities, including feeding, bathing, dressing, toileting; and disciplining children with disabilities, as well as keeping them safe from harm. Mothers also discussed how their children worked and

relaxed at home as part of typical family activities. Mothers' stories predominantly portrayed life in the home and few family activities out in the community in Qatar. For children who did not receive educational services, such as at the Shafallah Center, it is likely that there were even fewer opportunities for family participation in activities in the community.

Routines of daily living. Routine activities included prayer time together, eating, and time spent with siblings or cousins; these were activities common to those with and without disabilities alike. Mothers shared happiness seeing their children play with other children and copying the positive things that other children did. Mothers noted that some children with disabilities did not go out into the community often or on a routine basis with their families and that the children with whom they interacted with most were their siblings or cousins.

Mothers responded about their children's routines when waking up, napping, going to bed, eating, and going to the bathroom. The most common behaviors noted were tantrums, food stealing, or pedantic or ritualistic behavior. Mothers stated different levels of discipline in response to these behaviors, such as same punishment as siblings, rewards of food for good behavior, or the promise of trips out into the community.

Typically, male children were able to go out in public more easily than female children with disabilities in Qatar, due to cultural gender issues. Mothers had to rely on their husbands, sons, or a family driver to take them out into the community with their children. Children's behaviors in the community were not appropriate at times. Reluctance also stemmed from the barriers to acceptance that made community

integration difficult, as discussed in previous sections. These included: the history of hiding those with disabilities, the lack of options for participation within the community, and the stigma attached to individuals with disabilities and their family members.

Changes in the household. Mothers reported that they had to safety-proof their homes for their children with disabilities so that they could safely interact. Sharp items, TVs, glass, and mirrors were removed or placed out of reach. Refrigerators, doors, and windows were locked in some households. Several mothers taught their children about items that can be dangerous, such as electricity and matches, and one mother preferred that her child not cross the street while playing. The impact of fear for a child's safety was imbedded in the responses of mothers about family challenges of daily living. Medical, communication, and safety issues were at the forefront of mothers' thoughts. These concerns were similar to those expressed in a study of mothers of children with disabilities in Texas (Abbs, 2005). In Qatar mothers seemed to focus on teaching their children about dangers and to compensate for the specific instruction that children may not have received in school.

Learning activities. Homes were often the place where instruction first started. If children did not initially have a place at the Shafallah Center, their other options were limited, so many started any academic training at home. Mothers reported that in Qatar parents were less likely to declare that their child had a disability if the disability was not immediately evident, because most general education schools turned children with disabilities away (personal communication, M. Al Rwaili, February 12, 2007).

Instruction of children at home was the responsibility of mothers, siblings, and/or hired educational assistants.

Household chores. Few children with disabilities were expected to do chores, such as cleaning, folding clothes, retrieving items for others, and taking out the trash. Mothers responded according to their perceived ability level of their children, but some mothers had higher expectations for their children to carry out household chores despite the existence of a disability. The researcher realized that most cleaning or household chores were the responsibility of maids in the home; therefore, far fewer children in the general population participated in chores at home than might have been typically expected. It was probable that the few children in the study who did hold the responsibility of completing chores in the home may have been from one of the four households that did not have a maid, since maids typically cleaned the house and cared for the children in the household.

Household responsibilities for children with disabilities may help to establish a sense of responsibility that will later assist those children in transition activities that will lead to employment. If children with disabilities were to have practice with responsibilities within their homes, they might have been better prepared for future employment opportunities. There seemed to be a lack of motivation to teach the children to obtain work skills or to have them do chores since outcomes were limited for children with disabilities. Furthermore, mothers reported low expectations that their children would work in the future.

Relaxing at home. Leisure activities at home fell into several simple categories. Daydreaming and drinking tea were noted as past times for some children while at home, but watching TV, playing with toys or playing on the computer, and gardening or simply watching the gardener were the activities that most frequently emerged. It was common for mothers to describe that their children played by themselves when they were relaxing at home, rather than with other family members. In the general population tea drinking and watching TV were common activities. Mothers noted that their children without disabilities commonly played with friends and visited places outside of the home, especially shopping malls. Perhaps the community response to disability encouraged solitary activities at home for children with disabilities.

Hired help. Mothers with maids told how frequently children interacted throughout the day with maids who worked for the family. Employment of maids to assist families was very common of the general population as well as the mothers of the study. Maids lived with and cared for most Qatari children with and without disabilities, usually with little time off work. The oil-rich Gulf Region has been employing migrant workers under these poor conditions for several decades (“Migrants”, February 28, 2009).

The typical salary for a maid working for a local family in Qatar was approximately 400-700 Qatar Riyals (\$109.59-\$191.78) per month and contracts were usually for two years of service. During this time a maid lived far from her home country. Maids were relied on and expected to help ensure the children’s safety. Not only did maids take part in lessening the impact of disability on the family, but they also

made it possible for children with disabilities to be involved in family activities for which they may not otherwise have been included. Maids filled the role of “primary caregiver” in many areas of care for Qatari children with disabilities; whereas, in other cultures that role is held primarily by family members.

Besides providing typical care for children, there was a great reliance upon maids to fulfill the typical parental role of disciplining children. Maids were put in a position as friend, caregiver, and disciplinarian for the children with whom they worked.

Research Question 3: How Does the Child Participate in Community Activities?

When families went outside of the home children’s disabilities impacted the level of community integration that was possible. Mothers described the difficulty of going out in public as a family; the need for added assistance to do so; common places to visit, such as homes of extended family; travels outside of Doha or abroad; popular places like grocery stores or malls; and a few mothers shared stories of fathers taking children into the community. Mothers also described their ideas about what community programs were available and how children with disabilities participated. Most mothers stated that there was only one community program and described their children’s experiences at the Shafallah Center.

Family Outings within the Community

The occurrence of activities in the community for children with disabilities predominantly consisted of varying levels of interaction with immediate and extended family. Responses of “rarely go out” and “never go out” were given by mothers repeatedly. Mothers reported that there were not many places to take their children with

disabilities, while it was very common for children without disabilities to be out in the community in the evening with their families.

Family activities most commonly included trips to the homes of close relatives, local malls, play centers, parks, the market, video stores, the Corniche, the desert, the beach, or a family farm. Family-centered activities were the most common form of community activities, which was typical in a culture where immediate familial relationships were not impacted by gender segregation. However, these activities did not typically include interaction between the child and other children out in the community. For example, when mothers shared how they took their children with disabilities to the desert, at the beach, or to the family farm other children outside of the family were not mentioned, nor were playmates brought along for family trips. Children without disabilities had interactions with other children in school and after school, while children with disabilities, were restricted in their interactions.

Community Programs

The most unclear phenomenon was the idea of available community programs. The idea of including and educating children with disabilities in Qatar was a very new field. In 2004 preliminary efforts for inclusion in schools began, but although children with disabilities could attend school, there opportunities typically were not in inclusive settings if there was room for them in schools providing services (“Country Reports,” February 25, 2004). In the history of education in Qatar, children with disabilities had remained segregated and this also was reflected in community programs. Culturally, there was not a mission to tailor community programs for all children with or without

disabilities. The lack of awareness about disability, lack of easily accessible facilities in the community, limited number of educational programs for children with disabilities, and few post-school options for children who completed the available programs at the secondary level (Salhab, 2006) meant there were few programs and activities for individuals with disabilities in Qatar. The majority of mothers responded that there were no programs available for their children.

Mothers mentioned the rarity of community programs for children with disabilities and others responded that the Shafallah Center (a center-based school) was the only community program for their children. The challenges imminent in including children with disabilities in the community, when programs simply were not available, further impeded a change in community perceptions and interactions referred to by Giangreco (2006): If children with disabilities were not typically seen in the community in Qatar it reinforces the idea that they were not meant to be out in the community.

Shafallah Center. Twenty-nine mothers said that the Shafallah Center was the only community program available for their children; although, it was really a school setting. The researcher hoped to hear about more specific programs such as after school sports, music, arts, and crafts that offered adaptations for children with disabilities. Culturally, for those who were fortunate to have a place at the Shafallah Center, parental expectations had been met at the most basic level. For those whose children did not receive services at the Shafallah Center there may have been fewer ideas about how children with disabilities were integrated into the community.

Mothers mentioned training provided by the Shafallah Center for parents, which were not directly in reference to programs for children with disabilities. Mothers shared that there were events scheduled at the Shafallah Center, for example birthday parties or trips out into the community. There was hippotherapy, and physiotherapy provided through a local hospital. These activities were typical for a center-based special education school, but offered limited opportunities for varied interactions in the community. Mothers of children with disabilities expressed a desire for more parent training for themselves and more opportunities for their children.

At the time of interviews the center was able to serve approximately 200 children, but there were 300-400 more children on the waiting list. According to the numbers on the waiting list, there were many children with disabilities in the community who were most likely not receiving any suitable educational instruction according to their abilities.

The education system in Qatar did not allow for smooth inclusion and integration of children with disabilities into the general education setting, especially for students with severe disabilities. Alghazo and Gaad (2004) found that the isolation and separation of those with disabilities was common in the Middle East and that these beliefs made integration into the school setting exceptionally challenging. This was reflected in the perceptions of mothers of children with disabilities in Qatar. In several situations, due to family fears about including a child in the community, children started school later than their counterparts without disabilities, and mothers strove to obtain placements for their children on a special education campus.

Similar sentiment was expressed in a study of interviews carried out by Gaad (2004) of mothers of children with disabilities in the UAE and Egypt. The research described that in the recent past children with Down syndrome in Egypt remained at home due to rejection by individuals without disabilities in the community. Similar to that of the UAE, the community response to disability in Qatar was less accepting of disabilities, particularly intellectual disabilities, and similarly, children with moderate to severe disabilities were not admitted into the general education system provided in the local schools (Gaad, 2004). This exemplified segregation by choice of parents of children with disabilities within the culture. Regret was expressed by almost all of the mothers that their child with a disability would never attend a general education campus with peers, yet there seemed to be a level of comfort expressed because their children with disabilities would not have to navigate the unwelcoming system.

Segregation by choice. The idea that social pressure in an inclusive setting would be too extreme seemed related to culture and the prominent idea that those with disabilities typically were pitied in Qatar. In Qatar the process of inclusion was formed by unprepared schools and untrained teachers when it did occur. Schools were not mandated to provide services to children with disabilities and could turn them away if the necessary services were not available (personal communication, M. Al Rwaili, February 12, 2007). In a study by DeFossett (1999) one of the necessities of inclusion of those with a disability is a welcoming classroom in a school where he or she would normally attend if living without a disability. However, mothers in this study perceived

inclusive education settings were not appropriate for their children or that segregated settings were safer for them.

Reduction of Community Activities

Mothers reported that they tended to reduce their own social visits because of their children. Mothers refrained from the most common leisure activity “visiting” because it became too difficult with a child with a disability. The cultural impact of reduced social visits was that mothers of children with disabilities had fewer relationships and support (Green, 2003) and their children also received less exposure to other individuals without disabilities in the community. Mothers who are well supported are better able to positively influence the progress of their children with disabilities (Lessenberry and Rehfeldt, 2004).

A reason that mothers reported not being able to take their children out in public, due to fathers’ inclinations, was that the family was dependent on the father or a family driver, with the father’s permission, to provide transportation for any outings. Perhaps the fact that many mothers could not drive lessened the potential number of opportunities for integration into the community for children with disabilities. Perhaps community access would be more plausible if children with disabilities had access to community transportation specific to their needs or bathroom facilities that were easily accessible with enough room for an assistant to join someone.

Further problems included issues of discriminatory inaccessibility, such as social clubs not allowing maids or, in one case, a child with a disability, to enter an establishment. The goal of the office of Sheikha Hissa bint Khalifa Al-Thani, a Qatari

and U.N. Special Rapporteur on Disability, was to remove social barriers allowing persons with disabilities full access to resources and to make known within the community the contributions of persons with disabilities (“Plan Drafted,” October 3, 2004). Assessment of the current situation in Qatar and active promotion of policy and public awareness are needed for this goal to become a reality.

Perhaps the notion of the benefits of integration into the community remained too elusive. Mothers expressed concern about the development of their children’s skills, especially by example from other children without disabilities; however, mothers did not believe that individuals without disabilities were very accepting and willing to include those with disabilities in their activities. Characteristics that could be developed in Qatar through community integration are: 1) exposure to peer examples of social and developmental skills (Turnbull, 1982; Diamond & Hestenes, 1996); 2) promotion of acceptance and greater opportunities for same-age peer playmates without disabilities (Turnbull, 1982; Nabors, 1997, Costenbader, 2000), 3) provision of the opportunity to be in a like-setting with peers (Turnbull, 1982; Odom, 2000, Erwin & Guintini, 2000), and 4) opportunity for those without disabilities to become familiar with individual differences and to be sensitive to and accepting of them (Turnbull, 1982; Diamond & Hestenes, 1996).

Research Question 4: What do mothers suggest to improve opportunities for their children in Qatar?

One mother’s statement, “Shafallah is not enough. People are waiting” expressed the essential point. Mothers offered a variety of ideas about ways that community

integration opportunities could be improved, such as access to better medical care, schooling, and parent training. Some mothers also suggested special family centers, clubs, and play centers for both their families and their children with disabilities. Furthermore, some mothers requested more financial assistance, special privileges, and public broadcasts about the inclusion of those with disabilities into the community. Mothers hoped for greater acceptance by their own families and the community; some mothers extended that wish to greater acceptance from the general education school system for their children with disabilities. These desires expressed by mothers were very specific to the culture in Qatar and were not mentioned in the few studies available relating to the Arabian Gulf Region.

Mothers repeatedly noted a need in the community for increased services for children with disabilities. The Shafallah Center did not have the ability to meet the needs of all community members in need of its services. Mothers suggested a list of tangible needs that they noticed in the community beginning with a request for information about disability caused by close familial marriages.

Genetic Testing

Genetic testing was a requested need made in a culture where the most favored marriage was arranged for sons and daughters with a close relative. According to mothers, the profusion of developmental disabilities from this practice did not correlate with the limited information given to parents, before a child was born, about disability or the possibility of disability due to consanguineous marriage, so common within the Islamic Khalifate and a recognized problem in the area (Korotayev, 2000).

Medical practitioners knew little about disability and most likely also knew little about disability caused by close familial marriages. Mothers perceived that knowledge about consanguinity and its perpetuation of disability would better prepare families to make informed decisions. It seemed that mothers were not aware of the center in Qatar that provided checks for potential genetic issues in children born to Qatari parents, as the center had only served 30 couples from 2003 to 2006 (“Premarital Medical Health,” June 18, 2005; Nationals Call for Tests,” February 18, 2006). Perhaps the common practice of marriage between first cousins was such a foundational tradition of the culture that the potential outcomes for children born to those couples were overlooked.

Education

Mothers requested appropriate education in the form of a specialized curriculum for children with disabilities that might be used at either the Shafallah Center or in independent schools. Trained teachers and assistants were another need, as supported by the waiting list at the Shafallah Center. However, the country of Qatar had a severe lack of trained teachers in both special and general education. Staff of the Shafallah Center noted that the waiting list was due to the lack of qualified special education teachers who could speak Arabic (personal communication, S. Hannibal, June 7, 2006). Due to personnel issues, across the spectrum of ages there were very limited educational opportunities for those with disabilities in Qatar.

Community Leisure

When mothers answered questions about activities there were complaints that there were not many things for children with disabilities to participate in or those

activities were not accessible, especially to those with physical disabilities (Salhab, 2006). Mothers expressed their perceptions that recreation and leisure activities were not easily found in the community. Mothers requested special centers that could serve the entire family, sports clubs for exercise, special clubs for activities other than sports, and special play centers with interaction with children without disabilities and provision of assistance to children with disabilities, including those with physical disabilities.

Mothers seemed to conceive of the ideas for their suggestions based on what they saw that children without disabilities had in Qatar. These desires expressed by mothers were very specific to the culture in Qatar and were not mentioned in the few studies available relating to the Arabian Gulf Region.

Disability Incentives

Finally, mothers requested tangible assistance in the form of special identification, discounts, and priority service, such as first place in lines, as well as higher monthly funding. Mothers of children with disabilities in Qatar received a monthly stipend in the amount of 600 Qatar Riyals, the equivalent of \$164.38, which one mother noted was only enough to pay for the monthly assistance of her maid. Mothers also wished to see public service announcements on TV that would help to break down social barriers for those with disabilities. These desires expressed by mothers were very specific to the culture in Qatar and were not mentioned in the few studies available relating to the Arabian Gulf Region.

Acceptance, Awareness, and Support

Non-tangible needs were actually the necessary provision that seemed powerful enough to change other aspects of life in Qatar for those with disabilities, albeit more difficult to attain. Mothers said that although there had been a change in negative perspectives of persons with disabilities over the years, more change was still needed. In other Arab countries research revealed similar challenges. In Egypt the premise of denial of disability was prevalent (Reynolds, 2006) to avoid family disgrace and to protect dignity (Finlay & Lyons, 2005). In Lebanon family isolation was extreme upon the birth of a child with a disability (Azar and Badr, 2006). Acceptance, awareness, and support were the three primary requests. However, cultural issues in Arab culture seemingly made these desires difficult to attain: 1) succession by a child with a disability was not easily accepted in Arab culture (Khouzam, Chenouda & Naguib, 2003); a sense of resentment or ambivalence was common toward children born with disabilities due to the importance of heritage, especially in reference to male children (Khouzam, Chenouda & Naguib, 2003); and many superstitious beliefs surrounding the birth of a child with a disability stigmatized the family (Al-Fuhail, Al-Hamdan, & Suyyagh, 1993).

Mothers said that they wished for more preparation for their children for work once they became adults in the community. In spring 2007, inclusion of children with disabilities was very limited in the local independent school setting (personal communication, F. Al Madaadi, February 7, 2007). It was not a common practice for individuals with disabilities to be employed in the community. Mothers expressed a

desire for their children to be perceived as important individuals in the community who had the same rights as others.

Conclusions

Dembo, Leviton, and Wright (1975) addressed *disability spread* and its impact when society holds a focus more on the presence of disability in a given individual than on the abilities of the individual. In order to integrate individuals with disabilities and their families into communities within the Middle East in general and in Qatar, there needs to be a societal shift towards greater acceptance of those with disabilities. In the Middle East, disability label rejection seems an expression of denial to self-protect, which then leads to a distancing from group membership (Finlay and Lyons, 2005), not only for individuals with disabilities, but also for their family members. This distancing from community negates the importance that those without disabilities adjust to disability (Dembo, Leviton, and Wright, 1975). The idea that the perception of individuals with disabilities in the Middle East is focused on what those individuals cannot do perpetuates the stigma attached to disability and a sympathy-based mentality. This concept has also colored the Qatari perceptions that had been formed about disability over time. These beliefs appeared to be deeply ingrained even though Qatar is a member the United Nations that, in theory, abides by the International Convention on the Rights of Persons with Disabilities (United Nations, 2006). In spite of this, provision has not been made to increase programming in Qatar or to provide more activities for individuals with disabilities.

A problem with access to resources for those with disabilities in Qatar seems to be the incomplete application of the laws regarding disability that have been set in place (“More NGO Efforts,” 2006). In a National Human Rights Committee seminar in November 2006, Qatari adults with disabilities and parents of children with disabilities expressed a lack of awareness about disability, a lack of easily accessible facilities in the community, a limited number of educational programs for children with disabilities, and few post-school options for children who complete the available programs at the secondary level (Salhab, 2006). Mothers believe that any negative impact of disability upon the lives of these children and their families would be lessened if there were adequate and more enriching services available to them.

There has been slow progress toward equity for individuals with disabilities because of deeply imbedded precepts of culture, tradition, and religion in Qatari society (“More NGO Efforts,” 2006). These precepts established by culture and tradition impact each family who has a child with a disability born to them. The higher rates of disability in the Gulf Region are expected to continue because of the functional pattern between Islam and consanguineous marriage most prevalent in the region (Korotayev, 2000). Bener and Alali (2004) noted the drastic increase in asthma, mental retardation, epilepsy, and diabetes with closest consanguinity present in 54% of marriages. Several mothers in this study express cognizance of the ramifications of close intermarriage and want to see more genetic testing and counseling based upon their own experiences. Although cognizance is reflected by mothers, consanguineous marriages continue to rise. In Qatar there was a recent movement to test for potential disorders in children in order to prevent

marriages that might potentially result in the birth of a child with a disability due to consanguinity (Elshamy, 2008). According to a professor of Shariah Law, marriages between individuals who are prone to have children with “incurable diseases” are prohibited in Islam (Elshamy, 2008). This has serious implications concerning the violation of human rights for a member state of the United Nations.

To comply with the United Nations and certain human rights watch groups, change must occur, most likely spurred on by family members of individuals with disabilities. However, the researcher has noticed, according to mothers’ suggestions for improvement, they are the most likely candidates to give momentum to advocacy-based thinking in the community regarding individuals with disabilities. This was similar to the research of Wickham-Searl (1992) who noted the advocacy skills of mothers who tried to obtain better services for their children with disabilities.

Some mothers of children with disabilities are not supportive of advocacy skills and thinking. Reasoning for this may be that in some cases mothers struggle with depression over their children’s disabilities. Zahr and Hattar-Pollara (1998, as cited in Azar & Badr, 2006) found a high level of depression (60%) in Lebanese mothers of children with disabilities. Much like the mothers interviewed for this project the mothers in the study are the primary individuals responsible for their children and a lack of paternal engagement has been noted. Attitudes against advocacy skills and thinking also might have been due to the stigma that mothers face due to their children’s disabilities (Azar & Badr, 2006).

An anti-discrimination law was established in Qatar, which was a start to progress toward change and one of the characteristics of the country that offers hope that a respect for all persons would become more visible in the future (“Country Reports,” February 28, 2005). As mothers share their stories, it is evident that their children face a great deal of discrimination within the community, whether according to the reaction of others around them or when facing rejection from a program or facility because of the presence of a disability. Local schools in Qatar reject students with moderate to severe disabilities. This characteristic of Qatari education aligns with the study referenced by Alghazo and Gaad (2004), who attributed anti-inclusion sentiments to the lack of a “pro-inclusion culture” in general education schools and higher education institutions. Alghazo and Gaad (2004) deemed a country’s aim for inclusion as the first factor in changing discriminatory culture, second to a change in the attitudes within the levels of the education system.

Accessibility to community resources for those with disabilities is mandated in Qatar, as well as free health care and educational services; although educational services are not inclusionary under most circumstances, they were intended to be provided to all children with disabilities (“Country Reports,” February 25, 2004). However, numerous children are unable to receive educational services because the system is overloaded and unable to meet the needs of all children with disabilities. The lack of personnel in schools would likely require greater incentives of employment, such as tuition reimbursement for any individuals who desire to receive training and, perhaps larger salaries for special education teachers.

Mothers note problems with diagnoses for their children. As those with disabilities are properly identified and given educative provisions that meet their needs, a more inclusive educational and social setting could develop. The lack of a strong foundational model for inclusion in the Middle East is a concern found in the literature (Al Hail, 2005). Attempts at inclusion have led to inappropriate placements in Qatari schools that do not offer much support to children with disabilities in a general education setting. Typical of developing countries, Qatar has a clear lack of services, materials, and staff to carry out service implementation (UNESCO, 1997, as cited in Eleweke & Rodda, 2002).

The difference between Qatar and most developing countries is that poverty is not a risk factor as serious as that of consanguineous marriage (Eapen, Al-Gazali, Bin Othman, & Abou-Saleh, 1998, as cited in Eapen, Zoubedi, Yunis, Gururaj, Sabri, and Ghubash, 2006). The necessary financial resources could be made available to develop more opportunities for children with disabilities.

Surprises

During the course of this research study there were unanticipated outcomes that were revealed. First of all, the choice and use of language does not place the person before the disability in Arabic. The translation preserves this. For example, the description of physical attributes of children with Down syndrome as looking “Filipino” was used by three mothers as a descriptor. This descriptor is based on race and a derogatory term according to the hierarchical social system in Qatar, an issue that is predominant in many facets of the research. Secondly, the Shafallah Center is primarily

intended to meet the needs of Qataris only, but in a few instances has welcomed expatriate children to receive services. There is not provision for non-Qatari children with disabilities. Although the system in Qatar is not adequate for those in need of services for nationals, considerations should be made to serve all children with disabilities in the country according to the International Convention on the Rights of Persons with Disabilities (United Nations, 2006).

Ninety percent of interviewed mothers have from one to four maids in their household, which could be viewed as evidence that poverty is not a large risk factor. However, mothers request more governmental assistance in order to raise their children with disabilities. It is doubtful that most Qatari families could not obtain the financial resources to provide extra services to their children with disabilities. Welfare is provided by the state, so it seemingly has come to be expected that Qataris will receive whatever they needed. It comes into question how much interaction occurs between parents and their children with disabilities if families are extensively dependent on the assistance of drivers and maids who live within the home.

An unintended benefit of this research is that it served as a form of narrative therapy for mothers as they shared from their experiences; value is present in sharing a unique story and in having another person listen (Green, 2003; Romanoff, 2001). Mothers discussed how their families were first affected upon learning that they had a child with a disability. Ferguson (2002) described how the interpretation of life with a child with a disability is imbedded in the attitudes and history of the community.

Limitations

During the course of this inquiry certain limitations became known. Since there is limited research on the topic of disability in the Middle East it is important to highlight these limitations for those who carry out future research in the region. Data on disability and practices for those with disabilities is very limited, inaccurate, or not available in English. Inaccurate information on disability statistics was reported by the Planning Council of Qatar (2003). Per the study by Karam, et al. (2006), limited research on disability in the Middle East is due in part to the fact that public opinion research is not common and although researchers declare anonymity and confidentiality, the persuasive quality of this declaration is met with skepticism. Dinero (2002), considering the high prevalence of disability, notes a serious lack of research on the topic in the Middle East. Public awareness of the possibilities for those with disabilities also is limited.

Due to difficulties for social workers to find candidates and the frequent cancellations and rescheduling of interview appointments by mothers in this study, each mother could be interviewed only once. Mothers were not available for member checks or triangulation of research findings. Another complication was that there are limited interviewees who lived in rural areas, as opposed to the city of Doha. The perceptions of community integration for the children from families in rural areas is not as prevalent in this study, perhaps consisting of two to three interviewees.

The mothers who were interviewed for this study comprise of a willing and available sample in a culture where *disability* is not a common topic of discussion and a

family code of honor might prevent open public discussion about a child with a disability. A further limitation is that this research was carried out by a non-native researcher who worked for a large university in another country.

This study also does not represent the views of all Qatari mothers of children with disabilities. This sample is limited in that the perceptions of mothers whose children are receiving services are the interviewees. It is likely that if mothers of children who are not receiving services were interviewed the responses might reflect different perceptions regarding community integration, or lack thereof, in Qatar. Some mothers who do not receive services for their children with disabilities may not want services or do not know how to obtain them. Non-Qataris who have children with disabilities in Qatar may desire services, but cannot obtain them because those services are only offered to Qataris. It would be informative to broaden the scope of interviews to those in different circumstances.

Audio taping and videotaping are not culturally appropriate means of technology use to accurately transpose interview transcripts. The trustworthiness of this research is thus reliant upon the ability of translators to collect accurate interview transcripts while they interviewed and relied upon their memory of each interview to recall further details for field notes and the translation of interviews into English. Data were not analyzed immediately due to time constraints imposed by the need to translate data immediately.

Due to the immense amount of data produced from 40 interviews it would have been more practical to interview a smaller sample of mothers from different institutions that provided services to children with disabilities. However, a more comprehensive

picture has been developed of the services offered by the Shafallah Center, the main provider of services in the community. Follow-up interviews with the same mothers would have been helpful to confirm the accuracy of the data. If future researchers were able to meet with the same mothers for consequent interviews, it would provide a data check important to confirm knowledge and perceptions.

The researcher was present and available during each interview to take notes about each interview, to answer any questions that staff or interviewees at the Shafallah Center might have, and most importantly, to take full responsibility for the interview process. This presence potentially could have impacted mothers' responses to the translators.

Innate in value-bound inquiry are the values held by all participating parties (Lincoln & Guba, 1985). This includes the values of the American researcher and Iranian interviewers who spent the greatest number of hours collecting and processing data in this study. The values and perceptions of the mothers remain those of utmost importance and it is unintentional if, in any portion of this study, those do not resonate as most prominent.

Per the naturalistic paradigm the interview protocol is ever changing as new information is gathered during the interview process. In order to be consistent with Institutional Review Board requirements at Texas A&M University, the interview protocol was left in its original state for the 40 interviews that were used for data analysis. However, probing questions were included by translators based on prior interviews with mothers.

Implications for Future Research

Currently, there is little published data and a lack of reliable statistics on disability in the Middle East. Future research in this field relies on a foundational base of accurate information about disability. The topic of disability in the Middle East is a relatively new focus of research and an implication for researchers in this area is that there is little accurate data in the extant data.

The Shafallah Center primarily reaches families in the city of Doha and the center primarily meets the needs of those who were Qatari or privileged with a connection. Services are allotted primarily to Qataris. Future studies would benefit by evaluating rate of disability and level of services, not only in the city of Doha, but also in rural areas. Other important information would be to find out how many individuals with disabilities are not receiving any services, especially for those who have expatriate status, and are financially responsible for any services their children receive. There are approximately 700,000 expatriates living in Qatar. Research for this study reveals that in the United States, arguably a different culture with different characteristics and perhaps a different definition of “disability,” has prevalence rates of 10-12% of the population with disabilities, although fewer than 1% of the population has a severe disability (Giangreco, 2006). Mishra (2007) reports that worldwide 6% of births involve birth defects. Although difficult to speculate, due to a high population of mostly transient, single, male employees, there potentially could be several thousand children with moderate to severe disabilities in Qatar who are not receiving adequate services for their disabilities.

It would be important for future research to include: the impact of findings from the 2007 disability survey and a more diverse cross-section of the Qatari population of mothers of children with disabilities. This would include interviews of Qatari mothers not seeking services for their children with disabilities, mothers of children with disabilities in rural areas of Qatar, non-Qatari mothers of children with disabilities in Qatar, and mothers not receiving services for children with disabilities due to unavailability of services. This would provide a more holistic picture of what is and what is not available for the population of individuals with disabilities in Qatar.

Suggestions for Improvement of Services

From the research of interviews with mothers of children with disabilities and from a review of the minimal information that is available on the topic of disability, it would be beneficial if there were to be an official definition of *disability* in Qatar. It would be beneficial to have community-wide standards that are clear and equitable in order to decide who will receive services and how these will be obtained, including by non-Qataris with disabilities.

A search for children with disabilities, similar to that carried out after PL 94-142 was passed in the U.S. (Case & Johnson, 1987), would benefit the Qatari government to locate children who are receiving no services. Children with disabilities from birth to school-age could be found through dissemination of literature to promote the campaign or by referrals from parents or doctors. Screening and evaluation of children would then be carried out to determine if they are in need of special services. However, the problem remains that there are not enough qualified personnel in Qatar to serve the population of

children with disabilities who have been diagnosed and are currently seeking services, let alone those children who have not been diagnosed as having a disability.

Another suggestion is to provide community options for those with disabilities. Families do not have many options in the community where they can take their children for social integration. This lack of appropriate community activities creates anxiety for families when taking their children with disabilities into the community. If there is ever to be an increase in awareness about disability within the Qatari community, children with disabilities will have to be a visible part of the community. The Shafallah Center is currently providing a great number of services to children with disabilities. It is important to explore community options so that children with and without disabilities have exposure to one another. Children with disabilities also need to spend time in non-segregated placements since the Shafallah Center is viewed as the primary community program by mothers who have children receiving special services.

Furthermore, mothers of children with disabilities face deleteriously high pressures on a daily basis and they have few viable options for quality care for their children with disabilities. It is recommended that the government provide a center for respite care. If mothers could take their children for several hours a week to a center where their children would be adequately cared for by trained caregivers, it would provide mothers the respite needed to recharge in order to continue to care for their children.

In order for there to be more community integration, the Qatari community would have to advocate for acceptance and normalization to overcome the current lack

of awareness that is present. This is not realistic at this time since there is a cultural system in place that favors hierarchy and inequality. Perhaps change would require public recognition of disability by well-known and respected public figures. It would also require that families who have children with disabilities progressively take their children out into the community on a more regular basis. The occurrence of community outings is increasing.

It is hoped that if there were more community options available for children with disabilities, or simply establishments that welcomed individuals with disabilities, there would not be further segregation of children with disabilities. In some cases a segregated model is more comfortable to some mothers who interviewed. Due to the high prevalence of disability, the suggestions mothers offer to better community opportunities are highly pertinent and come from first-hand accounts of the needs of children according to their family members impacted by disability. As families overcome the social stigma of disability and continue to advocate for their children with disabilities by taking them into the community, awareness will increase.

At the most basic levels of the education system children with disabilities need to be present to foster greater awareness and acceptance of persons with disabilities. The education reform has instituted change on a small scale level for small numbers of those with mild disabilities, but this effort must be further expanded. First of all, this would require trained teachers, incentives for those teachers to desire to be trained, and staff training in schools to properly facilitate inclusion of students with disabilities. Qatar only has one university that provides training to fewer than 40 special education teachers each

year. The Shafallah Center has classrooms, but not enough teachers. Also, mothers note a desire for parent trainings to be available so they could learn more about their children's disabilities and how they could help their children to succeed. In order for change to be affected in the future extreme differences must come about in the way the Qatari community perceives disability.

Life is so generous a giver,

*But we, judging its gifts
By their covering,
Cast them away as ugly
Or heavy or hard.*

*Remove the covering
And you will find beneath it
A living splendor,
Woven of love, by wisdom,
With power.*

Fra Giovanni

(As quoted in Soper (Ed.), 2007)

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Al Ghuwairiya	Congenital	1	0	0	0	1	0	0	0	0	0	خلفي	الغويرية
	Accident	0	0	0	0	0	0	0	0	0	0	حادث	
	Pathological	3	0	3	0	0	0	0	0	0	0	مرضي	
	Others	0	0	0	0	0	0	0	0	0	0	أخرى	
AL Jemaiya	Congenital	9	1	3	1	2	0	1	0	1	1	خلفي	الجميلية
	Accident	1	0	0	1	0	0	0	0	0	0	حادث	
	Pathological	2	0	0	1	0	0	0	0	1	1	مرضي	
	Others	1	1	0	0	0	0	0	0	0	0	أخرى	
Jeryan Al Betna	Congenital	5	0	0	1	2	0	1	1	0	0	خلفي	جريان البطنة
	Accident	2	0	1	1	0	0	0	0	0	0	حادث	
	Pathological	8	0	1	4	0	0	0	2	1	1	مرضي	
	Others	1	0	0	0	0	1	0	0	0	0	أخرى	
Total	Congenital	1307	85	276	165	414	36	122	67	142	142	خلفي	المجموع
	Accident	205	11	54	71	9	29	10	6	15	15	حادث	
	Pathological	776	37	275	260	46	38	19	30	71	71	مرضي	
	Others	111	7	69	12	8	2	1	2	10	10	أخرى	

APPENDIX B

The Planning Council
The General Secretariat



مجلس التخطيط
العام
الإمانة العامة

REF. : P.C/219720

DATE : 25/1/2007

Appendix B

الرقم :

التاريخ :

Messrs/ Ahmed H. Belal For Trading & Construction Company
Belal Sweet Tower
Doha,

Dear Sir,

The Secretariat General of the Planning Council is conducting Multi Purpose Survey, Disability Survey during January and February 2007.

We request you to facilitate the task of the following individuals while performing their duties at Belal Sweet Tower during the period 9th January until 15th February 2007

Mr./ Ahmed El-Sayed A. Huseein Head of group

Mr./ Mohammed H. I. Al-Aasr Enumerator

Thank you for your cooperation

Best Regards

Hassan M. I. Al Emadi
Director, Statistics Department

APPENDIX C

30th Jan., 2007

Bilal Suites**Circular**

Dear Sir / Madam,

We have been informed by the State Planning Council, that as part of the Multi-purpose Survey and Disability Survey, they require the following details relating to each and every person residing in your Suite. It is our obligation to abide by the requirements of the Government, which are in our own interests.

Suite No.

Name

Nationality

Any physical Disability and its nature (only if permanently disabled)

We would appreciate it if you could furnish us the information to our offices in a sealed envelope, marked "CONFIDENTIAL" addressed to the following latest by 01/02/2007

Mr. Nasser Ahmed Hassan Bilal

Finance Director

Yours truly,


Nasser Ahmed Hassan Bilal

Finance Director

APPENDIX D

**INTERVIEWING AS PART OF NATURALISTIC INQUIRY
(QUALITATIVE ANALYSIS):**

Thank you for expressing your interest in the interviewing process of mothers of children with disabilities. Please attend the training session on Sunday at 8:00 a.m. at Qatar University so that you can learn more about this process. There will be several interview times with mothers at Shafallah that you can then sign up for next week as we begin this process, which will be ongoing until June.

At the training the following will be discussed about this method of research:

- ❖ Qualifications for an interviewer
- ❖ Details of the study
- ❖ Interviewing as a method for qualitative analysis
- ❖ Steps to carrying out an interview
- ❖ Stages of the investigation
- ❖ Interview procedures
- ❖ Safeguards and Trustworthiness in qualitative analysis

Thanks,
Alyn

APPENDIX E

Statement of Confidentiality

I state that as a participant in this research on: **Perceptions of Qatari Mothers of Children with Disabilities on Community Integration Opportunities for their Children,** I will not disclose any information about the identity of the mothers, children, or any other people that would likely reveal the identity of interviewees. The information and data are to be kept strictly confidential as a fieldworker and translator in this area of research. I agree to abide by this statement of confidentiality.

Signed

Date

Witness

Date

Alyn Kristin Abbs

APPENDIX F

Informed Consent

Perceptions of Qatari Mothers of Children with Disabilities on Community Integration Opportunities for their Children

Principal Investigator seeking consent:

Supervisor:

Alyn Abbs
205 Riviera Gardens
Doha, Qatar
586-4937
aka@tamu.edu

Dr. Patricia Lynch
4C Nightingale Al Jazi Gardens
Doha, Qatar
586-2185
pslynch@tamu.edu

Purpose of the inquiry:

I have been chosen by an educator or a social worker in Doha to be interviewed. The purpose of this interview is to obtain my perceptions as a mother of a child with moderate to severe special needs about my home and community experiences and the resources available for my child. I will be one of approximately 40 mothers interviewed. I will be asked approximately 25 questions and the interview will last 30 minutes to 1 hour. I may be contacted for further clarification after the initial interview.

This information will be collected in the spring of 2006. The information obtained in this study is for research by a Texas A&M University graduate student. This research is being done while completing a degree plan to earn a Ph.D. in Educational Psychology with a focus in the area of special education.

Participation in this research is completely voluntary and without compensation. I may withdraw from this inquiry at any time and withdraw my data with written request. Because some questions may be personal, I understand that I am under no obligation to answer any questions that create an uncomfortable feeling. There may be a risk of emotional discomfort in answering some questions. A benefit of participating is that I will learn what other Qatari families are experiencing with their children. Shafallah Center will obtain information about how they can improve services to families with children with disabilities in Qatar.

My name will not be used in the final report, but will be substituted with an alias. This will help to insure my confidentiality. A statement of confidentiality will be signed by all involved in conducting interviews.

I am aware that this research study has been reviewed and approved by the Institutional Review Board of Texas A&M University. If I have any problems or questions regarding my rights as a subject in this research, I understand that I can contact the Institutional Review Board through Ms. Angelina M. Raines, Director of Research Compliance, Office of Vice President for Research at (979) 458-4067 or araines@vprmail.tamu.edu.

I have read and understand the information supplied here. I have had the opportunity to ask any questions, which have been answered adequately. I do agree to participate voluntarily in this study.

Participant's Signature

Date

Principal Investigator's Signature

Date

Researcher Copy

الموافقة بعد الاطلاع
انطباعات الامهات القطريات ذوات الاطفال من ذوي الاحتياجات الخاصة عن فرص التكامل الاجتماعي لأطفالهن

المشرف

الباحث الرئيسي طالب الموافقة

د. باتريشيا لينش
حدائق عندليب 205 حدائق الريفييرا

الين ابس

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الدوحة، قطر
586-2185
pslynch@tamu.edu

الغاية من الاستبيان:

لقد تم اختياري من قبل باحث تربوي أو مشرف اجتماعي في الدوحة لإجراء هذه المقابلة. والغاية من هذه المقابلة هي الحصول على انطباعاتي عن بيئتي وخبراتي الاجتماعية كأم لطفل ذي احتياجات الخاصة ما بين المتوسطة والكبيرة وعن المصادر المتاحة لطفلي. علماً بأنني سأكون واحدة من 40 أم تقريباً ستتم مقابلاتهن. المقابلة ستستغرق ما بين نصف الساعة إلى الساعة وسأسال خلالها ما يقارب الخمس وعشرون سؤالاً. وقد يتم الاتصال بي لمزيد من التوضيحات بعد المقابلة الأولية.

هذه المعلومات ستجمع في ربيع 2006. والمعلومات المحصلة في هذه الدراسة ستستخدم لأغراض بحثية من قبل طالبة بالدراسات العليا بجامعة تكساس ايه اند ام. وهذا البحث تم اعداده أثناء اتمام خطة للحصول على درجة الدكتوراه في علم النفس التربوي مع التخصص في مجال الاحتياجات الخاصة في التعليم.

مشاركتي في هذا البحث هو عمل تطوعي كامل من دون أي تعويض، ويمكنني الانسحاب من هذا الاستبيان في أي وقت واستطيع سحب بياناتي بطلب مكتوب، وذلك لكون بعض الاسئلة شخصية. كما أنني لست مجبرة للإجابة عن أي سؤال يولد عدم الشعور بالارتياح. ومن الممكن أن تكون هناك مضايقة عاطفية في الإجابة عن بعض الأسئلة. والمشاركة في هذا البحث ستمكّنني من معرفة المزيد عن خبرات العائلات القطرية الأخرى مع أطفالهن.

عند كتابة التقرير النهائي سيتم استبدال اسمي باسم مستعار لتأمين سرّيتي. سيتم التوقيع على تصريح السرية من قبل المشتركين خلال إجراء المقابلات.

تم إعلامي أن هذا البحث تمت مراجعته والموافقة عليه من قبل مجلس المراجعة المؤسسية لجامعة تكساس ايه اند ام كما اعلم انه بإمكانني الاتصال بمجلس المراجعة المؤسسية من خلال الأنسة انجلينا ام ريبينز ، مديرة الالتزام البحثي بمكتب ، في araines@vprmail.tamu.edu نائب الرئيس للأبحاث على رقم 4067 - 458 - 979 أو على البريد الإلكتروني حالة وجود أي مشكلة أو استفسار عن حقوقي كعينة في هذا البحث.

لقد قرأت وفهمت المكتوب أعلاه. وكانت لدي الفرصة للسؤال عن أي أسئلة لم يتم الإجابة عليه بطريقة مناسبة. وأنا اوافق على المشاركة تطوعاً في هذا البحث.

التاريخ

توقيع المشارك

التاريخ

توقيع الباحث الرئيسي

نسخة الأمهات

APPENDIX G

Interview Questions

The following questions are intended to help others to understand the awareness and knowledge that a mother has of her child with special needs. Perceptions of the child's interactions within the home and community will be discussed. Any questions that one considers too personal can be omitted from the interview.

1. Please explain how or when you first realized that your child might have a disability.
2. What are the best aspects of being the mother of your child?
3. What do you find to be most challenging in dealing with your child?
4. What activity would you like to see your child participate in that he or she does not do now? Why?

Daily Living Activities:

5. Typically, who feeds, bathes, and dresses your child? (F=feeds, B=bathes, D=dresses)

Mother	Father	Sisters or Brothers	Nanny or Maid	Independent

6. Please tell me what a typical morning routine looks like in your household for your child.
7. Please describe the activities that your family commonly does together outside the home. How is your child with a disability included in these activities?
8. In what ways has your family had to change routines to meet the needs of your child?

Community Activities:

9. How frequently does your child with a disability go to the following places with other family members?

10. How frequently does a maid or nanny accompany your child when visiting the following places?

Please choose from the following:

More than 3 times per week	2-3 times per month
2-3 times per week	1 time per month
1 time per week	2-3 times per year
	Never

Place:	Mosque	Grocery Store/Malls	Friend's Home	Relative's Home	Play Centers	Other
9.						
10.						

11. How important do you feel that it is for your child to play with children without disabilities?

Very Important	Important	Moderately Important	Not Important	Not Suitable

Please explain:

Resources:

12. Tell me about the programs that your child attends in your community.

13. In your opinion, what resources are needed for your child in the Qatari community (i.e. sports, arts, therapy, other programs etc.)?

14. What types of jobs can you envision for your child/children without disabilities?
(Names/Ages)

15. Do you think your child with disabilities will work in the future? Yes _____ No _____

16. What type of job can you picture your child doing as an adult?

Demographics:

17. Age of child _____ Boy _____ Girl _____

18. Disability _____

19. Number of children in the home _____

20. Mother: Qatari _____ Non-Qatari _____

21. Father: Qatari _____ Non-Qatari _____

22. Does Mother work outside the home? Yes _____ No _____

Average working hours per week _____ Occupation _____

23. Does Father work outside the home? Yes _____ No _____

Average working hours per week _____ Occupation _____

24. Mother's level of education:

Not Educated	Finished Primary	Finished Intermediate	Finished Secondary	Diploma Program	College Degree	Post-Graduate

25. Father's level of education:

Not Educated	Finished Primary	Finished Intermediate	Finished Secondary	Diploma Program	College Degree	Post-Graduate

Date _____ Interview #: _____ Interviewer Name: _____ Researcher Initials: _____

Alias M: _____ Alias C: _____

أسئلة المقابلة

تمت صياغة الأسئلة التالية بهدف مساعدة الآخرين لفهم مدى وعي ومعرفة أمهات الأطفال من ذوي الاحتياجات الخاصة الإمكان حذف أي سؤال من أسئلة في بأبنائهم. سنتم مناقشة كيفية تفاعل الطفل داخل البيت والمجتمع الخارجي ، علماً بأنه المقابلة في حال اعتباره سؤالاً شخصياً.

1. كيف ومتى أدركت لأول مرة بأن طفلك من ذوي الاحتياجات الخاصة ؟
2. ما النعم والنواحي الايجابية التي حصلت عليها كونك أمّاً لطفلك؟
3. ما هو أكثر تحدي واجهته في التعامل مع طفلك ؟
4. ما هي الأنشطة التي ترغبين أن يقوم طفلك بممارستها، وهو لا يمارسها حالياً؟ولماذا؟

أنشطة الحياة اليومية:

5. من يقوم عادة بإطعام طفلك و الباسه وتحميمه؟ (ط = يطعم، ح = يحمم، س = يلبس)

الأم	الأب	الأخوة أو الأخوات	المربية أو الخادمة	الطفل نفسه

6. ما هو مسار الحياة اليومية التي يمارسها طفلك منذ الصباح ؟
7. ما هي الأنشطة التي تمارسها أفراد الأسرة معاً خارج المنزل؟ وكيف تتم مشاركة طفلك في هذه الأنشطة؟
8. ما هي التغييرات التي قامت الأسرة بإدخالها على حياتها لتتوافق مع احتياجات طفلك؟

نشاطات المجتمع:

9. كم مرة يتردد ابنك على الأماكن التالية برفقة أحد أفراد الأسرة؟
10. ما نسبة مرافقة الخادمة لأبنك أثناء زيارته للأماكن التالية؟

- | | |
|----------------------------|-----------------------|
| أكثر من ثلاث مرات أسبوعياً | 2 الى 3 مرات في الشهر |
| 2 الى 3 مرات أسبوعياً | مرة في الشهر |
| مرة في الأسبوع | 2 الى 3 مرات في السنة |
| | أبداً |

المكان:	المسجد	البقالة/ المجمعات التجارية	بيوت الاصدقاء	بيوت الأقرباء	مراكز الألعاب	أماكن أخرى
9.						
10.						

11. من وجهة نظرك، ما مدى أهمية أن يلعب طفلك مع أطفال أسوياء؟

مهم جداً	مهم	معتدل الأهمية	ليس مهماً	غير ملائم

أشرحي ذلك:

المصادر:

12. هلا تحدثتي عن البرامج التي يحضرها طفلك والمتوفرة في المجتمع .
13. من وجهة نظرك، ما هي المصادر التي يحتاج اليها المجتمع القطري لذوي الاحتياجات الخاصة.
14. ما نوع العمل الذي تطلعين أن يقوم أبناءك الأسوياء بمزاولته في المستقبل؟ (أسماء، أعمار)
15. هل تعتقدين بأن ابنك ذا الاحتياجات الخاصة سيتسنى له العمل في المستقبل؟
نعم ___ لا ___ .
16. ما نوع العمل الذي تتصورين أن ابنك سوف يقوم بمزاولته في المستقبل؟

معلومات عامة عن الطفل

17. عُمر الطفل: _____ ولد _____ بنت _____
18. نوع الإعاقة: _____
19. عدد الأطفال في البيت _____
20. الأمّ : قطري _____ غير قطري _____
21. الأبّ : قطري _____ غير قطري _____
22. هل الأمّ تُعملُ خارج البيت؟ نعم _____ لا _____
وظيفة الأمّ؟ _____
متوسط ساعات العمل بالأسبوع _____
23. هل الأبّ يُعملُ خارج البيت؟ نعم _____ لا _____
وظيفة الأبّ؟ _____
متوسط ساعات العمل بالأسبوع _____
24. مستوى الأمّ التعليمي: _____

غير متعلم	ابتدائي	إعدادي	ثانوي	دبلوم	جامعي	دراسات عليا

25. مستوى الأبّ التعليمي: _____

غير متعلم	ابتدائي	إعدادي	ثانوي	دبلوم	جامعي	دراسات عليا

Date _____ Interview #: _____ Interviewer Initials: _____ Researcher Initials: _____

Alias M: _____ Alias C: _____

APPENDIX H

Advocate for Children with Disabilities

("Making a Difference," 2004)

In a personal interview with Eman (April 3, 2006), an appointed advocate of the Royal Family for those with disabilities in Qatar, the importance of educating others to accept children with disabilities was at the forefront of her agenda. This mother serves as an advocate for children with disabilities in Qatar and was appointed for this role by Her Highness Sheikha Moza. Eman has a three year old son with Caudal Regression Syndrome caused by maternal diabetes during pregnancy (Kahilogullari, 2005). Her son, Ghanem, was born missing 75% of his bones. He was never expected to walk. He has learned to walk on his hands when he is not in his wheelchair. Ghanem is in an inclusion program in his school. His mother notes that as she has served as an advocate for Ghanem's inclusion program at school and as an appointed advocate for the Royal Family of Qatar her son was the first child in Doha, Qatar, as well as in the Gulf Region, to be filmed for the media in a wheelchair in public on Al Jazeera Network.

Ghanem was also the first child in his school to be in a wheelchair. Eman had to work with the school for one year to get a ramp and to prepare the principal and teacher for Ghanem's admission. His parents paid for any accommodations that would be necessary for his inclusion at school. Many Qatari children have maids who assist them throughout the day, but in this case a nurse is present for Ghanem and goes to the school midmorning with his mother so that he can be catheterized, which must occur once every four hours. Ghanem's experiences with inclusion are helping to make inclusion a

possibility for those with disabilities in the future in Qatar. The family offers funding to children who are in need of wheelchairs in order to attain mobility, as accessibility is one of the greatest barriers to inclusion of those with disabilities. Eman believes that services to those with disabilities need to begin as early as age three or four. Ghanem's education will be paid in full for life by the Shafallah Center.

VITA

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