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# An Exploration of the Development of Disability Organizations

by

## Alyaa Jamal Hemdi

A Thesis submitted to the Faculty of Graduate Studies of

The University of Manitoba

in partial fulfilment of the requirements of the degree of

## **Master of Arts**

**Department of Disability Studies** 

University of Manitoba

Winnipeg, Manitoba, Canada

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## An Exploration of the Development of Disability Organizations In Saudi Arabia

By

## Alyaa Jamal Hemdi

A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University of

Manitoba in partial fulfillment of the requirement of the degree

Of

## **Master of Arts**

## Alyaa Jamal Hemdi©2009

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Last but not least, my thanks go to all the Head Managers of disability organizations who I interviewed and shared with me their experiences and thoughts. I sincerely hope this thesis will contribute to the understanding of the development of disability organizations in Saudi Arabia.

## Dedication

This thesis is dedicated to four special people in my life.

To my generous and beloved parents for their unconditional love and endless encouragement and prayers.

To my supportive and loving husband. Thank you for standing by me in the hard times and for always reminding me there is only one way to go down the hill.

To my lovely daughter Leen. You mean the world to me.

,

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#### Abstract

In this study, an Islamic perspective was used to examine the development of disability organizations in Saudi Arabia. As disability research in Saudi Arabia has most often been approached from a medical perspective, the purpose of this study was to focus on a social model of disability as well as the Islamic model of charity. Using inductive analysis of interviews, documents and website data, both the Islamic perspective of charity and the social model of disability were evident throughout the research. The findings concluded that the development of disability organizations have been and continue to be affected by charity, staff, Islamic beliefs and values, their role in society and the need for a place. The development and continuation of disability organizations were also strongly supported by dedicated Head Managers and staff who loved their work and especially the children, and felt they would be rewarded by Allah [God].

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#### **Chapter 1: Introduction**

## Presentation of the Study

This study explored the development of disability organizations in Saudi Arabia and the connection that Islam has had in that process. As a country whose only officially recognized religion is Islam and whose native population is known to be 100% Muslim, the beliefs and practices of Islam cannot be separated from government policies, cultural attitudes and the day-to-day life of each citizen. As Saudi Arabia has undergone tremendous economic change since the discovery of oil, this study also recognizes the impact of oil discovery on the development of services for people with disabilities in the country.

Through the lens of the social model of disability and the charity model in Islam, the development of disability organizations was explored using face-to-face interviews with Head Managers (HM) of disability organizations, the public relations brochures for those organizations, and the websites of other disability organizations referred by the HMs. Although 'disability' has been most often approached using a medical perspective of disability research in Saudi Arabia, it was the purpose of this study to focus on exploring the development of disability organizations in the country from a social model of disability as well as the Islamic model of charity.

Situating the study in the last two decades, there has been substantial growth in the number of government and private organizations that provide services for people with disabilities in the Kingdom of Saudi Arabia. Thirty-six disability organizations have come into existence in the last 20 years (Al-Turaki<sup>1</sup>, 1996); however, the actual recognition of people with disabilities in Saudi Arabia began ten years earlier with the planning of economic and social development programs in the country (Al-Maghlooth, 1999).

This chapter begins by giving an overview of Saudi Arabia and the significance of its only recognized religion, Islam. Because charity is an important belief and practice of the Islamic tradition, I cover its historical significance and implications both for Saudi Arabia and disability organizations. Islam in The Kingdom of Saudi Arabia is a religious entity that cannot be separated from the day-to-day life of Saudis. For that reason, I also present the role of the Saudi government in the development of disability services and organizations in the last three decades. Finally, the aims of this study and the main research questions are presented.

#### **Overview of Saudi Arabia**

Saudi Arabia occupies around four-fifths of the Arabian Peninsula and lies to the extreme southwest of Asia (Saudi Ministry of Foreign Affairs, 2006). On its northern border lies Kuwait, Iraq and Jordan, and to the south are Yemen and Oman. It is bordered on the east by the Arabian Gulf, Qatar and United Arab Emirates, and on the west by the Red Sea. The Saudi Ministry of Foreign Affairs (2006) reports that according to the census of 2006, an estimated 21.4 million people live in Saudi Arabia, of whom 16 million are Saudi citizens. Saudi Arabia ranks first in world oil production which accounts for the largest part of its economy (Saudi Ministry of Foreign Affairs, 2006). Saudi Arabia is the birthplace of Islam, the only state-recognized religion and the second largest religion in the world with an estimated 1.5 billion followers (Robinson, 2002). As the homeland of Makkah (Mecca) and Madinah (Medina), these two holy cities for Muslims are situated in Saudi Arabia (Saudi Ministry of Foreign Affairs, 2006). Each year, hundreds of thousands of Muslims from around the world journey to Makkah to perform Hajj, "the pilgrimage to the holy city of Makkah and its surroundings at a specific time every year" (Al-Qaseer, 2006, p. 18). As Islam is the only official religion in Saudi Arabia, non-Muslims are allowed to live and work in the country but cannot practice their religion in public (Saudi Ministry of Foreign Affairs, 2006).

After giving a brief overview about the country of Saudi Arabia, it is vital to discuss the importance of religion there. This is because Islamic beliefs play a vital role in the day-to-day activities of people in Saudi Arabia, which means their beliefs and actions are connected (Al-Zahrani, 2007). Islam is based on five practices called the five pillars of Islam (Hallaq, 2005). These pillars consist of "Shahadah, Salah, Zakah, Sawm and Hajj" (Hallaq, 2005, p. 208).

Shahadah is "the Muslim declaration of the oneness of Allah<sup>2</sup> and the acceptance of the Prophet Mohammad as his final prophet" (Ministry of Islamic Affairs, Endowments, Da'wah and Guidance, Introduction to Islam section, Para. 5, n.d.). This is the most important pillar of Islam as it sets the foundation for all the other practices. Without the declaration of *shahadah*, none of the other practices will be accepted (Hallaq, 2005).

The second pillar of Islam is *Salah*, which is to pray five times a day at specific times facing Makkah (Ministry of Islamic Affairs, Endowments, Da'wah and Guidance, n.d.). *Salah* is more than a physical prayer to Allah; it is "personal communication" between Allah and his followers (Chastain, 1995, p. 161).

The third pillar of Islam is Zakah, or Zakat al Mal, which requires every Muslim to pay a minimum specific percentage of their Zakatable assets every lunar year to the poor or needy people in their society (Zakat Foundation in America, 2008). Zakat then is required of all Muslims and all Islam countries.

Sawm, the fourth pillar of Islam, requires fasting during the month of Ramadan (Ministry of Islamic Affairs Endowments, Da'wah and Guidance, n.d.). During fasting, all Muslims are to abstain from food, drink and sexual intercourse from dawn to sunset. Of the important moral lessons of that fasting during Ramadan are to express one's obedience to and love of Allah, practice discipline and self-control, and experience the hunger the poor feel for the entire year, which should encourage more charitable donations to those in need (Badawi, 1991, p. 4).

The fifth pillar of Islam is *Hajj*, the pilgrimage to the holy city of Makkah. Every Muslim who is physically and financially able is obligated to perform Hajj at least once in his or her lifetime (Ayub, 1986).

Islam is a religion that maintains its importance in all aspects of life (Ayub, 1986). It is not just a set of several practices that every Muslim should perform. Instead, it is a guide for Muslims in all aspects and phases of their lives. According to Hallaq (2005), the Qur'an and Sunnah<sup>3</sup> contain all the behaviors that control and regulate every aspect of a Muslim's life. The seventh item of the basic system of governance of the Kingdom of Saudi Arabia dictates that "rulers in the Kingdom of Saudi Arabia draw their authority from the book of Allah [Qur'an] and the Sunnah of his Prophet" (Saudi Ministry of Foreign Affairs, 2006, political system section, Para. 6).

The Kingdom of Saudi Arabia bases its laws on Islam. The four basic references in Islamic law are the Qur'an, Sunnah, *ijma'* (juristic consensus)<sup>4</sup> and *qiyas* (juristic analogy).<sup>5</sup> However, "the application of Islamic law is subject to a high degree of flexibility and development" (Ministry of Islamic Affairs, Endowments, Da'wah and Guidance, flexibility of Islamic rules section, Para. 4, n.d.). It is acceptable for a new law to be added or for an old law that no longer works to be changed as long as the new law does not violate any of the Qur'anic verses or the Prophet Sunnah's. An example of this would be the now widely accepted practice of blood transfusion procedures, which did not exist in the Prophet's time. Although under particular circumstances laws can be changed, the general population does not make those decisions. "It is not the task of every Muslim to invent a new law; it is the work of a specific group of people who are specialized in Islamic studies, known as *Fuqahaa* meaning jurists" (Ibn Taymiah, 1995, p. 227).

Since the context for this study is Saudi Arabia, the homeland for the Muslims' holy cities, it is vital to give a historical account of the connection between Islam and the beliefs pertaining to charity institutions during the different historical Islamic eras in which they flourished. These charitable institutions are the basis of today's disability organizations in Saudi Arabia.

#### Historical significance of charitable institutions and waqf in Saudi Arabia.

Because of the religious importance of Makkah and Madinah for all Muslims and because Makkah has been the centre for pilgrimage for nearly 1,400 years, its history of charity and charitable institutions is more unique than in other parts of Saudi Arabia.

Muslim rulers during the different Islamic historical eras took extra care to establish charitable waqfs<sup>6</sup> - an income that would benefit the two holy cities (Bearman, Bianquis, Bosworth, van Donzel, Heinrichs, 2002). Waqfs were the main financial and gift source for the maintenance of the two holy mosques (Al-Kibasi, 1977). Waqf was distinguished from other charitable sources as a permanent voluntary charity and defined as "forbidden movement, transport or exchange of something" (Raissouni, 2008, introduction, para.1). Raissouni defines Waqf in "Islamic Waqf Endowment" as:

"A canonical Islamic concept, which refers to a special kind of charity given for the purposes of benevolence. The word is used for charities and gifts that have permanence and continuity, so that people can benefit from them for years, generations or even centuries. This means that waqf endowment is made up of entities from whose usefulness, yield and fruit people can benefit, while the capital asset of the entity lasts and stays for a short or long period of time, such as a lot, a building, a well or a tree" (2008, Introduction, para. 2).

According to Hallaq (2005), there are two kinds of waqf: the "private or family waqf" and the "charity waqf" (p. 372). The private or family waqf benefit only family members and offspring to whom the waqf has been donated. Charity waqf, on the other hand, is addressed to all Muslims who are in need. "Persons and public utilities, such as mosques, schools, bridges, graveyards and drinking fountains, can be the beneficiaries of a *walf*<sup>3</sup> revenue" (Bearman et al., 2002, p. 60). There are two types of charitable waqf. : "*walfs* consisting of the mosque or the utility itself (school, bridge, fountain) and *walfs* generating the income for the maintenance and operation of these utilities" (Bearman et al., 2002, p. 60). According to many historians, such as Sayyid (1998) and Ibn-Iyas (2007), waqf helped to serve and stabilize the different social and economic needs of the Muslim communities. This was because of the unlimited ways in which its revenue could be spent. Whenever there was a need in the Muslim community, the waqf revenue would help in financing that need. It was this type of waqf that set the foundation for charitysustained disability organizations.

The Mumluks'<sup>8</sup> era in Egypt was considered by many historians as the golden era for waqf, which was mainly established to finance the needs of the two Muslim holy cities.

The Mumluk sultanate was an Islamic "regime established and maintained by (emancipated) Mamlūk in Egypt" from 1250 A.D. to 1517 A.D. (Bearman et al., 2002, p. 319). The western part of what is currently Saudi Arabia, including Makkah and Madinah, was under the power of the Mamluk regime at that time. According to Shaban (1984, p. 50), "Waqf's income was the main source of income to the two holy cities during the Mumluk era," and the Mumluks<sup>9</sup> did establish an independent administrative department in Egypt with a specific yearly budget to manage the different waqfs designated to benefit Makkah and Madinah (Al-Kibasi, 1977). They also allocated many pieces of agricultural land, buildings and real estate in Egypt as wagfs for the benefit of the holy cities. An example was the Takitit Makkah waqf established in Cairo during the Mumluk era (Al-Kibasi, 1977). Waqf revenue was directed to the development of the different roads to Makkah and the maintenance of the Jeddah seaport for the convenience of pilgrims who came to the holy cities every year. The Mamluk state also sent money with its pilgrims to Makkah every year for the maintenance of the holy mosque in Makkah and the needs of the people living there (Yakon, 1966). In addition, Ka'ba's<sup>10</sup> cloth was one form of donation that Egyptian rulers were sending to Makkah every year (Shaban, 1984).

Mumluk Egyptian rulers established many charitable educational and social institutions to increase the educational level of people living in Hijaz<sup>11</sup> (Yakon, 1966). Educational institutions included schools, libraries, schools for memorizing Qur'an and private lessons groups. Many people during the Mumluk era had also contributed to the establishment of educational institutions in Makkah, such as the school established by Yusef al Masry in 1415 inside the holy mosque at Makkah (Shaban, 1984). Social institutions included hospitals and houses for the poor. One of the very well known social institutions established at Makkah in 1409 was Ahmad al-Turoji's house of the poor (Yakon, 1966).

Even after the fall of the Mumluk state, the charitable institutions they established as charitable waqfs at Hijaz continued to function under the Ottoman regime. The Mumluk regime ended in 1517 as the state came under the power of the Ottoman Empire (Bearman et al., 2002): "a power flourished by the republic of Turkey" (Yakon, 1966, p. 20). The Empire lasted from 1299 until 1923 and at the peak of its power governed three continents: Southeastern Europe, the Middle East and North Africa (Bearman et al., 2002). The Middle East, including Egypt and Hijaz, did not come under its power until 1517. Similar to the Mumluks, Ottoman rulers continued to establish waqfs to benefit the two holy cities (Bearman et al., 2002). They allocated agricultural land and real estate as waqfs with revenue spent on establishing new schools and hospitals in Makkah and Madinah, and for the maintenance of the older ones to contribute to the educational and health of Muslims living in these holy cities (Shaban, 1984). Ottoman waqf revenues were also spent to maintain the two holy mosques in Makkah and Madinah (Yakon, 1966). "Wakfs networks in Ottoman lands were the essential infrastructural links in the transmission of knowledge" (Bearman et al., 2002, p. 319). The Ottoman era was marked by the establishment of many religious schools, mosques and libraries that "were almost exclusively subsidized by wakf" (Bearman et al., 2002, p. 319).

Many Muslims contributed to the development of charitable institutions in Hijaz during the Ottoman regime (Yakon, 1966). Mohammad Khayat and Abdulkarim Trabulsi, for example, were amongst those who established charitable schools and public libraries for educating not only the Makkan people, but for the many scholars around the Islamic world (Shaban, 1984).

The year 1923 marked the end of the Ottoman Empire and the establishment of a new country called the Kingdom of Saudi Arabia (Bearman et al., 2002). King Abdulaziz, the founder of Saudi Arabia, united Hijaz with other cities in the Arabian Peninsula under the name of the Kingdom of Saudi Arabia. Maintaining the geographic and religious traditions, the Saudis continued to give special attention to waqfs (Shaban, 1984). The governors in the different cities of the country were assigned to supervise waqfs in their area (Bearman et al., 2002). In 1925 the Saudi government established a specific waqf management department in Makkah to care for the maintenance and supervision of the already established charitable waqfs in Hijaz (the western part of Saudi Arabia today). In 1961 the government integrated that department with the newly formed Ministry of Hajj and Awqaf<sup>12</sup> (Bearman et al., 2002). According to the Encyclopedia of Islam, this ministry had three main functions (Bearman et al., 2002). First, it continued to maintain and supervise the already established charitable waqfs in Hijaz. Second, it gave special care to the maintenance and development of the two holy mosques<sup>13</sup>. Third, it funded the construction and maintenance of mosques around the country. In 1993 the Ministry of Haji and Awgaf was divided into the Ministry of Hajj and the Ministry of Awgaf (Bearman et al., 2002). The main task of the Ministry of Awqaf became the supervision and maintenance of already established mosques and the construction of new ones around the country. Sayyid (1998) and Ibn-Iyas (2007) suggested that Hijaz was historically the only part of the Arabian Peninsula where charitable institutions and waqfs had been established, "due to the religious importance of Hijaz to all Muslims during the different Islamic historical eras" (Shaban, 1984, p. 26). According to Yakon (1966), charitable institutions had only recently started to appear in other cities of Saudi Arabia due to the efforts of the Saudi government.

Since the discovery of oil in 1939, the Kingdom of Saudi Arabia has undergone modernization in many areas, especially in the development of services for its people (Al-Turaki, 2007). In 1970 the Ministry of Social Affairs, which advises and guides the work of charitable and private organizations, established its first department responsible for charitable and private organizations in the country (Al-Turaki, 2007). It also provided financial support for the different needs of these organizations. According to al-Maghlooth (1999) and al-Turaki (2007), charitable organizations played a major role in the development of people's lives living in Saudi Arabia. This was manifested in the many programs and services established in the country. Services mainly included health counseling programs such as smoking-cessation clinics, seniors' care programs, educational and vocational training, conducting research about issues related to the development of social lives of the people in Saudi Arabia, and providing financial support to prisoners' families and any individuals or group of people who were in need. Some charitable organizations did provide educational and rehabilitative services and programs for people with disabilities in addition to their services to non-disabled people. One great example of this is the al-Wafa charitable organization established in Riyadh in 1972. This organization has continued to provide rehabilitative and educational services for females with disabilities, and also provides services and care for orphan girls and the elderly.

The actual acknowledgement of people with disabilities in Saudi Arabia began in 1974 when the Ministry of Social Affairs established its first department to put up with people with disabilities and address their social and economic concerns, such as housing and employment (Al-Turaki, 2007). The government established this department in response to the expectations and various needs of people with disabilities as well as the needs of disability organizations. These needs came to the forefront as a result of the changes that affected the lives of people with disabilities in the last century. The situation of people with disabilities in Saudi Arabia has been affected by the social, economic, and educational changes that the country and its people have experienced since the discovery of oil (Qurati, 2001; Shenawi, 1998).

A particular change was the migration of farmers from rural communities to urban centers. Farmers left their land and moved to cities, searching for better jobs and higher salaries. With this influx of people increasing the size of the cities came the need for structural changes to meet the needs of all people. Urban life, for example, demanded extra effort and certainly new ways of adapting for the person with a disability (Al-Maghlooth, 1999). City life could often require travelling long distances where transportation was not conducive to meeting the needs of people with disabilities.

People with disabilities were now living within a structure where the disability was not only limited to the scrutiny of family or a close-knit rural community. Moving about in urban centers meant people with disabilities would have to face the challenges of "fitting into a different social structure or group that was not accustomed to them" (Shenawi, 1998, p. 265). Another important change as a result of moving into urban centers was the modification of the family structure (Sharief, 1998). Families were shifting from the extended family towards the nuclear family which consisted only of the husband, wife and their children (Qurati, 2001). This change led to limitations in familial and social relationships between people, and "families had to adjust to the demands and costs of city life" (Sharief, 1998, p. 7). Some wives and mothers who traditionally stayed at home and were the caregivers of their families started to have jobs, and those with disabilities were left alone at home to look after themselves (Qurati, 2001). As a result of the above changes, "Saudi citizens started asking for equal services for the disabled and non-disabled populations" (Sharif, 1998, p. 8). In response, the government began to develop services for people with disabilities.

An important step was the Saudi government's agreement with the recommendations of the Council of Ministers in 2000 to improve the living situations of people with disabilities and to develop services for them. This government council was the highest legal authority in Saudi Arabia for reviewing and releasing government legislation and recommendations (Sharief, 1998). These recommendations therefore acted as a "disability code" and measuring stick for all disability organizations in the country (Ourati, 2001). For example, it affected the way these organizations responded to disability and how they formulated their goals and missions. The first recommendation defined disability, a disabled person, and the prevention of and rehabilitation of disability. Disability was defined as "having one or more of the following: visual disability, hearing disability, mental disability, physical or movement disability, learning disabilities, speech and talking difficulties, uncontrolled behavior, autism, multiple disabilities and any other disabilities which require special care" (Ministers' Council Proceedings, 2000, p. 6). In the past, the dominant definition of a "person with a disability" under the Labor and Workman Law in Saudi Arabia was "any person whose capacity to perform and maintain a suitable job has actually diminished as a result of physical or mental infirmity" (Umm al-Qura Post, 1969, p. 1). Both the old and new definitions of disability shared the medical framework and approached 'disability' as a physical or mental state and ignored the social aspects, such as the inaccessible environment. Disability in both definitions is still approached as a medical problem that needs to be fixed. However, the new definition did not state that having a disability

would be cause for unemployment or loss of a job. One of the 16 recommendations released by the Ministers' Council stated that "every organization in the country should employ people with disabilities so they can earn enough income to live like non-disabled citizens" (Ministers' Council Proceedings, 2000, p. 6). However, as the new definition approached disability from a medical framework, the social impact may continue to be that people will continue to think that disability was a disease that needed to be fixed and cured, and the embedded nature of a social component might be overlooked.

The second recommendation guaranteed the rights of people with disabilities to receive health care, rehabilitation and educational services in the country, as well as encourage private institutions to provide charitable services for people with disabilities.

The third and fourth recommendations set out the need to make surroundings accessible for people with disabilities, stating "authorities should abide by the regulations for architectural specifications required to provide access and accommodate people with disabilities in all centers for rehabilitation, training, education, medical care and public places, as well as all other areas, to enable people with disabilities easy access of movement and transportation" (Ministers' Council Proceedings, 2000, p. 10).

The fifth and sixth recommendations supported the rights of people with disabilities to get a government loan to begin their own businesses.

The seventh recommendation discussed the establishment of a trust fund under the control of the Ministers' Council, which would control all donations, endowments and revenues from waqfs to provide services to people with disabilities and for disability organizations. By establishing the trust fund, the government was encouraging charities and donations that would be used to benefit people with disabilities. However, because of the religious importance of charity in Islam, the provision of charitable services to any group of people does not mean they are less respected than others (Sharief, 1998). The remaining recommendations referred to the importance of organizing a separate council, connected to the Ministers' Council, to take care of the various issues of people with disabilities and to work on implementing the Ministers' Council's recommendations.

As discussed previously, the situation of people with disabilities has been affected by the social and economic changes the country has gone through since the discovery of oil. To meet the needs of people with disabilities, the government has paid attention to and developed disability services and organizations in Saudi Arabia, particularly since 1974.

## **Purpose of the Study**

At present, there are no studies that explore the recent growth and development of disability organizations and services in Saudi Arabia. The first purpose of this study therefore is to fill that gap. A study that examines disability in a country that recognizes Islam as its only practiced religion will add to the Disability Studies knowledge base. This is important because it will provide scholars in the field of Disability Studies with more than one view of disability and how it is perceived in another cultural and religious context.

As discussed earlier in the history of the development of charitable institutions in Saudi Arabia, Islamic charitable endowments have contributed to the development of charitable institutions and then to the development of disability organizations in Saudi Arabia. As a student in Disability Studies, I recognized a gap in the literature regarding Islam in relation to disability approaches and organizations in Arab and Muslim countries. The second purpose of this study therefore was to discover the different ways that Islam has influenced the development of disability organizations in Saudi Arabia, a Muslim country that "tries to implement Islam fully as a comprehensive way of life" (Al-Maghlooth, 1999, p. 19).

## **Research Questions**

- What are the key issues that contributed to the development of disability organizations in Saudi Arabia?
- In what ways has Islam influenced the development of disability organizations in Saudi Arabia?
- How do Head Managers (from disability organizations) view the development of disability organizations and the role these organizations play for people with disabilities in Saudi Arabia?

Chapter Two: The Literature Review presents and discusses the research relevant to disability organizations and people living with disabilities in Saudi Arabia. The review is in three sections: issues related to disability research in Saudi Arabia, disability research in Saudi Arabia, and Western literature specific to studying disability in an Eastern context. This review situates this study in the already existing body of knowledge.

Chapter Three: Carrying out the Methodology was complex, as I lived and studied in Canada, yet needed to conduct interviews and gather brochures from organizations in Saudi Arabia. This chapter outlines how I prepared for the interview process, the interview questions, the gathering of brochure data, and the use of disability organization websites. This section also discusses the qualitative method of data gathering.

Chapter Four: My Data Findings reveal the details from interviews I conducted with Head Managers, information from brochures and the technologically-framed information from websites.

Chapter Five: In the Discussion/Analysis, all data from the various sources were information within the context of an Islamic country. This was interesting as the discourse of 'disability' and 'disability organizations' never moved outside the realm of government/religion that defines these organizations, their development, and their connection to Islamic beliefs and charity. The interviews, brochures and websites – although very different in nature – revealed a homogenous religious discourse embedded within disability organizations in Saudi Arabia.

Chapter Six: In the Conclusion, I close the study by recognizing that during my analysis, I expanded my scope from the development of disability organizations and the connection to Islam and charity to what I came to recognize as an embedded process steeped in deep religious tradition. This tradition and way of life in Saudi Arabia seemed to continue to evolve with the development of disability organizations in Saudi Arabia. I close with the conclusion, limitations of the study, and recommendations for further research in the area.

## **Chapter Two: Literature Review**

The literature for this topic was diverse and covered materials from Saudi Arabia as well as Western literature that discussed issues related to the topic. The review of the literature of this topic is presented in three sections.

- As the context of this study was placed Saudi Arabia, it was essential to look at the literature related to disability organizations in Saudi Arabia to find the focus of earlier studies and what was missing from the literature. Therefore, the first section of this review focuses on literature related to disability organizations in Saudi Arabia.
- The second section of the literature review explores issues related to disability research in Saudi Arabia.

Both of these sections are important as this study was conducted in Saudi Arabia and would add to the body of knowledge on disability organizations in that country. It is also essential to understand how disability is presented in research and whether this study was going to contribute something similar or different to the existing disability research in Saudi Arabia. Although this study was conducted about disability organizations in Saudi Arabia and research took place there, it was still part of a graduate degree at the University of Manitoba, Canada. This thesis would therefore be part of the Western literature studying disability in an Eastern context. It was important to have an awareness of other Western research in this area. This body of knowledge presented some valuable points that would add to the understanding of this thesis' topic.

• The third section of the literature review discusses Western literature about disability in the East.

This chapter also discusses the conceptual framework that helped situate the

methodology and analysis of this thesis.

## **Disability Organizations in Saudi Arabia**

Although there are many organizations for people with disabilities in Saudi Arabia, there are few studies or written material about these organizations or the people with disabilities for whom they benefit.

According to the literature, there are many types of disability organizations in Saudi Arabia. Al-Maghlooth (2000), in his *Welfare and Rehabilitation of the Handicapped in Saudi Arabia*, classified disability organizations according to their governing agencies and specified three types: those that are government governed; organizations that are privately governed; and those which are supported mainly through charity. Charitable organizations could be government or privately governed. Al-Maghlooth listed the names of all the organizations in Saudi Arabia, classifying them by type. He also described the services that each of these organizations provided for people with disabilities. With regards to information about the development of disability organizations in Saudi Arabia, he stated "I could not locate any study that looks at organizations' development" (Al-Maghlooth, 2000, p. 5). This complies with one of the main arguments in this thesis regarding the need for research that explores the development of disability organizations in Saudi Arabia.

Unlike the work of al-Maghlooth, al-Turaki (1996), in his Daleel al moaawaq ela al khadamat al mutaha laho bilmamlaka al Arabia al suadia [A Disabled Person's Guide to the Services Available to Him in Saudi Arabia], classified disability organizations into three categories according to the role they played in society. Social care and rehabilitation organizations "provide a living environment for those people with disabilities whose families could not take care of them because of their severe mental or physical

disabilities" (p. 14). Al-Turaki explained this type of organization was inaccessible to researchers and visitors, therefore not much information was known about them. People with disabilities in these organizations were isolated and sheltered from society. Al-Turaki argued that disability services "should work on the inclusion rather than the exclusion of people with disabilities from their society" (1996, p. 6). This argument agreed with one of the basic premises of the social model of disability which argues for the inclusion of people with disabilities into mainstream society. The social model of disability was used as part of the theoretical framework which informed the discussion about the development of disability organizations in this thesis. The second type of organization was vocational rehabilitative, which looked "forward to rehabilitate a people with disabilities who were working before his disability" but since lost their jobs (Al-Turaki 1996, p. 17). This type of organization worked to bring those people who lost jobs because of their disability back into the workforce. In addition, they also provided vocational training for unemployed people with disabilities to help them re-enter the workforce. The third type of organization was the "complete rehabilitative". Al-Turaki defined these organizations as "those that combine both the social rehabilitation and vocational type of organizations" (1996, p. 20). These organizations provided the living environment for people with disabilities as well as vocational training to help them join the workforce. "Each one of these three types of disability organizations could be governed by any one of the three governing agencies in Saudi Arabia" as identified by al-Maghlooth (2002, p. 15). The vocational rehabilitation organizations, for example, could be governed by the government, private or charitable institutions. Both al-Maghlooth (2000) and al-Turaki (1996) studied disability organizations in Saudi Arabia but focused on the kind of services these organizations provide for people with disabilities. Their

studies acted mainly as guides for people with disabilities and their families to the available services in Saudi Arabia. These studies did not, however, explore the development of these organizations.

#### **Disability Research in Saudi Arabia**

This section outlines the nature of disability research in Saudi Arabia and gives some examples. The focus is to show how disability has been represented in research conducted in Saudi Arabia.

Gain and Abdulwahab (1998), in *Issues and Obstacles in Disability Research in Saudi Arabia*, discussed the dominance of the medical model in disability research in Saudi Arabia and the lack of research applying the social model of disability. They argued that issues such as the attitudes of the community towards people with disabilities, employment equality and income equity have not been addressed in disability research in Saudi Arabia. They suggested that disability research should consider "the values and attitudes of disabled and non-disabled people about disability" and that "a few limited attempts at research have considered some of these issues" (p. 6). Most of the research has focused on the physical aspect of the body. These studies explored disability from a loss perspective without considering any aspect of ability.

An example of a recent disability study conducted in Saudi Arabia was the *National Research Studying Disability in Children in Saudi Arabia* by al-Hazmi (2000). This was one of the most heavily funded research projects in Saudi Arabia, sponsored by numerous funding agencies and involving many researchers. The aim of this research was to establish a database concerning the number of children with disabilities in different age groups and geographical areas of the country. The study also examined the different types

of disabilities and reasons behind them. It was to provide the government with information about the condition of children with disabilities in Saudi Arabia and establish "new services and programs for children with disabilities in the future" (Al-Hazmi, 2000, p. 12). The results of the study indicated that the ages of and the poor health conditions of mothers were the two reasons behind the birth of children with "various mental and physical disabilities" (p. 60). One of this study's recommendations discussed the importance of increasing pregnant women's awareness about their health conditions. Another recommendation was the importance of establishing libraries for children with disabilities. "Books and other educational means within these libraries should be available in audio and visual formats to allow for an easy access" (p. 60). This study recommended that disability organizations hold continuous training courses and workshops in different rehabilitation areas for special educators and caregivers "to increase their educational levels and update their information about new issues in the disability field" (p. 61). As a final recommendation, al-Hazmi (2000) argued that "scholars and academics in Saudi Arabia should consider conducting more research in topics related to disability, including research about the prevalence and characteristics of disabilities in Saudi Arabia and research about disability organizations that exist in different parts of the country" (p. 62). This argument supports one of the main reasons behind the formulation of this thesis' topic: the need for more research in issues related to disability organizations in Saudi Arabia.

Al-Hazmi's research is important because it established a database about disability in Saudi Arabia. His study detailed the types of physical impairments and limitations for people with disabilities. Classifications were according to their physical conditions whereby people with disabilities were recognized as patients. Therefore, this

study focused on the physical aspects of people with disabilities. In other words, it focused on what people with disabilities were missing instead of what they had. The Inclusion of Children with Special Needs in Public Schools: Survey Study for the Inclusion Programs in The Kingdom of Saudi Arabia by Kashrami (2003) is another example of national research published in Saudi Arabia: "inclusion programs had started ten years ago as individual efforts in some schools to include children with disabilities" (p. 5). According to Kashrami, however, there was not enough information about these programs in terms of what they were and how they were implemented in the different schools around the country. The main aim of this study was to "explore the inclusion programs which benefit children with disabilities at the public schools in Saudi Arabia and the effectiveness of these programs" (p. 6). It also explored the difficulties these programs encountered. The results of the study indicated that over the past ten years, there was substantial growth in the number of schools providing inclusion programs. There was also, however, a lack of formal guidelines that defined and governed the inclusion programs in all schools, leaving each to find its own way. Each school determined its own program or method of inclusion (Kashrami, 2003). The results of this study also indicated that the lack of qualified special educators in most schools and the negative attitudes of people in schools towards children with disabilities were the main obstacles that hindered the effectiveness of inclusion programs.

While al-Hazmi's study focused on exploring the prevalence of the different types of physical or mental disabilities, Kashrami's study focused on exploring issues related to the inclusion of people with disabilities and attitudes toward them. Such issues have rarely been explored in disability research in Saudi Arabia. Kashrami's study discussed children with different mental and physical disabilities within the same school where they received the same inclusion program. Nevertheless, the children were classified according to their different mental and physical disabilities, thus medicalizing the issue of disability. Much of the research about disability in Saudi Arabia explored the health and medical aspects of disability. More research is needed to examine the other issues that people with disabilities face in their lives. People with disabilities, like any one, have many other issues in their lives that need to be addressed in addition to medical factors. As well, there is a need for more research in Saudi Arabia that does not specify people with disabilities according to their physical bodies. Specifying people with disabilities by their physical difference does not always add to the understanding of the topics being researched. However, it would be more valuable to examine what is shared by the disability community instead of what is different.

## Western Literature about Disability in the East

There have been few attempts by academics and scholars in the West to study disability in an Eastern context. This section will view this body of literature in its relationship to this thesis.

Scalengh's (2006) Being Different: Intersexuality, Blindness, Deafness and Madness in Ottoman Syria noted the absence of discussion about disability or people with disabilities from the history of the Middle East region. "They were omitted from history" (p. 1). Therefore she examined the "various manifestations of embodied difference in a particular Arab-Islamic context, seeking to reveal the ways in which such manifestations of difference were enacted, interpreted and accommodated" (p. 2). She wanted to look at "how physical differences were presented" in different historical texts in the "Ottoman Syria" (a region that roughly corresponds to today's Syria, Lebanon, Jordan and Israel/Palestine) between 1500 A.D. and 1800 A.D., and whether people with disabilities were included or excluded in these texts (p. 1). The primary sources she examined included "biographical dictionaries, chronicles, fatwa collection, medicine, and treatises on a wider range of other subjects" (p. 1). Her study is therefore historical in context.

She argued that disability should be viewed in its own cultural and religious context. This was because disability "is conceived differently in different contexts" (Scalengh, 2006, p. 260). Her study had two goals: first, "to identify and explain how embodied differences were conceptualized and experienced in the early modern Arab East" (p. 260). By viewing how disability was perceived in an Eastern society, her second goal was to provide "new insight" about disability for North American and European scholars in the disability-related fields. The results of her study indicated that the historical contexts that were examined did not mention the word "disability" or "people with disabilities". Moreover, she found that people with disabilities were labeled by their physical characteristics. Physical differences, however, did not appear to affect the moral, spiritual and intellectual abilities of people with disabilities, and it only appeared as "marker of differences" (p. 6).

Scalengh acknowledged the significance of the religion of Islam as a set of "beliefs and practices" for the Ottoman Syrian society that she was studying (2006, p. 216). Similarly, this thesis also acknowledges the importance of Islam in Saudi Arabia and how it was perceived and practiced by people there.

Scalengh (2006) also acknowledged a lack in the literature with regards to studies that addressed disability in the Middle Eastern region and suggested the need for more research. This supports one of the reasons behind this thesis - the need for more research that addresses disability organizations in Saudi Arabia which is part of looking at disability in the Middle Eastern region.

Rispler-Chaim (2007) is another Western scholar who studied disability in an Islamic context. In her book titled: Disability in Islamic Law, she points out the lack of academic literature that discussed disability in Islamic law. Her aim was to depict the Islamic social attitudes towards people with disabilities as presented in the "expressions" of Islamic law" (p. 93). She therefore analyzed attitudes to people with various disabilities based on Muslim jurists' works (figh) in the Middle Ages and the modern era. and argued that "Islamic law does provide an insight into the basic perception of people with disabilities in those societies that follow the Islamic path" (p. 6). Rispler-Chaim depicted the place and status that Islamic law assigned to people with disabilities, as well as how the law envisioned their participation in religious, social and communal life. The results of her research indicated that "Attitudes to the disabled in Islamic law has been marked by tolerance, acceptance, accommodation, and forgiveness regarding the fulfillment of the religious duties or not fulfilling them" (p. 93). People with disabilities could perform their religious duties "to the extent that their individual condition allows" (p. 93). Rispler-Chaim has provided a description and examples of the different ways that religious duties could be performed by people with disabilities.

Similar to one of the main premises of this thesis, Rispler-Chaim mentioned that Islam does respect people with disabilities and their rights in society. The results of her study indicated that people with disabilities were considered to be "an integral part of society according to the Islamic law" (2007, p. 92) since people with disabilities were "granted the right to participate in public services" to fulfill their religious duties like non-disabled people (p. 93). An example of that were people with disabilities participating at the Holy mosque in Makkah to perform their religious duties with all Muslims.

Similar to Schalengh (2006), Rispler-Chaim noted there was no mention of the word "disability" in any of the Islamic texts she examined. People with disabilities were labeled by their physical differences, however, "no emotional attitude, such as remorse, anger, despair, or disappointment" accompanied any of these labels within the legal literature (2007, p. 93). She also expressed that the literature was sparse concerning issues of disability or people with disabilities in Islamic countries in general and the Middle East region in particular. Schalengh (2006) also acknowledged the same lack in the literature. Both Rispler-Chaim and Schalengh's studies reinforced the need for more research that addresses disability issues in the Middle Eastern region.

Abu-Habib (1997) in her *Gender and Disability: Women's Experiences in the Middle East* reviewed "disability related work by Oxfam in the Middle East" (p. 1).<sup>14</sup> The objective of the Oxfam program in Lebanon was "to identify the interaction between gender and disability in order to improve program planning and policy making" (p. 3). Abu-Habib's discussion reflected "the efforts of Oxfam as an advocate for change of the status of marginalized groups of people in the Middle East region" and found that gender did limit the access to several services for women with disabilities (p. 3). She stressed the importance of listening to disabled women in the Middle East, and recognizing the policies and cultural and religious attitudes and traditions that sustained or increased inequality, particularly those that undermined the life chances for women.

Abu-Habib argued that disabled people "have become more organized [in Lebanon lately], taking a proactive role rather than merely remain recipients of aid, stepping into the public arena to discuss injustice and discrimination and their root causes [specifically discussing injustice with regard service provision]" (1997, p. 10). This concept of Lebanese people with disabilities becoming more active in asking for equal opportunities does reflect the situation of people with disabilities in Saudi Arabia during the last three decades when they started asking the government for more disability services in the country. Abu-Habib (1997) gave the example of *The Lebanese Sitting Handicapped Association* established in 1981 as a strong advocate for people with disabilities in Lebanon. The main aim of this organization was to "stress the need for equal opportunities, and unrestricted access to services, for disabled people, and the need to increase public awareness about the issue of disability" (p. 28). However, Abu-Habib argued that "our perceptions are conditioned by our cultural background" and changing attitudes towards people with disabilities in society took time to achieve (p. 2). She stressed the importance of viewing disability in its own cultural domain which made it easier to understand existing prejudices and challenge them.

Abu-Habib acknowledged that Islam is one of the most practiced religions in Lebanon; however, the study did not discuss any relationship between Islam and disability organizations and services or their development in the Middle Eastern region. She acknowledged a gap in the literature with regard to discussion about people with disabilities in general and women with disabilities in particular in the Middle East (Abu-Habib, 1997). This point has been raised several times in the literature by other Western scholars, like Scalengh and Rispler-Chaim, who studied disability in the Middle East. This agrees with and supports one of the main arguments behind the focus of this thesis the need for more research about disability in Saudi Arabia.

Similar to Abu-Habib, Coleridge (1999) emphasized that disability needed to be seen in its social and cultural contexts. This was important because every society has

different cultural values and beliefs that impacted the ways in which people in each particular society viewed disability and people with disabilities. In his Development, Cultural Values and Disability: The Example of Afghanistan, Coleridge (1999) presented issues and lessons learned from The Comprehensive Disabled Afghans' Program (CDAP), a United Nations agency that helps disabled people in Afghanistan, a country which has suffered two decades of war. Although CDAP is a foreign agency in Afghanistan, most of the staff working in the development programs were Afghans, with the exception of the manager who was a foreigner. Having Afghan citizens who were fully aware of culture, tradition, policy and expectations working on the development programs was, according to Coleridge, empowering to the development of these programs. He has discussed how issues related to the religion and culture of any community, if viewed by a foreigner, might appear as obstacles to development. The word "integration", for example, has different meanings in different cultures. In Afghanistan, "segregation is the norm" for women and "interaction occurs within the private space of home", while interaction with the outer community occurs at social events "such as weddings and funerals" (Coleridge, 1999, p. 158). Coleridge recognized one factor leading "to the segregation of disabled people" in Afghanistan: "the importance of being able to marry in order to conform to the social norm of acceptance" (p. 161). He emphasized that "a detailed understanding of social relations and values especially the relevance and meaning of integration in a society that practices and values social segregation - is enormously important for the design of the social development program"(p. 9). According to Coleridge, understanding the cultural and religious values in a society is an integral part of developing services for the people.

Coleridge argued that Islam occupied an essential position in Afghanistan. He

stated, "The one thing that is common to all Afghans is their commitment to Islam as both a belief system and as a social program" (1999, p. 6). However, his research did not make reference to any relationship between Islam and the development programs of CDAP in Afghanistan. Similar to Coleridge's argument, this thesis also recognizes the centrality of Islam in Saudi Arabia.

Identifying "Islamic charitable duty" as one of the basic religious values in Afghanistan, Coleridge argued that in Afghanistan as well as other Islamic countries, day-to-day decisions and actions are done with an understanding and awareness of an afterlife. "Helping deprived people, including disabled people, is a religious (and therefore charitable) duty through which the giver accrues credit for the hereafter" (1999, p. 6). This thesis also identifies the importance of Islamic charity and its role in the development of disability organizations in Saudi Arabia.

Another Western scholar who researched disability in the Middle East was Turmusani, who titled his study *Disability Policy and Provision in Jordan: A Critical Perspective* (1999). This work provided an outline of the current existing disability services and legislations in Jordan. A new Jordanian law had been issued for people with disabilities in 1993. He stated that "the mission statement for this law is to ensure the rights of disabled people for services and provisions which will promote their integration into society" (p. 12). This law included the right of people with disabilities to employment, education, rehabilitation, accessible transportation and many other services in Jordan. It also included some issues similar to the ones raised by the Council of Ministers in the disability law of Saudi Arabia. As discussed in Chapter One, the disability law of Saudi Arabia stressed the rights of people with disabilities to employment, education, different types of services and an accessible environment. According to Turmusani (1999), disability organizations in Jordan were providing various types of services including rehabilitative services, educational services and vocational training, while some organizations took its main task to promote employment for people with disabilities.

The government also played a role in the employment of people with disabilities in Jordan. The "Ministry of Labor and the Vocational Training Cooperation" were "the two government bodies in Jordan responsible for employment policy and the creation of economic opportunities for disabled people" (Turmusani, 1999, p. 5). However, Turmusani noted a severe shortage of disability centers and trained staff to support people with disabilities.

Turmusani pointed out that the medical model of disability was the dominant model of viewing disability and people with disabilities in Jordan. He mentioned that a medical model of disability "affected attitudes towards disability in Jordan" (1999, p. 13). People with disabilities, for example, have historically been looked at as patients that needed to be cured. He suggested that "what is required is a transformation of this approach to what has been called the social model of disability, which focuses on social solutions rather than individual solutions" (p. 13). He suggested that service providers, for example, should consider looking at other social aspects related to disability away from the body. As has been discussed earlier in this chapter, the medical model of disability has also been the dominant model of looking at disability in Saudi Arabia. Therefore, similar to Turmusani's suggestion, this thesis suggests that the physical body is not the only framework with which to view, think about, and respond to disability.

Turmusani acknowledged the dominance of the religion of Islam in Jordan for more than 92% of the population. He also noted that "the perception of disability as a test of the faith and as God's will plays a major part in shaping attitudes towards people with disabilities" (1999, p. 13). However, there were no references to whether there was a connection between Islam and the disability policies and services in Jordan that he studied.

In summation, Coleridge (1999), Abu-Habib (1997) and Turmusani (1999) were all Western scholars who studied issues related to disability services and organizations in Eastern countries. They all acknowledged the importance of Islam as a practiced religion and a way of life in the countries they studied. However, there was no mention of any effects of Islam on the disability services and organizations they studied. This suggested the need for more research that studies the influence of Islam on the development of disability services and organizations in Eastern countries.

### **Conclusions from the Literature**

The body of literature that helped develop my research questions and form my basic research ideas was classified under three sections. The gaps in the literature have been identified and addressed in this thesis. Following is a summary of the gaps identified in each section of the literature review and how this thesis addressed each of them:

• There is a need for more research on issues relating to the development of disability organizations in Saudi Arabia. This was because most of the literature about disability organizations in Saudi Arabia has focused on the kind of services these organizations provide for people with disabilities. Issues related to the development of the organizations have never been addressed. In order to address this gap in the literature, the main research

question in this study was formed.

- More research is needed in Saudi Arabia to address the different issues that people with disabilities face outside of their physical bodies in their daily lives. Most of the studies done about disability in Saudi Arabia were related to the health and medical aspects of disability. Although some studies explored issues related to disability apart from the physical body, the focus was with the medical terms that focused on classifying them according to physical differences. Therefore there is a need for more disability research in Saudi Arabia that does not label people with disabilities pertaining to the body. In order to address this gap in the literature, this study has focused on studying the development of disability organizations in Saudi Arabia outside of any medical component or medicalized discourse. Throughout this study they were referred to as "people with disabilities" or "disabled people".
- There is a need in the Western literature for studies that explore the relationship between Islam and the development of disability services and organizations in the Eastern countries. This is because the connection between Islam and the development of disability services and organizations has not been addressed by Western literature that studied disability services and organizations in the East. This study has addressed this gap by looking at the ways in which Islam has influenced the development of disability organizations in Saudi Arabia.

# **Conceptual Framework**

This research was informed by two models that helped frame the ideas and enhance the discussion of the findings in this thesis. The first was the charity model in Islam and how it was conceived and practiced in Saudi Arabia. The second was the social model of disability proposed by Shakespeare and Watson (2002).

## The charity model of Islam.

The charity model is the dominant model of disability in Saudi Arabia. The origin of establishing disability services in Saudi Arabia goes back to charitable organizations which started to appear around the 1970s when the Ministry of Social Affairs established its first department responsible for charitable and private organizations in the country (Al-Turaki, 2007). Charitable institutions in the western part of Saudi Arabia, particularly Makkah and Madinah, however, have a long history in the region, well before the establishment of the Saudi government. Charitable organizations in Saudi Arabia have had a great impact on increasing society's consciousness of the value of these services, and increasing the government's awareness of the necessity of taking responsibility for such organizations. Charitable organizations accept donations from government and private sectors (Qaruti, Sartawi, & Sammadi, 2001). Saudi Royal family members support public and private organizations and facilities for people with disabilities (JICA, 2002, p. 7). Because of the religious importance of charity in Saudi Arabia, the donation of money is considered to be a very respectable act, and those who must receive charity are not looked upon with disrespect. That people with disabilities are often supported by charity, and because charity might be viewed differently in Saudi Arabia than in Western societies, it is important to review the significance of Islamic law pertaining to Saudi Arabia and charity. Zakah is the third pillar of Islam. The literal

meaning of the Arabic word Zakah means "purity" and also "blessing or growth and development, of course growth and development are also related to purification through the act of payment of Zakah" (Badawi, n.d.). However, the legislated terminology of Zakah in terms of Islamic jurisprudence is "the payment of a certain percentage of one's assets to the rightful beneficiaries as an act of love of God and expression of obedience and grateful to him" (Badawi, n.d.). Zakah is required by Allah, as it is stated in one of the Our'anic verses: "And be steadfast in praver: practice regular charity" (2:43).<sup>15</sup> The Hadith, spoken through the Prophet, also emphasizes the importance of Zakah: "The superstructure of Islam is raised on five pillars: the belief in the oneness of Allah [God]. performance of the prayer, payment of Zakah, fast of Ramadan and pilgrimage to Makkah" (Al-Nawwawi, 1929, p. 177).<sup>16</sup> The Prophet emphasizes the importance of paying the Zakah and achieving innate purity because they are adhering to Allah's orders (Hallag, 2005). An important effect of Zakah on Muslim society is the reduction of crime rates because it prevents financial disparity between those who have enough financial means and those who do not (Al-Sultan, 1997). Therefore, Zakah leads to a more loving society because it unites people like a single family in which those who have enough money show sympathy with those who are in hardship.

From the importance of Zakah came the importance of charity in the Muslim world. The main difference between Zakah and charity is that Zakah is required by Allah to be paid and those who refuse to pay it will be punished by Him. One of the Qur'anic verses says: "And let not those deem, who are niggardly in giving away that which Allah has granted them out of His grace, that it is good for them; nay, it is worse for them; they shall have that whereof they were niggardly made to cleave to their necks on the resurrection day" (3:180). "Charity is a donation that [you] give from anything that [you] have to any person or group of people who are in need" (Hallaq, 2005, p. 212). Charity, for example, could be given to organizations that take care of any group of people who might be in need. There are many charitable organizations in Saudi Arabia that care for different groups of people, such as orphanages and educational organizations for people with disabilities (Al-Maghlooth, 1999). Another form of charitable organization is research institutes which take care of issues such as cancer studies. These organizations are usually funded by the Saudi Ministry of Health (Al-Maghlooth, 1999).

Although it is important to lay out the relationship between Islam, disability organizations and charity, I must also state that charity is intimately tied to disability in many religions. Western ideology and practice have specifically followed Christianity. The New Testament of the Bible connects charity to the teachings of Jesus Christ through his works (Striker, 1997). The work of scholars such as Striker (1997) has connected charity and religions such as paganism and Christianity. The practice of giving to religious institutions has been historically recognized as charity or alms (Striker, 1997).

Charity is not only intimately tied to Islam in Saudi Arabia, but is tied to many countries and many religions around the world, including poorer Muslim countries and communities who practice Islam. For example, the practice of Zakah as one of the five main pillars in Islam is also practiced by poorer Muslims outside of Saudi Arabia.

### Social model of disability.

The second model that informed the conceptual framework of this research was the social model of disability that Shakespeare and Watson (2002) proposed in their article "*The Social Model of Disability: An Outdated Ideology*". They claimed that the British social model developed "in the 1970s by activists in the Union of the Physically Impaired Against Segregation (UPIAS)" needs to be modified to account for impairment, a part of life that cannot be ignored (2002, p. 3). The British social model identified disability as "the social oppression not the form of impairment" and claimed it is society that is behind the oppression of people with disabilities and not their physical limitations (p. 4). Barnes (1991), a British social model activist, argued it is society that discriminates against its disabled members by not removing environmental barriers. However, even if the British social model did not take impairment into account, this does not mean it is not important. As Shakespeare and Watson (2002) argued, the British social model played an essential role in empowering people with disabilities and advocating for their rights.

The British social model is important in two ways. First, it encourages society to remove the barriers, such as environmental, architectural and political, that keep disabled people from full participation and inclusion in society (Shakespeare & Watson, 2002, p. 5). Second, it creates a new way of viewing disability away from the body (Shakespeare & Watson, 2002). This is especially important because it challenges the way people with disabilities are seen and the medical discourse that defines how they live. It locates the 'disability' outside of the person's responsibility. By moving our view away from the body, the British social model provides a new agenda whereby the day-to-day life of people with disabilities is viewed within a social context.

The "new social model" that Shakespeare and Watson proposed carries the same assumptions as the British social model of disability, but it takes into account the element of impairment. Shakespeare and Watson argued that "impairment is part of our daily personal experience, and could not be ignored in our social theory or our political strategy" (2002, p. 11). Thus the new social model of disability does not imply that the body is the reason behind the disability as the medical model has. Instead, it adds to the British social model the element of impairment that it ignored.

This research has been conducted in Saudi Arabia, a Muslim state, and so it is important to show how the social model, which I used in my conceptual framework, is applied to Islam. Islam encompasses the physical, economic and social needs of disadvantaged groups in society while encouraging changes in people's attitudes and actions (Hallag, 2005). "The Qur'an concentrates on the notion of disadvantage that is created by society and imposed on those individuals who might not possess the social, economic or physical attributes that people happen to value at a certain time and place" (Bazna & Hattab, 2000, p. 2). Islam also promotes esteem and respect for disadvantaged people in society and proclaims the rights of the disadvantaged to full inclusion and full support (Bazna & Hattab, 2000). The idea that people with disabilities are now present at the holy mosque for religious events, for example, is in keeping with one of the important notions of Islam, the inclusion of people with disabilities in the Muslim community (Zahrani, 2003). Islam affirms the duty and responsibility of society towards its disadvantaged members, for it encourages the donation of money from those who have plenty to those who are in need (Malik, 1999). However, the responsibility of society towards its disadvantaged members is not only financial. People in society are also required to work together to include disadvantaged members in every part of their community (Bazna & Hattab, 2000).

The social model of disability and the religious tenants of Islam share the same element of respecting people with disabilities and their rights in society. This is because the teachings of Islam respect people with disabilities and guarantee their rights and respect in society as much as its non-disabled population (See figure 1).

## **Chapter Three: Methodology**

### **Qualitative Inquiry**

In this chapter, I will outline the method of inquiry and data collection process used to carry out this research. Applying qualitative inquiry to this study would allow for an in-depth exploration of the development of disability organizations in Saudi Arabia from a macro historical and structural position and a micro interactional position. Qualitative inquiry is described as "a distinct field of inquiry that encompasses both micro – and macro analysis drawing on historical, comparative, structural, observational and interactional ways of knowing (Hesse-Biber & Leavy, 2004, p. 1). I needed to research the historical growth of disability organizations, as well as how organizations operate now and so used interviews of the Head Managers, brochure and pamphlet materials, and organizations' websites. Qualitative inquiry provided an inclusive method allowing for a detailed exploration.

Patton (2002) stated that methods of qualitative inquiry are "reasonable ways to find out what is happening in programs and other human settings" (p. 137). As there is no academic research on the development of disability organizations in Saudi Arabia, qualitative inquiry was the best place to start. Patton argued "in new fields of study where little work has been done, few definitive hypotheses exist and little is known about the nature of the phenomenon, qualitative inquiry is a reasonable beginning point for research" (p. 193). Qualitative inquiry helped me find answers to my research questions.

"Orientational qualitative inquiry," introduced by Patton (2002), refers to qualitative inquiry that "begins with an explicit theoretical or ideological perspective that determines what conceptual framework will direct fieldwork and the interpretation of findings" (p. 129). This implies that the orientation the researcher chooses for her research will affect the whole process of the research from forming the research questions to the interpretation of the data. The orientation for this study was the Islamic perspective which aimed to explore the development of disability organizations in Saudi Arabia from the social model of disability and the Islamic perspectives - including the charity model. The Islamic perspective pays attention to the teachings of the Qur'an and Sunnah and follows its beliefs and values. The teachings of the Qur'an and Sunnah demand that followers practice charity. It was very important to look at Islam with regard to the development of disability organizations and take it into account during the entire research process. This was because Islam is at the centre of life in Saudi Arabia.

I wanted to explore how people who worked in disability organizations understood the connection between Islam and their work and the development of the organizations. Badawi and Beekun (1998) expressed the importance of looking at and discussing the leadership of Muslim organizations from an Islamic perspective. In a Muslim community, businesses operate under Islamic influence, and government policy is written within the context of Islamic beliefs. They used verses from the Qur'an and the Hadith to support their arguments and discussions (Badawi and Beekun, 1998).

Al-Zeera (2001) argued that "religion in Islam is a way of life; it is not just a ritual performed on Friday in mosques. Our daily activities are coloured with Islamic values, so learning, making meaning, and interpreting new situations are all done in an Islamic frame of reference" (p. 46). Al-Zeera tried to convey the message that for the Muslim community, Islam is not just a religion; it is a way of living and viewing the world around it.

Al-Zeera argued that Islam, when used by scholars in research, should be treated

as a paradigm by itself, referring to it as the "Islamic paradigm". According to her, the "Islamic paradigm is derived directly from the divine book [the Qur'an]" (2001, p. 26). According to al-Zeera, the Islamic paradigm is created by Allah and rooted in the teachings of the Qur'an. She argued that any scholar who is doing academic work within an Islamic framework is using what she called the Islamic paradigm and that they should make sure to derive their information from the teaching of the Qur'an and the Sunnah (Al-Zeera, 2001). Because the Islamic perspective was the orientation for this study, the teachings of the Qur'an and the Sunnah have been taken into account during the whole process of this research.

Asad (1986) stated that when writing an anthropology of Islam, one must start with the Holy Scriptures - beginning at "the discursive tradition that includes and relates to the founding texts of the Qur'an and the Hadith" (p. 14). Because the inclusion of the scriptures is a part of Islam, I knew I must recognize this if it appeared in the data and embed it into the framework of the research. The scripture "organizes various aspects of social life" (p. 1) - people's lived experiences, at home and at work. In The Idea of an Anthropology of Islam (1986), Asad explained that many social sciences had been developed in the West and therefore researchers had mistakenly applied a Western framework to Eastern research. He suggested that research terminologies are grounded in the particular culture that is being studied. When looking at Muslim societies, it is important to pay close attention to the Islamic terminologies and traditions used in these societies. In this study, my background as a Saudi Muslim was helpful in both understanding Islamic terminology and relating my research to its cultural context. My data was collected in Saudi Arabia, a Muslim society where Islam is at the center of beliefs, action and policy.

As a Muslim, I felt it was my honour and obligation to contribute to the field of disability studies from an Islamic perspective. I sensed an urgency to contribute to and "facilitate the responsible expression of a variety of ideas and analyses of the Arab world and its development" (Asad, 1986, p.1). And as a student in disability studies recognizing a gap in the literature, I understood that applying the Islamic perspective to the development of disability organizations would provide a valuable contribution to these fields in both the East and West.

#### **Research instruments.**

I used various data sources in my research. Patton (2002) argued that by using different data sources, the researcher could "build on the strengths of each type of data collection while minimizing the weakness of any single approach" (p. 307). The reliability of the research collection process is critical and the use of different data sources, or triangulation, allows for the "comparing and crosschecking the consistency of information derived at different times and by different means within qualitative methods" (p. 559).

My first source of data was collected from interviewing Head Managers of Saudi Arabian disability organizations. It was important to explore how Head Managers understood the development of their organizations. I then chose to look at two sources of data that disability organizations used to reach the public. I wanted to explore how the brochures and pamphlets were important and if they would contribute to the understanding of these organizations within the Islamic perspective and social model. I analyzed the brochures and pamphlets from the organizations where I conducted interviews and then analyzed the websites of Saudi disability organizations that were suggested by the participants. The websites were not representative of the other organizations.

## Interviews.

From Canada I conducted an intense search of disability organizations using the Internet and studies on disability by other researchers. Once I had a good number, I chose to look more closely at organizations in the cities of Makkah and Jeddah. This served two purposes: they were close to the area where my family lived, and because Makkah is the holy city, it has a history steeped in charity and charitable institutions. The research was more 'do-able' because I could stay with my family when I travelled to Saudi Arabia, and the research would be situated in a unique part of Saudi Arabia shaped specifically by Islam. Kirby and McKenna (1989) suggested that "amongst the criteria for identifying appropriate research participants, accessibility was important" (p. 98).

Preliminary work was done from Canada. Once the cities were chosen, I e-mailed a recruitment letter and answer sheets (Appendix A) to the Head Managers of three disability organizations that I thought could provide rich data and from whom I could learn a great deal (Patton, 2002). I received a reply from all three organizations agreeing to participate. One Head Manager suggested another organization and that continued until I had another five organizations who agreed to participate. I received agreements to participate from the rest of those organizations after I arrived in Saudi Arabia to conduct interviews.

These methods of finding participants are called purposive sampling and the snowball technique. In purposeful sampling, researchers select their participants on the basis of "what cases they can learn the most from" (Patton, 2002, p. 230). Patton defines

this as "an approach for locating information - rich key informants" (p. 237).

Before meeting with the Head Managers, I developed a semi-structured questionnaire with supplementary interview questions in case participants needed clarification. I also used what Berg (1989) referred to as "throw-away questions", questions used to set the participant at ease, and "probing questions" which drew out more complete answers (p. 22). The "semi-standardized interview," a term defined by Berg (2001), is a type of interview that "involves the implementation of a number of predetermined questions and/or special topic. These questions are typically asked of each interviewee in a systematic and consistent order, but the interviewers are allowed freedom to digress; that is, the interviewers are permitted (in fact expected) to probe far beyond the answers to their prepared and standardized questions" (p. 70). I already had specific topics and themes in mind. In this kind of interview, the interviewees are also allowed to add as much detail and information about the topic as they like.

The main aim of this research was to explore the development of disability organizations in Saudi Arabia; some of the themes of the interview questions included the basic philosophies and goals of each organization. Other questions were about the services these organizations provided, their funding, history and future plans. I also asked some questions about donations and charitable acts and their effect on the organizations. As the purpose of this research was to explore how Islam affected the development of their organization, I specifically developed questions probing into that area. At the suggestion of the first three Head Managers that I interviewed, however, I changed one question to reflect how Islamic beliefs and values affected the development of their organization, not how Islam as a religion had an effect.

I travelled to Saudi Arabia and stayed for one month to conduct the interviews. As

a Saudi student in Canada, I had to obtain approval from a university research authority in Saudi Arabia in order for me to conduct my thesis research there. As such, I applied for and obtained approval from the Vice-Dean for Graduate Studies and Scientific Research at the Faculty of Medicine of Umm Al-Qura University in Saudi Arabia. I attach with this thesis a copy of a certified English translation of the Vice-Dean letter confirming this approval, directed from Umm Al-Qura University to the Saudi Arabian Cultural Bureau in Canada (see Appendix E). However, it should be noted that only my advisor Dr. Hansen and one of my committee members Dr. Badawi and I had access to data collected from the interviews. I was also required to go through the Ethics Board of the University of Manitoba; therefore, I applied for and obtained approval from the University of Manitoba Human Research and Ethics Board.

I asked all participants to sign a consent form written in both English and Arabic (Appendix C) after they read the research statement (Appendix A). Although Head Mangers understand English, interviews were conducted in Arabic, my native language and the language all participants were most comfortable speaking. Several in fact stated they were happy to see a Saudi researching disability. It should be noted that one of my committee members does read and understand Arabic and he had access to the data collected from the interviews.

I interviewed the Head Managers of eight different disability organizations in Saudi Arabia. Patton (2002) suggests "there are no rules for sample size in qualitative inquiry" as "it depends on what you want to find out, why you want to find it out, how the findings will be used, and what are sources (including time) you have for the study" (p. 244). The number of participants in qualitative research is not as important as the quality of the information they provide to the research. "The validity, meaningfulness, and insights generated from qualitative inquiry have more to do with the information richness of the cases selected and the observational/analytical capabilities of the researcher than the sample size" (Patton, 2002, p. 245). In consultation with my advisor and committee, I felt that eight organizations plus the two other forms of data would provide enough in-depth information to establish an understanding of the development of those organizations with respect to the Islamic, charity, and social model frameworks. The interviews indeed provided rich data.

I interviewed three Head Managers the first week of my trip, two during the second week, and the last three during the third week of my trip. Participants in the study were asked a set of questions (Appendix B) in which they were encouraged to add as much information as they liked.

Faden and Beauchamp (in Israel and Hay 2006) suggested that to encourage the participants to talk and "engage actively in the process", the researcher should "ask questions, elicit the concerns and interests of the subject and establish a climate that encourages the subject to ask questions" (p. 61). As I am a Saudi female and Arabic is my first language, it appeared there was trust and rapport established between each participant and me. Although I am a Canadian student, I conducted the research in my home city in Saudi Arabia and so did not have to deal with what Israel and Hay refer to as "complex risks, uncertainties and problems of culture and linguistic divides" (p. 61). Due to cultural and religious reasons, males are separated from females in most disability organizations. All the Head Managers I interviewed were females, and four of them worked in female-only organizations. Another two worked as Head Managers in female sections of disability organizations which had separate sections for males and females.

Two of the organizations I visited had one Head Manager of both the male and female sections in each of these organizations. Coincidently, these two Head Managers were also females.

Each interview lasted from 45 minutes to an hour and the interviews took place in the Head Managers' offices at the organizations where the participants worked. I conducted the interviews during daytime business hours of the organizations.

I transcribed all transcripts into Arabic and sent copies to participants to ensure their accuracy (Maxwell, 2005). All responded that I had accurately interpreted what they wanted to say.

### **Brochures.**

My second source of data was the brochures produced by the disability organizations where I had interviewed the Head Managers (HM). I collected these brochures from the organizations when I visited them. These documents were public information that could be published or used without fear of violating confidentiality. Some Head Managers, however, requested absolute confidentiality, so names of organizations will not be released. Brochures and pamphlets will be referred to as numbered 'documents', such as D1, D2, D3: D1 will be from the organization where I interviewed Head Manager 1 (HM1) and so on.

I felt the documents were an important source of primary data as they provided the outside face of the organizations. They were what the public could easily see. Patton (2002) considered documents to be a "rich source of information about many organizations and programs" which could "provide the evaluator with information about many things that cannot be observed" (p. 293). Brochures are not only pieces of information, but material used to tell the public what the organization wants them to focus on. Brochures are a form of education and public relations. They are produced using specific colors and images and represent the organization's logo or branding information. Documents produced by organizations provide valuable information such as the organization's philosophies and goals, past events and future planning. Head Managers also kept referring to the brochures of their organizations.

BNET.com (2009), an online subsidiary of CBS International and a high-profile tool for business building, suggested that companies can "communicate effectively" through their brochures. In no way did I want to disregard the importance of the information and these public relations documents. *BNET* suggested that the "overall goal of a company brochure is to describe a company and help persuade decision-makers that it will be a good business partner" demonstrating "corporate success, financial stability, and other important attributes"(introduction, para. 2). The editors state the brochure should be a "statement of confidence whose principle goals is to reassure customers" (para. 3). There is no reason to assume that the use of brochures for disability organizations would be less important in the West or East.

I analyzed the documents' visuals, graphics and information, keeping in mind the Islamic perspective, looking for Islamic beliefs and values, and a connection to the charity model. I also considered if they were a visual representation of the organization for which they stood. The documents are very tactile pieces of information, and unlike having a discussion with a person or reading a long transcript, brochures can be easily carried in a handbag or book. They are easily accessible, pleasant to look at, and even 'feel' nice because of the glossy and smooth surface. I had not anticipated the drawing power of the brochure and they served as a valuable data source in the research.

#### Websites.

My third data source was information from the Internet websites of disability organizations in Saudi Arabia. *Internet World Statistics* reports that as of March 31, 2009, there were 1,596,270,108 Internet users in the world, a 342.2% growth from 2000-2008. The number of users in the Middle East was at 45,861,346, a staggering growth of 1,296.2% from 2000-2008. With 186,727,854 websites recorded on the Internet in December 2008 (pingdom.com), researchers must seriously consider the Internet a potentially important and viable source of data. Because of the growth of Internet users in Saudi Arabia and disability organizations choosing this source to disseminate information to the public, I could not disregard them.

Websites provide information to a group of people who have access to the Internet. This puts the information in the public domain and very often in an interactive format. Visitors to the websites click their way through pages and windows to explore the information or link to other sites. In *Data Mining Your Website*, Mena (1999) suggests "The Web is like an organism made up of millions of cells that are all interconnected, intertwined, and communicating... where billions of business transactions flow and evolve" (p. 1). It is clear that organizations understand how critical it is to use the Internet to get their message out.

DiMaggio, Hargittai, Neuman and Robinson (2001) stated "many observers suggest that the internet is changing society" and encourage sociologists to "contribute actively to such research" (p. 1). The importance of using the Internet for research comes in part from its integrative ability for "reciprocal interaction, broadcasting, individual reference-searching, group discussion, person/machine interaction" and access to "different kinds of content such as text, video, visual images, and audio" (p. 2). Using the websites from Saudi disability organizations provided the opportunity to research current up-to-date information from the other side of the world that linked me to an interactive network of like interests.

The disability organizations' websites helped me gather information that I could not otherwise obtain due to physical, time and money constraints. I chose eight websites from disability organizations in Saudi Arabia that were recommended by the Head Managers I earlier interviewed.

## **Ethical Considerations**

As I needed to abide by the ethical guidelines in Canada, Saudi Arabia and the specific organizations, I knew it was going to be a complex process. I have since been guided to read Van den Hoonaard's *Walking the Tightrope: Ethical Issues for Qualitative Researchers* (2002) and have a clearer understanding of the ethics process I entered. Van den Hoonaard posited that researchers "who work in corporate settings (commonly universities)" should consider "five major spheres: personal, research, intellectual, professional and corporate" (p. 62).

Van den Hoonaard suggested that personal ethics are broader than all other forms of ethics and include what we would consider to be "normative expectations, our morals and ethical obligations" (p. 63). Personal ethics, not controlled or mandated by research boards, demanded that I reflect on my own awareness of honesty and integrity in carrying out this research. As a Muslim, the ethics and morals that guide me are taught in the Qur'an and the Sunnah, and were consistent with the framework of my research. Wanting to have honest research and to treat people with dignity and respect were my foremost concerns.

Research ethics, the second category Van den Hoonaard suggested, are those canons enforced by research boards such as informed consent, confidentiality, control of research information and detailed reporting (2002, p. 65). To ensure that I met the research ethics board's standards, I e-mailed disability organizations my research statements which gave a full explanation of the study. Although upon my first meeting with each participant they signed English and Arabic consent forms, their agreement to participate in the study implied free and informed consent. Israel and Hay (2006) suggested that consent forms require a high degree of literacy and may be difficult to follow. However, the Head Managers were highly educated and stated they fully understood the research study, consent forms and my directives.

The names of participants and organizations have been kept confidential. Only the names of those cites in which the research took place have been given and this was specifically because of the unique connection to Islam and charity. To ensure confidentiality, pseudonyms were used to refer to the Head Managers when quotations were extracted from the interviews. Upon the request of the Head Managers, I decided to refer to them by assigning numbers. These numbers refer to the order of the interviews. For example, I will refer to the first Head Manager that I interviewed as HM 1.

The third category of research ethics listed by Van den Hoonaard is intellectual ethics which concern problem/study selection, "how to sponsor and pursue such inquiries and how to discern and report the truth" (2002, p. 65). The recognition of this type of ethical dilemma is important when conducting research under a particular funding agency and not letting the funding control the findings. Although I am sponsored by the Saudi Arabian cultural Bearue in Canada, there is no expectation to produce a particular type of research finding. The research is wholly my own and not under the influence of an organization.

Professional ethics, stated Van den Hoonaard, include the responsibility of academics to adhere to the "normative rules of plagiarism; authorship; giving appropriate credit to those who participate in research, writing or other professional projects" (p. 65). Using careful note-taking, transcribing, validity and a controlled process, I was diligent to give credit to the appropriate contributors of this study.

The last form of ethics is corporate ethics (Van den Hoonaard 2002). I did abide by the ethical guidelines of not only the University of Manitoba research ethics board, but the Faculty of Medicine in Umm Al-Qura University in Saudi Arabia, and those organizations where I carried out interviews. A very important ethical issue that was taken into account when interviewing Head Managers was they may not have felt comfortable with the interview being tape-recorded. These participants occupied important and sensitive positions in their organizations, so they might not have wanted to feel as if they were under investigation. Patton (2002) emphasized the importance of note-taking "when it is not possible to use a tape recorder because of some sensitive situation" (p. 381). Participants were asked before the interview if they felt comfortable with tape-recording. Six Head Managers agreed to tape-record the interviews. For those participants who did not feel comfortable with the process, extensive note-taking was used to record their answers. Another important ethical issue that was taken into account when interviewing Head Managers was that I had to arrange interview times making sure they did not interfere with prayer times. There is an afternoon prayer called Duhur prayer which coincided with lunch hour in most of the organizations. Therefore I tried to arrange the timing of my interviews to start after the Duhur prayer time or an hour before,

depending on the Head Manager's time. Van den Hoonaard (2002) suggested that "all ethical decisions involve highly complicated responses to and deliberation about complex interactions, usually among and between several individuals, parties and interests where there are many unknown aspects of the interactions between one's intentions and one's guesstimates of taking one course of action over another" (p. 66). During the course of this study, I recognized how integral it was to work with advisors who understood the ethical process of the university, were aware of the ethical concerns and traditions of my own country, and kept at the forefront the need for research that was honest and would contribute to the research in the field of disability studies.

## Validity and Reliability

To explore the development of disability organizations in Saudi Arabia within the frameworks of Islam and charity, I could have used only historical and chronological data. It was important, however, to corroborate that history with data drawn from current disability organizations.

As external reviewers concerned about the lack of rigor in qualitative research, Morse, Barrett, Mayan, Olson, and Spiers (2002) argued for a "plea for a return to the terminology for ensuring rigor that is used by mainstream science" (p. 14). Validity, reliability and rigor are critical components to valid research. "Without rigor, research is worthless, becomes fiction, and loses its utility" (p. 15).

Using different data sources enhanced the validity of my results. Patton (2002) argued that "triangulation, in whatever form, increases credibility" (p. 563).

"Respondent validation" is one way to achieve validity in qualitative research. Maxwell (2005) defined it as "systematically soliciting feedback about your data and conclusions from the people you are studying" (p. 111). In this way the researcher can make sure that he or she does not misinterpret what the participants have said (Maxwell 2005). In my research I used respondent validation to check the correctness of my findings. I contacted participants via e-mail and asked them to look at the transcripts and check if I misinterpreted something they said. All the participants did check their interview transcripts and most of them replied to my e-mail by saying "go ahead", "great job" or "no more comments".

Morse et al. (2002) stated that validity, reliability and rigor are "built into a study" and "Data are systematically checked, focus is maintained, and the fit of data and the conceptual work of analysis and interpretation are monitored and confirmed constantly" (p. 17). In this study, I constantly worked back and forth between transcripts, documents, websites and coding information, keeping in mind the context and framework of the research. Morse et al. stated that "verification strategies that ensure both reliability and validity of data" are applied by "developing a dynamic relationship between sampling, data collection and analysis, thinking theoretically, and theory development" (p. 17). During this study, I matched the "research question and the components of the method" (p. 17). The sample represented those who would best "have knowledge of the research topic" and ensured saturation of the data (p. 18). As I collected data, I analyzed what I had collected, working back and forth forming "a mutual interaction", and keeping at the front the theoretical frameworks of the study

"Low-inference descriptors" is a term introduced by Seale (1999) which described a way to achieve reliability in qualitative research (p. 148). Silverman (2001) identified three ways to achieve low-inference descriptors in qualitative research. The first one is by "tape recording all face-to-face interviews". The second way is by "carefully transcribing these tapes", and finally "presenting long extracts of data in your research report" (p. 230). In my research I tape-recorded six interviews and took extensive notes for the other two. Then I carefully transcribed them, and when reporting my findings I included extracts from the participants' replies to verify my findings. This was because "sufficient description and direct quotations should be included to allow the reader to enter into the situation and thoughts of the people represented in the report (Patton, 2002, p. 503).

## **Data Analysis**

I analyzed the data by "inductive analysis". Patton (2002) defined inductive analysis as "discovering patterns, themes, and categories in one's data" (p. 453). Strauss and Corbin (1998) called this procedure "open coding" (p. 223) "to emphasize the importance of being open to the data" (Patton, 2002, p. 453). The first step was to read the interview transcripts many times to make sense of the data and discover categories, themes or patterns. I looked at the brochures and websites using that same type of exploration. "The first reading through the data is aimed at developing the coding categories or classification system" (Patton, 2002, p. 463). Patton argued that "developing some manageable classification or coding scheme is the first step of analysis" (p. 463).

Berg (1989) referred to Strauss (1987) to remind us of the basic guidelines when conducting open coding: "(1) ask the data a specific and consistent set of questions, (2) analyze the data minutely, (3) frequently interrupt the coding to write a theoretical note, and (4) never assume the analytic relevance of any traditional variables such as age, sex, social class, and so forth until the data show it to be relevant" (p. 236). To follow these suggestions, I looked at the data within the framework of Islam, charity and the social model, asking the same questions: "How does the data support the Islamic perspective of charity?" "How is it shown?" "If it is missing, where, why, how?" "Is there an indication of the social model?" "How is it shown?" "If it is missing, where, why, how?" and so on. As I read through the data, I wrote notes on the side using different colors for different themes or patterns, eventually seeing similarities, differences and cross-references. I worked back and forth going from the broad to the narrow - thinking of the concept of a funnel - until only the most relevant data dripped from the bottom of the funnel. I would go through the data once, then leave it for a few days before returning, and followed that process five times. My advisor suggested I let the data speak to me and that I let the themes grow from the data. I did not go into the data, therefore, looking for keywords or phrases.

During the data analysis, I did not lose sight of the working models for the study: the social model of disability and the Islam perspective of charity. As themes and patterns emerged, however, I also had to keep in mind that the data grew from three very different types of information: interviews, brochures and websites. I did not know whether the different types would produce different results. I was still concerned with content analysis in whatever form that took. To analyze the interviews, I paid attention to the verbal and non-verbal; to analyze the documents, I looked at text and images. Analyzing websites is a fairly new field with very little written about the process. I tried to pay attention to not only the text and images, but repeated text and images throughout the site and links to other information. DiMaggio, Hargittai, Neuman & Robinson (2001) stated that "the Internet presents researchers with a moving target" (p. 308). What I did not know was whether the Saudi Arabian government created policy directing the building and online publication of websites or how those sites were used by Saudi organizations. Kirby and McKenna (1989) reminded us that "doing research is a human activity" and we as researchers actually "construct meaning" (p. 25). My interpretation of the data was affected by my own 'vantage point' and where I 'stand in the world'. As a Saudi Arabian Muslim woman, my research was affected by my understanding and practice of Islam. The Islamic beliefs and values are internalized and an intimate part of my understanding. Kirby and McKenna (1989) suggested "we should be aware of and keep track of our conceptual baggage - those preconceived ideas" (p. 51). They suggest that by keeping track of your conceptual baggage during the research, you can "identify, at a later point in the research, whether any pre-established goals, assumptions or responsibilities may be overly influencing how your research is developing" (p. 51). If knowledge is socially constructed, we clearly cannot separate ourselves from our research. "Accounting for yourself as you research is essential" (p. 70).

### Challenges

There were many challenges I encountered while exploring the development of disability organizations in Saudi Arabia. It was very difficult to get reference material from libraries in Saudi Arabia. I accessed the databases of King Fahd National Library, King Fisal Research Institute and Prince Salman Disability Studies Institute to look for reference material. These three agencies were in Riyadh and held the largest collection of academic and non-academic references in the country. I sent each agency a letter explaining my topic and asking for photocopies of book chapters and articles that I found in their databases. They generously sent photocopies of all the materials I asked for to my parents' home in Makkah. My parents then sent them to me in Canada. On my trip to Saudi Arabia to conduct interviews, I also made several trips to the university library to

research the topic. I had access to the library of Umm Al-Qura University where I had permission from its ethics division. One of the challenges I faced during my trip was that I had to have a driver with me all the time to take me to several locations, including libraries and disability organizations. I could not use my Canadian driving license as women are not allowed to drive cars in Saudi Arabia, and I could not use public transportation due to the extreme hot weather during the summertime.

Another challenge was making arrangements for interviews as employers in Saudi Arabia had different holidays than we have in Canada. Collections of reference materials and interview arrangements were two very time-consuming processes in this research.

### Limitations

This study had some limitations. I used a specific type of purposeful sampling called "snowball" or "chain" sampling. Patton (2002) defined it as "an approach for locating information-rich key informants" (p. 237). I recognized there were also limitations using this type of sampling. The participant might refer me to someone based on personal preference and/or might not recommend someone else for the same reason. In the case of my research, I needed to access people who had a deep understanding of their organization and who had access to the information I needed. I did use this method but with a caution of not selecting all my participants upon the recommendation of one participant. Instead, I chose my participants from different organizations that different Head Managers recommended.

Another limitation in this study was that I only interviewed Head Managers who were in the cities of Makkah and Jeddah due to physical and financial limitations, and also because I felt Makkah particularly was an integral Islamic area for this research. I did, however, compensate for this limitation by collecting data from Internet websites of eight disability organizations located in different parts of Saudi Arabia.

While perhaps not a limitation but a direction of the research due to Saudi Arabian tradition, I ended up interviewing only women. As a female researcher, I was not given access to male-centered disability organizations or was allowed to interview male HRs. Another study could perhaps explore the same questions in these organizations using the same Islam perspective of charity and social model of disability and interviewing both men and women, or men only. It may provide interesting additional information.

## **Chapter Four: Data Findings**

This section of my thesis identifies and describes the main issues and ideas that came from the three data sources: interviews, documents and websites. I began breaking down the data with a broad look and categorized it into different themes and sub-themes according to the issues that were raised in the interviews, documents and websites. I then looked at the three data types (interviews, brochures, websites) to see if they used different ways of talking about these themes and sub-themes.

## Interviews

I conducted interviews with the Head Managers of eight different disability organizations in Saudi Arabia.

- A 12-year-old government-owned organization that provided educational and rehabilitative services for children with physical disabilities under the age of 12.
- A ten-year-old government-owned organization that provided educational and rehabilitation services for children with physical disabilities under the age of 12.
- A four-year-old government-owned organization that provided rehabilitative services for people with autism.
- A 20-year-old privately-owned organization that provided educational, rehabilitative, and vocational services for people with mental disabilities and counseling sessions for their parents.
- A 20-year-old privately-owned organization that provided clinical and educational services for people with communication disorders of all ages.

It also provided support groups for parents of children with communication disorders.

- A seven-year-old privately-owned organization that provided rehabilitative and vocational services for children with mental disabilities under the age of 12.
- A six-year-old privately-owned organization that provided educational and rehabilitative services for children with mental disabilities under the age of 12.
- A three-year-old privately-owned organization that provided vocational and educational services for females with disabilities above the age of 12.

I identified five main themes that were recurrent in all the interviews. Under each main theme I identified sub-themes which were ideas and issues related to the main theme. The five main themes were charity, staff, role in society, Islamic beliefs and values, and the need for the place.

## Charity.

Charity was one of the main themes that I identified in the interview data and its sub-themes were donations, sponsorship, waqf and charitable work. Each one of these sub-themes reflected the different ideas the participants talked about during the interviews. All participants of this study emphasized the importance of charity to their organizations. They talked at length about charity in terms of donations, sponsorship and waqf, and all participants stated they did accept donations.

Donations. HM 5 stated, "We accept donations in terms of anything." She explained to me their organization accepted money as well as donations in other forms

such as supplies. However, not every Head Manager agreed with that participant, as two of the participants explained they accepted donations in any form except money.

"We do not accept money and we do not even ask for it because we are private and if there is any deficit the founder will pay for it. We have this organization because we want to do something for people with disabilities, we do not want to collect money. However, we do accept donations in term of supplies to our organization" (HM 2).

HM 8 stated, "We accept donations in term of things - not money – and, by the way, our building was donated to us four years ago". Another participant, however, told me they accepted donations in term of money and refused other forms. HM 4 said, "We do not accept food or supplies because our kids might not need them and we get rid of them and that's unfair as others might need it".

Most of the Head Managers mentioned there was no one source for donations. For example, some donations came from schools, companies or people willing to donate from their own money. For example, HM 7 noted, "Sometimes a person passes by the door and drops off an envelope with a huge amount of money in it." One of the organizations told me they asked for donations if they did not receive them. HM 5 explained how they may target a specific organization. "We do ask for donations from schools and universities." In contrast, another Head Manager told me they accepted donations but never asked for them. This shows how different organizations have different policies in terms of what they accept from others. The commonality was that all the Head Managers did accept donations for their organizations – in one kind or another.

Most Head Managers emphasized the role of the Royal family when it came to donations. HM 8 indicated, "We always receive donations from members of the Royal family and sometimes we ask for it and they always give it to us."

Sponsorship. Sponsorship was another form of charity that reoccurred in the interview data. All eight participants referred to sponsorship in their discussion about charity and donations. According to the participants, sponsorship occurred when people came to a disability organization and gave a specific amount of money that would be enough to sponsor a disabled member in that organization. This usually occurred when the disabled member could not pay for his tuition to stay in the organization, HM 6 indicated, "Sponsorship is just for people who cannot afford it." One participant indicated that in their organization they accepted Zakah and spend it in the form of sponsorship. HM 1 talked about the importance of Zakah. "We do accept Zakah because one of its basic conditions is that it should go to those who are in need and we have some people that could not pay the fees for their disabled child or children so we sponsor their children from Zakah money." HM 8 indicated that sponsorship was vital to her organization as she told me, "We always ask for sponsorship because it helps our kids and their families who really need the service but cannot afford it. By the way, we never refuse a child because of money, so if we do not have enough sponsorship money I can pay it myself as a founder of this organization."

*Waqf.* All participants expressed how important waqf was to disability organizations in Saudi Arabia. They all pointed out how waqf, if available to them, could make them feel financially secure - as waqf provided continuous income for the organizations. HM 8 stated, "I wish that every organization had its waqf - as it will help a lot." However, only two Head Managers mentioned their organizations actually benefitted from waqf. Each one of those two organizations had two buildings endowed to them by rich business men. Those two buildings were rented out and the rent each year went back to the organizations. All the participants in this study insisted that waqf was better than occasional charity to them. HM 5, whose organization had a waqf, indicated that "charity does play a role in our organization in terms of waqf - which is better than occasional charity as we can know that we will have the money every year". HM 3, whose organization had a waqf, encouraged people who would like to donate to think about putting their money in waqf which would be of more benefit to the organizations.

"With waqf, we feel financially secure and I wish that all organizations had it. I also would like to encourage people who have enough money and would like to donate to buy a property and give it to disability organizations as waqf so they can benefit continuously from it".

*Charitable work.* Charitable work was another recurrent sub-theme under charity and all of the participants had the feeling their work in disability organizations was charitable work. They insisted that although not financially rewarding, their work made them happy and satisfied because they were contributing to the well-being of somebody. HM 6reported:

"I feel that I am a person who was born with the duty to do charity work, and work that has a humanitarian aspect to it. It is not something that you learn and this is my personal opinion. I am the only member in my family by the way, who always liked to help my mother and have this thing on me so I always worked in that environment of helping others. It is something that came naturally to me. I never worked in a profit-oriented organization. With regards to my previous work experience, I worked for the United Nations, Regional Commission Services, a hospital - and all these were non-profit organizations".

HM 3 also said, "I love my work as it is charitable and humanitarian at the same time."

All the participants in this study agreed that what encouraged them the most to work in disability organizations was their feeling they were doing charity work. HM 8 expressed, "Whenever I have the feeling that I want to quit my job and then I remember how charitable and humanitarian it is, I always say 'no' to myself." Similarly, Abu-Habib (1997) argued that "concerns with the welfare of disabled people are seen as 'charitable"" (p. 3).

## Staff.

Staff was another main theme discussed in the interviews with three sub-themes: availability, training and love of the work. I identified these three sub-themes from issues and stories raised by participants during the discussion about staff who worked in the disability organizations. All participants agreed that the staff working in their organizations contributed a great deal to the development and continuity of the organizations.

Availability. The availability of staff was one sub-theme and all the participants discussed how difficult it was finding staff for their organizations. They all agreed that finding educated and well-trained staff was their main problem. HM 1 stated,

"Our main issue is to find staff for our organization and this is because there is not any formal degree in special education in the country except in one city - and for a society like the Saudi Arabian society with its culture, girls are not allowed to travel to another city away from their families to have jobs. So, what happens is that graduates with special education degrees from that city work in their city while other cities are in need of special educators".

The above participant discussed two reasons why it might be difficult to find special

educators in the country. The first one was the lack of formal education programs in special education and the other was the Saudi culture which prevented the girls from moving to other cities away from their families.

Other participants indicated the shortage of staff was not just for special educators but also for other people who worked with people with disabilities, such as speech therapists, occupational therapists and physical therapists. Most participants agreed they had to search for therapists from outside the country and bring them to work in their organizations. HM 6 pointed out "we need speech and occupational therapists and they are very limited in the country so we have to rely on foreigners". HM 5 spoke at length:

"We need therapists not because our children are sick - but sometimes a child for example might need a few sessions in speech in order for him or her to be included in the public school system and we are here to help - but how can we do that while it is very difficult to find a therapists? And then to keep the therapists in the organization is another challenge".

Similarly, Turmusani (1999) acknowledged a shortage of staff as one problem that faced many disability organizations in the Middle East. Kashrami (2003) also argued "there is a severe shortage of special educators in Saudi Arabia" (p. 18).

*Training.* The training of staff was another sub-theme that I identified. The participants discussed how having a staff with a formal degree was not as important as having well-trained staff. Formal training by the organization was essential, especially for new staff. HM1 noted:

"We do whatever it takes for us to train our staff and educate them. We provide two years of formal training and only those who succeed can work in our organization. Only three trainees out of 20 succeeded every year, so we have high standards. We always also send and encourage our staff to attend conferences and courses related to the disability field that could benefit them in their work. We also provide scholarships for those who are willing to continue their education, so as you can see, we invest a lot in our staff".

HM 8 was insistent. "I do not care if my employee has a formal degree or not. What I care about the most is that he or she would be able to work with our kids in the organization and for that reason we have to provide our own training to make sure of that."

From interviewing Head Managers from eight different disability organizations, I noticed that every organization had its own training program for its new staff. This was because, as HM 3 mentioned, "We want our new staff to learn our policies, missions and the way our organization works because as you know, every organization is unique."

All the participants agreed that one main reason behind their success was their well-trained staff. As HM 1 noted, "We are nothing without our staff. They are the moving engine of our organization. We always respect their ideas and suggestions because they know the kids better than we do." When I asked HM 3 about what helped the most in the development of her organization, she replied, "Our staff helps us to reach our goals and they are who made us what we are today. Without them and their endless efforts, I promise we could never be at what we are here." Most participants agreed that once you had a well-trained staff in your organization, you wanted to keep them. HM 1 stated the importance of keeping staff: "Ninety per cent of the organization's budget goes to staff salaries and do not be amazed because they are important to us and we want to keep them." HM 6 also spoke about the importance of training and keeping staff. "We do spend a lot on our staff and their training but if we do not pay them well they will

leave us."

Love of the work. Love of the work was another sub-theme and participants agreed that the staff working in their organizations did love their work and most of them did have passion for what they were doing. As HM 8 indicated, "We employ people who have love and passion about working with people with disabilities. We do not just need people who hold degrees."

Most of the participants argued that the most important things that should be available in their staff were love of work combined with honesty and love of the people they were working with. As HM 4 noted, "Honesty and the love to serve society are two things that must be available in our staff." "All our staff love the kids in the organization as their own kids and we've never had an incident" (HM 8). HM 5 also noted, "Our staff are honest people and have the love of giving - which is essential in our work." All the participants in this study agreed that having staff who are honest, giving and love their work had contributed a lot to the development of their organizations. HM 1, for example, expressed, "What helped us the most to reach where we are today was the passion that our staff had towards their work." Another participant talked about the importance of honesty and love for their work: "Honesty of our staff and their love of what they are doing is one of the main factors behind our development."

### Role in Society.

The role of disability organizations in Saudi society was the most recurrent theme in my interview data. Each participant I interviewed spent a great amount of time discussing this theme. Under this main theme came the three sub-themes: awareness, advocates and inclusion. Each one of these sub-themes reflected the different opinions and ideas that participants had about the role of disability organizations in Saudi society.

Awareness. Awareness was one of the sub-themes and the participants mentioned that their organizations' main mission was to increase the public's and parents' awareness about disability.

According to many participants, increasing the public's awareness about disability was one part of increasing society's awareness about disability. This was because as many participants noted, lecturing at universities and public places about disability and people with disabilities' rights was one way of increasing public awareness about disability and therefore society as a whole. As HM 7 noted,

"We lecture at universities and public places to let people know what having a disability means. We also want to send the message that people with disabilities can achieve a lot of things if they find the suitable environment".

According to that participant, people in Saudi society did not have accurate information about disability or people with disabilities. This was because "people with disabilities were invisible to the public in the last years. Our mission these days as a disability organization is to educate people - and lecturing is one way of doing that" (HM 7). HM 5 argued that lecturing at public places "increases awareness about people with disabilities and shows that they are part of society that cannot be ignored". Many participants mentioned that when lecturing at public places, they often raised the point that everyone in the community is disabled. As HM 4 so clearly identified, "I feel that I am disabled - not the kids in the organization - because I am the one who cannot communicate with them."

According to the interview data, increasing the awareness about disability in parents of children with disabilities was another part of increasing society's awareness

about disability. Most participants agreed that increased parent awareness about their children's disabilities could be achieved through the provision of enough information for parents about their children and their abilities. According to many participants, this could be achieved by letting the parents know that their children with disabilities have abilities and they can achieve many things like other children. As HM 6 noted, "We are working with the parents to let them know their child's needs and abilities by giving them lectures and educating them about many things that they might not know." HM 5 was quite serious when she indicated how parents' lack of knowledge about their child's abilities could diminish these abilities.

"Many parents do not know what having a disability means and they think that if their child is disabled he or she can do nothing except stay at home eating and watching TV and that's not the case. I think by ignoring the valued abilities in their children with disabilities, parents are going to unconsciously diminish these abilities. When parents come to our organization with their disabled children, we give them a hope for the future of those children by letting them know the options and facilities available to them inside and outside the organization".

Abu-Habib (1997) also argued that most parents of children with disabilities are ignorant "of how to help the child develop" because they do not believe in their children's abilities (p. 3).

Six of the participants mentioned their organizations did provide counseling sessions for parents or any other members who live with people with disabilities. They insisted these counseling sessions helped to educate people about the needs and abilities of people with disabilities surrounding them. HM 6 noted, "We want them to know that people with disabilities can think and they know everything surrounding them." During the discussion with one of the participants about the importance of counseling sessions for family members, she pointed out, "People with disabilities have emotions and needs that they can express and we should look at those needs and start from there." HM 4 gave an example, showing the importance of these sessions.

"Some people continue to ignore the fact that they have disabled members in their families. They do not know that by doing that they are hindering people with disabilities from achieving many things in their lives. They have to know that some people with disabilities might just need a few sessions of speech or physio to be able to talk or walk. We are trying our best in the counseling sessions to increase people's awareness about the importance of paying more attention to their disabled family members".

*Inclusion.* Inclusion was another sub-theme and all the participants talked about the importance of the inclusion of people with disabilities into society. They argued that their organizations were advocates for the inclusion of people with disabilities in Saudi society in different ways (See figure 1).

All of the participants except one were proud that their organizations helped many children with disabilities be included in the public school system. According to those seven participants, this happened by providing quality services for those disabled children who attended their organizations. To be included in the public school system they helped the children overcome disabilities that could be corrected. As HM 5 explained, "We help to rehabilitate children with disabilities so they can join the regular school." HM 4 indicated, "Our organization's main mission is to discover the hidden abilities and capabilities of children with disabilities. We want society to know that those children can go to school and have a normal life if they find the suitable support and environment."

Likewise, Kashrami (2003) argued the "importance of the inclusion of children with disabilities at the public schools in Saudi Arabia" (p. 6). It should be noted that not all the children in the organizations were able to join the public school system. As HM 6 explained, "Some cases are very severe so we work with them to help them to depend on themselves in their daily living tasks." There was only one participant who did not mention the inclusion of children in public school in her interview. This was because her organization provided services only for adults with disabilities.

All the participants mentioned that their organizations were against the segregation of people with disabilities. Seven of the participants argued their organizations were against the segregation of people with disabilities in segregated institutional settings. HM 7 argued, "People with disabilities have feelings - and families have to know that by sending their disabled family members to segregated institutions they are silently killing them." HM 5 argued strongly,

"I am against segregated institutions like organizations where people put their beloved ones and only see them once a year. I want to tell you something... do you know that most people send their disabled family members to private institutions outside the country and they never ask about them?".

HM 4 spoke with a great deal of heart when she said, "I am against segregated institutional settings because people with disabilities need their families' care and love, like non-disabled people."

HM 2 was the only participant who favoured segregated institutional settings: "Segregated institutional settings help relieve the families from their disabled members." I believe that people with disabilities should have the right to live with their families. This participant's opinion regarding institutional settings was totally different from all the other participants in this study.

It was important for participants to tell me their organizations got people with disabilities involved in one way or another with decisions concerning them. HM 6 noted, "We let our disabled members dictate our policies." HM 2 explained, "We always ask our girls each term if they like the designed courses for them and if they do not, or they favor something else we always go with their decision."

*Advocacy.* Advocacy was another sub-theme and all participants agreed their organizations stand as advocates for people with disabilities in Saudi society. This was because, according to the interviews, those organizations called attention to the rights of people with disabilities when others did not. Without an advocate, people with disabilities are essentially voiceless. HM 6 said,

"Our role in society is getting people to think about things once kept out of their minds. We hold a symposium once every four years to shine the lights on issues and needs of people with disabilities. We did a huge symposium on employment; we got factory owners, business offices, and government people to talk about the importance of work and jobs for people with disabilities. As a result, the biggest research centre in the country formed a committee and they drafted by-laws and the owner of our center was in this committee. They drafted the bylaws for Saudi Arabia and it came out that five per cent of the workforce of any working place should be disabled people".

HM 1 pointed out, "We are lobbying for jobs for people with disabilities." All the participants mentioned their organizations emphasized the importance of a barrier-free environment for people with disabilities in Saudi Arabia. According to HM 7, removing physical barriers was "A very important step in the inclusion of people with disabilities on our society". HM 3 mentioned, "An accessible environment is a must for everyone not just people with disabilities. Older people for example need the accessible environment and I think that one of our missions as a disability organization is to call for that environment whenever we can."

All participants in this study, except two, explained that their organizations were conducting research in the field of disability and were advocating for people with disabilities in Saudi Arabia. The research was exploring issues regarding policies and rights of people with disabilities in Saudi Arabia. HM 1 pointed out, "We conduct research about issues such as employment, accessibility and education for people with disabilities which will help in increasing the awareness about disability issues in Saudi Arabia." HM 6 explained, "One way of letting the government know about people with disabilities and their needs is through published research which studies all aspects of people with disabilities' lives in Saudi Arabia." One of the recommendations of al-Hazmi (2000) is "the importance of conducting more research on issues related to disability in Saudi Arabia" (p. 33). Only two organizations out of the eight I visited did not conduct research in the field. This was because they had recently opened and were planning to conduct research in the future.

## Islamic beliefs and values.

Islamic beliefs and values was one theme in the interview data with three subthemes identified: standards for life, reward from Allah and fear of Allah. These subthemes reflected the ideas that were discussed during the interviews of all participants.

Standards for life. Standards for life was one of the sub-themes identified under Islamic beliefs and values. All the participants explained that Islamic beliefs provided standards for their lives which have guided them in all their decisions. HM 1 noted, "Islamic beliefs provide my own intrinsic values that guide me in everything." HM 8 argued that Islam did "provide faith that pushes us to work every day". Most participants mentioned that Islam encouraged kindness to all people. According to those participants, kindness helped them to continue working in their organizations despite all the challenges. HM 3 shared,

"Islam has encouraged us to love and respect all people - especially those who are disadvantaged by society - and people with disabilities are among those ... you know, our religion encourages kindness and humanitarian work and that's what gives me the courage to continue working in this field, despite the challenges".

Most participants argued that one of the important things that helped their organizations to continue and develop was their Islamic beliefs that provided a set of values for their lives.

"My Islamic beliefs act as my code of ethics which guide me in all my life decisions, and one example of that is when there is something related to the organization that I feel hesitant about - I always go back to my faith and it never fails. Following our Islamic beliefs and values has helped our organization continue because whenever we have any problems, there is always something to go back to and find solutions for it" (HM 1).

A similar point was raised in the literature when Coleridge (1999) argued that when workers of the CDAP programs were questioned on their motivation for the job, "they frequently report that religion does play an important role" (p. 12).

*Reward from Allah.* Muslims believe that Allah rewards those who do good deeds for others (Arnoot, 2003). One of the Qur'anic verses stated, "Whoever does

righteous deeds – whether male or female – while he (or she) is a believer; then We will certainly give them a good life, and We will certainly grant them their rewards in proportion to the best of what they used to do" (l6:97). Hallaq (2005) argued that "the belief in Islam that good deeds is going to be rewarded by Allah has encouraged members in the Muslim community to help each other to please Allah and be rewarded by him in life and the day after" (p. 25).

Thus reward from Allah was another sub-theme under the main theme of Islamic beliefs and values. All participants mentioned "reward from Allah" during their discussions about working in disability organizations. Most participants believed that when working in disability organizations, they "work for Allah" and therefore they are going to be rewarded by him. HM 8 was pleased to tell me that some of the staff in her organization were volunteers and they never asked for money. This was because, as she mentioned, "They always know that Allah is going to reward them in the afterlife". HM 5 mentioned that "anything for Allah does not go[unrewarded]", explaining she was considering her work in a disability organization as a work for Allah and she was confident Allah would reward her for that.

According to many participants, their feeling that their work in disability organizations was rewarded by Allah encouraged them to love their work and work harder.

When I look at my friends who have the same experience and qualifications that I have and who work in other fields with higher salaries I feel depressed, but then all the sudden when I remember that in my work I am going to be rewarded by the Creator in my life and in the day after, it makes me even love my work more (HM 3).

This HM mentioned she would be rewarded "in the day after". According to Coleridge (1999), that is one of the basic beliefs in the Muslim communities which displays their belief in the "after life" (p. 22).

*Fear of Allah.* One of the Islamic beliefs is that the fear of Allah is the path to forgiveness, salvation and the attainment of his mercy (Hallaq, 2005). One of the verses in the Qur'an stated, "And whoever fears Allah – He will pardon him his sins and grant him a great reward" (65:5). Muslims believe Allah is watching them all the time and so this prevents them from sinning and encourages them to do good deeds (Hallaq, 2005). Hanbali ( as cited in Arnoot 2003) defined *Taqwa*, or Fear of Allah as "fear of Allah and watching him in every step so that he is to be obeyed not disobeyed and remembered, not forgotten" (p. 50).

Fear of Allah was one sub-theme and all the participants mentioned they had the feeling that Allah was watching them and therefore they could never do anything that would displease Allah. As HM 8 indicated, "We have a monitor in each room in our organization and although our staff's salaries are not high, we never had a single incident towards our kids and this is because our staff have fear of Allah and they know they have been watched by Him before us." HM 6 explained, "My work is between me and Allah so I know that he is always watching."

Although all the participant mentioned Islamic beliefs in their discussions about their organizations, one participant specifically held very strong belief that Allah predestined her to be in this position. This Head Manger had three children with disabilities which encouraged her to do the type of work where she was today. When asked about the importance of Islamic beliefs to her organization, she replied,

"Huge ...huge impact! It was the founding reason - when I look at my life, I feel

that Allah let things happen the way they happened because he wanted to see what I was going to do. I really feel that Allah wanted this to happen. I work for Allah and I feel that everything I do He watches me, and then at the end of the day after I finish my prayer and go to sleep I can sleep soundly - and I really believe [this] in my heart because I have no skills whatsoever for me to lead this organization. I am convinced that I am predestined [to this position] and that motivates me" (HM 1).

I could not help but take note of this participant's tone and words, as they were very strong when she was talking about Allah and Islam. She really felt that Allah had chosen her to establish her organization, and the call to work with disabled people was clear to her.

## Need for the place.

The need for the place was another main theme in the interview data. All the participants mentioned the need for their organization in society and their area as the main reason for its existence. Two sub-themes were identified: unavailable services and parents' needs.

Unavailable services. Unavailable services for people with disabilities are common in some areas of Saudi Arabia and most participants agreed that the unavailability of some services in their cities was the main reason behind their opening.

"There are not many organizations in the Kingdom for autistic children and especially in our city, therefore, parents who are seeking autistic services used to travel to the nearest city which have the service. For that reason we decided to establish our organization to serve this community" (HM 8). A similar point was raised in the literature when al-Hazmi (2000) recommended "there is a need for the establishment of more disability services and organizations for people with disabilities especially in the rural communities in Saudi Arabia" (p. 22).

Some participants argued that their organizations were established because some groups of people with disabilities were not welcomed by other organizations. As HM 2 indicated, "Most disability organizations are for children with disabilities - so we decided to establish an organization for girls with disabilities above the age of 12 because this group does not have any other place to go in other organizations." HM 7 argued that people with multiple disabilities were not accepted in most disability organizations and therefore she decided to establish her organization to accommodate the needs of this group. Each participant explained what they considered to be ways in which society restricted inclusion for people with disabilities, so their organizations were critical for the provision of services for people with disabilities (See figure 1). Certainly, it appeared that some of the most common problems were non-accessible buildings for those using wheelchairs, buildings, instruction manuals, and everyday utilities that did not have Braille, schools that did not have inclusive classrooms, sporting facilities that did not recognize the needs of people with disabilities, insufficient support services, inaccessible transportation or public areas, and not being able to network and be with friends.

HM 8 stated that even the organizations themselves were not always accessible for people with disabilities. For instance, if the organization meets the needs of people with hearing impairment, they do not necessarily meet the needs of people using wheelchairs. They would not be able to access the building and so people with multiple disabilities meet challenges accessing some disability organizations. HM 2 also mentioned that disability organizations do not usually have a place for girls with disabilities after the age of 12 and they do not get accepted into public schools.

Answering parents' needs. Answering parents' needs was another sub-theme and most participants discussed the importance of their organizations for parents of children with disabilities. Some participants mentioned their organizations did provide support groups for these parents. HM 6 explained with passion, "Our organization provides support groups for parents of children with disabilities in the organization and we also provide an online support group for parents of children with disabilities who cannot come to the organization." HM 5 spoke unreservedly when she explained, "Mothers do not need to know the reasons for their kids' disabilities - what they need to know are the available options for their kids and the best way to achieve that is through support groups because trust me, mothers do not listen to professionals, but they listen to other mothers!"

HM 1 noted, however, that the attitudes of the parents themselves were often a restriction for children with disabilities. "Saudi parents usually try to deny the disability their children have and feel ashamed of having a 'different child'. They try to hide that child from the community and do not seek help from disability organizations" (HM 1). The HMs felt these parents were closing their eyes to their children's needs, disabilities and abilities. HMs 1, 2, 3 and 5 stated, "Parents do not even ask about their kids' progress, or seek to sit down with teachers and ask questions, while others (parents of children without disabilities) do their best to know everything happening to their children and how they can help." HMs 1, 3 and 4 were upset that many parents left their children with disabilities to their maids' care and attention, while the parents cared for their other children.

The data I received from having face-to-face conversations through interviews were rich and provided me with a great deal of information. The HMs appeared to speak honestly from their hearts and with a great understanding of their organization, the needs, the community, religious and cultural traditions and an understanding of what the future should look like in this area. The data would not be nearly complete, however, without adding information about the women who participated in this research. HM 1 was so excited to see me and asked why I got involved in doing my Masters degree in disability studies. She said it was interesting for her to know because she thought my topic was unique and important. She was excited to answer every question in as much detail as possible. She became very emotional and cried during the interview when she discussed how much she felt that Allah loved her and gave her the honour to be the HM of this organization. She felt she was contributing a great deal to society by working in that organization.

HM 2 felt quite conscious and asked me about confidentiality. She became more comfortable as we talked and was anxious to tell me her life story of how she got involved in disability work. Her friend studied 'special education' and always talked to her about disabilities and how people with disabilities did not gain the public's attention until lately. HM 2 became interested in opening a place that would provide those services, but wanted the organization to provide services for that group of girls above the age of 12 who could not find places. She found a friend who could financially assist her to get the organization started. Her answers were very detailed and she was excited to tell me the main reason she got involved in the organization to work with people with disabilities was she felt "honesty and love in their eyes". She wanted to serve in that capacity for the rest of her life.

HM 3 insisted that working in the disability organization was not at all financially rewarding, as her degree would have allowed her to be employed in an area where she

would receive double her current salary. She felt though that another job would not contribute to her "moral happiness" and felt that doing "charitable work" would help ensure that Allah would reward her later. She said she preferred to be happy and it was clear from our discussion how much she loved her work. She was incredibly busy, but wanted to participate in the research and so our interview took place after hours.

HM 4 was very emotional in her answers. She was anxious to share many stories about situations that happened in her work and how she was so emotionally attached to the children in her organization. Her stories and storytelling will impact me far beyond the scope of this research. I could feel her love for the children as she referred to them as "my kids".

HM 5 was incredibly happy to "see a graduate student studying abroad and still thinking about doing a topic about her country". She answered every question confidently, giving me numbers and examples to support her answers. She had worked in other charitable organizations and did not hesitate in her answers. She was involved in many community organizations and was extremely busy as indicated by the phone calls and faxes received during the interview. She was, however, anxious for me to recontact her if needed.

HM 6 felt she was called to do charitable work and was in fact "born with a gift for that". She felt a passion for her organization and her work. She spoke quickly and answered questions nearly before they were asked, anxious to offer as much as she could. It was important for her that I understood the organization could not function without its staff and the collaboration between staff, charity, Islamic beliefs and values, and the love each one felt for the work.

HM 7 was extremely emotional at the beginning of the interview. She stated she

felt there was a great need for her organization in Saudi society and there was a general lack of spaces. HM 7 lost her first son at the age of six. He died with a serious complication after he had an operation on his stomach and doctors told her that he would either live with a disability or die as a result of the complications. She wished for him to live with a disability, but he died suddenly. She wept when she told me that ever since, she started feeling attached to every disabled child in society as if he/she were her own child.

HM 8 was keenly interested in her organization. She could barely stop talking about the programs and services, particularly the organization's future plans. She was anxious to work towards the fulfillment of the plans and considered her work with people with disabilities an important part of her life.

All participants were very excited during the interviews. They all said that generally students would come to the organizations to conduct surveys about people with disabilities, but no one had come to talk to them about their work, the organization, or listen to the stories in the organizations. Most HMs insisted on confidentiality, but were excited to tell their life stories and why they came to work in the organizations.

## **Document Data**

Documents such as booklets and pamphlets produced by those disability organizations where I conducted interviews were used in this research as a way of exploring the type of information that was given out to the public. I was also interested to see whether they provided additional information to what I received from interviewing and, if so, what. These brochures and pamphlets ranged from one to 15 pages in length and have been referred to throughout this thesis as 'documents'. Although the actual text from the documents was not as long as the interview transcript text, the contents provided a great deal of information on the organizations and showed the face each presented to the public.

The use of documents in this research provided valuable information that was not discussed in the interviews. Patton (2002) indicated that documents produced by organizations could help the researcher discover many things about these organizations and how they "came into being" (p. 294). The documents used in this research were public documents that perhaps could be used without the fear of invading confidentiality of these organizations. However, several participants were concerned about confidentiality - therefore the names of documents have been supplied with numbers, as were the participants. HM 1 and D 1 are from the same organization, HM 2 and D 2 are from the same organization – and so on through to HM 8 and D 8.

D1 was a ten-page booklet summarizing the organization's activities and programs for the last ten years. The mission statement was to "improve the well-being of people living in Saudi Arabia and neighboring countries by providing premium services for two of the most cherished human faculties: speech/language and hearing". The organization also provided counseling services for parents of children with hearing or speech disabilities. A description of educational training programs the organization offered for diplomas in speech and hearing therapy was explained, as well as a list of community services, events and conference information. The development of the organization and programs over the past ten years was explained.

The images on the booklet were of staff working with people with disabilities. There were also pictures of company managers sitting with the HM of the organization with text indicating the organization worked with companies to employ people with disabilities.

D 2 was a four-page pamphlet representing an organization working with females with special needs above the age of 12. The main mission of "education and rehabilitation of females with disabilities to enable them to join the workforce" was explained. The pamphlet outlined how the organization advocated for women with disabilities to join the workforce and had as its aims to provide different educational services, vocational training (including the occasional summer course), and social services for people with disabilities and their families.

The images were of the staff in community activities such as the library and activity rooms. There was also artwork produced by the females with disabilities in the organization and a picture of the main funder.

D 3 explained in its five-page pamphlet that its main mission was to "provide quality services for children with physical disabilities" and its philosophy was to "increase society's awareness about disability and people with disabilities in Saudi society". The pamphlet recognized the lack of disability research in Saudi Arabia that deals with social aspects of disability away from the body. The pamphlet also listed various types of services the organization provided for children with disabilities and encouraged donations to the organization.

A picture of the Royal family and people who contributed to the organization was highlighted on D 3. Other images were of community events the organization held. There were also pictures of waqf buildings that were endowed to the organization and a "donation form" at the end of the brochure where interested persons could fill in their names and contact information.

D 4 was a three-page pamphlet explaining the need for the centre for children

with disabilities to overcome their disabilities and get integrated into society. The pamphlet also listed educational and vocational programs, as well as the clinical and rehabilitative programs offered by the organization. The pamphlet gave a description of the structure of the building and its capacity to provide the needed facilities. This booklet contained no images.

D 5 explained in its 15-page booklet its main mission was "to provide comprehensive care for children with disabilities". Its list of objectives included: increasing society's awareness of the capabilities of people with disabilities; providing services for families of children with disabilities, including counseling and training sessions; and providing educational, clinical and vocational services. A portion of this booklet was dedicated to discussing the importance of waqf as a continuous means of financial aid and encouraged people to donate waqf properties to the organization.

The images in D5 were of the Royal family who contributed financially to the organization. There were also pictures of the artwork produced by the children in the organization. Images of the buildings endowed as waqf to the organization were also on the document, as were some pictures of staff members working with children with disabilities..

D 6 provided a 15-page booklet that highlighted its mission statement to be "ensuring that every individual child can assume a rightful place in society". The philosophies and history of the establishment were outlined as well as the different educational and training programs for children with mental disabilities. A portion of the document focused on donations to the organization and its important role for children with limited financial means. This document outlined the various community services that the organization provided for children with disabilities and their families. Lively images of staff with children were displayed throughout this document. There were also many pictures of community events where children with disabilities were participating, artwork of the children, people with disabilities employed in different businesses, and images of the organization's facilities.

D 7 was a small two-page pamphlet that outlined its main mission to be "the provision of the best services for people with disabilities so they can achieve selfdependency". The pamphlet listed educational, rehabilitative, psychological and vocational services for people with disabilities in the organization, the age group that the organization accepted, and dedicated space to the importance of charity to the organization and its continuance as a non-profit charity.

This was a small document, but there were images of the staff with the children in class and doing different activities.

D 8 provided a small two-page pamphlet outlining its role to provide a space for people with autism. Listing educational and vocational services for children with autism, the main mission was to "provide quality services for people with autism to further their inclusion in society". The pamphlet described the importance of early intervention programs, training sessions for staff and parents, support groups for families, the importance of the organization's efforts in the community to increase public awareness about disability, and the importance of the inclusion of people with disabilities in public events.

The HM of this organization mentioned the brochure was fairly new and needed work. There were no images in their document.

I identified five main themes throughout the eight documents when I read the text and looked at the images. These main themes were in some ways similar to the themes identified in the interview data. This was because the main ideas discussed in the interviews were also evident in these documents. The five main themes in the documents were charity, staff training, role in society, Islamic beliefs and values, and the need for the services.

## Charity.

Charity was one main theme identified in the documents. The sub-themes were: donations, waqf, and sponsorship, and according to the documents, all of these were considered to be different forms of charity.

**Donations.** Donations as a need to the organizations was evident on most documents. D 3 (2004) stated, "Donations play a major role in the continuity and success of our future plans" (p. 17), while another stated, "Financial donations help us to open our doors for more children" (D 7, n.d., p. 1). Donations could be a specific amount of money donated to the organizations or it could be any intangible thing like commodities needed by the organizations. D 3 stated, "We encourage donations and accept them in any form that can benefit the organization, such as furniture, books or cars" (D 3, 2004, p. 22).

All the eight documents mentioned their organizations did accept Zakah. D 5 (2001) noted, "We put Zakah money in a special account for the organization and we spend it on helping children with disabilities whose families cannot pay for all their medical and educational expenses" (p. 25). Another organization indicated, "We do accept Zakah and we spend it on sponsoring disabled members who are in need" (D 1, n.d., p. 3). The documents explained how people could donate by explaining that Zakah money should be made payable to their organization, that they should also include their

bank account number, and indicate whether the organization could receive donations year-round on that account. The documents also indicated that non-cash donations should go directly to the organization upon the approval of HM, as they would not accept anything they did not need.

Sponsorship. Sponsorship of disabled members of the organizations was another form of charity outlined in the documents. In most documents, there was a sponsorship form on which people could indicate how many persons they wanted to sponsor, whether they wanted to pay the full amount at once or distribute the amount throughout the year. The form usually indicated the amount needed to sponsor somebody in the organization. Most often, these forms were at the end of the documents and colored, but also there was an indication at the front - usually highlighted - so people could refer to the correct place in the document to find information about payment. Organization contact information was also included on each document. D 4 and D 7 did not have a sponsorship form but they indicated that anyone who wanted to sponsor an individual could give the money directly to the organization by cheque once or distribute the amount throughout the year. As D 1 (n.d.) noted, "We established a sponsorship fund to provide financial aid for people unable to pay the fees for services" (p. 2). Most documents indicated that sponsoring disabled members in the organizations helped a lot of families who were in need of the services but could not afford it.

*Waqf.* Waqf was another form of charity mentioned in the documents. All documents produced by the eight disability organizations insisted on the importance of waqf to their organizations. This was because waqf would provide constant financial resources for the organizations. D 2 mentioned that "one way of donating to our organization could be in the form of waqf that will provide continuous income for us" (p.

2). D 8 mentioned that "donations could be provided to us in term of waqf which will help us develop our building and expand our capacity to accommodate more children who need our services" (p. 2). Although HMs of these organizations talked about the importance of waqf, not all organizations wanted the public to think they experienced deficiencies or deficits. There were documents that did not mention waqf helped them recover deficits. The document of one new small organization did put on their brochure that they preferred waqf, as it would help cover any deficiencies. Scalengh (2006) suggested "that the powerful religious and cultural imperative of charity [including waqf] was particularly sensitive to the needs" of people with disabilities in Islamic societies (p. 150). Not all organizations, however, benefited from waqf.

## Staff training.

Staff training was another theme outlined in the documents. All the documents stated they provided and encouraged constant training for their staff. According to the documents, training their staff helped in the development of their organizations because "Trained staff members help us to achieve our missions and goals" (D 6, n.d., p. 3). Some organizations provided scholarships for their staff to get more training and education, and as one document stated, "We provide international scholarships for under-graduate, graduate and post-graduate studies" (D 1, n.d., p. 6). Not only was training encouraged, it was provided by the organizations and outlined on several documents. D 2 mentioned, "We provide constant training for our staff and we send them to attend national conferences and workshops" (n.d., p. 2). Some larger organizations like D1 had their own training program for their staff. "We provided in-organization training for our new staff" (D 3, p. 3). Al-Hazmi (2000) argued the importance of staff training: "Disability

organizations should hold training sessions for their staff members on a regular basis" (p. 13).

## Role in society.

The role of disability organizations in Saudi society was another main theme in the documents that I reviewed and four sub-themes were identified: advocacy, inclusion, awareness and educating family members. All these sub-themes reflected ideas mentioned in the documents produced by the disability organizations.

Advocacy. Advocacy was outlined in many documents. The documents indicated that disability organizations were advocates for people with disabilities in Saudi society. This was because most of these organizations expressed advocating for the rights of people with disabilities in society as one of their main missions. One document stated "our fundamental goal is to see our children grow into a person who can enjoy as much independence as possible and assume a rightful place in society so we consider ourselves to be allies for the rights of all people with disabilities on society" (D 6, n.d., p. 5).

*Inclusion.* Most of the documents insisted on the importance of inclusion of children with disabilities into public schools. One document stated, "We work on the implementation of the inclusion of children with disabilities into public schools and this year we have 20 of our children who have successfully joined the public schools" (D 3, 2004, p. 6). Most of the documents mentioned the employment of people with disabilities as another way of including them into society. "We are advocating for the inclusion of the communicatively impaired to provide them with services enabling them to function in the workplace" (D 1, n.d., p. 7).

Awareness. Awareness was another recurrent sub-theme in the documents' data.

All the organizations used their brochures to highlight that one of their main missions was to increase the need for society's heightened awareness about people with disabilities. One brochure stated, "We do lecture at public places to increase society's awareness about disability and people with disabilities' abilities" (D 3, 2004, p. 5). Another brochure stated, "We participate in conferences with papers and presentations about communication disorders to increase the public's awareness about our people" (D 1, n.d., p. 7).

Educating family members. Educating the parents about the different needs of their children with disabilities was a recurrent issue discussed in the documents. One brochure stated, "We provide extensive support and guidance to all family members through regular meetings as well as home visits" (D 6, n.d., p. 4). Another organization mentioned it provided lectures for parents of children with disabilities to let them better understand "what can be done to help their children" (D 1, n.d., p. 3). Al-Hazmi (2000) argued the importance of staff training. "Disability organizations should hold training sessions for their staff members on a regular basis" (p. 13).

#### Islamic beliefs and values.

Islamic beliefs and values constituted another main theme, while help from Allah and Islamic standards were sub-themes identified when analyzing the documents.

Help from Allah. Muslims believe in the importance of the help of Allah in their lives (Hallaq, 2005). "Muslims ask Allah for his help and guidance in every aspect of their lives because they know that He is capable of supporting them" (p. 5). The Qur'an also mentions Allah's help and Muslims who worship Allah do ask for his help as one of the Qur'anic verses state: "You (alone) we worship, and you (alone) we ask for help (for each and everything)" (1:4).

All the documents I reviewed insisted on the importance of Allah's help in the development of their organizations. Some organizations believed that only with the help of Allah could they achieve their goals and missions. As one brochure stated, "Our continuous efforts to develop and enhance our services and to expand their scope to reach every disabled child, would not have been possible without Allah's<sup>17</sup> help" (D 3, 2004, p. 8). Another organization noted, "With Allah's help and his continued support, we will be able to extend our help to our beloved disabled children" (D 7, n.d., p. 1). Other organizations agreed that Allah's help had helped them to continue to exist and serve people with disabilities in the community. As one document noted, "With the help of Allah, we may continue to serve our children and their families" (D 6, n.d., p. 12).

Islamic standards. Islamic standards were another sub-theme mentioned and all the documents mentioned their organizations' functions were subject to Islamic standards. One organization stated, "Islamic beliefs provide us with ethics and standards that we should follow in all aspects of our lives" (D 7, n.d., p. 5). Likewise, Coleridge (1999) argued that Islamic beliefs are visible in disability organizations in Muslim countries. Another organization displayed "Everything in our organization follows Islamic standards. An example of that are the teaching materials that we bring from abroad. Those materials have been modified to confirm to Islamic rules and standards" (D 1, n.d., p. 7). HM 1 mentioned her organization did bring materials from abroad but adjusted them to fit Islamic rules. She mentioned the material brought from abroad did not mention things like prayers and how they are performed. The material had to be modified to include these things, as prayer is an important part of Muslims' lives.

# Need of the services.

The need of the services provided by disability organizations was another main theme recurrent in the documents. All eight organizations mentioned in their documents that the services they provided were needed by the community. These organizations documented the need for their services by citing the disabled community as one reason behind their existence. According to one document, one of the main goals behind their establishment was "to provide unavailable services in the region for all people with communication disorders" (D 1, n.d. p. 8). Another organization noted that most disability organizations provided services for children with disabilities until the age of 12, while they tried to cover the age group from 0-18 (D 6, n.d. p. 5). One organization also mentioned "we serve people with speech and hearing impairments from birth to geriatrics" (D 1, n.d. p.3). By serving people with disabilities above the age of 12, these organizations helped to meet the needs of many disabled people and their families that were not previously met in the community.

#### Website Data

Internet websites were another source of data in this research besides interviews and documents. I collected the data from websites of eight different disability organizations from different regions across the country of Saudi Arabia (hence they can be named as they are in the public domain). I chose those eight websites from a list of recommendations provided by the Head Managers who participated in this study. Websites added more ideas and information about the development of disability organizations in Saudi Arabia.

The websites of the eight disability organizations used to collect data were as

follows:

- Harakiyah Disability Organization for Adults: a two-year-old non-profit organization that provided services for adults with physical disabilities. The mission statement for this organization was to "increase society's awareness about people with physical disabilities". The stated philosophy was to provide different services such as employment services whereby the organization acted as an advocate to help people with physical disabilities find suitable employment. The organization provided vocational training and advocated for accessible transportation to help people with physical disabilities achieve their goal. The website listed events happening in the community that were of particular interest to those with disabilities. Contact information for this organization was on the site and one could call or send an e-mail.
  - The photos on this site were of people with visible disabilities participating in different social settings, such as parties and events held by the organization. There were also images of those people who contributed financially. There were no links to other organizations.
- Saudi Association for Hearing Impairment [SAHI]: an eight-year-old organization with two branches, one in Jeddah and one in Riyadh. Its main mission was to end the idea that hearing impairment is a disability and increase society's awareness about the abilities of people with hearing disabilities. It also listed the services available in Saudi Arabia for people with hearing disabilities. This organization acknowledged the need for

more disability research in Saudi Arabia focused on people with hearing disabilities and included information linking readers to a forum that discussed several issues relating to hearing disabilities. The site had a link to a forum that was established specifically so people could discuss their concerns and different issues about the organization, including people with disabilities and their families. The site indicated this organization was open to all age groups and gave contact information including phone and fax.

- There were photos of people from the organization at social events and ceremonies held at or by the organization. There were also images of the Royal family interacting with people from the organization.
- Saudi Autistic Society [SAS]: a five-year-old organization with two branches - one each in Jeddah and Riyadh. It provided its services to people with autism. This organization also acted as a link between all organizations in the country serving people with autism. This was because this organization was the biggest and first established organization for people with autism in the country. Its mission was to "help in establishing policies and services that participate in the development of more services for people with autism in Saudi Arabia". One of the main aims stated was to increase awareness about autism in the country. Providing quality training for staff who work with people with autism in Saudi Arabia was highlighted. The website indicated that training courses were provided for staff working in that organization as well as staff working in other

organizations around the country. The site also had a specific area encouraging donations to help support the organization. The main income, or charity, was noted. The site also had links to books and articles and educational websites about autism. Contact information via phone or fax was given for anyone with questions.

- There were photos of academic activities in the organization, such as teaching and children from the organization with staff in different classrooms.
- Fatat-al-Ahsa Charitable Organization: a ten-vear-old charitable organization that depended on donations as its basic financial resource. This organization provided its services for children with mental and physical disabilities from birth until the age of 12, and then from the age of 13 and up to only females with disabilities. This organization was located in Ahsa<sup>18</sup> and its main mission was to "provide charitable services for people with disabilities". The site praised charity as a means of implementing Islamic tradition. It indicated the provisions of many vocational and educational programs for people with disabilities and discussed that the organization provided training for its staff. The website also mentioned the organization took as its main job to implement the Ministers' Council policy that stated the right for people with disabilities to employment in Saudi Arabia. This was achieved by acting as a mediator between people with disabilities and the government and private sectors in the country to arrange suitable employment. The site provided links to

many charitable organizations in the country. Those with questions could contact the organization through the posted e-mail address.

- The photos on this site were of children and staff in activity rooms, on trips and at community events held by the organization. Some of the community events appeared to be staff giving speeches in public places.
- Down Syndrome Charitable Association [DSCA]: a six-year-old nonprofit organization established in Riyadh. Its mission was clearly stated to serve the needs of children with Down Syndrome and their families regarding services available in Saudi Arable. It provided its services for children from birth until the age of 12. The site explained the different programs and services the organization provided, include early intervention and educational programs. The site included an online library with many published books and articles about different topics related to disability. The website mentioned the sponsorship fund and charitable work as two means in which people could donate to the organization. The site also explained that the Royal family members participated in the establishment of this organization. Contact information for those with questions was provided by phone, fax, mailing address and e-mail address.
  - The photos on this site were of children with Down Syndrome and staff doing activities in the different activity rooms in the organization.
- Care Center: a non-profit organization for children with mental disabilities from birth until the age of 12. The site outlined how the organization

provided rehabilitative and educational services for its children with disabilities. The organization was located in the city of Dammam at the eastern part of Saudi Arabia, and the site stated its main mission was to "increase self-dependency for children with disabilities". The site listed many articles and books related to disability in Saudi Arabia as well as any media coverage of many disability events in the country. The website included archived information on disability events and dedicated a portion of its site to the discussion of online donations.

- The only image on this site was of children playing in the backyard of the organization.
- Fatat-al-khaleej Female Charitable Organization [FECO]: a 20-year-old organization in the city of Khubar, located at the eastern part of Saudi Arabia that provided services for all women with any disabilities. It provided rehabilitative, educational and vocational training, and the website listed rehabilitative, educational and vocational services for women with disabilities and explained its main goal was to help women integrate into society. The site mentioned its main financial resource needed for the continuity of the organization was donations. The site encouraged donations as a rewarded Islamic act. This organization was part of a larger organization that provided charitable services such as vocational training for jobless people and homecare for orphans. Anyone with questions could contact the organization by phone or fax number provided on the site.

- The photos on this site were of female children with disabilities at many different social events. There were pictures of the children with the Royal family. Artwork done by the children was also displayed on the site.
- Al-Jubail Organization for Down Syndrome [JODS]: a six-year-old non-profit organization that provided rehabilitative and educational services for children with Down Syndrome. It served children from birth until the age of 14. This organization was located in the city of al-Jubail and the site explained the importance of early intervention programs. A space was dedicated to outline the importance of charity, as the organization was non-profit. It showed how most of its income was built around donations. The website also included the main community events and a conference the organization participated in mentioning that many businessmen and members of the Royal family played a major role in the establishment of the organization. There were links to other organizations who worked with Down Syndrome children. Phone and fax numbers were provided on the site.
  - There were photos of the Royal family and people from the private sector who contributed financially to the organization.

I identified five main themes in the website data. Each main theme had one or more sub-themes which represented the different ideas and issues discussed in the eight different websites. The main themes that were identified were charity, staff training, role in society, Islamic beliefs and values, and the need for the services.

# Charity.

Charity was one of the main themes discussed across the websites reviewed in this study. Donations, sponsorship fund and volunteer work were three recurrent ideas mentioned in the websites.

Donations. Most organizations insisted on the importance of donations to their establishments' continuity. These organizations accepted donations in the form of Zakah or as a yearly or monthly fund donated to the organizations. FECO (2002) expressed, "We receive yearly funds from different rich people in the country in our donations account, and these funds helped us to expand and develop our facilities to serve the community" (Missions and goals, para. 5). Fatat-al-Ahsa Charitable Organization (2008) also mentioned, "We collect Zakah money and encourage donations because we need the money to continue to provide our free services as we are a charitable organization" (Fund and donations, para. 4). JODS (2002) mentioned the organization was established from a fund donated to the organization by three major companies in the country (Establishments and Goals, para. 2). Rispler-Chaim (2007) also has acknowledged the importance of donations for the development of disability services in Muslim societies.

Sponsorship and fund. Many organizations mentioned sponsorship fund as one way of charity that could benefit people with disabilities who could not pay for the services. DSCA (n.d.) noted, "donations could be in the form of sponsorship funds to help families of children with disabilities who could not pay at all or who could pay only a specific amount of the fees" (Donations and Funds, para 4). FECO (2002) indicated, "We have a 'disability friends' account' which accepts donations for sponsoring children in the organization" (Accounts, para 3).

Volunteer work. Volunteer work was another form of charity recurrently

mentioned in the websites. Many organizations encouraged volunteer work and considered it to be charitable donations for the organizations. DSCA (n.d.) indicated, "Volunteer work is a very respectful charitable act because the workers are donating their times and efforts and they will be rewarded by Allah" (Charitable work, para. 3). Fatatal-Ahsa Charitable Organization (2008) also mentioned, "Our religion Islam has encouraged the charitable and humanitarian works to achieve the principle of solidarity in the Muslims' society, and volunteer work at the organization is one way of achieving that principle" (Charitable work, para. 3).

# Staff training.

Staff training was another main theme identified in the websites. Many organizations argued they continuously provided training for their staff members. JODS (2002) indicated that one of its main goals and missions was to provide proper training for its staff. SAS (2008) stated, "We pay attention to the training of our workers to best serve the needs of the Autistic group" (Missions, para. 2).

# Role in society.

The role of disability organizations in society was another theme mentioned in the websites of the disability organizations. Parents' education, co-operation between agencies, advocates and awareness were all sub-themes under the role of disability organizations in society. These sub-themes reflected the ideas presented in the websites of the eight disability organizations about the role of these organization in society.

Parents' education. Most organizations mentioned parents' education as one of their main missions and goals. The website for Fatat-al-Ahsa Charitable Organization

(2008) states, "We train parents to help them understand their children's disabilities so they can work with them to achieve their best" (Missions and Goals, para. 4). JODS (2002) also indicated one of their main missions was to provide training sessions for parents and family members of children with disabilities because "We want them to know that children with disabilities can contribute many things to their society" (Missions, para. 3).

*Co-operation between agencies.* Most websites mentioned its organizations' efforts to co-operate with other disability organizations and government sectors in the country. SAS, for example, was the biggest and first established organization for people with autism in the country. Therefore one of its main goals was to "adapt services and programs that contribute to the development of comprehensive services required by autistic people and their families in coordination with governmental and charitable rehabilitation services provided to this group within the kingdom" (Aims and Goals, para. 4). DSCA (n.d.) indicated that one of their aims was to "co-ordinate between the efforts of government agencies and charitable organizations to care for children with Down Syndrome in the country" (Aims and Missions, para. 2). Turmusani (1999) also acknowledged the importance of co-operation between disability organizations and argued that in order to make people with disabilities' rights a reality, "there is a strong need for all relevant parties to co-operate and co-ordinate their efforts" to "involve society and raise awareness of disability and the law, and so forth" (p. 12).

Advocacy. All the organizations reviewed in this study considered themselves to be advocates for people with disabilities. This was because these organizations were advocates for the rights of people with disabilities to be included in society. Harakiyah Disability Organization (2008) mentioned, "we advocate for the employment of people with disabilities and work with agencies to employ them" (Missions, para. 2). JODS (2002) indicated, "our main aim is to advocate for the inclusion of people with disabilities in society and this could be achieved by developing our children's skills so they can join the public schools like other children" (Missions and Goals, para. 2).

Awareness. Awareness was another sub-theme mentioned in the websites. Most organizations argued they work to increase society's awareness about people with disabilities issues (See figure 1). Fatat-al-Ahsa Charitable Organization (2008) stated, "We lecture at public places and participate in disability national events to increase society's awareness about people with disabilities" (Missions, para. 2). SAS (2008) stated, "We work with the media to increase awareness about autism in society" (Missions, para. 1). Most websites mentioned their organizations had great connections with the media. They insisted the media had helped them increase society's awareness about people with disabilities and their needs. DSCA (n.d.) noted, "We lecture about disability at social events trying to increase society's awareness about disability issues and the media always captures that and presents it on T.V. and in newspapers" (Missions and Goals, para. 2). SAHI (2008) mentioned that Channel One had started to transcribe the daily news and most of its programs using signal language so people with hearing impairments could watch the news. SAHI (2008) indicated in their website that the use of signal language on T.V. "will increase public's awareness about the presence of people with hearing impairments in society and the importance of including them in the media" (Missions and Aims, para. 3).

### Islamic beliefs and values.

Islamic beliefs and values were another theme mentioned in the websites of the

eight disability organizations reviewed. Reward from Allah and help from Allah were two sub-themes which reflected the ideas presented in the websites.

*Reward from Allah.* Reward from Allah was a recurrent sub-theme discussed in the websites. Most websites mentioned their belief that their work would be rewarded by Allah had encouraged them in many ways. DSCA (n.d.) indicated, "our staff never panic even if they have to work for extra time because they know that their work will be rewarded by Allah" (Staff, para. 2). Fatat-al-Ahsa Charitable Organization (2008) mentioned that one of the main aims behind their establishment was to be rewarded by Allah for "serving the community" (Aims, Para. 2).

Help from Allah. Many organizations indicated in their websites they believed Allah was helping them. DSCA (n.d.) mentioned, "we have confidence in Allah that he will help us to continue despite challenges" (Missions and Goals, para. 3). FECO (2002) indicated the help they received from Allah had helped their organization to develop and grow. As they noted, "Through the past twenty years and with the help of Allah, we have developed and expanded our services to meet the needs of people with disabilities in our community" (History, para.1). Fatat-al-Ahsa Charitable Organization (2008) mentioned "we started as a speech clinic and then with the help of Allah we have developed to a full organization" (Establishment, para.1).

# Need of the services.

The need for the services of the disability organizations studied was another recurrent theme in their websites. All the websites mentioned the need of the services that their organizations provided as one reason behind their establishment. Different types of services, events and activities were also displayed in various images on the sites. DSCA (n.d.) indicated, "we were found on a need basis" (History, para.1). SAS (2008) also noted, "our organization has been established to answer the needs of all the people with autism in the kingdom" (Establishment, para.1). JODS (2002) was the first organization to provide its services for people with Down Syndrome in al-Jubail. JODS (2002) mentioned that the idea behind the establishment of the organization came from a mom and dad of two Down Syndrome children. "Those parents pointed out the need of all parents of children with Down Syndrome to the services our organization provides" (History, para.1). The need for the services of disability organizations was raised in the literature by Turumsani (1999) who discussed the shortage of disability organizations in the Middle East.

# Summary

This chapter discussed the main issues and ideas that came out from interviews, documents and websites. The data was categorized into different themes and sub-themes as shown in Table 1.

WEB TEXT		BROCHURES TEXT		INTERVIEWS	
DONATIONS		DONATIONS		DONATIONS	CHARITY
SPONSORSHIP	-  CH	SPONSORSHIP		SPONSORSHIP	
	CHARITY	WAQF	CHARITY	WAQF	
VOLUNTEER WORK				CHARITY WORK	- ·
STAFF TRAINING	STAFF	PROVIDE STAFF	STAFF	AVAILABILITY	STAFF
	STAFF TRAINING	SCHOLARSHIP FOR	STAFF TRAINING	TRAINING	
	- G		n	LOVE OF THE WORK	
AWARENESS	ROLE I	AWARENESS	ROLE I	AWARENESS	ROLE IN SOCIETY
ADVOCACY	IN SOCIETY	ADVOCACY	IN SOCIETY	ADVOCACY	
COOPERATION BETWEEN AGENCIES	- 7	INCLUSION	Y	INCLUSION	
PARENT EDUCATION		EDUCATION OF FAMILY			
	ISLAMIC BE	ISLAMIC STANDARDS	ISLAMIC BELIEFS	STANDARDS FOR LIFE	ISLAMIC BE
REWARD FROM Allah	MIC BELIEFS AND VALUES	HELP FROM Allah	ELIEFS AND	REWARD FROM Allah	MIC BELIEFS AND VALUES
HELP FROM Allah	VALUES		VALUS	FEAR OF Allah	
UNAVAILABLE	NEE	NEED FOR SERVICE IS	NEED	UNAVAILABLE	NEE
SERVICES	D FO	THE REASON BEHIND	DFOR	SERVICES	D FO
PARENTS' NEEDS	NEED FOR THE SERVICES		R THE SERVICES	PARENT'S NEEDS	NEED FOR THE PLACE

# Table 1: Data themes and sub-themes.

Disability Organizations in Saudi Arabial15

### **Chapter Five: Discussion/Analysis**

This study explored the development of disability organizations in Saudi Arabia through the social model of disability and the Islamic perspective. As a Saudi Arabian and practicing Muslim, I understood that my "daily activities are colored with Islamic values, so learning, making meaning and interpreting new situations are all done in an Islamic frame of reference" (Al-Zeera, 2001, p. 46). It was important to make this distinction, because although the research needed to adhere to the research tenants of reliability and validity, it would be within the framework of subjective qualitative inquiry. The social model of disability focused on the inclusion of people with disabilities, and the social, religious and cultural barriers that exist for people with disabilities. These barriers reduce the opportunities for education, work, and even friendships for some groups of people and increase those same things for other groups. People living with disabilities experience problems associated with particular physical realities because of social, religious and cultural barriers. People living without disabilities do not experience the same problems of exclusion. Although the two perspectives are not necessarily dependent upon or synonymous with each other, the Islamic perspective of charity and the social model of disability were found to support each other.

This research was meant to answer three main research questions. Data was collected from three different sources, and then analyzed and coded into main themes and subthemes to provide answers to the main research questions. This chapter also discusses data that lay outside the main themes and sub-themes and links between the findings of this research and the existing literature about disability organizations in Saudi Arabia. What are the key issues that contributed to the development of disability organizations in Saudi Arabia?

According to the data findings of this research, five different key issues contributed to the development of disability organizations in Saudi Arabia. These issues were charity, staff, Islamic beliefs and values, role in society and the need of the services provided by the organizations. These five themes did not reinforce a medicalized discourse, nor separation or exclusion from society, but supported inclusion in schools, the workplace, social settings and the family, and moved away from speaking about particular physical limitations.

1) Certainly 'charity' as a theme, not only from the data, but from the study of the history of disability organizations in Saudi Arabia and before it became a kingdom was one of the key issues that contributed to the establishment and continuity of disability organizations. Charity was also integral to the future planning of those organizations. All the Head Managers interviewed in this research, the documents that were collected and the websites that were studied insisted on the importance of charity, which was broken down into donations, sponsorship and waqf, to the development of their organizations Donations did help cover financial deficits when they happened and helped in the establishment of some of the organizations by donating the buildings, furniture or providing financial support to the organizations. Sponsorship helped the organizations continue to provide their services for people with disabilities who could not afford to pay for it, although the organizations did not refuse people with disabilities because of their inability to pay for services. The importance of waqf to the development of disability organizations was critically important as they could feel financially secure by having

continuous income provided for the organizations. Waqf did help the organizations which benefitted from it in building their future plans as they had constant financial income. Waqf was discussed by HMs and also pointed out in both brochures and on websites.

2) Staff who worked in the disability organizations was another key issue that contributed to the development of these organizations. According to the data, having well-trained and honest staff did help tremendously in the development, continuity and future of the disability organizations. This was because well-trained staff helped the organizations in achieving their goals and missions. According to the data, all the disability organizations in this study provided and encouraged constant training for their staff to help them in achieving their goals. Educated and trained staff, in fact, was so important that HMs discussed how Saudi Arabian culture did not accept women to travel to another city or area to work, and so educated and trained female staff members had to either come from outside the country or from the city to be retrained by the organizations. A great deal of effort and money was put into the training and retention of good staff members.

3) Reward from Allah, help of Allah, and Islam as a standard for life were identified as Islamic beliefs and values that contributed to the development of disability organizations. Most participants in this study believed that when working in disability organizations, they "work for Allah" and therefore would be rewarded by him. According to those participants, their belief that their work would be rewarded by Allah encouraged them to love their work and work harder, which helped in the development of their organizations. Most organizations mentioned in their brochures and on their websites that their belief that their work would be rewarded by Allah encouraged their staff to work harder and therefore contributed to the development of their organizations. HMs and all the documents and websites insisted on the importance of Allah's help in the development of their organizations. This was because they believed that only with the help of Allah could they achieve their goals and missions. They also believed that Allah's help had helped them to continue existing and serving people with disabilities in the community.

All the participants, the documents produced by their organizations and the websites of other organizations discussed that one of the important things that helped their organizations continue to develop was their Islamic beliefs that provided a set of values and standards which the organizations used to guide all their decisions. Organizations also had to operate within the confines of the Saudi government which is intimately linked to Islam and uses it in policy.

4) The need of the services provided by disability organizations was another key theme found in this study that contributed to the development of disability organizations. All the organizations insisted that one of the most important reasons behind their existence was the need in the community for the services they provided. They mentioned they continued to exist and develop their services because they served the needs of the disabled community in Saudi Arabia. All HMs acknowledged that without the need, they would not have to exist. They also felt there was a need for their own specific type of organization which targeted or focused on specific age groups, gender or particular type of disability. The development of these organizations grew out of the HMs' personal experiences or what they felt to be a calling.

5) The need of the services also linked to the role in society that the organizations played. The HMs, documents and websites all pointed to the importance these organizations had in bringing educations, awareness and advocacy to the broader

community. Without the organizations, these roles could not be filled and people with disabilities would have no voice. They would continue to be hidden and excluded from society, unable to attend school or access the job market. They would be less apt to be independent and contributing members of society. Their families would continue to hide them away at home and the severely disabled would be put into institutions and forgotten (See figure 1).

In what ways has Islam influenced the development of disability organizations in Saudi Arabia?

The second main question in this research looked at the ways in which Islam influenced the development of disability organizations in Saudi Arabia. The Islamic model of charity and how it was conceived and practiced in Saudi Arabia has been important to the development and growth of these organizations – particularly since the early 1970s. Zakah, the third pillar of Islam, was discussed as one form of charity required in Islam. Zakah is required by Allah, as stated in many of the Qur'anic verses and mentioned by the Prophet in the Hadith. Influenced by and following Islam, the Saudi government also recommended Zakah be given to disability organizations. Zakah was highlighted by HMs, documents and websites as affecting the development of the disability organizations. All organizations mentioned they accepted Zakah and used it to sponsor people who could not afford the services so they could continue to serve the disabled community. The organizations also mentioned accepting Zakah and putting it into the organizations' accounts so it could be used to develop more services for people with disabilities.

From the significance of Zakah came the importance of charity in the Muslim

world. The main difference between Zakah and charity is that Zakah is required by Allah to be paid and those who refuse to pay it will be punished by him. Charity is optional but encouraged in Islam as mentioned in the Qur'an and the Hadith. This was mentioned by all HMs, in the brochures and on the websites. Charity, in all its forms - including donations, sponsorship and waqf - contributed to the development of disability organizations in Saudi Arabia. Islamic beliefs and values, including reward from Allah, help from Allah and standards for life, contributed to the development of disability organizations. Zakah, charity, and Islamic beliefs and values were some ways in which Islam has influenced the development of the disability organizations that I studied in Saudi Arabia.

The key issues that contributed to the development of disability organizations in Saudi Arabia have been shown to be intimately linked to Islam. The HMs insisted on the connection of Islam to their work and the organizations' missions. Brochures from their organizations backed up and were consistent with that data, and websites from eight other organizations supplied this similar and consistent data through text, images and in some cases links to other sites. The disability organizations, whether government-run or private, all worked and developed within the framework of Islam – as a religious and cultural belief and practice. The practice of Islam was prevalent and affected government legislations and this recognition played heavily into the development of disability organizations of the Council of Ministers acted as a 'disability code' that governed all the aspects of disability organizations in the country. The government disability recommendations do not and cannot have anything that goes outside the realm of Islam. HMs revealed that when teaching materials were brought in from outside of Saudi Arabia, they were adapted to reflect Islamic values and Saudi Arabian policies. This would indicate that Saudi disability organizations operate within an Islamic constructed worldview. There is no opportunity for a disability organization to operate in any other way.

How do Head Managers from disability organizations view the development of disability organizations and the role these organizations play for people with disabilities in Saudi Arabia?

The third question in this research explores how HMs view the development of disability organization and the role that these organizations play for people with disabilities in society.

Head Managers viewed the development of their organizations as a result of charity, staff, Islamic beliefs and values, role in society and the need of the services. All the HMs strongly felt that their work in disability organizations was charitable work. They agreed their feelings that their work was charitable and would be rewarded by Allah encouraged them to continue to work harder despite the challenges, and therefore helped in the development of their organizations.

All the HMs agreed that having honest, giving and staff who loved their work contributed a great deal to the development of their organizations. This was because, according to interview data, staff who had passion and loved for what they were doing were able to give more and work harder. As a result, those staff members would help the organizations achieve their goals and continue serving people with disabilities. HMs argued that the most important character traits in their staff were love of the work combined with honesty and love of the people they were working with.

According to the HMs, fear of Allah also helped in the development of their

organizations. All the participants mentioned they had the feeling that Allah was watching them and therefore they could never do anything that would displease Allah. Fear of Allah prevented the staff and HMs from any negligence in their work.

The second part of this third main research question asked how HMs viewed the role of disability organizations for people with disabilities. According to interview findings, disability organizations had three major roles for people with disabilities. These roles were increasing awareness, inclusion of people with disabilities, and advocates for the rights of people with disabilities. This supports the social model of disability to remove the barriers in the community that restrict the inclusion and movement for people with disabilities, giving unfair opportunity for life-chances.

According to many HMs, lecturing at universities and public places about disability and people with disabilities' rights was one way of increasing the public's awareness about disability and the restrictions placed on them. HMs also felt it was critically important to increase parents' awareness about their children's abilities, rather than disabilities. According to many participants, this could be achieved by letting the parents know their children with disabilities also have abilities and they can achieve many things like others their age. Many HMs were excited to talk about their counseling sessions for parents of children with disabilities.

All participants in this research argued that their organizations were advocates for the inclusion of people with disabilities in Saudi society in different ways. Seven HMs talked about how their organizations helped many children with disabilities to be included in the public school system. Also, seven argued they were against putting people with disabilities in institutional settings where they would be left and separated away from family and community. Lastly, most HMs mentioned their organizations got people with disabilities involved in one way or another with decisions concerning them. Although they did not directly write policy, their thoughts and ideas were considered when the organizations pondered what they should or should not change.

All HMs agreed their organizations stood as advocates for the rights of people with disabilities in Saudi society. Many, for example, indicated they were advocating for the employment of people with disabilities and emphasized the importance of a barrierfree environment for people with disabilities in Saudi Arabia. This was because, according to those participants, removing environmental barriers would help in the inclusion of people with disabilities in society. They all strongly agreed it was not the person who had the disability, but society restricted the movements and inclusion of some groups of people and therefore put a disability on them. This was consistent with the social model of disability that recommends and supports the removal of barriers that keep people with disabilities from full inclusion into society (Shakespeare & Watson, 2002).

Both al-Maghlooth (2000) and al-Turaki (1996) studied disability organizations in Saudi Arabia and focused on the kind of services these organizations provided for people with disabilities. This research contributed to those studies as it explained how the organizations that delivered those services were developed, are maintained and how they hope to move into the future.

Gain and Abdulwahab (1998) pointed out that most research about disability in Saudi Arabia has been framed within the health and medical discourse of disability and more research was needed to examine the other issues that people with disabilities face in their lives. One of the main questions in this study was to explain the role that disability organizations play for people with disabilities, and thus it did not study the physical or medical aspect of disability. Instead, it studied the key issues affecting the development of disability organizations and the role these organizations played for people with disabilities in Saudi Arabia.

There were additional themes and ideas raised in the data. Internet websites were the only source of data in this research that discussed the importance of media and its role to disability organizations. There was no mention of the media or its role to disability organizations in the interviews or the documents. This might be because I had not asked the HMs about media or its possible role to their organizations. Another interesting thing to point out was that most of the organizations were for children with disabilities. This was not due to my choice of the organizations but because most of the disability organizations in Saudi Arabia were meant for children with disabilities. Most Head Managers reported the lack of enough services and organizations for adults with disabilities in Saudi Arabia.

The Islamic perspective of charity is linked to the development of disability organizations. Of the five pillars of Islam - shahadah, salah, Zakah, sawm and hajj - only Zakah was discussed by HMs or outlined in the brochures and websites. Ayub (1986) pointed out that, for Muslims, Islam maintains all aspects of life and directs them in all decision-making. Although the religious tenants of Islam dictate the connection of Islam to disability organizations, the data findings pointed to mostly the importance of Zakah – perhaps through the belief of shahadah.

The development of disability organizations has grown because of the influence of Islam, and government recommendations and legislation. The financial needs of the organizations could be taken care of through donations and charity, but the acceptance and social inclusion of people with disabilities appeared to be not as easily obtained. Organizations worked hard towards inclusion through education and workplace programs, pictures and images on brochures and websites, and putting people with disabilities into the social arena. The Council of Ministers recommended inclusion in the workplace and schools, and through the construction of new buildings. HMs recognized there was a great deal of education that needed to take place for policymakers and the public at large, to shift from a medical understanding of disability to a social understanding of disability.

Gain and Abdulwahab (1998) discussed this focus of disability research on medicalizing disability – that people with disabilities needed to be fixed or cured. HMs recognized it was society that created the disability, but they still stated that family members needed to be educated about their children's abilities, recognizing that 'disability' is still understood at the most intimate level as a physical limitation – not a social or environmental one. Even in their own organizations, some were not accommodating to people with disabilities. Kashrami (2003) studied the inclusion of children with special needs in public schools, and although the HMs discussed the importance of this inclusion - consistent with the findings of Kashrami - there appeared to be a lack of qualified special educators in most schools.

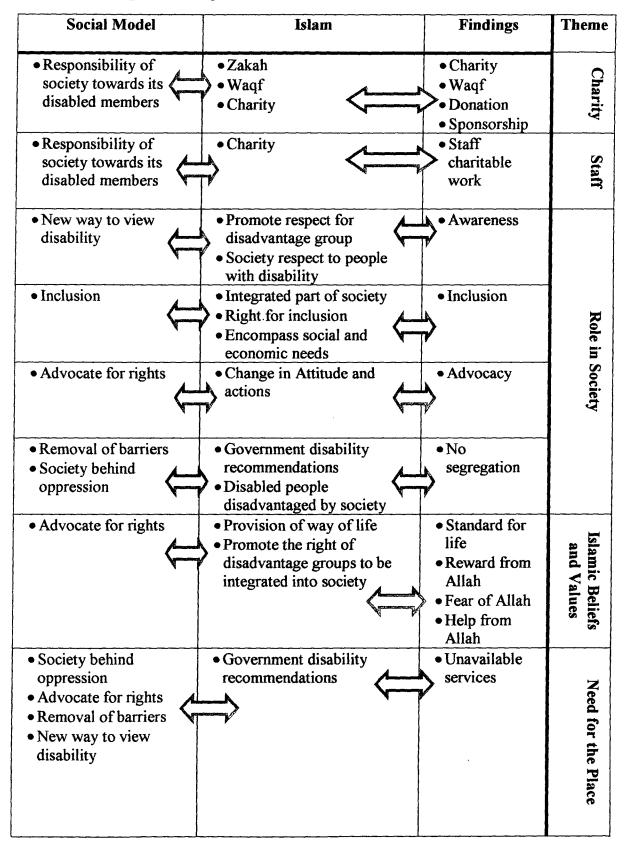


Figure 1 Findings and conceptual framework

# **Chapter Six: Conclusions**

This final chapter of my thesis will give a brief summary of this study. Then I will discuss the contributions of this study with some suggestions for future research. The main purpose of this study was to explore the development of disability organizations in Saudi Arabia. The context for the study was introduced to the reader and provided a brief discussion about the country of Saudi Arabia and its connection to Islam. It also presented the historical background to the development of charitable institutions in Saudi Arabia which was the framework for developing disability services in the last three decades. A gap was identified in the Western and the Saudi literature with regard to a discussion of disability approaches and organizations in the Arab and Muslim world and helped frame the questions within the frameworks of 'the charity model of Islam' and 'the social model of disability'. Also, the two models, the charity model in Islam and the social model of disability, which helped shape the conceptual framework of this thesis were also presented. An explanation of the qualitative methodology used in this study was presented. Interviews, documents and websites provided three very different types of data for an inductive analysis which led to specific patterns and themes that fit into the Islamic perspective of charity and the social model of disability.

The findings of this study were presented in chapter four and found that:

- The development of disability organizations in Saudi Arabia has been heavily influenced by charity, staff, Islamic beliefs and values, their role in society and their need for a place.
- 2) The development of disability organizations in Saudi Arabia has been influenced and affected by Zakah, one of the five pillars of Islam and the

Islamic perspective on charity – whether through the giving of money, buildings, resources or time. The organizations' beginnings, growth, maintenance and plans for the future have depended on the Islamic model of charity supported by the Qur'an and Hadith and the Saudi Council of Ministers' recommendations. Education, religion and state are all intimately connected to Islam, and for a disability organization to operate outside of Islam using another religious model would not be supported, and would be illegal if the religion was practiced.

3) HMs recognized that charity, staff, Islamic beliefs and values, role in society and the need for a place were important to the growth of their organizations, but were most passionate about their own work. Several cried and became extremely emotional telling stories about 'their' children or people they worked with. Some became emotional talking about the families and parents. They were emotional about their own understanding of how they were working for Allah and would be rewarded by him. They understood this work to be not only voluntary or charitable, but of a higher calling. The love of this type of work and love of the people was critical to the development of their organizations, as they felt that staff must also feel this connection to the people and have a love of their work.

Both the Islamic perspective of charity and the social model of disability were evident throughout the research, but not in isolation from other models. "Disability", although not characterized by individual physical differences, was still referenced as a problem that needed to be addressed by their organizations. HMs recognized that the reason people with disabilities had unequal opportunity was because of environmental and social barriers, and although these barriers were addressed through education and actions towards inclusion, they understood that society's understanding was within a medicalized discourse. I think that the media in Saudi Arabia should focus more on increasing society's awareness about the different abilities and capabilities of people with disabilities instead of their physical limitations.

The social model of disability was visible throughout the research in discussions with the HMs and in the images and text of the brochures and websites. This was because one of the main premises of the social model advocates for the inclusion of people with disabilities in society by removing environmental factors. According to the findings of this study, disability organizations were advocating for a barrier-free environment for all people including people with disabilities. I think that there should be more cooperation between the different private and government sectors in the country to work on removing environmental barriers and therefore promote a more inclusive society.

Chapter five discussed the answers to the three main research questions. It then linked this study with the existing literature about disability organizations in Saudi Arabia. Finally, it pointed out some of the ideas and issues mentioned in the data which I thought were interesting to discuss because it said some important things about disability organizations in Saudi Arabia (See figure 1).

# Contributions

This research made a number of contributions to the area of disability studies. As this topic of exploring the development of disability organizations in Saudi Arabia through an Islamic perspective of charity and the social model of disability has not been studied before, the findings of this study will add to the North American and Saudi literature that explores disability organizations in Saudi Arabia, an Islamic state. It is necessary to have more than one worldview of disability issues to help contribute to a more complete picture of what is happening in other parts of the world. Viewing disability in an Islamic country is also important because most research in this area has been done from a Western perspective. Other voices need to be heard.

Another significant aspect of this study was that it approached disability from a non-medical perspective, which is not common to disability research in Saudi Arabia. I am a Saudi Arabian Muslim, studying in Canada, sponsored by the Saudi government. After getting the approval and copyright for this research, I will return to Saudi Arabia where my research will be translated into Arabic and then published. Therefore this research will open the door for future disability research in Saudi Arabia which looks at other components of people with disabilities' lives instead of just focusing on the body.

The need of the services was one of the key issues identified in the data to contribute to the development of disability organizations. Therefore this research may assist policymakers to consider providing more services and establishing more organizations to meet the needs of people with disabilities. Policymakers must begin to address 'disability' through the lens of social barriers, not physical limitations. I suggest that disability organizations, as advocates for the rights of people with disabilities, should communicate the various needs of people with disabilities to the government and policy makers and could lead in making connections between policy-makers and people living with disabilities so that policies are built from the bottom- up.

### **Recommendations for Future Research**

This study has some suggestions for future research. It was found in the data there

were five key issues contributing to the development of disability organizations in Saudi Arabia. These issues were charity, staff, Islamic beliefs and values, role is society and the need of the services. However, more research is needed to study each key issue in detail and discern the impact on the development of disability organizations in Saudi Arabia.

This research took part in two main cities in Saudi Arabia. I recommend that more research needs to explore the disability organizations, parents of children with disabilities, different issues, limited resources and so on in rural areas. Each of the above five key issues also needs to be researched in rural areas as do the political policies, religious beliefs and cultural practices for people in these areas.

Internet websites were the only source of data in this research that discussed the importance of media and its role to the disability organizations. Media can be critically important in framing a topic or issue, the understanding of society and its response. I think that how media frames the development of disability organizations and the relation to Islam needs more attention.

Although the cultural restrictions to women that were addressed by HMs looking for staff were not focused on in this study, it is important this be addressed in future research. I recommend this gender-related aspect of culture should be explored, and whether it can affect the success of disability organizations and therefore the inclusion of people with disabilities or further contribute to their limitations and exclusion.

# Endnotes

<sup>1</sup> The transliteration of Arabic names in this thesis follows the International Journal of Middle East Studies' guide of transliterating non-English names. This guide is available online at : http://assets.cambridge.org/MES/MES\_ifc.pdf

<sup>2</sup> Allah is the Arabic name for God in Islam. It is the identical term used by Christian Arabs to refer to God.

<sup>3</sup> "Sunnah literally means a way, practice, rule of life; and refers to the exemplary conduct or the model of behavior of the Prophet in what he said, did or approved" (Dio, 1984, p. 7).

<sup>4</sup> *Ijma* ' (juristic consensus) refers to "the agreement of the jurists of a given era on a legal ruling" (Al-Qaseer, 2006, p. 15).

<sup>5</sup> *Qiyas (*juristic analogy) means "taking an injunction that applies in one specific situation or case and applying it in another because they share a characteristics that is the effective cause of the injunction being applied in the first case or situation" (Al-Qaseer, 2006, p. 15). The rules of the Qur'an and/or the Sunnah may be extended to a new problem provided that the precedent and the new problem share the same operative or effective cause.

<sup>6</sup> A form of charitable giving in Islam.

<sup>7</sup> The Encyclopedia of Islam spells the word wqf with the letter "K" as wakf. However, I am using the spelling with the letter "Q" as this research follows the transliteration system of the International Journal of Middle East Studies. <sup>8</sup> "Slave dynasty of Egypt that was formed by white slaves in their capital city of Cairo" (Yakon, 1966, p. 44).

<sup>9</sup> Many Muslim people in Egypt had endowed their properties and lands as charitable waqfs for the benefit of the holy cities. However, all waqfs revenue, whether it came from waqfs allocated by people or rulers, were governed and distributed by the state.

<sup>10</sup> Ka'ba is defined as "Cube shaped shrine located in the centre of the Grand Mosque in Mecca, the focal point for daily prayer and the pilgrimage" (Esposito, 2005, p. 274).

<sup>11</sup> The western area of what is currently Saudi Arabia used to be called "Hijaz".
Hijaz included cities such as Makkah, Madinah, Jeddah and Yunbu (Shaban, 1984).

<sup>12</sup> The Arabic plural word of waqf.

<sup>13</sup> One prominent example of the Ministry's efforts to take care of the holy mosques was in 1968 when it ordered the expansion of the main entrances to the holy mosque in Maddinah to accommodate the increased number of pilgrims every year (Ministry of Islamic Affairs, Endowments, Da'wah and Guidance, n.d.).

<sup>14</sup> Oxfam is "a confederation of 13 organizations working with over 3,000 partners in more than 100 countries to find solutions to poverty and injustices towards oppressed groups in society" (Oxfam International, n.d.).

<sup>15</sup> All translation of the Qur'anic verses is taken from Ali (1985). The number between parentheses indicates the location of the verse in the Qur'an. The first number is the chapter, and the second number refers to the number of the verse within the chapter.

<sup>16</sup> This Hadith was narrated by Muslim. Al-Nawwawi was the compiler of this

Hadith.

<sup>17</sup> Allah is the Arabic name for God in Islam. It is the identical term used by Christian Arabs to refer to God.

<sup>18</sup> A city in the northeast side of Saudi Arabia.

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# Appendix A.

#### **Recruitment** Letter

**Research Title**: An Exploration of the Development of Disability Organizations in Saudi Arabia

Researcher: Alyaa Hemdi

School: University of Manitoba

April 15th, 2008

Dear Sir or Madam,

My name is Alyaa Hemdi. I am a Master's student in the Interdisciplinary Master's Program in Disability Studies at the University of Manitoba. The University of Manitoba is a Canadian university located in the city of Winnipeg. A Master's thesis is a requirement for my Master's degree. I am writing to tell you about my research topic. The topic of my thesis is "An Exploration of the Development of Disability Organizations in Saudi Arabia." My study has been approved by the University of Manitoba's Joint-Faculty Research Ethics Board, and this letter has been sent to you on my behalf from \_\_\_\_\_\_(name of individual who refers to that key informant) of (name of organization).

The main purpose of my study is to explore how disability organizations developed in Saudi Arabia, and what led to that development. My study involves interviewing Head Managers in disability organizations and asking questions about the development of their organization, its basic philosophies and the services that they provide for people with disabilities. What I will learn from the interview will be presented in the form of a Master's thesis.

I am contacting eight Head Managers from different disability organizations in Saudi Arabia for my thesis interviews. The interview will be arranged at a time that is convenient for you. The interview will take place in the organization where you work (if this does not cause you discomfort). The interview will take from 45 minutes to an hour. I will ask you to read and sign a consent form and you will have a copy of this form to keep with you. The consent form will be written in English and an Arabic translation will be provided; both need to be signed by you.

The interview will be audio-recorded and then transcribed. If you do not feel comfortable with recording, you can let me know when signing the consent form before the interview, so I will take extensive note of your answers instead of recording them. You also have to know that you have the full freedom not to answer any of the interview questions. Should you wish to withdraw from the study, you can do so at any time without any penalty or prejudice. The information that you provide during the interview will be kept confidential and nobody except me, my advisor Dr. Hansen and Dr. Badawi will have access to the data of the interview. Your name and identification information will be removed from the transcripts before the final report and only a reference name will be given to you to refer to your answers. Your reference name carries the number of the order of your interview. For example, I will use the reference name ("interview 1") to refer to the first Head Manager who I interview.

Once the study is complete and the final report is ready I can provide you with a copy of it if you would like. I am expecting the final report to be ready in February 2008.

If you are interested in participating in this study or if you require more

Response Sheet

My name is \_\_\_\_\_\_ of \_\_\_\_\_ (name of organization) and I am interested in

taking part in your study about the "Exploration of the Development of Disability

Organizations in Saudi Arabia."

□ I would like to be contacted by telephone

Phone no. \_\_\_\_\_(work) \_\_\_\_\_(cell)\_\_\_\_\_

The best time I would like to be reached at is between \_\_\_\_\_(time) on \_\_\_\_\_(day)

 $\Box$ I would like to be contacted by e-mail

My e-mail address :\_\_\_\_\_

# Appendix B

#### Head Managers' Interview Questions

Below are the main questions that I am going to ask the **Head Managers** about during the interview. I may ask additional questions that will assist me in gathering more information related to the main questions or to clarify my understanding of any of the answers.

1. Tell me about yourself (i.e. education, degrees, years of experience, previous work positions), and how you started working in this organization.

2. Tell me a little bit about the history of this organization (i.e. the year of opening, basic philosophy), and about the aims of this organizations.

3. What kind of services does your organization provide for people with disabilities (i.e. educational, physical, medical, vocational, daytime care, school-like program, and evening care)?

4. Who are the people working in your organization?

5. What is the key role of your organization in Saudi society?

6. What age group of people with disabilities does your organization provide services for?

Prompt: On what basis do you decide who is eligible for entering the organization and who is not?

7. Could you identify the factors that have led to the development and growth of your organization?

8. What is the importance of your organization to people with disabilities in the community?

9. How do you think does our religion Islam has influenced your organization?(its philosophy, development)

10. What is the role of donations to your organization?

11. Where does your organization get its funding from? (i.e. government, charity, Zakah, private sectors)

Prompt: What is your yearly budget? How much does your organization spend every year? Does your organization have extra money in its budget? If yes, what does the organization spend the money on?

12. What are the future plans of your organization (i.e. new services, employee choice, building, facilities, research)?

Prompt: On what does your organization base its future development plans?

13. Is there anything else that you would like to add, change, or clarify before ending the interview? Is there anything related to the development of the organization that you feel might be important to discuss and I did not ask you about?

.

# Supplementary Interview Questions

- 1. What would you like to say about yourself? (i.e. education, degrees, years of experience, previous work positions).
- 2. How did your organization come to existence? (i.e. the year of opening, basic philosophy), and about the aims of this organizations.
- 3. What is the contribution of your organization to people with disabilities? (i.e. educational, physical, medical, vocational, daytime care, school-like program, and evening care).
- 4. Who do get employed in your organization?
- 5. Explain the duty that your organization serves in Saudi society as a disability organization?
- 6. What is the basis for deciding who benefits from your organization and is there any specific age group that the organization provide services for?(what age group)
- 7. What are the key things that can identify as the turning points in the development of your organization?
- 8. How your organization could serves people with disabilities in the community?
- 9. How apparent is the teachings of Islam in your organization?(in the organization philosophy, aims)
- 10. Could you talk about how significance is charitable acts to your organization?
- 11. What is or are the main financial resources for your organization? how do you spend the money?
- 12. How would you see your organization in the future?(do you have plans for new services, facilities, funding).
- 13. Is there anything else that you would like to add, change, or clarify before ending the interview? Is there anything related to the development of the organization that you feel might be important to discuss and I did not ask you about?

Appendix C: Informed Consent Form



UNIVERSITY of Manitoba

# **Informed Consent**

Research Project Title: An Exploration of the Development of Disability Organizations in

Saudi Arabia

Researcher: Alyaa Hemdi

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

#### What is the purpose of this study?

The main purpose of this study is to explore the development of disability organizations in Saudi Arabia and what conditions or factors have led to that development. Another purpose of this study is to look at how Islam has influenced the development of disability organizations in Saudi Arabia.

#### Who is conducting the study?

This study will be conducted by Alyaa Hemdi who is a Master's student in the interdisciplinary master's program in disability studies at the University of Manitoba. The University of Manitoba is a Canadian university located in the city of Winnipeg. This research project is going to be presented in a master's thesis form as a fulfillment of the requirement of the Master's of Arts at the University of Manitoba.

#### Who will be involved in this study?

Eight Head Managers from eight different disability organizations are going to be involved in this study.

# If I give my consent to participate in this research, what I would be asked to do? If you agree to participate in this study then the reseacher will conduct an interview with you which last from 45 minutes to an hour. The researcher will send you a copy of the interview transcript by e mail so you can verify that the information is correct and/or request deletion of any part of the interview that they think might lead to the discovery of their identity. You may do this by e-mailing your written comments to me or by talking with me by phone. (My contact information is provided at the end of this form.)

#### What are you going to look for in your interview questions?

If you agree to participate in the study, the researcher will ask you questions about the basic philosophies that your organization is built around, its history, stages of development and services that it provides for people with disabilities. If you misunderstand a question or you feel that you would like more clarification, feel free to ask during the interview.

#### Where and when will the interview take place?

The interview is going to take place in your office at the disability organization where you work. The time of the interview will depend on what time is convenient for you. We will work together to arrange a time that will not interrupt any of your work or any of my other interviews.

#### How will the information I provide be used in this study?

The information will help the researcher to identify the different factors and conditions that have led to the development of your organization. It will help build knowledge about disability organizations in Saudi Arabia. A report on the findings of my study will be written at the end of this project. The report will be in the form of a master's thesis. The final report will be completed by February 2008. If you would like a copy of the full report and/or the executive summary, you can obtain one by emailing the researcher at umhemdi@cc.umanitoba.ca. The researcher expects the findings of this study to increase awareness in Saudi society and Saudi government about disability organizations in Saudi Arabia.

#### What are the risks of participating in this study?

The researcher does not anticipate that your participation in this research will cause you any harm or put you at any potential risk. This study is not aimed at eliciting of information that is deemed sensitive, emotional or personal.

#### Can I stop participating in this study at any time during the study?

Yes. If you consent to participate in this study and then later you decide to stop participating, you can simply let the researcher know that you want to withdraw from participating completely, or you may refuse to answer a particular question. There will be no penalty or prejudice associated with your withdrawal from the study.

#### What are the benefits of participating in this study?

Your participation in this study will help build the knowledge base about disability organizations and their development in Saudi Arabia. The findings of this study might

lead to policy changes for people with disabilities in Saudi Arabia. This is because this study will highlight some of the issues that people with disabilities at these organizations are facing, like the availability of services and the sufficiency of these services in meeting their needs.

# What steps will be taken to keep the information and my identity confidential in this study?

The researcher will take notes and use a tape recorder during the interview. After the interview, the researcher will transcribe the recorded interview. Your name will not be included in any reports or presentations about the study. Any unique characteristic that might lead someone to identify you will be removed from the transcripts. The researcher, the researcher's advisor Dr.Hansen and Dr.Badawi are the only people who will have access to the gathered data. Quotes from the interview will be used in the final report. When quotes are presented, participants will be labeled by numbers (for example, "Head Manager no. 1"). Any information in the quotes that could reveal your identity will be removed. It should be noted that information obtained from the interview might be used for publication purposes. If you do not feel comfortable with having the interview recorded, please do not hesitate to let the researcher know and extensive notes will be taken instead of tape recording. Audiotapes and notes will be kept at the researcher' place of residence in a locked drawer and destroyed after the final report has been completed on-or-before 30 August 2009.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

If you have any questions or concerns about the study you can contact Alyaa Hemdi at: 902-405-6266 or e-mail at: umhemdi@cc.umanitoba.ca .you can also contact the researcher's advisor, Dr. Hansen, at her office number: ... or at her e-mail: hansenn@ms.umanitoba.ca

The Joint-Faculty Research Ethics Board at the University of Manitoba is connected to the Government of Canada's research ethics polices via the TriCouncil policies. For more information on this you can visit:

http://umanitoba.ca/research/ors/ethics/human\_ethics\_index.html

This research has been approved by the Joint-Faculty Research Ethics Board at the University of Manitoba. If you have any concerns or complaints about this project

# you may contact any of the above-named persons or the Human Ethics Secretariat at 204-474-7122, or e-mail margaret\_bowman@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.

I have also obtained approval from the vice-dean of graduate studies and scientific research at Umm-Alqura University to conduct my interviews under their observation. However, please note that nobody except me the principal researcher, my advisor Dr. Hansen and my Dr. Badawi will have access to data collected from the interviews.

# I give my permission for an audio-tape recorder to be used during the interview. Yes \_\_ No \_\_\_.

I \_\_\_\_\_ (print name) understand what the study is about and my signature below indicates that I consent to participate in this study.

Participant's Signature, Date

Researcher's Signature, Date

•

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Appendix D

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Arabic Translations of Appendices A, B and C

An Arabic Translation of the Recruitment Letter (Appendix A)

ملحق أ : خطاب دعوة للمشاركة عنوان البحث : استكشاف تطور المراكز المعنية بالاعاقة في المملكة العربية السعودية الباحثة : علياء بنت جمال حمدي 14 الجامعة : جامعة مانيتوبا 25 /ابريل/2008

صاحب / صاحبة السعادة سلمه الله السلام عليكم ورحمة الله وبركاته وبعد، بدايةً أشكر لسعادتكم الإطلاع على خطابي هذا. أنا علياء بنت جمال حمدي ، طالبة في مرحلة الماجستير ، أدرس في برنامج ماجستير در اسات الاعاقة في جامعة كندية هي جامعة مانيتوبا وتقع في مدينة وينيبيغ. يشترط لحصولي على درجة الماجستير تقديم بحث موسع هو رسالة الماجستير وأبعث إليكم هذا الخطاب لإحاطتكم بموضوع بحث رسالتي وهو " استكشاف تطور المنظمات المعنية بالاعاقه في المملكة العربية السعودية ". وقد وافقالمجلس المشترك لأبحاث كلية الاداب بجامعة مانيتوبا على قيامي ببحث رسالتي هذا و تم او سالة اليكم باسمي عن طريق ( اسم الشخص اللذي أشار اليكم) من

إن الغرض من هذه الدراسه هو استكشاف الكيفيه التي نهضت وتطورت بها المراكز المعنية بالاعاقة في المملكة العربية السعودية والعوامل التي أدت لهذا التطور . وتنطوي الدراسه على اجراء مقابلات مع المسئولين الرئيسيين في المراكز المعنية بالاعاقة وسؤالهم عن مراحل تطور المنظمات ، وتوجهاتها الاساسية ، والخدمات التي تقدمها للمعاقين. وسأقدم نتائج ماأتعلمه من معلومات في هذه المقابلات في رسالة الماجستير .

لقد قمت بتوجيه الدعوة لثمانية مدراء من مختلف المراكز المعنية بالاعاقة في المملكه العربية السعودية- يتضمنون سعادتكم- وذلك لأجري معهم مقابلة تختص ببحثي في رسالة الماجستير . وآمل ترتيب المقابلة في وقت مناسب لكم حيث سأقوم بإجرائها في نفس مركز عملكم (إذا كان هذا لايز عجكم) وستستغرق من 45 إلى 60 دقيقة. وسأطلب منكم قراءة وتوقيع استمارة الموافقة لإجراء المقابلة (باللغة الإنجليزية وترجمتها للعربية) وسأزودكم بنسخة من هذه الاستمارة يمكنكم الإحتفاظ بها.

سيتم تسجيل المقابلة على شريط مسجل صوتي (كاسيت) ومن ثم كتابتها. أما إذا كنتم لا تفضلون تسجيل المقابلة على شريط فبإمكانكم إعلامي بذلك عند توقيع الموافقة وقبل إجراء المقابلة لأتمكن من كتابة المقابلة أنثاء الحوار بتأن وبشكل مفصل وأود إحاطتكم ايضا ان لديكم الحرية الكاملة للإمتناع عن الإجابه على اي من أسئلة المقابلة. وبإمكانكم الإنسحاب من هذه الدراسه إن رغبتم في اي وقت وبدون اي عقوبة أو أضرار. ستحفظ المعلومات المقدمة منكم بشكل سري ولا يمكن لأحد غيري أو مشرفتي الرساله الدكتوره نانسي هانسن والدكتوره اليز ابيث اليكساندرن من الإطلاع أو الوصول إلى تلك المعلومات. وسيتم إز التم المقابلة إسمار من صفة يمكن أن تدل على ذلك من المستندات قبل تقديم التقرير النهائي وسيستبدل ذلك برمز يحمل رقماً مسلسلاً. فعلى صفة يمكن أن تدل على ذلك من المستندات قبل تقديم التقرير النهائي وسيستبدل ذلك برمز يحمل رقماً مسلسلاً.

سبيل المثال ساستخدم الرمز (المقابلة الأولى) للدلالة على أول مسئول تمت مقابلته. وسيسعدني تزويدكم بنسخة من التقرير النهائي عند انتهائي منه وفور اكتماله في حالة ر غبتكم في ذلك علماً أنني اتوقع ان تكون النسخة النهائية جاهزة في فبراير 2008.

أرجو من سعادتكم في حال ر غبتكم المشاركة في هذه الدراسة الاطلاع علىنموذج الإستجابة المرفق مع هذا الخطاب والتكرم بإرفاقه مع الرد وذلك قبل الخامس عشر من ابريل 2008 على بريدي الالكتروني ajh\_10000@yahoo.com وساسعد بالإجابة على أي آستفسارات تختص ببحث رسالتي عن طريق بريدي الإلكتروني.

ختاماً أود ان أشكركم مرة أخرى على وقتكم وتعاونكم. متطلعة الى استجابتكم.

مع خالص تقديري،

Disability Organizations in Saudi Arabia158

علياء بنت جمال حمدي

طالبة الماجستير في جامعة مانيتوبا

An Arabic Translation of the Response Sheet نموذج الاستجابه

اسمي \_\_\_\_\_ من \_\_\_\_ ( اسم المنظمه) وانا مهتمة بالمشاركه في دراستكم عن " استكشاف تطور المراكز المعنية بالاعاقة في المملكة العربية السعودية ".

> □ اود ان يكون الاتصال بي هاتفيا رقم الهاتف.\_\_\_\_\_( العمل) \_\_\_\_\_( خلية)\_\_\_\_\_\_ أفضل وقت يتم التوصل فيه الي هو ما بين \_\_\_\_\_( الوقت) في \_\_\_\_\_\_( اليوم)

□ اود ان يكونالاتصال بي عن طريق البريد الالكتروني عنوان البريد الالكتروني :

#### An Arabic Translation of the Interview Questions (Appendix B)

# ترجمة أسئلة مقابلة مدراء مراكز الاعاقه

فيما يلى أهم الأسئله التي ساسالها للمدراء خلال المقابلة و قد أطرح اسئله اضافية من شانها ان تساعدني في جمع مزيد من المعلومات حول الاسئله الرئيسية او لتوضيح اي من الاجابات المبهمه.

- أخبرني عن نفسك؟ ( التعليم ، وسنوات الخبرة ، المناصب السلبقه) ، وكيف بدأت العمل في هذه المنظمه.
  - أخبرني قليلًا عن تاريخ هذا المركز ( سنة الافتتاح ، الفلسفه الاساسية) ، وحول اهداف هذه المنظمه.
  - 3. ما هي أنواع الخدمات اللتي تقدمها منظمتكم للمعاقين؟ ( تعليميه ، الطبية ، المهنيه ، الرعايه النهاريه ، مثل برنامج المدارس ، الرعايه المسانيه)
    - 4. من هم الأشخاص الذين يعملون في مركزكم؟
    - 5. ما هو الدور الرئيسي الذي يقوم به مركزكم في المجتمع السعودي؟
  - 6 ماهي الفنات العمرية من ذوي الاعاقه اللتي تقدمون خدماتكم لها؟ إضافه: على أي أساس يتم تحديد من يستحق دخول المركز ومن هم اللذين لايستحقون ذلك؟
    - 7. هل يمكنكم تحديد العوامل الأساسية التي أدت الى تطور ونمو مركزكم؟
      - 8. ما هي أهمية مركز كمبالنسبه لذوي الاعاقه في المجتمع؟
    - ماهو في اعتقادكم تأثير الاسلام على مركزكم؟ (التاثير على فلسفة المركز, تطوره).
      - 10. ما هو دور التبر عات بالنسبه امركزكم؟
- 11. من هو الممول الرئيسي لمركزكم؟( الحكومة ، والصدقه ، والزكاه ، والقطاع الخاص)إضافه: ما هي الميز انيه السنويه الخاصة بك؟ ماللذي تنفقه منظمتكم كل عام؟ هل يوجد لديكم فائض في الميز انيه؟ إذا كانت الاجابه بنعم فاين يتم صرف الفائض؟
  - 12. ما هي الخطط المستقبليهامر كزكم(اي الخدمات الجديدة ، اختيار الموظفين ، بناء ، المرافق ، البحوث)؟ على ماذا تعتمدون في بناء الخطط المستقبليه لمركزكم؟
  - 13. هل هناك اي شيء آخرتود أن تضيفه او توضحه قبل ان تنتهي المقابلة؟ هل هناك اي شيء فيما يتصل بتطور مركزكم تظن انه من المهم مناقشته ولم أسألك عنه؟

# An Arabic Translation of the Supplementary Interview Questions

# ترجمة الأسئله البديله

- ماذا تريد أن تقول عن نفسك؟ ( التعليم ، سنوات الخبرة ، الخبرات السابقة في العمل).
- 2. كيف ظهر مركزكم الى الوجود؟ ( اي سنة تم افتتاحه، الفلسفه الإساسية, اهداف المركز)
- 3. ماهي مساهمات مركزكم لخدمة ذُوي الاعاقة؟ (تعليميه ،الطبية ،المهنيه ،الرعايه النهاريه ، مثل برنامج المدارس ،الرعايه المسائيه)
  - من هم اللذين يتم تعينهم في مركزكم؟
  - 5. هل يمكنكم وصف الواجب اللذي يقدمه مركزكم كمركز إعاقه لخدمة المجتمع السعودي؟
  - 6. على أي أساس يتم تحديد من هم المستفيدين من خدمات مركزكم و هل هذاك فنه عمريه محدده يخدمها مركزكم؟ وماهي هذه الفنه؟
    - 7 ماهي الأشياء البارزه اللتي يمكن اعتبارها كنقاط تحول في تطور مركزكم؟
      - 8. كيف يمكن لمركزكم خدمة الأشخاص المعاقين في المجتمع؟
        - كيف يعكس مركزكم تعاليم الدين الإسلامي؟
      - 10 هل يمكن الحديث عن أهمية الإعمال الخيريه السركزكم؟
    - 11 من هو الممول الرئيسي لمركزكم؟ كَيفَ يَتَم صرفَ الميزانيه؟
  - 12. كيف تنظرون الى منظمتكم في المستقبل؟ هل لديكم خطط لتوفير خدمات جديدة ، مرافق ، التمويل).
- 13. هل هناك اي شيء آخرتود أن تضيفه او توضحه قبل ان تنتهي المقابلة؟ هل هناك اي شيء فيما يتصل بتطور مركزكم تظن انه من المهم مناقشته ولم أسألك عنه؟

An Arabic Translation of the Informed Consent Form (Appendix C)



# UNIVERSITY of Manitoba

إقرار بالعلم

عنوان مشروع البحث إستكشاف تطور مراكز الإعاقة في المملكة العربية السعودية

الباحثة: علياء حمدي

هذا الإقرار ماهو الاعباره عن شكل من أشكال الموافقة على المشاركة في هذه الدراسة. سوف تبقى معكم نسخة من هذا الإقراركمرجع لكم. الإقرار يهدف إلى إعطائكم فكره عن ماهية البحث وماستنطوي عليه مشاركتكم. اذا كنتم تودون الحصول على مزيد من التفاصيل حول ما ذكر أوعن أي معلومات غير مدرجة هذا فلا تترددوا في طرح أسنلتكم. ويرجى اخذ الوقت لقراءة هذا الإقرار بعناية وفهم المعلومات المرفقة به.

ما هو الغرض من هذه الدراسة؟ الغرض الرنيسي من هذه الدراسه هو استكشاف تطوُّر منظمات الإعاقة في المملكة العربية السعودية وما هي العوامل التي أدت الى هذا التطور . الغرض الآخر من هذه الدراسة هو النظر في كيفية تأثير الاسلام في تطور مراكز الإعاقة في المملكة العربية السعودية. Disability Organizations in Saudi Arabia 63

من يجري هذه الدراسة؟ هذه الدراسه سوف تقوم باجرائها علياء حمدي و هي طالبة ماجستير في برنامج ماجستير دراسات الاعاقة في جامعة مانيتوبا جامعة مانيتوبا هي جامعة كندية في مدينة وينيبغ هذا البحث سوف يتم تقديمه على شكل أطروحة ماجستير والتي تعتبر شرطاً من شروط الحصول على درجة الماجستير في الآداب من جامعة مانيتوبا.

من اللذين سيشاركون في هذه الدراسة؟ سوف يشارك في هذه الدراسة ثمانية رؤساء من ثمانية مراكز إعاقة مختلفة في المملكة العربية السعودية.

مالذي سوف يطلب مني القيام به بعد إعطاء موافقتي للمشاركة في هذه الدراسة؟ إذا وافقتم على المشاركه في هذه الدراسة فستقوم الباحثة بإجراء مقابلة معكم تتراوح مدتها من 45 دقيقة الى ساعة واحدة. كما سيتم إرسال نسخه مما تم تدوينه في المقابله على بريدكم الإلكتروني حتى تتمكنوا من التحقق من صحة المعلومات و/ أو طلب حذف اي جزء من المقابلة ترون انه قد يؤدي الى كشف هويتكم. يمكنكم فعل ذلك عن طريق مراسلة الباحثة على بريدها الإلكتروني أو عن طريق محادثتها هاتفياً. ( معلومات الاتصال بها موجودة في نهاية هذا النموذج).

#### ما اللذي تدور حوله أسئلة المقابلة؟

إذا وافقتكم على المشاركة في هذه الدراسة فإن الباحثة سوف تسألكم عن الفلسفات الاساسية اللتي بنيت حولها منظماتكم وتاريخها ومراحلها التنموية والخدمات التي تقدم للمعاقين. اذا كان هناك غموض في فهم سؤال او كنتم تظنون انكم تودون الحصول على مزيد من التوضيح فلا تترددوا في السؤال خلال المقابلة.

اين ومتى سوف تتم المقابلة؟ المقابلة ستجرى في مكتبكم في مركز الإعاقة اللذي تعملون به أما بالنسبة لوقت اجراء المقابلة فسيعتمد على الوقت المناسب و المريح لكم وسنعمل معاً لترتيب هذا الوقت بحيث لا يتعارض مع اي من أعمالكم او اي من المقابلات Disability Organizations in Saudi Arabial64

الاخرى اللتي سوف أجريها.

كيف سيتم استخدام المعلومات اللتي سأزودكم بها في هذه الدراسة؟ هذه المعلومات سوف تساعد الباحثة على التعرف على مختلف العوامل والظروف التي ادت النطور منظمتكم. كما أنها ستساعد على بناء قاعدة معرفية عن منظمات الاعاقة في المملكة العربية السعودية. وسوف يتم كتابة تقرير بالنتائج اللتي سيتوصل إليها هذا المشروع بعد الانتهاء من هذه الدراسة. سيكون هذا التقرير على شكل أطروحة ماجستير ويتوقع أن يتم إنجاز التقرير بحلول فبراير 2009. إذا أردتم الحصول على نسخة من التقرير الكامل و/أو ماجستير ويتوقع أن يتم إنجاز التقرير بحلول فبراير 2009. إذا أردتم الحصول على نسخة من التقرير الكامل و/أو ماجستير ويتوقع أن يتم إنجاز التقرير بحلول فبراير 2009. إذا أردتم الحصول على نسخة من التقرير الكامل و/أو ماجستير ويتوقع أن يتم إنجاز التقرير بحلول فبراير الاعوم. إذا أردتم الحصول على نسخة من التقرير الكامل و/أو الإستندامة على ماجستير ويتوقع أن يتم إنجاز التقرير بحلول فبراير الامكام والا أردتم الحصول على نسخة من التقرير الكامل و الإلى ماجستير ويتوقع أن يتم إنجاز التقرير بحلول فبراير ولا والي على ماحسول على نسخة من التقرير الكامل و الإلى ماجستير ويتوقع أن يتم إنجاز التقرير بحلول فبراير ولا والي عن المحسول على نسخة من التقرير الكامل و الإلى مالي المالي المالي المالي المالي المالي التنفيذي فبإمكانم ذلك عن طريق ارسال بريد الكتروني للباحثة على التوقع الباحثة أن تؤدي نتائج هذه الدراسة إلى زيادة الوعي في المجتمع السعودي والحكومة السعودية عن منظمات الإعاقة في المملكة العربية السعودية.

هل أستطيع التوقف عن المشاركة في هذه الدراسة في أي وقت أثناء الدراسة؟ نعم. اذا تمت موافقتكم على المشاركة في هذه الدراسة ثم قررتم بعد ذلك التوقف عن المشاركة فيمكنكم ببساطة فعل ذالك عن طرق إخبار الباحثة رغبتكم الانسحاب من المشاركة تماما أو رفضكم الاجابة على سؤال معين ولن يكون هذاك اي عقوبة او مساس بكم اذا تم انسحابكم من الدراسة.

ما هي فوائد المشاركة في هذه الدراسة؟ ان مشاركتكم في هذه الدراسة ستساعد في بناء قاعدة معلومات عن المنظمات المعنية بالاعاقة وتطور ها في المملكة العربية السعودية. نتائج هذه الدراسه قد تؤدي الى تغييرات في السياسات بالنسبة للاشخاص المعاقين في المملكة العربية السعودية ذلك أن هذه الدراسة ستسلط الضوء على بعض القضايا التي يواجهها المعاقين مثل توافر الخدمات ومدى كفاية هذه الخدمات في تلبية حاجاتهم

ما هى الخطوات التى سيتم اتخاذها للحفاظ على سرية هويتي في هذه الدراسة؟ سوف تستخدم الباحثة آلة تسجيل خلال المقابلة. بعد المقابلة ، وستقوم الباحثة بعد المقابلة بكتابة تسجيل المقابلة. لن يتم ادراج اسمكم في في اي من التقارير او العروض عن الدراسة كما سيتم إزالة أي سمة فريدة يمكن ان تؤدي الى التعرف على هويتكم من النصوص. الأشخاص اللذين يمكنهم الوصول الى بيانات الدراسه هم فقط الباحثة والمشرفتين ....والدكتورة ...على الرساله و هما الدكتورة

سيتم استخدام مقتطفات من المقابلة في التقرير النهائي إلا أنه عندما يتم الاقتباس من اي إجابة فسيتم از الة أية معلومات في تلك الاقتباسات يمكن ان تكشف عن هويتكم. وسوف يوصف المشتركون في الاقتباسات بارقام، على سبيل المثال: المدير رقم 1. كما تجدر الاشارة الى ان المعلومات التي سيتم الحصول عليها من المقابلة يمكن ان تستخدم لاغراض النشر. اذا كنتم لاتر غبون في تسجيل المقابله بآلة التسجيل فيمكنكم ان تخبروا الباحثة حيث سيتم تدوين المعلومات كتابيا خلال المقابلة في تلك الحالة. سوف يتم حفظ البيانات في درج مغلق في مكان اقامة الباحثة وسيتم اتلاف جميع هذه البيانات بعد الانتهاء من كتابة التقرير النهائي في أو قبل تاريخ 30 أغسطس 2009.

توقيعك على هذا الاقرار يتضمن ان لديك الخلفية التامة والقتاعة الكاملة للمشاركة في هذه الدراسة كما أنك توافق على ان تكون مشاركاً في هذا البحث. هذا القرار لايتضمن باي حال تنازلك عن حقوقك القانونية كما انه لايخلي الباحثين او الجهات الراعية أو مؤسساتهم من واجباتهم المهنية. لديك الحرية التامة اذا اردت الانسحاب و/أو عدم الاجابة على اي سؤال. مشاركتك تتضمن استيعابك لمجريات الدراسة لذا يجب ان لا تتردد في طلب ايضاحات او معومات جديدة خلال مشاركتك.

-902+إذا كانت لديك أية اسئلة او استفسارات حول الدراسة فيمكنك الاتصال على علياء حمدي على الرقـــم كما يمكنك الاتصال بمشرفة umhemdi@cc.umanitoba.ca أو بالبريد الالكتروني على العنوان: 6266-405 hansenn@ms.umanitoba.ca أو على البريد الألكتروني : + في مكتبها : ... البحث الدكتورة

إن مجلس الأبحاث المشترك لكلية الآداب في جامعة مانيتوبا يرتبط ارتباطاً وثيقاً بقوانين الحكومة الكندية لأخلاقيات البحث. إذا اردتم الاطلاع على مزيد من المعلومات بهذا الخصوص يمكنكم زيارة الموقع: http://umanitoba.ca/research/ors/ethics/human\_ethics\_index.html

وقد حظي هذا البحث بموافقة مجلس الأبحاث المشترك لكلية الآداب في جامعة مانيتوبا، فإذا كان لديك أي شكاوى حول هذا المشروع يمكنك الاتصال بأي من الاشخاص المذكورين أعلاه او بسكرتارية أخلاقيات الأبحاث على الرقم وقد تم تزويدك margaret\_bowman@umanitoba.ca او على البريد الالكتروني 7122-474-204+ بنسخة من هذا الاقرار كمرجع لك في سجلاتك.

كما أفيدكم أنه تم الحصول على موافقة وكيل كلية الطب للدراسات العليا والبحث العلمي بجامعة أم القرى لإجراء المقابلات المتعلقه بهذا البحث تحت عنايتهم. ويرجى ملاحظة أنه لن يكون هناك إطلاع من اي جهه أو شخص على أي معلومات يتم جمعها في المقابلات فيما عدا الطالبة المعدّة للبحث والمشرفتان الدكتورة نانسي هانسن والدكتورة اليز ابيث اليكساندر حيث سيكنّ فقط من سيطلع على أي معلومات يتم جمعها في هذه المقابلات.

أوافق على استخدام آلة التسجيل خلال المقابله نعم لا

أنا \_\_\_\_\_\_ (اسم المشارك) أعي ماهية هذه الدراسة وتوقيعي أدناه يشير إلى أنني أعطى الموافقة على المشاركة في هذه الدراسة.

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Appendix E

سيد بيها ما تحسير للسيمر للمحادة المتحراة . وتكانت المرزق الأراب في يرزيان المتحد الألف ومبل ا