

Bethel University

Spark

---

All Electronic Theses and Dissertations

---

2013

## My Child Is an Angel from Allah: Perspectives from Muslim Parents of Children With Special Needs in the United Kingdom

Katie J. Bonawitz  
*Bethel University*

Follow this and additional works at: <https://spark.bethel.edu/etd>



Part of the [Educational Leadership Commons](#), and the [Special Education and Teaching Commons](#)

---

### Recommended Citation

Bonawitz, K. J. (2013). *My Child Is an Angel from Allah: Perspectives from Muslim Parents of Children With Special Needs in the United Kingdom* [Doctoral dissertation, Bethel University]. Spark Repository. <https://spark.bethel.edu/etd/82>

This Doctoral dissertation is brought to you for free and open access by Spark. It has been accepted for inclusion in All Electronic Theses and Dissertations by an authorized administrator of Spark.

MY CHILD IS AN ANGEL FROM ALLAH: PERSPECTIVES FROM MUSLIM  
PARENTS OF CHILDREN WITH SPECIAL NEEDS IN THE UNITED KINGDOM  
AND THE UNITED STATES

Katie Jean Bonawitz

A dissertation submitted to the faculty of Bethel University  
in partial fulfillment of the requirements for the degree of  
Doctor of Education.

Saint Paul, MN

2013

Approved by:

Advisor: Louise Wilson, Ph.D.

Reader: Katherine Nevins, Ph.D.

Reader: Clayton Keller, Ph.D.

## **ABSTRACT**

My Child is an Angel from Allah: Perspectives from Muslim Parents of Children with Special Needs in the United Kingdom and the United States. Katie Bonawitz, 2013: Applied Dissertation, Bethel University. ERIC Descriptors: Muslim Parents, Religion and Education, Religion and Special Education, Culture and Faith, Disabilities and Faith, Qualitative Research

This applied dissertation investigated how Muslim parents of children with special needs bring understanding to raising their child with special needs. This researcher conducted a qualitative study to find out if Muslim parents from different ethnic backgrounds had similar experiences to those studied by Jegatheesan, Miller, and Fowler (2010). The researcher developed and administered qualitative interviews to four Pakistani Muslim parents in England and three Somali Muslim parents in Minnesota. These Muslim parents were asked questions regarding background of their child, community experiences, positive and negative school experiences, and whether faith or culture played a greater role as they reflected on the first four questions. The data revealed that these seven parents relied on their faith in all instances; two of the seven parents identified faith equally with something else (culture for one, and science for the other).

## **DEDICATION**

This dissertation is dedicated to my father, Niilo Raisanen, who went home to heaven on February 10, 2010. My father was always my biggest cheerleader when it came to academics and he fully believed I would eventually be Dr. Katie Bonawitz. I look forward to celebrating this accomplishment with him when it is my turn to go home to heaven. Thank you, Dad, for always believing in me.

## ACKNOWLEDGEMENTS

I want to acknowledge my committee for their amazing support and encouragement through this process. Dr. Louise Wilson, Dr. Kathy Nevins, and Dr. Clay Keller each helped me grow in new and important ways in the world of research. They are a big reason why I am looking forward to taking part in more research in the incredibly important and exciting field of special education. I am so grateful for each of them.

Also, I want to give a huge shout of gratitude to my husband, Luke. He took over the role of being my biggest cheerleader after my dad died. He took this role seriously and encouraged me every step of the way. On the days I wanted to bury my head under the covers, he was there to cheer me on. His faith in me was so evident; thank you, Luke; I love you so much!

Finally, I fully recognize that God was with me on every step of this journey. There were many passages from the Bible that were a constant reminder to me that He was there; in particular, Hebrews 12:1-3. There were hundreds of prayers that went straight to our Lord and Savior on my behalf. Thanks be to God that He was beside me regardless of my prayers being eloquent or simple utterances. Oh Gracious God, I pray that I would honor and serve you well with the addition of three little letters after my name. Without You, they mean nothing to me.

## TABLE OF CONTENTS

DEDICATION .....	3
ACKNOWLEDGEMENTS .....	4
TABLE OF CONTENTS.....	5
LIST OF TABLES .....	8
LIST OF FIGURES .....	9
CHAPTER 1 .....	10
Introduction .....	10
Background of the Study .....	12
Statement of the Problem .....	14
Purpose and Rationale of the Study.....	16
Significance of the Study.....	17
Definition of Terms .....	18
Delimitations .....	23
Nature of the Study.....	23
Organization of the Remainder of the Study .....	23
CHAPTER 2 .....	25
Introduction to the Literature .....	25
The Religion of Islam .....	26

Muslim Populations in the United Kingdom .....	32
Muslim Populations in the United States .....	34
A Study of Parental Beliefs in South Asian Muslim Immigrant Families .....	39
Religious and Cultural Beliefs, Attitudes and Behaviors .....	43
Contemporary Islamic Practices and Issues Related to Disabilities.....	52
Religion’s Connection to Special Education .....	61
Summary.....	78
CHAPTER 3 .....	80
Methodology .....	80
Background.....	80
Purpose of the Study.....	80
Research Questions.....	81
Research Design .....	82
Participants .....	86
Data Collection Procedures .....	88
Data Analysis Procedures .....	91
Researcher Background.....	93
Ethical Implications .....	94
Potential Limitations.....	95
CHAPTER 4 .....	97

Results .....	97
Seven Muslim Parents of Children with Disabilities.....	98
Parent Responses to Interview Questions.....	108
CHAPTER 5 .....	147
Discussion, Implications, Recommendations.....	147
The Study.....	147
Conclusions .....	150
Implications .....	162
Recommendations .....	167
Concluding comments .....	169
REFERENCES .....	171
APPENDIX A.....	183
Interview Questions.....	183
APPENDIX B .....	184
Request for Approval .....	184
APPENDIX C .....	190
Letter of Consent.....	190



## LIST OF TABLES

Table 4.1 Description of Interviewees .....	108
Table 4.2 Description of the Child’s Disability and the Needs Associated With It.....	115
Table 4.3 Differences Between Mild Disabilities and Moderate-Severe Disabilities.....	116
Table 4.4 Context of “Accept” as it Relates to Disability.....	120
Table 4.5 Fitting Into the Community .....	125
Table 4.6 Connections Made to School Experiences .....	136
Table 4.7 Parents’ Reasoning: Faith or Culture? .....	142

## **LIST OF FIGURES**

Figure 4.1 Similarities and Differences Between Pakistani Muslim Parents in England and Somali Parents in Minnesota .....	153
--	-----

## **CHAPTER 1**

### **Introduction**

Since the 1970s, parents in the United Kingdom and the United States have had educational opportunities for their children with disabilities. Although the services have looked very different in these two countries, the common theme is that services in some form have been provided to all children with disabilities. The families who receive these services for their children may come from different faith backgrounds, but these backgrounds have been fairly similar and have likely been representative of the Christian faith. For most of these 30-plus years, educators have not had to contemplate whether or not the services they were providing would be concerning to the child or the family because the majority of families would simply accept the common practices of the schools. And the schools were built, after all, in countries where Christianity was the predominant faith. Up to this point, when educators have met with families to share information on whether or not their child has a disability, the common practice has been to discuss the results, determine if there is a disability, and then put an educational plan in place. The thought of whether or not the assessment, diagnosis, or plan may be concerning to one's faith has not played a big part in the decision making for the child.

When first learning their child has been diagnosed with a disability, families often lean on their belief systems when trying to bring meaning to this new information (Ault, 2009; Jegatheesan, Miller, & Fowler, 2010). Many families, who belong to specific religious institutions and have a belief system grounded in a specific religion, have reported positive feelings as a result of these religious affiliations (Ault, 2009). In addition to finding meaning of child's disability within their faith, they also have reported

positive experiences which come from social opportunities provided for their children within the faith community. Support received from people within the religious institution is another positive facet of belonging to a specific faith.

So, if a family's religious beliefs help bring meaning to raising a child with a disability, it seems it would be important then for professionals serving these children to understand what these beliefs are and why they are important to a family. Jegatheesan, Miller, and Fowler (2010) found this to be true in their ethnography of three Muslim families with children with autism. Jegatheesan and colleagues found that these families' Islamic belief system played an integral role in how they viewed the actual disability, how they parented their child with autism, and their beliefs in how they wanted their child to be educated.

Although educators have been formally serving students with special needs for more than 30 years, the faces of the children in the schools have changed. Schools in the United Kingdom and the United States are populated with many different ethnicities and cultures; and when religious backgrounds are added to the mix, these populations become even more complex. With this great diversity comes the need to understand the family systems that go along with these differences.

With the increase in Muslim populations across the United Kingdom and the United States, it is important for educators to become familiar with Islam and the people who believe in this religion. Muslims have been immigrating to the United Kingdom and the United States for hundreds of years and non-immigrants converting to Islam are on the rise (Pipes & Duran, 2002), yet a clear understanding of the Islamic belief system appears to be unknown for professionals working in special education. In addition, it is

important to know the history of Muslims in these western countries in order to build a foundational background of who Muslims are and where and how they live because some Muslim immigrant populations represent refugees of war whereas others may represent a desire for new jobs and better living conditions (CIA World Factbook). Understanding and learning this background will help professionals learn important aspects of the unique qualities that make up a Muslim family and therefore work more effectively with these families.

### **Background of the Study**

While being involved in an inter-faith dialogue on Christian and Muslim perspectives of special education (Keller, Khalifa, & Bonawitz, 2010), it became evident to this researcher that the educators in attendance were seeking any information they could find in order to better understand the Muslim families in their schools. Following this inter-faith dialogue, this researcher began searching for resources related to Muslims in special education and found limited information. The study conducted by Jegatheesan and her colleagues (2010) provided a good starting point and their recommendations for further research inevitably lead to the foundation of this work.

In the study by Jegatheesan and her colleagues (2010) three Muslim families were observed and interviewed over the course of 17 months to determine how their Islamic belief systems affected child-rearing and decision-making for their children with autism. They also learned how the parents felt about and responded to the professionals working with their children. One specific conclusion highlighted by Jegatheesan et al. (2010) was that “awareness of and respect for [religious] differences” (p. 107) would help in building relationships between professionals and Muslim parents.

Other specific studies on Muslim parents in the United Kingdom and the United States were not found, but a journal article on the presence of religion in special education literature was discovered (Ault, 2009). In her review of 10 years of special education journals from multiple divisions of The Council of Exceptional Children (CEC), Ault (2009) found only 69 articles with some reference to religion. Of these 69 articles, most of the references were related to Christianity, but there were three with some content possibly related to Islam. (The countries or ethnic backgrounds mentioned are generally known to be Muslim, but even this does not mean the articles had anything to do with Islam). Still, there was nothing specific on how Islamic beliefs affect a family when disabilities are present or how special education professionals should work with families when religion plays such an integral role in their lives.

Following the review of these scholarly publications, this researcher looked into parent advocacy groups in the United Kingdom and the United States (which will be identified in Chapter 2) to determine if support was available specific to issues parents may have related to their religious beliefs. Although some information was found through specific Christian Ministries serving people with disabilities (e.g., support for people with disabilities during Sunday services), nothing connected to religious support was found from actual parent advocacy groups. These basic findings have provided further information to this researcher about what seems to be a lack of resources for Muslim families in the United States and the United Kingdom dealing with the educational and life planning for their children with disabilities.

## **Statement of the Problem**

Parents in the United States have always been an integral part of special education and were a major reason behind the passage of PL-94-142, the Education for All Handicapped Act (EHCA) in 1975. Prior to the EHCA (now known as Individuals with Disabilities Education Act, or IDEA), parents played a critical role in advocating for the rights of children with disabilities. Parent advocacy for their children with disabilities was especially strong following the Supreme Court decision of *Brown v the Board of Education of Topeka* wherein schools could no longer legally separate Black and White students (Turnbull, Stowe, & Huerta, 2007). Parents of children with disabilities fought for equal education rights for their children and won this right with the passage of the EHCA. It is no surprise then that parents continue to play a major role in advocating for the rights of their children with disabilities. With each amendment of IDEA, most recently in 2004, parents continue to play an important role in the lives of their children with disabilities (Turnbull et al., 2007). Regardless of a parent's cultural, ethnic, or religious background, each parent is a critical member of the diagnosing and planning for their child with a disability. However, based on Jegatheesan et al.'s study (2010) the question arises as to whether or not the current system takes into account different belief systems when working with and proposing educational plans for individuals.

In their ethnography of three South Asian Muslim families living in the United States, Jegatheesan, Miller, and Fowler (2010) shared insights that the parents' voices representing their Islamic belief systems were not understood or taken into account when special education professionals were recommending certain educational practices for their children with autism.

Jegatheesan and colleagues (2010) further learned how important it would be for special education professionals to be aware of a family's religious background. The stories shared from these three Muslim families on their experiences with professionals working with them to meet the needs of their children were very negative. The frustration felt by these families stemmed from the fact that these professionals always focused on their child's deficits rather than on their child's abilities. This was felt from the onset of assessment all the way through specific educational programming. A major reason behind this frustration felt by the parents lies in the fact that these three families believe that Allah (God) gave them this child as a special gift and, as such, seeing the deficits of their child first was not something they practiced. They desired that their child's abilities or gifts would be the focus.

Beyond the fact these families were frustrated with the focus on deficits, Jegatheesan and her colleagues (2010) further learned these families were not interested in the educational services being suggested if the services went against their cultural and religious beliefs. When a child is receiving special education services, there will always be a team of people making decisions for that child, but what does that team look like? What do they do? An optimal team working together to plan for the needs of a student with a disability is one where there is respect for diverse opinions and diverse backgrounds. What if the parents have a completely different cultural, ethnic, or religious background than that of the professionals? Can a team still come to agreement for what is necessary for the child?

In order to better meet the needs of children with disabilities that come from families with Islamic belief systems, it would seem important for professionals to



understand something of these belief systems. To do that, it is important to have a good understanding of Muslim parents and their Islamic beliefs and what it means for them to parent a child with a disability.

After examining Ault's review of special education literature's limited coverage of religion (2009), and Jegatheesan et al.'s study (2010) of three Muslim families and how their Islamic belief systems play a major role in parenting practices and decision-making for their children with autism, it is apparent to this researcher that religion and special education is an under-examined topic in the United Kingdom and the United States. Further questions remain such as: whether or not these problems exist in other countries; if specific ethnic backgrounds within the Islamic faith provide different viewpoints; and if the specific disability of a child makes a difference.

### **Purpose and Rationale of the Study**

Christianity has been a fundamental part of the religious landscape in the United Kingdom and the United States for hundreds of years and educators have had a fairly clear understanding that the basic procedures that go on in schools are likely going to be accepted from the majority of families whom they have been serving. As stated earlier, the population in British and American schools is changing and religion is included in these changes (May 7, 2003, retrieved on October 17, 2011, from <http://www.mcb.org.uk/library/statistics.php>; Salatomic, retrieved July 19, 2013 (<http://www.salatomic.com/sp.php?d=&t=mosques&r=10&l=Minneapolis%2C+MN>)). Schools in the United States are required to keep Church and State (the schools) separate, but when a family's religious beliefs encompass every facet of their daily lives, this researcher believes it is important for the schools to at least understand what a family's

beliefs are and why some educational decisions may not be openly accepted because of these beliefs. And even though British schools do have some integration of Church and State, these needs still exist and would appear to be important.

Since Ault's review (2009) found only three journal articles that mentioned anything related to Islam, and Jegatheesan et al.'s work (2010) only studied three Muslim families each having a child with autism, and other research specific to Islam and special education does not seem to exist, it is this researcher's goal to find more information and answer the following questions: How do Muslim parents in the United Kingdom and the United States make sense of having and raising a child with a disability within their cultural and religious meaning systems? And, how might Muslim parents desire that the schools work with them?

To help answer these questions, Muslim parents of children with disabilities in the United Kingdom and the United States were interviewed. The interview questions will be based on questions similar to those used by Jegatheesan et al. (2010), as well as additional questions created based on the findings of Jegatheesan et al. (2010) [See Appendix A].

### **Significance of the Study**

Since Muslims make up an increasing percentage of students in the United Kingdom, and numbers of Muslim immigrants continue to grow in Minnesota, it is important for education professionals to be aware of the religion of Islam and how it relates to raising a child with a disability. This belief system plays an integral part of Muslims' lives and they have a great desire to hold on to the cultural and religious fabric of their Islamic faith (Azmi, 1997). Therefore, it is appropriate for professionals working

with Muslim families to have some foundational understanding of this cultural and religious fabric. By expanding the study by Jegatheesan, Fowler, and Miller (2010), this researcher will learn more about Muslim parents' beliefs about their children's disability and schooling specific to the various ethnic backgrounds of Muslim peoples. These backgrounds include Bangladeshi and Pakistani parents in the United Kingdom and Somali parents in the United States. Although this is just one small step in helping professionals begin to understand Muslim families with whom they work, it is an important one because it is the foundational piece to then begin proposing strategies on how to best serve students with disabilities and their families who are Muslim. This study will bring needed data to professionals in special education who work with Muslim families.

### **Definition of Terms**

The definitions included in this section are specific to Islam and are used throughout this study. It should be noted that each definition could be expanded upon, but for the purpose of this work, information is included that will provide the reader a basic understanding. For more thorough explanations, the specific references should be reviewed.

**Allah.** God. Used in Islam. ([www.merriam-webster.com](http://www.merriam-webster.com), retrieved December 27, 2011).

#### **Hadith.**

Report of the words and deeds of Muhammad and other early Muslims; considered an authoritative source of revelation, second only to the Qur'an (sometimes referred to as sayings of the Prophet). These were collected,

transmitted, and taught orally for two centuries after Muhammad's death (Esposito, 2003, p. 101).

Geaves (2006) adds to this definition that hadith "are different from the Qur'an in that they were inspired by Muhammad's own initiative rather than by Allah" (p. 36).

### **Hajj.**

The annual pilgrimage to [Mecca] and the fifth of the five pillars of Islam. It is a religious duty for every Muslim to complete at least once in their life if they are in good health and can afford to go. However, it is possible to have the Hajj undertaken on [a Muslim's] behalf by proxy (Geaves, 2006, p. 37).

There are specific rituals that take place during Hajj.

### **Imam.**

One who stands in front; a role model for the Muslim community in all its spiritual and secular undertakings...In North America, in the absence of official ordainment, religious leaders who connect with different Islamic centers often use this title to indicate their religious standing in the community (Esposito, 2003, p. 135-136).

**Islam.** "Literally 'submission' or 'surrender' from the word salam meaning 'peace'. The religion revealed to the Prophet Muhammad" (Roraback, 2004, p. 59).

**Islamic Education.** Receiving education in Islam; learning to recite the Qur'an; learning other religious duties related to Islam. Sometimes called a madrassah. (Anzar, U., 2003). An Islamic education is generally separate from the regular education required of Muslims in Western countries.

### **Muhammad.**

The name of the final Prophet who was born in [Mecca] around 570. Somewhere around the age of 40 he began to receive a series of revelations in which he was commanded to recite the Qur'an, the final book of God containing the complete instruction which leads to submissions and obedience to God's will...All Muslims acknowledge Muhammad as the final Prophet of God and the exemplar of Muslim belief and practice...(Geaves, 2006, p. 74-75)

**Muslim.** An adherent of Islam ([www.merriam-webster.com](http://www.merriam-webster.com)) and "One who submits to the will of God. To demonstrate that one has become a Muslim, one must recite the shahadah, witnessing that there is no God but Allah and that Muhammad is the messenger of God" (Esposito, 2003, p. 246).

### **Pillars of Islam.**

The five pillars of Islam comprise five official acts considered obligatory for all Muslims. The Qur'an presents them as a framework for worship and a sign of commitment to faith. The five pillars are the shahadah, salat, paying zakah, fasting during the month of Ramadan, and performance of the hajj(Esposito, 2003, p. 247).

### **Qur'an or Qur'an.**

The final Revelation of Allah to humanity and believed to be God's speech or the Word of God...Muslims believe that the Qur'an has been kept in the pure form revealed to Muhammad by the angel Jibril...As the book is literally the speech of God, it is not only the meaning which is important. The actual Arabic words are imbued with sacredness and potency and will give blessings if recited...(Geaves, 2006, p. 88-89).

**Ramadan.**

The ninth month of the Muslim year which is observed as a fast lasting from sunrise to sunset. The fast is [fourth] of the five pillars of Islam and during this period Muslims should abstain from food, water and sexual activity. The fast is commanded by Allah in the Qur'an and is therefore obligatory for all adult Muslims except in special circumstances such as illness or menstruation. In such circumstances it is permissible to make up the period of the fast at a later date. The period of Ramadan includes some of the holiest occasions of the Muslim year... (Geaves, 2006, p. 91)

**Salat.** This is the second pillar of the five pillars of Islam.

It is the regular observance of the five prescribed daily prayers...Serves as public, physical evidence of the believer's adherence to Islam. Prayers are to be performed just before dawn, at noon, in midafternoon, just after sunset, and in the evening, between an hour after sunset and before midnight. Prayers are to be made in the direction of Mecca and must be carried out in a state of ritual purity..." (Esposito, 2003, p. 247)

The opening chapter of the Qur'an is spoken as well as other Qur'anic verses. Specific motions and movements take place; each one has specific meaning. Additional processes take place, different prayers are recited, and all steps are repeated (different amounts of time depending on what is being prayed) (Esposito, 2003).

**Shahadah.** This is the first pillar of the five pillars of Islam.

Witnessing the oneness of God and the prophethood of Muhammad...This consists of two declarations: The first, there is no god but God, affirming belief in

a single divine reality. The second, Muhammad is the messenger of God, affirms submission to God via acceptance of His message as revealed to humanity through Muhammad...(Esposito, 2003, p. 247).

**Shii Islam.** “Shii Muslims, the followers or party of Ali, believe that Muhammad’s religious leadership, spiritual authority, and divine guidance were passed on to his descendants, beginning with his son-in-law and cousin” (Esposito, 2003, p. 292). It is also spelled as *Shi’a* and Geaves (2006) defines it as “the first division amongst Muslims after the death of the Muhammad and the most important schism in Islam” (p. 101).

**Sunni Islam.** Sunnis represent the largest branch of the Muslim community, at least 85% of the world’s 1.2 billion Muslims. The name comes from the Sunnah, the exemplary behavior of the Prophet (although all Muslims are guided by this, Sunnis stress it). Sunnis tend to reject excessive rationalism or intellectualism, focusing instead on the spirit and intent of the Qur’an (Esposito, 2003, p. 306).

**Zakah.** This is the third pillar of the five pillars of Islam.

An alms tax typically paid to a religious official or representative of the Islamic state or to a representative of a local mosque...traditionally set at 2.5 percent of the believer’s assets. It is used to feed the poor, encourage conversion to Islam, ransom captives, help travelers...and any other purpose deemed appropriate. The zakah serves as a reminder of one’s broader social responsibilities to the community (Esposito, 2003, p. 247).

## **Delimitations**

1. This study looks at the religion of Islam in Muslim families, from different Muslim subcultures, in the United Kingdom and the state of Minnesota in the United States. This further provides a small spectrum of how different ethnicities affect being Muslim.
2. This study is extended from an ethnography conducted on three South Asian Muslim families in the United States who have children with Autism. This study extends beyond the ethnography by interviewing multiple families, by choosing different ethnic backgrounds, and by including any disability categories, not only Autism.

## **Nature of the Study**

This study is qualitative in nature and the researcher conducted semi-structured interviews to gather data from the participants. Participants included four Muslim parents from the United Kingdom and three Muslim parents in Minnesota. Data was analyzed and synthesized in order to find common themes and differences from the study conducted by Jegatheesan et al. (2010).

## **Organization of the Remainder of the Study**

This study will be organized into five chapters, a reference section, and appendices. Chapter one provides a brief synopsis of the purpose and significance of understanding Muslim families which directly relates to this study. Chapter two reviews the literature on the current studies related to Muslim parents of children with disabilities; the religion of Islam; religious and cultural beliefs, attitudes and behaviors towards



disabilities; 21<sup>st</sup> Century practices and issues of Islam related to disabilities; and how religion is connected to special education. Chapter 3 describes the research design including (a) methodologies, (b) explanation of the instrument, (c) data collection procedures, and finally the (d) analysis and verification of the data. Chapter 4 will describe the findings of the study and Chapter 5 will provide a discussion of the work, any implications and the researcher's recommendations.

## **CHAPTER 2**

### **Introduction to the Literature**

The literature reviewed revealed limited studies specific to the topic of Muslim parents' perspectives of having a child with a disability. Specifically Jegatheesan, Miller, and Fowler (2010) in the United States, and Crabtree (2007) in the United Arab Emirates, provided the main studies. However, other studies were reviewed which relate to this topic and literature was found on subjects that connected to religious views and disabilities even if the main purpose of a study was not focused on this. Studies relating to parents and professionals were also reviewed to provide background on the importance of parents working with special education professionals. Beyond the analysis of specific research, articles from scholars in the Muslim community were also reviewed in order to get an overview of historical and present day teaching in Islam. Some articles incorporated in this chapter covered in-depth analyses of literature covering topics of religion. The topics reviewed in the literature included: (1) the religion of Islam, current Muslim populations in the United Kingdom and the United States; (2) religious and cultural beliefs, attitudes and behaviors towards disabilities, (3) ethnography of three Muslim families with children with special needs, (4) contemporary practices and issues of Islam related to disabilities; (5) religion's connection to special education; and (6) Muslims living in Western cultures. Each of these topics played a role in some way in the Jegatheesan et al. study (2010) and since this research is based off of Jegatheesan et al.'s study, it is important to review literature in each of the aforementioned areas.

## **The Religion of Islam**

Since educational professionals are likely to be of different faith and cultural backgrounds than their Muslim students (Jegatheesan et al., 2010), it is important to be familiar with their students' backgrounds and daily lives. Many teachers are not familiar with Islam beyond what they see in the media. For many Muslims, religion is an all-inclusive way of life. The Qur'an, the holy book of Islam, provides guidance for Muslims in their personal faith and theology as well as in the religious and cultural regulations for both the community and the individual (Laird, Amer, Barnett, & Barnes, 2007). A Muslim's main religious duties are embodied in the five pillars of Islam (as stated in Chapter 1). They include shahada, the salat, fasting during the month of Ramadan, zakat, and hajj. Each of these five religious duties is required of every Muslim dependent on a person's ability to perform them. If a person is too poor, he need not pay zakat; if a person is too ill or disabled, he may not be physically able to pray or complete the hajj. Allah can see this and will know the intention of the heart so it is allowed in these circumstances (and other circumstances as needed). Beyond the Qur'an, Muslims also follow the hadith, or the sayings and teachings of the Prophet Muhammad. Both the Qur'an and the hadith provide the religious guidance necessary for all Muslims (Adam, A., personal communication, July, 2011).

To Muslims, the Qur'an represents "the ultimate manifestation of God's grace..., the ultimate wisdom, and the ultimate beauty of expression: in short the true word of God" (Asad, 1980, p. ii) which was revealed to the Prophet Muhammad. It further speaks to Muslims with a message that is meant for all people, all time, and all locations in the world (Bazna & Hatab, 2005).

Muslims are careful about the version of the Qur'an they read. In order to know they are reading the true word of God, they believe the Qur'an is in its truest form if and only if it is in Arabic. Other versions and translations of the Qur'an are simply the author's interpretation and therefore not the true word of God (Lang, 1997). Since the Qur'an was revealed in Arabic, if it is read in Arabic, it is thought to be the highest quality of literature (Bazna & Hattab, 2005).

This review will focus on a few specific verses and sentences from the Qur'an that relate to the topic of disability or disadvantage, but it should be known that in the truest understanding of the Qur'an, each sentence and verse has specific bearing on other sentences and verses further explaining and strengthening one another. When read out of context of the entire Qur'an, a sentence or verse's true meaning cannot truly be grasped (Asad, 1980, p. vii).

While there is only one true Qur'an, there are numerous denominations in Islam which follow the Qur'an. These include the Sunni and Shi'a, the two denominations most prominent in the United States and worldwide. These two denominations formed after the death of Muhammad when a new leader needed to be chosen. The Sunnis were so named because the sunnah or "custom" of the prophet is followed. They formed the majority and accepted Abu Bakr as Muhammad's successor. He was Muhammad's closest companion and was known to be an effective leader. Those who follow the Shia tradition have chosen to follow Ali, Muhammad's closest relative, cousin and son-in-law. The Shi'a bear this name as it is a shortened form of Shi'at-Ali, or the "party of Ali" (Laird et al., 2007).

Within Islam, there are some similarities and some differences within the different denominations and cultures around the world. For example, the five daily prayers, or salat, are central to the practice of Islam and are recognized around the world (Abd-Allah, 2004). Conversely, the Islamic requirement of modest dress varies according to the local customs of the culture or country of wherever a Muslim lives. Abd-Allah shares this quote where Islam is compared to a clear river: “Its waters [Islam] are pure, sweet, and life-giving but—having no color of their own—reflect the bedrock (indigenous culture) over which they flow. In China Islam looked Chinese; in Mali, it looked African” (Abd-Allah, 2004, retrieved from <http://www.crosscurrents.org/abdallahfall2006.htm>).

Additional expectations within Islam include guidance for parents and children. In Islam, children can expect to have parents who will raise them well as the parent is instructed to have a role in developing good qualities in the child. Moreover, in Islam, children have the right to have a father; being fatherless is not seen as an option in Islam (in some cases children can be adopted by a different father or by society in order to not be fatherless) (Morad, Nasri, & Merrick, 2001). Islam further recognizes that all children have the right to have equal life chances regardless of being male or female or being abled or disabled; and a parent who does not recognize this equality is accused of committing injustice (Morad, Nasri, & Merrick, 2001, p. 68).

**The Qur'an and Hadith.** Both the Qur'an and hadith provide guidance to Muslims on how to live their lives according to Islamic tenets. Since this study relates to Muslim individuals with disabilities, specific details from both the Qur'an and hadith, as they relate to the topic of disabilities, will be shared. There are numerous references to the prophet Muhammad being involved with people with disabilities throughout many

hadith. This is important to note because Muslims look at the thoughts and actions of Muhammad to be the standard for everyday living (Miles, M., 2002A) and therefore try to live their lives according to what they read in the hadith and the Qur'an. The Qur'an does not give specific guidance in this area so the hadith provide this guidance. As Muslim parents wrestle with the expectations of raising a child with a disability, they can look for direction and guidance from these sources.

As Muslims closely follow Islamic teachings, this quote from Asad (1999) provides a good background to Islamic expectations.

Mankind's duty is to make the best of [themselves] so that they might honor the life-gift which [their] creator has bestowed upon [them]; and to help [their] fellow-beings, by means of [their] own development, in their spiritual, social and material endeavors. But the form of [one's] individual life is in no way fixed by a standard (p. 11-12).

Bazna and Hatab (2005) provide further insight: "In Islam, humans' original nature is essentially good. The Islamic teaching holds that people are born pure and, in the sense explained [earlier], potentially perfect" (p. 11). So, a Muslim parent can be encouraged by the words closely connected to their religion as seen in these quotes.

The Prophet Muhammad is very specific in communicating this message of a pure heart, even if one's body is not perfect, in the following hadith (Bazna & Hattab, 2005): "Verily, God does not look at your bodies or your appearances, but looks into your hearts" (Muslim, 2564, as cited in Bazna & Hattab, 2005). So, although one whose physical appearance may be different and may be the cause of being disadvantaged, it is still his heart that is noticed by God.

Different examples written in the Qur'an around the subject of those who are disadvantaged encompass the position and attitude of Islam and how it evaluates people: "the real merit of people lies in the degree with which they seek the truth" (Bazna & Hattab, 2005, p. 13). In the early years of Muhammad's mission, he often sought out wealthy and powerful people to follow him. It was during these early years when verses in the Qur'an explain that Muhammad first experienced the opportunity to connect with people who were disadvantaged. Through these experiences of the Prophet, the verses explain that the value of a heartfelt seeker of God, even though weak or disabled, is more than that of one who may be wealthy and powerful, but is unmindful of God (p. 13).

To further expand on this thought, the following message comes from a well-known hadith. This hadith tells of a blind follower of the Prophet Muhammad listening to him in Mecca. This blind man approached Muhammad and desired further explanation of certain verses in the Qur'an. It is shared that Muhammad was annoyed by these questions because it interrupted his spreading of the message of Islam to some influential pagan people in Mecca (Bazna & Hatab, 2005, p. 12-13). The Prophet turned away from the blind man and it was at that moment when 10 specific verses of the Qur'an were revealed to him (p. 13). The ten verses that were revealed to him (Qur'an 80.1-10) relate to Islam's position and attitude that the true heart of mankind is determined by the degree with which truth is sought (p. 13). This blind man demonstrated a true heart and thus being in the hadith, is a lesson from Muhammad that should be followed by Muslims.

Finally, Muslims "are expected to constantly do the best they can, within their powers, and people with certain conditions are no exception" (Bazna & Hattab, 2005, p. 15). Another listed hadith is one where a blind man requested an accommodation from

Muhammad to pray at home. However, when he was asked by the Prophet if he could hear the call to prayer, and his response was ‘yes’, the Prophet told him, ‘then respond to it’ (p. 14-15). The permission to pray at home did not apply to this blind man because he was capable of getting to the Mosque. It is known to many Muslims that the Prophet Mohammad, the messenger of Islam, took special care to ensure that people with disabilities were able to come to prayers (Bazna & Hatab, 2005). It is evident from these teachings that Muhammad always looked at the capabilities of the believer.

Just as daily prayer, or salat, is one of the five pillars of Islam, so is almsgiving, or zakah (also written as sadaqah). It is evident in this pillar as well that Muhammad gives guidance according to individual persons. When asked how one gives sadaqah without possessing any property, the Prophet Muhammad replied,

The doors of sadaqah are ...guiding the blind; listening to the deaf and mute until you understand them; guiding a person to his object of need if you know where it is; hurrying with the strength of your legs to one in sorrow who is appealing for help; and supporting the weak with the strength of our arms (Sabiq, 3.98)  
“thus laying down the responsibility of everyone to treat the deaf and mute with patience and courtesy” (Bazna & Hatab, 2005, p. 16).

In summary, the Qur’an and hadith share the message that every human being is potentially perfect as long as each person continues to develop towards his or her own capacities, to the best of his/her ability, keeping in mind that all individuals are different. Any physical differences in people should be viewed as morally neutral (Bazna & Hatab, 2005, p. 23-24). It was determined in specific studies of the Qur’an that physical conditions are not considered a curse or a blessing; they are simply a part of the human



condition (Musse, 2002, Bazna & Hattab, 2005; Al-Thani, 2008). A father's Islamic faith brings specific meaning to parenting a child with autism as he shares, "in the words of Allah, it is written that not every human being is the same" (Jegatheesan et al., 2010, p. 102).

From their research on the disadvantaged in the Qur'an, Bazna and Hattab (2005) found that Muslims are expected to always seek out opportunities to help the disadvantaged, advocate for their needs, and generously provide from one's own time and property. They stated that the concept of disability, in the conventional sense, is not found in the Qur'an. Rather, 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 (p. 5-6). Bazna and Hatab (2005) concluded that the Qur'an expects society to be responsible in correcting this injustice by constantly urging Muslims to be aware of the great needs of the disadvantaged and to help improve their disadvantaged state as well as their status.

### **Muslim Populations in the United Kingdom**

The population of Muslims has been increasing in the United Kingdom and the United States for many years and the patterns of immigration have changed throughout these years. References to Islamic scholars in the United Kingdom go back as far as 1386 as they were mentioned in the prologue of Chaucer's *Canterbury Tales* (www.bbc.co.uk/religion/religions/islam/history/United\_Kingdom\_1.shtml, BBC, 2011) with the largest group of Muslims arriving in Great Britain about 300 years ago. These Muslims were mostly recruited sailors from India. The first English version of the Qur'an

was translated during this time by Alexander Ross in 1649. Another known group of Muslims to arrive was in 1873 from Sylhet, which is now known as Bangladesh. The next major wave of Muslims to arrive in Britain came from Yemen after the opening of the Suez Canal in 1869. Today, the Yemenis are the longest-established Muslim group living in Britain. The Muslim population today is 2%-4% of the population, with over half of them being born in Britain. The majority of Muslim immigrants arriving in the 20<sup>th</sup> Century came from Pakistan and Bangladesh with the most recent immigrants coming from Africa (CIA World Factbook).

Data from 2011 show that 2.7% of the population or 1.7 million people in the United Kingdom are Muslim (CIA World Factbook). In 2003, data show that 1.6 million Muslims were living in Britain. At this time, 50% of Muslims in the United Kingdom were born there; 60,000 of them are of Eastern European origin, and of Pakistanis and Bangladeshis, 54.5% and 46.6% respectively, were born in the United Kingdom (May 7, 2003, retrieved on October 17, 2011, from <http://www.mcb.org.uk/library/statistics.php>).

**Special education needs in the United Kingdom.** For the purpose of this study, the specific numbers of Muslim children receiving some kind of special education services is also being sought. Since data are not provided for specific religious affiliation, the ethnic backgrounds of Pakistani and Bangladeshi pupils were sought. The following data from all schools in England in 2011 indicate: Pakistani and Bangladeshi primary students in England, identified as having Special Education Needs (SEN) with statements<sup>1</sup>, is 1.5% and 1.6%, respectively. Pakistani and Bangladeshi secondary students in England, identified as SEN with statements, is 1.7% and 1.6%, respectively. There is also a category of students with SEN in England who do not have formal

---

<sup>1</sup> The formal paperwork identifying services for students with special education needs in England.

statements. These students fall under a “learning difficulties” category which does not require formal paperwork. These percentages are greater than those with statements and include: primary students who are Pakistani and Bangladeshi 21.6% and 19.1%, respectively. For secondary students who are Pakistani and Bangladeshi and identified as SEN without statements, the percentages are 21.8% and 19.0%, respectively (Department for Education 2012, <http://www.education.gov.uk/rsgateway/DB/SFR/s001075/index.shtml>).

When breaking down the data for special schools, schools for students with moderate, severe, and profound special education needs, the numbers of Pakistani students increases. Pakistani and Bangladeshi students identified with SEN who have statements in special schools are 5.2% and 1.5% respectively (Department for Education, <http://www.education.gov.uk/rsgateway/DB/SFR/s001075/index.shtml>).

### **Muslim Populations in the United States**

The first major wave of Muslims into the United States was the arrival of African slaves in the eighteenth century. The next wave of Muslim immigration came from Arab nations and took place in the late 19<sup>th</sup> and early 20<sup>th</sup> centuries when Muslims came seeking economic opportunities. As they sought manual labor jobs, they often ended up in industrial cities such as Detroit, Michigan (Pipes & Duran, 2002).

The next wave of Muslim immigrants came in the 1950s, but represented a different demographic than earlier waves of immigrants. They were largely professionals and university students seeking better opportunities than what they could find in their homelands (Hasnain, Shaikh & Shanawani, 2008). It became common for Muslims who came to study at American universities to remain in America even after they completed

their education. These later waves of Muslims tended to have higher incomes and were less likely to assimilate into American culture.

The final group of immigrants most recently arriving in America is considered non-professional. They come from many parts of the Muslim world and a significant number come from Bosnia and Somalia where tragedy and conflict have occurred. Although considered non-professional in the United States, many of these individuals had high paying jobs in their homelands. Because of tragic events in countries such as Somalia, Afghanistan, and Bosnia, there has been a mass exodus to the United States in order to find safety. Other reasons for the mass exodus include escaping conditions such as underdevelopment, tyranny, persecution, lawlessness, poverty, civil strife, and war trauma because of dictatorial regimes leading these countries (Haboush, 2007).

Data from the CIA World Factbook (2011) show that 1.8 million Muslims live in the United States. This equals 0.6% of the U.S. population. Additional statistics from the Pew Report in Washington D.C. (<http://religions.pewforum.org/reports>) (2010) show similar data of Muslims with regard to religions in the United States. In a study conducted over three months in 2007, more than 36,000 Americans were surveyed on matters related to religions. There were many data, but for the purpose of this work, the percentages of different religions are included here: Christians, 78.4%; Other religions, 4.7%; Jewish, 1.7%, Buddhist, .7%, Muslim, .6%, Hindu, .4%; Unaffiliated, 16.1%, and Don't Know/Refused, .8%.

In a special report for the United States Institute of Peace, Qamar-ul Huda (2006), former professor of Islamic Studies and Comparative Theology at Boston College, found the biggest difference between Muslims living in the United States from Muslims living

in the United Kingdom is that American Muslims have more social and economic opportunities and do not feel marginalized, isolated, or locked out of political participation. Additionally, they feel that greater America has accepted them and therefore they are included in the common facets of American life such as creating professional, cultural, human rights, civil rights, educational, and political organizations. Creating these organizations allows them to feel a part of American society and a liberal democracy. Since the mid-late 1990s, Muslims in America have even started participating in local community events. Their participation includes interfaith dialogues, school boards, city councils, parent-teacher organizations, chambers of commerce, and even the election of Keith Ellison, a self-described Muslim, to the House of Representatives. These are good examples of Huda's (2006) work on American Muslim identity formation and Islamic approaches toward mediation and peace building.

Specific to Minnesota, Muslim immigrants have been calling it their home since the 1960s, but the largest influx of Muslims, specifically Somali immigrants, was in the 1990s following the outbreak of civil war when thousands fled their homeland (Federal Reserve Bank of Minneapolis,

[http://www.minneapolisfed.org/publications\\_papers/pub\\_display.cfm?id=2476](http://www.minneapolisfed.org/publications_papers/pub_display.cfm?id=2476)).

Regarding actual numbers of Muslims in Minnesota, specific data are difficult to find because religious affiliation is not listed on census forms. However, the Minnesota Department of Education estimates the number of Somalis at 14,000-15,000 statewide, with the majority living in Minneapolis and the surrounding area (Minnesota Department of Education, retrieved December, 27, 2011

<http://w20.education.state.mn.us/MDEAnalytics/Maps.jsp>). The MDE draws this number

based on students who speak Somali at home. Other statewide Somali information is based on American Community Surveys from 2008-2010 estimating the Somali population in Minnesota to be more than 32,000 (Williams, 2011, retrieved from <http://www.startribune.com/132670583.html>). Regardless of the varied data it is evident that Somali families, of which Islam may be the common religion, make up a critical piece of the religious fabric of Minnesota. Another way to show the richness of this fabric is to know that there are 24 mosques within the immediate surrounding area of Minneapolis, Minnesota (Salatomic, retrieved July 19, 2013 (<http://www.salatomic.com/sp.php?d=&t=mosques&r=10&l=Minneapolis%2C+MN>)). This is more than twice the number from 2001 when there were eight identified mosques in Minnesota (Allied Media Corp, retrieved December 28, 2011 from <http://allied-media.com>). The families that attend these mosques likely have children attending the local schools.

**Special education of Somali students in Minnesota.** The data representing the number of all students receiving special education services in Minnesota are 128,812. The breakdown of different races does not specifically include Somali, but the Black category, under which Somali would fall, is 12.2%. (Minnesota Department of Education, retrieved July 19, 2013, <http://w20.education.state.mn.us/MDEAnalytics/Data.jsp>). It should also be noted that these numbers do not necessarily represent Muslim students because not all Somalis practice Islam. Other data that may shed light on special education students who are also English Language Learners (ELLs), which would include Somali children, comes from federal child count data. According to child count data, which includes all students identified with a disability, 518,088 students were classified

as limited English proficient (LEP) for the 2009-2010 school year. This represents approximately 8.5% of all students with disabilities (Data Accountability Center, retrieved July 19, 2013 <https://www.ideadata.org/default.asp>). It is interesting for this particular literature review to note that the largest group of ELL population of 10 states across the United States is Somali (Watkins & Liu, 2013).

According to the MDE, the counties including and surrounding the Minneapolis area show the following population of families who speak Somali as their home language: Anoka 642, Carver 61, Dakota 1336, Hennepin 6914, Ramsey 2283, and Scott 130. But again, it is unknown how many of these families have children who receive special education services and of those families, how many practice Islam.

While this study is specific to Muslim parents of children with disabilities, it is important to recognize that Muslims encompass an exceedingly diverse group of people who represent numerous cultures and geographic regions throughout the world, therefore simply knowing the data should be cautioned. Moreover their culture and region of the world cannot be contingent on the basis of religion alone. Additionally, it should not be assumed that if a person comes from a certain geographic region that they are Muslim (Hasnain, Shaikh, & Shanawani, 2008). Conversely, Abd-Allah (2004) and Hassan Samanter (personal communication, July 12, 2012) say that most Muslims see faith and culture as one; the two are naturally woven together in their minds and in their lives. Based on these two different views, one should use caution when referencing Muslims in any context.

### **A Study of Parental Beliefs in South Asian Muslim Immigrant Families**

Jegatheesan, Miller, and Fowler (2010) determined there was a great need to learn more about Muslim families who have children with autism because, at the time of their work, there was little research on children with autism coming from diverse backgrounds. They found that Muslims were an especially neglected group. With Muslims having deep-seated intergenerational family values, a desire to preserve their ethnic and religious identities and choosing limited acculturation to principles of the Western world, it was deemed important for this team of researchers to spend time in the homes of three South Asian Muslim families in order to learn more about how their culture system plays a role in understanding why their child has a disability as well as raising a child with a disability. Their study spanned 17 months of fieldwork that included more than 700 hours of participant observation in the home and community environments of the three families (p. 99).

**Findings.** Jegatheesan et al. (2010) found that all three families made connections to their Islamic faith in everything they understood about their child with autism. They felt chosen by Allah to raise their child. They believed Allah had considered the factors necessary in parenting a child with autism and chose each of them because of their “moral character, loving nature, resilience; their ability to protect the child; and their fate or Karmic connection to the child” (p. 101). Additionally, they felt closer to Allah and this allowed them to have a deep understanding of parenting a child with a disability.

These South Asian Muslim parents felt a strong responsibility to do whatever was necessary in order to meet the needs of their child. They believed that since this child was



given to them by Allah, this child had special gifts and it was up to them to help guide their child according to these gifts.

The parents' resilience was demonstrated through their ability to "be a good person" and "not break down" (p. 102) no matter what challenging situations arose with their children with autism. They believed Allah chose them to be parents because of these factors. All three fathers shared that Allah was testing them spiritually through these difficult situations and it was up to them to either pass the "test with flying colors", or, they would fail the test by living immorally and conducting themselves in negative ways, such as "becoming depressed or developing addictions" (p. 102).

The need to demonstrate to Allah their ability to protect their children with autism was especially strong. Each of the mothers protected her child in some way as each one went to school. One of the mothers drove her child to school because she was worried about him being safe on the bus; the other two mothers rode the bus with their boys in order to ensure they would be safe. Other ways they demonstrated protection of their children included showing up unexpectedly at school to see if their child was being treated fairly at school by peers and teachers, as well as asking specific questions of their sons upon arrival at home after school to determine if they were treated fairly.

The fathers in these families believed in "human diversity" (p. 102) and told other family members that this child with autism is a part of that diversity. Each of these fathers also made it clear that, in the words of Allah, no human being is the same – not necessarily less or more – just different. Jegatheesan et al.(2010) adds this: "the fact that autism manifested itself in different kinds of behaviors and ability did not change the fundamental humanity of a person with autism" (p. 102).

Fate and Karmic connections to the child were different in the families depending on their denomination of Islam. The two families, who were Sunni Muslim, believed in accepting what was given to them and never questioning Allah, because they believed in fate and destiny. One mother did not think of having a child with autism as anything negative; it was simply determined before this mother was even born. On the other hand, the family who was Shiite, believed in reincarnation and therefore believed in the “cycle of rebirths and the salvation of the soul” (p. 102). This mother believed that it was her son’s “last rebirth” because he had autism. She also believed that she and her son had known each other in a previous life and that because of some “unfinished matters” in her previous life she was now his mother. She felt a special responsibility to be a good mother because of this being his final life on earth. These Karmic beliefs were reiterated by other family members as well.

Each of the families believed their child with autism was a gift from Allah and, because of such belief, did not support the educators’ focus on their child’s deficits. From the first point of contact with the school as it related to assessment, diagnosis, and planning, the families noted how the educators only focused on the problems – never the gifts the child had. These parents were constantly looking for someone to notice what their children could do rather than only noticing the deficits their children had.

Each of these families’ goals for their children with autism was to integrate them into ordinary daily life as much as possible. This included involvement in religious activities, family activities, and social gatherings. Immersing the children in every aspect of life is what is interpreted from the Qur’an and therefore what these families strived for. It was not always easy for these families, but each one noted progress in their children.

They celebrated the small steps made in ordinary things. Their goal was to continually provide opportunities for their children to take part in the daily happenings of the family.

Other goals of these parents for their sons with autism included speaking more than one language and praying to Allah. It was common in these families that three languages would be spoken: a native language spoken with and to the elders in the family, Arabic for prayer and religious activities, and English for American society (including work, school, and community social functions). Although these boys with autism were not fluent in all three, each family tried different ways to get them to speak the different languages. Arabic was seen as the most important of the three as reciting the Qur'an in Arabic is what it means to be Muslim (Jegatheesan et al., 2010).

The researchers pursued this work to study how the cultural system in which these families were nested played a role in their understanding of and raising their child with autism. However, it was the families' Islamic faith that played the primary role in their lives (Jegatheesan et al., 2010). It was because of this belief system that the families had such difficulty agreeing with the professionals working with their children. These researchers believed that the parents and educators actually could have agreed on the outcomes or goals of the services being recommended, but, because they could not agree on a starting point, progress was never made with the educational planning for these three families. The parents felt that the recommendations from the school ran counter to their belief systems and therefore were never appropriate for their child.

Jegatheesan, Miller, and Fowler (2010) address two main challenges in their work. The first is that most research on effective strategies for children with autism has focused on white Euro-American families. The second challenge is to address cultural

knowledge and competencies in the professionals working in early intervention and special education. Most of these professionals are female, white, and college educated, and because they likely differ in culture, values, race, and socioeconomic status they clash with the families they may serve (p. 106).

So, as schools in the United Kingdom and the United States see increasing numbers of Muslim students, it was important to review this study conducted by Jegatheesan, Miller, and Fowler in great detail since this researcher will expand on their findings.

### **Religious and Cultural Beliefs, Attitudes and Behaviors**

Jegatheesan et al. (2010) found that different religious and cultural beliefs, attitudes, and behaviors were evident in the Muslim families and were a critical aspect of their daily lives. Since there was limited literature specific to Islam, other religions and cultures were also reviewed to see how these other religions and cultures demonstrate beliefs, attitudes and behaviors related to disabilities. A thorough review of the literature was conducted to attempt to find some answers, but it is important to first recognize that seventy percent of the world's disabled population lives in countries without a westernized view of disability. Often, the terms used in these other countries are considered 'outdated' or 'barbaric' (Miles, M., 2002B). Although it is healthy to continue to do work to help change these views, it is important to note that the attitudes are not coming from an intention to do harm, rather because they are the only ideas that are known.

An overview of studies covering varying religious and cultural beliefs, attitudes, and behaviors will be discussed. Many of the studies were not specific to religion, but

had elements of religious views that were either intentional or simply came out in the responses from participants and became a critical part of the findings. Several of the studies come from other parts of the world and although the parents being interviewed in this researcher's work currently live in the United Kingdom and the United States, it is important to be aware of the views in other countries since many of these parents still have family in these countries, are still personally connected with them, and will likely experience different views their families may have towards their child with a disability (Raghaven, Weisner, & Patel, 1999). Some of the views shared in this review are positive, some are negative; but each one sheds some light on why raising a child with a disability can be so complex.

**Positive Responses.** Many families, regardless of faith backgrounds, see their children including those with disabilities, as gifts from God (Poston & Turnbull, 2004; Crabtree, 2007; Skinner, Bailey, Correa & Rodriguez, 1999; Skinner, Correa, Skinner, & Bailey, 2001; Shaked, 2005). They see these children with disabilities as gifts because they feel that God has specifically chosen them to parent these children with disabilities. They feel that by being chosen, God sees them as capable, and therefore special.

Poston and Turnbull (2004) found positive connections between religion and disabilities. They conducted a qualitative inquiry investigating conceptualization of family quality of life in 187 individuals who either had a disability or were connected with children with disabilities in some way. Through focus groups and individual interviews, the collected data were organized into 10 domains of family quality of life (Poston et al., 2003). One of the specific themes of the study was on participants' perspectives on spirituality, specifically faith and the participation in religious

communities. Poston and Turnbull (2004) did not specifically recruit individuals from diverse religious backgrounds and did not ask respondents to list their religious affiliation, but it was clear based on the comments from the participants that most were Christian. Most of the participants see their child as being a gift from God; some Christians in this study see this gift as being a test of their faith or a specific blessing in their life (Poston & Turnbull, 2004). Another positive element some of these participants noted was the fact that participating in church activities brought great joy to their child with a disability.

Other positive notes come from a 2-year ethnographic study of 20 Asian Indian Hindu families living in the United States (Gabel, 2004). Gabel found that these parents of children with mental retardation also believe their children with disabilities are gifts from God, but that their children were given to them because of committed offenses in a previous life. This idea fits with the beliefs of karma and reincarnation which Jegatheesan et al. (2010) also learned from one of the families they studied. Since the child was given to them because of actions in a previous life, it was not a burden to raise this child; it was simply an expectation.

Crabtree (2007) conducted an ethnographic study of 15 participants in Sharjah, United Arab Emirates by using in-depth, open-ended interviews to learn the views of family care-giving and the provision of formal services. All of the participants were Arab Muslims, and although not specifically sought, were all mothers. One of the positive findings related to religion from this study included that if a Muslim mother openly accepts the disability of her child, this will demonstrate her acceptance of Islam

because others will see her as accepting the will of Allah. This will shed a positive light on her (Crabtree, 2007).

In yet another study, 30 Jewish Israeli families were interviewed to determine how their faith played a role in raising a child with autism (Shaked, 2005). A positive response from this study was that twenty of the parents saw their child as having a special religious assignment on earth which relates to the doctrine of reincarnation, one of the Jewish variants.

Many other Muslim parents illustrate how their Islamic beliefs positively affect their parenting of a child with a disability. Some parents in the United Arab Emirates report feeling that their home was blessed and that additional rewards were provided to them because of parenting a child with a disability (Crabtree, 2007). The parents felt they were stronger because of this; these rewards were from Allah. The Muslim parents in Jegatheesan et al.'s study (2010) shared similar positive stories. They felt that Allah had specifically chosen them based on their qualities and character of being good parents before blessing them with a child with autism. They also credited Allah for helping them understand more deeply what it meant to have a child with autism. These same parents felt a strong desire to protect their child because this child was not only theirs, but also Allah's.

**Negative Responses.** Just as children with disabilities can be viewed as a blessing from God, other more negative viewpoints exist as well. Some parents of children with profound disabilities, not related to specific religious background, described their experiences as being “bleak and stressful” with regard to family resilience (Brett, 2002). For some Muslim families in the United Arab Emirates, the idea of tragedy can be

heavily applied to them if they have a child with a disability (Crabtree, 2007). Mothers in particular can receive harsh consequences because it is the mother that brought the child with a disability into the world. This particular thought is experienced by Arab Muslim mothers as well as by Pakistani and Bangladeshi Muslim mothers in the United Kingdom. Mothers in the United Arab Emirates also experience fear of rejection from their husbands because of bringing a child with a disability into the world. Other negative experiences of parents of children with disabilities in the United Arab Emirates include a mother being told her child is a second-class citizen, a baby being removed from an incubator when it was determined its life was not worth surviving, and an Imam being angry when he saw a boy with a disability out in public (Crabtree, 2007).

Although maybe not as harsh as some of the negative experiences in Arab countries, there are still negative experiences related to religion in the United States. About half of the Christian respondents in Poston and Turnbull's qualitative study (2004) shared the challenges they faced when attending church with their child with a disability. Some felt as though their child was rejected by others in the church; some of the churches simply did not have the appropriate facilities to adapt to their child's needs; and still others felt they their needs were not supported by the church.

***Negative beliefs of causality of disabilities.*** There are many other negative beliefs surrounding disabilities, but these are specifically connected to reasons why disabilities exist. These beliefs include the idea that children born with disabilities are usually connected to misfortune, sent to a family either by deity, fate, or karma, and/or connected to personal sin (Miles, M., 2002A). Beyond religious meanings, some parents consider their socio-cultural characteristics or lack of education as causes for a disability



(Kleinman, 2006). A child being born with a disability may also be connected to folk explanations. These include, but are not limited to Turkish mothers suggesting that God and Fate, the Spell, the Evil Spirit, and becoming pregnant on Holy days as reasons why their child was born with a disability (Diken, 2006). Still other reasons that parents would assign to why they have children with disabilities include simply making up stories (i.e., he fell off the roof, when he was 2 years old, therefore it is not my fault), or feeling that there is something fundamentally wrong with themselves, even spending their time putting blame on others for their children's disability (Miles, C., 2002).

More harsh explanations for the reason for disabilities are experienced in Asian Muslim families in the United Kingdom (CIO, 1986 – in text, Ali, Fazil, Bywaters, Wallace & Singh, 2001) and Kenyan Muslim families (Hasnain, 1993) where they feel a curse has been put on them or they are being punished for some sin they have committed. Some Muslims in Pakistan (Miles, C., 2002; Miles, M., 2002B), Turkey (Diken 2006), and Egypt (Endrawes, O'Brien, & Wilkes, 2007) believe that djinns (evil spirits) are the reason behind the disabilities of their children.

Other beliefs, attitudes, and behaviors that exist in Muslim communities are demonstrated through these experiences from Christine Miles (2002). While living and working in Peshawar from 1978 to 1989, Christine Miles was the head of a school and counseling center which served people with disabilities. She came to know the local Muslims very well and also provided training to staff in many other centers. Through her experiences, she learned that females living in this society in Peshawar were dealing with the reality of marriage being more like a contract in that the woman would be financially well off if she produced healthy sons. If healthy sons were not produced by her, the

“contract” could be broken by the man at any time either through divorce or through the man taking on another wife (Miles, C., 2002). The fear of having a child with a disability was very real for these mothers; it meant their lives could change forever if a healthy child would not be birthed by them.

Finally, it is important to note that although attitudes and views held by different communities may be negative with regard to disabilities, one must have some perspective and realize that even though the studies and stories shared may reference Muslims, it could very well be more cultural thinking than religious-based thinking. Begum (1992 in text Ali et al., 2001) shares this perspective:

A lack of information and knowledge about disability leads people to formulate their ideas, opinions and expectations on the basis of myths and superstition. In many situations religious and cultural beliefs have become intertwined and confused. For example, the notion that Muslims believe that disability is some form of punishment is likely to be based on cultural rather than religious grounds, because in Islam disability is not seen as a punishment but rather as gift from God. As in any other community there was a lot of diversity in the attitudes and ideas which prevailed, some being more positive than others (p. 62).

**Cultural and religious responses to disabilities.** Given the views mentioned previously, a mother may choose to keep the child hidden because of the shame and humiliation associated with it. If the child is disabled and female, even more stigma is associated with it and the mother’s and her child’s entire life may be spent hidden away (CIO, 1986 – in text, Ali et al., 2001). And although not as harsh, a 1987 report by the Greater London Association for Disabled People (GLAD), reported it was common that

Asian families would see disabilities as a stigma and that if a child had a disability; it was up to the entire family to care for the child rather than society's responsibility.

If a family cannot care for a child, there are other ways they may choose to deal with the disability that is seen as a curse or a punishment. These may include visiting a holy shrine, a "gila" or fakir" (equivalent to a "saint") to remove the curse or punishment so the child may live a normal life. Still other Muslims in Peshawar, would not hesitate to go to Christian institutions in hopes of getting help or even a cure because they have great respect for Jesus, especially his role as healer (Miles, C., 2002).

Additionally, some believe that if they take care of a person with a disability, they will go straight to heaven when they die; caring for and being connected to individuals with disabilities are considered by some to be the "gateway to heaven" (Hasnain, 1993). Miles (2002A) also found that people with disabilities can be regarded as being lucky, feared, or even holy. Nisa Hassan (1990) echoes this and says that in traditional Muslim culture the needs of children who are mentally handicapped can be met by other Muslims' gestures of seeking goodwill from Allah, not out of pity.

**Present day issues related to disability in highly Muslim concentrated regions.** Beyond present day religious and cultural beliefs or attitudes, there are current day issues and legitimate causes surrounding disabilities that are important to mention. These issues relate to geographic regions, cultural behaviors, and even governmental views and provide additional insights associated with causes for disabilities. Sheikka Hissa Khalifa bin Ahmed al-Thani, from Qatar, was a Special Rapporteur on disability of the United Nations Commission for Social Development for the period 2003-2005. Her work is provided for the World Programme of Action concerning disabled persons

(retrieved from <http://www.un.org/esa/socdev/enable/diswpa00.htm> on October 17, 2011)

and provides important information for this review. Hissa Al-Thani shares that Arab countries are dealing with an increase in disabilities because of the tragedies of war; one statistic shows that with every death occurring from war three people are left with a disability. Furthermore, disabilities exist because of the accepted tradition of inter-familial and consanguineous marriages. Disabilities due to these familial connections stretch through the generations. Although not necessarily popular in all countries, this tradition is practiced in all of them (Thani, 2008).

Disabilities also exist because of the conditions present for mothers and their newborns in the poorest regions of the Arab countries – often including rural and agricultural areas. Poverty and illiteracy are prevalent in these areas and can lead to inadequate pre- peri- post- and neo-natal health care for the newborns of young mothers (Thani, 2008).

From her survey of individuals with disabilities in 18 Arab countries, Thani (2008) learned that these individuals continue to lack appropriate government support. The governments in these regions have standard rules related to disabilities, but have yet to implement them. These critical areas of need include raising public awareness about causes and prevention of disability, and the rights and potentials of persons with disabilities; passing legislation; gathering and using information and statistics on disability; supporting organizations of persons with disabilities, and ensuring their representation; and creating an accessible physical environment (retrieved from <http://www.un.org/esa/socdev/enable/diswpa00.htm> on October 17, 2011). Thani found that within these 18 Arab countries, the notion of disability is not being recognized.

Without proper recognition of disabilities it is more difficult for these Arab countries to gather accurate and reliable data in order for programs and services to be put into place to meet the corresponding needs. Societies within the Arab countries are unlike many Westernized societies in that they are more family- and- community -centered rather than individualistic in nature. It is commonly believed that families will simply take care of their own members; therefore government sources are not a necessity (Thani, 2008). Persons with disabilities living in a society with a government that does not support them, along with living in cohesive family units have a forced integration of sorts.

### **Contemporary Islamic Practices and Issues Related to Disabilities**

Thus far, positive and negative religious and cultural attitudes, beliefs, and behaviors towards disabilities have been shared as well as some basic teachings of Islam. So, how do these two areas of thought come together in the 21<sup>st</sup> Century? The marriage of these ideas will be reviewed in this section.

The Qur'an includes specific teachings and some verses which directly relate to disabilities. One particular verse (24:61) addresses people who are lame or blind. The verse provides specific instruction that no blame is to be attached to these people (and includes a list of other conditions or situations unrelated to disabilities). Yet, Crabtree (2007) provides information that some Muslim parents feel as though they have been punished when they have a child with a disability. These families feel excluded because of actions and words brought upon them from other Muslims in their communities (Crabtree, 2007). However, when reviewing this particular verse with the instruction to not blame these individuals, the Qur'an reverses earlier customs people may have had

about superstitions, and even today, encourages the inclusion of people with disabilities into society (Bazna & Hatab, 2005, p. 17).

Another positive Islamic teaching relates to one of the five pillars of Islam, zakat. An example of zakat as shared by M. Miles (2002B) is that a local Muslim committee in Pakistan decided that zakat could be used to pay a special teacher to help children with severe disabilities rather than just pay for “Food, Soap, Clothing, Textbooks” (p. 60) (which was the normal restriction for zakat). The committee determined it was the same as purchasing textbooks and was therefore accepted.

There are other ways where Islam directly addresses the needs of people with special needs. Some hadith provide examples of religious teachers giving “feeble-minded” students two or three opportunities to learn something and to be able to take notes (Tritton, 80, 81). M. Miles (2002B) feels this is a good example of how sensitivity to learning abilities could play a role in religious teaching. And although memorization of the Qur’an is an expected step for all Muslims to take, there is evidence that a notable historian and sociological theorist Ibn Khaldun, (transl. 1958, III:303-304) had concerns about the “inappropriately advanced and restricted curriculum, i.e., study solely of the Qur’an” (Miles, 2002, p. 87).

Miles (2002) provides another reason for Muslims to be encouraged about their children with disabilities as it relates to Islam. When they hear different stories of Muhammad being involved with individuals who were blind or who had other disabilities they can be assured that having a child with a disability is nothing new and that even their Prophet Muhammad was personally involved with individuals with disabilities.

When a society is deeply rooted in their religious beliefs, such as Islam, it is critical to use the tenets of the faith to help with social change such as attitudes and discrimination towards persons with disabilities as well as the advancement towards appropriate accommodations and services. With Thani's (2008) work for the United Nations in advocating for the rights of persons with disabilities in Muslim communities, she depends on prominent Muslim scholars to help her cause by connecting the Islamic faith to specific issues with disabilities.

Although negative attitudes towards disabilities such as curses, shame and financial challenges are not as common as they were a decade or more ago, it is important to recognize the importance of raising awareness in the Arab region because the attitudes do still exist (Thani, 2008). Again, Thani depends on Muslim scholars to help in this work so that people see a direct connection to the Islamic faith rather than misunderstood cultural beliefs.

While there are some wonderfully positive elements of Islam and its connections to disabilities, it can still be challenging for professionals working with Muslim families to try and move beyond some of the negative beliefs and attitudes associated with disabilities as those seem to be most prevalent. The professionals who worked with Christine Miles in Peshawar often tried to make connections to Islam and explain to families that if the child's disability is the will of Allah, then it is also the will of Allah to manage whatever condition the child may have. These professionals argued that it would be important to use any available information, i.e., support from special schools or centers, to help the children and if not used it would basically be demonstrating to Allah that the support He has given them is not welcomed or appreciated (Miles, C., 2002).

**Contemporary issues in the United Kingdom.** Communities of Muslims in the United Kingdom are experiencing both negative and positive outcomes for families with children with disabilities. Raghavan and Waseem (2007) conducted a service mapping technique to determine the scope of support available, type of services, and degree of contact with professionals of 35 young people with learning disabilities from Bangladeshi and Pakistani communities in Northern England. Semi-structured questionnaires were used with these 35 young people and their caregivers. Two key themes emerged from the study: (1) types and range of services accessed by Pakistani and Bangladeshi families and (2) the key barriers faced in accessing and utilizing services. More than 70% of families were utilizing general health care providers in the mainstream, but only 23% of the families utilized mental health or behavior services even though all participants were reported to have a behavior/mental health problem. Half of the families utilized social services for benefit and domiciliary support and more than half of the participants accessed voluntary services for a support worker for day and leisure activities. Using religious or traditional healers from the Muslim community was an important service accessed by 16 of the 35 families. These involved Imams from local mosques or religious healers in Pakistan and Bangladesh.

Raghavan and Waseem (2007) found that some of these families had great concern over what other people might say about their child with a learning disability and therefore did not openly seek support. Within this community there is a close relationship between the families and a negative stigma of one's own family is to be avoided. Families will even take extra steps in order to keep the disability of a child secret. Although most of the families sought out help and support in some way or another, they



felt frustrated with the lack of activities available for their children. The activities that were available were not accessed because families felt the activities were inappropriate based on cultural and religious beliefs and/or because of language barriers. However, there were other instances where activities were simply not readily available, or were not known about. The most common support was that of volunteers working specifically for the South East Asian community. There were several instances where the voluntary support was of limited benefit because the volunteer had no understanding of the Bangladeshi and Pakistani cultural and religious backgrounds (Raghavan & Waseem, 2007).

With limited literature available on Bangladeshi and Pakistani children with disabilities in the United Kingdom (Raghavan & Wasseem, 2007; Ali et al., 2001), this researcher looked to a popular online Muslim lifestyle magazine, *emel*, and found some anecdotal stories related to Muslim children with disabilities that took place in the United Kingdom. A particular issue from April 2011 provided articles related to Muslims with disabilities.

It was found that parents of Muslim children in the United Kingdom have a great desire to have their children learn and recite the Qur'an regardless of whether their child happens to have a disability (*emel*, 2011, Retrieved from: [http://www.emel.com/article?id=86&a\\_id=2409](http://www.emel.com/article?id=86&a_id=2409)). When their child has a learning difficulty of some kind some parents are told by teachers of the Qur'an that their child can no longer attend Islamic school to learn the Qur'an because these teachers do not know how to help the child (*emel*, 2011).

Although most Muslims closely follow and live the teachings of the Qur'an, which includes reciting the Qur'an in Arabic, there are times when the teachings need to be modified. In the Greater Manchester area of the United Kingdom, the Bolton Council of Mosques works hard at providing all children what they need in order to learn the Qur'an (*emel*, 2011). Learning to recite the Qur'an in Arabic is a goal for most Muslim individuals, but it can be a challenging ritual for some children with disabilities (Jegatheesan et al., 2010). At the Bolton Council of Mosques no child is turned away, but they readily admit, it is hard to find enough resources to meet the individual needs of all children. All of their teachers are professionally trained to meet the needs of children with learning difficulties, but because of the high number of students in a class, it is not always easy. They continue to do the best they can with the resources they have (*emel*, 2011).

Other positive experiences for Muslim students with learning difficulties occur throughout the United Kingdom. At the Islamia Primary School in London, the United Kingdom's first Muslim primary school, Najma Merchant is passionate about meeting the needs of children with learning difficulties. Not only does she help the children learn and recite the Qur'an, but she is also the school's Inclusion Coordinator. While using appropriate teaching strategies, Najma has seen children succeed in reading, reciting, and loving the Qur'an (retrieved on July 14, 2011, from [http://www.emel.com/article?id=86&a\\_id=2409](http://www.emel.com/article?id=86&a_id=2409)). When reviewing what Muslim parents shared in Jegatheesan et al.'s study (2010), it appears to be a similar goal they would desire for their children with autism (retrieved on July 14, 2011, from [http://www.emel.com/article?id=86&a\\_id=2409](http://www.emel.com/article?id=86&a_id=2409)).

Although it would seem there are many positive opportunities for Muslim students with disabilities in the United Kingdom, at least in the private schools mentioned here, there also exist issues related to parents admitting their child has a disability. A common issue among other Muslim schools in the United Kingdom is that many families do not disclose the fact that their child has a learning difficulty. In the United Kingdom, it can take years before a parent will actually acknowledge there is a problem even after a teacher addresses it (retrieved on July 14, 2011, from [http://www.emel.com/article?id=86&a\\_id=2409](http://www.emel.com/article?id=86&a_id=2409)). This may stem from the fact that parents do not want others to know about their child's learning difficulties because of how they feel the Muslim community will treat them (Crabtree, 2007).

Elyas Ismail combats these concerns by facing disabilities of Muslim individuals head on (retrieved on July 14, 2011, from [http://www.emel.com/article?id=86&a\\_id=2409](http://www.emel.com/article?id=86&a_id=2409)). He established Baseera in Northern London to meet the needs of Muslim students with learning difficulties. It was first established for blind children in the United Kingdom, but it quickly became apparent to Ismail that families from all over the United Kingdom were desperate for support for children with a wide variety of disabilities. Ismail understands the sensitive nature surrounding everything involved with a child with unique needs. He works closely with Muslim families helping them understand topics related to assessment and services in the public schools as well as encouraging them to make sure they know their child has a right to an Islamic education. He says, "Every single Muslim child has a right to an Islamic education and it should be possible to deliver this at their level of development and understanding" (retrieved on July 14, 2011, from

[http://www.emel.com/article?id=86&a\\_id=2409](http://www.emel.com/article?id=86&a_id=2409)). Although this is anecdotal data from a Muslim lifestyle magazine, the actions of these Muslims in the United Kingdom fit with viable research from Christine Miles (2002) and Bazna and Hattab (2005). Specifically, it seems evident that Elyas Ismail follows the teachings of the Qur'an. His heart reflects the idea expressed in Bazna and Hattab's (2005) research on the Qur'an when they concluded that Muslims are expected to always seek out opportunities to help the disadvantaged, advocate for their needs, and generously provide from one's own time and property.

There is other research conducted in the United Kingdom that provides evidence to contemporary concerns of Muslim parents of children with disabilities. In a national study of minority ethnic deaf people conducted by Ahmad, Darr, and Jones (1998) three stages of data were collected to provide a national overview of initiatives and services addressing the needs of minority deaf people and their families. It was determined that the achievement and preservation of a Deaf identity was at the expense of losing ethnic and religious identity. They experienced marginalization in their ethnic and religious communities because of language barriers; and although it was easier to make alliances within the Deaf community they also experienced some racist marginalization in the white Deaf society.

Many parents of these deaf children living in England feared the loss of their cultural and religious identities in their children. They felt their children identified more with being British rather than being Bangladeshi or Pakistani. If these parents pressure their children too much about culture and religion, they fear the children will choose to leave the home.

Other concerns noted from Ali et al. (2001) state that individuals who are disabled and have a different ethnicity other than white face challenges in both areas of racism and ablism. The disability movement in the United Kingdom has done much for people with disabilities, but it has not accounted for the differences that exist in these individuals with disabilities. Ali et al. (2001) additionally express that Muslims with disabilities may also experience sexism and classism.

**Contemporary issues in the United States.** Muslims with disabilities living in the United States are experiencing some similarities and differences as those living in the United Kingdom. Although Islam has a professed ideology of inclusion, this is not necessarily experienced in the mosques located in the United States. The exclusion of congregants with disabilities from the mosques reflects limited awareness of understanding the needs of people with disabilities (Bazna & Hatab, 2005). The challenge that exists is that of changing these attitudes so that people with disabilities will be supported as equal and contributing citizens of their community.

Another belief that exists in some American Muslim communities is the idea that wearing good luck charms will remove a disability (Khedr, 2006). Further, many families who have the financial means bring their children to the United States with the hope of finding a cure for their child's disability (2006). It is common for the beliefs and attitudes that were present in Muslims' lives in their native countries to still persist upon arrival in America or European countries.

Even though some traditional beliefs and attitudes still exist upon arrival in America, many Muslim families are sensitive to and supportive of the needs of children with disabilities. It is common that rather than being treated in a special way, children

with disabilities are treated like any other children. It is expected that children with disabilities will participate in education and social life like everyone else (Bywaters, Ali, Fazil, Wallace, & Singh, 2003, p. 503). This inclusiveness fits well with the teachings of Islam.

What does having a disability mean in the practical sense for Muslim families from developing countries in the 21<sup>st</sup> century? Many Muslim families do not look at a disability the same way it may be viewed in developed nations such as the United Kingdom and the United States. In these countries, it is common that a disability is viewed as some kind of cognitive deficit determined from standardized testing. Rather, the Muslim individual's ability is based on what he or she can do for the family or the community. Many Muslim immigrants and refugees are illiterate and therefore may not be concerned with a teenager not being able to read. The issue for the family comes if and when a child's abilities inhibit them from taking part in family or community activities such as serving tea, selling fruits and vegetables, or making polite conversation (Hussain, 2003). This particular example demonstrates that "concepts of normalcy are not universal and that impairment must be seen in its social and cultural context" (Hussain, 2003, p. 111). Since these beliefs contrast with educational processes in the United Kingdom and the United States, this can become a concern in the schools because identifying disabilities may be ignored.

### **Religion's Connection to Special Education**

Specifically in the field of special education, there are several laws in place to ensure students and families are involved in the process of identifying students with disabilities, in addition to the professionals who are involved. In the United States, these

include the Americans with Disabilities Act (ADA, 1990), the Individuals with Disabilities Education Act (IDEA) Amendments of 2004, and Section 504 of the Rehabilitation Act of 1973. In the United Kingdom, there exists the Warnock Report (Retrieved December 28, 2011, <http://www.educationengland.org.uk/documents/warnock/warnock20.html>). However, none of these laws include specific guidelines as to where religion fits or what the boundaries should be between families and educators (Lord Nelson, Summers, & Turnbull, 2004).

Although not specific to special education, there is a deep history connecting Islam and education. The Muslim Council of Britain (Bari & Alam, 2007) created a guide for British schools in order to meet the needs of all Muslim students. The document provides a practical guide and short Islamic history for all teachers who teach Muslim students. The guide addresses the fact that Islam has always had its roots in religion and education.

Knowledge and learning has traditionally been divided into two categories - revealed knowledge (Qur'an and Prophetic sayings) and acquired knowledge (natural sciences, physics, astronomy, history, mathematics etc.) and the pursuit of both has historically been a preoccupation of Muslim scholars. Empowered with this open-minded attitude to knowledge and learning, Muslims were able to absorb and assimilate the various contributions of the Greek, Roman, Persian, Indian and Chinese civilisations (Bari & Alam, 2007, p. 11).

As seen through this example, Islam has always been amenable, or embraced education. This connection is important because as more knowledge is learned about disabilities, the

Islamic community may recognize the need for specifics related to disabilities and therefore families may feel more supported. Although this guide is specifically for education professionals, the history behind it is not. If Muslim parents of children with disabilities feel their needs are important to the Islamic community, they may be more likely to seek and know what support their child requires.

**Legal requirements for parents - United Kingdom.** The basic provision for parents in the United States, as stated in IDEA, requires that the student's parents must be members of the evaluation and individual education program (IEP) teams (20 U.S.C. Sec. 1414(d)(1)(B)). They have the right and responsibility to be a part of each step of the process from diagnosis of a disability to educational programming for their child.

In 1978 the Warnock Report was written in the United Kingdom providing guidelines for the education of children with special needs. This report recommended that children with special needs be educated in the local schools, but it did not require it. The report included information for parents, but there was never a requirement that parents give any kind of permission for services such as assessment and putting a plan in place. Parents were given information on special schools and special services, but it was laid out that permission from them was not required. An important recommendation in this report is that parents' anxieties concerning their child's potential disability should be taken seriously by the professionals and followed up by supporting the parents (Warnock Report, 1978).

Although parents in the United Kingdom have the right of appeal to the appropriate Secretary of State against a decision by a local education authority to record or not to record their child as in need of special educational provision (paragraph 4.74),



there are limited other steps in the Warnock Report that require participation by the parents. They do have opportunities to give input on their child's needs (paragraph 4.60) and they should be given access to the documents on record of their child (paragraph 4.70). Additionally, one person should be designated as the Named Person to provide a point of contact for the parents of every child who has been discovered to have a disability or who is showing signs of special needs or problems (paragraphs 5.13 -14). This Named Person may change once a child has been assessed and will likely then be someone who works with the child (paragraph 5.15). It is important for reinforcement and skilled support to be provided for parents of children with disabilities or significant difficulties in the earliest years. A range of different forms of such support should be available in every area (paragraphs 5.31-32).

The Special Educational Needs and Disability Act of 2001 (Retrieved from <http://www.legislation.gov.uk/ukpga/2001/10/contents>) updated the Warnock Report. Some of the changes include: a stronger right for children with SEN to be educated at a mainstream school, new duties for Local Education Agencies to arrange for parents of children with SEN to be provided with services offering advice and information and a means of resolving disputes, and a new duty on schools and relevant nursery education providers to tell parents when they are making special educational provision for the child (Department of Education UK website, retrieved December 26, 2011).

**Legal requirements for parents - United States.** Although parents have these rights, a concern may arise if a family's belief system is different from the common belief systems known to the school. With growing numbers of Muslim students in American schools receiving special education services, it is important to know that the Individuals

with Disabilities Education Act of 2004 connected religion and spirituality to its overarching goals and quality of life outcomes (Poston & Turnbull, 2004). The educational planning, therefore, for students with disabilities should include how his/her religious or spiritual background will affect his/her quality of life as it relates to the disability. This brings further light to the fact that a deeper understanding of the Islamic belief system is necessary given the growing percentage of Muslim families in the United Kingdom and the United States, specifically Minnesota.

Beyond the basic involvement expected of parents, Turnbull, Turnbull, Erwin, and Soodak (2006) point out seven basic roles that parents have played in the education of their child with a disability. These include:

1. Parents or families as the source or causes of their children's disabilities,
2. Parents and families as members of family-centered, family-directed organizations that exist to satisfy families' needs,
3. Parents and families as developers of services for their children, including education, recreation, residential, and vocational services,
4. Parents and families as the relatively passive recipients of professionals' decisions, as the second (and less active) party in the principle of deference to expert opinion,
5. Parents and families as the follow-through educators of their children, as auxiliary teachers who are expected to carry out school-planned education and other interventions,

6. Parents and families as political advocates, as the primary constituency behind laws such as IDEA and others that create rights or entitlements or protection from discrimination,
7. Parents and families as education decision-makers, as partners with educators in developing “I-plans” and helping to carry them out – this being the current role envisioned by IDEA (p. 293).

An eighth and new role is also being considered from the most recent passage of IDEA in 2004. The role being that of “decision-maker partner role: parents, family members, and professionals as trust-driven collaborators” (Turnbull et al., 2006, p. 293). This new, eighth role digs in more deeply into the idea of a relationship between team members where trust is the most important element (Turnbull et al., 2006, p. 293).

The seventh and eighth roles fit nicely with this study in that Muslim parents should have a voice in the decision making of their child’s education. If educators understand a bit more about how parents’ Islamic faith plays a role in their lives, a true partnership is more likely to happen.

**Parent participation.** As learned earlier, parents may initially view their child’s disability as a punishment from God, but Shah (1995) makes a clear point that these feelings are fleeting once parents begin to accept the situation and seek help from appropriate providers. Once the parents are ready to accept help from the educational providers, there should be an element of trust based on what Shah (1995) and Jegatheesan et al. (2010) found in their work.

Trust is a critical piece because a Muslim family will likely have differing opinions from those of the professional(s) on what is good and necessary in order for

their child to progress. One example provided from Jegatheesan et al. (2010) is that traditionally, children with autism are given very specific structures in which to attain different life skills. These may include, but are not limited to (1) having a visual daily schedule that is followed and the visuals changed when necessary; (2) using a communication method of some kind; and (3) completing tasks in a structured format. Other recommendations made to families included ways to provide quiet areas in the home for the child, have limited people surround the child, and use only one language with the child, preferably English. Muslim parents of children with autism felt that meeting these specific requirements would undermine their religious beliefs and their critical family obligations (Jegatheesan et al., 2010), therefore causing frustration towards the school. It is not clearly defined whether some of this frustration could have been alleviated for the family had there been a relationship built on trust, and the family felt listened to.

There are other issues beyond building trust. Many minority families may miss out on critical services for their child because of language barriers or the fear that their cultural needs may be ignored (Lo, 2012). When language barriers exist, parents may miss out on opportunities for choice of school and assessment of their child. When contemplating respite or child care centers in order to help their child with a disability, parents often would not bring their child to these centers because of issues such as the potential of males working with their female children, halal food not being provided, and daughters possibly interacting with peers of the opposite sex (Shah, 1999, in text Ali et al., 2001). Shah found that when social service agencies lack understanding and cultural sensitivity towards their clients, they are not likely to be effective. Furthermore, it is the

‘poor communication’ between parent and service provider that leads to ‘misunderstanding and alienation’ (Shah, 1999, p. 9, in text Ali et al., 2001).

Misunderstanding can happen for parents no matter the age of their child with a disability. A team of researchers set out to learn more about families and how they adapt when a child has a disability. Raghaven, Weisner, and Patel (1999), conducted a study to investigate South Asian family adaptation patterns to children with developmental delays. They met with 10 Hindu families who lived in California. Their meetings consisted of two hour interviews as well as having the parents fill out questionnaires on the related topic. This team of researchers compared their findings to Euro-American Families taken from the Child Project sample (Gallimore, Weisner, Kaufman, & Bernheimer, 1989; Gallimore, Weisner, Guthrie, Bernheimer, & Nihira, 1993; Gallimore, Coots, Weisner, Garniers, & Guthrie, 1996; Nihira, Weisner, & Bernheimer, 1994). Adaptations were made from the Child Project methods by adding key questions to fit South Asian families from India.

Some of the critical differences between the South Asian families and Euro-American families included: (1) South Asian families have a hard time finding help they would normally get from family arrangements if they lived back in India; (2) there are big challenges for South Asian families to find child care that is culturally sensitive as well as finding adequate social support; (3) Hindu or other religious and spiritual practices are prominent in certain situations, but formal worship is less important; (4) services and care found in America are rich when compared to South Asia; families recognize they likely would have had nothing comparable there; (5) mothers chose to stay home with their children and accepted this quite easily; and (6) relationships with

spouses improved in nearly all of the families because of having a child with developmental delays.

Just as it is important to realize how different families adapt to having a child with a disability, it is also important to realize the critical role they play once a child is identified and receives special education services. According to PL 94-142 and the Warnock Report, parents should have a voice as decisions are made for their child and the natural place for this to occur happens during Individual Education Program (IEP) meetings when goals for the child's future are being discussed. In relation to the four IDEA goals of (1) equality of opportunity, (2) full participation, (3) independent living, and (4) economic self-sufficiency for individuals with disabilities (Turnbull, Turnbull, Wehmeyer, & Park, 2003), students with disabilities, with the help of their parents, should be able to determine what is important to them with regard to their religious practices. If being an integral part of a faith community is important, then special education professionals should help guide these individuals so they can fulfill these goals (Ault, 2009). It is important that learning and social opportunities for students with disabilities happen in natural settings; in the context of religion these opportunities should exist in churches, synagogues, temples, or mosques. A natural setting for the personal development of students with disabilities in relation to religious beliefs should take place at individual places of worship where specific activities relating to their personal interests are taking place (p. 187).

**Parent advocacy.** One way for parents to feel heard is through the help and support of other parents. Because of the great advocacy work done by parents for the past 50 years in the United States, any parent who has a child with a disability, regardless of

cultural background, can access support through a variety of advocacy programs specific to helping them as a parent. Although some cultural groups are represented by parent advocacy groups, information is lacking in this area. Any parent can still access these advocacy groups, but support may not be available for their specific cultural or religious needs.

One such advocacy group is the Parent Advocacy Coalition for Education Rights, or better known as PACER. The PACER Center was developed in Minnesota in 1976, one year after PL 94-142, Education for all Handicapped Act, was signed into law. PACER's mission is "to expand opportunities and enhance the quality of life of children and young adults with disabilities and their families, based on the concept of parents helping parents" (retrieved July 18, 2011 [www.pacer.org](http://www.pacer.org)). Similarly, The Arc of Minnesota is another advocacy group for parents with their mission being "to secure for all people with intellectual and developmental disabilities and their families the opportunity to realize their goals of where and how they live, learn, work and play" (retrieved from [www.arcgreatertwincities.org](http://www.arcgreatertwincities.org), July 18, 2011).

The Warnock Report in the United Kingdom, also provides insight to the importance of parent advocacy. It states that parents of children with disabilities or significant difficulties should be informed at an early stage about available organizations to help and support them (paragraph 5.19). In the United Kingdom, all local authorities (LAs) have a duty to provide information, advice, and support to parents of children with SEN. This should be provided by dedicated staff working separately from the Local Authority's Special Education Needs team so a parent is assured that the advice and information is impartial, and that the people they are receiving it from are not involved in

the SEN decision making process. Some parent partnership services are based in the voluntary sector but most remain within the LA. Most services also offer access to Independent Parental Supporters (IPs) who are volunteers trained to provide individual support to parents. The parent partnership services provide support in all matters related to children with disabilities receiving services.

A list of five different parent partnerships is provided on the United Kingdom Department of Education website (Retrieved July 20, 2013 <https://www.gov.uk/government/publications/special-educational-needs-sen-a-guide-for-parents-and-carers-revised-2009>). Each site, although different, includes specific areas of support for parents of children with disabilities.

Although it seems obvious that each of the organizations is readily available to support families who have a child with a disability in both countries, there is very little if any information on how a family's religious beliefs may affect how decisions are made in relation to their child's disability. Given the fact that religion often plays a role in families' quality of life indicators (Poston & Turnbull, 2004), it seems then that religious ideations ought to be considered when providing services or support to families.

When searching the different advocacy groups' websites for information on anything related to religion, limited information was found on religion in general and no information was found specific to Islam. The Arc website ([www.arc.org](http://www.arc.org)) had a list of resources on including people with disabilities in faith communities. This list had 84 different resources of which 82 appeared to represent Christianity (terms used were Christianity, Christian, or church) and two which were specific to the Jewish faith (terms used were Jewish and synagogue). To dig deeper, specific contact was made to four



common parent advocacy groups including: PACER and The Arc in the US; and Nasen (Retrieved on July 19, 2013 <http://www.nasen.org.uk/links/>) and National Parent Partnership Network (retrieved on July 19, 2013 <http://www.parentpartnership.org.uk/>) in the United Kingdom. Contact was made requesting information on whether or not they provided any resources for Muslim families specific to their Islamic beliefs, in which no answer was given by PACER, Nasen, and the National Parent Partnership Network. The Arc responded, but shared that no information was available.

Although Christianity has been the largest religious group in the United States (Pew Report, 2010, Retrieved December 28, 2011 <http://religions.pewforum.org/reports/>), it is clearly not the only religious background of families with children with disabilities. Christian families have access to specific Christian-related resources when trying to find help and answers about their child with a disability (common sources included Joni and Friends ministry at [www.joniandfriends.org](http://www.joniandfriends.org) in the United States, and Prospects ministry at [www.prospects.org.uk](http://www.prospects.org.uk) in the United Kingdom), but for other religions it is more difficult and in some, such as Islam, it appears to be completely non-existent, at least according to Internet searches and phone calls made in the United Kingdom and the United States.

**Professionals and service providers in special education.** The original Warnock Report from 1978 provided strong statements related to the problem of professionals disregarding parents' anxieties and suspicions about their child's development. Even in the 1970s, it was clear that professionals needed to play an important role in the lives of children with disabilities who required special services.

Although special education teachers are required to have training in diversity, often this training does not include specifics on different religious belief systems (Poston & Turnbull, 2004), therefore giving them little or no background in understanding these important beliefs that can dictate everything a family does.

In Minnesota, teachers are prepared by institutions of higher education that follow standards of effective practice (SEP) (<http://education.state.mn.us/MDE/EdExc/StanCurri/index.html>). Within standard 3, which covers issues surrounding diversity, there are eight specific SEPs that address needs surrounding topics covered in this study. They include:

- 3D understand how to recognize and deal with dehumanizing biases, discrimination, prejudices, and institutional and personal racism and sexism;
- 3E understand how a student's learning is influenced by individual experiences, talents, and prior learning, as well as language, culture, family, and community values;
- 3F. understand the contributions and lifestyles of the various racial, cultural, and economic groups in our society;
- 3H. understand cultural and community diversity; and know how to learn about and incorporate a student's experiences, cultures, and community resources into instruction;
- 3J. know about community and cultural norms
- 3O. use information about students' families, cultures, and communities as the basis for connecting instruction to students' experiences;

3P. bring multiple perspectives to the discussion of subject matter, including attention to a student's personal, family, and community experiences and cultural norms;

3Q. develop a learning community in which individual differences are respected

(Retrieved December 27, 2011

<http://education.state.mn.us/MDE/EdExc/StanCurri/index.html>).

Beyond understanding the foundational elements of students from diverse backgrounds, it is also important to know how to build relationships with these families. Lord Nelson, Summers, and Turnbull (2004) express the importance of developing appropriate guidelines for relationships between families and professionals in order to maintain quality relationships. They conducted a study to learn the preferences of parents and professionals and what each thinks the boundaries should be. They studied transcripts from 34 focus groups and 32 individual interviews and determined three main themes related to boundaries:

(a) accessibility/availability (being reliably and flexibly available to families), (b) breadth of responsibility (going beyond strict interpretation of one's job description in working with families), and (c) dual relationships (fostering friendships, mutual support, or other roles in addition to a strict parent-professional relationship) (p. 153).

A code of ethics does not currently exist with regard to guiding teachers or families as to what the boundaries should be when working together. There are not any guidelines for either end of the spectrum – extreme conflict or basic everyday situations (Keim, Ryan, & Nolan, 1998).

Finally, Lord Nelson, Summers, and Turnbull (2004) stress the importance for educators to think through their own preferences when building relationships with families. It is necessary for each educator to think in advance how much they plan to put into relationships beyond what is required in their contract. Much self-reflection is necessary to know what can be provided during any given year. And although special education has a Code of Ethics put forth from the Council for Exceptional Children, and parent relationships are included in these, again no guidelines are provided as to what boundaries should look like between parents and professionals (Lord Nelson, Summers, & Turnbull, 2004).

It is important to note that cultural values play a significant role in how parents will develop relationships with professionals (Kalyanpur & Harry, 1999; Lynch & Hanson, 1998; Turnbull & Turnbull, 2001). A family's cultural values may determine how formal or informal they wish to be with the professional, whether the relationship is hierarchical or egalitarian, and whether or not it is close and personal or distant and professional

Dr. Fazil Rizvi (2005), a Professor of Education Policy, Organization and Leadership and Director of the Global Studies in Education online program at the University of Illinois at Urbana-Champaign, passionately argues that schools have great responsibility in understanding the ways of Muslim students. He challenges leaders to look beyond the historical and political representations of Islam and provide opportunities that open communication in ways that hear specific cultural voices, no matter how contentious they may be. There need to be safe places for these conversations to take place. The media is not helping with this in the United States or the United

Kingdom so productive conversations need to start somewhere. Rizvi (2005) talks with great concern about the different scenarios across the United States that have caused Muslims to be worried about where they stand in the United States. One example includes the fact that well-known Christian religious leaders have shared unnecessary anti-Muslim rhetoric.

Rizvi (2005) further discusses the importance of how current events outside of school inevitably affect the students back in school and may in effect silence the students. He says, “this must surely require intercultural dialogues that are both democratic and critical” (Rizvi, 1997, in text of Rizvi, 2005).

M. Miles (2002) suggests that in order for individuals to have appropriate resources when working with people from other cultures one should “study people’s cultures and their concepts of disability, so as to communicate appropriately” (p. 56). Understanding Muslim practices such as close-kin marriages may help professionals better understand what families may be facing with regard to the disability.

***Current recommendations related to religion and special education.*** Melinda Jones Ault (2009) did a thorough review of 69 different journal articles relating to religion and special education. The journal articles were selected based on the likelihood that professionals in special education would be exposed to the material. She determined this by choosing journals directly affiliated with the Council for Exceptional Children (CEC) because the CEC is the “largest international professional organization dedicated to improving educational outcomes for individuals with exceptionalities, students with disabilities, and/or the gifted” (CEC, 2005, in text of Ault, 2009) and special education professionals are a large portion of CEC’s audience. She categorized the 69 journal

articles into four sections: topic of the article, methodology used, subjects (if applicable), and reference to religion or spirituality. In her review, Ault (2009) found seven articles that had religion or spirituality as the main topic including (1) descriptions of how persons with disabilities could be integrated into religious institutions and what kinds of support were available; (2) spiritual characteristics of a particular culture; and (3) parochial schools and how special education is delivered within those schools. Beyond these seven articles, other individual topics relating to many aspects of religion shed light on the need for more teacher training. Some of these specific topics included whether or not a family's religious affiliation will affect IEP team decisions; the importance of making sure materials provided by a school district reflect all religions of that area, not just the common ones; connecting respected, local spiritual leaders with education professionals, in order to build trust; books being provided for teachers with explanations of different religions; and the need for teachers to be aware of their own religious bias. Each of these topics was covered in some capacity in the 69 articles reviewed by Ault (2009). Although each topic is important and it is positive they were covered in some small way, there is still a great need for more detailed coverage of each one and more specifically, detailed coverage of Islamic belief systems practiced by families with children with special needs.

Further indication that special education teachers need more training comes from Jegatheesan et al. (2010). They learned that teachers can play a major role in helping a parent see and accept their child's disability as something positive as long as the teachers understand the family's belief systems. Newton (1997) further argues that parents may be

more likely to have a positive view of their child's disability if their child's teacher would approach the parents and the child's disability with a positive attitude.

With parents and schools currently doing little to work together to recognize cultural and religious identities, students' individuality starts to fade away in terms of religion, language, country of origin and race (see for example, Atkin, Ahmad, and Jones, 2002). It seems it would be important for parents and schools to work together to remove this limited and/or non-recognition of individuality so that all families can be heard and their belief systems acknowledged.

It is thought that special educators and Muslim parents of children with disabilities would ultimately have similar goals for the child, but when there are broad misunderstandings of how a Muslim family perceives disability from a religious perspective, frustration builds on both sides and the process is halted (Jegatheesan et al., 2010).

When professionals meet with families to discuss specific strategies and interventions for a child with a disability, it is important to first learn about the belief and value systems of that family and to remember to focus on a child's strengths before talking about the deficits (Jegatheesan et al., 2010). If a professional does not implement this practice, they risk the all-out rejection of the strategies or interventions by the family.

## **Summary**

This chapter provided a review of the topics surrounding Muslim parents of children with disabilities. It covered current Muslim population data in the United Kingdom and the United States, which showed evidence of an increase in numbers in the past 20 years. This increase in numbers means that schools will inevitably serve Muslim

students; therefore education professionals should have an understanding of who Muslims are and how they believe. In order to do that, Islam and its basic tenets were presented along with how disabilities are viewed within the faith. This current study is specific to Muslims with disabilities, so connections to that were explored. A detailed review of Jegatheesan, Miller, and Fowler's work (2010) on three Muslim families with children with autism was provided to demonstrate the need for more research in this area. Jegatheesan et al.'s study demonstrated the importance of the parents' Islamic beliefs in their daily lives. To expand on this, religious and cultural beliefs, attitudes, and behaviors towards people with disabilities were reviewed from a historical context. Literature covering contemporary practices in Muslim areas of the world was also included. Finally, there were studies reviewed that showed the connection between religion and special education and why parent and school partnerships are so critical as well as professionals' knowledge of diversity and their approach to these families.

With the literature reviewed, it is clear that the topic of religion and special education is under-researched and it is especially lacking in the area of Muslim parents of children with disabilities. Further work is necessary in this area in order to better meet the needs of these parents.



## **CHAPTER 3**

### **Methodology**

#### **Background**

Religion can be an important foundation for parents raising children. Whether the religion is Judaism, Christianity, Islam, or any other religion, it can be one of the driving forces in parenting. Dependence on a family's religious beliefs can be even greater when they have a child with a disability (Jegatheesan et al., 2010). Parents may lean on these religious beliefs in order to find answers, support, and direction for raising their child with a disability. "There is growing recognition in research on children with disabilities that religious beliefs can play an important role in how individuals interpret and explain disability" (Jegatheesan et al., 2010, p. 98).

#### **Purpose of the Study**

The purpose of this study was to "generate...theory and contribute to knowledge for the sake of knowledge" (Patton, 2002, p. 10) in the area of religion, specifically Islam, and special education. Since there is limited information found on religion in special education, and even less found on Islam (Ault, 2009), it is a growing concern in the field of special education to have more knowledge on how Islamic beliefs affect a family's parenting decisions for the life of their child with a disability. Jegatheesan, Miller, and Fowler (2010) provided more specific findings on this need particularly as it pertains to Muslim families. After spending 17 months with three Muslim families, these researchers found that Muslim families parenting a child with autism depend and rely on their Islamic belief systems in all that they do in raising this child.

When a family's belief system is as integral a part of their lives as these three families shared (Jegatheesan et al., 2010), it is important that professionals understand these belief systems in order to know how to approach and work with the family. To continue to learn how Islamic belief systems affect Muslim parents with children with disabilities, further research is needed. This study replicated portions of Jegatheesan et al.'s work (2010) in that more Muslim parents of children with disabilities were interviewed. Additionally, Muslim parents were interviewed in two different countries addressing the need, as discussed by Jegatheesan and her colleagues (2010), to begin to understand similarities and differences among different sects of Islam, as well as similarities and differences when disabilities other than Autism are present and similarities and differences when different ethnic and cultural backgrounds are present.

### **Research Questions**

Since the most recently amended Individuals with Disabilities Education Act in 2004, the role of parents in the education of their child with a disability has increased (Turnbull, Turnbull, Erwin, & Soodak, 2006). With greater partnership expected between the school and the parents it is important that teachers have some background in understanding what is important to families and why (Jegatheesan et al., 2010). In the case of Muslim families, their Islamic beliefs direct and guide everything they do each day (Jegatheesan et al., 2010). Having a child with a disability does not change that. This work extended the study by Jegatheesan, Miller and Fowler (2010) and searched for more information related to the topic of Muslim parenting practices in a family with a child with a disability.

The research questions were replicated in part from Jegatheesan, Miller, and Fowler's study and are:

1. How do Muslim parents in the United Kingdom and the United States make sense of having and raising a child with a disability within their cultural and religious meaning systems?
2. How do Muslim parents desire that the schools work with them?

### **Research Design**

This qualitative study was phenomenological in its approach. "Phenomenological research is a method of inquiry in which the researcher identifies the essence of human experiences about a phenomenon as described by participants" (Creswell, 2009, p. 13). The process probed to understand the lived experiences of the participants and as such marked phenomenology as a philosophy as well as a method. The procedure involved studying a small number of participants through personal engagement to develop patterns and relationships of meaning (Moustakas, 1994). The phenomenon studied was how Muslim parents of children with disabilities bring meaning to raising their child based on religious and cultural expectations. This researcher sought to learn more about this phenomenon from the participants' experiences in order to determine patterns and relationships of meaning within the phenomenon.

A qualitative study was conducted so as to replicate, in part, and extend Jegatheesan, Miller, and Fowler's study (2010) in order to get a broader sample of their work. Patton (2002) gives specific support for qualitative research and states that "Qualitative inquiry is especially powerful as a source of grounded theory, theory that is inductively generated from fieldwork, that is, theory that emerges from the researcher's

...interviews out in the real world rather than in the laboratory or the academy.” (p. 11)

Brantlinger, Jimenez, Klingner, Pugach, and Richardson (2004), researchers in the field of education, define qualitative research as being “a systematic approach to understanding qualities, or the essential nature, of a phenomenon within a particular context” (p. 195). Given the fact that limited information exists in the area of how Islam affects parenting and education of children with special needs, qualitative research is appropriate because of the exploratory nature of this topic. The nature of the questions used in this study, and the potential contribution of the qualitative findings for further research and practice, provided additional rationale for the appropriateness of qualitative work.

Odom, Brantlinger, Gersten, Horner, Thompson, and Harris (2005) share a rich history of different methodologies that have been used throughout the centuries. They speak to the importance of using different methodologies within special education research; these include qualitative methods. These researchers contend that multiple methodologies are critical in special education research because of the complexity of the field. The history of utilizing multiple methods in special education research has resulted in the identification of sound practices (2005). Qualitative research is not new to the field of special education; in fact two centuries of qualitative research on topics related to special education exists (Brantlinger et al., 2004).

Qualitative research provides a way to study people in their natural surroundings and learn reasons behind why people do what they do. Merriam (1998) says, “Qualitative researchers are interested in understanding the meaning people have constructed, that is, how they make sense of their world and the experiences they have in the world” (p. 6).

A researcher utilizing qualitative measures has many different options in designing the research (Cresswell, 1998; Merriam, 1998; Patton, 2002). When reviewing basic or generic qualitative research, a general characteristic recognized with this type of research includes identifying patterns, such as themes and categories. This process was completed during this study.

Since it was this researcher's goal to study the phenomenon of how Muslim parents make sense of and raise their child with a disability, a qualitative study with semi-structured, in-depth interviews was conducted in order to have "conversation[s] with a purpose" (Dexter, 1970, p. 136, as cited in Merriam) wherein participants' experiences were documented. These conversations will provide important information for educators working with Muslim children with disabilities.

Qualitative research is known as acceptable research in the field of special education; there is extensive qualitative research contributing to the field (Brantlinger et al., 2005). Brantlinger and colleagues (2005) provide guidelines for researchers to use in order to ensure that the conducting and evaluation of the research is credible and trustworthy.

**Verification.** Establishing credibility up front is important so that the reader can trust the work that has been done (Brantlinger et al., 2005). Brantlinger et al. (2005) outline specific strategies to be used in qualitative research in order to establish credibility. Although they outlined 11 different strategies, the list here includes two of their strategies and the third strategy listed is addressed by Creswell (2009). Creswell considers these strategies as validity strategies. Each strategy used for designing this study is listed as well as how the strategy specifically fits with the study.

1. Member checks – having participants review and confirm the accuracy (or inaccuracy) of interview transcriptions... (Brantlinger et al., 2005,p. 201)

Following transcription of the interviews, the researcher provided interview transcripts via email or postal service to the participants in order for them to review and confirm the accuracy (or inaccuracy) of the transcription.

2. Peer debriefing – having a colleague or someone familiar with phenomena being studied review and provide critical feedback on descriptions, analyses, and interpretations of a study's results (Brantlinger et al., 2005, p. 201; Creswell, 2009)

This step was used in order to enrich the accuracy of the work. This strategy provided interpretation beyond the researcher and added validity to the findings. The peer debriefing this work was Abdisalam Adam: Somali Community Specialist, Director of Islamic Civic Society of America, Board Chair of Ar Al-Hijrah Mosque.

3. Clarifying Researcher Bias. This particular strategy is outlined by John W. Creswell (2009). He states that reflectivity is a core characteristic of qualitative research so this researcher reflected on and acknowledged her background, gender, culture, faith, and socio-economic origin because her interpretation of the findings were shaped by this.

**Reliability procedures.** In qualitative research, ensuring validity and reliability requires conducting the investigation in an ethical manner (Merriam, 1998, p. 198). The following procedures took place in order to ensure reliability was present in this study: (1) transcripts were reviewed in order to make sure obvious mistakes did not exist

(Gibbs, 2007); (2) intercoder agreement or crosschecking took place to determine agreement or coding of the text (Creswell, 2009); this step took place with another researcher within the same field of study; and (3) coding occurred multiple times in order to determine a level of consistency of the coding. Miles and Huberman (1994) recommend that the consistency of coding be in agreement 80% of the time for good qualitative reliability.

**Meeting high standards.** Finally, Brantlinger et al. (2005) outline suggested quality indicators necessary for qualitative research to meet high standards. They state that “quality indicators are distinct from, and perhaps more important than, standard credibility measures” (p. 201). They suggest different quality indicators for two types of qualitative research and two steps in the research process, including (1) interview studies, (2) observation studies, (3) document analysis, and (4) data analysis (p. 202). According to Brantlinger et al. (2005), using these indicators helps plan for qualitative research that meets high standards (p. 201). For the purpose of this study, quality indicators one and four were used and are explained in the following sections covering participants, data collection and data analysis. Brantlinger et al. (2005) further state that quality indicators should always relate to the research questions of particular studies (p. 202).

## **Participants**

One of the details associated with the quality indicators outlined by Brantlinger et al. (2005) includes the importance of appropriate participants being selected in that they are purposefully identified and effectively recruited, there is an adequate number, and a representative number of the population of interest. According to Creswell (2009), this is identified as purposeful sampling. Purposeful sampling was used in this study so that

individuals were selected based on their experience with the phenomenon being studied (Creswell, 2009).

Participants were selected from two schools in the United Kingdom and a total of four schools in the Twin Cities area of Minnesota in the United States. Head Teachers in the United Kingdom and principals in the United States were asked to help make connections with Muslim families with children with disabilities. However, no principals in Minnesota followed through with contacts; participants were found by a Cultural Liaison in a large public school district. Since the researcher was not personally connected with any of the schools, she depended on the Head Teachers and the Cultural Liaison to establish a participant-researcher relationship with the parents.

The researcher selected participants in an area southwest of London, England because of the high population of Muslim students from Bangladeshi and Pakistani backgrounds. The researcher selected participants in Minneapolis and St. Paul, Minnesota because of the high Muslim population of Somalis. The participants were selected based on their identification of being a Muslim parent of a child with a disability (mother or father). Specific disabilities were not sought as the pool of participants would have likely been too small. The criteria required that the child have a disability and this was determined by the Head Teacher and the Cultural Liaison who identified Muslim students who had disabilities in their schools. The final criterion was that the parents had to be willing to participate. Informed consent was obtained by the researcher and participation was completely voluntary (Appendix B). In order to extend the study conducted by Jegatheesan et al. (2010), where information was gathered from three families, in this study, seven participants were selected from the United Kingdom and four showed up for



the interview with the researcher. Five participants were selected in Minnesota and three followed through with the interviews.

Although having participants from a variety of backgrounds existed in this study, generalizability was not sought as generalization is used in a limited manner in qualitative research (Creswell, 2009) and with seven participants it is too small. Qualitative inquiry's intent is not to generalize findings to individuals, sites or places outside of those under study (p. 193). This qualitative study focused on particularity rather than generalizability since this researcher provides particular description and themes developed in the context of the participants' lives in Chapter 4 (Greene & Caracelli, 1997).

### **Data Collection Procedures**

**Instruments.** The main instrument in this study was the researcher as she was collecting the data as the interviewer for all participant interviews. She also analyzed the data once they were collected. An interview protocol was used (Appendix A) which included five main questions and additional probes as necessary to gather further information. The interviews were conducted face to face at location preferences of the participants. Public settings were offered, but the researcher also went to participants' homes when it was requested by them.

Interviews are a useful form of data collection when participants are not being directly observed (Creswell, 2009). They provide participants the opportunity to share historical information as well as allow the researcher control over the line of questioning (p. 179).

According to quality indicators outlined by Brantlinger et al. (2005), interview questions need to be reasonable by which they are clearly worded, not leading, appropriate and sufficient for exploring domains of interest (p. 202). The interview protocol (Appendix A) for this study was determined to be reasonable because the questions asked were considered clearly worded, not leading (Keller, Nevins, Wilson, personal communication, March 14, 2012), and provided data answering the research questions in this study. The interview protocol was pilot tested by the researcher with two Muslim individuals, one male and one female, in order to learn timing and question appropriateness. These Muslim individuals also identified any potential sensitivity issues of which there were none.

Further reasons demonstrating reasonability with the questions (Brantlinger et al., 2005) is that they were drawn from Creswell's (1998) conceptual framework in order to explore the informants' experiences of parenting a child with a disability within the religious constructs of Islam. There was an opening prompt followed by four specific questions with additional probes used as necessary. The interviews were intended to be no more than one hour in length in order to be respectful of the participants' time. One interview went over the planned hour; the participant shared many stories and much information beyond the questions asked.

The adequate mechanisms (Brantlinger et al., 2005, p. 202) used to record and transcribe the interviews included a digital recorder, a laptop recorder, and interviewer notes (Kvale & Brinkmann, 2009). The researcher practiced with the digital recorder and laptop recorder ahead of time in order to know optimal distance from the interviewee with the intention of getting the best sound quality. Immediately following the interview,

the researcher downloaded the interview from the digital recorder onto on a laptop computer as well as saved the laptop recording. Interview notes were compared with the digital recording and any necessary changes to the notes were made. Each interview was saved in two locations – the researcher’s laptop as well as on a flash drive. These items were in a secure location at all times. The interviews were transcribed by an experienced transcriptionist. The researcher reviewed the transcriptions of all seven interviews and compared them with the digital recordings in order to ensure appropriate specificity with the transcription (Kvale & Brinkmann, 2009). Additional checks were made in order to ensure accuracy throughout all interviews.

Different kinds of review from a variety of people took place following the collection of data. These reviews took place in order to represent the participants sensitively and fairly (Brantliner et al., 2005, p. 202). Participants had the opportunity to review the transcribed interviews. Only two participants responded to the researcher and they were satisfied with the transcriptions. Further, to ensure sensitivity in the actual report, Abdisalam Adam reviewed the report in order to check for specific sensitivity issues as they relate to Islam. He questioned one particular Arabic word, but upon listening to the audio recording, agreed with the researcher. A parent (non-participant) of a student with a disability reviewed the report in order to ensure sensitivity to parents of a child with a disability; no issues were found.

Further, Brantlinger et al. (2005, p. 202) outline the importance of sound measures being used to ensure confidentiality. Confidentiality in this study was assured through each step of the research process. Specific names and locations were not used. Participants were identified only as a mother or father. For data analysis, each participant

was assigned a number. The disability and age of the child was identified; the country and type of city was identified. Specific contact information has been saved in the private location of the researcher's laptop and flash drive in order to remain in contact with the participant for review of the transcriptions and report. Contact information was saved in a separate digital file with no label connection made to dissertation work. Contact information of participants will be destroyed following the approval of the study. A letter of gratitude and small thank you gift was given to each participant following the interview to show appreciation for their involvement in this work. A copy of the completed work will be provided so the participants will be able to see the results from their involvement in the study.

### **Data Analysis Procedures**

The analysis of data was completed according to the six step process outlined by John W. Creswell (2009). Creswell is a Professor of Educational Psychology and teaches courses and writes about qualitative methodology and mixed methods research (xxix). He has been at the University of Nebraska for 30 years and has authored 11 books, many of which are related to qualitative research. The six steps and how each one fits with this study are outlined here (p. 185-189):

1. Organize and prepare data for analysis. The interviews were transcribed and field notes were typed up.
2. Read through all the data. The researcher read through all the data in order to get a general sense of the information and reflected on its overall meaning. The researcher looked for general ideas from the participants' responses as well as the tone of their ideas. Additionally, she sought to get an impression of

the overall depth, credibility, and information that was used. At this stage, the researcher began recording general thoughts about the data.

3. Begin detailed analysis with a coding process. The researcher organized the material into smaller chunks or segments of text before bringing meaning to the information (Rossman & Rallis, 1998, p. 171). The material collected during data collection was segmented into categories; the categories were labeled with a term. This term was usually based in the actual language of the participant. Although there are several ways to determine coding, this researcher chose the traditional approach in the social sciences where she allowed the codes to emerge through the analysis of data. Codes were created by hand through notes, charts, and files.
4. Use the coding process to generate a detailed description of the people as well as categories of themes for analysis. This was done by charting each particular code in order to see the themes.
5. Advance how the description and themes will be represented in the qualitative narrative. A narrative passage with detailed discussion and visuals were used to convey the results.
6. Making an interpretation or meaning of the data. The researcher completed this final step by finding meaning of the data.

By following these six steps outlined by Creswell (2009, p. 185-189), another quality indicator is met because the methods are trustworthy and credible (Brantlinger et al., 2005, p. 202).

Once the data was collected, the researcher ensured the other quality indicators outlined by Brantlinger et al. (2005) were utilized for the analysis of data in this qualitative research study. These included sufficient rationale being provided for what was included in the report; conclusions that were substantiated by sufficient quotations by participants; and connections made with the related research.

### **Researcher Background**

Since 1996, the researcher has been working in the field of special education. She was an elementary special education teacher for six years, a secondary special education department chair for four years, a special education administrator for one and a half years, and for the six most recent years, she has been an associate professor in education (specific to special education) and the Program Director for a special education graduate program at a Christian liberal arts university. The researcher is Christian.

Through different professional interactions, the researcher began to do some work related to religious perspectives and special education. Initially, the researcher took part in religious-based conversations with professors from Qatar University. These conversations were the precursor to a poster session at the national Council for Exceptional Children conference in Washington D.C. where the researcher provided insight from a Christian perspective and her colleagues from Qatar University shared insight from an Islamic perspective. The researcher also hosted an Inter-Faith Dialogue of Christian and Muslim Perspectives in Special Education in April 2011 at Bethel University. Different educational professionals from the local public schools and universities attended this event. It was during this event when it became apparent to the researcher that there was a need to better understand Muslim families as they relate to

children with disabilities and/or special education. It is this association that created the research interest.

Since this researcher is Christian, it was important that she become familiar with Islam and the Muslim people. In order to further educate herself about parenting practices, child rearing, and religious practices of Muslim parents, the researcher visited Muslim Community Centers in England and Minnesota, spent time in schools with high populations of Muslim students particularly at the beginning and end of the school day when parents were likely to be present, and sought out other opportunities to simply communicate with and get to know Muslim families (i.e., took part in a Somali Community Event for Parents of Children with Disabilities).

Additionally, she read portions of an interpretation of the Qur'an with English translation of the meanings (Garnet Publishing, 2000) in order to become familiar with different sections of the Qur'an that relate to this study. This version of the Qur'an was also reviewed by Abdisalam Adam, a religious leader in the Muslim community who speaks Arabic, in order to verify its contents and the English translation. Additionally, the readings were done for the purpose of reflecting on any comments provided by respondents that referenced the Qur'an or their religious beliefs. However, no participants specifically referenced the Qur'an.

### **Ethical Implications**

Kvale and Brinkmann (2009) discuss the ethical issues at each stage in the research process. Ethical concerns were considered in the design of this study. One was that the researcher's faith background is different than the participants and bias could have been a factor if not closely monitored. As stated earlier, the researcher addressed

this through the study of Islam, getting to know Muslim people, and providing checks and balances throughout the work with a Muslim community member. Another was that parents disclosed information about their child's disability which is highly sensitive and could have entered into confidentiality issues. The letter of consent (Appendix B) addressed this issue.

Kvale and Brinkmann (2005) further discuss the importance of being aware of differences when interviewing participants across cultures. Since the researcher is not Muslim, it was important for her to be aware of Islamic beliefs in order to be sensitive to the participants during the interview process. As noted earlier, input was sought from both a Muslim male and female and guidance from devout Muslims was continuously sought throughout the study. Beyond input from these particular individuals, it was also identified in the previous section how the researcher became more familiar with the Islam faith and the people who practice this faith. These factors meet the expectations set forth by Kvale and Brinkmann (2005).

### **Potential Limitations**

Since the researcher is not Muslim and does not speak the native languages of the participants who were interviewed, there could have been some situations where the participants did not feel comfortable responding to the questions. This did not seem to be the case except for one parent who felt her husband would have had better words for the researcher (P. R. personal communication, January 18, 2012). Since the researcher sought assistance from individuals who knew the families, it helped with the trust of the parents towards the researcher. And although English was not the parents' first language in all



cases, the interviews were conducted in English. A translator was offered ahead of time, but declined by all participants.

Other potential limitations as described by Patton (2002):

Interview data limitations include possibly distorted responses due to personal bias, anger, anxiety, politics, and simple lack of awareness since the interviews can be greatly affected by the emotional state of the interviewee at the time of the interview. Interview data are also subject to recall error, reactivity of the interviewee to the interviewer, and self-serving responses. (p. 306)

Final limitations include the fact that specific ages of children with disabilities were not sought, and the length of time a child had been receiving special education services was not sought. These two items could have affected the degree of certain attitudes of Muslim parents and/or their willingness to share information with the researcher, although it did not seem to make a difference.

## CHAPTER 4

### Results

The purpose of this study was to investigate the religious and/or cultural factors that contribute to Muslim parents raising a child with a disability as well as to determine how they desire that their children's school would work with them. Seven Muslim parents who have a child with a disability were interviewed: four Pakistani Muslim parents from England and three Somali Muslim parents from Minnesota. The parents and children are referenced with numbers to help preserve anonymity. Because of the sensitive nature of disabilities, further anonymity will be used when referencing the schools and cities connected to each individual. The schools will be referenced as the level and type of school and the cities will be referenced by size and region, not actual names. The data shared in this chapter represent the participant results from the five interview questions as well as a preliminary analysis of how the responses connect to the two over-arching research questions.

Data from the participants demonstrate that Muslim parents do indeed rely on their faith at some level in every case. The parents shared personal connections to faith in response to three of the five questions asked, even though only one of the questions specifically asked a faith-based question. The parents were satisfied with current schooling situations in all cases with some dissatisfaction in earlier years. Details surrounding these issues will be specifically addressed in this chapter.

Within this chapter, background information of the participants and their children is included in order to give a clear sense of who these individuals are [See Figure 4.1]. It should be noted that since the first question simply asked the parents to *"tell me about*

*your son/daughter”* the background information for each family is not consistent from one parent to the next. This researcher will again attempt to provide as full a picture as possible with the collected data. This chapter further includes the responses from each parent which are summarized into themes that emerged within the context of each question.

In order to gain an understanding of whether or not faith and/or culture provides a context for Muslim parents when raising a child with a disability, it was important to find out some personal things about their children, as well as their experiences with the school and community [See Figure 4.1]. Their responses then led into the final question of whether it was their faith or culture that was more influential in the raising of their child. What follows the personal information about each parent and child is a detailed description of the parents’ responses to each of the five questions and the themes that emerged from their responses.

The final participant list included seven parents; three fewer than the minimum number originally sought. Three parents cancelled multiple times and when the researcher contacted them to reschedule, there was no reply. Further contact with new participants was attempted, but four different principals did not return calls the researcher made multiple times. These results represent the data gathered from four Pakistani Muslim parents in England and three Somali Muslim parents in Minnesota. Each participant will be identified as Parent 1 (P1), Parent 2 (P2) and so on.

### **Seven Muslim Parents of Children with Disabilities**

**Parent 1.** The first interview took place in England. Parent 1 (P1) invited the researcher to have the interview in her home. She greeted the researcher at the door with

a very pleasant demeanor, welcomed her and offered tea, which the researcher accepted. She wore a hijab, the traditional Muslim head covering. It was lightly covering her hair; she often readjusted it during the interview. The interview took place in the living room at a coffee table. The researcher sat on the couch; P1 sat on the floor near the coffee table. Tea was sipped by both the researcher and P1 during the interview. There were various Islamic images in the living room such as a ceramic book with a picture of Mecca on it. The mood was comfortable and easy conversation took place. P1 spoke perfect English, although it was her second language. The interview lasted 39 minutes.

She is a mother of a 12 year old son diagnosed with Trisomy 21, also known as Down syndrome. She is Pakistani; was born, married, and started her family in Pakistan. The family moved to England when her son with Down syndrome was a young boy. She lives with her husband, one teenage son, and Child 1 (C1), her son with the disability. The family lives in a city with around 100,000 people in the South East area of England. Their immediate neighborhood is made up of families that come from a variety of diverse backgrounds living in attached single-family homes. Although not working at the time of the interview, P1 is a licensed English teacher. She has chosen to stay at home to manage the needs of C1.

The family is Muslim and practices their Islamic faith daily. The father attends the mosque each week. The other family members attend the mosque during special times of the year such as Eid.

Her son, C1, is picked up by a taxi each day at 7:45 a.m. and rides for about a half hour to get to a school for students with special needs. He returns home each day the same way by 4:00 p. m. He is in Year 7 and attends classes with eight other students.

There is one lead teacher and two assistants. In addition to academics, C1's school day includes Speech Therapy, Occupational Therapy, and swimming. Some students live at the school; P1 says "I can't bear to be apart from him. I can't do that."

**Parent 2.** The second interview took place in England. The interview with Parent 2 (P2) took place at a school in the office of the Head Teacher (principal). The room was small with four chairs; it was noisy in the hallway as children were heading to their classrooms. Because of the noise, the door was closed which made it feel more crowded. P2 appeared comfortable and sat with a calm demeanor. Once the interview started, he used a lot of different hand gestures when responding to the questions; he laughed at various times. His voice was very loud throughout the interview. He answered his mobile phone during one part of the interview. P2 spoke English throughout the interview although English was his second language. His thick accent made it difficult for the researcher to understand some parts of the interview. The interview lasted 54 minutes.

P2 is a father of several children ranging in age from early 20s to age seven. His youngest daughter, (C2) is seven years old and has learning difficulties. A specific disability was not identified, even with prompting, and because of confidentiality the researcher did not ask the Head Teacher what the disability was. However, the researcher knows the parent was asked to do the interview because he is a father of a child with an identified disability. The family lives in the immediate vicinity of the school where the neighborhood is made up of mostly Pakistani families with a few other ethnic backgrounds included. The neighborhood is in a city in South Eastern England with approximately 80,000 people. P2 was born in England and identifies himself as

Pakistani; he and his family speak only Punjabi at home. He is a cab driver and has no formal education.

P2 is Muslim and practices the Islam faith on a daily basis. His passion for his faith and his desire for the researcher to know and understand Islam was evident throughout the entire interview. Each time a question was asked during the interview, P2 would bring the conversation to issues of Islam and would ask the researcher different questions regarding her understanding of Islam. It was not clear if all family members take part in daily Islamic activities, but it was clear P2's Islamic faith was the most important part of his life.

C2 attends a Church of England Voluntary Controlled Infant School for 3 - 7 year olds; this is a common school that most children in the neighborhood attend. She is in a mainstream classroom each day where she receives extra help and she also attends some specialized classes for children with learning difficulties. She is in Reception, or Stage 2 with other 6-7 year olds.

**Parent 3.** The third interview took place in England. The interview with Parent 3 (P3) took place at a school in the office of the Head Teacher (principal), the same setting as P2. The room was small with four chairs. P3 appeared a bit nervous (feet tapping and rocking back and forth), but sat in a very proper way (with hands folded in lap) and smiled throughout the entire interview. She wore a hijab, the traditional Muslim head covering. P3 spoke English throughout the interview; it wasn't clear if English was her first or second language. P3 was born in England; Urdu is spoken in the home. The interview lasted 11 minutes.

P3 is a mother of several children (number wasn't shared). Her son, (C3) is six years old and has Developmental Delay. The family lives in the immediate vicinity of the school where the neighborhood is made up of mostly Pakistani families with a few other ethnic backgrounds included. The neighborhood is in a city in South Eastern England with approximately 80,000 people. P3 identifies herself as Pakistani; she was born in England. She did not share if she works or stays at home.

P3 identified herself as Muslim although she admittedly does not practice her faith on a daily basis. She believes it is a very important part of the upbringing of her son; he attends religious classes where he studies Arabic and Islam on a daily basis after school.

C3 attends a Church of England Voluntary Controlled Infant School for 3 - 7 year olds; this is a common school that most children in the neighborhood attend. He is in a mainstream classroom each day where he receives extra help through 1:1 instruction as well as in small groups. He is in Reception, or Stage 2 with other 6-7 year olds.

**Parent 4.** The fourth interview took place in England. The interview with Parent 4 (P4) took place at a school for students with special needs in a small conference room. The room was small with four soft chairs, a conference table, and office-type chairs around the conference table. To keep the setting more casual, the researcher suggested they sit in the casual, more comfortable chairs. P4 had canceled the interview two other times before, but with the encouragement from the Head Secretary, she stayed this time. She commented, *"I don't think I have the right words for you. I think my husband has better words."* She wore a hijab, the traditional Muslim head covering. It was lightly covering her head and was wrapped once around her neck. P4 spoke English throughout

the interview; at various times she paused to find the appropriate words. Her English was clear and easy to understand; English is her second language. The interview lasted 22 minutes.

P4 is a mother of two children, a son and a daughter. Her son, (C4) is three years old and has Autism. The family lives in the same city as the school, although not in the same neighborhood. The neighborhood where they live is made up of many different ethnic backgrounds. Although there are Muslim families, there other religions represented as well. Their home and the school is in a city in South Eastern England with approximately 80,000 people. P4 identifies herself as Pakistani; she was born in Pakistan. She did not share if she works or stays at home. She commented that her mother-in-law lives with the family.

P4 identified herself as Muslim although she does not attend the mosque. Her husband attends mosque while she stays home with her daughter, son, and mother-in-law. The only time she attends mosque is for special holidays, such as Eid. She reads<sup>2</sup> daily.

C4 attends a special school for students with special needs. He is at the Infant Stage and attends class with seven other children with moderate – severe disabilities. There is a lead teacher and four assistants. In addition to academics, he receives support in Speech Therapy and Occupational Therapy multiple times a week. P4 drops him off and picks him up from school three days a week. C4 attends mainstream nursery two days each week.

**Parent 5.** The fifth interview took place in Minnesota. The researcher first met Parent 5 (P5) at a Somali Community Event that was held for parents of children with

---

<sup>2</sup> Muslim individuals will often use the term “reads” to mean pray. The researcher inquired about this from the participants who used this word.



disabilities. They agreed to meet at another time for a formal interview. P5 did not have a car and requested that the researcher pick him up and they could go to a coffee shop for the interview. The car ride included light, easy conversation. P5 shared a lot about his background during this five-minute drive. The interview took place outside the coffee shop in order to have a quieter environment for the recording of the interview. The mood was natural and easy conversation took place. P5 spoke English with a Somali accent. He answered his cell phone a few different times throughout the interview. The interview lasted 34 minutes.

P5 is a father of a 5 year old daughter who was born with a chromosomal disorder. He is Somali; was born, married, and started his family in Somalia. He was orphaned as a young boy and grew up with a family in Italy. P5 and his family are fairly recent immigrants to Minnesota; the exact date was not provided. He lives with his wife, several children (ages and amount not provided) including Child 5 (C5), his daughter with the disability. The family lives in a suburb of a large metropolitan area in Minnesota. Their immediate neighborhood is made up of families that mostly come from Somalia; their home is in a large apartment complex. Although not working as of the time of the interview, P5 is an educated man. He identified himself as a “*man of science*” multiple times throughout the interview. He is of retirement age and has chosen to stay at home to manage the needs of C5.

The family is Muslim and practices their Islamic faith through weekly attendance at a mosque and daily with prayers.

His daughter, C5, attends school each day in an Early Childhood Special Education program where she receives basic academic instruction as well as support in

Occupational Therapy, Physical Therapy, Social Skills, Speech Therapy, and Behavior Management. She also meets with professionals outside the school.

**Parent 6.** The sixth interview took place in Minnesota. The researcher first met Parent 6 (P6) when she volunteered to help drive Somali parents to a Somali Community Event that was held for parents of children with disabilities. During the 15 minute car ride to the event, P6 was very conversational. It was after this car ride when the researcher asked the parent if she would be willing to be interviewed. The parent was eager to do so; they agreed to meet at another time for a formal interview. The interview took place at P6's home. P6 was sleeping on a mat in the living room when the researcher arrived and an ECSE teacher was working with P6's son in the living room. The researcher sat on the couch near the sleep mat and P6 stayed seated on the sleep mat. She wore a hijab which was lightly wrapped one time around her neck. She adjusted it frequently throughout the interview, often putting it back on her head when it had fallen down. The mood was light and easy conversation took place. P6 spoke English with a Somali accent. Her English was easy to understand, although she had some word finding issues. English is her second language. Her son continued to receive ECSE services in the same room during most of the interview. P6 was very happy during the interview; she smiled and often clapped her hands when talking about different things. The interview lasted 22 minutes.

P6 is a mother of a seven year old son who has Autism, C6. She is Somali; she was born, married, and started her family in Somalia. They are fairly recent immigrants to Minnesota; exact date was not provided, although some time since 2003. She lives with her husband, and two sons age 9 and 7 (C6). The family lives in a suburb of a large

metropolitan area in Minnesota. Their immediate neighborhood is made up of families that mostly come from Somalia; their home is in a large apartment complex. P6 stays at home each day and commented that she has had no formal educational training beyond high school.

The family is Muslim and the father takes the two sons to mosque each week. P6 identifies herself as Muslim, but admitted that she sometimes forgets to pray five times a day.

Her son, C6, attends school each day for half days in an Early Childhood Special Education program where he receives basic academic instruction as well as support in Occupational Therapy, Physical Therapy, Social Skills, and Speech Therapy. He also sees professionals who come to the home to help meet his needs.

**Parent 7.** The seventh interview took place in Minnesota. The researcher first met Parent 7 (P7) at a Somali Community Event that was held for parents of children with disabilities. They agreed to meet at a different time for a formal interview. The interview took place at a coffee shop in a busy metropolitan area. The mood was comfortable and easy conversation took place. P7 spoke clear English with a Somali accent. P7 often commented during the interview that he was very happy that this research was being done and that he was very happy to be a part of it. P7 is an educated man and at the time of the interview was working for a large school district as a Somali Translation Specialist. The interview lasted 1 hour, 7 minutes.

P7 is a father of a 12 year old son, Child 7(C7), who is Deaf and has identified psychological issues. C7 has two siblings; more details of the siblings were not shared. P7 is Somali; he was born and married in Somalia. It was not clear where his son was

born and it was not made clear when he immigrated to Minnesota. He shared that he is divorced and that this has been a major challenge in raising his son. C7 lives in a suburb of a large metropolitan area in Minnesota. The school is located about a half hour from home; it is close to the center of a large metropolitan area and not far from P7's work place. P7 did not share about the neighborhood where C7 lives; he focused on the peers C7 is with at school. P7 chose C7's school based on proximity to his work because previously his son had frequently needed to be picked up from school during the school day because of health issues.

P7 is Muslim and he commented that although his faith is very important to him, he has fallen short in this area. Because he does not live with his son, C7, he feels that he does not do enough in the area of practicing and modeling faith.

His son, C7, attends a Charter school for Deaf students. He is at the middle school level and receives all instruction through American Sign Language. Most of the staff are also deaf. C7 additionally receives services to help meet his psychological needs.

Table 4.1 Description of interviewees

Parent	Education background or Profession	Language Spoken	Location	Ethnic and Faith Background	Immigrant?	Child/Disability
P1 – mother	College Education, Teacher, currently staying at home	English, was born in Pakistan so likely speaks another language - unknown	City of 100,000 in South Eastern England	Pakistani Muslim	Yes	Son, 12, Down Syndrome
P2 – father	Cab Driver, no formal education	English was his second language; Punjabi his first	City of 80,000 in South Eastern England	Pakistani Muslim	No	Daughter, 7, Learning Difficulties
P3 – mother	Unknown -	English, and Urdu – unknown which is her first language	City of 80,000 in South Eastern England	Pakistani Muslim	No	Son, 6, Developmental Delay
P4 – mother	Unknown	English was her second language, unknown what was her first language	City of 80,000 in South Eastern England	Pakistani Muslim	Yes	Son, 3, Autism
P5 – father	College Education, currently retired and staying at home	Somali , Italian, English, (order of languages learned)	Metropolitan Area in Minnesota	Somali Muslim	Yes	Daughter, 5, Chromosomal Disorder
P6 – mother	No formal education, currently staying at home	English was her second language; Somali her first	Metropolitan Area in Minnesota	Somali Muslim	Yes	Son, 7, Autism
P7 - father	College Education, Somali Translator for a large school district	English was his second language; Somali his first	Metropolitan Area in Minnesota	Somali Muslim	Yes	Son, 12, Deaf with psychological disorder

## Parent Responses to Interview Questions

When reviewing the data from the seven interviews, there were distinct themes that emerged from each question as well as some themes that cut across all questions.

When connecting the responses from the interview questions with the two main research questions, the themes clearly fit under one or the other research question: 1) *How do Muslim parents make sense of having and raising a child with a disability within their cultural and religious meaning systems?* And, 2) *How do Muslim parents desire that the schools work with them?* The following sections describe the interview question asked,

the themes that emerged from the responses to each question, specific details from the parents within each theme, how the themes connect to the literature, how the responses fit with the overarching research questions and finally, a chart for each section in order to provide a summarized, visual format.

**Research question 1.** *I know that you have a child with special needs. Tell me about your child and his/her education plan.* (The researcher used the child's name in each interview in order to make it more personal.) There were five themes that emerged out of this first question: 1) medical responses, 2) type of school, 3) disability, 4) characteristics of the disability, and 5) the parent's knowledge of the disability.

The parents' responses ranged in the amount of details each one shared about their child with this open-ended question. P1 shared numerous positive details about her son; the researcher was really able to "know" C1 because of the specific details P1 shared about his personality, demeanor, and the relationships he has with other people. She even requested that the researcher meet him at his school. P5 also shared a great deal for the first question. It was mostly about the difficult journey his daughter had in the first years of her life which involved significant medical and educational needs. P4 also shared about the journey of her son from birth to today and that it had been difficult. P7 similarly shared a lot of details about his son's journey; it was mostly about medical issues which he felt ultimately caused the different challenges his son has today. P6 did not share much, except that it was after age 2 when concerns arose and her son was diagnosed with autism. P2 and P3 talked mostly about their children being happy with going to school. Further details follow within the five themes that emerged.

**Medical responses.** Although medical information was not specifically sought, six of the seven parents shared medical stories [See Figure 4.2]. These experiences related to whether their child's disability was evident at birth or if there were health complications at a different point in the child's life. The term *doctor* was used 26 times from five parents. Their medical descriptions included: son born with Trisomy 21 (P1); daughter born with heart problems (P2); difficult birth of a son with continuation of tests to present day (child was 3 years old at the time of the interview), and her son missed all developmental milestones (P4); difficult pregnancy and daughter was born with chromosomal disorder (P5); parents were told it was autism, but they did not know why (P6); son had chronic ear infection as a young boy, he had seizures which are now controlled with medication, was hospitalized for psychiatric needs, and experienced negative side effects to medicines (P7).

During his response to question one, P5 shared the process he and his wife went through when learning that their daughter had a chromosomal disorder:

*And this took a process starting from the first day when their ultrasound revealed that was something wrong with [our daughter]. And we had disbelief at the beginning. And then when she came at this world, and we found ourself in a real situation of denial and not admitting that our daughter was a special kid. And this took us a long time to realize or to accept the situation as it was.*

And although not shared during question number one, P4 made a direct response back to number 1 at the end of my questions when asked if she had anything else she wanted to add. She paused and then started to share that her doctor said her son's disability (autism) was because she and her husband were related.

*So, this type of problems happens. And me and my husband is first cousin, so we don't know [about the disability]. I know there's not perfect reason, but the doctor said because everybody get some good genes and some bad genes, sometimes a bad luck. So in the future, yeah, I don't want to do that to my daughter or my son."*

This particular statement that P4 shared directly connects to the research from Hissa Thani (2008) who shares that a present-day custom in many Arab cultures is the tradition of inter-familial and consanguineous marriages. It is openly accepted. P4, now aware of what her medical doctor shared, appears to have no interest in this tradition being passed on to her children. As Thani expressed in her work, knowledge and education are critical in helping families understand how some disabilities materialize.

**Type of school.** Current schools at the time of the interviews included: special school for students with disabilities – early childhood and middle school age in England (P4, P1 respectively), mainstream nursery in addition to special school (P4), primary school in England (P2, P3), early childhood special education in Minnesota (P5, P6), and a charter school for deaf children in Minnesota (P7).

Parents discussed the type of school their child was currently in as well as what types of schools they had tried earlier in the child's life [See Figure 4.2]. Five of the seven parents shared stories of previous schools. The two that did not had children with mild disabilities.

The reasons for previous schools included: natural progression to new special schools because of age; the family chose to move schools because of a very negative experience (P1). Receiving specialized services in the home or at private clinics prior to



being able to attend a formalized school (P4, P5, P6); trial and error to find what kind of school would be best for his deaf son (P7). P7 shared, *“Before 2003, he was a mainstream class, and [my son] was not learning anything. Ya. And I always felt annoyed [that he] lost all those years of education. But, . . . the spring of 2003 we found [the Deaf Charter school], and we transferred him [there] midyear, and he started learning. So, his education and learning changed.* The kind of school a child attends seems to make a big difference for the child and the parents as well.

According to where other students with special needs attend school in both England and Minnesota, these seven children receive services in the most common setting to meet their needs in their respective locations. Although Minnesota has Setting IV<sup>3</sup> schools that would provide a somewhat similar setting as the special school where C1 and C4 attended, the disability and needs represented by C1 and C4 could be met in a regular public school in Minnesota. The mild disabilities represented in C2 and C3 are served in the mainstream classroom in England, just as they would be in Minnesota. C5 and C6 are in early childhood special education settings where they will transition into Kindergarten and receive Setting II<sup>4</sup> or Setting III<sup>5</sup> services in special education. C7 is in a public charter school for deaf students, not necessarily common, but very appropriate for his needs.

**Disability.** Six of the seven parents shared the disability of their child without further prompting from the researcher. One parent never shared what the disability was even

---

<sup>3</sup> Setting IV is defined as students needing special education services for 50% or more of their school day in a separate facility from non-disabled students.

<sup>4</sup> Setting II is defined as students needing special education resource room services for 21-60% of their school day.

<sup>5</sup> Setting III is defined as students needing special education resource room services for more than 61% of the school day (sometimes referred to as “center-based programming”).

with prompting, but based on his response related to services the child received and the type of school the child attended in England, it was determined the disability was likely mild in nature. The identifications shared from parents included: P1 – Down Syndrome, P2- not shared, P3 developmental delay, P4 – autism, P5 -chromosomal disorder, P6 – autism, P7 – Deaf with psychological needs [See Figure 4.2].

As some of the parents shared about the actual disability, they added statements such as: *“He have autism. That's what they told us, but I don't know how they understand autism. Maybe they know the signs.”* (P6) And from P7: *“But about the psychiatry problem - I don't know how - I'm a little bit concerned. But I am hopeful at the same time. His deafness I'm sure will not be disability to him.”*

***Characteristics of the disability.*** Five of the seven parents shared strengths and needs of their child [See Figure 4.2]. Two parents shared only their child's needs; they both talked about progress their child had made, but not actual strengths [See Figure 4.2]. It may be because the child is still young (3 and 5 years old) and both children had significant needs at birth. Also, it should be noted the researcher did not specifically ask a question surrounding the topic of strengths.

The strengths five of the parents shared included: spelling (P3), very social (P1 and P7), emotionally connected (P1 and P6), speaking (P2), reading (P2), physically strong (P6), sense of humor (P6), loving (P6), active (P7), artistic (P7), and helpful (P7).

The needs shared by the parents included: speech (P1, P4, P5, P6), English (P2), lack of ability to concentrate (P3), fear of birds, animals (P1), math (P2, P3), sensory and communication (P4, P6), global delay (P5), negative behaviors (P5, P6, P7), and psychological (P7).

***Knowledge of the disability.*** Five of the seven parents shared how they had learned more about their child's disability in order to understand their child's needs better [See Figure 4.2]. P1 stays active in the Down Syndrome Association. P4 understands more about autism by reading a website and listening to the doctors. P5 depends on all of the experts such as doctors, specialists, county and school professionals, and neurodevelopmental specialists. P6 has learned many new things to help her son with Autism from his teachers and community/school outreach. P7 relies on his own research as well as information from the doctors.

To summarize question one, it is evident to the researcher that each of these parents knows their child well and recognizes all of the factors affected by the child's disability. It was particularly interesting how medical factors became such a relevant piece even though no specific question was asked about it. This caused the researcher to think that having a doctor's diagnosis of some kind may make it easier to reason why and how parents raise their children with a disability within their cultural and religious communities.

Responses to question one fit under research question one in that parents initially make sense of and raise their child with a disability by knowing and understanding their child well. They would not be able to respond to other interview questions without this foundational component. It is evident that some of the themes which emerged from interview question one directly connect with content in the literature including:

- The parents' backgrounds fit the immigrant patterns described in Chapter 2;
- The descriptions of the types of schools fit the current make-up of special education systems in England and Minnesota;

- There are similarities in the children's needs to those represented in Jegatheesan's (2010) study, albeit they are not all autistic; and
- The literature spoke of the importance of parents connecting with other parents in order to feel supported ([www.pacer.org](http://www.pacer.org)).

Table 4.2 Description of the Child's Disability and the Needs Associated with It

	<b>Medical Responses</b>	<b>Type of School</b> (all are considered public schools)	<b>Disability</b>	<b>Characteristics of the Disability</b>	<b>How the Parents Educate Themselves about the Disability</b>
P1	Trisomy 21	Special School	Down Syndrome	Needs: communication, fine motor skills, low cognitive level	Down Syndrome Association
P2	Heart condition	Mainstream School	Learning Difficulties	Needs: Reading and Math	
P3		Mainstream School	Developmental Delay	Needs: Reading and Math	
P4	Blood disorder, Doctors diagnosed Autism	Special School 3 days a week and mainstream nursery 2 days	Autism	Needs: non-verbal, fine motor skills, gross motor skills, social skills, low cognitive level	Internet and Doctors
P5	Difficult pregnancy, Chromosomal Disorder	Special School	Chromosomal Disorder – educational diagnosis is Developmental Cognitive Disability – Moderate-Severe	Needs: communication, fine motor skills, gross motor skills, social skills, low cognitive level, behavior management skills	Experts such as doctors, neurodevelopmental specialists, county and school professionals
P6	Doctors diagnosed Autism	Special School	Autism	Needs: communication, fine motor skills, gross motor skills, social skills, low cognitive level	Teachers and school/community outreach
P7	Chronic ear infections, seizures, psychiatric hospitalization, medications	Charter School	Deaf, Psychological needs	Needs: communication via ASL, mental health, medication for seizures	His own research and doctors

The researcher also felt it was important to differentiate the characteristics between mild disabilities and moderate-severe disabilities as throughout the five

questions, it became apparent that there were important distinctions to make [See Figure 4.3].

Table 4.3 Differences between Mild Disabilities and Moderate-Severe Disabilities

Mild Disabilities	Moderate-Severe Disabilities
<ul style="list-style-type: none"> <li>• No concern with others accepting their child's disability</li> <li>• Have friends outside of school</li> <li>• Do not do anything with outside organizations connected to disabilities</li> <li>• Limited details shared about other family members</li> </ul>	<ul style="list-style-type: none"> <li>• All experience judgment and issues of acceptance</li> <li>• No friends outside of school</li> <li>• Educate themselves about the disability</li> <li>• Significant details shared about family members in 4 of 5 instances</li> </ul>

**Research Question 2.** *What is it like to raise this child in this community?*

Probes included: *Out in public? At the Mosque?* There were four themes that surfaced in the participants' responses to question number two: 1) acceptance by others or others' understanding of the disability, 2) religious practice, 3) family, and 4) connection with their home countries.

Within the context of community, parents shared about their neighborhoods and what it's like being in public places. Some of the parents also shared what kind of culture was represented within the neighborhoods nearest their home and school. The four parents from England shared that their neighborhoods were a mix of cultures, but the majority of people practiced Islam. Two of the three parents in Minnesota (P5, P6) shared that their neighborhoods are mostly represented by Somalis; and P7 shared that he considers his son's neighborhood as Deaf, Somali, and American.

***Acceptance by others or others' understanding of disability.*** Parents shared experiences of how others in their community treated them as parents of a child with a disability. Five of the seven parents talked about people around them that do not understand disability and therefore do not accept them [See Figure 4.5]. *"People aren't educated; they don't understand"* (P1, P7); *"They have no idea of autism"* (P6); *"My mother-in-law don't understand"* (P4); *"They blame you."* (P6); *"I'll only choose people to be with who'll accept my son"* (P1); *"They're not comfortable with disability."* (P1); *"It hurts what others think."* (P1, P7); and *"...we used to hide our daughter...because we were afraid of comments..."* (P5). The two parents who did not speak of negative experiences about others' understanding of disability have children with mild disabilities. Their children do not have any physical or behavioral characteristics that would identify to outside people that there is a disability of some kind.

The parents spoke around this topic of acceptance. P1 shared:

*Because most of the families - they're not comfortable with a special needs child, because they don't understand how to react to it. Maybe - I don't know whether I should be saying this - maybe they're not educated enough, or maybe it's just that sort of a block - I don't understand that. But what hurts is when people say, don't bring him over...(because of his disability)*

P1 further shared about the challenges of parenting a child with Down Syndrome, *"and when people don't understand that, and they don't understand that I've got limitations because of my son, that really hurts. That REALLY hurts."*

P5 shared about the process of acceptance: *"Practically, we used to hide our daughter from the seeing of other people, because we are afraid of comments or*

*something like that.” Then he stated about the present day, “Yes, definitely it is better because we face the community; we stay in the community with [our daughter], and we have passed the period of discomfort or denial, and for us, actually, you know, [she] is just like another kid.”*

When talking about raising her son with autism in the Somali community, P6 shared:

*It's very hard. Because they don't understand, and the issue he had. And Somalia people back home we don't have this problem. It's very hard to have [my son] and being Somali, um, because the community, young and adult, they don't accept it yet. They still look at it, they still, you know, question - then they blame you - you are not talk to him, you are not teach him, you are not, you know - many things. So, the conclusion is, they are not accepted yet. They blame me instead to understand.*

And P7, Somali father of a son who is Deaf shared his feelings in response to other Somalis who call his son names or say negative things:

*Well, I . . . I can say this . . . to me, it's not a problem. I'm proud that [he] is my son. But they don't understand it. They need to understand. Even if it is not intentional, it still hurts. So they need to learn that and change that behavior and make the - call the person his, or her, exact name. P7's experience fits with that referenced by M. Miles (2002A). Miles shared that often, the terms used in these other countries are considered 'outdated' or 'barbaric'. Although it is healthy to continue to do work to help change these views, it is important to note that the attitudes are not coming from an intention to do harm, rather because they are the only ideas that are known. P7's response speaks to*

the personal side of this, that even if it is not intentional, it still hurts. The optimistic side for P7 is that he is also doing things to make improvements. He is helping to educate other Somalis' understandings of disability and deafness.

When considering why some people may not accept the family who has a child with a disability, Begum (1992 in text Ali et al., 2001) reports that often it is because of inaccurate or lack of information and the inability to discern the difference between religious and cultural beliefs. The literature also included documentation that sometimes people make up stories in order to bring meaning to why a child has a disability (Miles, C., 2002). Five of the seven parents shared stories that directly relate to these ideas demonstrating that regardless if a parent is a fairly recent immigrant or had immigrated 15 years ago, the negative judgment from others still exists in both England and Minnesota. The negative judgment and/or the rejection of the child with the disability may come from within the family's own neighborhood and/or the family's home country of Pakistan or Somalia. The two parents who did not express negative judgment or rejection both have a child with a mild disability. Based on the results from seven parents it appears that the type of disability may play a factor in how the parent and child are treated.

In summary of the topic of acceptance of disabilities, four of the seven parents had a lot to say around the core word of "accept". Figure 4.4 shows the frequency and context of the use of the word, *accept*.



Table 4.4 Context of “Accept” as it Relates to Disability

	Context of “accept” used during interviews as it related to their child’s disability
P1	“acceptable here (in England), but not in Pakistan” – shared 2 different times
P5	“we had to accept the situation as it was” – shared 2 different times “We’re working hard on acceptance” “Typically, C5 is not accepted” “We’re working on her behavior so she’s accepted” “I use my faith to accept things as they are.” – shared 2 different times “Relatives in Somalia are conditioned by religion to just accept it.”
P6	“Community, young and adult don’t accept [autism] yet” – shared 4 times “But now I accept everything.” “You have to become patient and accept many things wrong.”
P7	“It’s up to us to accept it or neglect it.” “Allah wants to know if I accept the disability and the responsibility” – shared 3 times.

**Religious practice.** All seven parents discussed their level of involvement with their Muslim faith and whether or not their child with a disability practices the Muslim faith at any level [See Figure 4.5]. Specificity was not probed; the researcher simply transcribed what they shared. It should be noted that each of these parents may likely take part in more religious practices than what they shared; the researcher did not probe further. Five of the families pray at home; four families attend mosque; four families celebrate Eid; and two families take part in religious lessons.

It was evident in some of the responses how important religious traditions are to some families: P1, the mother of a middle-schooler with Down Syndrome, said this in response to other Muslim Pakistani parents of children with disabilities when they keep their child sheltered and won’t bring them out in public:

*That really hurts me, and that's when I do put a word in, and I do tell them - no, you can't do this. If it's Eid for you, it's Eid for them. You have to tell them - you have to tell them that they're part of the family. You ignore them now - a day will come when they will ignore you. And you can't ignore them, they're just too lovely.*

Having her son involved in important religious traditions is very important to this mother; so much so that she advocates for other Muslims with disabilities.

Two parents expressed the fact that their children, both with mild disabilities, attend religious lessons. When discussing what the child does with regard to religious lessons, P2, a Pakistani father of a daughter with a mild disability said: *“They only go to general basic Islamic knowledge. Read the holy book. Every day, Monday through Friday, they go to one hour, There she learn basic knowledge - what is Islam, what is a prayer, and read holy book.”* P3’s son also attends religious school every day. Attending religious school is a common practice in England (retrieved on July 14, 2011, from [http://www.emel.com/article?id=86&a\\_id=2409](http://www.emel.com/article?id=86&a_id=2409)) and some children even receive accommodations for their disability at religious school. It was not apparent if either of these children received any kind of accommodations. The other two children in England have more significant disabilities and do not attend religious school. Both parents shared that it is too much to expect their sons to learn Arabic.

While sharing the importance of praying even though the family does not attend mosque, P3 said, *“If you pray in the home, your children watch you”*. The idea of raising a child this way was clearly important to her even if it was not her own central focus each day.

It was not apparent to the researcher if all of the seven children attend mosque, but for those who did, they openly shared their experiences. Somali parent, P6, does take her son to mosque and smiled as she said: *“and he call mosque ‘mosca’ - ‘I need mosca’.”* When at the mosque, she commented that her son is too active and it gets really difficult. She talked about the others at the mosque, *“They just sit and ask you questions . . . um . .*

*. they feel sorry little bit, but sorry doesn't help him. You need a helping hand.*” Both P5 and P6 have included their child in attending the mosque, but said that it is very difficult. They both commented that people in the mosque do not know what to do with their child, but they did not necessarily feel completely excluded. Although there is a long way to go, it appears the mosques in this metropolitan area of Minnesota are moving in the right direction of some awareness compared to what Bazna and Hatab found in 2005. They found that there was an exclusion of congregants with disabilities from the mosques which reflected limited awareness of understanding the needs of people with disabilities.

The response to question 2, although not directly asked, included how the practice of Islam fit into their lives. The parents’ responses directly connected with the literature reviewed on Islam. Although all five pillars of Islam were not mentioned by any parent, there were one or two tenets of Islam mentioned by each parent. The most common were the first two tenets: belief in Allah (as in their identification of being Muslim) and daily prayer (also called reading). P2 mentioned all five tenets when sharing an overview of Islam with the researcher, but he did not reference himself completing each of the 5 Pillars. Even with no specific questions asked about their religious practice, each parent still shared responses that directly connected them to their Islamic beliefs. In addition to the parents’ responses to question five about whether its faith or culture that plays a greater role in their lives, the responses connected to faith in question two demonstrate that faith is naturally integrated into daily life for these families. Jegatheesan, Miller, and Fowler (2010) observed this same integration while spending 18 months with three Muslim families.

**Family.** Although no specific questions or probes were asked about family, all seven parents shared information within the category of family [See Figure 4.5]. The parents' responses fit into three sub-categories including: relationships, language spoken, and answers connected to their home countries.

**Relationships.** Throughout the interviews, parents shared these responses about different relationships within the family. Pakistani mother, P1, shared that her son with Down Syndrome was really attached to her and his older brother. Pakistani father, P2, talked a lot about his daughter in conjunction with all of her siblings in a very positive light. Pakistani parent, P4, mother of a 3 year old with autism shared that her mother-in-law lives with them and is quite involved and that there are other siblings. P5, Somali father of a five year old daughter with chromosomal disorder, shared that initially when his daughter was born, there was great difficulty with his wife. In addition, he spoke of training his older children on how to care for C5 if/when he cannot care for her. And both Somali fathers, P5 and P7 shared that the parents must work together for the benefit of their child with the disability.

P5 further shared:

*and my wife, she's very religious lady, and . . . she was not trusting - We're in a very good relation. And with all of this she would say now, you are wasting time, you know, this is from God and God knows and . . . Also I trust in God, but God said to help yourself. [And now] she talks with other mothers - and at the beginning she wouldn't talk with nobody as saying that her daughter is a child in need. So we work hand in hand now - the whole family.*

When talking about his separation from his wife and how it affects his son, Somali father, P7, of a teenage son who is Deaf with some mental health needs, said: *“Unless we help each other, we cannot help [our son].*

*Language spoken.* Within the homes of these seven families, four different languages were spoken: English and unknown (P1), Punjabi (P2), Urdu (P3), unknown (P4); English and Somali (P7), Somali (P5, P6, P7). Based on these data, there were no consistencies with the Pakistani parents, but there were consistencies with the Somali parents.

*Home countries.* When talking about their families, three of the parents added information about relatives back in their home countries. P1 shared that her son is not accepted in Pakistan; P5 said that family back in Somalia accept what is because of religion; P6 shared that her home country of Somalia does not have autism and that they blame her for her son’s disability: *“It’s always - fell - you fell in the car, you fell in the road . . .OK. That why it happens.”* This directly connects with the literature from C. Miles (2002) who shared that some people make up stories about why someone has a disability. P6 is experiencing this reality from those she knows in Somalia.

Responses to question two fit under research question one in that parents are dealing with many different things when trying to raise this child with a disability and some of these things directly impact them in positive and negative ways. Although their responses to the questions asked are personal to them, their responses can be connected to similar scenarios in the reviewed literature, as stated in each of the previous sub-sections.

Table 4.5 Fitting into the Community

	<b>Others don't understand my child's disability</b>	<b>Disability Type – is it visible to an outsider?</b>	<b>Religious Practice</b>	<b>Reference to God or Allah</b>	<b>Family</b>	<b>Relationship with their home countries/relatives</b>
P1	Yes	Yes	Identified as Muslim; Daily Prayers; Take part in Eid; husband attends mosque	Allah	Spouse and siblings	Relatives in Pakistan don't understand
P2	Nothing stated about this	No	Identified as Muslim; Daily Prayers; Attends mosque; Take part in Eid; child attends daily religious lessons	Allah	Spouse not known; siblings	
P3	Nothing stated about this	No	Identified as Muslim; Daily Prayers; Take part in Eid; child attends daily religious lessons		Spouse not known; siblings	
P4	Yes	Yes	Identified as Muslim; Daily Prayers; Take part in Eid; husband attends mosque		Spouse; siblings; mother-in-law	Relatives in Pakistan don't understand unless they move to England
P5	Yes	Yes	Identified as Muslim; daily prayers; Attends mosque	God	Spouse; siblings	
P6	Yes	Yes	Identified as Muslim; Daily Prayers (uses DVD to teach her son); Sons and father attend mosque	Allah and od	Spouse; siblings	Relatives in Somalia don't understand – they make up stories
P7	Yes	Yes	Identified as Muslim	Allah	Siblings	

**Research Questions 3 and 4.** *Tell me about a time that worked well with your child's education.* Possible probes included – *classroom activities? school-wide activities? Teachers? Peers? What was it that made it work well in your mind?* Followed by: *What hasn't worked well?* Four themes emerged from the responses: 1) progress of

child, 2) parents' satisfaction level, 3) services for their child, and 4) involvement at the school.

***Progress of child.*** All of the parents expressed noting progress in their child [See Figure 4.6]. The mother of a son with Down Syndrome, P1, mentioned her son's progress eight different times in a very positive light. Parents P4, P5, and P6 said progress was really slow in the beginning, but now it is much better. The mother of a young boy with autism, P6, felt that he's making progress, but it doesn't seem like enough. P2 smiled very big at one point when describing his daughter's progress and said: *"When she go kiss me and I say I very proud for you.* P3, when talking about the school and her son's progress, sat up very tall, smiled and said, *"Yes, I feel happy with what they do. He does well in the community as well, because, I mean, like after school I take him to mosque where they learn our own religion in Arabic and he does even well there as well."* In summary of his daughter's progress, P5 shared, *"When she gets a little bit up, we don't get happy too much. And when she get a little bit slow, we don't demoralize ourself. We just continue to do what we have to do."* P2 shared that sometimes the progress is difficult for Pakistani children because they speak English all day at school, then they go home where Punjabi is spoken and then go to religious classes where Arabic is spoken. And although his daughter has learning difficulties, she takes part in each of these three languages. He said, *"...but some children pick up quick. Some children pick up a little bit late."*

Extra "carer support" provided at home helps P2's daughter with her progress. This is provided by a grant through the local political party since she has special education

needs, or SEN. He said, *“but when we have 25-30 children in one class, only one teacher, she can't handle everybody. And then they give me that help one-to-one and I very happy.*

P1 and P4 both acknowledged the progress their child made with eating once they started at a special school. This was a very happy occasion for each of them because it was a daily functional activity that was incredibly challenging prior to a professional teaching their child how to eat. P4 shared, *“you can send him for the lunch, and then maybe he can do it, and he start eating here. I am very pleased.”* P1 said, *“And it was really nice. And because - he's got a problem with eating, actually...and holding a banana and eating is a very big thing. So he started this with [his teacher]- and the first bite he took, they took a picture, and they send me a picture - it's lovely, just lovely.”* Even the little steps of progress make a big difference to these parents.

When asked if his daughter had positive experiences in the school, P5 had much to share and specifically talked of all of the supports that have made a difference for her.

*Definitely. I say that this year was probably the best time, that we see some concrete improvement. Considering from where [C5] was coming and where she is now, we see a lot of improvement. And, in the same time, I have to say that this improvement didn't come by itself. It is because of the work of many peoples, starting from doctors, therapists, teachers, parents, siblings, and . . . all parts which . . . and support [C5] to make some achievement. If I remember the first time that she was going to school, it was a disaster. She used to vomit, crying, fighting, because she doesn't want to go in. We had to stay in the class for some time, and so she passed over that. She is very social with the teachers now....She is more gentle with the other kids. And she start also to follow certain directions,*



*even, and . . . this is improvement, but, um . . . it is not enough, definitely for a kid of her age...She is far behind. But we have to continue to do that. We have no other options.*

When asked if things had ever been difficult with C5, P5 shared:

*Definitely, especially at the beginning. And . . . we didn't see any progress. Going to school was really a big problem. And, also we parents become very bad mood and a little bit hopeless. And . . . but we overcome all this things, you know . . . staying in the system of child and special need child education. Working with the system, and . . . I saw the situation of [C5]. It was very hard at the beginning. But then, talking with teachers, talking with social workers, talking with doctors and so on, I come to realize if we work closely with [C5], if we work with the specialist people in the field, at least we can reach a certain level of independence for [C5]- not in one year, two years, three year, five year, even more, but at the end we will reach a certain point. The only thing that was needed to be done was to work closely with [C5] and . . . we are still working.*

So even in the challenging times, P5 recognizes the importance of all of the supports in place to help his daughter.

Although supports may be more evident in the classroom, when asked about support outside the classroom, there was a different response from the parents. P6 shared:

*He cannot do that, because he's not sitting, he's not standing, he's not wait for you to do something. You have to hold him very hard, and he's strong. He's try to escape any chance, any moment, so . . . from school, bus to home, bus to home,*

*our home is lock all the time. Even - this is summertime, you go outside, but you have to [watch very carefully] ...But not . . . not happy environment.*

And about C6's progress in the classroom:

*But . . . um . . . they teach him a lot. But still using it - it's very hard for him. He is - they teach speech, how to speak, how to use words, how to write, how to read, how to - you know - how to use. . . but not yet. He's good, he's good. Some, but . . . it's not there yet."*

And although P6 knows they are teaching her child a lot, she desires more for her son.

When describing times she is not happy with his schooling, she said, "*Because . . . he's going [to school], but he's not well, he's not done anything. He's not moving up. He stay the same. So I think he's not doing well.*"

Finally, P7 shares about his satisfaction with C7's progress in school, although the beginning was very challenging:

*Before 2003, he was in a mainstream class, and [C7] was not learning anything...then we found the [Deaf Charter School] ...He grow and kept growing, until 2010 - November 2010 - when he developed the psychiatric problem. That was new to us. Then . . . in between that span of his life, the education - his learning, his education, his cognitivity - were good, very good. I was satisfied. And it was because of - only because of that school,[the Deaf Charter school].  
Ya.*

When reflecting on the responses these parents shared about their child's progress, the end result was generally positive. This runs counter to the findings in Jegatheesan's (2010) study. Even though Jegatheesan's study did not specifically discuss

progress, their findings showed that the parents had general dissatisfaction with their child's educational programming.

*Future concerns.* Although not specifically asked, four parents expressed concerns about their child's future – P1, P2, P4, and P5. P1, a Pakistani mother of a son with Down Syndrome, was very emotional when talking about her son's future and when she will no longer be there. She does not feel that her older son should have to take care of C1, yet she does not trust anyone else. At this point, she does not know what she will do; she is just very worried about this. She tearfully shared,

*and that's what scares me, actually. That's what scares me. That when I'm not here . . . That's the only thing that scares me, because obviously...my other son is there, he loves him. But, he'll have a family of his own one day. I can't blame him - don't want to blame him - will have to put his family in front of other things - and if I'm not there - I don't know, I can't trust anyone else with him, I can't. That's the thing which really - one of the reasons I came here - he's much more acceptable in the community here, not in Pakistan he wasn't - it's more of - that's what I've said .*

The Pakistani father of a 7 year old daughter with a mild disability spoke often about her future. *“Only prayer for God right away and good friendship Very important. Very very important.”* For this father, it was the people that would surround his daughter someday that were most important to him.

A Pakistani mother of a 3-year old with autism was calm and seemed trusting as she thought about the people who will help her son in the future. *“I think in the future these peoples help to how do you - how these children spend their life how to handle this life.”*

A Somali father of a 5-year old daughter with chromosomal disorder was very matter-of-fact as he first talked about his daughter's future. "*We know where she is now, but we don't know where she can go. Can be far, can be short, but we have to do the job.* And as he continued it was evident a lot of thoughtful planning had already happened even though his daughter was only five. "*We are parents, we are aging too, and we have to think about the future. And we are preparing some of the siblings also to take over one day when [she] would need.*"

And although not specifically sought, the parents' responses about future planning for their child also connect to the literature, both in related and unrelated ways. For example, it is commonly believed that families will simply take care of their own members; therefore government sources are not a necessity (Thani, 2008). In an opposite response, P1 does not want to rely on family members being responsible for C1's future. She knows her older son loves and cares for C1, but she does not want to put that kind of responsibility on him, the responsibility of taking care of C1 when she and her husband are not here anymore. In this way, she does not want to do as they may do in Pakistan, where the family is expected to care for the person with the disability. She does not feel that it is fair for her other son. P1 trusts the schools and the current systems supporting her son; she's not so sure about his future.

On the other hand, P5 has already started planning for his daughter's future even though she is only 5 years old. He has the older, adult siblings attending meetings with him so that they could take over for him at any time. And even though he feels strongly that family plays a role, he also trusts the system in place (county and school) to appropriately care for his daughter's needs. P4 feels a similar way, "*I think in the future*

*these people's help to how do you \_how these children spend their life how to handle this life", she trusts the school district.*

***Level of satisfaction – parent and child.*** Six of the seven parents specifically expressed happiness or that they were pleased with their child's schooling [See Figure 4.6]. P1 expressed her happiness seven times and her son's happiness five times in her response to question four. P1 had one bad experience and moved schools because of it. P2, P3, and P4 expressed happiness five times, two times, and one time respectively for themselves and six different times, one time, and two times respectively, that their child was happy. P6 specifically acknowledged the good teachers her son had in school. While talking about a particularly caring Aide who worked with her son, P1 animatedly shared: *"She had no clue what to do, but she really -you know, she really - she was one of the persons who really cared - she gave me strength"*

P1 shared many details of the three different schools her son has attended. She had mostly positive things to say about each school except for the mainstream school. She talked of the bullying that happened from other children as well as the ignorance towards her son from the mainstream teachers. She felt they simply did not understand her son's needs and were not prepared to meet his needs. There were a few staff that simply ignored some of her son's needs which made for a very negative experience for both her son and her. When she felt she was not listened to, she made the decision to move him to a special school where she knew his needs would be more appropriately accounted for.

Although some parents only shared limited details about satisfaction, it was still evident. P2 gave very few details about why he was satisfied with his daughter's schooling, just that he was very happy. He talked a lot about the government providing

the schooling and that he was happy with that. P3 shared that the small group her son has received instruction in has helped him be more confident in the general classroom. She is very happy about this.

Although no particular educational desire was shared by the parents, it became very clear that they were not dissatisfied in any major way as they talked about their child's progress, their level of satisfaction, and their involvement with the school. What is interesting to note is that the school experiences shared by these seven Muslim parents in this study are quite different from what Jegatheesan, Miller, and Fowler found in 2010. The three Muslim families in their study were very unhappy and dissatisfied with the relationship and recommendations put forth by the professionals. Although this researcher's work had only one moment in time with these families versus many months being spent in their homes like the Jegatheesan study, it was still very evident that these parents were quite satisfied. It did not appear that they were trying to impress anyone when sharing their satisfaction. Each one shared quite a few details about their satisfaction, demonstrating to the researcher a genuine response. Further analysis of this particular component will be analyzed in Chapter 5.

***Services the child receives.*** The parents shared the following types of services their son or daughter receives [See Figure 4.6]: Speech (P1, P4, P5, P6); Occupational Therapy (P1, P4, P5, P6); 1:1 help (P2, P5, P6); small learning groups (P3); carer support (outside of school) (P1, P2, P4); tutoring (P3); Picture Exchange Communication System (PECS) lessons (P4, P6); behavior therapy, physical therapy, case workers, and social workers (P5); and American Sign Language interpreter (P7). When comparing the literature that was covered about current special education programming in England and

Minnesota, it is clear that each of these children was receiving the appropriate services put into place by educational laws in each location.

Raghavan and Waseem (2007) found that many families in Northern England were not open to receiving outside services because it meant their child's needs would be visible to others. It is encouraging to see that these parents who were interviewed openly accepted services that were provided outside of school. It could be that since these parents agreed to this research study that it already shows acceptance of their child's disability and those that wish to keep their child hidden would have naturally declined to be interviewed. Either way, it is a positive fact that they are open to accepting the available resources.

***Involvement at the school: Parents and children.*** All of the seven parents participated in individualized meetings set up for their child [See Figure 4.6]. Two of the parents spoke specifically about the process of paperwork or meetings. When asked if she is ever given any paperwork for her son, P3 responded:

*They do. I mean, because he's in small group, they give me - just to let me know how he's getting on - and then I have to come in and sign it, and then they tell me how I should help him at home as well, which is a great help, you know, they guide me I mean, although OK, I have to speak enough English, you know, I still don't know like what to teach him.*

When asked if she attends meetings at school for her son, P6 responded, “ *Yes. Very important. 'Cause I wanna know what he get, what he didn't get. Yeah, is very important, very important.*”

Some of the parents had further involvement with the school. P1 attends parents' evenings at the school. P4 and P7 attend parent classes that are offered to help parents understand the specific disability of their child. P7 has also attended American Sign Language classes at his son's school so that he can better communicate with him. P1 has started attending transition meetings because of her son's age. P4 communicates via email with her son's teachers and aides. And one parent, P7, had to step in with some specific cultural knowledge for the Deaf Charter School. "*They misunderstood the needs of the Somali disabled children. They totally misunderstood.*" So, his involvement is not only for his benefit, but also to help educate others.

When probed about the level of involvement their child had with activities outside of the classroom, there was little consistency from the seven parents. Three of them, P3, P4, P7 did not have anything to share. P1 and P2 said their child is involved with swimming. P6 was interested in having her son get involved, but "*[I]t is too hard. He is always running away.*" P1 shared that her son enjoys going to movies. P1 and P5 expressed happiness that their son and daughter, respectively, enjoy music and dancing. And finally, P5 says his daughter has shown a desire to paint.

Without prompting, a few of the parents expressed the situation of friendships with their child. P2, P3, P7 shared that their children do have friends within the community. P1 and P6 shared that their sons do not have friends in the community. Of those that have friends in the community, their disabilities are milder in nature.

As parents reflected on their experiences with the schools, it provided answers to research question two, in learning what their desires would be for the schools servicing their children.



**Table 4.6 – Connections Made to School Experiences**

	Progress of Child	Concerns About the Future	Negative/Positive Experiences	Services for Their Child	Parent Involvement at the School	Child's Involvement in School/Community
P1	Expressed satisfaction with his progress 8 times – smiled big and voice was light	Yes	Negative in previous school/positive now that they moved schools	Needs: Speech, OT, Academics PLUS Carer support in the home	Attends individual meetings for child and parent evenings	Swimming/movies, music, dancing – no friends outside of school
P2	Expressed satisfaction of her progress – smiled big and pointed to his cheek where his daughter kisses him after he tells her he is proud of her.	Yes	Positive	Needs: Academic support through small group and 1:1 instruction PLUS Carer support in the home	Attends individual meetings for child	Swimming Has friends outside of school
P3	Expressed satisfaction with his progress – sat up very tall and smiled big when sharing this	Not shared	Positive	Needs: Academic support through small group and 1:1 instruction PLUS tutoring company	Attends individual meetings for child	Has friends outside of school
P4	Expressed satisfaction with his progress, but spoke of the fact that it's been very slow	Yes	Positive now that he's in school	Needs: Speech, OT, PT, Social Skills, Academics PLUS Carer support in the home	Attends individual meetings for child and parent classes; communicates via email with staff	
P5	Expressed satisfaction with her progress, but spoke of the fact that it's been very slow	Yes	Negative with previous case worker/positive now that everyone is working together	Needs: Speech, OT, PT, Social Skills, Academics, Behavior Management PLUS outside support from county social worker and private therapy	Attends individual meetings for child	Music, dancing, and painting outside of school
P6	Expressed satisfaction with his progress, but spoke of the fact that it's been very slow	Not shared	Positive	Needs: Speech, OT, PT, Social Skills, Academics, Behavior Management PLUS therapy in the home	Attends individual meetings for child	Wants him involved, but he runs too frequently/no friends outside of school
P7	Expressed satisfaction of his progress now, but it has taken a long time because of the different issues that have surfaced over the years	Not shared	Negative until they found answers to son's needs and found an appropriate school/positive now	Needs: communication via ASL, support from Psychologist	Attends individual meetings for child and parent classes; has taken an ASL class; provided cultural information to the Deaf school about Somali culture	Has friends outside of school

**Research Question 5.** *As you reflect on your responses would you say that your faith or your [Pakistani or Somali] culture is more influential? Why?* Three themes emerged:

1) How and why they reason with faith or culture, 2) attaching religious meaning to the disability, and 3) feelings towards Islam.

***How and why parents reason with faith or culture.*** As parents reflected on their previous responses, they identified whether their faith or their culture was more important as they brought meaning to raising a child with a disability. Five of the seven parents, without hesitation, responded to this question with “faith” (P1, P2, P4, P6, P7). P3 said it was about the same, and P5 talked about a balance of science and faith [See Figure 4.7].

A few of the parents shared why they did not choose culture, even though not prompted to do so. For example, P6 connected culture to one of her earlier responses about why other Somalis think her son has autism.

*Doesn't have good choice and connected to falling and hitting your head – that's culture. Because always our country, if it's child is disabilities or adult disabilities or whatever, it doesn't have good choice in our culture.*

Some other specific comments made about culture versus religion include:

*P1 - Culture is very different from my religion. Completely two different things. We've acquired our culture from a lot of different countries - from India, from China, da-da-da . . . whatever popped in... we just mix it up - jumble it up - but faith is . . . whatever faith says, what I've experienced - are very different. Religion is different - culturally a lot of people would stop inviting you to their homes because you have a special needs child - they think it's like an ill omen or something - but - in religion it doesn't say that and that's what hurts me.*

*P2: “Pakistani culture is no important. Culture is culture. Religion is religion. Culture no important. Religion is important.”*

*P7: “Why . . . because . . . I don't mind if he takes the American [culture] but culture is not that big a deal to me.”*

P6 – *“Faith. Yeah. Because our religion tells us and raise your kids very good way - any disability or not disability - then raise your kids good way, **especially** disabilities more - take care of it, then you get good deeds.”*

Some of the parents were not quite as assertive with their responses, although they still openly shared that faith was more important than culture. Smiling big, P4 said: *“Um . . . I think Muslim faith. Because we are Muslim, and I believe that, and that's why I teach my children. P7 stated: “Well, I think, as far as we are in the United States, the faith is more important. So, I want him to learn and know this faith. As far as his . . . as far as I'm raising him. Ya. I want him to raise with this faith”.*

In contrast, P3 was not convinced it is one or the other. She said, *“I mean, faith is important as well, and obviously education - everything - I mean, I would say, you know, they are all important.”*

And one parent, P5, spoke passionately about how science and faith come together for him as a Somali father of a 5-year old daughter with a chromosomal disorder.

*Basically, I am a man of science. I believe a lot of in science, and the knowledge of the human being. Although I am a Muslim in faith. These two points, they are complementary . . . they help each other. So, I take the best from the field of science and I use my faith to stay strong, to accept the things how they are, and to go on. The religion give you strength, and . . . to be out of denial - to accept what is there. But the science give you solutions. And we use the science, you know, and it's not written nowhere to not use the science. And the science is the knowledge of the human being. To use the knowledge of the human being.*

When responding with faith over culture in five of the instances, it directly correlates with Jegatheesan's (2010) work when she and her team found that culture was not important at all to the three families they studied. In fact, it was faith that played the greater role. Further, the families in their study and some of the parents in this study identified that their strength they had in raising this child came directly from their faith.

***Attaching religious meaning to disability.*** Throughout the interview, a few of the parents brought specific religious meaning to some of their responses [See Figure 4.7]. For example, P1 shared that “...for me he is normal - because that's the way God made him. He's absolutely fine for me”. She also specifically shared “Faith is my strength.” Further, a Somali mother of a son with autism, P6, shared that “Allah says he's innocent” and again later said, “God not make mistake.” And P7 shared “Everything you get – all is a creation of Allah.” Some other specific examples of the parents attaching religious meaning to their child with a disability include:

P1: *As far as I understand my religion - he's like an angel. And, um, what we are told - I mean what I understand from Qur'an, was like - such kids are a gift to you. Especially for you to have a way to heaven. So they are like a gift to you. So you look after them. You look after them properly, and you are there.*

P1 also talked about the importance of her son practicing even the smallest bit of Islam. *I've just taught him one word which I think he was comfortable learning - it is Allahuakbar - which means 'Allah is great.'* As she reflected on her response, she continued, “*This was the strength I have - my faith - because that's what is written in the Qur'an and that's what everyone says - this is like a gift, and you have to look after them.*”

As P6 connected religious meaning to her son's disability, she added, "*Allah say, [he] is innocent.*" She also talked about how her son's autism was planned long before he was born. She shared that Allah planned her future as a mother back when she was in her mother's womb. "*Then Allah send you angel, and angel wrote everything you will do.*" And P7, in a relaxed response, "*Whatever you get . . . everything is the creation of Allah. So the way I see it is that, with disability or without disability, my [child] is gift from Allah.*"

Three of the parents directly spoke of their son or daughter being a gift from God. Many researchers shared this same message (Crabtree, 2007; Jegatheesan, Miller, & Fowler, 2010; Poston & Turnbull, 2004; Shaked, 2005; Skinner, Bailey, Correa & Rodriguez, 1999; Skinner, Correa, Skinner, & Bailey, 2001). Further similarities connect with Hasnain's (1993) research. Hasnain identified that parents who raise a child with a disability are given a chance to go to heaven for the good work of raising that child well.

***Feelings towards Islam.*** Four of the seven parents gave specific responses to their feelings towards Islam, although not specifically prompted [See Figure 4.7]. P3 was indifferent to it. P2 was very proud of Islam. P5 spoke specifically about how the religious scholars have no knowledge of the field of special education. A Somali mother, P6, shared how the Qur'an and hadiths are important in her life.

*So, then our choice is, when you get something - something good - you have to appreciate a lot. And say thanks God. When you get something you don't like, whatever it is, then you appreciate God. 'Cause God give it to you. And God is not made a mistake. It's good. So, I believe in that. So I'm not . . . sometimes if you didn't know something, you get confused the first time, then - you have to*

*learn your religion back and check what's Qur'an says. Qur'an says, say [something], say thanks God, move on, and do whatever you can. But, if you get problem, that's our answers everything of a life, everything. Covers everything. (when referencing the Qur'an/Hadith).*

A Somali father, P5, shared a passionate response towards Islam and science:

*I have to say that [religious leaders] have no knowledge of [special education] because this field is complicated. It is not enough to be a religion person. You know, and not only relatives in Somalia, but here, they are all conditioned by the point of view of the religion people. The religious people, they say that this is, you know, something from God, and God knows why He did this, and to accept. But the religion people, they don't give you the know-how, they don't give you how to do - how to improve. They don't tell you these things. These things you find from the specialists, from the science. So . . . this is the basic difference. The religion people, do you know, they cannot say that. They said she will talk if God want. You know, this the reason why I give a lot of care to the science, because the science give answers.*

As these parents spoke about their feelings of Islam, there was one particular parent, P5, who shared about his frustration with the religious scholars because he felt they do not know anything about special education. Ahmed al-Thani (2008), who has done a lot of work for the United Nations, sees it a bit differently. She believes it is the religious scholars who need to come alongside the families and show them how Islam is open and accepting to disabilities in order that families who have members with disabilities would not feel rejected

and ostracized by the greater community. P5 wants more than acceptance. He says that Muslims accept the disability of his daughter, but he wants more. He wants them to understand that it is just more than “God made her.” He wants the religious scholars to know that because of science and education, more can be done for his daughter. He does not want basic acceptance.

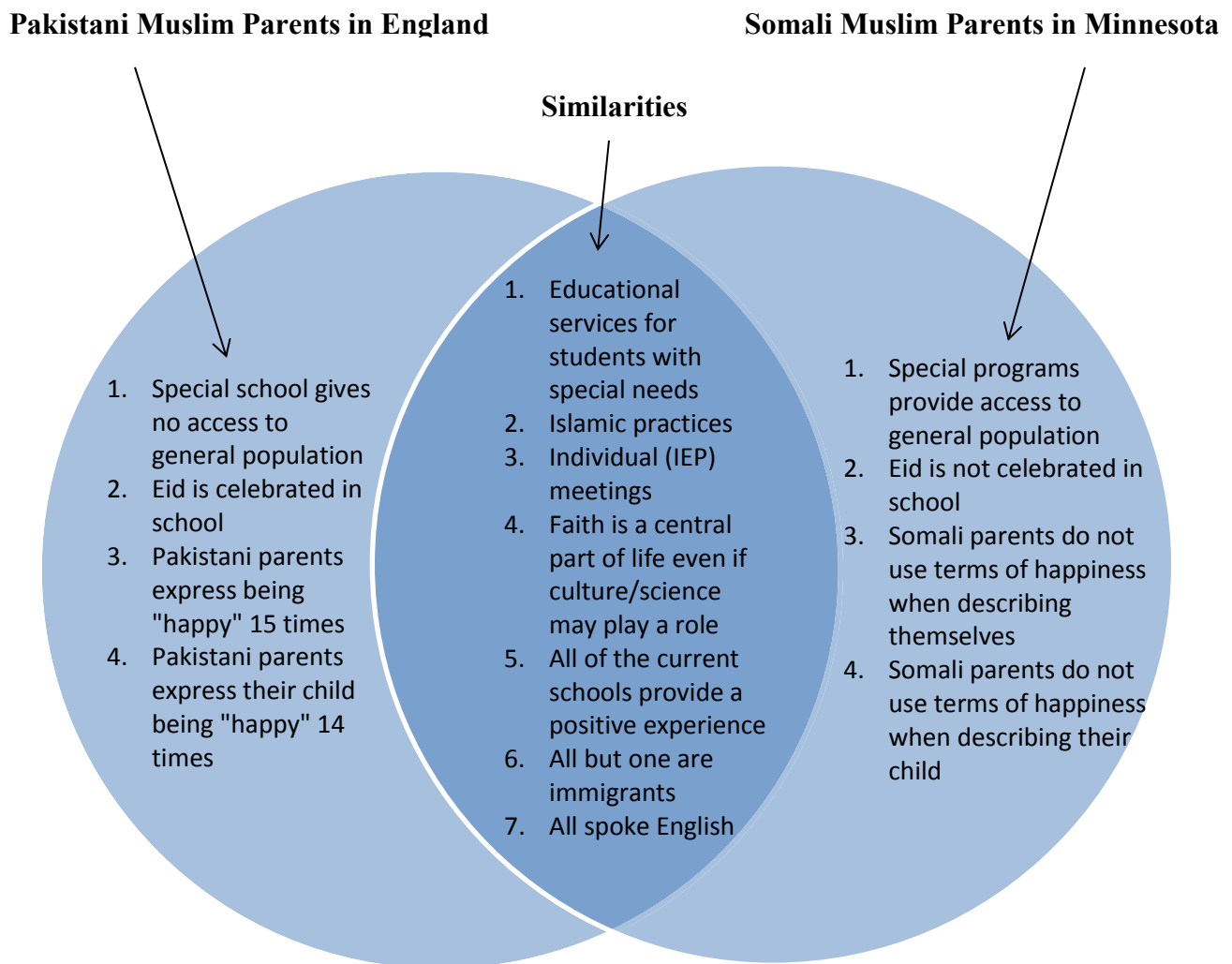
Responses to question 5 fit under research question one because these parents provided very detailed responses to why they chose faith, culture, or both in what plays a greater role when raising their child with a disability. Most of the answers shared by these parents directly connect to the literature reviewed in Chapter 2, as shared in each of the previous sub-sections.

Table 4.7 Parents’ Reasoning: Faith or Culture?

	Faith or Culture?	How/Why the Parent Reasons This	Why Not Culture?	Attaching Religious Meaning to the Disability	Feelings Towards Islam
P1	Faith	Culture comes from many different countries coming together; faith stays the same	Culture considers disability an ill-omen. Faith does not.	Son is an angel sent from Allah; “My faith is my strength” Son is a gift; ...a way to heaven.	Positive
P2	Faith	Culture is not important; faith is important –guides your living	Culture is food, TV, media and teaches kids bad habits		Proud of Islam
P3	Faith and Culture	They are both important – education, too – all important			Indifferent to Islam
P4	Faith	Because I am Muslim it is important to me			Positive
P5	Faith and Science	Use faith to stay strong; Use science to understand my daughter’s disability			Religious scholars have no knowledge of special education
P6	Faith	Because Islam teaches to raise children in a good way	Culture gives bad reasons for disability	“God says [my son] is innocent”; “God not make mistake” All is a creation of Allah – gift from Allah.	Important to show appreciation for all things in life
P7	Faith	American or Somali – culture doesn’t matter. Faith matters.		“Everything you get – all is a creation of Allah”	Positive

Finally, Figure 4.8 shows the similarities and differences between Pakistani Muslim parents in England and Somali Muslim parents in Minnesota based on the results shared in all previous sections.

Figure 4.8 Similarities and Differences between Pakistani Muslim Parents in England and Somali Muslim Parents in Minnesota



***Final responses from parents.*** At the end of each interview, the researcher asked the parent if he or she had anything else they wanted to add. Some of them had quite a



bit to share and a few just repeated things they felt were important from their earlier responses. The researcher felt it was important to include these because some of their responses reflect goals that were shared in the literature (e.g., getting parents involved, connecting with external resources, etc.) Their answers included:

P1 wants others to know that there are great opportunities to get involved. She said, *“Because of my involvement with the Down Syndrome Association, CI is involved with music/dancing sessions every other weekend, gets special passes to a Theme Park, and attends films”*. She also attends coffee parties where they discuss things such as “how to deal with teenagers.

Although he had already shared the importance of friendships in his daughter’s life, P2 added again: *“and my experience is only friendship more important [than] your families. If friendship is no good, you can't think about future.”*

P3 added this, *“Nothing, to be honest. He's getting the help he needs. He's happy and he's doing well.”*

P4 had been hesitant to do the interview because she felt she had nothing to share. At the end, she added: *“I'm happy to do [this], but I think, my husband, if he's there, he can tell you more. Yeah, that's why I said [to him] please, can you do that. And he come to me, and he said . . . why you not doing that?”*. The researcher felt P4’s responses demonstrated a good understanding of and response to the questions asked.

P5 shared his passion for parent involvement: *The parents, first of all, they have to be in the front line, [but] so many parents, they don't like to talk about these things.*

P6 laughed at this point and talked about how she has changed as a mother since having a son with autism. *He - ya - because - before I get [C6], maybe I'm not*

*that patient mom. But now I'm changing very much. I have a lot of patience, because he brought things...I change many things. I cannot explain. I change way way way way better. Because before, everything was OK [before giving birth to C6]. You're like everything is perfect. But now, I accept everything. Many things. (laughter) So . . . So, I like my kids very good education, and whatever I get, I have to get good kids - good education kids. But that's not what Allah says. Allah's choice for her children was different than what this mother would have chosen; she has now accepted this.*

P7 –He explained the complexities of culture and communication in the Deaf world of his Muslim Somali son.

*Well another problem [my son] has is...how [he] needs to know the difference between the two worlds he live in. Ya. And that's what I'm struggling with too. I don't wanna make [him] disabled because he confuse the culture. I mean it's obviously a barrier than we cannot deny. We try to - we try our best to be part of the mainstream culture, but it is reality. We cannot act a culture that we are a stranger to it. We cannot act comfortable.*

P7 expressed further sadness about the difficulty with teaching his Muslim faith to his son because of not knowing ASL as his father and not having access to another Muslim who knows ASL who could maybe teach his son.

*Absolutely, I'm short of that strength and resource, and financially I cannot, you know, hire someone who can take [him] like he needs. He needs a lot of time. Investment of a lot of time, actually. So, I cannot get someone who is fluent in sign language and the faith I want to teach [my son].*

So, as learned from the seven parent interviews, there will continue to be barriers for most of these families, but each parent shared such hope in their overall responses to the interview. When considering the questions for the interview were designed from the study done by Jegatheesan, Miller, and Fowler (2010), it is encouraging to recognize that most of the parents in this study had much more positive stories to share – especially as they related to the services their child received.

In reflection of the first overarching research question, “How do Muslim parents in the United Kingdom and the United States make sense of having and raising a child with a disability within their cultural meaning systems?” it is clear from the results that the parents’ Muslim faith helps them make sense of raising a child with a disability and that culture may play a role, but not one of significance.

Finally, in summary of the second overarching research question, “How do Muslim parents desire that the schools work with them?”; the parents did not end up answering this specific question because each one was already satisfied with the services being provided for their child. Although specific responses were not given, based on their positive responses, it would seem that communication, collaboration, and providing multiple supports for families makes a positive difference for these families. It was evident through the examples parents provided about their satisfaction with the schools (i.e. 15 uses of the term happy when describing their own feelings; 14 uses of the term happy when describing their child). [See Figure 4.6]

## **CHAPTER 5**

### **Discussion, Implications, Recommendations**

When special educators partner with parents to plan for their child's special needs, the topic of religion is generally not discussed. However, several different researchers have found faith to be an integral part if and when religion is an important part of a family's life (Poston & Turnbull, 2004; Jegatheesan, Miller, & Fowler, 2010). Jegatheesan, Miller, and Fowler sought to find out what cultural factors played a role with three Muslim families when raising a child with autism. During their 18 month ethnography, they found that the parents' Muslim faith played a far greater role than the family's South Asian culture. This researcher used her doctoral research to extend their work and to determine if other Muslim parents of children with disabilities felt the same way.

#### **The Study**

The purpose of this qualitative study was to "generate...theory and contribute to knowledge for the sake of knowledge" (Patton, 2002, p. 10) in the area of religion, specifically Islam, and special education. There is a growing awareness in the field of special education that more knowledge is needed on how Islamic beliefs affect a family's parenting decisions for the life of their child with a disability (Jegatheesan et al., 2010). Since there is limited information found on religion in special education, and even less found on Islam (Ault, 2009), the data gathered from this study will add to the limited pool of research on Islam and special education.

Additionally, by extending and doing a replication of sorts of Jegatheesan, Miller and Fowler's (2010) work, this researcher wanted to find out if there were similarities

and/or differences when working with a different sample, to their study which included South Asian Muslim immigrants in the Midwest who were parenting a young child with autism. Two of the core findings from Jegatheesan's study were that the families' Muslim faith played a central role in raising a child with autism and that the families were dissatisfied with the education personnel because the focus was always on their child's deficits rather than their child's gifts. Since each of these families believed their child was a gift from Allah, they did not want to focus on their child's deficits. This researcher interviewed seven Muslim parents in order to learn about their child, their experiences with the child's special education programming, and whether or not it was faith or culture that played a greater role in raising their son or daughter with a disability. These questions addressed the needs presented by Jegatheesan et al. (2010).

The two overarching research questions of this study included: 1) How do Muslim parents in the United Kingdom and the United States make sense of having and raising a child with a disability within their cultural and religious meaning systems? 2) How do Muslim parents desire that the schools work with them?

The participants for this study included seven Muslim parents, each one raising a child with an identified disability. The participants were chosen from two areas where the researcher has had professional special education experiences: South Eastern England and the state of Minnesota in the United States. Both of these locations have a high percentage of Pakistani or Somali immigrants, respectively, who practice Islam.

The researcher conducted semi-structured in-depth interviews with four Pakistani Muslim parents from England in January 2012 and three Somali Muslim parents from Minnesota in April 2012. Specific disabilities and ages were not sought; simply having a

child with an identified disability was sufficient. These parents were asked to participate with help from two different Head Teachers (principals) in England and a Somali Cultural Liaison in Minnesota.

This project was guided by five interview questions to determine if faith or culture was an integral factor in Muslim parents' lives when raising a child with a disability as well as whether or not these parents were satisfied with their child's special education programming. The questions asked of each participant were:

1. I know that you have a child with special needs. Tell me about your child and his/her education plan. (I would use the name if it is shared with me)
  - a. Possible probes beyond question #1 – disability type? What kind of special services?
2. What is it like to raise this child in this community? (I would use the name if it is shared with me)
  - a. Possible probes beyond question #2 – Out in public? At the Mosque?
3. Tell me about a time that worked well with your child's education.
  - a. Possible probes beyond question #3 – classroom activities? school-wide activities? Teachers? Peers? What was it that made it work well in your mind?
4. Tell me about a time that didn't work so well.
  - a. Possible probes beyond question #3 – classroom activities? school-wide activities? Teachers? Peers? What would you have liked to have happened instead?

5. As you reflect on your responses would you say that your faith or your \_\_\_\_\_ culture (Bangladeshi, Pakistani, or Somali) is more influential? Why?

## **Conclusions**

It was evident to this researcher that Muslim parents in South Eastern England and Minnesota rely on their faith when raising a child with a disability. This study found their Muslim faith had played some kind of role for each of the seven parents. When responding to whether it was faith or culture that played a greater role, five of the seven parents replied ‘faith’ without hesitation and added that culture played no role. The remaining two parents included ‘faith’ in their response, although they asserted other reasons as well. One parent said it was equal, and one parent said that science and faith played a role – each being complementary to the other. Additionally, these Muslim parents were satisfied with current programming for their child and did not specifically desire anything different. Before reaching these conclusions, the researcher heard poignant stories from the parents as they shared about their child. The following details describe the conclusions made from this work.

This qualitative study intended to focus on practicality rather than generalizability because the researcher was seeking particular descriptions and themes developed in the context of the participants’ lives (Greene & Caracelli, 1997). However, even with the small number of participants, there were some themes that can be generalized. Those are also included in the following details.

**Types of Disabilities.** It would seem that the type of disability and whether the disability was mild or moderate-severe makes a difference in the experiences these

families had within their communities. When the child had a mild disability, two of the seven parents said that they did not experience negativity or non-acceptance from others within their cultural community. However, when the disability was more moderate to severe, five of the seven parents did experience negativity and non-acceptance within their cultural community. These five parents have a child whose disability is likely visible to some degree to other people (e.g., in the actions or behaviors of the child, in their physical appearance, or in the way they communicate). Crabtree (2007) found in her research, in the United Arab Emirates, those Muslim families who have a child with a disability feel excluded because of actions and words brought upon them from other Muslims in their communities. It would seem that issues of acceptance happen across the world for Muslim families, as seen in five of the families in this study.

When digging deeper into the idea of acceptance, it is interesting to note that the two parents with a child with a mild disability were not immigrants and everyone else was an immigrant (the range of years varying greatly). Maybe there are no conclusions to make from this, but perhaps acceptance looks and feels different to a person who is not an immigrant.

It was particularly interesting to the researcher that medical terms were used so freely from six of the seven parents since no medical questions or probes were asked during the interviews. Five of the six parents who shared specific medical details were describing particular connections to the disability; one parent, P2, although he spoke of medical issues at his daughter's birth, did not connect the medical terms to her present needs. The five parents who shared medical connections to the disability each have a



child with a moderate to severe disability. It would seem that by bringing medical characteristics into their story they were making sense of the disability.

Other differences between mild disabilities and more moderate to severe disabilities included the topics of friendship, connections with outside organizations, and other family members' involvement. The two children with mild disabilities had friends outside of school, whereas the five with more moderate to severe disabilities did not. The two parents with children with mild disabilities did not mention any involvement with outside organizations that provide support for families dealing with disability issues; whereas those parents of children with more moderate to severe disabilities did. Those same parents provided quite a few details about other family members whereas the two parents of children with mild disabilities did not. It would seem that when a parent has a child with a more moderate to severe disability they access outside organizations to help them understand the disability as well as to lean on and receive support from others in similar situations. It also seems that other family members play a greater role when a child has a more severe disability. All of this provided a clearer picture as the researcher sought to find out how these parents reason about raising a child with a disability.

One particular disability type, deafness, had some unique perspectives. The researcher feels it is important to include those here because they relate to previous research done with Muslim deaf students in England. Although only experienced by one parent, it is important to make the connection for the Muslim deaf community, a minority group in multiple ways. Ahmad, Darr, Jones, and Nisar (1998) found that achievement and preservation of a deaf identity was at the expense of losing their South Asian ethnic and Muslim identity in England. These deaf students experienced marginalization in

their ethnic and religious communities because of language barriers; and, although it was easier to make alliances within the deaf community, they also experienced some racist marginalization in the white deaf society.

In this current study, P7 shared stories about his son that are very similar. As much as he desires for his son to practice Islam, he has not been able to because P7 cannot find a Muslim male who knows American Sign Language. And, although his son has friends at his deaf school, many in the Muslim community do not accept him and P7 feels that it is because they do not really understand deafness and disability. Within his school, the marginalization comes from the staff who do not understand the Somali culture or Islam. Based on previous research and the input from P7 in this study, it is likely that deaf students who are Muslim have greater barriers than other deaf students (Ahmad, Darr, Jones, & Nisar 1998).

**The role of the family.** The idea of family support came through clearly from the five parents who have a child with a more moderate to severe disability [See Figure 5.1]. Each of these parents described the role of family in different ways, but it was evident that the role of family was important to them. And although only one parent specifically stated that raising her son with a disability will provide a special way for her to get to heaven, the researcher wonders if the other parents believe there is a direct route to heaven if one has helped a person with a disability (Hasnain, 1993) and therefore involve all family members in the process.

Table 5.1 Variations of how parents reason raising a child with a disability

	Used medical terminology to describe child's background	Acceptance from others in the community	Discussed family support	Child had friends outside of school	Parents involved with or accessed outside organizations
Mild Disability (invisible) P2, P3	No	Yes	No	Yes	No
Moderate-Severe Disability or Sensory Impairment (visible) P1, P4, P5, P6, P7	Yes	No	Yes	No	Yes

**Special education programming.** The services the children received were similar between countries; it was clear the services reflected the needs of the child. Although the types of schools varied between the countries, the schools reflect the systems in place in both countries.

All seven parents expressed satisfaction in their child's educational programming, demonstrating that ethnic background and disability type did not appear to matter in these seven cases. Three expressed previous negative experiences, but now that they found the right school and right providers, things were positive. It was interesting to find that there was a particular difference in the way the Pakistani parents from England spoke about their satisfaction versus the Somali parents in Minnesota. The Pakistani parents frequently used the word "happy" to express how they felt about their child's educational services. It is not clear if it is common to use this term in England or if it is cultural that Somali parents tend not to use this term when describing their satisfaction. As will be noted in the next section, this satisfaction is a sharp contrast to the findings from Jegatheesan et al. Additionally, all seven parents were involved with their child's

educational programming and attended meetings to discuss progress and programming. It may be that satisfaction would be higher for any parent who is involved with their child's programming, but this too is in contrast with Jegatheesan's study on Muslim families.

When comparing this study to the work from Shah (1995), there are correlations with P5's experiences. When P5 and his wife first learned of their daughter's chromosomal disorder, they were in denial and disbelief. It was not until they started getting support from a social worker and county worker that they could start to accept what was. And although P5 never talked about feeling punished by God, he and his wife did go through a similar process as the parents Shah describes in her work. Shah explained that although parents may initially feel punished by God with the birth of their child with a disability, these moments are fleeting and are replaced with acceptance as the parents seek help from appropriate providers. However, if the social service agencies lack understanding and cultural sensitivity towards their clients, they are not likely to be effective. An element of trust is necessary in order for the work to be effective. This is a similar scenario P5 experienced with his daughter. Although very satisfied with all of her services now, there was a time when things were very difficult and it was because he did not trust the providers. With some new providers and a great deal of communication, P5 spoke often about how much he trusts everyone who now works with his daughter.

When reflecting on the overarching question of how the families desire the schools work with them, it is evident through their high levels of satisfaction that in their minds, nothing needs to change. One of the probing questions in the interview protocol included, "What would you like to have happened instead?" (this was used to probe if

they were not happy with services). This question provided no data because all seven parents were satisfied and did not desire for anything to be changed. This is in contrast to Jegatheesan et al. (2010) study where each of the three parents experienced dissatisfaction. One of the reasons for this difference may lie in the age of the child and the types of services he/she receives. In Jegatheesan's study, the children were at early childhood age, i.e., under five years old. This meant the professionals went into the home to provide services and therefore were in a more personal space than what would have in the school. However, in this current study, the one parent who did receive services in her home was satisfied with the services she received. This is not enough data to come to any formal conclusion, but it brings an important point to light. When faith plays an integral role in the home, and when educational services are provided in the home, it may be even more important for the education professional to understand and respect that family's religious actions.

**Religious practice.** Although the religious practice of each family differed, it was evident that having their child with a disability be involved in some way with their Islamic faith was important to them. Whether it was attending mosque, celebrating Eid, going to daily religious lessons, or taking part in daily prayers, each parent had their child involved in whatever way they felt their child could manage it.

P2 and P3, both Pakistani parents living in England with a child with a mild disability, have their child attend daily religious lessons. This is similar to the multiple stories shared in the popular Muslim online magazine, *emel* (2011). Having a son or daughter attend daily religious lessons is important for many Muslim families and Ismael, a religious teacher in the London Muslim community, is doing what he can to make sure

families know that all children can attend religious lessons regardless of ability. It was not shared by the two parents in this study if their son and daughter receive special supports, only that they do attend on a daily basis.

Two other parents have taught their sons simple acts of Islamic faith, similar to the families in Jegatheesan et al. study. P1, a Pakistani Mother of a boy with Down syndrome, has taught him “Allah is great” in Arabic because she knows he can understand that. P6, Somali mother of a boy with autism, has taught her son how to pray by using special DVDs. It is evident, that regardless of disability, these parents desire that their children take part in Islamic practices whenever possible and appropriate.

As noted in the literature review, the Qur’an has verses that specifically address these actions demonstrated by the families in this study. The verses speak to the value of a true heartfelt seeker of God, even though weak or disabled, is more than that of one who may be wealthy and powerful, but is unmindful of God (Basna & Hatab, 2005, p. 13). Although these parents may not have used specific words identifying these verses, it is evident through their stories that they believe this of their sons and daughters.

**Faith or culture.** As each parent responded to the final question in the interview on whether it was faith or culture that played a greater role in raising their child with a disability, five of the seven said “faith” with no hesitation. Additionally, they quickly added reasons why culture did not play a role. The other two parents admitted that their Muslim faith played a role, but it was equal to culture for P3, and P5 shared that science and faith played an equal role – that they were complementary. This is similar to Jegatheesan et al., in that each one connects their Muslim faith when reasoning why and how they raise their child with a disability. Within the two studies, there is a minor

difference connected to religion in that only three of the seven parents specifically attached religious meaning to the disability of their child in this present study, whereas in Jegatheesan's study, all three families attached specific religious meaning to the disabilities. The researcher did not ask a specific question about this which could be the reason behind this particular difference.

This finding about faith contrasts with the literature from Abd-Allah (2006) who shared that most Muslims see faith and culture as one; the two are naturally woven together in their minds and in their lives. Although there may be aspects of these participants' lives where culture and faith are woven together, they definitely felt that it was faith that played the more significant role in raising their child with a disability. Abd-Allah's work was not specific to individuals raising a child with a disability, but it was specific to Muslims' lives, which of course connects to any Muslim. Further, these present findings contrast with the feelings of Somali advocate, Hassan Samanter (2012), who shared that Somali parents would not know the difference between culture and faith.

As these findings demonstrate the importance of Muslim faith in each of these parents' lives, and as they shared the stories of raising their children with disabilities, they are clearly following the teachings of their Islamic faith. One of those teachings is that "all children have the right to have equal life chances regardless of being ... abled or disabled" (Morad, Nasri, & Merrick, 2001, p. 68). The parents in this study clearly hope for their child with a disability to have equal life chances even if it may look different than other children.

It was particularly interesting to review the response from P5 as he talked about faith and science being complementary to each other. Although no other parent shared

this particular sentiment, it fits with the thinking of the Muslim leaders who wrote the introduction to the Muslim Council of Britain's Educational Guide for Schools in Great Britain (Muslim Council of Britain, 2007). As noted in the literature review, this guide speaks to the importance of education in the history of Islam: "Knowledge and learning has traditionally been divided into two categories - revealed knowledge (Qur'an and Prophetic sayings) and acquired knowledge (natural sciences, physics, astronomy, history, mathematics etc.) and the pursuit of both has historically been a preoccupation of Muslim scholars" (p. 10). This fits beautifully with the passion shared by P5. Faith and science are truly complementary for a Muslim.

**Relationship of conclusions in this study to Jegatheesan's work.** Since the researcher used questions in her interviews that extended and replicated, in part, the work of Jegatheesan, Miller, and Fowler (2010), it is important to share the similarities and differences that were found in this work compared to their work. This study did not ask specific questions about the topics shared here, but responses from the parents in this study do fit under similar categories.

Jegatheesan et al. found that each of the three families they observed over the course of 18 months believed their child with autism was a gift from Allah. Three parents from the study reported here used words in their responses that are comparable. In the study done by Jegatheesan et al., they found that, because of seeing their child as a gift from Allah, it was especially difficult that the educators' focus was on their child's deficits. In the study reported in this paper, all seven parents were satisfied with their child's present programming and the negative experiences three of the parents had had in the past were not related to faith.



Another similarity connects with one particular mother in Jegatheesan et al.'s work who shared that having a child with autism was not anything negative; it was simply determined before the mother was even born. That directly relates to the comments from P6 in this study where she also shared that Allah planned for her to have a son with autism when she was in her mother's womb.

When looking at the goals the families had for their children, there were a few similarities between the studies. In the work from Jegatheesan et al., the goal was that their children would be immersed in every aspect of life because that is what is interpreted from the Qur'an. In this study, P1 specifically addressed this same idea, and three other parents discussed how their son/daughter was involved with other aspects of life beyond school. Three parents specifically desired that their child be involved in more things, but the child's behaviors are too significant at this point for that to happen.

One of the major differences between the two studies relates to the parents' satisfaction with their children's special education programming. Jegatheesan et al. (2010) found that all three families were frustrated with the educators' focus on their child's deficits as well as the fact that strategies being recommended for the child at home came from a Euro-American focus and therefore did not always work for these Muslim families because of the deep integration of religious practices in the home. In this study, all seven parents were satisfied with present special education programming. Another important similarity is that four of the seven parents in this study have special education support personnel coming to their homes, or did at one point. This was a critical element in the work done by Jegatheesan et al. One piece from this study that could be loosely connected to Jegatheesan et al.'s work, is that one parent, P7, although

completely satisfied with his son's special education programming, expressed concern about the school staff not understanding the Somali culture, albeit not faith. Seeing this great need directly, he then provided this training for them.

This difference in satisfaction could possibly lie in the participants who participated in each study. The Pakistani Muslim parents in this study were chosen by the Head Teachers from their son/daughter's school. As far as the researcher knows, the Head Teachers simply chose potential participants based on the fact that the child had a disability and that the parent was Muslim, but there could have been bias in this process. And although it did not appear that the parents were giving responses to please anyone, this also could have played a role (See Appendix C for consent form).

Finally, when looking at the main purpose for doing this work, it is encouraging to see that one of the main findings from Jegatheesan et al. was also found in this study. When Jegatheesan et al. originally started their work, they set out to study how the cultural system in which the families were nested played a role in their understanding of and raising their child with autism. In the end, they learned it was the families' Islamic faith that played the primary role in their lives. In this study, too, when responding to the final interview question on whether it was faith or culture that played a greater role in raising their child with a disability, five of the seven parents had no hesitation when responding with "faith". The other two parents included faith as an important factor, but culture and science also played a role for them.

One of Jegatheesan's desires for future research was to determine whether or not different ethnic backgrounds of Muslims make a difference. Based on the results from this study, it does not appear that being Pakistani Muslim or Somali Muslim makes a

difference in how a parent raises their child with a disability. The biggest difference between the two ethnic backgrounds was how they described their satisfaction with the schools. However, the researcher feels this has more to do with living in England than it does with being Pakistani.

## **Implications**

There are many implications that have come from this study, albeit a small qualitative study. These implications can be directly connected to Muslims and the Islamic faith, but they may also be potentially connected to any other faith groups because issues with disabilities are clearly not confined to one religion or ethnic background.

**Schools.** Many school districts in Minnesota provide informational brochures and handouts on the different ethnic backgrounds that may be represented within a district; the Minnesota Department of Education also provides some information on the ethnic backgrounds represented across the state. This researcher does not believe this is enough. There could be more and improved materials provided for teachers and schools so that they may understand their students better and especially those whose faith directs everything they do. These materials could include (1) guides for professionals who provide services in the homes and how particular religions may have specific requirements within the home; (2) guides for how particular religions may identify disabilities so that there is a clear distinction from specific cultures; and (3) guides for transition age students related to religious activities.

England has a good start on the Muslim guide they currently use in their schools, although there is not anything related to special education in it. The Muslim Council for

Britain (2007) has created a 70 page guide for schools to use in order to understand their Muslim students better. In addition to giving British teachers a good understanding of their Muslim students, it provides practical guidance on common educational practices that may be offensive to Muslim students or even some things that Muslim students may need accommodated or modified because of their religious beliefs. It is a practical guide and one that could easily be replicated for all schools with Muslim students.

**Special educators.** This study should be able to help special educators understand the importance of finding out if and when families have a strong faith component in their lives as it may be their faith that is helping them deal with and reason about how to raise this child. This is especially important when a family is first told their child has been identified with a disability because it may be the piece that helps them process through those first difficult decisions. Yes, in America there is separation of church and state, but a special education teacher will be able to do so much more if they truly understand the values that are most important to a family. The importance of the relationship between the family and the education professionals cannot be underestimated (Lord Nelson, Summers, & Turnbull, 2004; Poston & Turnbull, 2004). It is this relationship that can help build a strong and successful program for the student with the disability and when the teacher takes the time to dig in and understand the family's values, this relationship will likely be strengthened.

Additionally, for Muslim students with special needs who are at transition age (14-21 in Minnesota) it is critical that discussions of religious activities and involvement be discussed. If faith plays an integral part of a student's life, then special educators need to help them appropriately plan their goals so they can be as independent as possible in

taking part in their religious rituals (Ault, 2009; Poston & Turnbull, 2004). It is known in the special education community that in order for students to reach their goals, it is best for them to reach them in natural settings. In this case, Muslim students should be able to work on their goals at their local mosque, which could include goals for attending mosque or goals for attending religious classes. This researcher would even recommend that parents know that they can invite the religious teacher or other religious leader from the mosque to the IEP meeting to be a part of the planning; this is true wrap-around services.

Finally, as it relates to special educators, it may prove helpful to partner with doctors if and when a disability has a medical diagnosis. In this particular study, it identified five of the seven parents openly defined their child's background with connections to doctors and the medical field. Could this potentially help other Muslim parents get to a point of acceptance of their child's disability?

**Parents.** Any parent of a child with a disability can benefit from the results of this study if they have a strong faith background of any kind. This researcher believes it is very important for parents to speak up about their beliefs and to make sure the school recognizes how their faith impacts every part of their life, not just one day of the week.

With the most recent amendment of IDEA (2004), there was an addition to the parent roles that have historically been a part of IDEA. This new seventh role speaks to the importance of partnership: "Parents and families as education decision-makers, as partners with educators in developing 'I-plans' and helping to carry them out – this being the current role envisioned by IDEA" (Turnbull, Turnbull, Erwin, & Soodak, 2006, p. 293). As this researcher found, these seven parents were satisfied with their child's

educational programming, but Jegatheesan, Miller, and Fowler (2010) found the opposite; it is clearly important that partnerships exist in order for quality programming to take place.

**Islamic religious community.** It seems evident from this study that although each of these families is involved with their Islamic faith in some way or another, each of them would like more involvement. In order for that to happen, they need support from the religious community. These families are not alone. Bazna and Hattab (2005) reported that when mosques exclude congregants with disabilities it reflects limited awareness of understanding the needs of people with disabilities. Islamic religious leaders can help combat this. They could encourage their congregants to get involved with and help those with disabilities in their faith communities. This would allow more individuals to get to know those with disabilities and to begin to learn acceptance through their own experiences with these individuals. This demonstrates ideas straight from the Qur'an that Muslims are expected to always seek out opportunities to help the disadvantaged, advocate for their needs, and generously provide from one's own time and property (Bazna & Hattab, 2005).

Further, Islamic scholars could do more with providing opportunities for all children to take part in religious lessons, regardless of their abilities. As Miles (2002) shared, there are some hadith (Tritton, 80, 81) that give specific examples of religious teachers giving "feeble-minded" students multiple opportunities to learn things. Again, this is an example that comes straight from the teachings of Muhammad that are so important to the Islamic faith, the hadith. Focusing on and utilizing specific connections to disabilities from the Qur'an and hadith may help other Muslims begin to understand

and accept these individuals. The faith community could be a great catalyst for this. Thani (2008), in her work for the United Nations in Arab countries, is depending on prominent Muslim scholars to help her cause in advocating for the rights of people with disabilities in Muslim communities. There is no reason Muslim communities in England and Minnesota cannot be doing the same thing.

**Muslim communities.** During this study, three Muslim parents specifically mentioned how they are trying to give back to their communities by helping other Muslims understand what disabilities are in order to help encourage acceptance of individuals with disabilities. Further, they desired to help other parents of children with disabilities get to the point where they're at and become a support for one another. Two parents shared that by telling their story to the researcher, they were helping other parents in some way. That should not go unnoticed; their stories should be told and hopefully many other parents will be encouraged and inspired. They are not alone.

**Teacher preparation programs.** When students are being trained to become teachers, they are required to fulfill standards which the state has identified. In Minnesota, standard three covers issues surrounding diversity (see page 59 for the specific standards). Religion is never mentioned in these standards, but one could fit it under several categories – specifically standards 3E, 3F, 3H, 3J, 3O, 3P, and 3Q. This researcher believes training programs need to be more intentional with identifying how faith is different from culture and a teacher needs to do more than just understand differences across cultures. As this study demonstrated, six of the seven parents do not connect culture and faith at all.

## **Recommendations**

**Recommendations for practioners.** Based on the findings from this current study, this researcher feels it is important that practitioners would recognize the great importance that faith can play in a family's life. Particularly, Somali and Pakistani families exude their Islamic faith, as shared in detail in chapter 4 of this dissertation, pages 138-144. All seven parents in this study connected to faith on some level; five of the seven parents had very strong feelings about faith. A parent's faith should not be hidden or be made to feel like it cannot be discussed. This researcher wants to encourage education practitioners to not be afraid of a faith that may be unknown to them, but rather to dig in, learn about it, ask the family. The Muslims' stories will likely be heartwarming, encouraging, inspiring and probably not so unlike the practioners' own stories, if they happen to have a deep faith conviction.

Practioners should also be aware that just because they might understand certain cultures, such as Somali or Pakistani, does not necessarily mean they will understand the family's faith. As learned in this study, culture and faith are separate to families and that should be recognized and respected.

Also, practioners should be encouraged that some Muslim families are satisfied with the services received (Bonawitz, 2013) and, based on this study, it appears that is because of communication and collaboration with the families (P1, P5, P6, P7). This level of satisfaction may be more difficult to attain when education professionals provide services in the home (Jegatheesan et al., 2010), so it is especially important for early childhood educators to be aware of religious practices that take place in the home and that these religious practices may require changes in educational programming.



**Recommendations for academics.** This researcher feels this study is just the beginning of other important research and activities that should happen related to Islam and special education as well as other religions and special education. It is evident there is a great need that exists as Jegatheesan, Miller, and Fowler's study (2010) and this researcher's study only touched upon the lives of 10 Muslim families combined. There is so much more out there waiting to be uncovered. This researcher believes the following ideas would enrich the field of research. They include:

- Creation of a survey that includes a combination of questions from Jegatheesan, Miller, and Fowler's study, as well as from this study. This would allow for more parents to be involved and potentially easier to obtain since it would be less intrusive to the parents. Surveys could be written in multiple languages therefore removing the limitation of only parents who speak English. With a survey, more questions could be asked and there would be less variation in the responses. This could be a partnership with multiple researchers obtaining input from different parts of the world (e.g., The Midwest, Minnesota, England, Qatar – to name a few).
- Continued partnership with the Qatari professors. Expand on the presentations already conducted to put together recommendations for professionals in Qatar and the United States.
- Conduct a Case Study on Parent 1 and Parent 5. These parents had particularly rich stories to tell; stories that continued when the interviews officially ended. There is so much more to share and the information

could be extended into many new directions (parent advocacy, the exploration of faith and science, etc.).

- Investigate further into the idea of whether or not medical diagnoses change the level of acceptance for families; conduct this study across all population groups with disabilities.
- Create a Muslim guide for schools in partnership with the local Muslim community and the Minnesota Department of Education. Use the British Muslim Council's guide as a starting point; include a specific section on special education and early childhood special education.
- And, even though getting policies changed can be an insurmountable task, this researcher wonders if it is time to add the terms "faith" and "religion" to the required standards for all teachers.

### **Concluding comments**

This researcher went into this work with great excitement to learn about Muslim parents of a child with a disability in England and Minnesota. She came away with a much richer experience than she could have anticipated. It was one thing to be inspired by the work of Jegatheesan, Miller, and Fowler (2010), but it is a quite another thing to be inspired by actual Muslim parents who care so much about their children with disabilities. To hear their beautiful stories during the interviews and then have the opportunity to listen to them over and over again was such a blessing.

Conducting a qualitative study was desired by this researcher because she wanted to get at the heart of what Muslim parents go through when raising their child with a disability. She wanted to know their stories, hear their pains and praises. That goal was

accomplished. The interviews, and more importantly the persons behind the interviews, brought their stories to life. The researcher has stayed in touch with a few of the parents and looks forward to continued friendships with them. An added bonus will be getting to see how their child continues to grow and whether or not there will be changes related to acceptance within the greater Muslim communities.

Finally, even though there are still so many things the researcher would like to know, such as asking more questions of the parents in order to get responses in all of the categories that surfaced, there is a definite sense of fulfillment and peace from this experience. There will never be a time when all of the questions will be answered; therein lies the gift of research. There will always be more to learn. For the moment, it is enough for this researcher to know that faith really is important to these Muslim parents and it really is different than culture. There can be other factors, too, that parents rely on when raising a child with a disability, but it is comforting to this researcher that families rely on something far greater than themselves.

## REFERENCES

Abd-Allah, U.F. (Fall, 2004). Islam and the cultural imperative. *Crosscurrents*.

Retrieved from <http://www.crosscurrents.org/abdallahfall2006.htm>

Ahmad, W.I.U., Darr, A., & Jones, L. (2000) 'I send my child to school and he comes back an Englishman': minority ethnic deaf people, identify polics and services, in W.I.U. Ahmad (Ed.) *Ethnicity, Disability and Chronic Illness* (Buckingham, Open University Press).

Ahmad, W., Darr, A., Jones, L., & Nisar, G. (1998). Deaf people from minority ethnic groups: initiatives and services. <http://www.jrf.org.uk/system/files/scr818.pdf> retrieved on March 8, 2011.

Ali, Z., Fazil, Q., Bywaters, P. , Wallace, L., & Singh, G. (2001). Disability, ethnicity and childhood: a critical review of the research. *Disability & Society*, 16(7) 949-968.

Allied Media Corp (n.d.) Retrieved December 28, 2011 from Allied Media Corp for Muslim American Market <http://allied-media.com>

Anzar, U. (2003). Islamic education: A brief history of madrassas with comments on curricula and current pedagogical practices. Retrieved from [www.uvm.edu/~envprog/madrassah/madrassah-history.pdf](http://www.uvm.edu/~envprog/madrassah/madrassah-history.pdf)

Arc, The. Retrieved on July 18, 2011 from The Arc of Minnesota <http://www.arcmn.org/>

Asad, M. (1980). *Message of the Qur'an*. Lahore, Pakistan: Maktaba Jawahar Ul Uloom.

- Asad, M. (1999). *Islam at the crossroads*. Kuala Lumpur, Malaysia: The Other Press  
(original work published 1934).
- Atkin, K., Ahmad, W. I. U., & Jones, L. (2002). Young South Asian deaf people and their families: negotiating relationships and identities1. *Sociology of Health Illness*, 24(1), 21-45.
- Ault, M.J. (2009). Inclusion of religion and spirituality in the special education literature. *The Journal of Special Education*, 44(3) 176-189.
- Azmi, S. (1997). Canadian social service and the Muslim community in metropolitan Toronto. *Journal of Muslim Minority Affairs*, 17, 153-167.
- BBC Religions (n.d). Retrieved December 27, 2011, from BBC for Religions:  
[http://www.bbc.co.uk/religion/religions/islam/history/uk\\_1.shtml](http://www.bbc.co.uk/religion/religions/islam/history/uk_1.shtml)
- Bari, M. A., & Alam, T. (2007). Meeting the needs of Muslim students in state schools. *Muslim Council of Britain*. Retrieved from [www.mcb.org.uk](http://www.mcb.org.uk)
- Bazna, M.S., Hatab, T.A.(2005). Disability in the Qur'an. *Journal of Religion, Disability & Health*, 9(1) 5-27.
- Begum, N. (1992). '...Something to be Proud of...' the lives of Asian disabled people and carers in Waltham Forest (London Borough of Waltham Forest, Race Relations Unit and Disability Unit).
- Brantlinger, E., Jimenez, R., Klingner, J., Pugach, M., & Richardson, V. (2004). Qualitative studies in special education. *Exceptional Children*, 71, 195-207.
- Brett, J. (2002). The experience of disability from the perspective of parents of children with profound impairment: is it time for an alternative model of disability, *Disability and Society*, 17(7), 825-843.

- Bywaters, P. , Ali, Z., Fazil, Q., Wallace, L.M., & Singh, G. (2003). Attitudes towards disability amongst Pakistani and Bangladeshi parents of disabled children in the UK: Considerations for service provides and the disability movement. *Health and Social Care in the Community*, 11(6), 502-509.
- CIA World Factbook (n.d.). Retrieved December 28, 2011, from the Central Intelligence Agency's World Factbook: <https://www.cia.gov/library/publications/the-world-factbook/geos/us.html>
- Cicourel, A. (1974) *Cognitive Sociology*. New York: Free Press.
- Corsaro, W.A. (1985). *Friendship and peer culture in the early years*. Norwood, NJ: Ablex.
- Crabtree, S.A. (2007). Family responses to the social inclusion of children with developmental disabilities in the United Arab Emirates. *Disability & Society*, 22(1), 49-62.
- Creswell, J.W. (1998). *Qualitative inquiry and research design: Choosing among five traditions* (Rev.ed). Thousand Oaks, CA: SAGE Publications, Inc.
- Creswell, J.W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches*. (3<sup>rd</sup>. Ed.). Thousand Oaks, CA: Sage Publications
- Data Accountability Center (2013).
- Department for Education (2012, July 12). Special Educational needs in England – First statistical release.  
<http://www.education.gov.uk/rsgateway/DB/SFR/s001075/index.shtml>
- Department for Education (2013, July 20). Special Education needs in England: A guide for parents and carers. <https://www.gov.uk/government/publications/special-educational-needs-sen-a-guide-for-parents-and-carers-revised-2009>

- Diken, I.H. (2006). Turkish mothers' interpretation of the disability of their children with mental retardation. *International Journal of Special Education*, 21(2), 8-27.
- Emel. (n.d.) Muslim Lifestyle Magazine. *In the shade of the Qur'an*. Issue 81, June 2011.  
Retrieved from: [http://www.emel.com/article?id=86&a\\_id=2409](http://www.emel.com/article?id=86&a_id=2409)
- Endrawes, G., O'Brien, L., & Wilkes, L. (2007). Mental illness and Egyptian families. *International Journal of Mental Health Nursing*, 16(3), 178-187.
- Erickson, F. (1986). *Qualitative methods in research on teaching*. In M.C. Wittrock (Ed.), *Handbook of research on teaching* (3<sup>rd</sup> ed., pp. 119-161). New York: Macmillan.
- Esposito, J. (2003) *The Oxford Dictionary of Islam*. Oxford University Press: New York, NY.
- Federal Reserve Bank of Minneapolis (n.d.). Retrieved December 27, 2011 from Federal Reserve Bank of Minneapolis  
[http://www.minneapolisfed.org/publications\\_papers/pub\\_display.cfm?id=2476](http://www.minneapolisfed.org/publications_papers/pub_display.cfm?id=2476)
- Gabel, S. (2004). South Asian Indian cultural orientations toward mental retardation. *Mental Retardation*, 42, 12-25.
- Gallimore, R., Coots, J.J., Weisner, T.S., Garniers, H., & Guthrie, G. (1996). Family responses to children with early developmental delays II: Accommodation intensity and activity in early and middle childhood. *American Journal of Mental Retardation*, 101, 215-232.
- Gallimore, R., Weisner, T.S., Guthrie, D., Bernheimer, L., & Nihira, K. (1993) Family response to young children with developmental delays: accommodation activity in

- ecological and cultural context. *American Journal of Mental Retardation*, 98, 185-206.
- Gallimore, R., Weisner, T.S., Kaufman, S., & Bernheimer, L. (1989). The social construction of ecocultural niches: Family accommodation of developmentally delayed children. *American Journal of Mental Retardation*, 94, 216-230.
- Gaskins, S., Miller, P. J. & Corsaro, W.A. (1992). Theoretical and methodological perspectives in the interpretive study of children. In W.A. Corsaro & P. J. Miller (Eds.), *New directions for child development: 58*. Interpretive approaches to children's socialization (5-23). San-Francisco: Jossey-Bass.
- Geaves, R. (2006). *Key Words in Islam*. The Continuum International Publishing Group Ltd.: London, U.K.
- Greater London Association for Disabled People (1987) *Disability and Ethnic Minority Communities – A study in three London boroughs* (London, Greater London Association for Disabled People).
- Haboush, K. (2007). Working with Arab American families: Cultural competent practice for school psychologists. *Psychology in the Schools*, 44(2), 183-198.
- Hasnain, R. (1993). *Attitudes towards Pakistanis toward children with disabilities: A pilot study*. Unpublished paper, Boston University.
- Hasnain, R., Shaikh, L. C. & Shanawani, H. (2008) *Disability and the Muslim perspective: An introduction for rehabilitation and health care providers*. Center for international rehabilitation research information and exchange (CIRRIE).
- Hassan, I.N. (1990). An overview of Muslim spiritual therapy and other practices in dealing with mental health problems in Pakistan. In: MH Mubbashar & AR Syed



- (eds) *Proceedings of the Eighth International Psychiatric Conference*, Dec. 11-14, 1990, Vol. 2, Islamabad: Pakistan Psychiatric Society.
- Huda, Q. (2006). *The diversity of Muslims in the United States* [Special Report, United States Institute of Peace]. Available at [www.usip.org](http://www.usip.org)
- Hussain, Y. (2003). Transitions into adulthood: Disability, ethnicity and gender among British South Asians. *Disability Studies Quarterly*, 23 (2), 110-112. Available at [www.cds.hawaii.edu/dsq](http://www.cds.hawaii.edu/dsq)
- Jegatheesan, B., Miller, P. J., Fowler, S.A. (2010). Autism from a religious perspective: a study of parental beliefs in south Asian Muslim immigrant families. *Focus on Autism Other Developmental Disabilities*, 25(2), 98-109.
- Joni and Friends Ministry (n.d.) Retrieved on December 27, 2011 from Joni and friends ministry [www.joniandfriends.org](http://www.joniandfriends.org)
- Kalyanpur, M., & Harry, B. (1999). *Culture in special education*. Baltimore: Brookes.
- Keim, J., Ryan, A.G., & Nolan, B. F. (1998). Dilemmas faced when working with learning disabilities in post-secondary education. *Annals of Dyslexia*, 48, 273-291.
- Keller, C., Khalil, B., Bonawitz, K. (2011, April). *Interfaith dialogue: How world religions of Islam and Christianity impact special education*. Interfaith Dialogue hosted by Bethel University, St. Paul, MN.
- Khedr, R. (2006). *Putting disability on the Muslim agenda*. Retrieved from <http://onislam.net/english/family/moms-and-dads/the-family-home/435536.html> on March 8, 2011.
- Kleinman, A. (2006). Anthropology in the clinic: The problem of cultural competency and how to fix it. *PLOS Medicine*, 3(10), 1673-1676.

- Kvale, S. & Brinkmann, S. (2009). *Interviews: Learning the craft of qualitative research interviewing*. (2<sup>nd</sup> Ed.) Thousand Oaks, CA: SAGE Publications.
- Laird, L.D., Amer, M. M., Barnett, E. D., Barnes, L. L. (2007) Muslim patients and health disparities in the UK and the US. *Archives of Disease in Childhood*, 92, 922-926.
- Lang, J. (1997). *Even angels ask: A journey to Islam in America*. Beltsville, MD: Amana Publications.
- Lo, L. (2012). Demystifying the IEP process for diverse parents of children with disabilities. *Teaching Exceptional Children*. 44 (3), 14-20.
- Lord Nelson, L.G., Summers, J.A., & Turnbull, A.P. (2004). Boundaries in family-professional relationships: implications for special education. *Remedial and Special Education*. 25 (3), 153-165.
- Lynch, E.W., & Hanson, M.J. (1998). *Developing cross-cultural competence: A guide for working with children and their families* (2<sup>nd</sup> ed.). Baltimore: Brookes.
- Merriam, S.B. (1992). *Qualitative research and case study applications in education*. San Francisco: Jossey-Bass.
- Merriam, S.B. (1998). *Qualitative research and case study applications in education* (Rev.ed). San Francisco: Jossey-Bass.
- Miles, C. (2002). On working in Peshawar with disabled children and families. *Journal of Religion, Disability, and Health*, 6:2, 145-148.
- Miles, M (2002A). Disability in an eastern religious context: historical perspectives. *Journal of Religion, Disability, and Health*, 6:2, 53-76.

- Miles, M. (2002B). Some historical texts on disability in the classical Muslim world. *Journal of Religion, Disability, and Health*, 6:2, 77-88.
- Miles, M.B. & Huberman, A.M. (1994). *Qualitative data analysis: An expanded sourcebook* (2<sup>nd</sup> ed.). Thousand Oaks, CA: SAGE Publications.
- Minnesota Department of Education (n.d.) Retrieved on July 17, 2013 from the Minnesota Department of Education Data Center's Web site:  
<http://w20.education.state.mn.us/MDEAnalytics/Maps.jsp>
- Minnesota Department of Education. (n.d.) Retrieved on December 28, 2011 from the Minnesota Department of Education  
<http://education.state.mn.us/MDE/EdExc/StanCurri/index.html>
- Morad, M., Nasri, Y., & Merrick, J. (2001) Islam and the person with intellectual disability. *Journal of Disability Religion and Health*, 5:2, 65-71.
- Moustakas, C. (1994). *Phenomenological research methods*. Thousand Oaks, CA: Sage.
- Muslim Council of Britain (n.d.). Retrieved October 17, 2011, from the Muslim Council of Britain: <http://www.mcb.org.uk/library/statistics.php>
- Musse, I.A. (2002). Disability: An Islamic insight. Retrieved December, 28, 2011 from <http://www.icv.org.au/ps20011018.shtml>
- Nasen. (n.d.) Retrieved on July 19, 2013 from nasen: helping everyone achieve  
<http://www.nasen.org.uk/links/>
- National Parent Partnership Network (n.d.) Retrieved on July 19, 2013 from the National Parent Partnership Network <http://www.parentpartnership.org.uk/>
- Newton, R. (1997). *The Down's Syndrome Hand Book: A Practical Guide for Parents and Carers* (London: Vermillion).

- Nihira, K., Weisner, T., & Bernheimer, L. (1994). Ecocultural assessment in families of children with developmentally delays: Construct and concurrent validities. *American Journal of Mental Retardation*, 98, 551-566.
- Odom, S.L., Brantlinger, E., Gersten, R., Horner, R.H., Thompson, B., and Harris, K.R. (2005). Research in special education: Scientific methods and evidence-based practices. *Exceptional Children*, 71 (2), 137-148.
- Pacer Center. (n.d.). Retrieved July 18, 2011 from Parent Advocacy Group <http://www.pacer.org/>
- Patton, M.Q. (2002). *Qualitative Research & Evaluation Methods*. 3<sup>rd</sup> Ed. Thousand Oaks, CA: SAGE Publishing.
- Pew research report (n.d.). Retrieved December 28, 2011, from The Pew Forum on Religion and Public Life Web site: <http://religions.pewforum.org/reports>
- Pipes, D., & Duran, K. (2002) *Muslim Immigrants in the United States*. Backgrounder. Center for Immigration Studies.
- Poston, D.J., & Turnbull, A.P. (2004). Role of spirituality and religion in family quality of life for families of children with disabilities. *Education & Training in Developmental Disabilities*, 39, 95-108.
- Poston, D.J., Turnbull, A.P. , Park, J., Mannan, H., Marquis, J., & Wang, M. (2003). Family quality of life outcomes: A qualitative inquiry launching a long-term research program. *Mental Retardation*, 41, 313-328.
- Prospects Organisation (n.d.) Retrieved December 27, 2011 from Prospects Christian organisation for people with disabilities [www.prospects.org.uk](http://www.prospects.org.uk)

- Raghavan, C., Weisner, T.S., & Patel, D. (1999). The adaptive project of parenting: South Asian families with children with developmental delays. *Education and Training in Mental Retardation and Developmental Disabilities*, 34(3) 281-292.
- Raghavan, R. & Waseem, F. (2007) Services for young people with learning disabilities and mental health needs from South Asian communities. *Advances in Mental Health and Learning Disabilities*. 1(3) 27-31.
- Rizvi, F. (2005). Representation of Islam and education for justice. *Race identity and representation in education*. (2), 167-178.
- Roraback, A. (2004) *Islam in a Nutshell*. Enisen Publishing: Santa Monica, CA.
- Salatomic. (n.d.). Retrieved on July 19, 2013 from <http://www.salatomic.com/sp.php?d=&t=mosques&r=10&l=Minneapolis%2C+MN>).
- Shah, R. (1995). *The Silent Minority – children with disabilities in Asian families* (London, National Children’s Bureau). [likely will change this reference to the updated version from 2004 – waiting for the book to arrive]
- Shah, R. (1999). *Summary Report of the Developmental Work and Research Undertaken for Washwood Heath Young Disabled Peoples Project* unpublished (available from Naseby Centre, Naseby Road, Alum Rock, Birmingham).
- Shaked, M. (2005). The social trajectory of illness: *Autism in the ultraorthodox community in Israel*. *Social Science and Medicine*, 61, 2190-2200.
- Skinner, D., Bailey, D., Correa, V., & Rodriguez, P. (1999). Narrating self and disability: Latino mothers’ construction of identities vis-à-vis their child with special needs. *Exceptional Children*, 65, 481-495.

Skinner, D., Correa, V., Skinner, M., & Bailey, D.(2001). Role of religion in the lives of Latino families of young children with developmental delays. *American Journal on Mental Retardation*, 106, 297-313.

Special Education Needs and Disability Act (n.d.). Retrieved January 15, 2012 from The National Archives at <http://www.legislation.gov.uk/ukpga/2001/10/contents>

Thani, A.S.H.K. (2008) United Nations *enable*. Retrieved from <http://www.un.org/esa/socdev/enable/diswpa00.htm> on October 17, 2011

Turnbull, H.R. (2005) Individuals with disabilities education act reauthorization: accountability and personal responsibility. *Remedial and Special Education*. 26(6) 320-326.

Turnbull, A. P. , & Turnbull, H. R. (2001). *Families, professionals, and exceptionality: Collaborating for empowerment*. (4<sup>th</sup> ed.). Columbus, OH: Merrill.

Turnbull, H. R., Stowe, M. J., & Huerta, N. E. (2007). *Free appropriate public education: the law and children with disabilities* (7th ed.). Denver: Love.

Turnbull, A., Turnbull, H., Erwin, E., & Soodak, L. (2006). *Families, professionals, and exceptionality: Positive outcomes through partnership and trust* (5th ed.). Upper Saddle River, NJ:Pearson Education, Inc.

Turnbull, H.R., Turnbull, A.P. , Wehmeyer, M.L., & Park, J. (2003). A quality of life framework for special education outcomes. *Remedial and Special Education*, 24(2), 67-74.

Warnock Report. (n.d.). Retrieved December 28, 2011 from Education in England <http://www.educationengland.org.uk/documents/warnock/warnock20.html>

Watkins, E. & Liu, K. K. (2013). Who are English language learners with disabilities?  
*Impact*. 26(1), 2-3, 33.

Williams, C. (2011, October 27). New census data: Minnesota Somali population grows.  
*StarTribune*. Retrieved from <http://www.startribune.com/132670583.html>

Woessner, P. (2002). Size of Twin Cities Muslim population difficult to determine.  
*Community Dividend*. Retrieved from:  
[http://www.minneapolisfed.org/publications\\_papers/pub\\_display.cfm?id=2476](http://www.minneapolisfed.org/publications_papers/pub_display.cfm?id=2476)

## **APPENDIX A**

### **Interview Questions**

I know that you have a child with special needs. Tell me about your child and his/her education plan. (I would use the name if it is shared with me)

Possible probes beyond question #1 – disability type? What kind of special services?

What is it like to raise this child in this community? (I would use the name if it is shared with me)

Possible probes beyond question #2 – Out in public? At the Mosque?

Tell me about a time that worked well with your child's education.

Possible probes beyond question #3 – classroom activities? school-wide activities? Teachers? Peers? What was it that made it work well in your mind?

Tell me about a time that didn't work so well.

Possible probes beyond question #3 – classroom activities? school-wide activities? Teachers? Peers? What would you have liked to have happened instead?

As you reflect on your responses would you say that your faith or your \_\_\_\_\_ culture (Bangladeshi, Pakistani, or Somali) is more influential? Why?



## APPENDIX B

### Request for Approval

Request for Approval of Research with Human Participants

In Social and Behavioral Research

Institutional Review Board for Research with Humans

Bethel University P. O. Box 2322 3900 Bethel Drive St. Paul, MN 55112

College and Federal policies require that each project involving studies on humans be reviewed to consider 1) the rights and welfare of the individuals involved; 2) the appropriateness of the methods used to secure informed consent; and 3) the risk and potential benefits of the investigation. Bethel has a three-level review structure, such that not all research proposals need to come to the IRB committee. The levels of review and their associated criteria may be viewed on Bethel's website. **Research may not be initiated prior to formal, written approval by the appropriate committee or person.**

The information on the following pages is necessary for review. Answer each item thoroughly, and put N/A for those that do not apply. Label each piece of information by section letter (A – G), item number (1, 2, etc.), and the boldface headers for each item.

**Proposals lacking information will be returned without review.** Attach your typewritten pages to this cover sheet.

Submit the completed form to the committee, either at the above address or, if this is Bethel student research, to your research advisor. You *will not* receive this proposal back, so be sure you keep a copy of the materials you submit. You will be notified by letter of the committee's decision.

## Identifying Information

**1) Date – December 14, 2011**

**2) Principal Investigator –**

Katie Bonawitz, Education Department – Bethel University.

3900 Bethel Drive St. Paul, MN 55112 PO #14

Ph# 612-670-6825

katie-bonawitz@bethel.edu

**3) Co-investigators – N/A**

**4) Project Title -** *Muslim Parents of Children with Special Needs: Perspectives from immigrants to the United Kingdom and the United States*

**5) Key Words –** *Special Education, Parents, Children with Special Needs, Muslim, Islam, Qualitative, Interviews.*

**6) Inclusive Dates of Project –** January 2012 – April 2012

**7) Research Advisor –**

Louise Wilson, Education Department – Bethel University

3900 Bethel Drive St. Paul, MN 55112 PO #14

651-638-6507

louise-wilson@bethel.edu

**8) Funding Agency – N/A**

**9) Investigational Agents – N/A**

## Participants

**1) Type of Participants –** Adults: Muslim parents of children with disabilities

- 2) **Institutional Affiliation** – Participants will be recruited from administration at the school where their child attends.
- 3) **Approximate Number of Participants** 15-20
- 4) **How Participants are Chosen** – Muslim parents of children with disabilities will be referred to the investigator from an administrator at the school where their child attends. Parents who sign the consent form and agree to a 1 hour semi-structured interview with the investigator will be included in the study.
- 5) **How Participants are Contacted** – Participants will be contacted by the administrator from their son/daughter's school based on the fact that they are Muslim and have a son/daughter with special needs. This will be a purposive sample. A letter will be provided at that time in order for the parent to determine if they wish to take part in an interview.
- 6) **Inducements** – The administrator of the school in England has offered to provide cake for the parents. The investigator has accepted this offer because the administrator has shared that it is a welcoming gesture for these parents. A small, \$10 thank you gift will be given to each participant from the investigator upon completion of the interview.
- 7) **Monetary Charges** – N/A

**C. Informed Consent** –All participants must sign the informed consent form before the interview takes place. The informed consent form is attached to this file

**D. Abstract and Protocol**

- 1) Hypothesis and Research Design** – The purpose of this study is determine how Muslim parents make sense of and raise their child with a disability within their cultural and religious meaning systems while their child is receiving special services at a public school. The two main questions guiding this research are as follows: 1) How do Muslim parents in the United Kingdom and the United States make sense of having and raising a child with a disability within their cultural and religious meaning systems? 2) How do Muslim parents desire that the schools work with them? This will be a qualitative study using semi-structured interviews to gather data from the participants.
- 2) Protocol** –The investigator will conduct 5-10 individual interviews with Muslim parents in England and in Minnesota (total of 10-20). The England interviews will take place in January 2012 in an area southwest of London, England. The Minnesota interviews will take place in February and March 2012 in Minneapolis and St. Paul schools. Prior to the interviews taking place, individuals will be contacted by the administrator at his/her child's school and asked if they would be interested in taking part in this study. At that point, they will be given letter of consent further explaining the purpose of the study (either from the investigator or the administrator will provide a copy). If the parent agrees to take part, he/she will be given the consent form and an interview time will be set up in a conference room at his/her child's school. An individual that the parent knows and trusts from the school may also sit in on the interview if the parent would so choose. Prior to the interview beginning, the informed consent will be reviewed again, the purpose of the study will be reviewed and the participant will be asked

if he/she has any questions or concerns about the process. As stated in the informed consent, the parent may stop the interview at any time and request that the notes and recording be destroyed if they decide to change their mind and not partake. Interviews will be recorded with a digital recording device as well as by written notes.

## **E. Risks**

**1) Privacy** – The information being shared in the interviews will be provided solely by the participants. Names of parents, their children and the school their child attends will be changed in order to insure anonymity. The only identifying characteristic will be the name of the region or area where the school resides and what age range of children the school serves (Windsor Borough in England; Urban District in a mid-western state). Upon completion of this study, all personal information will be destroyed (both digitally formats and hard copies).

**2) Physical stimuli** – No known risk identified.

**3) Deprivation** – No known risk identified.

**4) Deception** – No known risk identified.

**5) Sensitive information** – There is a great possibility that information being shared will be personal and sensitive as it relates to a child with a disability and the parent's religious beliefs. As noted earlier, all identifying information will be changed in order to protect the participants. Also, participants will know the topic in advance and will be able to determine if they want to participate.

**6) Offensive materials** – No known risk identified.

**7) Physical exertion** – No known risk identified.

**F. Confidentiality** –Each interview will be audio-recorded with a digital recording device. During the interview, the investigator will also take notes. The interviews will be transcribed and once the interviews have been transcribed, parents will have the option to review them and determine if they are accurate or if they wish for anything to be removed (this will be done in person when possible and via email or postal delivery – dependent on parent’s request). Any identifying characteristics will be changed in order to insure anonymity. The investigator will collect, maintain, use and destroy all interview materials. Destruction of all hard copy materials will take place through a reputable shredding company. Destruction of all digital materials will take place with the help of an IT expert at Bethel University.

**G. Signatures** – Type the following paragraph at the end of the proposal and have all investigators and the research advisor (if applicable) sign and date below it.

“I certify that the information furnished concerning the procedures to be taken for the protection of human participants is correct. I will seek and obtain prior approval for any substantive modification in the proposal and will report promptly any unexpected or otherwise significant adverse effects in the course of this study.”

## APPENDIX C

### Letter of Consent

Dear \_\_\_\_\_,

You are invited to participate in a study of *Muslim Parents of Children with Special Needs: Perspectives from the United Kingdom and the United States*. I hope to learn how Muslim parents of children with special needs make sense of having and raising a child with special needs. I also hope to learn how you feel about what the school is doing for your child. You were selected as a possible participant in this study because the Head Teacher/ Principal knows that you are a Muslim parent of a child with special needs. I am conducting this research for my doctoral studies in the Ed. D program at Bethel University in St. Paul, Minnesota. If you decide to participate, I will spend one hour with you conducting an interview on this topic. Although the interview questions will be directed to you, you are welcome to have someone you know and trust with you during the interview. I will be recording the interview with a digital recording device as well as taking notes during the interview. The questions will be provided in a written format as well as asked by me. If at any time during the interview you wish to stop and no longer take part in it, you have that choice. You may also choose to have any information you shared removed from my records. Following the interview, I will transcribe all of the information and you will have the option to review the transcription in order to determine its accuracy. The purpose of conducting an interview is so that I may listen to you and hear your story. To show gratitude for your time and participation, there will be a small gift given following the interview.

Any information obtained in connection with this study that can be identified with you will remain confidential and will be disclosed only with your permission. In any written reports or publications, no one will be identified or identifiable and only aggregate data will be presented. The audio recordings and written notes will kept by me and will be destroyed upon completion of this research.

Your decision whether or not to participate will not affect your future relations with your child's school or with Bethel University in any way. If you decide to participate, you are free to discontinue participation at any time without affecting such relationships.

This research project has been reviewed and approved in accordance with Bethel University's Levels of Review for Research with Humans. If you have any questions about the research and/or research participants' rights or wish to report a research-related injury, please call Katie Bonawitz, Lead Investigator, at 651-638-6724 or Craig Paulson, Program Director, Ed. Program at Bethel University at 651-635-8025.

You will be offered a copy of this form to keep.

You are making a decision whether or not to participate. Your signature indicates that you have read the information provided above and have decided to participate. You may withdraw at any time without prejudice after signing this form should you choose to discontinue participation in this study.

Signature	Date
Signature of Witness (when appropriate)	Date
Signature of Investigator	Date