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Disability and the Muslim Perspective: An Introduction for Rehabilitation and Health Care Providers

Rooshey Hasnain
Center for International Rehabilitation Research Information and Exchange (CIRRIE)

Laura Cohon Shaikh
Center for International Rehabilitation Research Information and Exchange (CIRRIE)

Hasnan Shanawani
Center for International Rehabilitation Research Information and Exchange (CIRRIE)

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Disability and the Muslim Perspective: An Introduction for Rehabilitation and Health Care Providers

Abstract
[Excerpt] This monograph offers an introduction to and overview of a broad spectrum and diversity of Muslims with disabilities and chronic health conditions who come from a variety of backgrounds and circumstances. The perspective provided here also highlights larger issues of human rights. Given the current immigration trends in the United States, it is critical that service providers work across cultures and systems to help Muslims access disability and health care services and resources in their communities. Over the years, service professionals and researchers have come to recognize that individuals with disabilities and health conditions do not always hold the same health beliefs, understandings, objectives, and priorities as the service providers they encounter. The result is an intercultural gap in understanding between clients and providers that may result in a poor treatment or rehabilitative outcome. This monograph will use the terms client, consumer, and patient interchangeably to denote those seeking disability services, medical services, or both. We emphasize that to bridge the gap between Muslim service users and mainstream U.S. service systems, service providers in disability and rehabilitation systems need to increase their sensitivity and ability to accommodate differences between their services and the needs of their clients.

Keywords
disability, Muslim, healthcare, public policy, accommodation, rehabilitation

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Rooshey Hasnain
Laura Cohon Shaikh
Hasan Shanawani

This monograph is part of the series *The Rehabilitation Provider's Guide to Cultures of the Foreign-Born*, published by the Center for International Rehabilitation Research Information and Exchange (CIRRIE). This series is available on the CIRRIE website at http://cirrie.buffalo.edu/monographs/

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CIRRIE
Center for International Rehabilitation Research Information and Exchange

University at Buffalo
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Center for International Rehabilitation Research Information and Exchange
(CIRRIE)
515 Kimball Tower
State University of New York, University at Buffalo
Buffalo, NY 14214
Phone: (716) 829-3141 x 125
Fax: (716) 829-3217
E-mail: ub-cirrie@buffalo.edu
Web: http://cirrie.buffalo.edu

This publication of the Center for International Rehabilitation Research Information and Exchange is supported by funds received from the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education under grant number H133A050008. The opinions contained in this publication are those of the authors and do not necessarily reflect those of CIRRIE or the Department of Education.

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Disability and the Muslim Perspective: An Introduction for Rehabilitation and Health Care Providers

Preface

In its initial monograph series, the Center for International Rehabilitation Research Information and Exchange (CIRRIE) focused on the cultures of eleven major countries of origin for immigration to the United States. No predominantly Muslim country was included, because no single Muslim country was among the top tier of immigration. Taken as a whole, however, immigration from the Muslim world to the United States is substantial. The Census Bureau estimates that 2.34 million Muslims live in the United States, and nearly two thirds of adult Muslims in the United States were born elsewhere (Salmans, 2007). Moreover, Islamic perspectives in many areas of life, such as disability and rehabilitation, are not always widely understood in the United States. As disability service providers are increasingly called upon to work with persons with disabilities from Islamic backgrounds, knowledge of these perspectives may enable them to provide more effective services. Consequently, by publishing this monograph, CIRRIE hopes to fill in an important gap in its earlier series.

Previous CIRRIE monographs focused on the influence of various cultures. This monograph is somewhat different, given that Islam is a religion rather than a specific culture. Religion is an important aspect of culture, but it must be recognized that Islam is a religion that spans many regions of the world and many cultures. Some aspects of Islam are nearly universal, however, and it is these aspects of Islam that are the focus of the monograph. At appropriate points, the monograph notes the cultural variations among different Islamic countries.

The authors of this monograph have extensive experience with this topic. *Rooshey Hasnain, Ed. D.,* is a Visiting Research Assistant Professor at the University of Illinois at Chicago (UIC). She works at the Center for Capacity Building on Minorities with Disability Research that is funded by the National Institute for Disability and Rehabilitation Research under Grants H133P060003 and H133A040007 and is affiliated with several departments at UIC, including the Department of Disability and Human Development, Occupational Therapy, Asian American Studies and the Honors College. She has more than 16 years of experience in the disability and rehabilitation fields. Dr. Hasnain was formerly at the University of Massachusetts, Boston, and Children's Hospital Boston, where she coordinated several initiatives for the Institute for Community Inclusion that focused on culturally competent disability services for immigrant and refugee communities.

Laura Cohon Shaikh earned her undergraduate degree in biochemistry from Harvard University, then attended the University of Michigan Medical School in Ann Arbor. She is currently completing her residency in physical medicine and rehabilitation at Schwab Rehabilitation Hospital in Chicago.

Hasan Shanawani, MD, MPH, is an Assistant Professor of Internal Medicine at the Wayne State University School of Medicine in Detroit, Michigan. He is also a research fellow for the Institute for Social Policy and Understanding (ISPU), an independent nonprofit research organization studying U.S. domestic policy issues. His teaching and research interests are in cultural competency of physicians providing end-of-life care to patients from minority ethnic and religious backgrounds. He advises the Association of Muslim Health Professionals and the Islamic Medical Association of North America on professionalism, bioethics, and patient needs in North America.

This monograph on Islam and disability was developed by the Center for International Rehabilitation Research Information and Exchange (CIRRIE) at the State University of New York at Buffalo. The mission of CIRRIE is to facilitate the exchange of information and expertise between the United States and other countries in the field of rehabilitation. CIRRIE is supported by a grant from the National Institute for Disability and Rehabilitation Research of the U.S. Department of Education.

We hope that the publication of this monograph will contribute to improved disability services for Muslims with disabilities in the United States.

John H. Stone, Ph.D., Director
Center for International Rehabilitation Research Information and Exchange (CIRRIE)
Series Editor

Reference:

Salmans, S. (2007). "Muslims in America." *Trust, 10*(3), 10-15.

Disability and the Muslim Perspective: An Introduction for Rehabilitation and Health Care Providers

Acknowledgements (Rooshey Hasnain)

Thanks are due to the individuals and families who generously shared their views and feelings about disability issues. The information they provided contributed greatly to our understanding of complex issues that face Muslims with disabilities, both locally and globally.

Special thanks go to those who provided specialized information. Lance Laird generously shared his own research on Muslims and disability and provided relevant information and resources. In addition, Aqil Sajjad and Imam Yucel provided information about disability and health from the cultural and religious points of view.

Several others gave specialized support. Rabia Khehr provided constructive comments. M. Miles provided detailed and very useful information and critiques of earlier versions. Mary Ann Jezewski and Paula Sotnik drew me to the cultural brokering framework so central to this work. Shakil Sattar, an undergraduate student at UMass invested his time and energy to create a map of the Muslim world as the inside cover of this monograph.

Personal support came from several others. Helen Snively helped greatly in refining, tailoring, and completing this work. Jon Queijo provided valuable support and input throughout the project. Kathleen Wisniewski provided constant support in pulling together our edits and references.

In particular, I acknowledge my father, Riaz Hasnain, who has always inspired me to take a step that can make a difference in the lives of others. This monograph is a step in that direction; we hope it serves as a catalyst to bring public awareness and research to issues of disability and rehabilitation facing Muslim individuals and families to the forefront.

Finally, very special thanks to John Stone who supported the idea and development of this monograph for the CIRRIE series given that so little has been published in this area. We cannot thank him enough for this opportunity.

Disability and the Muslim Perspective: An Introduction for Rehabilitation and Health Care Providers

Introduction

As communities become increasingly multicultural and multilingual, professionals in the disability and health care fields face both tremendous challenges and great opportunities as they work with individuals from diverse and complex Muslim backgrounds. Unlike previous monographs in the series published by the Center for International Rehabilitation Research Information and Exchange (CIRRIE) that focus on the cultures of specific countries, this publication focuses primarily on the broad category of Muslims living in the United States, including immigrant, refugee, and indigenous Muslims. Although we focus primarily on Muslims in the United States, the ideas presented here should transfer well to other countries, such as the United Kingdom, Australia, and Canada. By addressing a population that has been seriously overlooked and misrepresented, we hope this monograph will fill a void in the literature on disability intended for use by rehabilitation and health care professionals. We highlight both the difficulties and the successes that Muslims with disabilities experience as they seek access to the opportunity to live a meaningful life. The growing number and diversity of Muslims in the United States challenges disability and health care providers and researchers to understand this population's perspectives, experiences, and ways of practicing Islam, particularly relative to health care, disability, and rehabilitation.

Organization and Purpose of the Monograph

This monograph offers an introduction to and overview of a broad spectrum and diversity of Muslims with disabilities and chronic health conditions who come from a variety of backgrounds and circumstances. The perspective provided here also highlights larger issues of human rights. Given the current immigration trends in the United States, it is critical that service providers work across cultures and systems to help Muslims access disability and health care services and resources in their communities. Over the years, service professionals and researchers have come to recognize that individuals with disabilities and health conditions do not always hold the same health beliefs, understandings, objectives, and priorities as the service providers they encounter (Ali, Fazil, Bywaters, Wallace, & Singh, 2001). The result is an intercultural gap in understanding between clients and providers that may result in a poor treatment or rehabilitative outcome. This monograph will use the terms client, consumer, and patient interchangeably to denote those seeking disability services, medical services, or both. We emphasize that to bridge the gap between Muslim service users and mainstream U.S. service systems, service providers in disability and rehabilitation systems need to increase

their sensitivity and ability to accommodate differences between their services and the needs of their clients.

This monograph is divided into eight major sections. In this introductory section, we provide an overview and rationale for our work. We focus on the issues, needs, and assets of this population and offer some conceptual frameworks for professionals to consider. Section II provides an overview of Muslim demographics and of migration and immigration patterns of Muslims. We discuss racial/ethnic characteristics and cultural factors related to the interaction of Muslims with disabilities and the support systems that exist for families, both locally and globally. Section III presents an overview of Islam and the attitudes and perspectives commonly held by Muslims that may affect Muslim families caring for a member with a disability or a chronic health condition.

Section IV provides a detailed account of cultural and religious perspectives related to health and disability, along with the implications of such beliefs and issues. This includes concepts of independence and collectivism within the culture as well as perceptions of the role of the family in health care and rehabilitation. Section V discusses Muslim perspectives and the culture of the U.S. service systems as they relate to serving people with disabilities. We examine how they clash and how differences can be accommodated so that the unique needs of this population are addressed adequately. Section VI provides culture brokering tools and strategies that may help close the gap between Muslims with disabilities and service providers in the United States. Section VII contains our conclusions and recommendations. Section VIII lists resources for furthering one's understanding of Muslim communities with respect to chronic health conditions and disability.

The Gap Between Persons Served and Service Professionals

For years, service professionals have been adjusting and broadening their capacities so as to respond more sensitively to the increasing cultural diversity of service users. In particular, recent geopolitical events have resulted in an increasing interest in the lives of ordinary Muslims, along with a desire to reach out in a friendly and better-informed way to those who need rehabilitation services but are fearful of rejection and prejudice (M. Miles, personal communication, 2007; all citations of M. Miles [2007] refer to personal communications). Despite the best efforts of service professionals, misperceptions or breakdowns in communications remain common, and the term Muslim often is used in inappropriate and/or inaccurate ways. For example, it is not uncommon for Westerners to express, either consciously or unconsciously, a belief that most Muslims are religious extremists of Middle Eastern, Arab, or South Asian descent, forgetting or being ignorant of the fact that most Muslims are secular moderates and that they reside in many areas of the world, including the United States, Canada, Europe, Australia, Indonesia, Malaysia, among others.

Negative portrayals of Muslims in the news, in various forms of media, and in popular entertainment have become an integral part of public consciousness (Laird, 2006). These portrayals directly affect the well-being of Muslims both in the United States and globally. Given the increasing diversity of the United States, many providers of rehabilitation and other health care must learn to tolerate and manage many complex cultural differences in identity, communication styles, attitudes, behaviors, belief systems, expectations, perceptions, and worldviews related to health, illness, and disability. The need to tolerate and manage differences is particularly relevant when working with Muslims, who as a group have their own distinct and diverse characteristics and worldviews (Lambert & Sevak, 1996). Service professionals must pay attention to cross-cultural perspectives and work harder to include Muslims with disabilities and their families in all aspects of health and rehabilitation systems, with the goal of multicultural advocacy and integration into mainstream American life.

In this monograph we offer information across a broad range of social and cultural issues, including gender, culture, ethnicity, class, religion, appearance, and language, and we discuss how these conditions and characteristics affect the participation in everyday life of Muslims with disabilities and chronic medical conditions. In addition, we hope to offer professionals a deeper understanding of the contextual factors that can affect outcomes, in both facilitative and limiting ways, as Muslims try to access resources and achieve a better quality of life. To clarify our population of study, we use the term Muslim to refer to a worldwide community of people who adhere to Islam as their religion, in varying ways. This community, in and of itself, does not constitute a distinct country or race; it includes individuals of every race and ethnicity. Despite their vast diversity, Muslims are connected by their common religion, which has been and continues to be misrepresented and misunderstood. One fifth of the world's population has Islam as an ethical tradition, and Muslims are the majority of the population in about 57 nations. In total, Muslims speak about 60 different languages, and they come from a variety of ethnic and cultural backgrounds (American Muslims, n.d: Demographics of Islam, 2006).

Focusing on Muslims

Because research on Muslims with disabilities in the United States is limited, we draw on the growing literature on Islam, especially from countries such as Canada and the United Kingdom, as well as from parts of the Muslim world (Khedr, 2005, 2006, Raghavan & Waseem, 2006). Because Islam is not understood fully in Western societies, CIRRIE and the authors of this monograph are looking at ways to further the understanding of disability issues from an Islamic perspective. As for any effort to characterize a cultural system or group, we must caution against overgeneralization or stereotyping. Assumptions about any cultural or religious group can lead to racism or stereotyping in human society (Kleinman, 2006). As often is the case with racism, individuals who believe they are well in-

formed about a certain group may in fact take one small example that might be true of an individual and apply it to everyone of that individual's race, nationality, culture, or gender.

Although knowledge of a client's culture can provide a starting point for interaction, two individuals of similar backgrounds may have widely different worldviews, ideas, and opinions and will, therefore, react or respond differently to various stimuli or circumstances (Trimble & Fisher, 2006). Because this point is very important we will repeat it throughout this monograph.

Few authors have asked or considered how attention to the issue of disability itself affects the health and rehabilitation of Muslims living in Western societies (Laird, Amer, Barnett, & Barnes, 2007; The Peninsula, 2006). Human health and disability encompass a wide and complex range of physical, psychological, and social functions and abilities. Human beings represent a mixture of good health and normal functioning alongside characteristics that might be labeled as a "disability," based on a physician's or psychologist's diagnosis. It is important, therefore, that we define terms such as *health, illness,* and *disability*, given the broad approach of this monograph. Is there a difference? Is one condition less stigmatizing than another? Does "disability" imply poor overall health, or vice versa? To clarify the meanings given to illness, health, and disability in this monograph, we offer some insights about these concepts in the next section.

Defining Illness, Health, and Disability

Anthropologists and sociologists have thoroughly discussed the range of meanings given to illness, disease, and disability across and within the world's cultures. The English word disability was first used at least 500 years ago in the legal field. Since the 1960s, along with impairment, handicap, and disablement, it has been placed on an international battlefield of words, as specialized meanings have evolved in the rehabilitation field. Discussions have resulted in several classification of terms, the most useful being the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) and ICIDH-2, followed by the International Classification of Functioning and Disability, or ICF (World Health Organization, 2001). Meanwhile, in Western nations, the more common uses of terms have shifted somewhat.

It is appropriate to assume that U.S. professional providers of rehabilitation and health care services should be familiar with the recent semantic changes in the field of health and disability. In popular usage, the terms disability and health are hardly one and the same but certainly do overlap. For example, some illnesses (lack of full health) lead to disabilities, or at least to impairments, which can be disabling under certain conditions. The effects of some chronic conditions count as disabilities in some legal and insurance contexts. In addition, some people with disabilities are as healthy as most non disabled people most of the time but may

suffer from disease or have an illness and then recover with or without treatment, or the illness may exacerbate their disability (Miles, 2007). For example, Groce states that "children with disabilities, particularly those with visible disabilities, are frequently assumed to be in frail health and unlikely to survive into adulthood" (2004, p. 47). For some individuals and groups, especially in democratic environments where the human rights of all are respected, difference is a healthy sign of potential growth. In some Muslim societies, however, difference may generate fear, and fear may generate more difference, thus leading to the public exclusion of those perceived as different from the norm (Miles, 2007).

It also is important to consider the range of meanings that various disability-related terms have in English, and then to broaden their definitions to recognize that in other cultures or religions, such as Islam, the semantic range may be constructed differently. As just one example, some languages or cultures may lack a generic term such as disability or may have a broader generic term that embraces both illness and disability. Another aspect of this complexity is seen in the overlap and differences in the use of the terms among professionals and in comparison with popular usage. Some scholars have discussed the recognition of ambiguity and linguistic difficulty in the Islamic terms for illness and disability. Rispler-Chaim (2007), whose research is widely recognized, notes that early Arabic languages had separate words for specific disability categories, and that generic modern terms are used as equivalents for the disabled. For example, she suggests that the words marid and marad, as used in the Qur'an, may have constituted a generic term covering both the sick and the disabled.

In 2006, Rooshey Hasnain interviewed Aqil Sajjad (personal communication, 2006; all citations of Sajjad [2006] refer to personal communications) a Pakistani PhD student at Harvard University, who is blind. Sajjad provided a perspective on the difference between health and disability. He initially articulated the notion of disability and health in a generic way and blended this explanation with his own disability. He remarked that

> disability can be considered an extreme health issue, medically speaking, but there is an objective and subjective reality of disability. The objective part is the medical condition—physically, an average person has certain faculties and can do certain things (or function in certain ways), but a person with a disability is somehow restricted from certain functions in one way or another. So a person who is blind can do certain things, in terms of functionality, but not others.

Sajjid (2006) also described his experience of how disability is defined in the United States.

> There are formal definitions or labels of disability (if you have this much

> vision you are considered blind) and, thus, given the label of having a visual disability. This label of disability can essentially be considered a serious health problem that can't be cured, so it's there with you permanently. Being blind can't be cured. What is subjective is how people think about it, and what is objective is the actual extent of the condition itself; however, the magnitude of society's reaction is much more amplified for some disabilities than others.

Asked whether the term [chronic] health condition (e.g., diabetes, heart problems) might be less stigmatizing in Muslim communities than the term disability, he responded, "I think a health issue is less stigmatizing in the Pakistani Muslim community. Disability is a permanent condition, whereas a health condition often can be cured."

We offer this example not to simplify the complexity of these terms but to share a perspective from a Muslim who has a disability. Without a doubt, the amount of stigma associated with terms such as health and disability, or their equivalents in languages other than English, are likely to vary among groups using Urdu, Punjabi, Pushto, Sindhi, Baluchi, or smaller local languages or the dozens of other languages spoken by Muslims. The point is that many terms are in current use. Some are more blunt than others, some are rural and some urban, and they range across a spectrum of what might be considered politically correct or incorrect. In other words, it is wise to be cautious about the way these terms and concepts are used or portrayed to avoid reducing them and their users to a simplistic level of thinking (Miles, 2007).

Several other aspects of terminology should be considered when discussing culturally based definitions and meanings of the term disability. For example, among many Muslim families of a particular class or of a modest educational level, the functionality of a person with a disability is given more weight than the specific label or diagnosis of disability. These perceptions can reinforce the way a person or family perceives the disability, or they may be meaningless as long as the person can function in his or her community. Some individuals may not even think of themselves as having a disability or a significant health issue, given the way the issue of disability is seen within their culture (Ypinazar & Margolis, 2006).

In addition, individuals' experiences of having a disability can vary across a wide range, depending on the severity and type of the disability and the person's living environment, including the human and technical support available as well as the person's individual character, maturity, age, and resilience. Two people with apparently identical disabilities, support, environment, and beliefs may have very similar experiences or sharply different experiences, as a result of the frame of mind with which they approach their situation. For example, one Muslim with a disability may magnify the difficulties and make a self-pitying career out of being triply disabled (e.g., being a quadriplegic, and a woman, and a Muslim religious

minority). In contrast, another Muslim may reason, for example:

> This is my personal test with Allah, and it is my belief that Allah gives strength to meet every test. I laugh at the problems, because they are nothing compared with the mercy of Allah. I smile at the doctors, be cause they seem so burdened with all their medical knowledge and gadgets and rushing about. I laugh with the porter who pushes me on a trolley around the hospital, because he talks to me like a human, not just a sad case. (Example constructed by Miles, 2007)

Meanwhile, a hundred other Muslims with disabilities may have less dramatic viewpoints that fall somewhere between these extremes. Like individuals of all faiths, many Muslims with disabilities face a spectrum of issues. Some run into very few of these issues, and others encounter all the problems, yet still find the cultural and religious strength to live a worthwhile life (Miles, 2007). The key point is that difficulties associated with a disability can become larger and more complicated for Muslims who are seeking rehabilitation and heath care services in the United States if the service providers are not aware of this potential range of differences.

The Use of Culture Brokering to Bridge Service Gaps

This monograph provides a holistic approach to help professionals understand the service disparities that are so common in Muslim communities and offers potential solutions. It also adopts what Jezewski and Sotnik (2001, 2005) call "culture brokering," a theoretical framework that offers a systematic and multifaceted approach that can lead to better outcomes for Muslims who have disabilities or are dealing with a medical condition. Jezewski and Sotnik define culture brokering as the act of bridging, linking, or mediating between groups or persons of different cultural backgrounds to effect change. The broker in this case is someone familiar with the experiences of Muslims who helps bridge the gap between U.S. service providers and consumers despite their immigration status. The person acting as a culture broker advocates on behalf of a Muslim with a disability and his or her family. Another perspective was provided in a 2004 report by the National Center for Cultural Competence, which defined culture brokering as a health care intervention through which a professional increasingly uses knowledge and skills of both the differing culture and the health sciences to negotiate with the individual and the service system to develop an effective treatment or rehabilitation plan.

Over the past ten years, the concept of culture brokering has gained momentum both in the United States and internationally, especially in health care and rehabilitation. Throughout this monograph we will draw on the concepts of culture brokers or cultural competency in health care delivery for diverse communities, developed by researchers in the 1960s. Those in the disability and rehabilitation sector, in the United States and abroad, have begun to apply culture brokering

in practice as a mechanism to minimize disparities and to improve outcomes for Muslims and persons of other faiths (or no faith) who have disabilities.

When discussing culture brokering, it is important to understand that many factors originating from either side can facilitate or impede the process. To achieve the best outcomes, U.S. professionals may need to improve their intercultural skills while, conversely, Muslim leaders may need to improve their skills in informing and engaging their communities so that individuals with disabilities and their families can best benefit from available services (Haboush, 2007).

In this monograph, we suggest five directions for action based on the culture brokering framework:

1. Better understand the demography of Muslims, including issues of identity, immigration, country of origin, gender, and educational level.
2. Identify the barriers, challenges, and successes that face Muslims with disabilities and those with medical conditions as they access services and supports of all types.
3. Solicit the participation of Muslim people with disabilities and those with medical conditions and their families in various aspects of service delivery and planning.
4. Promote collaborative research and support for disability-specific development activities that can help build lasting links between mainstream U.S. and Muslim institutions.
5. Cultivate a broader cultural understanding and mutual respect concerning the inclusion of persons with disabilities through strategic partnerships and collaborations with Muslims and non-Muslims.

How Conceptual Models Vary by Culture

Another key issue is that many ethnic and minority populations, including Muslims, have their own long-standing beliefs and practices and their own support systems; as a result, they do not define or address disability and chronic illness in the same way as mainstream American culture. Because the concerns and values of such populations are not necessarily identical to those of mainstream America, their solutions are not always the same. In fact, many cultural groups can offer alternative and sometimes superior ways of addressing needs that merit our careful attention. To better serve diverse populations, it is imperative that we understand the cultural beliefs and attitudes that determine behaviors, guide decisions, and affect interactions between a provider and a client and family (Groce & Zola, 1993, p. 1048).

Historically, research on racial and ethnic minority groups (such as Muslims in the United States) has focused on a deficit perspective in which European American standards are used to determine success. If non-mainstream populations,

such as Muslims, vary from these standards, they may be seen as unsuccessful or deficient. As a result, using non-minority counterparts as a standard, researchers traditionally have evaluated minority individuals with disabilities without considering the many ways in which their lives and worldviews may differ, given their different cultural, sociopolitical, financial, and religious contexts (Bywaters, Ali, Fazil, Wallace, & Singh, 2003).

Moreover, as Trimble and Fisher (2006) point out, it is critical that any research in the field consider individual and group beliefs, values, language system, traditions, customs, and worldviews. For intervention to be effective, health care providers must not only understand various issues that originate from within the Muslim communities, but also look at the variables that are part of their own health care and disability systems, and how those variables color various views and assumptions. The effective and meaningful delivery of services to non-mainstream populations must take into consideration a range of variables and assumptions, both overt and implicit, in both the U.S. service delivery system and the minority community being served.

Perhaps as important as the larger community issues are the differences among Muslim individuals and families. As is true of any culture, Muslim families are not all structured in the same way. Their needs and circumstances may differ. They may interpret the same situations differently. They can vary greatly in their cultural heritages and religious practices. Their patterns of immigration and migration will vary, and they may have vastly different attitudes and perceptions about their country of origin or about the United States and the particular communities in which they have settled. All of these factors, and more, may influence health or rehabilitation processes and outcomes. In this monograph, we emphasize cross-cultural and cross-ethnic perspectives within the Muslim community, looking for how they influence families of various geographic origins that face health and disability issues (Lynch & Hanson, 2006).

Understanding the challenges faced by Muslim populations is only part of the story. We believe in using an assets-based approach with an emphasis on case studies of individuals and families that have succeeded as a result of innovative culture brokering interventions. Brokers play an important role in supporting Muslims who are using rehabilitation and health care services, but it is equally important to note that many Muslim families with members with disabilities serve as their own brokers, and succeed by their own efforts, making an adjustment to host-community norms and expectations without giving up any essential parts of their culture and beliefs, and without relying on any professional intervention. In fact, important insights can be gained by studying individuals and families who simply did it "their own way." Such individuals and/or families manage to obtain services and supports by searching out sources of information, perhaps by building friendships with neighbors through a series of small steps, which can range from smiles, small gifts, and polite gestures to taking an interest in other people

with disabilities and their families and learning from their experiences (Miles, 2007), all in the effort to obtain mainstream services and supports. Certainly some Muslim families and communities have succeeded in these ways, but the examples are scarce.

In a similar vein, some families, when presented with the opportunity to work with a rehabilitation professional, may already have a repertoire of social skills useful in getting the best out of the professional service providers. Providers need to recognize that not all Muslims are fearful, disempowered, easily affronted, or unable to acquire fluent English. Many capable and resilient individuals and their families are active in Muslim communities in the United States and elsewhere. These families may not be typical, or they simply may not attract much attention in service systems because they solve their own problems and so are rarely noticed by professionals who are focused on clients facing problems (Miles, 2007). In the next section, we explore various barriers and challenges facing Muslims with disabilities living in the United Kingdom and Canada, because we believe this information can help inform U.S.-based professionals experiencing similar scenarios.

Barriers for Muslims in the West

Like other racial and ethnic minority groups living in the United States, Muslims encounter many barriers and challenges as well as successes as they access and use mainstream services and supports for their family members with disabilities and/or health conditions (Khedr, 2005). Among the many barriers is terminology. Terms such as developmental disability, autism, bipolar disorder, and schizophrenia often appear on brochures and in conversations, but rarely with culturally sensitive definitions or explanations (Raghavan, Waseem, Small, & Newell, 2004). Anyone acquiring English as a second language may be confused by these terms, as well as even simpler terms such as advocate. How might a word like advocate, so commonly and presumptuously used among U.S. professionals, be interpreted by individuals from non-U.S. communities and cultures? What meanings, if any, do commonly used service delivery terms have in Arabic, Urdu or Farsi? Examining young Muslims with learning disabilities and their families in the United Kingdom, Raghavan et al. (2004) noted all of the things that made life difficult for this sample of individuals with disabilities seeking disability services and supports. Six situations were on top of the list:

- Families are unaware of clinical and rehabilitative services and supports.
- Few services and opportunities are available for young Muslim adults.
- Families need better housing, access to respite services and social/recreational programs, and health insurance.
- Mental health and other significant disabilities may still be seen as taboo in some Muslim South Asian communities. (This also is true in

other Muslim communities, including African and South Asian communities.)

- Inappropriate perceptions of formal supports can minimize contact with the mainstream system.
- Language and linguistic differences and varying systems of cultural beliefs can cause communication breakdowns between client and provider.

This is only a partial list of barriers and challenges and does not completely describe the experience in these families' lives. For example, many of these individuals and families are using their own cultural strengths and resources without any professional intervention, and experience positive outcomes. They obtain additional education, get good jobs, and build successful social lives (Hussain, 2003; Hussain, Atkin, & Waqar 2002). Al-Krenawi and Graham (2000) noted that many members of one particular Muslim community have less access to help or are reluctant to get it and thus have fewer medical or disability-related services and personal supports. Factors that limit such access include language, opposing cultural belief systems, gender role limitations, levels of acculturation, social class differences, and differing perceptions of illness and disability. Moreover, many U.S. systems lack bilingual service providers, and assessment tools are culturally insensitive or invalid. In addition, because disability is still taboo in parts of the Muslim world, little progress has been made in disability rights movements (Bibbo, 2006).

For these reasons, among others, many Muslims are not aware of services even when they have lived in the United States for considerable periods of time. When asked about such services, responses such as "I don't know . . . we don't know how to get help and we have been here for 26 years" are not uncommon. Other obstacles that further overwhelm Muslims or discourage them from seeking mainstream services and supports include information limitations of European American–based service provision systems, limited access to opportunities, negative religious beliefs, stereotyping, and communication/language difficulties. Stigma also plays a role. For example, families from Pakistan and Bangladesh who live in the United Kingdom have reported that they worry about what others say about them or their loved ones with a disability. Many people also worry about their reputations and the possible stigma associated with a disability (Crabtree, 2007). As a consequence of these and other barriers, Muslims with disabilities may not be seeking beneficial treatment and rehabilitative options. Thus, they often miss out on opportunities for work, postsecondary education and training, and community life (Raghavan & Waseem, 2006) or other kinds of supports. To address these issues, local service professionals must increase efforts to provide information in culturally sensitive and appropriate languages and at places or times that are appropriate with regard to the availability of services (Haboush, 2007). As one example of the potential for communication problems, some local authorities in London use more than 100 languages in the community. In fact, among

the indigenous population of the United Kingdom, there are problems with differential access to health services based on class, gender, and location, though the government makes various efforts to overcome this and equalize provision. It is interesting to note that in some areas, the access to health care and education services by people of South Asian origin is substantially higher than the access by white working-class young men, mainly because the South Asians tend to be educated and middle class, and they know how to work the system, whereas the white working-class families do not possess these skills. Religion does not enter the equation (Miles, 2007).

Although many foreign-born Muslim individuals have come to the United States from South Asia, Central Asia, and Middle Eastern countries in recent years, the U.S. Census (2000) does not specifically identify Muslims as part of the heaviest influx of immigrants or refugees. In fact, there is a clear lack of data about the Muslim experience, and the few bits of data that exist tend to group different Muslim groups (for example, Pakistani and Bangladeshi children) into one category called "Asian" (Ali, Fazil, Bywaters, Wallace & Singh (2001); Trimble & Fisher, 2006). Because of growing tensions worldwide, however, Muslims are entering and living in the United States in numbers significantly higher than in earlier decades. Although many of these individuals have disabilities and medical needs and, thus, need the services and resources available through the mainstream system, a large majority of them underutilize these services.

Service providers must address these needs, and as interventionists and culture brokers, they need to better understand the cultural patterns and behaviors of this group. At the same time, however, health and rehabilitation service professionals face an ever-lengthening list of challenges, including different medical/disability conditions that they should know about, legal obligations they must meet, and a diversity of people of different religions and ethnicity with whom they must try to interact successfully. Unfortunately, front-line service providers often are the least likely to understand the diversity of the many different people and cultures, family needs, medical conditions, laws, and obligations. Even specialists who are knowledgeable about a given ethnic background, language, culture, and religions admit that the complexities and varieties are hard to describe or comprehend. Thus, it can be futile, if not counterproductive, to issue unrealistic exhortations and rhetorical demands to front-line service staff. Instead, as we argue in this monograph, it is more realistic to implement and emphasize a vocabulary of "skills improvement"—that is, the generic skills for culture brokering that can be used to acquire necessary information and interact successfully with people having a wide variety of cultural practices (Miles, 2007). With that in mind, in the next few sections, we summarize some characteristics of this understudied and under involved group of Muslim individuals and families.

Since September 11, 2001, Muslims in the United States and other parts of the world are facing greater levels of discrimination, suspicion, and racism. This negative attention makes it vitally important to understand the diversity of refugee, immigrant, and indigenous Muslim experiences, along with the various ways of practicing Islam.

Various U.S. professionals at service-client interfaces have engaged with Muslims during the past century, trying to bridge cultural barriers. The disability field is not the only field in which professionals have needed to improve culture brokering skills. The latest edition of Ethnicity & Family Therapy (McGoldrick, Giordano, & Garcia-Preto, 2005) has chapters on African-American Muslim families, Indonesian families, Asian Indian families, Indian Hindu families, Pakistani families, Arab families, Iranian families, Lebanese and Syrian families, and Palestinian families. These chapters amount to 120 printed pages on Asian and Middle Eastern family cultures, family problems, and how therapy can be provided more appropriately. Most of the information is specifically about Muslim families and cultures. This book is by no means the only American manual addressing cultural diversity and its role in the fields of therapy and rehabilitation service provisions. The book's various chapter authors address Islamic customs and practices in a variety of ways, not all of them handling it with equal skill. It is interesting to see how they tackle their topics, given that the limits of a single chapter obliged each of them to choose and present what they considered the most salient points of Islam in family cultures (Miles, 2007).

Despite the pockets of important research being conducted on Muslims, the study of disability and social justice in our monograph provides a unique lens for understanding this culturally rich and complex community (Laird, 2005, 2006). Although American Muslims may feel less marginalized or isolated from political participation than are Muslims in Europe, they are increasingly challenged by threats to their civil rights as a result of the actions of extremists or radicals, particularly the September 11 attacks. In response to such events, both here and abroad, some American Muslim communities formed several organizations and began to serve as "critical consultants" or culture brokers on U.S. policy regarding Iraq and Afghanistan. Other groups have worked with law enforcement agencies to point out Muslims within the United States who are suspected of fostering "intolerant attitudes." Still others have worked to invite interfaith dialogue and have improved relations between Muslim and Americans of other faiths, spiritualities, and traditions (Huda, 2006).

In addition, through the Cultural Bridges Act of 2002, Senator Edward Kennedy of Massachusetts, along with a bipartisan coalition of U.S. senators, has pointed out the importance of promoting the national security of the United States through international educational and cultural exchange programs between the

United States and the Islamic world. As authorized through this legislation, approximately $75 million was spent in fiscal years 2003 through 2007 to expand the activities of the State Department's existing educational and cultural programs in relation to the Islamic world. Such spending shows the United States' commitment to connecting to the 1.5 billion people who live in the Islamic world (NAAA-Action Alert: Support Cultural Bridges Act of 2002 [S.2505], n.d.) in the hope of bridging cultural barriers. Unfortunately, despite such efforts to reach out, many in the Muslim community remain marginalized. In addition, the average American is unfamiliar with the disability issues facing this community, having heard little from the voices and perspectives of Muslims with disabilities, whether elderly or young. This knowledge gap is due, in part, to the lack of data and research concerning the experiences of Muslims with disabilities (Ali et al., 2001).

Unfortunately, being both Muslim and disabled, rather than one or the other, often doubles a person's risk or experience of discrimination, which can further alienate that individual. On the positive side, in 1990 the U.S. Congress passed the Americans with Disabilities Act and the disability rights movement is now growing across the world. In addition, the United Nations recently developed a treaty on the Rights of People with Disabilities. Nevertheless, in virtually all societies, inclusivity and acceptance of difference falls short of what these laws require, and this shortfall applies to the Muslim community. This situation was articulated well in the Legander-Mourcy Azizah article (2000) where Rosina Abdulshakur, a Muslim woman with multiple sclerosis was interviewed by the magazine. For her, the issue is not simply being a Muslim, but that "people in general tend to have a mentality toward people with disabilities that says 'I'd better not get too close or say anything'" (p. 1). In other cases, people with a disability are patronized through unwanted pity, underestimated, or undermined. As sometimes seen in mainstream life in North America, a person with an obvious visible disability in the Muslim community may also be unfairly judged as being inept, unproductive, unintelligent, and/or unmarriageable. These attitudes obviously must change.

Aminah Rasullah, also interviewed in Azizah Magazine, (Legander-Mourcy, 2000) shared her perspective as an amputee who, since the age of seven, has walked with the support of crutches. Pointing to the triple threat of "the marginalizing effects of society's stereotyping" with regard to race, gender, and health, she said, "It's like—you're an African-American, a woman, and disabled! It's as if I have three strikes against me without even having to swing the bat!" (p.3). In other words, a Muslim with a disability must deal not only with alienation from the dominant American community but also with alienation from her own community. Similarly, Stuart (1995, cited in Ali et al., 2001, p. 950) writes about "the perception of disability in the United Kingdom, which differs depending on one's skin color and his or her ethnic identity", along with many other factors (age, gender, physical attributes, accent), and which can influence the way people perceive disability. In order words, a person with a disability may experience dif-

ferential treatment because of various aspects of their identity. Therefore, at different times of their lives Muslims who are disabled may experience classism, sexism, racism and/or ableism. "People with disabilities are second-class citizens," according to an interview mentioned by Ali et al. (2001). Another writer summed it up differently: "When you are Black, Asian or Muslim you are considered third class" (Confederation of Indian Organizations, 1986, p. 960 in Ali et al. (2001). These examples point to the fact that, similar to their non-Muslim counterparts, Muslims with disabilities have to contend with varying levels of discrimination and disadvantage that need to be addressed by service systems.

The Need for Cultural Competency to Better Understand Muslims

As discussed throughout this monograph, service providers and researchers are increasingly seeing culture brokering or cultural competency as a key element in the ongoing quest to provide optimum services and outcomes for Muslims with disabilities (Giger & Davidhizar, 2002). The outcome of a medical visit or rehabilitation does not depend solely on the ability of the provider to properly identify and treat a particular condition, though this is often challenging enough. Outcomes also depend on the quality of the exchange between the provider and the person with a disability. For a treatment or rehabilitation program to succeed, Muslims with disabilities and their families must believe in the probability of success and be willing to participate in the plan.

This is particularly true in the field of rehabilitation, in which results depend largely on the effort expended by the person being treated. Cultural perspectives can influence a person's approach both to seeking rehabilitation and to peripheral issues that impact service use, and thus they are critical to consider when developing a rehabilitation or treatment plan. Long-term effective culture brokering will require a research and service agenda that addresses the needs and issues of an underserved community of Muslims. This monograph is a step in that direction.

II. General Sociocultural Background

This section presents an overview of Muslim immigrants and refugees living in the United States, including recent patterns of migration and immigration. We also provide a brief introduction to the history of Islam.

An Overview of Muslim Immigrants and Refugees

Coming from over 100 countries, immigrant Muslims in the United States are ethnically and linguistically diverse. According to the World Almanac (The World Almanac and Book of Facts 2006, 2006; Nasr, 2005) approximately 4,657,000 Muslims live in the United States. The largest numbers of immigrants come from

three main areas: South Asia, Iran, and the Arabic-speaking countries. The single largest group of Muslim immigrants comes from South Asia (Bangladesh, India, and Pakistan). The next largest groups consist of approximately 300,000 Iranians and 600,000 Muslims from the Arab countries.

Islam originated on the Arabian Peninsula as a "continuation of the biblical faith of Abraham, Moses and Jesus, all respected prophets in this system" (The World Almanac and Book of Facts 2006, 2006, p. 669; Nasr, 2005). As the Arabs took their religion abroad, Muslim majorities developed in countries across the globe, from Gambia to Indonesia. Significant Muslim populations exist in areas as diverse as Eastern Europe and China. More recently, immigration and conversion have led to large communities of Muslims in Western Europe, the Americas, and Australia. Differences in cultural systems can exist even within a given nation because people of different ethnic backgrounds settled in different regions.

For all these reasons, Muslims are a highly varied group of people whose geographic origin and culture cannot be inferred solely on the basis of religion. Moreover, a person cannot be assumed to be Muslim based on geographic origin, as many Muslim-majority regions have considerable number of individuals of other faiths who may nevertheless share many cultural traditions with their Muslim neighbors. Religion, geographic origin, and culture therefore are separate entities; one cannot be assumed based on the others.

Because Muslims differ so much, it is critical, as a first step to understanding their needs and issues, to understand the specific countries they come from and the many cultural experiences they bring. Muslims live in, and have official status in, many regions.

- Southwest Asia: Both Arab nations, such as Saudi Arabia and Iraq, and several non-Arab nations, such as Turkey, Azerbaijan, and Iran
- Africa: North African countries such as Morocco, Algeria, Tunisia, Libya, and Egypt and sub-Saharan countries such as Mali, Nigeria, and Somalia
- The Balkans: Albania, Bosnia and Herzegovina, Serbia, the Republic of Macedonia, and Montenegro
- Eastern Europe: Parts of Russia and Ukraine (especially in the Crimea)
- Central Asia: Afghanistan and former Soviet states such as Uzbekistan
- South Asia: India, Pakistan, Bangladesh, and the Maldives
- Southeast Asia: Indonesia, Brunei, and Malaysia

Other important centers of Muslim population include Kosovo in the former Federal Republic of Yugoslavia and Chechnya in the Russian Federation, where Muslims are in the majority.

Sizable Muslim minorities also live in other regions, including the following:

- several countries of the European Union (especially France and Germany)
- several regions of the Russian Federation
- the People's Republic of China and other regions of northwest China
- Singapore, Thailand, and the Philippines
- the United States and Canada

Once we understand the origins of Muslim immigrants and refugees, the next big challenge is identifying them within U.S. communities. The U.S. Census is no help in this task because, by law, it cannot collect data on religious identification. Other resources offer population estimates for Muslims, but their figures are inconsistent. For example, according to the CIA World Factbook (2003), of the more than 1.4 billion Muslims in the world, an estimated 9 million reside in North America. This is roughly twice the estimate offered by the *World Almanac*, cited above. Population estimates have been a source of controversy. Tom Smith (2001), a researcher at the University of Chicago, is explicitly critical of the survey methodologies that have led to "high end" estimates. In fact, some journalists allege that numbers have been inflated for political purposes.

Muslim groups, on the other hand, suspect that most recent independent studies and surveys undercount the Muslim population for a variety of reasons, including possible anti-Muslim sentiment, the high level of intermarriages, Muslims' wariness and distrust of U.S. government surveys, and the fact that mosque-based studies miss the many Muslims who do not regularly attend mosques, especially those with disabilities.

Reasons for Migration and Immigration

After Africans, many of whom were Muslims, were taken as slaves to the United States, the next major wave of immigration to the United States took place in the late 19th and early 20th centuries. Large number of Muslims, mainly from Arab nations, migrated to the United States seeking economic opportunities, along with many people from Eastern and Southern Europe. Many found work as manual laborers and factory workers, especially in industrial cities such as Detroit, Michigan. As their numbers grew, they began to establish communities and mosques.

The next wave of Muslim immigrants began in the 1950s. These immigrants came for a variety of reasons and represented a different demographic from earlier immigrants. They were largely professionals, such as physicians, who sought better opportunities for advancement than they could find in their home countries. Large numbers also came as university students, and they often sought professional degrees as well, with some remaining in the United States even after completing those degrees. This group of professionals typically is wealthier and more

assimilated than other subpopulations of immigrant Muslims. Over the years, other Muslim students and young professionals have continued to immigrate, for many of the same reasons. These later waves of Muslims tend to have larger incomes than their predecessors and are relatively less assimilated (Demographics of Islam, 2006).

A final group of arrivals includes the more recent non-professionals. These individuals hail from varying parts of the Muslim world; significant cohorts have arrived from areas touched by conflict, such as Bosnia and Somalia. In their countries of origin, these immigrants may have been professionals with good incomes, but many have had to accept non-professional jobs (e.g., taxi driving and low-level retail work) upon their arrival. They generally are in lower income brackets and are less fluent in English, and many lack benefits from their jobs such as health insurance (Siddiqui, n.d.) and need to assimilate or acculturate to the majority culture (Laird, 2006). Many have immigrated because of tragic events; in Muslim countries such as Somalia, Afghanistan, and Bosnia, such events have led directly to the mass exodus of Muslims seeking safety. Because many Muslim countries suffer under rule by dictatorial regimes, many Muslims have left their countries to escape from such conditions as underdevelopment, tyranny, persecution, unlawfulness, poverty, civil strife, and war trauma (Haboush, 2007).

Professionals in the disability and health care fields who understand the situations of immigrants might be more sympathetic or empathetic and therefore might be more motivated to deliver appropriate care. They might be happy to reassure families that, despite initial discomfort and cultural conflict with the mainstream U.S. culture, the family member with a disability will benefit from the services offered in the United States, which are very likely to be an improvement on what was available in the country of origin. This perspective provides motivation for service professionals to become more aware of and more sensitive to the original situations and circumstances of their service users.

It is also worth noting that the U.S. government has taken at least two possibly contradictory stances toward accepting immigration applications from families containing members with disabilities. In the 1980s, some families were required to sign verification that their member with a disability would never become a charge on U.S. public services and that the family had sufficient means to care for the member and pay the costs of care, and actually would do so. In an apparent contrast, since 2000 some families have gained admission to the United States by claiming that appropriate services for their member with a disability were not available in their home country. These people were later investigated and asked, with notice, to leave the United States unless they could provide evidence that they still had a valid claim for their admission. On behalf of such families, U.S. lawyers began emailing people in South Asian countries, asking for expert testimony that such services were not available in the families' home countries. The following vignette illustrates some of these concerns.

An infant born in Pakistan with a severe heart condition was evacuated by air to a large heart referral center in the United States for urgent surgery. His father was a permanent resident of the United States who had emigrated from Pakistan years earlier. The wife became pregnant immediately after their arranged marriage in Pakistan and before she had completed the paperwork required to move to the United States, so she chose to deliver the baby in Pakistan, near her immediate family.

The staff at the U.S. referral center was curious to learn more about this case, as the hospital fees were entirely covered by the Pakistani embassy. Interested in generating more referrals, the hospital management dispatched a team of hospitality staff to Pakistan to learn more about the referring physicians. How had they heard of this particular U.S. hospital, and why did they choose the particular heart center over others? As the questioning proceeded, the newborn's father became visibly anxious. He spoke at length about his "love for America" saying that he was "not a terrorist" and that he was "working on his wife's paperwork." Further questions revealed the father's fear that the hospital staff intended to report him and his family to the Immigration and Naturalization Service (INS), since he had yet to complete the paperwork necessary for an emergency visa that had been awarded to the child and his mother to come to the United States for surgery. Only after substantial assurances to the contrary did he believe that the hospital had no intention of contacting federal authorities.

These contrasting features of U.S. immigration policy, which have specific impacts on families caring for a member with a disability, seem to have colored the perceptions of some Muslims as to how they might be treated by U.S. service providers, and thus may impact a family's help-seeking patterns. Although rumors of such requirements (i.e., immigration policies) probably continue to circulate in some communities, adding further inaccuracies in the minds of service users, they are outside the scope of this monograph.

In general, like other immigrants to the United States, Muslims tend to settle first in major metropolitan areas such as New York, Los Angeles, and Chicago. For example, many Iranians settled in California, especially in Los Angeles, and many South Asians live in Texas. The Midwest triangle includes many Arabs, American Blacks and African Americans, whereas Chicago has East Europeans (Albanians, Bosnians, Turks) and Detroit has the country's largest concentration of Arabs, mostly Lebanese, Iraqis, Palestinians, and Yemenis (Center for Immigration Studies, 2002).

Over time, however, Muslim immigrants and refugees in the United States have dispersed widely throughout the states. Many live in other highly populated ethnic communities of big cities, though not exclusively in those areas, whereas others (e.g., Somalis) are found in rural communities in states such as Maine, New Hampshire, and Massachusetts.

Differences in the Regions of Origin

Approximately 52 countries have Muslim majorities, and as a result of immigration, significant minorities exist in many more (Wikipedia, 2008). Brief descriptions of Muslim communities in different parts of the world are presented below. It is important to note that the exact number of Muslims is difficult to establish and although census figures are often questioned, we provide some estimates here

The Middle East
Muslims form the majority in virtually all 22 Arab countries, the notable exception being Lebanon. Despite the frequent association between Islam and Arabs in popular culture, Arabs make up only 15% to 18% of the world's Muslims. Moreover, a significant minority of Arabs are not Muslims; millions are Christians. Approximately 75% of Arab-Americans are Christians (District of Columbia, Maryland, and Virginia Advisory Committees to the U.S. Commission on Civil Rights, n.d.).

Southeast Asia
Indonesia has the largest Muslim population, with approximately over 213 million Muslims (CIA World Factbook, 2008). Malaysia also is predominantly Muslim. Other parts of Southeast Asia have smaller, but still large, Muslim communities.

South Asia
Pakistan has the second largest population of Muslims, at about 164 million (CIA World Factbook, 2008). As a region, South Asia, including Pakistan, Bangladesh, and India, has the largest population of Muslims, at approximately 420 million (Nasr, 2005).

Africa
Approximately 40% of the world's Muslims live in Africa. The majority of these Muslims are in North African countries such as Egypt, Libya, and Morocco, but a substantial percentage live in sub-Saharan Africa. Muslims are a majority in countries across Africa from Gambia to Somalia. The precise numbers of Muslims in Africa are unknown.

Europe
Approximately 34 million Muslims live in Europe. Although many of them are recent immigrants, particularly from countries previously colonized by the countries of Europe, the Ottoman Empire left significant Muslim populations in Eastern Europe. Muslims form substantial communities in Bosnia and Albania (Nasr, 2005).

North America

Estimates of the number of Muslims in the United States are as high as from 7 to 9 million (Woodrow Wilson International Center for scholars, 2003). Although Muslims in the United States often are thought of as immigrants, a large proportion of the American Muslim population was born in the United States. This includes children of immigrants as well as white Americans, Latinos, and Native Americans who have converted to Islam. These converts constitute a growing segment of the American Muslim community. The African-American Muslim community makes up 14% to 30% of the total population of Muslims in the United States (Council on American-Islamic Relations [CAIR], n.d.), and it deserves special mention. Africans were the first true wave of Muslims to enter the United States, coming by way of the slave trade. Estimates are that 10% to 20% of African slaves were originally Muslim. Most slaves were forbidden to practice their religion, however, and often were forcibly converted to Christianity (Public Broadcasting Service, n.d.).

Data on Muslims With Disabilities: Who Is Counting?

Although many U.S. researchers have examined the differences in care among clients of various ethnic and racial groups, far less is known about individuals with disabilities of various Muslim subpopulations. This is because the broad racial and ethnic categories used by the U.S. Census Bureau provide no information on such immigrant groups or religions. In Muslim countries, many professionals have carried out national censuses that included disability questions, and they have conducted ongoing large-sample housing, economic, and demographic surveys with specific disability-related items. More specifically, interest in disability increased after 1981, which the United Nations declared the Year of the Disabled; it then declared 1983-1992 as the Decade of the Disabled. Asia-wide disability initiatives also have increased interest in persons with disabilities.

Although data continue to be collected and government reports continue to be published, rarely are they widely disseminated in Muslim countries, and the data often are difficult to compare across countries. Often, the disability groups in Asian and African countries are unaware of the data available in their own nation because these data are not given prominence and their interpretation invariably requires some expertise (Miles, 2007). In other words, despite broad data-collection processes in Muslim countries, most people with disabilities remain unheard and unseen, and often are denied the same opportunities as those without disabilities Adding to the difficulties in data collection and interpretation, experts in various countries often disagree as to what constitutes disability; this can happen even within a given country (Groce, 2004), making it difficult to know how many people, Muslim or not, have disabilities or are considered marginalized or underserved.

Many groups in Muslim countries fall into the category of marginalized groups.

In Pakistan, for example, several hundred thousand bonded laborers are still working in semi-slavery in rural areas, particularly in the Sindh, with children inheriting their parents' debts and thus being bonded for life. In rural Punjab, communities of Hindu sweepers are still treated as "untouchable," due to caste-based differences even though such discrimination is both illegal and against the teaching of Islam. People with particular kinds of disability, such as leprosy sufferers, bear a comparable level of stigma suffered by the "untouchables" (Miles, 2007). In Pakistan, for example, some categories of persons with severe disabilities are rarely provided services or opportunities because they are considered unworthy of them. The attitudes of unworthiness behind exclusion from services is often found in other Muslim countries and is carried by some Muslim families that move to Western societies hoping to find better options (Haboush, 2007). Many individuals with disabilities may face overwhelming barriers in education, skills development, and other facets of daily life. In their countries of origin, the few available services and community life options focus on children, with few options for adults with disabilities, particularly in vocational and postsecondary education. On a positive note, several hundred thousand children and young people with mild to moderate impairments (e.g., Pakistan, Qatar) are casually integrated in ordinary schools without anyone taking official notice.

Characteristics of Immigrant, Refugee, and Indigenous Muslims

Rough estimates suggest that two-thirds of all Muslims in the United States are immigrants. "Thirty-six percent of Muslims were born in the United States, while 64 percent were born in 80 different countries around the world". Of all the Muslims in the United States, "the largest ethnic subgroups are of South Asian origin (32%), Arab origin (26%), and U.S.-born African-American (20%) origin". (Woodrow Wilson International Center for Scholars, 2003, p. 9).

Table 1 shows the breakdown of several ethnic subgroups of Muslims living in the United States.

Table 1: Ethnic Subgroups of U.S.-Based Muslims

Ethnic Grouping	Definition of Terms
African-American	Those persons of African descent native to the United States
South Asians	Those of Indian/Pakistani, Bangladeshi, Sri Lankan, or Afghan descent now residing in the United States as citizens or permanent residents
Arabs	People from Arabic-speaking countries of the Middle East and North Africa who are permanent residents or citizens of the United States

Africans	People from the African continent who are citizens or permanent residents of the United States
Iranians	People of Persian descent, usually from Iran, who are citizens or permanent residents of the United States
Turks	People of Turkish descent who are citizens or permanent residents of the United States
Southeast Asians	People of Thailand, Malaysia, Indonesia, Indochina, or the Philippines who are citizens or permanent residents of the United States
American Whites	Those of West European descent who are native to the United States
East Europeans	People from various regions of Eastern Europe who are citizens or permanent residents of the United States
Other	All other groups

Source. Islam 101 (n.d.).

In the United States, one distinct group, known as the Nation of Islam, arose in the 1930s. Founded by Wallace Fard Muhammad and made famous by Elijah Muhammad, the Nation of Islam's ideas attracted many African-Americans. The Nation of Islam considers itself to be quite different from the larger and older Sunni and Shi'a denominations of Islam. The Nation of Islam faced its own schism in the 1970s between followers of the original Nation of Islam, led by Minister Louis Farrakhan, and those who became Sunni Muslims, led by W. D. Mohammad, the son of the Nation of Islam's founder. Malcolm X greatly influenced the decision of many followers to shift to Sunni Islam.

Several other characteristics should be considered when discussing Muslims living in the United States. These are presented in the next few sections and a few salient facts are summarized here. For example, about 79% of all Muslim immigrants living in the United States are between the ages of 16 and 65. Most American Muslims are men, with roughly two Muslim men for every Muslim woman (Mujahid, 2001). Among African-Americans, it has been speculated that about 60 percent were converts to Islam. "Nearly 38% who converted to Islam said they converted after having read about the religion and 22% cited the influence of a fellow Muslim". Of Muslims in the United States, 59% hold at least an undergraduate degree, making them the most highly educated group in America (Woodrow Wilson International Center for Scholars, 2003, p. 10).

The distribution of income within the U.S. Muslim community is spread more evenly across members than is the case for non-Muslims; that is, Muslims have more members at both extremes and fewer in the middle. Muslims tend to hold professional jobs, and one in three Muslims earns more than $75,000 a year. Mujahid (2001), however, points out that many Muslims who are less educated have entered the country recently, including Liberian farmers and Iraqi soldiers. Similar to most illegal immigrants, they find it difficult to obtain employment, and many are in fact in the U.S. illegally.

A Brief History of Islam

Islam is derived from the Arabic verb Aslama, which means to accept, surrender to, or submit to God (Wikipedia, 2006). The religion arose in Arabia in 610 C.E., when, according to Islamic teaching, Muhammad received the first of a series of revelations from God that would span 23 years. These revelations were collected and organized into the Qur'an (the word means "recitation), which Muslims consider to be the direct word of God and the highest source of religious authority. Muslims draw further religious teaching from the hadith literature, a collection of the sayings and actions of Prophet Muhammad, whose life they consider to be the perfect example of putting the verses of the Qur'an into practice.

Islam considers itself to be one of the great monotheistic faiths. Allah is the Arabic term for "The God," emphasizing this tenet of monotheism, and is the same term that Christian Arabs use for God. Muslims also believe in a long line of prophets who also are recognized in Judaism and Christianity and are mentioned by name in the Qur'an. These include Adam, Noah, Abraham, Moses, and Jesus. Muslims believe that the last of this line, and the vice regent of God's final religion and law on Earth, is Prophet Muhammad.

Islam is one of the fasting growing religions in the United States and in the world as a whole. Many scholars describe the diversity of the Muslim community and say that contrary to the widely projected views of Islam as monolithic, Islamic practices vary widely, as do Muslim cultures. It is natural to focus on the considerable number of cultural similarities among individuals originating from one particular country and discount their differences. Moreover, although some Muslims in the United States are immigrants, there is also a large and growing indigenous population, both among the children of immigrants and within the African-American community. Although some immigrants assimilate more to local practice and culture than others, they often continue to hold to beliefs and practices that seem "foreign" to American providers because of their membership in the Muslim-American subculture. Similarly, they hold on to elements of their cultures of origin; this is especially true of Muslims from such geographic origins such as Lebanon, Turkey, and Malaysia.

The great cultural variations among Muslims across the globe preclude generalizations about a single "Muslim culture," although other groups certainly perpetuate stereotypes. One element binds all Muslims, however: their common faith and its reliable features of belief and practice. In this section of the monograph, we summarize elements of the religion that are shared across cultures (despite

variations among individuals) to show providers what issues they might need to consider in interacting with a Muslim.

For Muslims, religion is a comprehensive way of life. The Qur'an addresses not only personal faith and theology but also religious and cultural regulations for the individual and the community. The main religious duties of a Muslim are embodied in the five pillars of Islam. These are the *shahada*, or declaration of faith that "There is no god but God and Muhammad is the Messenger of God"; the *salat*, or the five daily ritualized prayers; *fasting* during the month of Ramadan; *zakat,* the annual alms tax of 2.5% of one's wealth; and *hajj,* or pilgrimage to Mecca once during the Muslim's lifetime (Ahmed, Arabi, & Memish, 2006). Each of these pillars, and indeed any religious duty, depends on each person's ability to perform it. For example, a person need not pay zakat if his wealth is below a certain level, and prayer may be modified if a person is physically unable to perform it, perhaps due to illness or disability (Laird et al., 2007).

Islam has many denominations, but two groups are dominant both worldwide and in the United States. The division between these two groups, the Sunni and Shi'a, stems from the decision early Muslims faced upon the death of the Prophet Muhammad: who would be his successor as the leader of all Muslims? The Sunnis or Sunnites, so named because they consider themselves to follow the sunnah or "custom" of the Prophet, formed the majority who accepted Abu Bakr, Muhammad's close companion and an effective leader, as his successor. Followers of the Shi'a tradition, known as Shi'ites, are those who followed Ali, Muhammad's cousin and son-in-law, who was his closest relative. The Shi'a draw their name from a shortened form of Shi'at-Ali, or "the party of Ali." Shi'ites also frequently refer to themselves as followers of Ahlul-Bayt, the family of the Prophet.

With 940 million adherents, Sunni Islam is by far the largest denomination of Islam. In comparison, there are approximately 120 million Shi'ite Muslims worldwide. Sunnites and Shi'ites are as diverse within their denominations as they are different from one another. Their sources of religious guidance, practice, and custom vary from region to region, and their interaction with cultural norms is also quite varied. The balance of Sunnite and Shi'ite Muslims varies from region to region. In Algeria, nearly 99% of Muslims are Sunni. In Kuwait, 70% are, and in Afghanistan 80%. In Iraq, 45% to 60% are Sunni Muslims, concentrated mostly in the central and northern parts of the country. Sunni Muslims are a minority in Iran (10%) and Bahrain (30%). In the United States, statistics on the Sunnite and Shi'ite balance are unreliable. What is clear is that although most Muslims in the United States are Sunnite, large communities of Shi'ites exist, especially in southeast Michigan and northern California. Other, smaller denominations of Islam include the Nation of Islam, unique to the United States and described earlier.

Although Islam lays down certain beliefs and principles, their application is subject to interpretation among Muslims. The practice of Islam is shaped by the cultural influences of the diverse societies that Muslim populations inhabit. Virtually all Muslims agree on what forms the bedrock of belief and practice. For example, the five daily prayers are universally recognized as central to the practice of Islam; there is little room for diversity on this topic. In contrast, the Islamic requirement of modest dress varies according to the local customs of a particular country or culture. One scholar likened Islam 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, 2006). Few people make a strong distinction between what is "culture" and what is "faith," weaving the two together in their minds. As cultural elements are incorporated into religious practices, the two become interwoven in people's lives and minds.

Such a blending of culture and religion is not unique to Islam and is common across all religions. Among Catholics, for example, Mardi Gras, St. Patrick's Day, and the Day of the Dead are culturally distinctive holidays that combine a Catholic religious foundation with Creole, Irish, and Latin American cultural traditions, respectively. This incorporation of cultural elements into religious practices has resulted not only in culturally distinctive expressions of religious traditions but also in a blurring of the lines between religion and culture, because people consider cultural customs to be important parts of their religious practice.

Given the diversity around the bedrock of belief and practice, one question of Islam that puzzles outsiders is the question of how "correct doctrine' is decided. What is the authoritative source for interpreting the Qur'an? Who decides on and promulgates a "fatwa" (in the Islamic faith, a fatwa is a ruling on Islamic law issued by an Islamic scholar), and how do they do so? What happens when scholars of Islam disagree with one another, or when major schools of Islamic law produce different conclusions? Such questions have been debated within Muslim communities since the first century of Islam, and the answers are not easy to explain. The health and rehabilitation service provider nevertheless may wish to know why some Muslims permit themselves to relax a certain practice in a disability situation, while others forbid any deviance from prescribed practices, as well as what definitive authority could settle the issue. A key answer is the development of "fiqh"- (which is an expansion of the Sharia Islamic law—based directly on the Quran and Sunna—that complements Shariah with evolving rulings/interpretations of Islamic jurists, Wikipedia, 2006) and the processes by which modern Muslim scholars study both the major schools of Islamic law and current thinking and issues. Over time, these processes make it possible to reach a more formal consensus and to harmonize various opinions, based on the best available information as seen practiced in Judaism and Christianity (Miles, 2007).
It is also important to note religious practices in the mosque, in comparison to

practices in other faiths. An important point is the absence of paid staff. This is one of the strengths of Islam, not the result of negligence or poverty. Those of other faiths may not be aware that Islamic practice generally has not followed Christianity's pattern of a paid priesthood. The work of the mosque as a religious center, a community center, and a focus of educational and charitable activity has been largely based on the voluntary giving of time, skills, and money by the local Muslim community. This has reinforced the egalitarian nature of Islam and the notion of people serving their community as a "service to Allah" rather than as a salaried career (Miles, 2007).

Islam's Perspective on Disability

In Islam, a person's worth is based not on any physical or material characteristics but on piety. Piety includes both faith in the tenets of Islam and a genuine attempt to adhere to Islam's obligations to the best of one's ability. For example, Muslims say 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). Despite Islam's professed ideology of inclusion, however, mosques in the United States today reflect their communities' immigrant origins and limited awareness of measures to accommodate the needs of congregants with disabilities, making those people relatively more isolated than their counterparts in other faith-based institutions. This presents a challenge: how to change attitudes so that people will support Muslims with disabilities as equal and contributing citizens of their community.

Indications of this problem come from other sources as well. Lorraine Thal, a program officer of the religion and disability program at the National Organization on Disability, reported that her agency failed in its efforts to reach out to mosques (Akram, 2006). This reflects the fact that Muslim religious leaders and the Muslim community as a whole take little initiative on this issue. The result is further isolation for Muslim families who need additional support yet are often not well connected to mainstream resources; their own Muslim communities have paid little attention to these issues.

This lack of initiative is further reinforced in an anonymous article titled "What Does Islam Say About Disability?" (Muslim Youth Net, n.d.). The article says disability is not widely discussed among Muslims as a community agenda; often, the misconceptions associated with disability cause this silence. Bazna and Hatab (2005) evaluated the position of the Qur'an and hadith on disability and concluded that disability is considered morally neutral; it is neither a punishment from God nor a blessing, and it does not reflect any spiritual deformity. A human's worth in the sight of God depends on spiritual development rather than any physical or material attributes. One saying of Prophet Muhammad recorded in the hadith is "Verily Allah (God) does not look to your bodies nor to your faces but He looks to your hearts" (Sahih Muslim, n.d., 32:6220). Although the Qur'an

removes any stigma for people with disabilities and theoretically should remove all barriers to their inclusion, full inclusion for many Muslims with disabilities remains an unfulfilled reality.

A Muslim's effort to continue ritualistic practice despite a disability reflects his own personal sense of the faith's requirements as well as ability to act on beliefs. Muslims with disabilities and chronic health conditions are given dispensation from those requirements they cannot meet, but they are expected to adhere to all others. Muslims who acquire a disability later in life and who have absorbed their religious responsibilities as an integral part of their routines and self-image often go to great lengths to develop adjustments that will allow them to continue accustomed religious practices.

One of the most integral parts of a Muslim's day is prayer. Orthodox Muslims pray five times daily at specified times: dawn, midday, afternoon, sunset, and night. The prayer is ritualized and has certain requirements. Before they pray, Muslims perform a traditional wash of their head and extremities to attain a state of ritual purity. They must properly cover their bodies and must face in the direction of Mecca as best they can. The prayer itself involves a variety of postures including standing, bending at the waist, kneeling in prostration, and sitting.

This combination of conditions can prove extremely challenging for some persons with disabilities or chronic health conditions. Ritual washing requires that one clean a minimum of the hands, face, arms to the elbows, head, and feet; the ears and inside of the nose and mouth typically are also included, in accordance with the habits of Prophet Muhammad. Reaching these areas, particularly the feet, may be a challenge for those with limited range of motion. The state of purity is broken if one passes urine, stool, or gas; this loss of purity is often a particular source of stress for patients with incontinence. In a British study, Pakistani women with incontinence reported that a significant source of stress was their sense of being constantly unclean and thus unable to perform their prayers (Wilkinson, 2001).

Exceptions are made from Islamic regulations, such as ritual purity, when circumstances make adherence too difficult. For example, religious scholars say it is acceptable for those with incontinence to make an ablution once just before each prayer and to disregard any leakage of urine. The various prayer positions can also prove difficult for certain persons with disabilities. Prayer involves a variety of muscle groups and requires a significant range of motion from certain joints as well as the balance to maintain standing and bending postures. Dispensation is available here as well. Muslims who cannot carry out the usual postures can pray while sitting or even lying down. Such persons should still be helped to fulfill the other requirements of prayer, including ablution, covering, and positioning toward Mecca.

In many cases, Muslim patients do not know of such religious edicts or may personally dismiss them. The psychological impact of accepting their condition as it limits their ability to observe conventions regarding prayer, therefore, can be significant. In such situations, culture brokers can play a key role by informing Muslims about religious accommodations that will allow them to avoid any risk to their health and still be able to be part of religious and spiritual activities. Because prayer is such an integral part of daily life for Muslims, at least two researchers have tried to modify an existing assessment scale to include prayer. In the Health Assessment Questionnaire given to rheumatoid arthritis patients, "Praying from the standing position" was substituted for "Vacuuming or yard work" among Arab Muslims. The researchers found that it correlated with other measures of function as closely as the original question as did in the original population (El Meidany, El Gaafary, & Ahmed, 2003). Another study added prayer, including washing, recitation of the Qur'an, and physical movements, to an Activity for Daily Living (ADL) scale for Muslims. This measure was found to correlate well with the rest of the scale; in fact, it could identify weaknesses in patients who had scored as fully independent on the other parts of the scale (Margolis, Carter, Dunn, & Reed, 2003). Thus, the rehabilitation provider may find it extremely useful to collect information about the person's ability to perform prayer rituals and to plan therapy that can help restore this ability.

Another religious duty needing considerable discussion and advance planning is the hajj, or pilgrimage. Although many Muslims with disabilities can fulfill this duty, it may require significant preparation and careful planning, health precautions (Ahmed et al., 2006), and cultural responsiveness, as the following case study shows. Betty Hasan Amin (2000) tells a moving story about her experience performing the hajj as a paraplegic. Her trip required extensive preparation, including packing extra medical supplies, bringing a manual rather than an electric wheelchair, carefully planning methods of transport, and traveling with people who had nursing experience and could attend to her medical needs. Like every traveler, even those with well-laid plans, she encountered unexpected difficulties. She was initially denied entrance into the main sanctuary at Mecca and had to try several entrances before she found a guard who was willing to let her in and had a more accepting attitude toward her disability than did other guards. Her wheelchair cushion, strapped to the top of a bus for transport, blew away, and though she substituted pillows, by the end of her trip she had developed an advanced decubitus ulcer that required surgery after she returned to the United States.

In another incident, her traveling companions stepped off the bus to use the restroom, and the bus departed without them. Unable to explain her condition to the other passengers, who did not speak English, she spent that night on the bus alone before anyone understood her situation and helped her reunite with her group the next day. With the aid of her companions, however, she was able to perform all the rites of the pilgrimage. Looking back on the experience, she found herself both grateful for the opportunity to do so and sensitive to the plight

of individuals with disabilities living in parts of the world where society is far less accepting of them.

This vignette demonstrates that although certain religious practices may be difficult and may require advanced planning, even the most strenuous of religious duties may be fulfilled by persons with disabilities, and every reasonable effort should be made to help plan them. In fact, according to Kingdom of Saudi Arabia's Ministry of Hajj, the Grand Mosque in Mecca, unlike many mosques, is well equipped for Muslims of varying abilities and features escalators and ramps to enable people who use wheelchairs to participate fully in the religious yearly event (Ministry of Hajj, Kingdom of Saudi Arabia, 2006). Fasting during Ramadan, another major religious responsibility, is discussed in Section IV, along with other holidays and practices associated with them.

III. Family and Community Perspectives on Health and Disability

This section discusses attitudes about and treatment of disability from Muslim perspectives, as well as how attitudes and treatment may vary within and across families. The section is divided into four major parts: (a) concepts of and treatment of disability in Islam; (b) attitudes and beliefs; (c) labeling, stigma, and superstition; and (d) views on acquired versus lifelong disabilities.

The Concept of and Treatment of Disability in Islam

We stated earlier and wish to emphasize again that the diversity of Muslims precludes delineating one "Muslim" viewpoint. In this monograph, we take ideas from religious writings that pertain to the concept of disability. Although the Qur'an makes few references to disability (Bazna & Hatab, 2005), most sources tend to focus on the disadvantages created by society that face the disabled population. Like other faiths, Islam emphasizes the community's responsibility to protect and care for those needing assistance, and it encourages the inclusion of all people, regardless of ability, in the larger society. We discuss these two concepts, responsibilities regarding those needing assistance and inclusion of all people, in further detail in the sections on community and religious views on disability.

In an analysis of the Qur'an and Hadith that looked specifically for references to disability, Bazna and Hatab (2005) found that the generic term was not used in the conventional sense, but the Qur'an does refer to disability in a progressive sense. For example, the Qur'an uses Arabic terms for descriptions of people with disabilities including blind, deaf, lame, mentally retarded, and leprosy. It also includes some broad terms for weak, lame, sick, orphaned, destitute/needy, wayfarer and disadvantaged (Bazna & Hatab, 2005), which very likely would have

been understood to embrace people who might now be categorized as "having a disability" (Miles, 2007).

Islam understands that disadvantage can be created by society and imposed on individuals who might not have the social, economic, or physical attributes they need to gain access to services and opportunities. Islam views disability as morally neutral, neither a blessing nor a curse: It is considered an inevitable part of the human condition, one that Muslim society and individuals must address. The Qur'an and hadiths certainly do record physical disabilities (e.g., impairments of body and sense resulting in people being unable to do things that would be normal, such as walking, hearing and seeing). As mentioned above, there are also metaphorical uses of concepts surrounding disability, such as "deafness to the voice of Allah," which might be called a disability of the "heart," or of the human will. This point was echoed by Imam Yucel, the Muslim chaplain serving Brigham and Women's Hospital in Boston during a workshop presentation on disability and health issues in Islam. Yucel emphasized that in Islam, "there is no disability of the body as such but rather of the heart." This statement relates to various attitudinal aspects of disability addressed by individuals and societies.

Rehabilitation providers dealing with Muslim patients, particularly those discouraged by a new diagnosis or ongoing disability, can emphasize this point. When reminded of this concept, many patients or consumers will respond well to the idea of judging self-worth on the basis of inner characteristics rather than physical abilities. The ways that these concepts of disability are put into practice depends on the individual and the surrounding culture. For example, in a short-term study of attitudes toward the disabled in Afghanistan, Armstrong and Ager (2005) noted an emphasis on the responsibility of society, similar to Islam's doctrine, which is to provide care and support for people with disabilities. Based on this outsider perspective, Afghani programs were found to place lesser emphasis on enabling individuals to live more independently (Turmusani, 2004).

Despite the concept of moral neutrality discussed above, the Armstrong and Ager study (2005) found that disabilities, whether congenital, physical, or developmental, sometimes were seen as punishment from God for poor character, in both rural and urban areas, depending on the multiple social factors linked to a family. This negative stance toward disabilities with regard to religious rituals and morality stands in some contrast to other aspects of life in Afghanistan that revealed positive resources for enabling people with disabilities to play their part in community life. In fact, as they rebuild their community from the devastation of warfare, Afghans are working hard to make better provisions for people with disabilities, particularly amputees who lost limbs as a result of land mine explosions and people who have become blind as a result of the war (Miles, 2001).

Many Muslims see disability in the context of qadar/kismat, or fate, a cornerstone of Muslim belief. This concept is often expressed as the belief in preordination,

that what was meant to be will be, and what was not meant to happen does not occur. Muslims also acknowledge the concept of free will and its nuanced balance with fate. Advice by Prophet Muhammad from the hadith literature instructs people to "Trust in God, but tie up your camel." In other words, human beings should be active rather than passive participants in the world, and at the same time they should realize that the ultimate outcomes of their efforts lie with Allah.

Each individual finds a different balance between these concepts of fate and free will. Sometimes these concepts can help people accept their situation and be more motivated to overcome disability. An excessive focus on destiny and fate, however, also can lead to self-pity, questioning, and decreased hopefulness. An Israeli study of Bedouin Arab Muslim parents of children with disabilities in Israel found that those who believed more deeply in destiny and fate were less likely to comply with instructions and to be satisfied with their care; the negative reactions that accompanied these beliefs were a key issue in their children's recovery (Galil, Carmel, Lubetzky, Vered, & Heiman, 2001).

Attitudes and Beliefs

As is true for adherents to any religious beliefs, parental views of a child's disability as an act of God lead to a variety of actions and interventions (Bywaters et al., 2003). Although many families may identify with biomedical causes of illness and disability as defined by disability professionals, they also may often link disability with religious or folk explanations. For example, Turkish mothers suggested God and Fate, the Spell, the Evil Spirit, and becoming pregnant on Holy days as some explanations for their having children with disabilities (Diken, 2006). Other families may see their sociocultural characteristics or lack of understanding as causing the disability (Kleinman, 2006). Strong traditional beliefs about the chances of a child's recovery can shape parents' actions regarding seeking help or treatment (Diken, 2006).

Muslim parents may have a range of other reactions and experiences. Some may not believe their child has a disability, or they may misunderstand its nature (Crabtree, 2007). They may try to compensate when they see others treating their children with indifference. Others may even think that working with a disability is not worth the time. During our interviews with Muslims, some people said such things as, "We need to help a lot of other people before we help the disabled." In other circumstances, families may well encounter attitudes ranging from pity to downright hostility (as when other families forbid their children from playing with children with disabilities) and fear (as when people ask parents if they're scared of their child's unpredictability resulting from a disability).

Often, these experiences and attitudes lead families to try everything possible to address their child's disability. Their initial reaction may be so amplified that they see the disability as a highly acute health issue needing subspecialty care (Sajjad,

2006). Parents with this attitude run from one specialist to another, hoping that something can be done to make their child normal. According to Khedr (2006), traditional treatments for disability, such as wearing amulets, are still popular among families of all backgrounds and social classes. Although literate families in the Muslim world tend to seek doctors, some families from all classes, in both urban and rural areas, still seek help from traditional healers. Surprising numbers of families (who can afford it) take their children to the United States in the hope of finding a cure. These beliefs and practices persist when families move to the United States or Europe.

Of course, many Muslim families, as well as the professionals they encounter, treat children with disabilities with sensitivity and support. Many are treated like any other child, rather than being given special treatment. The children participate in school, employment, and community life like anyone else.

Cultural factors both limit and facilitate attitudinal factors that lead to positive opportunities for Muslims with disabilities. For example, family attitudes and beliefs about their children and family members with disabilities play a major role in promoting "inclusiveness" in education, employment, and community living. For other families, it is crucial that children work, despite their disability, if the family is to survive. These factors may keep children with disabilities from attending school in some Muslim nations. "Such attitudes are at odds with either medical or scientific accounts of disability, on one hand, or rights-based accounts of disability on the other" (Bywaters, et al., 2003, p. 503).

Many Muslims from developing nations are not deeply aware of the needs and talents of people with disabilities and the opportunities open to them. As a result, both children and adults with disabilities are kept at home because they are perceived as being unable to learn or in need of protection and extra care. Their disability may be emphasized more than their ability, seriously limiting their educational, rehabilitative, and social opportunities. Rosina Abdulshakur stated in her interview with Azizah magazine (Legander-Mourcy, 2003), "Allah {God} includes all . . . and although exclusionary practices are prevalent . . . this comes from lack of awareness about the capabilities of people with disabilities, rather than maliciousness" (p. 2).

Although many Muslim people and governments consider it a humanitarian responsibility to assist people with disabilities, few Muslim societies have made the effort to advance a systematic social foundation, at a country level, to assist those with disabilities. For the past 15 to 20 years, Saudi Arabia has targeted the development of such a social foundation, providing a large budget and recruiting expert advisors. Brunei and Qatar have made similar, if smaller, efforts. In fact, "in Egypt, caring for people with mental illness in a community setting dates back six centuries" (Endrawes, O'Brien, & Wilkes, 2007, p. 180), long before the movement in Western countries to deinstitutionalize such treatment.

In 1993, a professor of economics at a major university in Boston (who insisted on anonymity) noted during an interview that cultural attitudes toward the disabled could be generally divided into two categories: conservative and liberal. The "conservative view" of disability, as he described it, is based more on supernatural or folk explanations and less on a physical or physiologic understanding of disability. He attributed the conservative view to poorer Muslim immigrants or refugees, who conclude or believe that disability is the result of God's will. The conservative view often considers disability as a curse on the family or a punishment for a sin a family member or ancestor may have committed in an earlier era (Hasnain, 1993). Given this view, persons with a disability may hide themselves or even be hidden by the family because of the shame associated with the disability. For example, some Muslims in Kenya believe that a child who is congenitally deaf is concealing a divine secret from his family. Such attitudes may explain why some Muslims choose not to seek outside supports or services.

The liberal view, in contrast, dismisses religion as the cause of disability and considers itself to be more objective and scientific. Families holding the liberal view attribute disability to genetic disorders, medical conditions, or accidents. Such a family may seek medical or rehabilitative supports, but often the notion prevails that the entire family will care for the person and may or may not overlap with alternative care by professionals. It remains unclear whether the "liberal" view is more characteristic of educated modern Muslim families or educated Western/post-Christian families.

The few empirical studies conducted on parental attitudes toward disability often have been concerned with cognitive disabilities, and most have been carried in large cities. For example, studies have found that tradition-based members of communities have more positive attitudes toward disability. The children most accepted by their families and the community were those with physical rather than mental disabilities; those with mental disabilities were less accepted and were given less familial and interpersonal attention (Ansari, 2002).

In many cases, Muslim families from developing countries understand a cognitive deficit, such as an intellectual disability or a form of mental retardation, differently from the way it is understood in developed nations. In the developing world, judgments about cognitive ability are based less on standardized testing and more on a sense of what the family and community demand of the individual. Given that many immigrant and refugee Muslims are not literate, they are not likely to see a teenage child as mentally impaired if he or she has not yet learned how to read. If the inability to read is coupled with the inability to serve tea or sell fruits and vegetables at a local market or make polite conversation, however, then the individual may be considered as having a mental impairment. This example highlights the facts that concepts of normalcy are not universal and that impairment must be seen in its social and cultural context (Hussain, 2003).

Labeling, Stigma, and Superstition

Muslims from South Asia may be quick to label individuals with disabilities, as often happens in Western societies. For example, in Pakistan, the Urdu word "paagal," commonly used to describe an individual with a cognitive disability, means "mad" or "crazy." The word describes a variety of disabilities, including behavioral, mental, physical, and emotional. Disability also may be evaluated based on a person's functionality. For instance, in both Pakistan and India, the community may classify a person by his or her specific disability or lack of functionality (Komissar, Paiewonsky, Hart, & Hasnain, 2001). In an interview conducted in Boston, one woman described her experience back home in Pakistan: "My sister and I had a lady neighbor in Pakistan who was deaf. She had a name, of course, but nobody called her by her name. Instead, they would call her the 'gougi bachee,' which means 'deaf girl.'"(Hasnain, 1993). Similar attitudes appear in South Asian television and movies. More recently, however, people in South Asia seem to understand a moral obligation to support those who are at a disadvantage because of poverty or who lack access to education, doctors, and opportunities. For example, a woman interviewed in her native Pakistan (personal communication with anonymous source, Pakistan, 2006):

> If we go by Islam, we would look at disability differently. If you believe in Islam and something undesirable happens, we tend to feel depressed and ask ourselves "why me?" or actually "why us?" given the family-oriented, collective worldview Muslims have. . . . [The Quran] says that Allah puts us on trial and sees how much we can take to test us. If you look at it in that standpoint, it's a challenge a person takes.

According to another Pakistani woman, a family who has a child with a disability is not necessarily viewed as being a bad family. Islam forbids this thinking. When asked what causes a disability, she responded by saying "It just happens." (personal communication with anonymous source, Pakistan, 2006). The reactions of others ranges from "It was destined to happen" to "it's a blessing" to "It was Allah's (God's) will or a test from Allah" (Bywaters et al., 2003).

The issue of marriage plays a critical role in Muslim families and communities (Crabtree, 2007). Broadly speaking, compared to North Americans, Pakistanis carry a higher expectation that everyone will get married. If the candidate for marriage is perceived as somehow "different" (e.g., from a lower social class, financially unstable, not well educated, disabled in some way, or from a family with social "disgrace"), however, this may be taken into account in the marriage arrangement. Each family will accept some approximately equivalent adverse factor in the other proposed spouse, or one will make a suitable payment to the other family in compensation. The key point here is that the arranged marriage is contracted between two families, rather than between two young individuals. The older generation looks at a prospective daughter-in-law as one who will be

"the mother of our grandchildren," just as much as "the wife of our son" (Miles, 2007).

Because of the regimented nature of immigrant Muslim society, people with disabilities may face greater difficulty than others in finding companionship and long-term intimate relationships. A Pakistani Muslim woman who lives in Massachusetts related this story during an interview (Hasnain, 1993).

> One of my cousins was against an arranged marriage because the person she was going to marry turned out to have a limp and they were disgusted by the situation. . . . People are scared of those who do not look right or normal. They said things like "I think it's scary" and "I don't want to be close to this person." The marriage never took place.

Such attitudes may be changing, however. Wallis (2006) describes a successful marriage between a young Indian-born man with Down syndrome and a young woman born in the United States who also has Down syndrome; their marriage seems to be succeeding. Other stories point to an evolving attitude of Muslim communities toward individuals with disabilities.

Another important issue is the controversy that surrounds the link between high rates of consanguineous marriages, especially among Middle Eastern and Pakistani immigrant Muslims, and congenital or genetic disorders. The term consanguinity, also known as close-kin marriage, refers to marriage between individuals who are closely related, no further apart than second cousins. Islam does not encourage close-kin marriage, but important factors promote the practice in Muslim societies (as in many others): economic factors revolving around the preservation of land and wealth, psychosocial advantages, and geographical or cultural traditions. Understanding these practices may help service professionals better understand the conditions that families may be facing regarding their child with a health condition or disability.

Finally, a variety of cultural superstitions and rituals revolve around the disabled population. In South Asia, Muslims with disabilities may be taken to a "gila" or "fakir," the Punjabi equivalent to a saint. People believe that if they take care of a person with a disability, they will go directly to heaven when they die. Indeed, some Muslim families take great care of such children because they are considered the gateway to heaven. Other Muslims think that children with disabilities are a problem for society. They believe that a child's mental problems and behaviors derive from curses placed on the child. Muslims in Pakistan (Miles, 2007), Turkey (Diken, 2006), and Egypt (Endrawes, 2007) believe in djinns (evil spirits) and blame them for disabilities their child suffers. In response, one Muslim doctor described a unique practice of care: A person with a disability was taken to a shrine where holy people were asked to take the spirit out of that person with a disability so the person could function normally. This illustrates the popular fear

surrounding a child or adult who has a cognitive disability or cerebral palsy.

Djinns are described in the Qur'an (6:100, 15:27, 34:41, 46:29-32, 55:15) and the Surah Al-Jinn (72:1-15) as well as by many modern authors, such as Diken (2006) and Miles (2000/2007), as beings created by Allah. In at least a dozen well-attested hadiths, the Prophet Muhammad is reported to have used the term "djinn." It is not surprising, therefore, that most Pakistani Muslims believe in djinns, as do orthodox Muslims in most countries. Djinns are believed to be spirits, though not always evil ones (Miles, 2007).

Muslims educated in a modern, scientific ethos may feel some discomfort with such beliefs, so they put them aside and normally allow them to play no part in their thoughts. Muslim beliefs and modern reactions are closely paralleled by Christian beliefs in this regard. The Christian scriptures depict Jesus commanding spirits and expelling them from some people with disabilities. For health and rehabilitation workers in the United States who need to understand the concept more deeply, it may be useful to compare Christian approaches to "spirits" to Muslim approaches to djinns. Similarly, both Muslims and Christians traditionally believed in the efficacy of visiting saints' shrines for the benefit of children or adults who seem to be oppressed or possessed by an evil spirit. Such practices co-exist with modern scientific medicine in most countries. Modern science cannot either prove or disprove the existence of djinns, but scientific evidence usually leads to theories that make no reference to either djinns or shrines (Miles, 2007).

Sickness theories involving djinns are often invoked to explain epilepsy. In one approach described by Christine Miles (2007), a health provider in England successfully introduced the modern theory of epilepsy in terms of "brain electricity" to an Asian Muslim family that holds traditional beliefs about djinns, without any heavy-handed dismissal of their beliefs. The provider enabled the Muslim family to both accept a Western-based intervention (i.e., administering anti-epileptic medications) to Imran, their son, while still respecting and incorporating their worldview and spiritual frame of thought into her approach. Most people who struggle with disability have deep and contradictory feelings about disease and disability that are not easy to sort out, understand, or control. This example shows how effective brokering can benefit all those involved, especially the child who is dealing with the condition and the family who still feel like they are in control of their child's situation.

To that end, Muslims, like other ethnic groups from developing nations, embrace both positive and negative attitudes toward disability. Each person's view may be based on a combination of factors. Although it is correct to emphasize the variations and permutations of belief among Muslims from different cultural backgrounds, the question may arise as to whether anything constitutes a common core; that is, is there something that almost all Muslims believe about disability?

It is not quite that easy. Still, such awareness by disability specialists may prevent further stereotyping of a group that is already stereotyped by others.

Perspectives on Acquired Versus Lifelong Disabilities

The Islamic teachings discussed earlier do not distinguish between acquired and lifelong disabilities; however, individuals may make a distinction based on certain interpretations, cultures, or social situations. Miles (1995, no page number) relates the following story.

> One man brought to a Peshawar disability center his child, who had cerebral palsy from birth and later suffered post-polio paralysis. The father requested treatment for the paralysis, but forbade action on the cerebral palsy, since the child had come like that in the first place. He saw polio as a disease- and "for every disease, Allah has appointed a remedy." Cerebral palsy was a condition, to be accepted with fortitude; to try to change it would be rebellion.

This anecdote illustrates two points we have discussed earlier. First, when faced with acute or acquired illnesses, many Muslims place a great deal of faith in the potential for a cure, so they may be more discouraged if recovery is slower or less complete than expected. At the same time, they may not view a chronic or lifelong condition as an "illness" at all, despite its disabling features. Thus, they may need to be convinced to pursue interventions that might improve the quality of life for a child with a condition such as a developmental disability, Down syndrome, or autism.

In rural communities of northern Punjab, Ansari (2002) explored some of these issues by studying the attitudes of Pakistani parents toward their children with disabilities. The parents in this study showed more warmth toward their children who were deaf, blind, or physically disabled than toward those who had cognitive or mental disabilities. Moreover, Shahzadi (referenced in Ansari, 2002) found that parents with cognitive disabilities felt a great deal of distress raising their children because they feel ashamed and embarrassed about the child.

Views of disability can also be heavily influenced by their cause, especially in developing nations, where a heavy burden of disability results from decades of conflict and violence. For example, in Afghanistan, Armstrong and Ager (2005) found that awareness of disability centered on traumatic injury. They admit, however, that their sampling methods may have played a role. They used "nominated sampling"—a list of "suitable people to be contacted"—to recruit their focus group participants. As a result, the "views of people with congenital disabilities are under-represented" in their study (p. 91). Given this situation and biased sample, their findings are not surprising. Apparently, those with traumatic disabilities elicited more feelings of respect and were seen as more self-reliant,

whereas those with congenital disabilities were spoken of paternalistically and seen as being needier. These attitudes also have been reflected in the provision of services. In Afghanistan, more resources are in place to support those with traumatic disabilities than congenital disabilities, as discussed earlier (Miles, 2002a). One must use caution, therefore, in making generalizations that these findings apply to the country itself (Armstrong & Ager, 2005).

Although the beliefs associated with disability vary, many of the underlying difficulties come from attitudes found in the Muslim community itself. "Sometimes I feel invisible in my wheelchair," said Majeeda Harris, a paraplegic woman who lives in New York City (News Watch, n.d.). In the mosque, she gets looks that seem to ask, "Why are you here? What are you doing here?" Her response is, "Well . . . why shouldn't I be there?" She believes "Muslims have a long way to go in gaining awareness of the needs of the disabled," and she is shocked by their insensitivities (News Watch, n.d.). In most Muslim countries, as in much of the world, people are only slightly aware of the needs and talents of people with disabilities. Consequently, they focus on an individual's disability more than that person's abilities, seriously limiting the educational, vocational, social, and cultural opportunities of people with disabilities. Given this background, many immigrant and refugee Muslims, especially those who come from homelands with limited or no disability supports, enter the United States knowing little about the systems of care and are unaware that they have access to such resources or infrastructures.

IV. Overview of Muslim Culture and Its Impact on Persons Served

This section provides a general overview of the ways that elements of Muslim culture affect individuals with disabilities and families who are being served. In the six subsections we address the following issues: (a) the concept of independence and collectivism within the culture, (b) family structure and the role of family in health and rehabilitation, (c) gender issues, (d) the role of community, (e) important holidays, and (f) dietary restrictions and preferences.

— *The Concept of Independence and Collectivism Within the Culture* —

One of the most important examples of the way that American cultural assumptions can directly contradict those of other cultures comes in the Muslim view that an adult Muslim with a disability should live with the family rather than on his or her own. This is not surprising given that, in most of the world's cultures, particularly in Muslim culture, the family structure and society at large takes priority over individual independence (Nisbett, 2003), especially if you are dealing with a disability (Abd El-Khalek. 2004). Family members are felt to have a responsibility for one another, and individuals usually are not expected to function

independently of the family unit. Generally speaking, a family's responsibility for supporting persons with disabilities extends to aunts, uncles, cousins, grandchildren, and grandparents.

Indeed, in much of the world, including parts of Europe, governments have been, and still are, reluctant to deploy public resources to care for people with disabilities who traditionally would look to their families for care. In itself, the family support system constitutes a large part of social services: Governments have understood that not only should they do nothing to damage the family support system, but they also should cherish and encourage it. Family duties and responsibilities have been taught by all the major religions throughout human history. They are a major basis for the rise of community-based rehabilitation as a development strategy in the past 30 years. The idea that disabled or aged members would be better cared for by strangers who are hired for that purpose would be repugnant to many families across the world; it would seem as odd as the idea that parents should hand over their children to the care of strangers (Qureshi, Berridge, & Wenman, 2000).

Muslims often express a religious duty to care and provide for the weak or disabled. This feeling can engender a reliance on family and community that may overshadow the goal of self-empowerment that is key to the rehabilitation model (Armstrong & Ager, 2005). Studies of South Asian families in Britain found that parents were often overprotective of their children with disabilities and underestimated the children's abilities to negotiate daily activities. The families expressed a felt responsibility (and even an expectation) to continue to care for their children into adulthood (Hussain, 2005). Similarly, young people with disabilities in the United Kingdom, although they described loving and supportive family dynamics, noted that their families often had reduced expectations of what they could do and were overprotective, particularly toward young women (Hussain, Atkin, & Waqar, 2002; Thomas, 2001).

Some see this emphasis on the extended family as a result of inadequate institutional sources of support (e.g., pensions, insurance, and benefits) provided through either the government or the private sector. They explain that "the elderly in Muslim countries, such as Bangladesh, are for the most part completely dependent on primary kin for aid" (Rahman, 1999, p. 227). Immigration to Western societies removes the access to extended family members on whom they previously relied for social services and support (Fazil, Bywaters, Ali, Wallace, & Singh, 2002). When families lose this extended family support, they often do not replace it with a search for social support services outside the family, often for the reasons described above.

Having emphasized the value of family over individuals, we do not recommend abandoning typical goals of independence. In time, many immigrant families come to appreciate the importance of independence for both individuals and families.

Although the Muslim families mentioned above expected to care for their children with disabilities, they also wanted to encourage the children's (eventual) independence and maximize their opportunities as much as they thought possible. A study in Pakistan found that job satisfaction was the factor that correlated most with subjective well-being, suggesting that individuals greatly valued the independence required for work (Suhail & Chaudhry, 2004).

A case study of a Muslim Ugandan woman who was disabled by childhood polio further illustrates this point. In Uganda, the woman's parents encouraged her education, hoping she could be seen as a contributing member of society, but in many ways she still felt dependent on and sheltered by them. When her family moved to Canada, she intended to continue her education, but a social worker arranged to place her in a skilled nursing facility so that her parents could work. Eventually she moved on her own into a group home and enrolled in college, earning a degree in social work. She had difficulty, however, securing a job in which she would be treated as an equal in income and would have opportunity for advancement. She eventually became an activist with disability organizations working to combat such inequalities (Dossa, 2005). This Muslim woman greatly valued the independence that came with education and employment, and it became a focus of her life's work. The types of activism and attitudes exhibited by this woman help to build the leadership needed in Muslim communities (Dossa, 2006).

The question of whether people with a disability should depend on others or instead be given more independence is hardly a modern one. As long ago as the ninth century of the Christian era, the major Islamic law schools were engaged in a debate about the age at which a person with weak intellectual abilities should be considered to have "adult" status. The debate asked when such a person could be considered able to manage his or her own affairs, and even whether such a person could ever gain such status because his or her capacities remained similar to those of a child. Muslim lawyers still have not reached a consensus on the issue, a fact that highlights its importance in society for the past millennium (Miles, 1992, 2002b). Of course, the drive for independence will vary from one individual to another, depending on many factors. As might be expected, the independence required for work is often most strongly emphasized among traditional wage earners. One study of disability in rural Bangladesh found that economic factors played an important role in determining which individuals sought services for their disabilities. Those between the ages of 15 and 59, the most productive years, were most likely to seek services, and men in this group were more likely to seek care than women. People apparently saw the chance to regain their earning capacity as an important reason to pursue rehabilitation services (Hosain & Chatterjee, 1998).

Similar economic concerns seem to be among the reasons why less emphasis continues to be placed on education and employment for women compared to men

in predominantly Muslim countries. Education can be costly for families with limited financial resources; books and transportation may cost money, and the family loses labor within the home when girls go to school. Resources are preferentially given to boys, who are expected to earn higher incomes than girls (Taylor, 1993a, 1993b). Women are increasingly pursuing higher education and employment, however, slowly resulting in higher ages at marriage and a lower fertility rate (Al Riyami, Afifi, & Mabry, 2004; Conly, 1998; Fargues, 2005). Young women continue to face cultural barriers to their independence and traditionally do not leave their parents' homes until they are married (Hussain, 2005). Young women might work only until they are married, when they see their role shift to that of wife and mother (Taylor, 1993a/b). We speculate that women with disabilities may be less inclined than men to pursue educational and vocational rehabilitation, which is less central to their role in society than it is to men. Such attitudes may be more prevalent among recent immigrants than among immigrants who have had longer to assimilate or Muslim women born in the United States, as well as among those who are older and those who have relatively more opportunities to pursue education and employment, and those who, for various reasons, see education and employment as more important in achieving their goals and fulfilling their roles in society.

Various behaviors described in this section could be found among other religious communities or communities at different stages of socioeconomic development. Often, it is not clear whether belief systems among Muslim families arise specifically from Islamic belief or practice. Two features affect Muslim families in the United Kingdom in ways that may be significantly different from those living in the United States. First, the United Kingdom's National Health Service (NHS) provides free or low-cost access to high-quality treatment by physicians and surgeons in hospital and community-based clinics; care is available to practically everyone in the country, regardless of whether they are or have been in paid employment. Although the NHS is paid for by insurance contributions deducted from everyone's salary, access to it has nothing to do with an individual's contribution record (or lack thereof). Only short-term visitors to the United Kingdom are ineligible for free treatment, except in an emergency, in which case they are covered (Miles, 2007).

Second, in the United Kingdom, as in the United States, immigration laws and policies have changed quite a bit in the past 40 years, and for much of this period members of Pakistani families, for example, with a legal immigration status have found it relatively easy to come and go between the two countries. Of course, it is more difficult for migrants and refugees, as well as those who have yet to decide in which country they will live. The United States and United Kingdom differ with regard to how people are treated with respect to such issues, and people's behavior is correspondingly different. This should be kept in mind when drawing on U.K. research studies concerning ethnic minorities and immigrants (Miles, 2007).

Family Structure and the Role of the Family in Health Care and Rehabilitation

In many Muslim communities, the family is considered to be the most fundamental and important social unit. It can be difficult for individuals to avoid the mediating influence of their family. Even as adults, Muslims rely on their parents and other family members for many necessities of life, such as food, clothing, and housing. A major emphasis on maintaining family harmony and stability can lead to efforts to avoid conflict and defer decision making to a figure high in the family hierarchy. In traditional families, members relate to one another based on hierarchies (the older the member, the more authority and respect the member is afforded, though this rule has its exceptions). Within this structure, obligations are seen as more important than rights, and family interests outweigh personal interests (Stone, 2005). Given the cohesiveness of family life among Muslims, across the life span, the care of both children and parents tends to be a lifelong commitment.

Traditional families have particular roles for and expectations of their members. Mothers typically are the primary caretakers of children, especially those with disabilities. Fathers tend to be less involved with child care responsibilities, but this is not always the case. For example, Ansari (2002) found that fathers were more accepting of their children with disabilities than were mothers, who were more rejecting. This finding is consistent with earlier studies conducted by Haque (1987) and Sarfraz (1991). Fazil et al. (2002) highlight the central role that families play in the care of their children, as well as the efforts families make to care for child members with a disability, despite their often difficult material, practical, and emotional circumstances. The example of Imran's djinn, mentioned above, and the theories of epilepsy described in Section II highlight the collectivist approach to caretaking.

Worldviews of independence vary between Western and Eastern societies, and collectivism often is given comparatively more emphasis among the Muslims in Western societies than among the mainstream population. A culture of pity for the disabled, coupled with a desire to keep family struggles and affairs secret, may lead Muslim families to hide their children with disabilities from society. Seclusion of a child also may be a means of escaping the shame or humiliation associated with having a child with a disability. Thus, families of children with disabilities may be less likely to visit friends or go out; and when they do go out, they are more likely to leave the child at home (Bywaters et al., 2003; Kobeisy, 2004). Moreover, many Muslim families deal with family matters privately and therefore seek only minimal outside support, if any. Similar behaviors can be seen in many societies that have very few Muslim families, however, so they can hardly be considered characteristically "Muslim."

Different societies have quite different belief systems concerning keeping persons with disabilities outside public view and away from attention. Miles (2007) mentions Benedicte Ingstad, a leading anthropologist whose work concerns disability in areas other than Europe and the myth of the hidden disabled. Her work, along with several publications, rejects the view that many people with disabilities are concealed by their families. Ingstad conducted most of her field work in Botswana. She found that some urban families sent their disabled members back to their village of origin, where the pace of life was more relaxed and the people with a disability could have a simpler life. Although this example may be overgeneralized, it serves as a reminder to look for evidence that contradicts popular beliefs. Questions remain concerning whether the "concealing" behavior is approved, tolerated, disapproved of, or forbidden in various interpretations of Islamic teaching. (Miles, 2007). Such questions are worthy of further exploration but are beyond the scope of this monograph.

Islam includes an emphasis on taking care of the weak and disabled. The Qur'an stresses respect for parents and the duty of children to care for them in the frailty of old age. One of the most commonly cited verses in the Qur'an states the following:

> Thy Lord hath decreed that ye worship none but Him, and that ye be kind to parents. Whether one or both of them attain old age in thy life, say not to them a word of contempt, nor repel them, but address them in terms of honor. And, out of kindness, lower to them the wing of humility, and say: "My Lord! bestow on them thy Mercy even as they cherished me in childhood. (Qur'an 17:23-4)

Because of this key responsibility laid out in scripture, the family is central in caring for persons with disabilities. This centrality is magnified for immigrants in a foreign environment, where they may have less trust in health and social providers and less access to community supports. In fact, many verses in the Qur'an emphasize the traditional practice of the younger generation caring for the older, who had once cared for the younger when they were children. Various Qur'anic verses focus more specifically on giving attention to people with disabilities, including 2:282, 4:5-6, 20:25-28, 24:61, 36:16-17, 48:16-17, and 80:1-10. In addition, verses 3:49 and 5:110 mention Jesus healing people with disabilities. Readers of this monograph, who are likely to be part of the Judeo-Christian tradition, may be surprised at the high status given to Jesus in the Qur'an and at the recognition of his healing activities. This prominence of Jesus in the Qur'an has resulted in Muslims showing reverence toward Jesus (Miles, 2007).

One can see from the preceding discussion that a combination of factors may influence the choices made by Muslim families with regard to their members with disabilities. Emotional concern over the importance of caring for family members, coupled with a reliance on family and general distrust of institutional social services and support, may lead patients and their families to refuse external and

unfamiliar services in favor of home care, which they see as allowing them to better control their environment and keep it in line with their cultural norms.

Extended families, when present, remain an important part of the family structure in many Muslim-American communities and can be an asset to practitioners trying to determine the most effective treatment plan. Willing members of the extended family can provide emotional and material support for the core family that is caring for a member with a disability. In many cases, members of the extended family should be included in discussions about care plans. Of course, many immigrants are separated from the bulk of their extended families, who were left behind in their countries of origin (or live in other cities in the same country) and thus cannot be a direct source of support (Florian & Shurka, 1981, Khedr, 2005).

Getting individuals and their families the support they need is a particularly important and difficult challenge for disability professionals. Those families most likely to refuse outside help are at the highest risk of becoming overwhelmed during the course of treatment and are the least likely to ask for the help they need. Practitioners should acknowledge and address concerns of such patients and families in order to encourage greater involvement with the rehabilitation system and access to support when it is needed. The following case illustrates this principle.

A social worker in Boston was performing a home visit to interview a Pakistani Muslim woman who became quadriplegic as a complication of a lumbar spinal surgery. Her daughter lived with her and was caring for her. The daughter expressed bitterness about the lack of support from family and friends in the Muslim community. She expected them to help, as they would have "back home." When the social worker offered her a variety of external services, however, she immediately replied, "Oh, no, we don't need those services. How can I let a stranger care for my mother? We don't do this."

This scenario of complaining about the lack of family and social support, then promptly rejecting external services, is immediately recognizable by many health care practitioners and illustrates a frustrating result of cultural barriers. The story is incomplete, however, and does not provide a clear explanation to why such a response may have occurred. What strategy should the social worker use to reach past this daughter's knee-jerk reaction? How can providers gain a better understanding of this response without making assumptions? The need to take a patient-centered approach becomes critical, as does knowledge of how different factors (e.g., gender) can either facilitate or hinder a person's treatment process. We discuss some of these factors in the following pages.

Gender Issues

Gender is connected to many of the most misunderstood aspects of Islamic practice and culture (Rehabilitation International, 2005-2006) and routinely becomes a source of conflict. According to stereotypes, which can be promoted by advocacy groups (Laird, 2006), Muslim women are oppressed, secluded, vulnerable, considered inferior, and denied basic human rights. For example, veiling stereotypically is equated with oppression and linked to health risks such as preventing the absorption of Vitamin D, even though a study concerning this topic found neutral or minor negative effects (Laird, 2006). Many stereotypes hold true, however, especially in developing countries with large Muslim communities.

Navigating between competing worldviews can be extremely difficult, even for health professionals who are working in their home countries. People often conflate cultural and religious practices with political agendas; they use religious principles, taken out of context, to explain and justify cultural traditions or local laws that negatively affect women. It takes time for immigrant women to shake off some of these restrictions, and the process can be highly controversial. That said, women from developing nations increasingly practice their faith based on their own personal convictions. Service providers should not be afraid to discuss and question their attitudes and decisions if doing so will lead to a better understanding of the women's needs.

Modesty is highly valued in Islam, and many Muslims consider dress to be an important expression of modesty. Both men and women are instructed to dress modestly and to avert their gaze when encountering someone of the opposite sex. Clothing is generally, but not always, expected to be loose for both men and women. Commonly stated rules are for men to be covered from the navel to the knees and women to be covered over their whole body except for their face and hands. These rules vary country to country, region to region, and family to family, and they do not apply universally across any group. The issue of modesty can provoke significant debate, however, and Muslims hold varying opinions as to what is considered to be modest dress (e.g., many South Asian women wear saris, but saris are not considered to be modest by all Muslims).

Regardless of the level of modesty deemed appropriate by an individual, many Muslims, like many non-Muslims, are uncomfortable when forced to wear garments that provide little cover, such as hospital gowns. The Maine Medical Center in Portland recently made news by redesigning its hospital gowns to provide better coverage. The hospital made the change after it found that its Somali Muslim patients were canceling their appointments because they feared having to wear revealing gowns during outpatient procedures and in public areas (Associated Press, n.d.). Even in the fairly secular nation of Iraq, many female Muslim patients do not remove their clothes or change into a gown for a

medical exam, and only a small portion of the body is uncovered at any one time. This is considered standard practice in the country (Gawande, 2006).

For 1,400 years, Islam has provided a code of mutual respect and modest behavior between males and females; many of the prescriptions are similar to traditional Christian rules of conduct. The Islamic code, with some local variations in its application, has successfully reduced the pressures of romantic and sexual attraction for millions of people living in close quarters. It also has enabled Muslim women to develop into maturity without the harassment and obscene remarks, in the workplace, street, or neighborhood, that occur in many societies that have reduced their level of religious observance. The code also has enabled young Muslim men to mature without constant sexual distractions (Miles, 2007).

Muslims hold a diversity of views regarding precisely how to put these principles into practice. At the very least, interactions between males and females must remain on a professional level. Although this does not mean being unfriendly, interactions that are excessively familiar generally are discouraged. The directive for modesty includes modesty of character, and overly informal interactions sometimes are seen as violating a religious sense of personal space. To ensure an appropriate conversation, many Muslims prefer to have others of the same gender present when they are speaking to persons of the opposite gender. Some also may prefer to avoid shaking hands or otherwise coming into bodily contact with individuals of the opposite gender.

Many of these principles of modesty carry over to interactions with health care and rehabilitation providers of the opposite gender. Muslims often express a preference for a provider of the same gender. Abiding by this preference can help them relate more openly and be more accepting of care. The treatment of illness and disability is different from other situations; and with this in mind, some Muslims are more willing than in other situations to work with and accept help from people of the opposite gender. Many scholars of Islam agree that individuals can seek medical treatment from providers of the opposite gender, even though the interactions may cross the bounds of generally accepted male-female interactions. Most guides stipulate that a same-gender provider is preferred when available. When it is not possible to be seen or treated by someone of the opposite gender, especially during a physical exam, a third party of the same gender as the patient should be present (Hathout, n.d.). Although such measures may well be appropriate for non-Muslims as well, they are often crucial to a Muslim patient's perception of sensitive and appropriate care. We emphasize again that opinions and patterns of interaction vary widely, and patients should be encouraged to discuss openly what level of interaction they find comfortable and which situations make them uncomfortable.

What are the implications of these beliefs for disability and health care providers in the United States? Providers are likely to be aware of Jewish dietary restrictions and of the emotional conflicts surrounding blood transfusions that can face people adhering to some Christian denominations, such as Christian Scientists and Jehovah's Witnesses. Providers accept that people have religious objections to certain types of treatment and that they try to avoid such treatment, even when doing so leads to a significant possibility of death. In this context, information about Islamic dietary prohibitions and other practices should not be shocking. For example, aspects of Islam strongly restrict practitioners of one gender from conducting hands-on examinations of patients of the other gender, or seeing them in the state of undress. A considerable portion of the non-Muslim population also is uneasy in such situations. When these issues are addressed in culturally relevant ways, providers' interactions with Muslim service users will improve, and better outcomes likely will result.

The Role of Community

In general, the Muslim community in the United States is diverse, and the nature of a particular community of Muslims will vary based on its geographic location, size, time of immigration, and ethnic makeup. Some communities are small, close-knit groups of recent immigrants from a particular area, with a great deal of community support. Examples include the Somali Muslim communities in Rochester, Minnesota, and in Jamaica Plain, Massachusetts. Other communities, such as the Muslim community in Chicago, may be large and diffuse, with immigrants of varying ethnic backgrounds and widely varying years of arrival. Large communities may include smaller enclaves of closely knit groups. Larger communities, as well as immigrants who have been in the United States longer, also may have more extensive links to the general population and may therefore serve as credible gateways to underserved Muslim communities.

Muslims, perhaps more than members of most other religious groups, consider each other "brothers and sisters". Certainly in Pakistan, as well as elsewhere in the world, people use a wide range of innocent family relationship terms to frame other relationships. For example, when speaking to an unrelated woman 10 or 20 years older, a young man might use the vernacular terms for "elder sister" or "auntie," and a young woman may address any man of the older generation as "uncle." Normal proprieties are thus gently reinforced in many subtle and pleasant ways. This practice might seem stifling or naïve to people accustomed to the endless flirtatious discourse between males and females of all ages that occurs in some societies. The Pakistani custom has the merit of generating a more inclusive, less competitive environment in which those who are shy, lack confidence, and are less physically attractive can play their roles without embarrassment. It also avoids forcing children and young people into sexualized conversations before they are mature enough to handle them.

Visiting the sick is considered a religious responsibility, and being visited while sick is one of the essential rights of a Muslim (Sahih Muslim, n.d., 24:5129). Ac-

cording to the holy saying below recounts the hadith in which the Prophet Muhammad reports the words of Allah.

> Verily, Allah, the Exalted and Glorious, would say on the Day of Resurrection: O son of Adam, I was sick but you did not visit me. He would say: O my Lord; how could I visit Thee whereas Thou art the Lord of the worlds? Thereupon He would say: Didn't you know that such servant of mine was sick but you did not visit him and were you not aware of this that if you had visited him, you would have found Me by him? (*Sahih Muslim,* n.d., 32:6232)

Many health and rehabilitation workers in the United States are familiar with texts in the Bible reporting the sayings of Jesus, and may notice that they resonate strongly with this hadith. The companions of Jesus recorded him saying that, on the day of judgement, the people who behaved rightly will be rewarded:

> For I was hungry, and you gave me food, I was thirsty and you gave me drink, I was a stranger and you welcomed me, I was naked and you clothed me, I was sick and you visited me, I was in prison and you came to me.

Jesus' companions also asked Him when it was that they did these things for him. Jesus replied that whenever they did these kind deeds to another person, they were also doing it to him, and whenever they failed to take these actions, they were failing to do it to him (Matthew 25:31-46).

Although these principles can lead to a great deal of support for acutely ill patients, Muslim communities are only slowly beginning to recognize the needs of two drastically needy groups: Muslims with disabilities and senior members of the Muslim community. For example, accessibility may be limited in older mosques without curb cuts, wheelchair ramps, or other alternatives to stairs. Individuals with disabilities may find it difficult to attend community events or even to participate fully in public prayers, leading them to avoid such events and practice their religion at home on a more personal level, further isolating them from their community (Hussain, 2005).

Although some services and resources are slowly becoming more available within the community, more effort is needed to make the community accessible to all and thus more fully integrate individuals with disabilities. As Legander-Mourcy (2000) writes, "It is rare to find a mosque or a Muslim facility fully equipped with such accommodations as curb cuts, widened doorways, sign language interpreters, Braille Qur 'ans or other Islamic books, or such basic accommodations as the parking spaces and wheelchair ramps" (p. 1) in various parts of the United States and in other countries.

Muslims with disabilities routinely face difficulties with religious participation, as illustrated by the following scenario. Mohammed Kazi, who lives in California, has a teenage son who uses a wheelchair. In his attempts to get his son to a mosque and to classes on Islam, Mohammed has encountered multiple challenges.

> First we had to fight for a spot to be designated in the parking lot. Then we had to carry him up and down the stairs because the classroom was upstairs. We requested that an elevator be installed, and so that money wouldn't be an excuse, the father offered to pay for it. That was years ago. I think the committee is still meeting to discuss it and now his son is too heavy to be carried upstairs, and so is excluded from the teenagers' classes (Legander-Mourcy, 2003, p. 1)

Many immigrant families and community members prefer to function independently from the rest of society. When immigrants arrive in a new country, they often undergo significant stress in adjusting to their new surroundings. They find comfort and nostalgia in their culture and see the surrounding society as a hostile force trying to impose itself and obliterate their sense of identity. As they retreat within their own community or family and remain independent from the surrounding society, they reject external services. They may especially reject services that conflict with their cultural norms, even when these are provided by their own community. For example, ACCESS (Arab Community Center for Economic and Social Services) in Dearborn, Michigan, started a child care service, but y for several years it did not attract any clients except the children of ACCESS employees, but eventually it did reach to the broader community.

This story of ACCESS illustrates that with time and sufficient exposure to build trust, people may accept services they initially refused. Patients and families may feel some discomfort with Muslim faith-based organizations that provide many useful services. They may be even more uncomfortable with services provided by other faith groups. Unfortunately, the Muslim community has not yet developed a system of support comparable to that offered in the larger community. Although some avenues exist for supporting the sick and disabled, the complex nature of rehabilitation and the slow pace of development of Muslim community-based social services mean that for some years to come, Muslims will not have fully effective resources from within the Muslim community.

It is hard to know how general such feelings are, or why some people feel discomfort when other Muslims are providing useful services. One might expect a certain proportion of refugees or immigrants to feel particularly attracted to services offered by people who understand their cultural preferences. Perhaps some services are offered by Muslims in the United States who have become so assimilated into the middle-class American way of life that they feel distaste and embarrassment at interacting with newly arrived Muslims from poorer countries

who hold to traditional customs. For example, in some English cities with large Muslim populations, a curious situation has developed. Many Muslim children attend primary schools run by the Church of England, sometimes representing up to 90% of the enrollment. Muslim parents often prefer these schools to the ordinary schools, which are under government control. The Church of England schools often have a better reputation for inculcating the kind of decent behavior that Muslims value, and most of them also avoid indoctrinating children with specific religious teaching (Miles, 2007).

Distrust often hampers health care professionals' efforts to provide services to Muslim immigrants, who may have concerns based on their own sense of identity and who may fear that their values will not be respected. In one study that compared the attitudes of South Asian and white clients toward home and hospital treatment of mental illnesses Khan and Pillay (2003) found that both groups of clients preferred home treatment; however, the South Asian respondents were more likely to mention diet, language, practice of their faith, and use of faith healing or traditional complementary medicine as reasons for that preference. This study can be read as implying that it was important for the clients to maintain some control over the cultural aspects of their treatment.

Community involvement also can have an impact on the mental health of individual Muslims. According to Laird (2006), Muslims are committed more to the honor and stability of family and community than to any individual's mental health. Consistent with this finding, in rehabilitating a family member with mental health issues, Egyptian families often involve that person in farming or other related work activities. The person who is rehabilitating is encouraged to stay in a useful occupation, where he or she is encouraged to interact and feel a sense of belonging and contribution within the family and community. Such individuals respond better to treatment and have lower relapse rates, outcomes that have been attributed to the collective orientation to life held by families living in rural Egypt (Endrawes, et al, 2007).

Important Holidays

The Islamic year follows a lunar calendar with no leap year; thus, Islamic dates rotate throughout the Gregorian year. Islam's three main holidays are the month of Ramadan and the two holidays of Eid-al-Fitr and Eid-al-Adha. Friday is considered a weekly mini-holiday of sorts; it is the day on which congregational prayers are held. Ramadan is the ninth month of the Islamic calendar and is one of the most anticipated times of the year for Muslims. Tradition holds that Prophet Muhammad had his first revelation during Ramadan, and Muslims commemorate this event every year with fasting throughout the month. Fasting means not eating any food or drink, not smoking, and refraining from sexual relationships between dawn and sunset. Although this practice may seem rigorous compared to religious proscriptions followed by non-Muslims, Muslims generally greet Ramadan as a time of spiritual renewal.

Muslims see fasting as beneficial in several ways. First, it helps them strengthen their intellectual control over their physical desires. Their hunger also helps them remain conscious of God and their submission to His will throughout the day. Finally, it helps them feel sympathy for the poor, who experience hunger without the comfort of knowing when they will have their next meal.

Ramadan provides Muslims with opportunities for acts of worship other than fasting. Many Muslims perform extra prayers, and many increase their donations to charity during the month. Ramadan is also a month of community and socializing, as Muslims often gather in the evenings to share in fast-breaking meals. It is important to mention that exemptions to fasting are available for people who may be at risk or may put others at risk. This applies especially to people in jobs that make them directly responsible for the safety of others (e.g., bus drivers, pilots, surgeons, and even certain teachers). In Pakistan, and presumably elsewhere, some Muslims take the view that the fast is primarily a spiritual affair. Its rules are to be followed as well as possible by each individual, but allowances can be made for individuals who have other commitments that make fasting difficult or dangerous. Conscientious Muslims make up missed days of fasting during Ramadan with additional fasting at other times (Miles, 2007). Several concerns related to health and rehabilitation can arise during Ramadan. As people abstain from food and drink, their lack of energy can drop significantly, particularly later in the day. This can make it harder for individuals who are fasting to participate in physical therapy sessions. Rescheduling such sessions to times earlier in the day might lead to better results. A fasting person's blood pressure also may drop during the day, and people taking medication may need to reduce their doses during the month of Ramadan (Athar, n.d.). Furthermore, after a day of fasting, a person can be tempted to binge in the evening, after sunset, leading to poor dietary choices and weight gain or weight loss. A review of public health studies pertaining to Ramadan showed that fasting had both positive and negative effects on existing medical conditions, and that it could be a precipitating factor for conditions such as complications of pregnancy (Laird, 2006).

Medications can pose another issue during Ramadan. Consuming anything by mouth, including medication, breaks the fast, so Muslim patients may be reluctant to take medications scheduled during the daytime hours. Some people may stop taking medications entirely, and others may try to fit all their doses in during the evening or early morning hours, when they can eat. For some medications this may not matter, but for others the change may have dramatic effects. It is very important, therefore, for health care providers to discuss medication scheduling for Muslim patients during Ramadan, so that the patients and health care providers can work out a system that is satisfactory from both a religious and a medical perspective.

Non-oral medications—those that are inhaled, applied to the skin, or injected—also pose a challenge. In general, the rule is that such medications will not break the fast unless they act as a source of nutrition. Some patients may be concerned about intravenous medications, but they also are allowed unless they provide nutrition (Hathout, n.d.).

Some people have conditions that make fasting unsafe from a medical perspective. Fasting can result in dehydration, for example, and dehydration is especially dangerous for people with certain medical conditions. People with insulin-dependent diabetes require strict control of their food intake. People with either type of condition, along with others, are not required to fast; in fact, they are discouraged from fasting because Islam prohibits doing harm to oneself. Muslims nevertheless may have a deep psychological attachment to Ramadan, and many are often extremely resistant to forgoing the fast. Involving the local imam, or an elder or a family member in forming the medical treatment plan may help encourage such persons to follow medical advice.

Eid-al-Fitr, or the "Holiday of Fast-Breaking," marks the end of Ramadan. Eid-al-Adha, the "Holiday of Sacrifice," occurs at the end of the pilgrimage and commemorates Abraham's submission before God and his willingness to sacrifice his son. These holidays are marked with a congregational prayer in the morning. Muslims generally spend the rest of the day on each holiday at gatherings with family and friends. In-patients may be disappointed at missing these festivities, the traditions built around them, and the company of friends and family. They likely would be grateful to service providers who acknowledge the holidays, and they likely would welcome the chance to share their traditions. If family members cannot be with them on these holidays, the local Islamic community may be able to locate people who can visit and help them celebrate. One resource for finding local Islamic centers is www.islamicfinder.org.

The Shi'ite community has an additional important holiday, Ashura, which commemorates the death of Hussain, the grandson of the Prophet. Shi'ite Muslims mourn the death of Hussain, whom they consider to be "a symbol of the struggle against injustice, tyranny, and oppression (Wikipedia, 2006). Sunni Muslims also celebrate Ashura, but for very different reasons. The differences can lead to conflict between the two communities. Service practitioners should be aware of this sensitive time, during which passionate feelings can be ignited in their patients.

Congregational services for Muslims are held on Fridays during the time for the midday prayer; they consist of a sermon followed by the ritual prayer. Men are required to attend Friday prayer, and many women also attend. Providers should make every effort to allow patients to attend services. Many hospitals now set up services for Muslim patients and staff, or arrange transportation to such services. If such arrangements are not available, the local Muslim community may be able to help.

Dietary Restrictions and Preferences

Muslims are forbidden to consume pork, blood, carrion, and alcohol. The slaughter of an animal for food requires a certain ritual. A Muslim (such as a butcher or imam) recites the name of God, slits the throat of the animal, and drains the blood. Meat from an animal slaughtered this way is called zabiha and often is also called halal, which simply means "allowed." Many Muslims will eat meat only if it has been prepared this way. Many Muslims also accept meat prepared according to the rules of Jews; thus, many will also eat kosher food. Seafood is almost universally allowed, regardless of how it has been prepared.

Muslims vary in the extent to which they follow these regulations. Many Muslims object to food or medications that are even indirectly derived from pigs or non-zabiha animals. For example, some Muslims will not eat cheese unless they are certain it was prepared with enzymes that were not derived from pigs. Such restrictions can have medical impacts. Certain medicines, such as cough syrups, contain alcohol, making them forbidden. Muslims may avoid gelatin, which is often derived from non-zabiha animals and often pigs; this can be problematic because it is present as an inactive ingredient in many pills. Muslims may object to medications that are derived from pigs. Such conflicts between religious beliefs and common medical practice may require frank discussions with patients about the health effects of refusing certain medications. It often helps to point out to patients that not taking such medications would seriously threaten their health. Foods or medications that typically are forbidden are permissible when the alternative is starvation or serious risks to health. The local imam or some other respected community leader or family member may be able to resolve such difficulties.

Food also can have strong cultural associations. Muslims from foreign countries may be used to, and have a strong preference for, particular types of food. When it is medically safe, food from outside the hospital may prove a great comfort to a patient and encourage improved nutrition. The importance of talking to the patient, family, and friends to understand food restrictions and preferences cannot be overemphasized.

V. Accommodating Service Delivery to Muslim Clients with Disabilities

This section discusses the systemic barriers that may play a significant role in how Muslim service users engage with U.S. systems of support. Although multiple initiatives encourage people to use rehabilitation services, providers consistently find that individuals with disabilities who are members of ethnic minorities, especially Muslims, utilize health and rehabilitation services and supports less than do white, mainstream peers. Several factors contribute to the disparity in service use,

which is sizable in some communities, and to the poor outcomes for Muslims individuals with disabilities. Researchers are finding increasing evidence that people with disabilities are disproportionately concentrated in disenfranchised communities across the United States. Such individuals often lack adequate housing, transportation, financial resources, and language skills. Some perceive a sense of marginalization simply because of their status as immigrants.

The Culture of the Health Care and Rehabilitation Systems

Shortcomings in the service system itself also may cause problems for Muslims with disabilities. For example, few medical centers near large Muslim communities have outreach efforts or Muslim professionals trained in disability issues. Even when services are available, agency personnel often are not well informed about the cultural and religious values and the practices of clients and their families, or they are not able to respond appropriately to the unique stressors felt by Muslims. Medical and rehabilitation centers often lack staff with the language skills and cultural literacy that can improve communication between client and provider. In addition, many concepts taken for granted in the U.S. rehabilitation system, including independence, self-determination, independent living person centered planning, and self–advocacy, may be unfamiliar or isolating to Muslims with disabilities and to their families. It may be appropriate to address these concepts with clients and their families in culturally sensitive ways (Hasnain, Sotnik, & Ghiloni 2003).

Rehabilitation services in developing countries vary widely. In general, people pay for their own care. The Gulf countries are exceptions; they usually maintain free health care for nationals and virtually unlimited access to physicians. Patients seen in the United States may be accustomed to such free benefits and flexibility in service provision (Nazzal et al., 2001). In Pakistan and Afghanistan, and probably to a lesser extent in South Asian countries, medical doctors generally have little training in or experience with special education and rehabilitation; nevertheless, their opinions normally override the professional views of special education and rehabilitation practitioners. This is an example of the separation and hierarchy in the caring profession in Muslim and Western countries, rather than co-existence and mutual respect. The entire scientific basis of Western medicine, in particular its continuous change and development through critical experiment and evaluation, runs sharply counter to the worldview of perhaps 95% of Middle Eastern and Asian populations. Among those populations, "knowledge" is largely static and is handed down by the wise from antiquity. Differences in viewpoints in general, create difficulties that may occur anywhere; by no means are they confined to Muslims who migrate from developing countries to the United States and encounter the differing views of rehabilitation professionals (Miles, 2007).

Throughout the Muslim world and in developing nations in general, rehabilitation is only starting to gain recognition. In some countries embroiled in conflict, including Afghanistan and areas influenced by Palestinians international aid originally was aimed at developing a "community-based rehabilitation" model, which was promoted largely by Nordic countries. This model has been difficult to implement in Afghanistan because it requires extensive deployment of resources and forces to navigate the differences between local and foreign concepts of disability. In the Palestinian territories, this model was found to be unsustainable. It relied on volunteers, so few staff members were women, reinforcing gender disparities. Thanks to this model, however, information and services have been provided through existing systems in Afghanistan, and in the Palestinian territories a rights-based disability law was signed in 1999 (Giacaman, 2001; Miles 2002a). Rehabilitation thus is a nascent and growing field in many Muslim-majority nations, and many Muslims still may not be clear about what rehabilitation and disability services can offer to them and how they might benefit from such services. The limited number of Muslims working in this field in the U.S. contributes to this difficulty.

Country of origin may influence a client's patterns of interaction with medical and rehabilitation service providers. In general, Muslim communities place their doctors on a social pedestal. Muslims are encouraged to seek medical services, citing hadiths "for Allah has not made a disease without appointing a cure for it, with the exception of one disease, namely old age" (Sunan Abu-Dawud, n.d., 28:3846). Patients may also seek traditional or complementary treatments, and they may ask for explanations of Western alternatives. Prayer and medicine are seen as complementary, and if the patient recovers, the doctor is seen as "an instrument of God" (Yamey & Greenwood, 2004).

VI. Tools and Approaches for Culture Brokering

Throughout this monograph, we have stressed the value of cultural competence for health and rehabilitation providers who want to provide the best service. Culture brokering is not so much a knowledge or skill set requiring mastery as it is an important set of attitudes and actions. In many ways, culture brokering may be better described as a package of skills and practices that a service provider uses to help guide cross-cultural interactions and outcomes. The key skills are paying close attention, skillful listening, and respectful questioning, along with the ability to find ways forward. An analyst might be able to see, describe, and measure all the complex obstacles, but that person becomes a culture broker only by successfully guiding people on each side past some of the obstacles and finding appropriate ways to help them meet one another on a basis of mutual respect (Raghavan, Waseem, Small, & Newell, 2007).

Even those who have studied another culture in depth cannot always predict the responses of a client from the culture because of individual variations and

circumstances. When the culture is as diverse as the "Muslim culture," brokers encounter extra layers of complexity. The critical skill therefore is not mastery of all the subtleties of a culture, but instead knowing what questions to ask and being open to asking those questions and truly listening to the responses (Kleinman, 2006). One of our goals in writing this monograph was to help rehabilitation providers formulate culturally appropriate questions by becoming familiar with issues specific to Muslims that may have an impact on their interactions, treatment, and outcomes but can also influence change in institutional systems. These issues can include both the effects that specific Muslim cultural and religious practices may have on treatments and the culture-specific rehabilitation goals of Muslims. Another important goal was to help providers become more familiar with typical patterns of interaction and concepts of disability, and thus to improve their communication with Muslims. All of these improvements in understanding and communication contribute to the culture brokering approach.

Religious and Cultural Issues That Affect Treatment

Several issues discussed throughout this monograph may directly affect treatment or rehabilitation plans for Muslims. First, Muslim patients may object to treatment plans that keep them from observing their religious duties. Health care professionals should approach such issues gently, showing their respect for the relevant practices. We advise practitioners to become familiar with some of these practices so that they can develop a consistently respectful approach as they advise patients about adjustments to different situations in which they find themselves.

The Kochi case highlights these issues. At the Stanford University Hospital in California, Mohammed Kochi, a 60-year-old-man from Afghanistan who was diagnosed with stomach cancer, struggled with whether to pursue chemotherapy following surgery. His decision to seek treatment was delayed by some misunderstandings about his ability to pray if he proceeded with the treatment intervention. That delay resulted in his death. This case shows how miscommunication and misunderstanding between people from two very different worlds—medical professionals at the Stanford University Hospital and Kochi and his Afghani family and friends—led to decisions, based on cultural and religious beliefs, that led to Kochi's death. This story highlights the needs of both doctors and Muslim patients to bridge cultural divides and to address the roots of disparities in health care and rehabilitation systems that leave members of U.S. racial and ethnic minorities at a disadvantage (Stanford Center for Biomedical Ethics, 2003).

The deeply held beliefs of Muslim patients, like those of any patient, must be respected; if health care professionals react to them dismissively, that can permanently sour the relationship. Whenever a patient resists a doctor's initially proposed treatment plan, service professionals should spend time understanding the patient's apprehensions and try to initiate an alternative plan. Doing so will at

least build trust and at best achieve desired goals of care. Islam and Muslim culture have built-in exceptions to its rules when following those rules would cause harm, but a patient may not be aware of those exceptions. Local religious leaders can help the doctor and patient, as well as the culture broker, to seek out any flexibility in both the medical and religious standards, then find a balance. An imam or Muslim elder can be helpful when conflicts arise within the patient's family or between the patient or family members and staff.

Cost also may be a major difficulty, especially for immigrants and refugees who arrive without any health insurance, and perhaps with a history of long-standing adverse medical or disabling conditions. Some professionals find themselves more motivated to respond to the needs of wealthy clients, who have the funds to pay for treatment that is more Islam-friendly treatment than is the norm. The vast majority of Muslims do not have the funds to motivate providers to develop such care; the motivation must come from their natural inclination to provide good care. Anything that can increase this motivation or make provision of Islam-friendly care easier obviously is of benefit to the patient.

Issues surrounding prayer also are important. Performance of religious duties, especially prayer, can be crucial to the daily routine set out in a rehabilitation plan. Muslims pray five times a day and directly ask Allah (God) for guidance or strength. For many, the spiritual and religious associations to hope and well-being help clients and patients to cope with life circumstances. During the time of prayer, Muslims face towards Mecca (or the Kaabah, or Kiblah); depending on where a person is geographically, the direction to be faced would also be different. Prayer may be so integral to a person's life that some type of it should be considered an Activity of Daily Living (ADL) for Muslims (Margolis et al., 2003). Because Islamic prayer combines several physical activities that may actually challenge some persons with disabilities or health conditions, it can be useful in evaluating function. Providers should ask their clients whether they are having difficulty with their prayers and what aspects in particular cause problems. This can help identify aspects of function that may have been missed in the provider's evaluation of function. Moreover, providers should assess the person's goals for improving the ability to perform prayer, then formulate a treatment plan that includes these goals. For example, a person may wish to improve stamina to be able to stand for prolonged periods, or be able to kneel unaided, or gain control of incontinence that affects the purity needed for prayer. More important, providers may need to prompt a patient to voice such goals.

Friday services also are important. Providers should try to accommodate patients who want to attend the Friday congregational prayer. Some hospitals conduct services in the building, so providers need only provide patients with the time and location, then arrange transport if necessary. If no services take place in the hospital or rehabilitation facility, providers can help patients set up a visit to a nearby mosque when that is medically safe.

Partnering With Brokers From the Muslim World

Few of those involved in U.S. disability and health care service systems have put enough emphasis on creating linkages with community and spiritual leaders of diverse and marginalized cultures to explore ways to improve access to services and opportunities for their community members with disabilities, despite the importance of such work and its potential to improve care. To date, efforts have been limited and rarely have focused on understanding the assets and strengths of Muslim communities in the United States. An important next step, which is taking place in a few places around the world, is including Muslims with disabilities, both men and particularly women, in leadership roles and initiating dialogues about the needs and opportunities for Muslims with disabilities and their families (Thomas, 2001). Mobility International USA has begun taking such steps. It fosters exchange programs in Muslim countries for individuals with disabilities to travel and explore life in other places (Mobility International USA, 2006). In Section VIII, the last section of the monograph, we offer other suggestions for how to engage the Muslim community in the disability rights movement in the United States as well as in countries of origin in order to develop an inclusive human rights perspective in which disability becomes a part of everyday life.

Many health and rehabilitation professionals in the United States generally know and use the "correct" thinking and attitudes toward disability and know that those ideas must be applied to people from other countries and with different cultural backgrounds. The main point of understanding traditional Muslim views and practices is not to remove those aspects as soon as possible and replace them with "correct" modern views but instead to incorporate a more humane perspective toward issues of difference (Miles, 2007). Such a perspective, which is not uncommon among professionals, is itself one of the main features in culture brokering. If conducted effectively, brokering takes into account the present thoughts and life experiences of people from differing backgrounds and belief systems, then offers them culturally relevant options and opportunities.

When working with a large, rather diverse group such as "Muslims," one that has monotheistic cultural roots in three or four millennia of history, large-scale and significant shifts of thinking and practice can come only from within. This is what the culture brokering process promotes. This process sometimes can be facilitated by culture brokering on the conceptual and scholarly levels, or by the traditionalists themselves, but it will happen most effectively if the efforts are combined.

Lobbying for Better Access: Establishing Leadership

Currently, those who organize Muslim religious or community events rarely make efforts to include persons with disabilities. Moreover, the majority of the roughly 1,200 mosques in the United States (Woodrow Wilson International Centers for

Scholars, 2003) have inadequate handicap access, as measured by the standards of the Americans with Disabilities Act (http://www.ada.gov/). For example, the National Council on Disability found that only 47% of Muslims with disabilities attend religious services, compared with 65% of those without disabilities, possibly for reasons such as inadequate access (Akram, 2006). Betty Hasan Amin, whose hajj (Muslim pilgrimage) was described earlier, developed a proactive way of dealing with such barriers. She decided to publicize the fact that she, as a quadriplegic, was unable to access her local mosque, as well as the more general problem of poor access for her fellow Muslims with disabilities (Akram, 2006; Amin, 2000). Through her lobbying, she convinced her mosque to include wheelchair ramps and a ground-level floor prayer room.

Many individuals with disabilities, especially women, have been stigmatized because people do not understand who they really are (El-Khalek, 2004). Often, disability is considered to be a personal or family matter rather than an issue to be addressed at the social, state or country level. Even though many success stories exist in the Muslim world, often it is the efforts of the individual or their family that have made the difference. El-Khalek illustrates this statement by describing four Muslim women with disabilities living in Egypt who succeeded in various aspects of life without any professional intervention or formal supports. Few Muslim communities have significant disability movements or even leadership by persons with disabilities. Despite the positive work being done, Muslims with disabilities must make their voices heard in all aspects of life and citizenship, not only to empower themselves but also to help others in the community to overcome their fears of encountering people with disabilities.

VII. Conclusion and Recommendations

The number of Muslim immigrants and refugees in the United States is increasing. As a group, they are probably among the least understood and studied of the many subgroups in the country. The next step toward understanding Muslims is studying this extremely varied group and beginning to promote collaborations and partnerships. One large challenge is to find culturally relevant ways to better link Muslims with disabilities to health care and rehabilitation systems and to avoid a one-size-fits-all approach. The next few pages provide a few suggestions based on topics discussed earlier in this monograph. They are grouped according to the major type of problem being addressed.

Language Barriers

When working with any immigrant whose first language is not English, providers should assess the barriers to communication caused by language discomfort or lack of abilities. Certified translators who specialize in the area of service can

confirm that the patient understands all discussions. Of course, many Muslims are not immigrants, and English may well be their first language. Many Muslims, particularly women who wear head scarves, have noted that although they were born in the United States and speak English as their first language, people initially will speak to them very loudly and slowly, assuming they have difficulty with English. These are only some of the factors that can cause miscommunications between a patient and a provider who may not be familiar with the patient's culture and worldviews pertaining to their illness. Miscommunication of various types easily can lead to problems in treatment and rehabilitation. It also is important to consider training those at the first point of contact, such as receptionists, telephone operators, and those who create websites and post information on them. No matter how open to other cultures professional practitioners may make themselves, a considerable proportion of the people who could benefit from treatment may never get near the provider because they are stopped close to the front door by the receptionist or discouraged by the telephone operator who simply has read from a script, or was less than welcoming, or who would do no more than ask the caller to bring an interpreter to the phone.

Cross-Gender Interactions

Muslims may have views concerning proper interactions between genders that are different from those held by mainstream American society. Their views, however, generally are not difficult to understand and accommodate. Many would accept an opposite-sex provider but likely would be more comfortable and open with a same-sex provider. These desires should be accommodated where possible because doing so is likely to improve the quality of the interaction, the patient's satisfaction and comfort with it, and the patient's compliance with recommended treatment.

When caring for any patient of the opposite-sex, Muslim or not, providers must be careful to follow the patient's lead in the interaction and should tend toward a manner that is more professional and less familiar. Providers also should recognize that practices such as shaking hands have varying acceptance among Muslims. Providers should consider investing in relatively modest hospital garments (Gawande, 2006) for all patients, and they should help and encourage patients to find ways to supplement the garments with their own clothing in a way that will not impede treatment. Patients will appreciate this respect for their preferences, and this appreciation will facilitate better interaction.

Trust

Another important aspect to keep in mind is the distrust some Muslims may feel toward the medical and rehabilitation system. Often they fear that some aspect of the service provided will conflict with their deeply held cultural or religious convictions. Special fears arise over their legal status in the United States. Various fears may lead them to avoid "mainstream" systems of care altogether, or refuse to participate in certain aspects of them. Patients in such situations should be encouraged to express their concerns and should be accommodated wherever possible. If health care and rehabilitation providers anticipate such concerns, patients will worry less and trust more.

Support Systems

Because Muslims carry a strong sense of responsibility to care for persons with disabilities, the family can provide a built-in support system that providers may wish to encourage. The strong sense of duty toward the sick or disabled can, however, lead to an overflow of well-intentioned visitors. It also can lead to well-intentioned family members questioning the treatment provided, which interferes with provision of care and compliance with it. The same problem occurs with some non-Muslim ethnic groups. Whenever such problems come up, providers should focus on determining what the patient wishes and should not be afraid to enforce limits on visits.

In general, Muslim families are closely knit and often wish to provide a great deal of support, reflecting the responsibility they feel toward family members. Providers should involve family members in services and treatment plans. Moreover, providers should support families, who may take on responsibilities before they are ready and thus risk becoming overwhelmed. Clients and families also should be supported in finding the proper balance between providing for the patient's needs and encouraging independence.

In work with all people with disabilities, but especially those from non-mainstream background, it helps to encourage the patient's and family's religious and cultural search for meaning. Living with a disability can be difficult not only physically but also mentally and emotionally. Religion can be a powerful tool to help people cope with their disabilities, and its use should be encouraged. For some stigmatizing issues that often are linked with disabling illness, such as AIDS and homosexuality, sharp conflicts arise between medical science and the traditional teachings of the three monotheistic religions. Conflicts concerning the attitudes and activities that are permissible are likely to remain sharp for the foreseeable future (Miles, 2007). Referring to religious concepts such as the moral neutrality of disability and the interplay of fate and free will can help people accept their condition, put it into perspective, and feel motivated to work hard to make the best of it. If a patient or client is finding it hard to apply religious principles in a positive and productive way, a local imam, elder, or respected family member may be able to help.

It also is important to be cautious about compromising services. Providers must respect cultural and religious traditions but also must be cautious about letting traditions compromise treatment. Some people use their religious or cultural be-

liefs as an excuse to avoid certain aspects of treatment. As discussed earlier, physical needs often provide a reason for making exceptions to religious or cultural rules. Providers cannot let their patients fall back on religion or culture as socially acceptable reasons to refuse elements of treatment that make them uncomfortable, even when the religious grounds for refusal are not entirely solid. In such cases, it may help to address the root of the patient's concern, such as lack of trust in the health care or rehabilitation system. When the patient's wishes conflict with the recommendations of the medical or rehabilitation provider, it may help to involve a counselor, an elder, a spiritual or religious leader, or a traditional healer (Al-Krenawi & Graham, 2000).

Knowledge of Issues and Respect for Patients

Some patients may be reluctant to discuss all the implications of the interplay between their treatment and their religious or cultural practices. To encourage more openness, providers must show an interest in these issues and acknowledge patients' practices. For example, a provider should know when Ramadan is approaching and broach the subject with Muslim clients, both expressing good wishes for the holidays and anticipating any concerns that might arise during the month. This kind of approach opens the door for discussing such issues and lets patients know that they, and their beliefs and concerns, will be treated with respect.

Although knowledge of both culture and religion can be useful in identifying a patient's potential concerns, providers cannot be expected to be experts either in Islam as a religion or in the Muslim culture. The topics discussed here apply to most Muslims, but other religious and cultural issues may be important to individuals. Providers must try to discover each individual's unique concerns and beliefs, then address them. Providers also must have the courage to say "I don't know" when an unfamiliar issue arises and the willingness to engage in sensitive questioning and thoughtful listening. Such an approach is vital to the mutual effort of developing an effective care plan and following through on it. It also can help identify a particular patient's beliefs regarding the issues discussed in this monograph. Numerous important issues related to care and treatment can be uncovered. Finally, an open, caring, and interested demeanor sets the stage for an interaction in which the patient feels comfortable bringing up issues of concern, even without being asked. That type of behavior is encouraged when the provider has shown an obvious interest in making sure such issues are addressed.

The most important single action for any provider is listening to the patient's concerns, thoughtfully and with an open mind. Although the patient and provider may not always agree regarding certain issues, an open discussion is the only way to arrive at a mutually acceptable plan. If clients believe that their concerns are not being addressed or taken seriously, they are unlikely to follow the resulting plan, regardless of how sound it is. Each encounter with a client is an opportunity

to build his or her confidence that any expressed concerns will be heard and taken into account.

Although the above culturally relevant approaches apply to many Muslims, perhaps the most important point we can make is that members of the Muslim community hold a wide diversity of opinions and practices relevant to many of the issues discussed in this monograph. A recent Bosnian immigrant, a Pakistani who immigrated in the 1960s, and an African-American Muslim born in the United States likely will have widely different cultural practices and views on a variety of issues, and each may consider his or her point of view the "Islamic" one. Even within a given ethnic group or wave of immigration, different individuals will have different points of view. No set formula can predict which beliefs and practices are important to a particular person, even when that person's religion or geographic origin is known. The only way to know is to ask each person. We hope that this monograph will serve as a guide to the types of issues to consider and questions to ask when dealing with Muslims with disabilities or health conditions.

Additional Recommendations

The following recommendations are based on the literature, interviews, and ongoing interactions with Muslims with and without disabilities. We hope they will help a variety of professionals and practitioners address the unique needs of Muslims with disabilities and health care needs, as well as their families. We also hope they will send powerful messages, both conscious and subconscious, that a Muslim with a disability can be just like anyone else without a disability in regard to hopes, dreams, and visions. We suggest that practitioners make efforts in the areas of outreach, service delivery, and research.

Outreach Efforts

- Promote ongoing education in various diverse underserved Muslim communities through traditional and nontraditional outreach, including public awareness campaigns.
- Reach out to local mosques, Islamic centers, and Muslim organizations to identify, recruit, and engage the community in conversations about disability and health (Barrio, 2000; Laird, 2006).
- Promote positive images of Muslims with and without disabilities on television and in movies, as well as in newspaper and magazine articles.
- Use nontraditional outreach methods such as conducting informal information workshops at community events, use ethnic cable and radio programs, and post information at groceries and other local stores about health and disability resources.
- Increase local and national efforts to recruit and train Muslim students to enter disability studies and rehabilitation fields by promoting human service professions as valuable career options (Mobility International USA, 2006).

Service Delivery Efforts

- Encourage use of well-thought-out inclusion policies in schools, vocational training programs, work settings, recreational and social activities, and spiritual and religious community events.
- Use certified bilingual interpreters and traditional healers who have made themselves open to scientific medicine and who understand the mentality of its providers to serve as culture brokers between minority Muslims clients/patients and the majority culture of service and support systems (Ferguson & Candib, 2002; Kim, 2006).
- Assess the perspectives of health care and disability providers on the care of Muslim patients in order to develop cross-cultural training educational curricula, and other institutional interventions that will ensure culturally appropriate health care and access (Laird, 2006).
- Identify important family, school, religious, and community variables related to favorable treatment and rehabilitation outcomes for Muslims with disabilities and their families.
- Involve Muslims with disabilities in all stages of research activities and program and policy development to develop culturally appropriate materials and interventions.

Research

- Build and establish trust and practice respect with the Muslim community and research study participants.
- Develop culturally validated health and rehabilitation services to address current health disparities among Muslims.
- Increase outcome-based research (Moffat & Tung, 2004) in Muslim ethnic communities to identify and address needs that remain unmet as a result of the lack of outreach and understanding from disability and health systems.
- Conduct forums and focus groups to identify the authentic needs of Muslims with disabilities and their families and to incorporate those findings into future interventions.
- Develop data collection instruments and surveys that reflect cultural values and differences rather than using mainstream American standards and norms to make comparisons.

VIII. Resources on Muslim Culture

Several organizations have compiled helpful information for health care providers who work with Muslim patients. The Council on American-Islamic Relations (CAIR, http://www.cairnet.org) has a brochure available through its Web site. The Web site of the Islamic Medical Association of North America (IMANA, http://www.imana.org) contains a section on medical ethics related to Islam. The

Islamic Networks Group provides speakers on Islam as it pertains to a broad variety of topics; a list of local speakers can be found at http://www.ing.org. Conversing with members of the local Islamic community also can provide valuable experience and insight. A list of local mosques and Islamic organizations can be found at http://www.islamicfinder.org. A list of other useful sources on Islam and Muslims (suggested by Miles, 2007) is provided below.

Pertinent Recent Studies

Aksoy, S. (2005). Making Regulations and Drawing up Legislation in Islamic Countries Under Conditions of Uncertainty, With Special Reference to Embryonic Stem Cell Research. *Journal of Medical Ethics, 31*, 399-403.

Chabara, A., El-Sabbahi, S., El-Gazaar, E., & Abushadi, N. (2002). Items of Disabled Care and Prevention of Disability in the Holy Qur'an and the Hadith. *Saudi Journal of Disability and Rehabilitation, 8*(1), 33-37.

Gannage-Yared, M. H., Chemali, R., Sfeir, C., Maalouf, G., & Halaby, G. (2005). Dietary Calcium and Vitamin D Intake in an Adult Middle Eastern Population: Food Sources and Relation to Lifestyle and PTH [parathyroid hormone]. *International Journal for Vitamin and Nutrition Research, 74*(4), 281-289.Morad, M., Nasri, Y., & Merrick, J. (2001). Islam and the Person With Intellectual Disability. *Journal of Religion, Disability & Health, 5*(2/3), 65-71.

Musse, S I. A. (2001). Disability: An Islamic insight. Retrieved on May 19, 2008 from http://muslimyouth.net/campaign.php?a_id=474&id_fk=17&id_fkis=59&id_fkt=197

Muyesseroglu, J. (2006). *The Deaf Muslim experience: Education and Islam.* Retrieved December 10, 2007, from http://edf3.gallaudet.edu/diversity/BGG/!ISLAM/Deafan~1.htm

Books and Book Chapters not cited in this monograph

Al-Issa, I. (Ed.). (2000). Al-Junun: Mental illness in the Islamic world. Madison, CT: International Universities Press.

Contains useful chapters on mental illness, with contributions on religion, history, forensic psychiatry and Islamic law, the differences made by Muslim beliefs, and the practice of Islam and treatment of Islamic people in various countries. In particular, see "Regulations for the Disabled" (pp. 101-134), quoting the Qur'an and hadiths regarding disability and Muslim duties. Discusses "Western" rehabilitation

approaches, with some appreciation, some criticism, and some warnings concerning practices that Muslims should avoid.

Al-Jibaly, M. (1998). Sickness: Regulations & exhortations: Part 1. The inevitable journey. Arlington, TX: Al-Kitaab and As-Sunnah Publishing.

Dols, M. (1992). Majnun: *The madman in Medieval Islamic society* (D. E. Immisch, Ed.). Oxford: Clarendon.

El-Hessen, S. S. (2006). Disabilities: Arab States. In S. Joseph et al. (Eds.), *Encyclopedia of women & Islamic cultures* (Vol. 3, pp. 98-99). Leiden: Brill.

Contains an outline of historical disability and discusses social roles of disabled women in the Middle East.

Fernea, E. W. (Ed.). (1995). *Children in the Muslim Middle East*. Austin: University of Texas Press.

Provides a useful variety of perspectives on children and child rearing in modern Middle Eastern cultures.

Hagrass, H. (2006). Definitions of Disability and Disability Policy in Egypt. In C. Barnes & G. Mercer (Eds.), *The social model of disability: Europe and the majority world* (pp. 148-162). Leeds: Disability Press.

Iwama, M. K. (2005). Situated Meaning: An Issue of Culture, Inclusion, and Occupational Therapy. In F. Kronenberg, S. S. Algado, & N. Pollard (Eds.), *Occupational therapy without borders: Learning from the spirit of survivors* (pp. 127-139) Oxford: Churchill Livingstone.

McGoldrick, M., Giordano, J., & Garcia-Preto, N. (Eds.). (2005). *Ethnicity and family therapy* (3rd ed.). New York: Guilford.

Includes relevant chapters on African-American Muslim families, Indonesian families, Asian Indian families, Indian Hindu families, Pakistani families, Arab families, Iranian families, Lebanese and Syrian families, and Palestinian families.

Nasir, J. J. (2002). *The Islamic law of personal status* (3rd ed.). The Hague: Kluwer Law International.

Contains notes on mental and physical conditions and a review of legal capacity and interdiction of people with mental disabilities in modern legal systems.

Ouertani, M. (1999). Social Welfare or Socio-Political Entitlement: Disabled People Caught Between the Poles of Their Tunisian Origin and Acculturative Pressures. In A. V. Holzer and G. Weigt (Eds.), *Disability in different cultures: Reflections on local concepts* (pp. 146-153). Bielefeld: Transcript-Verlag.

A thoughtful account, by a well-educated blind Tunisian living in Germany, contrasting the benefits and problems encountered by disabled people in two very different countries. Discusses the role of religious belief.

Rispler-Chaim, V. (2007). Disability in Islamic law. Dordrecht: Springer.

A useful, detailed study, drawn from many years of experience in the Middle East. Weaves together the various perspectives and vocabulary of law, religion, and medicine to show legal and social responses to people with disability, in everyday Muslim life. An appendix translates modern fatwas concerning disability and deafness.

Sachedina, A. (1999). Can God Inflict Unrequited Pain on His Creatures? Muslim Perspectives on Health and Suffering. In J. R. Hinnells & R. Porter (Eds.), *Religion, health and suffering* (pp. 65-84). London: Kegan Paul International.

Describes a variety of positions taken by Muslims on questions of health, suffering, and divine purpose, with reference to the Qur'an and hadiths.

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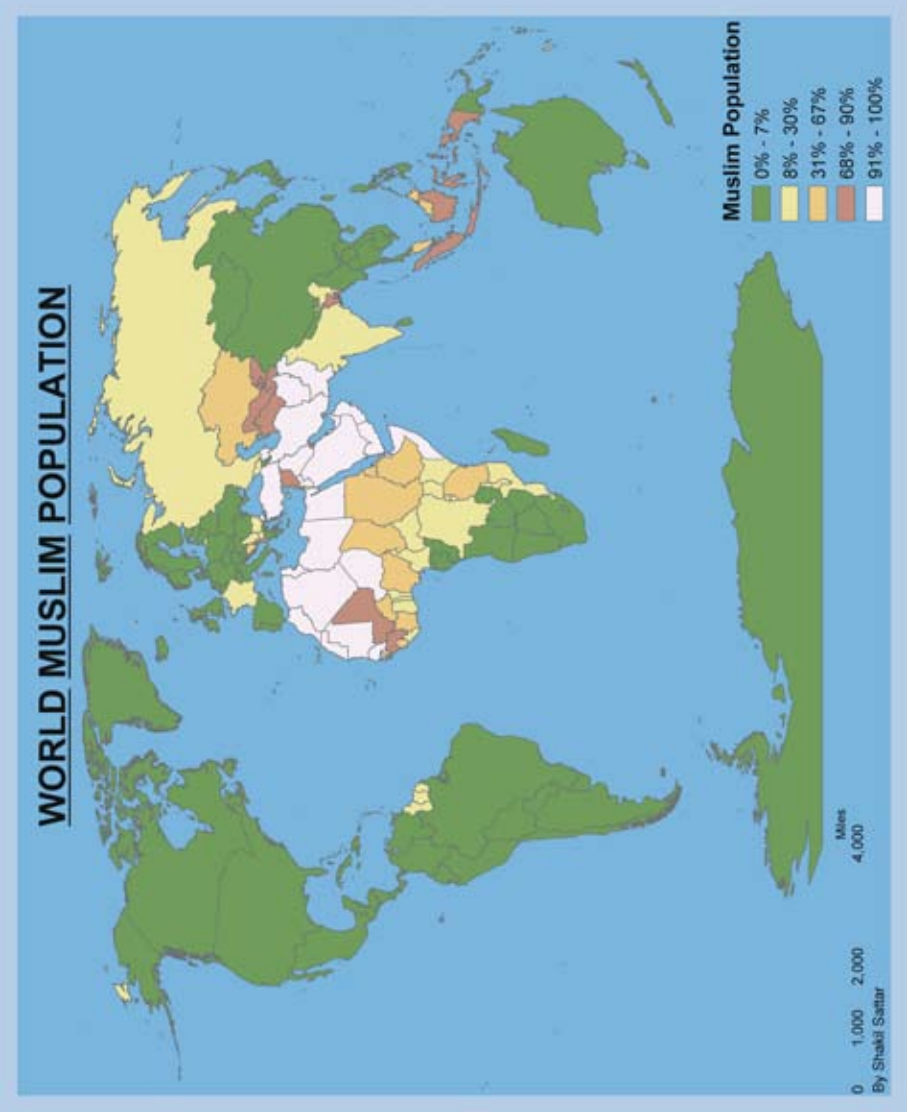
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