DISABILITY IN THE MOUNTAINS:
CULTURE, ENVIRONMENT, AND EXPERIENCES OF DISABILITY
IN LADAKH, INDIA

by

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Submitted in partial fulfillment of the requirements
For the degree of Doctor of Philosophy

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CASE WESTERN RESERVE UNIVERSITY

January 2016
CASE WESTERN RESERVE UNIVERSITY
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ACKNOWLEDGEMENTS

It has been a long journey. There are far more people who have inspired me, encouraged me, and supported me than can be acknowledged here. This research was funded in part by a National Science Foundation Doctoral Dissertation Research Improvement Grant, a Wenner-Gren Foundation Dissertation Fieldwork Grant, and a Baker Nord Center for the Humanities Research Grant. I would also like to acknowledge the funding that allowed me to travel to Ladakh for the first time to conduct preliminary fieldwork, an Eva L. Pancoast Fellowship.

I would like to thank my committee: Dr. Charlotte Ikels for asking the hard questions and sticking with me until the end; Dr. Janet McGrath for letting me be a student colleague since the day I arrived at CWRU; Dr. Melvyn Goldstein for inspiring me to challenge myself; and Dr. James Spilsbury for graciously becoming a member of my committee as my defense approached. I would also like to thank Dr. Tom Csordas for encouraging me to go for it when I was first contemplating conducting my fieldwork in Ladakh. A deeply grateful thank you goes to Dr. Myra Bluebond-Langner for believing in me as a researcher.

In Ladakh, there are many people to whom I am forever grateful. I express my sincerest thanks to everyone who helped me through and helped me understand life in Ladakh – in particular my friends at PAGIR-pa and all my neighbors. My life was truly enriched my re-uniting with Kunzang, my sister in Ladakh, and spending the entire year of fieldwork with her as my closest friend and colleague.

Since finishing fieldwork there have been many more people who have encouraged me to push through to the end, no matter what obstacles were
temporarily placed in my way, or how difficult the journey seemed at times. They
know who they are, and to them I am forever thankful. I would like to thank Hillery
Oberle for being interested, being supportive, for creating the maps for this
dissertation, and for just being there.

Since the beginning, my family has been supportive, encouraging, and
understanding of the decisions I have made along the way. I believe they all know
how important this has been to me and how thankful I am for the role that each
individual has played. Though some of my biggest supporters are no longer here to
read the final product they continue to shape my life’s journey.

Finally, I thank my husband. He introduced me and guided me to the
wondrous place that is Ladakh. He got me through the times I wanted to leave the
field and go home, and those times my field notes and interviews made me too
emotional to write. He has been my most valuable teacher, and remains so as we
continue to learn together about who we are and what is most important in life.
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<tr>
<td>ADD</td>
<td>Action on Disability and Development</td>
</tr>
<tr>
<td>AMT</td>
<td>Auxiliary Medical Training</td>
</tr>
<tr>
<td>CAR</td>
<td>Cross-Cultural Applicability Research</td>
</tr>
<tr>
<td>CBR</td>
<td>Community Based Rehabilitation</td>
</tr>
<tr>
<td>CP</td>
<td>Cerebral Palsy</td>
</tr>
<tr>
<td>CWRU</td>
<td>Case Western Reserve University</td>
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<tr>
<td>ENT</td>
<td>Ear, Nose, and Throat</td>
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<tr>
<td>ESCAP</td>
<td>Economic and Social Commission for Asia and the Pacific</td>
</tr>
<tr>
<td>ICRAAS</td>
<td>International Consortium for Research and Action Against health-related Stigma</td>
</tr>
<tr>
<td>IRB</td>
<td>Institutional Review Board</td>
</tr>
<tr>
<td>JKAP</td>
<td>Jammu and Kashmir Armed Police</td>
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<tr>
<td>LAHDC</td>
<td>Ladakh Autonomous Hill Development Council</td>
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<tr>
<td>LEHO</td>
<td>Ladakh Environmental Health Organisation</td>
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<tr>
<td>LBA</td>
<td>Ladakh Buddhist Association</td>
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<tr>
<td>LNA</td>
<td>Ladakh Nuns Association</td>
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<tr>
<td>LPG</td>
<td>Liquid Petroleum Gas</td>
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<tr>
<td>NGO</td>
<td>Non-Government Organization</td>
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<tr>
<td>NIPWD</td>
<td>Namgyal Institute for People with Disability</td>
</tr>
<tr>
<td>NIRLAC</td>
<td>Namgyal Institute for Research on Ladakhi Art and Culture</td>
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<tr>
<td>PAGIR</td>
<td>Peoples Action Group for Inclusion and Rights</td>
</tr>
<tr>
<td>PWD</td>
<td>People with Disabilities</td>
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<tr>
<td>SNM</td>
<td>Sonam Norboo Memorial Hospital</td>
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<tr>
<td>UN</td>
<td>United Nations</td>
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<tr>
<td>UNESCO</td>
<td>United Nations Educational, Scientific and Cultural Organization</td>
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<tr>
<td>UNICEF</td>
<td>United Nations Children's Fund</td>
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<td>WHO</td>
<td>World Health Organization</td>
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Disability in the Mountains: 
Culture, Environment, and Experiences of Disability in Ladakh, India

Abstract

by

SARAH ANN BRIDGES

The purpose of this ethnographic study of disability in Ladakh, India is to understand disability as a subjective experience influenced by culture and the physical environment. Disability research demonstrates many of the social and physical challenges faced by those with disability and their families. However, these experiential domains are too often treated in isolation and do little to represent the lived reality of people with disability and those close to them. Additionally, research shows attitudes toward disability are often rooted in religion and local models of health, yet does not take the next step relating how such factors shape experience. While it is widely recognized that disability experiences are not homogenous, little attention is paid to intra-cultural variations that result from diverse local attitudes. By exploring experiences of disability in the context of two religions, Buddhism and Islam, this study contributes to debates within disability studies and provides a better understanding of disability in the context of culture.

The study objectives were: (1) to ascertain local definitions and attitudes toward disability in Ladakh; (2) to identify challenges the physical environment of Ladakh poses to people with disabilities; and (3) to determine the influence of religion on the management and experience of disability. Research included three overlapping study components – a village study; a study at a disability NGO; and a
broader community component – designed to gain understanding of experiences through the viewpoints of disabled individuals, family members, community members, and professionals.

This study concluded that in Ladakh disability is defined and identified through a combination of observable traits and causes, often characterized by religious explanations and influenced by age. Religion shapes the social management of disability, influencing attitudes about disability and the life chances of people with disabilities, and how people experiencing disability seek care from religious and health professionals. Limitations posed by the physical environment shape experience, and impact availability and accessibility of services. There is a dissonance between experiences of disability and expressed needs which leads to disconnects between traditional values and experience as people with disabilities approach their own futures in the context of social change in Ladakh.
MAP 1: Map of Location of State of Jammu & Kashmir
MAP 2: Map of “Ladakh”
MAP 3: Map of Fieldwork Area
CHAPTER 1: INTRODUCTION AND LITERATURE REVIEW

Purpose of the Study

The purpose of this study is to understand disability as a cultural phenomenon by examining how the interaction between the norms, values, and customs of a society and the challenges posed by the physical environment influence the subjective experience of disability. Disability refers to a long-term impairment which limits one’s ability to participate fully in society or typical daily activities. Research exploring experiences of disability illustrates many of the social and physical challenges faced by those with disability and their families. However, these experiential domains are too often considered separately and do little to represent the lived reality of people with disability and those close to them. Additionally, research shows attitudes toward disability are often rooted in religion and local models of health, yet such research does not take the next step relating the effects such attitudes have on experiences. For those who live with disability, the experience of life is affected not only by the nature of the disability itself, but by the specific circumstances unique to them as individuals participating in society. Despite this, little attention is paid to the intra-cultural variations in experience resulting from diverse local attitudes. By exploring the lives of people experiencing disability in the context of two religious traditions, this study contributes to debates within disability studies¹ and provides a better understanding of the disability experience in the context of culture.

¹ The phrases disability studies and studies of disability will be used interchangeably to refer generally to scholarly work examining the topical area of disability. However, Disability Studies will refer to the field as it is recognized within British sociology.
To address the weaknesses in disability research outlined above, this study focuses on experience. By doing so, specifically the experience of living in a particular body, it is possible to recognize the dynamic interplay between culture and the self— influencing and shaping each other. The conceptual and theoretical role of the body in understanding culture and the self has been under scrutiny in the social sciences. However, very little attention has been paid to the disabled or impaired body. Interdisciplinary approaches to the study of disability problematize the issue of the body, though they often lack theoretical grounding. The body was the original focus in studies of disability, with individual or medical models dominating discourse, particularly in legal, policy, public health, and clinical fields. In recent years predominant theorizing in disability studies began to focus on disabling aspects of society— for example, through failure to provide services, meet needs, or promote full inclusion— and conceptually separated disability from the notion of “impairment” (Oliver 1996). This social model has been critiqued for eliminating critical components of disability experience—the influence of the physical body on experiences of both the social and physical aspects of everyday life (Crow 1996; Hughes and Paterson 1997; Shakespeare and Watson 1995; Shuttleworth 2001; Turner 2001). Few studies of disability are meaningfully engaged with existing scholarly work on the body.

To investigate the role of intra-cultural variation in the experience of disability, research was conducted with Buddhists and Muslims, in both rural and urban communities, in Ladakh, India. Situated in northern India between the Himalayan and Karakoram mountain ranges, Ladakh is characterized by its rugged
terrain, dry climate, cold winters, and its relative isolation from outside areas during much of the year. Many people with disabilities in Ladakh are unable to participate in the domains of daily living most people take for granted such as education, employment or agricultural work, or simply enjoying the social activities of their family and community. Disability poses particular challenges in Ladakh due to the physical environment, both natural and built; extreme climatic conditions exacerbated by a lack of running water, electricity, or paved pathways; the remoteness of many villages; and rapid social change. Resources are limited for individuals, families, and social institutions. In this setting, the diverse traditions of Ladakh’s Buddhist and Muslim communities shape the lives of people with disabilities. The challenges posed by the physical environment are particularly marked, and the co-presence of two distinct religions highlights the influences of localized religious values on the experience of disability. This natural controlled experiment, where people’s lives share many similarities but also stark differences, allowed comparison of how social norms, customs, and values influence intra-cultural variation in disability experience.

Disability can limit one’s ability to participate fully in society or typical daily activities, such as receiving an education, contributing to a household income, establishing a family, doing daily domestic chores, daily self-care, or participating in daily social interactions. Considering that what may be disabling in one cultural,
social, or environmental context may not be in another, this broad definition allows for local understandings of disability to be explored.2,3

Goals and Objectives

This research builds on existing scholarship in anthropology and sociology, and contributes to the interdisciplinary fields of disability studies, Ladakh studies, religious studies, international health and development, and health policy and planning. Frameworks for understanding disability have evolved in recent decades. Proponents of a strict social model of disability view disability as the result of social barriers to full participation in society which they argue are imposed upon those with impairments (Barnes et al. 1999; Oliver 1996). Disabling aspects of society could include anything from the absence of laws that do not explicitly protect the rights of people with disabilities, to accessibility issues such as a lack of ramps or curb cuts, to social norms that lead to the discrimination of people with impairments. Supporters of this model stress the importance of inclusive social action that would eliminate such barriers to full participation in society. Critics of this model note that an impairment can be disabling in itself regardless of the

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2 Current paradigms of disability recognize disability as the result of an interaction between an individual's characteristics and the characteristics of the environment, which include consideration of natural, built, cultural, and social environments (e.g., National Institute on Disability and Rehabilitation Research 2006; United Nations 1993; World Health Organization 2001). Little is understood about these interactions and how they may vary in diverse contexts. The preceding definition of disability serves the purposes of this dissertation, while also highlighting the need for research defining disability within local contexts (also noted by Ingstad 2007; Whyte and Ingstad 2007).

3 Some argue that “people with disabilities” is preferred in contrast to “disabled people” because it puts the person first, thus avoiding using disability as an identity marker. Others contend “it implies that the impairment defines the identity of the individual, blurs the crucial conceptual distinction between impairment and disability, and avoids the question of causality” (Barnes et al. 1999:6). This dissertation does not aim to take a stand on this issue and will use both phrases.
influence of such disabling aspects of society (S. French 1993; Thomas 1999). Liz Crow (1996) argues that things like pain, fatigue, or depression can be what prevent many from fully participating in society. Sally French (1993), a visually impaired person, argues that her inabilities to recognize people, or to read or emit non-verbal cues, present more challenges in her life than a lack of beepers at road crossings or notices she cannot read. These challenges are neither caused by society nor likely to be solved through social action. Thus, many scholars are broadening the social model to consider individual bodily experiences in the context of culturally constructed, socially controlled environments (Crow 1996; Davis 1995; Hughes and Paterson 1997; Shakespeare and Watson 1995).

This new framework has been influential in drawing attention to the complexities of disability, and has been used by both the United Nations (1993) and World Health Organization (2001). Being concerned with human rights, these entities draw from social models of disability, but also acknowledge challenges people face as the direct result of their impairments. Yet, many questions remain unanswered regarding the structural and cultural forces at play in shaping experiences of disability. Health and development organizations increasingly address the issue of disability and seek further understanding of culturally appropriate ways to meet needs, particularly in less-developed areas. Though many organizations promote community based rehabilitation approaches, their limited success is linked to a lack of consideration of the experiences and needs of individuals, families, and communities within cultural context (Devlieger 1994; Ingstad 1995, 2001, 2007; Leavitt 1999).
Understanding disability as a cultural phenomenon requires paying attention to the interactive effects of individual, social, and environmental components of the disability experience. Conceptually, examining how living in a particular body shapes one’s experience of culture, and in turn collectively shapes culture itself, makes contemplating living in an impaired body, particularly in an environment such as Ladakh, quite compelling. Perhaps living in a particular disabled body shapes the experience of one’s culture in a particular way, or highlights aspects of a culture otherwise taken-for-granted. Using qualitative methods, this study provides a model for the study of disability which incorporates both physical and social realities. By broadening our understanding of those variables which may be most significant in shaping experiences of disability, we are better able to analyze disability in any cultural context. This approach complicates theoretical approaches both within the anthropology of the body and within disability studies, including social models of disability. In addition the anthropology of disability can reveal the importance of understanding the social, cultural, and physical context of experiences of disability to develop acceptable, accessible services and programs. Social scientists studying disability have tended to take approaches that are either theoretical or applied. Both are better served when engaged with one another.

Disability, like health or illness, is experienced not only by the individual with a disability but also by those close to them. From this perspective, disability is something that can be experienced by a whole community. This study was designed with specific objectives and questions suited to gaining a holistic understanding of disability as it is situated in Ladakhi culture. The specific objectives were: (1) to
ascertain local definitions of and attitudes toward disability in Ladakh; (2) to identify the distinct challenges the physical environment of Ladakh poses to people with disabilities; and (3) to determine the influence of religion (namely Buddhism and Islam) on how disability is experienced and managed. Other intra-cultural variations, such as those between urban and rural households, or among individuals, families, and the community are explored.

Several lines of questioning were investigated: (1) Are there significant differences between Ladakhi Buddhists and Muslims in how they define and understand disability? (2) How are people with disabilities treated, and what are their roles in the family and society? (3) Are there differences between disabled and non-disabled members of a household with regard to social expectations, educational opportunities, and health care utilization patterns? (4) How do environmental and socio-economic factors affect the utilization of services and the availability of opportunities for people with disabilities and their families? (5) What are the needs of people with disabilities and their families which are not met by available services?

**Significance**

By examining the interactions between experiences of disability and its social construction, this study addresses weaknesses in previous research and speaks to a key debate in disability scholarship regarding the nature of disability experience, that is, the significance of the social phenomenon of disability versus the physical reality of impairment. This research in Ladakh also addresses, as suggested by Susan Reynolds Whyte (1995), a common dilemma in the anthropology of disability
in which approaches that emphasize the cultural construction of disability fail to take into account disability as a subjective, embodied experience, while those approaches that focus on experiences often lose sight of its social context. To develop a social theory of disability which recognizes disability as a cultural phenomenon and includes social and physical aspects of experience, it is necessary to start with an approach that takes into consideration theories of embodiment, the social model of disability, and body image concepts. By studying disability at the community level, rather than focusing on a narrowly defined group of people, this research provides a holistic understanding of how variations in experiences of disability are influenced by local contexts and will help future applied research by providing a model for understanding disability experience.

Irving Kenneth Zola (1989) aptly noted the universal nature of disability and its relevance to all people, an argument which is becoming ever more profound. As the nature of disability and chronic illness changes around the world – as a result of, for example, HIV/AIDS, political violence and trauma, the effects of political economic situations on mental health, and aging populations – it will become increasingly important to have a means through which to understand disability in diverse cross-cultural and multi-cultural contexts. This research provides insight for those working in applied anthropology, public health, disability studies, and international health policy and planning who seek to develop culturally appropriate programs for people with disabilities in a diversity of environments.
Anthropological Theory and Disability

Though the body has long had a place in anthropological thinking, contemporary theorizing in anthropology has problematized the body to an extent that it is now possible to consider “anthropology of the body” a major topical focus in the field. The anthropology of the body has been influenced by many scholars both from within and outside the discipline. Michel Foucault’s (1973, 1977, 1978, 1980) work on social institutions and the nature of human sexuality has influenced contemporary discussions related to the study of biomedicine within anthropology (for examples see Csordas 1999; Lock 1993). Pierre Bourdieu’s (1977, 1990) concepts of practice and *habitus*, his thoughts on the body in everyday life and the influence of culture and discourse, have been widely used in the development of theory in the anthropology of the body (for examples see Csordas 1999; Lock 1993), as has Emile Durkheim’s (1915) evaluation of the relationship of the individual to society (see Scheper-Hughes and Lock 1987). Additionally, the influence of Sigmund Freud (1950), A. Irving Hallowell (1955), Marcell Mauss (1935, 1938, 1950) and many others are readily apparent in the anthropology of the body.

Early debates about the interactions between nature and culture serve as the foundation for anthropological theorizing on the body. Other dichotomies such as self/other and mind/body have been a major focus in the anthropology of the body. However, as the view that “bodies” were culturally constructed came into popularity so did efforts to break down dichotomies. Conceptualizing “having bodies” versus “being bodies”, the individual as subject versus the individual as object, self versus other, and the distinction between disease and illness have been at the core of
problematizing bodies in anthropology. Associations between bodies, power, and politics have generated much theorizing about bodies in anthropology as well, surrounding issues of medicalization, representation, resistance, agency, commodification, normality and construction of bodies, and body metaphors. J.M. Berthelot (1991) notes that usage of the term body since the 1970s has been so pervasive that it is difficult to formulate theoretical discourse on the body. The popularity of the subject in anthropology is such that a new lexicon has evolved around it, exemplified by flexible bodies (Martin 1994), technocratic bodies (Davis-Floyd 1992), cyberbodies (Featherstone and Burrows 1995) and mindful bodies (Scheper-Hughes and Lock 1987) to note just a few.

Mary Douglas began this mode of thinking within anthropology by proposing a physical body and a social body in her 1966 work *Purity and Danger*. She is widely considered to be the first to explicitly focus on an anthropology of the body. Douglas views the body as a symbol of society and uses this approach to explain social patterns by demonstrating interactions between physical and social bodies. She argues that not only does everything symbolize the body, but that the converse is also true, we find meaning in the experience of the self in the body and gain insight about society through that experience (Douglas 2002:151).

Influenced by Douglas, Nancy Scheper-Hughes and Margaret Lock (1987) break down dichotomies and propose three bodies for consideration in theory-building in the anthropology of the body. The individual body is to be understood through the lived experience of the body-self. The social body refers to the body as a representational symbol of nature, society, and culture. The body politic takes into
consideration the regulation, surveillance, and control of individual and collective bodies. Scheper-Hughes and Lock suggest that these bodies represent “three different theoretical approaches and epistemologies: phenomenology (individual body, the lived self), structuralism and symbolism (the social body), and poststructuralism (the body politic)” (1987:8). Emotion is set forth as the “mediatrix” of the three bodies. Emotion is the “missing link” that serves as a standpoint from which to collapse mind/body and self/other dichotomies as well as to join the three bodies together.

Perhaps one of the most important developments in recent years is the emergence of the concept of embodiment as an anthropological paradigm. The main proponent of this approach is Thomas J. Csordas, who was heavily influenced by philosopher Maurice Merleau-Ponty (1962, 1964) who coined “embodiment” to describe his particular brand of phenomenology. Viewing perception as an essentially bodily experience, Merleau-Ponty considered the “embodied” state of “being-in-the-world”, as he put it, to be fundamental to lived experience. Csordas (1990, 1994, 2002) then takes a theoretical stance which approaches cultural phenomena through embodiment – with the “lived body” as its methodological starting point.

According to Merleau-Ponty (1962) we experience, perceive and interpret the world with our body. His notion of embodiment is grounded in perception, which he argues is embedded in a cultural context. He discusses body image and perception primarily as they pertain to how bodies operate through movement in space and time. For him, body image is a “way of stating that my body is in the
Bodies actively and habitually move through space and time in a way which obscures the significance of movement because of the “commonplaceness of established situations” (2002:117). Further, in social settings, Merleau-Ponty points to how words and physical movements which are appropriate to the situation are almost automatic.

Taking this idea to a broader level of analysis, Pierre Bourdieu’s (1980) theory of practice explains culturally patterned behavior from the perspective that socially informed bodies make up collective social life. Living through and in our body we act in ways which are practical within our social or cultural context, a phenomenon which Bourdieu refers to as **habitus**. The **habitus** is a product of history and a structure for the future and can thus be understood to represent the collective folk ideologies of a culture.

Csordas (1990, 1994) argues that there is a dialectical relationship between perceptual consciousness and collective practice, proposing a paradigm of embodiment for the study of culture that understands the body not as an object of study but as an existential subject of culture. He argues that our bodies are not objects to us, but rather “they are an integral part of the perceiving subject” (1990:36). Further, we do not perceive others as objects prior to reflecting upon the possibility of doing so (Csordas 1990). The aim of an embodiment stance then is to recognize that in the space where opposed terms meet we find a “characteristic reflectiveness and the process of objectification that defines human consciousness, giving substance to representation and specificity to being-in-the-world” (Csordas 1994:20).
With attention to the study of disability, sociologist Bryan S. Turner (2001) has an embodiment stance that draws from the seemingly incompatible ideas of Foucault’s poststructuralism and Merleau-Ponty’s phenomenology arguing that phenomenology retains the body as an object of study. However he problematizes the relationship between the objectified body of rehabilitation and medicine, the subjective body of everyday experiences, and body image that “negotiates the social spaces between identity, experience, and social relationships” (Turner 2001:254). Turner recognizes the ways in which disability is socially produced, but points to the significance of the fact that our embodiment makes us who we are. Taking the ideas of Csordas and Turner together it becomes obvious that the cultural and historical setting in which one experiences disability or impairment must be taken into consideration.

The exercise of imagining how things might be different in a “different” body provides the opportunity to recognize how Merleau-Ponty’s and Bourdieu’s ideas are useful as a starting point to explore assumptions about physical space, cultural norms and expectations, and social interactions, and to begin to question how they may indeed have different meanings and consequences in daily lives of those experiencing disabilities. The “habits” of movement and social interaction described by Merleau-Ponty do not necessarily fit into the daily lived reality of people with disabilities. People with disabilities and those who assist them must consider, for example, how to negotiate space with a wheelchair, or may be unable to see visual social cues. People with disabilities are socialized within, and internalize, the
practice of the collective *habitus* of their culture. We must ask how this is subjectively experienced in the reality of everyday life.

These points can be further demonstrated by examining the ideas of some feminist body theorists. For Elizabeth Grosz (1994), objects, such as jewelry or clothing, become part of the body image when they are no longer an object but a means for expression. Gail Weiss (1992) notes that bodies are marked by assumptions about ‘natural’ abilities and people do not become aware of these assumptions until they are violated. When one’s functioning or communicating relies upon the incorporation of objects such as wheelchairs, or the use of sign language, or even another person, they are violating assumptions about the natural abilities of bodies and they do not go unnoticed. Disabled bodies may preclude individuals, or even families, from particular activities or expected life chances. Norms regarding body image, social interaction, and movement are established by the able-bodied society, causing impaired bodies to appear different, creating social dissonance.

The influence of these theoretical approaches to studying disability in the context of culture is evident in the works of several anthropologists, for example: Gelya Frank’s (1986, 2000) analysis of the life of a woman with congenital limb deficiencies; Lindsay French’s (1994) study of meaning in social interactions of amputees in a camp for people displaced by war on the Thai-Cambodia border; Matthew Kohrman’s (2000) analysis of marriage exclusion practices in China which demonstrates how social norms affect disabled men’s experiences of stigma, family relations, encounters with strangers, and cultural practices; Robert Murphy’s
(1987) discussion of stigma in his own life as one with an acquired disability; and Russel P. Shuttleworth’s (2001) research on sexuality and interpersonal relationships of a man with cerebral palsy. Perhaps most relevant to this study is the work of Majid Turmusani (1999, 2001a, 2001b, 2003). In an analysis of the economic needs of disabled people taking part in work programs in Jordan, Turmusani found that in addition to Islamic religious beliefs and the influence of Western medical models of disability, the ability for a disabled person to work had a major impact on how they were viewed as members of society. These variables affected not only their economic circumstances but also impacted sexuality and relationships, higher education, mobility and autonomy, and political participation, with different outcomes for men and women. Though important foundational research, many of the above examples are narrowly focused.

By studying varieties of disability experience, this research will engage with and challenge many assumptions held by body theorists. Further, the unique environmental extremes of Ladakh and the coexistence of two distinct religious orientations will serve to bring into high relief the centrality of both physical and social facets of the disability experience, and to reveal disability itself as a lens through which our understanding of culture can be enhanced.

**Overview of Chapters**

The next chapter provides an overview of approaches to the study of disability with attention to cross-cultural perspectives, including those that address disability in the context of religion. The chapter concludes with a brief summary of research on disability in international health with a focus on India. Chapter three
situates this study in Ladakh, India by describing the study setting – its environment, history, and social structure. Chapter four reviews the literature on the health care system in Ladakh. A discussion of available information regarding health and disability in Ladakh is the final component setting the scene for the study design for this research. The study design and objectives are detailed in chapter five, along with fieldwork procedures, an overview of the participant samples, and detail on the demographic characteristics of study participants and their family members.

Chapter six presents quantitative study findings, supplemented by qualitative data, providing a look at life with disability in Ladakh. The chapter concludes with four case studies that supplement these data with richer detail gained through participant observation and spending time with participants. The case studies provide readers with a more intimate look into the daily life of individuals and families experiencing disability in Ladakh. Chapter seven discusses the findings and case studies in the context of the study objectives and literature reviewed in previous chapters. Chapter eight concludes the dissertation with a summary of the research, followed by a brief discussion of the significance of this study for anthropology and its interdisciplinary relevance, and directions for future research.
CHAPTER 2: ANTHROPOLOGY AND DISABILITY

Frameworks and Significance for the Study of Disability

Interdisciplinary frameworks for understanding disability have evolved in recent decades, and anthropology is recognized as making invaluable contributions to understanding what disability is and how disability issues should be addressed. Various models and definitions of disability have been set forth throughout the history of disability studies, re-conceptualizing not only disability but also impairment in the process. Individual or medical models of disability were prominent prior to the rise of Disability Studies within British sociology. These models place emphasis on abnormalities, defects, or functional limitations of the body. Disability is portrayed as something causing problems for an individual, something in need of treatment, rehabilitation, cure, or charitable assistance for example. The focus is on the health condition or impairment, and medical management or treatment of the condition is seen as the ultimate goal (Frost 2000; WHO 2001). This model, though widely used in the past, has been criticized for further marginalizing people with disabilities by focusing on the negative aspects of impairment (Miles 1999).

Sociologist Erving Goffman (1963) was the first to elaborate on a social theory of stigma, particularly the association of stigma to diseases and disabilities. His work remains influential in many disciplines including medical anthropology. For Goffman, individuals are stigmatized if they possess a trait which is different from societal norms, whether this difference is social, behavioral, or physical. This difference affects their social interactions and relationships to a degree to which
they must practice “stigma management”, such as trying to pass as normal, social withdrawal, or selective interaction with others who share his or her stigma. Stigma is applied not only to individuals with a negatively valued difference, but also to others who are close to a stigmatized person in the form of “courtesy stigma”. This stigma most often affects family members or caregivers and may be particularly salient in close-knit communities. Expanding on work of Goffman, stigma is now conceptualized as a social process. Stigma processes are the result of complex interactions between socially shared negative valuations which are reified by cultural institutions—such as law, medicine, education, and religion, and the family—and how these are used as a mechanism to negotiate the dilemmas of difference in social interactions (Ainlay et al. 1986; Link and Phelan 2001).

Both within academia and beyond, disability has gone from being understood as a medical problem interpreted through Western medical models, to being viewed primarily as a social issue. In the 1970s, British sociologists and disability activists developed a strict social model which views disability as the result of social barriers to full participation in society which are imposed upon those with impairments (Barnes et al. 1999; Oliver 1996). Inequities faced by people with disabilities are viewed as social problems with solutions in inclusive social action that alleviates these barriers (Frost 2000; WHO 2001). The social model locates impairment in the body and disability in the social world. In so doing the social model lost touch with bodily experience. This is the point on which the social model has been critiqued, setting in motion a long debate about how to conceptualize disability.
The social model should be recognized, however, for what it has done for
disability studies and activism, particularly since many scholars pointing to its
limitations are advocates of the social model. Liz Crow says, for example: “It gave
me an understanding of my life, shared with thousands, even millions, of other
people around the world and I clung to it” (1996:55). Politically the social model
has provided a unified direction for social change. Disability rights activists have
succeeded in prompting change in civil rights legislation in many areas of the world.
Within academia, the social model has provided a framework from which to analyze
the experience of disability that goes beyond Goffman's stigma theory to a more
macro-level approach which examines the socio-cultural realities of oppression and
discrimination. The social model has fueled debates about methodologies and
theoretical approaches most relevant to disability research.

People with impairments increasingly realized however that the social model
was not accounting for their experiences, leading to debate about the limitations of
the social model and the role of the body in the lives of people with disabilities.
Within academia the social model has been critiqued for lacking theory, ignoring the
impact of other identities, the role of culture, and the importance of language and
discourse. Critics of this model note that impairment can be disabling yet have little
to do with disabling aspects of society, for example experiencing pain (S. French
1993; Thomas 1999). Thus, many scholars began to broaden the social model to
include consideration of both individual bodily experiences and socio-cultural
contexts (Crow 1996; Davis 1995; Hughes and Paterson 1997; Shakespeare and
Watson 1995). Though falling short of a new social theory of disability, these
approaches were influential in drawing attention to the complexities of disability and were used by the UN (1993) in their development of the Standard Rules on the Equalization of Opportunities for Disabled Persons, the WHO (2001) in their efforts to establish community-based rehabilitation (CBR) programs, and their development of the International Classification of Functioning, Disability and Health (ICF). Though not legally binding the UN Standard Rules has influenced policies and programs around the world. This is the atmosphere in which contemporary disability scholars are conducting research.

Yet, the contexts vary widely. The focus of research in the developing world has often been very different from that in Western settings. As human rights viewpoints enter areas that were once remote; advances in medicine and technology extend their reach; and as people move around the world the diversity of disability issues relevant in a particular local context may be much broader than it once was (see Ingstad and Whyte 1995, 2007). Before embarking on a more thorough review of relevant disability research, it is necessary to consider the barriers to participation in society faced by many people with disabilities around the world, including the remote but rapidly changing area where the research for this dissertation was conducted. This serves to remind readers about disability issues faced by international organizations and as an entry point for exploring the place of anthropology in the interdisciplinary study of disability.

**Contextualizing Disability**

According to geographer Brendan Gleeson (1999), physical inaccessibility and socio-spatial exclusion from social services are the two primary forms of urban
oppression. It could be argued this applies more broadly to non-urban environments too. Public information that is presented in ways that are inaccessible to vision and hearing impaired individuals limits potential access to public services. Physical barriers to mobility include building architecture and problems with transportation. These types of inaccessibility limit access to education, employment, and health services. The Economic and Social Commission for Asia and the Pacific (1995) issued a report which describes accessibility not only as a technical issue but an issue dependent upon social consciousness and the recognition of rights. “Unless those barriers are eliminated, people with disabilities will not be able to participate fully and avail themselves equally of the opportunities that exist in society” (ESCAP 1995:Introduction).

Limited access to health care is a widespread problem throughout the world. When health care is accessed, the effectiveness of treatment may be hampered by lack of communication about multiple types of health seeking that may be occurring, for example consulting traditional practitioners or religious specialists in addition to providers of biomedical services. For people with disabilities the situation can be exacerbated by a number of other factors. For some, access to care is limited by stigma and exclusion from social services in general. There may be communication barriers that arise from cultural differences (e.g. Dufort 1992), or from information not being provided in appropriate formats for deaf or blind people for example.

Many people with disabilities have limited opportunities for education (Department for International Development 2000; Elwan 1999; Priestly 2001). UNESCO has estimated that in developing countries only one to two percent of
children with disabilities receives an education (DFID 2000). UNICEF found that disabled children not only lack access to education but to child care services, recreation, and other social services. Many governments and organizations are working toward inclusive education, which involves mainstreaming disabled children into the regular school system, which can be a challenge in almost any setting (Barton and Armstrong 2001). Many children throughout the world are not attending school, even when governments have given them that “right”. A family may not be able to afford to send all children to school, a factor unlikely to work in favor of a child with a disability.

As adults, they are likely to be unemployed because of lack of training and illiteracy (Elwan 1999). “Disabled men and women throughout the world continue to be disproportionately unemployed, underemployed and underpaid (along with young people and women), resulting in conditions of extreme poverty for many millions of their families” (Priestly 2001:8). It is widely believed that people with disabilities are often the poorest of the poor. This is one reason governments and organizations have begun to develop employment programs for people with disabilities. Simply creating employment programs may not adequately address issues that may be most important to people with disabilities.

Opportunity and accessibility are still important areas of concern. Additionally, many major causes of disability are preventable or newly emerging. Political instability, war, and violence are significant contributors. Poor nutrition, limitations in access to vaccinations, health care, and maternity care, accidents, including those associated with increased road traffic and dangerous working
conditions, inadequate sanitation programs, poor hygiene, dangerous living conditions, infectious diseases, natural disasters, aging populations, and inadequate information about the causes of disability are all significant causes of disability (DFID 2000; Elwan 1999; Frost 2000; S. Miles 1999; Priestly 2001; Yeo 2001).

Generally, international development programs seek to reduce poverty, increase access to education and primary health care, reduce morbidity and mortality rates, decrease gender inequality, and implement environmentally sustainable development programs. The programs would, by their very nature, reduce preventable causes of disability. Programs specifically for people with disability have historically faced obstacles. In 1979 the WHO began testing a CBR approach to prevention and rehabilitation of disabilities in developing countries. Peter Coleridge notes that this was an attempt on the part of the WHO to “de-institutionalise, de-mystify, and de-professionalise rehabilitation” (1993:86). According to Ronnie Linda Leavitt, “CBR is a strategy for enhancing the quality of life of PWD by improving service delivery, providing more equitable opportunities and promoting and protecting their human rights” (1999:103). The family and community health workers are the primary resources in CBR programs. Though implementation of such programs has been widespread since 1979, they have faced numerous challenges and have had limited success. “Interestingly, the planning of services has benefited little from direct study of the life experiences of individuals with a disability in the communities concerned” (Devlieger 1994:41).
Disability and Culture

Despite increasing awareness of complexities surrounding disability, many questions remain unanswered regarding the structural and cultural forces which shape experiences of disability and how they vary by context. Most scholarly work takes place in developed nations with stable health care and social service systems (Albrecht et al. 2001b). Such research has limited applicability in settings such as Ladakh, especially when programs based on Western models are implemented in areas with scarce resources and diverse cultures, religions, and environments. Further, the applicability of such research in the diverse multi-cultural areas of many Western countries and the emerging contexts of disability more broadly have yet to be fully explored. Susan Reynolds Whyte and Benedicte Ingstad (2007) note that reality for people with disabilities and their families may not be as quick to change as awareness that change is needed.

Recent scholarly work has begun to demonstrate variations in cross-cultural attitudes toward disability and the range of factors that shape those attitudes (e.g. Albrecht et al. 2001a; Desjarlais et al. 1995; Driedger and Gray 1992; Fine and Asch 1988; L. French 1994; Holzer et al. 1999; Hubert 2000; Ikels 1991; Ingstad and Whyte 1995, 2007; Jenkins and Angrosino 1998; Kohrman 2000, 2003, 2005; Leavitt 1992; Marshall 1996; Priestley 2001). The most wide ranging example to date is the volume Disability and Culture (Ingstad and Whyte 1995) and the subsequent volume Disability in Local and Global Worlds (Ingstad and Whyte 2007). Several chapters in the former volume were in direct response to failing CBR programs, supported by the WHO with the aim of illuminating beliefs and attitudes.
about people with disabilities in cultural context in order to improve their programs. Overwhelmingly, past failures of such programs have been cited as being due to a lack of consideration for the local cultural context in which programs are implemented.

These programs have ignored a range of issues from understanding resource allocation in families, community priorities, accessibility of services at the state or national level, to cultural and religious beliefs and values (Devlieger 1994; Holzer et al 1999; Ingstad 1995, 1999, 2001; Leavitt 1999; Mpofu and Harley 2002). Additionally, the range of both disability and non-disability related challenges faced by families, communities, and states needs to be recognized (Devlieger 1994). Cross-cultural studies of disability provide examples of the array of challenges, for example: widespread poverty and remoteness of villages in India and Botswana (Ghai 2001; Ingstad 1995, 1999); families, communities, and health care systems being burdened by other issues, such as HIV/AIDS in Botswana (Ingstad 2001); class and gender inequalities such as those in India (Coleridge 1993; Ghai 2001); and lack of awareness of disability legislation and lack of communication between government and non-government organizations in many countries (Coleridge 1993; Devlieger 1994; Ingstad 2001; Mpofu and Harley 2002; Yeo 2001).

Several anthropologists have done in-depth studies of experiences of disability in Western cultures. These studies clearly demonstrate the potential significance of intra-cultural variation in both constructions and experiences of disability, however many are narrowly focused on a specific group of people. Nevertheless these studies are invaluable to the development of experiential studies
of disability within anthropology. The most notable examples include Joan Ablon’s (1984, 1988, 1999) studies of dwarfs and those with the disabling genetic condition neurofibromatosis; Gay Becker’s (1980) study of deafness and aging; Robert Edgerton’s (1967) study of stigma and mental retardation; Gelya Frank’s (2000) analysis of the life of a woman with congenital limb deficiencies; Robert Murphy’s (1987) analysis of stigma in his own life as one with an acquired disability; and Kenneth Irving Zola’s (1982) reflexive account of a participant-observer in a village for disabled people in the Netherlands.

Families and caregivers experience disability and in turn shape the experience of disability. In most cultures, norms shaping kinship systems act as a means of social control, even through stigma processes. For example, consider differential valuation of potential marriage partners on the part of parents. In the case of disabilities, analyses of these valuations may be particularly insightful. Familial views about dating and marriage prospects for a child can have lasting effects on the individual through socialization and social learning.4 Sara E. Green (2003) studied the impact of perceived stigma on the emotional and social lives of mothers of and children with disabilities in Florida. Several other examples of families coping with and adapting to stigma and disability exist.5 For example, Ablon (1984, 1988) describes the role of the organization Little People of America in normalizing stigma. Gail Landsman (2003) describes how mothers hold on to the

4 For the diversity of possibilities see for example, both Ablon (1999) on living with neurofibromatosis 1, a genetic disorder, and Ablon (1988) on families with dwarf children. 5 Banks 2003; Deshen 1992; Edgerton 1967; Gallagher and Stratton 2001; Leavitt 1992; and Taylor 2000 to name but a few examples. Though many are not specifically about disability and stigma in family context they provide relevant insight.
concept of “developmental delay” until eventually adjusting to the concept of
“disability”. The acquired presence of disability (or any serious health condition or
stigmatized label) in the family can change the dynamics of the family. The effects
are certainly felt in the immediate family or household, but can reach beyond that by
changing relationships with extended family members and close family friends.
Emotions, behaviors, relationships, and changes in role expectations can change
family dynamics. The roles of the family and extended social networks are receiving
increasing attention in disability research (for examples see Ingstad and Whyte
2007).

As Whyte and Ingstad (1995) argue, evaluations of the cultural context of
disability need to consider political and historical contexts, Western assumptions
about disability (including classification systems relying on medical models), social
organization, and differences in concepts of personhood. In a similar vein,
anthropologist Nora Ellen Groce (1999) asserts that social beliefs surrounding
disability are based on three categories. First, beliefs about causality influence the
way an individual with a disability is treated. Second, the attributes that are valued
or devalued in a society affect the ways in which people with specific impairments
are viewed, either positively or negatively. Third, an individual’s anticipated adult
status, or their future ability to contribute to the society, plays a role in how
resources will be allocated to the individual.
The Role of Religion

Present day social, political, legal, health care, and religious institutions in a culture are influenced by the historical traditions of dominant religions. This is demonstrated in a compelling account by Henri-Jacques Stiker (1999) describing how concepts of normality, personhood, and disability have been shaped through history in Western cultures. Similarly M. Miles (1995, 2000) has demonstrated how Eastern religious philosophies and folk tales have shaped attitudes and popular notions of disability in Asian contexts. These traditions simultaneously provide a means to cope with disability, and set often unattainable standards of normality by which people are judged. They also form the basis for culturally accepted ways of reacting to a particular disability, including whether stigmatization is appropriate and whether reaction to stigma is negative or positive (International Consortium for Research and Action Against health-related Stigma 2004; Üstun et al. 2001; White 2001). Often, ideas about causation are directly related to concepts of personhood and may be most readily apparent in traditional religions or illness theories. Stephen C. Ainlay and Faye Crosby (1986) assert that the socially constructed nature of the social order may be disguised through associating suffering to divine plans or evolutionary law. It is also a socially constructed means of creating order in society. Beliefs about causation often form the basis for the culturally accepted way of reacting to a particular disability.

6 Miles (1995) and Selway and Ashman (1998) include an array of scholarly sources that reference cross cultural attitudes that stem from religion.

7 The cultural applicability research conducted by the WHO in developing the ICF included cross-cultural comparison of the degrees of stigma for particular characteristics and the importance of beliefs about etiology in these determinations. See Room et al. 2001 for a summary.
Literature examining attitudes toward disability among Buddhists and Muslims, and that which examines views of disability in Islamic and Buddhist doctrine, are often contradictory (Eickelman 1989; Miles 1995; Samuel 1993; Turmusani 2003). For example, disability may be viewed as a result of parental or personal sin and have an associated stigma. At the same time, religious doctrine may promote an ethic of charity and kindness toward people with disabilities, or suggest that disability is sent to test faith. In Muslim contexts, for instance, disability is often perceived as an act of God and a test of faith (Turmusani 2003) and there are no active policies for preventing or remedying disabilities (Miles 1995). Muslims are encouraged to accept what is sent by God and therefore may not seek treatment or care for congenital disabilities. On the other hand, Muslims have a responsibility for those who are unable to earn a living or care for themselves, and this is a religious obligation and an issue of equal rights (Miles 1995; Turmusani 2003). Emphasis on the Buddhist doctrine of *karma* in Tibetan societies (Samuel 1993) also has strong implications for disability. Studies by L. French (1994) and Miles (1995) have demonstrated that disabled people become the recipients of compassion and charity, and are considered unable to achieve good merit and a favorable rebirth on their own. Among Buddhists, those with mental or physical disabilities may be unable to aspire to the religious ideals of moral self-discipline or conduct meritorious religious activities. On the other hand, particular disabilities which preclude one from regular domestic activities, such as lameness or certain mental illnesses, could be seen as enhancing one’s ability to attain enlightenment (Ardussi and Epstein 1978). However, it is important to keep in
mind that religious doctrine, professed attitudes, and actual behaviors rarely coincide. The comparison between Ladakhi Buddhists and Muslims in this study will advance understanding of the ways religion influences experiences of disability.

In many cultures beliefs about or conceptions of disability are closely related to conceptions of personhood, humanness, and illness theories (Ingstad and Whyte 1995; Jenkins and Angrosino 1998; Keck 1999; Marshall 1996). In societies that value individual autonomy and independence, a disability can alter or diminish perceptions of personhood and the self. The birth of a disabled child could be viewed as a result of sin or taboo violation on the part of the parents or the child in a previous life. A disabled person could be killed, or viewed as dangerous, or be viewed as a source of supernatural power (negative or positive). “Ethnographic research suggests that, although by no means universal, the denial of full personhood, and even of life itself, to infants born with disabilities is not uncommon (Landsman 2003:1949).” In a society where the cause or blame is not found in the individual they may be treated with charity and pity, as in the Christian tradition, or incorporated in the best way possible into the social structure.

Several studies have demonstrated cross-cultural variation in concepts of personhood, ideas about causation, and how societies may use these to deal with

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8 Statements such as this are highly controversial. Ingstad (2001) argues that although it may be true, perpetuating the myth that people in non-Western societies hide, abuse, or kill disabled family members is wrong; primarily because of the potential consequences and that the myth is largely based on “beliefs” or speculation. It may be more appropriate to investigate the “myth” in both Western and non-Western cultures. Infanticide, as well as rejection and neglect that at times leads to death, however are not unheard of (e.g. Devlieger 2000; Ingstad 2007; Weiss 2007). It is also important to give thought to the role of prenatal testing (e.g. Lock 2007; Parens and Asch 1999; Rapp 1999). Issues associated with neglect are relevant in aging research as well.
difference. The influences of religious or health-belief systems and the links
between concepts of personhood and constructions of disability are apparent.
Patrick Devlieger (1995) describes concepts of personhood among the Songye of
Zaire, including three categories of abnormal children: ceremonial, bad, and faulty.
Beliefs about personhood and causation create and maintain social order.
Ceremonial children (twins, one born with the umbilical cord around the neck, or
one born feet first) are believed to have healing capabilities and other special
powers and thus fill a niche, or may have a specific role in the society. Those
categorized as bad children (albino, dwarf, or hydrocephalic) may be those who are
initially less likely to survive in the physical and social environment in which the
Songye live and therefore associating them with death has a function. Faulty
children (those with bodily imperfections such as a limb deformity), minimally
serve as a reminder about food and sex taboos or relationships with the physical
environment, the importance of maintaining good relations with close kin (to avoid
being the target of sorcery), properly distributing bridewealth, proper treatment of
ancestors, and respect for God. Other studies of note include Mac Marshall’s (1996)
analysis of concepts of disability in Caroline Island societies and Verena Keck’s
(1999) study of concepts of disability among the Yupno of Papua New Guinea. In a
study of cerebral palsy in Nepal, Rebecca Saul and David Phillips (1998), call
attention to intra-cultural variation in beliefs about disability among parents of
disabled children, disabled children themselves, and the professionals who work
with them. They argue the variations stem from pluralistic religious beliefs and
health-beliefs systems, and differences between rural and urban populations.
Attitudes and Experience in the Context of Culture and Religion

Some studies add another layer by demonstrating the influences of not only religion but historical and political economic influences on constructions of disability. Lindsay French (1994) takes a phenomenological/political-economic perspective in discussing attitudes toward and social interactions of amputees on the Thai-Cambodia border in the context of the political and religious environment of this war-torn region. Another example of a political-economy based approach can be found in the work of Majid Turmusani (1999, 2001a, 2001b, 2003). In an analysis of the economic needs of disabled people taking part in work programs in Jordan, Turmusani found that in addition to Islamic religious beliefs and the influence of Western medical models of disability, the ability of a disabled person to work had a major impact on how they were viewed as members of society. This affected not only their economic circumstances but also impacted “sexuality and relationships, higher education, mobility and autonomy, and political participation” (2001b:197), with different outcomes for men and women. Both of these studies are notable for adding, though both limited in scope and to very specific people, some experiential dimension.

There are two in-depth studies which stand out for combining approaches, addressing attitudes and experiences in non-Western settings. These are Matthew Khorman’s work in China and Shlomo and Hilda Deshen’s work with blind people in Israel (Deshen and Deshen 1989; Deshen 1992; Kohrman 2000, 2003, 2005). Both of these projects were long-term and multi-faceted, thus taking a variety of approaches. For example, Kohrman (2003, 2005) analyzed how dominant national
and transnational discourses have shaped disability legislation in China and how this is differentially affecting groups of disabled people. Alternatively, Kohrman (2000) has used a phenomenological approach to analyze marriage exclusion practices which demonstrates how these social norms affect disabled men's experiences of stigma, family relations, encounters with strangers, cultural practices, the use of language, identity transformations, and disability identity. Similarly, Deshen and Deshen's research has looked at a broad range of cultural and religious ideals in Israel, investigating the impact in several realms of life for blind people. This research is exceptional in that it looks at the role of stigma in the family and the strain this puts on the family unit, including in-depth research with both families with sighted parents and blind children and those with blind parents and sighted children. Deshen (1992) has also analyzed how attitudes about disability affect blind people's use of technical aids such as canes or guide dogs and the impact that negative attitudes have on the ability of the blind to negotiate daily life, work, education, and social activities.

However, these studies do not take the necessary step of exploring attitudes and experiences within a single project. Most research either explores attitudes toward and constructions of disability within a culture or explores experiences of disability while making assumptions about attitudes toward disability within the relevant context based upon other research. Additionally, disability research needs to go beyond mere mention that religion plays a role in shaping cultural attitudes toward, and treatment of, people with disabilities to some explanation of how and why this occurs. Whyte asserts that there are two types of disability research: one
which examines the influences on cultural constructions of disability, and another which starts with experiences.

One method has broad vision but risks stereotyping; the other has depth and nuance, but may lose sight of the changing social context in which individuals exist. Future research must draw from both of these approaches, and it must build on field research that contextualizes and differentiates the situations of persons with impairments. [Whyte 1995:267]

Ladakh, India is an ideal location in which to conduct a study which attends to both the experiential and cultural components of disability as suggested by Whyte. Both the physical environment and religion are central organizing features of Ladakhi social life. By studying disability at the community level rather than by focusing on a narrowly defined group of disabled people (such as the blind, or children with cerebral palsy) this research begins the process of determining other cultural characteristics which may be most significant in affecting variability in constructions and experiences of disability. Before proceeding to a more detailed description of the study setting, brief consideration of disability in India will provide socio-political context to disability efforts in Ladakh.

**Disability in India**

In 1995, India implemented the Indian Persons with Disability Act, which was based in large part on the UN Standard Rules (Yeo 2001). The Act gives people with disabilities recognition within the constitution and has several aims. The major components are prevention and early detection, integration of students with disabilities into mainstream education, including people with disabilities in at least three percent of government and public sector vacancies, identification of jobs for people with disabilities, and job protection for those who become disabled. There is
also a provision that local authorities, when economically able, should make adjustments to the physical environment to meet access needs (Yeo 2001). There are substantial limitations to the legislation and amendments are likely to be added over the years. For example, the definition of disability used by the government was limited to recognition of only seven impairments. Many people are not aware of the Act, or the rights they have as a result. The disability movement in India is growing, and as more voices are heard the groundwork that has been laid by the Act will lead to its implementation becoming a higher priority throughout the country.

The situation for people with disabilities in India, as may be expected, is quite variable. Though programs exists and legislation has been enacted, extreme poverty along with the wide range of cultures, languages, and the vast expanse of the country itself means that many people in need of services do not have access. The obstacles to evaluating needs and providing services are vast. The cycle of poverty and disability, one leading to the other, in India cannot be ignored. Gender inequality worsens the problems faced by women, with women generally being at higher risk of acquiring or having disabilities, and with disabled women having even fewer ‘life chances’ than women generally (Coleridge 1993; Ghai 2001). Coleridge notes that probably three percent of the population is disabled to the extent that they are in need of specialized services, which as in many parts of the world, are concentrated in urban areas. It is important to note that reliable statistics related to populations or services for people with disability do not exist.

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9 To complicate matters, different surveys within the country are using different disability categories and definitions. See the Government of India Report (2011a) "Disability in India – A Statistical Profile" for an overview.
Two approaches dominate in India, a charitable approach in which funded services reach a small number of people, and a self-help approach which also has limitations. The self-help approach dominates in rural areas. Coleridge notes, “the task of trying to deliver services to disability people in rural India is so daunting that it has not generally been attempted: it is hard enough, it is argued, to deliver services to non-disabled people, so disabled people are off the end of the scale” (1993:161). Action on Disability and Development (ADD) India has played a major role in integrating social action on disability into existing rural development organizations, with the aim of stimulating the “formation of disability sanghams (associations) in each village which would assume responsibility for the needs of disabled people in that village. The members of these sanghams would be disabled people themselves” (Coleridge 1993:161). ADD provides initial training in several areas including communication, social analysis, management and administration, and planning and evaluation. Many of the organizations and programs stimulated by ADD have become quite large, employing many people and covering hundreds of villages. The WHO did cross-cultural applicability research (CAR) studies in three locations in India: Bangalore, Chennai and Delhi (Murthy, et al. 2001; Saxena et al. 2001; Thara and Srinivasan 2001). All three of these studies note the large numbers of people with physical disabilities, though focus much attention on the extreme stigma associated with people with psychiatric disorders. They all also noted the lack of awareness or implementation of the government policy noted above. All note positive attitudes toward people with disabilities in India, though likely referring only to people with physical disabilities. The results of the CAR studies
provide some insight into views of and about people with disabilities. They also indicate the vast number of problems facing disability related research or policy and service implementation in urban India. These findings can easily lead one to conclude that the community based or self-help approaches are likely the only viable options in rural India, and that awareness and implementation of any government policy will be slow to be realized.\textsuperscript{10}

\textsuperscript{10} This process was still underway in Ladakh during fieldwork for this study.
CHAPTER 3: SETTING – LADAKH, INDIA

Fieldwork for this dissertation was conducted over 12 months in Ladakh, India from August 2008 through August 2009. The purpose was to examine subjective experiences of disability, focusing on the interaction between the physical and social domains of experience and how they are shaped by local cultural constructions of disability. Fieldwork explored disability experiences in Ladakh with the goal of engaging findings with literature in disability studies and anthropology of the body. Thus, the research design was developed from review of the literature and preliminary fieldwork in Ladakh. This chapter will provide a brief description of factors in Ladakh that shape the lives of its people.

Landscape, Environment, and Resources

Ladakh is a remote mountainous region situated in the far north of India. Accounting for approximately 34,000 square miles of the Indian state of Jammu and Kashmir, Ladakh is bordered by the Karakoram and Himalayan mountain ranges to its north and south. The Zangskar and Ladakh mountain ranges, and the Indus river valley, define the geographic layout of the region (see Maps 1-4). Ladakh is in the westernmost portion of the Tibetan Plateau, with altitude ranging from around 8,860 to 25,100 feet (Pfister 2004). Permanent human habitation is found as high as 14,764 feet (Rizvi 1998), and often higher in nomadic regions and military outposts.

It is an arid, mostly desert landscape, dotted with sparse areas of arable land along narrow river valleys fed by glacial runoff. Most of Ladakh receives only about four inches of precipitation per year, primarily in the form of snow. Higher amounts are common in the mountainous regions to the west and south, cutting Ladakh off
from the rest of India for a significant portion of the year. During winter, temperatures in Ladakh can dip as low as negative 20 degrees Fahrenheit. In the summer temperatures are relatively mild, but often reach into the nineties. According to the 2011 Census of India, the population of Ladakh is estimated around 274 thousand, with 133 thousand in the Leh district (Government of India 2011b). Most settlements are concentrated along the Indus river valley, yet are widely dispersed.

Most Ladakhi families are involved in subsistence farming. Barley is the major food crop. Most houses have a substantial garden, whether or not the family is actively farming. Gardens have a variety of root vegetables and onions that can be stored through winter, and tomatoes that can be dried. Greens such as spinach or turnip leaves are a popular food and are increasingly grown in cold frames extending the season and providing a longer period of nutritional variety. Apricots and apples also grow well. Animal husbandry is an important aspect of life in Ladakh. Cows, yaks, dzos, goats, and donkeys are kept as sources of dairy products, fuel, fertilizer, and labor. Since very little wood is available for heating homes, more efficiently burning dried dung often serves this function. Muslim-run butcher shops provide a source of meat for both the Muslim and Buddhist population.

Ladakh has historically relied on trade with its neighbors – India, Kashmir, and Tibet. As a tributary of the Silk Road network, Ladakh has always been a truly cosmopolitan area. Pashmina goats have always played an important role in the

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11 Dzos are hybrid of yaks and cows.
economy of Ladakh. Apricots and pashmina wool are examples of the very limited exportable resources. Imported rice and tea have long been part of the Ladakhi diet. Today, the Ladakhi diet relies heavily on the import of rice and lentils from other parts of India. As Janet Rizvi (1998) notes, Ladakh does not, and probably never has, produced enough food to be self-sufficient.

**Study Area**

Politically, Ladakh is divided into two districts, the Leh district and the Kargil district. Each district is divided into blocks, six in the Leh district and seven in the Kargil district. The Leh district is a majority Buddhist area, whereas the Kargil district is primarily Muslim. Leh, Ladakh’s biggest city, is also its unofficial “capital”. The population of Leh is estimated at around 45,671 (Government of India 2011b). Leh includes Buddhists, Muslims, Hindus, Sikhs, Christians, and others. There are people in Leh with connections to all the villages in Ladakh, often living in distinct neighborhoods. Due to the presence of a large military base, there is actually representation from all of India. Study participants were recruited in Leh and the surrounding area. Though most were from villages throughout the Leh district, some were from the Kargil district. Most were living in or visiting Leh, a nearby village, or the study village.

Most government offices, businesses, larger schools, and NGOs are centrally located in the greater Leh area. Leh has recently become accessible by air year round and accessible via the Leh-Manali highway or the Srinigar-Leh highway seasonally. For most of the year however, Leh and the rest of Ladakh are virtually cut off. When highways open for the summer a rush of supplies and people come to
Leh. Ladakh has a very busy tourist season between June and September, with tourists coming from all over the world and throughout India. The array of nationalities is permanently apparent in the diversity of NGOs in Ladakh. Along with the tourists, come migrant workers from Bihar and Nepal; beggars, often disabled, from far flung parts of India; and Kashmiri shopkeepers from Srinagar.

Ringmo, the main study village, runs up a long valley between two mountain ranges. It is separated from Leh by a mountain range but accessible via the Srinigar-Leh highway that follows the Indus river valley. Its approximately fourteen hundred residents are primarily subsistence farmers. Ringmo is typical of rural Ladakhi villages in its geography, social structures, and economy. What makes it somewhat unique, and ideally suited for this study, is its mix of Buddhists and Muslims. Though the total population and the religious distribution are in flux, it is estimated to be about 75 percent Buddhist and 25 percent Muslim. Ringmo has both a Buddhist monastery and a mosque. The Buddhists are of the Drigung Kargyud sect of Tibetan Buddhism. The Muslims are Shia, many of whom have migrated from the Kargil district generations ago but still have close relatives from that area and move back and forth for work or social reasons. As more Ladakhis seek wage earning jobs, it has become increasingly common that one or more members of the household have government or private jobs outside the village. In many cases this requires relocation and has thus disrupted traditional household compositions.

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12 Ringmo is a pseudonym.
The characteristics of Ringmo that make it simultaneously an idyllic scene of beautiful farms and an extreme physical challenge are also changing the social structure and physical layout of the village. There is considerable glacial runoff that flows through Ringmo, creating a valley within the valley. Part of the year this is merely a stream that is cleverly re-routed into complex irrigation systems throughout the village. During other times it is more like a river surrounded by waterlogged pastures. In recent history flash flooding has had devastating effects on the village; destroying homes, fields, roads, bridges, and taking lives. As a result, some areas that were previously fertile farmland are now full of large boulders. Though the Buddhists and Muslims have traditionally lived in different areas of the village, and the residents of Ringmo are not immune to the history of Buddhist-Muslim conflict in Ladakh, these catastrophic events are having an inevitable impact on these divisions. As homes and fields have to be abandoned and relocated, as the whole village works together to re-build, and as land becomes less abundant, Ringmo is in a state of change.

**Shaping Contemporary Ladakh: History, Politics, and Culture Change**

Though Ladakh has a history of relations with India, Kashmir, and Tibet, Ladakh has developed and retained a unique cultural heritage (Bray 1991; Ribbach 1986; Rizvi 1998, 1999; Snellgrove and Skorupski 1977; van Beek 1997, 1999, 2003). With important trade routes running through Ladakh, Muslims began settling in this traditionally Buddhist area as early as the fourteenth century (Aabedi 2009; Dollfus 1995; Sheik 1995). Through immigration, conversions to Islam, and intermarriage between Muslims and Buddhists, Ladakhi culture incorporated
aspects from these diverse traditions (Bray 1991; Rizvi 1998). Four sects of Tibetan Buddhism are represented with most of the population associated with either the Gelukpa or Karma Kargyud sects. The Shakya and Nyingma sects are less prevalent. Buddhists are a majority in the Leh district, whereas Muslims are in the Kargil district. The Muslim population in Ladakh consists of two main communities. The Shia live primarily in the Kargil district, though some of this population migrated to the Leh area. Members of the Sunni community around Leh have migrated there from a wider geographic area. Table 1 shows the religious affiliations of Ladakhis by district.

Table 1: Religious affiliations of Ladakhis by district

<table>
<thead>
<tr>
<th></th>
<th>Leh District (%)</th>
<th>Kargil District (%)</th>
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</thead>
<tbody>
<tr>
<td>Buddhist</td>
<td>77</td>
<td>15</td>
</tr>
<tr>
<td>Muslim</td>
<td>14</td>
<td>80</td>
</tr>
<tr>
<td>Hindu</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>Sikh, Christian, and other</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

Rounded data from 2001 census (LAHDC Leh n.d.; LAHDC Kargil n.d)

Recent history reveals many significant social and economic changes in Ladakh. Despite sharing a rich cultural, historical, and linguistic heritage, distinct differences between the Buddhist and Muslim communities of Ladakh remain, primarily associated with kinship and marriage patterns, political alliances, and occupational roles (Brauen 1980; Bray 1991; Grist 1993; Peter 1963; Phylactou 1989; Srinivas 1998; van Beek and Bertelsen 1997). These differences have led to some conflict. The Ladakh Buddhist Association (LBA) was founded in 1934. Due to a concern that the Buddhist custom of polyandry was leaving many women unmarried, with a corresponding fear of Muslim population growth, the LBA persuaded the government in Kashmir to pass the Polyandrous Marriages
Prohibition Act of 1941 (Crook 1999). Since Indian independence in 1947, the Buddhist Ladakhis have sought greater autonomy from the Muslim-dominated Kashmiri state government (Crook 1999), which has been complicated both by the fact that the population of Ladakh is nearly equally split between Buddhists and Muslims, and the political significance of the area geographically (Bray 1991). Though Buddhists and Muslims had been living relatively peacefully for centuries in Ladakh, Buddhist feelings of preferential treatment of Muslims on the part of the government caused increasing animosity which began to increase in 1974 when the area was opened to international tourism.

Disputed borders have always been a part of Ladakh’s history. However, there has been a large and permanent military presence since India’s independence. India and Pakistan have been in dispute over portions of Jammu and Kashmir. In February 1948 Pakistan began an attempt to capture Baltistan and Ladakh and by summer had made it all the way to the village of Phyang. The Indian army sent reinforcements via the airstrip at Leh which seems to have been completed for this purpose. On January 1, 1949 a cease-fire came into effect and the cease-fire line is roughly the same border between India and Pakistan that exists today. There were, however, Indo-Pakistani wars in 1965 and 1971 and tensions remain high between the two countries. Continued intermittent military attacks result in ongoing instability in the Kargil area. Since 1984 there have been skirmishes on the Siachen glacier in northern Ladakh where a formal border between India and Pakistan was never established. In 1950 trade between Ladakh and Tibet was cut off. The Chinese, in order to assert control over Tibet, constructed a road through western
Tibet that also crossed through a remote portion of Ladakh. It was not until 1958 that the Indian Government took official notice of this Chinese intrusion into Ladakh. In 1961 China and India went to war over this border resulting in China gaining control over this corner of Ladakh. These border disputes and the resulting military presence and end of traditional trading culture have been significant factors in social and economic change in Ladakh.

The majority of foreign tourists visit Ladakh during summer. Since Ladakh opened to tourists in 1974, the number of annual visitors has increased steadily with 56,685 domestic and 22,115 international tourists recorded in 2010 (LAHDC Leh n.d.). Jean Michaud suggests there were several reasons for the opening of Ladakh: the Indian government saw the opportunity to augment the population by promoting internal migration and providing incentives for young Ladakhis to stay home; Kashmiri merchants saw the business opportunities associated with international tourism; and Ladakhi elders and Buddhist clergy were likely supportive since the "fear of seeing new-comers disturb the political, cultural and social order could not outweigh the prospect of new profits to compensate the losses incurred since the end of the caravan trade" (1996:293).

In 1989 there was an uprising when Ladakhi Buddhists formed the 'People's Movement for Union Territory Status' and demanded Ladakh be administered by the central government in New Delhi rather than the state government of Jammu and Kashmir (Bray 1991). Tensions escalated when Muslim youths beat up a young LBA leader in Leh. The next day the Jammu and Kashmir Armed Police killed a Muslim woman fleeing from her house which had been set on fire. There were at
least eleven bombings between the 7th and 12th of July when order was restored.

On August 27th a non-violent protest deteriorated into a battle with the JKAP,
during which three people were killed, many more were injured, and 150 were
arrested. The LBA started an economic and social boycott of the Muslims which
lasted until 1992. More recently there were clashes between Buddhists and
Muslims in 2006. An undercurrent of animosity between groups persisted during
the period of fieldwork.

In 1995 the Ladakh Autonomous Hill Development Councils Act was passed
by the state of Jammu and Kashmir which gave Scheduled Tribe Status to Ladakhis
and established the Hill Development Council of Ladakh which provides greater
political autonomy without independence, and permits self-government in areas
such as development and education. The council has power over

the use of land, the formulation of a development program and budget, the
alleviation of poverty, the promotion of languages and culture, the
management of forests, canals and deserts, public health, tourism, vocational
training and roads. It also holds powers with respect to education, ecology,
fisheries, cottage industries and non-conventional energy. Furthermore, the
council has the ability to raise revenues through taxation, the establishment
of tolls, and by levying fees for certain practices. [Crook 1999:148]

Ultimately each decision has to be approved by the government of Jammu &Kashmir
which can take significant time and involve extended negotiations.

There are countless local, domestic, and foreign NGOs operating in Ladakh.
Their interests are broad, ranging from ecology and environment to health,
education, ecotourism, agriculture, historic preservation, cultural revitalization, and
more. Many were established by tourists who visited Ladakh and were moved by a
cause. Others have been started by locals who feel there is an unmet need in their area.

The influx of outsiders and the resulting social and economic changes have been vast. For example, more and more Ladakhi students are leaving Ladakh for their education, both because they can afford to and because of the increasing value of education. Having spent years away from Ladakh, these Ladakhis themselves bring outside influences back to Ladakh. Young men who might otherwise have become monks decide to seek paid employment in government or the tourist trade. Cell phones, automobiles, bottled water, flush toilets, generators, and cars, for example, are changing the landscape of a region lacking the infrastructure or wealth to change at this rapid pace. Change from these influences begins in the capital city of Leh. Over time the effects of this change spread to even the most remote villages. NGOs spend more time in remote villages, local government aims to bring better education or hydropower, accommodations for tourists are developed, children leave for school, and adults leave for military service or paid employment. The very social structure of an entire region is impacted. Inevitable social gaps that did not previously exist are developing.

**Social Structure in Ladakh**

Topics covered in Ladakhi studies are quite varied (e.g. Crook and Osmaston 1994). Notable long term studies have described: the lives of nuns (Grimshaw 1994, Gutschow 2004), the role of a monastery (Goldstein and Tsarong 1987, Mills 2003), and kinship and marriage patterns (Brauen 1980, Crook and Shakya 1994, Peter 1963, Phylactou 1989). However, research in Ladakh has largely ignored the
Muslim population and there are few scholarly works which elaborate on the lifestyles, religious values, or norms and customs of Ladakhi Muslims with fewer still comparing the Buddhist and Muslim communities (Grist 1993, 1995; Srinivas 1994, 1998). Though some Ladakhi traditions are similar to those found in other parts of the Tibetan culture area, the social, political, and environmental contexts differ. Additionally, Ladakh has experienced different patterns of outside cultural influence – for example from Muslim populations, Indian rule, and international tourism – which continue to shape contemporary ideas and practices regarding social structure.

**Village Structure in Ladakh**

Smriti Srinivas (1997, 1998) describes village level political organization as having three components: (1) village headman and council; (2) symbolic unity of the village exemplified in the relationship between gods and humans; and (3) material culture of the village manifested in their irrigation system and labor system. Today political institutions beyond the village level have significant influence, thus diminishing the role of these traditional village level systems. The role of village headman, or *goba*, used to be a hereditary position but now rotates between households chosen by villagers. The village council operates under the same system. The power of these officials is not as it used to be, with their main roles now associated with water distribution, settling village disputes, communications between the village and district authorities, and leading some rites during village celebrations (Srinivas 1997). According to Valerie Labbal (2000) it is common for two or more households to share farm tools such as plows, some animals, and labor.
Work groups consist of households that come together for large tasks or to pool resources and may consist of a combination of kin, neighbors, or tenants under a common landlord. The entire village comes together as a work group for tasks like cleaning water canals (Labbal 2000; Srinivas 1997). Harvest periods (Labbal 2000) and the social organization of irrigation are managed at the village level (Osmaston, et al. 1994). Groups of farms rotate water rights for 24 hour periods based on need.

Households are comprised of related men and women whose gender and age-based division of labor for the household unit "creates a domain of social life firmly anchored within the territory of the domestic group—the altar for Buddhists, the hearth, the gardens and the fields of the household" (Srinivas 1994:196). Households are related to other individuals such as the cho-spun (ritual siblings) of household members, and local religious officials such as monks or an imam. Households relate to other households through particular practices, for example (1) the exchange of work, (2) ritual exchanges in the pha-spun (lineage) for Buddhists, (3) an agnatic group of Muslims which performs life-crisis rituals, and (4) village power structures. Households are also related according to ranked categories of occupational divisions in the village, but during times of conflict religious affiliations of households take precedence. Households are also related by marriage, "creating the category of the kindred which can, and does, include for any household member, members of various religious groups. This level of integration occupies a domain greater than the village given the dominant practice of village exogamy, with the occurrence of both virlocal and uxorilocal marriages" (Srinivas 1994:197).
The Pha-spun

Prince Peter (1963) originally stated that the *pha-spun* was a patrilineal clan or lineage, which led to misinterpretations about the nature of this important aspect of Ladakhi life. According to Martin Brauen the *pha-spun* "are people belonging to some more or less closely situated households who, through reciprocal privileges and duties . . ., through the adoration of a mutual tutelary deity (*pha-lha*) and through a jointly owned furnace for the cremation of their dead (*spur-khang*), form a single group" (1980:54). The *pha-spun* is not based on a common lineage, rather it is based on residence. Affiliation with a *pha-spun* can change when one leaves to marry, changes residence, or is involved in a local dispute. Sometimes a family will form a new group. The *pha-spun* comes together as a unit during life-crisis rituals (birth, marriage, death), and feasts related to village events or celebrations which are sponsored by each household on a rotating basis. Not all members of a *pha-spun* are blood relatives, allowing those within the *pha-spun* to carry out those funeral activities that are taboo for the blood relatives of the deceased. Brauen (1980) has described the *pha-spun* as being like a religious corporation, the function of which is to ease economic or emotional burden on a family. Rann Singh Mann (1990) notes how the increasing amount of assistance available from new agencies and institutions in the area are diminishing the value of the *pha-spun*, particularly in relation to dealing with disease and childbirth.

In the Suru valley in the Kargil District, households are also part of a network called the *pha-spun*, but based on male lineage. "Some people use the term *zāt* to describe a patrilineal kin group. This is a Kashmiri term and is used by the Sunni
families”, with some saying it is the same as *pha-spun* while others said the group is larger (Grist 1993:87).

**Division of Labor**

Most scholars note a lack of a rigid division of labor between males and females in Ladakh, with both beginning to help out with domestic chores at a young age. There is some disagreement however, since there are clearly activities specifically associated with males or females (Attenborough 1994; Srinivas 1998). For example plowing, slaughtering cattle, and felling trees are only done by men for reasons related to taboo (Reis 1983). Men are also primarily responsible for carpentry and masonry. Women are typically responsible for duties within the house, though men may cook and help with childcare to some degree. Some suggest these trends leave men with a lighter workload in winter months than women (Reis 1983). Increased outside employment among men, particularly government employment or military deployment, is increasing the agricultural workload of women. Unlike in the Leh district, there is not a significant water shortage in the Suru valley which allows for continued clearing of land. Shia men often work as laborers for part of the year, mainly for government run construction projects, and many also hold government jobs. The smaller Sunni population tends to be wealthier and better educated, and most men, and some women, work in government jobs.

Unlike the rest of India the region has no caste system although there is strong but informal class consciousness related to wealth and social connectedness among Buddhists. The egalitarian nature of Ladakhi society is noteworthy and
affects both Buddhist and Muslim women. In the Leh area, except for very high status families, women are not secluded. In Kargil attitudes are more traditional, except for families "of education and high social status. Today in Leh, and to a lesser extent in Kargil, women are playing an increasingly prominent role in professional and public life" (Rizvi 1998:133).

**Household Organization**

In Ladakh a household consists of a group of people who worship the same household god (*lha*) and use the name of their house, which may actually be a group of houses and buildings, as their family name. There is no "differentiation between household and family, building and residence. All those terms simply represent different aspects of the complex socio-economic system 'family'" (Sander 1983:190). There is a system referred to as “big house” / “little house” (*khang-chen* / *khang-bu*). Traditionally, the eldest brother of the reproductively active generation is the head of the household (Crook and Shakya 1994). The shift in household headship usually takes place upon his marriage or upon the birth of his first child. The parents move from the big house to the little house, taking remaining unmarried daughters and only the land and animals they needed to survive. Elder members of the household were freed from heavy responsibilities related to the family, the *pha-spun*, the community, and the government (Peter 1963). Though this is still the customary practice, today some parents may not necessarily move out of the *khang-chen* and may relinquish headship more gradually (Reis 1983). More recent researchers have found changes in traditional household practices, including a decrease in the practice of polyandry, an increase in
the diversity of kin types living in the *khang-bu*, and a delay in parents turning over
the household (Crook and Shakya 1994; Hay 1997; Reis 1983). During fieldwork
the extent of these practices was difficult to evaluate since Ladakhis are unlikely to
reveal practices such as polyandry which are now illegal and considered by some to
be immoral. Change has occurred more rapidly closer in to Leh.

Nicola Grist (1993), notably one of very few scholars to examine Muslim
social organization in Ladakh, conducted long-term fieldwork in the primarily
Muslim Suru valley in the Kargil District of Ladakh. This area is mostly Shia with
some pockets of Sunni populations. According to her informants, though
landholdings of households are smaller than in the Leh district there are no
households which do not own land. The typical household consists of several
brothers, each with a wife and children. They do not separate the household until
their children start to marry and grandparents are deceased. Unlike Ladakhi
Buddhists in the Leh District, the elderly parents stay in the main house. Grist
(1993) notes that the house is not as important for identity and ritual as in the Leh
district.

**Marriage and Inheritance**

There are very few ethnographic studies of Ladakh which fully explore family
structure and social organization. Most work was done after Ladakh became part of
India in 1947, though there are two early works of note. S.H. Ribbach (1986) wrote
an account of family life in Ladakh based on his experiences living there from the
late 1800s through the early 1900s. As part of an extensive study of polyandry in
1938 H.R.H. Prince Peter of Greece and Denmark (1963) investigated family
structures in Ladakh. Generally, literature on these topics contains discrepancies, making it difficult to know for certain the details of family structure and social organization in various parts of Ladakh over time.

When Ladakh became part of India, polyandry and traditional inheritance by primogeniture were made illegal. Land reforms reduced the power of some larger landholders, and many types of taxes were also made illegal (Goldstein and Tsarong 1985; Rizvi 1998; Srinivas 1994). Rizvi (1998) notes that polyandry slowly decreased after this, remaining mainly in the Zangskar region and other remote villages, but that a system of primogeniture remained common among most Buddhists. Melvyn Goldstein and Paljor Tsarong (1985) point out that as younger brothers began demanding inheritance, and the polyandrous family structure fell apart, the fragmentation of land, assets, and families which had been avoided through history was inevitable. With the increased presence of the Indian government and tourist economy there are opportunities for generating income outside the household, and according to Goldstein and Tsarong (1985) most of the split off (khang-bu) families have someone who works for wages.

Muslims never engaged in polyandry and have continually fragmented their land. Most Muslim males married, which was made possible by the excess of unmarried Buddhist females. Muslims had small holdings to begin with and have always relied on the non-domestic economic sector. They also had much higher rates of population growth. The contemporary Buddhist situation is becoming increasingly like that of the Muslims, fragmentation of land, increased reliance on generating income, and rapid population growth (Goldstein and Tsarong 1985).
Notably, though Muslims divide assets between all children, there is no indication that land holdings have decreased to the extent that they cannot be worked for economic stability (Rizvi 1998).

In the Suru valley, Grist (1993) found that Shia girls marry young, often to an older male. Unlike in Buddhist families the groom’s family pays a bridewealth. Marriages are arranged, and the female typically moves to the home of her husband, except in families where there are no brothers and a husband moves in. Marriage to relatives is common, though more frequent among the Sunnis, with marriage to first cousins being most typical and marriage to a relative of a different generation also being common. Grist (1993) notes a high rate of divorce, which means marriages often do not become permanent until much time has passed, additionally there is evidence of extra-marital relations. Though little research has been done in the Leh district, findings from this study are consistent with the patterns Grist found in the Kargil district.
CHAPTER 4: HEALTH AND DISABILITY IN LADAKH

To begin to understand disability experiences in Ladakh it is necessary to explore the health care system in which that experience occurs. Pluralistic notions of causality, the health care system, and health seeking patterns shape not only health and illness experiences in Ladakh but also disability experiences. The complexity of the interplay between culture, religion, and health in contemporary Ladakh is largely influenced by Tibetan medicine. Though some foundational knowledge can come from literature, in both the case of religion and health practices, local realities and meanings can only be discovered by seeing them first hand in Ladakh.

Practitioners of Tibetan medicine and its philosophies are called *amchis*. The theoretical foundations of the *amchi* system have a syncretistic history, the specific influences of which are still debated today. Most often Tibetan medicine refers to the text-based medical system introduced in Tibet from India around the 12th century (Adams 2001). The foundational text of the *amchi* system is the *Gyu-zhi* or “The Four Tantras”. The work combines aspects of Ayurveda with Indian Buddhist thought. Once this text reached Tibet it continued to evolve with supplements and commentaries added by many famous Tibetan physicians.

The spiritual core of Tibetan medicine is derived from both pre-Buddhist folk theories and Buddhist ideology. A central idea is that the cosmos is manifested in the body, and illness can be the result of an imbalance of body humors or a disharmony in the cosmos itself. Also at the core of Tibetan medicine is the Buddha’s teaching of the “Four Noble Truths”. The first truth is that of suffering
caused by knowledge of the impermanence of life. Second, craving is the cause of suffering. Third is the truth of the end of suffering, or the end of craving for existence, detachment from the ego. Fourth is the truth of the eightfold path, the path to the end of suffering – the ultimate goal. Illness and suffering are rooted in the mind and can facilitate the development of compassion and motivate one on the path toward enlightenment (Clifford 1990). Thus, Terry Clifford (1990) divides the practice of Tibetan medicine into three categories: Dharmic or religious medicine which heals the mind and emotions with medicine, prayer, and other religious practice; tantric or yogic medicine which addresses connections between the mental and physical; and somatic medicine based on the Indian Ayurvedic system.

The health care systems of the Tibetan culture area have undergone change along with shifting political and economic atmospheres. These pluralistic systems differ by region and include elements of Tibetan medicine, folk medicine and shamanism, Buddhist and Muslim ritual, and biomedicine. However, in both practice and utilization aspects of these health care systems have overlapping theories and philosophies formed by the cultures in which they exist.

Following a discussion of the health care system in Ladakh, this chapter will provide an overview of services and programs available to Ladakhis with disabilities at the time of this study. The chapter concludes by presenting available disability data from Ladakh, including the challenges associated with defining and categorizing disability in this setting.
Health Care System in Ladakh

The health care system of Ladakh and Tibet, though sharing historical similarities, differ from one another with regards to both local ideas about causality and healing practices available to the population. In his research in Tibet, Craig Janes (1995) describes how the nature of sickness is constructed with both social and individualist ideologies. For lay people notions of causality “mix notions of mind management, appropriate social behavior of self and others, pollution or defilement, the actions of deities and demonic misfortune, misfortune or bad luck, strong or ‘poisonous’ emotion, diet and weather” (Janes 1995:11). Takako Yamada on the other hand notes that Ladakhis think of illness in terms of “a bodily dysfunction not only as a pathological phenomenon, but also as a phenomenon caused by a certain supernatural being or by an astrological disorder” (1999:1). Tsering Norboo and Tsering Morup explain that in "ancient Ladakh health was considered an ecological relationship between man and man; man and nature; and between man and the supernatural world" (1997:205). Martin Mills (2003) outlines the diversity of “explanatory models for misfortune” identified during his research in Lingshed, Ladakh. First, karmic retribution stems from negative acts on the part of an individual (typically) in this or a previous life. Second, often a communal issue, are problems due to ritual pollution. Third, spirit attacks can be attributed to “water spirits that have been polluted by the victim, . . . the return of deceased spirits or the attack of malevolent neighbours manifesting themselves as possessing spirits” (Mills 2003:173). Fourth an imbalance within the humoral system may causes
illness. Finally illness can be attributed to a deteriorating life-force in an individual. Often several causes are attributed to a particular illness or misfortune.

This multi-causality means that various health and religious specialists may be consulted for treatment of illness, including: *amchi*, shamans, astrologers, monks and *akhon*. They are called upon to cure illnesses associated with their specialties. Four areas of the pluralistic health care system of Ladakh are explored here: the *amchi* system, shamanism or healing related to folk religion, the role of monks, and the influence and role of biomedicine. Unfortunately, other than through brief mention of their presence in Ladakh, no literature details the role or practices of Muslim healers. This is clearly an area for further inquiry, since most Muslims in this study did seek the advice of an *akhon* for illness or disability related matters.

**Amchi System**

One becomes an *amchi* through apprenticeship, usually starting in boyhood learning to read and write Tibetan, memorizing the four volumes of the *Gyu-zhi*, learning to diagnosis illness, make medicines, and identify and collect herbs. Textbooks are passed down in a family, as the position of *amchi* is often hereditary (Yamada 1999). Illness is usually treated by taking medicines and giving advice on restraints of food and daily life. *Amchis* also make use of other treatments including: bleeding, mineral mixtures, hot spring bathing, several kinds of cautery (including moxabustion, iron burning, silver burning, copper burning and gold burning), and prayer (Navchoo and Buth 1989; Norboo and Morup 1997; Yamada 1999). *Amchi*

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13 An *akhon* is a Muslim religious leader who practices both traditional Ladakhi (*amchi*) medicine and Muslim rituals.
training also emphasizes astrology. In addition to becoming astrologers, they must “attain a certain degree of spiritual development to enable them to administer medicine accompanied by tantric rituals” (Norboo and Morup 1997:206).

Combinations of treatments are often recommended, thus it is difficult to distinguish any physical effects of the herbs from psychological effects of the accompanying rituals (Navchoo and Buth 1989). Since the mid-1980s there have been efforts to revitalize the *amchi* system in Ladakh, which fell into decline when *amchis* were no longer able to go to Lhasa to receive advanced training.\(^{14}\)

In the context of this study, it was also difficult to determine what illnesses and disabilities may actually have been the result of *amchi* practices. Infections, loss of sensation, diminished use of a part of the body, and even hospitalizations were frequently described as occurring following burning treatments from an *amchi*. During one *amchi* healing session observed during this research the *amchi* gave the patient advice, and performed a combination of cupping and acupuncture. After the patient left, the *amchi* assured the researcher, who was relieved to be indoors after waiting for some time in the hot summer sun, that there was no need to sterilize their prized gold acupuncture needles since Ladakh is a “frozen place”. It was well over 80 degrees Fahrenheit outside with no possibility of anything freezing in the near future.

Yamada (1999), noting that there was a recognized practicing *amchi* in every large village, estimates that during his visit in 1988 there were approximately 70

\(^{14}\) For further exploration of the status of Tibetan medicine in Tibet and its role other parts of the world see Janes (1995; 1999a; 1999b), Adams (2001) and selections from Adams, Schrempf and Craig (2011).
amchi. While most amchis are Buddhist, they are trusted and utilized by people of other religions (Navchoo and Buth 1989). Nawang Tsering Shakspo (1995) notes that in the village of Khuksho there is a Muslim religious leader who, in addition to performing Shia rituals, also practices amchi medicine. During this research, many participants described practices of the local akhon that include aspects of amchi medicine. Today, through efforts of Ladakh Nuns Association (LNA), partially funded by a Swiss company, there are ongoing efforts to train nuns as amchis, along with generally supporting traditions of both nuns and amchis in Ladakh more generally. Generally, amchi medicine represents the more somatic side of the health care system and is the branch preferred for certain types of symptoms. However, given the often multi-causal explanations of illness and injuries of Ladakhis, there is much more to the system. In cases of serious illness an astrologer is consulted, and religious rituals and exorcisms are necessary for illness caused by evil spirits.

**Folk Religion and Shamanism**

In Ladakh shamanic healers called lha-pa (male) and lha-mo (female), which means 'divine person' or 'god person', are commonly consulted regarding health or social problems. Spirit possession causing an abnormal psychic state is usually considered an illness needing cure, but it can also indicate a calling to be a shaman. Shamans have social functions that include curing disease, divination, finding the lost, and exorcising evil (Yamada 1999). According to Frank Kressing (2003), it is an occupation many enter reluctantly. Ladakhi shamans have to be approved by a high ranking monk, preferably a rinpoche,\(^\text{15}\) thus subjugating folk religion to the

\(^{15}\) A rinpoche is a high ranking reincarnate Tibetan Buddhist, most often also a monk.
authority of the Buddhist establishment (Kressing 2003). Apprenticeship may be with a qualified monk, involving training “to harness the spirit-force and transform it into the power to heal” (Rizvi 1998:177). Shamans deal primarily with illness or social imbalances attributed to *lha*, or minor gods. *Lha*, an indigenous religious concept, are generally concerned more with the material matters of everyday life than the spiritual matters addressed by religion. They are given offerings by villagers and monks, and are the subject of purification rites often performed by monks for the well-being of the village or household. There are also evil spirits which can harm villagers, and nature gods which need to be treated well or they may cause damage or illness. As with *amchis*, it is not only Buddhists who consult shamans.

Village oracles whose practice is generally oriented towards individuals are different from monastic oracles, who tend to serve the whole community and have more prestige. Diagnosis of illness is made through measuring pulses, palpation of body parts, or through divination using a small drum called a *damaru*. Therapy includes sucking disease causing substances from the ill person’s body. Oracles also treat mental illness which may be caused by malevolent spirits. Some perform divination, offer advice, and mend community relations (Kressing 2003). During treatments and divination the oracle enters a trance, during which they are possessed by a deity or deities (*lha*). The ritual of inducing trance includes inviting *lha*, making offerings of barley, rice, water or *chang* (a fermented barley drink), beating a drum, and wearing a ritual costume. There are several similarities between the practices of the shamans and Buddhist ritual practices, including
components of costume and use of ritual implements such as the bell and *dorje* ("lightning bolt", it is a type of ritual dagger), further demonstrating the close connection between shamanism and Buddhism in the Tibetan culture area. Additionally, oracles often maintain a relationship with other aspects of the health care system and may recommend seeking monastic rituals or visiting an *amchi* (Mills 2003).

Astrologists, or *onpo*, are another category of religious specialist. They often divine by “performing *mo* (a divination using grains), or by comparing the age of a patient and the date when he fell ill according to astrology. If the karma of a patient is proved to be the root cause then the *om-po* performs rituals or suggests that the patient may perform rituals” (Yamada 1999:8). *Onpos* may perform rites to remove obstacles or avert harm from demons and are called on specifically for rites that are outside the realm of orthodox monastic practice (Mills 2003).

**Role of Monks**

At the community and household level monastic oracles, as mentioned above, may be called upon to perform purification rituals or to pacify the *lha*. As intermediaries between the spirit and physical world and in their role as astrologers “they are able to give authoritative advice as to the propitious time and manner for starting any enterprise, whether sowing or reaping, going on a journey or celebrating a marriage” (Rizvi 1998:137). Mills explored the role of the monastic sector in the village health care system, describing two dimensions of this role: first, “it represented one important part of the health-seeking strategies open to the sick and those suffering from misfortune, through the provision of relatively
standardized rituals, purifications and recitations”; and second “it represented—like astrology—an indispensable cornerstone of interpretative authority within the health care system as a whole” (Mills 2003:172).

Western Biomedicine

Though the traditional health care system in Ladakh has dealt with many common ailments for a long time, the introduction of new concepts from Western medicine have shifted ideas about causality and the means chosen to deal with these ailments. The Moravian missionaries of the 19th century were likely the first to introduce Western medicine to Ladakh (Norboo and Morup 1997). Today, biomedical treatments and facilities are increasingly used by Ladakhis (Rizvi 1998; Wiley 2004). The first biomedical hospital in Leh, The Sonam Norboo Memorial Hospital (SNM), was established in 1980 (Wiley 2004). This hospital is staffed by a limited number of physicians and other health professionals and has limited treatment capabilities.16 There is also an Army General Hospital located in Leh which serves those in the military and their families. Throughout the Leh district there are Primary Health Centers, dispensaries, and medical aid centers. These centers are often poorly run and inaccessible (Wiley 2004), and those encountered during village visits during this study never seemed to be open. Some of the help from NGOs toward meeting health needs in Ladakh are summarized by Stanzin Tondup (1997). The biomedicine-based health care options present in Ladakh,

16 During this study a local physician returned from psychiatry training outside of Ladakh and thus became the first psychiatrist to be stationed in Leh. His services were not yet being publicized and local disability organizations were struggling to coordinate a meeting to begin to understand what services he may be able to provide those with suspected mental illnesses in Ladakh.
either domestic or foreign in origin, are extensive and ever changing. It would be impossible to give an accurate overview of current organizations and services here.

**Programs and Services for People with Disability in Ladakh**

During fieldwork there were a variety of programs and services for people with disabilities. This section provides a brief overview. Overall, the most desired “service” mentioned by study participants was education. This can mean anything from therapeutic play to attending a regular school. In Leh and the surrounding villages there are several options for children with disabilities. At the time of this study there was an NGO therapy center for children, a government run school, an NGO run school, a school for the blind, and placement in regular schools. Each faced its own challenges and was extremely limited in the numbers and types of children it could serve. Once one reaches the late teens there are almost no options for therapy or education since many foreign NGOs prefer to focus on children. Even local NGOs feel that they can have the most impact with children; once one reaches adulthood he or she has either already adapted or have forever missed the chance to do so.

REWASociety is a physiotherapy center for disabled children initially founded by the German NGO Ladakh Hilfe. During the period of fieldwork for this study they had a therapy center in Leh where small groups of children, assisted by a family member, came twice a week for therapy and therapeutic play. REWA staff also did therapy home visits for those unable to come to the center, therapy in schools, and annual trips to more remote villages to provide services. At the time of this research REWA was funded and equipped entirely through foreign donations.
organized by Ladakh Hilfe, with the exception of one local donor, but was beginning to seek more funding from local sources. REWA was contemplating providing some paid therapy services for adults with disability to help raise money for the free services they provide for children.

Munsel School, founded and supported by a Swiss foundation, provided special education for a small but growing number of students with severe mental retardation during the period of fieldwork for this study. They picked children up from their homes to attend school in age appropriate groups a couple times each week. Some children with disability in Ladakh had found placements in regular schools but their retention and attendance rates were not consistent since the availability of special educators is always in flux. During this study the Mahaboudi International Meditation Centre had a hostel and school for blind children who came from several parts of India. They also had an old age home for elderly people who are still able to take care of themselves but need a more accessible living environment. Some younger disabled Ladakhis lived in this facility. Both of the programs were very small and limited in the number of people they could serve.

During fieldwork there were several government programs, including a government run hostel for people with disability. A small number of students with disabilities lived there, though they could not support those with severe disabilities. Special educators and therapists were scheduled to make regular visits to the hostel, though in reality this was very sporadic. The Social Welfare Department is responsible for pensions for people with disability who are also poor. There are a limited number of pensions available and those in far-flung areas are not necessarily
aware of the program or able to meet some of the requirements of the program, such as having an active bank account. Ladakh public schools are supposed to have special educators and accessible buildings. These government regulations are fairly new and are not being widely enforced. Similarly, newly constructed buildings are supposed to be accessible with ramps and government buildings are to be constructing ramps but this is also not being enforced.

People’s Action Group for Inclusion and Rights (PAGIR) is a local NGO, which at the time of this study was struggling to make ends meet financially and come up with new and innovative ways to raise money and expand their reach. PAGIR’s disability work consists primarily of advocacy, employment programs, and providing information, support, and guidance for people with disability with any issue from obtaining disability documentation to seeking health care to land disputes. During fieldwork for this study PAGIR had a membership of approximately 250 people with disability or their representatives from all over Ladakh. In addition, PAGIR has relationships with other disability oriented organizations, religious leaders, government offices, and many disabled people beyond their membership.

PAGIR is the main creative enterprise trying to find ways for people with disabilities to earn an income – if they display the desire and commitment to do so. Along with emphasizing helping people with disabilities and poor women, PAGIR focuses on environmental issues. It creates income-earning opportunities for people with disability through turning what would otherwise be waste into craft. One of the more common options for people in remote areas, or who are
homebound, is making paper bags. This not only recycles newspaper, it augments the plastic bag ban in Ladakh. Other crafts are made from cloth waste from tailors. PAGIR provides opportunities for training in various other handicraft type jobs, such as knitting or tailoring, and even works on job placement for those able to work in a shop for example and assists people with obtaining government jobs.

Though PAGIR’s resources and reach are limited, its impact is much more broadly significant for those involved. PAGIR provides a social network, a purpose to the day, a place to seek support or assistance, and awareness to friends, family, and perhaps most importantly the public. It does much more than those working at PAGIR may even realize. Though most people in this study, whether a person with a disability, a family member, or other specialist, did not know much about available programs and services for people with disability in Ladakh, most were aware of the people who run PAGIR, that the people at PAGIR know these things, so they do not have to. Though this puts an extraordinary burden on PAGIR, it speaks to the need for its efforts. Gladly PAGIR has been able to continue to grow and expand their reach since field work for this study concluded.

Disability in Ladakh

Preliminary fieldwork was conducted in Ladakh during the summer of 2004.17 The researcher observed daily life of Ladakhis, visited potential field sites, and developed rapport in the disability community by volunteering at the Namgyal Institute for People with Disability (NIPWD).18 At that time, the NIPWD was the

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17 This fieldwork was funded by an Eva L. Pancoast Memorial fellowship.
18 The Namgyal Institute for People with Disability is a former branch of the Namgyal Institute for Research on Ladakhi Art and Culture.
primary local organization focusing on disability issues in Ladakh. It had strong governmental support and close relationships with other NGOs. Its work was aimed at inclusion of people with disability in education, employment, and community social life. This early fieldwork experience was invaluable in beginning to understand disability in Ladakh. Gaining insight into both the daily struggles of families dealing with disability and the work of a disability-oriented organization was crucial to developing the study design for this research.

Estimating the number of people with disability in Ladakh is a formidable task. In the early 2000s the NIPWD conducted a disability census of the Leh district of Ladakh. Efforts to count and identify people with disability in Ladakh are still underway, conducted village by village, by different organizations with different goals and areas of interest. For example, when an organization went to Ladakh to help children with disability it only counted children. Similarly a group that went to provide eye care only noted those cases relevant to its specialty. Most counts come from groups who have gone to areas with the purpose of providing aid and thus only those who could be helped or who could benefit in some way from a return visit were noted in surveys. Several populations may be overlooked in such surveys, such as those over a certain age who are already coping with their disability, the elderly, those who never leave their home (and do not come out to be counted), those with unrecognized mental or psychological impairments, and those who may not consider themselves disabled. That being said, the NIPWD survey, currently being supplemented by PAGIR, is the most comprehensive dataset available at this time. It is a starting point for understanding the scope of disability in Ladakh.
As of 2009 this dataset indicated an estimated 725 people with disability in the Leh district of Ladakh.\textsuperscript{19} This survey did not include people over the age of 50, nor did it include people with mental illness. Resources have not been available to collect data in the Kargil district. PAGIR has added to this list but their data still falls short of census numbers they have received from the government, which may have included a broader range of disabilities, estimating 2.5 percent of the population is disabled. Given worldwide estimates of disability of approximately 15 to 20 percent of any given population (WHO 2011) both are extremely low estimates, which can be due to many of the reasons noted above. Standardized disability types or categories were either inconsistently used or not used at all. Either a person fit a standard category – such as polio, kyphosis, cerebral palsy (CP), or multi-disability – or they did not and a descriptive was used on a case-by-case basis – such as “short tongue”, or “no hole in ear”. People would often tell this researcher about someone with a disability they knew, providing the name, village, and disability description. When cross-checked with the database, oftentimes the individual was not listed. It is not known what percentage of the region’s population of people with disability is represented in this database, but it is the researcher’s estimate that it is significantly less than half.

Causes of disability in Ladakh include accidents, birth injury, illness (including those for which vaccinations are available such as polio, measles, and mumps), genetic causes, and factors associated with the availability of health care

\textsuperscript{19} It is important to note that this information has not been broadly disseminated. Permission to use the data was obtained in 2004 at the NIPWD and updates were provided in 2008-2009 by PAGIR and supplemented by the researcher.
services. Maternal and infant morbidity are not tracked (Gutschow 2011), though likely occur at high rates. These factors complicate understanding disability in Ladakh. Since diagnoses of impairments and illnesses are rare, disability is often classified in the most general of terms. “Hearing”, “speech”, “orthopedic”, and “one-sided-effect” are examples of common classifications. “Cerebral palsy” or “spastic” are commonly used to label any severely disabled children. Pluralistic explanations of causality are common: karma in combination with either an illness or accident, spirits in the natural landscape, environmental factors, or nutrition are frequently noted. Similarly, people with an impairment seek advice or treatment from every available source within the pluralistic Ladakhi health care system. Decisions about which advice to take are often made by consulting more experts, for example asking a rinpoche whether or not they should follow the advice of the physician. The complexity and diversity of disability experiences in Ladakh mirror that of life in general in Ladakh.

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20 Vital statistics, including births and deaths, are not consistently tracked in many parts of India. It is estimated that 50-80 percent are reported in the state of Jammu and Kashmir, and may not be accompanied by associated sex data (Government of India 2013). Generally speaking, reliable morbidity and mortality data are not available for Ladakh.
CHAPTER 5: RESEARCH DESIGN AND METHODOLOGY – THE FIELDWORK

The objective of the study was to examine the subjective experience of disability, focusing on the interaction between the physical and social domains of experience and how they are shaped by local cultural constructions of disability. To achieve this aim, the specific objectives were to:

(1) ascertain local definitions of and attitudes toward disability in Ladakh;
(2) to identify the distinct challenges the physical environment of Ladakh poses to people with disabilities; and
(3) determine the influence of religion (namely Buddhism and Islam) on how disability is experienced and managed.

Study Design

The study design incorporated three components: a study of a disability oriented NGO, a village study, a study of disability experience in the broader community.21 In each component three types of people were recruited to participate: people with disability, people who have a family member with a disability, and professionals with insight into disability experiences in Ladakh. Naturally, a single participant could fit into more than one participant type, that is he or she could be a person with a disability as well as a professional such as an employee at a health related NGO. Each study component was designed to address all three specific objectives. This study design allowed the overall objective of the study to be approached from three distinct directions.

The NGO study was designed to get an in-depth look at how an organization defines disability, how definitions and attitudes shape experience with regard to

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21 Broader community was chosen as a phrase to describe this study component which included participants selected to obtain a broad representation of the population of Ladakh as a whole. This study component includes participants from all over Ladakh.
available resources and services, and the various needs addressed by the organization or expressed to the organization by individuals. The NGO study complements the village and broader community studies by providing possible explanations for experiences those individuals may describe.

The village study was designed to include households with a disabled member as the unit of analysis. Fieldwork in a rural, village-based setting would inform analysis of the physical environment as well as Ladakhi norms and customs as experienced in a traditional setting. Additionally, the village study component was designed to foster observation of and discussion of: (1) what is considered a disability in Ladakh; (2) attitudes people have about disability within a community setting; and (3) interactions with or adaptations to the physical environment in and around people’s homes. The selected village was specifically chosen because it is Buddhist and Muslim, thus representing the overall population of Ladakhi and allowing comparison based only on religion that allow for many other variables to be controlled for.

The broader community study was designed to complement the village study by broadening the range of living conditions under consideration, including for example Ladakhis from rural and urban areas, richer versus poorer areas, and those living in more far-flung or nomadic areas. This study component further ensured inclusion of the religious diversity representative of the population of Ladakh and allowed for a broader representation of disability types in order to account for what may be disability type-specific views and experiences.
Professionals recruited within the three components included educators, religious specialists, NGO staff, and health care providers. Professionals were able to provide specialized information about very important aspects of Ladakhi culture and daily life pertaining to education, religion, health care, employment, as well as gain knowledge about disability activism in Ladakh. Additionally, including their perspective made it possible to explore variability in attitudes among those in professions that would likely provide services desired by people with disabilities, as well as any differences in viewpoints between those representing these institutions and those experiencing disability.

**Fieldwork Procedures**

This study of disability used a mixed methods approach relying most heavily upon participant observation, informal interviews, and semi-structured interviews. Participants were selected through variations of purposive sampling described in detail below.²²

**Research Assistants**

A research assistant was expected to serve as a translator, language tutor, and general research assistant. Based on experience and consultation with Ladakhis, it was determined that a Ladakhi Buddhist female would be necessary for this position, in part since the researcher was female. As indicated earlier tensions, differences of opinion, suspicions about motivations, and stereotyping exist among the various ethnic and religious groups. At the time of this study Ladakhi Buddhists

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²² Purposive sampling, also referred to as strategic purposive or judgmental sampling, allows the researcher to determine which participants would be representative of the sample needed to meet the research aims (Babbie 2001; Bernard 2002).
seemed to be generally more broadly accepted by those in other groups than
Tibetan refugees or Muslims. Additionally, given the varied terrain and schedule it
was essential that the assistant was a non-disabled female. That being said,
accomplishing the seemingly simple task of hiring a suitable research assistant
proved to be a long-term challenge to the conduct of this research.23

Consent Process

This study was reviewed and approved by the CWRU Institutional Review
Board (IRB). All research assistants were trained by the researcher to comply with
human subjects guidelines. All participants provided written informed consent,
either directly or via their caregiver. Written consent took the form of either a
signature or thumbprint. Separate consent questions were asked for permission to
record interviews and to take photographs. Signed consent for permission to
publish photographs was collected separately. A small number of Muslim
participants refused consent for publishing their photographs. This refusal seemed
to be rooted in the possibility that any piece of paper or page from a book could
potentially end up being used as toilet paper. See Appendix A for an overview of the
consent results and the consent forms.

23 One research assistant was educated outside of Ladakh. Her education was conducted in
English and Hindi. Though her English was very good her Ladakhi was rusty, particularly
regarding her ability to pick up on different Ladakhi dialects. Many Ladakhis educated
outside of Ladakh had the habit of mixing Hindi and English, which at times presented
challenges for the researcher. Another research assistant was offered a permanent
government job as a teacher in a remote village shortly after being hired. The researcher
was very supportive of her taking this highly sought after position. The English skills of
another research assistant were insufficient for the complex nature of the interviews. The
fourth research assistant accompanied the researcher during all semi-structured interviews
conducted for this study, all of which took place during later stages of fieldwork.
A total of 89 participants were consented into the study. Depending on their level of participation in the study all individuals, households, and the NGO received gifts upon the conclusion of their period of participation. Individuals participating in a single interview received a re-usable cloth bag, cookies, and pot-holders or a file-folder as appropriate for the individual. Individuals who participated in the study on a more long-term basis received some of the above items and more personalized gifts, for example, a seat-cushion, head scarf, stocking cap, or earrings. Households received additional food gifts including items like canned fruits and tea. The NGO was given gifts of needed supplies periodically throughout the study period.

**Participant Observation**

Participant observation was a key component of the study design for all study components. Throughout the duration of fieldwork, regardless of setting, observations of the management of and attitudes toward disability in households and the community readily informed all three study objectives. Observations focused on:

(1) the types and level of social interaction disabled individuals have;
(2) the roles of both disabled and non-disabled individuals within households and the community;
(3) participation of disabled and non-disabled individuals in activities such as health care seeking, religious activities, education, and employment; and
(4) daily routines of Ladakhis and features of the physical environment that could make those routines particularly challenging.

While not a formal component of the study design, experiencing life in Ladakh was an important means of acquiring supplementary data. Negotiating the physical environment, norms, and customs, and observing Ladakhis going about
their daily routines not only highlighted the physical aspects of a typical day in Ladakh for the researcher, but also facilitated data collection through informal conversation, photography and video, and attendance at public events.

**Interview Procedures**

Since semi-structured interviews were conducted with participants from all study components, the procedures for this more formal interview are outlined here. Seventy-three semi-structured interviews were conducted with a total of 72 people.²⁴ As previously mentioned, some participants fit into more than one category of participant type. For example, a person may have been interviewed as both a religious specialist and a family member of a person with a disability; or as a person with disability and an educator. To allow for such cases the semi-structured interview included a standard line of questions that were conducted with all participants, and sub-instruments specific to each type of participant. Every applicable sub-instrument was used for each interview. In some cases individuals were interviewed on multiple occasions in order to complete sub-instruments or for the purposes of follow-up interviews.

All semi-structured interviews were scheduled at the convenience of the participants in a location of their choice. In some instances interviews were conducted in English, or in a mix of English and Ladakhi. The research assistant was present to help with wording, particularly of the interview questions, even if the

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²⁴ In three instances two or three people were interviewed as a group. Two individuals were interviewed multiple times. Seventeen consented individuals did not complete a semi-structured interview, including five who did not due to their disability and one infant.
participant chose to answer in English. Interviews lasted from 10 minutes to 1 hour 42 minutes. The average length of a single interview was 47 minutes.

**Standard Interview Instrument**

The standardized portion of these interviews consisted of questions about basic demographics, such as age and level of education; typical daily activities, such as what they do when they wake up and who they share meals with; and health, such as whether they consider themselves healthy or have had any serious illnesses or accidents. At the end of the interview, after any relevant sub-instrument questions, participants were asked a series of questions about religion, such as questions about their own religious practices; disability experiences, such as whether they think people with disabilities can do all the same things as other Ladakhis; and life in Ladakh, such as whether Ladakh is an easy or hard place to live.

These interviews were designed to address all three study objectives through a mix of informal indirect and formal direct questions. Full interview instruments can be found in Appendix B. Each semi-structured interview was adapted to the individual and adjusted during the interview as needed.

**Interview Sub-Instruments**

Sub-instruments were included for: (1) a person with a disability; (2) an adaptation for interviews with a family member or caregiver; (3) and professionals with variations based on whether the participant’s professional role was in an NGO, education, government, or as a religious specialist. The disability sub-instruments consisted of questions such as the history of the disability, health care or religious services sought, and whether the disability has affected opportunities or
relationships. The sub-instrument for professionals working in an NGO, education, or government role consisted of questions such as the structure and services their organization or institution provides and their organizations’ successes and challenges. The sub-instrument for religious specialists included questions such as whether they give advice to people with disability or their family members, and what types of things a rinpoche or akhon might do for a person with disability or for someone who is ill.

**Fieldwork Timeline**

Fieldwork took place over a period of twelve months in Ladakh from August of 2008 through August of 2009. Table 2 depicts a timeline of the various study activities. The overlapping study components started at different points during fieldwork but all continued until the end of the research period.

<table>
<thead>
<tr>
<th>Date Range</th>
<th>Arrive</th>
<th>PAGIR</th>
<th>Village</th>
<th>Broader community</th>
<th>Depart</th>
</tr>
</thead>
<tbody>
<tr>
<td>8/08</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9/08</td>
<td></td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>10/08</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>11/08</td>
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<tr>
<td>12/08</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>1/09</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2/09</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3/09</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4/09</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>5/09</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6/09</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>07/09</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>08/09</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

25 The researcher first began visiting PAGIR regularly 9/4/08, received organization consent 10/14/08, and CWRU IRB approval 11/20/08.
Data Collection

The following section details data collection for each of the three study components: the NGO study, the village study, and the broader community study.

NGO Study

During the first month, a relationship was established with the Peoples Action Group for Inclusion and Rights (PAGIR), a local NGO that was the most active disability organization in Ladakh during the fieldwork period. PAGIR was selected for this study component due to its broad range of services, and because its mission was to serve all people experiencing disability throughout Ladakh. As the result of a falling out between NIPWD and its employees and board members, PAGIR was formed in 2007.26 All those with whom previous relationships were made at NIPWD were now associated with PAGIR. Arrangements were made to begin visiting PAGIR and start the process of securing permission to have PAGIR as a primary research site for this study. Ultimately permission was secured from the President of PAGIR in consultation with board members and approved by the CWRU IRB.

PAGIR’s network of members and relationships with other disability oriented organizations, religious leaders, government offices, and many disabled people

26 This falling out was the result of a much larger conflict between NGOs and local government in Ladakh. The details will not be discussed here. However, though NIPWD was still operational in an extremely limited capacity, and they were willing to participate in this project, the researcher felt that it was inappropriate to include this organization. Since there were ongoing disputes and hard feelings between staff at NIPWD and those who had left to form PAGIR, the researcher would have been in an awkward position detrimental to developing rapport within either organization. Similarly, members of the disability community seemed to have primarily “taken the side” of PAGIR, not wanting to talk with the researcher if they heard of the researcher’s previous association with NIPWD. For these reasons, NIPWD and an associated school were excluded from this research.
beyond their membership helped to expand the reach of this research. At the time of this study PAGIR was located in the southern part of Leh in a three room space at the back of a building with shops in the front and apartments above. One room was used for storage of waste products, such as newspapers, tailoring scraps or old schoolbooks, which would ultimately be used by PAGIR employees to make handicrafts. Another room served as a work space for making the crafts, and the third room was a main office and meeting area. PAGIR was about a 30 minute walk from what could be considered Leh’s main business district. The researcher frequently walked to PAGIR along with one or more of its employees. Throughout the duration of fieldwork extensive participant observation was conducted at PAGIR, as were interviews with staff and board members. Participant observation at PAGIR included activities such as meetings with people seeking assistance from PAGIR, running errands, observing activities associated with the work program, or attending PAGIR events.

A total of 15 people associated with PAGIR – either as employees, board members, or those active in PAGIR’s work program – were consented as study participants. Of those 14 completed at least one interview, one did not because of her disability. Six participants completed more than one interview sub.instrument. Table 3 summarizes interview instrument types completed at PAGIR.

<table>
<thead>
<tr>
<th>Table 3: Interview instruments completed at the NGO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number Completed</td>
</tr>
<tr>
<td>Person with disability 11</td>
</tr>
<tr>
<td>Family member of person with disability 3</td>
</tr>
<tr>
<td>Professional 6</td>
</tr>
<tr>
<td>Total 20</td>
</tr>
</tbody>
</table>
**Village Study**

Ringmo, the study village, was selected for its mix of Buddhists and Muslims living in the same environment, with similar access to resources and similar living conditions. Ringmo is a rural farming village of approximately 1,400 people that is 25 percent Muslim and 75 percent Buddhist. Muslims in the study village are all Shia, and the Buddhists belong to the Drigung Kargyud sect. Permissions and introductions in the study village began during October. The village component consisted of participant observation, household surveys, informal conversations, and semi-structured interviews within households that have a disabled family member. This continued until the end of the research period.

The study village was chosen based on experiences during preliminary fieldwork and a review of the updated disability database described previously. It was selected from a list of villages that were within one day of travel of the capital of Leh and had a mix of Buddhists and Muslims. Ringmo was just under an hour ride from the main bus stand in Leh. Accessing the homes of participants then required additional walking time of anywhere between five minutes and two hours. Buses were available three or four times each day.

During the first visit to the village, permission to conduct research was sought through discussions with village elders. The village *goba* granted permission and agreed to visit households which had a disabled member and briefly explain the study. The former *goba*, another village elder, and three monks were also consulted and agreed to spread the word about the study. It is noteworthy that none of them...
seemed to know of more than a few people with disability in the village. The *goba* had to be given a list of known people with disability in the village and he ultimately only went to the houses he could drive to.

The study design called for the inclusion of as many households as possible within the village that had a household member with a disability. Thus the disability database and contact information available from PAGIR was utilized as an initial sample frame. It was anticipated that more people with disabilities would be discovered throughout the study period or that some from the original list would no longer be living in the village. People with disabilities that were not part of the original sample frame were encountered through observations in the village and by talking with villagers about whether they knew anyone with a disability or who has difficulty with daily activities. The researcher continued to be made aware of people with disabilities in the village up until the last day of the study. Therefore, it was not only impossible to include every household in the study, but to even concretely determine how many households there were that had a member with a disability.

At the end of the study period it was estimated that the study village, which has a population of approximately 1,400 people, had at least 25 people with disability living in at least 24 different households. Estimated disability demographics for the study village are presented in Table 4. Though exact diagnoses are not possible, the range of disability types in the study village included: various manifestations of cerebral palsy (CP) symptoms from those severely or moderately disabled since birth to those with intellectual disability and one-sided physical symptoms; hearing impairments with or without associated developmental
delay or muteness; vision impairments including missing an eye, progressive blindness, day blindness, and night blindness; kyphosis\textsuperscript{27}; paralysis; orthopedic disabilities of the limbs; and progressive disabilities related to mobility, vision, and hearing associated with aging.

**Table 4:** Estimated disability demographics for study village

<table>
<thead>
<tr>
<th>Disability Type</th>
<th>Buddhist (n=16)</th>
<th>Muslim (n=9)</th>
<th>Total (n=25)</th>
</tr>
</thead>
<tbody>
<tr>
<td>CP-low functioning</td>
<td>3</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>CP-high functioning</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Vision</td>
<td>2</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td>Hearing/speech</td>
<td>4</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Kyphosis</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Paralysis</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Other orthopedic</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Multiple-aging related</td>
<td>3</td>
<td>0</td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sex</th>
<th>Buddhist (n=16)</th>
<th>Muslim (n=9)</th>
<th>Total (n=25)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>10</td>
<td>4</td>
<td>14</td>
</tr>
<tr>
<td>Female</td>
<td>5</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Unknown</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Buddhist (n=16)</th>
<th>Muslim (n=9)</th>
<th>Total (n=25)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-20</td>
<td>4</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>21-40</td>
<td>3</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>41-60</td>
<td>6</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>61+</td>
<td>3</td>
<td>0</td>
<td>3</td>
</tr>
</tbody>
</table>

During the first visit to a household the study was explained to those present and a follow-up visit to complete the consent process was arranged. This process continued throughout the study period as new households were identified or meeting times were finally arranged. During the first couple of months visiting the village, the researcher walked from place to place greeting people as a way to get them used to seeing her around. This was also a good way to observe village life

\textsuperscript{27} Kyphosis is a curving of the spine. In Ladakh the presentation is often severe, with a hunchback posture, difficulty breathing, leg problems and other associated difficulties. It is possible that some cases represented here are the result of polio.
since a good portion takes place outside. This study component consisted of two phases: a household survey and interviews.

The household survey was typically conducted during the second visit to the household immediately after finishing the consent formalities. The basic survey consisted of questions about those who live there, other relatives in the village, the number and type of animals the household had, and whether they had land. Additionally, a few questions about the person’s disability were asked, primarily to learn what the disability was, whether there were multiple disabilities, and whether there were obvious disabilities that were not mentioned.

Interviews were conducted throughout the duration of the fieldwork during return visits to consented households. These visits were oftentimes just to check in and see if anything was new. When possible, semi-structured interviews were conducted with available household members. Unless the participant was home alone at the time of the interview it was nearly impossible to conduct the interview in private. The study was designed for as many household members as possible to be interviewed. This proved to be extremely difficult to accomplish since the researcher could never be certain who would be home during any particular visit. For each household consented at least one member was interviewed. In most instances the disabled person and another family member were interviewed. Interviewees were selected based on availability during frequent visits to households. Attempts to schedule visits with particular individuals often did not work out, on the other hand sometimes entire families would be awaiting the researcher at the scheduled time.
A total of 40 people from Ringmo were consented as study participants, including two participants who were religious specialists. Of those, 24 completed at least one interview. One participant completed more than one interview sub-instrument. Fourteen households who had a person with a disability (8 Buddhist, 6 Muslim) participated in this study. Table 5 summarizes interview instrument types completed in Ringmo.

**Table 5: Interview instruments completed in the village**

<table>
<thead>
<tr>
<th>Interview Type</th>
<th>Number completed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with disability</td>
<td>9</td>
</tr>
<tr>
<td>Family member of person with disability</td>
<td>14</td>
</tr>
<tr>
<td>Professional</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>25</strong></td>
</tr>
</tbody>
</table>

**Broader Community Study**

To obtain a more broadly representative sample of people with disability, family members, and professionals in Ladakh than was possible from the NGO and village studies alone, a small sample (n=34) of purposively selected participants were recruited from a variety of places around Ladakh. This was also intended to serve to provide a degree of control for findings from the NGO and village studies that may have been influenced by circumstances unique to those populations. The aim was to recruit participants from religious groups not represented in the village study and to get a broad range of disability types. Using purposive sampling, representative categories such as Sunni Muslim father of disabled child or homebound adult Buddhist female, were listed based on review of the data. To recruit participants that fit remaining unrepresented categories, the disability

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28 Four villagers were not interviewed due to their disability, 12 others were not interviewed using the semi-structured format.
database was used as the sample frame and lists of possible participants that fit the categories were created. The research assistant contacted individuals on the list until an interview was scheduled and conducted in each category.

Additional professionals were recruited following the same logic, for example to reach educators, health care workers, and a greater diversity of religious specialists. After several months in the field it was possible to determine a strategic purposive sample and make appointments with selected participants. First, a list of categories was created, including for example different types of religious leaders, amchi, or NGO directors. Lists of possible participants were generated. In some cases relationships had already been developed with these participants through working with PAGIR or by the researcher on her own. In consultation with key informants participants were selected to be contacted by the research assistant. Interviews were conducted in most categories by the end of fieldwork. The researcher took advantage of opportunities to interview professionals who were disabled, to explore for example whether an amchi or monk with a disability would have different views than those without.

Due to challenges associated with complying with IRB requirements from this remote setting, no institutions or organizations other than PAGIR were consented as a study site. It was still possible however to interview individual professionals outside of their workplace regarding disability in Ladakh. Interviews were conducted with all recruited professionals, either at their home or at PAGIR. In many instances it was also possible to arrange for a partial day of participant
observation at their place of work – either as part of a site visit being conducted by PAGIR, or at events that were open to the public.

A total of 34 people from the broader community were consented as study participants. Of those all 34 completed at least one interview. Six participants complete more than one interview sub-instrument. Table 6 summarizes interview instrument types completed as part of this study component.

**Table 6: Interview instruments completed with broader community**

<table>
<thead>
<tr>
<th>Type</th>
<th>Number completed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with disability</td>
<td>18</td>
</tr>
<tr>
<td>Family member of person with disability</td>
<td>7</td>
</tr>
<tr>
<td>Professional</td>
<td>15</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>41</strong></td>
</tr>
</tbody>
</table>

**Sample**

A total of 89 people were consented as study participants. Participants are defined as those who consented to participate in this study. Demographics were collected for all 89 participants. Seventy-two participants completed at least one semi-structured interview. Of those, 13 participants completed more than one interview sub-instrument. Table 7 provides an overall summary of interview instrument types completed as part of this study.

**Table 7: Interview instruments completed overall**

<table>
<thead>
<tr>
<th>Type</th>
<th>Number completed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with disability</td>
<td>38</td>
</tr>
<tr>
<td>Family member of person with disability</td>
<td>24</td>
</tr>
<tr>
<td>Professional</td>
<td>23</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>85</strong></td>
</tr>
</tbody>
</table>

The remaining 17 participants did not complete a semi-structured interview, but were involved in participant observation and informal interviews.
Overview of Participant Demographics

Demographic characteristics of the overall sample are represented in Table 8. Of the 89 study participants 43 had a disability themselves, 36 were family members of someone with a disability and 10 participants neither had a disability nor a family member with a disability.

Table 8: Participant demographics

<table>
<thead>
<tr>
<th>Disability status</th>
<th>Number (%) (N=89)</th>
<th>Level of education completed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabled</td>
<td>43 (48.3)</td>
<td>None</td>
</tr>
<tr>
<td>Family member</td>
<td>36 (40.5)</td>
<td>Current student</td>
</tr>
<tr>
<td>Not disabled, not family member</td>
<td>10 (11.2)</td>
<td>1st-5th class</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6th-9th class</td>
</tr>
<tr>
<td></td>
<td></td>
<td>10th class29</td>
</tr>
<tr>
<td></td>
<td></td>
<td>11th-12th class</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>39 (43.8)</td>
<td>BA-MA</td>
</tr>
<tr>
<td>Female</td>
<td>50 (56.2)</td>
<td>Monastic</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Unknown</td>
</tr>
<tr>
<td>Religion</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Buddhist</td>
<td>53 (59.5)</td>
<td></td>
</tr>
<tr>
<td>Muslim</td>
<td>32 (36.0)</td>
<td>Unemployed</td>
</tr>
<tr>
<td>Christian</td>
<td>4 (4.5)</td>
<td>Housewife</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Employed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Religious</td>
</tr>
<tr>
<td>Age range</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-20</td>
<td>14 (15.7)</td>
<td>Child or student</td>
</tr>
<tr>
<td>21-40</td>
<td>45 (50.6)</td>
<td>Elderly</td>
</tr>
<tr>
<td>41-60</td>
<td>17 (19.1)</td>
<td></td>
</tr>
<tr>
<td>61+</td>
<td>9 (10.1)</td>
<td>Completed interview</td>
</tr>
<tr>
<td>unknown</td>
<td>4 (4.5)</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>35 (39.3)</td>
<td></td>
</tr>
<tr>
<td>Unmarried</td>
<td>39 (43.8)</td>
<td></td>
</tr>
<tr>
<td>Child</td>
<td>12 (13.5)</td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>3 (3.4)</td>
<td></td>
</tr>
</tbody>
</table>

29 10th class is similar to finishing high school, but schooling to this level is not available in most villages. Exams are required to continue to 11th class or to enter college at this stage.
**Participants with Disability-Demographics**

Among those study participants with a disability (n=43), 60 percent were Buddhist, 35 percent were Muslim and 5 percent were Christian. Table 9 provides an overview of the demographics of the participant sample of people with disability. Table 10 broadly categorizes the range of disability types among participants with disability.

**Table 9: Participants with disability - demographics**

<table>
<thead>
<tr>
<th>Sex</th>
<th>Number (%)</th>
<th>Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>26 (60.5%)</td>
<td>11 (25.6%)</td>
</tr>
<tr>
<td>Female</td>
<td>17 (39.5%)</td>
<td>2 (4.7%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Religion</th>
<th>Number (%)</th>
<th>Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Buddhist</td>
<td>26 (60.5%)</td>
<td>4 (9.3%)</td>
</tr>
<tr>
<td>Muslim</td>
<td>15 (34.9%)</td>
<td>3 (7.0%)</td>
</tr>
<tr>
<td>Christian</td>
<td>2 (4.7%)</td>
<td>2 (4.7%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age range</th>
<th>Number (%)</th>
<th>Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-20</td>
<td>4 (9.3%)</td>
<td>1 (2.3%)</td>
</tr>
<tr>
<td>21-40</td>
<td>25 (58.1%)</td>
<td>9 (20.9%)</td>
</tr>
<tr>
<td>41-60</td>
<td>9 (20.9%)</td>
<td>3 (7.0%)</td>
</tr>
<tr>
<td>61+</td>
<td>3 (7.0%)</td>
<td>2 (4.7%)</td>
</tr>
<tr>
<td>unknown</td>
<td>2 (4.7%)</td>
<td>0 (0.0%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Marital status</th>
<th>Number (%)</th>
<th>Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>14 (32.5%)</td>
<td>2 (4.7%)</td>
</tr>
<tr>
<td>Unmarried</td>
<td>27 (62.8%)</td>
<td>3 (7.0%)</td>
</tr>
<tr>
<td>Child</td>
<td>2 (4.7%)</td>
<td>38 (88.4%)</td>
</tr>
<tr>
<td>Unknown</td>
<td>0 (0.0%)</td>
<td>5 (11.6%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Level of education completed</th>
<th>Number (%)</th>
<th>Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>1 (2.3%)</td>
<td>11 (25.6%)</td>
</tr>
<tr>
<td>Current student</td>
<td>1 (2.3%)</td>
<td>9 (20.9%)</td>
</tr>
<tr>
<td>1st-5th class</td>
<td>4 (9.3%)</td>
<td>9 (20.9%)</td>
</tr>
<tr>
<td>6th-9th class</td>
<td>10 (23.3%)</td>
<td>10 (23.3%)</td>
</tr>
<tr>
<td>10th class</td>
<td>4 (9.3%)</td>
<td>4 (9.3%)</td>
</tr>
<tr>
<td>11th-12th class</td>
<td>3 (7.0%)</td>
<td>3 (7.0%)</td>
</tr>
<tr>
<td>BA-MA</td>
<td>2 (4.7%)</td>
<td>2 (4.7%)</td>
</tr>
<tr>
<td>Monastic</td>
<td>2 (4.7%)</td>
<td>2 (4.7%)</td>
</tr>
<tr>
<td>Unknown</td>
<td>1 (2.3%)</td>
<td>1 (2.3%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Employment</th>
<th>Number (%)</th>
<th>Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unemployed</td>
<td>10 (23.2%)</td>
<td>10 (23.2%)</td>
</tr>
<tr>
<td>Housewife</td>
<td>4 (9.3%)</td>
<td>4 (9.3%)</td>
</tr>
<tr>
<td>Employed</td>
<td>22 (51.1%)</td>
<td>22 (51.1%)</td>
</tr>
<tr>
<td>Religious</td>
<td>2 (4.7%)</td>
<td>2 (4.7%)</td>
</tr>
<tr>
<td>Child or student</td>
<td>2 (4.7%)</td>
<td>2 (4.7%)</td>
</tr>
<tr>
<td>Elderly</td>
<td>3 (7.0%)</td>
<td>3 (7.0%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Completed interview</th>
<th>Number (%)</th>
<th>Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>38 (88.4%)</td>
<td>38 (88.4%)</td>
</tr>
<tr>
<td>No</td>
<td>5 (11.6%)</td>
<td>5 (11.6%)</td>
</tr>
</tbody>
</table>
Table 10: Participants with disability - disability types

<table>
<thead>
<tr>
<th>Disability Type</th>
<th>Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>CP-low functioning</td>
<td>2 (4.6)</td>
</tr>
<tr>
<td>CP-high functioning</td>
<td>4 (9.3)</td>
</tr>
<tr>
<td>Vision</td>
<td>6 (14.0)</td>
</tr>
<tr>
<td>Hearing and speech</td>
<td>7 (16.3)</td>
</tr>
<tr>
<td>Kyphosis</td>
<td>5 (11.6)</td>
</tr>
<tr>
<td>Paralysis</td>
<td>2 (4.6)</td>
</tr>
<tr>
<td>Other orthopedic</td>
<td>9 (21.0)</td>
</tr>
<tr>
<td>Multiple aging related</td>
<td>3 (7.0)</td>
</tr>
<tr>
<td>Polio</td>
<td>2 (4.6)</td>
</tr>
<tr>
<td>Speech</td>
<td>1 (2.3)</td>
</tr>
<tr>
<td>Intellectual disability</td>
<td>2 (4.6)</td>
</tr>
</tbody>
</table>

Family Members of a Person with Disability-Demographics

A total of 36 family members of Ladakhis with disability participated in this study. This includes family members (n=25) of 13 of the disabled participants described above, as well as family members (n=11) of 11 additional people with disability who did not themselves participate in the study. One example of the latter type of participant is a woman who grew up with a blind mother. The woman was visiting Leh and her mother lives in a far flung area of Ladakh and was not part of the study. In addition, there were instances when more than one family member of an individual disabled study participant were included in the study, for example one's sister and mother. Among the family members 58 percent were Buddhist and 42 percent were Muslim. Overall 36 family members represented 24 people with disability. Table 11 provides an overview of the demographics of the participant sample of family members of people with disability. Table 12

---

30 Two households had two disabled family members. One of these had more than one family member participating in the study. In an additional six households there was more than one family member representing a single person with a disability.
summarizes the relationship the participant family members had to a person with a disability and Table 13 provides an overview of the disability types represented by this sample.

**Table 11: Family members - demographics**

<table>
<thead>
<tr>
<th></th>
<th>Number (%)</th>
<th>Level of education completed</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n=36)</td>
<td></td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>9 (25.0)</td>
<td>None</td>
</tr>
<tr>
<td>Female</td>
<td>27 (75.0)</td>
<td>Current student</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1st-5th class</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6th-9th class</td>
</tr>
<tr>
<td><strong>Religion</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Buddhist</td>
<td>21 (58.3)</td>
<td>10th class</td>
</tr>
<tr>
<td>Muslim</td>
<td>15 (41.7)</td>
<td>11th-12th class</td>
</tr>
<tr>
<td>Christian</td>
<td>0 (0.0)</td>
<td>BA-MA</td>
</tr>
<tr>
<td>Monastic</td>
<td>1 (2.8)</td>
<td>Unknown</td>
</tr>
<tr>
<td><strong>Age range</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-20</td>
<td>10 (27.8)</td>
<td>Unemployed</td>
</tr>
<tr>
<td>21-40</td>
<td>16 (44.4)</td>
<td>Housewife</td>
</tr>
<tr>
<td>41-60</td>
<td>7 (19.5)</td>
<td>Employed</td>
</tr>
<tr>
<td>61+</td>
<td>3 (8.3)</td>
<td>Religious</td>
</tr>
<tr>
<td>unknown</td>
<td>0 (0.0)</td>
<td>Child or student</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>17 (47.2)</td>
<td>Elderly</td>
</tr>
<tr>
<td>Unmarried</td>
<td>9 (25.0)</td>
<td></td>
</tr>
<tr>
<td>Child</td>
<td>10 (27.8)</td>
<td>Completed interview</td>
</tr>
<tr>
<td>Unknown</td>
<td>0 (0.0)</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No</td>
</tr>
</tbody>
</table>

**Table 12: Family members - relationship to person with disability**

<table>
<thead>
<tr>
<th>Relationship Type</th>
<th>Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n=36)</td>
</tr>
<tr>
<td>Parent</td>
<td>13 (36.1)</td>
</tr>
<tr>
<td>Sibling</td>
<td>11 (30.6)</td>
</tr>
<tr>
<td>Parent and Sibling</td>
<td>1 (2.8)</td>
</tr>
<tr>
<td>Spouse</td>
<td>5 (13.9)</td>
</tr>
<tr>
<td>Child</td>
<td>3 (8.3)</td>
</tr>
<tr>
<td>Niece/Nephew</td>
<td>3 (8.3)</td>
</tr>
</tbody>
</table>
**Table 13:** Family members - disability types represented  

<table>
<thead>
<tr>
<th>Disability Type</th>
<th>Number (%)(n=24)</th>
</tr>
</thead>
<tbody>
<tr>
<td>CP-low functioning</td>
<td>6 (25.0)</td>
</tr>
<tr>
<td>CP-high functioning</td>
<td>2 (8.3)</td>
</tr>
<tr>
<td>Vision</td>
<td>5 (20.8)</td>
</tr>
<tr>
<td>Hearing and speech</td>
<td>4 (16.6)</td>
</tr>
<tr>
<td>Kyphosis</td>
<td>1 (4.2)</td>
</tr>
<tr>
<td>Paralysis</td>
<td>1 (4.2)</td>
</tr>
<tr>
<td>Other orthopedic</td>
<td>1 (4.2)</td>
</tr>
<tr>
<td>Multiple aging related</td>
<td>1 (4.2)</td>
</tr>
<tr>
<td>Polio</td>
<td>1 (4.2)</td>
</tr>
<tr>
<td>Speech</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Intellectual disability</td>
<td>2 (8.3)</td>
</tr>
</tbody>
</table>

**Overview of Professionals**

The sample of professionals was comprised of 10 people with disability who are also included in the sample of participants with disability, two participants who were also included in the sample of family members of people with disability, and another 10 who were neither disabled nor were family members and only participated as members of the sample of professionals. Experts who participated in this study came from a range of professions. They were individuals who either directly served people with disability, or those who would have insight into traditions, norms, and customs of Ladakhi culture. Table 14 shows the types of professionals who were part of the study.

**Table 14:** Types of professionals  

<table>
<thead>
<tr>
<th>Profession</th>
<th>Number (%)(n=22)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Religious specialist</td>
<td>9 (41.0)</td>
</tr>
<tr>
<td>Health care worker (general)</td>
<td>1 (4.5)</td>
</tr>
<tr>
<td>Health care and religious</td>
<td>1 (4.5)</td>
</tr>
<tr>
<td>NGO (including health)</td>
<td>7 (31.8)</td>
</tr>
<tr>
<td>Educator</td>
<td>4 (18.2)</td>
</tr>
</tbody>
</table>
Combined Sample of People with Disability in the Study

As described above, 43 participants with disability were consented into this study. An additional 11 people with disability were represented in the study by a proxy, which were family members in all cases. These 11 people with disability were not consented because the researcher did not have direct interaction with them. These individuals were unable to represent themselves because either they could not travel to meet with the researcher or could not be interviewed due to their disability. In the latter cases their family member chose not to bring them to the interview, as was the case with some severely disabled children. These instances are not dissimilar to the five disabled individuals who were consented into the study but were not interviewed because of their disability. The main difference is that those five individuals were consented as participants because the researcher was interacting with and observing them on a regular basis.

To simplify analysis and presentation of findings these two samples of individuals with disability (n=43 consented, n=11 represented only by a proxy) were combined, bringing the total number of people with disability in the study to 54. It is this combined sample of people with disability that will be analyzed for the remainder of this dissertation. This combined sample also serves to simplify the presentation of data when distinguishing between the numerous study participants who may represent a single disabled individual is unnecessary. In contrast, when a distinction between what family members said versus what people with disabilities said is valuable for analysis data are presented accordingly.
Table 15 provides an overview of the variety of ways individuals in the combined disabled sample were represented during fieldwork.

Table 15: People with disability – representation in the study

<table>
<thead>
<tr>
<th>Representation</th>
<th>Number of PWDs (%) (n=54)</th>
<th>Number of PWDs interviewed (%) (n=38)</th>
<th>Number of family members (%) (n=36)*</th>
<th>Number of family members interviewed (%) (n=24)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self only</td>
<td>30 (55.5)</td>
<td>29 (76.3)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Self and 1 family member</td>
<td>7 (13.0)</td>
<td>6 (15.8)</td>
<td>7 (19.4)</td>
<td>5 (20.8)</td>
</tr>
<tr>
<td>Self and 2 family members</td>
<td>3 (5.5)</td>
<td>2 (5.3)</td>
<td>6 (16.7)</td>
<td>3 (12.5)</td>
</tr>
<tr>
<td>Self and 3 family members</td>
<td>1 (1.9)</td>
<td>0 (0.0)</td>
<td>3 (8.3)</td>
<td>1 (4.2)</td>
</tr>
<tr>
<td>Self and 4 family members</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Self and 5 family members</td>
<td>2 (3.7)</td>
<td>1 (2.6)</td>
<td>10 (27.8)</td>
<td>4 (16.7)</td>
</tr>
<tr>
<td>1 family member only</td>
<td>10 (18.5)</td>
<td>0 (0.0)</td>
<td>10 (27.8)</td>
<td>10 (41.7)</td>
</tr>
<tr>
<td>2 family members only</td>
<td>1 (1.9)</td>
<td>0 (0.0)</td>
<td>2 (5.6)</td>
<td>1 (4.1)</td>
</tr>
</tbody>
</table>

*Total is 38 (105.6) because two participants each represented two people with disability and therefore appear twice in this column.

Demographics: Among those with a disability in the study (n=54), 63 percent (n=34) were Buddhist, 33 percent (n=18) were Muslim, and four percent (n=2) were Christian. Table 16 provides an overview of the demographics of people with disability in this study. Table 17 broadly categorizes their disability types.
### Table 16: People with disability - demographics

<table>
<thead>
<tr>
<th></th>
<th>Number (%) (n=54)</th>
<th>Number (%) (n=54)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td>Level of education completed</td>
</tr>
<tr>
<td>Male</td>
<td>31 (57.4)</td>
<td>None</td>
</tr>
<tr>
<td>Female</td>
<td>23 (42.6)</td>
<td>Current student</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1\textsuperscript{st}-5\textsuperscript{th} class</td>
</tr>
<tr>
<td></td>
<td></td>
<td>12 (22.2)</td>
</tr>
<tr>
<td><strong>Religion</strong></td>
<td></td>
<td>6\textsuperscript{th}-9\textsuperscript{th} class</td>
</tr>
<tr>
<td>Buddhist</td>
<td>34 (63.)</td>
<td>10\textsuperscript{th} class</td>
</tr>
<tr>
<td>Muslim</td>
<td>18 (33.3)</td>
<td>11\textsuperscript{th}-12\textsuperscript{th} class</td>
</tr>
<tr>
<td>Christian</td>
<td>2 (3.7)</td>
<td>BA-MA</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2 (3.7)</td>
</tr>
<tr>
<td><strong>Age range</strong></td>
<td></td>
<td>Monastic</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Unknown</td>
</tr>
<tr>
<td>0-20</td>
<td>8 (14.8)</td>
<td>2 (3.7)</td>
</tr>
<tr>
<td>21-40</td>
<td>30 (55.5)</td>
<td></td>
</tr>
<tr>
<td>41-60</td>
<td>9 (16.7)</td>
<td></td>
</tr>
<tr>
<td>61+</td>
<td>3 (5.6)</td>
<td></td>
</tr>
<tr>
<td>unknown</td>
<td>4 (7.4)</td>
<td></td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>16 (29.6)</td>
<td>Child or student</td>
</tr>
<tr>
<td>Unmarried</td>
<td>32 (59.3)</td>
<td>Elderly</td>
</tr>
<tr>
<td>Child</td>
<td>6 (11.1)</td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>0 (0.0)</td>
<td></td>
</tr>
<tr>
<td><strong>Completed interview</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>38 (70.4)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>16 (29.6)</td>
<td></td>
</tr>
</tbody>
</table>

### Table 17: People with disability - disability types

<table>
<thead>
<tr>
<th>Disability Types</th>
<th>Number (%) (n=54)</th>
</tr>
</thead>
<tbody>
<tr>
<td>CP-low functioning</td>
<td>6 (11.1)</td>
</tr>
<tr>
<td>CP-high functioning</td>
<td>5 (9.3)</td>
</tr>
<tr>
<td>Vision</td>
<td>8 (14.8)</td>
</tr>
<tr>
<td>Hearing and speech</td>
<td>8 (14.8)</td>
</tr>
<tr>
<td>Kyphosis</td>
<td>5 (9.3)</td>
</tr>
<tr>
<td>Paralysis</td>
<td>2 (3.7)</td>
</tr>
<tr>
<td>Other orthopedic</td>
<td>9 (16.7)</td>
</tr>
<tr>
<td>Multiple aging related</td>
<td>3 (5.5)</td>
</tr>
<tr>
<td>Polio</td>
<td>3 (5.5)</td>
</tr>
<tr>
<td>Speech</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>Intellectual disability</td>
<td>4 (7.4)</td>
</tr>
</tbody>
</table>
Disability acquisition: Based on descriptions provided, the researcher classified people with disability in this study into two categories, those who were born with a disability and those who acquired their disability later in life. Table 18 shows these categorizations for each type of disability.

**Table 18: People with disability – acquisition and disability type**

<table>
<thead>
<tr>
<th></th>
<th>Born (%)</th>
<th>Acquired (%)</th>
<th>Total (%)*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n=18)</td>
<td>(n=35)</td>
<td>(n=53)</td>
</tr>
<tr>
<td>CP-low functioning</td>
<td>3 (5.7)</td>
<td>3 (5.7)</td>
<td>6 (11.4)</td>
</tr>
<tr>
<td>CP-high functioning</td>
<td>2 (3.8)</td>
<td>3 (5.7)</td>
<td>5 (9.5)</td>
</tr>
<tr>
<td>Vision</td>
<td>4 (7.5)</td>
<td>4 (7.5)</td>
<td>8 (15.0)</td>
</tr>
<tr>
<td>Hearing and speech</td>
<td>0 (0.0)</td>
<td>7 (13.2)</td>
<td>7 (13.2)</td>
</tr>
<tr>
<td>Kyphosis</td>
<td>1 (1.9)</td>
<td>4 (7.5)</td>
<td>5 (9.4)</td>
</tr>
<tr>
<td>Paralysis</td>
<td>0 (0.0)</td>
<td>2 (3.8)</td>
<td>2 (3.7)</td>
</tr>
<tr>
<td>Other orthopedic</td>
<td>4 (7.5)</td>
<td>5 (9.4)</td>
<td>9 (16.9)</td>
</tr>
<tr>
<td>Multiple aging related</td>
<td>0 (0.0)</td>
<td>3 (5.7)</td>
<td>3 (5.7)</td>
</tr>
<tr>
<td>Polio</td>
<td>0 (0.0)</td>
<td>3 (5.7)</td>
<td>3 (5.7)</td>
</tr>
<tr>
<td>Speech</td>
<td>1 (1.9)</td>
<td>0 (0.0)</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>Intellectual disability</td>
<td>3 (5.7)</td>
<td>1 (1.9)</td>
<td>4 (7.6)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>18 (34.0)</strong></td>
<td><strong>35 (66.0)</strong></td>
<td><strong>53 (100.0)</strong></td>
</tr>
</tbody>
</table>

* The researcher was unable to determine when or how one deaf participant became deaf. Given her inability to speak or lip read it was likely at birth or a very young age.

Those who acquired their disability later in life can be divided into five further categories, including those that were a result of childhood illness (n=18, 51%), childhood accident (n=8, 23%), adulthood illness (n=2, 6%), adulthood accident (n=4, 11%), and those that are the result of aging (n=3, 9%). However, in some instances it is difficult to know for certain whether those categorized as either having been born with a disability or having acquired a disability as a young child are appropriately categorized, particularly for those who were under the age of five (n=17, 32%). For example, family members may not have realized anything until the child was slow to reach a developmental milestone. In some instances the person with the disability is relying on various accounts of their life from family
members about their childhood which may have included various illnesses or accidents. Chapter 6 explores in more depth the causes and explanations for disability as described by participants, as well as general views about causes of disability in Ladakh.

Data Management and Analysis

During fieldwork, logs, household survey data, and notes were compiled into the qualitative data analysis software NVivo 8. Logs were kept for PAGIR visits, visits to the study village, visits to each household, and about daily work for each research assistant. A more general handwritten field notebook was also kept that included a mix of personal experiences, fieldwork experiences, and observations. The statistical software SPSS was used to analyze disability data in the study area in order to make sampling decisions. SPSS was also used to keep a database of demographic information, consent information, and interview dates for all participants. These data were analyzed periodically in order to re-evaluate the study and prioritize research activities. Digital recordings of interviews were uploaded from the digital recorder to a laptop on a daily basis. When necessary for ease of transcription sound quality was improved using Audacity. Photographs and videos were uploaded routinely. Tables were created to track progress toward study goals and research assistant tasks. Consent documents were scanned. All data was backed-up weekly onto an external hard drive and duplicated on flash drives. A log book of expenses was also kept up on a daily basis.

During fieldwork several transcriptionists were hired to translate Ladakhi portions of interviews into English. All transcriptionists were given a brief training,
signed a contract addressing confidentiality, and given samples of how their finished work should be formatted. They were asked to translate and transcribe the Ladakhi portions of interviews only. This included portions spoken by the participant, as well as portions spoken by the research assistant. This method served as a second translation of the interviews. All transcriptionists hand wrote their transcriptions. When possible, they handwrote both the Ladakhi and their English translation of the Ladakhi. Not all transcriptionists were able to write in Ladakhi using either the Roman alphabet or the Tibetan script. However, all were able to translate Ladakhi into English. The most active transcriptionists were paid periodically. All transcriptionists were given final payment upon return of all interviews and equipment provided to them.

Upon returning from the field, these handwritten transcriptions were scanned as a back-up and to be referenced during further transcription. The researcher and two additional research assistants typed handwritten portions while listening to and transcribing English portions of the interviews. In order to conduct further qualitative and quantitative analyses, transcripts and field notes were compiled into case summaries organized by topical themes based primarily on the semi-structured interview. From these case summary documents further coding was done using NVivo9. The cases were also searchable by several attributes such as answers to specific questions and demographic variables. Additional quantitative analysis was made possible by entering characteristics drawn from interview data into an SPSS database. These included disability type, age at onset, health care
utilization, religious specialist utilization, answers to quantifiable interview questions, and counts generated from qualitative analyses.

**Conducting Fieldwork in Ladakh**

**Fieldwork Challenges**

Obtaining written informed consent in a widely illiterate community was a barrier to developing rapport. Not only did the written forms widen an already significant gap between the researcher and participants, but also highlighted the class and education gap between the research assistant and the participants. Additionally, most Ladakhis are at least somewhat suspicious of having to sign papers they cannot read and are particularly embarrassed if they do not know how to write. The presence of papers, other than a school type notebook, was a distraction to participants and formalized the event to the degree that was unnecessary and uncomfortable. For example, they may have opened special packaged foods or brought out fancier dishes, or may have felt compelled to give the “correct” answers to questions. In many cases no meaningful interactions took place until subsequent visits where no papers were displayed.

**Anonymity and Privacy**

Privacy, confidentiality, and anonymity are very difficult concepts to explain in Ladakh. Though there seemed to be a general distaste for nosy neighbors, it was also challenging to explain any reason why anyone would want to keep something private or confidential. Early in the village portion of the study it became obvious that villagers were not always aware of people with disability living nearby. The research assistants were trained to give a generic but truthful answer about who we
were and what we were doing when approached by a villager. Reasons and strategies for maintaining confidentiality were routinely reviewed with research assistants, especially if the researcher observed an interaction in which the research assistant struggled with responses to queries from villagers.

**Scope and Limitations of the Study**

A number of limitations result from doing a qualitative study with a diverse sample. The total number of participants was relatively small, and in most instances analysis is of a smaller subset of those participants. This leaves little room for reliable, valid statistical analysis. Comparisons between groups are still possible but given the sample size it is difficult to assume they are replicable. Given the qualitative nature of the study, in some instances the researcher had to make an informed decision when developing quantitative findings, for example making a determination from the response to an open ended question about whether the participant gave a “yes” answer or a “no” answer to a question.

Generalizability to the whole of Ladakh, even just the Leh district, is limited by several factors. First this study took place entirely in the Leh district of Ladakh. Second, no portion of the fieldwork took place in any of the very remote villages of Ladakh and therefore did not capture factors that may influence the choice to remain in remote areas. It did however include people from very remote villages who have shifted to living in the Leh area to take advantage of the urban lifestyle. Including more far flung areas of Ladakh would have allowed for better urban rural comparisons. Third, the very small sample of disabled elderly was made up entirely of women without children. Not having children creates particular circumstances
for the elderly in Ladakh, so it was not possible to compare the circumstances of
disabled elderly with children to those without, or to compare women with men.
The study did include other non-disabled elderly, and the researcher was
acquainted with several other elderly non-participants. This did make it possible
for the researcher to have some idea of the variety of experiences of elderly people
in Ladakh. Fourth, it would have been ideal to include a broader range of
organizations and service providers, but as described above this was limited by the
combination of the duration of fieldwork and IRB rules. Finally, the sample did not
include many non-disabled Ladakhis who were not the family member of a disabled
person or working in a disability related field. This limits the possibility of
comparing PWDs and non-PWDs in Ladakh.

Perhaps the most challenging were limitations which were the result of the
duration of fieldwork, difficulty of the terrain, and availability of participants. As
mentioned previously, it took significant time to get to participants’ homes. It was
necessary to organize days based on geography, weather, and the physical
capabilities of the researcher. This limited the number of visits that could be made
to each household, and meant that for the broader community portion of the study
many participants actually came to the researcher leaving out the opportunity to
observe their living conditions.\footnote{Transportation was provided on an as needed basis for these participants.}\nThose participants who worked were typically
only available on Sundays and late evenings.

In one year it is not possible to visit with every family or participant on a
Sunday, therefore for some village households, for example, the researcher may
have never met particular family members, typically males who worked in
government jobs. These challenges also meant that the researcher could not make
enough visits to ensure the opportunity for private conversations with various
participants. These opportunities certainly came up, but not in every household.

Living in Ladakh Informs and Shapes Research

The physical challenges associated with living in Ladakh as an able bodied
healthy foreigner brought attention to the challenges those with a disability
necessarily face in this environment. Acquiring water, food, cooking fuel, and
heating fuel are a few significant examples of activities necessary for survival yet
either very physical or very expensive. Using a Ladakhi style toilet requires the
physical ability not only to climb stairs or a ladder to get to the toilet, but also to
squat over a hole in the ground. Going from one place to another requires walking
and often included steep rocky inclines, jumping streams or gutters, climbing walls,
avoiding unpredictable and large animals or traffic, or other equally hazardous
tasks. This says nothing of the dangers of these things or the lack of health care
available, for example as related to food and water borne illnesses, smoke
inhalation, carbon monoxide poisoning, or accidents associated with animals, traffic,
and falls. The level to which the challenges of living in Ladakh helped the researcher
develop rapport – the rapport between the one who is “not used to” and the one
who is “not able to” – was significant.
CHAPTER 6: FINDINGS

This chapter presents quantitative and qualitative findings from this research. Using data from three types of study participants – people with disability, family members of people with disability, and professionals – this chapter tells the story of disability in Ladakh. The chapter is loosely structured beginning with the acquisition of a disability to views about the future needs of people with disability in Ladakh. First, to illustrate local definitions of and attitudes toward disability in Ladakh selected explanations for disability given by study participants are presented. The second section explores how participants sought health and religious care and advice, findings pertaining to both the first and third study objectives. To explore how the physical environment shapes experiences of disability the third section provides a look at daily life with a disability in Ladakh, including associated physical challenges. Fourth, pertaining to all three study objectives, psychological and social aspects of disability experiences are explored. Fifth, in relation to the first study objective, general attitudes about disability and data about what participants think Ladakhis with disabilities need are presented. Where possible, comparisons are made within or between groups represented in the study. Additional insights or explanations from interviews with professionals are interspersed throughout the chapter. Finally, the chapter concludes with four case studies which demonstrate how the three objectives are intertwined and illustrate how the findings presented earlier in the chapter play out in daily life.
Explanations of Disability in Ladakh

This section begins with specific explanations for disability given by study participants for people with disability this study. This is followed by general causal explanations for disability given by study participants. These findings are most relevant to the first study objective, to ascertain local definitions of and attitudes toward disability in Ladakh, but they also begin to reveal how religion influences the experience and management of disability, which is another objective of this study, by demonstrating the prominence of religious causal explanations for disability. In addition to Buddhism and Islam, folk religious ideas are very strong and influential in Ladakh, particularly among Buddhists. One is often warned about the many ancient sites inhabited by spirits call *lu-skon*. If one cuts a tree or digs in an area inhabited by these spirits, some harm may come to them or something bad will happen in their life.

Causes of Disability for People with Disabilities in the Study

A variety of explanations for disability were given for the 54 people with disability in this study. For many people with disability there were multiple explanations given for their disability (n=26, 48% gave 2 to 5 reasons). Disability was attributed to at least one, in some cases many, causes. Table 19 provides an emic presentation of the range of causes given by participants. They do not think of these in terms of levels of causation, that is that one cause may outweigh another, rather they are simply presented as multiple co-existing causes and explanations. In some cases the progression of the disability, or even acquisition of multiple disabilities, was attributed to several incidents (n=7, 13% described 2 to 4
incidents). Twenty-three (43%) provided some type of religious explanation, for example that it had to do with *karma*, *lu-skon*, or was God given. This included 15 (44%) Buddhist, seven (39%) Muslims, and one (50%) Christian. Overall it included 15 (48%) males and eight (35%) females.

**Table 19: Causes of disability – people with disability in this study (n= 54)**

<table>
<thead>
<tr>
<th>Cause</th>
<th>Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Born disabled</td>
<td>19 (35.2)</td>
</tr>
<tr>
<td><em>Karma</em></td>
<td>12 (22.2)</td>
</tr>
<tr>
<td>Illness</td>
<td>9 (16.7)</td>
</tr>
<tr>
<td><em>Lu-skon</em></td>
<td>7 (13.0)</td>
</tr>
<tr>
<td><em>Amchi</em> treatments</td>
<td>4 (7.4)</td>
</tr>
<tr>
<td>Fell from a roof</td>
<td>4 (7.4)</td>
</tr>
<tr>
<td>God given</td>
<td>4 (7.4)</td>
</tr>
<tr>
<td>Auto accident</td>
<td>3 (5.6)</td>
</tr>
<tr>
<td>Fever</td>
<td>3 (5.6)</td>
</tr>
<tr>
<td>Aging</td>
<td>2 (3.7)</td>
</tr>
<tr>
<td>Parents not taking care of a child</td>
<td>2 (3.7)</td>
</tr>
<tr>
<td>Parents from two different religions</td>
<td>2 (3.7)</td>
</tr>
<tr>
<td>Polio</td>
<td>2 (3.7)</td>
</tr>
<tr>
<td>Possible meningitis</td>
<td>2 (3.7)</td>
</tr>
<tr>
<td>Boil or Abscess</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>Broken promise to Hindu god by father</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>Cold weather</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>Eating cow’s meat</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>Fell on the ice</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>Fever as a baby</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>Headache medicine during pregnancy</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>Ice skating accident</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>Lack of treatment for injuries</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>Liver jaundice</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>Mother fell while pregnant</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>Not breathing as a baby</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>Picking up a heavy load</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>Pneumonia</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>Rammed by <em>dzo</em></td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>Shrapnel</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>Sister fell on ice carrying child</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>Soccer accident</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>Sudden dry eye nerves</td>
<td>1 (1.9)</td>
</tr>
</tbody>
</table>
The following examples illustrate these points. A Buddhist man with kyphosis and a leg injury described how he became disabled:

In the beginning the problem was due to *lu-skon*. The H. H. Dalai Lama was visiting for the first time in Ladakh. I came for his teachings. There was a three day teaching break. During that time we were preparing mud bricks at a particular place and I played with mud those days. People say that the problem started right from there, *lu-skon*. For the Dalai Lama’s next teaching I could not walk. I could not walk for one year. After that I walked with one stick. When I was using one stick I fell from the roof. I fell from a two story building onto sand. That is why they say this back hump came out. I was maybe ten years old. Around this time I also fell on the ice. After a month of falling many times the pain started. I went to the *amchi* and he gave some medicine. As a result the swelling came out. Then I was admitted to the hospital and had an operation. They cut, then blood and pus came out. I was kept in hospital for three or four months and they were always changing the dressing and letting the pus out. (Buddhist male, 20s, kyphosis)

Another man described his disability:

I was playing with friends, ice skating, and fell. I was 16 or 17 years old. The leg was broken, the joint is now fixed, it won’t move. Now I also can’t wear heavy shoes. One leg is shorter . . . I did something not good in a past life. That is why I became disabled now. (Buddhist male, 30s, orthopedic impairment)

A Muslim woman with a very small, deformed forearm and hand described what mother told her about how she became disabled:

One day we went from Muharram with the *akhon* and I had sharp pain. I had a boil or abscess in my arm. That time it was so serious. I was 2 years old. The *akhon* didn’t know what happened so he gave me cow’s meat. Those days we used cow’s meat. Due to that I got really sharp pain and they immediately took me to the *amchi*. He put a hot gold needle everywhere, then from inside the pus came out and then all the nerves separated and went far. And then immediately they took me to the hospital. They carried me from so far to the hospital. Those days there was no vehicle. No! Not at all. The doctor said it’s due to cow’s meat. You had cow’s meat so it made your boil worse. They

---

32 To preserve anonymity ages are given only in terms of decade of life. In some sections type of disability is indicated, in others only type of participant in indicated. This limits a reader’s ability to piece together participant stories.
took two or three full small tins of pus from here. My mother told me that. From here it spread all over here. Before I was two years old here there were five fingers, after amchi put fire, this one finger was lost. Yes! It’s gone slowly, slowly. To recover it took three years. (Muslim female, 40s, orthopedic impairment)

A Buddhist woman with a child who has CP said that when she was three months pregnant she fainted and fell down. Her doctor said her baby was born disabled because of a head injury that was the result of the fall. She also described an illness:

When she was two months old she had a really high fever, then I showed her to the doctor and she was admitted in hospital fifteen days. And very, very high fever. And also she couldn’t breathe all one night and they gave oxygen. One day when she was not breathing, that day she never sucked the milk, didn’t eat. (Buddhist female, 40s, mother of child with CP)

The mother noted she did not notice any problem before the illness, not even after. When they visited the Dalai Lama he said this is because of karma, maybe parent’s karma, maybe the child’s karma, but not to worry it is only karma. A Muslim father of a child with intellectual disability said:

She has been like this since she was born. The lha-mo said this is because of your carelessness. When she was very young you did not clean her. That is why she became like this. (Muslim male, 30s, father of child with intellectual disability)

*Religious Explanations for Disability*

As the previous section demonstrates, Ladakhis’ narratives about their own or their family member’s disability often include a religious causal explanation for the disability (n=23, 43%). The semi-structured interview included a question asking participants whether their religion says anything about disability; a question not specific to them or their family member. Of the 72 participants who completed the semi-structured interview 63 were asked this question and 75 percent (n=47) responded yes. Seventy-nine percent of Buddhists (n=30) responded yes, while 65
percent of Muslims (n=15) responded yes, and 100 percent of Christians (n=2) responded yes. Four Muslim participants said their religion does not say anything about disability and did not offer other general explanations for disability. The remaining 12 participants responded they did not know. Among urban respondents 88 percent (n=22) said yes, none said no (n=0, 0%), and 13 percent (n=3) said they did not know. Among rural respondents 66 percent (n=25) said yes, 10 percent (n=4) said no, and 24 percent (n=9) said they did not know.

The 47 participants who responded yes elaborated on their answers. Buddhists tended to answer with causal explanations for disability. Christians elaborated about how people with disability should be treated. Muslims tended to discuss both causality and treatment of people with disabilities. Table 20 shows religious causal explanations for disability that were given as answers by Buddhists and Muslims.

<table>
<thead>
<tr>
<th>Table 20: Religious explanations for disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Explanations</td>
</tr>
<tr>
<td>-------------------------------------</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Karma</td>
</tr>
<tr>
<td>Lu-skon</td>
</tr>
<tr>
<td>Karma and lu-skon</td>
</tr>
<tr>
<td>God given</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td>Total</td>
</tr>
</tbody>
</table>

The quotes below demonstrate that though Muslims generally explain disability as God given, and Buddhists that it is because of karma, there are subtle overlaps. Belief in the concept of rebirth may be the main thing that distinguishes Ladakhi Buddhists and Muslims. A Muslim father of a disabled man said:

"There is not rebirth in our religion, so no previous births. We believe in fortune. We say he is suffering because of his bad fortune, he can’t see
because it was written in his fortune. (Muslim male, 70s, father of a person with a disability)

A Buddhist man provided another view:

It is karma, right, we call it bad fortune. (Buddhist male, 70s, religious specialist)

A Muslim man with a disability explained his views about disability:

God sends like this, disabled. For example, if people are seeing this and some people are doing many mistakes, then if they are looking at the disabled maybe they will stop doing mistakes. That is why God sent him. (Muslim male, 40s, with a disability)

A Buddhist woman who has a sibling with a disability said that,

Buddhism says if somebody is disabled in a previous life he did something bad. That is why he is now disabled. And also if you have good thoughts, do good work, good things, then maybe next life you become like us, not disabled. (Buddhist female, 30s, sister of person with disability)

Professionals in the study gave a variety of explanations for disability. Their comments demonstrate some of the complexity surrounding religious explanations for disability as they may relate to other layers of causality and the types of religious advice those experiencing disability in Ladakh may receive. During his interview, a geshe said that accidents are the result of bad deeds in a previous life. Another monk said that someone born with a disability cannot be cured, but those who have an accident can be cured. He went on to suggest it is best to consult a doctor, including a doctor outside Ladakh. He explained that accidents are not the result of karma and gave the example of someone falling from a roof as something that can be controlled with safety and therefore is not karma. One amchi who is also a nun indicated that if a person was disabled when they were born that it is the result of karma and all she would do is treat symptoms. She also feels that accident cases
without karma can be cured, but that many accidents are *karma*, including cases where the disability is the result of carelessness of the parents. She said having a disability is a good opportunity because people with a disability can have a life of prayer, then death, and a good rebirth.

Two sheiks, one Sunni and one Shia, were interviewed and asked what Islam says about disability. The Sunni sheik told the researcher of a teaching from the Prophet Mohammad. The teaching describes a woman with epilepsy whose body gets exposed when she is having fits. She asks the Prophet Mohammad to pray to God for her. He tells her if she chooses to be patient while suffering she will go to paradise. Or he can pray for a cure. She then asks that he only pray that her body not be exposed when she has fits. The Prophet Mohammad declared she would be going to paradise, heaven. This Sunni sheik says that Muslims must respect all beings. Those with disability are not a curse, rather something made by God that should be respected and helped. The Shia sheik similarly described how all people are made and blessed by God. He said that if a disability arises after birth it may be the fault of the parents. He elaborated that some people die in accidents or earthquakes and concluded by saying: “All I have to say is that everyone pays for his deeds in life. It is in God’s hands”.

Common religious causal explanations for disability are *karma* and God’s will. Buddhists, including religious specialists, do not consistently attribute *karma* to particular causes of disability, but on the other hand associate the possibility of cure with the presence or absence of bad *karma*. Muslims do not make these types of distinctions in relation to God’s will. General religious explanations of disability
are most often divided on lines of religious affiliation. Given these general statements, along with explanations for disability given for those in this study detailed in the previous section, it is not surprising that seeking religious care or advice is part of the experience and management of disability. Lack of certainty surrounding the Buddhist notion of *karma* may also contribute to some serially seeking advice from many religious specialists. This will be explored in more depth later in the next section.

**Health and Religious Care and Advice**

Perhaps the most interesting findings from this study are associated with the ways health care, traditional medicine, and religion are intertwined, particularly with regard to the health and religious care sought to address disability. The above quotes demonstrate that various forms of health care and religious advice are sought when experiencing disability. Because of the dynamic nature of disability, associated religious explanations, and varying causes or diagnoses, there are several layers to any plan to seek treatment or advice. There are many choices and specialists do not always agree with one another. This is the nature of seeking health and religious care and advice in Ladakh. These findings demonstrate not only the influence of religion on how disability is managed, study objective three, but also contribute to our understanding of attitudes toward disability, study objective one, by looking at the types of care sought and often the persistence with which Ladakhis continue to pursue disability related care throughout life. First, however, it is worthwhile to briefly explore study findings related to seeking health care generally prior to exploring seeking disability related care.
Seeking Health Care in Ladakh

Study participants who completed the semi-structured interview were asked a series of questions about illness, unrelated to disability. These included whether they seek care or advice if they are sick or injured, whether they do anything religious to avoid sickness, and if there is anything religious they would do if they were sick or injured. These questions were designed to capture more depth of knowledge about the role of family and the role of religion with regard to health and illness in Ladakh. Of the 59 people who answered whether they seek care or advice 85% (n=50) said yes. All of the Muslims (n=21) and 75 percent (n=27) of Buddhists indicated they would include a family member or friend in their health care. The remaining Buddhists indicated they go on their own to the doctor. Of the 52 participants who answered the question regarding whether they do anything religious to avoid becoming sick 69 percent (n=36) said yes. Seventy-six percent of Muslims (n=16) responded yes, while 65 percent of Buddhists (n=20) responded yes. Fifty-three people responded to the question about whether they would do anything religious if they were sick or injured, with 77 percent (n=41) answering yes. Eighty-five percent of Muslims (n=17) responded they would, while 73% of Buddhists (n=24) said they would do something religious. Living in an urban versus rural setting did not affect involvement of others in care but rural living did increase the likelihood one would incorporate religion. Seventy-seven percent (n=27) of rural respondents indicated they do religious things to avoid sickness, while only 53 percent (n=9) of urban respondents indicated likewise. With regard to doing something religious if one were to become sick or injured 81 percent (n=30) of rural
participants indicated they would, while 69 percent (n=11) of urban participants indicated they would do something religious.

Seeking Disability Related Care

For those experiencing disability the complexity of seeking care often leads to a long, possibly life-long, process where they seek guidance and treatments at every new opportunity. For example, they may seek care or advice when a rinpoche visits Ladakh, a new doctor begins work at the hospital, a foreign aid camp is held, or there is money to seek care outside of Ladakh. Of the 52 people with disability in this study who are native Ladakhis it was possible to learn some of these details for 46 of them. For some there is little recollection of their childhood. For others with hearing or intellectual impairments it was difficult to communicate about these details. The remainder of this section provides findings from these 46 cases. People with disability and their family members often visit multiple types of specialists. It is interesting to note that some Muslims visited Buddhist religious specialists. Table 21 shows how many Buddhists and Muslims mentioned consulting each type of

<table>
<thead>
<tr>
<th>Specialist</th>
<th>Buddhist (%)</th>
<th>Muslim (%)</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rinpoche</td>
<td>12 (41.2)</td>
<td>3 (17.7)</td>
<td>15 (32.6)</td>
</tr>
<tr>
<td>Lama</td>
<td>8 (28.0)</td>
<td>1 (5.9)</td>
<td>9 (19.6)</td>
</tr>
<tr>
<td>Onpo</td>
<td>3 (10.3)</td>
<td>0 (0.0)</td>
<td>3 (6.5)</td>
</tr>
<tr>
<td>Akhon</td>
<td>0 (0.0)</td>
<td>12 (71.0)</td>
<td>12 (26.1)</td>
</tr>
<tr>
<td>Lha-mo</td>
<td>7 (24.1)</td>
<td>3 (17.7)</td>
<td>10 (21.7)</td>
</tr>
<tr>
<td>Amchi</td>
<td>14 (48.3)</td>
<td>9 (53.0)</td>
<td>23 (50.0)</td>
</tr>
<tr>
<td>Doctor</td>
<td>25 (86.2)</td>
<td>17 (100.0)</td>
<td>42 (91.3)</td>
</tr>
</tbody>
</table>

33 Two disabled participants were not native Ladakhis. Their history of seeking care and advice outside of Ladakh is quite unique and was therefore excluded from this portion of analysis.
specialist listed, providing the percent within each religion and the total percent that consulted each type of specialist.

Interestingly, 91 percent (n=42) had visited a doctor at some point. Of those however, 17 percent (n=8) were taken to the hospital due to an illness or injury and 41 percent (n=19) did not visit a doctor until after a number of years of living with disability. One amchi in the study feels it is best to first try taking amchi medicine but many Ladakhis choose first to seek a doctor because of the perceived prestige associated with them. Of the four (9%) who have never seen a doctor about their disability, three live in a remote area.

Many participants were told at some point that nothing could be done (n=12, 26%). In these cases either the person was born with a disability or they are seeking care for a very old injury or the results of a past illness. In some instances specialists refer people with disability to another type of specialist, or advise them about what type of care they should or should not seek from others (n=14, 30%). Sometimes families are advised that perhaps something could be done outside of Ladakh (n=6, 13%). Eleven (24%) of the 46 did receive care outside of Ladakh and seven (15%) consulted doctors visiting Ladakh. Seven mention being advised to or wanting to seek care outside Ladakh, with money being the most frequent reason (n=5, 11%) for not doing so.

Not surprisingly, patterns of seeking care or advice change over time for individuals and families. The services available or desired at onset or recognition of an impairment may be quite different from those later in life. For example, though their parents may not have taken them to see a doctor when they were young, as an
adult a person with a disability may choose to visit a doctor. Some people experiencing disability may see every prominent religious specialist who visits Ladakh throughout their lifetime. Some go to different specialists for different aspects of their disability. Some simply settle into a pattern as they age. The following tables show the combinations of care sought by Buddhists and Muslims experiencing disability. Table 22 shows care sought during the early years of disability, typically about the first five years, while Table 23 shows care sought later on in life as their needs and opportunities may have changed. The tables demonstrate the complex and changing patterns of life with disability.

**Table 22: Types of specialist care sought during early years of disability***

<table>
<thead>
<tr>
<th>Specialist Types</th>
<th>Buddhist (%)</th>
<th>Muslim (%)</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n=29)</td>
<td>(n=17)</td>
<td>(n=46)</td>
</tr>
<tr>
<td>Religious specialist, <em>amchi</em>, doctor</td>
<td>2 (6.9)</td>
<td>6 (35.3)</td>
<td>8 (17.4)</td>
</tr>
<tr>
<td>Religious specialist and <em>amchi</em></td>
<td>1 (3.4)</td>
<td>1 (5.9)</td>
<td>2 (4.3)</td>
</tr>
<tr>
<td>Religious specialist and doctor</td>
<td>3 (10.3)</td>
<td>2 (11.8)</td>
<td>5 (10.9)</td>
</tr>
<tr>
<td><em>Amchi</em> and doctor</td>
<td>2 (6.9)</td>
<td>0 (0.0)</td>
<td>2 (4.3)</td>
</tr>
<tr>
<td>Religious specialist</td>
<td>3 (10.3)</td>
<td>1 (5.9)</td>
<td>4 (8.7)</td>
</tr>
<tr>
<td><em>Amchi</em></td>
<td>2 (6.9)</td>
<td>0 (0.0)</td>
<td>2 (4.3)</td>
</tr>
<tr>
<td>Doctor</td>
<td>8 (27.6)</td>
<td>2 (11.8)</td>
<td>10 (21.7)</td>
</tr>
<tr>
<td>None</td>
<td>8 (27.6)</td>
<td>5 (29.4)</td>
<td>13 (28.3)</td>
</tr>
<tr>
<td>Total</td>
<td>29 (100.0)</td>
<td>17 (100.0)</td>
<td>46 (100.0)</td>
</tr>
</tbody>
</table>

*detail may not add to total due to rounding

**Table 23: Types of specialist care sought for disability later in life***

<table>
<thead>
<tr>
<th>Specialist Types</th>
<th>Buddhist (%)</th>
<th>Muslim (%)</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n=29)</td>
<td>(n=17)</td>
<td>(n=46)</td>
</tr>
<tr>
<td>Religious specialist, <em>amchi</em>, doctor</td>
<td>6 (20.7)</td>
<td>3 (17.6)</td>
<td>9 (19.6)</td>
</tr>
<tr>
<td>Religious specialist and <em>amchi</em></td>
<td>0 (0.0)</td>
<td>1 (5.9)</td>
<td>1 (2.2)</td>
</tr>
<tr>
<td>Religious specialist and doctor</td>
<td>3 (10.3)</td>
<td>3 (17.6)</td>
<td>6 (13.0)</td>
</tr>
<tr>
<td><em>Amchi</em> and doctor</td>
<td>2 (6.9)</td>
<td>0 (0.0)</td>
<td>2 (4.3)</td>
</tr>
<tr>
<td>Religious specialist</td>
<td>1 (3.4)</td>
<td>1 (5.9)</td>
<td>2 (4.3)</td>
</tr>
<tr>
<td><em>Amchi</em></td>
<td>1 (3.4)</td>
<td>0 (0.0)</td>
<td>1 (2.2)</td>
</tr>
<tr>
<td>Doctor</td>
<td>11 (38.0)</td>
<td>6 (35.3)</td>
<td>17 (37.0)</td>
</tr>
<tr>
<td>None</td>
<td>5 (17.2)</td>
<td>3 (17.6)</td>
<td>8 (17.4)</td>
</tr>
<tr>
<td>Total</td>
<td>29 (100.0)</td>
<td>17 (100.0)</td>
<td>46 (100.0)</td>
</tr>
</tbody>
</table>

*detail may not add to total due to rounding
Though there may not be remarkable differences in care seeking patterns between the two tables, with the exception that Buddhists seek multiple care providers more often later in life than Muslims, individual patterns of seeking care change throughout life. Those who did not seek care early on, for example, are not necessarily the same who chose not to seek care later in life.

To further complicate matters, in the researcher’s experience, people seem to be quick to judge the efficacy of a particular treatment, often have misunderstandings about diagnoses or treatments, and express fear of particular procedures. As examples, one woman removed a cast because it was causing a rash, participants and friends of the researcher mentioned x-rays having no effect on how they were feeling, and four participants expressed at some point making a decision not to have an amputation. Though not specifically asked, thirty-eight people with disability or their family members commented about the effectiveness of treatments they received (Table 24).

**Table 24**: Satisfaction with treatments from health care providers (n=38)

<table>
<thead>
<tr>
<th></th>
<th>Amchi (%)</th>
<th>Doctor (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Made them better</td>
<td>8 (21.1)</td>
<td>14 (36.8)</td>
</tr>
<tr>
<td>Made them worse</td>
<td>6 (15.8)</td>
<td>1 (2.6)</td>
</tr>
<tr>
<td>Had no effect</td>
<td>3 (7.9)</td>
<td>10 (26.3)</td>
</tr>
</tbody>
</table>

Some Ladakhis have suffered disabling effects from *amchi* treatments.

Though many Ladakhis take pills prepared by an *amchi*, there are mixed opinions about whether or not one should allow an *amchi* to apply fire.\(^{34}\) Though some Ladakhis in describing their disability – its cause and various treatments they have had – tell about fire treatments and the associated infections or scarring, they do not

\(^{34}\) Some *amchis* in Ladakh have discontinued this practice.
often associate their continued nerve damage or chronic pain with those treatments. Admittedly, it is difficult to tell through conversation and recollection what may have caused what. There were clearly instances in which people say they were worse off after a fire treatment, or that the lingering pain is where the fire was, not where the original problem was. *Amchi* medicine plays an important role in the Ladakhi health care system, particularly in areas where there are few alternatives. Fire treatments are becoming less common, and referrals to other types of providers more common.

The following examples serve to illustrate the complexity involved in seeking health and religious care or advice among the 46 cases analyzed in this section. A Muslim man with an orthopedic impairment described his parents' and his own experiences with seeking care and advice:

> Until I was one year my parents showed the *akhon, amchi, rinpoche, lha-mo, lama* – they showed them all. The *lama* said keep him clean, he can sit happily, he can spend his life happily. Then some *lha-mo* said if he is not disabled then he will be an important person. The *akhon* said when he was born some spirits from the water were not happy, that is why he is like this. Then after two years they took me to a doctor in Chandigargh. Then the Chandigargh doctor said they have to cut one leg and put an artificial limb. Then he can walk if you people do regular therapy. Then my parents maybe did not understand too much. When I was older the doctor said we have to try to cut this leg but the medicine for not feeling when cutting the leg had no effect. The doctor said maybe after some years come again and it will work. Then after ten years I remembered and went to the *lama* and *lha-mo* and asked whether I should go or not. They all said no, don't go there, just leave it like this, you are very happy, you are lucky. That is why I didn't go back to Chandigargh. (Muslim male, 40s, orthopedic impairment)

A Buddhist woman with CP described her recollection of seeking care:

> I went to a *duba* (a monk) and he told me not to have medicines. He told me to go to the *lha-mo* next time. And also the *amchi*'s medicine and doctor's medicine are not very effective . . . The *lha-mo* said don't show the doctor without permission from the *duba*. The *duba* looked in his holy books when
my pain started getting worse and he told me from those books. The *duba* can read the paper then he knows. He can read and he shows the doctor a note about which medicine is okay. (Buddhist female, 50s, CP)

A Muslim man described a recent trip to a doctor to see if anything additional could be done for his vision:

A few days back I went to a doctor and he said that I won’t be treated as I have gone through an operation already before, but I could use spectacles for better vision if I want to. But I said if I use spectacles I cannot walk properly, I feel I am about to fall and the earth is rough. So he said I can use lenses because it is a better option and he told me to go home and discuss about the lenses with my family members, if it is suitable for us... He asked me to decide if I want to wear the lens and he told me that it all depends on me and gave me precaution that if I won’t keep it clean or rinse it with hands then it could make my vision worse. So he told me to go home and think and decide. After that I was scared and did not go back. (Muslim male, 30s, vision impairment)

A Buddhist man who had polio described his experiences:

I was fine until the age of 6 years but after 6 years I fell sick, so I became like this. I caught a cold and this happened. Then it converted this way. Yes the cold, and then I was not able to walk. For one year I was sick. Then I had consulted everyone. I was not cured by the doctor, so I went to the *amchi*, and after the *amchi* I went to the *lha-mo*. The *lha-mo* gave advice which was good for me. The *lha-mo* said that the fire put by the *amchi* was wrong. It had the wrong effects. The fire was put here, here on the ass. The *lha-mo* scolded me for the fire and also told me to pray to a great monk. I visited the great monk of the Drukpa sect. The *Rinpoche* himself gave me from his own hands, secretly from others and not showing the sky, he gave me a medicine. And it has had its positive effects. Yes, I went to the doctor, but the doctor himself was confused and could not diagnose the pain and only gave me some medicines like multivitamin tablets. (Buddhist male, 20s, impaired as a result of polio)

A Muslim man with a hearing impairment described his frustrations with seeking care and advice:

My parents showed the doctor when I was young. At that time the doctor said now he is very young, we can’t operate until after he is eighteen. After I was eighteen I went to a doctor, an ENT doctor. Then he said now we can’t do anything here, you can do something outside. Then the next day I went again, please can you write me a paper, then I am going to show it to some
doctor outside. This time he said don’t go there, there they also can’t do. So I never went . . . The amchi says here is some very thin thing, there is some problem with this . . . If some people have pus coming out, then he can put fire. He said now you don’t have pus, that is why I can’t do anything. You should go to the doctor. And the akhon also says you should go to doctor. The doctor also can’t do. (Muslim male, 20s, hearing impairment)

The wife of a Muslim man with vision impairments explained why her husband no longer seeks care for his eyesight:

Doctors said he can be treated successfully, but then we checked in our religion and it is said that the eyes will be okay but something bad will happen in the family. The akhon said if he has an eye operation something bad would happen in your family. So he never went for any treatment and he never goes to anyone about his eyes. (Muslim female, 20s, wife of man with vision impairment)

Interviews with professionals in the study provide further insight into this complex web of seeking health and religious care and advice. The Shia sheik explained that if a person with a disability visited an akhon about whether or not to go to a doctor or pursue a particular treatment that the akhon reads a book and says whether making a particular decision would be right or bad. He may also recommend doing a particular prayer. A monk described that disability is caused by karma and therefore a rinpoche would tell someone it would be futile to take their child outside to seek the care of a doctor. A geshe was adamant that if you believe in the lama or rinpoche you should first go there, and only after to a doctor. If it is karma it cannot be cured. A lha-mo and her family said that those who are born disabled cannot be cured, otherwise she does try to cure them. They went on to explain that there are some people who have curses. Some should seek the help of a rinpoches, some should take medicines, some should do particular prayers. The lha-mo can see these things and advise whether to go to a doctor, amchi or rinpoche.
One amchi says that if someone with a fracture comes to him then he tells them to first go to the doctor and get an x-ray, then he can treat them, but only after he feels the x-rays and his medicine are matching. Another said if he has been treating someone with a disability for a long time and they are not improving then it is the result of karma and they should be doing prayers. An amchi nun indicated that because the rinpoche knows your karma and thus why your body is the way it is, he can suggest whether you should seek care from a doctor because of an accident, or seek a cure from an amchi, or you should just be doing prayers.

A therapist gave an example of how even those providing care can face challenges with limited resources in Ladakh.

We focus especially on kids with cerebral palsy since birth. And we are really doing research about their diagnosis. If we are not finding a diagnosis from doctors, we are sending the reports to Germany and they are sending back the real diagnosis. Then we are doing the treatment. Without a diagnosis we cannot give treatment, because sometimes it is risky. We are not taking risks. So we are first consulting with the doctors from Leh . . . If they cannot tell or cannot diagnose we are sending reports like x-rays, lab tests to Germany, or also to Delhi. (Buddhist female, therapist)

**Daily Life and the Physical Environment**

This section explores data most relevant to the second study objective: to identify the distinct challenges that the physical environment in Ladakh poses to people with disabilities. This is accomplished by looking at the daily lives of people with disability in this study, including necessary daily attention given to the disability, a detailed look at the role of assistive devices in their lives, and finally how the physical environment shapes their daily life.
Daily Attention to Disability

For Ladakhis experiencing disability daily life comes with many challenges. These are often associated with being dependent on assistance from others or using assistive devices in physical settings that are not ideal for their use. Of the 54 people with disability in this study 43 (80%) require daily attention be paid to some aspect of their disability, either on their own part or by their caregivers. This attention ranged from simple exercises or seeking occasional mobility related assistance to being homebound or having total dependence on caregivers. Many (n=29, 54%) were dependent to some extent on others for their daily needs. Some (n=7, 13%) have near total dependence on their caregivers for the basic necessities of daily life including food and water, mobility, hygiene, and in some cases communication. Others (n=11, 20%) are less dependent but are still unable to acquire food and water for themselves. Table 25 outlines the types of daily attention related to disability those with disability in this study require. Some may attend daily to disability issues in more than one category.

Table 25: Daily attention to disability related issues (n=54)

<table>
<thead>
<tr>
<th>Issue</th>
<th>Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total dependence</td>
<td>7 (13.0)</td>
</tr>
<tr>
<td>Homebound</td>
<td>13 (24.1)</td>
</tr>
<tr>
<td>Depend on others for food and water</td>
<td>11 (20.4)</td>
</tr>
<tr>
<td>Need assistance from others for communication</td>
<td>8 (14.8)</td>
</tr>
<tr>
<td>Need assistance from others with mobility</td>
<td>14 (26.0)</td>
</tr>
<tr>
<td>Physical therapy</td>
<td>8 (14.8)</td>
</tr>
<tr>
<td>Attention to time and place*</td>
<td>14 (26.0)</td>
</tr>
<tr>
<td>Intellectual or memory issues</td>
<td>10 (18.5)</td>
</tr>
<tr>
<td>Use of assistive devices</td>
<td>17 (31.5)</td>
</tr>
<tr>
<td>No daily attention needed</td>
<td>11 (20.4)</td>
</tr>
</tbody>
</table>

* For example to be home before dark due to a vision impairment, to stay away from edges of buildings due to leg weakness, or taking precautions in cold weather due to a lack of feeling in a limb.
Of the 13 people (24%) who are homebound, four (7%) are children who are able to leave home a couple times a week because they are picked up in a vehicle to attend either the therapy center or the school for special needs children. It is of note that three of these children live in an urban area and the fourth, though rural, lives very near the main road.

The following interview excerpts provide examples of the daily attention given to disability issues, as well as some of the problems and challenges associated with being dependent upon others. A Muslim man with intellectual disability discussed his difficulty in finding odd jobs he can do:

Yes it is a real problem. If we are doing some work, I can’t think. I have to do all these things and I can’t think. That is why it is a problem. (Muslim male, age unknown, intellectual disability)

The following account is from an elderly Buddhist woman living in a rural area:

My walking problem started about 3 years ago. 15 days ago I started shaking in my whole body. One year before the flood I was not living with this family. The girls and their husband are not taking care of me. They only give food. When walking I am afraid but they don’t help me. I am afraid I will fall, so now I am crawling. When I am walking I am praying to God I won’t fall. I want to die. I am 90, so old, I can’t do anything and they don’t take care of me. It is not important for me to be alive anymore. (Buddhist female, 90s, aging)

A Muslim woman of a child with severe CP described her daughter’s needs:

She knows who is around. She doesn’t cry if we go around doing odd chores or we leave her in the same place. We only need to feed her from time to time. (Muslim female, 30s, mother of child with CP)

A Buddhist woman who is the mother of an adult child with CP described her daughter:

She cannot go alone to Leh. If we send her she does not know how to come back. She stays here and does all the household work, cooking and all the other things. (Buddhist female, 70s, mother of adult child with CP)
A man with an orthopedic impairment talked about the dangers of winter since he does not have full feeling in his foot:

Winter time is a big problem. I wear trekking shoes and three or four socks. The cold causes pain in the foot. I can't tell when it is getting cold. That foot is always cold like stone. (Buddhist male, 40s, orthopedic impairment)

**Assistive Devices**

One of the more interesting topics of discussion and observation during this field research was the use of assistive devices, what Ladakhis refer to as “aids and appliances”, whether they were homemade solutions or brought in from outside Ladakh. Thirty people with disability in this study (56%) used, possessed, or had used at least one type of assistive device. These included wheelchairs, chairs, sticks, a flashlight, rope, blind person’s cane, sunglasses, a dolly like those used to move furniture, eyeglasses, hearing aids, pieces of sheet metal, ramps, special shoes, a Western style toilet35, leg braces, crutches, a scooter, and a cane. However, only 17 people (31%) used an aid daily during the period of this research. Three people used a stick to walk in the past but no longer do so and one used to wear eyeglasses. Two people had hearing aids that they did not use at all. The remaining seven people who had aids but did not use them every day had blind person’s canes or wheelchairs.

A total of the seven people in this study have wheelchairs and three have blind person’s canes. The vision impaired people all stated that they cannot use

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35 Ladakhi toilets are typically a two story structure. They may be located outside away from the house or incorporated as part of the corner of the house itself. In some homes it is the only portion of the second story that is finished. The top floor has a small hole in the ground and mounds of dirt. The user kicks a bit of dirt down the hole after finishing. The lower level has a door to the outside so that the composted contents can be removed to spread on the fields. Disposal of this compost can be a challenge and an expense in urban areas.
their canes in most instances because the ground is too rough and rocky. Only one person uses their wheelchair as their primary means of mobility. Four others with wheelchairs only use theirs when someone takes them in a vehicle to a place where the wheelchair would be useful inside a particular building. None of these people are able to move the wheelchair on their own. The routine typically involves someone carrying the person and then wheelchair separately over thresholds, down stairs, and out through a home’s front gate. The person is pushed some short distance until another obstacle like a stream or a ditch comes up then the process repeats. The remaining two wheelchairs are used only to tie children in a seated position so they can look around within a room at their house or in their yard, a phenomenon witnessed by the researcher among other children with disability who were not part of this study. It is much more common for those whose mobility is limited to be guided by someone, to be carried by someone, to crawl, or use some other means of mobility (like being pulled on a piece of sheet metal like a sled, or sitting on something like a furniture dolly).

The following are examples of the use, or non-use, of “aids and appliances” by people with disability in this study. A Buddhist woman with CP explained that she is unable to sit on the floor in the traditional Ladakhi fashion and described an aid made for her by an amchi:

At that time there were no chairs so he made me a stool made of egg trays and wooden blocks. (Buddhist female, 50s, CP)

The daughter of a Buddhist woman who is blind described how her mother gets around:
She is very active, she walks everywhere. We have provided a very long rope to guide her. She is not able to go outside, not even to the toilet. Sometimes she is going for some prayers, then I am helping her. (Buddhist female, 20s, daughter of woman with vision impairment)

A deaf Muslim man who relies on lip reading commented on his experience:

Some years ago a doctor gave me a hearing machine but I can’t wear this, I can’t hear from this thing. (Muslim male, 50s, hearing impairment)

A young Muslim man with orthopedic impairments described his daily routine and his leg braces:

I can’t move my knees or below. The legs are straight, stiff. I don’t have pain but I can feel them a little bit. I wear these clippers (braces). I had to customize them to attach to my shoes. When they break I just have to figure out how to fix them. I think I have gotten a little better over time. When I was little my mother took me to Delhi to see a doctor. They said if I do regular exercise I will slowly get better. Other than that I only went once to a health camp to get crutches. In the morning I do the exercises I have done since I was a child, straightening and folding the legs using my arms. (Muslim male, 20s, orthopedic impairments)

A Muslim mother of a child with CP described how they use her assistive devices:

We bought her some special shoes but right now she is not using them. In winter time when we are free we practice walking with these shoes. It is a problem because she is stronger than me. She uses the wheelchair for going to school. We push her in the chair from outside the house to the road, and then she gets into the vehicle. (Muslim female, 30s, mother of child with CP)

**Challenges with the Physical Environment**

The physical environment in Ladakh – the steep rocky terrain, the snowy winters, and even the desert dust – are not just a problem for those who could be using a wheelchair or a blind person’s cane. Beyond the daily attention to disability described above, most (n=43, 80%) experiencing disability described further challenges they face due to the physical environment and getting around in Ladakh (Table 26). The semi-structured interview specifically asked whether those people
with disability in this study had any problems due to the environment in Ladakh, for example related to the weather, pollution, or the altitude. They were also asked whether they had problems with the landscape, for example the rocky terrain or hills. One question asked whether they had any problems with the way things are built in Ladakh, for example whether they had problems with stairs, ladders, bridges, curbs, or roadside gutters. While responding to these questions some participants also elaborated with general issues they have with getting around in Ladakh, for example with riding buses or walking long distances. Table 26 shows the number of people with disability in this study who face challenges with aspects of the physical environment in Ladakh.

**Table 26: Challenging aspects of the physical environment (n=43)**

<table>
<thead>
<tr>
<th></th>
<th>Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Environment</td>
<td>19 (44.2)</td>
</tr>
<tr>
<td>Landscape</td>
<td>34 (79.1)</td>
</tr>
<tr>
<td>Way things are built</td>
<td>26 (60.5)</td>
</tr>
<tr>
<td>Getting around</td>
<td>26 (60.5)</td>
</tr>
</tbody>
</table>

Many houses are built up onto the mountainsides. The paths to these houses, even in the more urban areas around Leh, can be very steep and rocky and sometimes require crossing streams by jumping from rock to rock or using a narrow footbridge. Within houses one encounters thresholds, stairs, and ladders. Common living areas are often on the roof which is only closed in by a section of wall about one foot high. A Buddhist woman with CP, which she refers to as “sidedness” described her mobility challenges:

Yes, it is a problem walking when there is no flat road. I cannot walk properly on the rocky road and also going up and down is a problem. If I am walking in these places, since the one side is so weak, I get pain in the other leg. I can’t cross a stream by going rock to rock . . . I am not comfortable
going near the edge of the roof. Since the one leg is weak it is always a little bit trembling. I am not comfortable going high places. I can't go up and down the ladder. I do but I am very, very afraid. I can only go up and down a stone stair. (Buddhist female, 20s, CP)

One study participant was a Muslim man with a speech problem that is likely due to cleft palate though that diagnosis was not mentioned during the research. He described his problems with the environment in Leh:

Yes, sometime there is too much irritation because of vehicle sounds, air pollution, and noise pollution. Irritating my mind. And eyes. Yes it causes a problem with my eyes. I am always walking on the road. Sometimes the problem with this lip causes me breathing problems. (Muslim male, 40s, speech)

A Buddhist man described his breathing problems which are exacerbated by his kyphosis:

When I am going to the high, high place it is a problem because of altitude. I have a breathing problem. Also when walking. When I go home, which is far from the gompa, I have this breathing problem. The bus does not go there, so I have to walk and I have a problem breathing... Actually it is a breathing problem in Ladakh. When I go out of Ladakh I can breathe normal. I often go outside of Ladakh during winter for about three months. (Buddhist male, 30s, kyphosis)

Kyphosis can also cause mobility problems as described by this Muslim woman:

Mostly I am at home. It is hard to go places far away. Yeah it causes problem (the landscape) but I'm not going to rocky places or hard places. I'm not going, yeah it is a problem. (Muslim female, 30s, kyphosis)

A Muslim man with a vision impairment described his experiences of the difference in environment between urban and rural areas:

I feel some pain like irritation in my eyes. When I go to Leh I have some trouble as there is smoke from vehicles and lots of pollution, but in the village I don't have much problem. (Muslim male, 30s, vision impairment)

A man with mobility impairments as a result of polio described the challenges of living in the remote primarily nomadic area of Ladakh during winter:
Yes it’s really very hard, especially in winter it’s very hard to live in Chang-Thang, especially in winter when there is snow. Since there is a lot of snow all the clothes get frozen and it’s difficult to walk. It’s better to live in Leh. (Buddhist male, 30s, impairments as result of polio)

As noted in a previous section some people with disability in this study depend on others daily for their mobility (n=14, 26%). Four (7%) need a guide due to their hearing impairment and six (11%) need a guide due to their vision impairment. The everyday dangers associated with being deaf or vision impaired in Ladakh are substantial. For example, irregular and uncontrolled traffic patterns make the use of automobile horns a critical part of Ladakhi transportation habits. It is often only a low growl that alerts one to the mood of a stray dog you may be passing. Public announcements are often made over a loud speaker or megaphone. Talking on a cellular phone has all but replaced face-to-face encounters as the prime medium for social interaction, particularly for younger Ladakhis. In recent times, noise was the first indicator of flash floods and landslides. For the vision impaired the uneven, rocky, and often steep terrain makes walking without a guide nearly impossible. In addition, walking around in Ladakh, in both urban and rural settings, often involves climbing walls, hopping from rock to rock to cross water, or avoiding stepping on lounging animals. As for those with hearing impairment, unregulated and unpredictable traffic patterns are hazardous for those with vision impairment. Ladakhis with hearing or vision impairments do not often go places alone, but rely on their social networks to keep them safe.

Psycho-Social Aspects of Living with Disability

Many of the physical challenges faced by people with disability in Ladakh are closely linked with challenges associated with emotional well-being and the
necessary social management of living with a disability, whether as a person with a
disability or as a family member. A paralyzed Buddhist man’s description of his
experiences illustrates the relationship between the physical environment and the
social management of disability:

There is a real problem because of the landscape and also stairs. Some
relatives invite me to lunch but I am not feeling comfortable. Then people
have to carry me, there is no flat land, because of the stairs I can’t go there. I
am never going there. Ten years ago my father died. I went to my home, for
the first time in seventeen years. This was a big problem. I couldn’t even go
inside of the house. It was summer time. I slept outside. Some people
offered to help but I was uncomfortable. Also sometimes I had to go to the
toilet and did not feel comfortable. I am only comfortable at home where I
can get around on my own with my wheelchair. (Buddhist male, 40s,
paralysis)

The semi-structured interview had a series of questions about opportunities,
relationships, concerns about the future, and goals for the future. A theme that
emerged from these questions, and throughout fieldwork, was that people were
quite concerned with issues related to the social management of disability. This
section provides data and narrative examples from family members and people with
disability, including how different groups may have perceptions of the disability
experience, lending insight into the first objective of this study by showing how
attitudes vary among different types of study participants. The influence of religion
on experiences and variations between Buddhists and Muslims are also explored,
objective three. This section thus continues to demonstrate the complex interplay
between the three study objectives.

**Opportunities**

Of the 62 people with disability and family members of people with
disability, 58 were asked whether or not they think disability has affected the
opportunities of the person with disability (Table 27). Family members were more likely to report that disability had affected opportunities than were people with a disability. Buddhist people with disability were somewhat more likely to express that their disability had affected their opportunities (n=16, 76%) than their Muslim counterparts (n=9, 60%). Similarly, rural people with disability were more likely to express that their disability had affected their opportunities (n=16, 73%) than their urban counterparts (n=9, 56%). There was no difference between male and female people with disability. There were no consistent patterns among people with disability in relation to level of education, employment status, marital status, or age categories. Among family members, there was no difference between Buddhists and Muslims. Females were less likely to say their disabled family member’s opportunities had been affected (n=13, 81%) than their male counterparts (n=4, 100%).

Table 27: Disability affected opportunities

<table>
<thead>
<tr>
<th>Interviewee</th>
<th>Yes (%) (n=42)</th>
<th>No (%) (n=16)</th>
<th>Total (%) (n=58)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with disability</td>
<td>25 (65.8)</td>
<td>13 (22.4)</td>
<td>38 (100.0)</td>
</tr>
<tr>
<td>Family member</td>
<td>17 (85.0)</td>
<td>3 (15.0)</td>
<td>20 (100.0)</td>
</tr>
<tr>
<td>Total</td>
<td>42 (72.4)</td>
<td>16 (27.6)</td>
<td>58 (100.0)</td>
</tr>
</tbody>
</table>

Several participants (n=12, 21%) expressed that many or all opportunities had been affected. Other frequently mentioned types of opportunities that were lost or affected were the ability to pursue or continue their education (n=17, 29%), to get good jobs (n=12, 21%), to get married (n=6, 10%), or to have a typical social life (n=9, 16%).
A Buddhist man who walked with a cane because of a bad knee described how his disability had affected his opportunities:

There has been too much effect on my opportunities from this knee. If I didn’t have this problem then I can do any kind of job, can live in a separate home, and can arrange for myself. I could also get an education so I could get a private job, I could join the army. (Buddhist male, 30s, orthopedic impairment)

A woman who has an adult brother who is deaf described her feelings:

Yes I think I feel so much pity. I feel that he is spending incomplete life. He can't hear, can’t communicate. And even he can’t get married. He had only half opportunity. (Buddhist female, 40s, sister of man with hearing impairment)

Some Ladakhis with disability are particularly isolated, primarily homebound until something prompts change. A Buddhist man with CP described his experience:

Until I was eight years I did not go outside, I was always staying at home. Then one day when my younger brother was going to school I thought I should go with him. One headmaster came saying he can’t be admitted in our school. One teacher was helpful for me and got me admission. Some people still do discriminate. If going to ask for a job they say you can’t do things, you just sit at home. Many people are saying things like this. Also, sometimes even your own family says you can’t do the big job. (Buddhist male, 20s, CP)

**Relationships**

Of the 62 people with disability and family members of people with disability, 57 were asked whether or not they think disability has affected the relationships of the person with disability (Table 28). People with a disability themselves were more likely to note that their disability affects their relationships than were family members of people with disability. Females with disability were more likely to feel that relationships had been affected (n=10, 77%) than males (n=13, 54%). This was similar to reports from female family members (n=8, 50%) compared to males (n=1, 25%). Disabled Buddhists were no more likely to express
that their disability had affected their relationships than Muslims, nor were there
differences between those living in urban versus rural areas. However, Buddhist
family members did say it had affected the relationships of their family member
(n=7, 54%) more frequently than Muslims (n=2, 29%). Among people with
disability, those with more education were less likely to express that their disability
had affected their relationships. All people with disability with no education said
their relationships were affected (n=7), as did many of those who attended fifth
class or lower (n=8, 89%). There were no consistent patterns among people with
disability in relation to employment status, marital status, or age categories.

<table>
<thead>
<tr>
<th>Interviewee</th>
<th>Yes (%) (n=32)</th>
<th>No (%) (n=44)</th>
<th>Total (%) (n=57)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with disability</td>
<td>23 (62.2)</td>
<td>14 (37.8)</td>
<td>37 (100.0)</td>
</tr>
<tr>
<td>Family member</td>
<td>9 (45.0)</td>
<td>11 (55.0)</td>
<td>20 (100.0)</td>
</tr>
<tr>
<td>Total</td>
<td>32 (56.1)</td>
<td>25 (43.9)</td>
<td>57 (100.0)</td>
</tr>
</tbody>
</table>

Participants mentioned relationships with family (n=8, 14%), relatives (n=18, 32%),
friends and neighbors (n=9, 16%), and other villagers or the public (n=6, 11%)
being affected by disability. One interesting note is that 3 people with disability
mentioned that their relationships improved once they had an income. This concern
about income came up even more frequently when discussing concerns and goals
for the future.

A Buddhist with an orthopedic impairment described challenges with his
relationships:

My brother and I have one wife and three children. Now that I have become
a handicap, now they don’t care for me much. Now we are living separate.
Until now we can’t decide what to do. Sometimes I can go there. If I want I
can go, but they are not showing too much love, the both of them, and she is
mean toward me. I am just going to visit the children. (Buddhist male, 30s, orthopedic impairment)

A Muslim man with a hearing impairment described his experiences:

I am never going to the relatives when there is some event. They have a problem understanding me, and I also don’t understand them. That is why I am never going anywhere, not even to relative’s homes. (Muslim male, 20s, hearing impairment)

Communication challenges and social isolation are a significant reality of everyday life. Education trends in Ladakh, though helpful to some, have complicated communication in Ladakh generally. Basic schooling has gone from being conducted primarily in Urdu, to now Hindi and English, and more recently includes some written forms of Ladakhi. To make matters worse, it is now fashionable for those educated outside of Ladakh to mix English and Hindi in everyday speech. When they return to Ladakh they mix all three languages. Therefore communication challenges go beyond those attributable to different Ladakhi dialects to those associated with timing and location of one’s education. People with disabilities are at a distinct disadvantage, particularly those with hearing impairments. Level of education and age at onset, due to the effect on speaking and reading abilities, are the most important factors impacting the level of social challenges those with hearing impairments face.

Some disabled participants faced greater challenges with their relationships than others (n=17), and described incidents of abuse, neglect, or mistreatment. Most participants and acquaintances of the researcher did not talk openly about abuse of disabled people. Participants were not specifically asked about forms of abuse or neglect so these numbers only reflect those who volunteered such
information. Two people with disability, and one parent of a child with disability, reported having been left by a spouse due to the disability. Five people with disability reported physical abuse at some point in their lives, three by family, one by a teacher, and one by other kids. Three reported being made to do all the household work while others in the house were not doing work. Three participants reported being kept primarily in their house for a number of years as a child, isolated from neighbors and relatives, one even made to live separately in the old house. One participant was pregnant and was unable to explain who the father was, a situation that will be extremely difficult for them socially in the future. During the researcher’s time in Ladakh three other cases of deaf and dumb pregnant women were being investigated. In cases where the woman could identify the father, child custody and child support terms were being handled through the legal system.

Four participants reported neglect, in these cases in the form of not getting necessary assistance for daily needs, or having not been giving enough food as a child. Two of these people were elderly. Some village participants (n=11) were asked whether they knew people who have trouble with daily activities. Of the four who said yes, two reported that those elderly were not being well taken care of by their family members. During a conversation with the Sunni sheik about helping people with disability, he said there are problems in Ladakh, particularly for the elderly.

The couples they are employed, wife and husband, and they are leaving their aged parents in villages. They are cared for there by child nephews and grand-daughter-in-laws. This is not good. (Muslim religious specialist)
He went on to say that the old age home at Mahaboudi is a shame for Ladakhis, emphasizing that it is good, they are doing good work, but that the need for this home is a shame. In general, for elderly study participants and acquaintances of the researcher, the circumstances of those living with their own children seemed to be slightly more favorable than those who were either living with the children of one of their siblings, or with a child they had adopted (most typically as a young adult). These latter types of arrangements are common among Ladakhis with no children of their own. Regardless of whom one lives with, the contribution of a pension or other source of household income, for example by a retired member of the military, seemed to result in an easier life.

**Concerns and Goals for the Future**

Of the 62 participants who completed the semi-structured interview 58 were asked whether they have concerns about the future for themselves or their family member (Table 29). Though there was not much difference between people with disability and their family members, Muslim family members were more likely to express concern about their loved one’s future \( (n=7, 88\%) \) than Buddhist family members \( (n=10, 67\%) \). There were no consistent patterns in relation to education status, age categories, urban or rural living, gender, or other variables.

**Table 29: Expressed concerns about the disabled person’s future**

<table>
<thead>
<tr>
<th>Interviewee</th>
<th>Yes (%) ( n=45 )</th>
<th>No (%) ( n=13 )</th>
<th>Total (%) ( n=58 )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with disability</td>
<td>28 (80.0)</td>
<td>7 (20.0)</td>
<td>35 (100.0)</td>
</tr>
<tr>
<td>Family member</td>
<td>17 (74.0)</td>
<td>6 (26.1)</td>
<td>23 (100.0)</td>
</tr>
<tr>
<td>Total</td>
<td>45 (77.6)</td>
<td>13 (22.4)</td>
<td>58 (100.0)</td>
</tr>
</tbody>
</table>
Fifty-five participants were asked whether they have goals for the future (Table 30). There were no demographic variables that differed significantly from these findings, including any notable differences between Buddhists and Muslims with the exception of marriage which is discussed further below.

**Table 30: Expressed goals for the disabled person’s future**

<table>
<thead>
<tr>
<th>Interviewee</th>
<th>Yes (%)</th>
<th>No (%)</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with disability</td>
<td>30 (85.7)</td>
<td>5 (14.3)</td>
<td>35 (100.0)</td>
</tr>
<tr>
<td>Family member</td>
<td>15 (75.0)</td>
<td>5 (25.0)</td>
<td>20 (100.0)</td>
</tr>
<tr>
<td>Total</td>
<td>45 (81.8)</td>
<td>10 (18.2)</td>
<td>55 (100.0)</td>
</tr>
</tbody>
</table>

All participants elaborated on their yes or no answers to one or both of these questions. They typically mentioned the same themes when describing their concerns and goals for the future. These themes were the same for both people with disability and family members. A main focus was how the person with disability would be cared for when they are old. Some worried about who would care for them (n=24, 41%). While some expressed concern about the person with disability not having children, others mentioned that you cannot trust the children of today anyway. Many mentioned saving money for future care (n=16, 31%), or needing a job (n=14, 24%). Some participants however were most concerned about their present financial situation and needs (n=6, 10%).

A woman with an intellectual disability expressed her concerns about who will take care of her in the future:

I worry about the future. I don’t believe my brothers will take care of me. I have one sister I believe will take care of me. Maybe later it won’t be like this. (Buddhist female, 20s, intellectual disability)

Another Buddhist woman described her concerns for her daughter's future care:
I worry about her future but I hope her sister will look after her. Actually now she is doing all the housework. She is doing too much in the house. That is why I am not worried that her sister will look after her. But sometimes she says to me – mother if you are not there then who will take care of me? (Buddhist female, 70s, mother of adult child with CP)

The wife of a Muslim man with a vision impairment described her worries:

I have some tensions. I think that right now he is able to do things on his own, but later, in the future, when he becomes old what will happen? These thoughts give me worries and tensions. We cannot trust the children of this generation to care for their parents. (Muslim female, 20s, wife of man with vision impairment)

Money is often considered, at least in part, one solution to being cared for in the future. A Buddhist man with kyphosis described his worries:

Now I am unmarried. My brother’s children are looking after me. I worry about the future. I don’t want to get married. I am just worried who will take care of me when I am old . . . I deposit some in the bank for life insurance. One day when I am old maybe this money will be used for me. My brother says maybe one of his children will look after me. I can’t believe it. One day they can leave. That is why I did this life insurance. (Buddhist male, 40s, kyphosis)

Another described the importance of money:

If I have no money then who will care for me. (Buddhist male, 30s, orthopedic impairment)

An aging Muslim father of a child with vision impairment described how he is planning for his son’s future:

While I am alive I get some pension. So I save it only for him and the rest I leave to God. So I have some concerns about him, but I have no other worries. (Muslim male, 70s, father of adult child with vision impairment)

A Buddhist mother similarly described how she is saving for the future of her child who has severe CP.

Now I am depositing 500 per month for him. Maybe if his name has some money then some people will take really good care of him. That is my hope. (Buddhist female, 40s, mother of child with CP)
Since so many expressed concerns and goals it is interesting to know what those who were not that concerned about the future had to say. Three examples nicely summarize their thoughts. A Buddhist man who has a sister with a hearing impairment, though he does not live with the family is not worried:

No, I think there will be people making sure she is okay. (Buddhist male, 30s, brother of woman with hearing impairment)

A Muslim man described his feelings:

No, I don’t worry much. I am happy with my life. I don’t feel sad. I believe we cannot stop things which are bound to happen. So I do not have even a little worry about that. (Muslim male, 30s, vision impairment)

Another Muslim man expressed his thoughts:

If we have managed until now then we don’t need to worry about the future. (Muslim male, 40s, orthopedic impairment)

Some of those who stated they had no goals for the future were young and did not know what to say or were shy about this question. Others expressed the sentiment that they have already done what they can to prepare for an unpredictable future. A Buddhist mother described her feelings:

I am not hoping he will get well. While we are alive he may not face any problem but definitely he will face problems in the future. Yes, I have collected some money but it is very difficult to trust even the children these days. I have never thought my daughter would help. Who knows if she is married, we can’t trust the children of these days. (Buddhist female, 30s, mother of child with CP)

The topic of marriage was discussed with many participants. For those who were unmarried this topic most often came up in interviews that included the questions explored in this section. Among people with disability in this study Muslims were more likely to either be married or hope to get married in the future
than Buddhists. Of the 54 people with disability in this study eight (24%) Buddhists were married or widowed, nine (50%) Muslims were married, and two (100%) Christians were married. Discussions about hopes, expectations, or goals for getting married in the future were part of interviews regarding most unmarried people with disability in this study, with the exception of monks and severely disabled children. If participants indicated, for example, they would like to get married someday or are saving money for future children, they were coded as having an expectation of getting married. If, on the other hand, they said, for example, they would never or could not get married they were coded as not having an expectation of getting married. These data, along with the demographic data for 43 people with disability in this study and is presented in Table 31.

<table>
<thead>
<tr>
<th>Table 31: Marital status or expectation of marriage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Buddhist (%)</td>
</tr>
<tr>
<td>(n=27)</td>
</tr>
<tr>
<td>Married or expectation of marriage</td>
</tr>
<tr>
<td>Not married, no expectation</td>
</tr>
</tbody>
</table>

The following section explores in more detail general attitudes among study participants about people with disability in Ladakh.

**General Attitudes about People with Disability and their Needs**

Participants who completed semi-structured interviews were asked a series of questions that were originally designed to provide insight into attitudes toward disability in Ladakh, objective one. These questions were also meant to gauge awareness of the types of programs and services available to people with disability and their families and to provide additional insight into some of the barriers they may face in meeting their needs. These questions included whether or not they
thought Ladakhis with disabilities could do the same things as other Ladakhis, what kinds of things Ladakhis with disabilities need, what changes could be made in Ladakh to make life easier for people with disability, and whether they knew of any programs or services for people with disability.

**Attitudes and Needs**

A total of 58 participants were asked whether they thought Ladakhis with disabilities could do the same things as other Ladakhis. Of these 23 (40%) said yes, 33 (57%) said no, and 2 (3%) said they did not know (Table 32). Interestingly there was a notable difference between urban and rural participants. Among urban people 50 percent (n=10) said yes and 50 percent (n=10) said no. Among rural respondents only 34 percent (n=13) said yes, 61 percent (n=23) said no, and five percent (n=2) said they did not know. Of course many responses were more nuanced.

**Table 32: Attitudes about whether people with disabilities can do the same things as other Ladakhis**

<table>
<thead>
<tr>
<th>Interviewee</th>
<th>Yes (%)</th>
<th>No (%)</th>
<th>Don’t Know (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with disability</td>
<td>15 (44.1)</td>
<td>19 (55.9)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Family member</td>
<td>8 (36.4)</td>
<td>12 (54.5)</td>
<td>2 (9.1)</td>
</tr>
<tr>
<td>Not disabled, not family member</td>
<td>0 (0.0)</td>
<td>2 (100.0)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>23 (39.7)</td>
<td>33 (56.9)</td>
<td>2 (3.4)</td>
</tr>
</tbody>
</table>

A Buddhist woman who worked at an NGO that served people with disabilities said:

Not all have trouble but maybe from their families there is some affect from when they were young – from the family saying you are disabled you can’t get married. This has some effect on their mind. They can do all things but sometimes the way people think can be a problem. (Buddhist female, 30s, NGO)
A Buddhist woman with a disability felt:

It is possible if we try. Trying is very important. Yeah it is possible. Why not? Everyone should try . . . Every disabled has to try to learn a thing, then it is possible, everything is possible. Same as non-disabled. (Buddhist female, 30s, person with disability)

A Muslim man with a disability said:

Some people can do, some people cannot. If they are visually impaired they cannot do, they are just sitting. (Muslim male, 50s, person with disability)

A Buddhist religious specialist provided his insight:

This is difficult. How? If no feet, no hand, how can they do their working in society, in their village? We want to help them. This is our work. Disability people don’t help society, we help them. (Buddhist male, 30s, religious specialist)

A total of 58 participants provided details about perceived needs of people with disabilities in Ladakh, or changes that could make life easier for them. Some participants did not really know other people with disabilities beyond themselves or their family. Therefore they may have only mentioned things that they themselves felt they needed. Nevertheless, their answers were not notably different from those who elaborated more generally about the perceived needs of people with disabilities in Ladakh. Table 33 shows the most frequent answers that were given. Some of these answers overlap with one another, for example those who said “facilities” meant health care, education, job training and schools, et cetera. Those who said jobs meant money, but those who said government assistance may have also meant money. Of course many respondents cited more than one answer.
<table>
<thead>
<tr>
<th>Need</th>
<th>Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jobs and job training</td>
<td>19 (32.8)</td>
</tr>
<tr>
<td>Aids and appliances</td>
<td>16 (27.6)</td>
</tr>
<tr>
<td>Education, a school</td>
<td>14 (24.1)</td>
</tr>
<tr>
<td>Good treatment</td>
<td>13 (22.4)</td>
</tr>
<tr>
<td>Facilities</td>
<td>10 (17.2)</td>
</tr>
<tr>
<td>Special doctors or therapists</td>
<td>7 (12.1)</td>
</tr>
<tr>
<td>Awareness among PWDs and public about disability issues</td>
<td>6 (10.3)</td>
</tr>
<tr>
<td>Money</td>
<td>5 (8.6)</td>
</tr>
<tr>
<td>Government assistance</td>
<td>4 (6.9)</td>
</tr>
<tr>
<td>Other (warmth since it is cold, they should do prayers)</td>
<td>4 (6.9)</td>
</tr>
<tr>
<td>Accessibility</td>
<td>3 (5.2)</td>
</tr>
</tbody>
</table>

Barriers to meeting needs were also a frequent point of discussion, along with the perceived needs themselves. A Buddhist man who had been disabled for many years expressed his frustration with the concept of *karma*, the assumption that the person or their parents have done something bad. He felt this causes disabled people to stay at home, or be kept at home by their family. He described how even when there are some special doctors visiting Ladakh, families do not bring their disabled because they feel shame. He has been outside Ladakh and has seen what disabled people can do. He thinks Ladakhis could do these things too, and hopes awareness of disability, perhaps through television, can make a difference in Ladakh. His answer to the question about what disabled Ladakhis need reflects these views:

*Aids and appliances. If some people can’t walk, then wheelchairs. Some people need a stick. And also a leg. This is very important … If some people come and give awareness to the disabled. Many, many disabled people are not going outside. They are always sitting at home. And also the government sometimes provides wheelchairs and sticks from outside, from India. Some people bring them. The disabled should go there. They should come out.*

(Buddhist male, 40s, with disability)
A religious specialist said:

The most important need is the warm temperature, and one who talks to them in a polite way, and one who takes care of them. They need a warm place. They need food and one who cares, and a doctor among doctors. They need many facilities. Good food, energetic food. And caring, yeah caring . . . They have to have more facilities because most of the disabled children belong to the poor families of Ladakh. I think so. Wheelchairs and medicine. (Buddhist female, religious specialist)

A disabled Muslim woman said:

In Ladakh we need anything, any kind of thing. Money also. If the disabled person has money then they interact with other people. Then they can do everything the same like other people. (Muslim female, 30s, person with disability)

An educator described her views based on experience she had working with disabled children. Her views in some ways are in contrast to other specialists who feel Ladakhis should be working toward inclusion, not always separate facilities.

The details though can be complex:

They need to have one place where these children can go. Someone who is following them for therapy, for some special teaching, for the parents to received notes and suggestions and information about how to help them. Now we are all different organizations and we have to be in touch, in contact with everyone. Collaboration is very important because we are working with the same people, so just work together, not everyone working separate. Now we are slowly starting to work with the government too. I think it is very important to work together and offer these families some place to help them. I have so many coming to ask, they are coming and saying please, please my daughter has been sitting seven years at home. She is doing nothing, she can walk, she can speak. (Female, educator)

Programs and Services: Awareness and Barriers

Fifty-four study participants were asked whether they knew of any programs or services for people with disability in Ladakh. Of these 74 percent (n= 40) said yes. Some of those (n=11, 20%) stated they only knew of PAGIR, leaving only 54 percent (n=29) more broadly aware of programs and services for people with
disability in Ladakh. However, fieldwork data suggests 36 (68%) people or families were actually taking advantage of a program or service. Even if they knew about programs or services, even if they were actually using them, there were still a variety of barriers to using those services. This excerpt is from the researcher’s field notes after visiting a Buddhist household with a disabled child:

In winter he does his exercises on sunny days and at night near the heater. The past couple of years he has not been going to the school for therapy like he used to. He is getting too big to move out to a car. It is quite a distance to any road, pretty much straight up hill for a long way in one direction, and even farther the other way with a narrow stream and brush along most of the path. The therapists now come to him about twice a month. (researcher’s field notes)

A disabled Muslim man described his difficulty obtaining the proper paperwork to qualify for the government jobs that are reserved for people with disability, one among many hurdles for those seeking these jobs:

I’m looking for another job. I applied for the government job as peon but was not selected. And also the ENT doctor did not give me the disabled certificate. [Another doctor] gave it, but many places do not accept that physician’s certificate, they have to get the ENT certificate. (Muslim male, 20s, person with disability)

A mother of a child with CP described her reasons for not taking her child for physical therapy:

Some people came from that office. But I did not take her to the therapy office because it did not seem to help. I could not take time out for that as I was busy moving from here to there. (Muslim female, 30s, mother of child with CP)

A local woman who worked at an NGO described ways they were trying to accommodate people with disability who were otherwise likely homebound:

We are doing some home visits. One child has a problem that she cannot move and since it is far we cannot get her to the therapy center. She is also older and she feels ashamed to go out of the house, but we are taking her out
during therapy. We are taking her out on the road, taking her to the monastery, things like that. (Buddhist female, NGO)

At the end of the semi-structured interview 65 participants were asked whether they thought life in Ladakh was easy or hard. Among Buddhists (n=42), 45 percent (n=19) thought life was easy in Ladakh, 45 percent (n=19) thought it was hard, and 10 percent (n=4) thought it was both easy and hard. Among Muslims (n=14), 67% thought life was easy in Ladakh, 28 percent (n=6) thought it was hard, and five percent (n=1) thought it was both easy and hard. Among Christians (n=2), none thought life was easy in Ladakh, 100 percent (n=2) thought it was hard, and none thought it was both easy and hard.

The following section takes a more intimate look at the daily lives of people in Ladakh who are experiencing disability, drawing together the findings presented thus far in this chapter.

**Case Studies: Experiences of Disability in Ladakh**

In the daily lives of Ladakhis experiencing disability components of all three study objectives intersect and have a dynamic relationship with one another. The influence of attitudes, customs, the physical environment, and religion cannot be separated from one another throughout the day. By combining data collected during a year of fieldwork – visiting most families several times, having conversations, conducting interviews, and observing their daily routines – it is possible to piece together how the study objectives fit into reality. This will be explored through the following case studies. Four case studies are presented, those of two Buddhist families and two Muslim families. Pseudonyms are used.
Singey is a 23 year old man who lives with his father and younger sister in his mother's village. His mother died many years ago following an illness. These days Singey never leaves his house except to sit out on the porch that overlooks his walled-in yard where he tends a small vegetable and flower garden. This routine is very different from just a few short years ago when he was living outside of Ladakh going to school, roaming around with friends, and only visiting home a couple months each year during his summer holiday. While he was away at school he was involved in a traffic accident.

Initially, Singey was paralyzed from the neck down and remained in a hospital outside Ladakh for seven months. His father closed his shop and house; his sister stayed with relatives. His father stayed at the hospital to help Singey and sold the car to pay the hospital bill. In general hospitals in India will not provide therapy or perform surgery unless there is a family member there to take care of the patient. In this regard Singey was lucky that his father could afford to come, making it possible for Singey to have the operations and subsequent physical therapy he needed.

When Singey returned to Ladakh there was a flurry of activity aimed at helping him recover. Physical therapists began coming to the house, an amchi was consulted, and religious activities began. Buddhists are taught to pray for all living beings, but not for themselves. During morning prayers they light butter lamps and offer water to the gods. Indirectly, praying for others increases your own merit and is good for future rebirth. The closest thing to praying for yourself is when a
Rinpoche tells you to do certain prayers or rituals to get well or overcome some problem. Instead, to have prayers for your household or an ailing individual, others are enlisted to pray for you. Singey’s father hosted a large puja, with 13 monks coming to the house and around 50 people helping. He even had a rinpoche come to the house. The rinpoche provided instructions for hanging prayer flags and reassured Singey that one day he would get better. Singey’s father spent a lot of money during the first couple years after the accident, paying monks 150 rupees per day to say prayers for Singey, feeding all the monks and villagers for the pujas at their home, and consulting with the amchi.

Before he began consulting regularly with the amchi, Singey could not walk at all. After taking the amchi medicine for some time, even paying some Nepali laborers to carry him to a hot springs for treatment with the amchi, he can now walk around his home using forearm crutches. Singey’s father feels it is the amchi medicine that is helping Singey to get better, that the physical therapy and exercises do nothing. Singey, on the other hand, is trying to do everything the rinpoche suggested, take all the medicine the amchi gives, and do his physical therapy exercises regularly. He takes amchi medicine three times each day for circulation and nerves. He says that taking this medicine makes it easier for him to do his exercises, which he does for an hour three times each day, unless it is too cold. His sister thinks he has gotten a lot better since he began taking this amchi medicine.

36 In usage puja applies to all rituals, however small or elaborate.
37 Many Ladakhis referenced receiving medicine from rinpoches as well as advice about rituals or prayers to perform. A rinpoche’s advice about whether or not to pursue other treatments is usually heeded.
Singey’s father does as much of the household work as he can so that his daughter still has time to spend with her friends. When he gets up at 5:30 he gets water for the household and the gardens, though he says sometimes this is hard to find. He cares for the cows. He also prepares breakfast for the family before leaving for work. Singey’s sister does a lot of the household work. After school she prepares lunch for Singey and works on her homework. Sometimes she takes a little time to play outside before preparing dinner with her father. Her father spends Sunday, his day off, doing more difficult chores. Lately he has had to spend several days working at the monastery, which means he has to close his shop. Though he realizes this is his duty, assigned to villagers by the monastery on a rotating basis, he feels the financial strain.

Singey feels like he makes a lot of progress during the summer when the warmth makes doing his physical therapy exercises easier. In winter he struggles to move as easily. His body gets stiff, and he cannot do his exercises in the cold. He tries to position himself in a sunny spot in the room so he can absorb as much warmth as possible. Even so, he loses much of the progress he made over the summer. Still, year by year he is a little bit better. He has, he must remember, gone from being in a wheelchair to walking with forearm crutches around the house in just a few years. His physical therapist comes to his house one or two times each month to show him exercises. He wishes he could go to a gym because he feels like he could make a lot more progress doing the kinds of exercises you can do at a gym, like the therapy room in the hospital outside of Ladakh. Not only would it be expensive to go to the private gym in Leh, he has no way to get there. It would
require someone taking him, staying with him, and bringing him home. He does not have relatives available to do that, not to mention the road that goes from the main road to his part of the village has been closed for many months. Already his medicine from the *amchi* costs his father enough money.

Singey is frustrated that he has not been able to finish his studies. When he first got home he was very bored spending most of every day home alone. Now he is used to it. His only real worry is the uncertainty of his future. He feels bad about the burden on his father and his sister since he cannot help around the house and they have to help take care of him. Singey's father would like for him to be able to continue his studies at home, but the private teacher is too expensive. He lost everything after Singey's accident and continues to struggle financially. He simply cannot pay for the teacher. He tries to bring magazines and newspapers for Singey to read so he can keep up with learning that way. His financial investment in education has to be toward his daughter now, who takes her studies very seriously and hopes to attend college outside of Ladakh one day.

Singey's father worries about saving money for his daughter to marry. He hopes that his daughter and her husband will care for Singey into the future, but he cannot be certain that will happen. He will also continue to try to save money for Singey's future. He says Singey cannot marry if he stays like this, but maybe if he gets better like the *amchi* says he will then he can find someone who would marry him. For Singey's father life in Ladakh is hard. He recalls a time when he became ill and his daughter was away for her studies. For a few days he and Singey only had
boiled water. He feels like if you have someone to take care of you, then life can be easy.

As a young Ladakhi man, who spent a few years away from Ladakh going to school, it is likely that Singey never gave much thought to disability. Now when asked whether he knows any other person with a disability he says no. It is obvious he feels very alone. When asked about people with disability in Ladakh, what they do, what they need, he does not really know what to say. Similarly, his sister does not know any other person with a disability in their village and there are none at her school. All day he is just sitting, but he feels like he could be doing more. He does think he could be sitting there learning to use a computer and maybe someday be able to do some work. The barrier is that he is in a house in a village with no way to get anywhere. He would like to live in an accessible facility where he could also be taking classes. Singey thinks life in Ladakh is both easy and hard. For now Singey is trying not to think too much about the future. He is just focused on getting better. He is planning an outing with his friends the next time they visit, and he is excited for them to see the improvement in his mobility. His father has no doubt the outing will be very good for Singey.

**Shareen, Shia Muslim Woman with Vision Impairment**

Shareen is a 26 year old woman. She has recently obtained a government job thanks to a newly established government program which dictates a certain percentage of jobs are to go to people with documented disability. Shareen was fortunate to get a job from which she will ultimately earn a retirement pension. This type of job is the envy of most Ladakhis. She is very concerned though since many
government workers frequently get re-stationed, having to move from village to village every couple of months, which would distance her from her much needed family support. In fact her father is stationed elsewhere for his government post and is only home on Sundays. Shareen has night blindness and very much relies on her mother and sister for many of her daily needs.

Shareen’s mother has a day very typical of other Muslim housewives. She wakes up at 5:00 in the morning, washes, and does morning prayers. After having tea she goes out and gives hay to the cows and collects dung. Shareen makes *chapatis* (a type of flatbread) so they are ready when it is time for breakfast. After breakfast with her mom and sister Shareen walks a half mile to the main road to wait for the bus to take her to work and her sister leaves for school. During the day her mother cleans all the rooms and cares for the animals. She can often be found out near the wall that keeps the animals in the yard gossiping with passing neighbor ladies, a common activity for Ladkahi women to do in their spare moments. Also like other women, she says if she has leisure time she likes to bathe, wash her hair, or tend the garden. In winter she knits. It was not uncommon for women to note the solitary nature of their daily routines. The most cherished moments and memories described by most Ladakhis in this research were associated with spending time with others. Shareen’s mother enjoys the longer days of summer when Shareen returns home from work in time to help with the early evening chores. Shareen and her mother prepare dinner and make the bread dough for the next morning. There are still a lot of household chores Shareen’s mother does after dark when the electricity comes on for a few hours. She uses electric machines for
chores like churning butter and making yogurt and uses an electric water pump to bring water up the side of the mountain to water the household vegetable garden.

Though this may seem like a simple life, Shareen is often sad. She cannot see beyond her very close vicinity and is totally blind after dark. Her mother realized there was something wrong with her vision when she was about two years old and began to walk. When she was outside at night she was just walking here and there with no direction. They took her to a doctor but there was nothing that could be done since she was born with this problem and has three relatives with night blindness. When asked whether she feels her disability has affected her opportunities Shareen immediately brings up the difficulties she has had with her studies. Reading causes pain and watering eyes so her studies were slow and only intermittent. Since she could not read the chalk board at school, or do homework in the evening like other students, she had a private teacher when the family could afford it. She is very proud though, she just recently passed the 11th class exams.

Though she can see at night with the help of a flashlight, it is only very blurry and in the very small area most illuminated by the light. Since getting to the toilet at night requires going outside and climbing a ladder to the second floor she cannot go without both a flashlight and someone to help her. This has always been the routine though. Even in daytime, shadowy areas with low hanging branches are a problem – she often does not see the branches and has been injured several times. She tries to avoid areas with thorny trees or bushes and makes sure to avoid going near the edge of bridges or the roof. What is most upsetting for Shareen is that she cannot do activities with friends or go to special events because she has to be home before the
sun sets. The hours of daylight can be very short during the long winter months in Ladakh.

Since her household is engaged in subsistence farming, Shareen is also often upset about not being able to help out as much as other children, particularly as her parents age and have difficulty with the rocky terrain. Since there is a shortage of water and many families share irrigation canals, it is common to water the fields at night. Shareen's house is in a very rocky part of the village, so their fields are some distance away from the home. When her parents and sister go in the night to work the fields, Shareen stays home. Her mother explains that sometimes watering the alfalfa field takes the whole night, sometimes they wait until 2:00 in the morning for the water to even get to their field. Since they are living on land inherited by their Buddhist relatives a couple generations back, in the 12th month of the Tibetan calendar on the day of the new moon they offer food to the ancestors who once worked their land. Shareen's mother notes that Shareen cannot participate in this annual ritual since it is at night.

Last year Shareen's mother twisted her knee jumping over a canal at night and has had pain in her leg ever since. She was glad her youngest daughter was there to help her. The doctor offered to give her an injection but she is afraid that it could cause a problem with her blood pressure. She is very conscious of her high blood pressure and takes medicine daily. Following the advice of her doctor, she no longer drinks the traditional Ladakhi butter tea. She first consulted a local amchi, who is also a monk, but his medicines did not help. The akhon advised her family to do good deeds such as inviting people, giving them food, and doing prayers.
Eventually she ended up visiting her clinic physician. Even though her husband will only visit a Muslim physician, she actually sees a Buddhist one.

On Sundays, her day off, Shareen helps her mother by doing the laundry. She does not do this the typical way other women do laundry by washing the clothes in a plastic basin then, after squeezing out as much water as they can, laying the heavy wet clothes to dry in the hot sun along the perimeter of the roof where the wall rises a foot or so above the rooftop. Since there is no supply of water to their house and she cannot go up to the roof anyway Shareen carries the laundry filled tub down the mountainside to the valley below where there is a stream. After washing the clothes she lays them out on the large boulders left behind by recent flooding. She comes back to collect the dry clothes before dark.

Shareen has an attitude similar to many other Ladakhi Muslims – there is not much need to worry or be too stressed about life generally. What is meant to happen will happen. It is God’s will. Even her disability was given by God. For now Shareen’s main hope for the future is that her eyes remain healthy, that her vision does not get any worse than what she is used to now. She wears a necklace, or tapiz (amulet with prayers inside to wear as a necklace), given to her by the local akhon to protect her from illness or harm. Once a year the akhon and many people from the village come to the house to perform annual rituals. Food is prepared for everyone and prayers are read for the household and its members to remain healthy and prosperous for the year, a similar tradition is also practiced by Ladakhi Buddhists.

Yet Shareen does not know of any disabled people in her village other than her deaf cousin who lives just down the path. She sees people with disabilities when
she goes places outside the village, but does not personally know any. Her mother on the other hand knows of four others who live between their house and their fields. Ladakhis often do not seem to know many people beyond their family and the immediate vicinity around where they live or work. Even in small villages, houses can be spaced far apart and people do not venture out too far. So it is not surprising that they often do not know of other people with disabilities, particularly since many of them likely stay very close to their house. Shareen and her mother are also typical in that they don’t know much about services or programs available to Ladakhis with disability, other than the widely publicized government pension program and employment plan. Shareen’s mother does not go to Leh because she suffers from motion sickness and worries she will get sick on the bus. She does not even know much about what is there.

Shareen says she has really never had happiness or sadness in her life, though she admits she is very happy about getting a permanent job. Someday she hopes to get married but is not thinking about it too much yet. Muslims with disability were more likely to be married, or have the expectation of marriage than Buddhists. Shareen’s deaf cousin was recently married so her mother is beginning to think about this aspect of Shareen’s future. In general Shareen thinks life is easy in Ladakh if you were born there and feels that people with disabilities in Ladakh can do all the same things as other Ladakhis if they are interested and have the will to do them; they just might have to do things differently.
Rinchen, Buddhist Mother of Son with Severe Impairments

Rinchen is a 33 year old mother of two. She is from a remote Buddhist village accessible following a three day walk from the nearest road. Now she is living in Leh with her 75 year old mother and her youngest child, a son named Ngawang. Ngawang is ten years old, a bright and cheerful child with severe developmental disabilities that are classified locally as cerebral palsy. He can speak a few words that only his mother can understand, he has uncontrollable spastic movements, and he cannot sit, hold his head up, nor walk. His vision is good and he is very observant. He understands everything that is said around him. He replies by laughing or smiling or making other expressions or noises. Rinchen’s elderly mother has extremely limited mobility, and she has long periods of illness, but she helps out when and however she can. Rinchen’s husband left her a couple years after Ngawang was born and she has not heard from him in several years. He never contributes to the care or welfare of Rinchen and the children.

When Ngawang was born the family was living a hard but simple life in the village. They had an old house and a bit of land, enough for their own subsistence needs. They had a of couple animals that provided food, fuel, and labor. After her father passed away and her siblings had moved either to Leh or other less remote villages in Ladakh, it became more and more difficult for Rinchen to care for her small family, particularly without a husband. These days it is becoming more common for Ladakhi women to live for extended periods of time with their husband away for work or the military, but Rinchen’s husband simply left. She says he
developed an alcohol problem after Ngawang’s illness and feels that in some ways they may be better off.

According to Rinchen, Ngawang was normal at birth. When he was about a year old he became very sick and had a high fever for a month. He got very weak. Rinchen took him to an amchi who put fire on several points on his back and neck. Many family members feel that the cause of Ngawang’s illness and subsequent disability was lu-skon. Rinchen believes it is karma. Before he fell ill, Ngawang could hold his head up and was beginning to feed himself. After the illness he could no longer hold his head up and his legs were just limp. Rinchen sought advice and health care for Ngawang for the next couple of years. The amchi said it was fits. One rinpoche said something was wrong, she should take Ngawang to a doctor. Another urged her not to worry, that maybe Ngawang would walk one day. The doctor said there is no problem, that Ngawang should exercise.

One summer a small group of foreigners trekked into their village. This was not the slightest bit uncommon, but what was different this time was that they took an interest in Ngawang’s living conditions. He was four at the time. The trekkers encouraged Rinchen to move to Leh. They told her that life would be better for her son there, that opportunities for rehabilitation and social interaction awaited him, that maybe one day he may even be able to walk. They offered to find her a job and give her a small living allowance to get her through her first year in Leh and to provide school fees for her eldest daughter. There was no doubt going to school in Leh would brighten the prospects of her daughter. This was a difficult decision for Rinchen. Though she knew it would not be easy, that living in the city would be very
different from what she was used to, Rinchen knew the only decision she could make was to provide opportunities for both her children in any way that she could. She and her mother sold the deteriorating family home for a small amount of money and gave up their rights to their small piece of land.

Rinchen, her mother, and Ngawang moved into a very small one room apartment in Leh. During the school year her daughter is boarded at her school, where she is supported by a foreign sponsor, but she stays with them when school is out for winter break. They have a small two burner LPG stove and a plastic barrel to store water. Their room has one window and enough room for two beds which also serve as sitting space during the day. They share a Ladakhi toilet with several other apartments. The apartment is up a very steep rocky path, quite literally set in the side of the mountain. There is a communal water spigot partway down, useable in the warmer part of the year. They have to rely on and pay for water delivery service for the rest of the year. Now they have to buy all of their food; they do not have any space for even a small garden.

Since Rinchen does not have much education, her prospects for employment are limited to labor type jobs. The trekkers had somehow made connections with local Ladakhis who were able to find Rinchen employment cleaning rooms, making tea, and preparing lunch for employees in an office building four days a week. The work is hard and the pay is only enough to cover a portion of her family’s expenses. On her days off Rinchen takes Ngawang to his group physical therapy sessions.

38 School breaks for winter in Ladakh due to cold which makes travel and heating buildings impractical. In other parts of India schools break for summer.
Ngawang spends two mornings a week at his "school" where he has physical therapy and play time with other profoundly disabled children. The school's car waits at the bottom of the hillside for the diminutive Rinchen to carry Ngawang's wheelchair down to the car, climb back up, then carry Ngawang down on her back. Rinchen knows she will not be able to do this much longer since he is growing bigger each year. Rinchen used to carry Ngawang to work with her. Now Ngawang stays at home with his grandmother. The only other time Ngawang leaves home is when he is ill. Since it is getting harder and harder to carry him, Rinchen takes him to the nearest clinic. The wheelchair is of such limited use it is easier to keep Ngawang tied to her back with a long piece of cloth. Rinchen has been suffering nearly debilitating back pain of late. Her biggest stress is what will happen when she can no longer carry Ngawang at all, a day that she knows is coming very soon. Now there are times when Rinchen is in pain the whole night after carrying Ngawang. She has had to go to the hospital because of this pain. Rinchen says sometimes she feels as if she will go mad. For now Ngawang loves going to school. His neck is getting a little stronger and sometimes he can eat a banana on his own. It has become apparent over the last couple of years that he will never be able to walk. Yet, this is still Rinchen's biggest hope.

Rinchen often feels that Ngawang's being able to walk is in fact her only hope. If he could walk, even just a little, she could leave him and go seek a position doing hard labor. The pay is good. Then she could get a small piece of land and build a one room house. She would not have to worry about carrying Ngawang up and down that hillside. She could grow some food. She would not have to struggle to
pay her rent. Now she can leave Ngawang at home with her homebound mother, obviously not an ideal situation. Mothers of children who are immobile often face the decision, perhaps on an almost daily basis, to either leave their child home unattended or leave them in the care of an elderly or disabled family member. Most often these decisions arise from necessity. When her mother is gone Rinchen worries she may not be able to leave home to work at all. In Leh Rinchen and her family have lost the support network they enjoyed in the village. Rinchen’s siblings do not ask about how she is doing, come to visit, or help out in any way. The household expenses are far greater in Leh.

One of Rinchen’s biggest fears is that she could fall sick. She thinks about this a lot since she has not been feeling well; she is sapped of all her energy and overwhelmed with the stresses of life in Leh. During a recent illness, after several days of the three of them just lying there, all she could do was ask her neighbor to bring food for her son and mother. Though she still believes that living in Leh provides the best opportunities for her family, she feels her world closing in on her. Everyday Rinchen prays and she lights a candle on her small household altar. She knows that if she falls sick all she can do is pay someone to light a candle for her at the monastery. She could not afford to have a monk come to her house to pray. They require cash, good food, and katags (silk scarves offered ceremonially to dignitaries). She cries as she expresses extreme worry over what might happen to her family if she dies. She still feels it is better to live in Leh. There is nothing to go back to in the village anyway. The key is to have money and right now she does not have enough to get by. She has contemplated begging. She knows life would be so
much easier in a house, in a flat area of town, nearby a road. All in all, Rinchen thinks life in Ladakh is very difficult; if you do not have money, you could die of hunger and thirst.

**Manzur, Shia Muslim Man with Kyphosis**

Manzur is a 38 year old man. He and his wife live in a small village in an area primarily populated by other Muslims. Manzur is unemployed and only went to school until fifth class. He does make a small amount of money through the work program at PAGIR. He makes paper bags by using recycled newspaper and glue that are delivered to his home. PAGIR sells these bags to women selling vegetables by the roadside or other small shops. Manzur receives a portion of the profits. Otherwise, Manzur and his wife have one small field and one cow.

Manzur cannot remember when he developed kyphosis but his parents say when he was young, about one or two years old, his sister was carrying him on her back when she slipped and fell on the ice. After that he could not walk for seven years and was just in the house. All during that time he kept trying to walk and one day he tried using a stick for support. He worked on this and eventually taught himself to walk. There was no *amchi*, nor *akhon*, nor *lha-mo* in their village back then. Some years later there was a health camp and his parents took him to see a doctor visiting from outside. That doctor said that maybe he could have an operation outside of Ladakh. His parents did not have money for this.

These days Manzur's day is made up of making paper bags, taking care of the cow, doing housework, and taking naps. He suffers from stress related headaches. He worries, since he is the only one in his household earning money, how they will
continue to get by. Last year he ended up in the hospital as a result of these headaches. As the more able bodied member of their household Manzur feels a lot of pressure, and has even had anxiety related chest pains. His wife has never gone to school and never learned any skills like knitting or tailoring. She married Manzur when she was 20 years old after being divorced by her first husband when she failed to produce any children during five years of marriage. Since marrying Manzur she has had a miscarriage. Manzur carries around a letter given to him by a physician that is handwritten in English. The letter says his 24 year old wife has pulmonary tuberculosis, that they are a very poor family, and she needs money for six months of medicine at a cost of 500 Indian rupees per month. His wife is really not well and spends much of the day sleeping. They know that in the area where they live, near the Indus river, people are breathing in a lot of dust, that there is a problem with silicosis.39 Manzur and his wife however, do not realize that she has tuberculosis, only that she is supposed to be taking very expensive medicine. It is not available in Ladakh and costs more per month than their total income. They would have to travel to Srinigar to find this medicine. They were able to raise some money and have a friend bring one month worth of medicine but this will be gone soon.

Manzur’s wife expresses concern about his health. She says he does not sleep because he is uncomfortable and has pain in his sides when he lies down. She also says he cannot do the heavy work in their field, like using a spade. But she agrees that it is she who has the most difficulty with breathing, and thus getting around or doing much household labor. To make matters worse, Manzur’s family never comes

to visit; they ignore him when they see him in town. It is as though he does not exist. His wife’s family helps them out from time to time but they do not have considerable resources either. They did give her some money when she was first hospitalized for her illness – some gave 50 rupees, some gave 100. Manzur and his wife are happy to have good friends and neighbors they get on well with, on whom they can call if they need help with household work or if one of them needs to go to the hospital.

Manzur’s main preoccupation now is getting a government loan to purchase a second cow. His hope is that this cow will produce enough milk for them to sell the milk. He knows this income is important for their future. Manzur’s wife’s main worry is about having a child and providing it with a good education. She has consulted both an akhon and a lha-mo about her desire to have a child. Similarly to when she becomes sick, she first consults the akhon, then when nothing changes, she goes to the lha-mo. The akhon made a necklace for her to wear that has powders inside that will help her become pregnant. Ladakhis repeatedly express the importance of having an income and having children. Both are a type of insurance for the future. The value placed on education in Ladakh now is such that even those who do not yet have children are planning for their children’s education. All the while there is increasing concern that this generation of children may not take care of their parents when they become old. Still it is better to have them, because relying on nieces and nephews is even more unpredictable. Manzur’s wife is focused on the future; Manzur knows their immediate financial situation and his wife’s health are of primary importance.
Manzur says that Buddhism and Islam say the same thing about disability, that it is because one did something bad in their past life, or that the parents have made some mistake or done something bad in their life or past life. Though this explanation is much more typical of a Buddhist, there are Muslims who express this shared Ladakhi notion of *karma*. When asked separately, his wife gives a more typically Muslim answer – disability is sent by God. Both Buddhist and Muslim Ladakhis have a mix of beliefs and practices that derive from their religion, Ladakh folk religions, and intermarriage between Buddhists and Muslims. As with other diverse cultures that are also increasingly exposed to outside influences, individual Ladakhis create their own opinions about what to believe and what to do.

Like many other Ladakhis, Manzur feels that people with disabilities need job training. This view seems to go along with an assumption that they will not get much education and they do not have the option of becoming laborers. Manzur and others pointed out that each person with a disability may only be able to do a certain type of work and should have the opportunity to train for something they are able to do. For example, if one cannot do labor work, then maybe they could sit and do tailoring. There are job training programs in Ladakh, particularly those associated with local handicrafts such as carpet weaving, but these are not necessarily adapted for people with disabilities. Nonetheless, Manzur thinks life in Ladakh is easy, that he has figured out ways he can easily earn money, which he thinks would be more difficult outside of Ladakh.
Conclusion

Data presented in this chapter begin to fulfill the three main objectives of this study by exploring disability experiences in Ladakh. In the following chapter some of the more compelling findings are discussed while continuing to highlight the interplay between the three objectives. Findings are situated in the context of literature reviewed in earlier chapters.
CHAPTER 7: DISCUSSION AND CONCLUSIONS

Examining experiences of disability in Ladakh within a village context, within households, from within and through the perspective of a disability NGO, and through conversation and observation of professionals and leaders within the various communities fulfilled the overall objective of this study – to examine the subjective experience of disability, focusing on interactions between physical and social domains of experience and how they are shaped by local cultural constructions of disability. To focus this discussion requires revisiting the study’s specific objectives: (1) to ascertain local definitions of and attitudes toward disability in Ladakh; (2) to identify the distinct challenges the physical environment of Ladakh poses to people with disabilities; and (3) to determine the influence of religion on how disability is experienced and managed.

This chapter begins by addressing the first study objective with a discussion of local definitions of and attitudes toward disability in Ladakh by exploring first how disability is defined and identified, including the role that religion plays in shaping these definitions and attitudes. This is followed by consideration of how these attitudes and definitions are shifting in contemporary Ladakh. Next, addressing the second study objective, we explore disability, the body, and the physical environment including consideration of the limitations of the body in the Ladakhi environment and consideration of rural versus urban living. The following sections address the third study objective, first exploring the interaction between religion and the social management of disability. The next section discusses the relationship between culture, religion, and health; providing an in depth look at how
the role of religion intersects with attitudes and definitions. This plays out in the daily lives of those experiencing disability through the social management of seeking care and the subsequent choices that are made to address disability issues, often leading to syncretistic health seeking behaviors. Finally, this discussion explores needs and experiences in the context of change in Ladakh, including a discussion of the dissonance between experiences and expressed needs, as well as how increasing demands for services and opportunities are not matched by availability and accessibility. Throughout, it is apparent that findings and topics of discussion revealed through attending to the three study objectives will continue to interact and shape experiences of disability in Ladakh.

The theoretical grounding facilitates discussion of the interactions between the physical and social realities of the disability experience, problematizing past work within anthropology of the body and disability studies. More importantly, it broadens our understanding of those variables most significant in shaping disability experience thereby providing a framework for the analysis of disability in any cultural context. This ethnographic study of disability in Ladakh provides insight into the variables that must be recognized within any social theory of disability in order for that theory to have interdisciplinary significance and meaning in cross-cultural settings. Along with this, we can begin to recognize the interdisciplinary relevance of the anthropology of disability, noting how interdisciplinary dialogue can address the importance of understanding the social, cultural, and physical contexts for those who aim to develop acceptable, accessible services and programs for people experiencing disability. To sum, the final portion of this chapter presents
conclusions, directions for future research, and significance and contributions of this study.

**Cultural Constructions of Disability in Ladakh: Local Definitions and Attitudes**

In Ladakh, disability is defined and identified through a combination of observable traits and causes, often characterized by religious explanations and influenced by age. Conceptions of disability in Ladakh are changing, influenced by social awareness campaigns and other outside influences. These findings achieve the first study objective, to ascertain local definitions of and attitudes toward disability in Ladakh. Findings related to the other two study objectives were also relevant in that the physical environment and religion, in general, influence Ladakhi attitudes. Findings in this section draw attention to the limitations of international standards of defining disability as means to address human rights and inclusion.

**Defining and Identifying Disability in Ladakh**

Though it may not be possible to provide a definitive Ladakhi definition of disability after only one year of field research, it is possible to discuss influences on definitions and attitudes toward disability in Ladakh, and the diverse ways these may be expressed in different contexts. In general, disability in Ladakh is defined through observation. Both formally and informally this is the primary way people are identified as disabled. There are few resources available to diagnose or treat most conditions in Ladakh, whether related to impairments, illnesses, or injuries. In Ladakh, people with disability are typically seen as having the potential for being, or becoming, productive members of society. The idea that disability is identified through observation, and is often associated with an observable cause as well as
given a religious explanation has similarities to Yamada's (1999) assertion that in Ladakh illness is seen as a bodily dysfunction with a supernatural or astrological cause, not a pathological phenomenon. These influences on defining disability could account for why people with mental illness, intellectual disability, and impairments associated with aging are not typically recognized as disabled in Ladakh.

The relatively recent establishment of governmental programs and NGOs focusing on disability has given new meaning to identifying oneself or someone else as disabled. As attempts to count people with disability increase – whether by a government census process or through efforts of NGOs trying to identify needs – along with the availability of government programs to assist people with disabilities, and awareness campaigns conducted by both government and NGOs, concepts of disability in Ladakh are changing. Along with this comes a broadening of disability issues that become relevant in this cultural context, a phenomenon also evident in much of the literature that examines disability in the context of culture and change (Ingstad and Whyte 1995, 2007).

The roles of language and observation: People with disability in Ladakh are identified through observation and usually specifically referred to in terms of the observed impairment or the associated or observed lack of ability – missing hand, those who cannot walk, those who cannot see, et cetera. Observable disabilities would be, for example, total deafness or blindness, missing or deformed limbs, a limp or lameness, spastic movements, or spinal deformities like those caused by kyphosis. Partial deafness or blindness, mental retardation, cleft palate, or “sidedness” would also result in observable differences, though maybe not in all
circumstances. Other than for those born with observable impairments disability is often caused by an observable event like an accident or illness that is often also explained by religion.

These observations are broadly reflected in language used to refer to people with disability. Most conditions are not identified by a specific word in the Ladakhi language, but rather as categories that are easily observable to the general population. Consider for example the possible causes or manifestations implied in “communication problem” or “walking problem”. In Ladakhi, the phrase zhukshi skyonba is used to refer generally to people with disability. Literally translated this means defectives or defective persons. People with disability are occasionally referred to using the English terms “handicaps” or “disables”, and in contrast to “normals”. These English words are inserted into conversations otherwise taking place in Ladakhi. One study participant referred to them as “people with incomplete senses”.

These observed categories of disability, and therefore those considered to fit within a broader category covered by zhukshi skyonba, did not include people with mental illness nor those with intellectual disabilities who did not also have some observable physical difference. All participants in this study who were categorized as having intellectual disabilities in the NIPWD and PAGIR data also had some observable physical difference. It is of interest that in some cases participants categorized as having some physical disability were described by their family members as having intellectual challenges associated with daily life, for example not being able to find their way around the village, yet they only discussed their physical
disabilities when answering interview questions specifically about disability. Mental illness did not come up, except in one instance in which someone having “gone mad” was discussed with the researcher. This was a case that was a near immediate result of an observable incident – a flash flood in which the individual lost their home, fields, and animals.

Age: In Ladakh, attitudes toward disability vary depending upon the age of the disabled person. Disability organizations, foreign aid workers, activists, researchers, and Ladakhis themselves place much greater emphasis on helping children with disability. That this researcher was interested in adults was a source of surprise to many. Adult study participants were moved by the fact that someone wanted to know about their lives. Simply put there is still hope for a child; it is still possible to change a child’s life. Families put great hope in the possibility that a severely disabled child who cannot walk will one day walk. Ideas like growing out of it, or getting stronger as he gets older, or hope of becoming old enough for some medical procedure often keep families hanging on to what at times seemed like certain expectation for dramatic improvements. Interviews with health care professionals and employees at local NGOs were most useful for understanding this attitude that children can still be helped. Impairments among the elderly are not even recognized as a disability. It is as though the concept of disability fades with age. The elderly have passed their productive stage of life. Though many could benefit greatly and have increased independence, there is little consideration of their needs, for example for assistive devices.
Self-identification: When someone comes to a village inquiring about people with a disability, it is unlikely everyone with a disability will be identified. If a person with an observable disability is successfully using the abilities they have, or has been provided with the things they need, they may not immediately self-identify themselves or their family member as disabled. Or, on the other hand, if there is a view that the disabled person has no hope of becoming a productive member of the household they may not see a reason to identify that individual. The following examples illustrate that even for those with observable impairments, in Ladakh identifying as disabled can be a fluid, context dependent process whereby individuals first evaluate the consequences, perhaps if there is something to be gained, of identifying as disabled. In three instances while interviewing the family member of a disabled person the family member themselves revealed a disability that, in the researcher’s mind, was not dissimilar from other disabled study participants. Since they were not self-identifying as disabled they were not included as disabled study participants. One person who did not participate in this study was born missing two fingers on one hand. This person only identifies as disabled when this could benefit him or his family, perhaps through direct donations of money or providing him with job training. Otherwise, he tries to hide the disability and avoids situations that could make it apparent; he seeks to avoid any potential social discomfort. On the other hand, his neighbor lost two fingers in a job related accident, but is still able to perform his job. He simply does not identify as disabled since he sees no benefit in doing so. The researcher was made aware of his status since he was the family member of a disabled study participant.
These were only some of the instances during which the complex and
dynamic nature of defining and identifying disability in Ladakh were made apparent
to the researcher. In the context of doing fieldwork the researcher had to rely on a
combination of definitions of disability, some provided by participants and others
that were more in line with Western and scholarly definitions. This allowed the
researcher to have conversations with key informants about differences observed
between various types of definitions. Even if there was someone with an observable
impairment, if others were not acknowledging that person as someone with a
disability, the researcher also did not. Only one person with a disability in this study
was included based solely on observations of the researcher. This person was, in
the researcher’s opinion, the most impaired elderly person in the study.

Multiple explanations: In the disability literature conceptions of disability are
closely related to conceptions of personhood, humanness and illness theories
and this can be particularly significant in relation to the birth of a disabled child
Weiss 2007). Findings from this study fit closely with Martin Mills’ (2003)
conception of explanatory models of misfortune which he developed in a remote
region of Ladakh. He argues that there are often several causes attributed to an
illness or misfortune, which may include karmic retribution, ritual pollution, spirit
attacks, humoral imbalance, and deteriorating life force. In this study explanations
of disability were often attributed to multiple causes which could include karma of
the individual or parents, lu-skon (not unlike Mills’ spirit attacks), and an observable
incident such as an illness or accident. It would be interesting to consider his idea of a deteriorating life force in relation to attitudes toward those born with a disability or those acquiring aging related impairments. Since the similarities found in this study were from both rural and urban areas, they could point to Mill’s explanatory models of misfortune being broadly relevant in Ladakhi culture, not just in remote areas similar to where his research was conducted.

Attitudes about disability rooted in religious traditions are closely associated with attitudes surrounding perceived cause or means of acquisition. In Ladakh, there are multiple layers of causality. One is the obvious present cause, such as an accident or illness. The other is the religious explanation fitting the generalized attitudes described further below. These multiple layers of causality complicate understanding attitudes toward disability in Ladakh. Disability in Ladakh then is often associated with an observable impairment or lack of ability, very often with an observable cause, but is frequently given a religious explanation. Seventy-nine percent (n=30) of Buddhists gave religious explanations with none saying their religion did not say anything about disability. Among Muslims 65 percent (n=15) said their religion said something about disability. This cannot be overlooked in any discussion of how Ladakhis define disability. Religion is available and a useful way to classify people. There are three overlapping sets of religious attitudes toward disability, those associated with Buddhist, Muslim, and Ladakhi folk traditions.40

When discussing disability Muslims were likely to have an attitude that this disability is God given and one must make the best of it. This is in contrast to

40 There are of course other religious traditions represented in Ladakh, but these represent a very small minority and were not explored in depth as a part of this research.
Buddhist notions of *karma* that classifies disability as the result of some wrongdoing, either in a previous life or on the part of one's parents. Aspects of both religious traditions have become part of Ladakhi culture so people from both groups share attitudes from the other, the most common being Muslims expressing some belief in *karma* or visiting Buddhist religious specialists. Two people with similar physical limitations could have very different social situations and outlook on life depending on whether they, or perhaps more importantly their family and community, lean more toward Muslim, folk, or Buddhist views of causation. Recall when discussing what religion says about disability Buddhists tended to answer with causal explanations for disability while Muslims discussed causality as well as how people with disability should be treated.

If someone is born with a disability and there were no apparent complications during delivery a Buddhist may speculate about potential wrongdoing on the part of the mother during pregnancy. This wrong-doing could be anything from something *karmic* in nature to nutritional habits. The parents of a child who acquired a disability as a result of an accident are viewed much differently than those who had an illness (unless that illness may have been caused by something the child did). Carelessness of parents comes up frequently in conversation. Whether a child fell off a roof, played in mud under a tree inhabited by a spirit, or was perhaps fed beef, the parents are likely to be blamed. Keep in mind that a child could have played in that mud as a result of a parent’s bad *karma*, not necessarily because the parents were careless letting their child play in that particular spot. If a disability was acquired during adulthood, presumptions about
karma are more likely to be associated with that individual than with the parents. Ascribing cause and blame among Buddhists remains in contrast to Muslim notions that both causation and subsequent treatment are dictated by God’s will.

**Shifting Attitudes and Definitions**

*The role of NGOs and other service providers:* In this setting, programs and services are implemented by ordinary Ladakhis who share the views of participants discussed above, they are sensitive to religion and traditional aspects of Ladakhi culture, but are also acutely aware that the concept of disability is one that is social in nature. NGOs, units of government, and educators are working in jobs where the concept of disability is distinguishable from the concept of impairment, more in line with contemporary scholarly and rights based conceptions held elsewhere in the world. In reality though service providers and NGO staff are individual Ladakhis who traditionally view disability as an observable impairment, and they are limited by a lack of resources to work much beyond that conception toward one that recognizes the social aspects of disability. They are local people with expanded viewpoints. At this early stage there is little activity that goes beyond awareness and advocacy efforts, which at the time of this fieldwork were being undertaken almost solely by PAGIR. Awareness campaigns aimed to bring the concept of inclusion, and the view that people with disability have the right to participate in society, to the public. Other service providers and NGOs were much more focused on their often very limited scope and tasks. Their work relied almost entirely on assessment of limitations and needs. In the context of extremely limited resources disability must remain tightly defined.
However, the efforts of NGOs like PAGIR, new government initiatives, special educators, and others are no doubt changing conceptions of disability and may ultimately have a role in influencing its definition in Ladakh. Though PAGIR typically – out of necessity and perhaps because they are Ladakhis working within traditional norms, values and customs – allowed people to self-identify as disabled. In some instances they intervened. For example, consider the case of a mentally retarded individual who was not given much attention at home and was valued primarily as a source of labor. With PAGIR's assistance processing the appropriate paperwork that individual could get a reduced bus fare to go to a job, making it affordable to get to the job and thus contribute financially to their household. Not only would the individual, who did not have the mental capacity to self-identify as mentally retarded, have an improved quality of life through the work experience, but also at home as a contributing member of the household. It is in instances such as this one that these types of groups in Ladakh take the first initial steps beyond awareness campaigns toward implementation of their own differing concepts of disability and newly established government initiatives.

The health care field also plays a role in shifting attitudes and definitions of disability in Ladakh, perhaps expanding ideas about what may be considered a disability. Coupled with the fluid and changing nature of self-identifying as disabled, health care provides a unique glimpse at the complexity of defining disability in Ladakh, and the cultural and structural forces that at the same time instigate change also indicate that the pace of such changes may be slow. During fieldwork a doctor from Leh had just returned from receiving training in psychiatry from outside
Ladakh. Health care practitioners are working with an impairment based approach to disability with limited resources for diagnosing or treating impairments in a setting where diagnosis is newly valued as a way to receive government benefits put in place to increase social inclusion for people with disabilities. All the while it is religion which is most highly valued as a source for making health care decisions among their patients. For Ladakhis who are experiencing disability this necessitates dual explanations, a religious one and a medical one. They may visit one practitioner for a diagnosis and another for care.

As Ladakhis’ conceptualizations of various disabilities change over time, with the advent of new programs or services, any attempt to give a local definition of disability is further complicated. If someone has the needed device, or had the necessary surgery, they may no longer be considered disabled by many Ladakhis. In particular, perceptions of disability in Ladakh are increasingly centered on assistive devices, especially those from outside Ladakh. This was a factor in developing appropriate recruiting methods for this study and was discovered as the researcher kept hearing about people who were “not disabled anymore”. More importantly, it is changing the way society is labeling people, and whether or not people are likely to self-identify as disabled. While NGO and health care provider definitions of disability, for example, are expanding the result in the general population may be a narrowing of conceptualization, literally associating disability with these new services and programs. People with disabilities themselves negotiate this through the fluid and context specific nature of identifying as disabled.
In fact it may even be difficult for a Ladakhi with a disability who has had some treatment to reduce the observability of their disability to decide whether or not they are still disabled. Consider the following example of how a conflict can arise between internalized local definitions from one’s own culture and one’s own subjective experience of disability. A study participant was recruited after the researcher was asked if she wanted to meet people who used to be disabled but were not anymore. This participant was deaf in one ear and had had surgery to alleviate his hearing impairment in the other ear. He was no longer observably deaf. He talked about how his hearing impairment made him feel insecure in his job and limited his social interactions with others. He talked about his disability in many of the ways other disabled study participants talked about theirs. Yet, he was not typically self-identifying as disabled nor considered disabled by others. His new wife was unaware of his impairment until after they were married. However, he was trying to acquire disability certification so he could receive government benefits. The problem here was rooted in the variety of possible ways to conceptualize disability, for both the health care provider and the individual. This was making it difficult for him to get this certification, even though he was still totally deaf in one ear. In this example the process of individual experience and culture interacting to shape one another was actually underway.

*The role of age:* Attitudes toward disability vary with the age, a phenomenon that is changing as new opportunities become available. Opportunities for children and the associated hopes for the future prompt some families to move to an urban area. For some this is a radical transition, for others with family living in both rural
and urban areas it may be shifting in nature. Some parents, seeking the best possible conditions for their children, even take them outside of Ladakh during the winter months, particularly if the child needs to continue physical therapy which is made more difficult by cold weather or is prone to illness in winter. Many Ladakhis however have the attitude that once young adulthood is reached there is little that can be done to help, or that those individuals have adapted to who they are and no longer need anything beyond assistive devices or job training. There is an assumption that adults with disability get by in their day to day activities, no longer needing physical therapy, medical treatments, or lifestyle adaptations. These assumptions may hold particular weight if an adult with a disability has already made the change from living in a rural area to living in Leh.

For the elderly, losing independence and acquiring impairments is a fairly traumatic process accompanied by despair and confusion. While their family members and neighbors casually accept that they can no longer do what they used to, the elderly individual struggles with the emotional, physical and social aspects of dramatic change in their lives. On occasions where this researcher was with elderly people without other family members around, they stated they were waiting, or in some cases wanting, to die. This was not always viewed negatively, just as a matter of fact. If the concept of old age homes becomes acceptable in the cultural setting of Ladakh it would most certainly cause a shift, or expansion, in the conceptualization of disability. Elderly people with aging related impairments would have needs, an opportunity if you will, for living an easier life in a home with many fewer accessibility issues than a traditional Ladakhi home. Major social and structural
change would have to take place, but given the rapid changes already taking place in Ladakh this shift is not outside the realm of possibility. Such a shift in attitudes toward the elderly could trickle down to adults with disabilities in some way.

**Summary**

Ladakhi attitudes and definitions of disability are complex, involving multiple explanations and are often shifting and context dependent. They vary depending on whether or not one is disabled, whether one has alleviated observability of their disability, by age, and whether services or opportunities are available. Attitudes toward disability are shifting, influenced by ideas from outside Ladakh that are slowly being incorporated into Ladakhi culture, like rights based approaches to inclusion and biomedicine. Change will no doubt be slow, particularly in rural areas. Awareness of social issues cannot always match availability and accessibility of services. Coupled with definitions which seem to be largely based on observations, these shifts may not impact all people with disability in Ladakh, that is all people with disability as may be perceived presently by outsiders. 41

**Disability, the Body, and the Physical Environment**

In Ladakh, limitations posed by physical bodies and the physical environment shape experience, and impact availability and accessibility of services. These findings achieve the second study objective, to identify the distinct challenges

41 During the summer of 2008, a Canadian and Ladakhi team of researchers did a two month rapid ethnographic assessment of disability in remote villages of Ladakh. Their aim was to understand local attitudes toward disability and determine the level of community readiness to taking actions that would meet the needs of people with disabilities. They faced many of the same challenges this research did, and drew some similar conclusions. Perhaps most noteworthy was their acknowledgement that if outsiders had stepped in to develop services and programs without first using ethnographic methods to understand the context, those programs would likely have limited success (McElroy, et al 2011).
the physical environment of Ladakh poses to people with disabilities, but was also influenced by data collected to achieve the other two study objectives, namely definitions and attitudes toward disability and how religion influences its management. Findings in this section demonstrate that this study of disability in Ladakh provides an ethnographic example that challenges both social models of disability that do not account for disabling aspects of impairments and anthropological approaches to disability and studies of the body that do not account for different types of bodies and variable cultural contexts.

The previous chapter highlighted a variety of often significant challenges Ladakhis with disability have negotiating their physical environment. Some of these challenges are associated with dependence on others, or with dependence on assistive devices. The rugged terrain, harsh environment, and even the way structures are built, are difficult for caregivers and people with disability alike. We have seen that in this setting the typical assistive devices which many Ladakhis feel people with disabilities need are not necessarily of much use to many of those who have them. These challenges inevitably impact the social management of disability. One would therefore expect Ladakhis’ descriptions of how disability has affected their lives to revolve around negotiating the physical environment, and how this in turn affected opportunities, thus shaping their discussion of goals and needs. To an extent the first part is true; they do talk about limitations in movement because of their impairments and because of the physical environment. To a lesser extent they discuss how this in turn limits opportunities. It is much less obvious that any
consideration of physical environment is shaping how Ladakhis with disabilities view their goals and needs, a topic which will be explored later.

The increasing attention to social issues and inclusion for people with disabilities is taking place in an area that is far from ready to accommodate the shift, situated in a physical environment that makes the logistics of change even more complicated, perhaps impossible, in some areas. There are two specific types of unmet need that stand out, a need for things and a need for money. There is a perception that someone with a particular impairment should have a particular thing. Influenced by aid programs in Ladakh, television and other awareness campaigns, there is practically a routinized list expressed by Ladakhis describing the needs of people with disability. Those who are deaf need a hearing machine. Those who have difficulty walking need a stick. Those who cannot walk need a wheelchair. Those without limbs need artificial limbs.\(^{42}\) In short, “people with disability need aids and appliances.”\(^{43}\)

**Limitations of the Body in the Ladakhi Environment**

All it takes is to imagine a person sitting in a wheelchair on a mountainside to realize that social models of disability that claim disability is something imposed on an individual by society (Barnes et al. 1999; Oliver 1996) are insufficient for understanding experiences of disability and must, as many scholars have since recognized, acknowledge that impairment can be disabling (Crow 1996; S. French

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\(^{42}\) The researcher does not know of anyone in Ladakh with an artificial limb.

\(^{43}\) This is how the general statement was most often translated, or even expressly stated with the English phrase “aids and appliances”.

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1993; Thomas 1999), and that bodily experience must be understood in the context of culture and society (Whyte 1995).

Observable limitations of the body in the Ladakhi environment stand out sharply, they serve as bold examples in any debate about whether or not experiences of impairment have a place in social models or theories of disability. In this study 80 percent (n=43) of those with disability had either a daily dependence or need to attend to issues related to their disability. The other 20 percent (n=11) consists of productive members of society with highly visible impairments. Some are housewives, some are educated and employed, some are uneducated and employed, and some are doing traditional agricultural work in their village. What makes them disabled? Scholarly and rights based conceptions of disability can only go so far. Limitations of the body and mind define these people as disabled in local context and no doubt shape experiences in daily life. Assistive devices have an interesting role to play.

Assistive devices help their users overcome physical barriers and subsequently, for those taking a social model approach, barriers to participation. Assistive devices from non-local sources, though of limited use in Ladakh, do play a role in changing views and increasing social awareness. Just as limitations of the body stand out, someone using a wheelchair brings into bold relief the realization that much more needs to be done. Using a wheelchair in Ladakh is not the same as using a wheelchair outside of Ladakh. Assistive devices may be accepted, in fact expected, well before there is a means within Ladakh to even diagnose or provide rehabilitation for impairments. Assistive devices bring a shift in social awareness
and play a role in how experience is shaped by culture and in turn begins to shape culture. We are reminded of Douglas’ (2002) notion that the body is a symbol and that we gain insight about society through the experience of the self in the body, and Bourdieu’s (1980) concept of *habitus* which describes how we live through and in our body and act in ways that are practical within our cultural context.

**Urban versus Rural Living**

There are notable differences between urban and rural Ladakhis with regard to how they feel about difficulty with the physical environment. Of those who expressed facing challenges with the physical environment (n=43, 80%), 65 percent (n=28) live in rural areas and 35 percent (n=15) live in urban areas. Distance to the nearest school, the terrain around the house and fields, access to water, and limited modes of transportation are but a few examples of challenges posed by rural living. In contrast, urban living is viewed as providing more opportunities and an easier life for people with disability. Education, jobs, accessible housing, increased mobility due to public transportation, and availability of food and water without the associated labor are some noted reasons.

Rural Ladakhis were more likely to think people with disability could not do the same things as other Ladakhis (n=23, 61%) than urban Ladakhis (n=10, 50%). In Ladakh, being a contributing member of a household is highly valued, whether that be through physical labor, skills, or money. For many people with physical impairments contributing to the household within the traditional rural lifestyle is simply not possible. For many (n=29, 54%) independence is not fully possible; contributions to the household may be limited, perhaps only possible by doing
activities outside traditional gender roles. For Buddhists in particular there have traditionally been limited options for pursuing skilled trades, leaving agricultural work as the main option in a village setting.\textsuperscript{44} Income earning possibilities are associated with urban living. In urban areas people with disabilities have a broader range of options, working in a shop or learning a new trade that may involve something like using computers, for example.

People with disabilities may experience more social isolation in rural areas, having social interactions primarily with family members. Recall, rural Ladakhis were more likely to feel disability had affected opportunities (n=29, 78\%) than urban Ladakhis (n=13, 62\%). For some, social networks of people more like them (in this case with disability), availability of health care resources, and the prospect of being able to contribute financially to their household have made re-location to urban areas a positive experience. For others, the perceived opportunities that exist for people with disabilities in urban areas come along with a loss of close social networks and significant dangers. The challenges associated with urban living one discovers upon re-locating can cause a shift in attitudes about whether urban or rural living is better for people with disabilities. Some even go back and forth seasonally in order to benefit from the opportunities associated with urban living and the securities they come to associate with rural living.

In a setting like Ladakh these feelings about the needs and capabilities of people with disabilities are unlikely to change anytime soon. In fact, cultural and economic change in Ladakh is more likely widening gaps between rural and urban

\textsuperscript{44} Exceptions include trades which typically are passed down through families or limited to specific villages, such as painting, amchi medicine, or metalworking.
populations in many areas. The pace of change in rural areas will be slow, if for no other reason than the physical environment. Changes associated with social awareness and inclusion may not even be possible in some areas. There is a general attitude that people with disabilities are better off in the city.

**Summary**

Gleeson’s (1999) assertion that physical inaccessibility and socio-spatial exclusion equate to a form of urban oppression is evident in both Ladakh's urban and rural areas. Children with disabilities have limited opportunities for education and the charge of inclusive education has presented insurmountable challenges. This situation is not unlike that in other parts of the world (Barton and Armstrong 2001; DFID 2000; Elwan 1999; Priestly 2001). The planning of services still takes place, as elsewhere (Devlieger 1994) with little attention paid to the life experiences of the people they are meant to serve. This happens at the local level, as well as on the part of those developing programs from outside an area. As noted by ESCAP (1995) opportunities and access can be limited by limitations of social consciousness, change must take place on all levels, but as similar to Whyte and Ingstad’s (2007) assertion, reality can slow change, in a sense outweighing an awareness of need.

**Religion and the Social Management of Disability**

In Ladakh, religion shapes the social management of disability, influencing attitudes about disability and the life chances of people with disabilities, including the likelihood of marriage. These findings achieve the third study objective to determine the influence of religion on how disability is experienced and managed.
Findings that resulted from fulfilling the other two study objectives were also relevant because of the dynamic interplay between religion, attitudes, and limitations of the physical environment in Ladakh. Findings in this section draw attention to the relationship between karma and stigma processes, religion as a factor influencing cultural and structural change, and generally how religion can affect disability experiences cross-culturally.

**Disability and Karma**

In Ladakh there are negative connotations associated with having bad karma, having been cursed by spirits (lu), having bad fortune, and even having a disability that is described as God’s will. Another interesting correlation then between the findings from this study and the literature is between the concepts of karma and stigma. Though stigma concepts and stigma processes could be studied in relation to attitudes about disability and disability experiences anywhere in the world, in Ladakh it is worthy of note because of differences in attitudes between Ladakhis who believe in karma and those who do not. As mentioned before this is not strictly along the lines of religious affiliation since some Muslims do believe in karma, but it is generally more ingrained in the Buddhist way of life. There is some similarity in reactions to lu-skon and other causes rooted in folk religion. It seems this is much more temporary in nature compared with one’s karma. Similar to Goffman’s (1963) concept of “courtesy stigma”, in Ladakh there is a level of uncertainty about whose karma is responsible for a disability, the disabled individual or one of their parents. This puts into effect stigma processes (Ainlay et al. 1986; Link and Phelan 2001) whereby social isolation, shame, and guilt can become part of the social
management of disability in Ladakh. However, it is difficult to determine whether this isolation was self-imposed, demonstrated by an expressed sense of shame or feeling that others would not want to be exposed to their bad karma, or whether they were in fact socially isolated by their community. In either circumstance the isolation is informed by social norms and values. There is less of this uncertainty about cause, or even outcome, for Muslims. The disabled person is that way because of God’s will and there is no uncertainty about whether the right things are being done to assure a favorable re-birth. Their concerns are more centered on doing the right thing, in line with God’s will, now.

These phenomena call to mind Bourdieu’s (1980) notion of habitus and Csordas’ (1990, 1994) paradigm of embodiment, allowing for experiences of individuals and communities to inform one another in the process of constructing cultural values, norms, and customs. In Ladakh the role of religious specialists – their explanations of disability, and their advice regarding how to manage disability – are central to Ladakhi everyday life. Mills (2003) also noted the role monks serve as an interpretative authority within the health care system in Ladakh. There is no doubt that variability in the social experience and management of disability stems from religiously rooted views and attitudes.

Recall that Buddhists were more likely to say disability had affected their opportunities and were less likely to be married or have an expectation of marriage. In instances such as not self-identifying or karma associated isolation, the social management of disability employs techniques to avoid potentially disabling aspects of society such as assumptions about capabilities or encountering obstacles trying to
access services. Choosing instead to deal primarily with impairment related issues demonstrates how the experience of the physical body influences the social and physical aspects of everyday life, as noted by those who critique social models of disability for ignoring those experiences (Crow 1996; Hughes and Paterson 1997; Shakespeare and Watson 1995; Shuttleworth 2001; Turner 2001).

Perhaps the most notable difference among those who were either born with or acquired their disability as children was found between Buddhists and Muslims. Though there was not an obvious difference in the most severe cases of disability, what was considered severe disability may be broader for Buddhists. In other words, an impairment that may be considered a severe disability among Buddhists may be perceived as less disabling for Muslims who also seemed more likely to adapt and thrive. Muslims often view disability as given to them by God. This religious conception of causality can have a much more positive spin than the concept of karma embraced by Buddhists. This study included both Buddhists and Muslims with very similar disabilities, where Buddhists were largely homebound with little education and no chances for marriage and Muslims have found ways to be mobile, pursue education, and have expectations of marriage. While Singey, for example, sits homebound, there are others who are perhaps less mobile than he is, or who may have more disabling impairments, who are out and about. Disability is still fairly new to him and his family, but one of the most revealing aspects of this research was that Buddhists did not seem to utilize adaptations or overcome social anxieties as readily as Muslims with similarly disabling impairments. Among those who said, in general, that Ladakhis with disabilities need good treatment (n=13,
18%), 77 percent (n=10) were Buddhist, and 23 percent (n=3) were Muslim. The concept of *karma* may be limiting to Buddhists with disability at individual, family, and broader societal levels.

**Awareness and Social Relations**

A Buddhist man with kyphosis poignantly described the social aspects of his disability. He described how people look at him, just stop to look at him. Sometimes they are afraid of him. It is not uncommon for people, particularly young people, to cross to the other side of the street to avoid him. This makes him feel bad; he said that he is also human, and that he did not do this to himself. He wishes people would have more awareness about disability and realize this could happen to them too someday. Singey expressed frustration about his education, as did many other people with disability in this research, both young and old. Those who know there are options out there express concern that parents do not even try to get education for their disabled children, that the government does not do anything to help disabled people get an education. Traveling by buses to get to a school that is trying to provide inclusive education is not likely to be realistic for a child with a disability. These limitations prompt some to have the contrasting viewpoint that there should be one place for them to go to school and perhaps live. Ladakhis in this study thought people with disabilities need accessible buildings, accessible education, and job training. Awareness is a topic brought up by those in the more activist oriented disability community. Awareness is a need those activists realize must be fulfilled before things like building schools and job training centers can be successfully implemented. Interestingly they feel that there is a need for awareness among
people with disability that they too can do things that able-bodied Ladakhis do and among the general public that people with disabilities are capable learners, workers, and in so many ways just like everyone else.

During fieldwork there was a disability awareness film being shown in the schools at the time that depicts a disabled boy being hit by family members. After viewing the film the researcher discussed the treatment of people with disability in Ladakh with a prominent disability leader from a local NGO. He gave an example, that sometimes if a family has two children and the elder one is disabled, that the family will not care as much for the disabled one. They will make sure the younger one has a good education. They will not think that one day the disabled one could read and write, one day earn money at a job. He went on to describe worse situations. In some richer families they may be giving good food to their disabled child but never saying “this is my son”. Instead they are made to work like a servant and are treated like the hired labor that many Ladakhis bring in from outside. If people are coming to the house, the disabled son may serve tea and go away. To a guest they just look like labor. He went on to say that in some poorer families the disabled child is used too much for begging. When asked if he felt there were any differences with these types of situations between Buddhist and Muslim families he said no, that this was in Ladakhi culture. Some aspects of his sentiments are in line with how disabled study participants described their own lives, though the differences between rich and poor may be much less obvious, and differences between Buddhists and Muslims may actually be more pronounced.
Recall there were in fact differences that were social in nature with regard to Muslims being more likely to be married or expecting to marry one day than Buddhists. There is a high value placed on marriage in Ladakh – as it is in many places like Ladakh – due to cultural and religious values, and especially for economic reasons. Marriage patterns in Ladakh have been changing since Ladakh became part of India, along with men increasingly working outside the home and leaving a greater part of the agricultural work for women, social organization and inheritance patterns are changing too (Goldstein and Tsarong 1985; Rizvi 1998). The importance of marriage, along with the challenges faced with getting married, meant that during the period of fieldwork for this research PAGIR was contemplating developing a means through which to facilitate marriages for Ladakhis with disabilities. Consider one avenue of explanation for this difference, that Islam values marriage, perhaps it is God’s will, but Buddhism values non-attachment and non-reproduction, the ideal individual in Buddhism is an unmarried monk. Buddhists in this study did mention that people with disabilities should be praying so they could have a more favorable re-birth. Perhaps it is this view that has hindered marriage of disabled Buddhists. This is in contrast to other studies that have indicated people with disabilities are often considered unable to achieve this merit on their own (L. French 1994; Miles 1995), which would more likely lean toward *karma* related stigma processes mentioned previously.

**Summary: Disability as a Religious Issue**

Ladakhi society likely holds a mix of views, which are not always in agreement with one another, that shape attitudes toward people with disability that
have been influenced by religion. Some of these views are common to Muslim and Buddhist values, which could range from notions of negative *karma* or testing faith surrounding disability, to having an ethic of charity and compassion (Eickelman 1989; L. French 1994; Miles 1995; Samuel 1993; Turmusani 2003). Yet, narratives of people experiencing disability in this study indicate that financial circumstances and associated concerns about future care influence the desire for education, job training, and possibly marriage. Their experiences of disability leave no expectation, for example, of charity and compassion. This is one way experiences of disability may trump religion. The next section will explore how this same phenomenon, the everyday lived experience of disability, may lead Ladakhis to syncretistic religious and health care seeking patterns just as it makes money a priority in Ladakh. The priorities of everyday life take precedence over social and structural changes which could ultimately ensure future inclusion in many realms of Ladakhi society for those with disability that are promoted in awareness campaigns.

As we shall see throughout the remainder of this chapter, disability puts Ladakhis in a situation where their attitudes, opportunities, and ultimately the social management of disability require that they negotiate between their culture and their own experiences of disability. The general public, family members, and people with disability themselves may not always end up in the same place, with some relying on religiously based attitudes toward disability to shape their experiences, while others may shape their lives based on their own physical experiences of impairment. As found by Saul and Philips (1998) in their study of cerebral palsy in Nepal, intra-cultural variation in beliefs about disability between
parents, children and service providers stem from pluralistic religious beliefs, health belief systems and rural and urban differences. These same factors have been shown to create varying levels of intra-cultural variation in Ladakh as well, primarily about attitudes and social relationships, but no doubt influencing opportunities and other aspects of living with a disability in Ladakh.

**Complex Relationship between Culture, Religion, and Health**

In Ladakh, there is a complex interplay between culture, religion, and health that shapes how people experiencing disability seek religious and health care advice. Pluralistic and syncretistic health care seeking patterns are coupled with confusion, uncertainty and lack of trust as Ladakhis negotiate between their cultural and religious traditions and their own experiences of disability. These findings achieve all three study objectives since definitions and attitudes, the physical environment, and religion all play a part in seeking religious and health care for disability related issues in Ladakh. Findings in this section engage with previous research in Ladakh that has focused on health seeking behaviors, calling into question how the presence of disability may supersede traditional patterns. Assumptions about causality, religious beliefs, and availability of resources come together to influence the order in which specialists are consulted and which of their recommendations are followed. Alternatively, families may forgo tradition – whether dietary, religious, or folk rituals – as they gain access to biomedical health care providers.
Seeking Care Intertwined with Social Management

Outside a hospital setting, biomedical understandings about sanitation and infectious diseases are not common. Recall the example of the amchi acupuncture treatment where needles were simply put away unsterilized because Ladakh is a “frozen place”. Similarly, the researcher observed people with mumps or eye infections working, preparing food, hugging others, and co-sleeping with small children with no thoughts of contagion. There are instances of infection after amchi treatments that required consultation with physicians, even hospitalization. Conversely, people frequently cannot follow the advice of the physician, due to cost or the lack of availability of medications or outside care. They then take the more affordable and accessible amchi medicines instead. Each individual’s unique experience negotiating the web of health care advice shapes how they will approach their next illness, injury, or impairment associated complication. One paralyzed man, for example, has given up completely on consulting monks, rinpoches, onpos, or even amchis since he has determined that they cannot help him. He strictly consults physicians. Prayer will not make him walk again. Others who cannot walk rely solely on prayer, or solely on amchi medicine, and others like Singey utilize all three. If one seems worse off after following the advice of one type of provider, he or she is unlikely to start there next time, perhaps placing blame on the last specialist consulted with no regard for the effects of taking advice (or not) from them. As demonstrated in the findings, many Ladakhis do not make health care decisions without calling upon their religion in some manner, or seeking advice from within their social network.
Religion is closely associated not just with disability in Ladakh but with health and illness generally. Though the topic of money does come up very often when people are talking about religious rituals, particularly the expense of having Buddhists monks perform *pujas*, this does not seem to deter participants from doing something religious, even if they cannot afford the more elaborate rituals. Disability, often the result of an illness or injury would be addressed, at least initially, in much the same way. With the development of a longer term impairment, efforts to seek answers and treatment, both through the religious and health care systems increase. Traditional values and norms along with a lack of availability of more advanced health care in Ladakh, and a lack of money and other resources for care outside Ladakh, likely play a role in the importance of religion as a way of dealing with illnesses, injuries and disabilities.

Among people with disabilities in this study for whom health seeking data was collected (n=46), 59 percent (n=17) of Buddhists and 45 percent (n=14) of Muslims consulted a religious specialist at some point regarding their disability. This included 69 percent (n=11) of urban participants and 67 percent (n=20) of rural participants. Recall that rural participants were more likely than urban participants to incorporate religion into their general health care. Disability seems to eliminate differences with regard to seeking religious advice. It is however difficult to say who among the participants actually made their health care decisions as a direct result of this religious advice. In a complex web of seeking advice from multiple care providers and involving family and friends a decision is not necessarily a straightforward result of any single variable. A lack of available
resources or options for treating some disability related issues may mean that religion plays a more important role for a family experiencing disability than one who is seeking treatment for more mundane illnesses or injuries.

**Conflicting Advice and the Choice between Religion, Tradition, and Modern Medicine**

Decision making is further complicated by conflicting advice, potentially a multitude of options, and limited resources. Recall the lack of agreement among professionals about causes, plans for care, and potential for cure for various types of disabilities – whether they were the result of accidents, illnesses, or present at birth. Conflicting advice was one of the biggest dilemmas described by participants, particularly when it was between a religious leader and another type of health care provider. Thirty percent (n=14) were referred by their health care provider or religious specialist to a different type of professional or given advice about whose care they should or should not pursue. For some Ladakhis the obvious choice is to follow the advice of the religious leader, for others their decision may be dictated by their financial situation. If a physician has recommended that they leave Ladakh for some type of surgery or other physical therapy, the decision to follow the advice of an *amchi* instead, for example, may be purely financial. However, choosing between religious advice and biomedical advice, though sometimes financially driven, can be a much more complicated decision about the future for individuals and their households, particularly for those who are told by a religious specialist that if they follow the physician’s advice, for example to pursue a surgery, they will have a short life or bad things will happen to their family. Within Ladakhi culture the lines
between Buddhism, Islam, folk religions, traditional medicine and biomedicine are
often blurred. For example, though rare, some Muslims may perform Buddhist or
folk agricultural rituals, or seek the advice of a monk regarding whether they should
follow the advice of a physician, or believe their disability is a result of *karma*.
Religious explanations are available to everyone; either as common knowledge or
through the ease of seeking advice from local religious specialists. Following
religious advice, on the other hand, may not be physically or financially accessible –
for example, hosting large *pujas*, putting prayer flags on top of a particular
mountain, or performing the Hajj.45

**Syncretistic Health Seeking -Disability Trumps Religion**

It is not only the multitude of specialists sought for disability related care
that causes confusion, uncertainty, and lack of trust. Shifting and conflicting ways of
defining disability in Ladakh are complicating the relationships between Ladakhis
and their service providers. There are so many health-seeking choices in Ladakh,
which are situated within a culture in which Buddhism, Islam, and folk religious
ideas are highly influential, and rapid social change necessarily associates prestige
with certain approaches to health care. Individuals seem to lack consistent patterns
of health care seeking. People with disabilities and their families struggle between
cultural and religious explanations and the causes and explanations that develop
from their own experiences.

Thus, in a setting where religion may often trump both traditional and
modern health care options, the nature of disability itself may trump religion, with

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45 As one of the Five Pillars of Islam, all able Muslims are encouraged to participate in this
pilgrimage to Mecca (Hajj) at least once during their life.
disability related care calling into doubt any health seeking trajectories that may otherwise be common in Ladakh. The experience of disability in Ladakh, a culture, as both Bray (1991) and Rizvi (1998) point out, that has incorporated aspects of many diverse traditions, is an ideal situation for a syncretistic approach to seeking religious and health care to develop. Findings from this study however do not show consistent patterns or shared syncretism, health seeking is more often seemingly improvised at the individual level. It is beyond the scope of this study to know whether this is common to all health care seeking or a special circumstance of disability, though experiences of disability seem to be a complicating and confounding factor in this context of syncretism. Norboo and Morup (1997) described health in Ladakh as an interactive relationship between man, nature, and the supernatural world. Disability necessitates employing all available options as Ladakhis experiencing disability struggle between their cultural and religious ideas and their own experiences. Some Muslims shared the Ladakhi notion of karma, some consulted rinpoches and lha-mos. As the result of centuries of intermarriage some participate in Buddhist rituals honoring relatives. The researcher also knew several people who had one Christian parent, while the other was either Buddhist or Muslim. Though they may explain things slightly differently both Buddhists and Muslims are influenced by Ladakhi folk religious ideas. Those experiences may include having been helped by the use of assistive devices, knowing a person who earns an income making handicrafts with PAGIR, not accepting karma as being part of their fate, and no longer being able to associate prayer with the physical experience of their bodies. In this context, along with increasing influence from
outside Ladakh, individual Ladakhis decide what things to believe, what opinions to hold, and how to seek health care. It is quite likely that this gives certain priorities, like seeking disability related care, priority over traditional religious or cultural beliefs or norms.

Complex Decision Making and the Role of Money

The dynamic nature of disability, associated religious explanations, and varying causes or diagnoses, necessarily make decisions about seeking treatment or advice complex. Confusion and uncertainty are unavoidable. Decisions are rarely made through consultation between an individual and a specialist. Families, often extended families, may be involved. Traveling to consult someone about a disability requires transportation, translation, money, other material resources, and often physical assistance. The case studies illustrate how the lack of a social network can limit choices already limited by a lack of finances. Having monks come to your household to conduct *pujas*, for example, requires money, *katags*, and nice food for many monks often over a period of days. It often also requires the resources and labor of at least an extended family and *pha-spun*. Similarly, seeking health care outside of Ladakh, or even just the purchase of medications from outside Ladakh, requires an extended network of support. For many of the individuals with disability in this study these resources (social, familial, financial, etc.) were simply not available. With children as a possible exception, it was not the norm for resources to be expended in these ways for someone with a disability. Changes in attitudes taking place between urban and rural populations are already evident, with fewer urban participants saying they would incorporate religion into their
health care. Yet, among those with disability there was little difference between urban and rural participants actually seeking religious advice.

**Summary**

The complex relationship between religion, culture and health, particularly situated within disability experiences, is but one example from this study which validates Whyte’s (1995) assertion that disability research must recognize experience within the context of social and cultural change. Ladakhis take advantage of all available resources. They do this as Ladakhis, irrespective of whether they tend toward Buddhist, Muslim, or folk traditions, or toward traditional Ladakhi or modern health systems.

**Needs and Experiences in the Context of Change**

In Ladakh, there is a dissonance between experiences of disability and expressed needs which leads to further disconnects between culture, religion and experience as people with disabilities approach their own futures in the context of social change in Ladakh. This change has led to increasing demands that have not been met with availability and accessibility of services, in turn creating more diverse intra-cultural variation in disability experiences, particularly between rural and urban populations. These findings contribute to all three study objectives by examining attitudes in this particular physical setting and how religion may address limitations posed by the physical environment. Findings in this section answer the call in the disability literature for studies of disability to simultaneously pay attention to experience and social context.
As Groce (1999) said, anticipated adult status as a contributing member of society plays a role in resource allocation. Also recall Gleeson’s (1999) notion that there is oppression stemming from physical inaccessibility and socio-spatial exclusion. In Ladakh, these play out in decisions not to send a child with a disability to school. People with disability are often not perceived as potential contributors and therefore not sent to school; all the while schools are not accessible nor are they adapted to other needs of students with disabilities. With such high value placed on education and being productive members of society, it is important to recognize, as several disability scholars have (Coleridge 1993; Devlieger 1994; Ghai 2001; Ingstad 1995, 1999, 2001; Mpofu and Harly 2001; Yeo 2001), both the disability and non-disability challenges individuals, families, communities and even societies may be facing. This is particularly relevant in Ladakh with regard to sending any child to school, particularly to send them to school outside of Ladakh. This is closely related to the value placed on work, whether that is work traditional to your demographic or the increasingly desired type of work that generates a cash income. During his research Turmusani (1999, 2001a, 2001b, 2003) found that the ability to work affected how society viewed an individual and affected their opportunities. Perceived ability to work seems to affect opportunities for individuals in Ladakh, perhaps well before they are old enough to do so, which may in turn be influencing relationships and opportunities for people with disabilities.

**Dissonance between Experiences and Expressed Need**

Whether the researcher had spent a lot of time with study participants or was meeting them for the first time, the semi-structured interviews repeatedly
provided surprising examples of the dissonance between their own lived reality and social management of disability and what they subsequently would say people with disabilities in Ladakh need.

Seventy-two percent of participants (n=42) felt that disability had affected opportunities. The opportunities most noted were having a job (n=12, 21%), getting an education (n=17, 29%), having a typical social life (n=9, 16%), and getting married (n=6, 10%). It would seem that many of these issues stem from the interplay between physical barriers and societal attitudes. Aside from the most well-known activists people generally do not talk about accessibility of buildings or walkways. They do not talk about the layout of traditional Ladakhi homes, or accessibility of public transportation. However, when specifically asked about challenges they face in daily life, these are the topics that come up frequently. They describe things they cannot do or places they cannot go to, particularly social activities they cannot participate in. These types of comments came up when they talked about disability affecting relationships, particularly among Ladakhis with disability who said their disability had affected their relationships (n=23, 62%). Yet when study participants were specifically given the opportunity to talk about needs or change in Ladakh, topics related to the physical obstacles that indeed affect their relationships and opportunities are rarely mentioned. Instead, participants expressed concerns about who would care for them or their disabled family member in the future (n=24, 41%), saving money for their future care (n=16, 31%), having the means to continue their own education or provide an education for their children (n=12, 17%), and about their current financial situation and needs (n=6,
10%). The association between their own productivity and their relationships with others was interesting. Fourteen participants (24%) expressed a need for a job for themselves or their family member. Education leads to jobs, educating a child leads to good future relations with that child and that child having money. There was a perception that money not only would improve relationships but also increase the likelihood they would be cared for in the future. These are the needs of people with disability in Ladakh most mentioned as a direct result of experiencing disability.

These same participants, none of whom mentioned needing assistive devices, when subsequently asked, in general, what Ladakhis with disabilities most need to make life easier said jobs and job training (n=19, 33%), aids and appliances (n=16, 28%), education (n=14, 24%) and good treatment (n=13, 22%). They talk about a facility where an individual could go to be assessed, where it would be determined what type of job they could do and they would be trained to do that job – anything from using a knitting machine to learning computer skills to becoming an auto mechanic. They specifically list wheelchairs, crutches, hearing aids, canes for the blind, special toilets, and even artificial limbs. Ladakhis expressed needs for assistive devices, along with some of the social and structural changes one would expect to hear based on their experiences. What was missing was a sense of how participants thought aids and appliances would make their life better, there was a disconnect from the lived reality of people with disability, including from their own experiences. On the other hand it was very clear how jobs and education would make their lives better. They would have money, which in turn would improve social relations and opportunities.
In short Ladakhis with disability are seeking ways to be valued, included members of society. Since these are for the most part the same people expressing one thing in relation to disability in general and another in terms of their own lives, it would be interesting to interview more Ladakhis not experiencing disability in their own lives about these same topics. Perhaps the disconnect stems from how the questions were asked, initially being asked specifically about their own experiences versus later in the interview when discussing disability in Ladakh more generally. Perhaps Ladakhis with disability feel alone in their own experiences; not convinced that their own experiences equate with the needs of disabled Ladakhis generally. Recall there were study participants who did not know other people with disabilities, and adult participants in particular were moved by the researcher's interest in them. These same people are exposed to awareness campaigns; they know there are other people with disability in Ladakh, and get an impression about what their needs might be. For those lacking a social network of other people with disability, similarities between their own experiences and that of others may not be immediately apparent. It is not the first time in this study there have been differences between general statements and actual actions or experiences. Again the relationship between social awareness and assistive devices comes to the forefront in this study.

_Assistive Devices:_ The researcher was repeatedly shown assistive devices that had been given out at various medical camps or by visiting health care workers or aid organizations. These included hearing aids with dead batteries, wheelchairs confined to a single room, bent or broken canes and crutches, and eyeglasses with
scratched lenses. It also included devices that had had an array of local
modifications, or were being used for purposes other than their original intent. As
noted by Susan Reynolds Whyte and Herbert Muyinda “global flows of technology
and artifacts take local twists and turns” (2007:295). These items are often
displayed with other more traditionally prized objects only used on special
occasions, or along with important paperwork that their proud owner cannot read.
Bringing these items to Ladakh is not easy, since they must come either by plane
under extremely tight security, or by hired truck on a possibly weeks long trip.
Additionally, little attention is given to the practical considerations associated with
Ladakhis using or maintaining such items.

Recall that 56 percent of people with disability used, possessed, or had used
some type of assistive device, but that only 31 percent used them daily during the
period of fieldwork for this study. Yet, 61 percent did note difficulty simply getting
around. Interestingly, what one sees Ladakhis using most successfully are much
simpler aids that are locally made with available materials. Sometimes these are
made with remnants of metal braces or crutches brought from outside Ladakh.
These usually have been repaired so many times that the original device, let alone
any additional customization or settings, is barely recognizable. Other examples
include a small, low wooden platform with casters maneuvered by pushing on the
ground with one’s hands. Unlike a wheelchair, these can easily be carried, moved,
and stowed by the user when not in an area where it is practical or possible to
wheel about. Sturdy slings or baskets are made for carrying individuals. Ramps to
toilets are constructed. Wooden canes or crutches are uniquely crafted to suit the
needs of the user. For the most part though, people get by doing what they can without any aids.46

When observing the daily lives of Ladakhis with disability, seeing the adaptations they make for themselves and others, and observing the built and natural environment that surrounds them, it is easy to imagine changes or adaptations that could have longer term benefit than assistive devices brought from outside Ladakh. Generous donors come from outside Ladakh with “aids and appliances” for people with disability, eyewear for people with vision problems, clinics for dental work, or other aid. Lacking access to many material goods or supplies, Ladakhis are apt to take what is offered to them, even if they do not see an immediate use for the item. There is an element of prestige associated with having nice things from outside of Ladakh. Alternatively they may have seen or heard that someone with their type of disability has such items and not immediately recognize whether or not it is practical for their life circumstances. Yet these devices hold meaning in Ladakh, and are perhaps directly associated with an awareness of need for social change and hold prestige similar to having money.

*Education and job training:* With the traditional value placed on being a productive member of a household, village, or even society, along with increasing reliance on and desire for money, Ladakhis with disabilities face new challenges regarding the social management of disability and their relationships. Money has a role in shaping norms and values. For people with disability, the role of money

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46 This is not to suggest that no Ladakhis have benefitted from the use of donated aids, but to note that the benefit is limited and the use is often not as anticipated. The most common uses for wheelchairs were described in the case studies in the previous chapter. Many successfully use canes, crutches, or braces for as long as they last.
opens opportunities for earning, with earning money as a way to be productive. As awareness campaigns begin to tackle the assumptions that people with observable impairment can go to school, can get jobs, the next logical thought is that they can be productive members of society. Simultaneously the value on education in Ladakh is beyond the limits of what the local education systems in Ladakh can provide. Families are increasingly sending children outside Ladakh for their education. Families require money, so their children can one day earn money. People with disability have traditionally been left out of the traditional local economy (because of a lack of ability), not sent to school (because of money and a presumed lack of ability), and now out of the job market.

Both young people with disability and their relatives expressed a desire for a school with a hostel so they could have accessible living and education. They expressed disappointment in having to abandon their studies before they would have liked, or not having gone to school at all. This is in line with many Ladakhis expressing a need for job training, or a facility for learning a craft or skill adaptable to the abilities of individuals. Disabled Ladakhis have difficulty finding paid employment, while at the same time are limited in their abilities to do traditional agricultural work. There are many practical concerns, some of which have become apparent through the experiences of existing service providers, and others that come up in discussions about what such facilities might look like or who might run them. For example, there are concerns about potential abuse, providing for the dietary needs of both Buddhists and Muslims, finding the skilled workforce necessary to operate, and cost, to name just a few.
Though Ladakhis frequently expressed a need for job training for people with disability, in reality there was another disconnect between expressed needs and experience. Participant observation at PAGIR during fieldwork revealed numerous examples of people with disability getting a job that was specifically sought to fit their needs and abilities. It was very common that after only a few days of working they stopped showing up. Usually when asked about why they stopped going to work after having said they needed the job, they would provide lists of other things they had to take care of on those days. Over time it became obvious that what many actually wanted was a way to earn money, not regular employment. They wanted to have their own shop rather than work at someone else’s. They wanted to own a cow, or help neighbors with odd jobs. Their expressed goals and concerns were frequently related to money and relationships, even needing a job, but there was a gap. Perhaps the desire for money was for anticipated needs that were too far in the future to give enough urgency to overcome habits of a lifestyle associated with not having regular employment.

**Disabled Elderly and the Future**

The situation of the elderly, particularly disabled elderly, in Ladakh is changing. This seems to be influenced by the value placed on productivity. If there is some association between being productive members of society, or the perception of that possibility through observing impairments, and how disability is defined, this could shed light on variations in how the elderly in Ladakh are treated by their family members. Impairments among the elderly are not even recognized as a disability. The elderly simply have passed their productive stage of life. During
fieldwork there were several groups in the early stages of planning for possible homes for the elderly, similar to nursing homes found in the US but presumably without the nursing care. The main idea seemed to be to build an accessible building and companionship for the elderly, not necessarily advanced or special care. In the context of both the social and physical environment of Ladakh, homes for the elderly could trigger an even bigger sense that money is necessary for the future and would be a sign of a dramatic shift in traditional norms in Ladakhi society. It may also necessitate recognition of disabled versus non-disabled elderly people since it is likely, similar to the old age home that does exist, residents would be expected to care for themselves to a large degree.

With this in mind it is interesting to consider what the future holds for those study participants who expressed concerns about their future care and had the goal of saving money in hopes this would increase the likelihood they would be well cared for. The perception that money improves one’s social situation is associated with concerns about their future care as they age. Three participants even talked about earning money to send a relative’s children to school, since they were unmarried themselves, so that those children would one day take care of them. For others they are most concerned about having money to pay someone to take care of them. In some cases this might be hired help from outside Ladakh, in others this might just be providing a comfortable and appealing lifestyle for relatives so they choose to take care of them.
Increasing Demands Not Matched with Availability and Accessibility

The variety of needs that were mentioned or observed during fieldwork, in relation to available programs and services is daunting. There are issues with transportation, needing assistance with care, a desire for live-in facilities with quality care and special educators, and money to seek health care outside of Ladakh. Some mentioned the value of seeing examples of what people with disability outside Ladakh can do, both to increase awareness among the public but also for people with disability in Ladakh. Some felt that public awareness of the needs of families with a disabled person and family awareness of the capabilities of people with disability so they can be supportive and encouraging, would slowly help to bring about changes. Accessibility to public places is a known issue that has a very long way to go to be achieved, particularly since the main emphasis is on actual physical accessibility only. Awareness and facilities, assistive devices, money for elder care – these are big categories that elicit very specific needs from each individual or family. Perhaps general attitudes toward disability in Ladakh among those who are not experiencing disability may be that the problem is not with the natural or even the built environment, but with the disabled body. The environment is what it is, and like all Ladakhis those with disabled bodies just need to find a way to negotiate that shared environment. Perhaps they see assistive devices as the final answer.

Summary

The previously discussed gap between urban and rural populations in terms of opportunities and attitudes are likely to create increasing intra-cultural variation in the expressed needs of Ladakhis with disabilities, both for disabled people
themselves and the general population. Similarly, the differences between Buddhists and Muslims regarding the management of disability will likely begin to shift as Ladakhi values change, either widening gaps between urban and rural Buddhists and Muslims, or begin to narrow the gaps between Buddhists and Muslims in general as religion plays less of a role in Ladakhi attitudes. These changes may play out differently for disabled Ladakhis than for non-disabled Ladakhis, as both face the same challenges associated with living in Ladakh in the midst of change. One wonders if the lack of attention to the barriers posed by the physical environment, both natural and built, and the attention to assistive devices which may be perceived as quick fixes, will shape this difference.

**Conclusions: Disability in the Mountains**

The complex realities revealed in the data demonstrates how culture is grounded in the human body. Individuals are socialized in the context of a sort of collective consciousness, the *habitus*, which influences their own perceptions of themselves. In Ladakh religion, the environment, and society all play a role in how this *habitus* shapes one’s own view of themselves. Outside influences, everything from human rights to wheelchairs, are incorporated into experience of one’s body. In turn, responses to this process further define culture, through influencing norms, actions, and attitudes. Observing how people experiencing a disability negotiate this lived reality exposes the taken-for-granted aspects of culture.

In Ladakh awareness campaigns draw attention to the presence, needs, and capabilities of people with disabilities, acknowledging both the similarities and differences between people with disabilities and able-bodied Ladakhis. Their
intention is to raise awareness among people with disabilities and the general public. This is a process that necessarily precedes any attempt to implement change. It is perhaps a sign of the success of awareness campaigns that observable disabilities are becoming increasingly associated with various needs. Yet, the mere presence of the wheelchairs in Ladakh demonstrates the necessity of attending to the influences of culture change (Whyte 1995) and the potential complexity of cross-cultural variations in attitudes and other factors like those that have historically caused CBR type programs to fail (Devlieger 1994; Ingstad 1995, 2001, 2007; Leavitt 1999). The wheelchair exemplifies how things like assistive devices have simultaneously been incorporated as an important part of the disability experience in Ladakh and how the reality of a need for change may lag far behind the awareness of that need (Whyte and Ingstad 2007). Ladakh has a history of rapidly incorporating ideas from diverse cultures and places, though they may not always have an immediate means for utilizing or implementing those ideas.

Are the users of “aids and appliances” in Ladakh – those who have incorporated those objects into their body image (Grosz 1994), those whose bodies are marked by assumptions of natural abilities (Weiss 1992), those negotiating the space between their objectified body and their subjective everyday reality through their own body image (Turner 2001) – the very symbols and agents of social change? These individuals are both the result of awareness campaigns and an awareness campaign in and of themselves, much like the processes suggested by Douglas (2002) and Bourdieu (1980). They are driven by a complex interplay
between their religions, physical environments, and changing attitudes toward
disability in Ladakh.

Interestingly, the health care system in Ladakh is caught in the middle.
Health care practitioners, whether biomedical or traditional, work with people who
are negotiating the interplay between their religion, their need for health care, and
increasingly these newer conceptions of disability that are bringing social
awareness and services to Ladakh. The complex relationship between health care
and religion demonstrated in this study is becoming more complex as the
responsibility for identifying individuals as disabled for the purposes of receiving
government benefits lands in the hands of the medical specialists who are relatively
new on the scene themselves. Local health care practitioners themselves are left
with little choice but to shift their own definitions of disability.

Findings from this study indicate that we still lack an understanding of the
cultural and structural forces at play in the context of culture, though this research
begins to uncover more of these variables and the extent to which these forces play
a role in disability experiences. It may even be the case that mental illness,
intellectual disabilities, and disability among the elderly are simply not
acknowledged in Ladakh in order to avoid dealing with them altogether, on the part
of individuals, families, and society as a whole. By not ascribing any meaning,
devaluation, religious explanation, or any other negative attribution then Ladakhi
society does not have to address its lack of solutions. In the context of shifting
definitions and attitudes surrounding disability, Ladakhis may be left with no choice
but to broaden the scope of their management of disability related issues. This is
reminiscent of Whyte and Ingstad’s (2007) assertion that the significance of disability depends on the existence of solutions, and in turn the solutions available influence perceptions about what the problem is.

Ladakh is in a time where the dissonance between experiences and expressed needs are the direct result of social model concepts butting up against impairment or individual model concepts, neither of which have been fully realized in this physical setting, nor likely in similar settings around the world. In the most general terms, the body and its limitations in a harsh physical environment can only overcome so much through the use of “assistive devices”, such as trekking poles or winter coats. Disabled bodies complicate the issues associated with such a physical environment to an extent that is incomprehensible for some, and too often forgotten by those developing services and programs who are thinking mostly in terms of social inclusion. In reality their services or programs play out differently. Even this is oversimplifying the broader issues, like the influence of religion, that come into consideration when cultural context is recognized.

As Ladakhis increasingly move toward a more cash based economy and away from subsistence based economy, the value of education and jobs are at the forefront of many people’s minds. When financial resources are available to a household it is common to make the decision to send a child to school. The quality and level of education available, even in Leh, is below that available elsewhere in India.47 Similarly available health care services, job training programs, and jobs

47 This assertion is based on the desire expressed by many Ladakhis to send children outside Ladakh for school; the observation that those who have received advanced degrees
themselves, lag behind in this remote region of India. This is the situation for all Ladakhis, not just those experiencing disability. For some people with disabilities though the need for money precedes contemplating any need for education and jobs. This is due to a need for care or services that cost money, perhaps for care or even a cure that may be possible outside of Ladakh, or the desire for a series of treatments or rituals advised by traditional healers or religious specialists within Ladakh. These needs are often put in direct competition with education for a non-disabled family member, the latter of which may receive higher priority. Ultimately, with limited cash the long-term benefits of expensive medical care are not given much attention. Perhaps in Ladakh, given the lack of available solutions, rather than a medical problem the disabled body becomes a problem to be addressed by religion.

The social and physical experience of disability in Ladakh will change. With the development of roads and increasing options for transportation, perhaps more local resources for receiving health care, more educational opportunities, and even trends moving away from the use of traditional Ladakhi toilets, will change what life is like for people with disabilities in Ladakh. The divide between urban and rural life will widen and the movement of people, both of which are already significant, will increase. The rapid pace of change in Ladakh inevitably comes into conflict with barriers posed by the physical environment in which Ladakh is situated. Services simply will not be available nor accessible to all Ladakhis who may need them. In fact, people experiencing disability may find their needs in competition with the

had gone outside Ladakh for their education at a fairly early age; and reports of lower college entrance exam scores among Ladakhis.
desire for rapid modernization. The realities of life in Ladakh and religion will likely still predominate over shifting ideals, particularly related to disability. It is interesting to contemplate what changes will result from efforts of NGOs, government initiatives, increased local services like the availability of psychiatric care, and an increasing reliance on money. Will these services be more frequently utilized, with religion taking a back seat, perhaps more so in urban areas? Or will people spend their money for religious rituals? It is unlikely that the complexity of decision making surrounding health, illness, and disability will decrease in Ladakh in the near future.

Subtle differences in any of the points discussed above, when played out in the lives of Ladakhis, can lead to vast differences in the disability experience. When several subtle differences are combined in one person or household it is nearly impossible to even compare two cases, for example of two people with the same disability. Arguments could be made that age at acquisition is the key to the differences, or that it is religion, or urban versus rural living, or education. It would not be possible to seek out study participants where everything is held constant except for one variable. There is too much variation in life. Ladakh was the only constant variable for this study. Yet the differences, though subtle have obvious significant effects in Ladakh. Many studies of disability have reduced potential difference in their study population by focusing on a particular disability. Though these types of studies provide valuable insight they lack the true depth of knowledge about a culture and the lives of people with disability within it that can be provided using a more holistic approach. As the example above demonstrates,
subtle differences that make a population heterogeneous can vastly change
experience. A few studies of disability that focus on a single disability type have
done thoughtful analyses of these types of differences, though with little emphasis
on one of the most significant factors in shaping experience in this study – religion.

Studies of disability that have focused on religion have analyzed narrow
topics such as concepts of personhood and causality. This study was designed to
use religion as a way to bridge the gap in disability literature, as suggested by Whyte
(1995) to look both at culture and experience. Often, in studies of disability or
anthropology of the body, a theoretical approach is applied to a particular
phenomenon – for example, taking a political economic approach to the study of
disability caused by war, or the concept of body image and identity to study obesity.
This research, on the other hand, accessed and embraced the subtle differences in
bodies and cultures. This research challenges embodiment scholars to rethink the
fundamental ontology of that paradigm. Disability problematizes an embodiment
approach by showing that the body as the existential ground of culture can itself
take on a variety of forms and even include man-made extensions of the body. It
suggests that the existential basis of experience must be something more
fundamental still than the body, something simpler. Suggesting that evidence of
complexity necessitates simplification may seem counterintuitive. Complexity
resulting from heterogeneity requires us to simply recognize that particular bodies,
in particular places, at particular moments in time are what shapes the lived reality
of individuals and contribute to the very substance of culture and to culture change.
Similarly, this research is a call for scholars within the anthropology of the body to
consider disabled bodies, to include in their scholarship more diverse differences. Scholars within the anthropology of disability should engage with body theories, and specifically address both the physical and social realities of disability.

Embracing the subtle differences between bodies and cultures, we are left able to address two questions: (1) how does culture shape experience?; and (2) what does living in a particular body tell us about culture? This study has demonstrated how the relationship between culture, religion, and health is expressed through the disabled body/self. Furthermore, disability gives us a holistic understanding of experience – the interaction between the subjective experience of the body and outside influences, whether they be physical, social, or cultural. We also get a unique viewpoint from which to examine culture – with disability as a lens. We are reminded of Zola's (1989) assertion that disability is something relevant to all of us.

**Directions for Future Research**

Disability provided a lens to Ladakhi culture that has highlighted several future areas of inquiry for the field of Ladakh studies. Overarching the specific topics that may be of interest – such as education, environmental issues, or economics, for example – is change. Ladakh is undergoing rapid culture change. One future direction for research would be to utilize a study design similar to that of this dissertation research to focus on culture change. During this field research the value placed on education and jobs was tremendous. It would be interesting to study, for example, the actual impact of education and jobs on Ladakhis. An exploration of change, its influences, and its consequences on things like social
structures, the environment, and Ladakhi culture would be a unique example of both the positive and negative effects of globalization.

Another future area of inquiry highlighted by this research is the apparent lack of engagement between the fields of disability studies and gerontology. This disconnect exists in society, in service provision, and in academic inquiry. Exploration of why this occurs and its impacts on the lives of the elderly in diverse cultural contexts may open new avenues for interdisciplinary collaboration – ultimately starting a conversation that could change the very approaches common to those disciplines.

The situation of the elderly in Ladakh, as for people with disability, is complex and in a state of change. A study that examines variations in treatment of and attitudes toward the elderly, along with experiences of aging, in the context of social change would be enlightening. One could further compare urban versus rural populations, as well as other parts of the Tibetan culture area to examine the influences of and rates of change in different cultural contexts. A comparative study of healthy elderly, people with disability, and disabled elderly would add further insight into the variability of elderly experiences observed during this research. This type of study would also lead to a better understanding of Ladakhi norms and values such as marriage and productivity in a household or society.

Stigma processes, grounded in local concepts of normality and difference, have profound influences on the self. They also shape society. Two directions for future research on disability and stigma processes are possible. First, in-depth analyses of the lives of individuals experiencing disability and how stigma processes
shape their decision making as they move through the life course would provide rich data on the psychological and emotional aspects of disability most influenced by culture and society. Second, evaluating stigma processes within social institutions, and among service providers and policymakers, would provide insight into how attitudes toward disability in these contexts may shape attitudes in a society more broadly. Taking these micro and macro levels of analysis together, we would gain a better understanding of the role of stigma processes and the societal impact of things like chronic or infectious diseases, aging populations, the effects of war, and such issues of relevance to global health.

In Ladakh, one could take a very specific approach to this line of stigma research examining the relationship between stigma and *karma*. A study comparing stigma experiences among Buddhist, Muslims, and other religions represented in Ladakh, perhaps in relation to disability as well as other differences that may be associated with *karma* would provide very specific insight into the ways in which religion shapes culture, and where individuals perhaps draw lines between religion, culture, and their own experiences of daily life.

Perhaps of most interest to this researcher is to explore health care seeking and religious activities between those who are healthy, those with illness or injury, and those who are disabled. A study such as this could also engage in an exploration of the meanings and experiences of mental illness and aging in Ladakh. To do such a study in both urban Ladakh, as well as more far-flung rural areas would be ideal and provide insight into the role of various types of changes taking place in Ladakh, analyzing potential widening gaps between urban and rural populations.
More broadly one could study experiences of disability as a means to study culture change in various cross-cultural contexts. In order to develop a robust social theory of disability that is interdisciplinary in nature – that is to further test the arguments set forth in the previous chapter – it is necessary to develop a method of study that is both feasible and meaningful. This approach would go beyond acknowledging and demonstrating the interplay between cultures and bodies, to show how experiences of being in particular bodies can provide meaningful insight into culture change, and a necessary understanding of how local and global worlds come together to shape future issues of relevance to individuals, societies, and beyond.

Of course repeating a study similar to this one in the Kargil district would provide interesting points of comparison between the majority Buddhist and majority Muslim areas of Ladakh, and would enable all of the above mentioned areas for research to be refined and more applicable to Ladakh as a whole.

Research in the Kargil district could also reveal more instances of Buddhist-Muslim syncretism. Future research could compare Buddhist-Muslim syncretism in Ladakh to that which may be found in other border areas with complex histories of folk religious traditions and immigration in parts of Southeast Asia.

**Significance and Contributions**

This study has examined subjective experiences of disability in Ladakh, India focusing on the interactions between the physical and social domains of experience, in the context of local cultural constructions of disability. The examples provided in this dissertation have demonstrated the multitude of factors that influence local
definitions and attitudes. Several case studies illustrated how norms, values, and customs interact with physical realities and environments to shape disability experience. Study findings brought to light how religion influences the experience and management of disability. Those very factors that make a population heterogeneous can result in vast variations in disability experience. The mixed method study design facilitated a holistic approach to the study of disability, providing an ethnographic example that problematizes the social model of disability and brings the body back to disability studies. Further, this dissertation takes a new look at the complexity of identifying needs and barriers to providing services for people with disability. Disability studies scholars have often viewed groups as homogenous. Disability activists have viewed needs as universal. This study demonstrates that the social model used by many NGOs is not adequate and that anthropological approaches to disability can be an invaluable resource in this necessarily interdisciplinary field. Whyte and Muyinda argue that “one important contribution of ethnographers is the elucidation of diversity, constraints, and resources so that policy makers and disability organizations can better address variation as they work to translate “paper rights” into opportunities, respect, and recognition” (2007:288). Through such ethnographic endeavors, anthropologists can contribute to these necessarily interdisciplinary efforts. Underlying all of this is the simple argument that disability cannot be separated from impairment:

Seeing disability in context implies understanding disability not (as it once did) in one particular isolated cultural setting, but in contexts in which modern ideas about rights for persons with a disability coexist with possibilities, constraints, and beliefs imposed by the local physical, social, economic, and cultural setting. [Ingstad 2007:250]
Due to the extreme nature of the physical environment and the pervasive influence of two religions, Ladakh proved to be an ideal place to conduct this research. Learning about disability experiences among a broad range of people highlights how recent changes in Ladakh are affecting Ladakhi lifestyle and values. Using disability as a lens through which to view culture may be a way to enhance our understanding of a culture and bring to light significant elements which may have otherwise been overlooked. Studying disability in this holistic manner can shed light on the changing structure and roles of family, households, support networks, and class differences in the broader context of Ladakhi society and the impact these changes are having on Ladakhi culture.

This study also demonstrated the possible limitations of the power of culture; disability experience often trumps the pull of culture and religion. In Ladakh religion plays a significant role in shaping both social and physical experiences of disability. It is the dominant influence on individual and professional constructions of disability, particularly related to causality. It can influence the attitude one takes toward their own or their family member's disability with regard to education, employment, social activities, seeking health care and participating in religious activities. Regardless of cause it is typical for individuals or families to seek advice from various religious and secular specialists. This often puts people in a position of having to make choices between familiar traditional ideas and modern approaches, or trying to attempt a balance between them. Particularly when resources are scarce, religious advice is often taken over the advice of a physician or
educator. This makes religious advice regarding the intertwined social and physical challenges of disability itself an important area of inquiry.

Having taken a broad, holistic approach to the study of disability within a culture it is now possible to consider how this same approach could be used differently. Research like this could be done on a smaller scale, during shorter periods in the field, providing crucial depth of knowledge that would benefit applied work in international health. The study design and data presented real life examples, that though rooted in anthropology could speak with interdisciplinary significance. These examples have shown not only the limitations of previous approaches, but also the strength of a holistic approach, an approach that recognizes the complexities of experience, culture and environment. This approach has relevance beyond disability to other topics and issues of importance across cultures – whether associated with illness, conflict, social justice, or agriculture, for example.

In short, studying the experience of disability teaches us about culture. We learn about normality, expectations, values, customs, and change. Intra-cultural variation becomes more readily apparent than previously acknowledged by scholars or applied practitioners. We see variation in attitudes and experiences, and the diversity of influences on them. These influences are socio-cultural, environmental, based in religion, age, gender, class and the like. These basic categories are in fact predictors of variation in social constructions and experiences. These are the same cultural variables that are already considered significant by those with applied approaches. This study of disability has clearly demonstrated that these same predictors of need, social patterns, and disparity are also predictors
of intra-cultural variations in experiences that interact to define culture. This
unique lens through which to view culture lets us begin to understand the necessity
of a holistic understanding of a culture in order to grasp the complexity of individual
experiences, and thus the complexity of evaluating need, for example, within a sub-
population or group in that culture.
APPENDIX A: CONSENT MATERIALS

Table A1: Overview of consent results*

<table>
<thead>
<tr>
<th>Consent form Used</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Household</td>
<td>28 (31.5)</td>
</tr>
<tr>
<td>Parent/Guardian Permission</td>
<td>6 (6.7)</td>
</tr>
<tr>
<td>Parent Permission with Child Assent</td>
<td>6 (6.7)</td>
</tr>
<tr>
<td>Representative</td>
<td>1 (1.1)</td>
</tr>
<tr>
<td>Multiple Interviews</td>
<td>13 (14.6)</td>
</tr>
<tr>
<td>Single Interview</td>
<td>35 (39.3)</td>
</tr>
<tr>
<td>Consent for Audio Recording</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>88 (98.9)</td>
</tr>
<tr>
<td>No</td>
<td>1 (1.1)</td>
</tr>
<tr>
<td>Consent for Photo to be taken</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>85 (95.5)</td>
</tr>
<tr>
<td>No</td>
<td>4 (4.5)</td>
</tr>
<tr>
<td>Consent for Photo to be published</td>
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</tr>
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<td>81 (91.0)</td>
</tr>
<tr>
<td>No</td>
<td>8 (9.0)</td>
</tr>
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<tr>
<td>Signed</td>
<td>70 (78.7)</td>
</tr>
<tr>
<td>Stamped</td>
<td>19 (21.3)</td>
</tr>
</tbody>
</table>

*detail may not add to total due to rounding errors

Consent Forms

STUDY SUMMARY: ORAL SCRIPT
The Experience of Disability in a Himalayan Community
Phase One: Single Interview

I am doing a research project for school about disability in Ladakh. I would like you to participate because I am interested in your experiences with disability. I go to school at Case Western Reserve University in Cleveland, Ohio in the USA. I want to learn what life is like in Ladakh and what life is like for people with disability. I will be in Ladakh for one year to talk to many people about their lives. I would like to talk to you about disability and daily life in Ladakh for about two hours. I would like to spend a day with you to see what you do during the day. If it is okay I would like to tape record us talking and take photographs. You can still participate if you do not want to be recorded or if you do not want to be photographed.

There are no foreseeable risks to participation in my project. There are no benefits to participating in my project. I hope this research will help people who develop services and programs for people with disability to understand: what life is like for people with
disability; what is important to them; and what they need. This could help people with disability and their families in Ladakh and other places in the world.

I will keep everything you say private. Records will be stored in locked trunks. When I give reports about my study I will use different names so nobody who participated can be identified. My teacher, my research assistants, and a committee at my university that helps protect human rights will be able to look at my records. I will keep the tapes in a locked cabinet. Photos will be kept and may be published.

Your participation is voluntary. It is okay if you do not want to participate or if you do not want to participate in certain parts of the study. There are no consequences for you, your employment status, or your group membership if you choose not to participate. You can stop participating or take a break at any time. If you participate you will receive a gift of appreciation for your time. Please ask questions before you agree to participate in my project.

Whenever you have questions or concerns, you can contact me (Sarah Rundall) at my home in Phyang, or my teacher Professor Charlotte Ikels. Her phone number is 216-368-5331. Her email address is charlotte.ikels@case.edu. You can also contact Case Western Reserve University's Institutional Review Board at (216) 368-6925 or write: Case Western Reserve University; Institutional Review Board; 10900 Euclid Ave.; Cleveland, OH, USA 44106-7230. I will give you a copy of this paper and the paper you will sign saying you agree to be in the project.

Signature of researcher Sarah A. Rundall: ______________________ Date: __________
Witness ___________________ signature: _____________________ Date: __________

STUDY SUMMARY: ORAL SCRIPT
The Experience of Disability in a Himalayan Community
Phase One: Multiple Interviews

I am doing a research project for school about disability in Ladakh. I would like you to participate because I am interested in your experiences with disability. I go to school at Case Western Reserve University in Cleveland, Ohio in the USA. I want to learn what life is like in Ladakh and what life is like for people with disability. I will be in Ladakh for one year to talk to many people about their lives.

I would like to talk to you about disability and daily life in Ladakh for about two hours, two or three times while I am in Ladakh. I would like to schedule a time to observe your typical daily activities and maybe special events you participate in. If it is okay I would like to tape record us talking and take photographs. You can still participate if you do not want to be recorded or if you do not want to be photographed. I would like you to participate in a group discussion with me, my research assistant and other participants about the topics of disability and daily life in Ladakh.
There are no foreseeable risks to participation in my project. There are no benefits to participating in my project. I hope this research will help people who develop services and programs for people with disability to understand: what life is like for people with disability; what is important to them; and what they need. This could help people with disability and their families in Ladakh and other places in the world.

I will keep everything you say private. Records will be stored in locked trunks. When I give reports about my study I will use different names so nobody who participated can be identified. My teacher, my research assistants, and a committee at my university that helps protect human rights will be able to look at my records. I will keep the tapes in a locked cabinet. Photos will be kept and may be published.

Your participation is voluntary. It is okay if you do not want to participate or if you do not want to participate in certain parts of the study. There are no consequences for you, your employment status, or your group membership if you choose not to participate. You can stop participating or take a break at any time. If you participate you will receive a gift of appreciation for your time. Please ask questions before you agree to participate in my project.

Whenever you have questions or concerns, you can contact me (Sarah Rundall) at my home in Phyang, or my teacher Professor Charlotte Ikels. Her phone number is 216-368-5331. Her email address is charlotte.ikels@case.edu. You can also contact Case Western Reserve University's Institutional Review Board at (216) 368-6925 or write: Case Western Reserve University; Institutional Review Board; 10900 Euclid Ave.; Cleveland, OH, USA 44106-7230. I will give you a copy of this paper and the paper you will sign saying you agree to be in the project.

Signature of researcher Sarah A. Rundall: ______________________  Date: __________
Witness __________________ signature: ______________________  Date: __________

STUDY SUMMARY: ORAL SCRIPT
The Experience of Disability in a Himalayan Community
Phase Two: Single Interview

I am doing a research project for school about disability in Ladakh. I would like you to participate because I am interested in your experiences with disability. I go to school at Case Western Reserve University in Cleveland, Ohio in the USA. I want to learn what life is like in Ladakh and what life is like for people with disability. I will be in Ladakh for one year to talk to many people about their lives. I would like to talk to you about disability and daily life in Ladakh for about two hours. I would like to spend a day with you to see what you do during the day. If it is okay I would like to tape record us talking and take photographs. You can still participate if you do not want to be recorded or if you do not want to be photographed.
There are no foreseeable risks to participation in my project. There are no benefits to participating in my project. I hope this research will help people who develop services and programs for people with disability to understand: what life is like for people with disability; what is important to them; and what they need. This could help people with disability and their families in Ladakh and other places in the world.

I will keep everything you say private. Records will be stored in locked trunks. When I give reports about my study I will use different names so nobody who participated can be identified. My teacher, my research assistants, and a committee at my university that helps protect human rights will be able to look at my records. I will keep the tapes in a locked cabinet. Photos will be kept and may be published.

Your participation is voluntary. It is okay if you do not want to participate or if you do not want to participate in certain parts of the study. You can stop participating or take a break at any time. There are no consequences if you choose not to participate in the study. If you participate you will receive a gift of appreciation for your time. Please ask questions before you agree to participate in my project.

Whenever you have questions or concerns, you can contact me (Sarah Rundall) at my home in Phyang, or my teacher Professor Charlotte Ikels. Her phone number is 216-368-5331. You can also contact Case Western Reserve University's Institutional Review Board at (216) 368-6925 or write: Case Western Reserve University; Institutional Review Board; 10900 Euclid Ave.; Cleveland, OH, USA 44106-7230. I will give you a copy of this paper and the paper you will sign saying you agree to be in the project.

Signature of researcher Sarah A. Rundall: ______________________  Date: __________
Witness __________________ signature: ______________________  Date: __________

STUDY SUMMARY: ORAL SCRIPT
The Experience of Disability in a Himalayan Community Household

I am doing a research project for school about disability in Ladakh. I would like you to participate because I am interested in your experiences with disability. I go to school at Case Western Reserve University in Cleveland, Ohio in the USA. I want to learn what life is like in Ladakh and what life is like for people with disability. I will be in Ladakh for one year to talk to many people about their lives.

I would like to talk to you about your household, daily life, and about disability. Sometimes we will talk in a group and other times we can talk in private. I would like to visit your household about ten or fifteen times over the next nine months. I will spend most of the day. When I visit I will observe what you do during the day and talk. These
visits will not disrupt daily routines. If it is okay I would like to tape record our talking and take photographs. You can still participate if you do not want to be recorded or if you do not want to be photographed.

There are no foreseeable risks to participation in my project. There are no benefits to participating in my project. I hope this research will help people who develop services and programs for people with disability to understand: what life is like for people with disability; what is important to them; and what they need. This could help people with disability and their families in Ladakh and other places in the world.

I will keep everything you say private. Records will be stored in locked trunks. When I give reports about my study I will use different names so nobody who participated can be identified. My teacher, my research assistants, and a committee at my university that helps protect human rights will be able to look at my records. I will keep the tapes in a locked cabinet. Photos will be kept and may be published.

Your participation is voluntary. It is okay if you do not want to participate or if you do not want to participate in certain parts of the study. You can stop participating or take a break at any time. There are no consequences if you choose not to participate in the study. If you participate you will receive a gift of appreciation for your time. Please ask questions before you agree to participate in my project.

Whenever you have questions or concerns, you can contact me (Sarah Rundall) at my home in Phyang, or my teacher Professor Charlotte Ikels. Her phone number is 216-368-5331. You can also contact Case Western Reserve University's Institutional Review Board at (216) 368-6925 or write: Case Western Reserve University; Institutional Review Board; 10900 Euclid Ave.; Cleveland, OH, USA 44106-7230. I will give you a copy of this paper and the paper you will sign saying you agree to be in the project.

Signature of researcher Sarah A. Rundall: ______________________  Date: __________
Witness _________________ signature: _______________________  Date: __________

STUDY SUMMARY: ORAL SCRIPT
The Experience of Disability in a Himalayan Community
Parent/Guardian Permission

I am doing a research project for school about disability in Ladakh. I would like your child to participate because I am interested in his/her experiences with disability. I go to school at Case Western Reserve University in Cleveland, Ohio in the USA. I want to learn what life is like in Ladakh and what life is like for people with disability. I will be in Ladakh for one year to talk to many people about their lives.
I would like to talk to your child about your household, daily life, and about disability. Sometimes we will talk in a group and other times we can talk in private. I would like to visit your household about ten or fifteen times over the next nine months. I will spend most of the day. When I visit I will observe what your child does during the day and talk. These visits will not disrupt daily routines. I would like to tape record us talking and take photographs. Your child can still participate if you do not want him/her to be recorded or if you do not want him/her to be photographed.

There are no foreseeable risks to participation in my project. There are no benefits to participating in my project. I hope this research will help people who develop services and programs for people with disability to understand: what life is like for people with disability; what is important to them; and what they need. This could help people with disability and their families in Ladakh and other places in the world.

I will keep everything your child says private. Records will be stored in locked trunks. When I give reports about my study I will use different names so nobody who participated can be identified. My teacher, my research assistants, and a committee at my university that helps protect human rights will be able to look at my records. I will keep the tapes in a locked cabinet. Photos will be kept and may be published.

Your child’s participation is voluntary. It is okay if you do not want your child to participate or you do not want them to participate in certain parts of the study. Your child can stop participating or take a break at any time. There are no consequences if do not want your child to participate in the study. If your child participates he/she will receive a gift of appreciation. Please ask questions before you agree for your child to participate in my project.

Whenever you have questions or concerns, you can contact me (Sarah Rundall) at my home in Phyang, or my teacher Professor Charlotte Ikels. Her phone number is 216-368-5331. You can also contact Case Western Reserve University's Institutional Review Board at (216) 368-6925 or write: Case Western Reserve University; Institutional Review Board; 10900 Euclid Ave.; Cleveland, OH, USA 44106-7230. I will give you a copy of this paper and the paper you will sign saying you agree for your child to be in the project.

Signature of person obtaining consent Sarah Rundall: _______________ Date: __________
Witness __________________ signature: ______________________  Date: __________

STUDY SUMMARY: ORAL SCRIPT
The Experience of Disability in a Himalayan Community
Representative Consent
I am doing a research project for school about disability in Ladakh. I would like the person you are representing to participate because I am interested in his/her experiences with disability. I go to school at Case Western Reserve University in Cleveland, Ohio in
the USA. I want to learn what life is like in Ladakh and what life is like for people with
disability. I will be in Ladakh for one year to talk to many people about their lives.

I would like to talk to people in your household about your household, daily life, and
about the life of the person you are representing. I would like to visit your household
about ten or fifteen times over the next nine months. I will spend most of the day. When
I visit I will observe what the person you are representing does during the day and talk to
other members of the household. These visits will not disrupt daily routines. I would
like to tape record and take photographs. The person you are representing can still
participate if you do not want him/her to be recorded or if you do not want him/her to be
photographed.

There are no foreseeable risks to participation in my project. There are no benefits to
participating in my project. I hope this research will help people who develop services
and programs for people with disability to understand: what life is like for people with
disability; what is important to them; and what they need. This could help people with
disability and their families in Ladakh and other places in the world.

I will keep everything I learn about the person you are representing private. Records will
be stored in locked trunks. When I give reports about my study I will use different names
so nobody who participated can be identified. My teacher, my research assistants, and a
committee at my university that helps protect human rights will be able to look at my
records. I will keep the tapes in a locked cabinet. Photos will be kept and may be
published.

Participation is voluntary. Please consider whether they would want to participate in this
study. It is okay for the person you are representing does not participate or does not
participate in certain parts of the study. They can stop or take a break at any time. There
are no consequences if you do not want them to participate in the study. Your household
will receive a gift of appreciation for participating. Please ask questions before you agree
for the person you are representing to participate.

Whenever you have questions or concerns, you can contact me (Sarah Rundall) at my
home in Phyang, or my teacher Professor Charlotte Ikels. Her phone number is 216-368-
5331. You can also contact Case Western Reserve University's Institutional Review
Board at (216) 368-6925 or write: Case Western Reserve University; Institutional Review
Board; 10900 Euclid Ave.; Cleveland, OH, USA 44106-7230. I will give you a copy of
this paper and the paper you will sign saying you agree for the person you are
representing to be in the project.

Signature of person obtaining consent Sarah Rundall: _______________ Date: ________
Witness ___________________ signature: _____________________  Date: __________
Hi, my name is Sarah. I am doing a project for school to learn about different people’s experiences with disability and what life is like in Ladakh. During the next few months I will be visiting your house several times, on about 15 different days. When I visit I will probably spend the whole day at your house. When I am at your house and you have time, I would like to talk to you about your life and your experiences with disability. I would also like to see what you do during the day. I would like to tape record when we talk and take your picture. It is okay if you do not want to do talk to me. If you say yes, it is okay to change your mind and we can stop talking. You can still talk to me even if you do not want me to record you or you do not want me to take your picture. Your parent(s) know I am asking you to help me with my school project. Would you like to be in my project? Is it okay if I tape record our conversations? Is it okay if I take your picture?

CONSENT DOCUMENT: SHORT FORM

The project has been explained to you. Your questions have been answered. You agree to participate in this research. You are 18 years old or older.

Choose one:
☐ Yes, you agree to being audio recorded.
You understand you can change your mind.

☐ No, you do not agree to being audio recorded.

Choose one:
☐ Yes, you agree to being photographed.
You understand you can change your mind.

☐ No, you do not agree to being photographed.

Print Name of Participant: ________________________________

Signature of Participant or Representative: ________________________________
Date: ___________

Signature of Witness: ________________________________
Date: ___________
It is okay for Sarah Rundall to keep and publish photographs.

Print Name of Participant: ________________________________

Signature of Participant or Representative: ________________________________
Date: ____________

Signature of Witness: ________________________________
Date: ____________

PARENT/GUARDIAN PERMISSION DOCUMENT: SHORT FORM

The project has been explained to you. Your questions have been answered. You give permission for your child to participate in this research.

Choose one:
☐ Yes, your child can be audio recorded.
You understand you can change your mind.

☐ No, your child cannot be audio recorded.

Choose one:
☐ Yes, your child can be photographed.
You understand you can change your mind.

☐ No, your child cannot be photographed.

Print Name of Participant: ________________________________

Signature of Parent or Guardian: ________________________________
Date: ____________

Signature of Witness: ________________________________
Date: ____________
It is okay for Sarah Rundall to keep and publish photographs.

Print Name of Participant: ______________________________________

Signature of Parent or Guardian: ________________________________
Date: ______________

Signature of Witness: ______________________________________
Date: ______________

REPRESENTATIVE CONSENT DOCUMENT: SHORT FORM

The project has been explained to you. Your questions have been answered. You allow the person you represent to participate in this research.

Choose one:
☐ Yes, information about the participant can be audio recorded.

You understand you can change your mind.

☐ No, information about the participant cannot be audio recorded.

Choose one:
☐ Yes, the participant can be photographed.

You understand you can change your mind.

☐ No, the participant cannot be photographed.

Print Name of Participant: ______________________________________

Signature of Representative: ________________________________
Date: ______________

Signature of Witness: ______________________________________
Date: ______________

It is okay for Sarah Rundall to keep and publish photographs.
Print Name of Participant: ______________________________

Signature of Representative: __________________________
Date: ____________

Signature of Witness: ________________________________
Date: ____________

CHILD ASSENT DOCUMENT: SHORT FORM

The project has been explained to you. Your questions have been answered. You will participate in this research.

☐ Yes, you agree to being audio recorded.
You understand you can change your mind.

☐ No, you do not agree to being audio recorded.

☐ Yes you agree to being photographed.
You understand you can change your mind.

☐ No, you do not agree to being photographed.

Print Name of Participant: ______________________________

Signature of Participant or Representative: __________________________
Date: ____________

Signature of Witness: ________________________________
Date: ____________
APPENDIX B: INTERVIEW INSTRUMENTS

Household Survey

*General Information:* date, house name, name of person with disability, location of house, landline, mobile, religion

*For Each Household Member:* name, relationship to person with disability, sex, age, marital status, education, occupation, employment for income, comments

Other HHs with same house name in village? If yes, number? Who lives in those houses and how are they related?

Does the family have other relatives in this village? If yes, number of houses? Who lives in those houses and how are they related?

*Household Subsistence Information:* crops, amount of land, animals, income

Demographics and Health Instrument:

Name, Sex, Age, Religion (If Muslim Shia or Sunni), Occupation, Education, Marital Status, Income, Where From, Primary Residence

Tell me what you do on a Typical Day from the time you get up until you go to bed.

Do you consider yourself to be a healthy person? Have you ever had a serious illness? Did you fully recover? Have you ever had a serious injury? Did you fully recover? Do you have any disability?

Interview Instrument For PWD or Family Member

PWD or FAMILY MEMBER QUESTIONS:

Tell me about your disability.

Probes: when acquired, changes over time, health care, religious or other services sought because of the disability, physical problems, etc.

Has your disability affected your opportunities?

Probes: education, employment, marriage

Has your disability affected your relationships with other people?

Probes: family, friends, community

Are there any challenges for you caused by the environment in Ladakh?

Are there any challenges for you caused by the landscape in Ladakh?

Are there any challenges for you caused by the way things are built in Ladakh?

Tell me more about other activities you do.

What have been some of the most significant experiences in your life?

Do you have concerns about your future?
What are your goals and aspirations for the future?

**Interview Instruments for Other Professionals**

**NGO QUESTIONS:**
Tell me about this organization.
   Probes: mission statement, structure, services and programs, other activities in day to day operation
What kinds of services and programs do you have for PWDs?
How many PWDs participate? Benefit?
Do you have any statistics about disability in Ladakh?
Are there people you feel your organization is not reaching?
Do you have plans to expand or for more outreach?
What things do you think your organization is most successful at?
What kinds of challenges does your organization face?

**HCP QUESTIONS**
Tell me about how you became a _________.
Tell me about what kinds of things you do for people.
Do a lot of PWDs come to you for your services?
What kinds of disabilities do they have?
What are the common causes of their disabilities?
Do you treat a person with disability different from someone who is sick?

Do you try to cure someone who has been disabled for a long time – or just treat their symptoms? Example: knee problem with pain – Do you try to make it so they can walk again or just treat the knee pain.

Are there differences in the type of treatment or advice you provide if some is disabled by birth or from an accident or illness?
Some people seek advice and others may seek treatment. How do you decide whether to advise or to treat?
What kinds of advice might you give someone?
What types of treatment might you offer?

Do both Buddhists and Muslims come to you for your services?
Is there a difference between what Buddhists come for than what Muslims come for?
Example: Buddhist come for common cold, Muslims only come with injuries
Do you do anything different when treating or advising Buddhists vs. Muslims?

**RELIGION QUESTIONS**
Tell me about how you became a _________.
What does your religion say about disability?

Have PWDs or their family members come to you for advice?
If a person with disability or family member comes to you about their disability or health care – what would you do for them?
Does it make a difference if the person is disabled from birth or from an illness or accident?
Do you advise people about what health care to utilize?

Many people say they consult a Rinpoche / Akhon – can you tell me about what they might do for a person with disability?

**GENERAL QUESTIONS:**
If you get sick or injured, do you seek advice or care from anyone?
Are there religious things you do to avoid getting sick?
Are there religious things you do if you get sick or injured?

Do you know any other people with a disability?
Tell me a little about them.
Do you know any other people who have trouble with daily activities?
Tell me about them.
Do you know if your religion says anything about disability?

Do you think a person with a disability can do all the same things as other Ladakhis?
What kinds of things do you think Ladakhis with disabilities need?
Are there things you think should be changed to make life easier for people with disabilities in Ladakh?
Do you know of any special programs or services for people with disabilities in Ladakh?

Do you think Ladakh is an easy or hard place to live?
Probe: What if you are sick, injured, old, or disabled?
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