January 2012

Responsiveness of the Federal Health System to the Needs of 18-45 Year Old Adults With Physical Disabilities in Islamabad, Pakistan

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Responsiveness of the Federal Health System to the Needs of 18-45 Year Old Adults

With Physical Disabilities in Islamabad, Pakistan

by

Shaista Habibullah

A dissertation submitted in partial fulfillment of requirements for the degree of Doctor of Philosophy
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Date of Approval:
July 3, 2012

Keywords: patient dignity, prompt attention, legitimate expectations, qualitative, cultural influences

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Dedication

To my mentors, Dr. Shakila Zaman and Syed Anwar Mahmood
Acknowledgements

This dissertation marks the culmination of a long academic, emotional and personal journey in which I was joined by a number of people, without whom this would not have come to fruition.

Thanks are due to my doctoral committee members for their guidance and support in an alien culture and an academic system I had no prior knowledge of. Thanks to Dr. Russell Kirby, my major advisor for always being there for me. Sir, your gentle encouragement helped me at every single step of this long and difficult road and I do not have enough words to express my gratitude to you. I am deeply grateful to Dr. Julie Baldwin for her personal warmth that immensely helped me through the rough spots during this program. I am grateful for your patience and guidance that helped me conceptualize my topic of interest at progressively higher levels of theorization. It is to you, Dr. Carla VandeWeerd that I owe all my knowledge of research methods and the ability to write concisely and clearly. You have been a beacon of light and a constant source of encouragement throughout my course work, research and dissertation writing. I appreciate Dr. Barbara Langland Orban for her role in helping me not to lose sight of the realities within which health systems perform, especially in the developing countries.

I am deeply grateful to the heads of the community-based, nongovernmental organizations of people with disabilities in Islamabad, who not only supported my research but shared my enthusiasm. Thanks are due to Mrs. Farah Ali Butt and Mr. Mohammad Ali Butt of the Disabled Persons Development Organization, Mr. Atif Sheikh of the Special Talent
Exchange Program, Mr. Agha Husnain Raza of the Milestone Society for Special Persons, and to Mr. Asim Zafar of the Saaya Association of People with Disabilities. I hope this collaboration continues in the future as we join hands for health and social policy advocacy for the disabled in Pakistan.

I deeply appreciate the United States Educational Foundation in Pakistan for providing me with this life-changing opportunity through the Fulbright student grant. It was owing to the financial security of my grant that I was able to focus on my studies full time. Thanks are also due to all my program officers at the Institute of International Education, New York, for their role in the smooth continuation of my grant over these four years.

I have made the best of friends in the United States and they will forever remain close to my heart. I owe a vote of thanks to Melissa Mercado, Natalie Hernandez, Jaime Myers, Roxann McNeish, Kristine Hernandez and Amy Lester, for being such sincere friends through thick and thin. Thanks are also due to members of the preceding and successive PhD cohorts in the Department of community and Family Health, for being my valuable social support network.

I am grateful to my parents, my children and my siblings for bearing the brunt of my physical absence during the course of this PhD. I know that you have missed me, and I have missed you enormously, but it has all been worth it.
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Abstract

The health system has been defined as all people, institutions and resources that undertake actions with the primary intent of improving health, while responsiveness of the health system refers to its objective of responding to the legitimate expectations of the population it serves. Although responsiveness is a non-health objective of the health system, it affects the health status of the population by influencing treatment compliance, patient-provider communication and health services utilization. Furthermore, responsiveness has a fundamental value as it concerns basic human rights of the individuals being served by the health system.

This study was undertaken to determine how well the Pakistani federal health system was responding to the needs of 18-45 year old adults with physical disabilities living in Islamabad, and the barriers that were hindering the government from responding to this vulnerable sub-group of the population. The study employed a qualitative approach. Data were collected through focus group discussions with 18-45 year old physically disabled consumers of healthcare in the three federal government hospitals located in Islamabad. In-depth, face-to-face interviews were conducted with health care providers, managers, policy makers, and disability rights advocates who had been operating within the same system.

Results of the study indicated that the federal health system falls short in responding to the needs of a large population of physically disabled adults living in the
Islamabad Capital Territory. This research has identified barriers operating at multiple levels of the health system, and within the policy making, financing and federal human resource milieu. The main barriers to responsiveness of the health system included vulnerability of persons with disabilities, lack of provider training, lack of priority accorded to issues confronting the disabled at the highest policy making levels, and the lack of a referral system. The pluralistic Pakistani culture also posed a barrier to responsiveness of the health system especially in case of women. The researcher expects this study to contribute to informed policy making and spur further research on the needs of this oft-neglected sector of the Pakistani population. The results of this study will be shared at multiple forums including top policy making levels, as well as at the level of healthcare management and provision and disability rights advocacy to address the issue holistically. This study focused on the federal health system and included only the federal government hospitals located within Islamabad. Future research may focus on responsiveness of the larger provincial health departments through quantitative as well as qualitative methods. Furthermore, the effects of responsiveness on healthcare seeking behaviors in vulnerable populations may also be studied. Larger scale studies may be undertaken to ascertain the association between responsiveness, healthcare seeking patterns and health status of the vulnerable populations. Such studies will not only contribute to the knowledge in the field but also provide much needed input for evidence-based policy making in the country.
Chapter 1: Introduction and Statement of the Problem

Overview

The health system has been defined as all people, institutions and resources that undertake actions with the primary intention of improving health (Murray & Evans, 2003). For the better part of two decades, health planners and decision makers romanced the idea of narrow-scoped vertical programs and locally administered primary care projects, only to realize that in the absence of strong health systems, fragmented health efforts were unlikely to achieve and sustain improvements in population health (Travis et al., 2004; UN Millennium Project, 2005). The World Health Organization has been a standard-bearer in this context, being the architect of the Millennium Development Goals and the World Health Report, 2000. The World Health Report 2000 focused on improving the performance of health systems and identified a conceptual framework of health system functions and objectives (Figure 1). According to this framework, health systems need to perform the main functions of stewardship -creating resources, financing and delivering of health services - to achieve three central objectives: health improvement, responsiveness to the legitimate expectations of the users, and fair distribution of the financial burden of illness (World Health Report, 2000). The rationale for including responsiveness as a key goal of the health system is that as a social system, health services should fulfill the legitimate expectations of the populace they serve. This should be a stand-alone goal, independent of the goal of health improvement.
Responsiveness has been further classified into two components: a) respect for persons which encompasses the issues of dignity, respect for individual autonomy in health decision making, confidentiality of personal health information, and clear communication (de Silva, 2000; Gostin, Hodge, Valentine, & Nygren-Krug, 2002; Murray & Frenk, 2000); and b) client orientation, which includes prompt attention to health needs, encompassing the factors of physical, social and financial access to health services, basic amenities like clean waiting rooms, adequate beds and quality food in the health facilities, access to social support networks during care and recovery at the health facility, and choice of institution and individual providing care (Murray & Frenk, 1999).

Furthermore, it is not only the level of responsiveness of the system as a whole that is important but also its distribution with regards to different socio-economic and demographic groups.

**Responsiveness of health systems and health of populations.** Although responsiveness relates to the non-health aspects of health systems, it has a direct bearing on the health status of the population. A responsive health system respects patients’ rights and offers an environment conducive to optimal healthcare utilization. In doing so, it encourages consumers to utilize care thus improving health of the population it serves (De Silva, 2000). Health systems have been described as inherently relational social systems, where development of relationships based on trust and mutual respect leads to higher likelihood of continued optimal healthcare utilization and desirable health behaviors (Gilson, 2003). Responsiveness serves to reduce barriers and promote use of health services by fostering trust between the providers and consumers of healthcare (Hall, Dugan, Zheng, & Mishra, 2001). Research evidence supports the contention that
patients who have had positive experiences with the health system tend to comply with medical treatments and continue using health services (Aharony & Strasser, 1993; Ware, Snyder, Wright, & Davies, 1983; Wouters, 1991; McPake, 1994; Gilson, Alilio, & Heggenhougen, 1994). Similarly, negative healthcare experiences have been found to lead to disruption in the use of health services (Mishima, de Paula, Pereira, de Almeida, & Kawata, 2010; Roblin & Roberts, 2010). Dissatisfaction with healthcare services has also been shown to be associated with changing healthcare providers (Wolff, Starfield, & Andersen, 2002) and use of complementary and alternative therapies (Montazeri, Sajadian, Ebrahimi, Haghhighat, & Harirchi, 2007). Frequent changes in health care providers have a disruptive effect on the patient-provider relationship leading to discontinuity in health service use. This leads to a lack of a usual source of care, which has been shown to have adverse effects on healthcare utilization as well as on the health status of the affected individuals (Bartman, Moy, & D’Angelo, 1997; Cheng, Chen, & Cunningham, 2007; Sambamoorthi & McAlpine, 2003). Furthermore, responsiveness has a fundamental value as it concerns basic human rights of individuals being served by the health system (Darby, Valentine, Murray, & de Silva, 1999).

**Responsiveness and optimal utilization of health services.** Responsive health systems promote optimal utilization of health services by fostering trust and attracting consumers. The Institute of Medicine (Millman, 1993) provides a broad definition of access to care, including the timely use of health services to achieve the best possible health outcomes. Healthcare utilization is optimal when people seek preventive services to avoid getting sick, and seek timely interventions in case of disease to reduce the length and severity of symptoms, as well as to stall the development of long term complications.
On the other hand delay in seeking healthcare has been shown to be associated with increased utilization of emergency (Petersen, Burstin, O’Neil, Orav, & Brennan, 1998) and in-patient care and adverse clinical outcomes leading to increased healthcare costs (Wolff, Starfield, & Anderson, 2002), and financial burden on the individual, the family, and the health system.

The importance of optimal utilization of health services becomes clear as we look at disability as a process in light of the disablement model (Verbrugge & Jette, 1994). This model describes the main pathway from functional independence to disability in four time-sequential stages including pathology, impairment, functional limitation and disability. The progression of a person along these stages is affected by a number of factors, classified into two main categories: intra-individual factors, including factors like genetic background and susceptibility to disease on the basis of personal dietary and lifestyle habits, and extra-individual interventions including the resources available in the community and society that affect peoples’ health and well being. Medical care is the mainstay of extra-individual interventions, and the time, volume and type of healthcare services sought by the patient have an effect on the subsequent level of disability and health status (Porell & Miltiades, 2001). Optimal utilization of health services occurs when patients seek health services in time such that pathology does not progress into disability, and this is facilitated by responsive health systems leading to positive outcomes at three levels. At the level of the consumer, responsiveness may lead to better health outcomes and enhanced health status. At the level of the health system, it may lead to cost containment and efficient utilization of resources. At the societal level, responsiveness may lead to improvement in human productivity and social capital.
Health systems and persons with disabilities. Disability is an issue that cuts across various social disciplines including health, education, economics, ethics and human rights. The disabled are an underprivileged and underserved section of the society especially in the low income countries where resources are already scarce and families and societies struggle to cope with economic hardships (Murray & Lopez, 1997). Research has indicated that persons with disabilities (PWDs) are at most disadvantage when it comes to receiving quality medical care (Emerson, Maty, Lynch, & Kaplan, 2007; Hong, Banta, & Betancourt, 2006). There is also evidence to link disability and poverty in a self-perpetuating vicious circle whereby one causes the other and vice versa (Chevarley, Thierry, Gill, Ryerson, & Nosek, 2006; Elwan, 1999; Emerson, 2007; Ghai, 2001). In such scenarios, responsiveness of the health system to the needs of the PWDs attains an even greater importance as the concept of responsiveness is meant to enable the health system to address those most in need.

Responsiveness of the health system to the needs of PWDs affects their health care seeking behavior, which may further have an impact on the timing and type of health care sought. This may have multifarious ramifications including worsening of the health problem due to delay (Hill, Freeman, Yucel, & Kuhlthau, 2008; Ngui & Flores, 2007; Scurlock, Zhang, & Xiang, 2008) and high likelihood of development of complications. In developing countries, PWDs have also been known to seek care from unqualified practitioners due to financial inaccessibility of available health services (Ahmed, Tomson, Petzold, & Kabir, 2005; Hosain & Chatterjee, 1998). Similarly, physical inaccessibility has been shown to hinder utilization of physical (Bigelow, Koreth, Jacobs,
Anger, Riddle, & Gifford, 2004) and mental rehabilitative care by people with disabilities (West, Luck, & Capps, 2007).

In addition to physical inaccessibility, the disabled also face discrimination at the hands of healthcare providers. Studies in the United States and the United Kingdom have identified that healthcare providers hold fixed, often incorrect, notions about PWDs (Kroll, Jones, Kehn & Neri, 2005). Due to incorrect preconceptions, healthcare providers have been shown not to communicate clearly with PWDs regarding disease prevention (Nannini, 2006) and are less likely to refer them for preventive screenings (Verger et al., 2005). Women with disabilities have also reported previous negative experience of health care providers as a barrier to seeking breast cancer screening services (Mele, Archer, & Pusch, 2005). Lack of responsiveness of the health systems to the needs of women with disabilities has repercussions for their reproductive health. Research indicates that women with disabilities are less satisfied with prenatal care and have fewer prenatal appointments (O’Hearn, 2006). This lack of preventive service provision may increase the likelihood of development of adverse health outcomes in PWDs (Diab & Johnston, 2004; Iezzoni, 2009).

**Significance of the Study**

As elucidated in the forthcoming sections, researchers have investigated the various individual constructs of responsiveness separately but as yet, there is a dearth of research studies on the concept of responsiveness of health systems as a whole. Furthermore, most research studies have been undertaken in the developed countries of Europe or in the United States and Canada, and corresponding research in the developing
countries is lacking. Research conducted in the developed countries cannot be
generalized to the developing countries for several reasons. First, these two groups of
countries are vastly different in the way they organize, finance and deliver healthcare
(Thomas, 2009). Second, the differences in the socio-demographic characteristics
including prevalence of poverty, disability, and disease patterns in the populations of
developed versus developing countries renders the dynamics of healthcare provision and
receipt incomparable (Leon, Walt, & Satariano, 2001). Third, due to cultural, religious
and philosophical dissimilarities, there are important differences in the way healthcare
providers interact with patients in eastern societies, which cannot be addressed from a
western point of view (Fan, 2002; Ghai, 2001).

Not only have there been very few research studies on the components of
responsiveness in the developing countries, studies that investigate these concepts with
regard to PWDs are even fewer. Concomitant with the lack of research, many developing
countries also lack public policies and laws enabling equal access of PWDs to healthcare,
education, employment and social functions. The disabled-friendly policies and laws that
do exist in the developing countries are not implemented in letter and spirit. This lack of
enabling public policies may condemn the PWDs to further marginalization, as they are
unable to perform their social functions and become dependent upon their families.
There are a myriad of reasons for emphasizing healthcare needs of vulnerable populations
including PWDs (Aday, 1994). First, these individuals usually have extensive needs for
coordinated and comprehensive health and social services. Second, if these needs are not
adequately met, the results may be sufficiently disastrous. Furthermore, the enhanced
needs of the vulnerable populations translate into greater demands on the health and

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social systems which still fall short of meeting them. Thus, there is concern in health policy and planning circles both at the level of individual countries (Aday, 2001) as well as internationally (World Health Organization, 2009) of the potential for a large number of PWDs to experience adverse health, social and psychological outcomes.

**Disability in Pakistan.** The prevalence of various disabilities in the Pakistani population, reported in light of the findings of 1998 Census shows that overall, 2.54% of the Pakistani population suffers from various degrees of physical and mental disabilities, which is approximately 3.3 million individuals. These percent of the population that is disabled may seem under-estimated. This can be attributed to various factors including under-reporting of disability due to social stigma associated with it in the Asian societies (The World Bank, 2012). It has also been found to be associated with differences in definitions of disability between Western and Asian countries (World Health Organization, 2011). While severe asthma, end-stage renal disease and heart failure leading to limitations of activities of daily living, are defined as disabling conditions in the United States and European countries, the definition of disability that is used in the population censuses in India, Pakistan and Bangladesh is very narrow, encompassing only obvious physical, mental, visual and hearing impairments. In addition to the difference in definition of disability, differences in data collection methodologies and varying quality of study design contribute to the apparent variations in disability prevalence among the developed and developing countries (Mont, 2007).

Out of the total Pakistani population having disabilities, 8% were reported as being visually impaired, 7% as hearing impaired, 7.6% as mentally challenged and 6.4%
with debilitating mental disease. Nineteen percent of the individuals (0.6 million) were reportedly suffering from physical disabilities, with 43% having multiple disabilities. Nine percent of the total disabled population was labeled under “Other” (Population Census Organization, Statistics Division, Government of Pakistan). However, these data are 13 years old and were computed as percentages of a total population of 132 million. Extrapolating these statistics to the present day population of 177 million, the conservatively estimated number of physically disabled individuals becomes 4.5 million (World Health Organization, Global Health Observatory, 2010). For the health system to fulfill the expectations of this large group of the population, it is imperative to devise evidence-based, enabling health policies, based on sound research and translated into effective and efficient health services. There is a paucity of dedicated health care, and a general lack of awareness of the health issues affecting persons with disabilities in Pakistan. The multiple governance problems confronting the country have left the health system chronically weak and inefficient (Siddiqa, 2008). The recent promulgation of the 18th constitutional amendment has led to the dissolution of the federal Ministry of Health, which will likely lead to far-reaching consequences for healthcare coordination and planning in the country.

The World Health Report 2000 ranked the 191 member states on general health system performance and responsiveness levels (de Silva et al., 2000; Valentine et al., 2000). Based on this report, Pakistan ranked 121 on the responsiveness level and 122 on the overall health system performance score. However it is noteworthy that these figures were imputed from the data from other countries and were not directly measured for Pakistan.
Developing countries shoulder a double burden of disease as they have both a high prevalence of infectious diseases and an increasing burden of chronic diseases (Murray & Lopez, 1997). Health systems in the developing countries are already constrained by high population growth rates, deteriorating economic conditions and the high prevalence of disability in the population. Due to the paucity of research in the field, little is known about the way the health systems address the needs of the PWDs. Under these circumstances the role of research in the field of health system performance assumes even greater importance. This study initiates research inquiry investigating the responsiveness of the Pakistani federal health system, with the aim of identifying changes in health and public policy to improve healthcare access and utilization for this vulnerable population.

**Research Questions**

This study addressed the following specific research questions:

1. How is the Pakistani federal health system responding to the needs of the population of 18-45 year old adults with physical disabilities? and

2. What are the barriers that currently exist to hinder the responsiveness of the Pakistani federal health system to the needs of young adults with physical disabilities?

These questions were addressed from the standpoint of healthcare consumers, providers, managers, policy makers as well as disability rights advocates, to obtain a wide variety of opinions and experiences related to the topic of interest. By addressing these
questions, this analysis aims to provide information for evidence-based policy formulation in Pakistan and to encourage further research in the field. The ultimate goal of the study was to contribute to knowledge and improve practice in the field of healthcare provision to persons with physical disabilities in Pakistan.

The study goals were realized by conducting primary qualitative data collection through focus group discussions with adults having physical disabilities living in Islamabad Capital Territory, who had utilized health services in any of the three federal governments hospitals located in the city. In order to curtail the potential confounding effects of gender and socioeconomic status (SES) on the outcome variable of interest - responsiveness of the health system to persons with disabilities (PWDs) -, focus groups were stratified and homogenized on the basis of gender and SES. Furthermore, in-depth, face-to-face qualitative interviews were conducted with disability rights advocates having physical disabilities, healthcare providers, managers and policy makers. This research design was established to gather at least two perspectives. One from PWDs themselves who had used health services in the past 12 months and could provide information on their experiences in the health system as consumers. The second perspective was from disability rights advocates, healthcare providers, managers, and policy makers who could comment on the barriers that hinder the Pakistani federal health system from adequately responding to the needs of the population of interest.
Chapter II: Review of the Literature

This chapter presents review of the relevant literature on the eight domains of responsiveness, organized under the two concepts of Respect for Persons and Client Orientation. This is followed by a discourse on the Behavioral Model of Healthcare Utilization which forms the theoretical foundation for this study, and a discussion of the said model as it relates to vulnerable populations.

The concept of responsiveness of health systems was first presented in the World Health Report 2000. The subsequent review presents the concepts related to responsiveness, aiming to situate it within the dominant paradigms in health services research and practice. This is followed by main features of the World Health Report 2000 and its subsequent critique by various public health researchers. As there is paucity of research on the concept of responsiveness in its entirety, what follows is a general review of the literature on the individual constructs of responsiveness as they relate to the healthcare experiences of PWDs.

Concepts Related to Responsiveness

Valentine and colleagues (2003) elucidate that the concept of responsiveness, though closely related to the concepts of healthcare quality and patient satisfaction, is fairly unique in its characteristics, boundaries and components from both these concepts.

Looking closely at the concept of health care quality, the authors contend that it is based on a number of different frameworks, the most notable of which is Donabedian’s
framework of structure, process and quality (Donabedian, 1980). Out of these, the concept of responsiveness is most closely related to the concept of process quality (also called interpersonal component of quality or service quality) which includes such dimensions as courtesy, provision of information, respect, choice and autonomy (Van Campen, Sixma, Kerssens, Peters, & Rasker, 1998). However, responsiveness captures additional concepts related to the non-health aspects of the health system which this framework leaves behind. These include the components of confidentiality, quality of amenities, prompt attention, and access to social support during in-patient care. Thus despite the fact that some of the interpersonal quality of care dimensions have been valuable in developing the constructs of responsiveness, the latter captures a wider spectrum of possible factors that affect the quality and utilization of care. Furthermore, the quality of care literature does not distinguish between factors that improve health outcomes and those that have a non-health focus, while responsiveness exclusively focuses on the non-health aspects of the health system.

Responsiveness also differs from the concept of patient satisfaction in many important respects. By definition, patient satisfaction is structured around perceptions of the consumer regarding the quality of health services. The measurement of patient satisfaction has offered a number of methodological challenges to researchers and policy makers (Avis, Bond, & Arthur, 1997). Patient satisfaction becomes ambiguous as patients recall multiple interactions with the health system, thus giving a general idea of satisfaction with care. The concept of responsiveness developed out of the need to capture the actual experiences of consumers in their interactions with the health care
system, and it encompasses not only how people are treated but also the environment in which they are treated.


On 24th June, 2001, World Health Organization (WHO), the health agency of the United Nations released its report for the year 2000. This report, titled Health Systems: Improving Performance, defined health systems as all people, institutions or resources that undertake actions with the primary intent of improving health. Health systems were described as having three important basic goals: a) improvement in the health of the population served by the system, b) responsiveness to the needs and expectations of the served population, and c) providing financial protection against the costs of ill-health. The World Health Report assessed and ranked the health systems of 191 member states on the basis of overall performance. This overall performance indicator was a composite of the three main health system goals of health improvement, responsiveness and fair distribution of economic burden of disease. The major indicators used by the World Health Organization were the level and distribution of health, the level and distribution of responsiveness and the distribution of healthcare economic burden. These five indicators were weighted and combined to yield the composite indicator of health system performance on which the health systems of all member states were ranked.

The concept of responsiveness of the health system was presented in the subject report under the premise that individuals coming in contact with the health system as consumers have a likelihood of losing their dignity owing to their illness and lack of control. This renders patients vulnerable in these interactions as healthcare providers
enjoy far more authority and control. Responsiveness was defined as a measure of the system’s response to the non-health expectations and needs of the population it serves. It has been further decomposed into those elements that are related to respect for persons, and the component of client orientation, the way the system responds to the concerns of the patients and their families as consumers of health care (Valentine, de Silva, Kawabata, Darby, Murray, & Evans, 2003).

Respect for persons includes:

- Respect for the dignity of the person, more generally it means not violating the human rights of people, not treating them in any demeaning or humiliating way.

- Clear communication encompasses the right of the patient to know all about his illness, the prognosis, the available medical and surgical treatments and the advantages and possible side effects thereof. This concept was not included in the original WHO report but was added later to the concept of responsiveness.

- Confidentiality, or the right to determine who can or cannot access one’s personal health information.

- Autonomy to make informed health decisions and participate in choices about what treatments to choose including the right to refuse treatment.

Client orientation includes:

- Prompt attention, including immediate attention in emergencies and reasonable waiting times in non-emergencies.
• Amenities of adequate quality in healthcare facilities including cleanliness of surroundings, adequate space and good quality hospital food

• Choice of provider, or the freedom to select the organization and/or individual providing care

• Access to social support networks including contact with family and friends while receiving in-patient care

Like other indicators of health system performance in the World health Report 2000, responsiveness was judged on two distinct criteria, the average level of attainment or goodness, and the distribution in the population served or fairness. This means that the system should respond well to the needs of the population in general, and also respond equally well to everyone without discrimination.

The methods involved in measurement of goodness and fairness of responsiveness by the WHO included selection of 50 key informants from each of the 35 countries and having each respondent fill out a questionnaire relating to his/her own country. The mean of the scores of the 50 key informants was calculated for each aspect. A separate survey of 1000 participants visiting the WHO website was used to develop weights according to ranking of the importance of the domains. Mean scores for each country were multiplied by their respective weights and added to obtain the overall score for responsiveness. Scores for countries other than these 35 were estimated adjusting for differences among countries and informant groups.
Figure 1: Functions and Objectives of the Health System (World Health Organization, 2001)
The same respondents were asked to identify groups that they thought were treated with less responsiveness than others. The number of times a group was mentioned was multiplied by its proportion in the population. The products for all subgroups were added and transformed to obtain an overall score for fairness of responsiveness (de Silva, 2000).

This report was subjected to widespread criticism at a variety of forums including scientific journal articles (Almeida et al., 2001; Blendon, Kim, & Benson, 2001; Walt & Mills, 2001), editorials (McKee, 2001; Williams, 2001), by public health experts (Navarro, 2000), research scientists, practitioners (Richardson, Robertson, & Wildman, 2001; Whitman, 2008), policy makers, and politicians (Pedersen, 2002). Those who belonged to countries ranked unfavorably were especially unhappy. Most of the criticism was based on the methodological aspects of the report.

Navarro (2000) in his critique of the subject report pointed out the discrepancy between the report’s rankings and perceptions of health policy experts in counties including Spain and Italy. Navarro clarified this discrepancy by pointing out that WHO was not a scientific but a political organization and its reports should be considered from both these perspectives. In his critique of the concept of responsiveness in the subject report, Navarro agreed with the conceptual clarity and logic of this concept and its included constructs, but expressed doubt as to its measurement and interpretation by the WHO team.

By far the most prevalent criticism of the World Health Report focused on the fact that while data were collected from 35 countries in all WHO regions, responsiveness of
the rest of the health systems was estimated on the basis of variables found to be predictive of responsiveness in these 35 countries (Almeida et al., 2001; Nord, 2002; Pedersen, 2002; Williams, 2001). Supplementing this criticism, Nord (2002) pointed out that measurement of such diverse constructs as patient autonomy and quality of amenities is difficult to standardize as the relative importance of the different items is different across countries and cultures. Almeida et al. (2001) contended that with data for responsiveness missing for 161 of the 191 countries, the imputed values were not comparable to standard projections of such annual estimates as per capita income or population size.

Another aspect of the report subjected to criticism was the data collection procedures. Researchers and public health scientists challenged the wisdom of collecting data from key informants contending that data collected from such a group of informants would not be reflective of the public opinion but of the conventional wisdom among experts (Navarro, 2002). Almeida and colleagues (2001) recommended that in future the selection of key informants and respondents, as well as the questions to be asked, should proceed with input from member countries and from experts in systems assessment. Critics also pointed out that cultural differences among countries (and indeed within the same country among people with different educational and socioeconomic levels) render the wisdom of weighting assigned to different aspects of responsiveness, and the further comparison among WHO member countries questionable (Wibulpraset & Tangcharoensathien, 2001; Williams, 2001).
In all of these critiques the concept of responsiveness and its content (the constructs of patient dignity, autonomy, confidentiality, clear communication, amenities, prompt attention, access to social support and choice of provider) was not challenged as being out of context or irrelevant. Most experts challenged WHO’s methods of data collection and grouping together of member states into one summary performance-ranking. As such, the criticism seems valid, as the cultural, financial and political differences between the countries indeed render their comparisons on such diverse variables inappropriate. Furthermore, the use of key informant interviews for assessment of level and distribution of responsiveness is also an effort to oversimplify a complex issue. It is only through systematic investigation of the perspectives of those involved in the process of care provision and receipt, that the deeper meaning of the reality can be determined. Therefore there is a need for systematic research at the level of individual countries to determine the level and distribution of responsiveness in the populations as well as marginalized sub-groups, and hence the significance of the present study.

Research on Individual Constructs of Responsiveness

As previously stated, there is a paucity of research on the concept of responsiveness in its entirety, although the individual constructs have been studied to varying degrees. In the course of this literature review, most of the research on the concept of Respect for Persons has been found in nursing literature. A vast majority of these studies have been performed using qualitative methods. The study of lived experiences of the PWDs in their interactions with the health systems necessitates uncovering and ascribing meaning to the phenomena as perceived by the PWDs. As
such, qualitative research is the most suitable medium to reveal social, economic and cultural factors as well as power relations and expectations that play their roles in determining how PWDs experience the health system and construct the associated reality. As qualitative research on marginalized and vulnerable populations gives voice to the voiceless, the quest for credibility, dependability and trustworthiness of findings takes on an even greater importance in this scenario. However, the vast majority of these studies did not entail triangulation of any kind. This underscores the importance of method triangulation to enhance the trustworthiness of data and transferability of the findings (Golafshani, 2003).

As far as the concept of client orientation is concerned, a number of studies were found in the health-systems research, health economics and policy journals which investigated the different aspects of prompt attention, quality of amenities at healthcare facilities, choice of providers, and access to social support networks during in-patient care. These studies were related mostly to managerial, economic and health policy issues associated with these domains of responsiveness. Thus there is a paucity of research on the concept of responsiveness of health system as such. The only organized research effort in this regard is the WHO Multi-country Survey Study on Health and Responsiveness (2001).

**Respect for persons.**

**Dignity.** The concept of dignity encompasses the right to receive care in a respectful, caring, non-discriminatory setting (de Silva, 2000), be treated with respect as a person, the right not to be treated in a humiliating way. It also encompasses the right not
to be discriminated against due to a physical or mental disability, and the right of protection against unnecessary and burdensome medical and surgical procedures.

Research conducted in the developed countries indicates that despite high levels of social awareness, the disabled were regarded as incompetent individuals in need of help, eliciting feelings of both sympathy and aversion (Cuddy, Fiske, & Glick, 2007; Dovidio, Pagotto, & Hebl, 2011; Livneh, 1988). Furthermore, research indicates that in the traditionalist cultures, disability is interpreted as a punishment for the sins of the forefathers or the PWDs themselves, giving rise to negative stereotypes (Diken, 2006; Groce & Zola, 1993; Mardiros, 1989). In a number of studies conducted in the developed countries (Courts, Buchanan, & Werstlein, 2004; Edvardsson, Pahlson, & Ahlströ m, 2006; Iaquinta & Larrabee, 2004; Kroll et al., 2006; Schaefer, 2005), researchers reported that healthcare providers failed to see disabled patients holistically, either focusing only on the disability or failing to anticipate the high likelihood of development of specific diseases in disabled patients. Participants of these studies reported a general lack of courtesy, sensitivity and respect when the doctors perceived them as unintelligent and showed pity. Other studies (Courts et al., 2004; Edvardsson et al., 2006; Schaefer, 2005) found that in case of insidious diseases leading to severe disability, doctors missed the initial diagnoses by not taking the patients’ complaints seriously. This led to development of complications and higher levels of disability for the patients. In the same studies, disabled patients also felt insulted when they were made to wait longer under the presumption that their condition was not acute enough to warrant immediate attention. Such behaviors of the healthcare providers lead to higher levels of patient dissatisfaction, further causing patients to change providers thus causing a disruptive influence on
continuity of care with its attendant health risks (Bartman et al., 1997; Cheng et al., 2007; Sambamoorthi & McAlpine, 2003).

Tying the findings of these studies back to the disablement model and continuity of care, it becomes evident that when patients’ dignity is compromised in healthcare interactions, it has the potential to lead to disruption of the patient-provider relationship and the resultant deterioration from pathology to disability.

**Clear communication.** Communication between the patient and healthcare provider is of paramount importance in the healthcare process for many reasons. It not only sets the stage for mutual trust but is also the first step in reaching a preliminary diagnosis. Furthermore, the ability of the patient to understand the information provided by the physician as well as asking questions is also emphasized in this domain. Another aspect of communication is the health communication through media that aims to educate people about disease prevention and health promotion. Clarity of communication slightly overlaps with the domain of dignity in that it entails the doctor listening carefully to the patient and providing answers to all their questions and concerns (Van Campen et al., 1998).

Longer visits have been found to be associated with greater patient satisfaction, indicating that casual and open conversation between patients and providers creates trust and comfort for the patient (Gross, Zyzanski, Borawski, Cebul, & Stange, 1998). Patients with communication difficulties may not be able to convey the full spectrum of their symptoms to their doctors. On the other hand, physicians have been shown to have
reduced expectations of the intellectual capacity of PWDs, thus hindering the two-way exchange of information between patient and provider (Hayashi & Kimura, 2008).

Many researchers have studied the problems faced by deaf people in the healthcare setting owing to their diminished capability to communicate with the healthcare providers. Research conducted in the developed countries has found that people with disabilities are more likely to report incomplete understanding of clinical information, lack of thoroughness of doctors in history taking and examination and inadequate communication (Iezzoni, Davis, Soukup, & O’Day, 2003). Research also indicates that physicians hold preconceived misperceptions about the hearing impaired being less cognitively competent leading to disruption of the patient provider relationship. Hearing impaired patients have also been found to encounter significant barriers in the health system environment. Researchers found that although both US (Americans with Disabilities Act, 1990) and British law (Disability Discrimination Act, 1995) require healthcare providers to ensure provision of sign language interpreters for deaf patients, this practice is the exception rather than the rule (Iezzoni, O’Day, Killeen, & Harker, 2004). Respondents in these studies also underscored the likelihood of medical errors and misdiagnosis due to communication gap between patients and providers (Iezzoni et al., 2003, 2004).

Another important aspect of the patient-provider interaction is the lack of communication during physical examinations and procedures, leading to incongruence between patient’s assumptions and provider’s actions. This has been demonstrated to cause significant anxiety and apprehension to the patients when undergoing invasive
procedures like surgery and genital examinations (Ubido, Huntington, & Warburton, 2002).

Health systems researchers have also demonstrated an association between communication problems and an increased risk of preventable adverse events during hospital admission. Patients with communication problems were three times more likely to experience a preventable adverse event, mainly drug related or caused by poor clinical management (Bartlett, Blais, Tamblyn, Clermont, & MacGibbon, 2008). These findings build on the earlier study by Iezzoni and colleagues (2003) where the deaf patients voiced their concerns about the lack of effective communication leading to potential for misdiagnosis and medical errors.

Similar themes have emerged in studies determining healthcare providers’ knowledge and attitudes toward deaf patients. Research conducted in the US indicates that despite knowledge of the relevant legislation, only 22% of physicians used sign language interpreters when interacting with hearing impaired patients. The physicians also believed that provision of healthcare to the deaf was more time consuming and labor intensive than for other patients (Ebert & Heckerling, 1995). Similar physician attitudes toward hearing impaired patients were reported in other studies which indicated a lack of communication and trust between doctors and hearing impaired patients (Ralston, Zazove, & Gorenflo, 1996). In an analysis of the data from the National Survey of Children with Special Health Care Needs, Smaldone, Honig and Byrne (2005) concluded that when parents perceived that the healthcare providers did not listen to their children’s complaints carefully, they were more likely to delay or forego care for their disabled
children. Due to the fact that children and adults with disabilities are more frequent and intense users of health services, such delays could indeed cause significant health problems and development of complications.

With improvement in life expectancy, there is a higher number of PWDs living longer and attaining advanced age. Age further predisposes previously non-disabled individuals to visual and hearing impairments as well as chronic conditions such as arthritis, heart disease, high blood pressure and diabetes. These conditions usually do not require hospital admission and can be managed at home by the patients by following therapeutic, dietary and lifestyle advice of the physicians. In this scenario, accurate and clear communication between patients and healthcare providers takes on an even greater importance (Bayliss, Ellis, & Steiner, 2007).

Almost all the studies of patient-provider communication focus on the patients with hearing impairment. However, other categories of disabilities also reduce the capability of patients to communicate with providers in an optimal manner. These include cognitive dysfunction, paralytic conditions of the face and tongue, speech and language problems and generalized neuro-muscular disorders. Research on patients suffering from these conditions is conspicuously lacking in the context of patient-provider communication.

**Confidentiality.** Confidentiality as a domain of responsiveness is closely related to the concept of privacy. Privacy is defined as “an individual’s claim to control the terms under which personal information—information identifiable to an individual—is acquired, disclosed and used” (Lowe & Hardy Havens, 1998). The concept of
confidentiality is however wider than that of privacy. Thus, not only the medical records, results of lab tests, details of treatment and the information provided by the patient are considered privileged, but also the provider is entrusted with making the physical surroundings of the medical consultations private, so that conversations are not overheard or the patient is not physically exposed to anyone but the provider. This, in a way, also overlaps with the concept of dignity especially in conservative societies when women seek care from male providers.

Both the concepts of autonomy and confidentiality are entrenched in the cherished western principle of personal freedom encompassing individual freedom of thought as well as freedom of action. In the Asian societies, rights of the family unit take precedence over the rights of individuals, especially in case of economically subservient individuals like women and PWDs. In these cases, the dominant family members, especially those providing economic support, are considered to have a right to access information about the patient and also a right to make decisions regarding treatment. Especially in cases of serious illnesses, the emphasis of the family is on protecting the patient from the stress of their gloomy prognosis (Tamura, 1994). The family structure is not limited to spouses and offspring, but includes grandparents, aunts and uncles. Even geographically dispersed families are bound together by these strong ties and every member of the family has a share in the major life decisions of another family member (Meer & VandeCreek, 2002). Thus it is not the principle of confidentiality in and of itself, but the principle of autonomy on which it is based that is at odds with the principles of South-East Asian cultural values, and frequently a cause of strife between the patient’s family and the healthcare provider as they demand access to patients’
confidential information as a right. Bioethicists in China have developed a model of doctor-family-patient relationship (DFPR) in contrast to the doctor-patient relationship (DPR) for obtaining informed consent which safeguards the strong Chinese cultural adherence to Confucian principles (Cong, 2004).

**Autonomy.** Autonomy in healthcare decision making entails four important components: the patients’ right to make their own decisions about treatment, the patients’ and their family’s right to information about the disease as well as treatment options, the need to obtain informed consent before testing and treatment, and finally, the right of patients of sound mind to refuse treatment (Sitzia & Wood, 1997). The physician may influence the decision but may not control or coerce the patient (Hebert, 1996). The traditional model of physician-patient relationship has been paternalistic with the physician dictating what treatment the patient may receive based on their expertise and knowledge (Emmanuel & Emmanuel, 1992). In this model, the physicians act on what they believe to be in the best interest of the patient without the patient’s consent and sometimes even contradictory to patients’ desires. In other variations of the same model, the patients may make the decision based on incomplete information received from the healthcare providers. This has been largely replaced in the US and European health systems by a more ethical model whereby the physicians act as only technical advisors to the patients. Middle models have also been popular in which both the physicians and patients act as partners in decision making with the physicians facilitating the patients’ acquisition of scientific knowledge. These latter models figure full disclosure, informed consent and patient autonomy as leading themes (Charles, Gafni, & Whelen, 1997).
The issue of autonomy becomes more complicated in the case of intellectually challenged individuals for whom decisions are made by surrogates. These include sensitive decisions regarding sterilization and end-of-life care (Gostin, 2005). In the present scenario, bioethicists (Beauchamp & Childress, 1994) as well as courts (Krais, 1989) approve of surrogate decision making for developmentally disabled individuals. For a person who has never had capacity, surrogates have to decide in view of the “best interest standard”. In cases of persons who previously had capacity, the standard that is followed is how the patient would have decided before losing capacity. In both these cases, individuals who are deeply invested in the patient’s welfare and who know the patient closely are most fit to act as surrogates.

There are, however, important differences in models of health decision making between the US/European and Asian societies. Bioethicists have elucidated that the concept of personal autonomy is sometimes impossible to apply in the case of patients hailing from pluralistic societies, where the family and husband are the ultimate decision makers, and their decisions are based on their religious beliefs and grounded in their culture (Fagan, 2004; McLaughlin & Braun, 1998; Senarath & Gunawardena, 2009). The Western model of autonomous decision making maintains the patient to be the final authority for making decisions. In this model, the family and the physician are under obligation to respect the desires of the patient. In contrast, the East Asian principle of autonomy is a family-determination-oriented principle, and the final decision making authority is the family. Interestingly, this principle is true both for incompetent and for intellectually competent patients. Even the desires of the patient may be overridden when their decisions regarding their treatment are thought to contradict prevailing standards of
morality and objective good. The major value advocated by this family-determination-oriented principle is harmonious dependence. Individuals who are incapacitated by disease are entitled to receive special care from family members and physicians, and decisions of life, death and treatment are considered to be too burdensome to be made by one person in isolation (Fan, 1997). Fan’s commentary is based mainly on Japanese, Chinese and Cambodian societies. However, many of these cultural characteristics hold true for other countries in the South-east Asian region owing to similar social value systems. Another important aspect of the Asian cultures that may impact autonomy is that disability constitutes a major aspect of the PWDs’ identity in these societies. Research indicates that PWDs who are deeply conscious of their disability, tend to be less autonomous in their decisions (Wang & Dovidio, 2011).

The practical implications of these principles of Asian culture affect not only the autonomy of the disabled patients but other domains of responsiveness as well. There has been a strong motivation within healthcare providers working in the Asian societies to develop a family-centered deliberative process of compromise and accommodation to reach optimal healthcare decisions for the disabled patients (Saadah, 2002). Similar efforts by Chinese bioethicists have yielded the family-based and harmony-oriented model of medical decision making which derives from Confucian philosophy, the cornerstone of Chinese culture (Chen & Fan, 2010). This underscores the reality that autonomy of healthcare decision making as well as other responsiveness domains within the category of respect for persons is heavily influenced by cultural norms.
**Client orientation.**

**Prompt Attention.** Another aspect of client orientation is prompt attention, which is defined in the Oxford Dictionary as care provided readily or as soon as necessary. It essentially means that patients should not have to wait excessively for receipt of care in facilities. It also includes people’s knowledge that they can access care in emergencies, convenient timing for accessing curative and preventive services and accessibility of health care services within a short physical distance (Mansour et al., 1993). Prompt attention also means that patients and their families do not have to wait unreasonably long for lab test results, birth/death certificates and other documentation or insurance claim settlements (Collins, 1996). A wider application of the concept of prompt attention also includes prompt information provision to the public in case of outbreaks and public health emergencies.

Healthcare researchers have also studied wait times in various healthcare settings including elective surgery, emergency care and outpatient care, and have universally found them to be negatively associated with patient satisfaction. Furthermore, long wait times are also associated with the patients’ decision to seek healthcare in the private sector instead of waiting (Besley, Hall, & Preston, 1999).

International health research indicates that non-emergency surgical patients’ dissatisfaction with waiting increased with the duration of their anticipated wait and the severity of symptoms (Dunn, Black, Alonso, Norregaard, & Anderson, 1997; Lofvendahl, Eckerlund, Hansagi, Malmqvist, Resch, & Hanning, 2005). Thus, long waiting times contributed to negative patient attitudes towards the health system before they actually
came into contact with it. However, researchers also found that patients were much more tolerant of the delay in the OPDs if the reason was explained to them (Becker & Douglass, 2008), thus underscoring the importance of communication and information in healthcare settings.

PWDs require medical, surgical and rehabilitative services of an amount and quality not required by the population in general. Their increased demand for treatment and rehabilitation places them at a higher risk of adverse outcomes should there be a delay in care provision. Research indicates that children requiring physical and occupational therapy had to wait unreasonably long (Feldman, Champagne, Korner-Bitensky, & Meshefedjian, 2002) with pre-school age children having to wait longer, sometimes up to a year (Halfon et al., 2004; Michaud, 2004; Shevell, Majnemer, Rosenbaum, & Abrahamowicz, 2001). Long waiting for therapy in case of children carries the attendant risk of development of complications and sub-optimal results of therapy, which has been shown to have an adverse effect on their quality of life (Feldman, Swaine, Gosselin, Meshefedjian, & Grilli, 2008). It has also been reported that long waiting times for provision of appropriate rehabilitative services to young stroke patients may lead to prolonged rehabilitation and a rise in costs (Jackson, Thornton, Turner-Strokes, 1999). In another study, the authors reported that for each month the disabled older adult participants waited for home modification, their difficulty in performing everyday life tasks increased (Petersson, Kottorp, Bergsrton, & Lilja, 2009), thus underscoring the importance of timely interventions to ensure independence and well-being in this vulnerable group. Thus long waiting times have been universally found to be detrimental to the health and well-being of disabled patients in all age groups.
**Quality of basic amenities.** Basic amenities include all features of the physical environment of health care facilities that make them comfortable, welcoming and pleasant (Allen, 1990). Also sometimes referred to as “hotel facilities”, these include clean surroundings, regular maintenance, adequate furniture, sufficient ventilation, enough waiting space, clean water, toilets and linen, and healthy food (Haddad, Fournier, & Potvin, 1998; Mansour, Muneera, & Al-Osimy, 1993). It is important to note that quality of amenities is equally important both for in-patient and out-patient care, encompassing preventive, ambulatory, in-patient and rehabilitation facilities (Valentine et al., 2003). Patients visiting healthcare facilities for out-patient care should have access to clean, spacious and well-ventilated waiting rooms and restrooms. Patients admitted to hospitals are entitled to the same quality of amenities in the wards. The quality of amenities not only affects patient comfort during the process of care but is inextricably linked to patient well-being and recovery from illness. For patient with disabilities, accessibility of healthcare facilities is an added concern.

Patients seeking healthcare should have access to clean, comfortable and adequate washing and toilet facilities, yet studies conducted even in developed countries have shown great disparities between patient needs and availability of facilities. Inadequate and unclean bathrooms are not only unsightly and uncomfortable, but also pose risks to the health and well-being of patients by increasing the risk of falls, injuries and infectious diseases. Monro and Mully (2004) conducted a study of 46 wards in three hospitals in the North of England to find out if bathroom facilities had improved since the last two surveys undertaken in 1969 and 1998. Interestingly, the authors noted that despite the lapse of 30 years there was still limited accessibility of showers for wheelchair users, lack
of bath aides and adaptations, lack of cleanliness and privacy, poor signage, missing locks, lack of heating, unimaginative décor, unpleasant smells, wet floors, seepage from bathrooms to wards, obstructive clutter from using bathrooms as storage and inaccessibility of mirrors and light switches for wheelchair users. In another study of toilet facilities for people with disabilities in a provincial teaching hospital in Leeds, Travers and colleagues (1992) found that no toilet in the hospital met the standards recommended by the British Standards Institution. In this survey washbasins in all toilets were higher than 75 centimeters, making them difficult or impossible for use by wheelchair bound individuals. Majority of toilets did not have rails. Many disabled elderly patients were unable to use the toilet due to these problems and the nurses had to recommend the use of commodes.

Provision of good quality food is another consideration for patients admitted to hospitals. For decades, it has been recognized that poor nutrition is a problem facing the patients admitted to healthcare facilities (Coates, 1985; Hill, Pickford, & Young, 1977; Lennard-Jones, 1992; McWhirter & Pennington, 1994). Older patients are at an even greater risk of under-nutrition in the healthcare setting (Lehmann, Bassey, Morgan, & Dallosso, 1991). More recent research shows the prevalence of under-nutrition in older hospitalized patients to be between 30 to 60% (Gazzotti, Arnaud-Battandier, & Parello, 2003). Under-nutrition is an independent predictor of an array of adverse clinical outcomes including increased complication rates, longer hospital stays, increased costs and premature mortality (Correia & Waitzberg, 2003). The factors associated with mealtime activity that enhance or hinder patients’ food intake have been studied in nursing research. Overarching themes reported in these studies included inflexibility of
mealtimes, physical inaccessibility of food trays, lack of assistance by staff, and disruption during meals from nurses and doctors (Dickinson, Welch, Ager, & Costar, 2005; Naithani, Whelan, Thomas, Gulliford, & Myfanwy, 2008; Xia and McCutcheon, 2006).

**Choice of provider.** The domain of choice entails the power to select among health care providers as well as institutions. Furthermore, choice also encompasses the patients’ right to seek a second opinion, for instance in cases of extensive surgery or life threatening conditions, and access to specialist care when needed (Van Campen et al., 1998). Valentine and colleagues (2003) raise the question if improving the choice of provider will impose additional burdens on resource-poor health systems. They maintain that in circumstances where financial and human resources are constrained, providing the consumers with choice may limit the expenditure on health and other domains of responsiveness.

Choice of provider depends upon various factors including payment mechanism and perceived competence of healthcare providers (Yip, Wang, & Liu, 1998). Choice of provider may be limited for those with limited physical or financial access to health facilities. There is a dearth of research on the issue of choice of provider vis-à-vis PWDs, but the fact that PWDs are more likely to be situated in socioeconomicly challenged families (Emerson, 2007) exposes them to the risk of limited choice when it comes to seeking healthcare. Research shows that people in the low socioeconomic strata often avail poor quality health care and seek healthcare less often, and if they do, it is more likely to be in emergencies (Becker, 2001; Burstin, Lipsitz, & Brennan, 1992; Franks,
Clancy, & Gold, 1993; Hadley, Steinberg, & Feder, 1991; Norredam, Krasnik, Sorensen, Keiding, Michaelsen, Nielsen, 2004; Swartz, 1994). PWDs have also been shown to have a preference for public healthcare (Balarajan, Selvaraj, & Subramaniam, 2011). This is indicative of the limitations placed on choice of provider for these patients by their socioeconomic disadvantage.

There is paucity of research investigating the effects of provider choice in patients with disability. Research, however, indicates that feeling in control of one’s life improves health status, perceived satisfaction with life as well as adjustment to disability (Argyl, 1999; Bandura, 1999). Clinical research also shows that when patients have a sense of control, they are motivated to exercise this control to reduce the disruptive effect of disease on their life and to resume normal activity (Griffin & Rabkin, 1998). The effect of feeling of control over recovery from disease has been studied in the field of Psychiatry. Failure to control one’s feelings, emotions and actions has been linked to poor functioning and increased risk of dependency (Davidson, et al., 1998). It is probably through the sense of mastery and control that the activity of choosing one’s provider exerts a beneficial effect on the patient.

Another aspect of choice of provider is the ability of the patient to seek healthcare from the same provider. Indeed, in cases where the patient is suffering from a longstanding illness, care may preferably be sought from the same provider because of greater familiarity of the provider to the course of the patient’s illness, and also because of the trust and confidence the patient and their families may develop in the skills of the provider. Reviewing the medical literature from 1966 to 2002, Saultz and Albedaiwi
(2004) concluded that there was a consistent and significant positive relationship between interpersonal continuity of care and patient satisfaction. However, this domain is also found to be sensitive to the age and educational level of respondents. Younger respondents and those with higher levels of education have been found to prefer free choice of physicians in comparison with older individuals (Anell, Rosen, & Hjortsberg, 1997).

**Access to social support networks during care.** The concept of social support has emerged as an important determinant of health and longevity since the 1970s. Having access to family, friends and other sources of social support is conducive to patients’ well-being when seeking care at health facilities (Kruse, Rohland, & Wu, 2002). The responsiveness domain of access to social support is defined to include visitation rights of family and friends to admitted patients, bringing food and other consumables for the patient, and the right to carry out religious and cultural practices that are not contrary to the sensitivities of other patients or healthcare providers and the right to follow alternative therapies not contradictory to the hospital policy. This domain also encompasses the right of the patients’ families to receive support and be kept informed by healthcare providers (Jenkinson, Coulter, & Bruster, 2002).

A number of studies have examined the beneficial effect of social support on areas as diverse as protection from dementia (Crooks, Lubben, Petitti, Little, & Chiu, 2008), recovery following myocardial infarction and stroke (Miller, McMahon, & Garrett, 1989), prevalence of anxiety and depression (Frydmann, 1981) and likelihood to commit suicide (Durkheim, 1951). The empirical literature provides evidence suggesting
possible links between social isolation and low social support and premature morbidity and mortality (House, Landis, & Umberson, 1988). Furthermore, the level of social support, or lack thereof, has been found to have an influence on the healthcare seeking and health promoting behaviors, as well as predicting adherence to treatment regimens (Vyavaharkar et al., 2007). A number of studies have investigated the association between social support and recovery from severe acute illness especially in the elderly. Most of these studies have focused on measurement of social support at varying intervals after discharge from the hospital. However, one important aspect of measurement of social support stems from the fact that it is not a static entity like a trait or a characteristic. It is a process of social exchange whereby supply of support by the providers changes in accordance with demand by the receiver. The level of support before a person falls ill determines the amount and type of support available during illness and later into the period of recovery.

Kempen et al. (2001) examined the role of socioeconomic status and social support on recovering ADLs and IADLs after limb injuries in the participants of the Groningen Longitudinal Aging Study. The study found long term recovery of activities of daily living (ADLs) and instrumental activities of daily living (IADLs) to be associated with social support. Other studies have reported similar findings in patients suffering hip fractures (Cummings, Phillips, Wheat, Black, Gossby, & Wlodarczyk, 1988; Kirk-Sanchez, 2004; Magaziner, Simonsick, Kashner, Hebel, & Kenzora, 1990).

Most of these studies have focused on social support available to patients after discharge from hospital, yet the WHO concept of responsiveness is concerned with social
support available to the patients while admitted to facilities. This support is different in
type and amount from the aforementioned and has more direct effects on patient
wellbeing and recovery from disease. Indeed support from family during hospitalization
has been found to reduce stress and promote well-being (Kruse et al., 2002) by helping
patients cope better with the illness and its consequences (Friedland, Renwick, &
McColl, 1996). Patients derive courage and strength from their family members who
serve to reduce the burden of anxiety on the patient, thus having a beneficial effect
(Tekle, Mariam, & Ali, 2002; Tomaszewska, 1996). However there is a dearth of
research investigating the effect of social support on PWDs during admission to
healthcare facilities.

Conclusion

Responsiveness is a valued goal for the health systems to achieve as it
encompasses the rights of healthcare consumers within the specified domains. As such,
the domains of the concept map well into patients’ rights as well as human rights
charters. Although the concept of responsiveness is still under investigation by its
proponent, the World Health Organization, in its present form it does provide an
important framework for improving the experiences of the vulnerable and marginalized
populations in resource-poor settings. This is based on the fact that improving the
responsiveness of health systems does not entail financial expenditure. Responsiveness
necessitates incorporation of sensitivity and cultural intelligence into the medical
education system and better organization of facilities at the managerial level so that
components of respect for persons and client orientation may be addressed respectively.
Although responsiveness captures the non-health function of the health care system, research shows that it has a definite positive effect on the patients’ well-being, treatment adherence and continuity of health care seeking behavior (Aharony & Strasser, 1993; Gilson et al., 1994; McPake, 1994; Ware et al., 1983; Wouters, 1991).

The medical and public health research literature shows that PWDs are marginalized as a group due to their likely disadvantaged socioeconomic, health and educational status. This population sub-group needs healthcare in far greater magnitude, and with much more urgency than the rest of the population, and as such is affected to a far greater extent by the factors that affect utilization behaviors. A responsive health system enhances the health of the population it serves by making it more conducive for people to seek care, to be more open to healthcare providers and more receptive to their advice. Contrary to this, if the health system is such that the patients feel insulted, slighted or threatened by the behavior of care providers or obstructed by the bureaucratic hurdles, the utilization of health services will be far below the optimal level despite the fact that they may be of superb technical quality. Research reviewed in the preceding section indicates a plethora of factors that shape the experiences of people with disabilities in the healthcare system, most of which can be addressed by improving the responsiveness of health systems.

In summary, healthcare services may be inaccessible for PWDs at various levels including physical inaccessibility due to visual, auditory, intellectual and physical impairments, financial inaccessibility due to lack of income and competing resource demands. Cultural inaccessibility of healthcare is important to be addressed in the case
of traditionalist societies where the health care needs of the family breadwinners are accorded first priority, and women are not allowed to seek care from male providers. Once in the healthcare system, the insensitivity of care providers regarding the patients’ complaints, lack of communication and the misconceptions may affect future decisions to seek care. The perceived or actual lack of quality amenities in hospitals, lack of confidence in provider competence and lack of choice in healthcare also affect the utilization of health facilities. Indeed research has shown that in Pakistan, 70-80% of healthcare is sought in the fee-for-service private sector despite the fact that the public sector facilities are free for all (Pakistan Social Standard Living Measures Survey 2004-05). It is due to lack of confidence in the public healthcare system that people pay out of pocket rather than seek free healthcare.

This study is the first step in assessing responsiveness of the Pakistani health system to the needs of young adults with disabilities from the perspective of healthcare consumers as well as providers, managers and policy makers. As such, this study endeavored to analyze the problem, highlighting issues from the level of health care provision and utilization, to issues of human and physical resource allocation and financing, and further looking at the policy environment that affected the responsiveness of the system. Triangulation of data from various sources contributed to the trustworthiness of the findings, which add to our understanding of the roles played by the different components of the health care system in facilitating or inhibiting healthcare utilization by adult PWDs. These findings are expected to generate knowledge about the factors that lead to dissatisfaction of the population of interest with the federally provided healthcare services in Islamabad. As a first step in this direction, in the long term this
study is expected to spur further research in the field of responsiveness of the health system and encourage evidence-based policy making.

**Theoretical Model**

The concept of responsiveness focuses on the actual experiences of persons coming into contact with the healthcare system and not just their perceptions. The different constructs under the two main concepts of responsiveness are grounded in social and cultural contexts. The concept of respect for persons is composed of the elements of dignity, confidentiality, autonomy and clarity of communication. As such, these constructs are based on characteristics of the persons with disabilities, the power differentials in the family and the patient-provider interaction, as well as in the broader social milieu. The constructs underlying client orientation (prompt attention, quality of amenities at healthcare facilities, choice of healthcare provider and access to social support networks during medical care) are more geared toward the experiences of patients with the healthcare system as a whole. They depend on the organization, financing and policy structure of healthcare system as well as the characteristics of the consumers that facilitate or inhibit their ability to negotiate the system (Feldman, Champagne, Korner-Bitensky, & Meshefedian, 2002). Thus factors such as education, income and health literacy levels of the persons with disabilities and their caregivers will affect their experiences within the healthcare system and so will the overall health policy governing organization (primary, secondary or tertiary level care) and financing of services (public or private).
Further adding complexity to the situation is the vulnerability of people with disabilities. Aday (2001) has defined vulnerable populations as those for whom the probability of poor physical, social and psychological health outcomes is appreciably higher, further describing a framework for studying the antecedents as well as consequences of vulnerability. Vulnerability of PWDs and other population groups included in this category has been described as stemming from the opportunities and resources associated with three sources. These include: 1) personal characteristics comprising age, gender, race/ethnicity, health and disability status; 2) the nature of social ties including family members, friends and neighbors; and 3) the structural and functional elements of the environment in which they live including schools, jobs, income, housing, criminal activity and political stability. These social arrangements translate into social status (prestige and power) at the individual level, and social capital at the collective level.

The concept of responsiveness of the health system to the needs of PWDs has a broad conceptual base with influences stemming from social and cultural environment, the health system; and the particular characteristics of the consumers (in this case people with disabilities) including their social, economic, educational status and access to resources. A concept this broad had to be framed, assessed and analyzed in light of a theoretical model that accounted for all the relevant concepts and clearly depicted the relationships among them.

Based on the demands of the research topic under question, the most suitable model to address the question of responsiveness of the health system to needs of people
with disabilities was the modified Andersen-Aday model of healthcare access and utilization (Phillips, Morrison, Andersen, & Aday, 1998) (Figure 2). This model is by far the most widely used to study healthcare utilization and was developed by Andersen (1968). It describes healthcare utilization as a function of factors predisposing to and enabling utilization, and factors that determine people’s need for healthcare services. The model was further refined in the 1970s (Aday, Andersen, & Fleming, 1980; Andersen, Smedby, & Andersen, 1970; Andersen & Newman, 1973; Fleming & Andersen, 1986) and in the decade between 1980 and 1990 (Andersen, Davidson, & Ganz, 1994).

An important modification of the model was made by Gelberg, Andersen and Leake (2000) whereby it was expanded to include characteristics of vulnerable populations. The authors contended that the factors that contributed to the vulnerability of different population groups also impacted their access and utilization of health services. Thus, in addition to the normative predisposing, enabling and need factors affecting healthcare access and utilization, this expanded model included factors specifically affecting vulnerable populations like substance abuse, homelessness and physical and mental disabilities. These new domains were named “vulnerability domains” of the model (Table 1). However, it is noteworthy that in this model the healthcare system with its volume, structure, organization, financing and processes was considered as a part of Community Enabling Resources, whereas in the original model the healthcare system along with the external environment was a primary determinant of health access and utilization. This separate modeling of the healthcare system was more conducive for the present study with its focus on the responsiveness of the healthcare system in conjunction with the needs of persons with disabilities. Thus, for the purposes
of this study, the modified behavioral model of healthcare utilization was used to guide research and analysis.

The behavioral model was especially useful for explaining and predicting healthcare utilization as it took into account factors operating at various levels that could affect healthcare access. The concept of responsiveness of the health system is linked to healthcare access and utilization in a double loop such that the system responds to those who seek care, and it is this response that modulates their future healthcare seeking behaviors as well. Thus a model that accounted for all important factors that affect healthcare utilization would also account for the factors that constitute responsiveness of the system as was elucidated in the present study.

The model envisaged the inter-relationships between the environment, the healthcare system, characteristics of the population, their health behaviors and health outcomes. The primary determinants of healthcare utilization in this model were the characteristics of the population, the healthcare system and the external environment. Population characteristics include predisposing, enabling and need factors.

**Population characteristics.**

**Predisposing factors.** Predisposing factors are the factors that predispose persons with disabilities to the use of health services and include demographic determinants like gender, age, marital status race/ethnicity, as well as health beliefs of the population including values concerning health and illness, knowledge of diseases and attitudes towards health resources and services available in the community. Thus not only do the healthcare facilities and personnel have to be present, but the consumers of healthcare
should also have the knowledge and agency to make use of them. Also included within
the predisposing factors are the characteristics of the social structures including
immigration status, education, employment, living conditions, mobility between
communities and dwellings, victimization, psychological resources and social support in
the form of family members, friends and neighbors.

People with disabilities have been found more likely to be older,
socioeconomically disadvantaged and having lower levels of education and employment
(Bureau of Labor Statistics, 2010; US Census Bureau, 2002). Unfortunately the
Population Census Organization in Pakistan does not report age and income
disaggregated data for various categories of disabilities. However, research in other
countries of the South-East Asian region indicates majority of PWDs to have low levels
of education and employment (Hiranandani & Sonpal, 2010). Studies carried out by
international donor organizations indicate that about half a billion disabled people are
amongst the poorest of the poor and comprise 15-20% of the poorest in developing
countries (Yeo, 2001). With 22% of the Pakistani population living below the poverty
line (The World Bank, 2010) it is reasonable to argue that poverty contributes to the low
social status of the disabled in Pakistan. This poses a barrier to seeking healthcare as the
cost of seeking care outweighs the perceived benefit in case of competing demands on
resources (Lee & Heinemann, 2010). A distinction also needs to be made at this point
between perceived and actual barriers. People in the developing countries, such as
Pakistan and Bangladesh seek care preferentially from unqualified faith healers and
“quacks” due to the perceived high costs of care, and low quality of medications provided
in the government sector hospitals (Hosain & Chatterjee, 1998; Thaver et al., 1998).
Figure 2. Modified Andersen-Aday Behavioral Model of Healthcare Utilization (Phillips, Morrison, Andersen, & Aday, 1998)
Table 1. Traditional and Vulnerability Domains in the Behavioral Model for Vulnerable Populations

| Population characteristics | Need | Health Behavior | Outcomes
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<td>Predisposing</td>
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<td><strong>Traditional domains</strong></td>
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<td>Health Beliefs</td>
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<td>Values-health and illness</td>
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<td>Attitudes-health services</td>
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<td>Knowledge of disease</td>
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<td>Social Structure</td>
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<td>Education, employment</td>
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<td>Social networks</td>
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<td>Personal/Family resources</td>
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<td>Perceived health</td>
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<td>Regular sources of care</td>
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<td>General Population</td>
<td>Health conditions</td>
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<td>Income, Social support</td>
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<td>Perceived barriers</td>
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<td>Community resources</td>
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<td>Evaluated health</td>
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<td>Residence</td>
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<td>General Population</td>
<td>Health conditions</td>
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<td>Region</td>
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<td>Health services</td>
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<td>Perceived health practices</td>
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<td>Personal health practices</td>
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<td>Tobacco use</td>
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<td>Adherence to care</td>
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<td>Financial aspects</td>
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<td>Time spent with provider</td>
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<td>Satisfaction with care</td>
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<td>General satisfaction</td>
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<td>Interpersonal aspects</td>
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<td>Coordination</td>
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<td>Communication</td>
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Table 1 continued

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<thead>
<tr>
<th>Vulnerability Domains</th>
<th>Personal/Family resources</th>
<th>Perceived health</th>
<th>Personal health practices</th>
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<tr>
<td>Social Structure</td>
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<tr>
<td>Country of birth</td>
<td>Competing needs</td>
<td>Vulnerable Population Health conditions</td>
<td>Food sources</td>
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<td>Acculturation</td>
<td>Hunger</td>
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<td>Hygiene</td>
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<td>Immigration</td>
<td>Public benefits</td>
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<td>Unsafe sexual behaviors</td>
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<td>Literacy</td>
<td>Self-help skills</td>
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<td>Sexual orientation</td>
<td>Ability to negotiate system</td>
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<td>Childhood characteristics</td>
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<td>Evaluated health</td>
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<td>Residential history</td>
<td>Case manager</td>
<td>Vulnerable Population Health conditions</td>
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<tr>
<td>Homelessness</td>
<td>Transportation</td>
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<td>Living conditions</td>
<td>Telephone</td>
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<tr>
<td>Mobility</td>
<td>Information sources</td>
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<td>Length of time in community</td>
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<tr>
<td>Criminal behavior</td>
<td>Community resources</td>
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<td>Victimization</td>
<td>Crime rates</td>
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<td>Mental illness</td>
<td>Social services</td>
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<td>Psychological resources</td>
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<td>Substance abuse</td>
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**Enabling resources.** Enabling resources are the resources that enable (or hinder) persons with disabilities to make use of needed healthcare services. These include community and personal enabling resources, both within the traditional and vulnerable domains. Traditional personal/family enabling resources include regular source of care, income level, and insurance status. Similarly, traditional community resources include facilitative and accessible transport systems, location of healthcare facilities and availability of community-based out-reach services.

The personal enabling resources in the vulnerability domains include competing needs, self-help skills, ability to negotiate system, case-managers, telephone and information sources (Gelberg et al., 2000). Community enabling resources for the vulnerable populations include social service resources. Many state and federally funded programs in the United States (e.g. Medicaid, Kid-Care, SCHIP, Supplemental Security Income and disability benefits) are designed to buffer PWDs and their families from effects of economic hardship and lessen the impact of this barrier. Comparable programs in Pakistan include the provincial and local Zakat funds and Pakistan Bait-ul-mal, both government funded charitable organizations designed to provide relief to the economically challenged including widows, persons with disabilities and the chronically ill (Pakistan Bait-ul-Mal, Government of Pakistan). Medical social workers are an important community enabling resource for vulnerable populations in the public health systems of the developing countries. These individuals perform the important task of coordinating health and social services for the patients who cannot afford them. They maintain close contact with local philanthropic organizations and individuals to mobilize
resources and protect indigent individuals from catastrophic health expenditures that would otherwise likely push the families over the brink of poverty (Hossain, 2005).

Enabling legislation which mandate the accessibility of buildings and vehicles as well as facilitate abolishment of discrimination on the basis of disability, gender, race and ethnicity is another important component of community-based enabling factors. Such legislation is sorely lacking in developing countries such as Pakistan where the concept of physical accessibility of buildings and transport is still rudimentary. Such legislation promotes optimum healthcare utilization and socioeconomic independence of persons with disabilities and improvement in their health status and quality of life as a whole (Sanderson-Mann & McCandless, 2005). Although there is provision for employment of a mandatory percentage of persons with disabilities in the low level government jobs, such a provision is lacking in the private sector and for higher government jobs. Thus there is no mechanism to protect PWDs from discrimination when it comes to employment opportunities, hence perpetuating their vulnerability.

Need factors. The presence of need for services is also an important determinant of care utilization, where patients and their caregivers perceive the need for accessing services for alleviation of disease symptoms. Both the traditional and vulnerability domains of need factors include perceived health and evaluated health as a very important force driving the utilization of healthcare. Research has consistently shown an inverse relationship between self-reported health status and use of health services (Al-Windi, Dag, & Kurt, 2002; Fylkesnes, 1993; Kennedy, Kasl, & Vaccarino, 2001; Miilunpalo, Vuori, Oja, Pasanen, & Urponen, 1997; Young, Dobson, & Byles, 2001).
Thus, while PWDs feel a greater need for health services, their ability to actually utilize them depends on a number of factors that facilitate or hinder their access. It is this interaction of predisposing, enabling and need factors, in conjunction with the characteristics of the health system and the external environment that drives utilization of health services by this vulnerable group.

**Disability as a predisposing, enabling and need factor.** Disability has a pervasive effect on the lives of the people it affects, who often find themselves defined by their disability instead of their personality (Harper & Richman, 2006). According to the behavioral model of healthcare utilization for vulnerable populations, disability status can be added to both the biologic as well as social determinants of healthcare utilization.

Being basically an anomaly of the biological function of the body systems, disability becomes a predisposing factor for healthcare utilization due to its attendant health effects that predispose the disabled individual to seek health care. Along with gender and age, disability represents a biologic imperative to use healthcare services.

As an enabling factor, disability exerts negative effects by constraining family resources and placing competing demands especially in situations of resource scarcity (Rolland, 2003). Due to low social status of the PWDs, their needs are often neglected by the families where breadwinners are accorded priority in terms of healthcare access.

In the Modified Andersen-Aday Behavioral Model of Healthcare Utilization (Phillips, Morrison, Andersen, & Aday, 1998), disability emerges as a need factor by exerting its effect on the perceived health status of the affected individual and is associated with higher levels of health care utilization (Tomiak, Berthelot, & Mustard,
Disability also acts as a need factor through its effects on the evaluated health status as healthcare providers have been shown to hold biased perceptions about the health needs of the persons with disabilities (Fisher, Haagen, & Orkin, 2005; Kroll et al., 2005; Mele, Archer, & Pusch, 2005; Verger et al., 2005). Thus the disability status of a person exerts its influence at all levels to drive, as well as inhibit, healthcare utilization. While it is a positive predisposing and need factor, it acts as a negative enabling factor.

**Characteristics of the healthcare system and external environment.** The second major class of primary determinants of healthcare access and utilization in this model is the healthcare system itself, with its policies, resources and organization as important elements. Healthcare systems are mostly organized around public and private financing sources with public health systems aiming to make healthcare universally accessible through governments’ subsidization of health facilities for the populations. Thus the public health systems aim to improve health care access of those who cannot afford the more expensive private market, and promote fair sharing of the burden of ill health (Lamiraud, Booysen, & Scheil-Adlung, 2005). The healthcare system in Pakistan is characterized by a government funded network of public sector facilities at the primary, secondary and tertiary levels in the provinces and federal territories, and a largely unregulated private sector in the form of clinics, hospitals, diagnostic centers and maternity homes. The focus of the private sector is mostly on the more expensive and high-tech diagnostics and tertiary care while the government policy is geared toward strengthening of primary care in the form of community out-reach workers and facilities (Ministry of Health, Government of Pakistan). While most of the facilities in the public sector are supposedly provided free of cost with nominal user fees, 70-80% of healthcare
utilization occurs in the private fee-for-service sector (Pakistan Social Standard Living Measures Survey, 2004-05). This not only shows the lack of confidence of the general population in the capacity of the public health system but also exposes the low-income families to catastrophic health expenditures and high likelihood of impoverishment (Shaikh & Hatcher, 2007).

These characteristics of the healthcare system have effects on the healthcare seeking and utilization behaviors of the persons with disabilities. Coupled with the predisposing, enabling and need factors as described in the behavioral model, it is the characteristics of the health system that determine how it responds to the needs of the persons with disabilities. The same characteristics of the health system also offer barriers to responsiveness in the form of adverse structure and process features.

The external environment includes the social, cultural and political milieu in which the healthcare system is located. Cultural and social norms, economic realities and historical influences all have a bearing on the way disabled people are portrayed and dealt with in the community. Especially when examined with respect to persons with disabilities, there are profound cultural differences affecting these interactions in the pluralistic Asian versus the individualistic Western societies. While the concept of patient dignity is identical in most cultures, the concepts of autonomy in health decision making and confidentiality of information are vastly different between the western and the more pluralistic Asian cultures. In Asian societies, the family takes precedence over the decisions of the patient (Meer & VandeCreek, 2002). Consent forms are signed, diagnoses are communicated and treatment decisions are made by the head of the family,
whose decisions may override those of the patient even when the patient is of sound mind (Fan, 1997). Thus while all these concepts are related to patient-provider communication, they are governed by higher level social and cultural influences, and it becomes imperative to study them in this broader context to derive valid consequences from research.

These determinants of healthcare access and utilization impact health behaviors including personal health behaviors as well as use of health services. While personal health practices like dietary and stress control, and regular exercise are dependent more on the population characteristics, use of healthcare system is impacted both by population and health system characteristics as well as the physical, economic and political environment in which the health system and the population are situated. The model includes the final element of health outcomes which include perceived and evaluated health status and consumer satisfaction. These outcomes are a product of the population characteristics and also of the health system and the external environment.

**Behavioral model of healthcare utilization and health of people with disabilities.** Research suggests that people with disabilities, despite being intense users of health services, rate their health status as low, and are less satisfied with the services they receive (Patrick, Scrivens, & Charlton, 1983). The behavioral model may explain this phenomenon as a result of their disability, low economic and educational status (predisposing characteristics) and their low social status, thus adversely affecting their ability to make independent decisions for their healthcare (enabling resources), as well as affecting their interaction with health care providers. Another very important enabling
resource or lack thereof for PWDs is the characteristics of healthcare providers and adverse experiences in the healthcare system which may affect their future decision making. Especially relevant to the traditionalist societies is the preference of women to seek care from female providers which may become a barrier in case of non-availability of the latter. Furthermore, female providers are also a product of the same value system and may experience the same constraints as other women in the society (Burn, 2008).

The behavioral model is comprehensive in taking into account all of the important determinants of health care access at the macro (social and organizational level) to the community level, and traces their effects on the intermediate outcomes (health behaviors) to the long term outcomes (health status). As such, it provides a valuable tool for study of the phenomenon in question and the amount of research that has utilized it as a guiding framework is testimony to that.

**Clarity and internal consistency of the model.** The constructs in the model are categorized into environment, population characteristics, health behavior and outcomes. Although this study did not aim to establish causality, the interrelationships among the different factors served to clarify the effects each of them has on the other group. An important modification was later incorporated into this model in the form of the individual/provider related variables and the contribution of community factors (Phillips et al., 1998). Indeed in all societies in general and in the pluralistic Asian societies in particular, community level factors play an important role in determining individual and group behavior, especially in regard to economically subservient individuals like women and people with disabilities.
Respect for dignity of the patient, confidentiality of information and autonomy of health decision making and clarity of patient-provider communication are closely related to the social status of the patient, the power differential in the patient-provider relationship as well as the social and cultural norms of the society. The social status of the patient is determined by the predisposing factors of age, sex, race/ethnicity and disability status and by the enabling factors including income and education (U. S. Census Bureau, 2002). The Pakistani population is racially and ethnically homogenous. However, the society is generally patriarchal with gender discriminatory practices prevalent at all levels. This has been linked to restricted mobility (Khan, A, 2003), low educational status and employment opportunities (Pakistan Social and Living Standards Measurement Survey, 2010-2011) and excess female mortality (Coale, 1991). Choice of provider is related to the aforementioned variables as well as with the area of residence, and the organization and financing of healthcare system (Yip, Wang, & Liu, 1998). The quality of amenities at health facilities and waiting times are affected by the amount of financial, human and physical resources dedicated to the healthcare system and by the staffing, organization and financing patterns of facilities (Donelan, Blendon, Schoen, Davis, & Binns, 1999; Murray & Berwick, 2003). Furthermore, the environment including the external social, political and economic milieu in which the health system and its consumers are situated, have direct effects on the health status and satisfaction with health services, and also through their effect on population characteristics and health behaviors.
Behavioral model of healthcare utilization and bio-psychosocial model of disability. Another factor contributing to strength of the Andersen-Aday model in the context of the present study is that it aligns with the bio-psychosocial model of health and disability as described further.

Previously, disability was mainly seen through the biological lens as an abnormality of the structure and function in the human body. This biomedical model presupposes that the source of the problems related to disability is the disabled person; with a focus on the body and whatever is “wrong” with it that needs to be corrected so that the person may conform to the “normal” human anatomy and physiology (Saxton, 2000). It sees disability as abnormal and hence unacceptable (Ralston, 2000). This model has been largely replaced by the bio-psychosocial model proposed by Engel (1977) which views disability as being biologically, socially and psychologically determined. It further posits that disability has biological, social as well as psychological consequences. This model is in stark contrast to the narrow biomedical model with its biological approach. In contrast, it contends that disease and disability be understood in the larger context of the society, the patient-provider interaction and the healthcare system. The bio-psychosocial model of disability has by far become the dominant paradigm in contemporary research including physical therapy (Jette, 2006), psychology (McLean, Clauw, Abelson, & Liberzon, 2005; Olson & Strawderman, 2003; Ricciardelli & McCabe, 2004), psychiatry (Ross, Sellers, Gilbert, Evans, & Romach, 2004) and chronic diseases research (Covic, Adamson, Spencer, & Howe, 2003). The fact that the
behavioral model of healthcare access aligns with this paradigm adds to the scientific plausibility of the latter.

Using a multi-level model to study a concept as broad as responsiveness of health systems was advantageous in terms of explaining and making sense of the observed phenomena. As the concept was basically ecological, with factors exerting their effects at different levels from the personal to the interpersonal, community and societal levels, a multi-level model helped keep the concepts organized and the propositions between them clear. Using a multi-level model ultimately assisted in elaboration of the study findings and their organization. The themes emerging from the data within the eight domains of responsiveness were organized into factors operating at the different levels of the model that hinder responsiveness of the health system. At the level of the healthcare consumers, the factors that impeded responsiveness of the health system included those associated with poverty, lack of education and dependence on family. Provider related variables that offered barriers to responsiveness included lack of training in the field of disability management, lack of sensitivity and lack of interest in treating the chronically disabled. The factors operating at the health system level included multiple flaws in its design and operation that had a negative effect on responsiveness. At the community level, the pluralistic, patriarchic Pakistani culture was indicated as an important barrier to multiple domains of responsiveness. The factors at the external environment level included those at the level of health policy and those beyond the jurisdiction of health ministry. Thus the researcher was able to organize all the themes that emerged within the domains of responsiveness in the framework of behavioral model of healthcare utilization.
The world of behavioral research is challenging due to human behavior, emotions, biases, social and cultural influences and myriad other factors affecting the findings. Multi-level models help impart meticulousness and orderliness in these situations for the researchers to be able to extricate findings and make better sense of the reality.
Chapter III: Research Design and Methods

This study addressed the following research questions:

1. How is the Pakistani federal health system responding to the needs of 18-45 year old adults with physical disabilities? and

2. What are the barriers that currently exist to hinder the responsiveness of Pakistani federal health system to the needs of young adults with physical disabilities?

These questions were addressed from the perspective of both the disabled healthcare consumers as well as the people involved in healthcare provision, management and policy making. In addition, the views of disability rights advocates were also included to impart further richness to the data. The study was conducted using the Behavioral Model of healthcare access and utilization as the theoretical foundation. The eight domains of responsiveness correspond with the constructs in the theoretical model as shown in Figure 3.

This cross-sectional descriptive study was conducted using the qualitative methods of focus group discussions with young adults having physical disabilities as users of healthcare services, and in-depth interviews with healthcare providers, managers and policy makers and disability rights advocates. Many attributes of qualitative research made it a suitable choice to investigate the issues in question. First, qualitative research is best suited to investigate a previously unexplored topic (Britten, Jones, Murphy, &
Stacy, 1995). In this instance, there was a general paucity of research in the field of responsiveness of healthcare system in Pakistan, and specifically with regard to the PWDs. Even studies by WHO on the concept of responsiveness including the Multi-Country Survey Study (2001) and the World Health Survey (2003) did not entail data collection in Pakistan; instead, findings from other member states were extrapolated. Second, the nature of qualitative research in general lends itself to study of the research participants in their natural setting. It takes stock of the various contextual factors that affect the way people construct their reality within their specific cultural, geographic and historical milieu (Neuman, 2006). As this study focused on the experiences of a specified group of people sharing common physical attributes located within a geographic region of Pakistan, the depth of meaning and the richness of description could best be captured through qualitative methods. Thirdly, qualitative methods have been found to be of special value in health systems research to study experiences of patients as recipients of healthcare, their interactions with providers and the system as a whole, and the meaning they ascribe to these processes (Pope & Mays, 1995). This research involved capturing the experiences of PWDs in regard to patient-provider interaction, by addressing the four domains of responsiveness included in the Respect for Persons. Furthermore, the interactions of the PWDs with the healthcare system were accounted for through collection of data within the four domains of Client Orientation within the framework of responsiveness.

The research entailed use of two separate samples. The first sample was composed of 18-45 year old persons with disabilities who had utilized healthcare services during the last 12 months, in the three designated federal government hospitals located in
Islamabad. Eight focus group discussions were conducted with this group, stratified on the basis of gender and socioeconomic level. The second sample was composed of healthcare providers including doctors, nurses and physical therapists, and healthcare managers who were serving in the same designated federal government hospitals for at least 3 years. This sample also included senior healthcare managers and policy makers at the level of the former Ministry of Health. Another important group of respondents included in this sample were the disability rights advocates who were active members of the locally registered community based non-governmental organizations. Forty face-to-face, in-depth interviews were conducted with this sample. To clearly organize and present the research methods employed with these two samples, they are being discussed separately, under independent headings in the forthcoming sections.

**Sample I: Subjects and Setting**

The study was conducted in Islamabad, the capital city of Pakistan, which is the home country of the study author. Pakistan is a developing country located in South Asia, covering an area of 796,096 square kilometers with current estimated population of 177 million. It ranks 6th in the world on the basis of its population, and is the most populous country in the Eastern Mediterranean region of the World Health Organization (United Nations Population Division, 2010). The study focused on the experiences of users of three tertiary care hospitals under federal control, located in Islamabad.

Research shows that experiences of PWDs in their interaction with the healthcare system differ by the type of disability they have (Winters & Story, 2007). Thus, in order to reach valid and trustworthy conclusions, this study focused on one subgroup within the
Table 2. Stratification of Focus Groups on the Basis of Gender and Socioeconomic Level

<table>
<thead>
<tr>
<th>Socioeconomic status</th>
<th>Middle</th>
<th>Low</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male PWDs (Two FGDs with 6 participants each)</td>
<td>Male PWDs (Two FGDs with 6 participants each)</td>
</tr>
<tr>
<td></td>
<td>Female PWDs (Two FGDs with 5 participants each)</td>
<td>Female PWDs (Two FGDs with 6 participants each)</td>
</tr>
</tbody>
</table>

Note. PWDs = Persons with disabilities; FGDs = Focus group discussions

The sample of PWDs was recruited from Islamabad Capital Territory to participate in eight focus group discussions to collect data on the responsiveness of the health system to their needs and the factors that hinder the system from responding. In addition, basic demographic information was collected from all respondents and analyzed quantitatively for descriptive purposes.

The sample consisting of physically disabled users of healthcare was stratified on the basis of socioeconomic level and gender as shown in Table 1, with two focus groups conducted within each cell shown in the table. Assessment and categorization of socioeconomic status is described in the forthcoming sections. Each focus group discussion consisted of six participants, except for the females in the middle socioeconomic group, whereby five women participated in each of the two discussions.

**Justification for stratification of sample I.** The sample was stratified on the basis of the Hollingshead four-factor index (Hollingshead, 1975), as described in further
detail in the next section. This stratification was necessitated by the research findings that indicate that these characteristics contribute to the vulnerability of the poor and women (Aday, 2001). These variables were built into the design of the study to improve trustworthiness of the data. As low socioeconomic status is a negative enabling factor in the behavioral model of healthcare utilization, it was expected to have an effect on the healthcare experiences of people with different resource availability. The focus on middle and low socioeconomic strata was justified by the research findings that persons with disabilities are more likely to belong to economically challenged families (Elwan, 1999). Furthermore, as described earlier, socioeconomic status is a major determinant of vulnerability in population subgroups. The public healthcare system aims to improve healthcare access for those who cannot afford the more expensive private market, and promote fair sharing of the burden of ill health (Lamiraud, Booysen, & Scheil-Adlung, 2005). Research has shown that people in the low socioeconomic strata avail more public health services, while those who are better-off prefer to benefit from private health facilities (Regidor, Martinez, Calle, Astasio, Ortega, & Dominguez, 2008). As the study was focused on experiences of PWDs, who were more likely to seek public healthcare on account of their vulnerability, this study focused on the federal government hospitals located in Islamabad.

Due to the economical subservience and low social status of women in the Pakistani society, their access to healthcare is different from that of men who enjoy more social power (Mumtaz & Salway, 2005). Conducting focus groups separately for men and women also respected the cultural sensitivities of a community where free interaction between members of the opposite sexes is considered objectionable.
The study was designed to focus on the healthcare experiences of persons between the ages of 18-45 years. This was done because healthcare needs of this age group are different from the older age groups who are likely to suffer more from chronic and metabolic diseases. Also people in these age groups are under higher social pressure to contribute to the family income by seeking education and employment (Mudrick, 1988). Any factors that dissatisfied them with the healthcare services being provided would likely have an effect on their ability to seek gainful employment and condemn them to further marginalization. Another important factor that justified the focus on the younger age women was the fact that 18-45 are the childbearing years. It is during this age that women come most in contact with reproductive healthcare service providers. Any attributes of the healthcare system that inhibited or discouraged women from seeking timely reproductive and maternity care would likely have adverse effects on the health of the mother as well as the child.

Due to the qualitative nature of the study, the sample size was not based on quantitative power calculations, but was estimated to facilitate data saturation and elicitation of a wide range of responses encompassing the area of inquiry. Furthermore, qualitative research is inductive in nature and the researcher did not go into the field with a preformed hypothesis. The proposed number of FGDs was meant to facilitate data collection to the point when no new information was forthcoming from the participants (Neuman, 2006).

**Sample I: Inclusion criteria.** The population of interest for this study was comprised of the following:
• Community dwelling, adult Pakistanis, 18-45 years of age, suffering from congenital and acquired physical disabilities, and residing in the Islamabad Capital territory between February and December, 2011.

• Respondents with acquired disabilities must have been disabled for at least 12 months.

• Respondents must have utilized in-patient, out-patient and/or emergency healthcare services in any of the three designated federal government hospitals in the last 12 months.

• Upon screening with the WHO DAS 2.0, respondents must have had a score of 6-12 on the domain of cognition and cumulative simple scores between 90 and 150 on the other 5 domains, including mobility, self-care, getting along with people, life activities and social participation. These cut-scores were specified to ensure inclusion of cognitively capable adults with moderate to severe functional limitation. Further details of this instrument may be seen in the Instruments and Measures section.

The designated hospitals for this study included the Pakistan Institute of Medical Sciences (PIMS), the Federal Government Poly Clinic (FGPC), and the National Institute for Rehabilitation Medicine (NIRM). These hospitals were retained under federal control after promulgation of the 18th constitutional amendment and subsequent devolution of the Ministry of Health. The recall period of 12 months has been used by the World Health Organization’s Multi-Country Survey Study on Health and Responsiveness (Valentine et al., 2003) to minimize recall bias in data collection. The specific cut-scores on WHO
DAS 2.0 enabled recruitment of respondents with none or mild cognitive impairment and moderate to extreme physical impairment. The psychometric properties of this instrument including its uni-dimensional structure and high internal consistency permitted such simple scoring and additive calculation (Ustun, Kostanjsek, Chatterji, & Rehm, 2010). The WHO DAS 2.0 does not specify disabling conditions for which it is to be used. However, to maximize the likelihood of capturing respondents with chronic disability, the diseases included, but were not restricted to, paralytic conditions (stroke, spinal bifida, traumatic spinal cord injury etc.); motor and balance dysfunctions (movement disorders, ataxia, Parkinsonism, cerebral palsy and others); acquired limb loss and congenital absence of one or more limbs; and skeletal abnormalities (kyphosis, scoliosis, club foot, osteogenesis imperfecta and others). The age of the respondents (18-45) was limited to maximize the selection of cognitively capable adults, with a lower likelihood of co-morbid conditions.

**Sample I: Exclusion criteria.** Persons suffering from physical disabilities that severely restricted their ability to communicate were excluded from the study. These included stroke patients with aphasia and patients with cerebral palsy with severe spasticity, or flaccidity, impeding their ability to speak. Persons having intellectual or sensory disabilities were also excluded, as were children less than 18 years of age. Institutionalized PWDs were also excluded. This study applied the World Health Organization model linking persistent limitations to disability (Albrecht, Seelman, & Bury, 2001). Thus persons momentarily disabled by injuries or other acute conditions were not considered as disabled, and hence not included. For the purposes of this study, a disability that had been present for the last 12 months was considered chronic.
Sample I: Sampling Methods and Subject Recruitment

Qualitative research is best conducted with purposively selected samples as it captures the experiences of those who have lived through the phenomenon in question and are in a position to provide maximum information about it. Participants were recruited from among young PWDs being served by the members of two locally operating Community-Based Organizations (CBOs), the Special Talent Exchange Program (STEP), and the Disabled People Development Organization (DPDO). The membership of the DPDO is mainly composed of people belonging to the low socioeconomic stratum, living in 25 adjacent villages, included in the municipal boundary of the Islamabad Capital Territory. STEP largely caters to the needs of the more educated urban youth living in Islamabad. Both organizations have extensive membership and are active in the field of healthcare, education, employment and independent living for all categories of the PWDs. The researcher met with the heads of these CBOs to explain the objectives of the study and to request for their support. The heads of both organizations agreed to support the research and provided letters to this effect, which were conveyed to the USF-IRB. As soon as the USF-IRB approved the study, participant recruitment was initiated from among their disabled beneficiaries.

Designated persons working at the main offices of STEP and DPDO were provided with the IRB-approved recruitment script (Appendix- I) and were also apprised of the inclusion criteria for the participants, including age, socioeconomic status, disability status and use of health services in designated hospitals. These recruiters contacted their beneficiaries afflicted by various physical disabilities within the 18-45
year old age bracket, and read the recruitment script to them. This was done in person if the potential participant was visiting the office of the CBO, or by telephone if the participant was not physically present at the office. The recruitment script provided information about the study objectives, data collection procedures and respondents’ right to confidentiality and right to withdraw from the study without suffering any backlash. Once the potential participants agreed to participate, the recruiter conveyed their telephone numbers to the researcher who contacted them over the telephone. Screening of the consenting participants was performed by administration of the screening questionnaire (Appendix- II) and WHO DAS 2.0 36-item interviewer administered version (Appendix- III). Subsequently, scores on the WHO DAS 2.0 and the Hollingshead index helped place the participants in the relevant focus groups. The researcher provided all participants with her contact information so that any change in schedule, or intention to participate may be communicated. Once a sufficient number of participants were recruited for particular gender and SES strata, FGDs were scheduled as per participants’ convenience.

**Sample I: Instruments and Measures**

Despite the qualitative nature of the study, it was designed to examine the differential responsiveness of the health system to respondents belonging to groups stratified on the basis of gender and socioeconomic status. Therefore these variables were treated as independent variables, whereas domains of responsiveness and barriers to responsiveness were treated as dependent variables. The data collection instruments are described as follows:
**Screening questionnaire.** The screening questionnaire was administered to establish eligibility of individuals consenting to participate in the study, in light of the inclusion criteria spelled out earlier. This instrument gathered information on the respondents’ age, sex, marital status, occupational group, educational level, functional impairment, utilization of health services in the past 12 months, affordability of health services, and specific diagnosis leading to disability.

**Hollingshead index of socioeconomic status.** Socioeconomic status was assessed using the Hollingshead index of socioeconomic status. This composite index takes into account sex, marital status, occupational group and educational status of individuals within nuclear families to place them into 5 main categories of social status. The information gathered through the screening questionnaire was used to calculate this index score for individual participants. This tool was especially suitable to the present study as it takes into account the educational and occupational status of the head of the family to account for the social status of a dependent respondent (for example housewives who do not work outside the home are assessed as per their husbands’ education and occupation). If both spouses were employed, the education and occupation scores of the husband and wife were summed and divided by 2 to calculate the status of the nuclear family. In the case of a single, unemployed participant, the educational and occupational scores of the head of family were used to calculate the index score. The occupational groups and educational levels were categorized and scored for use in the index accordingly (Hollingshead, 1975). The composite scores are calculated as follows

\[(\text{Occupational group} \times 5) + (\text{Educational level} \times 3) = \text{Total score}\]
Despite the fact that the Hollingshead index was devised in 1975, the occupational groups included in the original document corresponded to those of the respondents in a straightforward manner. The present study looked at the low and middle socioeconomic status individuals who belonged to the older professions as listed in the original paper by the author (Hollingshead, 1975). The Hollingshead index placed persons into 5 main categories on the basis of their composite scores. For the present study, the social classes 2 and 3 (scores between 54-30) were collapsed as middle SES while social classes 4 and 5 (scores between 29-8) were counted as low socioeconomic status (Falconnier, 2010). The Hollingshead index has been used as a tool yielding valid and reliable data across different sociocultural settings in countries such as Pakistan (Jafry, Yaqoob, Abid, Siddiqui, Awan, & Nizami, 2009), the US (Shields, Palermo, Powers, Grewe, & Smith, 2003; Witvliet, Phipps, Feldman, & Beckham, 2004), Turkey (Ersoy, Balkan, Gunay, Onag, & Egemen, 2004; Ersoy, Balkan, Gunay, & Egemen, 2005; Ozguven, Ersoy, Ozguven, & Erbay, 2010), and Spain (Babio, Canals, Pietrobelli, Perez, & Arija, 2009; Diaz et al., 2008).

**Functional limitation.** Functional limitation of the study participants was assessed through administration of the World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) (Appendix- III). The degree of activity limitation was used as a descriptive variable when reporting the sample characteristics. This instrument measured activity limitations in the 6 domains of cognition, mobility, self-care, getting along with people, life activities and social participation. Of the different versions available, the 36 item interviewer administered version was highly recommended by the WHO, as it captured the most complete profiles of respondents. This instrument
measured the level of activity limitation in the past 30 days on a scale of 1-5 (1= None, 2= Mild, 3= Moderate, 4= Severe, 5= Extreme/cannot do). For all activity limitations, the respondents were also asked to report the number of days they were present and the extent to which they interfered with their life. The WHODAS 2.0 is reported to be a valuable tool yielding valid and reliable data for measurement of disability (Garin et al., 2010; Kostanjsek, Escorpizo, Boonen, Walsh, Ustun, & Stucki, 2010; Kostanjsek et al., 2010). Factor loadings and internal consistency of the instrument confirm its latent structure. The reported Cronbach Alpha values have been 0.94 to 0.96 for individual domain scores and 0.98 for the total scores (Ustun, Kostanjsek, Chatterji, & Rehm, 2010).

For the purposes of this study, individual scores were obtained by simple scoring which entailed addition of the polytomous scores on individual domains as detailed in the manual for the instrument (Ustun et al., 2010). As the study focused on cognitively capable adults with physical disabilities, the individual scores on the domain of cognition were reduced to be between 6-12, signifying none to mild cognitive impairment. Cumulative simple scores on the other 5 domains were limited between 90-150, which corresponded with moderate to extreme functional impairment.

**Utilization of health services during the past 12 months.** Utilization of healthcare was assessed by asking the respondents if during the past 12 months they had utilized in-patient, out-patient or emergency services from any of the three federal government hospitals, namely the Pakistan Institute of Medical Sciences (PIMS), Federal Government Services Hospital (aka. Poly Clinic Hospital), and the National Institute for
Rehabilitation Medicine (NIRM) located in Islamabad. The response categories to this question were Yes/No.

**Affordability of outpatient and inpatient health care.** Financial access was assessed by asking if during the past 12 months the respondents ever had to forego healthcare because he/she could not afford it. The response categories for this question were Yes/No.

**Focus group guide.** Focus group guide (Appendix- IV A&B) for the study was developed by the Principal Investigator to collect data on the eight responsiveness domains from adult participants with physical disabilities. The questions focused on the responsiveness of the three designated federal government hospitals located in Islamabad, i.e. PIMS, FGPC and NIRM. The dependent variables measured by this instrument were the following:

- Experience of being treated with respect and dignity by healthcare providers and staff
- Confidentiality of health information and records
- Autonomy and freedom from coercion in health decision making
- Communication with healthcare providers in clear and understandable terms
- Prompt attention at the healthcare facilities
- Having a choice of healthcare provider and facility
- Having access to social support networks during care at a facility
• Quality of amenities at healthcare facilities including physical accessibility of buildings, appropriate ramps for wheelchair access, comfortable waiting areas and wards, provision of quality medication and diet when admitted.

The introductory questions inquired how important the individual responsiveness domains were to the respondents. For example the introductory question to the domain of dignity was “In your opinion, how important is it that doctors and nurses treat you with respect when you go to the federal government hospitals?” This was expected to stimulate reflective thinking. The questions which followed served to direct the conversation into the main topic areas and elicit a discussion of all important aspects of responsiveness. Respondents were asked to recall their experiences as patients interacting with healthcare providers. They were then requested to provide their opinions, views and comments in light of actual experiences. Probes were designed to be used when a deeper understanding of an issue was needed.

At the end of the focus group discussion, the participants were asked if there was anything that they thought was important or was missed. They were also asked to contribute one piece of advice for health policy makers to improve healthcare for PWDs.

**Sample I: Pilot Testing**

The PI translated all pre-existing and newly developed instruments into Urdu and then back into English to ensure conceptual equivalence. This was facilitated by equal proficiency in both languages. Translations were rechecked and certified by a professionally trained interpreter, an Assistant Professor at the National University of Modern Languages, Islamabad. The instruments were pilot tested as follows:
The focus group guide was pilot tested with a group of PWDs (n= 6) to determine how the discussion was led by the formulated questions. The questions were found to be fairly easily understandable; however, the sequence of domains had to be changed to give it a more logical flow. The domains were rearranged in the following sequence; 1) Dignity, 2) Confidentiality, 3) Clarity of communication, 4) Autonomy, 5) Prompt attention, 6) Quality of amenities, 7) Choice of provider, and 8) Access to social support networks during care. Furthermore, definitions of each domain were provided in the relevant sections of the guide to facilitate the respondents’ understanding of the questions.

The translated version of World Health Organization Disability Assessment Schedule 2.0 was pilot tested with community dwelling adults with physical disabilities (n= 4) who met inclusion criteria for the sample. The individual items on the translated instrument were examined by an expert panel consisting of two healthcare providers and two health care researchers to establish face validity. The translated instrument was found to be valid except for some minor changes in wording making it more easily understandable for low literate participants.

**Sample I: Data Collection Procedures**

*Focus group discussions.* Focus groups are group discussions on a specific set of issues (Kreuger, 1994), designed to capture different perspectives and views about a certain experience or topic. Group members are able to respond to and discuss each other’s comments, and to challenge and expose previously accepted assumptions (Bloor,
Frankland, Thomas, & Robson, 2001). In a focus group, apart from each member’s opinions, it is the group dynamics that are the focus of the investigators’ attention.

Six out of the eight focus groups were composed of six participants each, while two were composed of five participants each. These two were composed of females belonging to the middle socioeconomic status. This was owing to the fact that all FGDs were conducted on Saturday mid-mornings to allow people to participate without fear of losing out on working hours. A majority of the potential female participants belonging to the middle socioeconomic group were working women. Despite confirming their attendance, one of them in each focus group did not attend as their domestic chores over the weekend did not allow them the time to spare for this activity.

Focus group discussions ranged from 60 to 90 minutes in duration. The focus group participants belonging to the middle socioeconomic stratum were residents of the city of Islamabad. The four focus group discussions (FGDs) with these participants were conducted in the conference room of the National Institute for Rehabilitation Medicine for ease of accessibility and participants’ familiarity with the place. All the FGD participants belonging to the low socioeconomic group lived in the villages within the administrative boundary of Islamabad. The four focus group discussions with these respondents were conducted in the low-income neighborhood of Bari-Imam to ensure easy access for all participants. The venue for these discussions was the office of the DPDO.

Before starting the focus group discussions, all the participants were provided copies of the informed consent form (Appendix- V). A number of low-literate
participants had problems reading, so the PI read the informed consent form aloud for the participants, and answered subsequent questions. Participants were requested to sign the consent forms and keep a copy for their own records. Participants were reimbursed for travel costs and costs associated with work hours lost. These were assessed individually based on respondents’ reported distance traveled and type of work, and payments were made in cash. These payments ranged from 12-22 dollars in individual cases. Due to cultural inhibitions, male participants were hesitant to receive money from a female; however, the PI reiterated that it was their right and the ethical obligation of the researcher to reimburse them for their time and effort. Depending upon the time of day, lunch or light refreshments were served as a gesture of courtesy to the participants.

As there were no participants recruited from the OPD of the National Institute for Rehabilitation Medicine, all focus group discussions were moderated by the PI. The focus group discussions were digitally recorded with prior consent of the participants. Participants were asked about their opinion of the importance of individual responsiveness domains and the conversation was later steered towards their personal experiences as consumers of healthcare in the three designated federal government hospitals. The participants were told that the aim of the discussions was to improve understanding of the problems they were facing in utilizing services in these hospitals. The PI reiterated her resolve to use the research findings at higher policy levels to make the healthcare system meet their needs better.
Sample I: Data Analysis

Data obtained through focus group discussions was subjected to content analysis with regard to responsiveness of the Pakistani health system to the needs of adult PWDs. Audio-recordings were transcribed verbatim. All the focus group discussions were conducted in Urdu and transcribed in the same language. The handwritten Urdu transcripts were scanned and imported into the qualitative data analysis software, Atlas.ti 6.2, as pdf files.

The data were coded using an open coding scheme by two coders which included the PI and a healthcare researcher. The two coders independently coded the FGD transcripts in batches of four. An a priori codebook was not specified and data were structured by the FGD moderator’s guide, which was organized by the domains of responsiveness. The initial broad codes were derived from the domains of responsiveness, within which the perceptions, experiences and feelings of the respondents as users of the health system, were organized. Initial coding allowed pattern recognition and emergence of the initial themes. The two coders independently came up with themes and sub-themes within the domains of responsiveness for each batch of transcripts, after which they met to compare and discuss the codes. The differences in coding were discussed in detail and were resolved by refining the definitions of codes, creating new codes or collapsing low level codes. The coders then coded the next batch of four transcripts. Any new themes emerging from the data that did not fit into any of the agreed upon codes were assigned new codes. The coders met thereafter to discuss and compare existing codes as well as new ones that emerged from the data. Successive iterations
were made through the data as new themes emerged and this process eventually led to refinement and emergence of results in the form of coherent and logical patterns.

At the last stage of the analysis, comparisons were made across gender and income stratified focus groups to determine if their experiences indicated differential responsiveness of the Pakistani health system to the needs of these population sub-groups. Comparisons among groups were made by looking at the themes emerging in the male versus female and low versus middle SES group transcripts. Themes related to unfair treatment on the basis of socioeconomic and gender status were duly noted for reporting in the results section. Similarly, the experiences, perceptions and recommendations of the PWDs were compared with those of healthcare providers, managers and policy makers within each domain of responsiveness. This was done to detect conceptual differences, indicating disconnect in the perspective of the consumers versus that of the providers. Further linkages among data were fully explored as they emerged to draw maximum inferences from the data. For example the domains of confidentiality, clear communication and autonomy were closely linked in the milieu of the patient-provider interaction.

The two coders identified representative quotes within themes for each domain of responsiveness for inclusion in the final report. These quotes were translated independently by the two coders from Urdu to English and the translations discussed and amended to allow for maximum conceptual equivalence. Once the coders agreed on the translations as being the true reflections of the respondents’ meaning, they were included verbatim in the final report.
Table 3. Sample Stratification and Respondents for In-Person Qualitative Interviews

<table>
<thead>
<tr>
<th>Respondent categories</th>
<th>Specific respondents</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Healthcare providers</td>
<td>Doctors</td>
<td></td>
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<tr>
<td></td>
<td>Neurologists</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>General Physicians</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Orthopedic Surgeons</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Gynecologists</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Nurses</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Physical Therapists</td>
<td>4</td>
</tr>
<tr>
<td>Healthcare managers</td>
<td>Directors/Deputy Directors of federal hospitals</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Senior managers from Ministry of Health</td>
<td>2</td>
</tr>
<tr>
<td>Healthcare policy makers</td>
<td>Former Secretaries Health</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Former Directors-General Health</td>
<td>3</td>
</tr>
<tr>
<td>Disability rights advocates</td>
<td>Members of locally active CBOs and NGOs</td>
<td>4</td>
</tr>
<tr>
<td>Total number of interviewees</td>
<td></td>
<td>40</td>
</tr>
</tbody>
</table>

Note. CBOs = Community-based organizations; NGOs = Non-governmental organizations

Quantitative descriptive data collected through the demographic sheet for the PWDs were analyzed using SPSS. The characteristics of the sample were reported in terms of frequencies and means. However due to the small size of the sample, statistically significant differences among groups could not be calculated.
Sample II: Subjects and Setting

To address the issue of responsiveness from the perspective of the supply side of healthcare, four more categories of respondents were selected. These included healthcare providers, managers and policy makers working in the federal health system in Islamabad, who were selected on the basis of their experience in the field of healthcare provision and management. Senior level managers from the technical arm of the Ministry of Health were also selected for in-depth, in-person interviews. To resolve the issue of authority bias, the healthcare providers serving at the NIRM were interviewed by the Research Assistant.

Healthcare providers. Due to paucity of research indicating which specific specialties of healthcare providers were most commonly involved in care provision to young PWDs in Pakistan, expert opinion was sought from experienced healthcare managers and health service researchers to justify selection of specific healthcare providers as key informants. These experts provided their input as to specialties of providers who were most frequently approached by physically disabled patients between the ages of 18 and 45 in Pakistan. One of these experts was a previous Director of the National Institute for Rehabilitation Medicine who had worked in this capacity for a decade. The second was a healthcare researcher who had worked at the defunct Ministry of Health at the office of the Inspector General Hospitals and as such, had a wider view of the issues related to healthcare seeking of the disabled in this age bracket. The third on the panel was a rehabilitation expert who specialized in rehabilitative care of the physically disabled and had close contact with these patients over a number of years.
Thus all members of the panel had firsthand knowledge of the healthcare seeking patterns of the population of interest, and were able to provide reliable expert opinion on the topic under discussion. Apart from their experience in the field of healthcare management and research these experts shared the socio-cultural context of study participants, providing valuable information on the topic. The healthcare experts identified four specialties of healthcare providers, which included general physicians, neurologists, orthopedic surgeons and gynecologists (A. Ahmed, personal communication, April 28, 2011; S. I. Raza, personal communication, May 7, 2011; S. Mohsin, personal communication, May 10, 2011) from whom the 18-45 year old physically disabled people most commonly sought care. Four respondents belonging to each category of doctors were selected for in-depth interviews based on the inclusion criteria.

Nurses have a very important role for the in-patient management of PWDs as they provide round-the-clock care to admitted patients. Four nurses involved in the care of PWDs admitted to the National Institute for Rehabilitation Medicine were selected for interviewing by the Research Assistant. Similarly due to their greater contact with PWDs, four physical therapists presently employed at the National Institute for Rehabilitation Medicine were also selected for interviewing by the Research Assistant.

The physicians and nurses were selected through discussions with their respective heads of departments in the three designated hospitals. The heads of departments identified the providers who had maximum experience of working with physically disabled patients and could provide valid information.
**Healthcare managers and policy makers.** Healthcare managers selected for the purposes of this study included four Directors/Deputy Directors of the three designated federal hospitals (PIMS, FGPC and NIRM). Two senior level healthcare managers who had been working with the previous Ministry of Health at the time of its devolution were also interviewed due to their close association with the management of all federal government hospitals and knowledge of related issues.

In-depth, face-to-face interviews were also conducted with senior health policy makers including three former Secretaries and three former Directors-General (Health). Due to their experience within the healthcare system, these respondents contributed information on the different issues pertaining to staffing, recruitment, financial resource allocation and infrastructure development that offered barriers to responsiveness of the health system.

**Disability rights advocates.** Persons with physical disabilities who were active as disability rights advocates and were members of various CBOs and NGOs were also selected for in-depth face-to-face interviews, both to obtain their views on the responsiveness of the Pakistani health system as users and also their opinion on the factors which were keeping it from responding to the needs of PWDs. Four in-depth interviews were conducted with these key informants.

**Sample II: Inclusion criteria.**

- Healthcare providers currently involved in caring for PWDs, working in the designated federal government hospitals in Islamabad. Doctors, nurses and
physical therapists with at least 3 years of experience in the field of healthcare provision to PWDs were eligible for selection.

- Healthcare managers including Directors and Deputy Directors of the designated federal hospitals with at least 3 years of experience in the field of healthcare management were also selected. Two senior level health managers working at the previous Ministry of Health also fulfilled the eligibility criteria. This arbitrary 3 years limit for experience was set so as to enable the healthcare providers and managers to have sufficient experience from which to extract and report relevant information regarding their interactions in healthcare provision to people with physical disabilities.

- Health policy makers consisting of senior members of the technical arm of the defunct Ministry of Health including former Secretaries and Directors-General of Health. These officials were responsible for drafting and sending legislation to the National Assembly, the office of the President and the Senate, and as such, had valuable knowledge of the factors operating at the policy level that affected responsiveness of the health system. The reason for including former Secretaries and Directors-General Health was the recent reshuffling of appointees on these posts.
Table 4. Matrix Showing Linkages among Research Questions, Elements of Behavioral Model for Healthcare Utilization, and Study Respondents

<table>
<thead>
<tr>
<th>Research questions</th>
<th>Elements of the model</th>
<th>Variables</th>
<th>Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>How is the Pakistani healthcare system responding to the needs of 18-45 year old adults with physical disabilities?</td>
<td><strong>Population characteristics</strong></td>
<td>Sex</td>
<td>Adults with physical disabilities, males and females, belonging to middle and low income groups.</td>
</tr>
<tr>
<td></td>
<td>Predisposing, enabling and need characteristics</td>
<td>Socioeconomic level (assessed through scores on Hollingshead index)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>● Occupational level</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>● Educational level</td>
<td></td>
</tr>
<tr>
<td><strong>Individual/provider related variables</strong></td>
<td><strong>Respect for persons</strong></td>
<td>Dignity</td>
<td>Adults with physical disabilities and healthcare providers, managers and policy makers, and disability rights advocates</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Confidentiality</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Clear communication</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Autonomy</td>
<td></td>
</tr>
<tr>
<td><strong>Healthcare system characteristics</strong></td>
<td><strong>Client Orientation</strong></td>
<td>Prompt attention</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Quality of amenities at healthcare facilities</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Choice of provider</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Access to social support during care</td>
<td></td>
</tr>
</tbody>
</table>
Table 4 continued

What are the barriers to responsiveness of the healthcare system to young adults with physical disabilities?

<table>
<thead>
<tr>
<th>Healthcare system characteristics</th>
<th>Health policy issues (evidence-based policy making, consensus development, political will)</th>
<th>Health care providers involved in care of adults with physical disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Organizational issues (primary vs. Secondary vs. tertiary, general care vs. specialized care, public vs. private care, urban bias in health facility provision)</td>
<td>Healthcare managers</td>
</tr>
<tr>
<td></td>
<td>Financing issues (out-of-pocket expenditure by patients, health expenditure as percentage of GDP)</td>
<td>Health policy makers</td>
</tr>
<tr>
<td></td>
<td>Human resources issues (skill mix, training of staff, Private practice by public providers)</td>
<td>Disability rights advocates</td>
</tr>
<tr>
<td></td>
<td>Recruitment issues (availability of posts, selection on merit, political pressure)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Accountability issues (penalties for negligence/malpractice, redress of patient grievances, political interference)</td>
<td></td>
</tr>
</tbody>
</table>
Disability rights advocates having physical disabilities, who were associated with the designated NGOs and CBOs actively operating in the Islamabad Capital Territory. These included the following NGOs/CBOs

- Special Talent Exchange Program (STEP)
- Milestone Society for Special Persons
- Disabled People Development Organization (DPDO)
- Saaya Association of People with Disabilities

These organizations were selected on the basis of the fact that all of them were being operated by physically disabled individuals and had been actively operating in Islamabad Capital Territory to improve healthcare access of the population of interest. These NGOs were all legally registered in Pakistan. Members of these organizations who had extensive experience of working with the healthcare system for improvement of health provision to PWDs were purposively selected for in-depth face-to-face interviews. As policy advocates these respondents had close relationships with the healthcare system at multiple levels and contributed valuable information about the healthcare system as well as about the political, managerial and policy environment in which decisions were made. These respondents were able to provide information that the healthcare providers and managers might have held back owing to their official affiliation to the public healthcare system.
Sample II: Sampling Methods and Subject Recruitment

All respondents in the second sample were contacted by the PI through their parent organizations. The researcher scheduled initial courtesy calls on each of these respondents whereby she informed them of the objectives of the study and handed over the consent forms as a means to understand their rights as respondents. The researcher made it abundantly clear to the respondents that their participation in the study was absolutely voluntary and that they were under no obligation to participate. She also reiterated that all information disclosed during the interviews would be kept strictly confidential in line with the policies of the USF-IRB. Within a week of the initial meeting, the PI called the respondents over the phone to confirm their participation and schedule the interviews as per their convenience. Respondents employed at the NIRM were similarly contacted by the Research Assistant and apprised of the objectives of the study. The RA stressed the participants’ right to confidentiality and to withdraw from the study without suffering any adverse consequences in light of the guidelines of the USF-IRB. Respondents were requested to allocate enough time for a 60-90 minute interview, depending on the level of their interest in the topic.

The PI provided all potential participants with her contact information so that any change in schedule, or intention to participate may be communicated. Due to the PI’s strong professional links to all tiers of employees at the defunct Ministry of Health, participant recruitment for qualitative interviews did not pose a significant challenge. However, considerable difficulties were encountered in scheduling interviews with the high level managers and policy makers owing to the unstable political situation in the
Interviews with three policy makers had to be postponed at the last minute due to the participants being called for eleventh hour meetings at the national legislature, the Prime Minister’s secretariat or the President’s office.

Sample II: Instruments and Measures

**Demographic information sheet.** Before each in-depth interview, each participant filled out a demographic information sheet (Appendix- VI). Basic information related to the interviewees’ education, fields of specialization and service, and years of experience was obtained. This information was used for descriptive reporting of sample characteristics in the results.

**Interview guide.** The interview guide for healthcare providers, managers and policy makers, and disability rights advocates (Appendix- VII A&B), provided broad areas for eliciting information on the topic of interest. The guide served to steer the discussion into the domain areas without leading the respondents. The Principal Investigator provided just enough direction for the respondents to focus on the domains of responsiveness of the health system with reference to the patients with disabilities, and allowed the respondents to express their opinions and narrate their experiences freely. The broad areas covered in the interviews were derived from the eight domains of responsiveness. Additionally the healthcare providers and managers were asked about their opinions of the factors operating at the management and policy level that acted as barriers to the responsiveness of the system. Figure 4 provides linkages between questions in the focus group and interview guides, the elements of the theoretical model, categories of study variables and specific study variables.
Table 5. Linkages Between Instrument Questions and Elements of the Behavioral Model of Healthcare Utilization

<table>
<thead>
<tr>
<th>Instrument/Question no.</th>
<th>Question</th>
<th>Level of variable</th>
<th>Responsiveness domain</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus group guide /Q. 1</td>
<td>In your opinion, how important is it that doctors and nurses treat you with respect when you go to the government hospitals?</td>
<td>Patient/provider level variable</td>
<td>Dignity</td>
</tr>
<tr>
<td>Focus group guide /Q. 2</td>
<td>Think about your last visit to the hospital and please tell us how the doctors and nurses treated you?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Focus group guide /Q. 3</td>
<td>How important is it for you that doctors and nurses do not tell others about your illness, for example your laboratory-test results?</td>
<td>Patient/provider level variable</td>
<td>Confidentiality</td>
</tr>
<tr>
<td>Focus group guide /Q. 4</td>
<td>In your opinion, is it essential that no one hears your discussion with your doctor or nurse about your illness, or that no one sees you when your doctor or nurse is carrying out physical examinations or giving you injections or other treatments?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Focus group guide /Q. 5</td>
<td>Think about your own experience and tell us how you feel the doctors and nurses make any efforts to safeguard information about your illness and treatment.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Focus group guide /Q. 6</td>
<td>How important is it for you that your doctors provide you full information about your illness in language that you can easily understand?</td>
<td>Patient/provider level variable</td>
<td>Clear communication</td>
</tr>
<tr>
<td>Focus group guide /Q. 7</td>
<td>How essential is it that your doctors and nurses listen to your complaints before starting treatment?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Focus group guide /Q. 8</td>
<td>Think about your last visit to the hospital and tell us how the doctors and nurses listened to you and talked about your illness.</td>
<td></td>
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<tr>
<td>------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Focus group guide /Q. 9</td>
<td>In your opinion, it is important for you to make decisions about your treatment after getting the full information about your illness from the doctors and nurses?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Focus group guide /Q. 10</td>
<td>In your experience as patients, how often your doctors respect your decisions about the kind of treatment you want to receive.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Focus group guide /Q. 11</td>
<td>When visiting the hospitals, how important is it for you to see the doctor immediately?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Focus group guide /Q. 12</td>
<td>Please tell us about your experience of waiting your turn on your last visit to the hospital.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Focus group guide /Q. 13</td>
<td>In your opinion, how important is it that hospitals be clean, well lighted and comfortable?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Focus group guide /Q. 14</td>
<td>As patients, what are your views on the quality of food and medications provided to you in the hospitals?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Focus group guide /Q. 15</td>
<td>Thinking of your personal experiences, what kinds of problems do you usually have when moving around in hospital buildings?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Focus group guide /Q. 16</td>
<td>How important is it for you to have a choice of the doctors for your treatment, to have a second opinion from another doctor if you are not satisfied with the first?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Focus group guide /Q. 17</td>
<td>In your experience as patients, to what extent you have a variety of doctors to choose from at your own will?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Focus group guide/Q. 18</td>
<td>How important is it for you have your friends and families visit you when you are admitted to the hospital?</td>
<td>Health system characteristic</td>
<td>Access to social support during in-patient care</td>
</tr>
<tr>
<td>------------------------</td>
<td>-------------------------------------------------------------------------------------------------</td>
<td>-----------------------------</td>
<td>---------------------------------------------</td>
</tr>
<tr>
<td>Focus group guide/Q. 19</td>
<td>What was your experience of being in contact with your friends and family while admitted to the hospital?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Table 5 continued</td>
<td>How often were they allowed to visit you, bring you food and provide you company?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interview guide/Q. 1</td>
<td>In your opinion, to what extent do doctors, nurses and physiotherapists treat patients with physical disabilities with respect and dignity in the federal government hospitals?</td>
<td>Patient/provider level variable</td>
<td>Dignity</td>
</tr>
<tr>
<td>Interview guide/Q. 2</td>
<td>In your opinion, what are some of the system related factors that affect the way healthcare providers interact with this group of patients?</td>
<td></td>
<td>Barrier to dignity</td>
</tr>
<tr>
<td>Interview guide/Q. 3</td>
<td>What mechanisms are in place to ensure confidentiality of disabled patients’ personal and medical information in the health system?</td>
<td>Patient/provider level variable</td>
<td>Confidentiality</td>
</tr>
<tr>
<td>Interview guide/Q. 4</td>
<td>To what extent do the health care providers make certain that health information in respect of these patients is kept secure?</td>
<td></td>
<td>Barrier to confidentiality</td>
</tr>
<tr>
<td>Interview guide/Q. 5</td>
<td>To what extent do doctors ensure that disabled patients understand the diagnosis, the prognosis and the treatment of their condition?</td>
<td>Patient/provider level variable</td>
<td>Communication</td>
</tr>
<tr>
<td>Interview guide/Q. 6</td>
<td>What are some of the factors that obstruct open communication between doctors and physically disabled adult patients in our health system?</td>
<td></td>
<td>Barrier to communication</td>
</tr>
<tr>
<td>Interview guide/ Q. 7</td>
<td>In what ways do you think our system inhibits autonomous decision making by adults with physical disabilities in regard to their treatment and rehabilitation?</td>
<td>Patient/provider level variable</td>
<td>Autonomy</td>
</tr>
<tr>
<td>---------------------</td>
<td>-------------------------------------------------------------------------------------------------</td>
<td>---------------------------------</td>
<td>---------</td>
</tr>
<tr>
<td>Interview guide/ Q. 8</td>
<td>What factors, in your opinion, presently limit the participation of adults with physical disabilities in making autonomous decisions about their treatments?</td>
<td></td>
<td>Barrier to autonomy</td>
</tr>
<tr>
<td>Interview guide/ Q. 9</td>
<td>Based on your experience, how long do you think a physically disabled adult has to wait to get needed healthcare on outpatient or inpatient basis in our health system?</td>
<td>Health system characteristic</td>
<td>Prompt attention</td>
</tr>
<tr>
<td>Interview guide/ Q. 10</td>
<td>In your opinion, what are the factors that lead to delayed provision of healthcare to this section of the population?</td>
<td></td>
<td>Barriers to prompt attention</td>
</tr>
<tr>
<td>Interview guide/ Q. 11</td>
<td>What are some changes that can be brought about in the system to make it easier for physically disabled individuals to access care promptly?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interview guide/ Q. 12</td>
<td>What is your opinion concerning the accessibility of bathroom and toilet facilities in our hospitals for adults with physical disabilities?</td>
<td>Health system characteristic</td>
<td>Quality of amenities</td>
</tr>
<tr>
<td>Interview guide/ Q. 13</td>
<td>What are your comments on the physical condition of healthcare facilities in the Pakistani health system?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Table 5 continued</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Interview guide/ Q. 14</strong></td>
<td>What is your opinion of the quality of food and medications being provided to patients in the hospitals?</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Interview guide/ Q. 15</strong></td>
<td>What are reasons for the present condition of the physical infrastructure of healthcare facilities?</td>
<td>Barriers to quality of amenities</td>
<td></td>
</tr>
<tr>
<td><strong>Interview guide/ Q. 16</strong></td>
<td>In what ways do the physically disabled adult patients get the opportunities to choose their healthcare providers in the Pakistani health system?</td>
<td>Health system characteristic</td>
<td>Choice of provider</td>
</tr>
<tr>
<td><strong>Interview guide/ Q. 17</strong></td>
<td>In your opinion, what are the factors that determine their choices?</td>
<td>Barriers to choice of provider</td>
<td></td>
</tr>
<tr>
<td><strong>Interview guide/ Q. 18</strong></td>
<td>In what way do you think the Pakistani health care system inhibits the interaction of physically disabled patients with their families while they are admitted to hospitals?</td>
<td>Health system characteristic</td>
<td>Barrier to access to social support during in-patient care</td>
</tr>
</tbody>
</table>
This study was approved by the Institutional Review Board of the University of South Florida. Ethical concerns arising from the researcher’s official position as administrator of one of the hospital under study (the NIRM) were adequately addressed at each stage. At the stage of participant recruitment, the healthcare providers including doctors, nurses and physical therapists who were employees of the said hospital were approached by the Research Assistant (RA) and informed of their rights. It was made clear that their participation was voluntary and they would in no way, be treated unfairly as subordinates, if they refused to participate. At the stage of data collection, these specific respondents were interviewed by the RA to elicit frank responses. The focus groups were moderated by the PI because no participants had been recruited from the OPD of the hospital where she served.

**Sample II: Pilot Testing**

The interview guide was pilot tested by cognitive interviewing (Willis, 1999) of two healthcare providers and two managers. Overall, the interview guide worked well except for the need for introductory sentences at the beginning of each domain so as to clearly define the specific domains. For example, the domain of Confidentiality encompassed the concepts of confidentiality of patient-provider conversation, curtailing physical exposure of patients to unauthorized persons during examinations and treatment procedures, and security of patients’ medical records. As in case of the focus group guide, the domains had to be rearranged to give the instrument a logical flow. This entailed sequencing the domains as follows; 1) Dignity; 2) Confidentiality; 3) Clear
communication; 4) Autonomy; 5) Prompt attention; 6) Quality of amenities; 7) Choice of provider; and 8) Access to social support networks during care.

Sample II: Data Collection Procedures

**In-depth interviews.** Qualitative interviews are performed when information of a more detailed in-depth nature is sought (Kvale, 1996). These interviews are flexible in structure with open ended questions that permit exhaustive description of events as experienced by the respondent and the meaning ascribed to them. Thus the center of this exercise is the interviewee’s perspective (McCracken, 1988).

The Principal Investigator conducted in-depth, face-to-face interviews with healthcare providers, managers and policy makers, and disability rights advocates, as specified in the sample description. The respondents for each interview were contacted, as described in the section on sample selection and recruitment. Before each interview, the respondents were provided two copies of the informed consent form (Appendix- VIII) to study, sign, and retain one copy for their records. Interviews were conducted at mutually convenient dates and times, in private surroundings in the offices of the respondents. In cases where respondents did not have designated offices, interviews were conducted in the library or conference room of the hospitals to minimize disruptions due to official and patient traffic. The building structure in Pakistan is different from the US in that all walls, including those separating individual rooms are made of brick and cement, effectively blocking conduction of sound and ensuring privacy of conversation.

The interviewees signed the informed consent forms and were given copies for their records. They were also requested to fill out the demographic information sheets.
developed for the purpose. Interviews were digitally recorded with consent of the participants to ensure maximum accuracy. Questions about the broad concepts of responsiveness of the health system with special reference to the PWDs were asked to elicit detailed responses from the participants. Probes were used when more extensive information was required. The conversation was then guided into the specific details of the barriers hindering each domain of responsiveness. This approach elicited maximum information from the interviewees especially within their professional perspective.

**Reflexive journal and field notes.** The Principal Investigator kept a journal from the very beginning of the study with frequent entries relating to the processes occurring before data collection, including translation and pilot testing of instruments, contacts with key informants in the field, contacts with respondents with disabilities in the community and the healthcare facilities, as well as with healthcare providers and managers. The feelings and emotional responses of the PI were recorded so that they could be analyzed and contributed to the richness of data collected.

In addition to the journal, the PI also took field notes during the processes of participant contact, selection and data collection to record characteristics of the environment in which these activities took place. All important political, social and policy changes that had the potential to impact the study, its participants, the PI or the health care system were noted and accounted for at the analysis stage.

**Sample II: Data Analysis**

Data obtained through in-depth interviews with healthcare managers, providers, policy makers and disability rights advocates, was subjected to content analysis with
regard to responsiveness of the Pakistani health system to the needs of adults with physical disabilities. Audio-recordings were transcribed verbatim. In twelve out of the forty interviews the respondents conversed in English. Furthermore, many respondents used English words, phrases and even whole sentences during the course of interviews which were otherwise in Urdu. The data were thus transcribed in the language in which they were collected.

The data were also coded in the language in which they were collected, using Atlas.ti 6.2. The handwritten Urdu transcripts were scanned and imported into the software as pdf files, whereas English transcripts were imported in MS word format. The transcripts were coded employing an open coding scheme by two coders, the PI and a healthcare researcher. The Urdu transcripts were coded first. During the initial coding the two coders independently coded the first batch of three interviews. As in the case of FGDs, the initial broad codes were derived from the domains of responsiveness, within which the perceptions, experiences and feelings of the respondents were organized. This allowed them to recognize patterns emerging initial themes. The two coders independently identified themes and sub-themes within the domains of responsiveness for the first three transcripts, after which they met to compare and discuss the codes. The differences in coding were discussed in detail and were resolved by refining the definitions of codes, creating new codes or collapsing low level codes. The coders then coded the next batch of three transcripts each. Any new themes emerging from the data that did not fit into any of the agreed upon codes were assigned new codes. The coders met thereafter to discuss and compare existing codes as well as new ones that emerged from the data. The two coders, then, independently coded the last two batches of four
Urdu transcripts, using the pre-existing codes, and devising new ones for themes that were not present in the previous transcripts. Before analyzing the English transcripts, the two coders independently translated the Urdu codes into English and met to compare, contrast and discuss their translations and to reach consensus. English transcripts were coded once both coders were satisfied with the conceptual equivalence of the Urdu and English codes. Successive iterations were made through the data as new themes emerged, and this process eventually lead to refinement and emergence of results in the form of coherent and logical patterns.

As in the analysis of FGDs, the two coders identified representative quotes within each domain of responsiveness for inclusion in the final report. These quotes were translated verbatim as described earlier in the section on data analysis of sample I. Once the coders agreed on the translations as being the true reflections of the respondents’ meaning, they were included in the final report. The quotes culled from the English transcripts were reproduced verbatim.

Quantitative descriptive data collected through the demographic sheet for the PWDs were analyzed using SPSS. The characteristics of the sample were reported in terms of frequencies and means. However due to the small size of the sample, statistically significant differences among groups could not be calculated.
Chapter IV: Results

This chapter presents the main findings of the data collected from the two samples during the course of this research. Sample I consisted of the 18-45 year old physically disabled individuals who had utilized healthcare in any of the three designated federal government hospitals during the last 12 months. Sample II was comprised of the healthcare providers and managers working in the designated hospitals, and the healthcare policy makers and disability rights advocates. The findings are presented separately for the two samples.

Within each sample, the study findings are organized under the headings of the eight domains of responsiveness. Representative quotes are presented within the respective domains to further elucidate the findings.

The research questions for this study focused firstly on how well the Pakistani federal health system was responding to the needs of 18-45 year old people with physical disabilities. This question was addressed by asking the consumers of healthcare about how important each responsiveness domain was to them. Furthermore, the participants were asked to recollect and narrate their experiences within each domain, which provided their insights into the level of responsiveness of the healthcare system in general and also with regard to different socioeconomic and gender groups. This line of questioning also brought important cultural factors to light that shaped the beliefs of the respondents.
regarding various responsiveness domains, especially within the concept of Respect for Persons.

The focus group guide was designed to capture experiences of the disabled consumers of health system to determine how the health system was responding to their needs within each domain of responsiveness. The interview guide, similarly, obtained opinions and comments of the key informants within the individual domains which provided structure to the data as different themes emerged within distinct domains. Some of these themes were common to more than one domain, as factors affecting one also affected others.

The second research question addressed the barriers that currently exist to hinder the health system from responding to the population of interest. Healthcare providers, managers, policy makers and disability rights advocates were asked about what, in their experience, was the reason for the health system responding as it did to the population of interest. Due to their positions and experience at different tiers of the health system, these respondents provided an array of rich information on the different barriers that hindered the responsiveness of the health system. While the healthcare providers and managers started off at the barriers operating at the level of the patient-provider interaction, the managers and policy makers provided a bird’s eye view of the larger bureaucratic, political and policy environment in which the health system was operating. Findings from the different respondent groups complemented each other into cohesive and logical patterns. Thus, the factors operating at multiple levels came to light as envisaged by the theoretical model employed for the study and were organized as such. Table 4
presents the main themes that emerged within each domain of responsiveness in the data collected during focus group discussions with PWDs and interviews with key informants. The table further indicates linkages of these themes to the elements of the Modified Andersen-Aday Behavioral Model of Healthcare Utilization (Phillips, Morrison, Andersen, & Aday, 1998). The first column shows the domains of responsiveness, the second column contains the main themes that emerged within these domains and the third column indicates the elements of the Behavioral Model of Healthcare Utilization which are relevant to these themes.

**Sample I: Demographics**

Sample I was composed of 18-45 year old physically disabled consumers of healthcare services who were stratified into those belonging to middle (n= 22) and low SES (n= 24) on the basis of the Hollingshead four factor index. Participants belonging to this group participated in eight focus group discussions, stratified on the basis of gender and socioeconomic status.

Table 5 presents the demographic profile of the first group of participants. The average age of focus group participants was 32.5 years with a range of 20 to 44 years. Within this sample, the average age of males in both the low and middle SES group was higher than the females. The males in the low SES group (34 years) were, on the average, comparable in age to their middle SES counterparts (33.6 years). On the other hand, females in the low SES group (29.7 years) were, on the average, younger than women in the middle SES group (32.5 years). The Hollingshead index scores for the
middle socioeconomic status respondents ranged from 48 to 53 with an average of 50.7, while those for the low socioeconomic group ranged from 8 to 29 with an average of 18.

As measured by the WHO DAS 2.0, the FGD participants from the low SES group scored an average of 7 on the domain of cognition. The participants from the middle SES group scored an average of 6 on this domain, signifying minimal or no cognitive impairment in both the groups. While the range of cumulative scores on the other six domains were similar for the middle and low SES groups, the average scores for the middle group were slightly higher than their low SES counterparts. Thus the FGD participants were cognitively capable adults with moderate to severe physical disability. All focus group participants had utilized healthcare in the three designated federal hospitals within the past year. Thirty-one of the 46 participants (67%) reported utilizing OPD services only, 3 respondents (7%) reported using OPD as well as being admitted and 12 participants (26%) reported using in-patient services only.

No respondents in the middle SES group reported foregoing healthcare for want of financial resources during the last 12 months. However, 23 out of the 24 FGD participants from the low SES group reported that they had chosen not to seek healthcare on a number of occasions within the last 12 months due to lack of money.
Table 6: Themes Emerging Within the Domains of Responsiveness and Their Linkages to the Modified Andersen-Aday Behavioral Model of Healthcare Utilization (Phillips et al., 1998)

<table>
<thead>
<tr>
<th>Domains of responsiveness</th>
<th>Main Themes</th>
<th>Elements of the theoretical model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respect for Persons</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient dignity</td>
<td>General lack of respect for PWDs in the society</td>
<td>External environment characteristic</td>
</tr>
<tr>
<td></td>
<td>Dignity compromised due to overcrowding</td>
<td>Health system characteristic</td>
</tr>
<tr>
<td></td>
<td>Lack of healthcare provider training</td>
<td>Providers characteristics</td>
</tr>
<tr>
<td></td>
<td>Treating PWDs unrewarding for HCPs</td>
<td>External environment characteristic</td>
</tr>
<tr>
<td></td>
<td>Knowing influential people makes it easier to negotiate system.</td>
<td></td>
</tr>
<tr>
<td>Clear communication</td>
<td>Overcrowding barrier to communication</td>
<td>Health system characteristic</td>
</tr>
<tr>
<td></td>
<td>Culture affects communication</td>
<td>External environment characteristic</td>
</tr>
<tr>
<td></td>
<td>Dependence on family barrier to communication</td>
<td>Individual characteristic</td>
</tr>
<tr>
<td></td>
<td>Healthcare providers do not bother to communicate</td>
<td>Providers characteristic</td>
</tr>
<tr>
<td>Confidentiality</td>
<td>Language barrier to communication</td>
<td>Individual characteristic</td>
</tr>
<tr>
<td></td>
<td>Culture as a barrier to confidentiality</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Overcrowding as a barrier to confidentiality</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Lack of confidentiality of medical records</td>
<td></td>
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<tr>
<td></td>
<td>Lack of sensitivity of healthcare providers to issues of confidentiality</td>
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<td></td>
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<td>----------------------</td>
<td>-----------------------------------------------------------------</td>
<td>-----------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Autonomy</strong></td>
<td>Joint decision making by patient, provider and family</td>
<td>External environment characteristics</td>
</tr>
<tr>
<td></td>
<td>Importance of decision making by the provider</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Culture as a barrier to autonomy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Dependence on family as a barrier to autonomy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Imposition of providers’ decisions on patients</td>
<td></td>
</tr>
<tr>
<td><strong>Client Orientation</strong></td>
<td><strong>Prompt attention</strong></td>
<td></td>
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<tr>
<td></td>
<td>Disproportionate lack of healthcare facilities and providers</td>
<td>Health system characteristics</td>
</tr>
<tr>
<td></td>
<td>Lack of priority for PWDs at the level of hospital policy and practice</td>
<td></td>
</tr>
<tr>
<td><strong>Quality of amenities</strong></td>
<td>Inaccessible buildings</td>
<td>Health system characteristics</td>
</tr>
<tr>
<td></td>
<td>Poor repair and maintenance</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Lack of hygiene</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Inconsistent supply of medicines</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Questionable quality of medicines</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Quality of diet satisfactory</td>
<td></td>
</tr>
<tr>
<td><strong>Choice of provider</strong></td>
<td>Design and operation of hospitals affecting choice of provider</td>
<td>Health system characteristics</td>
</tr>
<tr>
<td></td>
<td>Choice of provider limited by lack of specialists</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Choice of provider limited by lack of awareness</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Economic constraints limit choice of provider</td>
<td></td>
</tr>
</tbody>
</table>
Table 6 continued

<table>
<thead>
<tr>
<th>Access to social support during care</th>
<th>Overarching themes</th>
<th>Health system characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need for observance of visiting hours</td>
<td>Lack of HCP interest in government jobs versus private practice</td>
<td>Health system characteristics</td>
</tr>
<tr>
<td>Easy access of family to patient</td>
<td>Lack of priority at policy level</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Lack of a referral system</td>
<td></td>
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<tr>
<td></td>
<td>Lack of monitoring and evaluation</td>
<td></td>
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<td></td>
<td>Fragmentation and inefficiency of health system</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Lack of qualified healthcare managers and policy makers</td>
<td></td>
</tr>
</tbody>
</table>
Table 7: Characteristics of Focus Group Participants

<table>
<thead>
<tr>
<th>Variables</th>
<th>Stratification</th>
<th>Range/Frequency</th>
<th>Mean/%age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low SES</td>
<td>Males</td>
<td>22-43</td>
<td>34</td>
</tr>
<tr>
<td></td>
<td>Females</td>
<td>20-43</td>
<td>29.7</td>
</tr>
<tr>
<td>Middle SES</td>
<td>Males</td>
<td>26-42</td>
<td>33.6</td>
</tr>
<tr>
<td></td>
<td>Females</td>
<td>26-40</td>
<td>32.5</td>
</tr>
<tr>
<td></td>
<td>Cumulative</td>
<td>20-44</td>
<td>32.5</td>
</tr>
<tr>
<td>Hollingshead index score</td>
<td>Middle SES</td>
<td>48-53</td>
<td>51</td>
</tr>
<tr>
<td></td>
<td>Low SES</td>
<td>8-29</td>
<td>18</td>
</tr>
<tr>
<td>WHO DAS 2.0 score</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low SES</td>
<td>Cognition</td>
<td>6-8</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Summative score on other domains</td>
<td>94-140</td>
<td>118</td>
</tr>
<tr>
<td>Middle SES</td>
<td>Cognition</td>
<td>6-7</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Summative score on other domains</td>
<td>94-140</td>
<td>121</td>
</tr>
<tr>
<td>Foregoing healthcare due to economic constraints</td>
<td>Middle SES (n = 22)</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td></td>
<td>Low SES (n = 24)</td>
<td>23</td>
<td>96%</td>
</tr>
</tbody>
</table>

Sample I: Domains of Responsiveness

**Respect for persons.**

**Dignity.** The FGD participants (sample I) were unanimously of the view that being accorded dignity and respect were very important to them. They sometimes reportedly opted for private care from local unqualified medical practitioners because they felt the doctors at the government hospitals were rude to them. Instances whereby PWDs felt their dignity had been compromised were reported more often by PWDs belonging to lower socioeconomic status.

Important themes emerging from the data in this domain included:
- Overcrowding compromises dignity
- Lack of healthcare provider training
- General lack of respect for PWDs in the society
- Treating PWDs was unrewarding for HCPs.
- Knowing influential people helped negotiate system

_Overcrowding compromises dignity (FGDs)._ Overcrowding was mentioned as a barrier to dignity of PWDs in five of eight focus group discussions. Due to the lack of dedicated healthcare facilities for the disabled, PWDs reported that they had to compete with the able-bodied patients to gain access to the OPDs and emergency departments. As they were unable to push their way through due to risk of bodily harm, they reportedly suffered the unfair indignity of waiting longer. The PWDs reported feeling “pushed around” and the sense of deprivation that no one cared for them.

Respondents also reported that PWDs had to suffer indignities due to physical inaccessibility of hospitals and lack of mobility devices. Detained due to these factors, by the time they reached the OPDs, they were told that the time for patient registration was over for that day.

_It happens often that you keep waiting for a wheelchair for hours, and when you do get it, you actually have to borrow it from another patient. Then the other person also gets impatient and tells you to hurry up because it has to be returned._
It's hurtful because you really need that wheelchair. (Female focus group participant)

Lack of healthcare providers training leading to compromised dignity (FGDs). Another important theme was the lack of training of healthcare providers leading to behaviors that compromised dignity of the physically handicapped patients. This theme emerged during the course of four focus group discussions. Another closely related theme was that healthcare providers did not see past the particular disability a PWD had, which the physically disabled persons belonging to the middle SES group found offensive. Due to the lack of standardized education and training in the field of disabilities, individual personality traits determined provider behavior towards patients in general and disabled patients in particular. It was also reported that healthcare provider behavior improved with increased exposure to disabled patients. Many FGD participants, especially from the more educated middle SES group, were of the view it was due to this reason that provider behavior was much better at the National Institute for Rehabilitation Medicine, which is a healthcare facility dedicated to the care of disabled patients. Focus group respondents from both the middle and low socioeconomic groups expressed that there was a great need for short courses to educate healthcare providers to understand disability related issues, and to sensitize them to the needs of the physically disabled patients.

General lack of respect for PWDs in the society (FGDs). The respondents overwhelmingly expressed the view that the Pakistani society lacks respect for the disabled. This lack of respect stems from the financial and physical dependence of the PWDs on their families, leading to their lower social status. In 2009, the Ministry of
Social Welfare and Special Education took an initiative to issue special national identity cards to the disabled. These cards were originally intended to provide special discounts and fee waivers at government facilities. The respondents in this study expressed resentment upon being labeled as disabled. They described that the said cards instead of facilitating their access to services, had further lowered their social status, as people now saw them as freeloaders who wanted to exploit the society in the name of disability. As one participant from a focus group discussion recounted:

*It is 5-6 months ago that I had to go to PIMS [Pakistan Institute of Medical Sciences] to have some X-rays done. They asked me to pay for them. I showed them my disabled National identity card and told them that being a disabled person I was exempted from paying for health services at government hospitals. There was a senior doctor there who gave me a nasty look and said, “Put that back in your pocket”…. I went to the office of the Deputy Director to complain… all I needed were 2 minutes of his time. Meanwhile another senior doctor appeared and scolded me, asking why I was creating so much noise. I showed her my disabled identity card and said that this card is meant to provide free health facilities to the disabled, to which she said very harshly, ”No, this card is meant to remind you of your worth, this red wheelchair on your card indicates your limits, so remain within those and stop shouting!” (Male focus group participant)*

The Pakistani culture was also cited as fostering dependence in the name of facilitation, sympathy and pity for the disabled. This was attributed to the religious belief
that helping the disabled was an act of piety. This negative attitude and condescending behavior was deeply resented by the focus group participants.

_Treating PWDs is unrewarding for HCPs (FGDs)._ The participants in seven out of eight focus group discussions lamented the lack of interest shown by the healthcare providers. They cited experiences whereby the healthcare providers had not only discouraged them from seeking repeated care at government facilities, but also advised them to go to private providers. This lack of interest on the part of healthcare providers translated into behaviors that the disabled patients labeled “being shrugged off”. As quoted by a male focus group participant:

_When they look at us they say, “Oh, they are just like that, let’s leave them as they are, and focus on someone else.”_

Thus, the disabled patients reported that they felt as if they were being passed around and not taken seriously enough. The difference between provider attitudes in public versus private settings was also pointed out by the disabled consumers of healthcare in all focus group discussions. Patients recounted experiences where the doctors had behaved totally differently when they paid a handsome fee for a private consultation versus when they presented in a public hospital.

_Knowing influential people helps negotiate system (FGDs)._ Another important theme with respect to patient dignity that emerged in five out of eight focus group discussions was that knowing influential people and making them put in a good word for you, made it easier to negotiate the system. Focus group participants both from the low and middle socioeconomic groups cited personal experiences where they were treated
differently when they sought healthcare in government hospitals with and without such references. They were accorded priority at all levels, not made to wait and were admitted and treated with utmost respect when they went in through someone’s (especially some doctors’) reference.

This happened around 4-5 months ago. I was having problems with my urinary bladder, I developed a stone.... I thought I should get it operated at the FGPC [Federal Government Poly Clinic], but then I recalled my previous bad experience..... Then I met this guy who .... gave me his card and told me to go to the doctor, and also called up the doctor for me.... The doctors took very good care of me, did all the paperwork... and admitted and operated on me right away. I was out of the hospital in a week’s time after the surgery. (Male focus group participant)

Healthcare consumers actually expressed their tendency to locate references within hospitals before seeking healthcare to safeguard their dignity and make it easier for them.

Clear communication. All consumers of healthcare were aware of the importance of clear communication between patients and providers. The focus group participants from the low socioeconomic group identified openness of communication with their dignity. They expressed the perception that doctors who listened to and talked to them respected them as equals, and those who did the converse were arrogant. They also expressed the opinion that when the doctors communicated openly with them, they felt their suffering was reduced by half, just by the interaction. The more educated PWDs
from the middle SES group went a step further to express their beliefs that open communication led to better outcomes as patients adhered to treatment and got well sooner. The PWDs recounted experiences when lack of communication had led to missed diagnoses and complications. Patients also expressed a tendency to seek private care due to the fact that providers in private settings took more time and effort to explain the disease to the patients, and answer all their questions.

Important themes emerging from the data in this domain included the following:

- Doctors do not bother to communicate
- Overcrowding barrier to communication
- Cultural affects communication

*Doctors do not bother to communicate (FGDs).* This theme was overwhelmingly pervasive, emerging in all eight focus group discussions. Respondents were of the view that doctors neither took enough time to listen to the full range of their complaints, nor to answer their questions. There was reportedly no concept of individual attention to patients and they were not seriously attended to at the OPDs.

*They never talked to me, they told my mother that they will put a rod in my leg. Neither of us knew if they were going to take the bone out, or replace it with something, or how they were planning to do it. Then when I had my first surgery, they did not even tell me what precautions to take in terms of movement and rest. That is why my surgery was unsuccessful...and I was unable to walk for 12 years.*

(Female focus group participant)
Overcrowding barrier to communication (FGDs). Overcrowding emerged as a barrier to communication in four out of the eight FGDs. Healthcare consumers actually justified the lack of communication on the part of healthcare providers who had to see scores of patients in an OPD during a short span of working hours.

When a doctor has to see 100-200 patients in 3-4 hours, he doesn’t have the time to make everyone sit down and narrate their story and then to guide them properly. All he can do is speak a couple sentences and hand over a prescription.

(Male focus group participant)

The PWDs considered it impossible for the healthcare providers to accord importance to each and every patient, listen to their complaints and educate them about their diseases due to overcrowding in the subject hospitals. Another aspect pointed out by women from the middle socioeconomic status was that when the doctors asked them to narrate their health problems in a hurry, they forgot to provide them the full information and missed out half or so of the details that they should have told the HCP about.

However, as reported in other domains, respondents reported that having a reference at the hospital in the form of a friend or acquaintance was helpful in this case too. Patients who came through references were reportedly listened to more attentively and allocated more time by the healthcare providers.

Cultural affects communication (FGDs). The values of the pluralistic Pakistani culture reportedly accorded priority to the family when it comes to patient-provider communication. In four of the eight focus group discussions, participants pointed out the
importance of not communicating dire diagnoses to the patient, and disclosing it to the family only. Participants were of the view that the patients already under the stress of disease are not able to cope with the added stress of their gloomy prognosis. The participants were of the view that it was more important for the healthcare providers to explain the disease and its treatment to the whole family and not only to the patient.

**Confidentiality.** The PWDs unanimously expressed the view that all three components of confidentiality including: confidentiality of patient provider conversation, privacy during physical examination and therapy, and confidentiality of medical records, were important to them. However, the FGD participants also defended their family’s right to know the diagnosis as the family members played an important role during treatment.

*Here people do not recognize their responsibility to the patient. I experienced it firsthand in Dubai. They said, Inshallah, he will be able to walk. They kept it a secret from me, but they called my wife and explained it to her that there was no hope for me and that I will remain bedridden for the rest of my days. But they guided my wife very well and I liked the way they handled my case there.*

The PWDs were of the view that the federal health system was seriously lacking when it came to implementation of confidentiality in all these three domains. The main themes that emerged within the context of confidentiality included

- Overcrowding as a barrier to confidentiality
- Culture as a barrier to confidentiality
- Lack of sensitivity of healthcare providers,
Lack of confidentiality of medical records

*Overcrowding as a barrier to confidentiality (FGDs).* Overcrowding as a barrier to confidentiality emerged in two of the eight FGDs. Participants reported that due to overcrowding in the OPDs the doctors had to take histories and examine patients in front of other patients, their attendants and other health personnel. The PWDs underscored the importance of their predisposition to develop urinary infections, incontinence and sexual dysfunction. All these sensitive conditions required strict privacy during their interactions with healthcare providers. However, no priority was accorded to their special health needs. Participants recalled experiences whereby they had foregone public healthcare in favor of private care for this very reason.

The PWDs drew parallels between government and private hospitals. They pointed out that if a system implemented in the private hospitals whereby only one patient is seen by the doctor at one time in the OPD, why the same system could not be implemented in the government hospitals.

*The very same patients go to Shifa International Hospital, but there they behave themselves, they go in turn by turn. There they know that they have to follow the rules otherwise the guy standing at the door would not let them in. It’s all a matter of principles. If principles are applied across the board, things will get better, if not, it will continue as it is. (Male focus group participant)*

Thus, PWDs were of the opinion that there was a lack of managerial will to strictly implement confidentiality of patient provider interaction in the government hospitals.
Culture barrier to confidentiality (FGDs). Another theme addressing confidentiality was the Pakistani culture whereby people in general do not understand the importance of this issue. Culture was cited as a barrier to confidentiality in three FGDs. First as a general lack of importance accorded to personal privacy and also due to the public’s undue curiosity about others’ affairs.

People just unnecessarily want to know. Suppose I’m diagnosed with T.B, and one of my relatives suspects it, he will, for no reason get curious about it. If he cannot find any source, he will access the record room and tip the receptionist there to find out what is wrong with me. This is an affliction of our whole society, we just so nosy! (Male focus group participant)

Culture also emerged as a barrier to confidentiality of medical records where lab reports and other documents were made accessible to family members without any prior consent of the patient as the family was supposed to have an inalienable right to information of the patient.

A very interesting finding with regard to culture was that while women PWDs did not report any inappropriate physical exposure during examinations or therapeutic procedures, men from the middle SES group in both focus group discussions expressed resentment at their experiences whereby they were inappropriately physically exposed.

I was admitted to PIMS for removal of this rod after my fracture.....when I came out of the O.T, there were so many people around me and when I suddenly regained consciousness I realized I was only wearing a shirt and there was only a
small towel for me to cover myself.... ...they should have taken care of this, not to physically expose me. (Male focus group participant)

Lack of sensitivity of healthcare providers (FGDs). The PWDs described providers’ lack of sensitivity to issues of privacy by recounting instances whereby they were questioned about their disease in front of tens of people including other patients, their attendants, other doctors and miscellaneous health personnel. The healthcare providers also reportedly examined male patients in full view of people around, which was offensive to the patients. The focus group participants attributed this lack of sensitivity to the cultural norms.

When I went there the last time, this is exactly what happened. Well, doctors are doctors, but there were other patients sitting in the same room, and they just raised the leg of my pants and started examining me. I felt really embarrassed about it, they should have shown more respect. (Male focus group participant)

Lack of confidentiality of medical records (FGDs). Lack of confidentiality of medical records featured during two focus group discussions. The PWDs reported that no special efforts were made to maintain confidentiality of records and that the patient files were easily accessible. Anyone who could read and understand medical terminology could easily come to know what a patient was suffering from.

If the patient is admitted, the normal practice is that the file is placed right next to the bed. Even if the doctors try to keep it secret, you can very easily get all the information from the nurses. This is my own experience. (Male focus group participant)
**Autonomy.** Different groups of participants expressed different views with regard to this domain. The majority of PWDs were of the opinion that healthcare decisions should not be left entirely to the patients, but the doctors as well as the family members should participate in decision making. On the other end of the spectrum, PWDs from the low socioeconomic stratum expressed their belief that patients have no role to play in making treatment decisions and that the doctors should do so based on their knowledge of what was best for the patient.

PWDs from the middle socioeconomic group expressed the view that it was important for the patients to make their own decisions based on the information provided by the healthcare providers. Accordingly, the important themes that emerged within this domain included:

- Joint decision making by patient, provider and family
- Decision making by the providers
- Imposition of providers’ decisions on patients

**Joint decision making by patient, provider and family (FGDs).** This theme emerged during five focus group discussions, two of them with PWDs from low SES and three with middle SES group. Participants stressed the importance of joint decision making due to the PWDs’ very limited exposure to the outside world. The opinion was that their knowledge of issues was limited, and they were much less confident of themselves. Furthermore, the stress of acute illness further affected their ability to understand treatment options. Therefore, it was considered important for the participants
that decisions were made jointly with the HCP acting as the advisor, and the family making the best decision for the patient in light of their particular circumstances.

*When I was seeking treatment for my foot, the doctor told me that he would operate both on my ankle and foot, so I got scared..... My family advised me that I should have one surgery at a time and see how much improvement there is and then opt for the next one. That is what I told the doctor and he was fine with it.*

*(Female focus group participant)*

**Decision making by the provider (FGDs).** Participants of three focus group discussions belonging to the low SES and one with the middle SES group were of the view that the patients should not play any role in healthcare decisions at all, and that the healthcare providers should make decisions on their behalf.

*Only doctors know better as they have the knowledge of the illness and the education to treat it. The patient is in so much pain and mental agony that all he wants is to get well. Even if he is given poison he will take it willingly, thinking it will cure him.* *(Female focus group participant)*

**Imposition of providers’ decisions on patients (FGDs).** Participants of four focus group discussions, three of them from the middle and one from low SES groups, expressed the view that healthcare personnel did not provide them with treatment options. They reported that the doctors just handed them prescriptions, telling them to take the medicine and return after so many days. Patients attributed such attitudes to arrogance of the doctors who thought of themselves to be educationally superior to them, and saw no point in trying to educate them about their illness or to give them treatment options.
No one ever gives you any options for treatment. I have never been told about the different possible options for my treatment. They just tell you to get these tests done, take this medicine and come back. (Male focus group participant)

Participants also described that overcrowding and lack of time were important factors affecting the process of informed decision making. The doctors were reported to be under enormous stress to see maximum number of patients in a limited span of time and there was only so much time for them to dedicate to one patient.

**Client orientation.**

**Prompt attention.** PWDs were unanimously of the view that short waiting times were of utmost importance to them. They expressed their tendency to go to the hospital early to get an early turn in the OPD as patients were served on first-come-first basis. The majority of them cited the reason that waiting for long periods of time at the OPD was more uncomfortable for them as compared to non-disabled people. They were of the view that the hospitals should have dedicated facilities for the disabled to make it easier for them to access healthcare providers. They also shared negative experiences regarding long waiting times that led to them giving up on public healthcare in favor of private care. Important themes emerging in this domain included the following:

- Lack of priority at hospital policy and practice
- Disproportionate lack of healthcare facilities

*Lack of priority at hospital policy and practice (FGDs).* PWDs reportedly suffered long waiting times in the OPDs for a number of reasons. PWDs pointed out that
transportation from their homes to the hospitals was a cumbersome and time-consuming process that led to them arriving late at the hospitals. Once at the hospital, lack of mobility devices like wheelchairs and stretchers caused them further delay in reaching the registration counters.

*There are more patients than available wheelchairs, so you have to wait for long periods of time in order to get to the OPD.* (Female focus group participant)

Due to lack of dedicated registration counters for the disabled, they had to wait with the non-disabled patients, and in a society lacking the etiquette for queue formation, PWDs could not push their way around to get their OPD slips. Once the registration slip was made, the patients had to wait their turn in the OPD where it reportedly took several hours to see the doctor.

An important subtheme that emerged from the data was that the patients had to run from pillar to post, waiting at multiple levels. These included waiting for laboratory samples to be taken and imaging procedures to be performed and then waiting for their results. Some investigations, not available at the same facility, had to be performed at other public or private facilities. Many participants reported getting tired of the whole exercise and foregoing healthcare as a result.

*My doctor referred me to an ENT specialist at the other hospital. I had to hire a cab to go there, ask an attendant to help me into it and place my wheelchair in the cab. When I got there, the peon said the doctor was not in. Now my doctor had told me that he had talked to this guy and the peon is telling me that he is not in.*
got so disgusted that I gave it all up and returned home. (Male focus group participant)

Disproportionate lack of healthcare facilities and providers (FGDs). This theme featured in two FGDs, one each with males and females from the middle SES group. They contended that the present number of healthcare facilities was grossly insufficient to cater to the needs of the increasing population of the federal capital.

Due to the high influx of patients, the OPD registration counters were closed at 12:00 noon. This resulted in a number of patients, including PWDs, going through the hassle of reaching the hospital but failing to make it to the OPD. Even if they did succeed in getting an OPD slip, their turn might never come as the OPDs closed at 2:00 pm. The remaining patients had to be seen on the next OPD day, which was usually an alternate day. The disabled consumers of healthcare further lamented that they had to incur expenditure on transport to and from the hospital without getting any treatment at all.

I got my hepatitis shots approved from Baitul Mal ...it was usually so hot and I got so tired.... many a time, I returned without getting my injection. After a while, the time for those injections lapsed....you go to the doctor, you get it prescribed from here, endorsed from there, then get the injections, then get the final approval...it was beyond my capacity to go through the hassle, so I gave it all up. (Male focus group participant)

Another theme closely related to waiting times, was that of jumping queues. Participants of seven out of eight FGDs pointed out the practice, whereby people coming
through some higher-up’s reference were seen by the doctors out of turn. This was reported to be very unfair to the general public and PWDs. Furthermore, these VIP patients were allocated more time for history taking, examination and even general social interaction to please the boss, leading to longer waiting times for rest of the patients.

**Quality of Amenities.** A majority of respondents were of the opinion that the quality of amenities at the three designated federal government hospitals was not satisfactory. The main themes included in this domain included the following:

- Hospital buildings inaccessible to PWDs
- Lack of accessible, clean washrooms
- Inconsistent supply of medications

*Hospital buildings inaccessible to PWDs (FGDs).* Participants expressed their dissatisfaction with physical accessibility of hospital buildings in seven out of eight FGDs. The lack of adequate places for disabled patients to disembark from vehicles and the lack of help available to access the buildings were mentioned as important concerns.

The PWDs were especially vocal in their demand for comfortable waiting areas. They pointed out that there was not enough room for them to move their wheelchairs in the waiting areas. Furthermore, the numbers of seats in the waiting areas of all three hospitals were reported to be insufficient. PWDs complained that there was not enough space for them to sit comfortably while waiting. Negotiating the various floors of the hospital was also cited as a challenge owing to lack or frequent malfunction of elevators.
Lack of accessible, clean washrooms (FGDs). Lack of washrooms in general, and of wheelchair accessible washrooms in particular, also emerged as an issue, featuring in two FGDs. Respondents pointed out that there was insufficient space in the toilets for them to move their wheelchairs. Similarly, the fittings in the toilets were not custom made to cater to their needs. Participants also complained of the toilets being very dirty due lack of supervision of janitorial staff. Respondents also blamed the lack of hygiene on the large number of attendants that accompanied the patients coming to the OPD and especially those admitted to the hospitals.

Inconsistent supply of medications (FGDs). The healthcare consumers belonging to the low socioeconomic group were more concerned about availability of free medicines at the hospitals, citing them as the main reason for them seeking public healthcare.

It is so hard going to the hospital and we get treated so badly, I cry when I come back home, but my family says, “It’s ok, we are only concerned with you getting your medicines”. (Female focus group participant)

Accordingly, PWDs expressed concern over the non-availability of medicines especially at PIMS where the patients’ attendants had to search for and buy everything out of pocket. The FGD participants also complained that while the hospitals provided less expensive drugs, the more expensive ones had to be bought out of pocket for both OPD and admitted patients.

Some FGD participants expressed their preference for private treatment when they thought the public healthcare facilities were not performing the primary task of
providing free medication. The FGD participants also pointed out corruption as a major reason why drugs were not available for public consumption.

*I went to the drug store to buy some medicine and when they gave it to me, it bore the stamp of a government hospital. So you see, drugs are procured for the hospitals and later sold in the open market. This is the level of corruption and pilferage. (Male focus group participant)*

The views of the PWDs on the diet provided to admitted patients were equally divided between the food being good and bad, however, they did not particularly complain about it.

*Choice of provider.* While the PWDs expressed the importance of having an array of providers to choose from, they underscored the importance of joint decision making by patients and their families in choosing the right provider. The focus group participants expressed their preference to seek care from less expensive and polite providers. The main theme that emerged from the data in this domain was the lack of awareness limiting choice of provider.

*Lack of awareness limits choice of provider (FGDs).* This was by far the most commonly cited barrier to choice of provider, emerging in five FGDs. Respondents were of the view that in most cases, people opted for providers purely on hearsay, without even knowing their qualifications and level of expertise. PWDs from the low socioeconomic group based their decisions on the information provided by friends, neighbors, and family members regarding their own experiences with various providers.
All we know is what is written on their name-plates displayed outside their clinics, otherwise we don’t know anything. (Female focus group participant)

**Access to social support during care.** The FGD participants expressed their opinion that having access to friends and family was very important to them and that having their friends and family around had a very supportive effect on them. They, however, had various complaints regarding restricted visiting hours and the alleged demand of bribes by the security staff. Interestingly, the FGD participants also condoned the restriction of visiting hours recounting their own experiences whereby they had been disturbed by the presence of people visiting other patients. The predominant themes that emerged from the data included:

- Need for observance of visiting hours
- Easy access of family to admitted patient

**Need for observance of visiting hours (FGDs).** This theme emerged during four focus group discussions and fourteen interviews. Participants were of the opinion that the hospital administration must enforce discipline in visiting. They cited examples where overcrowding due to large numbers of visitors disturbed other patients.

Many times it so happens that the patient is strolling outside and his visitors are sitting on the hospital bed. This is wrong, they should observe some discipline. There are six beds in one ward and all the patients are sick, so they should be mindful that other patients are not disturbed. When a freshly operated patient is shifted from the Operating room to the ward, they should take care not to make noise and disturb him/her. (Female focus group participant)
Easy access of family to patient (FGDs). Participants of two FGDs were of the view that the designated federal hospitals in general, did not offer any barrier to open access of family to admitted patients. However, the FGD participants also complained that if they did not “warm the fist” (bribed) the security staff or if they quarreled with the medical staff, they were penalized by restricting access to their family. They also complained that their families were not allowed access on the pretext of doctors doing their rounds. However, PWDs were of the opinion that restricted visiting hours were for the patients’ own good and that it provided patients with much needed rest.

Positive experiences shared by FGD participants. Participants of the focus group discussions did not seem to hold a fixed negative view of the health system and recalled experiences where healthcare providers and other staff at the hospital had gone out of their way to guide and facilitate them. In seven out of eight FGDs, the participants shared positive experiences of various kinds. However, in all these instances the providers seemed to have positive personalities and facilitated them out of the goodness of their hearts. As one female FGD participant from the lower socioeconomic group recounted:

Yes, he told me everything although my attendant was there. He talked to me about my surgery, that he would put in artificial bone and that I’ll be all right. Then I told him I could not afford such expensive treatment so he guided me to the Baitul Mal for financial assistance..... Then the doctor gave me a date for surgery, and by the grace of God, I was able to walk on my own two feet after just
7 days…. I was so happy that he took such keen interest in my case. It was wonderful to be able to walk after spending 12 years in a wheelchair.

A male FGD participant recalled how his complaint against obnoxious behavior of a hospital worker was addressed seriously by the hospital superintendent:

The ward boy misbehaved with me and my parents were very hurt. So they complained to the MS [Medical Superintendent]. He called up to find out who that person was, called him promptly into his office in my presence and told him strictly to apologize to me and my family and to touch my feet in humility. I said I did not want to humiliate him but all we need is for them to show respect to the disabled.

Participants were also appreciative of the good behavior of doctors when they guided them and listened to them patiently and when they addressed their pain and suffering with genuine concern. As a participant from the low socioeconomic group recalled his experience:

The doctor told me that the only treatment for my bladder stone was surgery. He gave me an appointment but on that day there were so many patients before me that my turn did not come. When the doctor changed his clothes and came out of the operating room, he saw me lying there on the stretcher and came straight to me…. The time for surgery was over by then but he wheeled me into the operating room by himself, stopped a number of his staff to assist him, and changed back into his surgical clothes to operate on me well past duty hours. He came back to check on me at night too.
Sample II: Demographics

The second sample was composed of the healthcare providers including neurologists (n= 4), orthopedic surgeons (n= 4), gynecologists (n= 4), general physicians (n= 4), nurses (n= 4) and physiotherapists (n= 4). This group also included healthcare managers (n= 6), policy makers (n= 6) and disability rights advocates (n= 4). In-depth, face-to-face interviews were conducted with the participants belonging to the second group. Table 6 summarizes the characteristics of this sample. The length of professional experience of healthcare providers ranged from 5 to 35 years with an average of 12 years. Thirteen of the doctors held degrees while 3 had completed their traineeships and were in the process of appearing in the relevant examination in their respective fields of specialization. All the nurses held basic diplomas in nursing and midwifery from recognized nursing schools and two of them held post basic diplomas in ward administration. The physical therapists all held the requisite basic degrees from recognized health education institutions. The healthcare managers all had basic medical degrees with Masters Degrees in the field of Public Health. Out of the health policy makers, three held basic medical degrees with two of them holding Masters and one having a Doctoral degree in Public Health, while three were senior-level retired bureaucrats with Masters degrees in diverse fields and the requisite trainings in public policy and administration. The disability rights advocates had an average of 8.5 years of experience in their field and education ranging from bachelors to masters level.
Sample II: Domains of Responsiveness

Respect for persons.

_Dignity._ Healthcare providers reported no discriminatory behavior towards the disabled patients per se. However, they contended that due to overcrowding and lack of time, they were sometimes gruff with the patients. Some providers also blamed the patients’ family members of misbehaving with them due to their impatience and ignorance of the system. As in the case of PWDs, the following themes emerged in the interviews with this group of participants:

- Overcrowding compromises dignity
- Lack of healthcare provider training
- General lack of respect for PWDS in the society
- Treating PWDs was unrewarding for HCPs.

_Overcrowding compromises dignity (HCPs et al)._ Overcrowding emerged as a barrier to dignity of PWDs in twenty-five of the forty interviews. The healthcare providers, managers and policy makers were unanimously of the opinion that overcrowded hospitals contributed to high workload of healthcare providers. They attributed the compromise of patient dignity to this increased work load of healthcare providers including doctors and nurses, who then tended to lose patience with PWDs.
Table 8: Characteristics of Interviewees

<table>
<thead>
<tr>
<th>Main categories</th>
<th>Sub-categories</th>
<th>Educational qualifications</th>
<th>%age (Freq)</th>
<th>Years of experience</th>
<th>Range</th>
<th>Means</th>
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<tr>
<td>Doctors</td>
<td>Physicians (n= 4)</td>
<td>Diploma chest and tropical diseases 50% (2)</td>
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<td>5-25</td>
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<td>Orthopedic surgeons (n= 4)</td>
<td>Fellow of the Royal College of Surgeons 75% (3)</td>
<td>75% (3)</td>
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<td>7-20</td>
<td>13.8</td>
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<td>Fellow College of Physicians and Surgeons (traineeship completed, exam pending) 25% (1)</td>
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<td></td>
<td>Gynecologists (n= 4)</td>
<td>Fellow College of Physicians and Surgeons 75% (3)</td>
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<td>Member College of Physicians and Surgeons (traineeship completed, exam pending) 25% (1)</td>
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<td>Neurologists (n= 4)</td>
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<td>Member College of Physicians and Surgeons (traineeship completed, exam pending) 25% (1)</td>
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<td>Post basic diploma in ward administration 50% (2)</td>
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<td>Physiotherapists (n= 4)</td>
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<td>Healthcare policy makers</td>
<td>Masters in miscellaneous fields</td>
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<td>PhD 33% (1)</td>
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<td>MPH 66% (2)</td>
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<td>Bachelors in miscellaneous fields</td>
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Note. MoH = Ministry of Health
It all comes down to the human factor. You being a consultant...being a PG trainee might have to see 50-60 patients in one go. Anyone, however humane, will likely lose his temper in such situations. (Orthopedic surgeon)

Similarly, healthcare providers reported that patients, and the family members accompanying them, also lost patience due to long waiting and got aggressive with staff leading to scuffles. Both healthcare providers and managers recounted incidents reported in the media, in which patients’ family members had physically assaulted young doctors who then went on strike, further creating backlogs and aggravating the overcrowding.

Respondents reported that PWDs had to suffer indignities due to physical inaccessibility of hospitals and lack of mobility devices. Nurses and physiotherapists pointed out that due to lack of mobility devices, PWDs could not reach the OPDs in time and were told off by the doctors for being late.

Lack of healthcare providers training leading to compromised dignity (HCPs et al.). Lack of training emerged as a barrier to dignity of PWDs during nineteen interviews with participants of this group. Disability rights advocates as well as physiotherapists were of the view that doctors, in general, had no idea when to stop active treatment and start rehabilitation. As one disability rights advocate put it:

Doctors act according to the medical model of disability and keep trying to get the patient “well”. They don’t understand that there is only so much you can do in terms of surgical and medical management. There must come a time when you declare that the patient is no longer a patient but a disabled person who needs to be rehabilitated to come back to life.
This not only led to unrealistic expectations but also wasted precious time and resources that could be better utilized in rehabilitating the patient to encourage independent living. Disability rights advocates especially expressed their resentment, recounting incidences when they had accompanied their wives and children to the hospital and the doctors focused on them as PWDs, instead of the family member who was in need of medical attention.

Participants belonging to this sample shared the opinions of the healthcare consumers that increasing exposure to disabled patients led to improvement in provider behavior toward the PWDs. Many healthcare providers working in hospitals other than the NIRM expressed their opinion that providers at the said hospital were known to have better attitudes towards patients with disabilities. Healthcare policy makers were of the opinion that in-service trainings along the lines of continuing medical education would be effective in improving healthcare providers’ understanding of disability related issues.

*General lack of respect for PWDs in the society (HCPs et al.)*. The respondents in this group, especially the healthcare providers expressed dismay at the society’s lack of respect for the disabled. They opined that the lack of respect for the disabled began at home where the parents saw their disabled children as less productive and potential lifelong liabilities. Lack of educational and employment opportunities were cited as perpetuating this vicious circle of dependence and indignity. As a physically disabled senior healthcare provider put it:

The thing is that with the passage of time we, health care providers.... if we see somebody suffering from a disease which is incurable... the message we convey to
their attendants is that don’t waste your time. Nothing is going to happen.... This is a very negative sort of an attitude.... As a result of which these physically handicapped patients are deprived of education, deprived of the care of their parents and as a result they lead a life of somebody that is dependent... They impart negative input to the parents and that discourages them.

This lack of respect at societal level was reportedly translated into social policies where no priority was accorded to the disabled population of the country and they were relegated as the responsibility of the erstwhile Ministry of Social Welfare and Special Education which has now been devolved as individual provincial departments.

The healthcare providers also reported the popular belief that disability was a punishment for the sins of the forefathers and how people would publicly touch their earlobes and nose in a gesture of seeking God’s forgiveness upon seeing a disabled person. The healthcare providers who worked predominantly with PWDs, found these negative behaviors deeply offensive.

_Treating PWDs is unrewarding for HCPs (HCPs et al.)._ The healthcare providers owned up to the fact that due to the lifelong nature of disability and lack of expectations for any favorable health outcomes, the healthcare providers in general, tended to lose interest in chronically disabled patients.

_Because the outcomes in cases of chronic disability are not as good from the doctors’ point of view, these are long-term cases, and there is also a lack of awareness on the part of doctors, especially in both these hospitals [PIMS and FGPC] about what is rehabilitation, what is quality of life. They accord more_
priority to the medical/surgical approach. In such circumstances if they see a case where there is disability and the outcomes are not bright, no one will accord any priority to it. (Senior physiotherapist)

The healthcare providers were also of the view that seeking free government healthcare was also a barrier to the dignity of these patients and being intensive and repeated users of healthcare services, they suffered indignities far more frequently than their non-disabled peers. The physiotherapists, healthcare policy makers and disability rights advocates also pointed out that doctors were much more polite and accommodating to the patients in their private clinics than they were in the government hospitals.

Knowing influential people makes it easier to negotiate system (HCPs et al.). In three out of four interviews the disability rights advocates reiterated the opinion that knowing influential people, especially doctors or healthcare managers made it easier to negotiate the system at all levels.

**Clear communication.** Within this group, each category of healthcare providers was of the view that they communicated well with the patients while the others did not. The nurses recounted instances where they had to allay patients’ anxiety when doctors failed to explain the reasons for extreme surgical procedures like amputations. The physiotherapists, similarly, reported that the doctors did not explain to the patients what exactly the prognosis was, and that they had to clarify the picture while the patients were receiving physical therapy sessions.

Important themes emerging from the data in this domain included the following:
Doctors do not bother to communicate

Overcrowding barrier to communication

Cultural effects on communication

Language barrier to communication

_Doctors do not bother to communicate (HCPs et al.)._ This theme emerged in nineteen of the forty interviews. Physiotherapists, nurses and disability rights advocates were of the view that the doctors did not bother to make the effort to communicate adequately with the patients, due to which, the patients and their families were reported to develop unrealistic expectations.

_I don’t see any clear communication between them as yet. ... I have yet to see a muscular dystrophy patient in my life who has complete information about what disease he has, what kind of problems will develop eventually..., “Ok this is a small problem which will be solved with surgery”,.... and the patient rests in the confidence that... now I will be cured. There is a large gap between the expectations of the patient and the approach of the doctor, because the doctor doesn’t have the time to explain to the patient._ (Senior physiotherapist)

Respondents were of the opinion that although chronically disabled patients needed more counseling and guidance to live with their disability, they were accorded no priority. Admitted patients were reported to have a better chance as the doctors worked up their cases but even then, the junior doctors communicated the main findings to the senior professors during the rounds and the patients very occasionally got the chance to communicate directly with the senior medical consultants. Doctors were also reported to
be less communicative with PWDs than with the nondisabled patients and showed a tendency to talk more to the attendants than the PWDs.

No, this never happens... “Ok, what happened? Alright, take this medicine and come back after a week”. That’s all the interaction you get, and when it’s a disabled person, there is no communication with the patient at all. They would talk to the family or to the attendants accompanying him. They don’t even talk to us! (Disability rights advocate)

Overcrowding barrier to communication (HCPs et al.). In eighteen out of the forty interviews, participants attributed the lack of patient-provider communication to excessive overcrowding of the hospitals under study. The healthcare providers, managers and policy makers all agreed that due to the high number of patients, it was practically impossible to listen to the full range of the patients’ complaints. It was reported that often the patient, on a subsequent visit, would describe a symptom which was missed by the providers earlier, thus forcing them to turn the treatment plan around. This reportedly led to sub-optimal health outcomes and longer recovery times.

Cultural effects on communication (HCPs et al.). The healthcare providers, managers, policy makers as well as disability rights advocates were unanimously of the view that it was very important to respect the cultural norms while communication with the patients. In doing so, they opined that the family had a right to know the diagnosis before it was communicated to the patient. As one senior physiotherapist shared from his experience in the culturally similar Japanese society:
This concept is totally different in the whole of Asia. Here we completely brief the attendant of the patient and sometimes, for some diseases we don’t disclose anything to the patient, there is logic behind this…. this is our Eastern culture, and I have experienced it firsthand. In 1964-65 a team went from Japan to America, which included people from orthopedics, rehabilitation medicine and neurology….In America ….the patient is provided all information in the beginning…. the Japanese thought of implementing this in their country... When they started practicing this, within one year the suicide rate among the disabled went up by 400%.

Another senior level healthcare provider pointed out the loss of interest of the family once they were told that the patient had no chance of recovering full function, hence underscoring the importance of providing information in a positive and optimistic way.

Cultural values fostering physical and economic dependence on family were also identified as important barriers to communication especially in the case of disabled women who were mostly unmarried. This subtheme emerged in fourteen interviews. These women reportedly came to the hospitals with their sisters-in-law and due to the sensitivity of the relationship, were unable to narrate their medical histories. On the other hand, the healthcare providers also reportedly found it difficult to communicate with the patients in front of their family members. Because of the low status of PWDs in the family as dependents and due to their lack of education and confidence, their attendants reportedly took the center stage in communicating with healthcare providers.
The reality is that these patients suffer from lack of confidence, you cannot tell them clearly that this is wrong with you. Secondly they are shy, so… Things have never been told directly to the patient in front of me. I never tell them directly! We tell her mother or whosoever is with her. (Gynecologist)

The healthcare providers reported that sometimes they had to send attendants out of the examination room to obtain a proper medical history and to educate the patient regarding sensitive issues like sexual dysfunction.

Language barrier to communication (HCPs et al.). The federal government hospitals in Islamabad have a large catchment area, receiving patients from as far north as the Federally Administered Tribal Areas (FATA) along the northern border with Afghanistan, Gilgit-Baltistan, Kashmir, and from as far south as Jhelum and Mianwali. Patients coming from these areas speak around ten different languages and dialects, including Potohari, Pushtu, Hindko, Pahari, Gilgiti, Kashmiri, Seraiki and Punjabi. Language was thus identified as another important barrier to communication where healthcare workers had to seek help of their colleagues hailing from the same areas or the patients’ attendants to act as interpreters.

We get patients from Kashmir to Jhelum, FATA to Mianwali….some speak Pushtu and some Hindko. In such instances we have to seek help of our colleagues or the patients’ attendants to translate, and that not only hinders communication but also compromises confidentiality. (Gynecologist)

Conversely, physiotherapists, nurses and disability rights advocates also reported language as a barrier when doctors used English words or medical jargon in their
conversation with patients, who could not understand either of them. Doctors, on the other hand, reported that they tried to explain to the patients in lay terms and even drew pictures and diagrams to overcome the language and knowledge barrier.

**Confidentiality.** The respondents in this sample were of the opinion that given the present state of affairs with excessive work load and lack of space in the OPDs and wards, confidentiality was not being maintained as it should. The main themes that emerging within this context included the following:

- Overcrowding as a barrier to confidentiality
- Culture as a barrier to confidentiality
- Lack of confidentiality of medical records

*Overcrowding as a barrier to confidentiality (HCPs et al.).* Overcrowding as an important barrier to confidentiality emerged in twenty-five of the forty interviews. The healthcare providers and managers reported that overcrowding led to relative lack of space in the OPD, forcing multiple doctors to share the same room for medical consultations. Consequently, three or four patients would be narrating their histories simultaneously in the same room, with no concept for individual privacy.

Overcrowding also emerged as a barrier to indoor patient care where eight to ten patients were housed in one ward. Under such circumstances it becomes very difficult for doctors and nurses to arrange for adequate numbers of screens to minimize physical exposure during procedures like intra-gluteal injections and urethral catheterizations.
For example, in the wards it’s an open general ward with eight beds in a single room and you have almost two attendants per bed so that means you have eight patients plus 16 attendants so that’s a lot of people plus you have the doctors and nurses coming in so it is not practically possible to have confidentiality in this sort of an arrangement. (Neurologist)

Culture barrier to confidentiality (HCPs et al.). Culture emerged as a barrier to confidentiality in twenty one out of the forty interviews conducted with this sample. The main barrier cited was the general lack of importance accorded to the individual right to privacy. As one healthcare provider put it:

Another unfortunate thing is that while waiting their turn, the patients themselves discuss their illnesses with each other. (Physiotherapist)

Culture especially was a barrier to confidentiality for PWDs, and especially women as they were not allowed to leave the house by themselves. Presence of attendants reportedly compromised confidentiality of conversation as well as examination.

In our setup, we cannot perform couple counseling, the mother-in-law is always there. These cultural hindrances of ours are always there. (Gynecologist)

Gynecologists recounted experiences where they had to separate the patient from the chaperone to get information about the husband’s sexual dysfunction. It was also pointed out that the female patients with disabilities were usually so afraid of their mothers-in-law that despite knowing that the infertility was due to the husband’s
dysfunction, they pleaded the doctors not to disclose it. In such cases, gynecologists reported dealing with the situation tactfully to sugar-coat the information so as to protect the patient as well as satisfy the in-laws. Similarly, educating disabled women about contraception and safe sex practices was reportedly a challenge for doctors when their attendants were not ready to leave their side

_And then sometimes the mother-in-law or the sister-in-law would insist… “No doctor sahib, we will stand right here”, then again we have to be rude to them, they must curse us when they go home, but we take it all upon ourselves for the sake of the patient._ (Gynecologist)

A very important cultural and religious effect on confidentiality was reportedly the sensitivity of providers to privacy of physical examination in case of female patients. Care was taken to ensure that women were mostly attended by female healthcare providers and in the absence of female providers, were always accompanied by a female nurse or attendant during physical examination and therapy. Care was also taken to screen the examination area to preclude physical exposure of women. However, the same caution was not reportedly exercised for male patients.

*Lack of confidentiality of medical records (HCPs et al.)* Lack of confidentiality of medical records featured during nineteen interviews in this sample. The healthcare providers pointed out that while the patients were admitted to the hospital, their files were placed on their bedsides during the rounds by senior doctors and at other times they were in the custody of the charge nurses at the nursing counter. However, a majority of healthcare providers were of the opinion that the files were not openly accessible, and
documents were only provided to close family members after adequate authorization. After the patient was discharged, a discharge summary was provided to the patient which was the property of the patient, who could share it with anyone they wanted. Similarly, medical records of outpatients were their own property, and the health system had no jurisdiction over their confidentiality as the patients were responsible for them.

Healthcare providers pointed out that a Health Management Information System (HMIS) that kept electronic records, such as the one at PIMS, would ensure confidentiality of patient records. However, senior level HCPs from the said hospital shared their experience that the said HMIS was only for diagnostic investigations and not for holistic medical records like history, examination findings and treatments records. A head of department from PIMS put it as follows:

*Medical records are unfortunately not maintained or secured... The information can be secured, the data can be secured but when you are so much over worked and seeing more that 50 patients in the OPD so there is very little time in which all the information can be typed into the computer.*

**Autonomy.** Within this domain, participants were of the opinion that although patients were provided treatment options, they most often left the decision making to their families or to the doctors. Disability rights advocates and neurologists expressed the opinion that patients themselves delegated decision making to their doctors, insisting that all they wanted was to get well. Accordingly, the themes that emerged within this domain included:

- Joint decision making by patient, provider and family
• Decision making by the providers

• Culture barrier to autonomy

• Dependence on family as barrier to autonomy

*Joint decision making by patient, provider and family (HCPs et al.)*. The interviewees including healthcare providers, managers and disability rights advocates expressed the view that in most instances treatment decisions were made jointly by the patient, the family and the healthcare providers. They described that since the PWDs were often less educated and had less experience of the outside world, they lacked the self confidence to make decisions all by themselves. Furthermore, due to cultural influences the family played a major role in healthcare decision making, especially in case of PWDs.

*Decision making by the provider (HCPs et al.)*. The healthcare providers recounted their experiences when they had to make treatment decisions because the patients were not educated or enlightened enough to understand and do it on their own. This was especially true for neurology where the development of signs and symptoms was usually beyond the understanding of the patients and their families. Neurologists especially pointed out that in most instances, it was futile to explain to the patients and their families the what, how and why of the disease due to the complexity of the symptoms and uncertain nature of disease progression. In such cases, the doctors made the decision in the best interest of the patient keeping in view their knowledge and experience of treating similar cases.
Culture as a barrier to autonomy (HCPs et al.). The pluralistic Pakistani culture emerged as a significant barrier to the autonomy of the physically disabled persons in general and the women in particular. This theme featured in eleven interviews. The healthcare providers gave important input in this respect, citing experiences whereby unrealistic expectations of the PWDs and their families, coupled with lack of awareness of cure versus management of chronic disability, led to adverse treatment decisions. The role of faith healers and the belief of people in their ability to work miracles also emerged as a barrier to informed and independent decision making.

In our society one person is getting information from multiple sources.... He comes to the doctor, he is told you have this disease like muscular dystrophy, this will progress like this, or that you have polio, we will rehabilitate you or have you fixed with a prosthetic leg. Once he goes out of here, he meets a homeopath or a traditional healer who says “Don’t you worry at all! I have already cured hundreds of patients who had the same illness as you; it will not take me more 2 months to do this...” This is how people get confused. (Physiotherapist)

Furthermore, the cultural practice of family, friends and neighbors providing conflicting advice in light of their own experiences of treatments, especially surgery, further confounded the decisions made by the PWDs and their families.

Dependence on family as a barrier to autonomy (HCPs et al.). Financial dependence of PWDs and their low status within the family structure was reported to have an adverse effect on their autonomy. This theme emerged during sixteen interviews. Majority of the interview respondents expressing this opinion included
healthcare providers, who had closely observed family dynamics during interaction with patients and their families. Families were reported to make an all out effort to have their disabled members treated, selling properties and doing all that was possible, but at other times, healthcare providers recounted instances where treatment decisions were purely based on family convenience and not for the patients’ welfare, especially in the case of women. As one doctor put it:

_There was this patient ….. She had post polio deformity and she had a very bad pelvis. ……. we told her that your baby cannot pass through this pelvis... The patient understood, her husband understood, the mother-in-law did not! ...she said...” Why don’t you give it a try?”...because obviously she would have to look after her during the post-operative period, and the patient was disabled, so we get lots of issues like that._ (Gynecologist)

Family members were also said to insist on free treatment especially for women PWDs because they were considered financially unproductive, and spending money on their treatment was considered wastage of precious resources. This led to further constraints on treatment options available for these women.

**Overarching theme: Lack of HCP interest in government jobs as a barrier to all components of Respect for Persons.** This overarching theme emerged within all four domains of the Respect for Persons concept, during four focus group discussions and also twelve interviews. PWDs recalled incidences where the healthcare providers had seen them with a lot of respect, taking care to maintain confidentiality of conversation and communicated freely with them in private settings while the very same doctors had
not listened to their complaints seriously enough in the government hospitals. The doctors attributed such discrepancies to the better structuring and organization of the private system and the lower number of patients. However, PWDs, non-doctor providers and healthcare policy makers reported that it was due to the doctors’ intentions to divert patients from the free government settings to their private practices, which was more financially lucrative for them.

Policy makers recalled incidences where private practice outside the government hospitals was banned, with emphasis placed on institution-based private practice, following the example of Military hospitals. In the Military settings, the specialists conduct evening private practice in the same hospitals where they serve, and pay a proportion of their private income to the hospital in return for using the physical infrastructure and diagnostic facilities. However, this ban in the civilian setting led to severe strikes and shutting down of government facilities. This backlash forced the government to retract the legislation and private practice by doctors serving in the government hospitals continues.

**Client orientation.**

**Prompt attention.** The respondents in this sample were of the opinion that waiting times were long mainly due to the large number of patients and lack of healthcare facilities. They shared the view that dedicated healthcare facilities should be established for PWDs to ensure prompt delivery of medical services to them. The following themes emerged in this domain:

- Lack of priority at the level of hospital policy and practice
Overcrowding of healthcare facilities

- Disproportionate lack of healthcare facilities

*Lack of priority at the level of hospital policy and practice.* Long waiting times were reported by participants in twelve interviews. Healthcare providers were of the opinion that PWDs were not accorded any priority in the general hospitals such as PIMS and FGPC, which led to long waiting times both at the OPD and for admissions. Healthcare providers pointed out that due to inaccessibility of public transport, the PWDs had to come to the hospitals in cabs which were very expensive, or in make-shift ambulances made out of pickup trucks. In any case it was cumbersome for the patient as well as the family and led to delays in reaching the hospitals. Other factors pointed out by the healthcare providers and managers included lack of mobility devices and lack of dedicated registration counters for the disabled due to which the disabled had to wait for longer periods than their non-disabled counterparts.

*As far as the PIMS and Poly Clinic are concerned, there the OPDs are very crowded and you might say it takes hours...on the average it takes you 4-5 hours waiting your turn in the OPD. This is for a person who has come as a patient, he got his OPD card made and has sat down to wait. (Physiotherapist)*

In the case of PWDs needing admission, waiting times varied according to bed availability. Healthcare providers described how acute trauma cases referred from the ER, were accorded priority over cold cases of chronic disability, leading to longer waiting times for PWDs. This was reported to be more of a problem at PIMS and FGPC which are general hospitals and have large emergency departments.
Due to absence of an emergency department at the NIRM, waiting times for admission were reported to be considerably shorter. Availability of beds for female patients was even better at the NIRM, due to the establishment of a 100 bed female spinal injury unit in 2005, which is now utilized as a general female ward for orthopedic patients. However, bed availability for male PWDs was a problem even at NIRM, due to fewer beds, and due to longer bed occupancy by PWDs.

*Disproportionate lack of healthcare facilities and providers (HCPs et al.).* All categories of study respondents in this sample were of the view that the lack of establishment of new hospitals and the low number of healthcare providers were overburdening the existing facilities. This theme featured in sixteen interviews. This lack of healthcare facilities and providers had an adverse effect on the length of waiting times both in the OPD as well as for admission and surgical procedures. It was pointed out that patients hailing from the lower SES preferred seeking free public healthcare, and suffered most when hospitals were overburdened.

Healthcare providers, managers and policy makers were unanimous in their opinion that the lack of a strong, integrated referral system was the main cause of overcrowding of health facilities. A proper referral chain ensures that the patients are seen by primary care providers first, who then refer them to specialists only if necessary. The absence of such a system, reportedly contributed to overcrowding of tertiary hospitals and all attendant problems including long waiting times, lack of communication, provider fatigue and patient dissatisfaction with care.
Quality of amenities. Majority of the participants in this sample were of the opinion that the quality of amenities at the three designated federal government hospitals was not satisfactory. The main themes included in this domain included the following:

- Hospital buildings inaccessible to PWDs
- Lack of accessible, clean washrooms
- Inconsistent supply and questionable quality of medications
- Quality of diet linked to number of patients

Hospital buildings inaccessible to PWDs (HCPs et al.). Respondents in twenty out of forty interviews were of the opinion that the three federal government hospitals included in this study were not fully accessible to physically disabled patients.

Mentioning individual hospitals, the healthcare providers, managers and policy makers pointed out that oldest hospital building, the FGPC, had been built as a small dispensary and was not meant to cater to the current high load of patients. Due to lack of planning at the initial stages, later renovations and modifications could only be made at a restricted scale. The newer buildings including PIMS and its associated Children’s Hospital and Maternal and Child Health Center, as well as NIRM, were cited as better planned and constructed, but still insufficiently accessible to PWDs.

When we talk of ..., PIMS and FGPC, they cater to general patients but still they must be accessible too, which they are not. But then our institute was built with the specific purpose of medical rehabilitation ..... They should have sought expert opinion for design of the building which they did not do. (Physiotherapist)
Healthcare providers pointed out that the ramps that were built as later additions to the hospital buildings were not up to international standards. This reportedly made it very hard for patients, especially wheelchair bound individuals, to negotiate them without help.

*None of them is disabled friendly in any form. The angle should be 5-7 degrees...*

*It is so that if you have to raise a surface by one inch, you need a slope length of one foot, so if you want to elevate someone by one foot, you need a ramp that’s 12 foot long... but this does not exist here. (Senior physiotherapist)*

*Lack of accessible, clean washrooms (HCPs et al.).* The healthcare providers were especially vocal about the lack of washrooms in general, and of wheelchair accessible washrooms in particular. This theme emerged in sixteen interviews. The width of the washroom door, the height of the commode and the absence of hand rails were barriers to accessibility pointed out by the healthcare providers and managers. The issue of lack of hygiene featured predominantly in the interviews. Respondents claimed that the large number of attendants who accompanied the patients were the cause for the lack of hygiene in the wards and toilets.

*There is an issue with cleanliness especially in the wards. ....you know, there are a lot of friends and family accompanying the patients and they are using the same facilities that are meant for the patients, so who suffers?....it’s the patients! The janitor can only clean the premises two to three times a day. (Neurologist)*

Healthcare providers also pointed out gaps in repair and maintenance of hospital buildings and equipment failures. They recounted experiences where they had to have
the relevant portions of the buildings renovated at their own expense. They attributed the lack of maintenance of buildings and equipment to paucity of funds, and lack of managerial interest. Another important determinant of the will to renovate hospital buildings was the hospital managers’ reported need to impress politicians. Thus parts of the buildings under administrative use were renovated to make the façade presentable, while the patient areas were neglected.

*If we can tile our floors overnight because the President’s wife is going to visit in the morning, why can’t these [accessible] washrooms be built?.... We can do a lot in the same amount of money.* (Senior physiotherapist)

**Inconsistent supply and questionable quality of medications (HCPs et al.).** Healthcare providers and managers blamed the inconsistent supply of medication on the lack of fund allocation and hospital policy. The “red tape” of public procurement was reported to cause delays in procurement of drugs, and promote purchase of low quality drugs. Furthermore, inconsistent supply of drugs and medicines was also attributed to lack of managerial interest. The supply of medicines was reported to dwindle as the financial year approached its end, with the last few months being the worst. The healthcare providers attributed this to faulty budgeting and lack of foresight at the managerial level.

*Quality of diet linked to number of patients (HCPs et al.).* The respondents were of the perspective that keeping in view the present state of inflation, it was commendable in the first place that hospitals were providing free food to admitted patients. The
respondents were largely of the opinion that the quality of food was good, and that there were no major issues there. As one disability rights advocate put it:

*The food is good. Even at our homes, some days are such that the wife may not cook a good meal, so it’s like that.*

The healthcare providers were of the view that the diet provided at NIRM was far better than the one provided elsewhere due to the smaller number of patients. Similarly the bad quality of diet at other hospitals was attributed to the large number of patients. Lack of effective managerial supervision was also pointed out as a factor contributing to the low quality of diet in the larger hospitals.

*The diet provided at the hospital used to be really good a while ago, now it has deteriorated a lot. I think it could be because of budget problems. The managers should foresee it in light of unbridled inflation and ask for a higher budgetary provision to cater to the needs of increased number of patients. (Healthcare manager)*

**Choice of provider.** The participants in this sample were of the opinion that owing to the absence of a referral system, PWDs had the opportunity to access any specialist without first going through a general physician. However, the choices were reportedly constrained by a number of factors. The themes that emerged from the data in this domain include the following:

- Lack of awareness limits choice of provider
- Economic constraints limit choice of provider
• Design and operation of hospitals limit choice of provider

• Lack of specialists limits choice of provider

*Lack of awareness limits choice of provider (HCPs et al.).* This was a commonly cited barrier to choice of provider, emerging in fifteen interviews. Respondents described that in most cases, people sought care from providers based on word of mouth as there was no objective means of determining which provider was the best or most experienced in the field.

Healthcare providers reported that providers were also sought on the basis of personal contact, even if their qualification or assignment of duties did not align with the patient’s needs. It was also pointed out that when a doctor referred a patient to another doctor, the patient would strictly follow the referral.

*As happens in FGPC, there is a surgeon Dr. A... Whenever a disabled patient goes to him, he straight-way sends the patient to Dr. A.N. Now that patient will come to me and say “Dr. A has sent me to see Dr. A.N”... I would say to him, “There are other doctors around, I can take you to them”...”No we have been told to go to Dr. A.N, we will only go to him”. This is how their mindsets are. (Gynecologist)*

*Economic constraints limit choice of provider (HCPs et al.).* The theme that choice of provider was constrained due to economic considerations emerged in seventeen interviews. The healthcare providers and managers described the disabled persons having a preference for public healthcare or cheap alternative medicine providers including traditional and faith healers due mainly to poverty. Healthcare providers
expressed the belief that choice of provider could only be exercised when there was an abundance of resources. They described that medical rehabilitation including physical therapy, training in activities of daily living and speech therapy, was universally expensive. Affording such extensive therapies for prolonged periods of time from the best providers could only be possible for those who had no financial restrictions.

Design and operation of hospitals affecting choice of provider (HCPs et al.). The healthcare providers, managers and policy makers expressed the opinion that due to lack of a referral system, there was no restriction on choice of provider, as patients may see any specialist without going through a general practitioner first. However, when accessing the federal hospitals in the capital as in other secondary and tertiary care hospitals, choice of provider was determined by the department/unit on call in the ER or OPD. Thus if a patient wanted to see a specific doctor, they would have to visit the OPD on the day that specific unit was on call. Furthermore, the choice of providers also was limited by the hierarchy of doctors from house officers, post graduate trainees, medical officers, registrars, senior registrars, assistants, associates and professors. Thus, only the patients that could not be treated at the junior levels of the hierarchy were taken to the senior level doctors.

If the patient comes in without checking first, he will end up with the unit who is running the OPD that day. Secondly, the patient is seen from the grass-roots up, I mean he is first seen by the medical officer, then the registrar, then the Associate Professor. This is how he moves, so you see his choice ends the day he comes to the hospital. (Healthcare manager)
Healthcare providers also pointed out that patients seen by one unit, could not seek a second opinion from doctors related to the second unit of the same specialty, in the same hospital.

*They will have to hide their old records and go to the second specialist as a fresh case.* (Gynecologist)

Choice of provider was also limited for admitted patients when their treating physicians called up doctors from other units for management of co-morbid conditions. Sometimes patients were also referred to other hospitals having better equipment and/or expertise in the related field, especially for diagnostic and oncologic support. In such cases, the patients did not exercise their choice and religiously followed the referral.

*Choice of provider limited by lack of specialists (HCPs et al.).* An important constraint on the choice of provider as pointed out by the healthcare providers was the lack of neurologists and rehabilitation specialists in the federal government hospitals. There is only one unit of neurology in PIMS and none in the other two hospitals. Thus there was no place for the patients to turn to if not satisfied with the care they were receiving

*No it is not enough, we need to have more institutes, more neurologists more rehabilitation setups because once they are through with neurology they may be needing speech therapy and rehabilitation or if they are having pain due to some intractable neurological disease they need to have a neurological setup.* (Senior neurologist)
Access to social support during care. The participants belonging to this sample were all of the opinion that although having friends and family visit the patients had beneficial effects, there was a general lack of observance of visiting hours that contributed to further overcrowding in the wards and discomfort for the patients as well as providers. The themes that emerged during interviews are as follows:

- Need for observance of visiting hours
- Easy access of family to admitted patient

Need for observance of visiting hours (HCPs et al.). This theme emerged during the course of fourteen interviews. Respondents opined that the hospital visiting hours were not observed and that led to overcrowding of wards by family members of the admitted patients. This created noise and was a source of physical discomfort as well as loss of privacy for the other patients in the wards. Healthcare providers also pointed out that presence of large numbers of visitors at odd times created barriers to confidentiality of history and examination.

The healthcare providers and managers blamed the patients and their families for bullying and harassing them if they tried to restrict access.

Now the patients have developed the habit of misbehaving with the watchmen to a large extent, and it is still there. “My cousin has come from very far to visit me”...now all you guys have cell phones, why don’t you call them and let them know the visiting hours. What can the hospital staff do? (Gynecologist)
Easy access of family to patient (HCPs et al.). Respondents of twenty out of forty interviews expressed the view that there were no barriers to access of family to the admitted patients. All categories of participants were of the opinion that access to admitted patients was easy, and visitors were frequently granted relaxation beyond visiting hours. Whole families were reported to accompany admitted patients, sleeping in the courtyards or open spaces in the hospitals. One of the main reasons for this was cited to be the fact that visiting sick relatives and friends was religiously and culturally binding.

In our culture, a lot of emphasis is placed on visiting sick relatives and friends. If you fail to do so, they will harbor ill feelings for the rest of their lives and will go to the extent of cutting all social ties with you. (Healthcare manager)

However, healthcare providers and managers also were unanimous in their opinion that designated visiting hours should be observed for the patients’ well-being, and to facilitate their rest. The healthcare providers described that access was only restricted during rounds, to minimize noise, so that doctors could focus on the patients.

The healthcare providers and managers added another insight to this phenomenon by pointing out that at least one attendant was needed to live in with the patient while the patient was admitted. This was necessitated by the fact that due to lack of staff, the patients’ attendants provided round-the-clock care to the patients. They reportedly catered to the patients’ intimate needs and often had to go out to buy medicines, or arrange blood and surgical disposables in case of surgery.
Factors hindering responsiveness at the policy level. The insights offered by the healthcare managers and policy makers added another dimension to this study. The main themes emerging from interviews conducted with this subgroup included:

- Lack of priority at the policy level
- Lack of monitoring and evaluation of hospitals
- Fragmentation and inefficiency of the health system
- Lack of qualified healthcare managers

Lack of priority at the policy level (HCPs et al.). A majority of respondents including users of healthcare indicated a need for separate specialized healthcare facilities for the disabled to improve service delivery and to address the domains of responsiveness. However, policy makers indicated that there was not only a paucity of knowledge but a complete lack of recognition of disability issues at the policy level.

No you cannot say they are not accorded priorities, they are not accorded any recognition of their existence. Let’s be very blunt with you, I am telling you this issue has never come on the agenda of the Ministry of Health of the Government of Pakistan.... I have not heard of this issue being discussed, a file being made, a proposal being made, solution being found. Why is the Directorial-General made the head of Health Directorate, because these are the kind of technical issues that have to be brought to the notice of the policy makers. I am telling you that for my four or five years I never heard of these issues, these issues are foreign words to me. (Senior policy maker)
Furthermore, in the face of chronic budget shortages and general lack of priority for health, issues related to control of communicable diseases featured more prominently and took away the lion’s share of the budget as well as bureaucratic attention and political will.

You see, as yet we are evolving our healthcare system, so at this point in time, we are in the very early stages as far as ethics and with regard to the marginalized population. Our major issues at the moment are maternal and child mortality and morbidity. So at this time we, as a general system we have not yet started thinking beyond mortality….. in this scenario, with limited resources, the luxury to think of other things has not been there.

The disabled population was reportedly made the sole responsibility of the erstwhile Ministry of Social Welfare and Special Education, which had neither the mandate nor the expertise for healthcare provision to the disabled. According to a senior policy maker, issues relating to responsiveness of the health system were first brought to light in a WHO report on managerial competence, which eclipsed when larger, more dramatic problems related to maternal and infant mortality hit the policy makers. However, issues related to disability again took the limelight in the aftermath of the earthquake of 2005 when thousands were rendered disabled due to spinal injuries and traumatic amputations. In response to this national disaster, staff were recruited on war footing and new facilities created. In addition, coordination between acute care and rehabilitative care facilities was established and strengthened. These linkages are still in force and provide much needed rehabilitative services to the disabled.
Lack of monitoring and evaluation of hospital performance (HCPs et al.). This was also identified by policy makers as a barrier to optimal functioning of the health system. Individual healthcare managers reportedly took interest in ensuring optimum service delivery to the disabled but there was no systematic effort to institutionalize such best practices. In contrast, development projects with financial implications were monitored more closely.

We very closely monitored what is the progress of development expenditure in this wing and that wing ... because the ministries are answerable to the Planning Commission and the report goes to the Prime Minister. But because there is no report on operationality which goes anywhere except stays at the level of the Medical Superintendent... of the hospital therefore .... Never has a performance audit along these lines been done by the Federal Directorates. (Senior policy maker)

Furthermore, it was reported that the monitoring and evaluation that was performed lacked the operational indicators of responsiveness and was focused primarily on statistics related to OPD attendance, inpatient admission, number of surgeries and death rates etc.

Fragmentation and inefficiency of the health system (HCPs et al.). Another important theme that featured in the discussions with managers and policy makers was the duplication of healthcare services and bias in their location within the various sectors of the city.
They only look for temporary solutions, just to hold the things in their hands and keep the system working so their status is maintained. This is not the solution. They should have looked at the whole system, you don’t need much for Islamabad you need a 4 by 4 map with the health facilities planned on it. Just look at it and you will find out that there are 15 dispensaries in one sector and the Public Secretariat and there are 14 dispensaries in the remaining sectors, and all other areas are without health facilities. If those are marked on the map of Islamabad every policy maker will make a decision to spread these and then link them through a referral link, but this can only be done by a technical person.

(Healthcare manager)

The lack of a strong, integrated health system was linked to the lack of a proper referral system leading to overcrowding of tertiary care facilities and resultant compromise in responsiveness.

The lack of primary and secondary healthcare facilities was mainly attributed to the fact that healthcare providers preferred to serve in the urban areas. The healthcare managers and policy makers described that the lack of a referral system was actually due to factors beyond the control of healthcare planners and decision makers. It involved external players like the Finance Division which allocated only 0.5% of the Gross Domestic Product to health, rendering the health system chronically anemic. In the absence of adequate funds it was not possible to establish, staff, equip and run primary and secondary facilities of adequate quality. Healthcare managers and policy makers were also of the view that in the paucity of general facilities like good schools,
infrastructure, security and urban life, healthcare providers did not opt to work in the periphery, leading to staff shortages at the primary and secondary levels. The policy makers pointed out that these staff shortages were further aggravated when the Establishment Division failed to recognize the importance of providing adequate monetary incentives for providers to work in these areas.

Managers and policy makers alike expressed their fears that the health system had further fragmented in the wake of the 18th constitutional amendment and that it would take a long time to bring the various sectors of the health system to optimally operate in tandem. Senior policy makers were concerned that after the promulgation of the 18th constitutional amendment, the federation had lost its role in health. They lamented the lack of clear guidelines on who would coordinate health-related activities in lieu of a dedicated Ministry of Health. If the Planning Commission were to take up this role, it reportedly lacked the capacity to do so. Similarly, coordination with international partners and donors was a major function of the erstwhile Ministry of Health since these donors contributed a significant chunk of the health budget. Participants reported that this function has now been delegated to the Economic Affairs Division, where it is one of many other functions. Participants were of the view that in both these cases the government will either have to develop the capacity of these units for the said functions or develop new entities for health planning and international coordination, which is expected to be a long and tedious process.
Lack of qualified health managers (HCPs et al.). Lack of qualified health managers was also pointed out as a major hurdle in the way of optimum service delivery, policy making and health planning.

Because you see... hospital administration is a subject which has been introduced recently.... The heads of these institutions have no experience of hospital administration and I have known personally that... administration is run by the office superintendent and the clerical staff. The Medical Superintendent... has no interest ... to look into these affairs. Now a lot depends on the individuals. I have seen the same hospital being kept in a very clean and tidy position because of one MS and the same institution turning into a dirty place... because of another MS. (Healthcare policy maker)

Here the problem is the technical decisions are being made by non-technical people. (Healthcare manager).

These inputs by the senior level bureaucrats and healthcare experts added another dimension to the findings of this study.

Summary of Key Findings

The results of this study addressed both the research questions. In the first instance, the physically disabled consumers of the healthcare system shared their experiences which indicated that the federal health system is not responding well to their needs. Interviews with healthcare providers, managers and policy makers provided
further insight on the various barriers that hindered the system from responding to the needs of the population of interest.

At the level of the external environmental factors, the pluralistic, patriarchic Pakistani culture which fostered dependence of PWDs on their families was identified as a barrier to multiple domains of responsiveness, especially for women with disabilities. Participants also pointed out the general lack of respect for the disabled at the societal level, which translated into provider behaviors that offended PWDs. At the level of the health system, multiple domains of responsiveness were affected by overcrowding at government hospitals. At the policy level, this was attributed to the lack of an integrated referral system of primary and secondary health facilities which forced patients to seek care at tertiary facilities. The increase in population and relative paucity of healthcare facilities and providers also contributed to overcrowding. Inaccessibility of hospital buildings, inconsistent supply of medicines and unhygienic surroundings also hindered responsiveness.

Lack of provider training and sensitivity to disability issues also featured as an important barrier to responsiveness. Other important barriers included healthcare provider preference for serving in large cities and for private practice versus government service. The participants described that at the policy level, health was not accorded priority in terms of funding, staffing, and proper structuring of the health system. Lack of monitoring and evaluation of hospital performance in regard to responsiveness to PWDs was also a cause for concern as it precluded improvement. Another important development was the promulgation of the 18th constitutional amendment which dissolved
the Ministry of Health and placed its different components under the control of various divisions. Participants expressed the concern that this had contributed to further fragmentation of the federal health system.
Chapter V: Discussion

This study was conducted primarily to determine how the three federal government hospitals located in Islamabad were responding to the needs of 18-45 year old persons with physical disabilities. The study also aimed to find out the factors that were hindering this health system from responding to this section of the population. The study was guided by the modified Andersen-Aday behavioral model of healthcare utilization (Phillips et al., 1998), which facilitated organization and interpretation of the research findings. The design of the study enabled the PI to get a 360 degree look at the matter under investigation. On the one hand, data collection instruments were designed and procedures conducted to assess how important the various domains of responsiveness were to the PWDs as consumers of healthcare, and what their specific experiences had been within these domains. The other important aspect of this study was the expert opinions of the healthcare providers, managers, policy makers and disability rights advocates who had inside knowledge of the system and could comment on the realities within which it was operating. Both these sources of information complemented each other, such that the consumers pointed out the gaps in the responsiveness of the designated hospitals, while healthcare providers, managers, policy makers and disability rights advocates described the technical faults that led to this state of affairs. The qualitative design of the study enabled the respondents to voice their experiences and concerns freely and in depth.
The results of this research indicate that the Pakistani federal health system is not responding well to the legitimate expectations of a large majority of physically disabled adults. The experiences of PWDs and the barriers hindering the responsiveness of the Pakistani federal health system may best be understood if they are organized in light of the theoretical model that guided this research, the modified Andersen-Aday behavioral model of healthcare utilization (Phillips et al., 1998). According to this model, healthcare provision and receipt occurs in an environment composed of the health system and the external environmental factors, and is further affected by the characteristics of the individuals, providers and the community.

**Individual Level Variables**

According to the behavioral model of healthcare utilization, certain characteristics of the population of interest rendered the health system less responsive to their needs. The most prominent among these factors were poverty, financial and physical dependence on family, and lack of awareness, especially in the case of women.

Poverty was an important barrier to dignity of the PWDs as they were more likely to seek care at the overcrowded, and under-funded free public hospitals. In a society where the poor are generally regarded with contempt, being poor as well as physically disabled increased their vulnerability and marginalization. This finding was consistent with research conducted in neighboring India (Ghai, 2001). Poverty also emerged as a major barrier to healthcare access of the PWDs in this study, as a vast majority belonging to the low SES group reported going without needed healthcare in the last 12 months due to lack of money. This finding is consistent with previous research, which indicates
disabled patients being unable to get necessary treatments due to financial constraints (Chevarley et al., 2006). Due to difficulties in transportation and financial limitations, many physically handicapped patients reported seeking care from unqualified medical practitioners. Research in Bangladesh has indicated similar findings with respect to healthcare seeking behaviors of PWDs (Ahmed et al., 2005). Poverty also was reported to be a barrier to autonomy, as the PWDs could only seek treatments that were affordable. Choice of provider was limited for the poor who preferred public healthcare, due to the free nature of medical consultation and medication. This finding has also been reported by health researchers in India, which bears cultural and socioeconomic similarities to Pakistan (Balarajan et al., 2011).

Findings in this study indicated dependence on family as a barrier to the dignity of the physically disabled, beginning with the home and family and extending to the social and health systems. This is consistent with the findings of research conducted in developed countries where despite high levels of social awareness, the disabled were regarded as incompetent individuals in need of help, eliciting feelings of both sympathy and aversion (Cuddy et al., 2007; Livneh, 1988). This dissertation study also indicated that lack of education and employment led to further marginalization of PWDs. This is consistent with research in other countries of the South-East Asian region (Hiranandani & Sonpal, 2010). Dependence on family was also a barrier to confidentiality as family members would accompany the physically disabled patient to the hospital and would be present at the time of history taking, examination and communication of doctor’s instructions. Similarly, presence of family members also posed a barrier to open and clear communication between patient and provider. This problem was especially acute in
cases of women accompanied by their sisters or mothers-in-law while consulting gynecologists. This has been shown to be common in Asian societies, where the family is regarded as having an inalienable right to the patients’ health information (Fan, 2002).

Dependence on family also was a barrier to autonomous decision making by the patient. This study indicated that in the case of male patients, the family tried their best to opt for the best possible treatment to make the patient less dependent and more productive. However, women were found to be at a disadvantage when gynecologists reported that majority of the patients were treated according to family convenience, without any input from the patient. This has been shown to be true for at least half of the households in Nepal, India and Bangladesh, where women’s opinions were disregarded concerning their own treatment (Senarath & Gunawardena, 2009). Dependence on family and lack of awareness also played an important role in the choice of provider for PWDs. In the absence of objective information about the providers’ actual qualifications and experience in the field, PWDs and their families chose providers mainly on hearsay. However in both the case of making healthcare decisions and choosing providers, the disabled individuals from the low SES group strongly believed that the role of the family was supportive and appreciated it. This can be explained not only by the socio-cultural milieu of the respondents but also by the fact that from the very beginning the PWDs are socially identified according to their disability status. This finding is consistent with psychological research, even in the developed countries, which indicates that the chronically disabled whose personal identity was linked to their disability were much less autonomous in their choices (Wang et al., 2011). Physically disabled individuals from the more educated middle class, and healthcare providers conversely thought the family
was imposing their decisions on the patient, and that the latter should have more say in the matter.

**Provider Related Variables**

A number of provider related variables contributed to the lack of responsiveness of the health system to the population of interest. Specifically, the lack of proper healthcare provider training in the field of disability management compromised the dignity of physically disabled patients. PWDs in this study were of the opinion that healthcare providers dealt with them in accordance with their individual personality traits. Thus, some were extra nice to them, while others treated them with contempt. The healthcare managers and policy makers attributed it to the lack of standardized training in the field of disability management, during basic medical, nursing and allied programs. In the absence of such trainings, healthcare providers acted according to their social and familial upbringing. To the extent that disability issues were just a small component of the basic healthcare provider training programs, there was a lack of emphasis on them, leading to the lack of translation of training into practice. It was also due to lack of training that healthcare providers were unable to recognize the specific health issues of the physically disabled especially their predisposition to develop certain types of infections or other illnesses like osteoporosis. Similar findings were reported by Kroll and colleagues (2006) where healthcare providers failed to recognize issues pertaining to disability and its associated health risks. Furthermore, lack of training also rendered the healthcare providers unable to see past disability which was very offensive for the patients. There were instances where patients had to educate healthcare providers
regarding their disability and its associated problems, which communicated a lack of interest on the part of the former. This phenomenon has also been reported in research conducted in developed countries where healthcare providers showed a lack of interest in patients with disabilities (Edvardsson et al., 2006; Schaefer, 2005).

Dignity of PWDs was also compromised when providers showed a lack of interest in their care due to their repeated and intensive use of healthcare. Providers also reportedly found that treating PWDs required more effort and was unrewarding due to the lack of favorable outcomes. These attitudes were attributed to the providers looking at disability through the lens of the medical model. Since PWDs could not be treated to such a level that the disability went away, it was viewed as a waste of provider’s time and energy. The perspective that persons with physical disabilities should be made more independent through occupational therapy and training in activities of daily living, was seriously lacking in the healthcare providers. This corresponds with the previous research where healthcare providers in the developed countries also showed similar attitudes toward treatment of disability (Ralston, 2000).

According to PWDs, healthcare providers also showed a lack of sensitivity to issues of confidentiality when they asked patients to narrate their complaints and when they examined male patients in the presence of other patients and their attendants. Although providers attributed this to the lack of space in the overcrowded hospitals, lack of provider sensitivity also appeared to play a part.

Provider related attributes also compromised clarity of patient-provider communication and informed healthcare decision making by the physically disabled
patients. Providers failed to educate the patients about their disease due to being overworked and also because they thought the patients lacked the capacity to understand. This finding corresponds to previous research where providers failed to communicate due to reduced expectations of the intellectual capacity of PWDs (Hayashi & Kimura, 2008). The lack of communication reportedly led to missed diagnoses and complications. This finding was also reported in earlier research where doctors missed the diagnoses due to lack of communication with PWDs, leading to worsening of the condition (Courts et al., 2004; Iaquinta & Larrabee, 2004; Schaefer, 2005). Another interesting finding in this research was that doctors would not listen to the whole spectrum of patients’ complaints and would prescribe medications as they came to learn of the patients’ problems one by one, on different occasions. This lack of thoroughness of healthcare providers has been indicated in earlier research conducted with PWDs (Iezzoni et al., 2003). The lack of communication also adversely affected the patients’ ability to make informed healthcare decisions. While in many instances, the patients themselves delegated the right to make healthcare decisions to the doctors believing them to be superior in knowledge, the healthcare providers also showed a paternalistic attitude. In many instances, the doctors took decisions on behalf of the patients, sometimes in consultation with the family, and sometimes imposing their own. These paternalistic attitudes of healthcare providers are supported by research on Asian cultures, where physicians are held in high esteem, and expected to take the best decisions for the patients (McLaughlin & Braun, 1998).
Factors Operating at the Level of Health System

Within the health system, lack of interest on the part of policy makers was made abundantly clear by the fact that the health policy in vogue today was formulated eleven years ago in 2001. Although efforts were made to develop a new policy in 2008, no headway could be made due to lack of political will. The current health policy focuses more on issues of maternal and infant mortality and does not recognize the needs of the disabled population as a vulnerable group. It was interesting to note during the course of this research that healthcare managers and policy makers who were public health experts exhibited a better understanding and acknowledgement of the issue of responsiveness. For those who had been trained as clinicians, prevention of mortality was the biggest priority, and issues related to responsiveness were a luxury the health system could not afford within the present financial constraints. Lack of properly trained healthcare managers and policy makers was also pointed out as a major issue when it came to quality service delivery to the population in general and PWDs in particular. Lack of monitoring and accountability of hospital performance at the level of higher authorities further compounded the problem.

Also within the healthcare system, an overwhelming problem was the lack of a proper referral system of primary, secondary and tertiary facilities. As mentioned earlier, the Establishment Division lacks a system to award enough incentives to doctors for serving in the primary and secondary healthcare facilities, which are usually located in the villages and small towns. Such places seriously lack decent housing, schooling, roads and other important amenities required by healthcare providers and their families. Under
these circumstances, a vast majority of healthcare providers opt to work in the tertiary urban hospitals, rendering the primary and secondary facilities inadequate and understaffed. Overtime, the general public has learned that the best way to get good quality healthcare is to access the tertiary hospitals. The three hospitals included in the present study were tertiary care facilities located in Islamabad, receiving patients from as far away as the Federally Administered Tribal Areas (FATA), Gilgit-Baltistan, Kashmir, Jhelum and Mianwali.

The lack of a referral system contributed to severe overcrowding which posed a barrier to multiple domains of health system responsiveness. Overcrowding was cited as a barrier to dignity of the physically handicapped patients when they could not fight their way to get their OPD slips made in time, and when overworked healthcare providers lost their tempers because the patients were unable to understand hurried instructions. Due to the patients coming from a large catchment area, patient-provider communication was seriously compromised due to the varieties of languages spoken by the patients. The healthcare providers had to request their colleagues or the patients’ attendants to act as interpreters, thus often leading to lapse in providers’ understanding of patients’ complaints, and the latter’s understanding of treatment. Using translators also compromised confidentiality of the patient-provider interaction. Overcrowding of OPDs and relative shortage of space reportedly resulted in several doctors sharing the same OPD room, compromising confidentiality of patient-provider interaction. Thus, providers had to take histories and give instructions to patients in the presence of other doctors, patients and their attendants.
Overcrowded wards also posed a barrier to physical privacy and comfort of patients, especially when there were attendants around. Similarly, overcrowding also posed a barrier to clear patient-provider communication, due to the fact that providers had little time to interact freely with the patients. Patients expressed feeling dissatisfied because they thought that the providers were in a hurry trying to get rid of them. Research indicates that longer visits with open and frank communication foster trust and comfort for the patient (Gross et al., 1998). Thus, overcrowding and the ensuing lack of communication between patients and providers was a source of disappointment for the patients.

Overcrowding also lengthened waiting times for the physically handicapped patients both at the level of the OPD as well as inpatient admission. At the OPD, the physically disabled had to wait longer as they were unable to physically compete to take their turn in a society sometimes lacking the etiquette for queue formation and general discipline. While waiting for palliative surgeries, the physically handicapped were relegated to the back of the wait list due to the priority accorded to cases of acute trauma, usually admitted through the ER. This finding corresponds with previous research that indicated healthcare providers made PWDs wait longer, as they perceived their problems to be less acute (Edvardsson et al., 2006). Overcrowding also led to physical discomfort when physically disabled patients had to wait for mobility devices like wheelchairs and stretchers at the hospitals, and when they had to stand and wait their turn in crowded waiting rooms with an insufficient numbers of seats.
Physical accessibility of hospital buildings was poor for older buildings and better for the newer buildings; however, none of the ramps had been built to international standards with resultant discomfort, and risk of falls for the physically disabled patients. There was a general paucity of washrooms and accessible washrooms in particular. Lack of hygiene in hospital buildings was a frequent complaint. Similar findings were reported by Monro and Mully (2004) in research undertaken in the United Kingdom where researchers found no improvement in accessibility of hospital washrooms and other amenities despite an elapse of 30 years between two surveys. The healthcare providers also complained that the management took more interest in renovating administration blocks for showing to the visiting politicians, but took no interest in the areas that were under patient use. Waiting areas were reported to be universally insufficient and uncomfortable for PWDs.

The quality and availability of medication was unsatisfactory. The patients frequently complained that they had to buy the more expensive medications out of pocket, both for outpatient and admitted patients. The quality of diet was described as good for the hospitals with a lower number of admitted patients while it was worse in larger hospitals. Healthcare managers reported lack of budgetary provision for diet, and rising prices of food items, to be the main cause of low quality of diet.

Design and operation of the healthcare system also posed a barrier to the choice of provider for the patients. This was due to the fact that the patients were seen by the specific medical/surgical unit on call in the ER or OPD. If the patients wished to see a particular doctor, they would have to wait for the day when that unit was on call.
Another interesting finding was that patients seen by one specialist in a hospital would not be seen by another specialist in the same hospital, unless they hid their records and appeared as new patients. This was probably because the doctors did not want to be held responsible for each others’ errors. However it was interesting to note that the lack of a referral system also promoted choice of provider by allowing the patients to access specialists without getting referred by general physicians first.

**External Environmental Factors**

The health care system does not operate in a vacuum: rather, it is influenced by factors at the higher policy and governmental levels, which are often out of its control. The healthcare policy makers and managers who participated in this study shed light on these factors. The policies of the Finance Division, that determined healthcare spending at less than 0.5% of the GDP, reportedly led to universal, chronic budget shortages at the health facilities. Another important player identified by the participants was the Establishment Division, which recruits federal government employees, including medical professionals. This division does not recognize the importance of providing adequate incentives for recruitment and retention of qualified healthcare providers in the small towns and villages. Thus, healthcare providers refrain from serving in the primary and secondary level healthcare facilities in these localities, leading to overburdening of tertiary healthcare facilities located in the large cities.

Another very important external influence on the health system was the recent promulgation of the 18th constitutional amendment, whereby the federal Ministry of Health was dissolved, and many of its sub-departments delegated to the provinces. The
three designated federal government hospitals were retained in the federal control under the umbrella of the newly constituted Capital Administration and Development Division (CA&DD). Other important organs of the erstwhile ministry were brought under the control of the Cabinet Division, the Economic Affairs Division, the Planning Commission and the newly created Ministry of Inter-provincial Coordination. The healthcare managers and policy makers were all wary of this arrangement citing two main reasons. Firstly, even after an elapse of two years from the promulgation of the 18th constitutional amendment, there was still no mechanism in place to ensure coordination and liaison between the health-related federal organizations, leading to uncertainty and confusion at all levels. Secondly, the erstwhile Ministry of Health was dedicated to providing a consolidated regulatory and operational framework for the different organizations under its control. However, the aforementioned new super-ordinate units have health as another of many components to look after. Thus, health will have to compete for bureaucratic attention and political will at multiple levels, which may or may not be garnered, owing to the lack of priority accorded to it. Therefore, the National Health Policy Unit was placed under the Economic Affairs Division which lacks the capacity to oversee its functioning. There was an overwhelming feeling within the healthcare managers and policy makers that the federal health system had fragmented and that it would take a very long time to recover some semblance of organized structure and function.
Community and Cultural Norms

Characteristics of the community and the prevalent cultural norms were found to play an enormous role in the responsiveness of the health system. This study was performed in Pakistan where culture is not only governed by strict Islamic values but is also heavily influenced by the Hindu culture and folklore due to centuries of cohabitation with them. Culture emerged as a significant barrier to multiple domains of responsiveness.

At the societal level, culture posed a barrier to dignity of PWDs when disability was often interpreted as punishment for the sins committed by the parents or forefathers, or by the person himself. This finding is consistent with previous research involving traditionalist cultures (Diken, 2006; Groce & Zola, 1993; Mardiros, 1989). In the sub-continental culture, derogatory terms are used to describe the physically disabled like “Langra”, “Loola”, and “Kubra”. The folklore says that the physically disabled individuals have some peculiar, odd habit, different from the non-disabled. It was an interesting finding that the Federal Bureau of Statistics still uses words like “Crippled”, “Deaf and dumb”, “Insane” and “Mentally retarded” in its annual reports to describe the various categories of disability (Federal Bureau of Statistics, 1998). As the healthcare providers were products of the same social system, they too carried their biases and culturally formed attitudes into the workplace. This was especially true in case of low educated workers like ward-boys and janitors, who were reported to behave with the PWDs in discourteous ways. Even educated healthcare workers like doctors reportedly insulted the physically disabled patients, thinking of them as unintelligent and less
educated. This finding is consistent with previous research where healthcare providers, even in developed countries were reported to hold fixed, incorrect notions about people with disabilities (Kroll et al., 2005). In the present study, such incidences of compromise in dignity were more commonly reported by PWDs belonging to the lower socioeconomic group.

Another way in which culture compromised dignity of the physically disabled was by fostering dependence, people taking pity on the PWDs and being over-sympathetic. This is consistent with research findings even in US, where the people with physical disabilities were found to be treated as helpless children and provided with relatively more help (Dovidio et al., 2011). Research indicates that such preferential treatment from the family or the society promotes increased dependence in young patients with physical disabilities (Hyman, 1975). While the less educated PWDs from the low SES group thought of such behaviors as “people being nice” to them, the more educated middle class were reportedly offended. This behavior of the healthcare providers reportedly stemmed from the religious belief that helping the disabled was an act of piety and would be rewarded in the afterlife.

Culture also was a significant barrier to confidentiality of conversation between patient and provider. Due to lack of awareness regarding confidentiality of health information, the patients and their family members shared health information freely with friends, neighbors and relatives. There are many reasons for this behavior. Firstly, the Pakistani society is a pluralistic society and people like to seek advice on matters of health from friends, family and neighbors, in light of others’ experiences with various
healthcare providers, home remedies that work, or faith healers that are known to work miracles. While seeking this information, they give away their health and personal information, and see no harm in it. Thus, due to the cultural background of all the actors involved, no special provision was made in the OPDs, ERs and wards to ensure that the conversation between the patient and provider was kept confidential. However, in case of sensitive information and patients’ demand, the providers reported ensuring confidentiality by taking different measures to isolate the patient.

Another cultural practice that compromised confidentiality was the tendency of family members to remain with the patient during the course of the medical interaction. This was common in cases of women accompanied by in-laws, who often demanded to know the diagnoses. It became difficult for the providers to safeguard the interest of the patient in such cases. Confidentiality of medical records was similarly compromised as the patients showed their blood and imaging reports to family and friends, especially if any of them were related to the medical field. The patient files were not kept under lock and key and anyone with enough education could read them. Culture was also a barrier to physical privacy of males in crowded OPDs when they were examined in front of other patients and their family members. However, in the case of women, strict cultural and religious taboos ensured privacy of physical examination and precluded physical exposure. For women seeking care from male providers, the providers ensured that a female attendant or nurse was always present during the examination.

The above cultural factors that hindered confidentiality, also posed important barriers to patient-provider communication. The patients were reluctant to share intimate
details of their illness in front of attendants of the opposite sex and in-laws. In such cases, the providers reported facilitating the patients by isolating them, so as to obtain valid medical histories. Once again, this was more prevalent in case of females seeking gynecological consultations. Another important aspect was communication in case of life threatening illnesses. In such circumstances, the diagnoses were first disclosed to the family, who may or may not divulge the information to the patient, keeping in view their mental and emotional state. This is a cultural norm prevalent in all pluralistic Asian societies, and was condoned by the vast majority of study participants in both the samples. Similar findings have been reported in research on Asian societies where the family’s right to information is inalienable (Meer & Vandecreek, 2002; Saadah, 2002), and relatives strived to protect the patients from upsetting information (Tamura, 1994).

Culture was also a barrier to autonomous decision making by the patient as the family was given priority in all cases of decision making. This finding is also supported by previous research which indicates that in the pluralistic Asian societies, families play the most important role as decision makers (Fan, 1997). In this study, the patients often reported being usually complacent and accepting the family’s decisions. These decisions were based on the perceived best interest of the patient in the case of male patients, while in case of majority of females, priority was accorded to family convenience, and the family elders opted for easy and short treatments.

Another domain where culture played a dominant role was that of visiting patients while admitted to the hospital. Both religion and culture place a great emphasis on visiting sick relatives and friends. This translated into lack of discipline and lack of
observance of visiting hours. Whole families accompanied the patients from their villages, sleeping in the hospital corridors and open spaces and remaining with the patients throughout the day. This led to severe overcrowding of the hospitals, lack of hygiene, and disturbance for the other admitted patients. This also interfered with medical management of the patients, as the attendants refused to leave the wards during round time, and made it difficult for the doctors to focus on the patients and their treatment. This overcrowding also posed a barrier to confidentiality of other patients’ interaction with the healthcare providers as well as their physical exposure during therapies and examinations carried out in the wards.

Limitations of the Study

This study was conducted in the Islamabad Capital Territory which is a federally administered area having three large tertiary hospitals. The ICT is a smaller administrative unit, and due to the relative proximity of its constituent sub-districts, the accessibility of health services is expected to be higher in the ICT as compared to the larger provincial districts with widely dispersed rural populations.

This study focused on healthcare experiences of young adults with physical disabilities, between the ages of 18 and 45. The rationale behind this decision was that individuals with similar types of disabilities have been shown to have similar experiences in their interactions with social institutions. The findings of this study may not be transferable to the hearing, visually and mentally impaired population, and children and elderly with disabilities. Furthermore, all the healthcare consumers who participated in focus group discussions were beneficiaries of the locally registered Community Based
and Non-Governmental organizations. Due to their close working relationship with
disability rights advocates, these participants were more likely to have higher levels of
awareness of their rights as disabled persons. The Pakistani population of PWDs in
general, and of low SES level PWDs in particular, may not have such levels of awareness
of their rights. Also the low socioeconomic level sample was mainly derived from the
people residing at the outskirts of Islamabad. It is reasonable to expect that they
experienced greater problems with regard to transportation to and from the hospitals in
comparison with their counterparts residing in the city. However, their contribution to
this study as a purposive sample is expected to have a significant impact on health policy
by highlighting the problems faced by PWDs in the health system, especially since there
has been no such study on the Pakistani health system as yet.

The healthcare providers, managers and policy makers who were interviewed for
this study were in the employment of the federal health system, which is a relatively
smaller component of the public health system in Pakistan. The employees of the larger
provincial health departments and private medical practitioners were not included in the
study due to logistic reasons. Similarly, traditional, complementary and alternative
medical practitioners were also not included in the study. Furthermore, a vast majority of
participants belonging to this sample were personally known to the researcher as she has
worked in the same health system for the past 16 years. The PI reiterated the
confidentiality of information shared during the study at multiple occasions, to garner
participant confidence and ensure comfort, which may have facilitated candid expression
of opinions, experiences and concerns by the participants.
The study was based on a qualitative approach and the findings thus obtained may not be generalizable to the whole Pakistani population of adults with physical disabilities. However, as there is paucity of research addressing the issue of responsiveness of the Pakistani health system to the needs of PWDs, this study is an important first step in this direction, and will, hopefully, spur further research on the subject. Purposive sampling was performed to recruit individuals who were most knowledgeable about the issues affecting the poor and disabled and who could provide trustworthy data and bring important issues to light. Although the study was based on healthcare experiences of adults with physical disabilities, it is expected that people with severe mobility limitations may not have been able to participate in the study due to transportation problems.

Due to the paucity of previous research, this study was not able to show trends in the responsiveness of health system after major administrative changes like devolution of financial and administrative powers to the District Governments undertaken in 2002, and the devolution of federal ministries after the recent 18th constitutional amendment. However, this study suggests that the health system is most in need of improvement in organization in terms of operationalization of existing primary and secondary healthcare facilities. In the same vein, establishment of a strong and integrated referral system is mandatory to reduce the burden on tertiary hospitals and save the people with disabilities from the burden of traveling far from their hometowns to seek quality healthcare. This study also identified PWDs belonging to the lower socioeconomic stratum as the most vulnerable group to whom the federal health system was the least responsive.
**Strengths of the Study**

This study has many important strengths. It is one of the first studies conducted to determine the responsiveness of the federal health system to the needs of persons with disabilities in Pakistan. Although focusing on a portion of the broader national health system, it has indicated important avenues for further research and development in this field. It not only focused on the level of responsiveness of the federal health system to the needs of the population of interest, but also determined the important barriers that hindered it. This approach lends itself to finding feasible solutions to real life problems. The qualitative design of the study enabled the researcher to obtain in-depth information from a variety of respondents. Especially important in this regard were the experiences and opinions of women with disabilities belonging to the low socioeconomic stratum, who were more marginalized as a group. The design of the study also facilitated the study of various components of the political, socioeconomic, religious and cultural environment within which the health system operates. Thus barriers operating at the various levels including healthcare provision, management, policy making and the broad political milieu were identified. Another important strength of the study was derived from the approach of triangulating data from multiple sources (including healthcare consumers, providers, managers, policy makers and disability rights advocates), collected through two different qualitative methodologies (focus group discussions and in-person interviews), thus contributing to the richness of the findings by encompassing a wide range of experiences and opinions. It also contributed to trustworthiness of the study findings as similar themes complemented each other from the data collected from various respondent categories. This study is an important step in underscoring the importance of
healthcare issues of the physically disabled in a healthcare system which is yet to recognize this marginalized group.

**Recommendations**

This study looked at the issue of responsiveness of the health system from multiple perspectives: those of consumers, providers, managers, policy makers and disability rights advocates. The purpose of this effort was to devise concrete recommendations that could be utilized to improve all domains of responsiveness in light of the data from these sources. The results of this research indicate barriers at multiple levels that hinder the federal healthcare system from responding to the needs of the population of interest. Many of these barriers simultaneously hinder multiple domains of responsiveness and by adequately addressing them, responsiveness of the Pakistani federal health system can be vastly improved.

**Recommendations for policy and practice.**

*Poverty alleviation and skill development for PWDs.* This study, as well as previous research indicated poverty to be an important factor contributing to overall vulnerability of PWDs. There are a number of poverty alleviation programs already operating in the country under various international donors, including the United States Agency for International Development (USAID), Australian Agency for International Development (AUSAID), and Department of International Development (DFID) of the United Kingdom. It is recommended that these agencies should be made aware of the importance of poverty alleviation through skill development of PWDs. As yet they are funding fragmented programs through various CBOs and NGOs, which fall short of
addressing the majority of PWDs. There is an overwhelming need for a national level, integrated program to impart skills to PWDs for their sustainable financial independence. This will lead to empowerment of this vulnerable group and improve their quality of life.

**Creating awareness on issues related to disability.** To ensure non-discrimination against PWDs it is imperative that social campaigns are initiated to reduce stigma associated with disability. According to the principles of social marketing, efforts should be tailored to address the general public, policy makers, healthcare providers, and the care-givers and family members of PWDs.

The awareness campaigns targeting the general public must be spearheaded by the department of Social Welfare and Special Education in collaboration with the CBOs and NGOs active in the field of disability advocacy. The state-owned Pakistan Television is recommended to participate in a media campaign to improve people’s understanding of issues related to disability and to reduce stigma associated with it. This can take the form of TV plays and talk shows that have a wide viewership in the public. Private TV channels should also be advocated to give back to the community by improving the public image of the disabled as productive members of the society. PWDs that are national figures should be encouraged to take on the role of disability ambassadors. These include distinguished writers, physicians, engineers, scientists, and social workers.

Advocacy for the rights of PWDs, targeting policy makers, will have to be undertaken by the management of the National Institute for Rehabilitation Medicine. The chair-persons of the Standing Committees on health, in the Senate and the National Assembly, should be taken on board to convene meetings of these committees to discuss
issues related to healthcare provision to the disabled and the responsiveness of the health system to the needs of PWDs. As these committees are legally based in the Constitution of Pakistan, it is realistic to expect that their recommendations will make a valuable contribution to improve the responsiveness of the federal hospitals.

The National Institute for Rehabilitation Medicine can also provide training to different cadres of healthcare providers in dealing with disabled patients and their special needs. Healthcare providers working at NIRM can provide trainings as continuing medical education at the other hospitals, using the existing forum of weekly clinical meetings. Disability rights advocates belonging to the various local community-based non-governmental organizations as well as disabled healthcare providers can impart valuable awareness and firsthand knowledge of the issues confronted by the disabled persons in their interactions with the health system. This does not entail any financial implications and can become a part of an ongoing academic activity. The Medical Education and Research section of the erstwhile Ministry of Health may provide overall liaison, management and evaluation of these trainings.

To support and educate care-givers and family members of the PWDs, the Patient Welfare Society of the NIRM can be effectively utilized as a central forum to constitute support groups for the various types of physical disabilities. These include but are not limited to support groups for people having paralytic disorders, cerebral palsy, limb loss, degenerative brain diseases and muscular dystrophies. The NIRM can sponsor the activities of these support groups by providing expert advice of physicians /surgeons, space for regular meetings and opportunity to recruit members from among patients.
**Improving responsiveness at the health system level.** In the short term, the Government of Pakistan can improve responsiveness of the federal health system by establishing separate reception counters, waiting areas and OPDs for the disabled persons within the existing hospitals. These facilities may be manned by dedicated staff specially trained for the care of the disabled.

Another important step in the short term is the expeditious implementation of development projects that are already in the pipeline, but are being delayed due to bureaucratic red tape. These include horizontal and vertical extension of the FGPC building and establishment of the new wing of the NIRM on an adjacent piece of land. The extended infrastructure of these building will allay some of the physical discomfort faced by disabled patients due to overcrowding. It is also recommended that accessibility of all hospital buildings must be ensured in light of international standards and the new buildings must be built accordingly. In this connection, the management of NIRM can play a pivotal role by liaising with the Capital Development Authority, that approves all building plans for construction in the federal capital.

The establishment of a proper forum for monitoring and evaluation of hospital performance is mandatory to implement best practices in care provision to the disabled. The office of the Director-General Health can provide technical input in the form of performance indicators relating to patient satisfaction, with special emphasis on the domains of responsiveness. The statistics departments of all hospitals should be linked to collect standardized data along these lines, which can further be used for informed decision making at the higher policy levels.
A mechanism should also be put in place to redress patient complaints in a timely and effective manner so that the patients do not feel neglected. This entails establishment of effective patient complaint cells at the level of individual hospitals, staffed by dedicated social workers, reporting to the hospital administration. It is also recommended that the input from these complaint cells should be used constructively to prioritize issues identified by the patients and to resolve them effectively. These activities should be included in the hospital statistics for reporting to the super-ordinate offices on a monthly basis.

In the short term, the lack of primary and secondary healthcare facilities may be rectified in light of the various experiments carried out by the provincial governments and carrying out regular monitoring and evaluation to assess their efficacy. One such experiment was the establishment of a central referral facility where doctors were recruited with the sole responsibility to visit the peripheral facilities under their jurisdiction on a weekly or bi-weekly basis. It is recommended that at least one such facility must be established in the federal capital, and surrounding villages clearly identified as its catchment area. The doctors recruited for the purpose will be responsible for all the peripheral health units located in the catchment area, where junior-level resident staff like midwives, lady health visitors and medical technicians may be deployed. This central referral facility may be placed under the administrative control of the Capital Administration and Development Division, which also supervises the federal government hospitals.
In the long term, it is recommended that all important external players including the Establishment Division, the Planning Commission and the Finance Division may be taken on board and the need for a strong, integrated referral system of primary, secondary and tertiary facilities may be advocated. Doctors and other cadres of healthcare providers must be provided sufficient incentives to serve in the underserved rural areas. The strengthening of primary and secondary healthcare facilities by provision of adequate staff, budget and supplies will reduce the burden on tertiary facilities.

Findings of this study indicate a strong need for separate, dedicated healthcare facilities for PWDs. It is recommended that new facilities dedicated to the care of the disabled may be established at least at the district level, where they provide specialized services like prosthetic and orthotic support, wheelchair training, physical and speech therapy and specialized healthcare in the field of medical rehabilitation. This study also indicated the inadequacy of public transport for wheelchair users. It is recommended that individual hospitals provide wheelchair accessible buses for the pick up and drop off of patients along specified routes. This can be taken up as a joint development project by the three federal government hospitals in this study, to ensure fund allocation by the Planning Commission. It is also recommended that the National Institute for Rehabilitation Medicine be reverted to its original status of a dedicated facility for the disabled. This entails curtailing its Authorized Medical Attendant status which has diluted its clientele of purely disabled patients with government servants and their families.
Recommendations for Future Research

The paucity of research in the field of responsiveness of the health system in Pakistan opens up a window of opportunity for future researchers. Further research should focus on the quantitative measurement of responsiveness in light of the WHO Multi Country Survey Study on Health and Responsiveness (2001) to establish baseline values. Studies may also be designed to compare individual provincial health departments with respect to responsiveness to the needs of vulnerable and marginalized populations, including the poor and the disabled. Furthermore, research is also recommended to determine the responsiveness of the federal and provincial health systems to the needs of persons with visual, hearing and intellectual impairments as there has been no research on this subject so far. As the findings of this study indicate, research may further quantify the differential responsiveness of the health system by gender and socioeconomic level of consumers, with the ultimate aim of improvement in responsiveness and promotion of social justice.

This research was limited to the primary determinants of healthcare utilization within the framework of the Anderson-Aday model. Future research may focus on the individual as well as comparative effect of these determinants on healthcare utilization, and ultimately on perceived and evaluated health status. Quantitative analysis may be designed to find the strongest predictors of seeking/foregoing healthcare. Similarly, predictors of perceived and evaluated health status may also be determined through quantitative studies performed at a larger scale with representative random samples. Such studies may focus on the general population, the vulnerable populations, as well as
sub-groups within them. The findings of this study indicate that there is much to be explored and discovered within the realm of healthcare provision to the disabled, which will not only improve our understanding of the processes and outcomes, but also lead to improvement in the quality of life for this vulnerable population.
References


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Appendices
Appendix-I-A

Introductory Script for the Focus Group Participants

IRB Study # Pro4994

We are requesting you to take part in a research study, and this is only possible if you are willing to participate in it.

This research study is titled “Responsiveness of the Federal Health System to the Needs of 18-45 Year Old Adults with Physical Disabilities in Islamabad, Pakistan”

The person in charge of this research study is Dr. Shaista Habibullah. This person is called the Principal Investigator. She is being guided in this research by Dr. Russell Kirby. This study is being conducted by the University of South Florida.

The research will be conducted at Islamabad

The purpose of this study is to:

- To determine how the Pakistani federal health system is responding to the expectations of the population of 18-45 year old adults with physical disabilities? and the factors that obstruct it from responding to the needs of young adults with physical disabilities.

- This study is being conducted by the Principal investigator as a part of her PhD program to complete her degree in Public Health.

If you take part in this study, you will be asked to:

- Participate in a survey in which questions will be asked concerning your disability status, education, marital status, occupation and monthly income. This will enable us to determine if you are eligible to take part in the study. Based on your answers, if you are found to have moderate to severe disability and belonging to middle and low socio-economic groups, you will be considered to be eligible to participate in the research.
Appendix-I-A continued

- Participate in a group discussion with people with physical disabilities. This discussion will be moderated by a trained moderator. During this discussion, people will talk about their experiences as patients seeking care in PIMS, NIRM and FGSH. You will be requested to share your experiences, make comments and express your opinions on the interactions you had with the doctors and nurses and within the hospital in general.
- You will participate in only one discussion lasting one to one-and-a-half hour.
- We will audiotape the discussion with your permission.

This research is considered to be minimal risk. That means that the risks associated with this study are the same as what you face every day. There are no known additional risks to those who take part in this study.

You will be reimbursed for any costs you incur on travel and losing work hours if you participate in the group discussion.

We will keep your study records private and confidential.

You should only take part in this study if you want to volunteer. You should not feel that there is any pressure to take part in the study. You are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study.

If you have any questions, concerns or complaints about this study, or experience an adverse event or unanticipated problem, call Dr. Shaista Habibullah at 0336-2210927.

If you have questions about your rights as a participant in this study, general questions, or have complaints, concerns or issues you want to discuss with someone outside the research, call the USF IRB at 001-813-974-5638.

IRB Number: **IRB Study # Pro4994**

IRB Consent Rev. Date: __

IC Adult Minimal Risk - SB Rev:9-3-2010
IRB Study # Pro4994

As a result of this study, participants may be asked to...

IRB Number: IRB Study # Pro4994

IC Adult Minimal Risk - SB Rev-9-3-2010

Page 1 of 2

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Appendix-I-B continued

As achieving may be your patient's health status, it is important to report any adverse events. It is also recommended to consult with your physician. If you have any questions or concerns, please contact your healthcare provider.

AGREEMENT TO SIGN AN INFORMED CONSENT FORM OF THE PARTICIPANTS

IRB Number: IRB Study # Pro4994
IRB Consent Rev. Date:________
IC Adult Minimal Risk - SB Rev.9-3-2010

Page 2 of 2
Appendix II-A

Interviewer ______________________ Date: 
__/__/____(mm/dd/yy)

Respondent ______________________ Time: ______________(AM / PM)

Location

Responsiveness of the Pakistani Health System to the Needs of Adults with Physical Disabilities
Screening questionnaire for adults with physical disabilities

Please answer the following questions as correctly as you can

| Q. 1) Have you received any kind of health services at any of the three federal government hospitals in Islamabad. This means Pakistan Institute of Medical Sciences (aka Complex Hospital or PIMS), National Institute for Handicapped (aka Handicapped persons’ hospital or NIRM) or Federal Government Services hospital (aka Poly Clinic Hospital). Note: If the answer is no, thank the respondent and terminate the screening. If yes, proceed to the next questions. | Yes/No |
| Q. 2) What is your age? | ________ years |
| Q. 3) Are you | a) Married  
b) Divorced  
c) Living separately from husband/wife  
d) Widowed |
| Q. 4) What is your /spouse’s occupational status | a) Presently employed  
b) Spouse employed  
c) Presently not employed  
d) Spouse not employed  
e) Retired |
| Q. 5) What is your /spouse’s education | a) Less than 7th grade  
b) Up to 9th grade  
c) Passed 10th grade  
d) High school graduate (Passed 12th grade, technical education, trade or public school)  
e) Partial college (at least one year) or |
Appendix II-A continued

<table>
<thead>
<tr>
<th>Q. 6) What is your/spouse’s occupation Note: Refer to Hollingshead’s occupational scale and circle the relevant occupation as per respondents answer.</th>
</tr>
</thead>
</table>
| f) Standard college or university graduate  
g) graduate professional training (graduate degree) |

<table>
<thead>
<tr>
<th>Q. 7) What kind of health services have you used in the last 12 months</th>
</tr>
</thead>
</table>
| a) Out-patient  
b) Admitted to hospital for overnight stay  
c) Emergency services |

<table>
<thead>
<tr>
<th>Q. 8) In the last 12 months did you ever not go to the hospital even when ill because you could not afford it.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes/No</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q. 9) What illness is the cause of your disability?</th>
</tr>
</thead>
</table>

*Note: After the respondent has answered these questions, administer the WHO DASII for assessment of functional impairment.*
Appendix II-B

Responsiveness of the Pakistani Health System to the Needs of Adults with Physical Disabilities

Screening questionnaire for adults with physical disabilities

Please answer the following questions as correctly as you can.

<table>
<thead>
<tr>
<th>Q.</th>
<th>Question</th>
<th>Yes/No</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>کیا آپ کے بھی وفاقی حکومت کے بیسٹل سے متعلق نیا طرح کی صحتی سہولتیں سے فائدہ اٹھایا ہے؟</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>کیا آپ ازدواجی حیثیت ہیں؟</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>شوہر/شوہرہ کی موجودہ روزگار کی حیثیت ہیں؟</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>شوہر/شوہرہ کی تعلیم کتنی سال ہے؟</td>
<td></td>
</tr>
</tbody>
</table>

Note: If the answer is no, thank the respondent and terminate the screening. If yes, proceed to the next questions.
Appendix II-B continued

<table>
<thead>
<tr>
<th>Q. ایا شوہر کا پیٹ کیا بے؟ (6)</th>
<th>جزیئی کالج (ب) ای او پی۔ سال تک (د) خصوصی تربیت (ج)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>میں ای او پی۔ سال تک اکراٹری، انجینئرز (ب) اکوائلنسی اور دیگری پاس وارانگ (ی)</td>
</tr>
<tr>
<td></td>
<td>تعیین اعلی جنرلکی تربیت</td>
</tr>
<tr>
<td></td>
<td>Note: Refer to Hollingshead’s occupational scale and circle the relevant occupation as per respondents answer.</td>
</tr>
<tr>
<td>Q. بچہ ایک سال مین اب نے کس فرم کی صحعت ہے؟ (7)</td>
<td>a) بیرونی میزبان</td>
</tr>
<tr>
<td></td>
<td>b) سیہال میں داخل بولے</td>
</tr>
<tr>
<td></td>
<td>c) شعبہ اپرائنسی</td>
</tr>
<tr>
<td>Q. بچہ ایک سال مین کا کبھی ایسا ہوا کہ اپ (8) پازور کی کمی کی وجہ سے صححت کی سیلیاٹ کی استعمال نہ گرا</td>
<td>پہن</td>
</tr>
<tr>
<td></td>
<td>لا</td>
</tr>
<tr>
<td></td>
<td>Q. ایا کی معدودی کی وجہ سے ہماری بے؟ (9)</td>
</tr>
</tbody>
</table>

Note: After the respondent has answered these questions, administer the WHO DASII for assessment of functional impairment.
Appendix III-A

WHODAS 2.0
WORLD HEALTH ORGANIZATION
DISABILITY ASSESSMENT SCHEDULE 2.0

36-item version, interviewer-administered

Introduction

This instrument was developed by the WHO Classification, Terminology and Standards team, within the framework of the WHO/National Institutes of Health (NIH) Joint Project on Assessment and Classification of Disability.

Before using this instrument, interviewers must be trained using the manual Measuring Health and Disability: Manual for WHO Disability Assessment Schedule – WHODAS 2.0 (WHO 2010), which includes an interview guide and other training material.

The versions of the interview available are as follows:

- 36-item – Interviewer-administered
- 36-item – Self-administered
- 36-item – Proxy-administered
- 12-item – Interviewer-administered
- 12-item – Self-administered
- 12-item – Proxy-administered
- 12+24-item – Interviewer-administered

* A computerized version of the interview (iShell) is available for computer-assisted interviews or for data entry

*b Relatives, friends or caretakers

*c The 12-item version explains 81% of the variance of the more detailed 36-item version

For more details of the versions please refer to the WHODAS 2.0 manual Measuring Health and Disability: Manual for WHO Disability Assessment Schedule – WHODAS 2.0 (WHO 2010).

Permission to translate this instrument into any language should be obtained from WHO, and all translations should be prepared according to the WHO translation guidelines, as detailed in the accompanying manual.

For additional information, please visit www.who.int/whodas or contact:

Dr T Bedirhan Üstün
Classification, Terminology and Standards Health Statistics and Informatics
World Health Organization (WHO) 1211 Geneva 27
Switzerland
Tel: + 41 22 791 3609E-mail: ustunb@who.int
Appendix III-A continued

This questionnaire contains the interviewer-administered 36-item version of WHODAS 2.0.

*Instructions to the interviewer are written in bold and italics – do not read these aloud. Text for the respondent to hear is written in standard print in blue.*

*Read this text aloud.*

### Section 1  Face sheet

<table>
<thead>
<tr>
<th>Complete items F1–F5 before starting each interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>F1</td>
</tr>
<tr>
<td>F2</td>
</tr>
<tr>
<td>F3</td>
</tr>
<tr>
<td>F4</td>
</tr>
</tbody>
</table>

<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>day</td>
<td>month</td>
<td>year</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>

F5  | Living situation at time of interview (circle only one) |

<p>| |</p>
<table>
<thead>
<tr>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Independent in community</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Assisted living</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Hospitalized</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>
### Appendix III-A continued

**WHODAS 2.0**

**WORLD HEALTH ORGANIZATION**

**DISABILITY ASSESSMENT SCHEDULE 2.0**

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**Section 2  Demographic and background information**

This interview has been developed by the World Health Organization (WHO) to better understand the difficulties people may have due to their health conditions. The information that you provide in this interview is confidential and will be used only for research. The interview will take 15–20 minutes to complete.

*For respondents from the general population (not the clinical population) say:*

Even if you are healthy and have no difficulties, I need to ask all of the questions so that the survey is complete.

I will start with some background questions.

<table>
<thead>
<tr>
<th>A1</th>
<th><strong>Record sex as observed</strong></th>
<th>Female</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Male</td>
<td>2</td>
</tr>
<tr>
<td>A2</td>
<td>How old are you now?</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>_____</td>
<td></td>
</tr>
<tr>
<td>A3</td>
<td>How many years in all did you spend studying in school, college or university?</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>_____</td>
<td></td>
</tr>
<tr>
<td>A4</td>
<td>What is your current marital status? <em>(Select the single best option)</em></td>
<td>Never married</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Currently married</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Separated</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Divorced</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Widowed</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cohabiting</td>
<td>6</td>
</tr>
</tbody>
</table>

---

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Appendix III-A continued

<table>
<thead>
<tr>
<th>A5</th>
<th>Which describes your main work status best?</th>
<th>Paid work</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(Select the single best option)</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Self employed, such as own your business or farming</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Non-paid work, such as volunteer or charity</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Student</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Keeping house/ homemaker</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Retired</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Unemployed (health reasons)</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Unemployed (other reasons)</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Other (specify)</td>
<td>9</td>
</tr>
</tbody>
</table>
Appendix III-A continued

Section 3 Preamble

Say to respondent:
The interview is about difficulties people have because of health conditions.

Hand flashcard #1 to respondent and say:
By health condition I mean diseases or illnesses, or other health problems that may
be short or long lasting; injuries; mental or emotional problems; and problems with
alcohol or drugs.

Remember to keep all of your health problems in mind as you answer the questions.
When I ask you about difficulties in doing an activity think about …

Point to flashcard #1 and explain that “difficulty with an activity” means:
• Increased effort
• Discomfort or pain
• Slowness
• Changes in the way you do the activity.

Say to respondent:
When answering, I’d like you to think back over the past 30 days. I would also like
you to answer these questions thinking about how much difficulty you have had, on
average, over the past 30 days, while doing the activity as you usually do it.

Hand flashcard #2 to respondent and say:
Use this scale when responding.

Read the scale aloud:
None, mild, moderate, severe, extreme or cannot do.

Ensure that the respondent can easily see flashcards #1 and #2 throughout the
interview.
Appendix III-A continued

Section 4 Domain reviews

Domain 1 Cognition

I am now going to ask some questions about understanding and communicating.

*Show flashcards #1 and #2 to respondent*

<table>
<thead>
<tr>
<th>In the past 30 days, how much difficulty did you have in:</th>
<th>None</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Extreme or cannot do</th>
</tr>
</thead>
<tbody>
<tr>
<td>D1.1 Concentrating on doing something for ten minutes?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>D1.2 Remembering to do important things?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>D1.3 Analysing and finding solutions to problems in day-to-day life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>D1.4 Learning a new task, for example, learning how to get to a new place?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>D1.5 Generally understanding what people say?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>D1.6 Starting and maintaining a conversation?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
Domain 2: Mobility

I am now going to ask you about difficulties in getting around.

*Show flashcards #1 and #2*

<table>
<thead>
<tr>
<th>In the past 30 days, how much difficulty did you have in:</th>
<th>None</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Extreme or cannot do</th>
</tr>
</thead>
<tbody>
<tr>
<td>D2.1 Standing for long periods such as 30 minutes?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>D2.2 Standing up from sitting down?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>D2.3 Moving around inside your home?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>D2.4 Getting out of your home?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>D2.5 Walking a long distance such as a kilometre [or equivalent]?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

*Please continue to next page...*
Appendix III-A continued

WHODAS 2.0

WORLD HEALTH ORGANIZATION
DISABILITY ASSESSMENT SCHEDULE 2.0

<table>
<thead>
<tr>
<th>Domain 3 Self-care</th>
<th>Self-care</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am now going to ask you about difficulties in taking care of yourself.</td>
<td></td>
</tr>
<tr>
<td><em>Show flashcards #1 and #2</em></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>In the past 30 days, how much difficulty did you have in:</th>
<th>None</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Extreme or cannot do</th>
</tr>
</thead>
<tbody>
<tr>
<td>D3.1 Washing your whole body?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D3.2 Getting dressed?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D3.3 Eating?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D3.4 Staying by yourself for a few days?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>D3.1 Washing your whole body?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>D3.2 Getting dressed?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>D3.3 Eating?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>D3.4 Staying by yourself for a few days?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
Appendix III-A continued

**Domain 4**
**Getting along with people**

I am now going to ask you about difficulties in getting along with people. Please remember that I am asking only about difficulties that are due to health problems. By this I mean diseases or illnesses, injuries, mental or emotional problems and problems with alcohol or drugs.

*Show flashcards #1 and #2*

<table>
<thead>
<tr>
<th>In the past 30 days, how much difficulty did you have in:</th>
<th>None</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Extreme or cannot do</th>
</tr>
</thead>
<tbody>
<tr>
<td>D4.1 Dealing with people you do not know?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>D4.2 Maintaining a friendship?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>D4.3 Getting along with people who are close to you?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>D4.4 Making new friends?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>D4.5 Sexual activities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

*Please continue to next page...*
Appendix III-A continued

WHODAS 2.0

World Health Organization
Disability Assessment Schedule 2.0

Domain 5 Life activities

5(1) Household activities

I am now going to ask you about activities involved in maintaining your household, and in caring for the people who you live with or are close to. These activities include cooking, cleaning, shopping, caring for others and caring for your belongings.

Show flashcards #1 and #2

<table>
<thead>
<tr>
<th>Because of your health condition, in the past 30 days, how much difficulty did you have in:</th>
<th>None</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Extreme or cannot do</th>
</tr>
</thead>
<tbody>
<tr>
<td>D5.1 Taking care of your household responsibilities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>D5.2 Doing your most important household tasks well?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>D5.3 Getting all the household work done that you needed to do?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>D5.4 Getting your household work done as quickly as needed?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

If any of the responses to D5.2–D5.5 are rated greater than none (coded as “1”), ask:

<table>
<thead>
<tr>
<th>D5.01 In the past 30 days, on how many days did you reduce or completely miss household work because of your health condition?</th>
<th>Record number of days</th>
</tr>
</thead>
</table>

If respondent works (paid, non-paid, self-employed) or goes to school, complete questions D5.5–D5.10 on the next page. Otherwise, skip to D6.1 on the following page.
Appendix III-A continued

5(2) Work or school activities
Now I will ask some questions about your work or school activities.

Show flashcards #1 and #2

<table>
<thead>
<tr>
<th>Because of your health condition, in the past 30 days how much difficulty did you have in:</th>
<th>None</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Extreme or cannot do</th>
</tr>
</thead>
<tbody>
<tr>
<td>D5.5 Your day-to-day work/school?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>D5.6 Doing your most important work/school tasks well?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>D5.7 Getting all the work done that you need to do?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>D5.8 Getting your work done as quickly as needed?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>D5.9 Have you had to work at a lower level because of a health condition?</td>
<td>No</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D5.10 Did you earn less money as the result of a health condition?</td>
<td>No</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix III-A continued

If any of D5.5–D5.8 are rated greater than none (coded as “1”), ask:

<table>
<thead>
<tr>
<th>D5.02</th>
<th>In the past 30 days, on how many days did you miss work for half a day or more because of your health condition?</th>
<th>Record number of days</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please continue to next page...
Appendix III-A continued

**WHODAS 2.0**

**WORLD HEALTH ORGANIZATION**  
**DISABILITY ASSESSMENT SCHEDULE 2.0**

---

**Domain 6  Participation**

Now, I am going to ask you about your participation in society and the impact of your health problems on you and your family. Some of these questions may involve problems that go beyond the past 30 days, however in answering, please focus on the past 30 days. Again, I remind you to answer these questions while thinking about health problems: physical, mental or emotional, alcohol or drug related.

*Show flashcards #1 and #2*

<table>
<thead>
<tr>
<th>In the past 30 days:</th>
<th>None</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Extreme or cannot do</th>
</tr>
</thead>
<tbody>
<tr>
<td>D6.1 How much of a problem did you have joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>D6.2 How much of a problem did you have because of barriers or hindrances in the world around you?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>D6.3 How much of a problem did you have living with dignity because of the attitudes and actions of others?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>D6.4 How much time did you spend on your health condition or its consequences?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
Appendix III-A continued

<p>| | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>D6.5</strong></td>
<td>How much have you been emotionally affected by your health condition?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>D6.6</strong></td>
<td>How much has your health been a drain on the financial resources of you or your family?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>D6.7</strong></td>
<td>How much of a problem did your family have because of your health problems?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>D6.8</strong></td>
<td>How much of a problem did you have in doing things by yourself for relaxation or pleasure?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
Appendix III-A continued

| H1 | Overall, in the past 30 days, how many days were these difficulties present? | Record number of days — |
| H2 | In the past 30 days, for how many days were you totally unable to carry out your usual activities or work because of any health condition? | Record number of days — |
| H3 | In the past 30 days, not counting the days that you were totally unable, for how many days did you cut back or reduce your usual activities or work because of any health condition? | Record number of days — |

This concludes the interview. Thank you for participating.
Appendix III-A continued

WHODAS 2.0
WORLD HEALTH ORGANIZATION
DISABILITY ASSESSMENT SCHEDULE 2.0

Flashcard 1

Health conditions:

- Diseases, illnesses or other health problems
- Injuries
- Mental or emotional problems
- Problems with alcohol
- Problems with drugs

Having difficulty with an activity means:

- Increased effort
- Discomfort or pain
- Slowness
- Changes in the way you do the activity

Think about the past 30 days only.
WHODAS 2.0

WORLD HEALTH ORGANIZATION
DISABILITY ASSESSMENT SCHEDULE 2.0

Flashcard 2

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>Mild</td>
<td>Moderate</td>
<td>Severe</td>
<td>Extreme or cannot do</td>
</tr>
</tbody>
</table>
36-item version, interviewer-administered

Introduction

This instrument was developed by the WHO Classification, Terminology and Standards team, within the framework of the WHO/National Institutes of Health (NIH) Joint Project on Assessment and Classification of Disability.

Before using this instrument, interviewers must be trained using the manual Measuring Health and Disability: Manual for WHO Disability Assessment Schedule – WHODAS 2.0 (WHO 2010), which includes an interview guide and other training material.

The versions of the interview available are as follows:

- 36-item – Interviewer-administered *
- 36-item – Self-administered
- 36-item – Proxy-administered *
- 12-item – Interviewer-administered *
- 12-item – Self-administered
- 12-item – Proxy-administered
- 12+24-item – Interviewer-administered

* A computerized version of the interview (iShield) is available for computer-assisted interviews or for data entry

* Relatives, friends or caretakers

* The 12-item version explains 81% of the variance of the more detailed 36-item version

For more details of the versions please refer to the WHODAS 2.0 manual Measuring Health and Disability: Manual for WHO Disability Assessment Schedule – WHODAS 2.0 (WHO 2010).

Permission to translate this instrument into any language should be obtained from WHO, and all translations should be prepared according to the WHO translation guidelines, as detailed in the accompanying manual.

For additional information, please visit www.who.int/whodas or contact:

Dr T Bedirhan Üstün
Classification, Terminology and Standards
Health Statistics and Informatics
World Health Organization (WHO)
1211 Geneva 27
Switzerland

Tel +41 22 791 3609
E-mail: ustunb@who.int
Appendix III-B continued

This questionnaire contains the interviewer-administered 36-item version of WHODAS 2.0.

Instructions to the interviewer are written in bold and italics – do not read these aloud.

Text for the respondent to hear is written in

standard print in blue.

Read this text aloud.

Section 1 Face sheet

<table>
<thead>
<tr>
<th>Complete items F1–F5 before starting each interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>F1</td>
</tr>
<tr>
<td>F2</td>
</tr>
<tr>
<td>F3</td>
</tr>
<tr>
<td>F4</td>
</tr>
<tr>
<td>F5</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

Page 2 of 10 (36-item, interviewer-administered)
### Section 2  Demographic and background information

For respondents from the general population (not the clinical population) say:

Even if you are healthy and have no difficulties, I need to ask all of the questions so that the survey is complete. I will start with some background questions.

<table>
<thead>
<tr>
<th>A1</th>
<th>Record Sex as observed</th>
<th>Female</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Male</td>
<td>2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>A2</th>
<th>اس وقت ایب کی عمر کتنی ہے؟</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>A3</th>
<th>اب نہ سکول کا لیکھ / بیوپریسن سے کتنی سال تعلیم حاصل کی؟</th>
<th>ممنون</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>A4</th>
<th>کہیں شادی انتی ہوئی ہے؟</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>A5</th>
<th>اگر کہیں شادی ہوئی ہے کاں کہاں کی ہوئی؟</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

---

**Page 3 of 10 (36-item, interviewer-administered)**
Appendix III-B continued
Appendix III-B continued

Section 4 Domain reviews

Domain 1 Cognition

I am now going to ask some questions about understanding and communicating.

**Show flashcards #1 and #2 to respondent**

<table>
<thead>
<tr>
<th>Domain 1 Cognition</th>
<th>#1</th>
<th>#2</th>
</tr>
</thead>
<tbody>
<tr>
<td>D1.1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>D1.2</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>D1.3</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>D1.4</td>
<td>4</td>
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<td>D1.5</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>D1.6</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>

**Domain 2 Mobility**

Please continue to next page...

---

Page 5 of 10 (36 items, interviewer-administered)
Appendix III-B continued

**Domain 3**  
**Self-care**

Show flashcards #1 and #2

<table>
<thead>
<tr>
<th>Domain</th>
<th>Description</th>
<th>Code</th>
<th>Score 1</th>
<th>Score 2</th>
<th>Score 3</th>
<th>Score 4</th>
<th>Score 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>D3.1</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>D3.2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D3.3</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>D3.4</td>
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</tr>
</tbody>
</table>

**Domain 4**  
**Getting along with people**

Show flashcards #1 and #2

<table>
<thead>
<tr>
<th>Domain</th>
<th>Description</th>
<th>Code</th>
<th>Score 1</th>
<th>Score 2</th>
<th>Score 3</th>
<th>Score 4</th>
<th>Score 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>D4.1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D4.2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D4.3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D4.4</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>D4.5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Please continue to next page...*
Appendix III-B continued

### WHODAS 2.0

#### Domain 5: Life activities

**5(1): Household activities**

<table>
<thead>
<tr>
<th>Domain</th>
<th>Description</th>
<th>Severity</th>
<th>Frequency</th>
<th>Duration</th>
<th>Caffeine</th>
<th>Other</th>
<th>Pain</th>
<th>Support</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>D5.1</td>
<td>1 day to 3 days per week</td>
<td>1</td>
<td>1</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D5.2</td>
<td>4 days to 7 days per week</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D5.3</td>
<td>8 days to 14 days per week</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D5.4</td>
<td>15 days to 21 days per week</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D5.5</td>
<td>More than 21 days per week</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If any of the responses to D5.2-D5.5 are rated greater than none (coded as "1"), ask:

**D5.01**

Record Number of Days

If respondent works (paid, no-paid, self-employed) or goes to school, complete questions D5.5-D, 10 on the next page. Otherwise, skip to D6.1 on the following page.
### Appendix III-B continued

#### Work or school activities

<table>
<thead>
<tr>
<th>Card</th>
<th>Description</th>
<th>Option 1</th>
<th>Option 2</th>
<th>Option 3</th>
<th>Option 4</th>
<th>Option 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>D5.5</td>
<td>Classrooms are noisy</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>D5.6</td>
<td>The classroom is too hot</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>D5.7</td>
<td>Cannot complete tasks</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>D5.8</td>
<td>Cannot complete tasks</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>D5.9</td>
<td>Cannot complete tasks</td>
<td>No</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D5.10</td>
<td>Cannot complete tasks</td>
<td>Yes</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If any of the responses to D5.5-D5.8 are rated greater than none (coded as “1”), ask:

<table>
<thead>
<tr>
<th>Card</th>
<th>Description</th>
<th>Option 1</th>
<th>Option 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>D5.02</td>
<td>Record Number of Days</td>
<td>Record Number of Days</td>
<td></td>
</tr>
</tbody>
</table>

Please continue to next page...

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Page 8 of 10 (36-item, interviewer-administered)
## Domain 6 Participation

**Show flashcards #1 and #2**

| Domain 6 Participation | کوئی | معمولی | کافی | زیاد | کمیابی
|------------------------|------|--------|------|------|--------
| **D6.1** Ab ko معذرت کی کا کمیابی میں عام لوگ یا نسیشن کرنا یا سرمائی مشکل پیدا ہو یا معاون، دیا ہو، اور دوسرے موضوعات میں عالمی | 1    | 2      | 3    | 4    | 5      |
| **D6.2** Ab ko مشکل پیدا ہو یا معاون، دیا ہو، اور دوسرے موضوعات میں | 1    | 2      | 3    | 4    | 5      |
| **D6.3** Ab ko مشکل پیدا ہو یا معاون، دیا ہو، اور دوسرے موضوعات میں | 1    | 2      | 3    | 4    | 5      |
| **D6.4** Ab ko مشکل پیدا ہو یا معاون، دیا ہو، اور دوسرے موضوعات میں | 1    | 2      | 3    | 4    | 5      |
| **D6.5** Ab ko مشکل پیدا ہو یا معاون، دیا ہو، اور دوسرے موضوعات میں | 1    | 2      | 3    | 4    | 5      |
| **D6.6** Ab ko مشکل پیدا ہو یا معاون، دیا ہو، اور دوسرے موضوعات میں | 1    | 2      | 3    | 4    | 5      |
| **D6.7** Ab ko مشکل پیدا ہو یا معاون، دیا ہو، اور دوسرے موضوعات میں | 1    | 2      | 3    | 4    | 5      |
| **D6.8** Ab ko مشکل پیدا ہو یا معاون، دیا ہو، اور دوسرے موضوعات میں | 1    | 2      | 3    | 4    | 5      |
Appendix IV-A

Moderator______________________ Date: ____/____/_____(mm/dd/yy)
Notetaker: ___________________ Time: _______________(AM / PM)

Responsiveness of the Federal Health System to the Needs of 18-45 Year Old Adults with Physical Disabilities in Islamabad, Pakistan

Focus Group Moderator’s Guide

INTRODUCTION Duration: 5 minutes

Thank you for taking the time to meet with us for this discussion. We know that your time is valuable and appreciate your participation. Before we start, let us take some time to introduce ourselves and explain why we are here to speak with you.

Introduce Moderator and note taker

Introduce moderator

My name is Dr. Shaista Habibullah and I am the moderator for this discussion. I will ensure that everyone participates in the discussion and that it is kept focused on the topic.

Introduce note taker

Rabia Rasheed will take notes during the discussion so that whatever we discuss today is recorded and no information goes to waste.

Introduce project

The main purpose of this discussion is to understand if the Pakistani health system is responding to the expectations of adult persons with physical disabilities. In order to do this we will ask your opinions and views of your experiences when seeing doctors, nurses and physiotherapists in federal government hospitals. This research will help us know how things can be improved to serve you better.

Note: Definitions of responsiveness, dignity, confidentiality, autonomy, clarity of patient-provider communication, prompt attention, quality of amenities, choice of provider and access to social support should be on the white-board. Read them aloud for the participants to hear clearly and answer any questions.
Appendix IV-A continued

This is one of many discussions that will take place in Islamabad. We want to know what are your thoughts, opinions and experiences about the healthcare system meeting your expectations. When discussing these issues please recall your experiences of meeting with doctors, nurses and physiotherapists as patients in the federal government hospitals in the past 12 months and share your stories and opinions with us. There is no right or wrong answer. We are interested in finding out what you think. This is a conversation so feel free to say what you think about the topic. The information we gather will be summarized and shared with the Ministry of Health so that they may improve health services for you

When you entered, there was a fact sheet with more detailed information on the project and name and phone number of the Principal Investigator for this research, in case you would like more information after you leave here today. Please make sure you have a copy of it when you go home.

Confidentiality:

What we discuss today will not be shared with anyone. We will make summaries of what was said and will not point out who said what or who took part in the discussions. Please use only your first name or an “alias” during the discussion.

In order to accurately report this discussion, we will write down notes and also use a voice recorder. What you say is very important and we want to make sure we do our best to get your exact comments. You do not have to answer a question if you do not want to and if you would like to make a comment without having the recorder on, just let us know and we’ll stop it. After this discussion the recordings will be stored in the investigators office and will be destroyed after we convert them to written form. Your full name will never be attached to the recording. Is this ok with everyone?

Ground Rules:

- You don’t have to answer any question you don’t want to.

- If at any point you feel uncomfortable or want to end the discussion, please let me know.

- Speak clearly and loudly.
Appendix IV-A continued

- Listen to the responses of other participants and try not to interrupt when others are speaking.

- If you cannot hear what I or other participants are saying, please ask us to speak up.

- Lastly, please do not discuss what others have said here when you leave here today.

Does anyone have any questions about anything I have said so far?

SECTION 1: PARTICIPANT BACKGROUND  
Duration: 10 minutes

Moderator: The first question is aimed at getting to know you a little better. I invite you all to introduce yourselves one by one and say a little bit on

a) Who you are

b) What is your professional background?

SECTION 2: EXPERIENCE OF DIGNITY IN CARE  
Duration: 10 minutes

Note: Define Dignity

Moderator:

Q. 1) In your opinion, how important is it that doctors and nurses treat you with respect when you go to the federal government hospitals?

Q. 2) Think about your last visit to the hospital and please tell us how the doctors and nurses treated you?

Note: After completion of the story the moderator should prompt the respondent for more information using the following probes, if necessary and not covered by the respondent:

Probes:

How did you feel about the way you were treated?

What did you do about it?

Did it have any effect on your attitude towards the doctor/ nurse/ hospital?
Appendix IV-A continued

*Did you go back to the same hospital for future health care?*

Note: The moderator then opens the discussion to the rest of the group.

Moderator: Now, please would the rest of you like to discuss your opinions about what has been described by X.

**SECTION 3: EXPERIENCE OF CONFIDENTIALITY IN CARE**  
**Duration:** 10 minutes

Note: Define Confidentiality

Moderator:

Q. 3) How important is it for you that doctors and nurses do not tell others about your illness, for example your laboratory-test results?

Q. 4) In your opinion, is it essential that no one hears your discussion with your doctor or nurse about your illness, or that no one sees you when your doctor or nurse is carrying out physical examinations or giving you injections or other treatments?

Q. 5) Think about your own experience and tell us how you feel the doctors and nurses make any efforts to safeguard information about your illness and treatment.

Note: After completion of the story the moderator should prompt the respondent for more information using the following probes, if necessary and not covered by the respondent:

Probes:

*How did you feel about the way you were treated?*

*Threatened, embarrassed, insulted*

*Did it have any effect on your attitude towards that hospital/ doctor/ nurse?*

*Would you go back to the same hospital if you fell ill again?*

Note: The moderator then opens the discussion to the rest of the group.

Moderator: Now, please would the rest of you like to discuss your opinions about what has been described by X.
SECTION 4: EXPERIENCE OF CLEAR PATIENT-PROVIDER COMMUNICATION

Duration: 10 minutes

Note: Define clear patient-provider communication

Moderator:

Q. 6) How important is it for you that your doctors provide you full information about your illness in language that you can easily understand?

Q. 7) How essential is it that your doctors and nurses listen to your complaints and understand your problems before starting treatment?

Q. 8) Think about your last visit to the hospital and tell us how the doctors and nurses listened to you and talked to you about your illness.

Note: After completion of the story the moderator should prompt the respondent for more information using the following probes, if necessary and not covered by the respondent:

Probes:

Did the doctor answer all your questions?

Were you satisfied with the information provided to you?

Did it help you understand your illness and its treatment?

Note: The moderator then opens the discussion to the rest of the group.

Moderator: Now, please would the rest of you like to discuss your opinions about what has been described by X.

SECTION 5: EXPERIENCE OF AUTONOMY IN DECISION MAKING

Duration: 10 minutes

Note: Define Autonomy

Moderator:

Q. 9) In your opinion, it is important for you to make decisions about your treatment after getting the full information about your illness from the doctors and nurses?

Q. 10) In your experience as patients, how often your doctors respect your decisions about the kind of treatment you want to receive.
Note: After completion of the story the moderator should prompt the respondent for more information using the following probes, if necessary and not covered by the respondent:

Probes:

*How do you feel about the way you are treated?*

*Important/ unimportant*

*Are your opinion respected?*

*Has it had any effect on your attitude towards hospitals/ doctors/ nurses?*

*Would you go back to the same hospital in case you fell ill again?*

Note: The moderator then opens the discussion to the rest of the group.

Moderator: Now, please would the rest of you like to discuss your opinions about what has been described by X.

**SECTION 6: EXPERIENCE OF PROMPT ATTENTION**

*Duration: 10 minutes*

Note: Define prompt attention

Moderator:

Q. 11) When visiting the hospitals, how important is it for you to see the doctor immediately?

Q. 12) Please tell us about your experience of waiting your turn on your last visit to the hospital.

Note: After completion of the story the moderator should prompt the respondent for more information using the following probes, if necessary and not covered by the respondent:

Probes:

*Having had the experience of waiting for your doctor, did you ever decide against seeking care?*

*How did it make you feel?*
Did you go back to the same doctor/hospital the next time you fell ill?

Note: The moderator then opens the discussion to the rest of the group.

Moderator: Now, please would the rest of you like to discuss your opinions about what has been described by X.

SECTION 6: EXPERIENCE OF QUALITY OF AMENITIES AT HEALTHCARE FACILITIES

Duration: 10 minutes

Note: Define Quality of Amenities

Moderator:

Q. 13) In your opinion, how important is it that hospital buildings be clean, well lighted and comfortable?

Q. 14) As patients what are your views on the quality of food and medications provided to you in the hospitals?

Q. 15) Thinking of your personal experiences, what kinds of problems do you usually have when moving around in hospital buildings?

Note: After completion of the story the moderator should prompt the respondent for more information using the following probes, if necessary and not covered by the respondent:

Probes:

*Did the wards, restrooms and other places have enough space for you to move your wheel chair?*

*Was there enough space for people to sit comfortably when waiting their turns in the OPD?*

*In case of in-patient care, were the wards spacious and comfortable enough?*

Note: The moderator then opens the discussion to the rest of the group

Moderator: Now, please would the rest of you like to discuss your opinions about what has been described by X.
SECTION 8: CHOICE OF HEALTH CARE PROVIDERS  

Note: Define Choice of healthcare provider

Moderator:

Q. 16) How important is it for you to have a choice of the doctors for your treatment, to have a second opinion from another doctor if you are not satisfied with the first?

Q. 17) In your experience as patients, to what extent you have a variety of doctors to choose from at your own will?

Note: After completion of the story the moderator should prompt the respondent for more information using the following probes, if necessary and not covered by the respondent:

Probes:

- How did your doctor react to your decision of seeking care elsewhere?
- How did you feel about the doctors’ reaction?
- How did the doctors’ reaction affect your behavior towards them?

Note: The moderator then opens the discussion to the rest of the group.

Moderator: Now, please would the rest of you like to discuss your opinions about what has been described by X.

SECTION 9: ACCESS TO SOCIAL SUPPORT DURING CARE  

Note: Define Access to social support networks during care

Moderator:

Q. 18) How important is it for you have your friends and family visit you when you are admitted to the hospital?

Q. 19) What was your experience of being in contact with your friends and family while admitted to the hospital? How often were they allowed to visit you, bring you food and provide you company?
Note: After completion of the story the moderator should prompt the respondent for more information using the following probes, if necessary and not covered by the respondent:

Probes:

*What was the behavior of security staff towards your visitors?*

*Was it easy or difficult for your family members to be with you?*

*How did you feel about it?*

Note: The moderator then opens the discussion to the rest of the group.

Moderator: Now, please would the rest of you like to discuss your opinions about what has been described by X.

SECTION 10: FINAL REMARKS Duration: 5 minutes

*Note: The moderator should close the session by thanking everyone for their participation in the focus group*

Moderator: Your stories and experiences have been very insightful and interesting. I would like to thank you all for participation in this discussion. Before we go, I would like you to respond to these last questions one by one.

Is there anything important in your opinion that we missed in today’s discussion?

Based on everything that you told us today, what do you think should be done to improve the health services to meet your expectations?

Thank you all very much for your time and effort.
Appendix IV-B

Responsiveness of the Federal Health System to the Needs of 18-45 Year Old Adults with Physical Disabilities in Islamabad, Pakistan

Focus Group Moderator’s Guide

INTRODUCTION

Introduction of moderator

Note: Definitions of responsiveness, dignity, confidentiality, autonomy, clarity of patient-provider communication, prompt attention, quality of amenities, choice of provider and access to social support should be on the white-board. Read them aloud for the participants to hear clearly and answer any questions.

Introduction of note taker

Note: If you need any clarification or have questions, please feel free to ask.

Project introduction

Note: This introduction will be followed by a brief overview of the project.
Appendix IV-B continued

Salam! Rukhsan eor aor an ky barre mein mein yad rakhna. Bewaakeh ghar aaur ko yeh jawab samajh bhi yeh viss mein bhi aatao ky kahan.

Eh mey baini se yeh muhafizato ekthar eor eis qaumi eor joint commission ko yeh jawab eor bahaar ki bahat ki janki. Aap ko qarai

ky janki eor bahaar ko sulath ko kyun yad rakhna?

Eh tafaq ek koi bari mein miaz muhafizato ko sakeen eor bahaar ko miaz muhafizato ko halal karana janki mein to inn ko bahaar kar

sakeen bihar yad raha ky janki mein bhi aap eor sulath mein aik kay ki ukhad prakrto kare?

Azaadari:

Jaowe ko hain bhum bhar abhin aise ky kar ke yeh meh mey mian ki kuch yeh janki gaa! Aap aye ky koi bahaar ko kyun yad rakhna?

Mukhtar kar ke ky bahar mein mian ki kuch yeh janki ka lata hai yeh saath mein bahut mein yeh ko kyun yad rakhna?

Eh janki mein ko yeh koi bahaar ko yeh janki ka lata hai yeh saath mein bahut mein yeh ko kyun yad rakhna?

Eh janki mein ko yeh koi bahaar ko yeh janki ka lata hai yeh saath mein bahut mein yeh ko kyun yad rakhna?

Eh tafaq ek koi bari mein miaz muhafizato ko sakeen eor bahaar ko miaz muhafizato ko halal karana janki mein to inn ko bahaar kar

sakeen bihar yad raha ky janki mein bhi aap eor sulath mein aik kay ki ukhad prakrto kare?
Appendix IV-B continued

SECTION 1: PARTICIPANT BACKGROUND
Duration: 10 minutes

SECTION 2: EXPERIENCE OF DIGNITY IN CARE
Duration: 10 minutes

Note: Define Dignity

SECTION 3: EXPERIENCE OF CONFIDENTIALITY IN CARE
Duration: 10 minutes

Note: Define Confidentiality
Appendix IV-B continued

SECTION 4: EXPERIENCE OF CLEAR PATIENT-PROVIDER COMMUNICATION

Duration: 10 minutes

Note: Define clear patient-provider communication

Note: After completion of the story the moderator should prompt the respondent for more information using the following probes, if necessary and not covered by the respondent:

Note: The moderator then opens the discussion to the rest of the group.
Appendix IV-B continued

SECTION 5: EXPERIENCE OF AUTONOMY IN DECISION MAKING

Duration: 10 minutes

Mizan:

سوال نمبر 9:
آپ کی نئیڈس پر بات کئی ایم سے کہ گاؤنہ / فیصلہ کریں / نرس سے مکمل معلومات ملتی ہے کہ بعد آپ کی علاج

سوال نمبر 10:
بطور مرضیش آپ کہ ترجیح کیں یا یہ، نظر انداز کریں کہ اس کا معاہدہ میں آپ کی کہاں یا

فیصلاؤن کا احترام کریں یا؟

Note: After completion of the story the moderator should prompt the respondent for more information using the following probes, if necessary and not covered by the respondent:

امس سون کی بارہ میں آپ کی کہا احساسات ہیں؟

سون / غیر اس محسوس کیا

کیا آپ کی راضی کو اپنی دوستی؟

کیا آپ اسنواں سے کہا گاہک/ نرس/ بستریکاہ سے بارہ میں آپ کی خیالات میں کوئی تبدیلی واقع ہوئی؟

اس کی دفعہ بیماری یا کیا آپ اسی بستریکاہ میں واپس گئے؟

Note: The moderator then opens the discussion to the rest of the group.

Mizan:

اب باتی خاصی کی بھگاری ہے کہ کے اسنواں سے بارہ میں آپ کی خیالات کا

اظہار فرمائیں.

SECTION 6: EXPERIENCE OF QUALITY OF AMENITIES AT HEALTHCARE FACILITIES

Duration: 10 minutes

Note: Define Quality of amenities

Mizan:

سوال نمبر 11:
آپ کی خیالات میں ہے کہ سیستم کی عمارت میں صاف، روشن اور آرام دہی?

سوال نمبر 12:
بطور مرضیش سیستم میں افراہم کی جانی والی ایمیل اور خوراک، کہ بارہ میں آپ کی کہا رائے?

سوال نمبر 13:
انہے دائرہ ترجیح کی بات کی ہے، سیستم میں خیالات میں چھوٹے / بھینے میں آپ کی کہا

مثبت ہوئی؟

Note: After completion of the story the moderator should prompt the respondent for more information using the following probes, if necessary and not covered by the respondent:

کیا وارث، غسل خانوں اور دوسری چیزوں پر اینٹی گیری تھی کہ آپ کو اپنی ہدایت کے ماتمہ ہوئے?

کیا شہری پیرپہتی مرضیش میں انتظار کہا کہ ہے؟

کہا سیستم میں داخل مرضیش کے لیے وارثہ کہا اور آرام دہی؟

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Appendix IV-B continued

Note: The moderator then opens the discussion to the rest of the group.

SECTION 7: EXPERIENCE OF PROMPT ATTENTION
Duration: 10 minutes
Define prompt attention

Note: After completion of the story the moderator should prompt the respondent for more information using the following probes, if necessary and not covered by the respondent:

- کی ہے ایسی یہ کہ ذاتی؟ کا انظار کرنے کے لیے اب نے کچھ جانے کو ترجیح دی؟
- اس سلوب کی وجہ سے یہ کا کو یہ مخصوص ہے؟
- اگر دفع بیمار پڑنا ہو یا اسی کا بھی بیمار یا وسیع ہو؟

Note: The moderator then opens the discussion to the rest of the group.

SECTION 8: CHOICE OF HEALTH CARE PROVIDERS
Duration: 10 minutes
Define choice of healthcare provider

Note: After completion of the story the moderator should prompt the respondent for more information using the following probes, if necessary and not covered by the respondent:

- اپنے کے اس دوسرے کا ذاتی سے مشور کرنے کے لیے اپنے کے اس کا کیا ہوئے تھا؟
- ہمارے کے اس روپ میں اس کا کیا اس کا کہاں تعلیم؟
- اس کے کا ذاتی کا ذد اس سے کا کہاں میں اس کا کیا کہاں میں تبدیل؟

Note: The moderator then opens the discussion to the rest of the group.

Appendix IV-B continued
SECTION 9: ACCESS TO SOCIAL SUPPORT DURING CARE

Duration: 10 minutes
Define access to social support networks during care

Note: After completion of the story the moderator should prompt the respondent for more information using the following probes, if necessary and not covered by the respondent:

Note: The moderator then opens the discussion to the rest of the group.

SECTION 10: FINAL REMARKS

Duration: 5 minutes

Note: The moderator should close the session by thanking everyone for their participation in the focus group.

*********************************************************************
Appendix V-A

Study ID: Pro00004994 Date Approved: 9/29/2011 Expiration Date: 9/29/2012

INFORMED CONSENT TO PARTICIPATE IN RESEARCH
INFORMATION TO CONSIDER BEFORE TAKING PART IN THIS RESEARCH STUDY

IRB Study # Pro4994

You are being asked to take part in a research study. Research studies include only people who choose to take part. This document is called an informed consent form. Please read this information carefully and take your time making your decision. Ask the researcher or study staff to discuss this consent form with you, please ask him/her to explain any words or information you do not clearly understand. We encourage you to talk with your family and friends before you decide to take part in this research study. The nature of the study, risks, inconveniences, discomforts, and other important information about the study are listed below.

We are asking you to take part in a research study called:

Responsiveness of the Federal Health System to the Needs of 18-45 Year Old Adults with Physical Disabilities in Islamabad, Pakistan

The person in charge of this research study is Dr. Shaista Habibullah. This person is called the Principal Investigator. However, other research staff may be involved and can act on behalf of the person in charge. She is being guided in this research by Dr. Russell Kirby.

The research will be conducted at Islamabad.

PURPOSE OF THE STUDY

The purpose of this study is to:

- To determine how the Pakistani federal health system is responding to the expectations of the population of 18-45 year old adults with physical disabilities and the factors that obstruct it from responding to the needs of young adults with physical disabilities.

- This study is being conducted by the Principal investigator as a part of her PhD program to complete her degree in Public Health.

STUDY PROCEDURES

If you take part in this study, you will be asked to:

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- Participate in a screening survey in which questions will be asked concerning your disability status, education, marital status, occupation and monthly income. This will enable us to determine if you are eligible to take part in the study. Based on your answers, if you are found to have moderate to severe disability and belonging to middle and low socio-economic groups, you will be considered to be eligible to participate in the research.
- If you are eligible and willing, you will be requested to participate in a group discussion with people with physical disabilities. This discussion will be moderated by a trained moderator. During this discussion, people will talk about their experiences as patients seeking care in PIMS, NIRM and FGSH. You will be requested to share your experiences, make comments and express your opinions on the interactions you had with the doctors and nurses and within the hospital in general.
- You will participate in only one discussion lasting one to one-and-a-half hour.
- We will audiotape the discussion with your permission, however, if at any time, you want us not to record any of your comments, please let us know. These tapes will only be listened to by the researchers and no other person. These tapes will not have any information that could identify you and they will be kept in a locked cabinet in the Principal Investigators custody. These tapes will be destroyed by computerized deletion 5 years after closing of the study with the USF Institutional Review Board of the University of South Florida.

Total Number of Participants
About 64 individuals will take part in group discussions in this study. A total of 104 individuals will participate in the study in group discussions and interviews.

Alternatives
You do not have to participate in this research study.

Benefits
We are unsure if you will receive any benefits by taking part in this research study.

Risks or Discomfort
This research is considered to be minimal risk. That means that the risks associated with this study are the same as what you face every day. There are no known additional risks to those who take part in this study.

Compensation
You will be reimbursed for any costs you incur on travel and losing work hours if you participate in the group discussion.

Privacy and Confidentiality
We will keep your study records private and confidential. Certain people may need to see your study records. By law, anyone who looks at your records must keep them completely confidential. The only people who will be allowed to see these records are:
- The research team, including the Principal Investigator, study coordinator and other research staff.
Appendix V-A continued

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- Certain university people who need to know more about the study. For example, individuals who provide oversight on this study may need to look at your records. This is done to make sure that we are doing the study in the right way. They also need to make sure that we are protecting your rights and your safety.

- Any agency of the federal, state, or local government that regulates this research. This includes the Department of Health and Human Services (DHHS) and the Office for Human Research Protection (OHRP).

- The USF Institutional Review Board (IRB) and its related staff who have oversight responsibilities for this study, staff in the USF Office of Research and Innovation, USF Division of Research Integrity and Compliance, and other USF offices who oversee this research.

We may publish what we learn from this study. If we do, we will not include your name. We will not publish anything that would let people know who you are.

Voluntary Participation / Withdrawal

You should only take part in this study if you want to volunteer. You should not feel that there is any pressure to take part in the study. You are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study.

You can get the answers to your questions, concerns, or complaints

If you have any questions, concerns or complaints about this study, or experience an adverse event or unanticipated problem, call Dr. Shiasta Habibullah at 0336-2210927.

If you have questions about your rights as a participant in this study, general questions, or have complaints, concerns or issues you want to discuss with someone outside the research, call the USF IRB at 001-813-974-5638.
Appendix V-A continued

Consent to Take Part in this Research Study
It is up to you to decide whether you want to take part in this study. If you want to take part, please sign the form, if the following statements are true.

I freely give my consent to take part in this study and authorize that my health information as agreed above, be collected/disclosed in this study. I understand that by signing / affixing my thumb impression on this form I am agreeing to take part in research. I have received a copy of this form to take with me.

Signature of Person Taking Part in Study ___________________________ Date ___________________________

Printed Name of Person Taking Part in Study ___________________________

Statement of Person Obtaining Informed Consent
I have carefully explained to the person taking part in the study what he or she can expect from their participation. I hereby certify that when this person signs this form, to the best of my knowledge, he/she understands:
• What the study is about;
• What procedures/interventions/investigational drugs or devices will be used;
• What the potential benefits might be; and
• What the known risks might be.

I can confirm that this research subject speaks the language that was used to explain this research and is receiving an informed consent form in the appropriate language. Additionally, this subject reads well enough to understand this document or, if not, this person is able to hear and understand when the form is read to him or her. This subject does not have a medical/psychological problem that would compromise comprehension and therefore makes it hard to understand what is being explained and can, therefore, give legally effective informed consent. This subject is not under any type of anesthesia or analgesic that may cloud their judgment or make it hard to understand what is being explained and, therefore, can be considered competent to give informed consent.

Signature of Person Obtaining Informed Consent / Research Authorization ___________________________ Date ___________________________

Printed Name of Person Obtaining Informed Consent / Research Authorization ___________________________

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Statement of Person Witnessing Thumb Impression

I confirm that the thumb impression imprinted on this consent form belongs to the same person who has heard to the reading of this consent form and has freely consented to participate in this research study.

I also confirm that this thumb impression was imprinted in front of me.

_________________________________________  ____________
Signature of Person witnessing thumb impression  Date

______________________________________________
Printed Name of Person witnessing thumb impression
Appendix V-B

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IRB Study # Pro4994

Ab Payee تحقيق من حمص ليني كاجاجات نهـ.

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• Bowen's test for the virus is different from that of the human respiratory system in
  which the virus is replicated to form a different type of disease. The study results
  show that the virus is present in the respiratory system and is capable of
  infecting different types of cells.

As per the study, samples were taken from different parts of the body to
investigate the presence of the virus. The results showed that the virus
was present in different parts of the body, including the respiratory system.

The study also showed that the virus is capable of infecting different types of cells
in the respiratory system.

The study results indicate that the virus is capable of infecting different types of cells
in the respiratory system. The results showed that the virus was present in different parts of the body, including the respiratory system.

The study also showed that the virus is capable of infecting different types of cells
in the respiratory system.
Appendix V-B continued

Statement of Person Obtaining Informed Consent

I have carefully explained to the person taking part in the study what he or she can expect from their participation. I hereby certify that when this person signs this form, to the best of my knowledge, he/she understands:

- What the study is about;
- What procedures/interventions/investigational drugs or devices will be used;
- What the potential benefits might be; and
- What the known risks might be.

I can confirm that this research subject speaks the language that was used to explain this research and is receiving an informed consent form in the appropriate language. Additionally, this subject reads well enough to understand this document or, if not, this person is able to hear and understand when the form is read to him or her. This subject does not have a medical/psychological problem that would compromise comprehension and therefore makes it hard to understand what is being explained and can, therefore, give legally effective informed consent. This subject is not under any type of anesthesia or analgesic that may cloud their judgment or make it hard to understand what is being explained and, therefore, can be considered competent to give informed consent.

Signature of Person Obtaining Informed Consent / Research Authorization

Date

Printed Name of Person Obtaining Informed Consent / Research Authorization

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Appendix VI

Interviewer ______________________ Date:____ / ____ / ____ (mm/dd/yy)
Respondent ______________________ Time: ______________ (AM / PM)

Responsiveness of the Pakistani Health System to the Needs of Adults with Physical Disabilities

Demographic information sheet for interviewees

Q. 1) How would you identify yourself

    Healthcare policy maker
    Health care manager
    Healthcare provider

Q. 2) Please indicate the highest educational degree you have attained.

Q. 3) What is your specialized field of practice?

Q. 4) How many years have you been working in this field?

Thank you for filling out this sheet. Your participation is highly appreciated.
Appendix VII-A

Interviewer ______________________ Date: ___ / ____ / ____ (mm/dd/yy)

Respondent ______________________ Time: ________________ (AM / PM)

**Responsiveness of the Pakistani Health System to the Needs of Adults with Physical Disabilities**

**Interview Guide for Disability Rights Advocates, Healthcare Providers, Managers and Policy Makers**

Thank you for agreeing to this interview. We understand that your time is precious and deeply appreciate your participation in this study. As you know, this study aims to determine how the Pakistani Federal health system is responding to the needs of adult persons with physical disabilities and to discover the factors that hinder it from responding to this section of the population. We would like to know your opinions and views in light of your experience in our health system.

**Dignity**

Note: Define Dignity

Q. 1) In your opinion, to what extent do doctors, nurses and physiotherapists treat patients with physical disabilities with respect and dignity in the federal government hospitals?

Q. 2) In your opinion, what are some of the system related factors that affect the way healthcare providers interact with this group of patients?

Probes

- Social and cultural factors
- Means to change healthcare providers attitudes

**Confidentiality**

Note: Define Confidentiality

Q. 3) What mechanisms are in place to ensure confidentiality of disabled patients’ personal and medical information in the health system?
Appendix VII-A continued

Q. 4) To what extent do the health care providers make certain that health information in respect of these patients is kept secure?

Appendix VII-A continued

Probes
- Privacy during history taking and physical exam in the inpatient and outpatient departments
- Right of the family to know the diagnosis
- Confidentiality of laboratory and radiology records
- Access to patient records after discharge

**Clear patient-provider communication**

Note: Define Clear patient-provider communication

Q. 5) To what extent do doctors ensure that disabled patients understand the diagnosis, the prognosis and the treatment of their condition?

Q. 6) What are some of the factors that obstruct open communication between doctors and physically disabled adult patients in our health system?

Probes
- Lack of adequate time for medical consultation
- Difference in educational level between doctor and patient
- Lack of understanding of disease by patients
- Lack of patience on the part of providers
- The issue is not considered important
- Cultural constraints

**Autonomy**

Note: Define Autonomy

Q. 7) In what ways do you think our system inhibits autonomous decision making by adults with physical disabilities in regard to their treatment and rehabilitation?

Q. 8) What factors, in your opinion, presently limit the participation of adults with physical disabilities in making autonomous decisions about their treatments?
Appendix VII-A continued

Probes
  ● Social, cultural and family influences
  ● Economic dependency of patients with disabilities
  ● Constraints posed by the health system

**Prompt Attention**

Note: Define Prompt Attention

Q. 9) Based on your experience, how long do you think a physically disabled adult has to wait to get needed healthcare on outpatient or inpatient basis in our health system?

Q. 10) In your opinion, what are the factors that lead to delayed provision of healthcare to this section of the population?

Q. 11) What are some changes that can be brought about in the system to make it easier for physically disabled individuals to access care promptly?

Probes
  ● Number of health care facilities
  ● Number of qualified staff
  ● Payment mechanisms

**Qualities of amenities**

Note: Define Quality of Amenities

Q. 12) What is your opinion concerning the accessibility of bathroom and toilet facilities in our hospitals for adults with physical disabilities?

Q. 13) What are your comments on the physical condition of healthcare facilities in the Pakistani health system?

Q. 14) What is your opinion of the quality of food and medications being provided to patients in the hospitals?

Q. 15) What are reasons for the present condition of the physical infrastructure of healthcare facilities?
Appendix VII-A continued

Probes
- Lack of funding
- Corruption and pilferage of funds
- Lack of managerial commitment
- Lack of managerial competence

**Choice of Provider**

Note: Define Choice of Provider

Q. 16) In what ways do the physically disabled adult patients get the opportunities to choose their healthcare providers in the Pakistani health system?

Q. 17) In your opinion, what are the factors that determine their choices?

Probes
- Cultural influences
- Economic constraints
- Lack of autonomy

**Access to social support networks during care**

Note: Define Access to social support networks during care

Q. 18) In what way do you think the Pakistani health care system inhibits the interaction of physically disabled patients with their families while they are admitted to hospitals?

Probes
- Visiting hours
- Special case of patients in ICU
- Family members bringing food
Appendix VII-A continued

**Concluding remarks**

In light of your experience as a healthcare provider /manager/ policy maker/ disability rights advocate in the Pakistani federal health system, is there anything you would like to add to what we have talked about today?

What are your recommendations for improving the responsiveness of the federal health system to the expectations of persons with physical disabilities in Pakistan?

Note: Thank the respondent for their time and effort.
Appendix VII-B

Interviewer ___________________ Date: __ / __ / ___ (mm/dd/yy)

Respondent ___________________ Time: _________________ (AM / PM)

Responsiveness of the Pakistani Health System to the Needs of Adults with Physical Disabilities

Interview Guide for Disability Rights Advocates, Healthcare Providers, Managers and Policy Makers

اس الترویج میں حاضر ہیں پر اگر کہ یہ شکر گزار بین بھی میں اندھاہے بہ کہ آپ کا وقت بہت قیمتی ہے اور استحقاق میں شمولیت ہے پر اگر کہ یہ ممتن بین پر اس تحقیق پر جانئے کے لیے کہ یہ ہیں جار بھی ہے پاکستان کا وفاقی نظام صحت جس میں افراد کا امیدون پر کس حد تک یہ توثیق ہے یہ تحقیق پر ہوا افراد کی یہ راہ میں رکاوتوں پدیدا کر رہے ہیں ہے پاکستانی نظام صحت کے ساتھ آپ کا تعلق کی وہ جہاں سے اس بارے میں آپ کی معاشرت رائے اور خیالات جاننا چاہیے۔

Dignity

Note: Define Dignity

سوال نمبر 1: آپ کی خیال میں اسلام آباد میں واقع وفاقی بستریالوں میں کام کرنے والے ذاکر ، نرس اور فرزیدہ نھیریاہ کی جس میں افراد میں موجود مرضی کے ساتھ کس حد تک ادب اور عزت سے پیش آتا ہے?

سوال نمبر 2: بمارے نظام صحت میں وہ کون سی عوامل بین جن کی وہ جہاں سے بمارے ذاکر اور فرزیدہ نھیریاہ کی جس میں افراد میں موجود مرضی کے ساتھ اس طرح کا روح رکھتے ہیں?

Probes:

- معاشرتی اور سماجی عوامل
- محکمہ صحت کئے ابٹکارے کی روپون کو تبدیل کرنے کے مکمل طریقے

Confidentiality

Note: Define Confidentiality

سوال نمبر 3: بمارے نظام صحت میں جس میں موجود مرضی کی طبی اور ذاتی معلومات کو صمیم راز میں رکھنے کو کسی بھی بڑھ سکتا ہے؟

سوال نمبر 4: بمارے مہکمہ صحت کئے ابٹکار کئے حوالہ کے تحت جس میں موجود مرضی کی طبی اور ذاتی معلومات کی حفاظت کرنے کی بھی
Appendix VII-B continued

Probes:

- شعبہ بانی بیروتو اور اندرنو مرضیاں میں مرضیوں کی حقیقت لینے اور جسمانی معنیات کرنے وقت
  - رازداری کا خیال رکھنے
- مرضیوں کے لواحقی کا ان کی بھیماری کے بارے میں جانتے کا حق
- مبتلائے کی ثبوت ایکسر اور دیگر تشخیصی طریقے کار کے نتائج، کی حفاظت
- بیسلاہ سے جھیل کے بعد مرضی کے ریکارٹ کی حفاظت

Clear Patient-Provider Communication

Note: Define clear patient-provider communication

سوال نمبر 5: ذاکر کسین تک اس بات کا خیال رکھتے ہیں کہ جسمانی معنیات مرضی اینی بیماری کی تشخیص، مستقبل میں پوسائے ایک ممکن پیچیدہ ہو یا آرام کے بارے میں مکمل طور پر سمجھ جاتی۔

سوال نمبر 6: بیماری کے نظام صحت میں وہ کون سے عوامل بین جین کی وجہ سے، ذاکر اور جسمانی معنیات مرضیوں کے درمیان آزادانگی کی مثال کو نہیں پا رہا ہے۔

Probes:

- طبی معنیاتی اور حقیقت کی لیے وقت کا ناکافی بونا
- ذاکر کی مرضی میں درمیان تعلیمی قابلیت کا فرق
- بیماری کے بارے میں مرضیوں کی ناکا فی سمجھ بھوج
- ذاکر کی بیٹی سیبڑی
- اس بات کو ام نہیں سمجھ جاتا
- سماجی رکاوٹین

Autonomy

Note: Define Autonomy

سوال نمبر 7: ایک کے خیال میں بماری اور نظام صحت کے طرح جسمانی معنیات مرضیوں کے اینی علاج کے سلسلے منی فصلہ کرنا کے۔ چنن کے صلاحیت پر منفی طریقے سے اثرات ناز ہوتا ہے

سوال نمبر 8: ایک کے خیال میں وہ کون سے عوامل بین جوحسمانی معنیات افراد کے اینی علاج، معا

Probes

معاشرتی سماجی اور خاندانی عوامل

معنیات افراد کا معنیاتی طور پر خاندان پر انحصار کرنا

 نظام صحت میں موجود رکاوٹین

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Appendix VII-B continued

**Prompt Attention**

Note: Define Prompt attention

سوال نمبر 9: آپ کے تجربے کے لحاظ سے آپ کے خیال میں ایک جسمانی معذور مریض کو طبی سپلیٹز
کے لئی پیروانی مریضان اور اندرونی مریضان کے شعبات بھی بنی اپنی بارہ کے لئی کئی دن انتظار کریں؟
پڑتا ہے؟
سوال نمبر 10: آپ کے خیال میں وہ کون سے عوامل بین جو ان افراد کو طبی سپلیٹز کی فوری فراہمی میں
روکنے نہیں بیان کرتے۔
سوال نمبر 11: نظام صحت میں وہ کون سے تبدیلیاں لائی جا سکتیں بین جن سے جسمانی معذور افراد کو
صحبت کے سپلیٹز کی فوری فراہمی کو پیچھے بنی جا سکے۔
Probes:
- طبی سپلیٹز کی تعداد
- تعلیم پاکتہ سطح کا فراہمی اور تعداد
- طبی سپلیٹز کے لئے اداگی کا طریقہ کار

**Qualities of amenities**

Note: Define Quality of amenities

سوال نمبر 12: بمار ہی بستریاں میں جسمانی معذور افراد کے لئے غسل خانوں کی سہولت کے بارے میں آپ
کی کیا رائے ہے؟
سوال نمبر 13: بمار ہی بستریاں میں عمارتون کی حالت کے بارے میں آپ کیا کہاں گی؟
سوال نمبر 14: آپ کی رائے ہے بستریاں میں عمارتون کی موجودہ حالت کیا ہو ہو ہو ہو ہو ہو ہو ہو ہو
سوال نمبر 15: بمار ہی بستریاں میں مریضون کو فراہمی کی جانئے والی خواہاں اور اہدبا ت کے معیار کے
بہتر ہیں آپ کی کیا رائے ہے؟
Probes:
- فنکار ہے کسی
- سب عوامی اور فنکار ہے کا ناکام استعمال
- انظمت، ہی طرف سے بہ حس
- انظمتی نالانقی

**Choice of Provider**

Note: Define choice of provider

سوال نمبر 16: پاکستان کی وفاقی نظام صحت میں جسمانی معذور مریضون کو کس حد تک اپنی مرضی کے
تاکنون سے علاج کروانے کا موقع ملتا ہے۔
سوال نمبر 17: آپ کے خیال میں وہ کون سے عوامل بین جو ان مریضون کی طرف سے تاکانز کے جانے پر
اثر اندوز پہنے ہیں۔
Appendix VII-B continued

Probes:

- سماجی اثرات
- معانی رکاوته
- خاندان پر انحصار بونا
- ازداده فیصلہ نہ کریں اگے کی مجبوری

Access to social support networks during care

Note: Define access to social support networks during care.

سوال نمبر 18: اپ کے خیال میں پاکستانی نظام صحت کس طرح جسمانی معذور مارپیشون کے دوران بہت
داخل دوست اہل نبی اور اپ کے خاندان اسی ملاقات کی حوصلہ شکنی کرنا یا یہ?

Probes:

- بہت حالات ملاقات
- انتہائی نگدہ شدہ کی شرعی منا مسائل
- اپ کے خاندان کا مارپیش کے لئے کہا بینے کی اشتباق لائن کے جین مرنی یا بر پر اثر

Concluding remarks

پاکستانی نظام صحت کس طرح اپ کے قربی تعلق اور تجربی کی بناء پر یا اب سمجھیں بین کہ اپ کے
انویرو میں کوئی امکان رہ گیا نہی؟
پاکستانی نظام صحت کو جسمانی معذور افراد کی امیدوں پر پورا اثر کے لئے اپ کے نین مرنی کی
تجاوز بین؟

Note: Thank the respondent for their time and effort.

*****************************************************************************
Appendix VIII-A

Informed Consent to Participate in Research
Information to Consider Before Taking Part in this Research Study

IRB Study # Pro4994

You are being asked to take part in a research study. Research studies include only people who choose to take part. This document is called an informed consent form. Please read this information carefully and take your time making your decision. Ask the researcher or study staff to discuss this consent form with you. Please ask him/her to explain any words or information you do not clearly understand. We encourage you to talk with your family and friends before you decide to take part in this research study. The nature of the study, risks, inconveniences, discomforts, and other important information about the study are listed below.

We are asking you to take part in a research study called:
Responsiveness of the Federal Health System to the Needs of 18-45 Year Old Adults with Physical Disabilities in Islamabad, Pakistan

The person who is in charge of this research study is Dr. Shaista Habibullah. This person is called the Principal Investigator. However, other research staff may be involved and can act on behalf of the person in charge. She is being guided in this research by Dr. Russell Kirby.

The research will be conducted at Islamabad

Purpose of the study
The purpose of this study is to:

- To determine how the Pakistani federal health system is responding to the expectations of the population of 18-45 year old adults with physical disabilities? and the factors that obstruct it from responding to the needs of young adults with physical disabilities.

- This study is being conducted by the Principal investigator as a part of her PhD program to complete her degree in Public Health.

Study Procedures
If you take part in this study, you will be asked to:

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Appendix VIII-A continued

Study ID: Pro0004994 Date Approved: 9/29/2011 Expiration Date: 9/29/2012

- Participate in a Face-to-face interview with the Principal Investigator. You will be requested to share your experiences, make comments and express your opinions on how the health system is responding to the expectations of the adults with physical disabilities and the factors that currently exist to hinder its responsiveness.
- You will participate in only one interview lasting one to one-and-a-half hour.
- This research will be conducted in Islamabad during summer 2011.
- The discussion will be audiotaped with your permission, however, if at any time, you want us not to record any of your comments, please let us know. These tapes will only be heard by the researchers and no other person. These tapes will not have any information that could identify you and they will be kept in a locked cabinet in the Principal Investigators custody. They will be destroyed by computerized deletion 5 years after close of the study with USF IRB.

Total Number of Participants
About 40 individuals will be interviewed in this study. A total of 104 individuals will participate in the study in focus group discussions and interviews.

Alternatives
You do not have to participate in this research study if you do not want to.

Benefits
We are unsure if you will receive any benefits by taking part in this research study.

Risks or Discomfort
This research is considered to be minimal risk. That means that the risks associated with this study are the same as what you face every day. There are no known additional risks to those who take part in this study.

Compensation
You will not be offered any compensation for your participation in this research.

Privacy and Confidentiality
We will keep your study records private and confidential. Certain people may need to see your study records. By law, anyone who looks at your records must keep them completely confidential. The only people who will be allowed to see these records are:
- The research team, including the Principal Investigator, study coordinator and other research staff.
- Certain university people who need to know more about the study. For example, individuals who provide oversight on this study may need to look at your records. This is done to make sure that we are doing the study in the right way. They also need to make sure that we are protecting your rights and your safety.
- Any agency of the federal, state, or local government that regulates this research. This includes the Department of Health and Human Services (DHHS) and the Office for Human Research Protection (OHRP).
Appendix VIII-A continued

The USF Institutional Review Board (IRB) and its related staff who have oversight responsibilities for this study, staff in the USF Office of Research and Innovation, USF Division of Research Integrity and Compliance, and other USF offices who oversee this research.

We may publish what we learn from this study. If we do, we will not include your name. We will not publish anything that would let people know who you are.

Voluntary Participation / Withdrawal
You should only take part in this study if you want to volunteer. You should not feel that there is any pressure to take part in the study. You are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study.

You can get the answers to your questions, concerns, or complaints
If you have any questions, concerns or complaints about this study, or experience an adverse event or unanticipated problem, call Dr. Shaista Habibullah at 0336-2210927.
If you have questions about your rights as a participant in this study, general questions, or have complaints, concerns or issues you want to discuss with someone outside the research, call the USF IRB at 001-813-974-5638.

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Appendix VIII-A continued

Consent to Take Part in this Research Study

It is up to you to decide whether you want to take part in this study. If you want to take part, please sign the form, if the following statements are true.

I freely give my consent to take part in this study and authorize that my health information as agreed above, be collected/disclosed in this study. I understand that by signing this form I am agreeing to take part in research. I have received a copy of this form to take with me.

Signature of Person Taking Part in Study

Date

Printed Name of Person Taking Part in Study

Statement of Person Obtaining Informed Consent

I have carefully explained to the person taking part in the study what he or she can expect from their participation. I hereby certify that when this person signs this form, to the best of my knowledge, he/she understands:

- What the study is about;
- What procedures/interventions/investigational drugs or devices will be used;
- What the potential benefits might be; and
- What the known risks might be.

I can confirm that this research subject speaks the language that was used to explain this research and is receiving an informed consent form in the appropriate language. Additionally, this subject reads well enough to understand this document or, if not, this person is able to hear and understand when the form is read to him or her. This subject does not have a medical/psychological problem that would compromise comprehension and therefore makes it hard to understand what is being explained and can, therefore, give legally effective informed consent. This subject is not under any type of anesthesia or analgesic that may cloud their judgment or make it hard to understand what is being explained and, therefore, can be considered competent to give informed consent.

Signature of Person Obtaining Informed Consent / Research Authorization

Date

Printed Name of Person Obtaining Informed Consent / Research Authorization
Appendix VIII-A continued

Statement of Person Witnessing Thumb Impression
I confirm that the thumb impression imprinted on this consent form belongs to the same person who has heard to the reading of this consent form and has freely consented to participate in this research study.

I also confirm that this thumb impression was imprinted in front of me.

_____________________________  _______________________
Signature of Person witnessing thumb impression          Date

_____________________________
Printed Name of Person witnessing thumb impression

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Appendix VIII-B

IRB Study # Pro4994

As a researcher, I am preparing a study to investigate the effects of a new treatment on patient outcomes. The study involves collecting data on a large number of participants over a period of time. I understand the importance of maintaining the confidentiality and privacy of the participants involved in the study.

I have completed the necessary paperwork and have reviewed the guidelines for ethical research. I have also obtained the necessary permissions from the institutional review board (IRB) and have been trained in the use of the data collection tools.

I will ensure that all data collected is handled in accordance with the IRB guidelines and that the confidentiality of the participants is maintained. I will also ensure that all results are reported accurately and that the findings are presented in a clear and concise manner.

I believe that this study will provide valuable insights into the effectiveness of the new treatment and will contribute to the advancement of medical knowledge.

Thank you for considering my proposal.

Sincerely,

[Your Name]
Appendix VIII-B continued

درحقین میں حسن لیہو اور کل افراد
اس حقیقی میں قربانی 40 افراد اٹروپوز میں حسن لیہو کے چک 64 افراد اٹروپوز میں حسن لیہو کے گھن
میں 104 افراد حسن لیہو گئے۔

تحقیق ہماری بحث کے سکاتے ہیں،
تحقیق ہماری بحث کے فاؤند پی اس حقیقی میں حسن لیہو سے آپ کو کوئی راز فہدہ نہیں ہے۔

تحقیق کے خطرات / نقصانات
اس حقیقی میں مس کا خطرہ ، اس کا نقصان بس اس حقیقی میں حسن لیہو سے آپ کو کوئی اسما خطرہ با
نقصان پیش کر کے نیا کو جو آپ کی عدم رون کر سے بہت کہ ہے۔

تحقیق میں حسن لیہو کا معاوضہ
اس حقیقی میں حسن لیہو پر آپ کو معاوضہ نہیں بنا گئے۔

رhaltی

آپ ہمارے حوالہ کر دکھے بے طرح کی معلومات کو صرف راز میں ہی رکھیں گے۔ لوگوں کو آپ کی دی معلومات
کو دیکھنے گے اس کے اس لئے آپ کو بات بات کیا جاتا ہے اور اس راحت کی طرف جو رکش کے ہو اس میں رہیں۔

تحقیق کے لئی ہم کہ اکثر جین میں حقیقی اعلیٰ، تحقیق/ ریکارڈ کار اور دوسرا افراد شامیہ بنی۔

یہ میں اس وقت جو اس حقیقی کے نظریات کی گاہی ہے۔

تحقیق صحیح طرفی سے گیا جاتا

امریکی حکومت کے وقتی ریاستی اور معاشریاتی جو اس حقیقی کے نظریات کی گاہی ہے۔

یہ میں اس حقیقی کے سوا کی امریکی حکومت کے گاہی ہے۔

حوالہ سے اس حقیقی کے نظریات کی گاہی ہے۔

اس حقیقی سے حامل کی معلومات کو سالمی جواد میں شائع کیا گیا، گاہی اس کا کہ اس میں کیمین میں آپ

کا تمام نہا شناخت استعمال ہے جس کا جائزہ گی۔

رضحالی سے شمولیت ہے دستوری
Appendix VIII-B continued
Appendix VIII-B continued

Statement of Person Obtaining Informed Consent

I have carefully explained to the person taking part in the study what he or she can expect from their participation. I hereby certify that when this person signs this form, to the best of my knowledge, he/she understands:

- What the study is about;
- What procedures/interventions/investigational drugs or devices will be used;
- What the potential benefits might be; and
- What the known risks might be.

I can confirm that this research subject speaks the language that was used to explain this research and is receiving an informed consent form in the appropriate language. Additionally, this subject reads well enough to understand this document or, if not, this person is able to hear and understand when the form is read to him or her. This subject does not have a medical/psychological problem that would compromise comprehension and therefore makes it hard to understand what is being explained and can, therefore, give legally effective informed consent. This subject is not under any type of anesthesia or analgesic that may cloud their judgment or make it hard to understand what is being explained and, therefore, can be considered competent to give informed consent.

Signature of Person Obtaining Informed Consent / Research Authorization  Date

Printed Name of Person Obtaining Informed Consent / Research Authorization
اجازت نامی پر نشان که گوئی کی گوئی میں گوئی دیتا ہو گا کے اس اجائزت نام پر اپنی صاحب/صاحبہ نے کہا کہ اگر نامی کی نشان کیا ہے اگر اس اجائزت نامی کو سن کر تحقیق میں حصہ لیے پر یہ ابتدائی دونوں بیوی میں اس کو پہلا کی پہلا گوئی دیتا ہو گا کہ نشان میں سامنے نیتا کیا ہے؟

نام گوئی

تاریخ

دستخط گوئی