

**DESIGNING DISABILITY SERVICES IN SOUTH ASIA:
UNDERSTANDING THE ROLE THAT DISABILITY ORGANIZATIONS PLAY IN
TRANSFORMING A RIGHTS-BASED APPROACH TO DISABILITY**

by

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Since the advent of the Disability Rights Movement in the 1960's and 1970's, practitioners and scholars have sought ways of conceptualizing disability and understanding the strategies employed in its management. The push for a rights-based approach to disability first begun in North America and Europe has become globalized, influencing the discourse, strategies, and day-to-day activities of international policy-making bodies, non-governmental organizations working on disability, and individuals with disabilities worldwide. Scholarship within disability studies has fixed attention on a small range of models for explaining the meanings and experience of disability. However, the adequacy of these models in describing the relationship between international institutions, disability organizations, and individuals with disabilities has not been examined. Similarly, scholars have not examined the influence these different theoretical models have on the everyday work of organizations working with individuals with disabilities.

This paper explores the way in which two organizations in South Asia have framed and defined organizational goals and a "rights based" approach to disability. It employs ethnographic data from preliminary field projects in Kathmandu, Nepal and Delhi, India to examine the underlying theoretical models of disability that each organization operationalizes through its

programming. Analysis of each organization's values, programming, and disability discourse suggests that organizations are differently defining disability rights, leading to heterogeneity in the types of services available to people with disabilities. I suggest that this heterogeneity in available services across organizations, as well as within a single organization is the product of organizations employing different theoretical understandings of the meaning of disability. However, programming opportunities available to an individual with a disability not only stem from different theoretical models of disability, but also forge new hybrid models of disability that incorporate multiple theoretical constructs in order to address the challenges facing individuals with disability. This suggests that disability organizations are actively engaged in defining and transforming disability policy and discourse at the local level and beyond. The paper concludes with a discussion of the implications these findings have on how we understand and study disability, as well as design and implement services for individuals with disabilities.

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1.0 CHAPTER 1: MANAGED BODIES MANAGED PERSONS: MEANINGS OF DISABILITY AND REHABILITATION STRATEGIES

“Bodily signification... is an inevitable component of all social practice: neither the most ethereal of expressions nor the most pragmatic of politics can escape being acted out through the human frame. However lofty their ideals, revolutions must also work their changes palpably on the persons they seek to reform.”

~ John and Jean Comaroff, *Ethnography and the Historical Imagination*

Rehabilitation of the disabled body is indeed a revolution – seeking to transform or restore the aberrant body to a normative state capable of fulfilling conventionally defined physical, social, or economic roles and functions. The revolution of rehabilitation brings to the forefront the very real way in which, as the Comaroffs state, revolutions enact their changes on the bodies of the persons they seek to transform. This statement suggests the intimate link between definitions of disability and modes of rehabilitation. It suggests that the project of rehabilitating the body is one that requires ideological, moral, and social conceptions of disability to be grounded in both the concrete physiological and anatomical functions of the body of a person with a disability, as well as the lived experiences of personhood. In some instances, this grounding has meant manipulating the body to conform it to ideological notions of normality and “rightness.” In other examples, this grounding has sought to imbue the body and the person with new meanings and metaphors. In still different cases, rehabilitation has meant “re-habiting” and re-embodiment one’s body through daily experiences. Given the plurality of ways in which rehabilitation

projects have been undertaken, an assessment of the coupled concepts of “disability” and “rehabilitation” demands analytical frameworks that can move between the way in which these terms are socially constructed ideologies representative of power relationships, as well as how they serve as referents to experiences in a lived world that are marked by immediacy and indeterminacy.

Within this chapter, I attempt to articulate several models that have been proposed for analyzing disability and rehabilitation. Such a discussion first necessitates an examination of the literature that seeks to define the term disability. This chapter proceeds first with a discussion of how disability is conventionally defined in the literature and discourse, as well as within this paper. This brief discussion will be followed by a discussion in which I hypothesize how these definitions of disability and rehabilitation influence and circulate between different individuals, organizations, and international institutions. I then move onto an examination of six theoretical models for understanding disability; a) medical b) political-social c) kinship d) charity e) experiential- embodiment, and f) critical post-structural. Within this examination, I also discuss various strategies for managing disability that emerge from how disability is defined.

In the three chapters that follow, I draw upon these models of disability found within the disability literature in order to explore how two organizations providing services for individuals with disabilities in South Asia operationalize these models of disability within their organizational definitions of disability, disability rights, and efforts to provide a disability rights based approach to disability services and programming. In Chapter 2, I discuss the methods used for data collection and analysis. Chapter 3 presents key features of these two organizations within two case studies of the organizations. Chapter 4 concludes with an analysis of these two organizations in which I discuss the organizational culture of each organizations with regards to

how each defines disability, personhood, the cause and goal change, and disability rights. This information as well as material from the case studies allows me to then examine how specific program features of each group maps onto 4 models of disability presented in this chapter. The analysis section of chapter 4 concludes with a description of how each organization operationalizes a rights-based approach to disability. Chapter 4 concludes with a discussion of the role that analyses such as that presented in this thesis might play in deepening our scholarship on disability and disability rights, as well as tailoring NGO programming to better advance disability rights and the well being of individuals with disabilities.

1.1 A NOTE ON TERMS AND DEFINITIONS

Drawing from conventional definitions of disability within international discourse, the general term of “disability” has been defined in a number of ways. Modeling the language of the World Health Organization (WHO), much of the discourse on disability has recently adopted a lexicon that aims to clarify and specify the multiple meanings and conditions commonly lumped together under the label of disability. Under the WHO framework, the unspecified concept of disability is replaced by three differentiated conditions labeled as *impairment*, *disability*, and *handicap*. *Impairment* denotes damage or loss of physiological, psychological, or anatomical function or structure (UNICEF and HMG 2000). Examples of *impairment* include disturbances at the level of body structure and function such as loss of a limb, poor eyesight, hearing impairment, paralysis of limbs, and epileptic seizures. *Disability* becomes delimited and specified as a term to reflect functional limitations in performing daily activities that are age and gender appropriate. *Disability* is an interaction between the physical body impairment and the physical environment

that impacts individual function. Examples of this level of interaction include communication disabilities, locomotion disabilities, and cognitive disabilities. *Handicap* is a disadvantage that an individual with a disability experiences due to their impairment or disability and their inability to perform the social roles expected of him or her within society. It is a loss or limitation of opportunities to take part in the community life.

However, this classification scheme is not without problems. I will delay a discussion of these critiques until a later point in this chapter. Yet in recognition that these relatively new, context specific and highly technical terms fail to capture the entire range of meanings that disability elicits, I will not strategically use them within this paper. Instead I will continue using disability in its more generic sense, and as a word that is interchangeable with “physical difference.” I recognize that there are inherent problems in my doing this. The term of “physical difference” brings to mind statistical ranges of normality found beneath a bell curve. Similarly, the phrase does not differentiate between differences that are particularly stigmatizing and those differences that are not. Perhaps also, the phrase places too much emphasis on the fixed visual image of disability (as opposed to, for example, different speech patterns uttered from someone with a speech impediment or hearing impairment or the jarred gait of someone with a mobility disability).

1.2 DISABILITY AND REHABILITATION: AN OVERVIEW

Of consequence to a discussion of disability and the identity of being “disabled,” is understanding what disability as physical difference signifies. Authors have engaged with the theme of disability in a multitude of ways. Topically, physical and mental disability has been

viewed as a marker of disease (ICD-10), of physical deficiencies, malformations, and malfunctions (WHO 2002), of abductions (Das and Addlakha 2001, Hyland 2000, Weiss 1994) or simply alterations to kinship expectations and domestic duties (Ingstad 1995), of circumscribed economic and productive roles (Stiker 1999, Foucault), or of social and wider community responses and obligations (Hyland 2000, Ingstad 1995, Goffman 1963). Contrary to popular representations and discussions of disability, the above list of meanings associated with physical difference does not necessarily or entirely generate negative and stigmatizing experiences for the individual with disability. Instead this range in meanings suggests a nuanced and multi-layered continuum of what disability signifies. At one end of this continuum are highly individualistic and indeterminate embodied experiences, while the other end is marked by socially constructed discourse in which the body becomes all but irrelevant.

In its broadest expression, rehabilitation is the management of the disabled body. The two terms of disability and rehabilitation are coupled through the way in which each mutually produces and defines the other. The meaning ascribed to disability is intimately linked to the strategies employed in its management. For as many reflections on the meaning of disability, there are an equal number of modes of managing the body and solutions for remediating the variably defined deficiencies of the disabled body. This focus on the disabled in need of anything from social charity, physical rehabilitation, state stipends, or citizenship and rights underscores the landscape on which disability is a created product whose rehabilitation/transformation is a fiercely contested project. –Within this context, the statement from the Comaroff’s examination of colonialism in Africa that began this chapter cues us to the significance of physical bodies within any social, economic, or political project.

Given that disability can be seen as a signifier of various alternative or deficient modes of being in kinship, social, economic, and political domains, disability may be and often is managed by a host of “others” ranging from family members, the medical profession, community members, local government, and international organizations. Just how these others manage disability varies depending on a confluence of factors that include cultural settings, how the individual’s disability is perceived and defined, and the involvement of international organizations.

Stiker’s work highlights one general trend in the management of disability. In speaking of rehabilitation efforts in the post World War 1 era, Stiker notes that “indeed earlier eras never failed to situate the disabled and their disabilities, but few if any ever had the ambition, pretension, and intention to relocate them in the machinery of production, consumption, work, and play in the day-to-day community” (128). Within this time period, integration and social normalization become the hallmarks of rehabilitation activities promoted by Western industrialized nations (Stiker 1994, Ingstad 1995).

The above statement by Stiker suggests how some recent rehabilitation activities have assumed new functions as ambitious projects for normalizing bodies in contrast to prior attempts to seclude, restrict, and circumscribe the disabled and their disabilities. In one case study on stigma and leprosy, the author concludes with a plea for a ritual of purification for those with leprosy to facilitate their social inclusion (Hyland 2000). This example is precisely situated in the nexus of two different means of handling disability – one which desires a modernist project of social integration and normalization, and another which manages disability by “othering” and excluding.

1.3 INTERNATIONAL DISCOURSE AND POLICY ON DISABILITY

Beginning our examination of the influence of disability discourse and policy with the role that national and international policy making institutions play in shaping disability meanings and management strategies is an appropriate starting point given the prevalence and broad impact of both biomedical institutions and policy statements generated by such institutions. Within the subjects of biomedicine and disability, Foucault's work demonstrates how such knowledge generating institutions as the health professions marshal specific social practices and techniques of inquiry and discernment to construct and subsequently institutionalize a medicalized view of the individual, normative body. Mathew Kohrman labels such forms of health institutions as *bio-bureaucracies* and notes their involvement in and support from "the accelerating proliferation, worldwide, of the biological and biomedical sciences, [and] a set of patterned ways of conceiving of and responding to normalcy and abnormality, health and pathology" (2005).

Since the 1950's, a variety of actors including the United Nations (UN) and World Health Organization, national governments, local NGOs, and people with disabilities have been prominent actors involved in the production and use of discourse on disability. Many of these institutions and collectivities have carved out definitions of disability firmly rooted in biomedical orientations to the body. Johnston notes that "the WHO model has been widely used as a model of disability and continues to be the implicit model adopted in the delivery of health care" (1997).

Within this paper, I define international institutions as including any organization that is engaged in generating disability or funding programs that serve individuals with disabilities. These two broad categories allow for the inclusion of international institutions such as the UN and WHO; national governments; biomedical institutions such as hospitals, professional

organizations, and accreditation agencies in industrialized nations; as well as donor agencies whether they be international, national, or regional.

These biomedical institutional definitions and their inherent conceptualization and construction of a biomedical body provide both the framework for many of the disability policy and rehabilitation program designs worldwide, as well as the approach from which much protest, critiques, and alternative conceptualizations of disability have arisen.

Scholars of US disability history have demonstrated the significant influence national disability policy definitions have had on how individuals with disability came to understand themselves. –In particular, this work reveals a tension between the construction of disability within US policy and the individuals whose experiences were impacted by this policy (Longmore and Umansky 2001). Scholars note that disability policy tended to flatten and fashion disability into a single generic category. However, attempts to impose this single classification onto disabled populations generated “anything but a monolithic grouping or singular experience of disability within people with disabilities” (Longmore and Umansky 2001).

However, this debate does not simply belong to the annals of US disability history. During June 2005 at a national conference of interpreters for the Nepalese deaf community, a heated debate took place on the topic of the Nepalese Government’s role in providing accommodations for people with disability. A ministry official had been discussing a proposed constitutional amendment that included only a generic statement noting the government’s obligation to provide “accommodations” for all disabled persons. In response, a young man with a hearing impairment stood and vehemently signed that the government and the constitution needed to recognize the *specific* needs of the deaf community, and explicitly identify “sign interpreters” as a necessary accommodation for the hearing impaired. As others joined the

debate, another deaf individual stood up and reminded audience members that current regulations allowed only one person at a time to meet with government officials. (This policy if literally interpreted and applied could bar an interpreter from accompanying a hearing impaired individual into a meeting with a government representative.) The members of the audience can be seen as resisting the government's attempts to lump all disability together by directly challenging the policy that did not adequately differentiate between the experiences and needs of a diverse disability community in Nepal (Baldwin Fieldnotes 2005). As these examples suggest, this tendency to flatten the heterogeneity of types and experiences of disability is found readily within current discourse and policy formulations on disability, rehabilitation, and disability rights.

Serving as an illustrative example of how *academic* discourse on disability has tended to overlook the variability in disability experiences, one mammoth 1,000 page edited volume on disability studies that labels itself as a *Handbook of Disability Studies* includes only two articles out of thirty-four contributions that explicitly explore disability in an international setting (meaning non-American and non-European) (Albrecht, Seelman, and Bury 2001). The authors of the remaining thirty-two articles assume the universality of both the experiences of disability, as well as the applicability of their arguments to disability studies. With few exceptions and across a wide range of topics and analytical approaches, these authors fail to contextualize their disabled subjects by failing to provide the reader with any sense of time, place, or difference in disability type. Thus, their arguments tend to portray both the subject and experience of disability as homogenous, while simultaneously implying the utilitarian applicability of their analytical approaches and conclusions to the understanding of all subjects of disability irregardless of time, place, or disability type.

Yet even within the “international” perspective featured in two contributions to the handbook, a closer look at these chapters similarly reveals that neither of these articles grounds itself within a particular cultural or national context but instead casts its argument for a cross-cultural perspective in the amorphous molds of the “developing world” or “international perspective.” The overarching structure and approach of such a handbook and its contributors to Disability Studies generates a number of critical questions for a transdisciplinary academic project. How do we approach the disabled body and the project of rehabilitating it as analytical topics? How does time and place effect how we come to know the disabled body – whether we ourselves assume the label(s) of “disabled individual”, “non-disabled family and community members”, “health and rehabilitation practitioners”, and/or “academic researchers” of the phenomenon of disability? What does examining disability from vantage points that align or overlay such topics as discourse, rehabilitation activities, individual experience, the body, national legislation and policy, international donor agencies, the community, and the family reveal about the plurality of meanings associated with the concept of disability? And how if at all can this range of approaches be synthesized to give a coherent and multifaceted narrative of disability within particular times and places?

At one level, the above questions and trends towards homogeneous and universalizing approaches to disability call for the body as an analytical topic to be inserted as a key focal point into disability scholarship.

Though some might argue that homogeneity is necessary for discerning analytical and theoretical generalizations, I suggest that approaches that either presume or arrive at homogeneity run the risk of poorly interpreting and misrepresenting their subjects. In speaking of an international feminist movement, the poet-activist Adrienne Rich calls for a mobilization

and recognition of a “We who are not the same. We who are many and do not want to be the same” (Rich 2001). Rich’s statement echoes a similar call from the disability community and participants in the disability rights movement for unity that can incorporate diversity. In returning to the example of the Nepalese interpreters conference, we see how the government’s attempt to “lump” all individuals with disability together and then design generic policy for this unspecified category was met with resistance that demanded individual recognition of a specific disability category through appropriate and specific accommodations.

International policies and documents face similar tensions between generalizable policy and representative definitions. The International Classification of Function, Disability, and Health (ICF) is the World Health Organization’s most recent installation of a framework for classifying health and disability. It functions as both a revision and companion to the WHO’s earlier classificatory scheme for health and disease delineated in the 10th edition of the International Statistical Classification of Diseases and Related Health Problems (ICDH-10). The ICDH-10 gives users an *etiological* framework for the classification of diseases, disorders, and other health conditions that employs biomedical diagnoses to provide information on the relative state of health of individuals at assessment levels ranging from the individual to the international (WHO 2002). This document largely focuses on the cause of mortality within populations. In response to complaints that this framework fixed “disabled” as distinct from “healthy” (or in other words equated being “disabled” as being “un-healthy”), the WHO developed the ICF to permeate the boundaries between health and non-health, and to instead reflect health as being a spectrum of functional capacities (and limitations) that arise from disease.

The ICF document is based on a classificatory scheme of health and health-related domains that place emphasis on describing changes in body function and structure, what a person

with a health condition can do in a standard environment (a person's level of capacity), as well as what they actually do in their usual environment (a person's level of performance) (WHO 2002). Within the ICF, the dynamic nature of health is classified by domains incorporating the body, individual, and societal perspectives by means of two lists: a list of body functions and structure, and a list of domains of activity and participation. In the ICF, the term *functioning* refers to all body functions, activities and participation, while *disability* is similarly an umbrella term that is inclusive of impairments, activity limitations, and participation restrictions (WHO 2002).

Given the explicit concern with the interaction of the physical body with the social and physical environment, the ICF identifies its model of disability as a *biopsychosocial model*. Within the ICF, *biopsychosocial* is a composite term reflecting the integration of two distinct, and opposing models of disability. The ICF is an integration of what has been labeled as the *medical* and *social* models of disability. The *medical model* views disability as a feature of the person, directly caused by disease, trauma or other health condition, which requires medical care provided in the form of individual treatment by professionals. The *social model* of disability, on the other hand, sees disability as a socially created problem and not an attribute of an individual.

While the ICF attempts to move away from a narrow and deficit-oriented definition of disability, this document and the definitions internal to it still articulate a particular approach to the body and disability – mainly one that articulates a body envisioned and carved out by a dominant bio-medical paradigm.

1.3.1 Organizations Providing Disability Services

National and international policy making bodies are not the only factors that influence definitions of disability and the experience of disability for people with disabilities. Within South

Asia, disability services are provided increasingly by non-governmental organizations (NGO). Disability organizations are those NGOs that offer services to individuals with disabilities. Increasingly this category is diversified in the types of services being offered. During preliminary fieldwork in Nepal and India, I found disability organizations engaged in providing services in the areas of physical and occupational rehabilitation, medical interventions, Community Based Rehabilitation (CBR) programs, vocational training, education, recreational activities, and advocacy and policy development.

Organizations serving people with disabilities are increasingly promoting what is referred to as a *rights-based* approach to disability. Yet, little attention has been paid to the ways in which international discourse and health policy on disability and rehabilitation impact the program design, implementation, and everyday work of organizations addressing disability. Further, there is little understanding of if, how, and why local disability organizations appropriate and transform this discourse; formulating local definitions of *disability*, *disability rights*, and *citizenship*. Critical questions remain with regards to a) how concepts such as *disability*, *disability rights*, and *citizenship* are defined by local organizations, b) the characteristics of local relationships between service organizations and disabled clientele, and c) how NGOs' clients' perceptions and experiences of disability form and are informed by local organizational definitions and programming, as well as international policy.

1.4 RELATIONSHIPS BETWEEN INTERNATIONAL INSTITUTIONS, DISABILITY ORGANIZATIONS, AND INDIVIDUALS WITH DISABILITIES

These questions suggest that the production, circulation, and transformation of disability discourse and policy are the products of the relationships that exist between individuals with disabilities, local non-governmental organizations providing disability services, and international and national institutions that generate and regulate disability policy. I suggest that each of these actors informs and is informed by each other, forming a triangulated system that produces, reproduces, and alters both disability policy, as well as the individual's experience as a person with a disability (Figure 1.). At the center of this relationship are theoretical models for understanding disability that also inform and are formed from the experiences and outcomes produced by each of the three actors.

1.4.1 Individuals with Disabilities and Disability Organizations

The relationship between individuals with disabilities and NGOs providing services to people with disabilities is defined by both actors influencing the understandings and experiences of the other. Traditionally, NGOs have been vehicles of change exerting their influence on their clientele and broader social groups in which they operate. However, NGOs activities and policies are also informed by the individuals and population that they serve. In the case of disability NGOs, the staff and administrative members of the organization are frequently members of the disabled population they hope to serve. This is particularly true of smaller, grassroots organizations. NGOs also must market a product that is deemed necessary by current and potential clientele. This necessitates that NGOs will be providing a service that is informed by the needs or wishes of individuals with disability and their families.

1.4.2 Disability Organizations and International Institutions

Researchers have documented the transformation that occurs when international social welfare discourse, agendas, and programming interface with local politics of development and cultural rationalities of illness, ethnicity, gender, caste, and class (Pigg 2001, Ingstad 1995). This transformation can occur between local NGOs and national and international institutions in which both actors influence the other. NGOs are informed by disability institutions through such things as the funding priorities and requirements of donor agencies, accreditation and certification standards, and the prominence given to the values and approaches of large scale institutions. NGOs frequently adopt (or at least integrate) the values and discourse of these institutions in order to acquire and retain donor funds.

However, the relationship between NGOs and international institutions also works in reverse with NGOs having the ability to influence international institutions and the policy they generate. In some contexts, NGO members sit on advisory councils, partner with national and international governments on disability projects, and participate as advocates for pushing or challenging policy. During my time in India, I met an individual whose leadership role in creating and sustaining a disability organization led to her appointment as a key government personnel charged with overseeing disability issues.

Within the UN's Committee on Economic, Social, and Cultural Rights (CESCR) (under which disability rights could arguably be placed), channels have been developed for promoting the participation of NGOs in defining social rights and bringing to light violations of the same. The CESCR has channels in which NGOs can participate orally and in written statements within issues being reviewed and discussed by the CESCR. Craven, suggests that NGO participation "is the most significant and perhaps the most controversial aspect" of the CESCR's monitoring and

leadership work. These channels open the way for unofficial petition systems for economic, social, and cultural rights.

However, these channels remain untapped and unrealized potentials for many NGOs. Few NGOs have utilized these channels. Some suggest that this underutilization of these petition systems reflect the marginalization of economic, social, and cultural rights within national and international contexts. Craven notes “the distinct reluctance of existing NGOs to become involved with [social, cultural, and economic] rights” (as cited in Hunt 1996). Few international NGOs devote adequate resources to promoting and protecting these rights (Hunt 1996). At the national and international level, there is a pervasive lack of knowledge about the CESC, let alone the informal petitioning pathways.

1.4.3 Individuals with Disabilities and International Institutions

As discussed earlier, the disability policy and rehabilitation program designs produced by international institutions worldwide have been sources from which much protest, critique, and alternative conceptualizations of disability have arisen. The transnational proliferation of bio-bureaucracies and discourse on disability with a biomedical orientation gives rise to questions on the impact of these policies on non-western, locally-based organizations such as NGOs, as well as individuals living in locales far removed from the sociopolitical issues and institutions that generated this discourse.

Kohrman’s examination of “how people [in China] came to fashion and be fashioned by the [People’s Disability Federation’s] development at the close of the last century” demonstrates how modern disability service programs incorporate international discourse and biomedical conceptions of the body. Like those in other nations, these disability programs continue to be

aimed at “developing a range of biomedical services, loosely termed rehabilitation medicine, extending those services to individuals deemed ‘disabled’, and producing media aimed at destigmatizing the disabled body.”

However there is evidence of the role that individuals play in informing the values and actions of international institutions. As discussed earlier in reference to the WHO’s ICF, this document was produced by the WHO as a reaction to public outcry against the negative portrayal of disability as a deficiency and unhealthy state within the WHO’s older ICD-10.

1.5 THEORETICAL MODELS OF DISABILITY

Informing all of these relationships are models of disability that extend from scholarship within disability studies and other disciplines. The medical and social models of disability are the first and second models, respectively, that are discussed within this chapter. The two models are well characterized theoretical models from which many disability scholars, advocates, and practitioners have developed a significant body of literature and applied to disability practices. The third kinship model of disability stems from anthropological and sociological approaches to understanding the meaning of disability cross-culturally. One particular notion of *connected body-selves* that falls within this larger kinship frame espouses a uniquely South Asian concept of disability that is intimately tied to South Asian kinship networks. The religious-charitable model of disability is the fourth theoretical model that I describe. This topic and approach to disability is a rather underdeveloped model of disability to which little attention has been given by disability theoreticians. However, I suggest this model as a potential means of understanding the meaning assigned to disability given its particular prevalence within South Asian disability

discourse. The fifth and sixth models present two additional means of assessing the meaning and experience of disability. I include a brief discussion of an embodiment and post-structural approach to disability as they are informative to understanding disability and its management from the levels of experience and discourse respectively. However, these two theoretical approaches are not central to the analysis and discussion of the two case studies that follow in chapter 3.

Key features of the first four models including each's definition of disability, the presumed origin of disability, and examples of discourse are summarized in Figure 2.

1.5.1 Medical Model

Historically, disability studies along with public policy, professional practice, and social responses to disability have been dominated by a medicalized view of disability, in which disability is primarily a pathology located in the body or mind. In viewing the disabled individual as a deviant subject with a deficit requiring rehabilitation, these approaches fail to examine the cultural, social, and political structures that equate “difference” with “deviance” and “pathology”. Within biomedical schemes, the body and world of the individual are rendered through a biomedical lens and thus restricted to a set of biomedically defined physiological functions.

As an illustrative and alternative way of visualizing the body, I turn to W.J.T Mitchell's description of his experience with temporary disability. During his convalescence from arthroscopic knee surgery, Mitchell comments on the strategic and careful arrangement of bottles of pills, furniture, medical equipment, and other daily items in the following manner:

It gradually dawns on me that I have moved into another world that may be invisible to the casual visitor. He or she may be blind to the order of things I am constructing, seeing it only as disorder, the way a sighted person might not understand that everything in a blind person's house has to have a place and be in that place. I come to realize that the sighted have a *seeing disability*. This is not because they fail to see the blind person, or to see that he or she is blind, but because they cannot see the ideal world of the blind as "ready to hand," in Martin Heidegger's words, and thus filled with dangerous displacements, removals, and disappearances (Mitchell 2001).

The same way that a blind individual's house is arranged in a logical and strategic pattern to reflect how space and objects are used in daily life, Mitchell has temporarily rearranged the spatial location and reformulated the relationships between everyday objects to accommodate the new functions these objects now serve in his everyday activities. Mitchell's disability can be defined as the experience of new spatial arrangements and modes of moving through this space that have resulted from his knee surgery. From this example, a biomedical approach would see Mitchell's disability as the decrease in his mobility due to pain, inflammation, and swelling that has resulted from a medical intervention to correct a pathology in his knee. This approach similarly would see his experiences and world as *limited* in comparison to a fully-abled person's (and in fact, Mitchell's prior state) due to a restriction in his mobility, just as it views blind individuals and their world view as deficient in sight. What Mitchell suggests in his term *seeing disability* is the tendency of those subscribing to a biomedical approach to overlook alternative meanings and logical renderings of life experiences that are associated with physical differences.

Similarly, this biomedically defined body becomes a predominant construct that is generalized and applied to all bodies through its use within international documents designed to

shape international policy. This generalization of an impaired biomedical body is clearly seen in the following statement from the ICF:

the ICF puts the notions of ‘health’ and ‘disability’ in a new light. It acknowledges that every human being can experience a decrement in health and thereby experience some disability. This is not something that happens to only a minority of humanity. ICF thus ‘mainstreams’ the experience of disability and recognizes it as a universal human experience (WHO 2002).

This statement assumes that “the notions of ‘health’ and ‘disability’” reside in a biomedically conceived human body, and that that body experiences disability in a homogenous and universal way. In stating this, the ICF articulates not only that the biomedical body is a singular and coherent entity existent everywhere, but also that the experience of disability by and through this body is similarly universal. Essentializing disability as a “decrement in health” highlights the assumption that health is an optimal set of conditions that is uniform and normative. Further, this definition of disability blurs temporary disability with long-term, irreversible disability and further reifies the latter as an unhealthy or suboptimal state of being. Though conceptually problematic, it should be noted that this blurring of multiple forms and durations of disability can be viewed as a political strategy that attempts to appeal to “able-bodied” individual’s sense of mortality so as to align them with the interests of those with long term disability.

This tendency to generalize, homogenize, and universalize the body through a biomedical construct is similarly demonstrated in the ICF’s reliance upon a uniform and standardized environment for assessing the functional capacity of an impaired individual. The point made by a disability model using a testing “standard” for all individuals is a nuanced, yet important one. The use of a standardized environment allows one to test and measure the experience of disability in a way that allows for both comparison between individuals, and documenting

changes within the same individual over time. Therefore the use of a standardized environment suggests that the experience and meaning of disability rests solely in an individualized body as a measurable entity, capable of being optimized over time, and similarly lived among all individuals.

Though this view of disability may recognize a relationship between physical differences and social influences through such terminology as *handicap* and *biopsychosocial*, this view gives primacy to medicalized meanings of bodily differences over alternative social and cultural meanings. Because a biomedical approach perceives the “problem” of disability as resting in a universal and uniform body, it can similarly presume uniformity in social and cultural meanings.

1.5.2 Social Model

As both a critique of the medicalized model and challenge to oppression, exclusion, and marginalization associated with disability, the social model of disability was generated and adopted as the approach to disability by the disability rights movement first within the United Kingdom and later by other disability communities. The following excerpt by Shakespeare and Watson exemplifies the perspective of the social model that defines disability as a socially created problem rather than an attribute of the individual.

the achievement of the disability movement has been to break the link between our bodies and our social situation and to focus on the real cause of disability, i.e. discrimination and prejudice (1997).

Here, Shakespeare and Watson note that the *real* cause of disability lies within social perceptions and actions.

The social model first produced a working lexicon for disability dividing the complex concept of disability into the categorical divisions between impairment, disability, and handicap

(discussed previously in this chapter). This precise terminology was an attempt to escape a model in which disabled people were identified by their impairments, and their struggles with life activities were seen as the consequence of a dysfunctional body. In speaking of these conceptual issues, Oliver notes that:

The conceptual issues underpinning this [division] is about determining which aspects of disabled people’s lives need medical or therapeutic interventions, which aspects require policy developments and which require political action” (1995).

Oliver’s quote emphasizes the utility and functional use of the social model for delineating a particular management strategy for disability. Within that management strategy, impairment and some dimensions of disability (because it is an interaction between the physical body and environment) are to be treated through medical interventions, while other dimensions of disability and social inequalities are to be managed through policy and political actions.

From Oliver’s and others definitions of the social model, we can see the following structural framework emerge (Turner 2001):

<u>The Biological</u>	<u>The Social</u>
Impairment	Disability and Handicap
The body	Society
Medicine	Politics
Therapy	Emancipation
Pain	Oppression
Medicalized model	Social model
Phys. Rehabilitation	Economic and Social Rehabilitation

As this framework suggests, the social model’s focus is on the right column. In its political articulations, the model’s emphasis on society, disability, and handicap demonstrates how the social model seeks to erase the body entirely by privileging interventions that focus upon social and political actions. However, Hughes and Paterson suggest that this framework does not actually erase the body so much as it concedes the body to medicine (1997). The social

model is not categorically denying that the body exists, but rather it relegates the physical body to the column that is under the domination and definitional power of medicine and the biomedical model. Relegating medicine to one column and society to the other leaves the model unable to directly challenge the institution of medicine as a social entity with power to discriminate and stigmatize the disabled body.

While the social model serves as a successful theoretical basis for emancipatory politics that emphasize redistributing power and fighting exclusion (Turner 2001), it is limited in two additional ways that stem from the dichotomies between impairment and disability, and medicinal therapeutics and social policy. The first problem inherent to this binary model is locating where exactly impairment ends and disability begins. In other words, the problem of Oliver's earlier statement is that we are left unsure how to distinguish between efforts that change the individual (physical impairment) versus changing society (the environment).

One additional critique of the social model is that it overlooks the fact that medicine and social policy have often colluded to manage populations deemed deviant. History is pocked with insidious instances in which social solutions to various types of disability involved legally mandated medical procedures (such examples include sterilization campaigns for "mentally feeble" persons and members of ethnic minority groups, medical quarantine for leprosy sufferers, and lobotomies performed on convicts and difficult children in Japan) or medical/scientific theories justifying social interventions (examples include race theory and slave medicine justifying the institution of slavery and colonization in Africa, and the medical phenomenon of female hysteria which reinforced the assignment of Victorian gender roles and women's exclusion from specific types of education).

Further, the above sets of dualisms frustrate the problem of identity politics (Hughes and Paterson 1997) in which the body is definitional to and a constructed site of one's identity. In its politics, the social model denies the body as a location of disability, and therefore categorically denies a disabled identity as being an embodied experience. Yet, we need look no further than such issues as abortion and a woman's body, torture and personhood, health disparities, and technologies that allow us to change physical attributes such as sex change surgeries, cosmetic surgery, or *in vitro* fertilization to realize expressions of one's identity that include "forms of resistance, struggles for bodily control, independence, and emancipation are all embodied processes" (Turner 2000).

1.5.3 Anthropological and Sociological Approaches to Disability

Erving Goffman's contribution to disability studies is chiefly through his work on stigma (1963). Within the fields of Rehabilitation, Public Health, and Development, disability has often been conceived as a stigmatizing identity category (Goffman 1963, Weiss 1994). – Goffman's application and elaboration of a symbolic interactionist framework for understanding stigma laid conceptual ground for many other social scientists.

First developed within the fields of social psychology and sociology, the theoretical concept of social interactionism incorporates a broad set of premises to explain the way in which an individual defines self and society (Blumer, 1969). Symbolic Interactionism views human beings as pragmatic, yet reflexive actors who perceive and subsequently act upon the symbolic meaning of other actors and actions (Goffman, 1958).

In contrast to those using earlier and alternative socialization models of human development, symbolic interactionists do not believe the individual to be a passive, conforming

supplicant of socialization who enacts culturally “programmed” responses to social stimuli. In this approach, the individual is both capable of recognizing the self, other, and action as meaning-filled symbols as well as imagining alternate modes of action and their outcomes before strategically acting. Though displaced by later discourses and examinations of hegemony and power, this basic premise of the self as a reflexive actor on which symbolic interactionism rests engenders issues revisited by scholars of later approaches in anthropology including interpretive and post-modernist works, and attentions paid to resistance and agency in political economy critiques.

While recognizing this theoretical framework as a useful departure point for understanding the arguments and approaches to disability discussed below, I will not be using it as a primary lens for understanding the meanings ascribed to physical difference in the case studies presented. Rather, I will focus on how disability is assigned meanings within different spheres of personal interaction that differ from and move beyond those meanings assigned to it by a biomedical view rooted in the anatomy and physiology of the body.

In contrast to accounts that largely restrict their discussions of rehabilitation activities to those “parameters of bodily restoration defined by the rehabilitation industry and its commodified services” (Seymour 1998), Wendy Seymour fixes attention on the activities that reflect what she calls “everyday rehabilitation” (1998). Her work reflects how individuals manage personal roles and social relationships through the management of their body. In her book on individuals who have experienced profound and permanent paralysis as the result of spinal injuries, Seymour discusses the way in which such everyday management tasks as eating, exercising, washing, grooming, and dressing engage individuals, defined as embodied social agents, in the production and reproduction of their bodies (1998). She notes that the body is

revealed and made meaningful in both a phenomenological and social sense through such social categories as appearances, social routines, sport, sexuality and intimacy, and embarrassment. Seymour assesses what she calls the “reflexive project of making, unmaking, and remaking one’s embodiment” through everyday tasks associated with these social categories.

Yet, the management of the body is not simply an individual project of management. As discussed in the following section, meanings of disability and subsequent strategies for managing these meanings are defined by a range of other social collectivities.

1.5.3.1 Kinship Model

One important site in which disability is assigned meaning and managed is the kin network. As the cases in this section will demonstrate, families do not exclusively espouse a medical or social model of disability, but instead see disability as extending to the kin unit and requiring different strategies for controlling and managing its meaning and consequences.

Daniel Wilson, a social and medical historian writing on Polio between the 1930’s and 1960’s in the US tells us that:

Although polio was sometimes fatal, parents more typically feared the crippling paralysis that was so characteristic of the disease. At a time when American society made few accommodations for the disabled, parents dreaded the potential of polio to cripple young lives full of promise (2005).

Wilson’s statement highlights the observation that the greater fear to be reconciled with regards to Polio was not one that threatened the existence of a child’s physical body, but rather the fear that a child’s social life extending from and beyond the biological body would be harmed by paralysis.

However, fears that disability could threaten the life projects of individuals were not simply parental anxieties over disability’s consequences for their disabled child’s lives. As Meira

Weiss's case studies demonstrate, an individual's disability can be seen as threatening the life projects of other family members. Meira Weiss's analysis explores parents' perceptions and reactions towards their children who have a visible disability or life limiting condition that alters the child's physical appearance. Her work:

is an account of how a child's appearance determines his or her parents' terms of affection. It explores practices of abandonment, dehumanization, territorial seclusion and abuse to which Israeli parents subject their appearance-impaired children (Weiss 1994).

In her study, Weiss observed 1288 cases of parents with their infant and/or children who had one or more diagnosed defects, injuries, or diseases including heart defects, Down's Syndrome, Cancer, burns, and cleft palates. At the time of her study, Weiss documented that 50.8% of all children born in Israeli hospitals who manifested a major physical or medical defect were abandoned at the hospital; of these, 68.4% were appearance impaired in that the child had a facial or other aesthetic, external deformity.

In an argument akin to Goffman's analytical focus on the management of stigma, Weiss concludes that Israeli parental attitudes, love, and acceptance of their child were conditioned upon the appearance of their child. She noted that often times those children whose appearances deviated from a normative look were subjected to practices of parental derision and abandonment even when the anomalies were not functional disabilities. In her case studies, we see that outer physical aberrancy signified familial exclusion through physical abandonment and parental discourse that dehumanized the child subject, fixed attention on the physical deviation, and censored all other emotional responses such as hope, grief, or ambivalence.

These parental responses that included stigmatizing labeling (such as "beast" and "bald headed monster"), abandonment, withholding food or medical treatment, and sequestering the child out of sight and away from other family members frequently ran against hospital and

professional policy and discourse. – Hospital and social work personnel encouraged parents to visit and hold their child, to permanently take home children whose health status permitted it, or to bring children requiring stricter hospital observation home for short visitations. Despite continuous efforts on the part of healthcare professionals to persuade parents to see their child as healthy and/or a member of their family requiring and deserving parental care and love, parents resisted this discourse, unable to overcome the threatening sense of danger that these “appearance impaired” children posed to the parents’ and other siblings’ social lives should they be brought home.

In the cases documented by Weiss, a child’s physical impairment cast the child out of claims to familial membership, and instead placed the child within the domain of the state. Management of the child’s disability was first handled by parental abandonment and then assumed by the state. In discussing this same work, Das notes that it is only within the domain of the state that these children’s rights, including the right to life, could be defended and claimed (2001).

In a sophisticated and singular article by Das and Adlakha, we find an argument that extends parental anxieties over their child’s disability to the fears of interrupted and tainted social lives voiced by members of extended kinship communities. Within their assertion of a theory of *domestic citizenship*, the authors locate disability “not in (or only in) individual bodies, but rather as ‘off’ the body of the individual and within a network of social and kin relationships” (2001). In order to clarify this analytical approach to disability, we must first understand that:

the stigma of disability, impairment, and body disfigurement is not treated as an individual affair in societies that place less importance on the individual as a locus of value – instead it is treated as a matter of *connected-body selves* (Das 2001).

Das's notion of *connected body-selves* is an attempt to move away from a Cartesian mind-body dualism. Moreover, it moves away from defining the individual within terms of a liberal political regime, in which primacy is given to the unique autonomous individual. -- *Connected body-selves* first links the physicality of the body to the identity and experience of personhood, and then specifies that the experience and meaning of personhood is fused to a network of other body selves. In this notion of *connected body-selves*, we clearly see the mechanism by which the parents in Weiss's examination presume the inevitable transferability of a disabled child's damaged life to their own and their other children's.

Further the construct of *connected body-selves* permits us to examine how actions and claims to rights are not made in the public domain as with a liberal political notion of citizenship, but rather within the politics of the domestic sphere. Domestic citizenship opens an analytical space for examining how an individual's agency, their possibilities and limitations are "linked to the nature of how they (disabled individuals) are positioned in (or excluded from) the domestic configuration" (Das 2001) of a network of body-selves. As we shall see in the following case study, this analytical approach also allows us to observe how people strategically negotiate various claims to citizenship of varying social and political domains. We can observe how individuals move within and beyond the domestic sphere in order to align resources needed to combat social pressures and exert agency over their life courses.

Das narrates the account of Mandira, a young Hindu Punjabi woman, which was constructed by Das through various observations, performances, rumors, and fragments of narrative which constitutes a collage of "performative speech acts" (as opposed to information gained through an interview modality of talk and voice). We learn that Mandira had a birthmark that covered half of her face, which was anxiously feared to ruin her marriage and reproductive

prospects. Indeed, older relatives proclaimed Mandira's parents to be extremely misfortunate given the perceived unlikeliness that a suitable husband would be found. As with Wilson's example, we see that Mandira's birthmark imperiled her ability to fulfill normative social and reproductive life projects in the minds of her parents and extended family.

In this example, the meaning ascribed to Mandira's disability may have incorporated bodily difference, but the nature of her disability extends beyond the physicality of her body. Indeed, the birthmark on her face signified to her family (particularly her extended kin group) an *inability* to perform normative kinship roles and duties such as daughter, niece, and potential wife, mother, and daughter-in-law. This point of disconnect between the physical capability of Mandira's impaired body to perform the roles required of her within her social and kin networks and the applied social and familial restrictions (perceived or actualized) on her ability of actually fulfilling these roles exemplifies Das and Addlakha's argument that disability is not located in an individualized body. Rather, this point of disconnect that mirrors the space between the individual and familial/social body is precisely where Mandira's disability lies. Disability is not necessarily located in the individual body but rather in the space that both exists off or around the body, and constitutes the social network of a kin group.

In wanting a normative life experience for their daughter, Mandira's parents situated themselves within the politics of the domestic sphere and against the larger kinship group that denied such possibilities as marriage and children to a woman with a facial deformity. This example also highlights how Mandira's parents' attempts to manage her disability required them to align themselves with different actors outside the domestic sphere. By invoking their claims to a wider state citizenship, Mandira's parents were able to pull upon alternative resources and opportunities for their daughter (such as civil marriages) than those limited rights and

opportunities given (and being withheld) by the kinship network. This strategic risk taking and negotiating that Mandira's parents engaged in exemplifies how domestic citizenship serves as:

a concept for capturing the nuanced relationship of norm and transgression and to see how families mediate between the collective level of social response to conditions of stigmatized disability and the individual life trajectories. (DAS 2001)

In a comparable example of rehabilitation activities in Botswana, we see how people made claims to the state in order to curb the state's ability and attempts to put into place resources and programming that rested outside the domestic domain. Here domesticity and the state align in a very different way in order to "maintain" a divide between the two domains. Ingstad presents how disability was largely viewed as the responsibility of the family to manage. Ingstad's case study also demonstrated how this locally held view influenced and transformed discourse on Community-based Rehabilitation (CBR) programs that were first conceived in Norway. Many in Botswana claimed that "it had always been Tswana tradition to accept and care for disabled family members" (Ingstad 1995). "In principle...care for disabled people has always been, and still is considered the responsibility of the family" (1995). Ingstad notes that familial responsibility and management of disability meant modifying expectations for the disabled individual and finding roles which that individual could fulfill and thus contribute to the family. This familial dimension of rehabilitation drastically impacted the implementation of Norway's CBR model in Botswana. Norwegian funders ran into conceptual and implementation problems both at the local and national government level as Tswana community members, elected officials, and policy makers were all reluctant to initiate any policies that might be seen as usurping the rights of the family or weakening the family as a support system. Tswana citizens conceptualized help to the disabled person as meaning support to the care-giving family in the form of food and clothes. Rather than viewing community programs that emphasized

equality and integration as beneficial services for a community's and disabled individual's empowerment, Tswana citizens felt cheated by such programs which used up resources that could otherwise be given to and used to support the disabled at the family level. Ingstad concludes:

While equality for the disabled individual became a powerful tool in the hands of political advocates in the North, it has less relevance where the disabled person is seen primarily as part of a larger whole – the care-giving family. Thus the question of input of public resources in a [community based rehabilitation] CBR program becomes not only a question of the allocation of scarce goods and giving priority to one type of need before others, but more a fundamental question of not taking responsibility away from the (extended) family thereby weakening it as the main sources of social security (1995).

Within Nepal, leprosy was not considered to be exclusively a responsibility of the family as seen in Botswana. In yet another alternative arrangement of domains of citizenship, the case study from Nepal demonstrates how familial meanings of disability and strategies for its managements are all but deleted by the domains of the state and local community. Discourses produced by the level of the local and state government construct permissible meanings and management modes for disability. From these techniques of management, we also see how the relationships between individuals are formed, negotiated, and changed in reaction to the particular system of bodily control.

As early as 1853, legislative policy within the *Muluki Ain* (code of laws) regulated community space so as to exclude those who were considered *Maharogi* (those with leprosy) from entering the city.

'Because *Maharogi* men are not permitted into the city, they are to be put outside and provided with food and two sets of clothes per year... by the *Guthi* (community committee)' (Hyland 2000).

Further, a provision existed whereby men married to *Kustha Rogi* (leprosy sufferers) could "return any betrothal gifts and leave his wife" (Hyland 2002). This example of the husband's

right to abandon a wife with leprosy supports Das and Addlakha's notion of connected body selves in which the disability is seen as extending beyond the individual to the kin unit, and therefore must be managed by the kin group. In this case, exclusion of the *Kustha Rogi* is the government sanctioned kin response. This particular iteration of community/governmental responsibility for disability continues despite significant revisions to the *Ain* regarding leprosy.

In 1886, those with *Maharog* were no longer simply cast out of the city limits, but were additionally to be placed in exclusionary facilities by the government in which they would receive their support of food and clothing from the *Guthi*. By 1935, the concept of alms giving and charity enters into the legal doctrine with the stipulation that *Maharogi* and fully blind individuals were to receive first priority in receiving alms from groups and organizations who administered such provisions. Additionally, policies from 1935 and 1963 allow that no wedding tax will be applied for an individual with *maharog*. However, in 1963 legislation was added that allowed for a spouse to divorce their wife or husband (and for a husband to remarry) if the status of *maharog* was concealed at the time of marriage. By 1978 confinement of leprosy patients to government centers was still maintained. However, the provision of medicine and treatment was added to the government's (mainly at the local ward level's) obligations and responsibilities for leprosy patients.

Within all of this legislation and government codes, there is a slight transition from the individual with leprosy being an object of contamination and exclusion to one of contaminated individual in need of charity and alms that is revealed between the 1856 and 1935-63 *Ain* legislation. It suggests that for at least the last 150 years, persons with leprosy were to be managed by the family and the state in a way that differs from the strategy employed in Botswana.

1.5.4 Religious-Charitable Approaches

This example of leprosy management from Nepal introduces an additional element and feature of disability and its management within South Asia. The concept of “alms giving” and charity are strategies that are used within many of the major religious traditions. Both alms giving and charity are conceived as moral and social obligations to provide for less fortunate members of the socio-religious community. While the concept of charity has acquired a secular saliency within North American and European communities, charity retains its religious association within India and Nepal.

The majority of global disability is experienced in non-western countries and contexts in which western ethics and epistemologies do not dominate. On the surface, cross-cultural attitudes towards disability differ little from earlier Christian attitudes of misfortune and evil. However, Sheer and Groce note that the majority of the field examining the intersection of non-western religions and disability suffers from a neglect of analysis that goes beyond Orientalist notions of the East’s fatalistic, barbaric, or outdated attitudes and practices towards disability (1998 as cited in Miles 1995). Such non-western meanings assigned to disability include the misfortunes dealt out by a deity, fate, or karma, and were often the consequence of parental or personal sins. Within the Law of Manu, a significant religious text of Hinduism, the following passage can be found:

Thus in consequence of a remnant of (the guilt of former) crimes, are born idiots, dumb, blind, deaf, and deformed men, who are (all) despised by the virtuous (Miles 1995).

A brief discussion of the meaning and treatment of disability from the Eastern religions of Islam, Hinduism, and Buddhism follows.

Islamic Responses to Disability

Often adherents of Islam are charged with holding fatalistic attitudes towards the treatment and prevention of disability and disabling conditions. Weiss's work on Israeli parents' rejection of their children with visual impairments supports this fatalistic attitude of Muslims. Despite knowing that their child's disability did not functionally impact their lives, the parents of such children employed religion to justify their behaviors. With regards to their child born with a cleft palate, one family stated, "Let it die, It is in Allah's hands." (Weiss, 1994).

However, Miles notes that this view of Muslims' attitudes towards disability is not completely accurate, and that the behaviors of Muslims are often more nuanced than such stereotypes suggest. He presents a case study in which a Muslim father of a child born with Cerebral Palsy sought medical intervention when his child suffered polio paralysis, yet still forbid treatment for his son's Cerebral Palsy. The father explained his rationale for his help seeking behaviors as his search for the remedy that Allah had appointed for all diseases including his son's polio. However, because his son was born with the condition of Cerebral Palsy, it was a state to be accepted with submission; to try to change this condition would be an act of rebellion against Allah (Miles 1995).

Beyond specific tenets on treatment, Islamic beliefs hold that an adult born with a disability that prevents him from working and thus supporting himself has the right to seek "justice" through begging for their livelihood. Rather than this being an act of begging for pity and charity, this act is seen to be a behavior sanctioned by Allah as a means for Allah and his servants to provide for all of Allah's people. Should this justice not be performed by other citizens, the balance of society would be disturbed as the result of violating the mutual responsibility and religious duty of the community (Miles 58). Here the notion of charity is

something that is conceived of as a deserved justice by those with a disability, and as a religious and communal obligation by those without a disability.

Buddhist Responses to Disability

The Young Prince Gautama's encounter with diseased and disabled persons and the suffering of humanity figures prominently in Buddhist philosophy (Miles 1995). Disability is one of the facts of human suffering and death that Gautama sets out to embrace, and from which he must derive meaning about how one should conduct oneself in this world.

From Buddhism, we find a notion of personhood that has the potential to directly challenge western disability thinking that emphasizes the autonomy of the individual and self-determination (Miles 1995). In contrast to Western philosophies, Buddhist approaches to disability might be configured as a focus on fulfilling one's dharma and attaining the state into which one was born. This conception of the individual with disability and the characterization of his or her life project and goals are notably different from Western renderings of disability. Western portrayal of disability frequently depict individuals with disability in extraordinary roles (i.e. super heroes, angelic, freakish, etc). Viewing the life goal for a person with a disability as fulfilling one's dharma is distinct from framing success as an individual with disability's ability to break out of a stereotyped mold to achieve exceptional goals.

Hindu Responses to Disability

The classical texts of Hinduism are filled with referents to disability and deformity. In the Ramayana, Vishnu appears as a dwarf to trick Bali out of the land he has stolen (Miles 1995). The hunchbacked Manthara was teased about her disability by a young Rama, who was later barred from his coronation by Manthara as retribution for her earlier treatment. In the

Mahabharata, a blind individual is deemed legally unable to inherit a kingdom. Other major characters appear with severe disabilities in the Hindu literature.

Within this cast of religious characters, disability is often portrayed as something fearful, and as a punishment for a misdeed. Twisted bodies are equated with twisted persons. Disability's meaning is often constructed within terms of retribution and the consequence of past actions. Miles notes that the Institute of Vishnu cross-lists several disabilities with the sin committed in a previous incarnation that resulted in each disability. Thus, one who steals a lamp will be blind; a usurer will be epileptic; one who consumes and does not share will be rheumatic. And as a note of caution to all of us wrapped up in the pursuit of higher education, those who have been domineering or over-intellectual in one life might need to be rehabilitated in the next through mental handicap to overcome arrogance and thus enable the soul to progress towards enlightenment.

Within Nepal, a Hindu kingdom where Buddhist and animist beliefs blend with the dominant religion, reasons for disability and subsequent exclusion of individuals with disability are attributed to folk-religious beliefs in the poor karma of the individual or parents. (UNICEF and His Majesty's Kingdom of Nepal, 2001)

The management of disability within these religious traditions was a significant preoccupation of South Asian rulers and government projects. The Laws of Manu entrust the family to care for its members who have disabilities. Additionally, positive epitaphs such as 'lucky', 'holy', having 'second sight', or protection against the evil eye are also found as referents for people with disability. Though disabled persons were barred from studying the Vedas within the Hindu religion, a special type of Upanayana was performed for youths with blindness, deafness, mobility disabilities, or mental disabilities that enabled them to start

educational studies. This initiation conferred onto them a special status that allowed them to marry. This loophole is remarkable because of the general negative tone and restrictions imposed by the Hindu Laws of Manu. In general, inheritance laws and the qualifications needed to be king, priest, royal counselor, monk, or doctor often prevented individuals with a disability or chronic illness from achieving these posts. Such detailed exclusion lists are common among Buddhism, Hinduism, Jainism, Zoroastrianism, and Judaism.

Additionally, various social and moral transgressions often were punished by treatments that disabled the individual. This link between physical anomaly and moral deviance is a theme oft repeated in the prevailing social attitudes in which “...madmen and drunkards, adulterers and gamblers, impotent men and lepers, blind men and one-eyed men” (Doniger and Smith as seen in Miles 52) were lumped together and prescribed the same social treatment.

Despite general attitudes that regarded disability in an unfavorable light, most of the early data on disability refers to services as much as it does laws and policies governing the participation and exclusions of people with disability (Miles 1995). Different institutions were put into place for the management of individuals with disability throughout Asia. Asoka, the third century BC Buddhist emperor, is said to have organized care institutions for people with disabilities. These practices were also employed by the Ceylonese ruler Buddhase: “For cripples [who moved about with the help of a chair-like frame] and for the blind he built refuges in various places...” In Buddhist North India there existed institutions for a short term care within residential facilities. In 1826, the Hindu Rajah Kali Shankar Ghosal, opened an asylum for the blind and other disabled people in Benares in 1826. This Asylum was followed closely by the Muslim Naisruddin Haider’s opening of the King’s Poorhouse for the ‘blind, maimed, leprous, infirm’ etc. at Lucknow in 1831 (Miles 1995, 54).

Charity vs. Rights-based Approaches to Disability

This theme of charity is a motif played throughout many South Asian religio-cultural groups in each's response to disabled populations. Adherents of most religions are instructed to not mock or harass people with disabilities, but to instead treat them with charity (Miles 52). The Christian community has a long standing history of establishing societies and organizations, including clinics, and hospitals, that continue the tradition of merging charity and healing for people with disabilities. As the case study on Nepal demonstrated earlier, the concept of charity is an evolved strategy in the management of disability. That case study suggests that despite different strategies for managing the social and physical conditions associated with Leprosy, religious notions that both stigmatized and pitied the disfigurement and social disablement of Leprosy were tightly interwoven with other notions of kinship, governance, and public welfare for at least the last 150 years.

One could ask why there is not a greater effort to mobilize charitable associations and actions from the religious organizations of the world if charity is perceived to be a common if not universal religious approach towards disability. The answer to this question is complicated and stems from the disability community's attempts to re-construct the meaning of disability and re-position the disabled person within societies.

The emergence of disability rights as a significant and politicized issue within larger socio-political agendas in the US and beyond has only recently occurred. Political action and lobbying that began in the US in the early 1960's gave rise to the international efforts to recognize basic human rights for individuals with physical and mental disabilities (Bickenback, 2001, 565). The rejection of charity approaches to disability in favor of rights was a strategic move on the part of people with disabilities and disability advocates that emerged from a

confluence of issues. The factors that shaped the early and current disability rights movement included returning veterans' push for benefits following World War I and World War II, the Civil Rights movements in the US, and frustration with the contemporary policies and modes of distributing resources for people with disabilities in the 1940's, 1950's and 1960's.

As a social movement, disability rights developed a support base between World Wars I and II when disabled American veterans organized to advocate for government benefits upon their return from World War I (Bickenback 2001). At the time when the disability rights movement was beginning, disability programs and policies were largely reactive and piecemeal responses to specific social conditions rather than fully coordinated and integrated into overall social policy. This trend in disability policy still persists today.

In an effort to expand and coordinate social policies for people with disability, disability advocates turned to other rights movements within the US and UK for models for achieving their goals. The disability rights movement—sometimes called the last human rights movement-- was in fact modeled after the Civil Rights movement in the US. Yet, the disability rights movement also pays homage to older rights movements including the antiwar and feminist movements. Some of the earliest manifestations of the disability rights movement can be found in early disability policy initiatives and entitlements of the US such as the anti-discrimination law Resolution 504 of the Rehabilitation Act of 1973.

The culture of rights that sprung up from the Civil Rights movement was enticing to those working in the field of disability. Disability advocates sometimes argued that rights discourses were simply too influential and powerful. (Bickenback 2001). --Others argued that the only realistic prospect for achieving social change was to embrace the entitlement-creating

notion of a right. The initial movement embraced civil rights as the *modus operandi* for actualizing the goals of disability advocates.

The traditional sociological distinction between civil rights and human rights is that the former, but not necessarily the latter, are inextricably bound to citizenship and so are bound to the existence of a state... The strategic virtue of this linkage, on which disability advocates relied heavily, was that one could demand civil rights by making the wholly unobjectionable demand that people with disabilities, despite their differences, are at least citizens and are owed the rights that are incidents of citizenship (Bickenback 2001).

The adoption of human rights as a strategy of the disability movement came later.

[Because] limitations on citizenship are commonplace, it was tempting to seek a rhetorically stronger basis for rights – hence to universal human rights, those rights that are fundamental entitlements owed to humans as such, independent of cultural or political context (Bickenback 2001).

The adoption of a civil and human rights agenda required disability advocates to renegotiate and reformulate not only the structure and approach to disability policy, but also the identity, citizenship, and social positioning of people with disabilities in society. Undergirding older views of disability and people with disabilities was the medical model's assumption that disability equated to abnormality, a deficit, and a limitation in capacity that rested solely within the individual. Disability advocates began to see religious beliefs and values of disability as complicit with medical models of disabling deficits and other stigmatizing social attitudes. These advocates reasoned that achieving appropriate services and a de-stigmatized place within society required both a rejection of older models and belief systems, and full citizenship and social equity. "Change for the better would flow once it was acknowledged that people with disabilities are not given their rights as a matter of charity or the goodwill of others; they are entitled to them as equal members of society" (Bickenback, 2001).

With this renegotiation came a rejection of charitable acts towards disability. Advocates argued that the practices of charitable societies had unintended and unforeseen implications on how people with disabilities were viewed by society.

As Eiseland notes,

the themes of individualistic charity and healing neglect the social and political needs of people with disabilities, failing to place as central emphases political engagement and social inclusion. When these associations are drawn between disability and pity, judgment, and perceived incompetence toward people with disabilities, disability can become perceived as a personal, spiritual burden for families to bear rather than a social issue with economic, and political implications for the welfare of the whole community that warrants an institutional response. (19 as cited in King 1998).

Drawing from the work of sociologists and sociopsychologists, disability advocates adopted the social model of disability. This new social model privileged the view of disability as a social construction that is shaped by cultural, linguistic, political, historical, and economic forces (Bickenback 2001). By extension, disability advocates concluded that “disability law and policy should not be a matter of charity, professional need, compensation, or economic necessity but instead must be grounded in human rights” (Bickenback 2001)

From these early days of the disability rights movement, disability rights have found legal expression through four basic types of policies: enforceable anti-discrimination legislation; constitutional guarantees of equality; specific entitlement programs; and voluntary human rights manifestos (Bickenbach 2001)

The above discussion of the emergence of disability rights as an approach and management strategy demonstrates how the four models (medical, social, kinship, religious-charity models) are inter-related, yet retain distinct differences in how each defines disability and the resulting strategies deemed appropriate for managing disability.

The medical model as a theory emerges from the work of scholars like Foucault who sought to characterize the emergence and power ascribed to the biomedical body, practices, and profession. Some critics argue that the social model further reinforces the notion of the biomedical body through its strategic work against social attitudes, policies, and practices that are derived from the medical model.

In noting the particular western value schemes and notions of personhood associated with these two models and the disability policies stemming from each, disability scholars have explored the cross-cultural differences that exist in the degree to which the individual is privileged as an autonomous unit in relation to other kin members. This work has led to interesting theoretical models such as the kinship model of disability presented here. In line with looking at cross-cultural differences in values and meanings assigned to disability, I have brought to light the potential roles that South Asian religions and concepts of charity and almsgiving play in defining and managing disability. This potential model is by far the least developed, and understudied model of the four presented thus far. However, given charities prominence in defining the strategies of the western disability rights movement, I suggest that it is a concept that requires further scholarship.

Two additional means of assessing the meaning and experience of disability are found within the disability scholarship. Embodiment theory is more aptly suited to examining the individuals experience with disability. On the other end of the spectrum, Foucaultian post-structuralist theory provides a broad-sweeping framework for understanding the rise of biomedicine, the concept of a disabled vs. normative body, and the production of particular types of knowledge and practices that create particular types of management strategies. Both embodiment and post-structural theory play a critical role in understanding the triangulated

relationship between individuals with disabilities, disability organizations, and international institutions. Therefore, I include a brief discussion of an embodiment and post-structural approach to disability as they are informative to understanding disability and its management from the levels of experience and discourse, respectively. However, these two additional models are not well suited to studying the role that NGOs play in producing, circulating, and transforming disability discourse.

1.5.5 Embodiment Model

In his book, *Body/Meaning/Healing*, Thomas Csordas asserts that his work examines “the meaning of being human, the meaning of our existence as bodily beings...” (2002). This concern with meaning that is grounded in one’s experience as a body-in-the-world bears acute relevance on the field of disability studies and parallel queries into how one’s existence as a disabled-body-in-the-world is perceived and experientially understood by the self and others. Csordas’s elaboration of a paradigm of embodiment and his notion of *somatic modes of attention* as a conceptual tool for this paradigm allow for examination of how the disabled individual perceives the self and/in the world, as well as an analysis of the dialectic relationship between the disabled individual and cultural practices and forms.

Csordas poses a *paradigm of embodiment* in order to collapse what he calls “troublesome dualities” and allow for a simultaneous analysis of both the self and culture. Csordas explains that the *paradigm of embodiment* can be understood as a methodological field that grounds the biological, material entity that is the body within indeterminate, perceptual experience (2002). Embodiment as a methodological approach captures meaning from bodily experience by attending to the body’s mode of presence and engagement in the world. Rather than merely

seeing the body's presence and engagement as a matter of degree or bounded cultural method, Csordas's own work builds upon a phenomenological approach to the body in which "embodiment is viewed as the existential condition in which culture and self are grounded" (2002). It is experience itself that is asserted to contain the:

meaningfulness of meaning, immediate both in the sense of its concreteness, its subjective openness, its breakthrough to the sensory, emotional, intersubjective reality of the present moment; and in the sense in which it is the unmediated, unpremeditated, spontaneous or unrehearsed upwelling of raw existence (Csordas, 2002).

Stemming from Merleau Ponty and Bourdieu's work, Csordas provides the concept of *somatic modes of attention* as an analytical tool to accompany his theory of embodiment. For Csordas, *somatic modes of attention* are culturally elaborated ways of attending to and with one's body in surroundings that include the embodied presence of others (2002). By extension, embodied experience rather than the objectified body becomes the analytical starting point for assessing human participation in cultural worlds and the nature of human experience in culture (Csordas 2002).

Through Csordas's notion of *somatic modes of attention*, we move away from understanding perception as merely a bodily process towards a thing that is both an elaboration of culture as well as a medium for reproducing it. This shift occurs within the dialectic between Merleau Ponty's notion of *perceptual consciousness* and Bourdieu's concept of *collective practice*. However, I wish to ask how far and to what extent can we move away from the bodily process of perception towards cultural practice when we are seeking to understand the experience of disability. What elements of the body are involved in individual perception? What elements of the body are critical to understanding the process of perception? Within cultural practices, does thinking with a disabled body versus a well-abled body fundamentally change the relationship between attending to versus attending with the body?

Csordas believes the body to not merely be a biological substrate through which culture is mediated. Instead, he defines the body as the existential ground of culture (Csordas 2002). This fine distinction allows for the development of the body as being more than biologically conceived by also encapsulating other experiences that include cultural, spiritual, and religious. Like other types of bodies, we conceive the disabled individual as any other body who comes to know itself as disabled, and even a body for that matter, after attending to and with itself and to the *preobjective milieu* of thoughts, emotions, sensations, and feelings. However, I would suggest that the culturally elaborated modes of attending to and with a disabled body differ between disabled and well-abled bodies within the same cultural grouping. Moreover, the perceived experiences differ between individuals with differently abled bodies given the different modes through which they perceive the *preobjective*. Though perhaps culturally constituted as well as constituting culture, the experiences that are derived from cultural elaborations of one's sensory engagement with an *intersubjective milieu* are markedly different between well-abled individuals and individuals with a particular bodily difference. Here arises a key challenge in identifying the cultural forms that Csordas assumes to be inherent to experience.

1.5.6 Post-Structuralist Approaches

All of the above discussions of what a disability is assume the facticity of the body. Before continuing, this statement requires some qualifications. The body that is assumed to exist is not the same between each approach. As discussed earlier, both the medical and social model employ a biomedical body. While the body of embodiment theory is not explicitly biomedical, an argument can be made that within certain contexts a biomedical body can be used. Csordas himself makes reference to a biological material entity. More generally, the body of an

embodiment paradigm is the medium through which one is in the world and experiences the world. However, within all of these models, the body exists as a taken-for-granted entity whose existence is natural and ontologically given. Yet, approaches to the concept of disability need not assume *a priori* the body as a naturally given entity in the world. To engage in this understanding of the body, we must approach the notion of disability differently. Rather than entering the body postulated in the disability scholarship from the assumed factuality of physical pathologies, anatomical deformities, and physiological anomalies, we must instead enter the body after passing through the contexts that conceptualize and solidify the notions of the body and disability using these particular constructs.

In his 1976 study, the medical sociologist Jewson concludes that the major distinctions between the bedside medicine that took place in the home and hospital medicine that was located in the new medical institutions of the hospital and clinic were the types of medical knowledge used and the nature of the patient-client relationship (Jewson 1976 as cited in Armstrong 1994). Under the practice of bedside medicine, the patient-client dominated the physician-patient relationship as consumers of medical care who informed the nature of the illness and medical diagnosis through his or her discussion of symptoms. After the emergence of hospital medicine, new institutional structures, therapeutic technologies, and a new doctor-patient relationship allowed the doctor to see pathologies and lesions “which were inaccessible to the patient without medical interpretation... The deployment of a new medicine based on pathology celebrated and reinforced a relationship between doctor and patient dominated by the former” (Armstrong 1994). Foucault describes in his analysis in the *Birth of the Clinic*:

the body became a static fact before the trained eye of the physician who would extract its visual data while refusing to acknowledge its activities within a wider social arena: [diagnosis] gave to the clinical field a new structure in which the individual in question

was not so much a sick person as the endlessly reproducible pathological fact to be found in all patients suffering in a similar way (19).

The doctor's dominant role in conjunction with a pathology-based body of medical knowledge were vital components of this new form of knowledge.

The significant impact of Jewson's work was to undercut the assumption that medical knowledge was discovered (Armstrong 1994). Thus the emergence of pathological medicine, in which disease was reduced to inaccessible lesions within the patient's body, was not the product of discovery but creation.

Armstrong notes that within Jewson's work there is a notion of the Marxist concept of alienation in that the move from bedside medicine to hospital based medicine marked the disappearance of the earlier conceptualization of the sick patient from the hospital cosmologies (Armstrong 1994, Jewson 1976). As evidenced by his focus on the role of the changing doctor-patient relationship in changing medical knowledge, Jewson felt that it was the social relations of production (the doctor-patient relationship) that produced a form of social order and associated knowledges (as cited in Armstrong 1994). Armstrong summarizes that the earlier eighteenth-century bedside medicine based on a patient-defined agenda was usurped by a medicine which treated patients as objects and ignored their words in the search for the underlying pathological basis of illness (1994). In consequence the autonomous identity of the patient was alienated by the new mechanistic forms of clinical practice which were in turn driven by a physician dominated relationship with the patient.

While Jewson's work introduces the notion that disease and medicine are fabricated categories, the work of Michel Foucault argues that so are the bodies within which disease is found. Foucault links the institution of medicine to other entities similarly deploying techniques

of disciplining and therefore producing bodies. His examinations of Bentham's Panopticon as an ideal prison type employing surveillance as a method of correcting deviant bodies within *Discipline and Punish* is an example of the type of projects in which institutions have been engaged (1977). These social institutions demonstrate the production of disciplinary power through various systems of governance. Unlike liberal-Marxist orientations which view power as repressive and concealing, disciplinary power is generative and concerned with manifesting the object of its focus (Armstrong 1994). Through processes of surveillance and objectification, the disciplinary power mechanisms that surround the body are responsible for the body's creation and maintenance within modern cosmologies.

Armstrong notes that in the prison, school, workshop, barrack, and hospital, "bodies were observed and analyzed with the purpose of affecting a passive and malleable body, but at the same time establishing those selfsame bodies as individual and discrete" (1994). This notion of individuality is a divisive point for Foucault and Jewson. Jewson viewed the medicalization of patients' bodies as the disappearance of the sick man and the loss of the patient's individuality as exchanged for a clinical gaze which viewed the patients as identity-less objects. Foucault begins at a radically different starting point than Jewson's western philosophical privileging of the autonomous individual. Foucault begins with the notion that autonomy and individuality as defined by discrete bodies did not exist prior to the emergence of the hospital and its clinical techniques. Within the institutions of the hospitals, prisons, and schools, the application of new social practices of surveillance and objectification such as clinical techniques created the individual body as distinct and separate from a collective "social body" (what Foucault labels as the sovereign body).

Rather than deleting the individual, Foucault defines this point in time as marking the emergence of the individual subject. -- Armstrong notes that this view of the individual and discrete body generates the notion of ‘ordinary individuality- the individuality of everybody’ (1994). The process of corporeal objectification becomes not so much an assault on human individuality, but rather the practice through which individuality is manifested and grounded (Armstrong 1994).

Foucault implicitly finds the body and the self to be one and the same (more accurately, I think that he dispenses with the possibility of the self as a phenomenological being in order to understand the amalgamated body/self as a product of discourse). Therefore the articulation of the objective body simultaneously brings into being the individuality of the self. -- Individuality is not “simply an idea but its concrete realization in the facticity of the body” (Armstrong 1994). Knowledge of human anatomy and pathological medicine mark the techniques through which medicine could know bodies while at the same time construct them in its own image. From this we see how new medical knowledge serves the practice of clinical medicine in order to produce the real object of the body.

What Foucault and others following in this post-structuralist tradition present us with is a theory of how disciplinary power is sourced from knowledge-generating social institutions and marshaled through social practices and techniques that identify and label in order to create new objects. The objectification of the body through ordinary clinical techniques of pathological medicine and the creation of “ordinary individuality” can be seen as generating an intense focus on the disabled body. Within the realms of biomedicine and disability, Foucault’s work demonstrates how the medical profession and its techniques of inquiry and discernment construct and subsequently institutionalize a medical model of the individual, normative body. Post

structuralist theory informs us of how the body becomes a fixed, “material entity subject to the empirical rules of biological science,” that is naturally given and not subject to history, politics, or cultural change (Turner 2001). Such analyses also lead us to viewing how the disabled body becomes constructed as non-normative and functioning like a “faulty machine.” More importantly, this work challenges the assumption that there is a fixed and unchanging essence of human disability (Turner 2001).

Foucault’s critical writings can be extended to demonstrate how social and political structures and institutions operate in the production, regulation, and governance of bodies, and disabled bodies in particular. Turner notes the radical nature of this regulatory approach by highlighting that the rehabilitation process functions as a normalizing mode of governance. (This is a thought echoed by Stiker earlier in this paper.) In this way the rehabilitation process is a micro-system of regulation that “exercises normative control over individuals and populations” by regulating the disabled person and discursively producing the rehabilitated person (Turner 2001). Rehabilitation can be viewed as the development of systems of social regulation that orchestrates various medical and social practices in order to exercise normative control over the disabled individual. As a project of governance, rehabilitation seeks to create the “rehabilitated” person.

Disabled individuals have felt a particularly potent and lasting social effect from the medicalization of their bodies. Such individuals have been collectively grouped as a distinct population through the practices that conceived and labeled their bodies as deviant relative to physical pathology of the body or mind. An example of the social effect of which I speak is found within recent public debate. In speaking on the case of Terri Schiavo and the right to life/die debate surrounding her life which was made the subject of much media attention and

social engagement, politicians and others made assertions intimately linking the personal circumstances and debate over the management of her personhood and body to the lives of other disabled individuals. Perhaps more interesting than simply observing how and which factions of US society emerged on the different sides of this polarized debate is examining the rhetoric used to justify such positions. As just one example of many, George W. Bush made allusions to disabled individuals as a population of the “weak in need of protection from the strong” in purporting a strong right to life position.

What this debate and statement highlights is how such social institutions as the medical profession, federal government, and religious organizations employ clinical techniques to both create and label individuals and populations such as Schiavo as “disabled,” “weak,” “incompetent,” and “mentally incognizant” (or cognizant so the debate goes). Clinical techniques allow a variety of institutions and individuals to observe signs and discern meaning regarding the presence or absence of personhood. Tests for brain activity, physical movement, and responsive interactions are wielded as tools for discerning other social concepts of personhood and autonomy. Yet the arbitrariness, mutability, and overlap of these clinical labels and meanings is seen by way of the alternative means of measuring and defining life posed by other factions of this debate (for example, religious organization’s use of moralistic and spiritual markers of knowledge and meaning). However as Bush’s statement suggests, such power wielded by social institutions to identify and infer meanings also grants these same institutions the authority (or obligation) to act in ways that regulate and govern the objects produced by institutional discourses.

1.6 CONCLUSION

This chapter has suggested a model of how different disability actors work in coordination with one another. The interrelationships between people with disabilities, disability organizations, and international policy-making institutions lead to the production and circulation of disability discourse that ultimately informs how disability is defined, managed, and experienced globally. Feeding into this triangulated system are several models of disability that seek to explain, as well as influence the many ways in which disability is defined and managed.

Some of these models have experienced particular popularity among policy makers and disability organizations around the world. In particular, the medical and social models of disability have significantly influenced the way in which services are delivered, as well as how the needs of individuals with disability are conceptualized and met.

Yet the discussion of four additional models of disability suggest the inadequacy of a social model and medical model of disability to fully explain the experiences and meanings of disability for all individual and in all locations. These four models taken collectively also suggest that alternative ways of understanding disability and managing it exist, and contribute to how individuals and organizations perceive and manage disability.

Few attempts have been made to understand how different notions of disability are negotiated by organizations serving individuals with disabilities. This striking gap within the literature is made more glaring in light of the popularity of disability rights discourse and rights-based approaches to disability among disability organizations. – The existence of multiple ways of defining and managing disability has the potential to generate many ways in which disability rights and rights-based approaches might be conceived. Beyond, the conceptualization of rights as anti-discrimination law, constitutional guarantees of equality, entitlements, and human rights,

the actual content and form of rights guaranteed to individuals with disability have the potential to be different based upon different models of disability at work in particular cultural and political contexts.

Much work remains for disability scholars to examine a) how different models of disability influence the work of disability organizations; b) the adequacy of existing models in explaining the experience and work of disability organizations in diverse geographical locations; and c) the roles that NGOs as agents of change play in constructing and transforming disability discourse.

In the chapters that follow, I examine these issues by analyzing case studies on two South Asian organizations that provide services to people with disabilities in Kathmandu, Nepal and Delhi, India. In chapter 2, I discuss the methods used to collect the data that informs these two case studies, as well as the analytical framework I use to address the questions and issues raised above. Chapter 3 presents the two case studies in detail. Chapter four moves into the analysis of these two organizations in which I discuss the organizational culture of these two organizations with regards to how each defines disability, personhood, the cause and goal change, and disability rights. Within this chapter I then move into a discussion of how specific program features of each group maps onto the medical, social, kinship, and religious-charitable models presented in this chapter. I conclude the analysis section with a description of how each group defines and operationalizes a rights-based approach to disability that integrates the discussions on organizational culture and the groups relationship to the four disability models. The paper concludes with a discussion of the role that analyses such as that presented in this paper might play in deepening our scholarship on disability and disability rights, as well as tailoring NGO

programming to better advance disability rights and the well being of individuals with disabilities.

2.0 CHAPTER 2: METHODS

2.1 FIELDWORK AND COLLECTION OF ETHNOGRAPHIC MATERIAL

The information presented in the case studies that follow was collected during two different fieldwork experiences. I conducted preliminary fieldwork with several organizations in Kathmandu, Nepal during July and August, 2004. The following year, I traveled to North India in August to work with two organizations in Delhi and Darjeeling, India.

The information was obtained from analysis of daily fieldnotes, primary documents and written sources collected in the field, and interviews with NGO leaders and staff members. In Nepal, organizations were selected using a combination of snowball and purposive sampling methodologies. Once one organization was located, contact information for additional organizations was requested. Other organizations were selected from published resource lists to obtain a sample of organizations that served a range of populations with disabilities (varied in age, gender, disability type) and provided a range of services (varied by their focuses on policy reform, vocational, educational, physical rehabilitation, or some combination of each). Because the India-based fieldwork was different in subject and more narrow in its focus, organizations were selected based upon their location in Delhi and Darjeeling, and their work with child and young adult populations.

For the purpose of this paper, the two organizations presented are representative of field sites in Kathmandu and Delhi. NDNWS is a local organization serving women with physical

disabilities in Kathmandu. Amar Jyoti is an internationally recognized organization located in Delhi with a branch in Gwalior. Amar Jyoti serves children and adults with disabilities, their families, and health and education professionals in these two areas. The two organizations are introduced at greater length in Chapter 3.

In order to protect the confidentiality of the individuals who participated in this research project, I masked the identity of all individual participants. Within this thesis, I employed culturally and ethnically relevant pseudonyms. I also elected to not disclose the location of the Nepali organization short of its being located in a suburban neighborhood of Kathmandu. In consultation with the specific individual participants that I mentioned in this paper, I decided to disclose some details regarding the nature and cause of their disability. This decision is reached jointly with the research participants, and made in the spirit of providing a venue for these individuals to share the experiences and circumstances of their disability, as well as enrich the picture of disability and individuals living with disability cross-culturally and globally.

Within the two case studies that follow, I have chosen to present the two organizations by highlighting key features that provide insight into underlying values and important influences on each organization, as well as the way in which the clientele is defined and served. Such information is important for interpreting how disability, disability rights, and a rights based approach is defined by the organization.

I have chosen to provide information about each organization's mission statement and guiding values; goals and objectives; history; physical space and building structures; target clientele; staffing and organizational structure; services; perceived barriers; and assets. The use of documenting organizational mission statements, values, objectives, and goals elucidates the underlying values and meaning of the work each organization does. Information about the

physical space provides an additional layer information about the expectations and treatment of organizational clientele, as well as the role that trends in international disability policies play in literally structuring and designing each organization.

While the physical space that an organization occupies is often a taken for granted feature of many discussions of non-governmental organizations, I argue that this feature can be an important tool for deepening our understanding of organizations that cater to individuals whose participation in and negotiation of the physical environment are often deeply and variably impacted by physical differences. The choice of clientele and labels used to describe this clientele is important for identifying not only the target clientele, but also popular social attitudes regarding disability and the underlying approach and values the organization employs within its programming. Information about staffing and organizational structure can reveal the impact external influences such as education, class, professional culture, or life experiences have on the design and day-to-day work of the organization. Documentation of the services provided by the organization sheds light upon both the types of challenges each organization sees as facing individuals with disability, as well as the solutions that each group offers to overcome these challenges. Finally, a discussion of the assets of each organization shifts the discussion of each of these organizations from a purely theoretical critique of each to a discussion of the strengths and capacities that each organization mobilizes to exert a change in the lives of the individuals each serves. It also allows for an avenue into thinking about community development and the role that these NGOs can play in community health endeavors.

2.2 ANALYTICAL FRAMEWORK

Triangulation of the program's own primary documents, interviews with staff members, and external documents and assessments was used to produce the following case studies. Wherever possible, I have used the organization's own words in order to accurately reflect the discourse each organization employs in describing themselves and the work they do. This information also allows for assessing the choice and strategic use of particular types of disability discourse employed by each organization.

I employ three types of analysis to the two case studies in order to address how each organization conceptualizes a Rights-based approach to disability. The first analysis evaluates the level of intervention that each organization is targeting in the services that they provide their clientele. This analysis assesses each organization's services with regards to whether it targets change in the individual, household, organization, community, nation, or international settings. This information is presented in the Chapter 3.

The second type of analysis uses material from the case studies to describe aspects of the organizational cultures of NDNWS and Amar Jyoti. I examined the case studies in order to conceptualize how disability, personhood, disability rights are defined. Additionally, I examined each organization's theory of change by assessing what each organization desires as change, what is targeted for this type of change to occur, and how each organization believes change to occur.

The third analysis returns to four of the models of disability presented in Chapter 1 and summarized in Figure 3. Using the material presented in the case studies, I determined which program features employed a definition of disability based on a medical, social, kinship, or religious-charity model of disability. Those program features that did not fit into any of these

four categories were assigned to a separate category for later analysis. This analysis allowed me to use the four disability models as lenses for understanding how the ideological frameworks and discourse from these four models influences how each organization operationalizes a Rights-based approach to disability.

3.0 CHAPTER 3: CASE STUDIES

3.1 NEPAL DISABLED AND NEGLECTED WOMEN'S SOCIETY (NDNWS) OF KATHMANDU, NEPAL

NDNWS is a community based, grass roots organization that is located within a suburb of Kathmandu. The organization provides social, vocational, respite, and educational opportunities and services to its clientele. Many of the clientele are long time members of the organization that serve as facilitators and teachers to newer members of the society.

In June 2004, I first came upon NDNWS as I was walking through the neighborhood in which the organization is housed. A sign on a gated entrance to the building stated the name and contact information for the group. Before I was able to contact NDNWS, I was again reminded of the organization when I met NDNWS staff member, Maya Devi at a conference hosted by the Nepali Government to address the constitutional rights and government policies for individuals with hearing impairments. Despite the limited focus of the conference, many disability communities were represented in the audience that day. Maya Devi had a physical impairment that impacted her mobility. She introduced herself to me at the conclusion of a conference work session to which we were each assigned. At her invitation, I made an initial visit to NDNWS the week following the conference. After this initial visit, I spent four additional days with the organization in which I accompanied them during social events, organizational

programming, and a visit to a local children's orthopedic hospital¹. On my third visit to the organization, I conducted a focus group with the staff and some of the clientele of the organization. This focus group pursued the organization's mission and core values, definition of rights, and the role of disability rights in the work of Women's Disability Society of Nepal and other NGOs.

Mission Statements and Core Values

The organization conveys many of its guiding principles and core values on program documents that are published as brochures and reports on organizational activities. These program documents are published in English, and are geared towards an English speaking audience which would include foreign and Nepali donors, members of the local and national disability community, as well as potential clientele. Much of the other materials identifying the organization are written in English. This is notable because few of the members of the organization, including the president speak or write in English.

Within program documents, the organization employs a range of phrases and statements that convey the group's guiding principles and core values. On the front cover of the organization's brochure is the phrase, "If you help the helpless, than god will help you". Given its placement on the front of the organization's printed materials this statement can be interpreted to be both the key principle of the organization, as well as a marketing slogan that advertises and attracts individuals to the mission of the organization. This statement suggests several things. It serves to frame the target populations as helpless. It implies a religious and spiritual association

¹ This day, I accompanied Maya Devi to the pediatric orthopedic hospital. At the age of 23, Maya Devi continued to visit for follow up doctor's appointments from a childhood surgery and to have adjustments made to the brace and calipers that aided her ability to walk.

or motivation behind the organization's work. It also suggests a particularly South Asian belief in a reciprocal cause and effect relationship between the sacred, the organization, and its clientele.

The group concludes that because of women with disabilities' physical difficulties" these women "fall behind and lack advantages in their life" (NDNWS brochure 2004). In order to rectify the situation and status of women with disabilities, the organization aims to "take care of these people and children providing them rights, freedom, opportunities, and [to] fulfill their needs." The organization works to "make life easier and overcome hardship for these people (women with disabilities)" by working "against the troubles of handicapped and oppressed women." The anticipated outcome of their efforts is handicapped women who are "self-dependant and versatile."

Within these more global goals of helping women (and children) with disabilities, the organization fixes attention on rural outreach and support, educational training, housing, and heightening social awareness (NDNWS Introduction and Objective of Organization 2004). Within program materials, they state goals "to upgrade the life style of handicapped and destitute women" and "support other handicapped and neglected women in rural areas" (NDNWS brochure 2004). They also view providing education as "the foundation of every successful steps [sic] [because] education can make these people's future brighter." They believe that by providing women with disabilities "training and housing ... before sending them back into the community... [they help to create] representatives [who can then] raise awareness in their society" (NDNWS Brochure 2004).

One member stated that "because they faced many problems in society, they conclude that they will completely destroy the problems for [other] handicapped girls and women"

(Baldwin Fieldnotes 2004) She went on to state that by eliminating the problem, future generations of women 1) “will not have to face discrimination on the basis of a traditional male society, or the notion that handicapped bodies are the result of bad events in previous lives or a lack of spirituality,” 2) “[will not be victims of] trafficking or violence,” 3) “will not lack literacy, human rights and opportunities, gender equality, an equal voice and equal rights as those given to able bodied persons, and” 4) “will live in a supportive system created by representation in government and [informed] policymakers” Baldwin fieldnotes 2004).

The core values of the organization also take issue with the Nepali Government’s historical and current response to people with disabilities. A second individual stated that the Nepali government and general society “take the handicapped and oppressed women as sympathy, and do not truly understand the crisis from inside their soul” (Baldwin fieldnotes 2004). As a result, organizational documents document that they “provide equal rights and opportunities and equal job posts in government offices as the able people because the government has not made policy to protect them (women with disabilities)” (NDNWS brochure 2004).

Organizational objectives and priority issues

The objectives of the organization center around themes of the economic/vocational environment; the social and government sectors; the material, educational, social, and economic, psychological/spiritual needs of the individual; and disability policy and research (NDNWS brochure 2004, NDNWS Introduction and objective of organization 2004). The organization priorities focus on achieving individual outcomes for individual women. Their goal is to “provide opportunities to every woman for self existence and make them economically and educationally sound and secure” (NDNWS brochure 2004). They hope to achieve these things

by working “in concert with social and government organizations to provide rights and duties of handicapped women through different seminars, meetings, rallies, concerts, etc.” They aim to coordinate with government, different organizations, and donor agencies to solve the problems of handicapped women and build the environment of livelihood for them. In relation to their general values and principles, the women list as their specific priorities to:

- raise national awareness and take steps to eliminate social prejudice,
- secure and protect the “special” rights of handicapped women,
- overcome humilities,
- make women conscious of their rights, opportunities, and individual abilities,
- boost morale of handicapped and seek practical ways of contributing to their “upliftment”,
- help women earn their own income,
- provide micro-credit programs,
- establish rehabilitation and training centers,
- find suitable vocational training for rehabilitation,
- find out job opportunities suitable to them and advocate for them, and
- organize meetings, training, workshops, seminars, studies, and research programs.

History

Sundara is the president and founder of the NDNWS. The organization began 11 years ago in 1995 (or 2051 Nepali calendar year) in its current location in a suburb of Kathmandu (NDNWS brochure 2004, Baldwin fieldnotes 2004). Sundara is originally from the Solu Kumbu region at the Everest base camp (Baldwin fieldnotes 2004). Like others in Nepal, Sundara acquired her disability at a young age when she, as a two year old, fell into a cooking fire in her home. Until eleven years ago, her main mode of moving was by crawling and dragging herself across the floor or ground. Her move to Kathmandu was concurrent with her marriage to her husband. Her son was born two years later. Through a series of events that were not completely clear to me, Sundara’s niece came to join her aunt and her family in Kathmandu from Sundara’s maiti/natal village. The niece attends school in Kathmandu, while also helping her aunt’s family and organization. From her home, Sundara started NDNWS.

During one of my conversations with Sundara, she requested to have a photo brought to her (Baldwin fieldnotes 2004). We had been talking about what had caused her disability and its impact on her life. In describing her injuries that resulted from her fall into a cooking fire, she gave to me the photo that she had had requested. The picture was a formal portrait picture in which Sundara sat in a chair with one of her crutches leaning against her leg, and facing directly into the camera. Within the picture, Sundara had chosen to raise her Sari above her knees to reveal legs that were two different lengths, badly misshapen, and covered in scar tissue.

What is remarkable about Sundara's pose in this picture is her choice to reveal her legs. Her floor length sari could have easily covered her legs, while her prosthetic legs would have entirely masked her disability from the audience of this photo. In this picture with the crutch at her side, prosthetic legs noticeably absent from the picture, and her legs revealed, it is clear that Sundara's disability is the focus that she wishes to direct your attention to in this picture. It is unclear what she was hoping to accomplish through this pose in the picture. Possible interpretations include charity or sympathy from the audience, a challenge to take notice of her disability, an accounting or documentation of her disability or a disfigurement that is shared by many others in Nepal, or some combination of the above.

Physical Space of Organization

The organization is housed within a two story residential building in a suburb of Kathmandu (Baldwin fieldnotes 2004). The organization's leader, her husband, niece (13 years), and son (5 years), and many of the main staff live on the second floor of the home. Despite serving a large number of individuals with mobility impairments requiring crutches, braces, and wheelchairs, the building is unmodified and possesses no features to make the house more accessible for individuals with disabilities. This observation is commonplace among many of the

organizations that I visited. In common with many other building structures in Kathmandu, the multiple floors of the house are accessible only by a set of steep circular stairs that lacks a guide rail for support.

The first floor serves as a work and office area (Baldwin fieldnotes 2004). Four rooms are located off of a central hallway on each of the two floors. The rooms on the first floor are designated for the organization's income-generating projects, training in handicraft production, and administrative functions. One room dimly lit by outside light contains a large table, couch and wheelchairs and is designated as the painting department to produce hand-painted, stenciled cards. The room adjacent is where meals are prepared and where one woman can weave textiles on a large loom. A second loom sat disassembled in the painting room due to a lack of space for setting it up. Across the hall is the smaller sewing room filled with a central table for cutting patterns and fabric. On the walls hung examples of childrens' cloths and traditional clothing items such as *choli* blouses and *kurta salwas*. The fourth room located across from the painting department is the office area where the president of the organization holds meetings with visitors and conducts the administrative business of the organization.

The living quarters of Sundara, her husband, and their child were located on the second floor (Baldwin fieldnotes 2004). Like many other middle to low income Nepali families, all family possessions and sleeping materials where in this single room apartment. The remainder of the second floor was also divided up into three sleeping areas for the other women who lived full time at the house. Four women and three children join Sundara's husband, son, and niece in living in the house. One toilet facility existed on the second floor. Cooking areas were present on the second and first floor, though no formal kitchen space had been designated. In a shared room, a one profoundly sick child and woman slept and lived. The woman suffered from

paralysis on one side of her body from a fall at her work in a hotel. Other members of the house frequently visited the room to help with toileting and feeding. The remaining young women of the house shared a large single bedroom filled with several beds.

Access to major transportation buses and minibuses was roughly a five to 10 minute walk out to the Ring Road that loops around the circumference of Kathmandu (Baldwin fieldnotes 2004). Additionally, the road directly in front of the house is easily accessible to taxi.

Clientele

Using various terminologies, the organization reports a clientele made up of women and children who are disadvantaged, from low-income families, with a physical disability, those who are neglected, helpless, disabled, distressed, or destitute, as well as children of handicapped parents (NDNWS brochure 2004, NDNWS Introduction and Objectives of Organization 2004). Program documents discuss the conditions of women in rural areas, and program objectives and future goals are oriented towards disabled women from all over Nepal.

What I observed at the organization were women who had a range of disabilities, but who could principally be grouped as individuals with physical/mobility impairments and disabilities (Baldwin fieldnotes 2004). Most had some sort of lower limb impairment as the result of birth (club foot and other deformities), fire (burns and loss of limbs), illness (polio), injury (fall), and improperly performed medical procedures (improperly placed vaccination needle). Many of them came from families of lower socio-economic status and/or castes. Many have not received a full 10 years of schooling (equivalent to high school). The women ranged in age from 6 to 42. Some came from Kathmandu and the outlying areas of the valley, others were brought from greater distances such as the Solu Kumbu (Mt. Everest) region. Women appear to be sought out

through acquaintances of the group's current members. Members also talk of their experiences with the organization to parents and others with disability².

Staffing and Organizational Structure

Many of the women who live in the home are also members of the executive committee (Baldwin fieldnotes 2004). This committee of seven members includes a program manager, office secretary, accountant, and president. Organization materials and documents note that the executive committee facilitates the planning of new projects and programs during monthly forums. It appears that while an executive committee exists (with a carved wooden sign having been constructed to officially document the board members for use during meetings and for visitors), the meetings of this committee are informal and held infrequently. One such meeting was orchestrated for my benefit while I was visiting the organization. One of the board members is a foreign donor from Japan who had many visits to the organization to teach handicraft skills such as block printing and card making. This individual was also instrumental in transporting several of the finished products to Japan to market and sell for the organization. She had also made financial contributions to the organization.

Women's Disability Society of Nepal reports an annual budget of Rs 1,400,000.00 (\$US 18,691.58 – conversion 74.9 rupees to US\$1), and a staff of five members³ (NDNWS brochure 2004).

² While visiting the hospital ward of the children's orthopedic hospital, Maya Devi spoke with a mother whose child was in the recovery ward. Maya Devi provided the mother with the organization's contact information, which she stated might be able to provide assistance when the child left the hospital.

³ I was unable to account for the identity and functions of these five personnel mentioned in their program materials. It is possible that the five women that I met at the organization besides the president were the current staff. Each of their roles was not clearly communicated to me. At a social event, I met three additional women who remained peripherally associated with the organization, as well as close friends of the current women living and working at the organization.

At the organization, I observed several of the women participating or leading several activities. Maya Devi, who did not live at the organization traveled from her home (accompanied by her brother) to the organization daily to instruct women in sewing. I observed Sungita whose mobility was impaired by a club foot working at a large loom producing a traditional Nepali textile pattern, that was in turn marketed as a women's wrap, placemats, or table clothes. Two other women, Beno and Swati worked to produce greeting cards by block painting templates onto traditional Nepali paper. It is unclear which women were support staff vs. clientele given that many of the women lived within the household.

Types of Services Currently Provided

Within organization documents, NDNWS reports a large and comprehensive list of services that they provide. These activities and programming include individual education and skill training, healthcare and rehabilitation services, community outreach and awareness campaigns, and intra- and inter-organizational partnering and development. Figure 3. reflects the type and range of services listed as being provided by the organization.

In a national survey of NGOs working on disability, the women's organization is reported as having trained 21 persons in tailoring and 10 persons in computer skills as of the 2000 survey on disability in Nepal (UNICEF and HMG 2001). At the time of my visit, five women and three children were living in the home (Baldwin fieldnotes 2004). Computer services were not currently being provided due to financial constraints. Training in sewing, painting, card making, weaving, and food preparations were provided. Sewing lessons were also being provided to women from the neighborhood who did not have disabilities. These women were reported as being from "very poor families." Education materials for reading were observed to be in the painting department.

On two occasions, members of the organization accompanied new members to the hospital for emergency care, but no rehabilitation activities were being provided by trained health workers at the organization (Baldwin fieldnotes 2004). I observed no data collection. During one conversation, the president was optimistic that she would be able to provide college level education for one of the girls at the hostel. Many of the young women attended public events such as the celebrations for the King's birthday and outings to the zoo. Some attended different training sessions for other impaired groups in which disability rights and legislative policy were discussed.

The organization's ideals of providing a "systematized working system to upgrade the handicapped and neglected women and children from the grassroots stage" and "education packages for women in adult education program and children providing scholarships in different schools (NDNWS introduction and objectives of organization 2004)" were being implemented, but in a partial manner that did not include all of the listed functions and did not implement the programs in the manner listed in organization documents. It remains unclear as to whether these services were at one time were being provided and are currently suspended due to lack of funds and skilled trainers, or are hopeful programs and directions into which the organization wishes to move. The considerable overlap and unclear distinctions between listed program activities and future objectives suggests the latter.

Future Services and Programming Plans

Though overlapping with some of the programming that the organization reports to be currently providing, the members hope to provide (and continue to provide) in the future:

- education, shelter, security, and medicare to neglected and handicapped women,
- a new permanent residence for these women,
- an increased number of income-generating projects that are marketable and a steady form of income and employment for disabled women,
- increased job placement opportunities for trained women,
- an increase in national awareness of disabled women,
- a national strategy for positive actions towards women with disability,
- physiotherapy “production” and clinical services,
- a handicapped “material” product center,
- scholarships for children of handicapped parents,
- expanded networks of women in rural communities, and
- research projects capable of generating accurate data that can be used to better plan programming for women based on population needs (NDNWS brochure 2004, NDNWS Introduction and Objective of Organization 2004).

Perceived Barriers to Implementing Programming and a Rights-based Approach to Disability

Women’s Disability Society of Nepal list the following barriers to actualizing their rights-based approach: financial difficulties due to lack of regular income; transportation barriers; and a lack of space, infrastructure, accessibility (both on the part of the organization reaching women and vice versa), and a comprehensive coverage of the country (NDNWS brochure 2004). They note that “because of the distance, it is not easy for us to reach the many women with disability who could use the services of the organization.” Additionally, they are currently not able to provide staff a salary for their skills and work at the organization (Baldwin fieldnotes 2004).

Assets

The organization has strong group cohesion and unity in which members support one another and feel able to speak on behalf of one another and advocate for each other’s rights.

Women who were first seen as clientele often become intrinsic members of the executive

committee and organization. The group also has good rapport with other organization's and a strong involvement in the at-large disability community in Nepal. The organization states one of its greatest strengths as being able to persist in the face of adversity. Program documents note "through these difficult problems the organization has continued to operate and expand its services" (NDNWS brochure 2004). The organization has had continuity in its membership and the service they provide. They also have eight years of experience working with individuals with disabilities. The organization also brings a multifaceted outlook to the causes of disabled women's position in society, and subsequently brings a diverse range of services and approaches to improving the lives of women with disabilities. This multifaceted approach is strengthened through a familiarity with key concepts and discourse on disability within Nepal and larger disability communities.

3.2 AMAR JYOTI CHARITABLE FOUNDATION OF DELHI, INDIA

In August 2005, I was first introduced to the organization, Amar Jyoti, while visiting the World Health Organization in Delhi. A friend and colleague introduced me to a man whose wife had started Amar Jyoti over twenty years ago out of their house. I followed up on our conversation by visiting the organization in their location in Delhi. I made two additional visits to the organization in which I toured the facilities, attended classes, participated on a case conference session, and interviewed administrative staff members of the organization and Child Guidance Center.

Mission Statement and Organization Principles

In its documentation, Amar Jyoti states that the organization's mission is "to provide equal opportunities to persons with disabilities and seek their full participation so that they can be seen on the same platform of entitlement and justice as others in society" (A profile of Amar Jyoti 2005). In a foreword to the organization's 2004-2005 annual report, the founder managing secretary also notes that the organization's "sincere desire" is for the "flame lit in 1981 [to] continue to glow and [become] brighter. It is [their] fervent prayer that Amar Jyoti should continue to reach out and help those with disabilities to realise [sic] their full potential. Only then would we be anywhere close to realizing our dream of an India where the disabled are treated with equality, dignity and justice" (annual report 2004-2005). These statements place emphasis on equality of opportunities and full participation in society for people with disabilities. These values stem from a belief that "disability does not mean inability for ... children. [These children] can go to any extent and attain what normally people would consider to be impossible for children with impairments (annual report 2004-2005."

In working towards achieving goals of equality and justice for the organization's participants, the group promotes other key values through their educational, vocational, rehabilitation, and other service programming. In the area of education, the group notes that it has been a path breaker in successfully promoting integrated and inclusive education (annual report, 2004-4005).

The organization also promotes what they term "holistic rehabilitative services" through all of its programming. This term reflects the organization's emphasis on treating the medical, educational, emotional, social, spiritual, recreational, cultural, and vocational wellbeing of their students and their families. As an example of this holistic approach, Amar Jyoti notes that "the

barrier free environment and provision of integrated sports and cultural activities make inclusion a reality” within their school (annual report, 2004-2005). Within the home visit program, this framework is applied through programming that aims to “empower the child by teaching skills required to carry out [the child’s] daily activities” independently (annual report 2004-2005). This goal of independence and empowerment carries over to the vocational training programming of Amar Jyoti. “Since there are very few jobs available, self-employment seems to be the best way to earn a livelihood [for a person with a disability]. With the help of awareness programs and personal counseling, [vocational program] candidates have been motivated about various training program and loan facilities available for starting any commercial activity” (annual report, 2004-4005).

Holistic modes of medical care place emphasis on “preventive, promotive, curative, and rehabilitation services” (annual report 2004-4005). In the theme of holistic rehabilitation, the prosthetic and orthotic department provides prosthetic materials to individuals so as to facilitate the independence and improved integration of people with disabilities into society (Baldwin fieldnotes 2005). Amar Jyoti believes that the regular use of mobility aids increases mobility, reduces further disability and dependence on the family and community.

Goals Objectives and Priority Issues

The chief objectives of the organization are to offer comprehensive rehabilitative services, to empower and mainstream persons with disabilities, and to develop human resources (Baldwin fieldnotes 2005, annual report 2004-2005). These priorities are reinforced within a school curriculum that integrates academics, cultural activities, physical exercise, vocational training, and arts and crafts exercises. With regards to sports and cultural activities, the organization identifies physical exercise and sports as important for children with disabilities as

academics. The organization imparts regular training in sports to children through the school curriculum. Amar Jyoti also places equal emphasis on the vocational training within the school curriculum. Additionally, arts and crafts activities are viewed as important elements that help to “develop the self-esteem and enhance fine motor control of children with disabilities” (annual report 2004-2005).

In the area of developmental delays, Amar Jyoti notes that “developmental delays and childhood disabilities need an interdisciplinary approach to mitigate the impact of disability on the growth of children with multiple problems” (annual report 2004-2005). The organization strives to provide early intervention services for children in order to prevent secondary disabilities and to reduce the impact of disability on the child’s ability to function in his or her life and society. Through all of its professional and parental training programs, Amar Jyoti promotes “capacity building in personnel in the field of disability” (annual report, 2004-2005).

History

In 1981, the organization started as an integrated group of 30 children under a tree (The Spirit Triumphs 1999). Today, the school has over 600 children with and without disabilities studying together in a barrier free environment (A profile of Amar Jyoti 2005). The organization began by serving students with locomotor disabilities (The Spirit Triumphs 1999). Today, the organization serves students with a variety of disability types, as well as well-abled children.

Physical space and building structure

The complex that houses the Amar Jyoti organization in Delhi is situated behind a large brick gate (Baldwin fieldnotes 2005). The complex is situated in a U shape. Several disability accessible vans are stationed immediately in front of the building complex and are one of the results of the Ableolympics that India hosted in 2003, as well as many of the reform efforts of

the managing secretary's work as Chief Commissioner of Disability for the government of India. The administrative building that also houses the Institute of Physiotherapy, Healing Touch Rehabilitation Clinics, and Child Guidance Center is the first building that you encounter upon entering through the large gate. It is accessible through a wide concrete ramp. These wide, fully accessible concrete ramps are found in the entrances to all of the buildings in the complex. The first floor of the Institute of Physiotherapy houses the outpatient clinic, surgical theater, and recovery areas. The second floor is the location of the Child Guidance Center, as well as several classrooms for physiotherapy students and other clinical students. A large conference room on the second floor is capable of hosting large conferences and functions and serves as a meeting area for the various disciplinary staff members when they meet to discuss weekly cases and issues. Recently an additional floor was added to the institute which houses four classrooms, two meeting/conference rooms, exercise and sports therapy rooms, a science laboratory, administrative offices, a physiotherapy laboratory, a library, and student common area. The library includes areas for students to study, as well as a small computer lab station.

A workshop area is adjacent to this building in a single story building. Here vocational training programs in manufacturing prosthetics are run, as well as the workshop that supplies durable medical equipment and prostheses for patients and students of the organization.

A large open air auditorium and performance house is situated in the northeastern corner of the complex. In addition to the large stage on which the students perform different cultural activities and school dance performances, this building is a congregating place for regular parent-teacher meetings. Tucked out of sight behind and to the right of the auditorium is the original structure of the organization. This single room building now houses a small temple dedicated to

an Indian Guru and Saint. *Puja* is done in honor of this deity daily by the founder-managing secretary, and other staff members.

The school is the “crowning jewel” of the complex. It was completed in 2004, and it completes the U complex shape as a two story building. A large wheelchair accessible ramp skirts up both stories and the entire length of the building. The barrier-free building includes several classrooms including a classroom for hearing impairments that is equipped with an FM auditory system for sound amplification. The entire building includes textured tiles that allow individuals with visual impairments to navigate into and out of classrooms. Classroom materials and school curriculum has been modified for both learning and sensory disabilities.

Target population or clientele

The organization defines its target populations as “persons with disability in India” (annual report 2004-2005, A profile of Amar Jyoti 2005). Through its different programs in Delhi, Gwalior, and outreach projects and medical assessment camps, the organization provides services to over 10,000 people per year. The bulk of the population served by Amar Jyoti comes from the Delhi and Gwalior areas. In the early days of the organization, Amar Jyoti catered to children with physical disabilities, mostly as the result of polio paralysis (Baldwin fieldnotes 2005). However, the organization has expanded its services to include children and adults with a range of disability types including developmental delays, sensory impairments, learning disabilities, cognitive impairments, as well as children with mobility impairments. The most recent population to be targeted through the organization’s services is children with hearing impairments. The chief label applied to the clientele of the organization is “persons with disabilities.” During my visits, I observed children with a range of impairments including

hearing, mobility, cognitive, and visual. The barrier-free facilities of Amar Jyoti reflect the organization's mission to accommodate a wide range of disability types.

The specific target populations for each of the programs offered by Amar Jyoti will be discussed later within the section on the services provided.

Staffing and organization

Identifying the key individuals of the organization is a difficult task given the size of the organization. The organizational staff fall into 13 categories: administrative, primary and secondary teachers, teachers for professional programs, vocational training staff, medical and physiotherapy specialists, curriculum and assessment development, child guidance specialists, social workers and community outreach workers, and job placement coordinators (A profile of Amar Jyoti 2005).

The above staff is organized into departments that are headed by supervisors. Each supervisor reports to the administrative officers who include the President, Managing Secretary, and Executive Director. Information about staff for some of the key programs of Amar Jyoti are discussed below.

Amar Jyoti School

The school has a managing committee that consists of government nominees, educationists, parent representatives, staff members, representatives of Amar Jyoti Charitable Trust, doctors, and therapists. Program documents note that "most of the teachers have been trained in special education which makes management of children with disabilities in classrooms more efficient and effective" (annual report, 2004-2005).

Healing Touch Medical and Rehabilitation Clinic

Eight orthopedic surgeons staff the orthopedic clinic (annual report 2004-2005). A renowned TB specialist and pulmonologist also volunteers his services to the medical clinic. Other clinical staff include primary care physicians, nursing staff, occupational therapists, physiotherapists, speech pathologists, and audiologists.

Institute of Physiotherapy

Specific staff members for the Institute of Physiotherapy were not specified in program documents.

Child Guidance Center

The clinic is staffed by three specialist teachers in the areas of visual impairments, hearing impairments, and learning disabilities (Baldwin fieldnotes 2005). Social workers are also on staff in the Child Guidance Center.

Services and Outcomes

Amar Jyoti provides services in 8 key areas. The main programming of the organization includes an integrated school for children with and without disabilities; medical and rehabilitative services; vocational training and job placement programs; child guidance center; advocacy and campaigns for raising social awareness; producing disability publications; and academic training programs for post-secondary and professional students in education, Physiotherapy and occupational therapy, social work, and other certificate programs (in conjunction with Indira Gandhi Open School and other university affiliates) (annual report 2004-2005, A profile of Amar Jyoti 2005, Baldwin fieldnotes 2005).

Amar Jyoti School

Within the area of integrated education, the organization provides an educational environment in which children with and without disabilities study together from the nursery level through Class VIII. Additional class levels are offered through level 10 through the National Institute of Open Schooling. The school also provides sports, cultural, and vocational activities within its curriculum. Students receive medical and therapeutic services as needed. Counseling services are available to students through the social work department. The school serves 107 children with special needs, 18 with speech and hearing impairments, 182 children with orthopedic problems, and 5 children with visual impairments. 111 children are served through the Home Training Program. There are also over 201 non-disabled children studying in the inclusive school. “While the mild and moderately disabled attend classes with the non-disabled, the profound and severely disabled have separate academic sessions with special educators” (annual report, 2004-2005). The 107 children with special needs are provided schooling in 9 special classes that are differentiated by age and ability. Children with mobility disabilities have been admitted since the program’s inception, while “slow learners and children with learning disabilities” have been enrolled in the school since 1990 (annual report 2004-2005). Recently (within the last two years) Amar Jyoti School has been enrolling students with hearing and visual impairments (annual report 2004-2005).

National Institute of Open Schooling (NIOS)

Amar Jyoti is an accredited center of NIOS. They offer certification for the 3rd, 5th, 10th, and 12th standard classes. This educational option in which students can prepare for the standard class exams outside of the traditional school environment is especially beneficial for individuals

who are either too disabled to come to school regularly or cannot complete school through the standard CBSE courses.

Special Education Classroom Programs

Nine special classroom sections are offered for special education. These classroom settings provide “remedial education services” or “partial integration”. 107 students attend these classroom settings. Five of the special education sections have children between the ages of 10-18 years of age, while four sections serve children 6-9 years of age. Each child in these classroom sections receives individual education plans (IEPs). Fifteen students are partially integrated with regular education classes and curriculum. These students receive remedial support from special education teachers throughout the school day.

Hobby classes

During the summer vacation, the school offers “hobby classes” in music, dance, casio [sic], clay modeling, flower making, soft toys (stuffed animals), drawing, aerobics, cutting and tailoring, computers, baking, beauty culture, and judo to students with disabilities as well as students from the local community.

Vocational Training Program

Vocational training is provided in watch repair, carpentry, textile designing, weaving and spinning, screen printing, tailoring, knitting, beauty culture, computing, baking, jewelry, prosthetic and orthotics manufacturing, and arts and crafts.

Vocational Placement Unit

The vocational placement unit facilitates employment opportunities for persons with disabilities. This unit previously oversaw the Urban slum CBR program in the slums of Delhi and the village of Gwalior. This program has since been turned over to the respective

communities per changes in WHO mandates on the oversight of CBR programming (Baldwin fieldnotes 2005). The Vocational Placement Unit has been successful in placing former students in programs in local bakeries, beauty salons, tailor shops, computer businesses, and in the organization's prosthetic department. Many individuals also go onto run their own businesses where they sell their own products or services.

Child Guidance Center

The Child Guidance Center is a resource center for families that offers counseling, psychological assessment, and individual and group therapy. The center holds weekly interdisciplinary case conferences, as well as regular instructional sessions with parents of young children with disabilities. The team of psychologists and special educators work towards "capacity building of children with special needs and their parents" (annual report 2004-2005).

The Child Guidance Center primarily uses disability categories to classify and identify their clientele. Examples of these categories include "children with cerebral palsy, muscular dystrophy, rickets, polio and other physical disabilities, attention deficit disorder, hyperactivity, and behavior disorders, speech and hearing impairments, mental retardation, slow intellectual functioning, learning disabilities, autism, down [sic] syndrome, hormonal and congenital disorders, emotional problems, neurological disorders, microcephaly, hydrocephaly, visual impairment, psychiatric illness, and congenital deformity" (annual report, 2004-2005).

The Child Guidance Center also facilitates a Home Training Program for early intervention and parental guidance. This home based program serves children who cannot be transported to the school, and provides home-based education for children with special needs. From statistics on the number of children served between 2004 and 2005, it is clear that the organization recruits most of its children for the Home Training Program between the ages of 2

to 5 years. During 2004-2005, some children were registered for early intervention services below the age of two years. Of the children who receive early intervention services through the Home Training Program, three students have been referred to regular public schools, while 22 have been referred to special schools.

The Child Guidance center was recently selected to serve as a center for tele-conferencing. Amar Jyoti was provided with all necessary equipment and hosts weekly sessions for rehabilitation professionals, parents, students, community leaders, and disability specialists.

Social Work

The department of social work regularly counsels individuals with disabilities and their families. “The problems are mainly regarding stipend, loans, vocational training, [government] concessions, disability certificates, aids and appliances, treatment and jobs” (annual report 2004-2005). The department also sponsors a parent support group for mentally challenged children. These children receive training in vocational skills, while their parents receive “regular professional guidance in management, vocational training and awareness” (annual report 2004-2005).

Healing Touch Medical and Rehabilitative Clinic

The medical and rehabilitative clinic at Amar Jyoti notes that “with polio well under control in and around Delhi, [the organization] is now catering to other physical, neurological and medical disorders like Parkinson’s disease, obesity and endocrine disorders including diabetes. The medical department includes an outpatient department; sub-specialty clinics for endocrinology, obesity, neurology, and Parkinson’s disease; an x-ray department; surgery theater; pathology laboratory; homeopathic research center; and services in physiotherapy, occupational therapy, speech therapy, audiometry, antenatal care and postnatal care; and

immunization programs. The medical department provides corrective surgery and cataract operations.

The medical clinic also conducts school health checkups, and refers children for follow up. Given the high prevalence of dental problems in the school population, the medical clinic arranged a mobile dental clinic to provide care to the school children. The clinic also runs an obesity clinic under the guidance of an endocrinologist, dietician, and physiotherapy.

In the past, the clinic has completed assessments of the medical needs of adolescent children “with the objective of providing required services on the premises.” The organization has also given attention to the needs of elderly with disabling conditions such as osteoporosis, arthritis, and spondylosis by promoting barrier-free living environments.

The organization reports its outcomes for the medical clinic through reports of the number of surgeries completed in a given year, as well as clinical vignettes that have had successful outcomes. One such example follows:

A nine year old girl was seen by an orthopedic surgeon in January of 2001. The child was a post-polio case with spinal deformity, pelvic tilt and contractures at the hip, knee and ankle. She used to crawl due to weakness in her quadriceps muscles. After a number of operations in 2002 and 2003 to release contractures, a tendon transplant and active physiotherapy, she now walks straight without calipers.

In their occupational therapy department, patients with challenges in self-care, mobility, communication, and home management are evaluated and treated. The clientele of the occupational clinic are both students in the school, as well as outpatients.

“The department of Speech Pathology and Audiology renders diagnostic and therapeutic services to persons of all age groups having difficulty in language communication and speech. The department has recently focused more attention on children with hearing loss that have recently been admitted to the school system. The department promotes skills in speech and lip

reading in an oral/aural environment. The department also provides an on-air treatment and referral helpline through FM Rainbow Air.

Prosthetic and Orthotic Department

The prosthetic and orthotic department designs and assembles mobility aids to meet the individual needs of the organization's clientele. The prosthetic department manufactures mobility aids such as crutches, calipers, artificial limbs, wheelchairs, and walkers. This location also serves as a vocational training and job placement center. Under the support of the Ministry of Social Justice and Empowerment, Amar Jyoti "provides mobility aids to poor beneficiaries free of cost". From 2004-2005, Amar Jyoti distributed 2136 mobility aids "to improve the mobility of persons with disability and to help them lead a productive and meaningful life.

The organization hosts camps throughout India to help diagnosis and identify individuals with disabilities and distribute mobility aids. During 2004-2005 period, the prosthetic department also hosted 35 camps in collaboration with other NGOs and government agencies throughout India. Each camp had on staff ophthalmologists, ENT specialists, orthopedic surgeons, prosthetic engineers, and therapists. 346 medical consultants provided voluntary services. Some of these camps were organized in response to requests from the Health department and municipal corporation of Delhi. Follow up clinics and home visits were also conducted to gain feedback from those who had received mobility aids at prior camps. Pamphlets regarding the use and maintenance of appliances were also distributed at the time of fitting mobility aids.

Through these medical camps, Amar Jyoti was an important force in transforming a slow and ineffective system for distributing disability certificates into an efficient location for individuals to obtain the proper validation and certification for receiving government disability support and benefits. Amar Jyoti in conjunction with the Chief Commissioner of Disability's

office arranged to have on staff at these traveling clinics the necessary officials required to approve such certificates and government pensions.

Special Education Teacher Training Program

The special education training program at Amar Jyoti offers one and two year diploma courses in Special Education. These programs combine classroom theory for special education with practicum experiences in special education classrooms. The students are trained in how to prepare Individual Educational Plans for children in the classroom. Amar Jyoti also offers courses in Special Education through a distance education program with a university, as well as three-month foundation courses in special education. The foundation courses are short-term training programs for teachers and parents to gain knowledge on special education. Amar Jyoti is also a special study center for Indira Gandhi National Open University (IGNOU). Amar Jyoti offers five training programs through IGNOU: Post-Graduate Diploma in Journalism and Mass Communication, Bachelor in Library and Information Science, Diploma in Early Childhood Care and Education, Diploma in Nutrition and Health Education, Certificate in Teaching Primary School mathematics. These programs often attract “housewives and working women” and allows them to “improve their qualifications” (annual report 2004-2005)

Additional Training Programs

The organization also has several affiliation with Delhi universities and organizations so as to provide training programs for a wide range of professional degree and certificate programs. Examples of such partnerships and degree programs include: Bachelor of Physiotherapy courses with the University of Delhi, two year Diploma program in Special Education recognized by the Rehabilitation Council of India, Bachelor of Special Education through the Distance Education program of Madhya Pradesh Bhoj Open University, Management of Disability in service training

for teachers, foundation course for CBR worker training, NIOS classes for school drop-outs, workshops on various disability and rehabilitation disciplines, and post-graduate internships in physiotherapy and occupational therapy.

Advocacy, Awareness Raising Campaigns, and Publications

Through publications, networking, and awareness and advocacy campaigns the organization produces and disseminates information on children with disabilities and works to inform the public debate on disability. The organization publishes a newsletter, research papers, books on the integration of children with different disabilities in education, and recently a book entitled “Better Care of Children with Locomotor Disability.” The organization also uses workshops, camps, health *melas* (fairs), rallies, and street plays to disseminate information and heighten social awareness.

Outcomes

In addition to the outcomes reported above, the organization marks its accomplishments by the degree to which its students participate in local and national events. Amar Jyoti’s students have participated in Delhi’s Republic Day Parade, the Abilolympic’s hosted in India (for which Amar Jyoti was a pioneer in the Abilolympic movement in India), and several other local art and academic competitions. Amar Jyoti has been a “winner of national and international awards for innovative services being rendered in the field of rehabilitation”.

Funding and Networking

Amar Jyoti has received financial support for their activities from a range of local, governmental, and international funding agencies. Amar Jyoti has “received support from the Ministry of Social Justice and Empowerment as well as the Ministry of Human Resource Development for [their] activities in Delhi and Gwalior. The Ministry of Social Justice and

Empowerment also helps to support the inclusive education, vocational training, prosthetic and orthotic workshop, and the hospital projects of Amar Jyoti. The Child Guidance center receives 50% of its operating budget from the Asha Educational Trust. Under the Nanhi Kali project of K.C. Mahindra Trust, Mumbai, 139 girls have been sponsored for their schooling. Additionally, the Child Sponsorship Program by International Hillsfond E.V. Germany, 120 children of underprivileged class have been sponsored.

Assets

The organization has financial assets in the form of grants from the Government of India, state governments, national and international bodies, as well as donations from philanthropists and individuals. The organization also is networked with other NGOs, government sectors, and international organizations for the purposes of exchanging programming ideas and services.

The case studies in this chapter serve as the basis for the analysis that follows in chapter 4. In chapter 3, I have presented key features of NDNWS and Amar Jyoti that contribute to our understanding of how a rights based approach to disability is conceptualized by these two organizations. In chapter 4, I assess this case study material by evaluating the level of intervention that each organization targets in their programming; aspects of each organizations culture with a particular emphasis on how these groups define disability, personhood, and change; and how four models of disability influence each program's definition of rights and operationalization of a rights based approach.

4.0 CHAPTER 4: ANALYSIS AND DISCUSSION

In the opening chapter, I suggested that disability organizations work in concert with international institutions and individuals with disabilities in the production, circulation, and transformation of the meanings and management strategies of disability. Emerging from these interwoven relationships is the concept of a rights-based approach to the provision of disability services. Yet little attention has been given to the multiple ways in which a disability rights-based approach is conceptualized by each of these actors.

Scholarship on the work of NGOs suggests that these organizations are actively engaged in the appropriation and transformation of international discourse and policy, assigning new meanings and values to each in relation to local norms and contexts. With regards to international discourse and policy on disability and rehabilitation, little is known about how local disability organizations utilize and operationalize this discourse, formulating local definitions of disability rights and a rights-based approach to disability. Critical questions remain with regards to a) how concepts such as *disability*, *disability rights*, and a *rights based approach to disability* are defined by local organizations, b) the relationship between theoretical models of disability and the everyday work and practices of local disability organizations, and c) the role that local organizations play in transforming international disability discourse and policy.

The analysis that follows fixes attention on these three interrelated questions by employing material from the case studies presented in Chapter 3. In order to examine how each

organization defines a rights-based approach to disability, I describe aspects of the culture of each organization and how it contributes to each organization's own theory of change. This discussion includes information on how *disability*, *personhood*, and *disability rights* are defined by each organization, as well as a summary of what type of change each organization aims for and their views on how this type of change occurs.

The second part of this analysis examines the relationship between local, South Asian rights-based practices and theoretical models of disability. I employ four of the disability models introduced in Chapter 1 to examine which types of organizational services map onto each model. Comparing the relationships between the two organization's programming activities and the four disability models allows me to suggest how a rights-based approach to disability is defined and operationalized by each of the organizations discussed. Combining this information with that presented on each organization's definitions of disability rights and theory of change, I am able to suggest some ways in which local disability organizations are actively engaged in appropriating and transforming disability discourse and policy.

The paper concludes with a discussion of the role that analyses such as that presented in this paper might play in deepening our scholarship on disability and disability rights, as well as tailoring NGO programming to better advance disability rights and the well being of individuals with disabilities.

4.1 ORGANIZATIONAL DEFINITIONS OF DISABILITY, THEORIES OF CHANGE, AND DISABILITY RIGHTS

Evaluating how programs view themselves as agents of change extends from program evaluation methods that ask how particular interventions work to produce particular outcomes. One such evaluation methods, often referred to as *theory-based evaluation*, assess how a program's own logical understanding of how change occurs (the organization's *theory of change*) contributes to the development of particular interventions and results in specific outcomes. An organization's theory of change models a "plausible and sensible model of how the program is supposed to work" (Bickman 1987 as cited in Green and McAllister 1998). This notion of an organization's theory of change is useful in understanding how the two organizations from Chapter 3 define the desired outcomes of change, view their role in creating this change, and specify the particular targets of their intervention and greater change.

Understanding how these two organizations's view themselves as agents of change in the world requires us to examine a) how disability is defined; b) how personhood is defined; c) each organization's theory of how change occurs; d) how disability rights are defined; and e) how a rights-based approach to disability is operationalized by each of these organizations. As demonstrated in the discussion that follows, both of these organizations share common features with regards to the above definitions and concepts. However, this analysis also suggests the each organization offers different notions of disability, personhood, disability rights, and how change is created with regards to disability. Both these commonalities and points of difference contribute to each organization's rights-based approach to disability.

4.1.1 NDNWS Organizational Culture and Theory of Change

NDNWS's definition of disability

From the case study material presented in Chapter 3, the NDNWS employs a definition of disability that emphasizes disadvantages and barriers that a disabled status brings to the individual. Members of the organization view disability as a disempowering state that leaves one with few resources, skills, and opportunities for participating in society. Disability is viewed as barring one's access to education, employment, and housing. (Though I believe that this group's belief in disability as barring one from housing is not so much the result of prejudice on the part of housing agencies, as it is the product of disabled women's difficulty in marrying which has the consequence of preventing housing opportunities.) Having a disability, leaves women susceptible to physical and psychological violence, neglect, poverty, and discriminatory practices. The organization's focus on women with physical impairments implicitly suggests that disability is defined within this group as a mobility impairment of different origins.

NDNWS's concept of personhood

We also see a concept of personhood that privileges an individualized, autonomous notion of the self. Individuals are constructed as capable agents of change in both their own lives as well as society at large. Within this group, personhood extends to several life domains in which the individual is an economic, political, spiritual, social, and physical/biomedical being. The group espouses the notion of equality among individuals, yet recognizes that this is an unrealized status for individuals with disabilities. By extension, citizenship carries with it the right to equal representation.

NDNWS's Theory of Change

Each organization fundamentally believes in an ability to change both the lives of the individuals they serve, as well as the larger society in which individuals with disabilities live. NDNWS works towards securing specific types of change for individuals with disability. These interventions aim to make life easier for people with disabilities. The changes that the organization desires fall into a continuum of outcomes with some changes leading to others of greater consequence for women with disabilities. At the more proximal end, NDNWS's interventions hope to provide direct services and care for people with disabilities through rehabilitation and health services; equal rights and opportunities to employment and education within society; the creation of alternative housing systems and communities; and greater awareness within society of the rights and needs of individuals with disability. The organization sees changes targeted at the individual and society as subsequently facilitating greater and lasting opportunities for women to earn their own income through jobs and self-employment, and thus foster independence and self-reliance within these women.

As Figure 3 suggests, the majority of the activities of this organization emphasize change at the level of the individual with disability. Specifically, the provision of direct services targets the physical, educational, and vocational dimensions of the individual. In addition to this focus on the individual, the organization emphasizes interventions aimed at the employment sector, community, and national level in order to raise awareness and provide jobs for individuals with disabilities.

Change is believed to happen through the assistance of a variety of actors and factors in the life of the individual with a disability. NDNWS privileges the individual with disability as a key agent of change within her life and community. The group emphasizes vocational and

educational training for individuals with disabilities as key elements that bring about change for these individuals. However, the group also views the Nepali national government as a significant actor in creating change with regards to providing rights, equity, and employment for individuals with disabilities. Indeed, NDNWS suggests that their actions as an organization are a temporary replacement for neglected duties of the government. This suggests that this organization feels that lasting and wide spread change is found in government actions, legislation, and mandates. Working with social and government agencies as well as donor agencies to advocate for individuals rights and heighten social awareness are also key strategies for actualizing the goals of change discussed above.

An additional theme that is mentioned throughout program materials is the role that the sacred plays in facilitating the work of the organization and thus changing the lives of individuals with disabilities. This theme emphasizes the significance and co-existence of both secular and sacred explanations of individual and broader social change.

NDNWS' s definition of disability rights

From these writings and goals, we can derive a definition of disability rights that is employed by NDNWS. Within NDNWS, disability rights is largely conceived of as the provision of direct services, such as healthcare; housing; employment, and educational and vocational training (mainly literacy and handicraft production, respectively). Through its programming and organizational goals, the group also suggests that an individual with a disability is entitled to protection from gender discrimination, mental and physical abuse, and a devaluation of their lives by others in society. Within this group, disability rights also includes a mandate for equal treatment and participation within society.

In response to the question, “What does it take for a person with a disability to have a successful and complete life?”, almost all of the women stated education (one woman did not have an answer) (Baldwin fieldnotes 2004). Many also stated the need for training in a skill and employment that is within their capacity to do. Still others stated that everyone is *aphno* or equal and entitled to equal rights as those of able bodied individuals. In speaking for one of the women who has an eight year old son as the result of rape, Sundara stated that getting financial compensation from the man who raped her was a right that should be ensured to upgrade both her and her child’s lives.

NDNWS’s concepts of disability, personhood, and change are clearly gendered in ways that reflect female gender roles and the experiences of women within South Asian societies. The highlighted barriers presented by disability that must be overcome for women with disabilities extend from the member’s own experiences as women with physical disabilities in Nepal. Similarly, the experiences of neglect, abuse, and poverty that these women describe are nested within the context in which Nepali women with disabilities find themselves. By extension, NDNWS’s work incorporates these gendered ideologies and experiences into their definitions and operationalization of disability rights and a rights-based approach. Fully understanding how gendered notions of disability and disability rights contribute to differences in how rights-based approaches are operationalized by local organizations requires a dialogue between disability studies and feminist critiques and scholarship. Though an important piece for understanding how NDNWS operationalizes disability rights in their everyday work, such analyses and discussions are beyond the scope of this paper.

4.1.2 Amar Jyoti's Organizational Culture and Theory of Change

Amar Jyoti's definition of disability

Amar Jyoti describes prevalent social attitudes towards disability as equating disabilities with limited or the absence of abilities. Such social concepts of disabilities are said to effectively exclude individuals with disabilities from social participation. However, Amar Jyoti's own notion of disability is set against these popular beliefs, and instead highlights the abilities, achievements, and contributions to be made to society by individuals with disabilities. Undergirding this uplifting approach to disability is the notion that disability, itself, is a condition that results from difficulties in learning, performing life tasks, using one's physical body, and accessing social and vocational opportunities. Though still framed as challenges, the organization views these difficulties as capable of remediation through the provision of technical and professional interventions.

Amar Jyoti's concept of personhood

The conceptualization of disability and the services the organization provides to individuals with a disability stems from a particular notion of personhood. The group sees the individual (and his or her abilities or limitations) as being rooted in a physical body that is transmutable through professional practices and services. The wide range of services applied to changing the physical body and individual suggests that Amar Jyoti's conceptualization of personhood sees the individual as connected to other domains and systems. Like NDNWS, Amar Jyoti conceives of humans as physical, social, cultural, political, and economic beings. Yet, Amar Jyoti moves beyond this multi-dimensional concept of personhood and elaborates a notion of the individual as being nested within and thus susceptible to kinship, educational, medical, political, occupational and economic systems.

Amar Jyoti's Theory of Change

In order to fundamentally alter the relationship between the disabled individual and these systems, Amar Jyoti views itself as an agent of change that operates by providing direct services to individuals with disabilities, their families, and professionals in education, healthcare, and community work. Amar Jyoti believes that lasting change in the lives of individuals with disabilities stems from broader social changes that guarantee equality, dignity, and justice for individuals with disabilities. The group desires for these individuals to be empowered through activities that promote both their independence and integration in society. Ultimately, the sum of individual and social change is the guarantee that people with disabilities are able to fully realize their potential and fully participate in society.

To accomplish these changes, Amar Jyoti targets interventions at multiple levels. On one level, the group believes that change stems from a holistic approach to the individual in which services are directed at meeting the medical, educational, emotional, social, recreational, cultural, and vocational needs of the individual with disabilities. These types of activities appear to target what can be called medicalized conditions of the individual. An example of this is provided in the organization's belief that interventions that increase the mobility or support of the physical body also promote social integration and the individual's ability to more fully participate in the management of their daily lives.

Like NDNWS, Amar Jyoti also targets broader social and governmental agencies as potential sites in which change can occur. Stemming from this belief, Amar Jyoti deems one level of change to occur through increasing the number of government supports and access to these supports for people with disabilities. The organization also views change to result from increasing awareness of the needs and rights of individuals with disabilities in society through

highly visible events that display the talents and skills of the children who attend the Amar Jyoti school. Amar Jyoti views itself as a partner with (as opposed to NDNWS's view of itself as a temporary replacement for) local and national governments, as well as other NGOs and communities. These combined efforts aim at increasing the ability of the individual with a disability to both gain independence in their life, as well as fully participate and integrate into society.

Yet in contrast to NDNWS, Amar Jyoti additionally targets the professions and professionals in the fields of rehabilitation, special education, and social work as loci of change. Through increasing the capacity of current and future practitioners (to essentially further professionalize their work with people with disabilities), Amar Jyoti believes that these professions will be able to better serve individuals with disabilities. Further these professionals target the environment of the individual with a disability as an area in need of change. By changing conditions in the household, educational setting, social, and recreational contexts, Amar Jyoti seeks to better tailor the attitudinal and physical conditions of each to meet the needs of the individual. However, in the area of education, these changes do not necessarily allow the child with a disability to participate in a typical classroom with peers who are not disabled. Instead, the typical classroom itself, is transformed into a specialized, disability specific classroom setting.

Similar to NDNWS, Amar Jyoti views spiritual and religious intervention as playing apart in the organization's ability to create change in the lives of their clientele and society at large.

Amar Jyoti's definition of Disability Rights

It is clear that one dimension of disability rights as defined by Amar Jyoti is the guarantee of direct services that incorporate multiple professional systems, as well as treat the entire individual. There is also a focus on equality and justice that suggests that a definition of disability rights for this organization must include a right to equal treatment and opportunity within society at large. From discussions with an administrative staff member, Amar Jyoti believes that a certain quota of government and public employment positions should be guaranteed to individuals with disability. This individual felt that these protected positions would help to overcome discriminatory hiring practices and guarantee representation of the interests of people with disabilities in multiple public sectors.

Similar to NDNWS's work being gendered to reflect the experiences of women with disabilities, Amar Jyoti's work also suggests that disability services are being gendered. Amar Jyoti's consideration of the implications of gender on their services is far more implicit than NDNWS's goals and work. However, some evidence of how disability is gendered is found within higher rates of male children being enrolled in Early Intervention services. Additionally, I observed that an individual's particular vocational training activities seemed to coincide with traditional gender roles and vocations within the greater Indian society. As discussed earlier, how disability services and rights are gendered is an important analytical topic for disability scholars and practitioners, but remains beyond the scope of this paper.

4.2 THE RELATIONSHIP BETWEEN ORGANIZATIONAL FEATURES AND DISABILITY MODELS

Examining the data collected and presented earlier in Chapter 3 through the lenses of different disability theories helps to enrich our understanding of how organizations conceive of a disability rights-based approach. The services provided by each organization map onto several different theoretical models of disability and notions of the disabled body. Figures 5 and 6 examine the relationship between key features of each organization and four different disability models discussed in Chapter 1. Figures 5 and 6 portray how the medical model, social model, kinship model, and charity model of disability can be used to map the organizational features (programming, mission statements, clientele, etc) of NDNWS and Amar Jyoti, respectively.

4.2.1 NDNWS program features and the underlying models of disability that inform each

Mission statements and values

The mission statement and objectives of NDNWS incorporate ideas from all four disability models presented in Figure 5. Those values and goals that seek to change features of the individual with a disability fall largely within the medical model of disability. Examples of value statements that fall under this medical model include activities directed at establishing rehabilitation clinics, providing educational and employment opportunities and boosting the moral or self-esteem of the individual. The group also targets social causes of disability that reflect a social model of disability. Values and objectives that exemplify this trend include efforts to overcome disadvantages in the individual's life, raising social awareness, and promoting gender equity and human rights.

Some of the values of NDNWS incorporate aspects of multiple disability models. Goals of making women self-sufficient and versatile target the individual as well as require changes at the community and society level, thus incorporating ideologies from both the medical and social models. Similarly, desires to overcome traditional values that see disability as a product of one's karma and the actions of other members of the family incorporate dimensions of both a kinship and religious-charity model of disability. The belief that god will intervene on behalf of organizations that assist people with disabilities also suggests the important role that a religious-charitable model of disability plays in managing disability.

Physical Building structure and space

The unmodified structure of the building that requires the individual with a disability to navigate barriers and inaccessible housing design is rooted firmly within a medical model of disability. The medical model demands the individual to adapt to the environment rather than altering building structures to accommodate different abilities to navigate space. Additionally, the space is only utilized by women with disabilities. This observation also indicates a medical model in which the physical space is used exclusively for services pertaining to disability.

Labels of clientele

Like the values and objectives of NDNWS, the clientele labels employed by the group fall under multiple disability models. The group employs terms such as "handicapped women" and "physically disabled women" that privilege the physical deficit of the individual and stem from a medical model of disability. While the terms used to describe their target population seem to center around deficits in the individual (eg. helpless, destitute), these descriptive terms also highlight and imply a social causation for the circumstances of these women (eg. disadvantaged, distressed, neglected). Indeed, program pamphlets and interviews with members stress the social

conditions that present barriers for women's ability to receive education and work. This information also highlights stigmatizing social beliefs that portray these women as useless and burdensome. Though the language used to describe their clientele is overwhelmingly descriptors of social convictions and positioning, there is evidence within these same documents of a counter discourse to these social views. –In a discussion of the type of women with which the organization is seeking to work, potential members are defined as creative and motivated which highlights individual intrinsic traits and capabilities rather than the social deficit view prevalent in Nepali society.

By targeting children of handicapped parents, a kinship notion of disability is employed in which disability extends beyond the individual to other members of the kin group. Similarly, the group targets individuals who hold more traditional notions of disability that are rooted in religious orientations towards disability. Targeting “individuals with backwards belief systems” stems from a religious-charity model of disability.

NDNWS appears to be using a large range of labels that stems from different discourse communities, such as charity, empowerment, and rights, in order to appeal to different peoples' rationalities and sensibilities of giving. This simultaneous use of charity discourse with other types of discourse demonstrate that the notion of charity is not necessarily mutually exclusive from obtaining individual rights as seen in the historical developments of the North American disability rights movement.

Programming

The programming of NDNWS also spans several disability models. The majority of the services currently being provided by NDNWS fall under the medical model seeking to adjust the individual to conditions in the environment. Examples of this include vocational training

programs, literacy and education training, and future healthcare programs. Use of a social model approach to disability are illustrated in social awareness and advocacy campaigns, and the creation of alternative social communities and activities.

While the organization did not really provide services that fit a kinship model of disability (outside of scholarships for children of parents with a disability), programming that incorporated “strict moral discipline” is also integrating a religious-charity model of managing disability.

4.2.2 Amar Jyoti program features and the underlying models of disability that inform each

Mission statements and values

The language of the mission statement, organizational values, and objectives of Amar Jyoti fall largely under the medical and social models of disability. Activities emphasize rehabilitating and promoting professional and medicalized interventions for the individual are given equal treatment with goals to actualize equal opportunities, justice and empowerment for individuals with disability. Given this, it is clear that the organization sees an integrated link between treating the individual and promoting equality and rights within society.

The kinship model serves as the basis for values that seek to foster independence from the family unit. Without further information, it is not possible to identify if Das’s notion of *connected body-selves* is specifically being targeted by Amar Jyoti as playing a negative role in the individual with disability’s life and is thus a concept from which the individual must be extracted. However, it is possible that this notion of *connected body-selves* does not figure into the organization’s conceptualization of the family. Instead, the organization could be privileging

notions of self-determination and autonomy prevalent within western and industrialized discourse and policy on disability.

Physical building structure and space

This integration of the medical model and social model is also observed in the physical structure of the building. The presence of a large medical and rehabilitation center, as well as a school with modified classrooms for individuals with specific types of disabilities reflect a medicalized approach to managing disability. Yet, the physical environment of the organization with its emphasis on barrier-free architecture, and a building complex that makes accessible multiple services in one setting also reflect principles of a social model of disability. Additionally, the presence of a small temple that houses a prayer center for daily *puja* to the organization's patron setting reflects the religious-charity model of disability. The use of this space by people with disabilities and their families underscores a kinship model.

Labels of clientele

The labels used to identify the organization's clientele fall within several categories of disability models. Within discussions of health and rehabilitation programming, Amar Jyoti uses medical and clinical terms such as Cerebral Palsy cases and polio cases to identify their target population. However, within discussions of the organization's mission statement, educational programming, and vocational training activities, Amar Jyoti uses the term People with Disability (PWD) that stems from both the social model of disability and People First language. The inclusion of parents within Amar Jyoti's target population suggests that the organization sees disability as not only affecting the child with a disability, but also other kin members. This notion of disability affecting the entire family can be seen as nested within a kinship theory of

disability in which the physical body and personhood of one individual impacts the identity and life projects of other related members.

Programming

The majority of the programming of Amar Jyoti stems from a medical model in which emphasis is placed on changing features of the individual with disability, or requiring that the adaptation be made to or by the individual rather than society or environmental features. This underlying theory can be seen at work in much of the activities that happen within the medical and rehabilitative clinic, as well as some of the school curriculum that encourages lip reading, enhancing motor control, specialized education in disability-specific classrooms, and behavioral modification systems.

Some of the programming that is undergirded by the social model include the advocacy and awareness raising programming, and dimensions of the vocational placement programs that work with potential employers to inform them of the potential contributions to the employer and accommodations that an individual with a disability needs in the work environment.

Training programs for medical and allied health professionals incorporate elements of both the medical and social model. On one level, training programs geared at teaching professional medicalized interventions for the individual with a disability fall under the umbrella of medical model. However, the social model can be seen in dimensions of this training that aim to inform professionals about the needs and abilities of the individual, make professional practices more responsive to the individual with disability's perspective, as well as build the capacity of professionals to better serve the individual with disability.

A similar blend of the kinship and medical model is also seen in the home training program. The kinship model of disability can be seen in the home training programs and parent

support programs. Attempts to teach professional rehabilitation and education practices in the home incorporate a medical model of disability, while acknowledging the impact of disability on the family.

4.2.3 Hybridity

The distribution of various features of each organization across multiple disability models suggests that each organization is developing a hybrid form drawn from two or more of these disability theories. This is most clearly illustrated in Amar Jyoti's mission to provide holistic rehabilitation. This approach interweaves values and programming from all four models in its attempt to treat the medical, educational, emotional, social, spiritual, recreational, cultural, and vocational well being of the students and their families. This rehabilitative approach does not fit under one theoretical model of disability. Rather, it demonstrates how these organizations are employing discourse, meanings, and management strategies from a range of theoretical understandings of disability.

While the example from Amar Jyoti above shows an integration of meanings derived from the social, medical, kinship, and charity models of disability, other combinations of these theoretical models result in different types of hybrid models of disability. These hybrid forms are found in both organizations and are exemplified in programming and values that fit into multiple disability model categories in Figures 5 and 6. One prominent combination is the blend of a social and medical model of disability. However, the previous case studies and analysis also show interesting combinations of the social and religious-charity models (NDNWS's notion of "if you help the helpless, god will help you"); medical and kinship models (Amar Jyoti's home training programs); and the social, kinship, and religious-charity models (NDNWS's and Amar

Jyoti's focus on changing traditional beliefs in karmic origins of disability). Additionally, in chapter one the integration of a medical and religious-charity model of disability was illustrated in the Muslim father's search for treatment for his child's paralysis, but not for the child's cerebral palsy in accordance with the father's interpretation of the tenets of Islam.

4.3 DEFINING AND OPERATIONALIZING RIGHTS-BASED APPROACHES TO DISABILITY

4.3.1 NDNWS

Like many other organizations in South Asia, NDNWS and Amar Jyoti claim to be using a rights-based approach to serving individuals with disability. As Bickenback's work suggested in Chapter 1, rights can and have been conceived of in many different ways. Rights can be interpreted to be anything from things that are to be given to individuals, protective measures, opportunities that one is entitled to, compensation or corrective measures taken for prior disadvantages and discriminatory acts, or even a means of framing the individual as a full and equal citizen of a society. From the prior examination of the meanings of disability and disability rights, we see that there is considerable variability in how rights are defined between and within organizations. Similarly, we can discern how each organization defines and operationalizes a rights-based agenda by assessing information on the definitions of disability, disability rights, and the theoretical models of disability employed by each organization.

Within NDNWS, a rights-based approach defines disability rights as several different things. NDNWS largely conceives of rights as the provision of direct services such as healthcare, housing, employment, education, and vocational training. Yet disability rights within this group

also includes protection from gender discrimination, mental and physical abuse, and a devaluation of women with disabilities lives' by others in society. As an organization, their work aims to guarantee the right of equal treatment and participation for women with disabilities in Nepali society.

For this group, a rights-based approach to disability targets individual levels of intervention. This approach stems from NDNWS's notion of personhood in which the individual is privileged as a capable agent of change. Similarly, the values underscoring the group's rights-based approach cut across all four models of disability presented in this paper. This observation is also explainable given the group's conceptualization of personhood. –Recall that the individual within NDNWS is seen as an economic, political, spiritual, social, and physical/biomedical being. Therefore, a rights-based approach to disability must acknowledge and target these dimensions within organizational values and programming.

Within NDNWS, the services of a rights-based approach are largely geared at the individual. This again is due to the privileging of the clientele as individualized, autonomous beings. Therefore, it is expected that individualized interventions stemming from the medical model would be used by this group. The group's primary focus on physical therapy, education, and vocational training illustrate these individualized services.

However, the group also claims to be targeting social and religious interventions that are not easily explained by the organization's concept of personhood. The rationale for these types of services and interventions within NDNWS's rights-based approach to disability can be found by examining the labels the group assigns to its clientele, as well as the group's theory of change. The labels employed by the organization highlight attributes of the individual, but imply a social causation for these attributes and conditions. Additionally, the organization saw change as

coming from NDNWS's ability to provide direct services to individuals with disabilities in order to ease the difficulties they experienced in life. However, these services were seen as temporary substitutes for the government's failure to provide rights, equality, and employment for these women. NDNWS's focus on raising social awareness in the community and society at-large thus contributes to their ultimate goals of having the government guarantee equal treatment and participation in society for individuals with disabilities.

With regards to the four models of disability discussed, NDNWS's operationalization of a rights based approach incorporates dimensions from the medical, social, kinship, and religious-charitable models. Additionally, the group employs medical-social and kinship-charity hybridizations that go beyond the domains of any single model.

4.3.2 Amar Jyoti

In their rights-based approach, Amar Jyoti defines disability rights as both the provision of direct services that incorporate multiple professional systems, as well as the guarantee of equal treatment and opportunities in society. These two definitions of rights require interventions at the individual and social levels. However, Amar Jyoti is like NDNWS in that it primarily employs individual levels of intervention in their programming activities. These intervention strategies are highly professionalized, focusing mainly on medical, educational, and vocational interventions. This emphasis on professional interventions that differs from NDNWS's rights-based strategies is explainable by Amar Jyoti's different conceptualization of personhood. Amar Jyoti's interventions are underscored by the group's notion of the individual as fundamentally grounded in a physical body that is supple and malleable to professional practices. The group also sees the individual as being nested within and susceptible to medical, kinship, educational, political,

economic, and occupational systems. Thus a rights based approach within this group would necessarily prioritize individual interventions by professionals. It also explains why the group incorporates professional training, household training programs, and social awareness as additional foci for interventions.

In its rights-based approach to disability, Amar Jyoti employs all four disability models. Many of the values of the organization stem from a hybridized medical-social model, as well as espouse notions that go against a kinship model of disability. The medical, social, and kinship model are also employed in the labels the group uses to identify its clientele. Amar Jyoti's programming activities are underscored by the medical and social models of disability, as well as hybridizations of the medical-social models and kinship-medical models.

4.4 COMMON THEMES OF NDNWS'S AND AMAR JYOTI'S RIGHTS-BASED APPROACHES TO DISABILITY

In contrast to North American and European assumptions that disability rights and a rights based approach stem from the values and approaches of a social model of disability, South Asian rights-based approaches incorporate value schemes from multiple models. In fact as the two case studies presented in this paper demonstrate, the medical model figures prominently into the values and services of these organization's rights-based approach to disability. Despite different geographical locations, different target populations, and different foundational ties, both Amar Jyoti and NDNWS share several additional features in common with each's attempt to operationalize a disability rights-based approach. This focus on the medicalized body also

highlight the fact that these two groups view disability as being nested in the physical body that also has social, economic, educational, vocational, cultural, and political dimensions.

Each organization overlaps in the services that they provide under a rights based approach to disability. Both organizations provide low cost direct services such as educational and vocational training; focus on remediating physical conditions (even if the service is not currently being provided by the organization as in the case of NDNWS) are engaged in heightening social awareness; foster a sense of community and acceptance within the organization; and work to establish employment opportunities for their clientele.

Both groups also blend the medical and social models in their rights-based approaches to disability. This may in fact be a consequence of the multiple ways in which the social model is conceived. In Chapter 1, one scholar noted that the real cause of disability did not rest in the body, but instead in society. A second scholar noted that the success of the social model rested on its ability to determine which aspects of disability required medical interventions and which required social strategies. While the first scholar rejects the medical model as playing a role in creating or managing disability, the second allocates particular management needs to medicine. It is clear that within these two organizations, there is a perceived need that the physical body needs tending.

The individual body is in fact the main target of the intervention strategies of both groups. Within these two organizations, the focus of a rights based approach can be extracted to be on recognizing and developing an individual's internal strengths and capabilities such as literacy, skilled work, self-confidence, self-advocacy, and social support and networking. As Figures 3 and 4 suggest most programming activities of each organization are targeted at the individual and seek to create changes at this level of interaction. This trend towards targeting

individual change becomes starkly apparent if we define Amar Jyoti's key population as children with disabilities and examine the services available to these children. Similarly, if we look only at those services being offered by NDNWS during my visit, all of those programs fall within the first category targeting change at the individual level.

The strategies that both NDNWS and Amar Jyoti use to operationalize a rights based approach integrate demands for entitlements as well as appeals to charity. As discussed earlier this blend of political actions with religious norms is not uncommon throughout much of South Asian and Asian religious traditions. Additionally, both organizations place a small amount of emphasis on changing social and attitudinal barriers through programming that seeks to raise social awareness of the capabilities and potential contribution of individuals with disability.

4.5 HETEROGENEITY IN RIGHTS-BASED APPROACHES

Despite the common themes within the programming offered by these organizations, heterogeneity does exist between the two organization's operationalization of a rights-based approach. Each group operates off of different conceptualizations and combinations of the forms that rights can take. Further, each group's notion of how a right is realized differs between the two. Additionally, each group implicitly uses different combinations of disability models that explain the heterogeneity in how the individual is conceptualized, the forms that rights take, and the services that each group provides.

In comparing these two organizations, we see that a rights-based approach to disability does not take one single form. Instead, each group's rights-based approach is highly diversified in its meaning, operationalization, and potential impact on people with disabilities and societies.

4.6 TRANSFORMATION OF RIGHTS-BASED APPROACHES BY DISABILITY ORGANIZATIONS

Returning to the model I presented in chapter 1 of how disability discourse and policy is produced and transformed, I suggest that this heterogeneity in rights-based approaches to disability is the result of disability organization's transforming international policy and disability frameworks in order to suit the local needs of their clientele, as well as local rationales of disability, values systems, identity, and configurations of power. One illustration of this transformation is the way in which definitions of disability are altered from both popular definitions circulated within International policy, as well as the definitions stemming from the four models presented in this paper. Within international discourse and policy, there is an overwhelming use of biomedical definitions of disability. Yet both of the organizations do not use a purely biomedical definition of disability, but instead blend religious ideology, notions of kinship, and the local social conditions in conjunction with biomedical understandings to define the meaning and cause of disability within their communities.

4.7 DISCUSSION

4.7.1 Challenges for Disability Scholarship

Recognizing and understanding the role that disability organizations play in transforming disability policy and theory has several implications for how disability is understood and studied, as well as how disability services are designed and implemented for individuals with disabilities. This work suggests that there is diversity in the meanings and strategies that organizations use in

providing a rights-based approach to disability. I have suggested that this diversity stems from different values and concepts of how these organizations define personhood, disability, and change. Taken independently, none of the four theoretical models of disability presented in this paper go far enough in explaining the diverse approaches to disability rights and subsequent heterogeneity in the services available to people with disabilities. The failure of any single model to explain this diversity is exemplified in organizations' implicit use of hybrid models of disability, as well as disability management approaches such as Amar Jyoti's "holistic rehabilitation" that cannot be easily placed under any one model. Even the social model which goes the farthest in integrating biomedical and social conceptualizations of disability fails to fully incorporate alternative meanings such as those suggested within kinship and religious-charity models of disability.

The discussion in Chapter 1 suggests some of the inherent problems with any one model's ability to explain the heterogeneity and transformation of rights-based approaches to disability. These four models are static in that they do not offer ways of explaining how meanings of disability might change over time or cross-culturally. They also do not permit "fluidity" between multiple meanings of disability that might co-exist within particular contexts. As ideological products of particular places and historical processes, these models also carry with them inherent values and assumptions about the utility and appropriateness of each model for explaining the meaning of disability and the appropriate management strategy that should be implemented. This is particularly true of both the medical and social models of disability.

In many ways the medical model of disability as a concept was created as a foil for disability advocates to vilify and push forward their agenda for a social model and its orientation towards disability rights. Yet we see that within the South Asian case studies, the medical model

remains a popular means of defining and operationalizing a rights-based approach. This popularity as well as the skill with which these two organizations employ international disability discourse and approaches to disability suggests that these organizations' reliance upon the medical model is more than outdated, backwards thinking. It suggests that the possible explanation of the two organizations' use of the medical model rests somewhere between Kohrman's observation of the proliferation and export of bio-bureaucracies with their biomedical means of framing experience and the undeniable efficacy of the medical model in managing certain dimensions and meanings of disability.

This work reflects a need for revising the theoretical models of disability in order to make them sensitive to the multiple meanings and experiences of disability in cross-cultural settings outside of the North American and European contexts from which they were first derived. To continue working with these models as they currently exist runs the risk of further fracturing our understanding of the experience of disability along the heuristic and historical lines from which each model first emerged. One possible solution is to allow more permeability and overlap between these four models than currently exists. In order to improve these models, I also suggest that we need to deepen our scholarship on underdeveloped models such as a kinship model or religious-charity model of disability. In deepening our understanding, I also argue that disability scholarship needs to pay heed to the body as an analytical topic, as well as cross-cultural differences with regards to familial and social structures, conceptualizations of the body, personhood, and value systems.

This work also has implications for how NGO programming design can be made to better reflect the multiple meanings, management strategies, and levels of intervention that stem from the experience of disability in different local contexts. While disability rights at the international

and national level are most commonly found as mandates and policies dictating how society should treat individuals with disabilities, the work of these organizations largely target changes at the individual level. In fact the least developed programming within each of these organizations are those efforts to “raise social awareness” within Nepali and Indian societies. This suggests a disconnect between the on-the-ground activities of organizations that work with individuals with disabilities and the policy and institutions that are working to guide the actualization of disability rights and how services are provided. One of the critical questions for policy and program developers is why this disconnect occurs. Is the focus on raising social awareness of the abilities and rights of people with disabilities just an example of “lip service” paid to disability rights that each of these organizations engages in as a result of international discourse and funding mandates? Or do these groups see this as a critical but currently underdeveloped dimension of their work?

Additional questions emerge regarding how universal or how localized should definitions of rights and rights based approaches be? While the North American and European disability rights movement framed its claims within civil and human rights discourse, questions remain as to whether this approach fits all contexts within an international disability rights movement. The heterogeneity in definitions of disability, personhood, and theories of change illustrated in this paper suggest that appeals to universal rights might not work for all contexts.

4.7.2 Public Health Leadership, Disability Rights, and Essential Functions of Public Health

As a matter of public health interest, disability is a topic to which little attention has been paid. However, its importance as a topic of research, program and policy development, and public

health leadership cannot be overlooked. The increasing prevalence and proliferation of biomedical practices and therapeutic interventions across the globe has contributed to the wane of several infectious diseases, but has also had the effect of increasing the prevalence of disability that is secondary to illnesses, once fatal birth defects, and complications associated with aging populations whose life expectancies continue to increase. This observation underscores the fact that global public health can not simply focus on disability as a topic of prevention, but must also better attend to designing and implementing policy and programming for disability as a chronic condition.

A 1976 study of disability conducted by the WHO estimated that 10% of populations in the developing country experienced disability (Upadhyaya 2003). Critics of this study have fallen on both sides of the debate simultaneously arguing that this estimate is too low as well as too high. Yet despite these incongruencies that suggest a need for further studies and refined definitions of disability, there is the undeniable fact that disability remains a part of the life experience for most individuals at some time in their lives. When viewed as a part of the life experiences of both aging and illness processes, the need for comprehensive, culturally competent policies and coordinated and effective public health programming becomes apparent. The potential role that public health leaders and community health practitioners can play in developing such models and implementing a rights-based approach to disability is significant.

The discussion above has outlined some research questions that can contribute to a better understanding of how disability and disability rights are experienced and conceptualized in diverse communities. However, there is also a significant role that public health leaders and practitioners can play in promoting disability rights, inclusion, and equality for individuals with disabilities in their everyday work.

Some of the activities into which a rights-based approach can be inserted are found within the Essential Public Health Services. The Essential Public Health Services Work Group outlined 10 key services of public health. These services include: 1) monitoring health status to identify and solve community health problems; 2) diagnose and investigate health problems and health hazards in the community; 3) inform, educate and empower people about health issues; 4) mobilize community partnerships and actions to identify and solve health problems; 5) enforce laws and regulations that protect health and ensure safety; 6) link people to needed personal health services and assure the provision of health care when otherwise unavailable; 7) assure a competent public health and personal health-care workforce; 8) evaluate effectiveness, accessibility and quality of personal and population-based health services; 9) develop policies and plans that support individual and community health problems; 10) research for new-insights and innovative solutions to health problems (Harrell, Baker, and Work Group 1994).

Within each of these services, there is both a need to reflect on the specific impact of these service goals on individuals with disabilities, as well as an opportunity to infuse a rights-based approach into each function of public health. In realizing a rights-based approach to disability within these key services, public health leaders and practitioners must first take a broad social-ecological definition of health that extends beyond the physical body in order to understand not only the physical health, but also the social and emotional well-being of the individual and the external factors that influence health outcomes. A definition of health that is aligned with recent trends in disability studies is found within what Rissel and Bracht define as the “community development approach” (1990). In this approach health is viewed within the broader context of social and economic improvement. Individual and community empowerment is seen as vital to improvement in health status (Rissel and Bracht, 1990). In this model, better

health is seen as the result of improvements in social, economic, political, and educational domains. Achieving better health involves improving the quality of life of individuals beyond increased access to and control of medical and preventative services and programs. Under this model, community members including individuals with disabilities benefit from increased representation and participation in social, economic, political, vocational, and educational domains. These benefits translate into communities taking greater responsibility and ownership of the health of members of their community.

This broad definition of health serves as a reminder to public health leaders and practitioners to think broadly, creatively, and collaboratively in their efforts to promote a rights-based approach within the ten essential functions of public health. Within the first public health service function of surveillance of community health problems, the definitions of community health and problems should include a focus on the degree to which disability rights are understood, implemented, and upheld within community services. Similarly, public health efforts to diagnosis and investigate health problems necessitates exploration of the multiple meanings assigned to disability and its management within the community, as well as local definitions of disability rights and their efficacy in promoting inclusion, equity, and the well-being of individuals with disabilities.

The role that public health plays in informing, educating, and empowering people can be extended to efforts that work towards increasing both awareness of the needs of individuals with disabilities, as well as the rights of people with disabilities in the community. In mobilizing community partnerships and actions to identify and solve health problems, public health leaders should take on leadership roles in facilitating partnerships with disability organizations and

community leaders in disability issues. Community health practitioners should also work towards ensuring that people with disabilities are sought out as fellow leaders and partners.

Additionally, public health leaders and community health workers can play a role in ensuring that disability rights are upheld. Their work should also aim to protect and promote the health and well being of people with disabilities. Activities that monitor the safety, well-being, and quality of life of individuals with disabilities, as well as evaluate the comprehensiveness and efficacy of services for people with disabilities help to enforce the vision and intention of disability rights within communities.

Public Health's role in promoting a disability rights-based approach within its mission to link people to needed services and assure the provision of service extends to facilitating access to disability services that are holistic and promote a rights-based approach to disability for individuals. Within these professional services, public health leaders can work to promote competency with regards to disability rights within the public and private health work force. Public health leaders can implement strategies that increase the ability of health workers to understand the experiences of people with disabilities; promote the increased presence of people with disabilities in this professional workforce; as well as integrate disability rights awareness within professional training.

In evaluating the effectiveness, accessibility, and quality of personal and population-based health services, evaluators must be attuned to those services that promote a rights based approach. If attuned to a rights-based approach to disability, leaders within the fields of program evaluation can work towards deepening our understanding of how disability services are provided, which program strategies best serve individuals with disability in particular locations, as well as how to better design effective disability services. In turn, information on program

efficacy and best practice allows public health leaders to develop better policy and programming that attends to the needs and rights of individuals with disabilities in different communities.

Finally, public health's essential function that mandates research into new insights and innovative solutions to health problems requires public health leaders and practitioners to increase the understanding of how a rights based approach is conceptualized within diverse communities. It also suggests the role that public health and community leaders can play in mobilizing community partners to visualize how disability rights and an inclusive community might look in the future. Community health strategies that garner information from the community about how different members of the community view disability and best mobilize community resources should be integrated into public health practices that seek innovative solutions. In turn, creative and collaborative solutions to actualizing community goals can be implemented through these community partnerships and shared vision.

With regards to both disability scholarship and program planning, efforts must be made to reinvigorate our current conceptual models of disability and rehabilitation with the multiple meanings and management strategies at work in the lives of individuals with disabilities. Possessing models that better attend to the meaning and experience of disability allows practitioners to improve upon assessment strategies, program planning, and evaluation measures of both disability services and community health. Such efforts on the part of public health leaders in collaboration with disability scholars has the potential to not only deepen our understanding of the experience of disability within different community contexts, but also realize communities in which everyone is equal in their health outcomes and their ability to participate in society.

APPENDIX

FIGURES

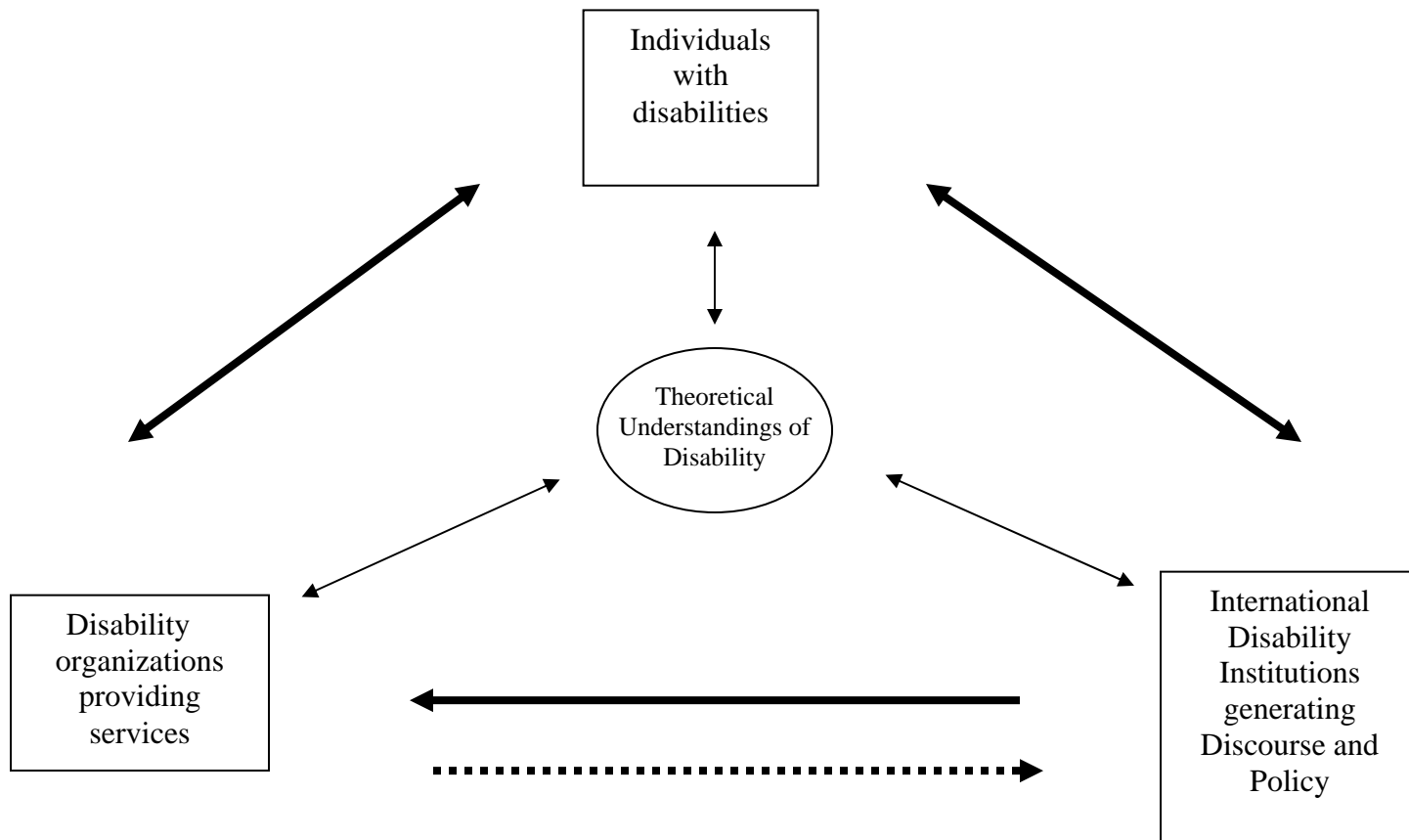


Figure 1. Theoretical model of relationship between individuals with disabilities, disability organizations, and international disability institutions

Theoretical Model of Disability	Medical Model	Social Model	Kinship/ Connected Body Selves	Religious Charity
Cause / Origin of Disability	deficiency or pathology of the physical body; bodies or conditions that fall outside a normal bell curve	Social conditions create disability for differently abled individuals;	Disability is experienced through the kin network in which the disabled body of one is fused to the personhood and life projects of others.	Moral Transgression of individual or family member
Solution	Medical intervention to correct the disability	Social interventions that change the environment rather than the individual	Kin network manages the disability	Charitable acts in the name of a sacred being
Example of Discourse	Physical rehabilitation, impairment, therapy, corrective surgery	Economic and social rehabilitation, disability and handicap, barrier-free environments, empowerment, independence	Karma, family responsibility,	Charity, god, alms,

Figure 2. Theoretical models of disability and examples of disability discourse

Targeted Level Program Type	Individual	Household	Organizational	Community	National	International
Education	<ul style="list-style-type: none"> Literacy and Education Program with scholarships to children to attend different schools 	<ul style="list-style-type: none"> scholarships to children to attend different schools 				
Vocation	<ul style="list-style-type: none"> Skill Development in leadership; office management; secretarial skills; computer and software skills; different skills in income generating to make them self-dependant such as : “hosiery”/clothes sewing, weaving, knitting, painting, embroidery, Dhaka making, flower painting, painting, greeting card making, food preparation. 					
Economic	<ul style="list-style-type: none"> Income-generating project 	<ul style="list-style-type: none"> Income-generating project 	<ul style="list-style-type: none"> National and International Fundraising 			
Health	<ul style="list-style-type: none"> Health care programs Medicare facilities and service, CBR 	<ul style="list-style-type: none"> Medicare facilities and service, CBR 	<ul style="list-style-type: none"> CBR 			
Housing and Respite Care	<ul style="list-style-type: none"> 8 months of circulating hostel facility 					
Research/data collection			<ul style="list-style-type: none"> Collection of disability data 	<ul style="list-style-type: none"> Collection of disability data 	<ul style="list-style-type: none"> Collection of disability data 	<ul style="list-style-type: none"> Collection of disability data
Spiritual	<ul style="list-style-type: none"> Strict moral discipline in a progressive environment 					
Awareness		<ul style="list-style-type: none"> exchange of views, cooperation and experiences 		<ul style="list-style-type: none"> Social Awareness exchange of views 	<ul style="list-style-type: none"> Social Awareness Exchange of views 	<ul style="list-style-type: none"> exchange of views,

Figure 3. Intervention levels of NDNWS programming

Targeted Level of interaction	Individual	Household	Organizational	Community	National	International
Program Type						
Education	<ul style="list-style-type: none"> • Amar Jyoti School and Special Needs Classrooms • National Institute of Open Schooling 					
Vocation	<ul style="list-style-type: none"> • Vocational Training Program • Vocational Placement Unit 					
Mobility	<ul style="list-style-type: none"> • Prosthetic Orthotic Unit 					
Health and Rehabilitation	<ul style="list-style-type: none"> • Healing Touch Clinic • Physiotherapy • Occupational Therapy • Speech Pathology and Audiology • Hobby Classes • Home Training Program 			<ul style="list-style-type: none"> • medical camps 		
Self Care	<ul style="list-style-type: none"> • Home Training Program 	<ul style="list-style-type: none"> • Home Training Program 				
Professional Training	<ul style="list-style-type: none"> • Special Education • Physiotherapy • Indira Gandhi National Open University 					
Social and Psychological	<ul style="list-style-type: none"> • Child Guidance Center • Hobby Classes • Social Work Unit • Prosthetic Orthotic Unit 	<ul style="list-style-type: none"> • Child Guidance Center • Social Work Unit 				
Awareness	<ul style="list-style-type: none"> • Advocacy • Awareness campaigns 	<ul style="list-style-type: none"> • Publications 	<ul style="list-style-type: none"> • Publications • campaigns 	<ul style="list-style-type: none"> • Publications • Advocacy • Awareness campaigns 	<ul style="list-style-type: none"> • Publications • Advocacy • Awareness campaigns 	

Figure 4. Intervention levels of Amar Jyoti programming

Theoretical Model of Disability	Medical Model	Social Model	Kinship/ Connected Body Selves	Religious-Charity	Other
Cause / Origin of Disability	Deficiency or pathology of the physical body; bodies or conditions that fall outside a normal bell curve	Social conditions create disability for differently abled individuals;	Disability is experienced through the kin network in which the disabled body of one is fused to the personhood and life projects of others.	Moral Transgression of individual or family member	
Solution	Medical intervention to correct the disability	Social interventions that change the environment rather than the individual	Kin network manages the disability	Charitable acts in the name of a sacred being	
Example of Discourse	Physical rehabilitation, impairment, therapy, corrective surgery	Economic and social rehabilitation, disability and handicap, barrier-free environments, empowerment, independence	Karma, family responsibility,	Charity, god, alms, pity	
Program Features					
Mission Statement and Objectives	Make women self-dependent and versatile; upgrade the quality of life for women with disabilities; provide educational and employment opportunities (direct service); establish rehabilitation and training centers; boost morale of women	Overcome the disadvantages in the life of women with disabilities; make women self-dependent and versatile; raise social awareness; gender equality; human rights, equal rights and representation; advocate for job openings	Overcome traditional views in which handicapped bodies are the result of bad actions committed by the individual or family in a past or the current life.	God will provide assistance for working with helpless people; Overcome traditional views in which handicapped bodies are the result of bad actions in a past or the current life.	
Physical Building	Unmodified structure requiring the individual to adapt to the physical structure of the building; space is utilized by women with disabilities only				Hostel facility
Clientele	Handicapped women; physically disabled women, mobility impairments; creative and motivated	Neglected, oppressed, disadvantaged, and destitute women; populations facing gender discrimination, physical and psychological violence; women viewed as useless and burdensome	Children of handicapped parents	Individuals holding backwards and traditional views of disability	
Programming	Healthcare programs; Collection of disability statistics; Literacy and Education programs; vocational skill development; Income Generating Projects,	Literacy and Education programs; vocational skill development; Collection of disability statistics; social awareness and consciousness raising; social events and outings		Strict moral discipline	Fund-raising, hostel facility

Figure 5. Analysis of underlying models of disability that inform NDNWS program features

Theoretical Model of Disability	Medical Model	Social Model	Kinship/ Connected Body Selves	Religious-Charity	Other
Cause / Origin of Disability	Deficiency or pathology of the physical body; bodies or conditions that fall outside a normal bell curve	Social conditions create disability for differently abled individuals;	Disability is experienced through the kin network in which the disabled body of one is fused to the personhood and life projects of others.	Moral Transgression of individual or family member	
Solution	Medical intervention to correct the disability; technical and professional interventions	Social interventions that change the environment rather than the individual	Kin network manages the disability	Charitable acts in the name of a sacred being	
Example of Discourse	Physical rehabilitation, impairment, therapy, corrective surgery	Economic and social rehabilitation, disability and handicap, barrier-free environments, empowerment, independence	Karma, family responsibility,	Charity, god, alms, pity	
Program Features					
Mission Statement and Objectives	Meet the rehabilitation, educational, and vocational needs of individuals with disabilities; promote early intervention; foster interdisciplinary professional approaches to disability; reduce and prevent secondary disabilities;	Equal Opportunities; full participation; equal positions in life; justice; Empowerment; inclusive education	Reduce the dependence of the family		Holistic Rehabilitation
Physical Building	Medical Clinic; Institute of Physiotherapy; Orthotics and Prosthetic Workshop;	Barrier free environment; complex housing with multiple services that makes each more accessible for an individual with disability	Space is utilized by youth and family members	Prayer location for daily puja to organization's patron saint	
Clientele	Disability case, such as CP case, downs syndrome case, autism case, etc.; healthcare professionals and other service providers	People with disability	Parents of children with disabilities		
Programming	Healing Touch Medical and Rehabilitative Clinic Institute of Physiotherapy Lip Reading and Speech Prosthetic and Orthotic Clinic, hobby classes for enhanced motor control and self esteem Child Guidance Center Medical camps; Professional Training; Special education; vocational training	Advocacy and awareness raising campaigns; social work; professional training; disability certificate identifiers	Home Training Programs, Parent support programs		

Figure 6. Analysis of underlying models of disability that inform Amar Jyoti program features

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