# THE ACCULTURATION OF INTERNATIONAL DISABILITY RIGHTS NORMS: PERSPECTIVES FROM MOVEMENTS IN THE UNITED STATES AND INDIA

By

Sarah Amin

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Chair:

Tamar Gutner, Ph.D

Julie Mertus, J.D.

Dean of the School of International Service

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# ABSTRACT

Despite the proliferation of inclusive policies on disability, there remains little academic literature grounded in the field of international relations that explains under which domestic socio-political conditions international disability rights norms are likely to flourish. This paper asks, "Which factors contribute to variation in the domestic promotion of political participation and social inclusion for persons with disabilities, as exemplified by the social model of disability and the UN Convention on the Rights of Persons with Disabilities (CRPD)?" The primary focus of the paper is to uncover certain historical processes that influence democratic and relatively wealthy countries to engage with international disability rights instruments by embracing the social-model language of the CRPD in their disability-related laws. With respect to this question, the author distinguishes the United States from India- two large, democratic countries with stable economies, which have adopted very different models within their disability laws in the 1990s. The case studies reveal that, although the U.S.'s disability laws comply with the standards of the CRPD, domestic tensions have hindered its participation as a leader in international human rights treaties. On the other hand, India's original disability law, which does not embrace the fundamental principles of the CRPD, was a product of on-going transitions in India's foreign policy and efforts to build a more globally engaged capitalist economy.

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#### CHAPTER 1

### INTRODUCTION

#### <u>Purpose</u>

Despite the proliferation of socially-inclusive disability policies, there remains little academic literature grounded in the field of international relations that explains under which socio-political conditions disability rights and the disability identity are likely to flourish. This thesis asks, "Which factors may contribute to variation in the domestic promotion of political participation and social inclusion for persons with disabilities, as exemplified by the social model of disability and the UN Convention on the Rights of People with Disabilities (CRPD)?" The primary focus of the paper is to uncover certain historical and political processes that influence democratic and relatively wealthy countries to engage with international disability rights instruments by embracing the social-model language of the CRPD in their disability-related laws. With respect to this question, the author distinguishes the United States from India- both large, democratic countries with stable economies, but which have adopted very different models within their disability laws in the 1990s.

The United States was among a handful of countries to have developed and launched social model norms via domestic processes (protesting, lobbying, etc) since the 1960s. Disability rights activists from these countries were instrumental in drafting the first UN Convention on disability and then in ensuring that the social model framework guided the language of the CRPD in the 2000s.<sup>1,2</sup> Surprisingly, although the inclusive language of the United States' Americans with Disabilities Act (ADA) of 1990 supports the basic principles of the CRPD, the United States signed the Convention in 2009, but has failed to ratify it as of early 2012. The

<sup>&</sup>lt;sup>1</sup> See Chapter 2 for in-depth explanations of the various models of disability

<sup>&</sup>lt;sup>2</sup> See "Ratify the UN Disability Treaty," Foreign Policy in Focus, Institute for Policy Studies http://www.fpif.org/articles/ratify\_the\_un\_disability\_treaty

United States played a very minimal official role during the negotiation of the treaty itself, but American activists and norm entrepreneurs continued to contribute to the process without the guarantee of official endorsement by the U.S. Therefore, although the social model norms were inspired in part by the disability rights movement in the United States, the country's refusal to fully endorse the Convention reflects a fundamental and troubling discrepancy between rhetoric and practice. Under the administration of George W. Bush, the United States felt that the ADA law sufficiently addressed the rights of persons with disabilities (PWDs) domestically, and did not require further international monitoring. However, since 2009 the Obama administration has reiterated the need to demonstrate an on-going commitment to the principles of the CRPD, as well as regain trust and build solidarity with other signatories. As of 2009 the United States is a signatory to the CRPD, and the ratification process is in the hands of the U.S. Senate.

On the other hand, India's Persons with Disabilities Act (PWD) of 1995 does not reflect the social model, but instead adopts a highly medical model. As a participant of the Economic and Social Commission for Asia and the Pacific (ESCAP) in the 1980s and 1990s, India agreed to take steps to address the rights of PWDs in its civil rights legislation. India both signed and ratified the CRPD by 2007 and, in an effort to fulfill its commitments, is in the process of redesigning the PWD act to reflect the principles of the social model. These decisions indicate that India has been gradually more influenced by international norms over the past several decades, and that certain values and incentives that were not present two decades earlier may have driven the country to cooperate with international standards. This paper seeks to retrospectively explore the factors that resulted in the differences between the original laws of both countries, as well as examine the causes for the U.S's reluctance and India's eagerness to engage with the treaty.

An investigation into the relationship between norm acculturation processes and the domestic political, social, and economic environments is useful when explaining what authors Goodman and Jinks refer to as "decoupling" – the circumstance in which countries formally commit to international treaties but are either unable or unwilling to conform to their principles in practice (Goodman & Jinks 2008, 730-731). Understanding domestic elements in relation to these discrepancies (such as, for example, the power and presence of a civil society, official foreign policies, or the effects of periods of social and political upheaval) may help to explain symbolic gestures by governments such as India. The United States assumes a very different problematic position of gesturing, in that the government supports the ideals of human rights worldwide, but is currently unable to commit to the CRPD in an official capacity due to internal political dissonance. This assumption aligns with the shift in scholarly focus from the study of transnational agents that influence the process of norm diffusion to the study of "how domestic political structures and agents condition normative change," as exemplified by the recent work of author Amitav Acharya (Acharya 2004, 240). Acharya promotes the perspective of norm diffusion that "looks beyond international prescriptions and stresses the role of domestic political, organizational, and cultural variables in conditioning the reception of new global norms" - a perspective which will be the backbone of the examination of the case studies within this paper (Acharya 2004, 243). Therefore, from a broad perspective, within-case analyses may reveal factors that could aid norm entrepreneurs and disability rights activists in predicting which countries would be less likely to simply symbolically sign and ratify the CRPD, and more likely to take measurable steps to fulfill their commitments in practice by establishing and implementing appropriate laws.

For the purpose of this paper, within-case analysis is necessary to understand a) which events in the United States led to a widespread recognition of the social model among the country's disability community (ultimately to be absorbed into the country's laws followed by international law), and why there was a loss of momentum in ratifying the CRPD; and b) which aspects led India to a very different perspective on disability through the 1990s, and how India is conditioned by international pressure to acculturate the norms represented in the CRPD. Ultimately, through the course of the research, the paper argues that democratic countries with strong economies are more likely to be receptive to international disability rights norms, but that certain other factors are also significant, including the cooperation of the country's private sector, the framing of disability as a contentious domestic political issue, incentives to engage with the international community, and more inclusive social policies towards human development.

# **Organization**

This paper is organized into nine chapters. Following this introduction, the paper will discuss key concepts such as the various models of disability and the history and principles of the CRPD. The third and fourth chapters will review literature on the acculturation of international norms and outline the research methodology that will be used to review the case studies. Chapters five and six will present the case studies, discussing historical conditions and developments that led to the current status of laws related to disability in the U.S. and India. Chapter seven will provide an analysis of findings from the case studies, and chapter eight will present the conclusion. The final chapter will discuss the paper's greater implications for the international relations discipline.

#### **CHAPTER 2**

## BACKGROUND AND KEY CONCEPTS

#### Comparing Models of Disability

Various models are implemented by different sectors of society in order to define disability, explain the causal relationships between disability and physical, economic, social, and cultural environments, and to develop appropriate strategies towards practical ends. Since the use of the word "disability" is contextual, a single, broad definition of disability cannot exist, or it would be vague and ineffectual. It is important to note that newer models do not necessarily replace older models. Newer conceptualizations of disability have been introduced concurrently with evolving societal norms, but without completely stripping older models of their relevancy or applicability. As a result, differing disability models have been utilized for the purposes of rehabilitation, medical research and technology development, health policy-making, economic progress, and political empowerment. That is not to say that there is no significant friction among the divergent perspectives. Newer perspectives have evolved away from positivist viewpoints, and moved towards post-structural, critical, and resistance theories, ultimately producing dichotomous relationships between the old and the new. Author Julie Smart warns of the dangers of the lack of collaboration across disciplines and the tendency to focus on one model. For example, she notes that health care professionals might adopt a certain model for their practice, without considering that their patients who have disabilities may wish to live within the boundaries of a different model of their own choosing (Smart 2009, 4). Moreover, if a country's education system incorporates only the medical model of disability, then social and cultural barriers may not be acknowledged as part of the lived experience of disability (Smart 2009, 4).

For the purpose of this paper, the social model of disability is considered to be the most conducive to political empowerment. The remainder of the section will elaborate on the most common disability models, concluding with a rationalization of the social model as the appropriate choice for achieving civil and political rights.

## What is a "disability"?

As will be explored in this section, each model assumes a slightly different definition of disability; however, within the socially-oriented models there is a crucial differentiation between "impairment" and "disability." Stemming from a 1975 proposal by the Union of the Physically Impaired against Segregation (UPIAS), social model proponents clarified the meanings of disability and impairment in response to the medical model's tendency to view the two as one experience (Siminski 2003, 708). Impairment describes the functional limitation or the actual condition of the body or mind (Burchardt 2004, 736). This may include the experience of missing a limb, or the inability to hear. On the other hand, "disability" is defined as the "loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers" (Siminski 2003, 708). Author Peter Siminski cites Olivier's definition of disability as "a consequence of the failure of social organisation to take account of the differing needs of disabled people and remove the barriers they encounter" (Siminski 2003, 708). Therefore, the impairment belongs to the individual, whereas the *disability* experienced in conjunction with it is largely due to socially constructed barriers.

#### Medical/Biomedical/Charity Model

The medical model, also termed as the "pathology orientation" or "deficit orientation," conceptualizes disability as a disorder that must be cured or rehabilitated so that the individual

can return to a "normal" level of function (Smart 2009, 4). It is a highly normative model that sets a physiological standard for the norm, and pathologizes conditions that deviate from that standard. The model reflects the medical field's practice of establishing strict classifications and definitions, which enhances clarity and precision within the discipline. The medical model is undoubtedly crucial for the health, rehabilitation, and treatment of patients. Moreover, the experience of disability, when conceptualized in terms of "impairment," is fundamentally a physical, mental, or sensory experience. Even the most staunch social model proponents would not deny the impairment aspects of disability or the vital role that health care plays in the lives of PWDs.

Although few can deny the necessity of medical research and practice, the medical model has been criticized as a perspective that inadvertently propagates prejudice and robs PWDs of their right to self-determination. When diagnosed with a disability, the dysfunction of the body belongs to the individual ("blaming the victim"), along with the responsibility to strive for normalcy (Smart 2009, 4). The social ramifications of this positioning of disability can be dangerous. As mentioned in the introduction chapter, the privilege to classify an individual provides medical professionals immeasurable power over the direction of their patients' lives. According to Smart, it creates a "power differential between the practitioner and the individual with the disability" (Smart 2009, 4). Because of the prestige and moral authority vested in medical professionals, the normative framework in which they practice spreads through society, and justifies the discrimination against those whose bodies and minds defy the conceived norm. Moreover, Smart notes that by relegating disability to the sphere of medicine and rehabilitation, the public is relieved of the responsibility to provide access, rights, and benefits (Smart 2009, 4).

The medical model views the environment as "fixed and neutral," which obligates the PWD to change to fit her environment rather than the reverse (Burchardt 2004, 736).

The charity aspect of this model adopts the belief that disability is a personal tragedy which can be "cured," and that society should take charitable steps to aid and protect PWDs. The charity model conceives PWDs as dependents, an infantilizing attitude which inevitably deprives them of their autonomy and dignity.

# The International Classification of Functioning, Disability, & Health

The International Classification of Functioning, Disability, & Health (ICF), or the biopsycho-social model, is a complex classification system that combines medical and social factors for a more comprehensive assessment of the experience of disability (World Report on Disability 2011, 4). The system was first introduced by the World Health Organization (WHO) in the 1980s, when it was named the International Classification of Impairments, Disabilities, and Handicaps (ICIDH). According to the WHO, the ICF "attempts to achieve a synthesis in order to provide a coherent view of different perspectives of health from a biological, individual and social perspective" (Mitra 2006, 238). Therefore, it strikes a balance between the medical and social models in a "dynamic interaction between health conditions and contextual factors, both personal and environmental" (World Report on Disability 2011, 4). When determining functionality and disability, the classification considers contextual factors such as a) an individual's personal background, the environment, his or her education and work, b) the services that are available within the community such as health care and transportation, and c) cultural factors such as attitudes towards disability (Mitra 2006, 238). It then grades capacity and performance each on a scale of 0-9 to assess the individual's overall experience and ability to perform activities (Mitra 2006, 238).

The ICF takes a step away from a purely medical model by understanding that economic and social factors contribute to the overall barriers experienced by PWDs. The ICF is a useful diagnostic system for research and development, health-related policies, and clinical purposes, and is a practical standard for assessing disability on a global scale. However useful this may be for classification, the ICF does not completely break away from the medical model, and its system of categorization continues to be problematic. Although it includes environmental factors such as the availability of public/community services in its classification, the ICF continues to give researchers and health care professionals the power to define and classify disability. Moreover, it continues to represent *disability* as the *lack* of functionality and a barrier to full participation. If the starting point is the impairment of the individual, then to a certain extent disability is still perceived as a personal weakness. Because of this, the ICF system is not an appropriate model for the political empowerment of PWDs- empowerment which requires a strong push away from the focus on individual impairments.

#### The Nagi Model

The Nagi model, also known as the functional limitation model, was developed by sociologist Saad Nagi in 1965 (Wang, Badley, & Gignac 2006, 135). Unlike the medical and ICF models, the focal point of this approach is not to measure, classify, or heal impairments, but to evaluate disabilities as limitations placed on the individual's roles and activities within the context of culture and society. These include occupational roles and responsibilities within the family and greater community. Nagi defined such a limitation as "an inability…in performing socially defined roles and tasks expected of an individual within a socio-cultural and physical environment" (Mitra 2006, 238). Since these expected roles depend upon gender, culture, geography, and socio-economic class, *functionality* is relativistic. For example, a role as a

mother may require different physical tasks from the role of a father within a given culture. Due to a disability, an individual may be unable to perform her proper role ("role failure") (Smart 2009, 6). As a result, depending on the role, certain disabilities may not present themselves as hindrances and may have little or no effect on a person's ability to function.

The focus of the Nagi model thus shifts even further away from the rehabilitation of individuals, and argues instead for the adaptation of roles and functions. A PWD can avoid the limitations associated with her impairment if the environment and expected functions could be adapted to her abilities. One major weakness in this model is its reliance on socio-cultural roles. Socio-cultural roles are multiple, fluid, ill-defined, and evolving. Moreover, a person's role will change with age. Culture is a dangerous way to conceptualize disability, because it is difficult to define exactly what a person's cultural role is and whether he or she accepts it. Furthermore, the Nagi model focuses on work, tasks, and activities to define functionality, which does not encompass the full range of the human experience. It especially excludes young children and the elderly who are not yet or no longer part of the formal workforce (Smart 2009, 6). Finally, the responsibility of the public within this model does not go so far as to provide universal access, but to only offer accommodations for the roles applicable to the person who experiences the impairment. Disability is still seen as an inability on the part of the PWD to achieve full functionality within a pre-determined set of roles.

## The Capabilities Approach

The capabilities approach is a framework that expands traditional measurements for "standard of living", "well-being", and "quality of life" in the field of economic development. The approach, championed by Amartya Sen, considers an individual's personal characteristics, resources, and environment to determine potential and actual capabilities (Mitra 2006, 236). The

concept of utility in economics is used to represent units of satisfaction or happiness in a subjective sense. The capabilities approach replaces utility with *capability*, described as "opportunities to achieve particular states of being or to undertake particular activities" (Burchardt 2004, 737). In other words, capability is the existing practical opportunities and resources that will allow the individual to achieve a desired level of well-being (Mitra 2006, 238). Traditionally, wealth is used as a proxy for utility because, in theory, wealth and income provide greater access to resources and higher standards of living. Thus, it is understood that "inequality in society is to be judged by the distribution of income, and the development of countries is to be measured by growth in national income" (Burchardt 2004, 737). However, Sen recognized that income is an inadequate measurement of utility, since certain people, particularly those with health concerns, require more income and resources to attain a satisfactory level of well-being. For example, patients with chronic conditions may need *more* income than others to maintain their health. Medications, hospital bills, and medical supplies deplete the income that could be applied to other resources, such as food or housing. Overall, as Tania Burchardt notes, "not everyone converts income into utility at the same rate" (Burchardt 2004, 737).

There are several strengths of this approach. First, nothing within Sen's construction of capability necessitates a measurement or definition of disability. Disability and functionality are intentionally omitted from the analysis. The focus on resources and subjective interpretations of well-being allow for more pluralism in application, whether it is used to assess the needs of those in poverty, those with disabilities, etc. The approach inherently discourages the attachment of value to ability; instead, it recognizes that the gaps between potential and actual achievement are matters of resource availability, and not an inadequacy on the part of the individual.

As Burchardt argues, critics of this perspective may claim that it is far too subjective and individualistic; on the contrary, the capabilities approach is able to take external societal constraints into account, which lends *more* objectivity to the framework (Burchardt 2004, 745). The recognition that inequalities in well-being result from not only the uneven distribution of monetary resources, but also differences in capability and access to goods, places the responsibility on the public to remove social and environmental barriers. The capabilities approach is thus a very useful tool for the study of economic inclusion in international development initiatives. Although the approach is quite compatible with the social model as an economic counterpart, since it does not explicitly discuss the social ramifications of disability, it offers little direction in terms of political engagement with the disability identity.

## The Social Model

The social model of disability (known among other literature as the sociopolitical model, the minority group model, the independent living model, or the "radical democratic approach") is understood as a backlash from the disability community against the medical/charity models (Smart 2009, 7). The model's name and principles have their origins in the disability rights movements of the United Kingdom, especially the UK organization, the Union of the Physically Impaired against Segregation (UPIAS), which was founded in the 1970s (Siminski 2003, 708). UPIAS overtly challenged the common charity-model perceptions of disability by centering its purpose on the politicization of the rights and needs of PWDs. Regarded as the conceptual basis of the disability rights movement, the social model interprets disability as a social construction. Within the social model, the disability community perceives itself as a subjugated population that is disabled by society through "sensory, attitudinal, cognitive, physical, and economic barriers"(Mitra 2006, 237). PWDs are defined not by their impairments, but by the obstacles that

they face as a result of societal discrimination. The disability community is the product of greater cooperation and activism among individuals with similar disabilities, as well as empathy and collaboration *across* disabilities. The social model differs from those previously discussed. Where other models attempt to define, measure, or eliminate the effects of impairment, the social model calls for social progress. A fundamental aspect of the social model is its insistence on autonomy and self-identification for PWDs, as well as the mainstream inclusion of their history and perspectives. The construction of disability as a societal issue naturally calls for greater public attention to barriers in transportation, education, employment, access to buildings and infrastructure, information, and technology. Barriers are framed as matters of social justice and rights, and, as Burchardt aptly asserts, "the needs of people with impairments are demanded as a matter of right, rather than being handed out as charity to supposedly passive, grateful recipients" (Burchardt 2004, 737). Most importantly, the social model demands for a change in laws, attitudes, politics, and culture, a transformative project that is not present in other models.

Adam Samaha argues that "a causal account of disadvantage, however insightful, is no substitute for norms" and that "the social model of disability is not a justification for any policy goal" (Samaha 2007, 1279)." This is a valid critique and a rather poignant concern for policy-makers and policy analysts in the disability community. The challenge will be to complicate the social model so that it goes beyond simply establishing a strong social link to disability experiences; it must be able to support effective strategies to achieve its goals. That is not to say, however, that the social model is not a good starting point for disability rights activists. The political empowerment of PWDs is necessary to combat discriminatory practices, and the social model's principle sociopolitical views are compatible with this goal. As mentioned earlier, a common sense of injustice fuels the mobilization of people with all types of disabilities, and the

social model delivers the power to form coalitions which can be an asset to any civil rights movement (Smart 2009, 7).

# **Conclusion**

As reviewed above, each model of disability displays a set of strengths that are applicable to particular scenarios. While the medical model and the International Classification of Functioning, Disability, & Health are useful as tools of classification in medical research, the Nagi and the Capabilities models follow more holistic and functional approaches, which can be applied to international development. Given that the CRPD's fundamental purpose is to protect the *rights* of persons with disabilities, medical or needs-based approaches are unsuitable frameworks for the conceptualization of disability. The social model offers the broad and inclusive language necessary for the rights-based focus of the convention; therefore, it is appropriate that the CRPD incorporated the principles of the social model.

# Disability in International Law: The Value of the UN Convention on the Rights of Persons with Disabilities

The decision in 2001 by members of the United Nations General Assembly to propose international instruments to protect the rights of PWDs arose out of the denial of basic rights and freedoms to PWDs in practice, despite the universal application implied in other international human rights documents. Notwithstanding the fact that PWDs were entitled to the same protection as others, this group was cast as "'objects' of welfare and medical treatment rather than 'holders' of rights" (The United Nations 2007, 4).

In an effort to embrace the principles of the Universal Declaration of Human Rights, the International Covenants on Human Rights, and the Declaration on the Rights of the Child, the UN General Assembly adopted the Declaration on the Rights of Mentally Retarded Persons in

1971 and the Declaration on the Rights of Disabled Persons in 1975 (Hendriks 2007, 274-276). While the 1970s recognized that disability rights is a fundamental global issue, the declarations still emphasized rehabilitation and medical care over social inclusion. It was not until the 1980s that disability came to be seen as a civil rights issue (Hendriks 2007, 274-276). In 1976 the General Assembly declared 1981 to be the International Year of Disabled Persons (IYDP), in order to urge the development of strategies to promote the full inclusion of (PWDs) on regional, national, and international levels.<sup>3</sup> This ambitious goal led to the adoption of the landmark document, the World Program of Action Concerning Disabled Persons (WPA) by the UN General Assembly in December of 1982.<sup>4</sup> The WPA further solidified and framed the goals of the IYDP as a human rights issue. As a global strategy, it promoted disability prevention, the expansion of opportunities, actions against discrimination, the right to independent living, and the participation of PWDs in public life. Recognizing the importance of the implementation of the WPA, the General Assembly declared 1983-1992 to be the UN Decade of Disabled Persons. The decade resulted in the adoption of the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities in 1993. This document provided a "basis for technical and economic cooperation among states" and created a monitoring mechanism through the appointment of a Special Rapporteur who would report to the Commission on Social Development (Lord, Suozzi, & Taylor 2010, 566-567). As early as the first international review of the implementation of the WPA in 1987, participants of the WPA, including the Special Rapporteur on Disability and the governments of Italy and Sweden, pushed for a convention on the rights of persons with disabilities (The United Nations 2007, 11). Although the Standard

<sup>&</sup>lt;sup>3</sup> See Disability Information and Resource Center. "International Year of Disabled Persons." Available from http://history.dircsa.org.au/1900-1999/international-year-of-disabled-persons/.

<sup>&</sup>lt;sup>4</sup> See UN Enable. "World Program of Action Concerning Disabled Persons." Available from http://www.un.org/disabilities/default.asp?id=23.

Rules included a framework for implementation via the monitoring work of the Special Rapporteur, supporters of the convention argued that it did not have the breadth or legally binding force of a convention (The United Nations 2007, 11). Italy and Sweden's proposals to adopt a binding treaty were met with resistance from UN Member States, who argued that a convention would unnecessarily reiterate principles that already existed in other human rights instruments (Hendriks 2007, 274-276). For the time being, the Standard Rules were adopted as a legally non-binding compromise between the two parties which advised a "strong and moral commitment on behalf of States" (Hendriks 2007, 274-276).

During an NGO summit on disability in 2000, participating organizations produced the Beijing Declaration on the Rights of Persons with Disabilities, which renewed the call for an official UN treaty that would address disability rights.<sup>5</sup> Advocates claimed that despite the inclusive language of other human rights documents, PWDs continued to be marginalized and denied basic rights. A convention with a focus on disability would list legal obligations on states that are geared specifically towards protecting and promoting the rights of PWDs. In response to this pressure from advocates, Mexico proposed negotiations for such a convention in December 2001, and just 5 years later a draft convention was unanimously adopted by the General Assembly, making this the fastest negotiation of any human rights treaty.<sup>6</sup>

The Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol was adopted by the General Assembly on December 16, 2006, opened for signatures in

<sup>&</sup>lt;sup>5</sup> See World Association for Christian Communication. Beijing Declaration on the Rights of People with Disabilities in the New Century. Available from http://www.waccglobal.org/en/20004-communicating-reconciliation-in-todaysworld/757-Beijing-Declaration-on-the-Rights-of-People-with-Disabilities-in-the-New-Century.html.

<sup>&</sup>lt;sup>6</sup> See UNCRPD India. "History." Available from http://uncrpdindia.org/about/history/

2007, and entered into force on May 3, 2008, after garnering a sufficient number of signatures

and ratifications. Article 3 states the convention's eight guiding principles: <sup>7</sup>

- A. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
- B. Non-discrimination
- C. Full and effective participation and inclusion in society
- D. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- E. Equality of opportunity
- F. Accessibility
- G. Equality between men and women
- H. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

From an international law perspective, Stein and Lord recognize the potential for the

acculturation of international disability rights, as it "moves beyond the traditional frameworks of

human rights conventions, [laying] out a template for comprehensive action, providing catalysts

for socialization, and outlining integrative mechanisms designed to address the cross-cutting

nature of disability" (J. Lord & Stein 2008, 456).

Unlike previous international initiatives, the language of the CRPD advocates the social

model by promoting autonomy and self-determination for PWDs and by emphasizing the

importance of inclusion and awareness of barriers created by society-

The tactical reframing of disability as a social construction emphasizes discrimination and affronts to human dignity inherent in medical and charity models and builds the foundation for disability as a human rights issue. This issue framing captures the insight that the full participation in society for people with disabilities will be achieved not by "fixing" people, but by breaking down the *barriers* that prevent realization of equal opportunity, full participation and respect for difference (J. E. Lord et al. 2010, 568).

What separates the CRPD further from other treaties are added dimensions, such as the ethics of care, and the scale of cultural transformation that a society may need to undergo in

<sup>&</sup>lt;sup>7</sup> See UN Enable. "Guiding Principles of the Convention." Available from http://www.un.org/disabilities/default.asp?navid=16&pid=156. Internet;

order to meet its requirements. The strength of commitment to the treaty depends on the degree to which norms of *social* acceptance can be embedded enough to completely reform institutions (educational, employment, etc) as well as renovate physical infrastructure. During women's rights or civil rights movements, changes required little more than the acceptance of a new group. The CRPD, however, calls for a complete overhaul of a system in some cases, requiring much more than non-discrimination obligations. Facilities will need to be made universally accessible, and assistive technology must be developed and integrated fully with other current technologies.

This brief history presents the evolution of ideals that have been espoused by United Nations and participating member states throughout the past several decades. What began as international resolutions to recognize and address the unique needs of PWDs that were overlooked by other treaties, resulted in calls for widespread changes in perception and a rightsbased justification for the autonomy and self-determination of PWDs. Although many countries today (both signatories and non-signatories to the treaty) include legal provisions for their disabled citizens, they focus more heavily on assistance and rehabilitation without considering the broader, long-term implications of the positioning of PWDs as dependents. The establishment of the CRPD, backed by the experiences of activists and members of the disability community worldwide, lends credibility to the notion that the medical/charity model is simply not enough.

#### The CRPD and Political Participation

The recognition of the dignity of the individual is the key to the transformation of societal attitudes towards disability. Human dignity for PWDs demands the removal of ablist language and ideas that privilege certain bodies and capabilities over others. Greater and more inclusive

access to employment, education, and health care no doubt contribute to changing cultural perceptions. But where the former can be mandated by law, it is much more difficult to command and direct the latter. In order to support the human dignity of every individual, governments would need to protect the civil and political rights of their citizens with disabilities as outlined by Article 29 of the International Covenant on Civil and Political Rights (ICCPR): "Every citizen shall have the right to take part in the conduct of public affairs…to vote and to be elected at genuine periodic elections which shall be by universal and equal suffrage…to have access, on general terms of equality, to public service in his country."<sup>8</sup>

<sup>&</sup>lt;sup>8</sup> The Office of the United Nations High Commissioner for Human Rights. http://www2.ohchr.org/english/law/ccpr.htm

#### CHAPTER 3

## **REVIEW OF LITERATURE**

#### The Spread of International Human Rights Norms

Many theorists over the past several decades have attempted to explain how norms originate and the processes by which international human rights practices spread and are embedded into domestic societal norms. Three broad perspectives are reviewed in this chapter: a) Early constructivist literature that describes international norm diffusion as a top-down cascading process beginning with international institutions to societies through the work of norm entrepreneurs and the momentum of acculturation; b) "Second-wave" norm diffusion literature that re-theorizes the role and influence of local structures and activists, the domestic political and social context, and pre-existing norms; and c) The alternative perspective that norms do not originate solely from international organizations with fixed purposes, but that IOs are norm recipients themselves, influenced as much by non-state actors, NGOs, and transnational advocacy networks as recipient societies they wish to influence.

Authors Jack Goldsmith and Stephen Krasner have pressed the realist-leaning argument that international human rights bodies are less effective for transmitting norms than economic and military coercion in cases where states are reluctant to engage, and can "damage rather than promote international ideals if they are incompatible with the interests of whose support is needed for their success" (Goldsmith & Krasner 2003, 61). A growing body of constructivist literature, however, examines alternative methods based on ideational changes and socialization. Most notably, Kathryn Sikkink and Martha Finnemore set the foundation for understanding the juncture between human rights and norms on individual and group levels. Using a broad definition of a social norm – "a standard of appropriate behavior for actors with a given

identity"- the authors developed a three-phase process whereby human rights become permanently embedded into social norms: norm emergence  $\rightarrow$  norm cascading  $\rightarrow$  norm internalization (Finnemore & Sikkink 1998, 891-895). New norms almost always contend with incongruous, pre-existing practices, so as new norms emerge they must be framed within the existing normative structures (Finnemore & Sikkink 1998, 908). The authors emphasize the important role of "norm entrepreneurs," or human rights advocates who take up the task to influence political and social leaders to enact change. Norm entrepreneurs may be influential themselves, or they may work as experts on behalf of underrepresented causes. They argue that many international norms, such as women's suffrage, began as domestic norms but have spread beyond national borders via the work of entrepreneurs (Finnemore & Sikkink 1998, 897-898). In addition, the authors insist that proper international institutional platforms *must* be in place before norm entrepreneurs begin to promote new norms (Finnemore & Sikkink 1998, 899). (In the human rights case, human rights documents, conventions, and monitoring/reporting mechanisms shape the formal foundation of any effort). Most relevant to this paper's research question is their concept of norm cascading- the socialization process of spreading norms internationally, which "involves diplomatic praise or censure, either bilateral or multilateral, which is reinforced by material sanctions and incentives" (Finnemore & Sikkink 1998, 902). Sikkink and Finnemore further note that norms involving "bodily integrity and prevention of bodily harm for vulnerable or "innocent" groups, especially when a short causal chain exists between cause and effect... are particularly effective transnationally and cross-culturally," which is a very insightful observation when it comes to the rights of PWDs, whose statuses in society make them a particularly vulnerable group (Finnemore & Sikkink 1998, 907).

Elaborating on this system, Finnemore and Risse expand the conceptual process of internalization by laying out a five-stage "spiral model" of negotiation and adjustment that recalcitrant states and societies must undergo: 1) repression and activation of international-transnational networks, 2) denial by the oppressing state, 3) tactical concessions by the oppressor, 4) prescriptive status, including the signing of treaties, and 5) rule-consistent behavior (Risse, Ropp, & Sikkink, 1999, 22-31). They argue that this five-stage model explains the variation in states' internalization of human rights norms. This can be helpful in understanding the causal links between events and compliance with rights norms. For example, during the "denial by the oppressing state" phase, the authors argue that the international human rights community usually mobilizes right after the perpetration of serious human rights violations (Risse et al.1999, 22). In the "tactical concessions" phase, a norm-violating state may make only symbolic concessions or expression intentions that will appease the human rights community, leaving a significant gap between activation and full internalization.

However, as Marsh and Payne have pointed out, these earlier studies focus on repressive states, and fail to take into account differences in culture and the dissonance between certain "Western" and "non-Western" conceptions of human rights (Marsh & Payne 2007, 672). Earlier analyses also do not account for more liberal societies and non-norm-violating states that reached human rights internalization through different processes. Marsh and Payne also emphasize the idea that the concerns of military and economic pressures are not the only incentives for accepting norms. They introduce the idea of *socialization*, a process whereby human rights norms take root in the culture: "The key rests with socialization, both at the level of argumentation and at the level of enculturation. Adjustment to a country's legal code alone thus

will not effectively guarantee the protection of human rights; changes at the cultural level are just as important" (Marsh & Payne 2007, 687).

Following in this new direction, Goodman and Jinks develop the concept of acculturation, "the general process by which actors adopt the beliefs and behavioral patterns of the surrounding culture" (Goodman & Jinks 2004, 626). This method relies more on cognitive pressures such as the "social-psychological costs of nonconformity" or the "social-psychological benefits of conforming", which are more benign but equally as powerful processes that influence societies to align with transnational norms (Goodman & Jinks 2004, 640). They systematically disprove the efficacy of methods of coercion and persuasion, arguing instead that acculturation captures the complexity of the internalization process (Goodman & Jinks 2004, 625). Acculturation, by their definition, "induces behavioral changes through pressures to assimilatesome imposed by other actors and some imposed by the self. Acculturation encompasses a number of microprocesses including mimicry, identification, and status maximization" (Goodman & Jinks 2004, 626)." The most salient point of this theory is that, similar to Marsh and Payne's arguments, the adoption of structural commitments do not necessary lead to a complete observation of human rights norms, especially where there is a disjuncture between local needs and an "internationally legitimated model" (Goodman & Jinks 2004, 651). Goodman and Jinks thoughtfully address critiques of their acculturation argument, which suggest that formal commitments to international norms have no effect on concrete practices within societies. They highlight the pervasiveness of "seemingly disingenuous acceptance of human rights instruments by states with poor human rights records", which lead critics to argue that "acculturation should not guide the design of international human rights regimes since any such regime would promote only shallow reforms" (Goodman & Jinks 2008, 727). The authors defend their original thesis, suggesting that acculturation is still an important step (although, not the only step) to the spread of human rights norms within countries. However,

Because global cultural models are not sensitive to context and because the social benefit of conformity is often captured by taking modest, largely symbolic steps, isomorphism is often accompanied by ' decoupling of general values from practical action '... Many states adopt the abstract forms of world culture without closely linking these forms to actual practice. Public conformity with global norms often has little to do with private acceptance of those norms (Goodman & Jinks, 2008, 726).

They identify types of decoupling – one type, in which societies are unable to conform in practice because their governments signed onto a commitment mostly out of social and cognitive pressure; and the other type, in which states cannot conform because they lack the material resources to do so (Goodman & Jinks 2008, 730-731). In the latter case the outcome is not directly linked to acculturation, and in the former, the authors argue that acculturation is still an active and viable precondition. They rely on Jon Elster's concept of the "civilizing force of hypocrisy," which proposes that false appearances cannot be sustained over time, because external pressures to conform will influence internal groups (Goodman & Jinks 2008, 738). The remaining inconsistencies should be mitigated through policy interventions and legal structures. A crucial point, then, can be extracted from their argument: acculturation is neither a necessary nor a sufficient condition for formal commitments to human rights treaties, since these signatures can be largely symbolic and not indicative of a full social and cultural investment in the norm.

A second perspective is provided by Amitav Acharya, who introduces the notion of "localization," a process which emphasizes the role of local actors in reinterpreting and framing an international norm so as to build congruence with local beliefs, practices, and the "preexisting normative order" (Acharya 2004, 244). He insists upon the crucial role of "domestic political, organizational, and cultural variables in conditioning the reception of new global norms," demonstrating the complexity of the localization process. Unlike the previous authors, Acharya

de-emphasizes the perspective of norm diffusion as "strictly dichotomous outcomes of acceptance and rejection," a view that *displaces* former norms and beliefs with new transnational norms (Acharya 2004, 241). He thus criticizes the "first wave" scholarship on norm change in which a) "moral cosmopolitan" writers frame norms as "universal" values, b) the actors who spread these norms are only transnational agents, and c) the focus is "moral proselytism" in which conversion of ideas is preferred over contestation (Acharya 2004, 242). The proponents of the cosmopolitan method have viewed the transfer of norms narrowly as flowing from transnational agents to society, without regard to the "agency role of local actors" (Acharya 2004, 242). Acharya hypothesizes potential conditions that may affect the process of localization, including systemic changes characterized by a redistribution of power in the international realm; domestic political changes in the receiving society, including regime changes; and the international demonstration effect involves "norm borrowing through emulation, imitation, and contagion" (Acharya 2004, 247). Some factors that may enhance the likelihood of localization include the belief by local agents that the new norms could bolster existing institutions without dramatically altering their identities, the strength of previously embedded local norms, and the potential influence and credibility of local actor who can "match or outperform outside norm entrepreneurs operating at the local level" (Acharya 2004, 248). Tied to Acharya's assertions, then, are the motivations for local agents and the social and political environment that calls for change. It is worthwhile to look towards causes and factors that contribute to local, grassroots mobilization and political activism among norm-recipients.

In 1993 Ted Gurr was among a group of writers who recognized a relationship between relative deprivation and political mobilization. He argued that "deep-seated grievances about group status" and the "situationally determined pursuit of political interests" motivate civil

conflict and rebellion among communal groups (Gurr 1993, 166-167). These grievances arise from poverty, economic gaps, the loss of autonomy, or discriminatory treatment against a particular cultural group that holds a group identity – "Economic disadvantages, especially those associated with discrimination and poverty, are consistently correlated with economic and social grievances and with demands for greater political rights" (Gurr 1993, 188). According to Gurr, both the grievance and the group identity must be strong in order to incite political mobilization against state authorities. However, when grievances are too deep and the group identity is too strong without structure or discipline, the chances of spontaneous and counterproductive violence increases (Gurr 1993, 188). When groups are organized, Gurr argues, opportunity structures within political systems help to determine the strategy that communal groups will follow (Gurr 1993, 183).

The work of Robert Benford and David Snow builds upon theories of social movements by examining the "politics of signification," or framing, by movement actors. Framing is the process through which actors are "actively engaged in the production and maintenance of meaning for constituents, antagonists, and bystanders or observers" (Benford & Snow 2000, 613). Benford and Snow's conceptualization of framing illuminates the work of organizers and political entrepreneurs who work to mobilize aggrieved populations. This suggests that social movement messages are not organically or arbitrarily formed, but are meticulously crafted to reinterpret occurrences and transmit a certain image that would captivate greater attention. In other words, frames "mobilize potential adherents and constituents, to garner bystander support, and to demobilize antagonists" by "render[ing] events or occurrences meaningful" (Benford & Snow 2000, 615).

Finally, writers such as Alain Touraine, Charles Tilly, Jeff Goodwin, and Alberto Melucci recognize a dramatic shift in social movements in the 20<sup>th</sup> century, from material and economic concerns to movements grounded in culture. For example, Touraine defines social movements as "organized conflicts or as conflicts between organized actors over the social use of common cultural values" (Touraine 2002, 90). As an example, he further clarifies,

both the working class and entrepreneurs accept industrial progress and rationalization but conceive it in different social terms. They share the same values but disagree about the social use of these resources and cultural orientations (Touraine 2002, 90).

Moreover, Touraine argues that today's movements no longer challenge established political boundaries, but instead confront the by-products of globalization (Touraine 2004, 717). Globalization has led us from a "post-industrialist" society to an "information and communications" society. In particular, he notes that the focal points of movements today are not social in nature but ethical, as with the contested meaning of human rights (Touraine 2004, 722). To signify the "displacement of conflicts towards a symbolic level," Touraine suggests that the phrase "cultural movement" should replace "social movement" (Touraine 2004, 722).

A final perspective departs from the previous two in suggesting that norms do not flow only from international organizations (IOs) outwards (from core to periphery). Susan Park suggests that the norm diffusion literature thus far has placed too much emphasis on the study of international organizations as "norm transmitters within the international realm" (Park 2006, 343). She argues that this type of scholarly work insufficiently explains how and from where some norms come to be part of the structure and mission of IOs before they are diffused, and how they themselves are "taught interests," much like the states and societies that they are designed to influence (Park 2006, 345). Park cites, Finnemore and Sikkink who have also admitted that "scholars demonstrating how global norms influence states sometimes overlook the fact that international norms have to come from somewhere and may not identify feedback effects from local agents onto global structures" (Park 2006, 344). Such realizations raise questions of whether IOs are necessarily norm makers themselves, or simply operate as norm diffusers. Drawing from the ideas of Checkel and Grigorescu, Park puts forward the idea that IO are not simply influenced by the rationalist needs of its member states, but also by "the social structure in which IOs exist and operate which includes both states and non-state actors" (Park 2006, 353). Following this vein Park suggests that norms sometimes emerge through socialization by non-state actors, NGOs, and transnational advocacy networks, which set the tone and identity of the IO (Park 2006, 353 and 358).

The three divergent perspectives above form the basis of my informal hypotheses, which will be presented as causal mechanisms. Despite the similarities between the United States and India in terms of their size, democratic ideals, large economies, and their active civil societies, the two countries followed unique and labyrinthine routes to arrive at their current statuses. The aim of this literature review is to assess these theories against the processes observed in the case studies for clues about the way that disability rights norms have spread, with the hope that they may be applied to future cases as well.

#### **CHAPTER 4**

## **RESEARCH METHODOLOGY**

The following sections will describe the objective of the thesis, as well as outline the research method that will be used to explore the theories reviewed in the literature.

#### **Research Question**

The thesis will investigate the question, "Which factors explain variations in the domestic promotion of political participation and social inclusion for persons with disabilities, as exemplified by the language of the social model of disability in the CRPD?"

## **Research Type and Parameters**

This exploration will be both heuristic and disciplined configurative in nature. The thesis will draw from constructivist literature that addresses the socialization and acculturation of human rights norms. While disability rights falls under the overarching theme of human rights, the paper argues for the need to investigate new causal paths leading to the domestic promotion of disability rights, which may potentially be differentiated from other processes of acculturation. Because discrimination against PWDs largely stems from a collective perception of the community as deserving yet incapable (or pitiable) individuals, the bias is not always overtly antagonistic, but is often expressed through patronization or indifference on a structural level. Therefore, the rights of PWDs may be distinguished as different from the rights of other marginalized groups. This feature of discrimination may reveal new, unique, or alternative variables in the study of how the human rights of PWDs can be secured. The results of the investigation may serve to confirm and validate previous theories, thus demonstrating that the acculturation process for disability rights operates in the same way as other human rights. Or, the research may uncover new variables and pathways that would be useful to disability rights

policy-makers. At the very least, the study should contribute to theories on disability in international politics by illuminating causal links among political and social variables associated specifically with disability – an area that has received very little attention in the IR field.

The primary fields for this research will be international human rights norms, norms embedding, and disability rights. The research objective will rely on the framework established by the CRPD and the social/sociopolitical model of disability. The unit of analysis will be the state, since the research question compares and addresses the overall performance from state to state. However, as explained in Chapter 1, the qualitative case study research will require withincase analyses, examining specific actors, events, and organizations that contribute to the process. The time frame of the research will encompass the evolution of disability norms over the past four to five decades, after official international human rights documents were launched and recognized, and when large-scale human rights activism began to emerge. The case studies will trace the historical events that led to either success or failure in the promotion of the social model (which is discussed under the "Dependent Variable" section of this chapter).

#### Causal Mechanisms

Based upon existing theories about the acculturation of norms, the thesis will explore three processes, rather than formal hypotheses. One suggests that socially and politically inclusive government initiatives for PWDs in a democratic state are achieved through a process of acculturation which involves solely a top-down cascading of international human rights norms via the work of external norm entrepreneurs. Another process suggests that norms are diffused from international organizations with the concerted effort of local activists within the context of existing norms and domestic concerns. In such cases, normative frameworks should already exist to complement the received norms. Therefore, it may be necessary that certain precursors of the new norms are already present. The third process identifies transnational actors and advocacy networks as the origin of norms, before they are projected onto international organizations (in this case, the United Nations), which then diffuse the norms to states.

## Independent Variables

The independent variables in this paper are democratic government and a strong economy - characteristics of states that would facilitate the practice and promotion of internationally recognized human rights standards. As a guide to democracy, the 2010 Economist Intelligence Unit report offers a snapshot of the current status of democracy within states across the world. It ranks countries by their level of democracy according to the electoral process and pluralism, the functioning of the government, political participation, political culture, and civil liberties (*The Economist: Democracy Index*, 2010, 3). As a guide to the strength of states' economies, this research uses 2010 statistics on GDP from the World Bank's World Development Indicators Database.<sup>9</sup> Both of these sets of statistics are used to select and justify the case studies for this paper.

Numerous studies have documented and analyzed the links between poverty and disability (Parnes et al., 2009).<sup>10</sup> Disability is most prevalent and least addressed in developing countries, due to insufficient health care, employment, and social security, all of which can be traced to resource constraints. Therefore, it is understandable that underdevelopment will pose very real challenges to providing adequate support to marginalized populations, and would have definite effects on the ways that governments are able to prioritize social welfare in their agendas.

<sup>&</sup>lt;sup>9</sup> See World Development Indicators Database, The World Bank.

http://siteresources.worldbank.org/DATASTATISTICS/Resources/GDP.pdf

<sup>&</sup>lt;sup>10</sup> See also (Foley & Chowdhury, 2007) and (Palmer, 2011)

The theoretical relationship between human rights and democracy, on the other hand, has been more tenuous, less defined, and more contested. Scholars and practitioners have generally taken democracy for granted as complementary to the global spread of human rights. Michael Goodhart has shown in his work that "human rights are a necessary condition for global democracy" (Goodhart 2008, 396). He concedes that democracy as a concept is still vague, and has been conflated with any concept or practice that is considered to be liberal. Despite this, most definitions of democracy express equality and freedom as fundamental principles, and these require constraints on the government so that individuals may "deliberate, influence, and contest political outcomes and processes, enabling them to shape the terms of their collective interactions and enterprises and to hold government to account" (Goodhart 2008, 396). At a minimum, respect for human rights is necessary to accomplish these goals; therefore, respect for human rights are necessary for a successful democracy. But, according to Anthony Langlois, the reverse is also true. He argues that democracy is absolutely necessary to fully observe human rights practices, because they "both share the philosophical ontology of liberalism, and...the observance of human rights is implicit within the idea of a properly functioning democracy" (Langlois 2003, 1013). As evidence of this, he cites the International Covenant on Civil and Political Rights (ICCPR), which includes, as its basic principles, the rights to equal and individual freedom and political participation.

There are certain assumptions regarding conceptual definitions and relationships which should be explicitly addressed before the case studies are presented. First, the paper will build upon discussions regarding the links among democracy, wealth, and human rights, by authors Michael Goodhart, Anthony Langlois, and others. The thesis will assume that disability rights will have the firmest establishment in democratic states, and that wealthier countries will have

greater resources to uphold their duties to promote human rights and prevent human rights abuses.

## The Dependent Variable

The dependent variable should be a measurement of the domestic promotion of the social model via the support for political participation and social inclusion of PWDs. "Domestic promotion" can be a vague and broad idea, and therefore, difficult to measure or define comprehensively. For the purpose of this thesis, the language in laws will be used as proxies for "domestic promotion." Ideally, in a democratic society laws and government schemes would reflect the views and attitudes of the general population. However, in many cases the inclusive or exclusive nature of the laws is more of an indicator of the attitudes of lawmakers and those who are in power to represent the interests of society. The language of disability-related laws will thus reveal elite perspectives of the needs of the general population.

Drawn from the guiding principles of the CRPD, an indication of inclusivity in laws would:

a) Explicitly prohibit discrimination on the basis of disability when it comes to access to public services, education, employment, transportation, and especially, social and political participation;
b) Embrace the social model and reflect in their language an inherent respect for the disability identity. In other words, attitudes would avoid a "medical model" understanding of disability as a condition that should be rehabilitated. Access to preventative and rehabilitative medical care are certainly crucial from a public health perspective, but they do not speak to the civil and political rights of PWDs; and

c) Leave the meaning of disability open to subjective interpretation. This is another demonstration of the application of the social model in disability laws. Laws that seek to

circumscribe "disability" with medical terminology undermine the concept of disability as a social identity. Self-identification is as crucial for the civil rights of those with disabilities as one's right to self-identify race, gender, or sexuality. A blank categorization of disability within laws is an imposition that is incompatible with the social model's principles.

### Global Examples of Variation in the Dependent Variable

Beyond India and the U.S., there are other wide variations in the language and implementation of disability laws established by countries that have pledged to uphold the principles of the CRPD. A strong example of anti-discrimination law is Australia's Commonwealth Disability Discrimination Act (DDA) of 1992. Australia signed and ratified the CRPD by 2008. The DDA addresses discrimination against PWDs in employment, education, access to services, goods, and premises, and even distinguishes the harassment and victimization of PWDs as an offense punishable by imprisonment of up to six months (Center for International Rehabilitation 2005, 127).

The People's Republic of China signed the convention in 2007 and ratified in 2008. Although China's disability law, the 1991 law of the People's Republic of China on the Protection of Disabled Persons, is wider in focus than the ADA, according to the 2005 Center for International Rehabilitation's report on country disability laws, the language that defines disability is highly medical and does not reflect the inclusive intent of the CRPD (Center for International Rehabilitation 2005, 145). For example, disability is defined as "abnormalities, the loss of a certain organ or function (psychologically, physiologically, or in anatomical structure), or the loss wholly or in part of the ability to engage in activities in a normal way" (Center for International Rehabilitation 2005, 145). The casting of disability in terms of "normal" and "abnormal" upholds ablist language, which is counter to the inclusive objectives of the CRPD,

whose guiding principles include "respect for difference and acceptance of persons with disabilities as part of human diversity and humanity."<sup>11</sup>

The Czech Republic is another example of a country that has signed and ratified the CRPD but whose laws do not convey the convention's message. Although accessibility provisions are written into several laws, the "purpose of the various provisions on persons with disabilities is to improve their living conditions" and does not address equality of treatment, a core principle of the CRPD (Center for International Rehabilitation 2005, 156).

A final example, Egypt, which signed and ratified the convention by 2008, established the law on Rehabilitation of Disabled Persons. Although the law includes provisions to assist PWDs with vocational rehabilitation, its purpose is "to give people with disabilities access to training and employment, rather than to eliminate any discrimination against them," which does not adequately address the principle of anti-discrimination in the CRPD (Center for International Rehabilitation, 2005, 158). These few examples demonstrate variation and inconsistencies among signatories of the CRPD in practice, which point to the problematic phenomenon of accountability and non-compliance.

Another unique perspective is that of the United States which has *not* ratified the convention, and therefore, is not obligated to abide by its principles. Despite the fact that the ADA reasonably reflects the principles of the CRPD, the lack of support for the convention in writing sets a poor example and may send a troubling message to the international community indicating that the United States perceives itself as above international monitoring.

<sup>&</sup>lt;sup>11</sup> See "Guiding Principles of the Convention," United Nations Enable. http://www.un.org/disabilities/default.asp?navid=16&pid=156

#### Research Methods: Mill's Method of Difference and Process Tracing

The author will first utilize the method of difference approach (also known as most similar case studies) and then process tracing, to investigate the research question. The method of difference analyzes two cases that are similar in every independent variables but one, and which display different outcomes (dependent variable). The logic is that the variation in the dependent variable is caused by the single independent variable that differentiates the two cases. In the example of this study, if D = Democratic, and W = Wealthy, the aim is to arrange the research so that:

Case1: D + W + Unknown Process A = Poor domestic promotion of the social model Case2: D + W + Unknown Process B = Successful domestic promotion of the social model

In the conceptualization above, wealth and democracy are not only independent variables, but in terms of case study research, they act as control variables to isolate the "Unknown Processes." The "Unknown Processes" A and B, once uncovered, will be evaluated to discover whether the three causal mechanisms described above are of any value in explaining the processes observed. In other words, the paper argues that wealth and democracy are necessary components but not sufficient components and the "Unknown Process" of acculturation may reveal practices that correlate to any of the causal mechanisms reviewed. To gain a more nuanced understanding of these, the author will trace processes in each country chronologically and thematically to understand the social and cultural atmosphere, the key actors, and the events that transpired before the establishment of disability laws. Process tracing should shed a new light on the causal chain that influences disability-related laws and government initiatives.

## Case Study Selection & Justification

India and the United States are chosen as case studies because they are well-suited for the research methods outlined above. First and foremost, they display variation in the dependent variable – the language and purpose of disability laws. The United States' ADA and other disability-related laws demonstrate a more inclusive language, whereas India's law exhibits a more medical model perspective. Below is an assessment of the laws and initiatives within each government, in accordance with the definition of the dependent variable stated above. Second, both India and the United States are classified as democracies according to the Economist's Democracy Index 2010, with the United States ranked at 17 and India ranked at 40 out of the 165 states examined worldwide (*The Economist: Democracy Index*, 2010, 3-4). Finally, according to the 2010 World Bank World Development Indicators, the United States and India are among the top five countries with the highest GDP.<sup>12</sup>

Apart from wealth and the level of democracy, similar factors between the two countries make India and the United States particularly suitable as case comparisons. Both India and the United States have large, politically and culturally diverse countries. India's population is nearly four times that of the United States, yet it is important to note that the U.S. is the third highest populated country in the world after India, with China as the most populous (Population Reference Bureau, 2010, 2). Both countries are comprised of a collective union of states that share the responsibility of government with the central or federal government. Finally, both countries have histories of civil rights protests and movements, which make for a complementary comparison.

<sup>&</sup>lt;sup>12</sup> See World Development Indicators Database, The World Bank. http://siteresources.worldbank.org/DATASTATISTICS/Resources/GDP.pdf

In terms of international engagement, the United States and India are particularly interesting because the United States has *not* ratified the CRPD as of early 2012, although American activists were instrumental in the formal development of the treaty. Social Model norms have transferred from the countries that embrace them within their laws, such as the United States, to the United Nations. Curiously, however, the United States is not a full party to the convention. On the other hand, India ratified the CRPD in 2007 and is now in the process of addressing the discrepancies between the treaty and India's 1995 law.<sup>13</sup> It is worthwhile to evaluate the processes that led to the original wording of the PWD act, as well as the steps that influenced the decision to finally revise the law.

# The United States

The following evaluates the disability laws of the United States according to the threecriterion definition of the domestic promotion of the social model:

a) The purpose of the Americans with Disabilities Act (ADA) as amended in 2009 is to extend

the rights outlined in the Civil Rights act of 1964 to PWDs. It prohibits discrimination in

employment, state and local government activities, public transportation, public

accommodations, and telecommunications relay services.<sup>14</sup>

b) The language of the ADA maintains a neutral attitude towards disability, and focuses more on discrimination rather than disability itself. The ADA finds that

...historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem; ... discrimination against individuals with disabilities persists in such critical areas as employment, housing, public accommodations, education, transportation, communication, recreation, institutionalization, health services, voting, and access to public services;...unlike individuals who have experienced discrimination on the basis of race, color, sex, national origin, religion, or age, individuals who have experienced

<sup>&</sup>lt;sup>13</sup> See Office Memorandum, April 30, 2010, Ministry of Social Justice & Empowerment, Government of India. http://socialjustice.nic.in/pdf/om-pwd.pdf

<sup>&</sup>lt;sup>14</sup> See "A Guide to Disability Rights Laws."Civil Rights Division, U.S. Department of Justice http://www.ada.gov/cguide.htm

discrimination on the basis of disability have often had no legal recourse to redress such discrimination;... individuals with disabilities continually encounter various forms of discrimination, including outright intentional exclusion, the discriminatory effects of architectural, transportation, and communication barriers, overprotective rules and policies, failure to make modifications to existing facilities and practices, exclusionary qualification standards and criteria, segregation, and relegation to lesser services, programs, activities, benefits, jobs, or other opportunities...<sup>15</sup>

The purpose of the ADA is stated as

(1) to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities;

(2) to provide clear, strong, consistent, enforceable standards addressing discrimination against individuals with disabilities;

(3) to ensure that the Federal Government plays a central role in enforcing the standards established in this chapter on behalf of individuals with disabilities; and

(4) to invoke the sweep of congressional authority, including the power to enforce the fourteenth amendment and to regulate commerce, in order to address the major areas of discrimination faced day-to-day by people with disabilities.<sup>16</sup>

The neutral attitude towards disability in the selections above is compatible with the social model

because it does not place a value on physical ability or function, and emphasizes protection

against discrimination.

c) The definition of disability in the ADA is nonspecific and centers on activities, which leaves

impairments to the interpretation of individuals. It defines disability as "a physical or mental

impairment that substantially limits one or more major life activities of such individual," where

major life activities include

caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working... functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions.<sup>17</sup>

<sup>&</sup>lt;sup>15</sup>See Americans with Disabilities Act of 1990, as Amended http://www.ada.gov/pubs/adastatute08markscrdr.htm <sup>16</sup> *ibid.* 

<sup>&</sup>lt;sup>17</sup> See the Americans with Disabilities Act of 1990, as amended http://www.ada.gov/pubs/adastatute08markscrdr.htm

To conclude, the disability laws in the United States are positive examples of legislation that reasonably fulfill the criteria for the "successful" domestic promotion according to the threepart definition. The ADA provides anti-discrimination measures to protect the civil rights of PWDs, takes a neutral stance on the nature of disability (without emphasis on the rehabilitation of impairments), and allows for a broad interpretation of disability. The United States, therefore, serves as an appropriate study of a case that is compliant with the CRPD even though it has not yet ratified the treaty.

# <u>India</u>

The following evaluates the disability laws of the India according to the three-criteria definition of the domestic promotion of the social model:

a) Chapter V of the 1995 Persons with Disabilities Act (Equal Opportunities, Protection of Rights and Full Participation Act) ensures "that every child with a disability has access to free education in an appropriate environment till he attains the age of eighteen years."<sup>18</sup> Subsequent chapters endeavor to increase access to employment opportunities; enact affirmative action schemes in businesses, residences, schools, research centers and recreation; and improve access to buildings and other infrastructure.<sup>19</sup>

Although the act makes provisions to increase access to employment, education, and transportation, it makes no mention of exclusion or discrimination. Moreover, the Act does not explicitly cover the rights to political participation or voting.

<sup>&</sup>lt;sup>18</sup> See the Persons with Disabilities Act of 1995, National Human Rights Commission, New Delhi, India http://nhrc.nic.in/publications/Disability/Annexure-1.html
<sup>19</sup> *ibid*.

b) Chapter IV of the Act is titled "Prevention and Early Detection of Disabilities."<sup>20</sup> This chapter urges governments and local authorities to

undertake or cause to be undertaken surveys, investigations and research concerning the cause of occurrence of disabilities; promote various methods of preventing disabilities;...screen all the children at least once in a year for the purpose of identifying "at-risk" cases; ... create awareness amongst the masses through television, radio and other mass media on the causes of disabilities and the preventive measures to be adopted.<sup>21</sup>

As a major component of the act, the prevention of disabilities does not align with the social model disability, which embraces diversity in ability.

c) The PWD Act delineates specific boundaries for the definition of disability. In the Act "disability" may refer to "(i) Blindness; (ii) Low vision; (iii) Leprosy-cured; (iv) Hearing impairment; (v) Loco motor disability; (vi) Mental retardation; (vii) Mental illness."<sup>22</sup> Other categorizations of disability include

'hearing impairment', which means loss of sixty decibels or more in the better year in the conversational range of frequencies;... 'Leprosy cured person' means any person who has been cured of leprosy but is suffering from-(i) Loss of sensation in hands or feet as well as loss of sensation and paresis in the eye and eye-lid but with no manifest deformity;(ii) Manifest deformity and paresis; but having sufficient mobility in their hands and feet to enable them to engage in normal economic activity; (iii) Extreme physical deformity as well as advanced age which prevents him from undertaking any gainful occupation, and the expression 'leprosy cured' shall be construed accordingly;

The Act continues with similar definitions of the remaining listed disabilities, with language that is not attuned to the spirit of the social model, including phrases like "suffer," "cured," and "subnormality of intelligence." Such language implicitly reflects the lawmakers' perception of incapacity with relation to disability.

 $<sup>^{20}</sup>$  ibid.

<sup>&</sup>lt;sup>21</sup> See the Persons with Disabilities Act of 1990, Disability India Network

http://www.disabilityindia.org/pwdacts.cfm#ch8

<sup>&</sup>lt;sup>22</sup> See the Persons with Disabilities Act of 1990, National Human Rights Commission, New Delhi, India http://nhrc.nic.in/publications/Disability/Annexure-1.html

To conclude, India is a suitable case study that reveals a departure from the United States in its legal treatment of disability. Although the PWD Act mentions accessibility and inclusion with respect to education and employment, anti-discrimination is not a focal point. Second, the prevention of disability does not reflect the CRPD's view of disability as an element of human diversity. Finally, the language used to clarify and define disability is inconsistent with the social model's opposition to medical language. In spite of the fact that India is a signatory to the CRPD, the 1995 law is not consistent with the values of the treaty.

# CHAPTER 5

# THE DISABILITY RIGHTS MOVEMENT IN THE UNITED STATES

"It did not matter if disability came at birth or later, whether the person was rich or poor, or even if it did not interfere with one's accomplishments. To be disabled meant to fight someone else's reality. Other people's attitudes, not one's own disability, were the biggest barrier." Joseph Shapiro (Shapiro 1994, 112)

## Identifying the Need

Like other American civil rights movements, the disability rights movement, from the mid-20<sup>th</sup> century onward, recognized the need for PWDs to integrate into society, and the right to receive equal opportunities in education and employment along with the mainstream population. As with civil rights leaders before them, people with disabilities understood that political activism, via "grass-roots campaigning activity, self-organisation, direct democracy, and direct action," was the ultimate path to their goal (Shakespeare 1993, 253). Integral to their objective was to first challenge paternalistic attitudes towards the disabled in American society – the poster-children for disability cures, fund-raising telethons, and charity drives – which embraced the medical model's view of disability as a tragedy (Fleischer and Zames 2011, 10-11). The American disability rights movement depended upon its image as a large, powerful, proud, and autonomous group of citizens and consumers. Autonomy and self-determination was always a crucial theme, as exemplified in the independent living movement, which emphasized that people with disabilities understand their own needs better than medical professionals or rehabilitation specialists (Shapiro 1994, 52).

Authors Fleischer and Zames cite Lex Frieden, the former director of the National Council on Disability (NCD), in his assessment of the movement. Frieden identifies two "strands" of the American disability rights movement. One strand incorporates people with disabilities who live independently without the need for personal assistance. This group focuses

on equal access to "transportation, education, employment, housing, and healthcare" (Fleischer and Zames 2011, 201). The second strand includes individuals with severe disabilities who require personal assistance and who stress their right to receive services that will enable them to live independently (Fleischer and Zames 2011, 201). Fleischer and Zames identify a third strand which comprises institutionalized individuals with severe disabilities who emphasize the right to de-institutionalization (Fleischer and Zames 2011, 201).

The movement did not assemble overnight. Nor did it commence with instinctive group solidarity and a common purpose. It began with sporadic protests and maneuvers by individuals and small groups who had experienced discrimination first-hand. As the NCD reports in *Equality of Opportunity: The Making of the Americans with Disabilities Act*,

Even though most persons within the disability community shared similar goals—such as education, jobs, dignity, access, and equal participation—the wide variety of disabilities meant that subgroups of the disability community did not always seek the same objectives. The activities of one group were not only often unknown to others, at times they ran counter to the efforts of others (Young and the National Council on Disability 2010, 18).

Yet, the tireless coalition-building among a vibrant group of disability activists as well as national and local organizations proved to be fruitful, when a poll by Louis Harris and Associates in 1985 revealed that seventy-four percent of disabled Americans claimed to share a common identity with other people with disabilities (Shapiro 1994, 25). Moreover, among the participants, forty-five percent perceived themselves as a minority group comparable to racial minorities, which demonstrates that a strong civil rights consciousness had developed among PWDs through the decades (Shapiro 1994, 25).

When the Americans with Disabilities Act (ADA) passed, an estimate by the Institute of Medicine totaled the number of Americans with disabilities to be 35 million, where disability was defined broadly as a condition that interferes with daily activities (Shapiro 1994, 6). This constituted a large portion of the population, indicating that one in every seven Americans selfidentified as a disabled person. Several indicators exhibited the socioeconomic discrepancies between the disabled and non-disabled communities as a result of social barriers. Joseph Shapiro, in his celebrated book No Pity: People with Disabilities Forging a New Civil Rights Movement, cites a March 1986 Harris poll administered to determine why the disability community remained so isolated from the public. Among the group of disabled respondents, fifty-nine percent did not go outside for fear of being mistreated, forty percent claimed that physical barriers restricted their access to public places, and sixty-six percent were unemployed (Shapiro 1994, 106). Later in1994, a Harris poll revealed that only one-third of disabled people held jobs, and that seventy-nine percent of the remaining participants were eager to work, but were prevented from working due to discrimination in hiring or a lack of transportation (Shapiro 1994, 27). The evidence of discrimination was clear, as well as the need for legislation to address it. Justin Dart, a prominent disability activist and former member of the NCD, toured every state in the U.S. to speak with PWDs. Contrary to the expectations of other officials in the Council, Dart found that the most pressing issue among this group was the recognition and protection of their rights, above securing health benefits or welfare (Shapiro 1994, 108).

What is unique about the disability movement is its diversity. The heterogeneity of the disability community is at once its strength and its weakness, because although it has a strong potential for cross-disability coalition-building, it also has no single leader to lend visibility to the movement, and little commonality besides comparable forms of discrimination and prejudice experienced by its members. The passage of the ADA, which embraces the social model and extends civil rights protection to PWDs, was not the final struggle for the disability movement, although it was certainly a major milestone. There is still a long road ahead where the disability

community will explore the full potential of the law and the enforcement of disability-inclusive policies. But Shapiro insightfully points to the next challenge, which is to ensure that nondisabled Americans understand the way in which the disability community conceptualizes disability. He comments

The disability movement would seek civil rights protection in the Americans with Disabilities Act, but the act would not demand affirmative action programs or guarantee equality of results. Disabled people would optimistically argue that all they needed was integration and an equal opportunity to achieve...Will nondisabled Americans understand how disabled ones are reexamining what it means to have a disability? Will disabled people get a true shot at being fully included citizens? (Shapiro 1994, 104)

Other challenges ahead include the conceptual and practical negotiations between PWDs and health care professionals who are charged with the responsibility to care for their patients. As

Shapiro further notes,

To win passage of the ADA, disabled people had to forge historic alliances not only among different disability groups and politicians but with the professionals who had cared for them for so long...Many professionals felt threatened by the new group consciousness of disabled people. They were afraid or reluctant to share decision making or give up power that, in some cases, might even threaten their own jobs (Shapiro 1994, 127).

Several conditions and historical trends unique to the disability experience created a

fertile ground for a common political disability identity to take root, and which, ultimately, led to the passage of the Americans with Disabilities Act (ADA) in 1990. Among the broad themes are: war and the increasing prevalence of disability; the political environment of the 1960s, which included the intensification of political consciousness among university students; the unique ability of disability issues to transcend party politics; disability in the lives of key politicians; and, the perspective of an individualistic, competitive, and consumerist culture.

#### Catalysts of Change

## The Consequences of War & the Prevalence of Disability

Certain socioeconomic conditions and historically significant events of the 20<sup>th</sup> century created an environment that forced disability to become part of American public dialogue. Experimentation within the eugenics movement and the basic tenets of social Darwinism substantiated the medical model and produced a hostile social setting for those with disabilities in the 19<sup>th</sup> century (Shapiro 1994, 61). The beginning of the 20<sup>th</sup> century, however, saw more attention towards the welfare of exploited populations, with the rise of industrialization. "Muckraking" journalists documented the plight of thousands who acquired disabilities as a result of industrial accidents (Young and the National Council on Disability 2010, 6). This raised initial awareness about workers' rights, workplace conditions, and the nation's obligation towards PWDs. As a result, in 1918 and 1920 Congress passed rehabilitation programs that provided funding for vocational training (Shapiro 1994, 61).

Another major factor was the outcome of multiple wars – World War I, World War II, the Korean War, and the Vietnam War- on American soldiers. The thousands of wounded soldiers who returned home after each war sparked a national sense of gratitude and obligation to provide health care and vocational services to disabled veterans. The federal government established the Veterans Bureau in 1921, one of the first government welfare programs designed to address the specific needs of disabled veterans (Shapiro 1994, 62). During the Depression in the 1930s, disabled veterans took matters into their own hands and organized to protest discrimination. The League for Physically Handicapped, comprised of three hundred pensioners with polio and cerebral palsy, occupied the Works Progress Administration office in the nation's capital to object to program discrimination against PWDs (Shapiro1994, 63-64). In addition to the WPA,

Franklin D. Roosevelt signed the Social Security Act of 1935 as part of the Second New Deal, establishing for the first time a program to assist disabled adults (Shapiro 1994, 62).

World War II ushered in yet another period of national disability consciousness, and a "renewed national dedication to helping this most highly visible population of disabled Americans" (Shapiro 1994, 62-63). Disabled veterans had a particularly large impact on the American psyche, due not only to their visibility in large numbers, but also because of the honor and deference garnered by the veterans for their service. Their status as war veterans distinguished them in the minds of Americans and created a space to re-conceptualize the meaning of disability. Moreover, as Shapiro notes, those soldiers who acquired disabilities during war received a rare, first-hand glimpse of the drastic transition from being a respected, able-bodied individual, to becoming a second-class citizen, and many "saw no reason suddenly to forfeit the first-class citizenship they had grown up to expect as a birth right" (Shapiro 1994, 144). They began to advocate for their rights, starting with the formation of the Paralyzed Veterans of America in 1946. Other more inclusive disability organizations emerged concurrently, including the National Federation of the Blind in 1940, the National Association of Retarded Citizens in 1950, the American Council of the Blind in 1961, and the United Cerebral Palsy Associations in 1949 (Young and the National Council on Disability 2010, 7). This new awareness of the needs and barriers among PWDs points to the very beginning of a shift from the condescending perception of the disabled as unusual and unnatural, or as unfortunate victims of tragedy, to a positive recognition of their rights as human beings and as equal, deserving citizens of the country.

#### The Political Environment of the 1960s

The contentious political atmosphere of the 1960s and 1970s provided opportunities for the growth of the disability rights movement. Inspired by the philosophies and organizing techniques of the blossoming civil rights, women's, and anti-war movements, young disability rights activists began to challenge discriminatory norms that segregated them from the mainstream. For example, the independent living movement and proponents of deinstitutionalization drew from rights-based arguments, and advocated against the medical model, which "cast them as passive recipients of professional care," and instead, they "asserted their rightful place in society" (Young and the National Council on Disability 2010, 20). As the 2010 NCD identifies in Equality of Opportunity: The Making of the Americans with Disabilities Act, the disability rights movement was bolstered by the legacy of the civil rights movements in three ways: 1) it legitimated claims to protection and anti-discrimination, and proved that tactics like civil disobedience work; 2) it proved that discrimination in employment and transportation based on personal characteristics was an illegal practice; and 3) it provided a wealth of statutes and case law which could be used in future legislation (Young and the National Council on Disability 2010, 10). Hence, the civil rights movement helped to pave the way for the disability rights movement that followed.

Highly prominent among the early activists who were motivated by the political movements of the time are Ed Roberts and Judith Heumann, who both contracted polio at young ages. As a student at the University of California, Berkeley, Ed Roberts formed the Physically Disabled Student's Program (PDSP), the first student-led program to provide direct personal assistance services to students with disabilities. He and fellow activist John Hessler challenged

the discrimination inherent in university policies towards PWDs. Roberts applied concepts to the disability cause that were initially borrowed from the women's movement:

Women rejected that "anatomy was destiny" and were struggling to control their bodies. Disabled people, too, were questioning the medicalization of their lives. Particularly, Roberts noted how feminists used stereotypes about them – as the weaker, milder sex – to their advantage. The women would let their opponents fall into such tired assumptions, then catch them off guard with the force of their anger and the unassailable correctness of their demand for equality. Roberts saw that he, too, could use the charitable and protective instincts of his enemies (Shapiro 1994, 47).

In 1970 Judith Heumann founded the organization Disabled in Action (DIA) with other disability rights activists in New York City. Unlike Roberts's PDSP, DIA did not offer direct services, but worked as a *political* advocacy group for PWDs, recognizing a common theme with other civil rights movements. The DIA also used methods borrowed from the women's movement, including "consciousness-raising sessions" (Fleischer and Zames 2011, 74). To advance her cause, Heumann also knew to take full advantage of benefits of the media, whose coverage brought national attention to the civil rights movement (Fleischer and Zames 2011, 73).

Not only did the movement in its early days embrace the strategies of other civil rights movements, but members of the disability community also joined other leaders to build inclusive coalitions. The Disability Rights Education and Defense Fund (DREDF) is an organization that participated in the Leadership Conference on Civil Rights. The Conference, which began in 1980, connected civil rights leaders from a variety of movements to share a common cause. It was DREDF that led the task of bringing the concerns of the disability community to the broader civil rights movement (Fleischer and Zames 2011, 79).

However many lessons that disability rights activists drew from the civil rights movement, the political climate did not *always* work in favor of the disability community. The disability rights movement never quite achieved the prominence and public acknowledgement enjoyed by other movements. As Shapiro writes, Although its activists pointed to the black, women's, and gay rights movements as models, unlike those causes, the disability rights movement had never filled the streets with tens of thousands of protestors. It had no Martin Luther King, Jr., to bring it together, no Betty Friedan to write its manifesto. It had no unifying touchstone moment of courage or anger like the Montgomery Bus Boycott, the Freedom Rides, or the Stonewall riots...The fight for disability civil rights was a largely invisible, almost underground, movement (Shapiro 1994, 117).

There are a few explanations for the movement's slow progress. The diversity of the disability community may at times prove to be a weakness, as each of the hundreds of groups tends to focus on the immediate needs of its own disability. Moreover, since disability cuts across gender, race and class, "[persons] with disabilities generally [do] not inhabit the same physical communities that helped fuel the civil rights movement. Segregation for persons with disability [means] not only separation from mainstream society, but also isolation from each other" (Young and the National Council on Disability, 18). Therefore, even when a loose common identity exists among the spectrum of disability groups, the community does not always possess the cohesion necessary for consensus in a movement. A prime example of this type of discord was the withholding of support for the ADA by members of the National Federation of the Blind, who believed that people who are blind should reject public attempts to offer special assistance (Shapiro 1994, 126).

Finally, the aftermath of the civil rights era and the cultural backlash against the progressive movements in the 1960s, led to a shift to a conservative political climate with the election of President Richard M. Nixon in 1968 (Young and the National Council on Disability 2010, 10).

# Organizing on College Campuses

Hinging upon the political climate of the 1960s, student activists on university campuses across the United States were disillusioned by the rigid ideals of the 1950s, and organized

demonstrations to protest war and injustice, and to advocate for peace, freedom, and a more democratic society. Academic institutions became a valuable venue for such expressions of discontent, and student protests came to be an evocative symbol of the disenchantment and fragmentation among the younger American generation. Although not as widespread or well-publicized, young disability rights activists also began the exploration of their rights and freedoms on college campuses. The challenge for many students with disabilities was not only to validate their right to integrate into mainstream college life (as with women and racial minorities), but to also secure the rights to personal assistance, services, and accessible spaces that would allow them to reap the maximum benefits from their education. Shapiro and other leaders compare the relatively quiet, yet momentous, entrance of Ed Roberts to the University of California at Berkeley, with the historic moment when James Meredith was escorted into the University of Mississippi by U.S. marshals- the first African American student to be accepted into a traditionally segregated school. Both took place in the fall of 1962 (Shapiro 1994, 41).

Indicative of the politicization of the disability identity, Ed Roberts and fellow students with disabilities formed the Rolling Quads to discuss disability as a social issue in the wider context of other civil rights movements, as well as to demand accessibility and equal opportunities in education from school administrators and the city of Berkeley. Revolutionary ideas about protest and organization occupied the minds of these young activists:

In late-night bull sessions on the hospital floor, Roberts and his friends, in their wheelchairs and iron lungs, would strategize constantly about breaking down the common barriers they faced... and dissect the protests for self-determination of minority students" (Shapiro 1994, 47-48).

Their discussions were quickly translated into action. Roberts and the Rolling Quads led a protest when a university counselor attempted to evict two students with disabilities, on account of their low grades, from Cowell Hospital, an empty wing of the university hospital that was

converted into dormitories for disabled students. Although their academic performance would not have affected their enrollment had they been able-bodied students, the counselor placed unique restrictions on students with disabilities as a stipulation for receiving certain resources. Roberts argued that "it was unfair...for the freewheeling campus to apply stricter rules of behavior to a pocket of disabled students" (Shapiro 1994, 48). Therefore, he and his colleagues reached out to the media – television stations, the radio, and newspapers – to bring attention to their cause. After the counselor was reassigned, the Rolling Quads recognized that would need to ensure that PWDs, rather than bureaucratic authorities, should be in full control of the resources and funding available for them –

The Rolling Quads realized that they would have to think of themselves as consumers of state services, not as clients...Independence. Self-sufficiency. Mainstreaming. Disability as a social problem. These were the principles that guided the PDSP and the disability rights movement of which PDSP was the leading edge (Shapiro 1994, 49, 52).

The PDSP, or the Physically Disabled Students' Program, was organized by the members of the Rolling Quads to promote personal autonomy and decision-making power for students with disabilities. Roberts recognized the strength in cross-disability collaboration, as well – "It was not lost on Roberts, who was studying community organizing, that political power expanded with coalition building" (Shapiro 1994, 52). He worked to include students with various disabilities, and eventually to expand the program to non-students. This led to a milestone in American disability history – the start of the Center for Independent Living in 1972, symbolizing the birth of the independent living movement (Shapiro 1994, 53).

Berkeley was just one of several campus impacted by disability rights activism at the time. The University of Illinois also had a program for disabled students which began in 1950 as a rehabilitation plan for World War II veterans. This expanded throughout the decade to include a fraternity, an annual magazine, a much more accessible campus, and in 1961 the campus

boasted 163 disabled students (Shapiro 1994, 52). At Wright State University, Roland Sykes, who experienced a spinal cord injury, joined over twenty students with disabilities to advocate for campus accessibility (Young and the National Council on Disability 2010, 32).

One of the most memorable and groundbreaking university uprisings by students with disabilities was the protests at Gallaudet University in the spring of 1988. Gallaudet University in Washington, D.C., is the world's only university in which all programs are tailored specifically for students who are dead or hard of hearing. The students had developed a strong sense of pride of Deaf culture, and a growing resentment towards paternalistic university officials who misunderstood their cause. The protest was one of the strongest and most unified expressions of dissatisfaction among disabled students. Gallaudet University is federally chartered, and the savvy students knew to appeal to Congress for support. Their protests attracted wide media coverage and even swayed the agenda of Senator Bob Dole and Vice President George Bush, who were at the time competing for the Republican nomination for the Presidency (Shapiro 1994, 82).

# **Disability Transcends Political Affiliation**

One unique aspect of disability, exemplified clearly in American disability history, is its ability to cross and transcend partisan political lines. Among possible explanations are that disability itself affects every family and community in society, and that disability as a natural human experience can be understood by all, regardless of race, nationality, gender, class, sexuality, or political affiliation. Moreover, despite differing views on social policy and the role of the government in public welfare, politicians and lawmakers in every camp, at the very least, are able to acknowledge that disability is an issue that concerns society, whether it is viewed through the medical/charity model or the social model.

The United States presidential election of 1988 is a fitting example. It was expected that, by and large, PWDs would align with the Democratic Party, because "given that disabled people," by virtue of their poverty and dependence on government social services and welfare, were considered near monolithic in their support for any Democratic candidate" (Shapiro 1994, 124). However, when republican candidate George H.W. Bush (former Vice President of President Ronald Reagan) vowed during the 1988 Republican National Convention to "do whatever it takes to make sure the disabled are included in the mainstream," disabled voters' preferences took an immediate and sharp turn (Shapiro 1994, 125). Never before had a presidential nominee exclusively recognized the disability community as a separate, vital political group (Shapiro 1994, 125). This gave Bush an edge over his contender, democratic candidate Michael Dukakis. Louis Genevie, who worked for the market research firm Louis Harris & Associates, noticed that "disabled voters who had switched to Bush had constituted up to one-half of the four-million difference of popular votes between Bush and Dukakis...this reflected the tremendous overall shift by all voters to Bush" (Shapiro 1994, 125). The considerable margin indicated to pollsters that the disability community was "growing into an untapped constituency" (Shapiro 1994, 125).

Of course, these transitions did not occur organically. In May of 1988 disability activists met to strategically divide the presidential candidates amongst themselves, and then commit to working for each candidate to advance a statement of rights for PWDs (Shapiro 1994, 124). Moreover, the disability rights activist who undertook the Bush campaign, Evan Kemp, Jr, had already formed an understanding with the former Vice President during the Reagan administration's attempt to slash education funding for disabled students under Section 504 of the Rehabilitation Act (Shapiro 1994, 120). Ultimately, the Republican candidate's personal

experiences with disability, and the appeal to a uniquely consumerist argument, may have influenced a traditionally conservative party to bend to the demands of disability rights activists.

# Disability in the Lives of Key Political Players - The "Hidden Army"

As mentioned earlier, the prevalence of disability means that it is common for many to have an understanding of the social stigma within the disability experience, whether these are lessons from their own lives or the lives of family and friends. If one-sixth of Americans have a disability, it will inevitably influence almost every family (Fleischer and Zames 2011, 92). This powerful, shared experience has often motivated individuals with disabilities and their families to join together in support of disability rights. Disability groups that were formed by parents of children with disabilities became a driving force in the rights movement starting in the middle of the 20<sup>th</sup> century. According to Shapiro,

As more children survived disability, more parents sought to keep them from being institutionalized. They realized they shared a struggle with other parents who were also frustrated by the paltry support offered by doctors or social service agencies. Their biggest common concern was to get their children educated (Shapiro 1994, 64).

As a result of their advocacy efforts, Congress established a federal bureau for the handicapped, and began to provide education funds for children with disabilities in the 1970s (Shapiro 1994, 64). Extremely favorable for the disability rights movements, however, was the prevalence of disability among politicians and their families. Disability rights activist and former Representative Tony Coelho, who experienced epilepsy, believed that the movement's strength was derived from this "hidden army" of individuals on Capitol Hill who understood disability on a personal level (Shapiro 1994, 117). The "hidden army" would prove to be essential in drafting and gaining support for the Americans with Disabilities Act during a conservative administration. Coehlo originally sponsored the bill in the House of Representatives, while

Lowell Weicker, a republican whose son has Down's syndrome, advanced the bill in the Senate (Shapiro 1994, 118). Many other politicians who championed the bill also had personal experiences with disability. Edward Kennedy's son lost his leg due to cancer, Republican Bob Dole had a paralyzed arm as a result of a World War II injury, Democratic Representative Steny Hoyer's wife experienced epilepsy, and Democrat Senator Tom Harkin's brother was deaf. Despite their divided political affiliations, each of these "hidden army" politicians and many others reached a consensus over the need for a law that would recognize the political rights of PWDs (Shapiro 1994, 119).

The passage of the ADA bill, however, most depended on the administration of George H. W. Bush. The president understood disability from multiple angles in his personal life. Bush himself had three children with disabilities – a son who is dyslexic, a son who had a colostomy, and a daughter who passed away due to leukemia (Fleischer and Zames 2011, 92). Despite his early reservations, he was determined to lead a "'kinder and gentler' presidency," and made a commitment to the disability community by passing the ADA into law in 1990 (Shapiro 1994, 125).

## The Consumerist Argument

Another important aspect of the disability movement in the United States captures the uniquely American culture of individuality, competition, and consumerism. As author Shakespeare observes, "A large element of the movement in North America has stemmed from consumerism and self help...This is a particularly US tradition, of self-reliance and of individual rights" (Shakespeare 1993, 250).

Private businesses and fiscal conservatives in the government were the most significant roadblocks to the passage of any bill that would require funding and accommodations for PWDs.

When the ADA was proposed, the National Federation of Independent Business (composed of five hundred thousand members), the U.S. Chamber of Commerce, public and private transportation sectors (including Greyhound Buses), the Restaurant Association, and even the *New York Times* and the *Wall Street Journal* stood together against its passage (Fleischer and Zames 2011, 88). The ADA represented nothing more than unnecessary government intrusion in business.

It was with this perspective that, less than a decade earlier in 1981, the Reagan/Bush administration determined to deregulate businesses and considerably reduce government expenditure on social services (Shapiro 1994, 120). Reagan's Task Force for Regulatory Relief determined to diminish Section 504 of the 1973 Rehabilitation Act, which prohibits discrimination against PWDs in federal programs as well any institution or service that received federal funding (Shapiro 1994, 120). Furthermore, in response to local and state governments' complaints about the expensive education of children with disabilities, the Task Force moved to cut the Individuals with Disabilities Education Act (IDEA) of 1975, which promises free public education with accommodations tailored for students with disabilities (Shapiro 1994, 120). The backlash from the disability community was swift and powerful; the White House received approximately 40,000 letters and cards in protest (Shapiro 1994, 120).

It was then that Republican disability rights activist Evan Kemp, Jr, stepped in to persuade the vice president against the proposed cuts. Kemp recognized that the disability community represented a powerful group of consumers. Shapiro observes, "They are mighty in part because of the millions of dollars they spend. As more disabled people move into competitive jobs, they have more to spend" (Shapiro 1994, 36). Kemp also recognized that PWDs preferred to be part of the workforce, instead of relying on the welfare system for support.

Therefore, in his discussions with Bush, he tailored his argument so that it would appeal to conservative sentiments. Counter to prevailing perceptions of disability, Kemp argued that PWDs "were seeking self-empowerment...They did not need a paternalistic government to help them" (Shapiro 1994, 121). His rationale seemed to be convincing, because in 1983, the Reagan administration decided against its original cuts to Section 504 and IDEA (Shapiro 1994, 121).

# Conclusion: The Road to the Passage of the ADA

# Setting a Precedent for the ADA

By all accounts, the disability rights movement was a grassroots initiative strengthened by "personal networks, coalition-forming, and an increasingly active disability community" in the 1970s and 1980s, without which the ADA bill could not have passed into law (Young and the National Council on Disability 2010, 5). It was ironic, then, that the origin of the first civil rights law for PWDs, Section 504 of the Rehabilitation Act, was largely a fortuitous accident. Without prior lobbying, hearings, or debate among the disability community, President Nixon's administration decided to add the section, which authorized \$1.55 billion in federal funding to PWDs, as "no more than a legislative afterthought" (Shapiro 1994, 65). However, once the disability community came to understand the power behind Section 504, they rallied together like never before to protect it from the Reagan/Bush administration's social spending cuts (Fleischer and Zames 2011, 91).

The Disability Rights and Education Fund (DREDF) was formed in 1979 by the leaders of the Berkeley Center for Independent Living, with the pursuit of "integration and civil rights of people with disabilities, and 'to establish disability rights as the recognized equivalent of race and gender-based civil rights'" (Fleischer and Zames 2011, 77). It was DREDF that swiftly organized the nationwide, grassroots backlash in 1981 to protect Section 504 (Fleischer and

Zames 2011, 78). The ability to organize such a large scale response gave leaders of the disability rights community the tools and experience necessary to promote the ADA. Patrisha Wright of DREDF joined with existing disability-focused lobbyists in Washington, DC to introduce a *civil rights* angle to the existing lobbyists (mostly parents and medical and rehabilitation professionals) who embraced the medical model approach. Wright was, therefore, a key individual in pushing the civil rights aspect of the ADA in Congress (Shapiro 1994, 112). Prior to the proposal of the ADA, Wright and Ralph Neas of the Leadership Conference on Civil Rights set a crucial precedent with the passage of the Voting Accessibility for the Elderly and Handicapped Act of 1984, which opened the path to further disability rights laws (Young and the National Council on Disability 2010, 59).

## The Conception of the ADA bill

Combined with the social conditions mentioned in this chapter, a number of complex interactions and events finally culminated in the passage of the ADA. According to the 2010 NCD report, the leaders who organized for the ADA followed a four-part strategy: "overall strategy development; education and lobbying; grass roots mobilization; and legal writing and analysis"(Young and the National Council on Disability 2010, 59). Robert L. Burgdorf, Jr. drafted the first version of the ADA, which was introduced by the National Council on the Handicapped in 1988 under the Reagan administration (Shapiro 1994, 108). Surprisingly, it was the conservative members of the Council who supported the Burgdorf's civil rights bill, which proposed that everything- including businesses and transportation- would be required to be made accessible within two years. In addition, PWDs would be able to sue for damages resulting from discrimination by businesses (Shapiro 1994, 114). Introduced in its original form, the bill failed to make any progress in Congress and no consensus was reached (Shapiro 1994, 113).

When Bush came into office, Senators Tom Harkin and Edward Kennedy rewrote the ADA with the help of DREDF's Patrisha Wright (Shapiro 1994, 114). This second attempt limited the reach of the bill so that it would invite more supporters, especially those in Congress who worried about impingement on businesses. It proposed that only new buildings or buildings that are already receiving renovations must comply with ADA accessibility standards, and it would not allow PWDs to sue on the grounds of discrimination. The milder, and more business-friendly bill easily passed through Congress, guided by Senator Harkin and Representative Steny Hoyer (Fleischer and Zames 2011, 92). It was signed into law by Bush on July 26, 1990 (Shapiro 1994, 140). The bill was supported by 180 national organizations and charities across the country, and even companies "complied eagerly and reaped the rewards of new customers, new workers, and good publicity" (Shapiro 1994, 140). For Justin Dart, this momentous feat was the fruit of a

ragtag hodgepodge of advocates with disabilities, families, and service providers, who had never completely agreed on anything before, [who] joined together with a few far-sighted members of the older civil rights movement, business, the Congress, and the Administration to defeat the richest, most powerful lobbies in the nation (Fleischer and Zames 2011, 92).

Still, leaders and activists, as well as PWDs across the country realize that, despite this victory, negative attitudes, paternalism, and misconceptions persist within mainstream society. The passage of anti-discrimination legislation does not spell the end of discrimination, but merely presents a framework within which PWDs may legitimize and exercise their political rights. Even after two decades since the passage of the ADA, there is still widespread discrimination in employment, education, transportation, and accessibility – signs of overt

noncompliance with the ADA. The disability community has certainly come along way, but it still has a long way to go to achieve complete human dignity by way of political recognition.

# Engagement with International Human Rights Treaties and the CRPD

Historically, the United States has shown a poor record of ratification of international human rights treaties, having ratified only three of twenty-six as of 2009.<sup>23</sup> Although the United States has been in a position of leadership many times in the early international human rights movement, domestic political tensions have prevented full participation and compliance with international treaties. Strong non-interventionist forces in the country after two world wars and bitter tensions between liberal and conservative factions in the government forced President Dwight D. Eisenhower to make concessions and limit the country's role in the newly-formed United Nations.<sup>24</sup>

Eleven years after his father famously signed the ADA bill into law, President George W. Bush declared that a disability treaty was superfluous with regard to the interests of the United States. In fact, according to authors Stein and Lord, during early UN ad-hoc committee sessions in 2002 and 2003 that were convened to discuss the treaty, the United States' representative insisted that "disability was a matter of domestic, rather than international, concern."<sup>25</sup> The ADA, which had been in effect for years, was considered sufficient legislation that would not require further intrusion by international experts. It was curious that, despite the assistance of experienced American disability rights experts and the use of the ADA and other U.S. laws as model language for the CRPD, the United States under the Bush Administration neither engaged

<sup>&</sup>lt;sup>23</sup> See "Ratify the UN Disability Treaty," Foreign Policy in Focus, Institute for Policy Studies http://www.fpif.org/articles/ratify the un disability treaty

<sup>&</sup>lt;sup>24</sup> *ibid*. <sup>25</sup> *Ihid*.

actively during the negotiation phases, nor signed the treaty when it opened for signatures after 2006.

It was not until presidential candidate Barack Obama made PWDs a priority in his campaign that the CRPD began to receive attention from political leaders once again. In 2007, Obama insisted that the U.S. "lead the world in empowering people with disabilities to take full advantage of their talents and become independent, integrated members of society" by resuming the task of the ratification of the CRPD in the Senate.<sup>26</sup> President Obama signed the Convention in July of 2009.

The irony in the events over the past decade is that disability in the 1980s was heralded as one issue that could cut across political lines, since it was an experience familiar to individuals affiliated with every party. Ultimately, however, the underlying foreign policies of the Bush administration in the 2000s prevented the United States from engaging with a treaty that had been influenced so much by the principles of the country's own disability laws.

## CHAPTER 6

# THE DISABILITY RIGHTS MOVEMENT IN INDIA

### The Status of PWDs

Historically, as in many parts of the world, there has been little discussion or understanding of disability from purely social or political perspectives in India. Disability has been viewed mainly through the lenses of charity, development, religion, and culture. As Nilika Mehrotra writes

In India and much of south Asia, disability is largely seen as a product of cultural impediments such as beliefs and stereotypes as well as structural impediments like poverty, lack of development, illiteracy, unemployment and caste, class and gender barriers... The meaning of disability in India is embedded in this basic struggle for survival and cultural understanding (Mehrotra 2011, 2).

Consequently, PWDs in India have experienced discrimination in sectors that were considered inappropriate or impracticable for them, including education and employment (Mehrotra 2011, 2). Before the 1990s, PWDs could have been denied employment or admission to school simply based upon misinformed perceptions of their disabilities. Although legislation exists today to combat such discrimination, negative attitudes and beliefs are still embedded in cultural perceptions of disability throughout the country (Center for International Rehabilitation 2005, 51). According to the 2005 Regional Report of Asia by the International Disability Rights Monitor, there are 18.49 million PWDs in India, or 1.8% of the total population (Center for International Rehabilitation 2005, 45). According to a 2007 World Bank Report by the Human Development Unit, illiteracy among PWDs is 52%, compared with only 35% of the nondisabled population (The World Bank Human Development Unit, South Asia Region 2007, 16). Moreover, there is a discrepancy even within the disability community, as two-thirds of those with learning disabilities are illiterate, compared with 44% of PWDs with locomotor disabilities

(The World Bank Human Development Unit, South Asia Region 2007, 16). These statistics point to the relative lack of resources and attention given to the disability community over the past several decades. According to Pal, this neglect stems from a combination of the lack of constitutional provisions for PWDs, the unrealistic estimation of the prevalence of disability, and low visibility in mainstream academia, among other factors (Pal 2011, 161).

## The Disability Rights Movement

Before the passage of the Persons with Disabilities Act (PWD) in 1995, there were limited educational or rehabilitation programs for PWDs. Children with disabilities who could not attend (or were barred from attending) schools remained at home. In response, parents of children with disabilities began to organize activist movements in the 1970s to fight for the provision of adequate personal assistance for their children after they pass away. The question at the time was not necessarily of civil, political, or economic rights or even of independence for PWDs, but rather, the right to assistance in the eventual absence of other family members (American Society of International Law 2005, 92). It was not until the 1990s that the rightsbased approach would emerge as a framework for understanding disability in social and economic terms (American Society of International Law 2005, 92).

The disability rights movement expanded in the 1980s and 1990s as a result of greater accountability in state policies, the presence of similar identity-based rights movements, and a greater interest and observation from international development agencies (Mehrotra 2011, 1). India's commitment to the Asian and Pacific Decade of Disabled Persons in 1993 legitimized and obligated the central government to take more notice of its disabled population, although, international pressure alone would not have been enough (Mehrotra 2011, 3-4). Domestic lobbying and demands by activist organizations like the Disabled Rights Group (DRG) and the

National Centre for Promotion of Employment for Disabled People (NCPEDP) were integral in the passage of the PWD Act (Mehrotra 2011, 4). In addition, Mehrotra notes that the middle class component of the movement continues to leverage power over the media to disseminate information and raise awareness about disability issues, through journals, magazines, websites, and even a news service called Disability News India (DNI) (Mehrotra 2011, 5).

#### Challenges within the Movement

Faced with the complexities of a massive and diverse population, negotiation between cultural traditions and modernity, and socioeconomic discrepancies, the relatively young disability rights movement in India is still in the process of establishing its presence in society and solidarity among its members. Mehrotra presents several challenges within the movement.

First, although the disability rights movement of India benefited from the political environment created in part by a prominent women's movement, until very recently, women with disabilities have been left in the margins of the disability discourse. Women with disabilities experience multiple forms of discrimination throughout the world, and in India this cross-sectional experience is amplified by issues of class, religion, and caste (Mehrotra 2011, 5).

Furthermore, in terms of exclusion, the disability rights movement in India has been split along class lines. The movement's leaders have pushed mostly for the concerns of the middle class and their "fight for 'disability rights' subsumes agendas that are visible and significant only for the very privileged of the disabled," such as accommodations for air travel, for example (Mehrotra 2011, 5). However, the very basic standards of education, employment, and health care are still not met for the majority of PWDs in the country (Mehrotra 2011, 5).

Another issue is the continued lack of visibility for the diverse spectrum of disabilities in the movement. Merhotra points out that there seems to be a hierarchy of impairments, which

situates wheelchair-users and people with visual impairments in more powerful positions in the movement and allows them more access to resources (Mehrotra 2011, 5).

Finally, political participation is not the highest priority in the movement. Some might say that this is not necessarily a challenge or a weakness, because the country has focused (and rightly so) much more on meeting the basic needs of its population first (Mehrotra 2011, 9). Without the fulfillment of the basic needs mentioned above, some would argue that political participation is a luxury. On the contrary, this paper argues that political participation and representation is crucial at every level, for those who are most destitute as well as those who have already secured their basic needs.

# Crucial Themes

To fully understand the perspectives and attitudes towards disability and the path that led to the particular language and objectives advocated in the PWD Act, one must consider the historical, cultural, religious, and economic components of Indian societies, as well as familial and communal structures. It is important to also keep in mind for this case study comparison that the population of India is nearly four times that of the United States, with an immensely diverse set of languages, religions, and cultural traditions across the country. These factors, coupled with India's relatively recent independence from British colonial rule (1947), generated a very unique type of disability rights movement.

# Emphasis on Economic Development and Disease Prevention

India's early initiatives to address social welfare after its independence followed the charity and medical models, with the objective of curing and rehabilitating PWDs. Needless to say, the welfare of PWDs was left mainly to hospitals and health centers, reflecting the

assumption that physicians, social workers, occupational therapists and other health care professionals were best qualified to address disability (Mehrotra 2011, 3).

However, with the declaration of the Decade of Disabled Persons in 1983, and a general shift from welfare to development policies in the 1980s, "the disabled now figured not as recipients but as participants in the development process" (Mehrotra 2011, 3). Economists began to see the link between poverty and disability in developing countries, and realized that the "high costs incurred due to the stigmatizing effects of disability in mainly developing countries are said to result in low literacy rates, widespread unemployment, and high cost of health care" (Mehrotra 2011, 6). Because so much of the population lived without the security of basic needs, economic development was (and still is) considered as the key strategy to address the social and economic rights of marginalized populations. The disability rights movement benefited from the State's shift to development policies, and with the help of international funding, limited domestic protest and advocacy were needed to persuade the State to turn its attention towards the basic needs of those with disabilities (Mehrotra 2011, 8-9). In recent years, Amartya Sen's capability theory has gained popularity since it relates to development, yet also supports opportunities for complete social well-being (Buckingham 2011, 427).

The focus on development and the achievement of basic needs legitimizes the medical model's highly categorical terminology. The PWD Act specifically defines seven categories of disability, including mental illness, intellectual disability, locomotor disability, low vision, blindness, and leprosy-cured. Each disability is then determined to be mild, moderate, severe, or profound, and only those individuals who experience over 40% of a disability are eligible to receive protection under the PWD Act (Center for International Rehabilitation 2005, 40).

The Act specifies provisions for education, employment and vocational services, unemployment allowances, rehabilitation and insurance schemes, and housing for PWDs. The legislation also focuses on identifying measures to prevent disability, including the collection of information pertaining to causes and occurrences (American Society of International Law 2005, 87). The Ministry of Social Justice & Empowerment, which oversees services for PWDs, promotes schemes to improve health, nutrition, education, employment, arts and crafts, science and technology, and welfare programs (American Society of International Law 2005, 94). In 1985 the District Rehabilitation Center (DRC) was established in collaboration with the U.S. National Institute of Disability and Rehabilitation Research to conduct surveys about the disabled population, prevention and early detection, medical intervention and surgical correction, artificial aids, therapeutic services, vocational training and job placement, and the promotion of community awareness and family involvement (American Society of International Law 2004, 94). The Ministry of Labor plays a large part in ensuring economic opportunities for PWDs, including strategies to promote the inclusion of PWDs in the mainstream workforce. The Ministry implements programs such as the Apprentice Training Scheme, the District Rehabilitation Scheme, and the National Program for the Rehabilitation of Persons with Disabilities, and oversees 19 vocational rehabilitation centers (Center for International Rehabilitation 2005, 58). Moreover, the Rehabilitation Council of India provides doctors with training on early detection and prevention of disabilities (Center for International Rehabilitation 2005, 58).

#### Family and Community

Family and community support play both a crucial and a controversial role in the Indian disability rights movement. The individualistic "independent living," concept in Western

disability movements does not translate well as a current priority for PWDs in most of India. Instead, PWDs have preferred to negotiate their own conception of independence within their roles as family members rather than independently-living individuals (Mehrotra 2011, 8). Family cohesion and acceptance may be partly a characteristic of culture, but they are also mechanisms of social insurance in developing countries with weaker social welfare strategies (Mehrotra 2011, 9). It is also dangerous to allow a PWD's welfare to depend entirely on the support of family, especially if the family or community maintains discriminatory or exclusionary attitudes towards PWDs. In light of this, the State is beginning to acknowledge that "shrinking community and family support mechanisms" will make dependence upon family support unsustainable in the future (Mehrotra 2011, 9).

Promoted by NGOs, social activists, the Indian government, and international agencies, community-based rehabilitation (CBR) programs incorporate PWDs and their families in both rural and urban settings. CBR programs are

measures taken at the community level to use and build on the resources of the community...[and] envisages a social programme in which a community shows awareness and sensitivity to the special needs of its physically disadvantaged members and their families, and feels responsible for bringing about desired change (Dalal 2006, 378).

Thus, considering the vital role of community, the CBR method became popular in the last several decades. The philosophy does have its critics, however. As Mehrotra notes, since CBR utilizes program design and implementation methods such as surveys, advanced planning, budgeting, and outcome evaluations that are foreign to traditional, local, and religious practices, some have argued that CBR "clearly reflects the biases of the urban, educated social activists" and ignores cultural norms (Mehrotra 2011, 5-6).

## **Religious and Cultural Components**

To suggest that stigmatic perspectives on disability arise solely from a particular type of culture or certain interpretations of a religion is not only simplistic, but problematic and irresponsible. The observance and practice of religious traditions vary not only from community to community, but from individual to individual, and are heavily influenced by time and place. Culture, which encompasses faith, is a fluid and ever-changing set of shared beliefs, customs, values, and modes of communication. Furthermore, to say that Indian cultures are particularly influenced by religion in comparison with other nations is a careless juxtaposition that reflects tendencies toward essentialism within western perspectives of South Asia.

Nevertheless, with proper discretion one can consider the religious tenets, practices, and orthodoxy that have shaped attitudes and behaviors towards disability. India's population comprises people of many faiths, including Muslims, Christians, Sikhs, Buddhists, Jains, Jews, and Zoroastrians; however, approximately eighty percent are followers of Hinduism.<sup>27</sup> Jane Buckingham suggests that "while there may be similarities between the western and Indian high culture traditions of exclusion and stigmatization of people with disabilities, particularly in the pre-modern era, these cultures are grounded in different concepts of social inclusion" (Buckingham 2011, 421). She explains that while western Judeo-Christian traditions have historically linked moral failure with impairments, the Brahmanic textual traditions allowed for the disinheritance of those with disabilities in higher castes because they were thought to be incapable of carrying out necessary religious rituals (Buckingham 2011, 421).

On the other hand, the World Bank's 2007 report, "People with Disabilities in India: From Commitments to Outcomes," highlights the concept of karma and its implications on social

<sup>&</sup>lt;sup>27</sup> See Office of the Registrar General & Census Commissioner, Ministry of Home Affairs, Government of India http://www.censusindia.gov.in/Census\_Data\_2001/India\_at\_glance/religion.aspx

inclusion. Perceived as "divine justice," disabilities can be perceived as "punishment for misdeeds in the past lives of the PWD, or the wrongdoings of their parents" (The World Bank Human Development Unit, South Asia Region 2007, 21). More commonly, disability evokes a general feeling of inauspiciousness. For example, the report's research in the early 2000s found that forty percent of respondents from the state of Andhra Pradesh (AP) confessed to the belief that disability is a form of punishment or a curse from God (The World Bank Human Development Unit, South Asia Region 2007, 21). This conviction increased with the age of the respondents, and there was little difference between urban and rural attitudes in AP (The World Bank Human Development Unit, South Asia Region 2007, 21). However, these specific responses should not be assumed for rest of the country. In the state of Karnataka, for example, respondents in urban areas were more likely to attribute disability to medical causes (The World Bank Human Development Unit, South Asia Region 2007, 21).

Whether or not they are derived from religious tradition, it is clear that prevalent discriminatory attitudes socially marginalize PWDs across India – "attitudes of society, families and PWD themselves contribute to converting impairments into disabilities" (The World Bank Human Development Unit, South Asia Region 2007, 21). The report above emphasizes the complex interaction between community attitudes, and attitudes that are internalized by family members of PWDs. If the wider community creates a socially oppressive environment for PWDs, it will have an effect on a family's own perception of disability, their place in society, and the type of support that they can (or are willing to) offer to their household members with disabilities (The World Bank Human Development Unit, South Asia Region 2007, 21). This, in turn, places greater responsibility on public officials to enforce inclusive disability policies where collective community action is likely to fail due to negative perceptions.

According to Dalal, discriminatory attitudes are further aggravated by the stigma associated with poverty: "where basic life conditions are hard to maintain, such prejudices would have far more dehumanizing consequences...poverty, illness, illiteracy and massive unemployment [leads] to severe competition for diminishing resources" (Dalal 2006, 374). PWDs in India (as well as the United States) are more likely to be unemployed or underemployed, receive fewer opportunities to advance their education, and therefore, more likely to experience poverty which adds to the social prejudice associated with their impairments (Dalal 2006, 374).

## The Influence of Parallel Social Movements

Long before human rights movements began in the 1970s, India's first Prime Minister, Jawaharlal Nehru, established the earliest civil liberties organization in 1936, the Indian Civil Liberties Union (Gudavarthy 2008, 30). The rights extended to citizens then were not only a "means necessary to achieve a more just and egalitarian socio-economic order" but were also a "strategy that formed the basis of the anti-colonial struggle" against British colonial rule (Gudavarthy 2008, 30).

Human rights movements did not fully emerge until the 1990s, but the 1970s saw their roots in an urgent response to the authoritarian administration of Prime Minister Indira Gandhi (Gudavarthy 2008, 31). Under her authority, an emergency rule between 1975 and 1977 resulted in mass arrests, the arbitrary detention of students and political figures without trial, custodial violence, news censorship, illegal trespassing, and a general denial of civil liberties in the defense of national security (Patel 2010, 459-460). Particularly shocking was Gandhi's program of mass sterilization (Patel 2010, 459).

The violation of rights during this period gave birth to movements among hundreds of thousands students, environmentalists, dalits, women, the working class, peasants, backward castes, and finally PWDs, in an effort to protect Indian democracy (Patel 2010, 460). These movements shifted society's focus from simply welfare and civil rights, to democratic rights, and eventually, human rights in recent decades. In the 1970s and 19980s national and regional groups were activated across the country, including Citizens for Democracy, the People's Union for Civil Liberties, the Committee for Protection for Democratic Rights, the Association for the Protection of Democratic Rights, and the Andhra Pradesh Civil Liberties Committee (Patel 2010, 460). This period saw a growth in NGO and scholarly work on development and women's issues as well. Women's studies and development studies courses boasted a "wide variety of issues...from economic and political issues to health to [the] right to [an] equal and dignified life" (Mehrotra 2011, 2). The 1980s and 1990s brought closer attention to the dalit movement and issues of class and caste. Although the disability rights movement emerged from a development perspective, it certainly benefited from the civil and political rights frameworks that were put in place by the generations of movements before it.

# International Pressure and Transformations in the Indian Economy

India experienced several major economic and political transitions during the 1980s and 1990s that suggest that national disability rights legislation may have been tied to India's foreign policy strategy and its status in the international arena. India's foreign policy since its independence in 1947 rested on principles of non-alignment and solidarity with the third world, especially newly-independent countries (Mohan 2006, 2). Although India refused to align with either the United States or the Soviet Union during the Cold War, its socialist ideals in the 1970s and 1980s (India proclaimed itself a "socialist republic" in 1976), allowed for a natural partiality

towards the Soviet Union. An "in-ward focused, socialist-style, economic framework" was a backlash against the hitherto "exploitive mercantilist approach to India's development" after India's independence from Britain in 1947 (Wilson and Keim 2006, 29). In the 1950s, the national economy was heavily regulated by the state:

Firms wishing to raise capital needed prior approval to ensure that assets were directed in line with development strategy. In various sectors...the development of large-scale private enterprises was severely restricted. Private enterprises had little autonomy to lay off workers or cease operations. Many commercial banks were nationalized.... Laws also restricted foreign transactions: quotas and high tariffs existed for imports, exports required licenses, and foreign investment was severely controlled, if not forbidden (Wilson and Keim 2006, 29).

However, when the collapse of the Soviet Union ushered in a new era of globalization, India's leaders were forced to reassess their geopolitical position, and to redesign their foreign policies accordingly (Mohan 2006, 3). The cost of managing external debt, partially resulting from the Gulf crisis (which increased the cost of India's oil imports and ultimately prompted the country to seek assistance from the International Monetary Fund), brought about a balance-of-payments crisis in 1991 (Wilson and Keim 2006, 30). This event and, according the Deputy Governor of the Reserve Bank of India, Dr. K C Chakrabarty, the rapid success of China's socialist market economy in reducing poverty beginning in the late 1970s, caused India to question its own economic strategies and consider widespread reforms (Chakrabarty 2009, 2). These catalysts helped to initiate and then accelerate the liberalization of the economy- reducing restrictions on capital flows, and deregulating domestic industries as a result. This recognition of the need for rapid economic growth became a component of a broader outward shift in India's perspective of its relations with the international community during a time of greater globalization.

According to C. Raja Mohan, the rapid economic growth after transforming from socialism to capitalism in the 1990s shifted India's self-perception. Rather than remaining a leader and defender of anti-imperialism and the third world, India now had the capability to

position itself as a great world power. The leaders now had an incentive to abandon isolationist and anti-Western policies, and collaborate with international actors (Mohan 2006, 4). Despite its original anti-Western bias, as the world's largest democracy, India recognized that its fundamental principles were already aligned with Europe and North America. Therefore, the post-Cold War period saw greater multilateral engagement between India and international organizations. Globalization and the focus of development in the 1990s also led to better access to foreign aid and investment, greater NGO presence, and technology that allowed more efficient modes of communication and information transfer (Mehrotra 2011, 3).

Previously, the Indian government was prohibited from passing a nationwide law, because disability issues fell under state jurisdiction (American Society of International Law 2005, 78). The new commitment towards international cooperation in the 1980s-1990s may account for India's participation in the Economic and Social Commission for Asia and the Pacific (ESCAP). In 1992 India became a signatory to ESCAP's declaration of the Asia and the Pacific Decade of Disabled Persons (1992-2002), resolving to pass legislation to address the rights of PWDs (American Society of International Law 2005, 78). In terms of other disabilityrelated international agreements, India adopted the World Programme of Action (WPA) in 1981, the Standard Rules for the Equalization of Opportunities for Persons with Disabilities, and the Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care (Center for International Rehabilitation 2005, 50). Because of its obligations under ESCAP, India drafted the 1995 legislation for PWDs after a consensus was reached among the union government, state governments, and NGOs (American Society of International Law 2005, 78-79).

### CHAPTER 7

## ANALYSIS

Instead of a chronological assessment of events, this paper opted to analyze key themes and trends that influenced the language of disability laws and the perspective of lawmakers with respect to each case study. The historical review shows that social trends and changing norms do not present themselves linearly, but instead hinge upon one another and compound their effects. Although the case studies illuminate very important social conditions and historical events that substantiate the laws in each country, these observations cannot be extended to other cases without further research. Therefore, the author maintains that this paper seeks to explore two distinct cases that have experienced rather different outcomes and identify certain factors that may be useful for further research.

#### The United States

The literature that described disability movements in the United States each revealed the importance of war in the 20<sup>th</sup> century, a politically active society, academic discourses in collegiate environments, the framing of disability as a contentious political issue in public debate, and the consumerist argument at the crux of that debate.

A few important observations emerge from this history. First, because Congress members in the U.S. would likely not have reached a consensus on the Americans with Disabilities Act without the support of fiscally conservative members, the consumerist argument was (and still is) a necessary tactic in the fight for disability rights. These events lend credence to Goldsmith and Krasner's realist argument that economic coercion, and not simply the work of human rights organizations, is pivotal to the acceptance of human rights norms. Although Goldsmith and Krasner's theory was intended for application on the international level, the

example of the United States can be a microcosm of the political dynamics between liberal and conservative factions (as defined within American politics). The example shows that rights-based arguments alone have not been effective in the United States, further illustrated by the lack of initiative during the recent Bush administration. Unlike other civil rights movements in the U.S. that advocated for greater employment opportunities, the inclusion of PWDs in the workforce does not require a simple shift in social attitudes. Inclusion may often necessitate renovations and other accommodations that will incur additional costs (although, the costs are usually inconsequential). This aspect has triggered backlashes from the private sector that argue against government intervention in commerce. Economic arguments in favor of workforce participation for PWDs can thus be valuable to gain ultimate support in a country for which business and consumerism is vital, and also to pull disability rights organizing out of the sphere of radical fringe movements. The dilemma for disability rights activists is that such concessions may compromise the original principles of the movement – namely, that disability rights are human rights, and they should not be contestable or negotiable. To a disability rights activist who believes that participation in every sector is a matter of *right*, a consumerist argument is a rather superfluous and labyrinthine approach. Interestingly, though, the consumerist argument does not aid activist efforts today to persuade Congress to ratify the CRPD, which is geared toward the protection of rights. Perceptions of American exceptionalism and independence from international human rights treaties have created a very different environment in which the consumerist argument is no longer relevant to American business owners.

Reflecting Ted Gurr's assertion that organized groups determine their strategies according to opportunity structures within political systems, the American disability rights movement considered the typically bi-partisan nature of the political system and successfully

utilized its resources accordingly. As suggested by Benford and Snow, the movement leaders reinterpreted events and crafted their message in such a way that would generate the greatest attention in the public. For example, the grassroots organization ADAPT consciously framed the accessibility of buses as a priority for the disability rights movement, recognizing that the freedom to ride a bus had been a symbol of equality and desegregation rooted in American civil rights history (Shapiro 1994, 128). The disability rights movement reflected many of the concerns of the civil rights and women's rights movements before it, and the social model approach to the ADA law was conceived with a nod to the precedent set by earlier civil rights legislation and case law.

The literature suggests that disability rights legislation in the United States was a product of domestic processes, and not otherwise influenced by international commitments. When the movement began in the 1960s there was no international human rights document that specifically addressed disability. It was not until the 1970s that the international community expressed interest in the broad Declaration on the Rights of Disabled Persons, and even then the declaration followed the medical model perspective which clashed with the movement's objectives of equality and independence. Today, there is still little evidence to suggest that international commitments have a bearing on domestic disability policies in the United States since the United States has still not fully acknowledged the CRPD.

What seemed to be a simple case of organically initiated disability rights norms was further complicated and challenged by the creation of the CRPD with the aid and expertise of American activists who did not officially represent the interests of the state. It is no surprise, with the United States' unsteady record of commitment to international human rights treaties, that the American Senate has been slow to ratify the treaty. But the presence of a strong disability

community exposes the discrepancy between the wishes of a part of civil society and the foreign policy interests of the state. Those who oppose the ratification claim that it is a violation of the inherent sovereignty of the nation. But what these explanations reveal is the underlying reluctance of the United States to relinquish power in the international forum. The second Bush administration garnered for the U.S. the reputation of unilateralism and a steadfast refusal to cooperate in the international arena, especially with the United Nations. The incongruence between non-governmental sector support and the government's official position lends credence to Park's suggestion that norms do *not* simply begin with the support of member states of an international organization. The ADA influenced the CRPD via unofficial routes - the aid of non-state actors and transnational advocacy networks – even in the event that the host country, a member of the UN, did not explicitly support the treaty.

A closer review of the political environment in the United States supports Acharya's observation that norm diffusion depends, to a great degree, on a country's internal factors. Although disability rights norms began with the U.S., the reluctance to sign the CRPD is an indication that the norms were never completely absorbed by all factions of American society. The polarization of political parties in the 2000s, and the on-going oscillation between non-interventionist principles and active global engagement from one administration to the next points to Acharya's suggestion that political regime change is a factor that determines the reception of norms.

#### India

India's disability rights movement emerged within a very different context from that of the U.S., and thus, featured a distinct set of demands and objectives. Highlighted in the literature of the Indian disability movement is the emphasis on economic development and basic

needs, the support of families and local communities, persistent stigmas rooted in religious philosophies, international commitments, and the momentum of concurrent rights-based movements. Immediately evident are the "striking differences in the backdrops of western [disability rights movements]" including the vast population, cultural and linguistic heterogeneity, and issues of underdevelopment and marginalization (Mehrotra 2011, 8). Although the wording of the PWD Act does not reflect the values of the social model, the fact that anti-discrimination legislation was passed in recognition of certain rights of PWDs is itself a noteworthy and crucial stepping stone towards greater political recognition for the disability community.

With regard to the acculturation of norms, Krasner and Goldsmith's emphasis on economic and military coercion is worth another close look. Although domestic pressure was certainly a major factor in the passage of the PWD Act, India's shifting position as a growing regional power and its wish to remain an influential player in the international arena also created an incentive to adhere to international commitments. International human rights bodies may have influenced India's decisions as well (as in the country's commitment to ESCAP), but its broader foreign policy objective of greater global engagement may have led to the materialization of its commitments in the form of a domestic disability law. In this case, Krasner and Goldsmith's brand of coercion was unnecessary, as India is not a repressive state that routinely and purposefully denies rights to its citizens. However, a softer coercion, in the form of incentives such as greater power and economic development were more relevant. A more apt explanation, then, is Goodman and Jinks's suggestion that the socio-psychological costs of nonconformity and the benefits of conforming to international standards more strongly influence states to align with international norms. Indian leaders and foreign policy strategists sought greater cooperation

with the West during the post-Soviet era, and disability laws may have been a diplomatic gesture to avoid non-conformity on the global level.

Unlike the United States, India had both signed and ratified the CRPD in 2007. Presently, however, the PWD Act does not reflect the language of the CRPD, suggesting Goodman and Jinks's observation that the adoption of "structural commitments" is not always enforced "where there is a disjuncture between local needs and an 'internationally legitimated model" (Goodman and Jinks 2004, 651). The links between poverty and disability necessitate a focus on health care, employment, and rehabilitation in order to lift the most economically marginalized PWDs into a stable and sustainable standard of living. In this case the "internationally legitimated model" was tailored to the needs of the population, emphasizing social, economic, and cultural rights.

Furthermore, Finnemore and Sikkink's notion of norm cascading via "diplomatic praise or censure, either bilateral or multilateral... reinforced by material sanctions and incentives" is complicated by the position of disability as both a rights issue *and* a development issue, depending on the perspective (Finnemore & Sikkink 1998, 902). India has had a greater incentive to focus on development. Given the shift by international financial institutions to postcolonial and developing countries in the 1980s, the incentives for India came in the form of development aid that focused on health and welfare. The norms that "cascaded" from these institutions, therefore, focused more on the medicalization and the classification of disability at the time when disability rights laws were written in India. With so much international and national attention devoted to meeting the basic needs of underdeveloped segments of the population, it was a matter of course that India's disability laws were designed to address those immediate needs before turning to stigmas and social attitudes. The medical model would have been the most effective and logical approach to meet these objectives. The problem, however, is

that without addressing the underlying prejudice and misinformation, health care professionals will have the license to *cure* impairments rather than explore alternative and holistic approaches for PWDs to embrace and manage their conditions. Without raising awareness about persisting perceptions of incapability, PWDs will continue to experience discrimination in hiring. India's disability rights movement is fragmented by class, separating those in the community who accept the medical model as an appropriate framework, and those who push for the social model with the belief that society has reached a post-medical model era.

The phenomenon that the world is witnessing now is in keeping with elements from Finnemore and Risse's five-stage model of norm acculturation, which begins with the activation of transnational networks and leads to tactical concessions and a prescriptive status. India's original gesture in ratifying the CRPD was questionable, considering that its original PWD law lacked some of the basic elements necessary for compliance, and that the government is only now beginning steps to revise the legislation. India's engagement with the CRPD, as mentioned before, could be attributed to a foreign policy shift with the intention of greater global cooperation, but which will ultimately lead to rule-consistent behavior, in keeping with the final step of Finnemore and Risse's model.

On the other hand, it is important to apply Acharya's notion of localization to India. The CRPD is not meant to replace pre-existing norms, as the early norm diffusion authors would suggest, but to find a place within the cultural, social, and political context of the receiving society. Evidence from the review of India's history suggests that the reception of the disability rights norm was necessarily adapted to the economic needs of a growing developing country. The CRPD's versatility lies in the fact that it does not emphasize economic, social, and cultural rights over civil and political rights, and vice versa. The guiding principles emphasize the dignity

and autonomy of the individual, and the right to protection against discrimination, leaving further interpretation to the specific needs of individual disability communities.

## Lessons for Future Research

The Indian case study indicates that poverty and the lack of access to basic needs obstruct the path to political recognition and participation, and that economic development (as well as the influence of international development initiatives) may be important determinants for the type of model that is embraced in disability-related laws and initiatives. This discovery presents a contradiction and calls into question the original choice of India as an example of a "wealthy" country. In other words, if India was essentially wealthy, why was poverty and underdevelopment such a major policy focal point in the 1990s? The case study justification drew information about India's economy from a more recent 2010 report; however, even data from the 1990s when the PWD Act was passed reveals that India was still in the top ten countries in the world in terms of GDP.<sup>28</sup> Upon further investigation of the case study, the author discovered the greater nuances within the Indian economy of the early 1990s that shed light on the conundrum. India, in terms of GDP was a growing and wealthy country, as it emerged from its socialist-leaning isolationism in the early 1990s. Its situation was unique: although it was rich, India's economy was (and still is) dependent on agriculture, and vast numbers of people in rural areas experienced growth at different rates from the booming urban environments. Therefore, the utilization of GDP as a marker of wealth is a deceptive metric, and future studies will need to consider wealth discrepancies that will reveal a more accurate picture of deeper economic stratifications. As an independent variable, however, it is still valuable to note the correlation between increasing engagement and positioning as a powerful global actor, and India's steadily

<sup>&</sup>lt;sup>28</sup> See the World Economic Outlook Database, 2011, the International Monetary Fund,. http://www.imf.org/external/pubs/ft/weo/2011/02/weodata/weoselgr.aspx

growing economy since the 1990s. As Chakrabarty notes, "the Indian economy has registered an impressive growth in recent times with GDP recording an average of 7.2 per cent growth rate in the current decade from an average growth of 5.7 per cent in the nineties," and "in terms of incidence of poverty measured on the basis of consumption expenditure, there is a definite improvement over the years, both in rural and urban areas" with a decline of approximately 8 percentage points in the poverty ratio between 2004-05 and 1993-94 (Chakrabarty 2009, 1, 10). The increased wealth parallels the increased demand for social reforms –

the greatest change in the last 10 years has been the attitude towards reforms. Whereas the vocial supporters of reforms within India were rare during the 1980s, virtually every political party today recognizes the need for continued reforms...there is a near consensus with regard to the important role of [the] liberalization process initiated in the early nineties in placing the economy on a higher growth path (Chakabrarty 2009, 2).

The literature that specifically emphasizes disability rights in India points to many links between under-development and disability in the early years of the Indian disability rights movement, which only continues to reinforce the idea that wealth is indeed an important independent variable, even though the author realized the dramatic economic growth retrospectively in the research. India's renewed interest in complying with the CRPD may be a signal that, as the economy steadily grows, the government senses that it can provide sufficient resources to enact and enforce a more inclusive and equitable law. The original model (D + W + "Unknown" = Outcome) is still a valuable equation, although in the future it could be tested with a more robust and less economically disparate case study than India.

## **CHAPTER 8**

## CONCLUSION

The paper originally presupposed that "wealth" and "democratic government" were necessary but not sufficient ingredients to ensure the domestic promotion of international disability rights norms. Because India and the United States were characterized as democratic and wealthy nations, and yet, they exhibited different outcomes in the dependent variable, the author employed Mill's Method of Difference to deduce that there must be another set of processes that explain the observed discrepancy.

The case studies presented two different histories with similar characteristics. Both movements involve an active and vibrant civil society that galvanized into action following major social upheavals and constraints on civil liberties, whether it was war, segregation, or a temporary repressive government. But which factors led to different languages in disability laws, and hence, different state obligations to citizens? Progress in the United States was rooted in the independent living movement, which intrinsically tore away at the medical model from the start. Political rights were an evident goal of the protests, reflecting the American tendency to emphasize civil and political rights. In India, the disability rights movement took on a different flavor from the beginning – the medical model itself was not contested in the movement, and economic, social, and cultural rights took precedence.

Based on the cases, one of the key factors that determine greater success in acculturating the social model is achieving consensus among and cooperation with private businesses on issues of inclusion and accessibility. As countries develop and grow, disability rights activists must reach out to the private sector for support, which was true for both case studies. Another factor is framing disability rights as a contentious issue in domestic politics. As exemplified in the case of

the United States' political history, laws and official commitments were determined by the disability community's power to launch disability as an issue during political campaigns. A third factor, as shown by India, is the repercussions of underdevelopment, including poverty and the lack of health care. When international development organizations joined the effort to improve the welfare of the poorest parts of Indian society, the measurements for success did not coincide with social model language. The key to success would be to serve the basic needs of the most marginalized PWDs while also avoiding medicalized perceptions, by promoting and educating the greater society about the social barriers that contribute heavily to disability. Finally, incentives to engage in the international community prove to be a very important factor in the decision to commit to the CRPD. India's incentive lies in its wish to move towards a greater position of power, whereas the United States' reluctance indicates the reverse – the unwillingness to relinquish power over its own domestic matters.

Three causal mechanisms of norm diffusion were useful to frame and categorize the trends that were observed in the case studies: top-down norm cascading, norms travelling from states to international organizations, and the process of localization through the context of existing norms. The disciplined configurative objective of the study reveals that each of the causal mechanisms are supported through the case studies overall, and do not necessarily operate on a mutually exclusive basis. They are not three detached explanations for a single process of norm diffusion; rather, each mechanism serves to fill in the gaps where the other mechanisms are lacking. Therefore, multiple mechanisms can be present in one process of norm diffusion, as demonstrated by the case studies. Do the mechanisms better explain the cases? The author argues that they do. For example, without the examination of the political history of the United States, the top-down approach would have offered an incomplete picture of the origins of the social

model norms and the hesitance towards ratifying the CRPD. The top-down approach is useful when explaining the behavior of repressive states that may not have a normative framework already in place, but in a country like the United States, Park's and Acharya's additional theories were necessary to uncover the complexity of the case. In the case of India, although the external factors such as India's foreign policy and geopolitical repositioning are crucial in explaining the recent growth, the ways in which disability rights norms are received in the pre-existing norm structure reveals much more to practitioners and norm entrepreneurs on the ground. A one-sizefits-all approach to norm cascading by international organizations will be insufficient, and this is demonstrated by the relationship between the Indian case study and the nature of disability rights norms themselves. Disability rights activists and disabled people's organizations will need to thoroughly assess the existing norms, the state of civil society, and the state's capacity to enforce laws, in order to understand how to frame the social model in a way that is acceptable and comprehensible by the general population, and more importantly in the initial stage, by the country's lawmakers. India's case shows that local economic conditions and the value of family and community participation determined how disability rights were framed, which is in keeping with Acharya's understanding of the localization of in-coming norms.

### CHAPTER 9

## INTERNATIONAL POLITICS AND THE DISABILITY IDENTITY

The broader focus and contribution of this thesis is to further expand the disability identity into the realm of international politics. While international relations as a field may have once concerned itself primarily with the interplay of power and resources among sovereign states, ontological re-conceptualizations and critical analyses within the field over the past several decades have allowed for a more pluralistic understanding of the relevance of other global actors. As a result, non-governmental organizations, intergovernmental organizations, international financial institutions, sub-national groups, private enterprises, and other non-state actors including individuals, are acknowledged as influential players within liberal strands of international relations.

These changes explain why more and more theorists and practitioners in the field acknowledge the complexity and codependence of political, economic, and social factors that lead to cycles of insecurity and structural as well as physical violence. The focus on vulnerable, disenfranchised populations by human rights activists and development workers is gradually leading to more effective policies and practices that promote equality, economic inclusion, and greater political participation. And while disability as a social category of analysis has recently received much greater attention within the fields of international development and human rights, the relevance of disabled perspectives to *international politics* deserves further exploration.

What place does disability have in international politics? It is useful to consider a similar conversation drawn from the post-positivist "third debate" among international relations theorists. In 1997, feminist international relations theorist Ann Tickner made a case for the application of feminist ideologies to the study of international relations. She argued that

gender hierarchies serve to reinforce socially constructed institutions and practices that perpetuate different and unequal role expectations that have contributed to fundamental inequalities between men and women in the world of international politics (Tickner 1997, 621).

From a national security standpoint, she noted that a purely state-centric stance on security had historically failed to include women in upper-level decision-making processes, either before or during conflict situations, despite the fact that women experience disproportionately heavier burdens as a consequence of violence (Tickner 1997, 626). Therefore, traditionally, national security took precedence over human security. The question of citizenship was also troubling, in light of paternalistic ideas of men as active protectors of the state and women as passive symbols of the nation who required protection. Tickner's further critique of mainstream international relations theory regretted the lack of dialogue and critical engagement between traditional IR theorists and feminist theorists. Although feminist approaches to international politics had been discussed since the 1980s, apart from Robert Keohane the role of gender was not interrogated by staunchly traditional (and mostly male) scholars (Tickner 1997, 611). Epistemological divides further rendered feminism incapable of lending credible explanations for the behavior among states (Tickner 1997, 613).

Many of the questions of citizenship, power, and dialogue in Tickner's assessment raise similar concerns for the world's disabled population. As a natural facet of the human condition, almost everyone will experience impairment at one point in life, along with the social, cultural, and environmental barriers that are associated with it. According to the 2011 World Report on Disability, more than one billion people live with some form of disability, with the prevalence of disability projected to rise as populations age and chronic health conditions increase globally (World Report on Disability 2011, xi). In nearly every society PWDs experience lower access to education and employment, contributing to higher rates of poverty (World Report on Disability xi).

Ultimately, attitudes and perceptions of disability play vital roles in the disempowerment of PWDs. Persisting stereotypes and stigmas are deeply rooted in most cultures, perpetuating the image of PWDs as dependent, incapacitated, or even infantile. Charity and medical models have portrayed PWDs as either the innocent, deserving poor or as pathologies requiring rectification so as to conform to a specific anatomical norm. As a result, similar to feminist critiques against the inherent masculinism in international relations literature, widespread perceptions of incapability lead to "ableist" biases against PWDs. Ableism is a form of discrimination that considers the abled body to be the ideal, while inherently attaching negative connotations and symbols to the disabled body. Ablist language and culture represent disease, illness, and disfigurement as signs of weakness, deviance, or inadequacy. Historically, political rhetoric and propaganda have employed the language of the body to represent identities of state strength and weakness, using the abled versus disabled dichotomy. One author of security studies claims that the language of reframing states as bodies during 18<sup>th</sup> century Europe,

[demanded] purity as a condition of health and thus makes the temptation to defilement a 'natural' characteristic. This has endowed us with a mode of representation in which health and cleanliness serve the logic of stability, and disorder is rendered as disease and dirt (Campbell 1998, 82).

For instance, the phrase "the sick man of Europe" recalls the plight of impoverished European countries during the mid-19<sup>th</sup> century, applied most often to the eventual downfall of the Ottoman Empire. Moreover, as a classic example from the 20<sup>th</sup> century, one cannot forget the extermination of "incurable" individuals during the Nazi Third Reich, a decision which was believed to ultimately strengthen and purify the state, ridding the nation of its blemishes (Meyer, 1999, 64). The representation of social norms and morality in medical terms is extremely dangerous as the practice threatens the integrity of those who experience disability. Not only does it distract from the physiological realities experienced by the individual, but by attaching social significance to illness, power relationships emerge that place able-bodied individuals in morally and socially superior positions (Campbell, 1998, 84). Associations of disability with the state are still more dangerous, as they sanction politically motivated practices of exclusion.

Disability is an identity that cuts across race, nationality, gender, and class to generate a unique perspective and a particular brand of marginalization. Securing PWDs as a powerful political group in the international arena requires us to reach beyond disability as merely physical, developmental, or psychiatric conditions, and to recognize the ways in which the dynamic experiences of PWDs can contribute to global politics and traditional conceptions of power and security. Furthermore, the field would benefit from a more nuanced understanding of world politics from the point of view of disability theory within the areas of inclusivity and representation, democratic governance, and global citizenship.

## REFERENCES

- Acharya, Amitav. 2004. How ideas spread: Whose norms matter? Norm Localization and Institutional Change in Asian Regionalism. *International Organization* 58 (2): 239-75.
- American Society of International Law, American Association of Law Libraries. Foreign, Comparative and International Law Special Interest Section, Friends of the Law Library of Congress, Law Librarians' Society of Washington, D.C, Center for International Rehabilitation, and Law Library of Congress (U.S.). 2005. International disability rights: An overview and comparative analysis of international and national initiatives to promote and protect the rights of persons with disabilities. Washington, D.C: Law Library of Congress.
- Beckett, Angharad E. 2006. *Citizenship and vulnerability: Disability and issues of social and political engagement*. New York: Palgrave Macmillan
- Benford, R. D., & Snow, D. A. (2000). Framing Processes and Social Movements: An Overview and Assessment. Annual Review of Sociology, 26(1), 611-639. Annual Reviews. doi:10.1146/annurev.soc.26.1.611
- Buckingham, J. (2011). Writing histories of disability in India: strategies of inclusion. *Disability Society*, *26*(4), 419-431. doi:10.1080/09687599.2011.567792
- Burchardt, T. (2004). Capabilities and disability: the capabilities framework and the social model of disability. *Disability & Society*, *19*(7), 735-751. doi:10.1080/0968759042000284213
- Campbell, David. 1998. Writing security: United States foreign policy and the politics of *identity*. Minneapolis: University of Minnesota Press.
- Center for International Rehabilitation. 2005. International Disability Rights Monitor Regional Report of Asia. Chicago.
- Chakrabarty, K C. "India's Economic Transformation a snapshot." Inaugural address presented at the Antique India Markets Conference, Mumbai, India, September 7, 2009.
- Dalal, A. K. (2006). Social interventions to moderate discriminatory attitudes: the case of the physically challenged in India. *Psychology health medicine*, *11*(3), 374-382.
- Finnemore, M., & Sikkink, K. (1998). International Norm Dynamics and Political Change. (P. J. Katzenstein, R. O. Keohane, & S. D. Krasner, Eds.)*International Organization*, 52(4), 887-917. Cambridge Univ Press. doi:10.1162/002081898550789
- Fleischer, Doris Zames, and Frieda Zames. 2011. *The disability rights movement: From charity to confrontation*. Philadelphia: Temple University Press.

- Foley, D., & Chowdhury, J. (2007). Capital in Chuadanga, Bangladesh. Social Policy & Administration, 41(4), 372-385.
- Goldsmith, J., & Krasner, S. D. (2003). The Limits of Idealism. *Daedalus (Boston)*, 132(1), 47-63. Retrieved from http://www.jstor.org/stable/20027822
- Goodhart, M. (2008). Human Rights and Global Democracy. *Foreign Affairs*, 22(4), 395-420. doi:10.1111/j.1747-7093.2008.00177.x
- Goodman, R., & Jinks, D. (2004). How to Influence States: Socialization and International Human Rights Law. *Duke Law Journal*, *54*(3), 621-703. JSTOR. Retrieved from http://www.law.duke.edu/shell/cite.pl?54+Duke+L.+J.+621
- Goodman, R., & Jinks, D. (2008). Incomplete Internalization and Compliance with Human Rights Law. *European Journal of International Law*, *19*(4), 725-748. doi:10.1093/ejil/chn039
- Gudavarthy, A. (2008). Human rights movements in India: State, civil society and beyond. *Contributions to Indian Sociology*, 42(1), 29-57. doi:10.1177/006996670704200103
- Guernsey, Katherine, and Marco Nicoli, and Alberto Ninio. 2007. Convention on the Rights of Persons with Disabilities: Its implementation and relevance for the World Bank. TheWorld Bank.
- Gurr, T. R. (1993). Why Minorities Rebel: A Global Analysis of Communal Mobilization and Conflict since 1945. *International Political Science Review*, 14(2), 161-201. Sage Publications, Ltd. doi:10.1177/019251219301400203
- Helsing, Jeffrey W., and Julie Mertus. 2006. *Human rights and conflict: Exploring the links between rights, law, and peacebuilding.* Washington, D.C: United States Institute of Peace Press.
- Hendriks, A. (2007). UN Convention on the Rights of Persons with Disabilities. *European Journal of Health Law*, 14(3), 273-298. doi:10.1163/092902707X240620
- Hughes, G. (2011). THE CONCEPT OF DIGNITY IN THE UNIVERSAL DECLARATION OF HUMAN RIGHTS. *Journal of Religious Ethics*, 1-24.
- Karlberg, M. (2008). Discourse, Identity, and Global Citizenship. *Peace Review*, 20(3), 310-320. doi:10.1080/10402650802330139
- Langlois, A. J. (2003). Human Rights without Democracy ? A Critique of the Separationist Thesis Author (s): Anthony J. Langlois Source : Human Rights Quarterly, Vol. 25, No. 4 (Nov., 2003), pp. 990-1019 Published by : The Johns Hopkins University Press Stable URL : ht. *Human Rights Quarterly*, 25(4), 990-1019.

- Lord, J. E., Suozzi, D., & Taylor, A. L. (2010). Lessons from the experience of U.N. Convention on the Rights of Persons With Disabilities: addressing the democratic deficit in global health governance. *The Journal of law, medicine & ethics : a journal of the American Society of Law, Medicine & Ethics*, 38(3), 564-79. doi:10.1111/j.1748-720X.2010.00512.x
- Lord, J., & Stein, M. A. (2008). THE DOMESTIC INCORPORATION OF HUMAN RIGHTS LAW AND THE UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES. *Washington Law Review*, 83(4), 449-479. Retrieved from http://search.proquest.com.proxyau.wrlc.org/docview/213144989
- Marsh, C., & Payne, D. P. (2007). The Globalization of Human Rights and the Socialization of Human Rights Norms. *Brigham Young University Law Review*.
- Mehrotra, N. (2011). Disability Rights Movements in India : Politics and Practice. *Economic and Political Weekly*, 1-10.
- Melucci, A. (1985). The symbolic challenge of contemporary movements. *Social Research*, 52(4), 789-816.
- Melucci, A. (1992). Liberation or Meaning? Social Movements, Culture and Democracy. *Development and Change*, 23(3), 43-77. doi:10.1111/j.1467-7660.1992.tb00456.x
- Mertus, J. (1999). From Legal Transplants to Transformative Justice: Human Rights and the Promise of Transnational Civil Society. American University International Law Review, 14(5), 1335-1390.
- Meyer, J. C. (1999). The Forgotten Victims of the Holocaust The Forgotten Victims of the Holocaust. *Journal of Religion, Disability, and Health, 3*(January), 37-41.
- Mitra, S. (2006). The Capability Approach and Disability. *Journal of Disability Policy Studies*, *16*(4), 236-247.
- Mohan, Raja C. 2006. *India's New Foreign Policy Strategy*.Draft paper presented at a Seminar in Beijing by China Reform Forum and the Carnegie Endowment for International Peace, Beijing, China, May 26.
- Office of the United Nations High Commissioner for Human Rights. http://www2.ohchr.org/english/law/ccpr.htm
- Pal, G. C. (2011). Disability, Intersectionality and Deprivation: An Excluded Agenda. *Psychology Developing Societies*, 23(2), 159-176. doi:10.1177/097133361102300202
- Palmer, M. (2011). Disability and Poverty: A Conceptual Review. *Journal of Disability Policy Studies*, 21(4), 210-218. doi:10.1177/1044207310389333

- Park, Susan. 2006. Theorizing norm diffusion within international organizations. *International Politics* 43 (3): 342-61.
- Parnes, P., Cameron, D., Christie, N., Cockburn, L., Hashemi, G., & Yoshida, K. (2009). Disability in low-income countries: Issues and implications. *Disability & Rehabilitation*, 31(14), 1170-1180. doi:10.1080/09638280902773778
- Patel, Vibhuti. 2010. Human rights movements in india. *Social Change* 40 (4): 459-77. Population Reference Bureau. 2010. World Population Data Sheet 2010.
- Risse, T., Ropp, S. C., & Sikkink, K. (1999). *The power of human rights. Human Rights* (p. 338). Cambridge University Press. Retrieved from http://catdir.loc.gov/catdir/samples/cam032/98042345.pdf
- Saeed, R. (2009). Conceptualising Success and Failure for Social Movements. *Social Justice A Journal Of Crime Conflict And World Order*, (November).
- Samaha, A. M. (2007). What Good Is the Social Model of Disability ? *University of Chicago Law Review*, 74(4), 1251-1308.
- Shakespeare, T. (1993). Disabled People's Self-organisation : a new social movement? *Disability Society*, 8(3), 249-264. doi:10.1080/02674649366780261
- Shapiro, Joseph. 1994. No Pity: People with Disabilities Forging a New Civil Rights Movement. New York: Three Rivers Press.
- Siminski, P. (2003). Patterns of disability and norms of participation through the life course: empirical support for a social model of disability. *Disability & Society*, *18*(6), 707-718. doi:10.1080/0968759032000119479
- Smart, J. F. (2009). The Power of Models of Disability. Journal of Rehabilitation, 75(2), 3-11.
- Tadjbakhsh, Shahrbanou, and Anuradha M. Chenoy. 2007. *Human security: Concepts and implications*. Vol. 51. New York: Routledge.
- Tickner, J. A. (1997). You Just Don't Understand: Troubled Engagements Between Feminists and IR Theorists. *International Studies Quarterly*, 41(4), 611-632. JSTOR. doi:10.1111/1468-2478.00060
- Touraine, A. (2002). The Importance of Social Movements. *Social Movement Studies*, *1*(1), 89-95. Routledge. doi:10.1080/14742830120118918
- Touraine, A. (2004). On the Frontier of Social Movements. *Current Sociology*, *52*(4), 717-725. SAGE. doi:10.1177/0011392104043498

- United Nations. Office of the High Commissioner for Human Rights, Inter-parliamentary Union, and United Nations. 2007. From exclusion to equality: Realizing the rights of persons with disabilities : Handbook for parliamentarians on the convention of the rights of persons with disabilities and its optional protocol. New York: United Nations, no. 14.
- Wang, P. P., Badley, E. M., & Gignac, M. (2006). Exploring the role of contextual factors in disability models. *Disability & Rehabilitation*, 28(2), 135-140. doi:10.1080/09638280500167761
- Weiss, T. G. (2000). Good Governance, Global governance. *Third World Quarterly*, 21(5), 795-814.
- World Bank, and World Health Organization. 2011. World report on disability. Geneva, Switzerland: World Health Organization.
- Wilson, Beth Anne and Geoffrey N Keim, "India and the Global Economy," *Business Economics* (2006)
- World Bank Human Development Unit, South Asia Region. 2007. People with Disabilities in India: From Commitments to Outcomes.
- Young, Jonathan M., and National Council on Disability (U.S.). 2010. *Equality of opportunity: The making of the americans with disabilities act.* Washington, D.C. (1331 F St. N.W., Suite 1050, Washington 20004-1107): National Council on Disability.