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Disability Discourse in South Asia and Global Disability Governance

Hari KC, PhD Candidate
Global Governance Balsillie School of International Affairs
hkc@balsillieschool.ca

Abstract

Disability studies, although an emerging discipline, has already advanced in the Global North compared to the Global South in that the discourse around disability has shifted its focus from mere survival debates of the persons with disabilities to subtler and more nuanced forms and manifestations of disability existence. Even at the policy level, the “medical model” of disability has been substituted by different versions of the “social model.” The main idea of the “social model” of disability is that human beings are extremely diverse in terms of mental and bodily faculties, functions and structures, and disability indeed results from the “disabling” infrastructures and environment that society has created without taking this human diversity into account. Some versions of the “social model” go so far as to glorify the bodily and mental disabilities, deeming them merely as manifestations of human variation or diversity that offers a unique experience to be valued and celebrated (Roush and Sharby 2011). Disability in any form is merely a variation of humanity, but the disadvantages this diversity creates are the lived-realities that should not and cannot be left unattended. What I find even more problematic is the idea of glorifying and romanticizing disability. Such a glorified notion of disability, I argue, becomes yet another means to oppressing the persons with disabilities. The “medical model” that some disability studies scholars in the Global North have discarded can prove still relevant to the Global South, and particularly to South Asia. If disability activists and civil society organizations relish only in the rhetoric of disability as a “human rights” issue, and not pay ample attention to the physical and mental realities of the persons with disabilities, the “rights-based” discourse could ultimately be counterproductive.

Keywords

Disability Discourse; People with Disabilities in Nepal; South Asia; Disability Governance; Medical and Social Models of Disability

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Global Governance Balsillie School of International Affairs
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1. Argument and Methodology

Disability studies, although an emerging discipline, has already advanced in the Global North compared to the Global South in that the discourse around disability has shifted its focus from mere survival debates of the persons with disabilities to subtler and more nuanced forms and manifestations of disability existence. The disability discourse has progressed from the "issues of service delivery and rehabilitation to an engagement with the multiple nuances/meanings of disabled existence" (Ghai 2002, 88). This paradigm shift from the corporeal to the ontological dominates much of the disability discourse in the North. Scholars and activists in the North debate the "social model" that sees disability as a social and political construct (Haegele and Hodge 2016; Sherry 2008; Humpage 2007). Disability is not an inherent attribute of the individual; instead, it is created by the social environment that needs to be fixed, not the other way around (Mitra 2006, 237). Even at the policy level, the "medical model" of disability has been substituted by the "social model" that seeks solutions to disability problems not within persons with disabilities but in society at large by directing required interventions within the spheres of social policies and institutions (Haegele and Hodge 2016; Humpage 2007; Hussain 2005). The medical model of disability emphasizes rehabilitation and is based on the sense of personal tragedy (Hussain 2005, 524). Many activists and scholars engaged in disability studies in the North have, therefore, challenged the "medical model" of disability, arguing that the "medicalized" version finds faults with the "disabled body" that always needs fixing and correction through medical interventions (Haegele and Hodge 2016, 193; Humpage, 2007).

Nonetheless, the medical model of disability, when examined against the context of the South where a majority of people with disabilities are still deprived of receiving fundamental medical and other survival needs, cannot be completely eschewed. This article aims to explicate some of the critical issues facing the persons with disabilities in South Asia in general and Nepal in particular by situating the locus of the disability praxis in South Asia within a broader framework of global disability governance and the Western disability scholarship. The overarching question I investigate is: *To what extent do and can global disability governance and the rights-based discourse embedded into the "social model" of disability governance address the lived-experiences of the persons with disabilities in the South?* The subsets of questions to be examined include: *What do the conceptual shifts on disability in the North really mean to the persons with disabilities in South Asia, who are still enmeshed in struggles for survival? What issues should policymakers prioritize both at global and domestic levels to address the challenges facing the persons with disabilities in South Asia?*

I argue that the disability discourse that dichotomizes the medical and social models of disability fails to address the lived-challenges confronted by persons with disabilities in the South. The issues deemed pertinent to the persons with disabilities in the developed countries might not be of prime concerns, or of little relevance, for persons with disabilities in the South. The social model of disability stops viewing the "disabled body" as aberrant; what is rather "disabling" is the "able-bodied" mentality and all the negative ideologies and "ableist" grand narratives that are embedded into the *social consciousness* (Haegele and Hodge 2016, 198). These conceptual shifts are certainly welcoming developments for the global disability movement. However, in the context of the South, these are tall orders to be realized and embraced by the States. Moreover, the social model of disability ignores the subjective experiences of the persons with disabilities in the analysis and treatment of disability (Marks 1999, 612). The social model also fails to consider impairment as an observable attribute of an individual that is an essential aspect of their lived-experience (Palmer and Harley 2012). Additionally, the social model that preponderates "human rights" has resulted in the investment of the resources and energy in addressing the "first generation rights" – political and legal − of the persons with disabilities, while not sufficiently addressing the "second generation rights" such as social, cultural and economic agendas (Stein and Stein 2007). Against this backdrop, the two daunting challenges facing persons with disabilities in the South are: First, people with disabilities are compelled to live their lives with deteriorating physical and mental deformities and impairments that should be addressed through timely and proper medical interventions. Second, a vast majority of people with disabilities in the South confront what I would call an *existential angst*, resulting from the precarities and depravities of their living conditions.

Nine different versions of the social model of disability are debated and discussed in the Western disability scholarship (Mitra 2006).[1] The notion that underpins all those different versions of the social model is that human beings are extremely diverse in terms of mental and bodily faculties, functions and structures, and disability indeed results from the "disabling" infrastructures and environment that society has created without taking this human diversity into account. Some versions of the social model go so far as to glorify the bodily and mental disabilities, arguing that they are merely the manifestations of human variation or diversity that offers a unique perspective that should be valued and celebrated (Roush and Sharby 2011). I concede to the idea that disability in any form is merely a variation of humanity, but the

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[1] The nine models of disability include; the social model of the United Kingdom, the oppressed minority model, the social constructionist version of the United States, the impairment version, the independent living version, the postmodern version, the continuum version, the human variation version, and the discrimination version.

disadvantages this diversity creates are lived-realities that should not and cannot be left unattended. Moreover, what I find problematic is the idea of glorifying and romanticizing disability. Such a glorified or romanticized notion of disability, in my view, becomes yet another means of oppressing and exploiting persons with disabilities.

I contend that the medical model that some disability studies scholars and policymakers in the North have discarded can prove still relevant to the South. The medical model and the social model should work in tandem with each other in the South Asian context: only such an integrated, pragmatic and particularistic approach to disability can rightly gauge the predicaments facing the persons with disabilities and alleviate them: neither of the models alone is sufficiently compatible with combating the lived-realities of persons with disabilities in South Asia. If disability activists and civil society organizations relish only in the rhetoric of disability as a "human rights" issue and not pay ample attention to the physical and mental realities of the persons with disabilities, the "rights-based" discourse could ultimately be counterproductive. Disability is as much a subjective experience as a material reality, both of which are not adequately addressed by the social model. The corporeal needs should be addressed while attending to the metaphysical needs.

To write this article, I mainly draw on both primary and secondary sources. The primary sources include policy and legislative documents pertaining to disability, and the secondary sources consist of books, articles, reports and media outputs, including the firsthand observations of the realities with which persons with disabilities are forced to live in South Asia and the lived-experiences of the author in Nepal. Thus, the methodological approach I adopt in this article is what I would call an auto-ethnographical cultural analysis in the main. The main thrust of my argument is based on my understanding of disability that emanates partly from my own lived-experiences in Nepal and partly from the exposure to the Western disability scholarship. I witnessed how persons with disabilities, especially in remote parts of Nepal, were dehumanized and stigmatized as “wretched,” “worthless” and “sinful” lot both in their families and in society at large. During my work at the BBC Media Action in Kathmandu, in one of the episodes of a radio-cum-television programme called *Sajha Sawal*,[2] Indra Maya Gurung (2011), a member of the Nepalese parliament then, shared how she was battling against myriads of prejudices and discriminations for having a disability. If an educated female parliamentarian herself is victimized and discriminated against, what would the situation of uneducated, poor persons be like in remote areas of the country?

The article, divided into six sections, proceeds as follows. Followed by the first section that presents the main argument, methodology, and materials employed in this article, the second section charts out a brief overview of disability discourse and disability movements in a global context. The third section discusses global disability governance and examines to what extent it can address the issues of persons with disabilities in the South. The fourth section examines the disability praxis in South Asia, with a focus on situations of the persons with disabilities in Nepal. The fifth section discusses my argument that the medical model of disability that is already discarded in the North cannot be completely eschewed in the South Asian context. And, the sixth section concludes by proposing an integrated model of disability that can address the lived-realities of the persons with disabilities in South Asia.

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[2] *Sajha Sawal* is a weekly radio-cum-television programme in the Nepali language broadcast from the BBC radio and Nepal’s television channels, and the programme aims to give a voice to the voiceless groups of people by bringing politicians and policymakers into face-to-face conversations with the common people and thus exposing and exploring hidden issues and grievances of the marginalized and minoritized peoples.

2. Overview of Persons with Disabilities: Disability Discourse and Its Praxis

Disability is too complex and multidimensional to be precisely defined. Though seemingly uncomplicated, disability "is actually one of most difficult and controversial topics in disability studies" (Sherry 2008, 10). This conceptual complexity has indeed led to inconsistencies in empirical data on persons with disabilities. About 10 percent of the world's population − some six hundred million people − have a disability of some kind (Stein and Stein 2007). However, a joint report of the World Health Organization (WHO) and the World Bank puts the figures exceeding 15 percent of the world's population (Mitra et al. 2013). Yet in another report, persons with disabilities account for 20 percent of the world's poorest individuals, a phenomenon that exists in both developing and developed countries (Stein and Stein 2007). Persons with disabilities are often referred to as the world's largest minority, and experience high rates of poverty and poor health, low educational achievements and few employment opportunities (Meekosha and Soldatic 2011). They are often subject to violence and abuse, and have little or no knowledge of their rights as to how they can access services and seek legal remedies in situations their rights are violated (Meekosa and Soldatic 2011). Thus, persons with disabilities have always been in but not part of society (Rimmerman 2013, 9).

Anyone can become bodily or mentally dysfunctional at any point of time in life. In the present industrially and technologically driven society, people are far more likely to succumb to disabilities than ever before. Moreover, when people advance in age, the chances of having disabilities remain high. According to one report, most people are not born with disability, but acquire it at some point in life; only 15 percent of the population of persons with disabilities were actually born with some kind of disability (Jaeger and Bowman 2005).

Similarly, disability is a global phenomenon affecting the entirety of the world. It is not specific to any one particular country, creed, color, age, or race. Any person can have disability, although the chances of having disability for people from a politically, economically and culturally marginal group are high (Ghai 2009, 282). Thus, a vast majority of people (i.e. about 85-90 percent of the global population of the persons with disabilities) is estimated to have been residing in the developing world (Hiranandani and Sonpal 2010). The United Nations (UN) estimated that more than 1.3 billion people are living in abject poverty in the South, 600 million of which have some form of disability (Hiranandani and Sonpal 2010). The fact that such a large segment of the population of persons with disabilities resides in the developing world implies that they should be fighting against a combined burden of poverty and disability. The situations of persons with disabilities in developing countries therefore become more complicated due to pervasive poverty, discriminatory legal and institutional structures, ignorance, inaccessible physical infrastructures, and the unavailability of proper and timely medical interventions.

Conceptualizations of disability are influenced by what Haegele and Hodge (2006) call the “cognitive authority” that refers to professional organizations and individuals who have the power over knowledge within a particular field (193). In the North, disability was originally defined by the Western Judeo-Christian religious discourses (Humpage 2007, 216). The medical model was legislatively consolidated especially after the World War I that left hundreds of thousands of people wounded or maimed for life limiting their physical, sensory or intellectual functions (Toboso 2011). The medical model of disability locates disability on the individual’s body and conceives of it as an individual impairment that needs to be corrected and “cured” through medical interventions and rehabilitation (Humpage 2007, 216). The medical model links disability with conditions and length of illness or impairment of functional outcomes and the role of the physician is to assess and determine the medical deficit associated with the impairment (Rimmerman 2013, 25). Thus, the two features of the medical model are: first, the alleged causes of the disability are medical in nature; and second, for persons with disabilities to be able to contribute to society, they need to be rehabilitated or normalized, and thus integrated as much as possible with people of normal abilities (Toboso 2011).

The medical model of disability has been strongly criticized in disability scholarship and praxis in the North since it locates disability on an individual's body/mind. The medical model has, therefore, been replaced by the social model that perceives disability as something that is not intrinsic to the individual but as a phenomenon resulting from the social environment that is not friendly to persons with disability. The social model deems that, even though impairments exist at the individual level, disability is the direct result of society's failure to account for the needs of persons with impairments and their functional requirements (Toboso 2011). The social model differentiates "impairment" (physical or mental condition) from "disability" (negative social reactions or prejudice with those impairments) (Sherry 2008; Haegele and Hodge 2016, 197). This radical change in the way people look at disability has only been possible following a series of movements by persons with disabilities, activists and researchers in different periods and places (World Report on Disability 2011). Especially since the 1960s and 1970s, people's perceptions of disability completely changed, prompted largely by the self-organization of persons with disabilities, and by the growing tendency to see disability as a human rights issue (World Report on Disability 2011, 3).

The social model discards the notion of prioritizing government social services for persons with disabilities, demanding opportunities to develop their own independence and skills (Toboso 2011). This framework maintains that the socially engineered environment and the attitudes reflected in its construction play a central role in creating disability (Stein and Stein 2007). Disability does not lie in the body of the person with disability, but in the mindset of the so-called “able” people and the structures created by them. Disability is therefore considered as a social oppression, refocusing the agenda away from cure, treatment, care and protection to acceptance of impairment as a positive dimension of human diversity, and to the rejection of a social norm that results in exclusion (Kayess and French 2008).

The “diversity model” or the “functional model” looks at disability in terms of functioning–physical, mental, and sensory; human beings are diverse, and all societies should view this diversity as a source of enrichment (Toboso 2011). Similarly, the “human variation” model argues that “the physical, cognitive, sensory and emotional make-up of the individual was not the problem, but was a problem only because social institutions and human-made environments were created without taking into account the characteristics of all people” (Asch 2004, 13). The different versions of the social model remove “some of the pejorative ‘specialness’ and ‘exceptionality’– some of the ‘us’ and ‘them’ quality – from disability and reminds everyone that human beings come in a variety of physical, mental and emotional make ups” (Asch 2004, 14). Overall, disability does not lie on the “body” of the person with disability but on the “disabling” environment created by society.

3. Global Disability Governance

The UN has been concerned with disability issues for a long time. The General Assembly and the UN Economic and Social Council adopted a series of resolutions during the 1950s and 1960s directed both at preventing future disabilities and at rehabilitating existing disabilities (Stein and Stein 2007). The year 1981 was celebrated as the International Year of Disabled Persons (IYDP) by the UN with the theme of ensuring full participation and equality for persons with disabilities. A number of other international documents have stated that disability is a human rights issue, including the World Program of Action Concerning Disabled People (1982), the Convention on the Rights of the Child (1989), and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993) (Stein and Stein 2007). The UN defines disability as "[a]ny restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being." (as cited in Wendell 1996, 13). The UN also defines two other categories: an "impairment" as "[a]ny loss or abnormality of psychological, physiological, or anatomical structure or function" and a "handicap" as a "function of the relationship between the disabled persons and their environment" and it occurs when they "encounter cultural, physical or social barriers which prevent their access to the various systems of society that are available to other citizens" (as cited in Wendell 1996, 13). Thus the UN has recognized a distinction between disability, impairment and handicap.

For these conceptual shifts to develop, the civil rights movement in the 1960s helped the persons with disabilities and disability activists to become more organized and raise voices collectively for their rights (Rimmerman 2013). Against this backdrop and following a series of movements launched by persons with disabilities around the world, the UN passed the Convention on the Rights of Persons with Disabilities (CRPD) in 2006 (Megret 2008). A total of 189 countries have ratified the CRPD so far, including countries from South Asia (WHO and World Bank 2011). The CRPD defines disability resulting "from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others" (WHO 2011, 4). This definition marks a radical shift in that the locus of disability is shifted away from the body of the person with disability. We must then examine the barriers resulting from interactions between the person with a disability's bodily or mental impairments and the attitudes and environment around them. This definition takes into account both the physical reality and the barriers that prevent them from taking part in society like others. Additionally, the document was also a significant achievement in that it clearly outlined the civil, cultural, political, social, and economic rights of persons with disabilities (WHO 2011; Meekosha and Soldatic, 2011).

Following the CRPD, many countries in the world have "developed national disability strategies that set out how people with disabilities are to be included in domestic society as fully participating citizens through measures to improve access to education, employment, transport, housing, income, personal support" (Flynn 2011,1). South Asian countries, including Nepal and India, are also signatories to the document; Nepal ratified the treaty on June 3, 2008 and India on March 30, 2007. Nonetheless, no remarkable progress has been achieved even towards addressing the very fundamental survival needs of persons with disabilities, let alone their more nuanced, metaphysical issues and concerns.

In the development discourse, the issues of persons with disabilities have remained largely ignored or underemphasized, and more so in developing countries. Power creates a visible and audible discourse, and since persons with disabilities lack power, they are often not heard. For instance, the UN Millennium Development Goals (MDGs) that aimed to massively reduce poverty from the face of the globe by 2015 by addressing the needs of the world's poorest and most marginalized people failed to include disability into the agendas (WHO 2011). Is it because persons with disabilities, as a scattered population all over the globe with diverse problems, do not have a single homogeneous identity, or an organized group similar to those of women or racialized peoples to exert collective pressures? Is it because persons with disabilities are the voiceless subalterns that the "able" in power relish in oppressing? What indeed prevented the MDGs from prioritizing disability as one of its top agendas? The absence of the disability agenda from the MDGs was a serious drawback in global disability governance.

Addressing the drawbacks of the MDGs framework concerning disability issues, the Sustainable Development Goals (SDGs) explicitly state that persons with disabilities are "[p]eople who are vulnerable must be empowered. Those whose needs are reflected in the Agenda include all children, youth, persons with disabilities (of whom more than 80 percent live in poverty), people living with HIV/AIDS, older persons, indigenous peoples, refugees and internally displaced persons and migrants" (as cited in Brolan 2016, 7). In my view, two major challenges that should be overcome to realize the SDGs in the context of the South are *poverty* and *governance*.

Approximately 80% of the world's population with disability (i.e. about one billion people with disabilities) live in the South. Disability is both a cause and a consequence of poverty (United Nations 2011). Disability causes poverty and poverty in turn creates and exacerbates disability. Disability has a "bidirectional link to poverty: disability may increase the risk of poverty, and poverty may increase the risk of disability" (Brolan 2016, 3). Thus persons with disabilities in the South are trapped in a vicious circle that is not easy to break free from, and combating poverty should constitute an integral aspect of disability governance. Disability should therefore be an important development issue.

In global governance, the notion of s*ubsidiarity* refers to the "principle of locating governance at the lowest possible level" and this principle deals with those individuals and groups that are affected by the rules and decisions adopted and enforced (Slaughter 2004, 30). Global disability governance should act, based on the principle of subsidiarity, and any global disability governance frameworks, policies and actions should be guided by national, regional, and local needs. The "lowest possible level" in the context of disability governance would be the national level, and it should be based on "practicability" and not "a preordained distribution of power" (Slaughter 2004, 30).

In the Nepalese context, persons with disabilities and disability activists hailed the ratification of the CRPD by the government in 2008. The Nepalese government has also ratified a number of other international conventions and treaties that in principle promote and protect the rights of persons with disabilities.[3] Even in the newly adopted constitution of Nepal[4] (2015), Article 47 under the Right to Social Justice states: "people who are physically or mentally incapacitated or citizens of backward regions shall have the right of participation in structure of the State and public service on the basis of inclusive principles" (Eide, Neupane, and Hem 2016). The same Article also clearly states that every person with disability shall have the right to free education up to the higher-secondary level (Stein and Stein 2007). The constitution has also enshrined health rights of many socially and culturally disadvantaged groups of people such as persons with disabilities, *dalits*,[5] indigenous communities, *madhesis*,[6] and sexual and gender minorities, and these constitutional provisions are compatible with the SDGs (Simkhada et al. 2015). All of these provisions in the new constitution are laudable initiatives.

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[3] For example, the government of Nepal ratified the Convention on the Elimination of Discrimination against Women in 1991, and the Convention on the Rights of Persons with Disabilities in 2010.

[4] The Constitution of Nepal came into effect on Sept 20, 2015, replacing the Interim Constitution of 2007. The constitution was drafted by the second Constituent Assembly following the failure of the first Constituent Assembly to write a constitution in its mandated period

[5] In the Hindu caste system, the *dalits* belong to the bottom of the sociocultural ladder after Brahmins, *Chhetris* and *Baishyas*. The *dalits*, who are also called "*Sudras*," are ostracized as untouchables; they are not allowed to enter the houses of the so-called high-caste people and are deprived of even going to the public places like temples, mosques, wells and taps; the so-called upper-caste people do not even eat food or drink water touched by the *dalits*.

[6] The Madheshi are Nepali people who live in the southern part of Nepal, which is also called the Terai region, mostly a flatland and socially, culturally and geographically distinct from the hills and mountains, though it does not refer to a homogeneous ethnicity. According to the population census in 2011, Terai occupies 17% of the total area of Nepal, and has 51% of the population.

Nonetheless, the discrepancies between policies and actions are daunting challenges that the Nepalese government and other governments in South Asia should battle against. Having rights and privileges written in laws and polices is one thing, but it is quite another to bring them into practice. The South Asian context has failed to move beyond mere catchy slogans (Ghai 2009, 281). The most critical challenge is to scrutinize the execution of the existing legal and constitutional provisions and expedite further relevant steps (Eide, Neupane, and Hem 2016). For instance, persons with disabilities in Nepal are constitutionally entitled to receive information and public services through mediums that are accessible, but almost none of the government agencies have provided their information in formats friendly to persons with disabilities (Eide, Neupane, and Hem 2016). Similarly, the government policies ensure free training and employment for persons with disabilities by allocating them 5 percent reserved quotas; however, this provision has not yet been implemented (Paudel et al. 2016).

4. Disability and South Asia: Nepal a Case in Point

The disability movement in South Asia is still at its nascent stage, still battling against the "morality model" that considers disability resulting from one's "moral lapse and brings shame to the individual and to the family" (Das 2010, 132). Disability is conceived as a "*karmic"* payment for "the past sins, as trials and tribulations that one must bear in this life" (Parekh 2007, 154). Disability is "seen as a stigma; the outward manifestation of inner evil or depravity," and the person with a disability is regarded as a "blemished person, to be punished, segregated and isolated at worst, and avoided and pitied at best" (Das 2010, 132). Although the UN distinguishes "disability" from "impairment" and "handicap," the South Asian disability praxis is firmly grounded on destiny, and it "does not differentiate between impairment, disability or handicap and uses the terms synonymously" (Ghai 2002, 91). An individual with any kind of impairment is considered "disabled." Although the medical and social models are discussed in the Northern disability discourse, there are three models of disability in practice in the South Asian context – the moral/religious model, medical model and the social model (Rimmerman 2013, 23). The "moral model" of disability perceives disability as an act of God and a sin, or a curse inflicted upon an individual or family by an external, supernatural force (Rimmerman 2013, 24).

In Nepal and much of South Asia, what prevails in practice is the "charity model" of disability. People with disabilities are understood against so-called "normal" people and are comprehended as "abnormal," "deviant," and "people with special needs" (Ghai 2009, 282). Most persons with disabilities in Nepal live on charity, at the mercy of the so-called "able-bodied" people. Disability is viewed as a punishment for things a person committed in a past life (Lansdown 2003); a bad *karma* (as cited in Kamal 2011) and as a penance to the past sins (Panthi 2004). People in Nepal still strongly believe that disability is due to sins of the past, fate and God. Disability is, therefore, something to be endured and paid back for the sins committed in previous lives. In a survey, more than 50 percent parents of the children with disabilities reported that the disability of their children was due to fate and God's will, and such stereotypes prevent people from seeking timely medical treatment for persons with disabilities.

People with disabilities with no eyes, or hands, or legs begging for alms are common sights in urban Nepal – many live on the meagre food that kind souls passing by throw at them while clutching their noses. Civil society organizations, especially operated by religious groups, look at them as objects of pity. Rich families are sometimes found donating food or clothes to persons with disabilities around temple premises. Having a member with a disability in the family is often considered to be a disgrace. Thus, persons with disabilities are among the most deprived populations in Nepal, historically excluded from mainstream politics and socio-economic development (Puri 2015). Not only temples and shrines and community charities, but even the government looks at persons with disabilities as objects of pity and charity. Even when the government initiates any programmes for persons with disabilities, it is always out of an altruistic intention, and it looks as if "the government is doing them a special favor"[7] (Lamichhane 2012(b), *translation mine*). In South Asia, charity and philanthropy thus remain the "predominant response to the predicament of disability" (Ghai 2002).

In India likewise, the "charity model" was in principle replaced with a "human rights-based" model by the Indian government through the endorsement of the National Policy on Disability in 2006, which emphasized the provision of "equal opportunities in education, economic independence, rehabilitation and the removal of social and environmental barriers to full participation of disabled people in Indian life (Buckingham 2011, 422). In practice, however, the "charity model" predominates, and persons with disabilities lack basic support such as access to social safety nets, education, health services, and gainful employment (World Bank 2003).

The impaired body is an object of abjection and negation, which is reflected in people's reluctance to part from their body organs even after death (Parekh 2007). The "[l]abels such as *bechara* (poor thing) accentuate the victim status for the person with disability, and the roots of such attitude lie in the cultural conception that views an impaired body as resulting from the wrath of fate, and thus beyond redemption" (Ghai 2002, 91). Such an attitude has much deeper roots originating from the "cultural matrix that builds upon and emanates from the laws of the

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[7] Kamal Lamichhane in a television interview argued that whatever the government does for disabled people has this attitude, manifested through policymakers.

Manusmrti,"[8] which denounce persons with disabilities. The *Manusmrti* states that an ideal king should always abstain from "idiots, the mute, blind, or deaf; animals and very old people; women, barbarians, and those who are ill or who lack a part of the body" (Doniger and Smith 1991, 191) at the time of taking counseling on state affairs.

Persons with disabilities are chastised by families for bringing about loss of social prestige in the family (Panthi 2004). Above 70 percent of persons with disabilities in Nepal live with this stigma, which is more entrenched in rural areas (Lamichhane 2011). How stubbornly stigmatized disability in society is becomes manifest from the fact that persons with disabilities are kept out of sight in fear of social ostracism and contempt; so much so that people feel disgraced even to admit that they have a person with disability in the family. If people have a person with disability in the family, they want to keep him/her in a shelter for two reasons: first, this relieves them of being constantly reminded of the stigma of having a "sinful" person in the family, which is a matter of great shame; and second, having a family member with a disability adds additional economic burden to the already poverty-ridden family. For instance, lepers in some parts of Nepal are still ostracized and kept away from home in a segregated place. In many cases, people who have a person with disability in the family are looked down upon in society and even prevented from participating in social and especially religious/ritual activities.

The population census of Nepal in 2011 reports that persons with disabilities constitute only 1.94 percent of the country's population while the Central Bureau for Statistics (2011) states the figure to be 2 percent (Eide, Neupane, and Hem 2016). However, a joint report of the WHO and World Bank finds the disability prevalence rate in Nepal to be 15 percent (Eide, Neupane, and Hem 2016). Disability issues do not come under the top priority of the State, and

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[8] The Manusmriti, or Laws of Manu, is the most important and earliest text of Hinduism. Manu, progenitor of humankind, discourses about social system with seers.

are even excluded from official statistics (The World Bank and Disability in South Asia 2003, 2). Compared to the global disability data, the number of persons with disabilities in Nepal is lower, since only severe forms of physical, mental and emotional conditions are considered disabilities (Paudel et. al. 2016). Also, people feel reluctant to identify themselves or their family members as having a disability due to stigma in the society. The number of people with disabilities in Nepal is indeed increasing due to conflicts, disasters, malnutrition and the HIV/AIDS pandemic (The World Bank and Disability in South Asia 2003, 2). The Maoist armed conflict[9] resulted in the deaths of 12,000 people and left many injured who now have long-term physical disabilities (Paudel et al. 2016). Thus the lack of consistent, reliable data on disability in Nepal is a critical barrier to devising sound policies and implementing them.

One problem with the social model of disability is that it does not take into account various intersections that exist even within persons with disabilities. The social model ignores the intersectionality between different forms of oppression such as racism, sexism and classism (Haegele and Hodge 2016, 198). For instance, children with disabilities are treated even worse in Nepal; only a limited number of children have access to formal education, and even those who do drop out of school sooner (Eide, Neupane, and Hem 2016). Similar to the previous years, the enrollment of children with disabilities in primary and secondary education continued to decline in 2014, and 85 percent of all the school drop-outs in Nepal have some form of disability (Human Rights Watch 2015. In a survey, the parents of children with disabilities expressed worries that their children felt humiliated, ignored and discriminated by friends and teachers at

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[9] The Maoist armed conflict, which is called the People's War by the Maoists, was an armed conflict between the Nepalese government forces and Maoist rebels; the conflict lasted from 1996 until 2006. The war was launched by the Communist Party of Nepal (Maoist) on 13 February 1996, and some of the aims of the conflict include: abolition of the monarchy, end of caste discrimination and corruption and the establishment of a republic. The Maoist conflict came to an end following the Comprehensive Peace Accord signed between the State and the Maoist party on 21 November 2006.

schools, and experienced difficulties due to inaccessible physical infrastructures and the means of education (Eide, Neupane, and Hem 2016).[10] Children with disabilities in particular suffer under inhuman treatment even in their homes (Eide, Neupane, and Hem 2016). Parents in some rural parts of Nepal tether their own children with disabilities on poles with ropes like beasts while they go to work in fields. According to a report, an eleven-year-old boy with mental and physical challenges by birth, was trapped in a washroom for six months while parents went to work in the fields ("Disabled kids in sorry state" 2013). Poverty and social attitude were responsible for preventing them from receiving medical treatment ("Disabled kids in sorry state" 2013). When asked, the boy's mother said: "We are poor and have to work as laborers far from the village, so how can we leave him free in the house?"

Disability and poverty are inextricably interwoven lived-experiences in Nepal and much of South Asia. Disability is both a consequence and a cause of poverty. Disability is linked to poverty and deprivation at individual and household levels (Mol et al. 2014). Nepal was ranked 157 in the Human Development Index in 2011, which implies a "low level of human development"; moreover, a majority of persons with disabilities in Nepal are very poor (WHO 2011). In this situation, the economic burden of persons with disabilities falls exclusively on their families. An average Nepalese worker earns $1.15 USD while the annual cost of caring for a person with disability exceeds $375 USD (Kecskes 2015). The additional economic burden pushes the family into a cycle of poverty (Kecskes 2015). The Nepalese government provides a monthly allowance of $3 per month for people above 16 years with partial disability and $10 for those with severe disability (Paudel et al. 2016). The differences in lifestyles based on religion,

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[10] Eide, Neupane, and Hem mention a number of other problems facing the children with disability in Nepal that include no inclusive classroom environment, lack of disability friendly curriculum and teaching materials, insufficient assistive devices, no use of modern technology in classrooms, and negative attitudes on the capability of children with disabilities.

and family and marriage structures also create specific challenges among persons with disabilities that are largely absent from the disability discourse today (Hussain 2005, 525). The most daunting challenge to addressing problems of persons with disabilities in Nepal is invariably poverty (Subedi 2013).[11] Additionally, households with persons with disabilities in the family are more likely to own less land and earn less income than households without a person with disability (Saleeby and Yadama 2005). Despite the interconnectedness between disability and poverty, there have been inadequate efforts in linking development and poverty reduction with disability (United Nations 2011).

A majority of people with disabilities in Nepal are deprived of accessing basic medical services, let alone opportunities for self-advancement (Lamichhane 2011). 68.2 percent of the country's population with disabilities has no education (Lamichhane 2011). In line with its international obligations under the CRPD, the Nepalese government has made a commitment to inclusive education, but has failed to effectively implement the policy due to a lack of funding, inadequate infrastructures and competing priorities. Persons with disabilities are treated as "second-class citizens" in sectors such as health, education, economy and employment opportunities (Panthi 2004). Social stigma and ignorance result in discrimination and the exclusion of persons with disabilities from society, education, and work, leading to poverty and poor quality of life (WHO 2011). Similarly, the inaccessibility of health facilities, and the inability and unwillingness of health professionals to communicate well with persons with disabilities prevents them from receiving health and other public services as much as other individuals do (Paudel et al. 2016). While most developed countries have created a barrier-free society ensuing access to work and other facilities for people with disabilities, Nepal is still

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[11] Tika Dahal, General Secretary of National Federation of the Disabled Nepal said this in an interview with the author.

struggling to fight against the existing discriminatory provisions and deep-rooted social stigma (Lamichhane 2011). Neither does the country have any comprehensive anti-discrimination laws on disability (Lamichhane 2011). What is critically important for Nepal is to develop legal instruments that can address the local needs of persons with disabilities such as equal access to public services first (Lamichhane 2011).

Women with disabilities are triply jeopardized, for their gender, poverty and disability (NDWA 2013). However, the social model fails to account for differences in gender among individuals with disabilities (Haegele and Hodge 2016, 198). Violence against women with disabilities lies at the intersection of gender and disability, and is fostered by a culture that devalues, and systemically disempowers, both women and people with disabilities (Puri et al. 2015). Women with disabilities are vulnerable to multiple forms of violence including physical violence, exclusion, rape and incest (Puri et al. 2015; Subedi 2013). They are being subjected to violence even in their own homes (Puri et al. 2015). Over 80 percent of women with disabilities in Nepal have acquired their disability through abuse, accidents, disease (including obstetric complications), and environmental factors (Subedi 2013). Since the girls with disabilities have a feeble chance of being married, parents feel burdened and this pressure often manifests through hatred towards girls with disabilities (Subedi 2013). The parents see the birth of a "disabled child as a punishment for sins or a test from God" and this in particular promotes feelings of inadequacy, especially for mothers (Hussain 2005, 527).

The deep-rooted practices of stigmatization, humiliation and stereotyping of persons with disabilities engender far-reaching, wider psychological ramifications and repercussions that are far beyond the gaze of the States, activists, and the civil society organizations working in the disability areas. This critical issue pertaining to the psychological aspects of persons with disabilities has not been sufficiently raised in the disability discourse. An integral and internal part of the psyche of persons with disabilities is constituted by the experience of oppression and is seen to be without any social or political ramifications (Asch 2004). The psychic wound is something that is intangible but pernicious. According to a report, Nepal has the second highest rate of DALYs (disability adjusted life years) caused by depression in the world, trailing only the United States (Kecskes 2015). Persons with disabilities in Nepal are reported to have committed suicide in different parts of the country. Research on disability and depression has consistently shown that suicide rates among persons with disabilities are high. The repeated social message has it that life with a disability is miserable, and as a result, people with disabilities internalize oppressive images, making it extremely difficult for them to hope for something better in their lives, and at that point, suicide becomes the only option (Kecskes 2015).

I argue that the cases of suicide can be related to the sense of *hopelessness* that persons with disabilities are confronted with, and that in turn creates the sense of *self-contempt* and *meaninglessness* in them, resulting from their continued dehumanization and stigmatization, combined with depravities and precarities of their living conditions. The persons with disabilities, who become the objects of humiliation and dehumanization, develop the sense of self-hatred that might ultimately result into a kind of *nihilism*,[12] an attitude that looks on life with meaninglessness and hopelessness. A majority of persons with disabilities, who are struggling to survive against all kinds of vicissitudes, humiliations and ostracisms, are living with the sense of what I would like to call *self-contempt* and *nihilism*. However, the sense of nihilism and self-contempt confronted by persons with disabilities has eluded the focus of the disability discourse

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[12] I borrow these terms nihilism and self-contempt from Cornel West; West in the book *Race Matters* (1993) uses these words to describe the psychosocial situations of the Afro-American people. In this article, I use the words to describe the sense of hopelessness among persons with disabilities.

in South Asia in general and Nepal in particular. The civil society organizations which are working in the field of disability are not paying attention to this issue. The urgent need of the time is to pay attention to both physical and psychological issues that persons with disabilities are going through in Nepal and in the entire Indian subcontinent.

In the international development discourse, it is argued that people with disabilities are erroneously perceived as people whose lives are defined by medical and rehabilitative needs, or as individuals who were considered to be appropriate recipients of social and economic support (United Nations 2011, vii). Albeit ideally desirable and theoretically appropriate, the priorities of persons with disabilities in Nepal should lie elsewhere in the present context: the medical and social services to guarantee *survival*. The task of battling against poverty so as to bring medical care to the easy access of persons with disabilities should appear prominently prior to creating barrier-friendly environments (Paudel et al. 2016). Empowerment of persons with disabilities through strategies such as medical interventions, confidence building, skills, knowledge, and mobility is essential (NORAD 2012).[13]

As stated above, the disability discourse in the North has shifted its focus from the medical model to the social model, emphasizing the need to fix the social environment. The medical model is criticized due to the influence that medical professionals have over the treatment of persons with disabilities (Haegele and Hodge 2016, 193). The medical model "conflates individuals with disabilities with the sick role and discusses disability in a deficit model orientation" (Mitra 2006). Medical professionals act as gatekeepers in society and use diagnoses and labeling to determine who should receive social services and state benefits

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[13] The NORAD report also emphasizes on empowering persons with disabilities with hope, assertiveness, knowledge, skills, tools, communication channels, and legal mechanisms so as to enable them to improve their lives, claim their rights as stipulated in national laws and the United Nations conventions, and supporting and demanding that those in power respect and respond to these legitimate claims should be the primary objective.

(Haegele and Hodge 2016, 196). However, what intrigues me is: To what extent can this be justified in the context of South Asia in general and Nepal in particular, where what a huge segment of people with disabilities desperately need today is medical treatment/intervention first? Is it the body or the spirit that comes first? Is it the representational question or the survival exigency? The debates of eschewing the medical model of disability in the South Asian context must be a subject of academic and scholarly ratiocination, since the medical model "has significantly alleviated many discomforts with regard to the impairments" (Das 2010, 132). What is erroneous is the act of blindly transposing the Western notions of disability discourses that do not address "the lived experience of disabled people" in South Asia (Meekosha and Soldatic 2011). In a place where most people with disabilities are deprived of enjoying even the fundamental mobility rights and medical care, the debates on disability rights as "human rights" issues most likely remain confined to the rhetoric and not get translated into action. Particularly in Nepal, where people with disabilities are deserted on streets like strays, what meaning do different Western versions of the social model of disability really have for them? In Nepal and South Asia therefore, both models are necessary for the other's survival, and they can be considered "two sides of the same coin" (Marks 1999, 611).

5. Integrated Approach: The Medico-Social Model

Persons with disabilities in any part of the world are an "other-ed" and oppressed group. The dominant meanings attached to disability even in the developed world "still remain firmly rooted in the personal tragedy theory" (Oliver and Barnes 2012, 11). Nonetheless, unlike the South where people with disabilities are deprived of even the very basic survival needs such as food, medicine and housing, the developed world has comparatively fared better and is more congenial to persons with disabilities. Both theoretically and pragmatically, the issues and needs pertaining to the body and the soul have been emphasized in the North, and the States are able to attend to the basic needs of persons with disabilities.

However, the social model in the South Asian context “exists largely on paper and in few urban pockets” (Das 2010), and all people with disabilities are considered handicaps. The prevailing social attitude conceives of disability as an act of sin committed in past lives, and the stigmas attached to persons with disabilities and the continued physical or mental agonies are sheerly alarming. In Nepal for instance, a large number of people with disabilities are deprived of medical treatment due to many reasons: first, they lack awareness that impairments can be treated; second, they cannot afford to pay for medical treatment due to poverty; third, the health institutions are poorly equipped or the staff unqualified (Panthi 2004). In such a context, the “human rights-based” social model of disability that emphasizes considering “which people cannot perform which activities in given environments and question how to modify the environments so that they are not disabling” (Asch 2004, 14) carries merely rhetorical hollowness. Moreover, the different social models of disability that urge persons with disabilities to feel proud of their own idiosyncratic, unique life-experiences that the other “able-bodied” people are deprived of do not at all address the issues and problems facing persons with disabilities in South Asia.

The disability discourse in South Asia should focus on the very fundamental issues of human survival. First and foremost, the survival issues should be addressed. The medical intervention does not necessarily ignore people’s diversities; it simply means that the physical and mental deformities that the people have and the debilitating health conditions resulting from those deformities should be tackled prior to addressing more nuanced and subtle metaphysical needs. When physical problems or medical needs are taken care of, and persons with disabilities are prevented from being bestialized and dehumanized, and then comes the question of providing them with equal opportunities. The emphasis on disability as a "civil rights" issue may ensure equality in theory, but not in practice (Stein and Stein 2007). The governance models of disability should first address their survival angst by treating them as humans, not like animals. In Nepal's context, the policy framework must deal with disability issues as an important part of the social, economic and political agenda (Lamichhane 2011).

The two critical issues that prominently stand out are: First, the medico-social model of disability that integrates medical interventions with ensuring barrier-free environments, and anti-discriminatory legal and institutional structures, should be the modus operandi of disability governance. Second, the civil society organizations and activists, including disability organizations, should focus on exorcizing the sense of *self-contempt*, *worthlessness* and *meaningless*. Marks proposes a model that defines disability as "the complex relationship between the environment, body and psyche, which serves to exclude certain people from becoming full participants in interpersonal, social, cultural, economic and political affairs" (Marks 1999, 611). Unless these twin challenges are duly addressed, all other activism and scholarly discourses will engender no concrete output to alleviating the debilitating physical and mental impairment and deformities and the accumulated sense of self-hatred and hopelessness. Both the medical model and the social model should work in tandem with each other; the "medical model" should work from the bottom up, whereas the social model should adopt the "top down" approach. The medical approach should focus on ameliorating and addressing the immediacy and urgency of the now and here, reducing impairments and improving/compensating bodily functions. The social model should simultaneously focus on creating barrier-free environment to ensure inclusion and participation of persons with disabilities in all sectors of social life.

Besides providing medical and other social services and creating a barrier-free society for persons with disabilities, it is also critically important to prevent social-cultural-economic structures and institutions from "disabling" people or from exacerbating the impairments of persons with disabilities. The movie *Taare Zameen Par*[14] powerfully illustrates not only how the traditional educational institution and its pedagogy structured on "able-bodied" grand narratives nearly destroy the film's protagonist but also how his situation further exacerbates when the the social-cultural institutions exert force on him in collusion with the overpowering capitalism in the Indian society.

The social model of disability is undoubtedly based on equality and human rights of all human beings in no matter what bodily and mental variations or diversities they are born with. It perceives that disability lies in the society's failure to take into account the needs of those diverse groups of people. Therefore, disability is not a bodily notion; it is rather a cultural and political construct like gender or race. Nonetheless, the different versions of the social model of disability focus only on the "first generation rights" and the "second generation rights" of persons with disabilities are totally ignored. In the South Asian context, therefore, including Nepal in particular, the social model discourse orients more on addressing legal and institutional barriers and less on focusing on material and existential problems of persons with disabilities such as

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[14] *Taare Zameen Par* (Like Stars on Earth) is a 2007 Indian drama film produced and directed by Aamir Khan. The film features an eight-year-old boy in the role of Ishaan, a dyslexic boy. The film explores the boy's life and imagination: he excels in art but performs poorly academically and that leads his parents to send him to a boarding school, where his condition further deteriorates until an art teacher comes into his life.

proper and timely medical service, food, clothes and housing that first ensure the survival of persons with disabilities.

6. Conclusion

In conclusion, I have examined the disability discourse and its praxis in South Asia in general and Nepal in particular in the light of global disability governance and the Western disability scholarship. I have examined disability issues in the South Asian context from two angles: the micro (lived-experiences/challenges facing persons with disabilities in South Asia) perspective and the macro (global laws/global apparatuses of disability governance) perspective. I have discussed the nexus/(in)compatibility between the discourse embedded into the global disability policy documents and the lived-experiences of persons with disabilities in South Asia with a focus on Nepal. The article has thus put together the academic disability discourse, disability governance and the lived-realities of persons with disabilities in South Asia.

Although the "medical model" has been criticized and discarded by some scholars and policymakers in the North, against the backdrop of the South Asian disability praxis that places persons with disabilities on the same pedestal as animals, I have argued that the governance models of disability in South Asia should address survival needs and existential questions. For this, an integrated "medico-social model" of disability can attend to the lived-challenges facing people with disabilities in South Asia. The preponderance on the "human rights" model of disability results in the "first generation rights" of persons with disabilities but fails to sufficiently address the "second generation rights" that call forth urgent solution (Stein and Stein 2007). Although the medical model of disability is criticized in the North and the medical and social models of disability are considered as dichotomous concepts, each of the models has something important to contribute in understanding disability (Blustein 2012). Additional models, Mitra (2006) argues, can be developed as an extension of these two models. I do not intend to say that the social model and the “rights-based” approach to disability are wrong. What I have emphasized is that the medical model and the social model should work in tandem with each other in the South Asian context: only an integrated approach to disability can rightly address the lived-experiences of persons with disabilities in South Asia in general and Nepal in particular.

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