

BRIEF REPORTS

Accessibility to Power: Framing of the Disability Rights Movements in India and Nepal

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ABSTRACT

Purpose: *This paper explores the effect of inherent social inequalities on disability rights movements and their political activities in India and Nepal. The situation for persons with disabilities is similar in both countries. Many social and cultural phenomena coincide, and laws and policies are currently being formulated in line with the human rights agenda. In order to understand the current situation and the envisioned future for persons with disabilities, it is important to probe how, and under what circumstances, the disability issue is framed.*

Method: *Purposive sampling was used to access outspoken activists in Kolkata in India and Kathmandu in Nepal. Semi-structured interviews were conducted, coded according to recurring themes, and analysed with Nancy Fraser's theory on misrepresentation of social movements along with literature on framing. Though only 7 interviews were conducted (a limitation of the paper), together with informal discussions and previous knowledge they provided a sufficient overview of the social movements in the two countries.*

Results: *This paper increases the knowledge on the two social movements, and provides interesting case studies on how persons with disabilities engage in political activities in the Global South. The rights-based approach has a strong influence within both movements, and appears to be the main strategy adopted by them.*

Conclusions and Implications: *The Indian and Nepalese disability rights movements are affected by social inequalities. It seems as though the urban middle-class and their needs colour the movements and its framing. Further research is needed to probe what implications these inequalities have for the situation of persons with disabilities.*

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INTRODUCTION

Participation in political activities is important since it is a strategy to gain and exert influence in society. However, persons with disabilities in the Global South usually have little access to political activities, since living with a disability in the Global South is often linked to low literacy and poverty (Opokua et al, 2016). In this context, most persons with disabilities have few resources to articulate their needs and claim their rights and entitlements. The same scenario is found in India and Nepal, where political participation is generally limited to advocating for their rights within the countries' disability rights movements. Nonetheless, civil society groups are a vital part of political life in India and Nepal, and the disability rights movements are actively striving for the implementation of their rights.

The situation of persons with disabilities in India and Nepal is strikingly similar. Both countries have ratified the United Nation's Convention on the Rights of Persons with Disabilities - CRPD (UN, 2016). In line with the CRPD, the Indian Parliament passed a new Disability Rights Law in December 2016, and a similar Act is pending in the Nepalese Parliament. Even though persons with disabilities still face discrimination in their everyday life, improvements are being made at a policy level. These changes are an effect of tenacious advocacy work and pressure from the disability rights movements. They signal that there is a will to change the situation among government authorities and politicians, and these policy changes are to be seen as a sign of partial success.

The disability rights movements of India and Nepal are not based on open protest and social disruption, often defined as contentious politics (Tarrow, 2011). Instead, the movements make use of awareness-raising and advocacy work among the public and government authorities. The intention of these strategies is to change the understanding of persons with disabilities and their capabilities among decision- and policy-makers. However, much like contentious politics, the advocacy work of the two movements needs to be seen as a dynamic process that intersects with various social and political mechanisms (McAdam et al, 2001).

It is also important to keep in mind that divisions occur within social movements even though they often claim to be unified (ibid, 127). The members

of the disability movements in India and Nepal have various socio-cultural backgrounds, opinions and needs. Ingstad (2007) points out that there is a risk of elite-capture in the implementation of human rights for persons with disabilities in the Global South. In other words, the urban-based elite, who are well-connected with international and national organisations and institutions, set the agenda for the movement. This is not unique for the disability rights movement but a common phenomenon among civil society groups in South Asia (cfr. Bhatta, 2012; Robins, 2012).

It is important to keep in mind that social inequalities based on caste, religious belonging, and gender are common in India and Nepal, and poverty is a major social issue in both countries. This is also the case for persons with disabilities. They experience discrimination to a large extent, and poverty is common within the group due to lack of access to education and employment (Lamichhane and Okubo, 2014; Ghosh, 2016). There are tremendous social differences and inequalities between urban and rural areas due to the unequal access to education and employment opportunities, and cultural inequalities. In India, healthcare and education opportunities for persons with disabilities are mostly concentrated in the metropolitan areas, and in Nepal the same opportunities are largely found in the Kathmandu Valley. Due to poor infrastructure and inaccessible public transport in rural areas, the mobility of persons with disabilities creates further marginalisation and isolation there. These are systems and structures that increase the inequalities and strengthen the existing social relations between urban and rural populations. Since there are enough similarities between the Indian and Nepali movements, the author has treated them as analogous throughout this analysis. However, each of the two movements is, in reality, unique.

AIM

There is little knowledge regarding the disability rights movements in India and Nepal. It is important to understand the current situation for persons with disability in these countries, see how the current rights struggle reflects the envisioned future, and shed light on issues that need further inquiry. Therefore, this article aims to explore how the disability rights movements in India and Nepal are influenced by inherent social inequalities.

METHOD

Approach

The article is based on 7 semi-structured interviews - 4 with disability rights activists in Kolkata, and 3 in Kathmandu. Semi-structured interviews were suitable since it gave an opportunity to obtain in-depth information in a short time (Blee and Taylor, 2002), and the informants were an integral part of the study's development and construction. During the interviews, the author was critical of his own assumptions and open to unexpected insights (Brinkmann and Kvale, 2007); this allowed the informants to speak freely about predefined themes and to describe phenomena that mattered to them.

Sampling

Purposive sampling was used to access outspoken and prominent members of the movements in the two cities. All the interviews were conducted with well-educated urban-based activists, belonging to the middle-class. The interviews are obviously biased towards a specific group. However the selection is representative of active leaders in the disability rights movements in India and Nepal, and the interviews illustrate how the movements were formed, the main issues that are being pursued by them, and what social realities are constructed.

Analysis

Data was concurrently analysed during the fieldwork to ensure that the interview questions were relevant and appropriate. Additionally, preliminary findings were discussed with Indian scholars while the author was in Kolkata, to gain further insight on the data.

The interviews were transcribed and coded according to themes identified to be salient and relevant. The coded transcripts were continuously reviewed together with the author's field notes in order to make a thorough analysis of the interviews. Throughout the data collection process and analysis, a constructivist approach was applied. This has allowed for the informants' experiences to be interpreted within the social and cultural context, and this has led the analysis (Kitzinger, 2004). However, so as not to base the analysis solely on the informants' socio-cultural background, the data has been approached with an intersectional stance, and has been viewed as constituted of complex identifications (Christensen and Jensen, 2012).

Theoretical Framework of Framing and Misframing

An important function of social movements is to formulate grievances (Tarrow, 2011). Through these grievances meaning is created for the movement to frame its goals and visions. Snow and Benford (2000) write that: "Collective action frames are constructed in part as movement adherents negotiate a shared understanding of some problematic condition or situation they define as in need of change, make attributions regarding who or what is to blame, articulate an alternative set of arrangements, and urge others to act in concert to affect change".

By framing goals, the movement can effectively communicate people's desires and more people can be mobilised. It is a political instrument that evokes emotions, provokes action, and sets the agenda of the movement. However, framing is a selective process, and cultural and power aspects of this process need to be taken into consideration. Those who frame the movement are responsible for setting the agenda and create imagined realities that the movement strives for and, if successful, the Indian and Nepali society will in the future be shaped by the agenda (della Porta and Diani, 2006).

Social movements that strive for justice have often been faced with what Nancy Fraser (1995) calls "the redistribution-recognition dilemma", the dilemma of whether to demand economic redistribution or cultural recognition. The first case applies to an economically marginalised group, and needs to claim the same economic rights as other groups. The latter, applies to a group that faces cultural discrimination, and needs to claim their specificity as a way to be subjected to affirmative action. However, political economy and culture are often intertwined, and many marginalised groups cannot make this distinction. Persons with disabilities in India and Nepal need to strive for a situation where they are not treated in a different way economically, at the same time as they are recognised as having different cultural and physical needs. To paraphrase Fraser (1995), how can persons with disabilities fight simultaneously to abolish disability differentiation and to valorise disability specificity?

Fraser (2008) has further developed these ideas and added a third dimension to her theory on justice claims, namely representation. The author claims that one needs to consider who is striving for change and not only what social movements are struggling for. Within social struggle there is a risk of exclusion of the people who are to be represented, and this leads to what Fraser (2008) calls "misrepresentation" and further to "misframing". In other words, the ones who

are to be represented within a social movement lose their voice and their right to frame the agenda. This phenomenon occurs in social movements that are unequal in their structure. Fraser gives the example of transnational movements where Northern elite often monopolise the movement's framing. However, the author of the current study argues that these theories are also applicable to the national disability movements in India and Nepal, since there exist great inequalities within the movements. This leaves three dimensions of justice claims: economic, cultural and representational. These need to be addressed simultaneously, otherwise there is a risk that one dimension has a negative effect on the others (Mladenov, 2016).

RESULTS

The most commonly used frame of the Indian and Nepali disability movements is the human rights agenda. Both the countries' movements have adopted the rights-based approach, and the movements are coloured by the language and scheme of the CRPD. After many years of struggle, first for each government to ratify the CRPD and then advocating for a domestication of the Convention, the rights-based approach has left a mark on the two movements. Now that the Indian government has approved the new Disability Rights Act and the Nepali Parliament is in the last stage of approving an equivalent law, the strategy has yielded positive effects.

In line with Benford and Snow (2000), the collective action frame of the human rights agenda recognises a problem and suggests a solution, namely that the welfare approach, the previous normative approach, is patronising and that it is vital to grant persons with disabilities rights instead of welfare. The welfare approach focusses on structural support through economic handouts and redistribution of assistive devices, and is often talked of as charity. In the Global South the welfare approach has often led to a dependence on family members, other informal relations, non-government organisations and charities, due to the lack of governmental resources and support. The rights-based approach suggests that the attitude towards persons with disabilities needs to change and it is vital to create possibilities for them in order to change their own situation; it thus focusses on empowering the individual. This is an approach which advocates that persons with disabilities need to strive for a more individualistic lifestyle and become economically independent in order to prove that they can contribute to society and therefore are entitled to rights. The embracing

of the rights-based approach is driven by the movements' leaders, and they are making efforts to redirect the mindset of the actors within the movement towards this approach.

Examples of the main themes that are evoked during advocacy are: provisions within higher education and governmental employment opportunities, as well as universal design. These issues are of course very important but, for persons with disabilities living under poverty and in rural areas, these issues are generally not relevant in their everyday life. Among the population that lives under poverty, informal economic activities are most common and education and formal employment are far from possible. Even though the concept of universal design encompasses accessible public spaces, the infrastructure in rural areas is so deficient that the forms of accessibility that need to be addressed there are very different from the urban areas. The rights-based approach is directed towards the right to be fully part of society, by having access to activities that will empower the individual to take care of oneself. The strategy adopted by the movements places them in the recognition side of Fraser's (1995) above-mentioned dilemma, and focusses less on redistribution of resources. The movements struggle to be recognised as a marginalised group that need certain provisions to be able to participate in societal activities, and the individual's right is the focus of their struggle instead of purely economic issues. A main strategy among many organisations in the two countries is to educate members regarding their rights, and to raise awareness of the rights of persons with disabilities among other groups and authorities. The understanding of rights varies, but in India and Nepal the CRPD is used as a reference.

There is frustration among urban-based activists that persons with disabilities across the countries do not fully embrace the rights-based approach. A Nepali activist told the author:

"People don't know what rights are, they cannot read, they don't understand the international scenario, and human rights principles. They always believe that they should be asking for the disability allowance, and not asking for the rights to livelihood. Getting money without working is not good".

There is evidently a divide between the leaders' visions and the grassroots' acts. The inequalities within the movements are evident and are presented in its framing. This phenomenon is also common within other civil society groups in South Asia (cfr. Robins, 2012).

As an explanation for the misrepresentation of the less privileged population in the advocacy work, one of the interviewed activists identified the involvement of international organisations as a reason and said:

“Another reason why they get so cut off from the grassroots is probably because [the international organisations] are up there and [the urban-based organisations] are somewhere in the middle. [...] You are not looking at exactly what the grassroots are thinking”.

Collaborating with external organisations comes with benefits, such as resources and knowledge exchange. However, it often means that the cooperation is based on terms set up by the international organisation. Due to North-South relationships and neo-liberal development schemes, the Western notions of disability and the CRPD have become hegemonic around the world (Soldatic and Grech, 2014). However, in the process of rights implementation, it is vital to consider the cultural context of the countries and remember that the majority of persons with disabilities in India and Nepal live in a vulnerable economic situation.

While there is no question that all persons with disabilities need rights, a major part of the group still struggle to manage daily expenses and would benefit from economic support together with cultural recognition and political representation. However, many of the movements' leaders consider that economic redistribution reinforces the notion that persons with disabilities are incapable of taking care of themselves. While discussing this dilemma, an Indian activist who is critical of the rights-based approach said:

“I think grassroots-people are much more practical. They say that they want jobs. If there is no job, then they want money from the government”.

Another issue that comes with the rights-based approach is that it is based on individuality. India and Nepal have strong family-based cultures where the community is in focus and not the individual. This means that the approach conflicts with the lived reality of many persons with disability. Additionally, persons with disabilities are more likely to be dependent on family members to care for them, due to lack of social security systems and discrimination in the labour market. Persons with disabilities in India and Nepal are therefore often dependent on family and community support one way or the other, and will most likely find it hard to have a more individualistic lifestyle.

The Indian and Nepali societies are changing, and individualism is growing along with modernity and urbanisation. However, outside the metropolitan areas informal community care is still a strong institution, and often the only social security system that exists. One of the objectives of the rights-based approach is of course to change this scenario, to overcome discriminating barriers to create independence. In the meantime, people's needs must be catered for, and not only their rights. Additionally, activists in India have witnessed that the Indian government has pushed for individualisation of society in modernisation campaigns, but has tended to shift towards a more community-based stance when the resources run out. The government makes promises, but in the end the responsibility of care is again handed over to the informal systems. This dilemma further complicates the implementation of disability rights in countries with inherent inequality, and needs to be taken into consideration when discussing disability rights in India and Nepal.

DISCUSSION

The human rights agenda is a hegemonic frame within both the Indian and Nepali movements, where the agenda clearly dominates the efforts to improve the situation for persons with disabilities. The agenda is a global discourse that is articulated and translated into the Indian and Nepali context by civil society groups and the elite. In both countries, there is a clear divide between the needs of the urban and the rural populations, and those who live under poverty and those who do not. All the activists that the author interacted with were aware of this fact, and were making efforts to change the situation. However, the advocacy strategies and the majority of the addressed issues are based on urban needs from a middle-class perspective. When framing the movement, the leaders set the agenda of what to strive for and an idea of what the future of persons with disabilities is likely to be. It is a powerful act that will shape social and political realities to come (della Porta and Diani, 2006). The urban-based activists clearly frame the issue from their perspective. Even though they have the best interests of all persons with disabilities in mind, there is a clear divide between the educated and articulate activists and the persons with disabilities who struggle to survive from day to day. In Fraser's (2008) words, there is a misrepresentation of the group of persons with disabilities as a whole. Great divides in needs exist within the group, and urban middle-class activists are dominating the discussion about what to strive for and how policies are to be written.

The advocacy strategies and discussions regarding rights of persons with disabilities need to consider the social context of India and Nepal. There are many persons with disabilities who live in poverty and need support to cover their most basic needs, which in many cases means dependence on family members or other well-wishers. Even though the Indian and Nepali societies are moving towards a more individualistic social structure, persons with disabilities will find it increasingly hard to follow this societal development. When interdependency on family members is a cultural and economic element of life and survival, it is problematic that leaders of the disability movement push for legislation that is based on individuality. The differences and inequalities within the group are evident when those advocating for the more individualistic rights-based approach are those who are not vulnerable to these changes.

To be able to communicate and cooperate with international organisations, the activists need to be sufficiently articulate. This implies a certain amount of education and the ability to work full- or part-time with advocacy. Resources and specific language skills are needed to be able to perform advocacy work that is taken seriously. It is necessary to make time to visit governmental offices repeatedly and formal language and “development lingo” are needed for communication. In other words, advocacy work is dependent on human and economic resources, which are not a given among the members of the disability movements in India and Nepal. This means that in many cases people at grassroots level cannot speak for themselves. The inequalities within the movement may create a situation where the advocacy-elite capture the issue and are disconnected from the grassroots and those who have more urgent needs.

CONCLUSION

In this article, inequalities and conflicting interests within the Indian and Nepali disability movements have been highlighted. These are inequalities that reflect social injustices at the societal level and are not unique to the disability rights movements of the two countries. Nonetheless, certain issues have been brought to light that arguably are important to consider when advocating and writing policies for the rights of persons with disabilities.

It is clearly the urban middle-class population that frames the disability rights issues. Thus there is a risk that the already existing inequalities are deepened and can become entrenched if the current activities mostly benefit the urban middle-class population. Leaders are frustrated that the rights-based approach is not

embraced by all within the movement. At the same time, paternalistic attitudes towards the rural and poor population have been found among leaders. This is a sensitive issue for a group which is struggling to overcome the very same issue on a societal level. Throughout history, persons with disabilities have been infantilised in the same way and considered unable to voice and frame their own problems.

It is obvious that many difficulties emerge when advocating for rights in countries with repressive cultural understandings of disability and when striving to maintain an active movement in countries with vast social inequalities. India has, and Nepal soon will have, laws that have a rights-based approach, and the disability rights movements in the two countries must deal with this political context. This is not necessarily wrong, but it is important to keep in mind that this is a complex scenario where the voices of those who have the most needs also need to be heard. It is vital for the disability rights movements to create a political environment where perspectives and voices from all social categories are brought forward.

These issues need to be further researched in order to fully understand the implications and effects that these tendencies have. How can needs be met in a socio-political context that is so riddled with inequalities, and when the needs differ to such a large extent? How can an inclusive and more dynamic disability rights movement be developed? If social inclusion of persons with disabilities is to be realised, all persons with disabilities need to be heard, including those who struggle to articulate their needs.

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