

## **Claiming Voices and Spaces: Indigenous Women with Disabilities in Nepal**

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### **Abstract**

Indigenous women with disabilities in Nepal face discrimination on at least three counts: as women, as ethnic minorities, and as disabled persons. They are among the poorest, most marginalized, stigmatized and excluded groups in Nepal. They are also vulnerable to violence, abuse and rape. With little access to health care, and rights awareness, this group has learnt to endure oppression and violence in their lives as a given. This article explores the issues and concerns of indigenous women with disabilities and attempts to provide a rare glimpse into their position vis a vis the state and other stakeholders.

**Keywords:** Indigenous Women with Disabilities; Identity; Multiple Discriminations; Rights

### **Author Profile**

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## Claiming Voices and Spaces: Indigenous Women with Disabilities in Nepal

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### Indigenous Women with Disabilities

Indigenous women with disabilities in Nepal experience multiple forms of discrimination and marginalization. They are marginalized due to their gender, their disability, and their indigenous identity. These overlapping identities place them at the bottom of social hierarchy, denying them political agency. The marginalized position of indigenous women with disabilities is both the cause and the consequence of their lack of political agency in Nepal.<sup>1</sup>

Indigenous women and girls with disabilities, just like indigenous women without disabilities, are seen as custodians of tradition and culture and responsible for passing these values and practices on to future generations. Additionally, indigenous women with disabilities and indigenous women without disabilities are united in their common struggle for recognition as indigenous people and as indigenous women. They are an integral part of the indigenous people's struggle.

Despite their contribution, indigenous women continue to face denial of rights, discrimination, land dispossession, and violence. They are also most often forced to assimilate and integrate with the mainstream dominant culture. They form a large section of the poor and the illiterate in Nepal. Their lives are more at risk, and they are subjected to sexual violence, domestic violence, forced sterilisation, and neglect both within the home and their community, as well as in institutions. Thus, indigenous women with disabilities are invisible and isolated in society.

The distinct identity of indigenous women with disabilities is connected with their physical, biological, cultural, historical, intellectual state, as well as their social and environmental contexts. Their multi-layered marginalization demands that their needs are addressed not in isolation, but within a composite framework of rights.

Discrimination operates in different forms for an indigenous woman with disability some of this experience is shared with other persons with disability and some with indigenous peoples. However, the intersections of the multiple aspects of her identity exacerbate the disadvantages she faces. For instance, when a blind indigenous woman, is unable to access family planning services, because she lives in a remote village and does not receive information in her native language, it is the intersections of the multiple aspects of her identity that exacerbate the disadvantages she faces while trying to access healthcare.

The new Constitution of Nepal promulgated in 2015 denies the collective rights and aspirations for identity based federalism of indigenous peoples, in spite of the fact that Nepal has ratified the International Labour Organization (ILO) Convention 169 on Indigenous and Tribal Peoples, signed the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) and the World Conference on Indigenous Peoples (WCIP) Outcome Document 2015. However, their implementation is still in question. The recent amendments in the laws,

acts, and draft bills are not in line with the international instruments like UNDRIP and ILO Convention 169 and other international covenants that the state has ratified.

It is claimed that the recent Disability Act 2017, is in line with the United Nations Convention on the Rights of Person with Disabilities (UNCRPD). It includes policies and provisions for ten types of disabilities but there is no reference to address social, attitudinal and environmental barriers that marginalized and underrepresented groups like indigenous peoples, Dalit, Madhesis, Muslims, socially backward communities and other groups face. These marginalized groups comprise 70% of total population and there is no attempt to mainstream these groups in the recent Disability Act 2017. At present, bills, policies and provisions for persons with disabilities are in the process of being formulated, however, these processes exclude the voices and concerns of all these groups including indigenous women with disabilities. Most often these groups are not invited to meetings and consultations while making laws and policies that have an impact on their lives. (K. Magar, personal communication, 2017).

It has been found that most indigenous peoples with disabilities in Nepal do not know about their rights. They are not exposed or accustomed to being active, aware and in decision making positions in organizations and in Disabled People-led Organisations' (DPOs). Even if few indigenous peoples with disabilities are working in or with organizations or DPOs, they are just members and not in decision making positions. The organizations continue to function on the basis of the values of dominant caste groups, which influence and direct the disability discourse and agenda. For example, having a disability card is a prerequisite for people with disabilities in Nepal. Most indigenous people do not know how to obtain a card and face challenges in acquiring them (Lawyers' Association for Human Rights of Nepalese Indigenous Peoples, 2014). The disability services that exist are almost non-responsive to the needs of indigenous peoples with disabilities in terms of their cultural aspects. For example, access to information in sign language for deaf people and easy-to-read information for people with intellectual and mental disabilities are some of the major issues demanded by people with disabilities. However, access to information in the mother tongue for indigenous people and Madhesis is not discussed. That is why reports indicate that 81% indigenous peoples with disabilities have poor access to public facilities in comparison to other people with disabilities in Nepal (Lord, Sijapati, Baniya, Chand & Ghale, 2016).

Similarly, most services provided to persons with disabilities at the local level are provided individually, discussed within institutions or DPOs and framed by dominant worldviews. The decision making process excludes indigenous values like going through collective consultation with indigenous leaders and elders. There is no attempt to understand its value system and impact on the community. Any discussion or decision that could have an impact on the life of the indigenous community should only proceed from the prior free and informed consent of the community and should respect the indigenous way of life. However, disability services often function on the basis of the informed consent of individuals. This is disrespectful of indigenous customary law. Cultural assimilation is pervasive and it is the dominant worldview that shapes the disability discourse and agenda in Nepal.

In this context, indigenous women with disabilities in Nepal hold a marginalized position within a marginalized population. They are often excluded from disability, indigenous, and

women's movements because respect for diversity and addressing deep-rooted structural and historical discrimination faced by indigenous women and measures to address groups facing multiple and intersectional discrimination have not been prioritized. Instead, the disability, women's and even indigenous movements are framed within the culture, language, patriarchal values, and Hindu philosophical values and able mind set. As a result, most indigenous women with disabilities face attitudinal, social and environmental barriers.

Ethnic discrimination in Nepal is wide ranging, both in overt and subtle forms. Indigenous peoples are stereotyped as 'dumb', 'illiterate', 'backward', 'alcoholic' and 'ignorant'. Similarly, indigenous women are stereotyped as 'uneducated', 'unaware', 'offensive', 'free', 'easy', 'open', and 'sexually available'. They are mocked and humiliated for their traditional attire and accent. For instance, a parliamentary member from an indigenous community wore her traditional Jirel costume to be sworn in for the first time in front of the Prime Minister of Nepal. However, she was told that her traditional attire was informal and was asked to change into 'formal' attire. She was demeaned in the public sphere for wearing her traditional indigenous dress (Y. K. Bhattachan, personal communication, 2018). Due to such stereotyping and stigmatization, indigenous peoples in general and indigenous women in particular face physical, psychological and verbal abuse and are humiliated in public spaces but these instances of verbal abuse are not taken or treated seriously even if complaints are submitted. There are laws that include penalty clauses for such acts but these are not implemented. Such experiences have a negative impact, lead to loss of self confidence of indigenous women and avoidance of public services.

Disability is often explained as a punishment for the 'sinful deeds of a past life'. People with disability are viewed as 'useless' or as 'burdens on society'. This kind of stereotyping leads to depression, anxiety and other psychological issues among indigenous women, as a result of which they hide their identity. All these types of discriminations are apparent, however not all the discrimination that indigenous women with disabilities face is reported and documented (NIDA et.al, 2018).

Indigenous women with disabilities are included in consultations as "tokenistic representatives" or "offering garlands to guest with cultural attire" to add value and create a veneer of inclusion. The historical injustices and indirect discrimination indigenous peoples and women are facing are often denied in public forums and are never part of discussions. They are informed and projected in such a way that women from other marginalized groups are more vulnerable. As one participant shares her experience thus:

Indigenous culture mostly is quite open, easy, not restricted permits you to choose your husband and other decisions of your life. You don't have to follow and obey all social norms like us limiting ourselves in the patriarchal values and system in the order of family. The way we are taught and told is different from you, so you are at least free, open, and can be with us, you are not discriminated in fact you are enjoying your life as you want and you can be with us. We can teach you many other things if you can be with us and help us. <sup>2</sup>

- An indigenous young woman with disability, 26 years old.

While, many indigenous communities accept the above realities and acknowledge that women enjoy better status, women themselves are not in a position to challenge the structural discrimination they face and express it at public forums. It is only when individual women face critical life threatening situations that this indirect discrimination surfaces.

### **Indigenous Women and Women with Disabilities**

Indigenous women with disabilities in Nepal face the challenges faced by both indigenous women without disabilities and by non-indigenous women with disabilities. Indigenous women in Nepal, including indigenous women with disabilities, continue to face the appropriation of their customary and traditional lands, resulting in the loss of their livelihood and of their role in their society. Mega-projects, such as the Arun III Hydropower Dam<sup>3</sup>, led to appropriation of the lands of indigenous peoples. Additionally, land is lost to speculative buyers in Kathmandu, where male-headed households are coaxed into selling, and women lose all the security they have in the form of land which is replaced by cash over which the men maintain control and which the women are unable to access. (CEDAW, 2011). Thus, indigenous women experience loss of control over their lives and their resources. Indigenous women also face threats from in-migration and military and security personnel.

Indigenous women are victims of patriarchy in two different ways: first, since many indigenous peoples (under the influence of State-led process of Hinduization and Sanskritization), practice patriarchy and discriminate against women and girls in their communities. Second, the state itself is based on the ideology of Hindu patriarchy and treats all women, including indigenous women, as second-class citizens (CEDAW, 2018).

The uniquely challenging position of indigenous women with disabilities goes unnoticed and unaddressed. For example, a person with disabilities is provided access to social assistance, healthcare facilities, and training and employment programs. Even if all these services are available, it is a daunting, uphill task for women with disabilities to access these services. If the woman with a disability also happens to be an indigenous woman, it is even harder to obtain these services due to the systematic historical exclusion, and physical, cultural and attitudinal obstacles that she must face on account of her identity.

Indigenous peoples – and consequently indigenous women with disabilities – residing in remote rural areas often lack access to information and facilities. They are not informed about relief, procedures, and services provided to person with disabilities because they and their parents were not aware of and involved in DPOs. This posed a problem when it comes to receiving services during emergencies and exercising their rights in their daily lives (Lord, et.al 2016). Even if they do receive some disability services in their own local settings, the service providers might not be familiar with the cultural specificities of the indigenous communities (NIDA, NIDWAN, & AIPP, 2018).

Similarly, many other skills/services that are provided to indigenous women with disabilities might be derived from a wholly different cultural, linguistic, social, and community context than their own. This is often informed by western notion of disability and values of dominant social groups. Thus, it becomes crucial to examine how people experience and

construct identities within intersecting systems of power because questions such as who holds power and how this power is used and how it impacts the lives of indigenous woman and woman with disability are important. These questions are central to disabilities discourse and movement towards understanding the interseccion of gender, disability and other social identities.

### **Data and Indigenous Women with Disabilities**

Globally, statistics about indigenous peoples with disabilities from states and governments are hard to come by as they are inadequately recorded in official data, censuses and government surveys (Buvinic and Mazza, 2005; Meekosha, 2011; Mikkelesen, 2014). Three main reasons for this gap are suggested:

1. The reluctance of states to recognize their indigenous peoples;
2. Resource constraints for the development and application of more comprehensive set of data collection instruments;
3. Lack of engagement with indigenous perspectives on disability (Rivas Velarde, 2015).

In Nepal, the National Census 2011 reports that 1.94% of the total population has some kind of disability, whereas the National Living Standard Survey Report (NLSS) 2011 puts it at 3.6% persons with disabilities (CBS Report, 2011). However, both these figures are quite low as compared to the 15% disability prevalence claimed by the WHO and the World Bank in the World Report on Disability (WHO and World Bank, 2011).

According to the 2011 Census, the indigenous nationalities of Nepal comprise 36% of the total population of 26.5 million although indigenous peoples' organizations claim a larger figure of more than 50%. The 2011 census listed the population as belonging to 125 castes and ethnic groups, including 63 indigenous peoples; 59 castes including 15 Dalit castes and 3 religious groups including Muslims groups. Based on the data provided, organizations working on indigenous peoples with disabilities (including other districts reports and information) state that 1.3 million indigenous peoples in Nepal live with disabilities. This number has increased after the 2015 earthquake in Nepal (NIDA, NIDWAN, & AIPP, 2018) and organizations working for indigenous women with disabilities claim that 0.65 million indigenous women are living with disabilities in Nepal.<sup>4</sup> Even these estimates may be under-estimating the actual numbers since the prevalence of disability among indigenous communities is higher than other groups in Nepal (NFDN, 2013).

The Constitution enshrines protections for marginalized groups and ensures that women, Dalit, indigenous nationalities (Adibasi Janajati), Khas Arya, Madhesi, Tharu, Muslim, and backward regions get representation and their rights are protected. However indigenous women unlike Madhesi women and Muslim women are not mentioned as subcategory within women. No special measures are provided to mainstream them. As a result indigenous women are invisible in laws, plans, policies and programs. There is also lack of adequate disaggregated data on them.

In Nepal, greater levels of poverty and lower standards of living, poor quality of prevention, and lack of rehabilitation services, and increased exposure to environmental



degradation among other factors, contribute to higher levels of disability among indigenous people. Higher illiteracy, lower rates of immunization, inadequate nutrition, unemployment, and under reporting of disability are contributing factors as well. There is no information and understanding of disability among indigenous peoples. For example, the health care system of the state systematically segregates indigenous peoples. Health care services including other services are inaccessible (due to distance), unaffordable (due to poverty and cost of services), unapproachable (due to social/power relations), incomprehensible (due to language barriers), culturally insensitive and ineffective (due to the poor quality of services) to many indigenous peoples and indigenous people with disabilities (Subba, Rai, & Gurung, 2009).

In addition to this, some indigenous women and women with disabilities do not see themselves as 'victims'. Faced with hardship, discrimination and prejudice, indigenous women have been forced to develop skills and strategies for survival for themselves, their peoples and their cultures. They have learnt to survive in oppression, marginalization, discrimination and violence, without losing the wisdom and patience to build on and to share these experiences. They do not express the challenges and discriminations they face as vocally as non-indigenous or non-disabled women do<sup>5</sup>. The cumulative culture of silence and limited access in their own spaces most often confines voices and participation of indigenous women with disabilities and isolates them in public spaces.

Scholars argue that indigenous peoples' understanding about impairment is different from non-indigenous groups. Scholars like Ariotti (1999), Fitzgerald (1997), Gotto (2009), Connell (2007), Hickey (2008), King (2010) and Rivas Velarde (2014) have documented cultural practices of indigenous communities. They assert that indigenous communities find the term 'impairment' alien and rather contradictory to their traditional beliefs around impairment. In some indigenous languages, there is no translation for the term 'persons with disabilities' or the term that exists only covers certain types of disability (UNPFII Study, 2013).

The existing data and information on disability and people with disabilities are not from indigenous cultural worldviews. The understanding of disability is still based on stereotypes, dominant Hindu ideology and western models and values, which overlook traditional indigenous value systems. There is little engagement with indigenous peoples and women with disabilities.

In some indigenous communities, disability was once perceived as a gift, a source of wisdom, or a welcome contact with the spirits. This perception has given way to state led policies influenced by western models of disability that has resulted in forced assimilation. This has compelled indigenous peoples to change their traditions and way of life to adopt and fit into the western lifestyle (Elston & Smith, 2007). The traditional values and practices of indigenous peoples that previously had respectful attitudes towards disability are disappearing. Discriminatory behaviour was not common. They lived with their disability with the collective support of the community and with dignity. However, such values have been dismantled. It has been replaced with individual support that is inadequate to fulfil the needs of people living with disabilities and their families. The result is discrimination and neglect within the family. Data shows the level of discriminatory attitudes and behaviour are less severe among indigenous communities than others groups (Gurung, 2013). The influence

of globalization, modernization, Eurocentric and patriarchal values that are predominantly shaping the disability discourse are threatening this culture.

The Anangu in Western Australia and the Maori in New Zealand (Fitzgerald, 1997; Gotto, 2009) embrace human differences as uniqueness and not as impairment. For example, indigenous peoples in southern Mexico with intellectual disabilities are valued and respected members who are recognized for their contribution. There might be similar narratives and understanding of impairment among indigenous communities in Nepal, however those narratives have not been studied and documented.<sup>6</sup>

In addition, Gething (1994) explains, most indigenous peoples, including indigenous women consider social and economic disadvantages as the main priority in their lives. Women themselves, seldom recognize that disability compounds disadvantage and that socio-economic needs have to be articulated in the light of this additional impairment. It is seen as an individual fact of life and not something that needs to be addressed collectively. In addition, historical oppression and structural injustices such as lack of access to public services, education, health, sanitation and safe drinking water and others affect indigenous women. The existing knowledge on disability fails to acknowledge the exclusion, the historical oppression and cultural assimilation faced by indigenous peoples with disabilities (Lord et al, 2016).

### **Normative Framework and Indigeneity Discourse**

Three international instruments mainly provide the legal, conceptual and political framework for the protection and promotion of the rights of indigenous women with disabilities. The Convention on the Elimination of All forms of Discrimination Against Women (CEDAW) acknowledges women living in poverty, indigenous women, and women with disabilities as critical groups of population whose rights must be safeguarded. Additionally, it prohibits multiple and intersecting discrimination against indigenous women with disabilities.

Similarly, Articles 21 and 22 of the UNDRIP make specific references to persons with disabilities. The UNCRPD includes indigenous women with disabilities in all articles and has a specific reference to ethnicity, and indigenous identity in its Preamble and there are number of recommendations and general comments provided by UNCRPD Committee reflecting on underrepresented groups including indigenous peoples with disabilities. Moreover, there are more than 12 specific references to indigenous peoples/women with disabilities in the Concluding Observation provided by the CRPD Committee to Nepal Government in 2018.<sup>7</sup> Recommendations also have been provided to Nepal by the Committee on the Elimination of Racial Discrimination, The Convention on the Rights of Child and Universal Periodic Report, and others regarding indigenous peoples, women, children, and persons with disabilities. The Convention, like other human rights treaties, focuses primarily on individual rights, but also contains provisions that are more collective in nature, whereas the approach of the Declaration is primarily collective, but also includes references to individual rights. Both instruments have in common their comprehensive nature but both would have benefited from an explicit reference to indigenous women with disabilities.



Some conceptual and definitional issues give rise to special difficulties. The first is how to define the rights of indigenous people to self-determination or the questions of collective rights under international law. The second is how to make sense of disability from an indigenous perspective in contrast to a western understanding. This quandary mirrors some of the debates between universal and cultural relativist notions of human rights. Both the instruments fail to reflect an understanding of disability from an indigenous perspective. Neither comprehensively recognizes indigenous person nor women with disabilities (Hickey, 2013).

The global disability discourse is framed by two standpoints. First, disability studies is heavily influenced by western ideologies shaped by international policies and events such as the Disability Rights Movement and the International Year of Persons with Disabilities: a social, human rights model in line with the Convention, including classification and reports from after 1980s. Second, is the International Classification of Functioning, Disability and Health that reflects the principles of the bio psychosocial model (Birkenbach, Chatterji, Badley, & Ustun, 1999). It describes disability as an interaction between individual with health condition and personal environmental factors that includes negative attitudes, inaccessible transportation, public buildings and limited resources.

In this regard, disability discourse in Nepal is heavily influenced by the western notion of disability and reflects the views and opinions of majority groups. The majority group comprises Hill Bahuns-Chhetris, considered to be the “dominant” group and others who have been historically discriminated against are treated as minorities. This is the widely accepted and adopted approach to the study of ethnicity in Nepal (Neupane, 2000; Serchan, 2001).

This is reflected in the National Federation for the Disabled Nepal (NFDN); an umbrella organization that has more than 325 member organizations called DPOs that shape and direct the prevalent understanding of disability. The data indicates that only seven organizations out of more than 300 organizations are led by indigenous peoples with disabilities (Magar, 2012). Among these seven, most are acquainted with and influenced by the western viewpoint and the ideologies of the dominant groups.

Simultaneously analysing the institutional structure of NFDN, the 8th General Assembly of the NFDN has 42 board members out of which only one male and female are representatives from indigenous peoples. Members are politically chosen and are thus not in a position to raise indigenous issues in order to affect and implement meaningful change. The situation is similar in organisations for women with disabilities. They include no voices of indigenous and other marginalized groups. The terms ‘inclusive’ and ‘inclusive representation’ in disability domain is more grounded in terms of impairment from dominant groups. These groups have access to and control over disability resources, are able to influence the state and its structures, and have an advantage over people with disabilities living in rural areas or from marginalized sections of society.

This is described as ‘cultural interface’ (Nakata, 2007) or a space where indigenous peoples and non-indigenous peoples interact constantly. Gilroy (2009) argues that cultural interface is a metaphysical domain in which two different cultures and histories intersect and influence the participation of indigenous peoples in society. These interactions and intersections

between indigenous peoples and the western leading ideologies held by disability service sectors and leaders influence disability meaning/understanding and service provision.

Scholars like Cameron (1998), Bennett (2005), Gurung (2006), Bennett, Sijapati, and Thapa (2014) highlight that gender, caste, and ethnic identities strongly condition the levels of social exclusion faced by citizens; however how these patterns intersect with discrimination faced by people with disabilities is relatively understudied (Lord et al, 2016) in Nepal.

### **Situating Indigenous Women with Disabilities**

Existing state policies and provisions for marginalized groups such as women, indigenous people, Dalit people, people with disabilities and other groups have one-dimensional approach that does not make space for people and groups facing multiple disadvantages. Sharing her experiences, a young indigenous woman with disability argues,

Very often, I question myself, ‘where do I locate myself, my identity my space and my stories? I do this because most often I find myself nowhere, neither in women, disability, indigenous and youth discussion, organization or movements, where should I tell my stories and to whom and why?’<sup>8</sup>

- An indigenous young woman with disability, 28 years old.

The voices of groups experiencing multiple disadvantages are side-lined (J. Tamang, personal communication, 19 October, 2017). The representation and participation of indigenous peoples with disabilities in the state mechanism seems nowhere.

The available data from other parts of the world shows that indigenous women and girls including indigenous women with disabilities experience familial and sexual violence, and discrimination (UNPFII, 2013). In fact, research shows high rates of sexual violence, with the condition of women with intellectual disabilities particularly alarming (Sharma 2017). In Nepal, such data on sexual violence within the homes and outside is yet to be compiled. The Special Rapporteur on the Rights of Persons with Disabilities, Catalina Devandas Aguilar notes that indigenous peoples with disabilities living below the poverty line or in rural or remote areas face additional, multi-faceted barriers to their socio-economic wellbeing and participation (ILO, 2016). Devandas Aguilar, in her interview with CBM International<sup>9</sup>, reflecting on the multiple challenges for a girl with a disability living in an indigenous community noted that she is more than likely to be poor.

In addition, indigenous women with disabilities face challenges in representation and participation at all levels. One of the respondents in National Consultation on reporting of indigenous peoples with disabilities in CRPD report states:

“In most of the consultations, we find and realize that we are often left out so the policies and provision made for persons with disabilities are framed and implemented by people who are in positions and power or members of Disabled Peoples Organizations from the majority communities who have resources and who are mostly visible in the society

at large. Those groups frame policies in their own interest so it is not uncommon that representatives of indigenous peoples with disabilities and indigenous perspective is not represented or included in the overall framework of disability.<sup>7 10</sup>

-An indigenous woman with physical disability, 34 years old.

The status of indigenous women with disabilities in Nepal as historically oppressed and excluded from policies and unable to access services simmers under the surface during 'normal' conditions, but is thrown into sharp relief and becomes more evident during conflict or emergencies.

For example, a study conducted by NFDN in a post-earthquake situation shows that a 52 year-old indigenous Tamang woman who had become disabled during the earthquake in Nuwakot was unable to access relief material during early relief distribution because of the simple fact that she did not understand the Nepali language. She only understood *Tamang* language and there were no translators/interpreters in the relief team that could explain to her the procedure to obtain the relief material (Lord et al, 2016).

In this context, the expert meeting on indigenous peoples with disabilities report identified the following challenges faced by indigenous peoples with disabilities in their lives and having both disability and indigenous identity:

- Knowledge gap at grassroots level to global level,
- risk of cultural and social assimilation,
- diverse social perceptions of disability among different indigenous communities,
- situation of risk and vulnerability of indigenous women and girls with disabilities,
- lack of access to services and support for indigenous persons with disabilities,
- insufficient statistical information on indigenous persons with disabilities and
- need to invest in disaggregated data (ILO, 2016).

Moreover often dominant groups present and reflect indigenous people with disabilities agenda as a divisive agenda that promotes national disintegration and ethnic conflict. This makes it tougher to gain support and funds and come up with policies and programs that will benefit disadvantaged groups. This can be seen in the relative obliteration of the group in the recent Disability Act 2017. Despite having number of recommendations to improve the lives and ensure rights of marginalized and underrepresented groups among peoples with disabilities by UNCRPD committee, the government has not started any initiatives on this. The current funds dispersed by the government do not specifically mainstream and address the issues of underrepresented groups or indigenous women with disabilities<sup>11</sup>. So indigenous woman demand to ensure their rights:

We as indigenous women and women with disabilities as a change maker, have contributed as a mediator and negotiators to make peace happen in community and we hold our practices and belief that has supported our families and communities towards sustainable lives and well beings so our discussions should be brought into the front lines.<sup>12</sup>

-An indigenous woman with a physical disability a member of NIDWAN, 38 years old.

## Claiming Space and Integrating Indigenous Worldviews

Claiming is the act asserting identity in wider public spaces. This is something indigenous women with disabilities have been exercising in the UN system since 2012, after the formation of the Indigenous Persons with Disabilities Global Network (IPWDGN) and the 12th Session of UN Permanent Forum on Indigenous Issues. There have been efforts by different stakeholders (including indigenous women with disabilities) to make interventions, submit reports, organise meetings and conduct studies. Based on these initiatives at the level of the UN, indigenous women with disabilities from all around the globe have begun to reclaim their voice and reflect on the experiences and challenges they face as a group having multiple identities impacting their daily lives. With these concerns, they are claiming their space in the women, disability, and the indigenous movements. Additionally, they are seeking laws and policies that address intersectional issues at the national level. The president of NIDWAN asserts, “Today, we are claiming our space and voices to be at the table, making decision for ourselves and our communities we represent.”<sup>13</sup>

Currently, the global discourse on disability focuses on underrepresented groups among people with disabilities. The CRPD highlights the importance of data collection and consultation in ensuring that all aspects of one’s identity are recognized, particularly concerning those subgroups that remain largely invisible. The intersection of multiple discriminations has been recognized as a significant barrier to the enjoyment and exercise of rights by UN treaty bodies. Additionally, the concern shown by the UNCRPD Committee on the intersectional and multiple discrimination – including discrimination on the basis of gender, race, ethnicity and disability – have been the subject of Concluding Observations and General Recommendations and Comments by the CEDAW and the CRC Committees (UNCRPD, 2014).

Indigenous women are affirming their rights and implementing some changes on the ground by bridging the gap and building synergy among women, disability and indigenous movements and engaging in cross movement collaboration. They believe that the CRPD committee has to recognize diversity and existence of underrepresented groups within the disability community. “The understanding of CRPD in a holistic and [as a] comprehensive notion, with a paradigm shift would entail representation of all diverse groups within disability so that they can fully enjoy their rights as right holders with other stakeholders in the relevant government agencies,” says General Secretary of NIDWAN.<sup>14</sup>

## Conclusion

Indigenous women with disabilities face many challenges on account of their unique location as indigenous people, as women, and as people with disabilities. They share their challenges with each of the seemingly distinct groups to which they belong, but simultaneously face a unique set of challenges that are a result of the intersection of their multiple identities.

The World Report on Disability states that disability services should be designed to serve the majority of the population, and should specifically address the needs of people with disabilities to offer inclusive, equitable and culturally appropriate services (WHO & World Bank, 2011). This, as Weber points would operate at two levels. Firstly, at the individual

level, by intermeshing all the identities and respecting diversity by creating a broad range of opportunities, and secondly at the societal and structural level by revealing the ways in which systems of power are implicated in the development, organization and maintenance of inequalities and social injustice (Weber, 2001).

Indigenous women with disabilities must value research, writing, and participation and must include cultural perspectives in disability discourse. They also need to structure their perspectives and engagements at both the individual and the societal level. Their debates to challenge the one-dimensional and conventional way of addressing oppressed and excluded groups must reframe old knowledge while creating new knowledge alongside. Their conversations about power and equality have to be on going.

It is crucial that indigenous women with disabilities build on the indigenous holistic approach as Catalina Devandas Aguilar notes. It is important to mainstream indigenous people with disabilities and other marginalized groups with disabilities in disability discourse. She states that indigenous people with disabilities are often not included in mainstream work on disability or provided for in policies that safeguard the rights of people with disabilities. Consequently, policies and services are not responsive enough to their needs or cultural settings (Devandas Aguilar, 2016). It is important to learn about how the rights of indigenous persons with disabilities can be promoted in a way that is respectful and sensitive to the context specific needs of Nepali state and society.

Today, the UNDRIP must be read from a disability perspective, and the UNCRPD from the perspective of indigenous people (Devandas-Aguilar, 2016). Literature highlights the need to understand indigenous disability experiences within the context of indigenous identities (Hollinsworth, 2013; King, Brough & Knox, 2014). Disability discourse must open avenues and start exchanges and conversations that will integrate indigenous worldviews that are sustainable and safe not only for people with disabilities but also for the planet on which we live. It is time to recognise that gender, disability, and indigenous identity are important factors to be considered while working towards any policy and building any structure – we must consider these to be issues of collective responsibility of all for all.

Implementing the UNCRPD to affirm the inclusion and participation of indigenous women and girls is very central. It is time to recognise that gender, disability, and indigenous identity are chief factors to be considered while working towards any policy and building any structure – we must consider these to be issues of collective duty. This is crucial to the women, disability and indigenous movement, which are all founded on the discourse of leaving no one behind. This journey of claiming voice has just begun and we believe that the movements have a long way to go.



## End Notes

<sup>1</sup> This article is based on research titled Exploring the Subaltern Voice: A Study on Indigenous Persons with Disabilities in Nepal, submitted to the National Foundation for the Development of Indigenous Nationalities Research Division Sector in 2016. It also draws on information gathered on field visits to seven districts in Nepal: Kavre, Sindupalchowk, Ramechhap, Udayapur, Kathmandu, Bhaktapur, and Lalitpur. In addition, information was collected as part of the National Consultation Program that was held in 2017 and 2018 to prepare a report for the Committee on the Rights of Persons with Disabilities (CRPD) in 2018.

<sup>2</sup> Personal communication in the meeting with a member of NIDWAN, that took place on 18th August 2017.

<sup>3</sup> Arun III is an under-construction run-of-the river hydroelectric project in Nepal at the Arun River.

<sup>4</sup> National Indigenous Disabled Women Association Nepal (NIDWAN) is working for the protecting and promotion of the rights of indigenous women with disabilities at grass root level. Based on their working experiences and relating the numbers with the national data, NIDWAN claims 0.65 million indigenous women with disabilities in Nepal, see [www.nidwan.org.np](http://www.nidwan.org.np).

<sup>5</sup> One of the participants in the National Consultation on CRPD in the List of Issues and Shadow Report Submitted to the CRPD Committee, organized by NIDA, NIDWAN, on 31 October 2017 in Kathmandu.

<sup>6</sup> It is important to highlight that indigenous peoples discourse is largely absent from global initiatives. The UNCRPD definition, the social and psychosocial model have fully rejected indigenous peoples concept of disability, cultural beliefs, around human uniqueness, (Connell, 2011; Hollinsworth, 2012; Rivas Velarde 2014). The western model of disability ensures that all peoples with disabilities have the same opportunity to participate in disability services that are tailored to their needs; however “same opportunity for all”, excludes groups facing social, historical and cultural discrimination. So many factors influence how disability is conceptualized among indigenous peoples with disabilities (O’Neill, Kirove & Thomson, 2004; Gilroy, 2012).

John Gilroy describes social science as a producer of knowledge has radicalized, homogenized and subjugated indigenous knowledge by infusing western civilizations and non-aboriginals peoples impose disability and handicap with western values that go often unnoticed by people with or without any experience of disability as a result they experience colonization, power dominance and discrimination throughout (Gilroy, 2012). Indigenous qualities and integrities have been absent from most of all these global disability initiatives. Therefore there is lack of understanding of indigenous standpoints and notions in disability framework. Therefore, Meekosha (2011) identifies that disability discourses originating from the northern hemisphere do little to address indigenous peoples with disabilities residing in the southern hemisphere because their historical and contemporary experiences and needs differ. We find lack of knowledge and understanding on indigenous peoples with disabilities and their issues that affect their lives.

<sup>7</sup> See CRPD recommendation [https://tbinternet.ohchr.org/\\_layouts/treaty\\_bodyexternal/Download.aspx?symbolno=CRPD/C/NPL/CO/1&Lang=En](https://tbinternet.ohchr.org/_layouts/treaty_bodyexternal/Download.aspx?symbolno=CRPD/C/NPL/CO/1&Lang=En)

<sup>8</sup> Communication in Focus Group Discussion on the challenges of indigenous women with disabilities with lom lama, Treasures of NIDWAN, June 2016

<sup>9</sup> See interview of Catalina Devandas at <https://www.cbm.org/Interview-with-Ms.-Catalina-Devandas-481471.php>, accessed on 13 September 2018.

<sup>10</sup> One of the participants in the National Consultation on CRPD in the List of Issues and Shadow Report Submitted to the CRPD committee, organized by NIDA, NIDWAN, on 31 October 2017 in Kathmandu.

<sup>11</sup> Conversation in the meeting with the president of NIDA, Khadga Magar, 2018.

<sup>12</sup> Personal communication in the meeting with a member of NIDWAN, that took place on 12 September 2016.

<sup>13</sup> See interview of Pratima Gurung at <http://www.unwomen.org/en/news/stories/2018/4/compilation-indigenous-women-claim-their-space>

<sup>14</sup> Jamuna Tamang in preparatory meeting for the National Consultation on CRPD in the List of Issues and Shadow Report, on 15 October 2017.

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