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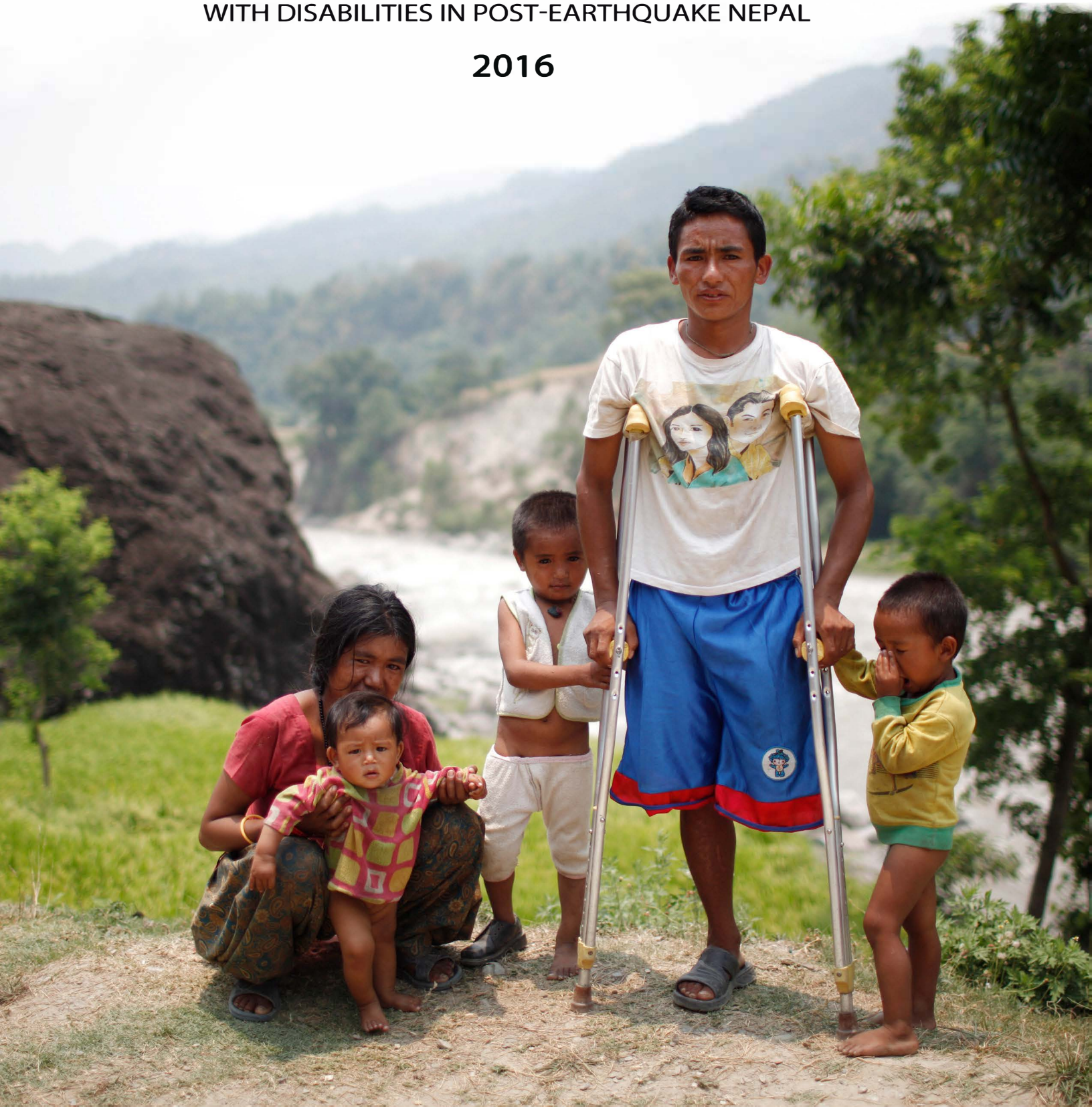
DISASTER, DISABILITY, & DIFFERENCE

A STUDY OF THE CHALLENGES FACED BY PERSONS WITH DISABILITIES IN POST-EARTHQUAKE NEPAL

2016



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Cover Photo by Niranjan Shrestha: "An earthquake survivor whose left leg was recently amputated stands with his wife and children near their tent along the Trishuli River in Nuwakot District of north-central Nepal. June 2015."

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List of Acronyms

CRPD	UN Convention on the Rights of Persons with Disabilities
DDRC	District Disaster Relief Committee
DPOs	disabled persons organizations
DRR	disaster risk reduction
FGD	focus group discussion
GESI	Gender Equality and Social Inclusion
IDP	internally displaced peoples
IPwDs	indigenous persons with disabilities
MoWCSW	Ministry of Women Children and Social Welfare
NDWA	Nepal Disabled Women Association
NFDN	National Federation of Disabled-Nepal
NRA	National Reconstruction Authority
PwDs	persons with disabilities
SDGs	Sustainable Development Goals
SFDRR	Sendai Framework for Disaster Risk Reduction Framework
UNISDR	UN Office for Disaster Risk Reduction
VDC	Village Development Committee
WASH	water, sanitation and hygiene
WDO	Woman Development Officer
WwDs	woman with disabilities

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1. INTRODUCTION TO THE STUDY

This research-based report seeks to empirically assess the contemporary landscape of disability in Nepal, with a focus on the unique challenges faced by persons with disabilities (PwDs) in the wake of the earthquakes that devastated Nepal in April and May of 2015.

Recognizing that it is often the most vulnerable segments of society who suffer the most in the wake of disaster, UNDP Nepal commissioned this study to analyze the uneven impacts of the earthquake on socially disadvantaged groups and persons with disabilities. Conducted during the Early Recovery phase, this study focused on identifying trends of structural inequality and social exclusion that affect differential patterns of resilience and recovery as well as ways these trends might be mitigated from the perspective of policy and practice. As the Reconstruction Phase officially begins, it is important to review and incorporate lessons learned during the Early Recovery period into the larger program of reconstruction and long-term recovery.

Further, because issues related to disability are relatively understudied in Nepal and only beginning to be analyzed in the context of disaster, this report also attempts to provide a thematic framework for understanding the social, economic, and institutional issues that shape specific patterns of vulnerability for persons with disabilities in Nepal. Drawing from fieldwork, systematic consultations with disabled persons organizations (DPOs) in Nepal as well as a review of the international literature on disability, this report seeks to place contemporary issues of disability in Nepal within the broader context of disability studies and global frameworks such as the UN Convention on the Rights of Persons with Disabilities (CRPD), which the Government of Nepal ratified in 2009.

Importantly, this report argues that the current historical moment of post-disaster recovery in Nepal and its focus on 'building back better' affords policymakers an important opportunity to recognize and operationalize the core principles of the recently adopted Sustainable Development Goals (SDGs), which emphasize better accounting for the needs and capabilities of persons with disabilities and the guidelines of the Sendai Framework for Disaster Risk Reduction Framework (SFDRR) that historically incorporated 'explicit recommendations toward a disability-accessible and inclusive environment not evident in previous disaster risk reduction conferences' (Stough & Kang 2015: 140). As the first country to face a major national disaster following the promulgation of these two groundbreaking agreements, Nepal is in a unique position to: a) reduce the social and physical vulnerability of persons with disabilities in Nepal; b) actively incorporate a commitment to social inclusion that will help to mainstream Nepali persons with disabilities within long-term development initiatives; and c) initiate a process of learning and evidence-based policy reform that can help to establish a precedent for future disasters.

The central goal of this report, however, is to investigate the situation of disability and social exclusion in Nepal using the 2015 earthquakes as a lens. It highlights the systemic inequalities that produce 'inequalities of opportunity' and uneven vulnerabilities for persons with disabilities in Nepal and identifying strategies and programmatic opportunities that can help promote patterns of post-earthquake recovery and development that are more inclusive of persons with disabilities in Nepal.

1.1 Disability & Disaster

Awareness about the inherent vulnerabilities of persons with disabilities (PwDs) during disasters has increased markedly in recent years. This recognition has occurred in part due to the increasing inclusion of the disability agenda in topics of international discourse such as inclusive development (i.e., SDGs) and disaster risk reduction (i.e., SDRRF) but also due to repeated and tragic incidents that demonstrate how persons with disabilities are routinely "ignored or excluded at all levels of disaster preparedness, mitigation and intervention" (IFRC 2007: 90).

A 2013 survey of over 5,000 persons with disabilities representing 126 countries conducted by the UN Office for Disaster Risk Reduction (UNISDR) found that only 20% could evacuate their living spaces without difficulty in the event of an emergency, highlighting the importance of accessibility during a national disaster (UNISDR 2013). Commenting on the report, he UNISDR head, Margareta Wahlström, stated: "The results of this survey are shocking. It clearly reveals that the key reason why a disproportionate number of disabled persons suffer and die in disasters is because their needs are ignored and neglected by the official planning process in the majority of situations. They are often left totally reliant on the kindness of family, friends and neighbors for their survival and safety: (UNISDR 2013). For example, "after the 2011 earthquake and tsunami in Japan the mortality rate among persons with disabilities was twice that of the rest of the population" (IFRC 2015, citing Government of Japan 2012)

Recognizing these systemic patterns of vulnerability, international humanitarian institutions have now come to a broad consensus that it is critical to consider disability-related issues in all stages of disaster planning and to include persons with disabilities as active and valuable stakeholders in disaster risk-reduction activities. The 2006 Convention on the Rights of Persons with Disabilities (CRPD) calls upon states to take "all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters" (UNCRPD 2006: Article 11). More recently, the Sendai Framework for Disaster Risk Reduction (SFDRR) represents the historic "infusion of disability-related terms and concepts such as accessibility, inclusion, and universal design... these disability-related concepts will now serve the field of disaster risk reduction as important overarching disaster-related principles" (Stough & Kang 2015: 140).

Despite the tragic circumstances, the 2015 Nepal earthquakes provide a unique opportunity to consider the current state of inclusion for PwDs in Nepal. Unfortunately, though this was the deadliest natural disaster in the history of Nepal, causing nearly 9,000 casualties and over 22,000 injuries, both the historical record and recent research conducted by several seismologists indicate that seismic activity is a near certainty in other regions of Nepal that remain geologically overdue for large earthquakes (~8.0 magnitude) in the not too-distant future. With these grim realities in mind, it is important to analyze the successes and failures of disaster preparedness and disaster response in Nepal in order to generate evidence-based lessons that can inform future disaster risk reduction (DRR) activities in Nepal. This report argues that the best lessons can be learnt by considering the experiences of the most vulnerable sections of society, which necessarily includes Nepalis persons with disabilities.

As Nepal remains in a state of transition between the ongoing recovery and the slow process of long-term reconstruction, there is a very real need to put this knowledge to use in real time. Within the rebuilding process, issues of social inclusion are particularly relevant with regard to Priority 4 of the Sendai Framework, which explicitly states that the empowerment of women

and PwDs "to publicly lead and promote gender equitable and universally accessible response, recovery, rehabilitation and reconstruction approaches are key" to the principle of 'Building Back Better' (UNISDR 2015: 17). Finally, the recent propagation of the 2030 Sustainable Development Goals, which include specific recommendations for the inclusion of PwDs, Nepal has a significant opportunity to operationalize those principles and also to enact legislation that reflects Nepal's 2009 ratification of the CRPD.

Based on empirical research conducted in some of the earthquake-affected areas and intensive consultations with Disabled Persons' Organizations (DPOs), this report seeks to promote greater dialogue about disability in post-earthquake Nepal. The challenges faced by PwDs in Nepali society remain highly under-recognized, and many issues related to disability are largely absent from an otherwise vibrant discourse on social inclusion in Nepal. A recent report on disability found that "policies alone have not translated to concrete benefits for people due to lack of awareness, advocacy and Government capacity to deliver its promise' and despite a small increase in institutional interest and investment in recent years, issues related to disability remain marginal with the disability movement has being 'able to promote mainstreaming, or to position the rights of persons with disabilities as part of the sociopolitical and development agenda" (Norad 2012: 10-12).

Disasters and other crises often exaggerate existing inequalities. But they also present opportunities to identify gaps in existing policies, to innovate new practices, and initiate greater efforts to correct for the uneven distribution of vulnerabilities. The SDGs and CRPD both provide a framework by which UN agencies operating in Nepal can affect this kind of change, yet these efforts must also be informed by a greater understanding of the myriad social challenges that exist in Nepal.

The implementation of these conventions, however, will no doubt be challenged by longstanding patterns of structural inequality. As Lynn Bennett once said of Nepal's social exclusion: "Successful policy reform must address not just the formal rules and procedures that are written down and enforced by law, but also the thicket of informal behaviours and deep-seated norms and values and networks of political alliances and obligations that stand between the formal policy statement and its actual implementation" (Bennett 2005: 2). Hence, any effort to promote the well-being of persons with disabilities in Nepal will require a commensurate effort to understand both the specific challenges faced by them and greater recognition of intersecting layers of social exclusion based on gender, ethnicity, caste, and class that exaggerate existing inequalities.

Recognizing both these challenges and the fecundity of the current historical moment in Nepal, this report concludes with a series of forward-looking policy recommendations focused on: a) promoting more inclusive and equitable patterns of post-earthquake recovery in contemporary Nepal; b) addressing the needs of persons with disabilities in Nepal in both the immediate post-disaster setting and the longer term; and c) promoting the principles of social inclusion across all activities focused on disaster risk reduction and disaster management, so as to limit the vulnerability of marginalized groups in the context of future disasters.

1.2 The Intersection of Disability & Social Exclusion In Nepal

> While disability-based subordination is recognized as a social phenomenon, there is often no integrated political attention to why disability manifests in particular individuals or communities.
> (Ribet 2011: 106)

The 1982 UN World Programme of Action Concerning Disabled Persons defined the principle goal of inclusion as 'equalization of opportunities' while the CRPD reiterates the importance of accessibility and inclusion, embodied in the principles of 'universal design' intended to provide equal access to all differently-abled people. Collectively, such international agreements represent an important shift in the conceptualization of disability from a 'medical model' of disability focused on impairment to a 'social constructionist model' focused on the progressive adaptation of structures and social attitudes to include or 'mainstream' persons with disabilities. "In other words, the focus of the 'new paradigm' is on eliminating the attitudinal and institutional barriers that preclude persons with disabilities from participating fully in society's mainstream" (Silverstein 2000: 1695).

Mainstreaming disability, however, is far easier said than done, particularly in developing nations and highly unequal societies. The literature on disability repeatedly affirms that "a strong cycle of disability and chronic poverty exists – those who are poor are more likely to become disabled and those who are disabled are much more likely to be poor. They reinforce each other, contributing to increased vulnerability and exclusion" (Wapling 2012: 4).

Similarly, removing barrier to equal participation and ensuring equal access in social, political, or economic terms is often only the first step toward counteracting the systemic disempowerment of persons with disability. Efforts focused on equality are insufficient, and must be complemented by further efforts to promote the voice and agency of persons with disabilities based on principles of equity and social justice. It becomes necessary to go beyond simplistic principles of 'equality' by adopting an equity-based model of disability that accounts for the wicked patterns of structural inequality and social exclusion that systemically disadvantage persons with disabilities. Recognizing the primacy of these social and political factors, this report seeks to situate the analysis of disability in Nepal not only within the international frameworks for the rights of the disabled, but also within the larger topic of social exclusion and structural inequality in Nepal.

One definition of exclusion deployed in Nepal states, "Exclusion restricts individuals social and economic opportunities on the basis of their initial circumstances, not on the basis of merit or skill," creating disadvantages that go beyond poverty or lack of human capital to social hierarchies that produce an 'inequality of opportunity' (Bennett & Parajuli 2013: 3). Social inclusion, on the other hand, is oriented toward the support 'equality of agency' understood as the capacity to act.

Decades of research in Nepal have demonstrated the ways gender, caste, and ethnic classifications and identities strongly condition the level of social exclusion faced by Nepalis (Cameron 1998; Bennett 2005; Gurung 2006; Bennett, Sijapati, and Thapa 2013) and yet the ways in which these patterns intersect with discrimination faced by persons with disabilities is relatively understudied (see 'References' attached). The existing yet limited literature on disability studies in Nepal and the rich scholarship on social exclusion thus provides the context for the report to demonstrate the various ways certain persons with disabilities face multiple or 'intersectional' layers of exclusion and discrimination, such as a Dalit woman with disabilities who is subjugated by hierarchies of gender, caste, and disability, severely limiting her educational, economic, and social opportunities. Using a framework based on multi-

dimensional forms of social exclusion, the research findings highlight the following overlapping issues of social exclusion:

a) Persons with disabilities in Nepal face additional challenges in the context of the 2015 earthquakes with regard to disaster preparedness, the immediate impacts of the earthquakes, access to relief, and trajectories of recovery.
b) The overwhelming majority of persons with disabilities in Nepal have not been adequately informed, consulted, or accounted for with regard to DRR in Nepal, creating a significant awareness gap.
c) The structural inequalities that perpetuated pre-earthquake discrimination create feedback loops which increase the negative effects of disaster for both persons with disabilities and their households and which decrease post-earthquake well-being and resilience.
d) Intersectional discriminations related to caste, gender, ethnicity, and class have proved to be significant in shaping the different post-earthquake experiences of persons with disabilities in Nepal.
e) Different kinds of disability create specific challenges in the post-disaster context, indicating that disaggregated data on disability is needed to understand the unique risks poses by different disabilities—particularly in terms of intellectual or developmental disabilities (the most marginalized and therefore at risk) and mental disabilities (the most misunderstood).
f) The 2015 earthquakes have both created new disabilities and exacerbated existing patterns of disability in Nepal that are 'emergent' rather than congenital (including mental disabilities) and that require greater policy consideration.
g) Persons with disability are not adequately informed about or included in the institutional process of recovery and reconstruction, reflecting a continued 'inequality of opportunity' that requires immediate action.

Many Nepali persons with disabilities, however, maintain a great deal of agency despite a complex array of physical, mental and social limitations, reinforcing the idea that PwDs have different capabilities and that these are often under-recognized. The report, therefore, also seeks to highlight existing successful case studies that indicate opportunities for positive change. Lastly, it reiterates the idea that the current moment offers a rare opportunity to reconfigure the landscape of disability in Nepal in ways that will ultimately promote a more inclusive future for persons with disabilities.

1.3 Research Methodology

This study was conducted between January and March of 2016 (eight to eleven months after the first earthquake of April 25 2015) during a critical interim period when hundreds of thousands of earthquake-affected Nepalis were struggling to begin rebuilding their lives while waiting for the Reconstruction Phase to officially begin even as Early Recovery programmes were ongoing and nearing completion. This report, therefore, provides a snapshot of not only a particular moment in post-earthquake Nepal but also a summary of several months of intensive activity leading up to that point and a sketch of the assemblage of hopes and concerns that structure differently imagined futures. Drawing on data collected from both abled and disabled groups, representing a socially and spatially diverse sample in earthquake-affected areas, this report attempts to capture both the variegated needs of differently positioned populations and the differential evolution of these needs over time.

Field-based assessments were conducted in four districts—Sindhupalchowk, Kavrepalanchowk, Nuwakot, and Gorkha—using a range of different research methods (surveys, semi-structured interviews, and focus group discussions) to collect data from 458 unique respondents distributed across 24 village development committees. Within this sample, 166 respondents, or roughly a third, were PwDs representing the full gamut of disability types, castes and ethnicities, and gender.[1]

A series of informational interviews were also conducted with representatives of the Government of Nepal and disabled persons' organizations operating in each of the districts while also engaging in institutional consultations with disability-focused NGOs in Kathmandu. Lastly, two 'Roundtable Discussions on Disability in Nepal' were held with representatives from both civil society[2] and government[3] to help validate the preliminary findings and solicit additional insights into the social and institutional landscape of disability in Nepal. In sum, the methodology was informed by a commitment to triangulation, whereby data was collected from a variety of differently positioned individuals representing earthquake-affected populations, government representatives, and civil society groups.

All of this was supplemented by a comprehensive literature review focused on: a) disability in Nepal; b) the international discourse on the rights of persons with disabilities; c) comparative disability policy frameworks; and d) the inclusion of issues of disability and PwDs in the context of disaster risk reduction, humanitarian disaster response, and post-disaster recovery. The study also referred to the broader literatures on social exclusion in Nepal, disaster risk reduction, and disaster and social difference as well as recently published research-driven assessments of post-earthquake relief and recovery in Nepal.

[1] Our sample of 166 PwD respondents from the four earthquake-affected districts includes 82 PwD survey respondents, key-informant interviews conducted with 29 PwDs, and 55 PwDs who were consulted as participants in the context of different field-based Focus Group Discussions.

[2] Civil Society organizations participating in the first Roundtable Event included: the National Federation of Disabled–Nepal; the Nepal Disabled Women's Association; UNDP Nepal, UNICEF Nepal; Handicap International–Nepal; the Karuna Foundation; CBM–Nepal; Koshish Nepal; the Nepal Association of the Blind; the Association of the Deaf and Hard Hearing Nepal; the Federation of Parents of Children with Intellectual Disability; the Transcultural Psychosocial Organization–Nepal; ENGAGE; the Hospital and Rehabilitation Center for Disabled Children; the Nepal Healthcare Equipment Development Foundation; the Nepal Spinal Trauma Center; and the Disability Research Center at Kathmandu University.

[3] Government of Nepal institutions represented at the second Roundtable Event included the Ministry of Women Children and Social Welfare, the Ministry of Health, the Ministry of Urban Development, and the National Reconstruction Authority.

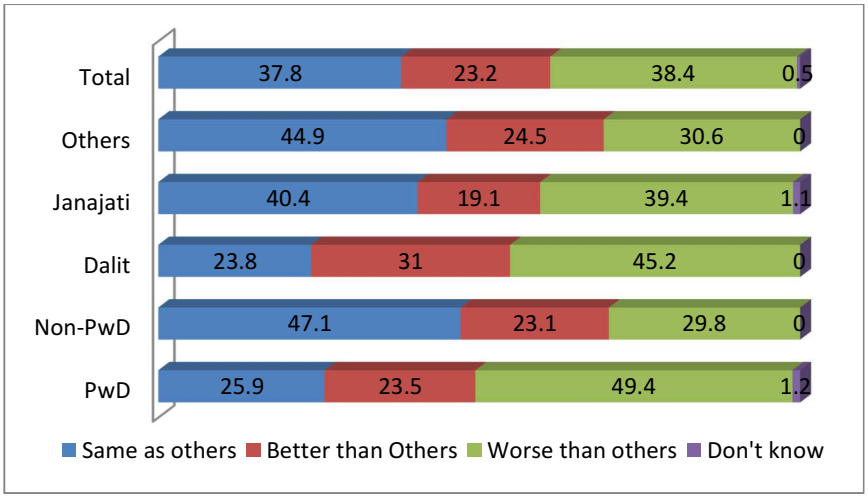
2. THEMATIC SUMMARY OF FINDINGS -

> Disability is an evolving concept resulting from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.
>
> - Preamble of the UN Convention on the Rights of Persons with Disabilities, 2006

> Ensuring inclusion of persons with disabilities during emergency response must be considered a core component of principled and effective humanitarian action. It is based not only on the humanitarian principles of humanity and impartiality, but also on the human rights principles of equity and non-discrimination. - Handicap International 2015: 3

Several international studies have indicated that persons with disabilities face heightened levels of risk and vulnerability[4] both during and after a disaster: "Emergencies have particularly serious consequences for persons with disabilities. New physical barriers are created and support networks are disrupted. Access to information is difficult for everyone, especially persons with sensory disabilities. Relief services are often not adapted to persons with disabilities, who struggle to cover basic needs and become increasingly dependent on outside support" (IFRC 2015: 40). Our study seeks to understand the needs of persons with disabilities in post-earthquake Nepal, to highlight intersectional patterns of social exclusion that exaggerate or intensify these patterns of vulnerability, and to understand the specific needs and capabilities of different kinds of disabled persons in the post-disaster context. Overall, our research indicates that structural inequalities and patterns of social exclusion affect highly uneven patterns of recovery and 'resilience' across different demographic groups in Nepal, and that these social exclusion disabilities face

Figure 1: Level of Damages Incurred in Comparison to Others in the Community



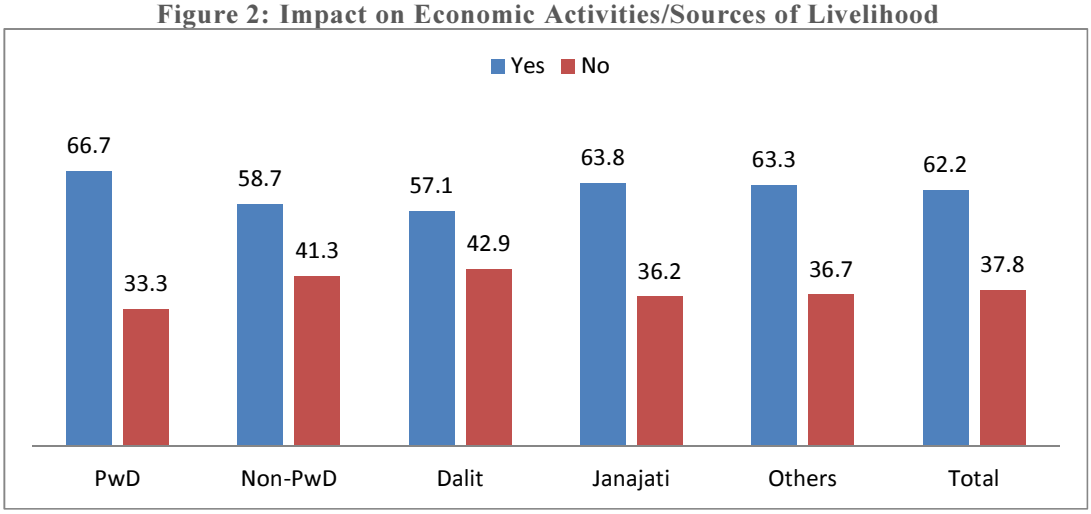
As the multidimensional exclusion perspective adopted for this study would suggest, the earthquake had differential impacts on the socially disadvantaged groups. In the aggregate,

[4] Following international convention (Handicap International 2015) this study understands vulnerability as "the characteristics of a person or group and their situation that influence their capacity to anticipate, cope with, resist and recover from the impact of a major event" (Blaikie et al 2014: 11).

when asked about the perceived level of damage experienced in comparison to others in the community, approximately, 38% of the sampled households indicated that they felt the damage they experienced was worse than the others (Figure 1). Amongst the families of persons with disabilities and Dalits, the perceived level of damages was much higher at 49% and 45% respectively. Though almost 90% of respondents indicated that their houses had been destroyed 'to the extent that it was not possible for them to either live in the house or to use it for other purposes', the level of overall damage was particularly high for Dalit households (94%), correlated perhaps from widespread use of weaker building materials resulting from caste-based socioeconomic marginalization (NNDSWO 2016).

The earthquake also led to significant impacts on households' economic activities and sources of livelihood. Approximately, 62% of the sampled households indicated that their sources of economic activities or livelihoods had been destroyed and this figure was particularly high for families which include persons with disabilities. Notably, a relatively lower percentage of Dalits (57%) indicated such an impact on their economic activities/sources of livelihoods which can be explained by the dependence of Dalits on wage-based livelihood sources[5] or traditional occupations (Figure 2).

Figure 2: Impact on Economic Activities/Sources of Livelihood



The following anecdote of a single woman with physical disability who suffered immense damages and losses during the earthquake highlights the sense of hopelessness that marginalized groups, including persons with disabilities, experience when a natural disaster strikes them.

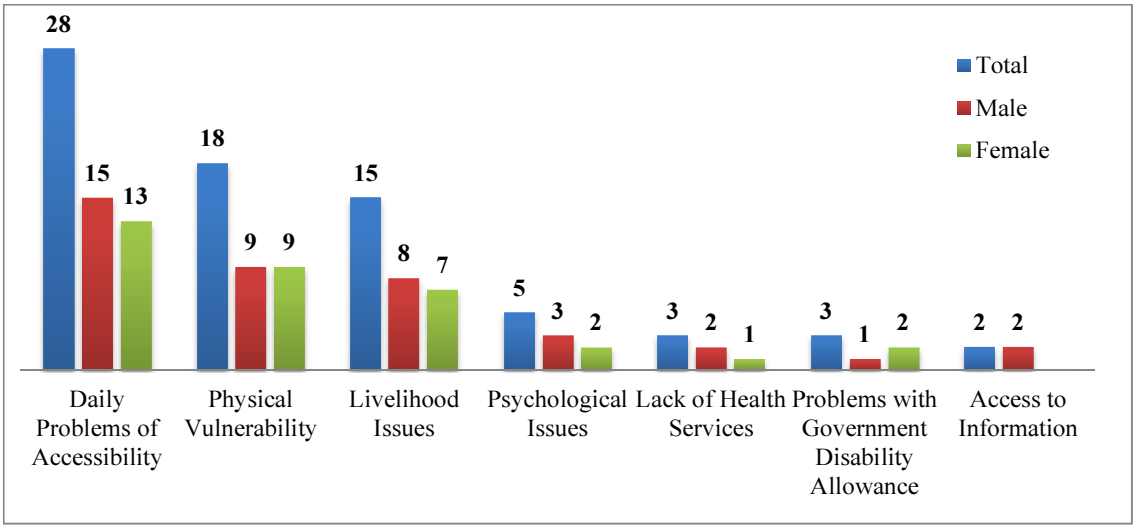
> There was a wound in my leg when I was fifteen. The wound healed but my leg started getting thin and became shorter. I got married because the boy's side told that they did not have a problem with my disability. However, later they started ignoring me and they stopped bearing my expense. I came back to my parents' house. But I thought I should not be a burden to them as I also had to cover my son's expense. So I started a shop with the help of my parents and brother. However, with the earthquake of April 25, my shop got destroyed along with the house.

[5] In our sample, 17% of Dalit households indicated that their primary source of income is wage-based labour (both agriculture and non-agriculture) while the average for all the households was only 11 percent. Similarly, a higher percentage of Dalits (24%) mentioned having their 'own business' when the average for the sampled population was 16%. The continued prevalence of caste-based occupational division in Nepal could mean that for Dalits, 'own business' is associated with blacksmith work, tailoring, leatherwork, goldsmith work, copper/bronze work, earth-digging, sweeping and cleaning, ploughing, musical instrument playing, human waste disposal and carcass disposal, where the damage by the earthquake could have been limited.

> All the materials got buried. I have not been able to re-start the shop because I do not have any money for investment.
>
> —Single Woman with a Physical Disability, Nuwakot

As part of our post-earthquake survey, we asked persons with disabilities to identify the most significant challenges faced in their everyday life. The following chart (Figure 3) represents the major trends in these answers, indicating that issues of accessibility, physical vulnerability and livelihood are the most pressing challenges.

Figure 3: Challenges Identified by Persons with Disabilities in our Survey in the Post-Earthquake Context



A majority of persons with disabilities who interviewed reported having daily problems in accessibilities to buildings, transportation and moving around their own locality due to difficult terrains, spatial exclusion, and in some cases their old age. A physically-disabled man from Kavrepalanchowk said, "It's difficult to move around here after the earthquake due to the tough landscape, so getting to places takes too much effort for an old man like me, so I hardly go anywhere and know much about what's going on in the village." This quote indicates that problems of mobility and problems of inadequate information are related in post-earthquake Nepal, as many relief activities require being physically present, which affects both PwDs and their caregivers. For example, the mother of an intellectually disabled woman in Sindhupalchowk said, "My disabled daughter and I missed out on several relief materials as there is no man in the house. An old woman like me cannot jostle with the crowd." In addition, a global study on "Disability in Humanitarian Contexts" recently conducted by Handicap International (2015) identified significant service gaps during times of disaster and crisis related to the inaccessibility of information, the lack of assistive devices and rehabilitation services. These are just one of the reasons why "Persons with disabilities too often fall through the cracks of humanitarian response." (Handicap International 2015: 4).

Importantly, as stated in the preamble of the CRPD which recognizes the diversity of persons with disabilities, disability is not a monolithic category. Instead persons with disability experience significant variations in the type and severity of disabilities that affect both everyday experience and the experience of disaster. Therefore, as one respondent with a moderate physical disability told us: "A disabled person like me who can easily walk and go anywhere could get access to all the information, but those who need assistance to move and deaf persons could not get information easily. And because of this situation, lots of *apaangata* [PwDs] did not get relief support after the earthquake." By comparison, a hearing impaired

Chettri man from Kavrepalanchowk said, "It is difficult for us as we don't understand/ hear clearly what people are talking about and feel left out. This creates further problems in communicating with others and getting information after the earthquake." In short, diversity within disability means that disabled people face various kinds of difficulties owing to their degree and type of disability—for example, a person who is both deaf and blind person might have a wholly different experience compared to someone who is mildly physically disabled. Therefore, it is necessary to disaggregate our understanding of both disability and vulnerability, to better account for the specific needs and capabilities of different kinds of persons with disabilities by recognizing diversity *within* disability.

With these broader framings in mind, the following sections provide specific details on the unique challenges and patterns of social exclusion faced by different kinds of persons with disabilities in Nepal. These findings highlight the ways that existing social inequalities within the 'opportunity structure' (Bennett 2005) of pre-earthquake Nepal have produced both uneven patterns of vulnerability to disaster and a variety of different trajectories within the processes of relief and recovery. The findings identify not only the effects of the social in the post-disaster landscape, but also operational strategies for countering the inherent biases created by social exclusion as well as case studies where post-earthquake efforts were able to promote social inclusion and opportunities for translating such policies into practice.

2.1 Gender and Disability

> Intersectional discrimination begins first from the family itself for women with disabilities (WwDs) affecting her life towards deprivation, pessimism and isolation. Slipping lower and lower in the social hierarchy, they are most of time perceived as 'unwanted and unproductive human resources' and are silenced. Having no social security, government unable to respond, identify and sensitize the rights and service delivery of WwDs both in private and public sphere, WwDs are 'excluded within exclusion'. (Gurung 2010: ii)

The CRPD critically acknowledges the importance of gender and "recognizes that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms" (CRPD 2006). Equally, understanding patterns of discrimination faced by people with disabilities in Nepal requires consideration of the gendered nature of these experiences and the ways systematic discrimination of Nepali women perpetuates certain patterns of disability and neglect. Issues of gender color the experiences of women with disabilities (WwDs) in the social, political, familial, economical aspects of their lives, and they are routinely marginalized by "double discrimination that is the root cause of the inferior status of women with disabilities, making them one of the world's most disadvantaged groups" (Dhungana 2006).

A 2007 survey by the Nepal Disabled Women Association (NDWA) indicated that 84% of disabled women reported not being able to lead a dignified life (Khanal 2007: 48) Further, "Disabilities were seen more prevalent among males than female. The result of sex differentiation reduces the chance of survival among females. The reason for the lower prevalence of disabilities in women could be because their disabilities were not identified. Girls and women are often able to perform certain activities, albeit at enormous personal cost (pain and/or effort), to hide their disabilities" (NPC 2001: 6). Despite these challenges and advocacy efforts by groups such as the NDWA, the policies and programs focused on disability in Nepal

do not adequately account for the additional challenges faced by women with disabilities in Nepali society.

This study brought out starkly the gendered differences in marital status between men and women with disabilities, as 75.6% of the men with disabilities surveyed were married compared to only 43.2% of women with disabilities; further 32% of WwDs in our survey were widowed, divorced, or separated. Similar findings have been reflected in other research as well with one suggesting that "most disabled women in Nepal are single and they may face increased stigma, being disabled, single and childless" (UNESCAP 1995, cited in Morrison et al 2014). Most WwDs themselves choose to remain single as they do not want to become a 'burden' for another family, as a single woman with a physical disability from Dhulikhel said. Marriage is often times connected to household work, reproduction and contribution to household economy through agriculture or other forms of labour, and women with disabilities are perceived as being unable to contribute fully or not at all. Being female adds another layer of complexity to the disability narrative. Being female and disabled not only affects your chances of getting married but decreases one's status. Male PwDs, on the other hand, have greater chances of marriage as the numbers suggest.[6] As a woman with disabilities from Sindhupalchowk says: "Even if men are disabled they have an inheritance. But we women don't. That is why a disabled man can marry an abled woman."

"As long as a disabled man earns a living his chances of getting married and having a family life are much higher than those of a disabled woman" (Dhungana 2006). It is clear that property and inheritance are important factors that determine one's 'bargaining power' and imbalance gender relations, which reproduces the perception that women are of diminished value for society (Agarwal 1997).

Numerous international studies have shown show that persons with disabilities are more vulnerable to harassment and abuse compared to able-bodied people (see Mays 2006). For example, a survey in Orissa, India, found that virtually all of the women and girls with disabilities were victims of domestic violence, 25 per cent of women with intellectual disabilities had been raped and 6 per cent of disabled women had been forcibly sterilized (UN Enable CRPD Fact Sheet). Similarly, NDWA has conducted numerous studies that show that 'gender related violence is a cause and consequence of disability' (De Alwis 2010, cited in Norad 2012).

This study found a higher proportion of men with disabilities (47%) reporting having faced problems accessing public facilities compared to women with disabilities (32%)—probably a reflection of the fact that WwDs are generally confined to their homes while men tend to be more mobile and hence more likely to experience such difficulties. As a visually impaired woman from Sindhupalchowk told us, "Men can go anywhere with the white stick but women are humiliated when walking with the white stick. In crowds and even in vehicles, there are problems of men trying to touch the private parts of the body."

A mother of an intellectually disabled woman in Sindhupalchowk also expressed fears of public violence: "I have heard about cases of rape. And since my daughter is disabled, I fear that such a terrible thing might happen to her. That is why I cannot leave her alone and go outside." This respondent's worry for her intellectually disabled daughter is not unfounded and should be treated with serious concern. Her worry for her daughter is based on the prevalent assumption/notion that underpins the vulnerability of disabled women (Chenoweth 1993, 1997, and Sceriha 1996 cited in Mays 2006) and also on the even more disturbing assumption about

[6] A study of the discriminatory laws of Nepal by the Forum for Women Law and Development (FWLD) highlights the fact that Nepal's Civil Code allows a man to remarry if his wife becomes disabled.

intellectually disabled women being promiscuous (Chenoweth, 1993, 1996, 1997; McMahon et al 1996).

In the wake of the 2015 earthquakes in Nepal, many persons with disabilities have now been living in temporary circumstances and collective housing, which includes internally displaced peoples (IDP) camps. These living conditions have been especially tough for women with disabilities who have to share the same living space and toilet facilities with others. A physically disabled woman from Sindhupalchowk says:

> Women had problems after the earthquake as they had to stay in the same shelter as everyone else. Personally, it was difficult for me as I had to share one tent with my parents, older brother and sister-in-law, so there was a lack of privacy. Maintaining hygiene was a challenge, especially during my periods. The water source was not nearby and we had to share public toilets with other displaced quake victims.

Likewise, a woman from Kavrepalanchowk who has speech and hearing impairment told us that she used to have her own room, but that after the earthquake she is required to share the same space with her brother and sister-in-law. The brother-in-law and sister in law feel that it is difficult to maintain personal privacy in such a space. She finds it difficult to change her clothes and feels uncomfortable, and she has difficulty in expressing herself. On a similar note, a physically disabled woman in Nuwakot told us that the simple act of going to the bathroom is a major issue for young girls with disabilities since fathers and mothers are able to carry a disabled boy to the bathroom, but gender norms limit the help that female children receive after a certain age. Parents and caregivers of PwDs, especially female PwDs also reported having a difficult time living in temporary shelters. One father of an intellectually disabled daughter in Nuwakot says: "Apart from life-threatening condition, this group of population especially female is more prone to other types of violence as well such as sexual violence. It can occur in an unsafe shelter or in the absence of parents."

Returning to issues of intersectionality (Tamang 2011, Nightingale 2013) or 'exclusion with exclusion', Pratima Gurung of the Nepal Indigenous Disabled Association (NIDA) provided the following statement: "The general public realizes only a single factors of exclusion, what is presented, like if a woman is disabled. If she has a severe disability then her disability is reflected and focused. If they can't see her disability, then maybe her gender is reflected, but not the other factors like poverty, caste, ethnicity, geographical location, education, awareness about the legal procedures, her language or culture. These reasons for exclusion and their impacts are not fully acknowledged." Again, it is crucial to understand disability as just one layer among the many factors and barriers that reproduce social exclusion, many of which may be invisible.

2.2 Social Exclusion Based on Ethnicity & Caste

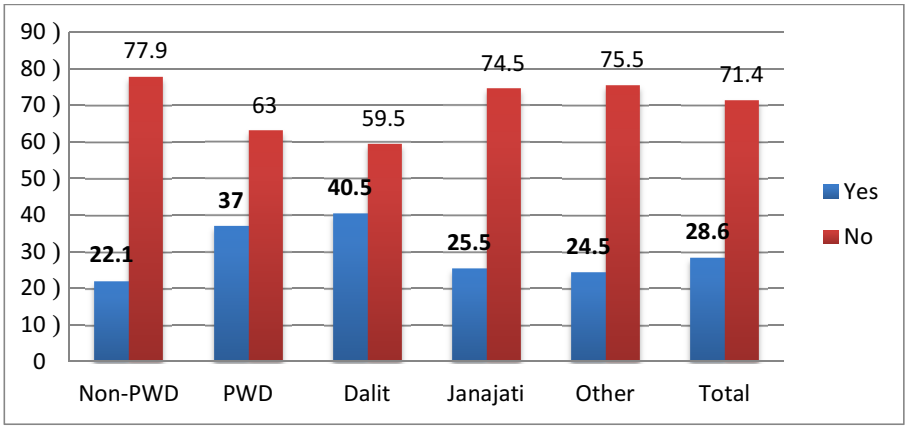
> Persons with disabilities are among those who have been historically excluded from the mainstream socio-politics and economic development. If they are women and/or belong to marginalized castes, class or ethnic groups, then they often face multiple discriminations.
>
> (Norad 2012: 7)

In Nepal, social exclusion is the product of interwoven patterns of inequity rooted in underlying norms of social hierarchy, behaviors and social practices that reproduce discrimination, material patterns of structural inequality related to economic production and livelihood, and spatial center-periphery dynamics that links marginalized people to marginalized geographies. As global statistics on disability indicate, poverty and underdevelopment also leads to a greater

incidence of disability within marginal populations, though official data disaggregated by ethnic or caste group is not available in Nepal, it is widely understood that disability is more prevalent within minority groups.

In highly unequal societies like Nepal, persons with disabilities must often overcome multiple or 'intersectional' layers of disempowerment and discrimination, a background condition of chronic underdevelopment, and patterns of structural inequality which perpetuate and intensify systemic conditions of poverty. The findings from indicate that the intersection of disability and social exclusion reinforce the disadvantages that are linked to the identity of the socially excluded groups and manifest themselves in their exclusion from access, opportunities, and resources.

Figure 4: Perceptions of Being Excluded from Public Life



Our survey results (Figure 4) directly indicated that perceptions of being excluded were highest amongst PwDs (37%) and Dalits (40%) compared to the overall average reported across demographic groups (29%).

Similarly, compared to PwDs from other caste and ethnic groups, a significant proportion of Dalit PwDs (62%) and Janajati [indigenous] PwDs (81%) reported having inadequate or poor access to public facilities. Likewise, a much larger proportion of Dalit PwDs (85%) reported less than adequate access to public services, as did Janajati [indigenous] respondents (74%).

Figure 5: Access of Different Categories of PwDs to Public Facilities

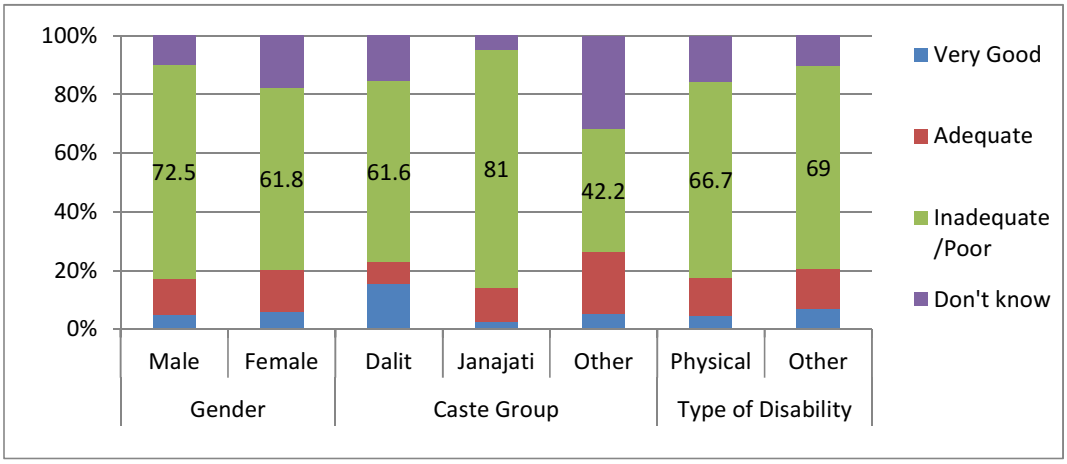
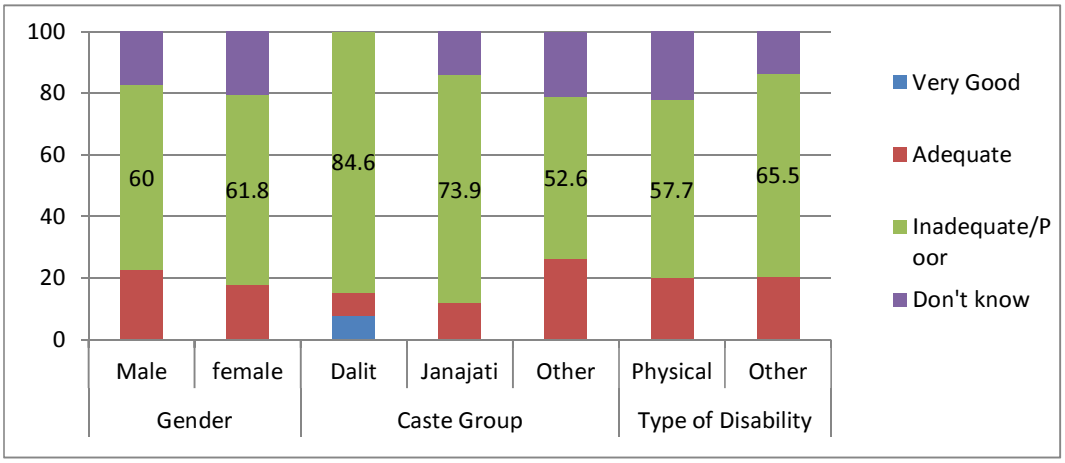


Figure 6: Access of Different Categories of PwDs to Government Services



In rural Nepal where the general socio-economic conditions are particularly bleak, lack of basic skills, educational opportunities and livelihood/employment options, PwDs from socially excluded groups experience stigmatization and negative stereotypes that cast them as unproductive and dependent. As a result, families of such PwDs tend to face poorer living conditions and higher levels of poverty as exemplified by the narrative below by a Dalit with a physical disability.

> Earlier, I used to make my living by playing instruments during wedding and other ceremonies. One day, around eight years ago, I fell down from my bed and broke my leg. I went to the hospital but the treatment did not go well. But because I did not have any money, I could not go to a better hospital. I need to carry a stick to be able to walk. And, since I can walk around with the help of a stick, the VDC has refused to categorize me as a disabled person even though I walk with great difficulty…I feel very sad that I am unable to work now and need to depend on others. The only son I had treats me as a stranger now. He does not come home either for Dasain or for Tihar. I cry a lot while I am alone remembering him. As we grow old we start becoming a burden to our children. On top of that I am disabled; he does not want to take care of me. If he would have wanted, he could have taken me to Kathmandu. But why would he? He does not love me anymore… I am also hurt by the attitude of the VDC secretary who has refused to categorize me as a disabled person. Because of that, I have stopped taking part in any of the VDC activities. I think the VDC is a corrupt body and they do nothing for the welfare of the Dalits or people who are disabled.
>
> —Dalit Man with Physical Disability, Sindhupalchowk

To make matters worse, the earthquake affected the socially excluded groups, namely, Dalits, Janajatis and women, particularly those with disabilities, disproportionately. The corollary to the existing structural and other barriers, as will also be discussed below, was that these groups either did not get equal access to the assistance and/or the assistance provided did not meet their requirements and special needs. As was pointed out in a report on the situation of Dalits in the aftermath of the earthquake, "Relief is perceived by the Dalit community as being '*hunekhaneko laagi'* ('for powerful and well-to-do people') which contradicts the idea of relief" (NNDSWO 2016: 13).

Regarding issues of ethnicity, findings also reinforce previous studies indicating that indigenous persons with disabilities (IPwDs) face additional layers of exclusion and that *janajati* ['indigenous'] and Dalit groups were disproportionately affected by the quake (Gurung 2013). According to a small study done by Nepal Indigenous Disabled Association (NIDA) across 6 districts (Sindhupalchowk, Dolakha, Ramechhap, Dhading, Nuwakot and

Kavreplanchowk), 65-70 percent of indigenous persons with disabilities affected by the quake and 50-55 percent of IPwDs did not receive relief. For example, NIDA informed us that among the 48 PWDs who lost their lives during earthquake in Sindhupalchowk district, 29 of them were indigenous persons with disabilities—indicating uneven vulnerabilities.

Similarly, based on a key informant interview, language was a barrier that prevented some groups of Janajati indigenous people from accessing both information about relief and relief materials. For instance a study conducted by one of our DPO respondents found that a 52 year-old Tamang single woman who became newly disabled during the earthquake in Nuwakot, was unable to access relief materials during early relief distribution due to the simple fact that she did not understand Nepali, only her native Tamang language, and there were no translators/interpreters in the relief team that could translate for her. An inclusive approach to disaster risk reduction and post-disaster recovery would require the recognition and mitigation of these barriers.

Despite the momentum gained by the Indigenous Movement in Nepal in recent years, Gurung & Thapa (2013) argue that this movement has not included a call for recognition of the rights of indigenous persons with disabilities. Though "the fundamental rights set forth in the Constitution and international human rights treaties like ILO Convention 169 and UNDRIP [the United Nations Declaration on the Rights of Indigenous Peoples] assure the right of minorities including indigenous persons to live a minimum standard for the survival, well-being and dignified life" (Gurung & Thapa 2013: 1) these conventions have not been adequately utilized to promote the rights of indigenous persons with disabilities. Thus "sensitization and implementation about IPwDs within Indigenous People Organizations (IPOs) about the rights of disabled people through the CRPD, the Disabled Protection Act" is needed alongside increased advocacy within DPOs about the specific rights guaranteed to indigenous PWDs through UNDRIP and ILO-169[7] (Gurung & Thapa 2013: 6). To prompt a greater recognition of these rights during the recovery phase, it is imperative that there should be adequate representation of Dalit PwDs and IPwDs in the reconstruction phase so that the agenda of 'minorities within minorities' are highlighted, particularly in parts of Nepal where indigenous groups represent a majority of the population. Given the disproportionate number of indigenous people affected by the 2015 earthquakes, the integration of these rights frameworks is perhaps more important than ever.

2.3 The Social Politics of Relief Distribution

> The relief distribution was not helpful to persons with disabilities. Blind people couldn't go there, other physically disabled didn't get there, and there were obstacles because to get the relief the person needed to be present him. —Physically Disabled Woman, Kavre

> 85% of humanitarian actors responding to our survey recognize that persons with disabilities are more vulnerable in times of crisis and 92% estimate that these persons are not properly taken into account in humanitarian response. (Handicap International 2015: 4)

As widely reported in the national and international media, access to relief materials and other post-disaster support services has varied significantly across different districts and even between different VDCs and Wards within the same district—the result of a complex mix of

[7] Articles 21 and 23 of the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) clearly state that special attention should be paid to vulnerable individuals and groups within indigenous communities.

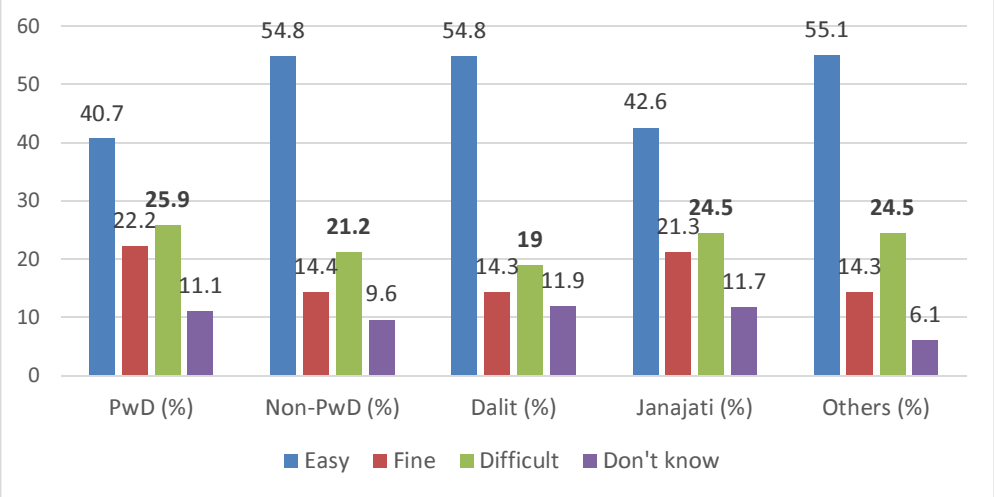
geographic, social and political factors. Importantly, there are also micro-political and social dynamics within individual settlements that dictate who has access to assistance and support and who does not. Importantly, our research indicates that persons with disabilities were both overlooked and marginalized during the Emergency or Relief phase that followed the 2015 earthquakes, reinforcing the findings of several other international studies which have reported that "persons with disabilities are too often neglected in the contingency planning, assessment, design, and delivery of humanitarian relief" (Handicap International 2015: 5, see also Handicap International 2015, IFRC 2015). Our research also indicates that information barriers are a significant driver of this trend, and that uneven patterns of relief distribution in Nepal are exacerbate by intersectional forms of social exclusion related to gender, ethnicity, caste, class and geographic marginalization. From the beginning, our study was informed by the idea that needs of differently impacted populations change over the course of the emergency phase that follows a disaster, that "the evolution of such needs will not only be a function of the intensity and nature of the impacts of the disaster but also of the disaster *response*." (The Asia Foundation 2015: III). To quote one of study respondents from Sindhupalchowk, it is obvious that "some people have moved on the recovery phase, but others are still stuck in the relief phase."

Throughout our research, it was clear that persons with disabilities faced greater difficulties in accessing relief materials and other post-earthquake assistance due to limitations on physical mobility and a relative inability to be physically present to be recognized.

> Those who could jostle would receive [the relief materials]. The elderly who were physically weak were unable to but there used to be situations where a family with physically strong sons and parents received even up to 10-15 sacks of rice.
>
> —Janajati FGD Participant, Sindhupalchowk

Information is an important lifeline in the wake of disaster, both in Emergency Phase and the longer-term Recovery Phase that follows, as it not only helps people save lives and property but also enables them to cope with the impacts. In the immediate aftermath of the earthquake, a relatively higher percentage of PwD households (26%) and Janajati households (24.5%) indicated that they found it difficult to get access to information related to immediate relief compared to other demographic groups (Figure 7).

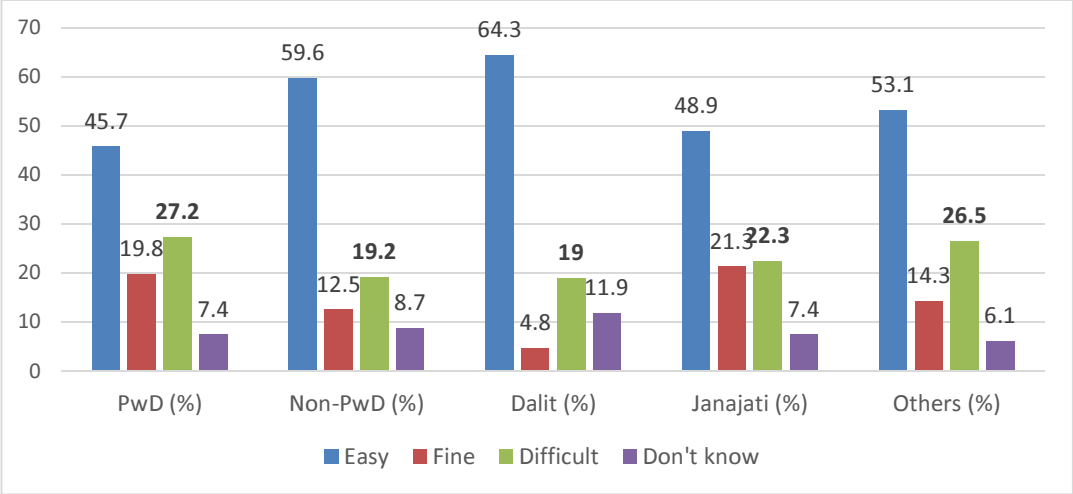
Figure 7: Access to Information in the Immediate Aftermath of the Earthquake



Our findings indicate that limited access to information evidently had bearings on the level of support that different groups were able to receive. In general, a lower percentage of PwDs

(46%) and Janajatis (49%) were able to get assistance relatively easily compared to other demographic groups such as Dalits, those from high-caste Hindu groups (listed as 'Others' below), and abled persons (60%, 64% and 53%, respectively) (Figure 8).

Figure 8: Perceptions of the Relative Difficulty of Receiving Relief



Findings from our qualitative research indicate that discrepancies and exclusions of some groups and individual households were less frequent in localities where local relief coordination mechanisms existed, and that these discrepancies were more likely in places where few materials arrived. Successful and equitable distribution was typically driven by the strategies of individual local leaders acting as coordinating individuals (many of them leaders within the Ward Citizen Forum which acts as the unofficial local government) who would inform each of the affected families and ensure that the relief is distributed to all of them.[8]

There was the lack of realization on the part of both state and non-state actors that some vulnerable groups like PwDs have special needs that require targeted relief distribution. The following quote demonstrates a common approach to relief distribution, which represents a lack of attention to the most vulnerable.

> We tried to distribute and facilitate all the available relief materials to all of the households across the village equally regardless of any special consideration to the particular vulnerable groups like single women, senior citizens, persons with disabilities and Dalits, because, the impact of the earthquake has been equally severe and devastating to all of the villagers whether they are rich or poor or persons with disabilities. —VDC Secretary, Sindhupalchowk

> Till now I have not heard of any distribution of relief materials for persons with disabilities. Neither are there any programs for them.
>
> —Physically-Disabled Dalit man, Karthali, Sindhupalchowk

Overall, we found only a very few programs that systematically distributed materials to persons with disabilities, and even fewer that distributed specific items to help counter disabilities (i.e. assistive devices). In Gorkha, we did find that the District Disaster Relief Committee did try to distribute a targeted one-time cash transfer of NRs 10,000 (~USD $100) to the 'most vulnerable

[8] This trend was reported by a diverse group of respondents in the four districts, representing men and women, different ethnic and caste groups, and both disabled and abled persons. Proximity to the road was variably identified as a major factor influencing relief both positively and negatively, promoting divergent patterns of increased coordination or conflict. However, perhaps predictably, PwDs living in settlements near the road seem to have had greater exposure to relief.

groups' which included PwDs during the early relief phase, but this was the sole example of such a coordinated activity. All other efforts targeted for persons with disabilities were conducted by DPOs or INGOs like Handicap International or CBM. Though these few disability-oriented organizations did provide specialized care, rehabilitation services, and assistive devices, they were not present in the majority of our study areas, indicating the difficulties in ensuring adequate coverage and pointing to the need for the integration of disability issues within large 'mainstream' humanitarian agencies.

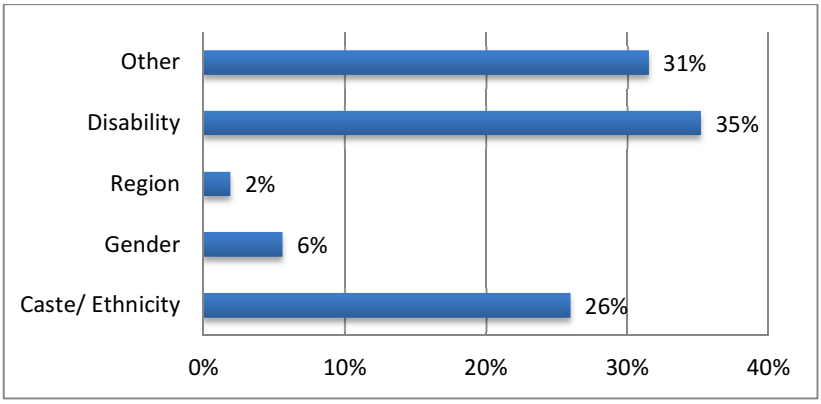
Importantly, difficulty in accessing emergency services and relief materials in a crisis situation not only has an impact on the household's ability to cope with the immediate impact of a disaster but can also have bearings on the mental and psychosocial wellbeing of the disaster victim. According to the 'Disaster Risk Management Global Platform Fact Sheet (2011) there are many factors that adversely affect the mental health of disaster victims and that 'psychological well-being is influenced by a variety of social factors such as dignified and safe provision of overall aid'. And, therefore, it is crucial that vulnerable groups such as persons with disabilties are targeted via specific risk reduction, emergency response and recovery measures.

On a broader scale, it is necessary to introduce a model of disaster response and relief that is based on principles of *equity* rather than the common approach informed by a loose commitment to equality, which reinforces and even exaggerates existing inequalities in the post-disaster context. To accomplish this, it is necessary to sensitize representatives from the Government of Nepal and other disaster-response institutions to the specific needs of excluded groups and persons with disabilities. As a recent report focused on caste-based discrimination in relief activities argued, it is critical to change the mentality of 'frontline actors' who shape disaster response (NNDSWO 2016). Most importantly, these principles of equity need to be incorporated into all disaster-risk reduction activities (see Part 4 on 'Disability and Disaster Risk Reduction' below), to increase the efficacy and appropriateness of the immediate disaster response and to increase awareness about social exclusion and disability before a disaster occurs.

2.4 Continued Exclusion and Increased Vulnerability

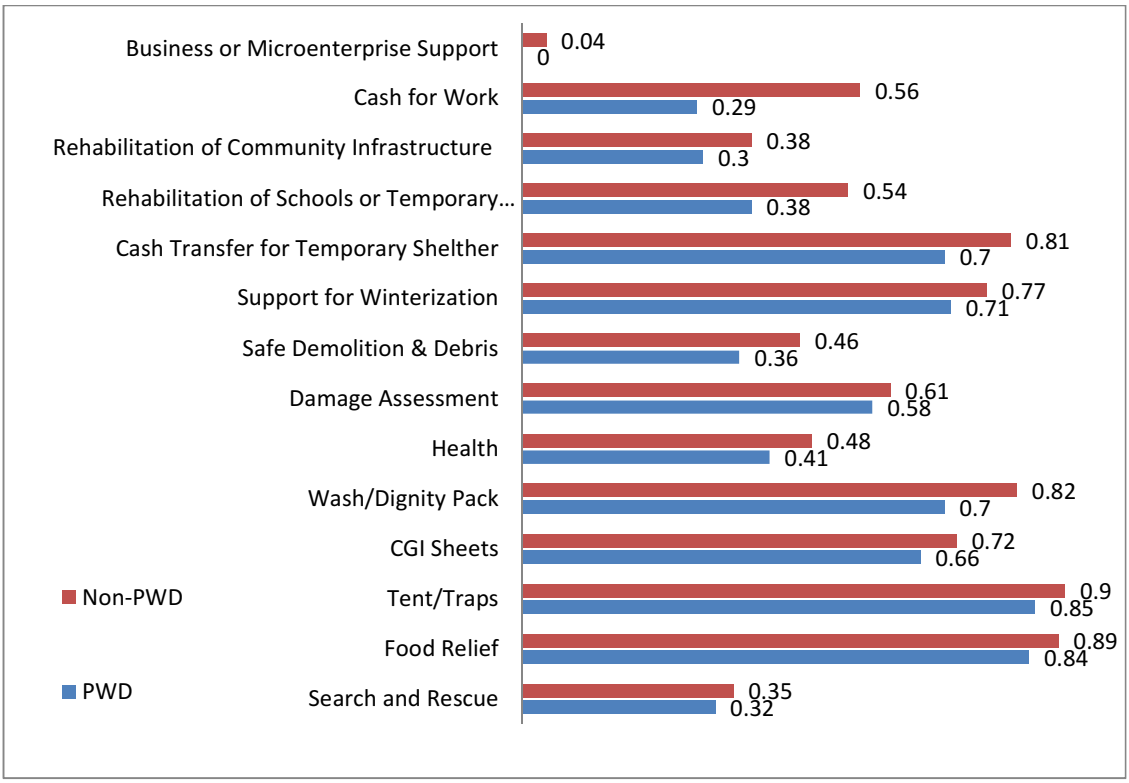
The differences in the severity of the impact of earthquake based on markers of identity and disability, as also documented in other reports, also defines the relative ease with which different population groups are able to deal with damages and losses during the recovery and reconstruction phase (Naujoks 2016). Findings from our study also indicate that the situation has not changed in the post-earthquake period and perhaps even worsened. The deeply entrenched social hierarchies, disabling social and environmental factors as well as their individual impairments have significant ramifications for the post-earthquake recovery of persons with disabilities, single women, and other marginalized groups. Across our broader sample, twenty-nine percent of our survey respondents indicated feeling excluded, with disability being the most commonly cited reason (35%).

Figure 9: Reasons Identified for Feeling Excluded in the Post-Earthquake Period



Further, of all the different types of services provided for relief and recovery, the weighted average of the support received is much less for households that include persons with disabilities (PwDs) as to opposed to those without (Non-PwDs). The following graph depicts this trend, with '0' representing 'No Support' and '1' representing 'Support'. The difference between PwDs and Non-PwDs is less (ranging from approximately 5 to 9 percentage points difference) for immediate rescue and the material needs of the Emergency Phase but much higher (ranging from 24 to 200 percentage points difference) for assistance that would help earthquake-affected households recover in the medium and long-term (e.g., safe demolition and debris management, health assistance, rehabilitation of schools and other infrastructure, and livelihood support such as cash for work and business/microenterprise support).

Figure 10: Differences in Access to Support/Assistance



Similarly, when our team conducted fieldwork in January, most people were still living in temporary shelters (many still are even now). Our survey data shows that 61.7% of persons

with disabilities in our sample were living in temporary shelter made of CGI Sheets and that they had been living in these conditions for an average of 7.2 months. Likewise, in terms of gender, Sita Adhikari, Woman Development Officer [WDO] in Gorkha district, said that during the emergency period, people were living in camps and their living conditions posed threats to women and children, especially persons with physical and intellectual disabilities. They were vulnerable to being physically abused. The camps also posed serious threats to the health and safety of pregnant and postnatal as well as lactating mothers. The living condition was difficult for single women as well. In addition, she added, the cases of violence had increased after the earthquake. At the time of the interview, her office was getting five or six cases every day relating to physical, economic, and sexual violence. These cases of violence appear to have risen partly due to increased alcohol consumption, a trend which places women and children at greater immediate risk, increases the economic instability for displaced households, and can cause both disabling accidents and long-term health problems, including congenital disabilities.

2.5 Public Health & Healthcare

Chronic public health problems in Nepal related to water, sanitation and hygiene (WASH), disease, malnutrition, and inadequate access to healthcare are both a cause of disability and a source of recurring health problems for persons with disabilities. Health problems and disabilities can exacerbate poor living conditions and erode the economic well-being of families, creating feedback loops that can lead to long-term impoverishment. The 2001 Situation Analysis of Disability in Nepal found that 30.3% of the disabilities are attributed to disease or lack of medical care, pointing to the fact that a significant percentage of disabilities in Nepal are preventable and that disability is deeply embedded in broader issues of public health (NPC 2001). The same study also found that 50% of different types of disabilities occurred before the age of five. Further, given that 15.4% of the disabilities were a result of accidents "indicates neglected traumas or, in other words, the lack of appropriate medical treatment following the accident" (NPC 2001: 7).

Healthcare and rehabilitation facilities are largely centralized at the national and district level. Government healthcare typically provides only emergency care and very basic needs. Rehabilitation and physical therapy services are available only to those with mobility-related disabilities or musculoskeletal conditions, and there are very few public treatment options for mental and intellectual disabilities. At the time of the Norad (2012) study, for example, there were 400 physiotherapists but only eight speech therapists in the entire country. During the consultations, Handicap International-Nepal pointed out a lack of technical capacity for the fitting of assistive devices as a major problem in rural areas, as there are typically only one or two technicians per district. Women's health is also a major issue for women with disabilities (WwDs) in Nepal, as indicated by a 2007 study conducted by the NDWA that found that 54% of WwDs reported ongoing health problems and 45% reported facing reproductive health issues (Khanal 2007) indicating a major gap in health services.

Access to and availability of health care facilities has emerged as crucial for PwDs in the post-disaster situation. Three respondents of the survey ranked problem in accessing health services and medicines is top most challenge in the post-earthquake context in their localities. While health problems were not commonly cited by PwD respondents as a major issue during our field research, this likely indicates the emergence of other problems in the wake of the earthquake rather than any kind of satisfaction with the healthcare system in Nepal. And despite the initiatives mentioned above, a key informant from Bahrabise, Sindhupalchowk, was quite

blunt: 'People with disabilities have not received health services after the earthquake in our community.'

Field observations at our research sites indicate that 'local' district-level and community-level health infrastructures are not accessible to people with disabilities, reflecting a broader trend across Nepal. In addition, this situation is similar in many public places. Though perhaps unavoidable, the centralization of most health services in market towns poses a challenge for persons with disabilities living in rural areas without road access, particularly in the wake of the earthquake when road and trails have been significantly damaged.

A select few institutions and DPOs have been working to create more inclusive and disabled-friendly health infrastructure and to provide specific care to persons with disabilities, and the role of these organizations in the post-disaster period has been praiseworthy. During our field research, we found a handful of high-quality post-earthquake programs offering specific health support for disability, such as the UNICEF-supported rehabilitation center at Chautara in Sindhupalchowk district; the field offices for Handicap International in Nuwakot; and the Hospital and Rehabilitation Center for Disabled Children (HRDC) treating and rehabilitating victims and providing relief materials and medical assistance in difficult-to-reach sites, as well as a few smaller volunteer efforts. As referenced in the section on 'Disaster Risk Reduction' below, these kinds of mobile response units are crucial in the wake of disasters. The majority of healthcare and rehabilitation, however, was provided thru pre-existing institutions such as the Spinal Injury Rehabilitation Center in Kavre district, which has been providing integrated facilities and services to disabled persons living with spinal injuries for years. Unfortunately, however, such centers are very limited, centralized in the Kathmandu Valley or district headquarters, and not available in the many of the more remote parts of the country.

One very telling example of an inclusive and disability-focused post-disaster healthcare intervention is the 'medication rehabilitation shelter' started by the Nepal Healthcare Equipment Development Foundation (NHEDF) in the immediate aftermath of the earthquakes. Based in Panipokhari in Kathmandu and started to provide shelter to ultra-poor and displaced Nepalis sleeping in the streets while seeking healthcare in Kathmandu, this facility has now provided accommodations, rehabilitation services, and assistance with medical treatment to over 300 persons injured or disabled by the earthquake. Created to fill a gap in disaster response, the continued existence of the NHEDF shelter represents both a failure within Nepal's healthcare system and the possibilities for innovation. Novel programs like these should be supported, expanded, and replicated in other settings across Nepal.

2.6 Unequal Educational Opportunities

UNESCO estimates that children with disabilities represent more than a third of the 67 million children who are out of school worldwide (UNESCO 2007). In 1998, UNDP estimated that the global rate of literacy among PwDs was 3% for men and only 1% for women while a UNESCO report states that 90% of children with disabilities in developing countries do not attend school. Summarizing this systematic underperformance, the Millennium Development Report stated: "Even in some countries that are closer to achieving the goal of universal primary education, children with disabilities represent the majority of those who are excluded" (MDR 2010: 18).

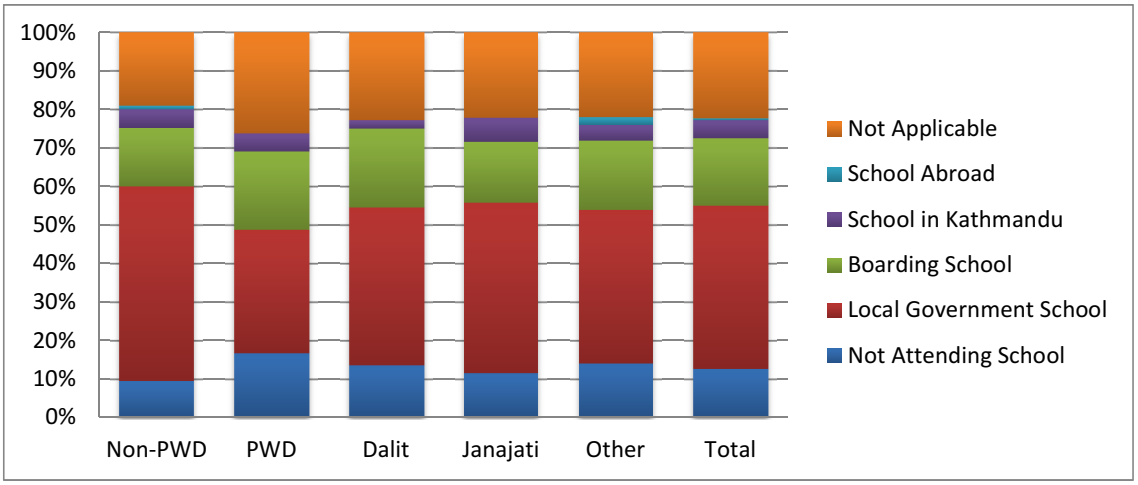
In Nepal, a range of studies indicate that disabled children systematically lack access to education, both in terms of inclusion and in terms of attention to special needs related to specific impairments (UNICEF 2001, Human Rights Watch 2013). Nepal's Child Protection Act 1992 states that disabled children cannot be discriminated against and states that disabled

children who cannot be cared for by their family must be provided for in children's homes and receive necessary education. Further, the CRPD obliges signatories to ensure that persons with disabilities are not excluded from the general education system on the basis of disability and particularly children with disabilities must not be excluded from free and compulsory primary education, or from secondary education. And yet, the 2001 Situational Report on Disability found that "68.2 percent of persons with disabilities have no education as compared with 44 percent of total population" (NPC 2001). A decade later, the Flash I Report 2011 released by the Ministry of Education shows that children with disabilities represent only 1.0% of total enrollment at the basic level, 1.1% of enrollment at the primary school level and 0.8% of enrollment in lower secondary schools (MoE 2011).

Although the Constitution of Nepal has established education as one of the fundamental rights of every citizen to enable him or her to live a life with dignity, the inclusion of PwDs in education remains highly problematic in Nepal. Hence, "despite a political commitment to persons with disabilities to provide the access to education, in practice it's falling short in implementation. Lack of disability friendly environment, inadequate learning and teaching materials, lack of special teacher, negative attitudes of teachers and parents people with disabilities are left behind from the mainstreaming of education" (NDWA 2013: 3).

According to our survey data a higher proportion of PwD children were not attending schools at all compared to non-PwD children. Of those attending schools, a lower percentage are attending local government schools, indicating perhaps that public schools are not PwD-friendly in terms of access. And as a 2013 study by Human Rights Watch states that "even if school buildings might be accessible the roads to schools are not" (Norad 2012) illustrating the host of infrastructural issues that need to be sorted out before education is truly accessible to disabled children and youth.

Figure 11: School Attendance by Demographic Group



Our survey data reflects this pattern of unequal education, as 28% of persons with disabilities in our survey were illiterate and an alarming 46% of women with disabilities were illiterate—providing more evidence of a significant gendered gap in the care for children with disabilities in Nepal. Only 7.3% of PwDs surveyed had passed their School Leaving Certificate (SLC) examinations and among females this figure was only 2.7%. The gendered difference in literacy rates confirms similar global trends which say that girl children with disabilities are the most excluded from going to school and education with both lower enrollment and higher dropout rates (Human Right Watch 2011). The research findings show that that the education of female PwDs is considered less of a priority in many households, reflecting a systemic cultural bias in

favour of the education of male children and hence severely limiting the collective ability of female PwDs to determine their own futures.

Additionally, multiple vulnerabilities of being female coupled with intellectual/mental/developmental disabilities ensures almost zero access to school and quality specialised education, as the mother of a 16 year old girl with learning and development difficulties from Sindhupalchowk said: "We don't know about special schools for children with disabilities. We send her to the school where other children go. She's not regular; she goes to school depending on her mood. Therefore she is still in Grade 3 and she's already 16 years old."

During interviews, a large number of the persons with disabilities expressed frustration about the gap in educational opportunities that has led to their marginalization in their families, in their communities, and within the broader economy and society; decreasing livelihood opportunities and possibilities for economic autonomy. One woman with disabilities from Sindhupalchowk simply stated that: "Due to lack of education I am behind and dominated by my community and family." Echoing her, an abled male from Sindhupalchowk described the cycle of disadvantage faced by PwDs due a lack of education: 'Persons with disabilities are marginalized because of their education. They are not as educated as others [abled people] and so they are unemployed and cannot earn money.'

For schools that do offer special education programmes for students with disabilities, the Government of Nepal has a scholarship policy to help cover the expense of education—with four tiers of funding, ranging from NRs 5,000 to 30,000 NRs per annum depending on level of dependency, severity of disability, and geographic location. These scholarships are made available through the District Education Office, and demand often exceeds available funding. In Nuwakot, for example, a local DPO representative said: 'There are four schools for PwDs: one school for the blind in Tupche; two for children with hearing problems in Bageshwori and Nuwakot; and one for students with intellectual disabilities in Majhitar. The government provides support for twenty students in each of these schools.'

The quality of special education programmes, however, is extremely uneven, reflected in the survey result that only 12.2% of PwDs think that the PwD Special Education Programmes are 'Good or Adequate'. Additionally, the lack of teachers trained or specializing in special education is also a factor constraining the quality of education for PwDs. A key informant from Sindhupalchowk said: "In Chautara there is a special school for the disabled with 181 students. They are good at their studies but the lack of teachers and equipment makes it very hard to study for them."

On the highly positive side, however, the research team did encounter a few PwDs who had been able to transition into higher education after attending these schools.

> I was enrolled in a special school for deaf children by my father in Class 8. I managed to acquire good results in my SLC and this encouraged me to pursue higher education and teach other deaf children. I am currently doing my BEd and teaching at the school [Kavre Deaf School, Banepa]. I want to be a role model for these children.
>
> —Hearing-impaired woman, Kavrepalanchowk

As the study showed, interruption of education among PwDs has increased due to:

- Problems of travel/mobility to relocated schools, which has affected everyone but particularly PwDs
- Damage to the limited facilities for special education that existed
- Many PwDs living in camps for internally displaced people

- Lack of PwD-friendly facilities in Temporary Learning Centers
- Exclusion and teasing when entering new learning environments
- Strain on household finances due to deaths, injuries, or lack of work among caregivers
- Barriers to adaptation for children newly disabled by the earthquake

During times of crisis and inadequate shelter and food, the ability of households to invest in their children's education is severely curtailed, and PwD children are often the least priority. Newly disabled children also have a particularly hard time as they adapt to their differently-abled bodies while their parents struggle to meet medical costs even as they restore their homes and livelihoods. Unable to go to school due to the difficult terrain coupled with their disabilities, many have been forced to remain home and miss out on school. The mother of a newly disabled, paraplegic 16-year-old girl from Sindhupalchowk said:

> We lost our house, one cow and one buffalo. I used to sell the milk here in the village and made a small income to buy vegetables for dinner. My husband lives in Kathmandu, he has a job there but he lost it last year because we were so busy running around hospitals for our daughter. We're in trouble now, we've borrowed money and have been living off of that. I don't know how we'll continue like this. And I worry so much for my daughter. She hasn't been to school in a year, she missed out on this year's SLC exam as well, let's see maybe next year we'll manage something…

2.7 Livelihood Struggles & Constraints Economic Recovery

> The community still doesn't understand the issues of *apaangata* [persons with disabilities]. We are seen as *'kaam na laagne'* [useless], unable to work and earn a living. —Dalit PwD in Kavre

Disasters have direct and indirect impacts on the livelihoods of those affected, and interruptions and dislocations of livelihood tend to have more severe effects on poor and marginalized households. Of our sampled households, 62% indicated that the earthquake had destroyed their sources of employment and livelihood. Consequently, individual households have adopted a number of strategies to cope with the effects of the earthquake. This was particularly evident in the form of changes in employment patterns and livelihoods strategies. There is a clear shift away from self-employment in agriculture towards other forms of livelihood with an overall average decrease of 11% following the earthquake, with this decrease being more pronounced in the case of PwD, Dalit and Janajati households.

Figure 12: Changes in Employment Status/Livelihood Strategies

Category of Work or Livelihood	PwD		Non-PwD		Dalit		Janajati		Others		Total	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Agriculture - Self Employed	42	30.9	55.8	45.2	42.9	31	54.3	41.5	46.9	40.8	49.7	38.9
Agriculture - Wage	0	0	1.9	1.9	2.4	2.4	1.1	1.1	0	0	1.1	1.1
Non Agriculture-Wage	11.1	9.9	9.6	13.5	14.3	14.3	10.6	10.6	6.1	12.2	10.3	11.9
Remittance	3.7	3.7	6.7	5.8	7.1	4.8	3.2	3.2	8.2	8.2	5.4	4.9
Operating Own Business	17.3	18.5	14.4	11.5	23.8	23.8	11.7	12.8	16.3	10.2	15.7	14.6
Private Sector Employment	3.7	3.7	2.9	1	2.4	2.4	2.1	2.1	6.1	2	3.2	2.2
Public Sector Employment	6.2	6.2	3.8	3.8	2.4	2.4	5.3	5.3	6.1	6.1	4.9	4.9

Social Security Allowance	9.9	4.9	0	0	0	2.4	6.4	2.1	4.1	2	4.3	2.2
NGO Employment	2.5	1.2	1.9	1.9	2.4	2.4	3.2	2.1	0	0	2.2	1.6
Others	3.7	11.1	2.9	4.8	2.4	7.1	2.1	7.4	6.1	8.2	3.2	7.6
Not Applicable	-	9.9	-	10.6	-	7.1	-	11.7	-	10.2	-	10.3

Across demographic groups, a decrease in self-employment in the agriculture sector was complemented by a slight increase in other categories of employment, but most importantly the self-reported rate of unemployment ('not applicable') went up significantly for all groups. Early recovery-oriented programs such as Cash for Work (CfW) and Food for Work (FfW) implemented by I/NGOs were reported to have been beneficial both in terms of coping in the post-earthquake situations and rebuilding/reviving various services such as roads, water sources and public buildings that are important to their livelihoods. These interventions created short-term employment opportunities to those who lacked other options or those whose agricultural land or livestock was damaged by the earthquake. For carrying out such activities, workers reported being paid between NRs 400-700 per day or being paid in food staples (rice and pulses) and working for anywhere from a few days to two months.[9]

> The major help was provided by UNDP. At a time when everything was devastated everywhere and no one had money in their pocket, UNDP took the responsibility of clearing the debris and also gave us money for doing that.
>
> —Local CfW Participant, Karthali, Sindhupalchowk

> The WFP program provided us with rice after we dug the road, cleaned the surrounding and constructed the roads to reach the source of water. We have been eating that rice.
>
> —Focus Group Participant, Sindhupalchowk

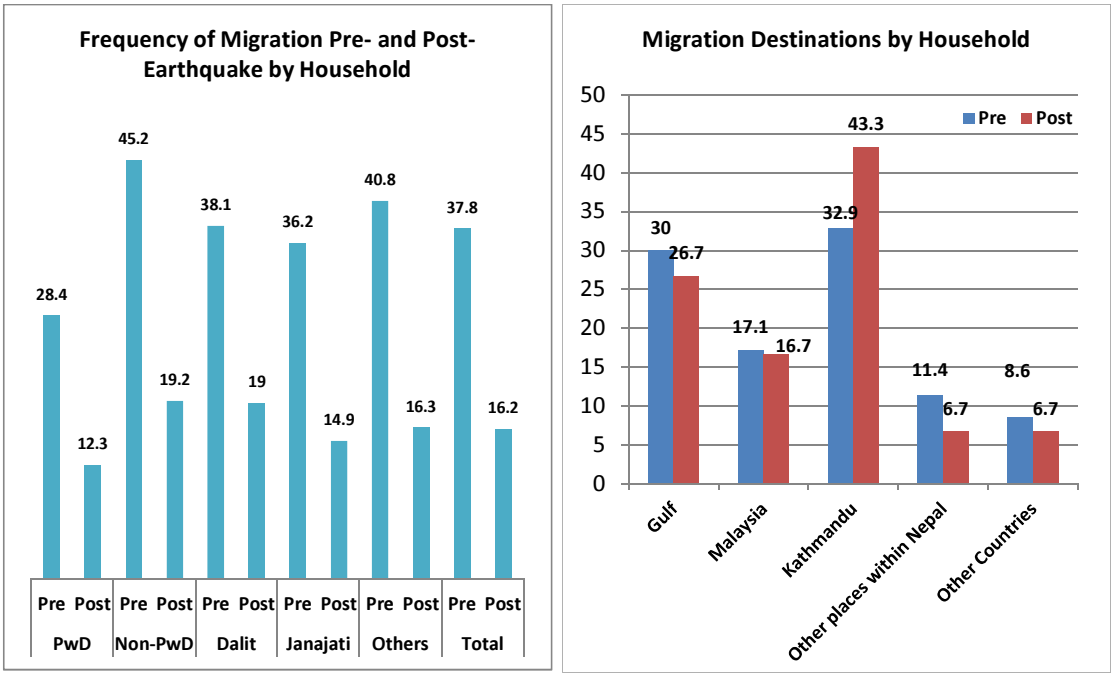
During the course of field research, we noted that a small number of persons with disabilities had participated in cash-for-work programs such as the UNDP Safe Demolition and Debris Management Programme and the food-for-work road restoration program implemented by the World Food Programme Roads Access Program (mostly people with less-severe physical disabilities). In general, however, PwDs were less likely to gain temporary or full-time employment within earthquake recovery programs, due to limitations (both real and perceived) that have systematically limited livelihood opportunities for persons with disabilities in Nepal. As one abled respondent in Sindhupalchowk told us: "Persons with disabilities are marginalized because they are disabled. PwDs cannot work and produce the things as expected as abled person." To mitigate these kind of attitudinal barriers to socioeconomic inclusion, post-disaster recovery programs should take a proactive role toward employing persons with disabilities as per their respective capabilities.

Reflecting a larger economic pattern in Nepal, one livelihood strategy adopted in the aftermath of the earthquake was an increased in the frequency of household members migrating outside the locality for employment. At the time of our data collection, eight to ten months after the earthquake, an an average, 38% of the households indicated that they had family members working outside their own Village Development Committee (VDC), whether elsewhere within Nepal or abroad in a variety of common locations (i.e. India, the Gulf States, Malaysia, Singapore, Korea, etc). After the earthquake, a further 16.2% of the households indicated that family members had migrated, with the largest proportion seen among abled populations and high-caste Hindus. The imperative to leave home at any cost is also apparent in 50% of the post-earthquake migrants choosing Kathmandu or other parts of Nepal compared to 44% of the

[9] Based on interviews in 24 VDCs within Sindhupalchowk, Nuwakot, and Kavrepalanchowk districts.

pre-earthquake migrants; with fewer people going abroad for work after the earthquake (perhaps due to financial constraints). Most importantly, the percentage of households with family members abroad was significantly lower both before and after the earthquakes for households with PwDs—28.4% for vs. 45.2% and 12.3% vs 19.3% respectively—indicating perhaps the economic challenges of being a caregiver

Figure 13: Changes in Migration Trends Prior to and After the Earthquake



Notwithstanding recent changes in foreign employment policies at the national level (namely, the initiation of 'free-visa and free-ticket' policies announced by the government just a few months after the earthquake in June 2015, which were weakly implemented) the continuing high costs associated with new foreign migration were perhaps prohibitive for most households after the financial losses and damages incurred by the households—an effect which was likely stronger within economically marginalized groups such as Dalits and PwDs. Though this data clearly indicates a rise in migration to Kathmandu—a function perhaps of displacement, the lack of market access in many rural areas, and new possibilities for casual labor in demolition and reconstruction—we also see fewer households migrating in the post-earthquake period, and a relatively smaller number going to the Gulf. Regardless, the qualitative data shows that migration has contributed strongly to coping with the impacts of earthquake[10].

> As my husband is abroad he has been sending money. If people have migrants in their home, the recovery is easier but for those who do not have any migrants it is difficult.
>
> —Tamang Woman, Karthali, Sindhupalchowk

> My husband is earning and supporting our family. Sons are abroad and they send some remittance at regular intervals. So, I am in better situation than others.
>
> —High-Caste Hindu Woman, Sindhupalchowk

[10] In some cases, Nepalis working abroad returned to Nepal after the earthquake if they were able (many could not easily break their contracts), but as anecdotal evidence also indicates many migrants and their families decided that sending remittances was more helpful to households struggling in the wake of the earthquakes than coming home to uncertain employment opportunities.

> Our father and mother have gone abroad and have started earning and have been sending money after the earthquake. Otherwise, we had to struggle to buy things.
>
> —Disabled Tamang Boy, Bahrabise, Sindhupalchowk

Predictably, the impact of the earthquake on land- and agriculture/livestock-based livelihoods also led the affected households to take out loans, which increased their debt burdens thus causing further psychological stresses. Prior to the earthquake, families with PwDs tended to be in less debt, with 37% indicating that they had no loans compared to the average of 25%. However, families of PwDs tended to rely somewhat more on informal sources (e.g., family relatives and money lenders) when they did require financial support than the average. However, after the earthquake approximately 33% of the sampled households also indicated that they had to take additional loans to cope with the effects of the earthquake. Amongst the different populations, a significantly larger percentage of Dalits (41.5%) have taken new loans which indicate not only the vulnerability of Dalit households but more importantly point to the possibility of them entering into vicious circles of poverty and vulnerability to natural and man-made disasters.

Figure14: Percentage of Households with New Loans Following the Earthquake

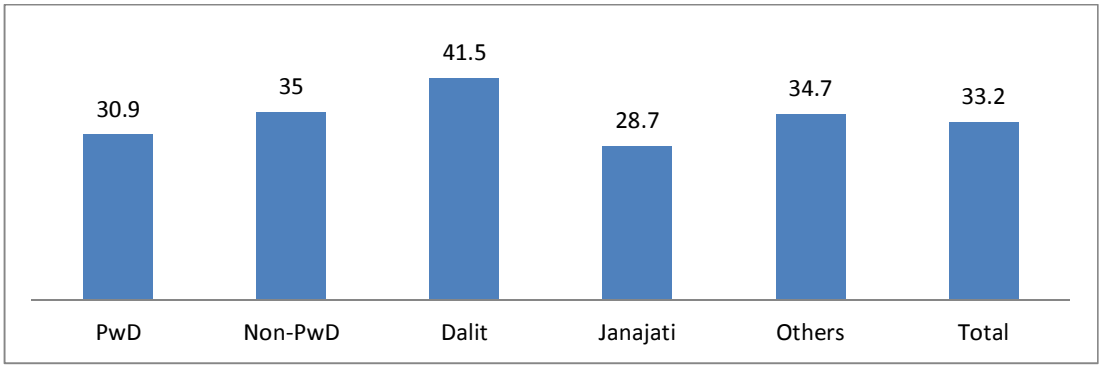
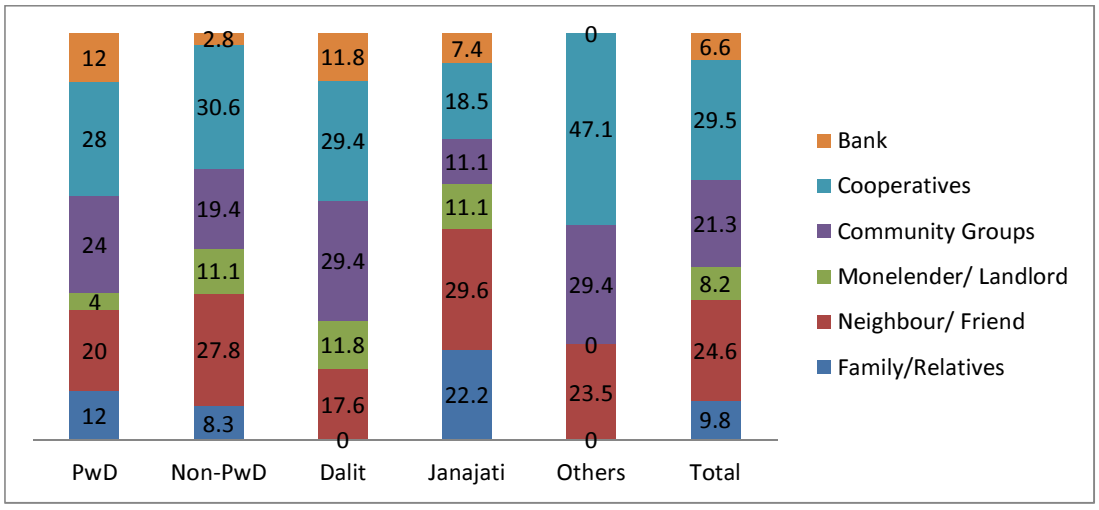


Figure 15: Sources of Loans/Credit After the Earthquake



Notably, most of the households (approximately 51%) who took loans following the earthquake mentioned cooperatives and community savings and credit groups as being the major sources of these loans, thus pointing to the importance of these local institutions prior to and after the earthquake, particularly since that is a 6% increase over the number who received loans from

the same sources. Access to these institutions also varied greatly with a much higher proportion of high-caste Hindus (77%) receiving credit from these institutions than other groups.

Although the research did not find many cases of projects that explicitly sought to provide assistance to the PwDs, the limited livelihood options available to them even prior to the earthquake, is notable. The limited livelihood and employment options for Dalits and families with PwDs is reflected in the low levels of savings—22% of Dalits and 23% of families with PwDs indicated that they have no savings. In such circumstances, the research findings indicate the need to evaluate the possibilities for technical/trades trainings in PwD-oriented schools (i.e. Kavre and Nuwakot) to ensure greater job placement.

> There should be mandatory provisions to allocate employment for persons with disabilities in wage-based employment suitable to their skills and capacities. Also, there is a need to introduce new and innovative vocational training packages that have a better chance of helping the disabled to secure jobs after completing trainings. —Sudarshan Neupane, Handicap International

A few good examples exist which demonstrate the success of livelihood programs focused on the employment of persons with disabilities. Consider, for example, an incense production facility in Nuwakot that was formed by a local DPO, is owned by a consortium of local persons with disabilities, and which provides employment to 10 PwD employees (continuing in the wake of the earthquake). On a more individual level, here is an account from physically disabled man from Nuwakot who took the initiative his own sericulture business after participating in a livelihood training program:

> I collected information from the agricultural office and then participated in a 50-day silk-farming training. An organisation in Dhading is monitoring the silk-farming, and it provides larvae and again comes to collect the silk. The silk is collected at 250 rupees per kg. Silk-farming can be done during three seasons of the year. I earn 20,000 to 25,000 rupees per season. Though the earthquake destroyed my house, animal shed, and equipment for silk farming, I was not disheartened and I started working harder. I am independent for my household expenses, and I am running my household well. In the future, I am thinking of extending my business and providing employment to others. —Physically Disabled Tamang Man, Nuwakot

Again, given chronic conditions of underemployment for persons with disabilities in Nepal, the relatively low rate of migration within PwD households, and widespread constraints on physical and financial mobility provided by the earthquake and its aftermath which disproportionately affect economically marginalized, it is crucial to initiate targeted livelihoods programs for persons with disability to help ensure both post-earthquake recovery and equal opportunity to economic autonomy.

2.8 Under-Representation of Disabled Persons Organizations

The study indicates that DPOs are highly under-represented within the institutional structure of disaster response in post-earthquake Nepal. Though issues of disability are ostensibly addressed in the context of the Protection Cluster, the findings showed that: a) local DPOs working for the rights of PwDs in each of the four districts were not meaningfully included in the Protection Cluster; b) disability-oriented organizations who did participate in the Protection Cluster were mostly INGOs that arrived post-disaster; and c) coordination between international and local organizations was low. In Nuwakot, for example, a National Federation of Disabled-Nepal (NFDN) representatives participated in the Protection Cluster as the representative of all the DPOs in the district: "We presented our work. Other NGOs also presented their work. But it was just sharing meeting. Nothing happened afterward."

Similarly, it became evident that the voices of PwDs were not heard in the District Disaster Relief Committees. Several DPOs reported that issues of disability were largely 'crowded out' or diluted within the conversation on protection by other more visible protection/GESI topics such as 'the needs of lactating mothers' and issues of post-earthquake trafficking. Interviews conducted with local government officials indicated a significant lack of awareness about issues of social inclusion and disability. When asked about the needs of marginalized groups, local government officials typically mentioned the same programmes focusing on 'lactating mothers' (understood perhaps as a proxy for 'women's issues') and that 'Janajatis are receiving their fare share of relief'. When asked about the programmes focused on persons with disabilities, government officials referred only to the disability allowance programme, and very few (with the exception of the Women's Development Officers) were aware of any post-earthquake programmes specifically targeting PwDs. Overall, there is a systemic lack of understanding and awareness about disability and different needs related to different kinds of disability among government officials. One ranking official went so far as to say rhetorically: "All uneducated people are disabled people." That is patently false and indicates a fundamental misunderstanding of the true reality of 'unequal opportunity'.

Lack of coordination and infrequent or imperfect local consultation of DPOs and PwD stakeholders also emerged as a major theme. The research team was repeatedly told by DPOs of international organizations implementing disaster relief management at the local level without consulting NGOs or other communities. One DPO representatives said that: "If NGOs have any programs related to PwDs, then we should be included. For interacting with PwDs in this district, they need a programme of interaction. We have all the contact numbers and so we can inform them about the programme." When asked if DPOs in Nuwakot had worked with INGOs in the past, a representative of a DPO in Nuwakot said:

> Before the earthquake there was no collaboration with INGOs here and there was no specific programme for PwDs by INGOs. All the DPOs are helped by the District Development Committee budget only. Now, we have heard about Handicap International working here. They came and distributed some 5-7 wheelchairs to PwDs, and they are providing physiotherapy service coordinating with District Health Office in their premises. But, this is of little help. We feel that Handicap International has not worked for most of the PwDs living in the villages. These INGOs bring programmes only to their target areas. They just work in the VDCs which are on their list.

A Ward Citizen's Forum leader in Tupche VDC of Nuwakot district reported a similar trend, indicating that while they were happy with the relief and early recovery efforts that targeted the local school for visually-disabled children, the narrow focus of the NGOs providing the material prevented them from seeing disability in the communities surrounding the school: "In the village, the visually-impaired students have benefitted from relief-based support. However, apart from the students other PwDs in the village did not get such attention though some of them live very near the temporary hostel of those disabled students."

During our data collection, several PwDs and DPOs repeatedly identified issues of spatial exclusion as the single largest challenge to inclusion; describing how it is extremely difficult to engage and include persons with disabilities living far from district headquarters. This leads to the micropolitics of exclusion within the PwD community, where some PwDs and DPOs living in the headquarters are able to achieve greater representation while others are not. During the fieldwork, PwD respondents living both far and near district headquarters frequently stated that they did not have their own local NGOs to represent their interests, saying that they were not aware of what the district-level DPOs were doing and that they had not been consulted. During the FGD among DPOs, an NFDN representative did iterate the need to focus on rural areas:

> Organizations have to go rural remote VDCs where PwDs need real support. If these organizations like UNDP can go to rural remote VDCs, then people in those areas can know about programmes related to PwDs. There is a major information gap for most PwDs in Nuwakot and other places in Nepal. Even during the meetings and programme held by big INGOs in Kathmandu the same PwD from here participates repeatedly. An opportunity to learn more should be given to the other PwDs as well.

In the post-earthquake context, the research also confirms that issues of spatial exclusion remain a significant factor limiting the equitable distribution of relief materials and recovery programming—of the few PwD-focused efforts that have occurred, many of them have been confined to easy to access places and existing infrastructure, reproducing patterns of spatial exclusion. However, problems of geography and access remain systemic challenges across Nepal, and local individuals and organizations often lack the capacity to actively seek the help they need. When asked how NFDN was attempting to disseminate information to PwDs living at rural remote villages, the same NFDN representative quoted above described some of the challenges limiting these efforts: "We have established village committee for PwDs in ten VDCs. The government has a policy for PwDs and local budget [Rs 20-30 thousand per year]. But they are unable to use that budget because they write a very general proposal, so even we learn nothing about their needs."

These kinds of sociospatial exclusion are major challenges for indigenous persons with disability and the DPOs representing them, as indicated during consultations with representatives from both Nepali DPOs representing Dalit and indigenous PwDs (in Kathmandu, Nuwakot, and Gorkha) who also reported feeling excluded within the disability movement itself. For example, Gurung & Thapa (2013) note that among the 245 disabled persons organizations affiliated with the National Federation of Disabled Nepal, only 17 organizations are led by indigenous PwDs—indicating the status of IPwDs as a 'minorities within minorities'.

The following anecdote from a consultation in Gorkha indicates both this pattern of institutional exclusion and a way that they might be overcome. During our consultations with the Local Development Officer (LDO) of Gorkha district, the President of a local Disabled Persons Organization openly expressed his frustrations with a lack of inclusiveness within the District Disaster Relief Committee, indicating that his small organization had no chance in expressing their voice and that persons with disabilities were therefore absent from these meetings. He also critiqued the DDRC and the lead NGOs operating in Gorkha for their failure to invite any DPOs to the 'Recovery and Planning Worship' held in Pokhara in November 2015 and stated that PwDs were being excluded from the conversation about relief and recovery. The LDO countered by saying that he had met with a few other DPOs in the past, but that they all presented different concerns and there was not clear policy recommendation; he suggested that these local DPOs needed to collectively agree on an agenda for recovery.

The DPO representative immediately responded indicating that there was a common and immediate need to collect data on disability in the district, but that there was too little money to support this effort within the typical district budget allocations. The LDO then responded quite positively and pledged to increase financial support to map out the number of PWDs across the district and prepare a 'district profile on Disability'. He said that this profile would provide the information required to develop an appropriate program for local DPOs that the District Development Office could more readily support, and he pledged to allocate more funds to that future program.

Though this kind of interaction is probably a rarity (and a product of the presence of our research team, which included the Vice President of the National Federation of Disabled-

Nepal) it indicates that dialogue can yield workable solutions. Further the creation of an actionable 'District Profile on Disability' (beyond the current pamphlet released by the Women's Development Office in some districts, which simply names disability ID card holders) would help greatly to foreground issues of disability at the level of district government and could help draw attention to the needs of all district-level DPOs. Though local DPOs are often focused on different issues related to the different kinds of disability, greater coordination at the local level (facilitated perhaps by an umbrella organization like NFDN) may increase the collective visibility of DPOs and disability issues.

2.9 Chronic Lack of Data on Disability

The lack of data and statistics on disability contributes to the invisibility of persons with disabilities. This presents an obstacle to achieving development planning and implementation to improve the lives and well-being of persons with disabilities."

-UN Enable: Why Disability Statistics Matter, 2016

Global statistics on disability typically estimate that 10-15% of the world's population are living with disabilities and that up to 90% of persons with disabilities live in the developing world (WHO, World Bank, UN Enable). The official statistics describing disability in Nepal that have been generated by the Government of Nepal and other institutions are however far lower, creating a highly contested information gap.

A number of surveys have been conducted to determine the prevalence of disability in Nepal, but their findings vary widely and are thought to systematically underestimate the number of PwDs in Nepal—the statistic most frequently cited for the percentage of the total population living with some kind of disability is 1.94% (CBS 2011). This number is significantly below the global averages that place the total disability of 10-15% and flies counter to the intuitive assumption that the number would reflect the often-quoted concept that 90% of PwDs live in developing countries like Nepal. In any case, all efforts to support and include or 'mainstream' persons with disabilities (PwDs) in Nepal are severely limited by problems related to inadequate data on disability at the national level

For example, the National Census of 1971 estimated that persons with disability represented 1.5% of the total population of Nepal (CBS 1971), while the censuses of 2001 and 2011 found that they represent 0.45% and 1.94% of the total population, respectively (CBS 2001; CBS 2011). Simultaneously, a national 'Situational Analysis of Disability in Nepal' in 2001 revealed that 1.63% of the total population was severely disabled, but this figure does not include those classified as mild and moderate disabilities (National Planning Commission 2001). 'These figures are in sharp contrast to studies carried out by specific impairment groups. For example a survey carried out in five districts in 1991 stated that 16.6 per cent of children aged over five were deaf while a study by the mental health organization Aasha Deep (2000) found that 10-12 per cent of the population had experienced some form of mental health difficulties' (DHRC Nepal 2006).

'Solid statistics on people with disabilities are needed for evidence-based policy making in the area of disaster risk reduction' (UNESCAP 2012 cited in Stough & Kang 2015: 147). Unfortunately, as is the case with any developing countries, disaggregated data is sorely lacking in Nepal, due to a lack of financial and technical capacity, geographic limitations to data collection, and a variety of social stigmas that lead to underreporting.

The only dataset that approximates the relative composition of Nepal's disabled populations comes from the 2001 'Situational Survey on Disability' covering 13,000 households. "Among the different types of disabilities in the disabled population, including multiple disabilities, it was mobility disability that was found to be the most common type, accounting for 19.5% of all types of disabilities. Speaking disability accounted for 19.4% while hearing disability accounted for 19.1% of all types of disabilities. Manipulation disability [difficulties using limbs and hands] accounted for 14.8% while epilepsy accounted for 11.1% of all types of disabilities. There were fewer cases of mental retardation (5.9%), seeing disability (functionally blind) (5.6%) and chronic mental illness (4.6%). ' (NPC 2001: 6) Interestingly, it was found that 31.0% of disabled persons in Nepal had multiple disabilities, which indicated that the prevalence of multiple disabilities in the total population was 0.51%" (NPC 2001: 5-6).

The 2001 study did however indicate that the incidence of disability varied in terms of ecological regions, finding that 'the prevalence of disability was highest in the mountain (1.88%), followed by the hills (1.64%) and the Tarai (1.45%)' (NPC 2001: 5). The lack of good quality and disaggregated data on disability in Nepal has prevented the creation of PwD-inclusive disaster risk reduction activities and greatly limited the advocacy efforts of DPOs who seek to demonstrate that persons with disability do in fact represent a significant percentage of Nepal's population. Enumeration is therefore a major barrier to the formation of policies and programs focused on disability in Nepal.

On May 6, 2016, however, a nationwide survey focused on 'Living Conditions among People with Disability in Nepal' was just released in May 2016 (Eide et al 2016). Conducted by the Norwegian research institute SINTEF (in partnership with the National Federation of Disabled-Nepal the Nepal Valley Research Council) and representing data collected in 2014 and 2015 (concluding just before the 2015 earthquakes) this study is essentially the first statistical study focused on disability since the 2001 'Situational Analysis' conducted by New Era. By establishing updated baseline data and providing statistical clarity on the inequitable living conditions of persons with disability, this study will be a great asset for a wide range of DPOs and NGOs with an interest in issues of disability. "Having established evidence for differences between disabled and non-disabled is an important step in the promotion of human rights and improved level of living among individuals with disability. The study offers an opportunity for boosting advocacy, for setting priorities, for assessing impact and developing policies, for monitoring the situation, and for increased knowledge among disabled and the public in general." (Eide et al 2016: 159)

Given the historical lack of good disability statistics, this new study represents a major contribution to the discourse on disability in Nepal. Even so, however, a significant need remains to collect census-level data on disability in Nepal,[11] and to update this data to reflect new disabilities caused by the earthquakes of 2015.

2.10 Limited Data on Newly Earthquake-Disabled Persons

> Despite the assertion that people with disabilities are disproportionately affected by disasters, international data on disasters have not been collected in a manner that allows analysis of the problem. Lack of such data

[11] Importantly, however, this new study does not include an estimate of the total population with disabilities in Nepal due to the research design and sampling methodology of the study, which sought to compare the living conditions of persons with disabilities against a control group. Therefore it remains incredibly important to improve the methods used to enumerate disability by the Central Bureau of Statistics (Government of Nepal) prior to the next Census of 2021.

> hampers efforts to effectively respond to the needs of people with disabilities in disaster as the levels and types of supports needed by people with disabilities cannot be accurately determined.
>
> —Stough & Kang 2015: 144

Importantly, disasters also cause new disabilities, exacerbate existing impairments, and decrease the overall mobility and autonomy of persons with disabilities. "Emergency situations such as conflicts or natural disasters can also generate an increased number of people who experience disability owing to new injuries, a lack of quality medical care, or the collapse of essential services." (Handicap International 2015: 5) For example, "after the Asian Tsunami, it was estimated that there was a 20% increase in the number of persons with disabilities in the affected areas. The Haiti earthquake in 2010 left 300,000 injured and resulted in between 4,000 and 6,000 amputations in the immediate aftermath." (Handicap International 2012: vii). Despite widespread recognition of the vulnerabilities of persons with disabilities in Nepal and periodic media attention on individual Nepalis who were disabled by the earthquake, it became apparent early on during the study that reliable data on the number of people who had become disabled as a result of the earthquake was not available.

Though it is widely acknowledged that over 22,000 people were injured during the earthquake, there has been no follow-up to indicate how many of these injuries have led to permanent disabilities. Though first responders and surgeons were rightly lauded for minimizing the number of amputations—estimates of amputations range between 42 and 150, which is remarkably low compared to other disasters[12]—it is possible that there are unreported new disabilities, especially in remote areas. Despite a handful of post-earthquake data collection efforts and one larger data collection program (UNICEF providing support to NFDN and the international NGO CBM to collect data in several districts) a full picture has not yet emerged as far.

Some DPOs have launched data collection programs in narrow geographic areas. A key informant in Gorkha who is both an NFDN focal point and the president of a local DPO explained that, "The lack of significant data study on PwDs in Nepal has remained a major challenge to address the need of PwDs and the same is true in the post-earthquake context, at least in the hard-hit districts." At the time of the interview, he mentioned a limited attempt to gather post-earthquake data on PwDs, with support from the District Development Committee and UNICEF, but the work had stalled with more than half the VDCs, including the remote areas of northern Gorkha, not yet covered[13]. He also told us that:

> Immediately after the earthquake, I participated in one of the Protection Cluster meeting that was planning for data collection with the participation of various NGOs and INGOs… When we wanted to have a separate data for the number of disabled people and how many of them had died, but the Protection Cluster didn't agree to have that. The Protection Cluster should have done it but they didn't listen to us…

In Gorkha, our research team met two individuals from Barpak, the epicentre of the earthquake, who had become disabled during the earthquake. Both of them had recently returned to the area after being treated for their conditions in Pokhara and Kathmandu, and they told us that they knew of at least three other new PwDs from the same area of Gorkha who had received

[12] Partly as a response to widespread critiques of medical responders who conducted unnecessary amputations in the wake of the 2010 earthquake in Haiti, Nepal developed specific medical protocols for first-responder and referral mechanisms as part of its disaster risk reduction strategy. By all accounts, this system was incredibly successful.

[13] The same respondent also added that data collection was constrained by a lack of people who can correctly identify disabilities; though he has these skills, he was unable to collect data in remote areas due to his own physically disability.

treatment in the same facilities. One of them had also received a disability identity card (Blue, indicating a 'severe disability' and entitling him to NRs 300 per month) which he 'came to know about through radio programmes' though he had not yet received any payments; the other (a women) was not aware of the disability card programme and was clearly still struggling physically and emotionally to come to terms with her condition. The man from Barpak told us his story as follows:

> I was trapped three feet under a collapsed wall for more than six hours. Later, my family and friends finally rescued me. I was sent to Pokhara for treatment, but the doctors suggested I go to a hospital in Kathmandu for better treatment. In Pokhara, people from the Gurung Society helped me by providing NRs 17,000 for further treatment. Finally after a two-month-long treatment in the Teaching Hospital, Kathmandu, I was able to come back home but without my hand.

Anecdotal information indicates that some areas have a significant amount of new PwDs, whereas others do not, dependent on both the damage pattern and patterns of medical response. When asked about the number of new PwDs in her area, one PwD from Nuwakot told us: "Last year there were 35 persons with disabilities in Manakamana VDC. After the earthquake the number reached 65. Amongst these people, most have lost either both their legs or a single leg. It is mostly women who are in such a condition."

There are differences of opinion about the classification of persons with disabilities following the earthquake, having mainly to do with procedural issues with identifying disabilities such as the difficulty of differentiating between injuries, chronic pain, and disability. Most respondents indicated the need to rapidly provide new PwDs with disability ID cards that would entitle them to disability allowances. There were some though who believed that an overzealous attempt to enumerate disability could create an incentive problem leading to over-reporting of false disabilities that will dilute the meaning of disability in the community—a concern that is perhaps valid given widespread poverty and the rampant levels of misrepresentation and fraud that accompanied the distribution of relief materials in many areas. Thus, while acknowledging that there are many new PwDs in Nuwakot with real needs, the Women's Development Officer told the team that many people have tried to (wrongly) collect disability allowances and also that 'after the earthquake, some people came here to get a disability card before even going to the hospital'.

Disagreements existed even among PwDs. As an NFDN representative from Nuwakot explained: 'It is challenging to determine the real PwDs after the earthquake now. Our recommendation is keep the injured person under treatment for two years and only then should the PwD card be issued for that person.'

A few DPOs also expressed concern over the fact that their own claims over public resources (i.e., the limited DDC budget distributed among 5-8 district DPOs in most areas) would be stretched further by an increasing number of claims, indicating how important the small sums of money allocated to the disability sector are. Tellingly, the woman from Manakamana VDC in Nuwakot also cited the need for new programs and funding to support the newly disabled population, saying: "We are hoping for assistance from the district and the VDC, but neither has fulfilled our expectations. The numbers of persons with disabilities in our VDC is now 65 and the budget is just NRs 25,000. How can skills training be provided with that amount?"

Importantly, many of these tensions and uncertainties could be resolved with official data on the number and the needs of earthquake-disabled persons. The post-earthquake survey currently underway by the National Reconstruction Authority (NRA) does include questions on disability—but only the results will tell how comprehensive and useful this information is. It can safely be assumed though that the enumerators have not been adequately sensitized to issues of disability (i.e., trained in using the Washington Group questions to identify

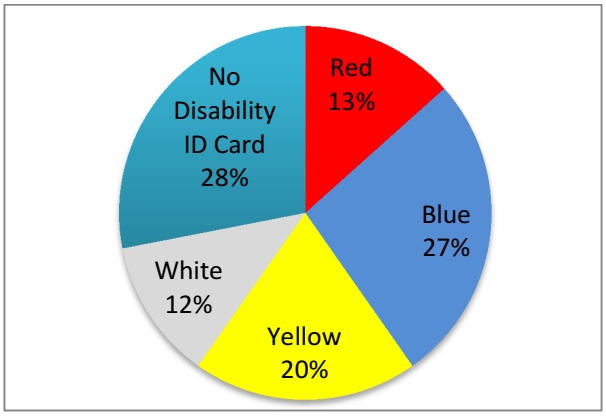
disabilities) as this is far from the central objective of the survey, and this study is only being conducted in 11 of the 75 districts of Nepal. Though the NRA survey may help to paint an initial picture of disability in post-earthquake Nepal, it is crucial to triangulate these findings with other more focused surveys being conducted by DPOs and to build on these findings to improve the overall quality of data on disability at the national level.

2.11 Issues with Disability Identity Cards

The Government of Nepal began distributing disability allowances after 2013, with the help of color-coded cards that ranged from red (for 'complete disabilities') to blue (for 'severe disabilities'), to yellow and white ('moderate' and 'mild disabilities'). Of the eighty-two persons with disabilities included in our survey, fifty-nine respondents (72%) had disability Identity Cards. Admittedly, this number is slightly high compared to data collected during past studies and relative to estimates derived from other ongoing studies (reflecting a possible sampling bias arising as a result of our referral-based survey methodology). For example, the current data collection effort from UNICEF & NFDN seems to be trending toward 55%. Therefore, though it seems that awareness about identity cards and government allowances is improving, there is still much work to do.

Our qualitative research indicates that spatial exclusion, bureaucracy, and uncertainty about eligibility for financial benefits (reserved only for those with 'complete' and 'severe disabilities) were the major limiting factors to registration. By all accounts, the process of getting a disability ID card is quite lengthy and starts at the local VDC Office and involves travel to the district headquarters and trips to certified hospitals to medically verify the disability. The chronic absenteeism of the few local government officials that exist in remote areas makes this more complicated (local elections have not occurred since 2002 and many VDCs have been without an appointed VDC Secretary for the same amount of time), a problem which seems to have worsened in the post-earthquake context, as the bureaucratic processes of the DDRC incentivize the majority of VDC Secretaries to spend their time in the district headquarters. These kinds of logistical issues and extra travel expenses keep ID cards out of reach for most PwDs living in remote areas, especially for women with disabilities who face additional limitations to physical, social, and financial mobility.

Figure 16: Type of Disability Cards among Persons with Disabilities Surveyed



A recently published statistical analysis on "Living Conditions of People with Disability in Nepal" states that despite the government's provisions for PwDs, "most of the people and in particular those from rural areas and with poor background, have neither knowledge nor access

to such facilities" (Eide et al 2016). 28 percent of our PwD respondents did not have disability cards owing to various factors such as lack of awareness and difficulty in understanding the procedures to receive them.

Within our study, 70 percent of the persons with disabilities regarded the disability allowance program positively, although many also said the amount of these allowances is inadequate. PwDs as well as DPO representatives wanted an increase in the monthly allowances for holder of red and blue cards. Red cards are usually given to severely disabled people who are in need of round-the-clock care and are unable to move or perform basic life functions and the allowance of NRs 1000 is far from enough. A key informant from a VDC-based DPO, a PwD himself says: "They need help with everything/ The allowance is not enough to even cover their medicine costs. It would be good to increase this amount so that they or the family can at least hire someone to look after them."

This view is concerned not only with a higher allowance but that the care of severely disabled people should not fall solely on the family. There is also a great degree of dissatisfaction with the white and yellow cards, neither of which entitles the holder to any monetary benefit. As an FGD PwD participant said, "What will I do with a card that doesn't give me an allowance?" There are also those who not go through the lengthy and bureaucratic process to obtain a card after being told what color of card they would get. As a mother of a PwD in Sindhupalchowk told us "Later, we found out she would get the white card which means getting nothing, so we left it at that."

Importantly, persons with mental or intellectual disabilities find it far more difficult to get the ID cards due both a general lack of diagnostic capacity and misunderstandings of the nature of these kinds of disabilities [see below sections]. For example, one mother of an adult woman with a mental disability said, 'The VDC office refused to give her a reference letter to apply for a disability card as they didn't believe she had a mental disability. She only suffers from mental breakdowns and attacks sometimes so they didn't think she needed it.' Such attitudes perhaps explains why, according to TPO Nepal, only two disability ID cards have been given for 'mental disability' in all of Nepal. Persons with intellectual disabilities do receive cards, but this also requires a significant investment of time for the individual and their caregivers, owing to the need to obtain official medical diagnosis.

As several respondents indicated, the complex bureaucratic procedure necessary to obtain a Disability ID Card and the corresponding allowance is often times confusing and misunderstood by persons with disabilities and their families. As the mother of one indigenous PwD from a remote area told us: "I had gone to the VDC office and they told me to get this paper, and then that paper, and sometimes something is not right. I don't understand at all, and there's no one to explain it to me either."

Unfortunately, the destruction caused by the earthquake has added further complexities. With most houses destroyed, important documents have been lost. Current ID holders are hesitant to go through the complicated process once again to receive a new ID card. A Janajati physically disabled man from Sindhupalchowk says, "I lost my ID card in the debris of my house; I have been thinking of making a new one but it's such a long and difficult process that I can't quite plan it right now when I have to think about shelter and food for my family." That said, many card-holding PwDs indicated that their allowance payments were interrupted only in the immediate aftermath of the earthquake, and that payments (for those with red and blue cards) had been relatively consistent once ID card issues were resolved.

However, many newly disabled respondents answered that they were not sure if they are eligible for the disability allowance. A key informant from a DPO in Sindhupalchowk said,

"Around 175 people have become disabled due to the earthquake, but they have not received the identity card yet because they are still in the process of diagnosis and treatment. We have one year. Those people who are not normal even after a year of treatment then will receive the disability identity card. This was decided by the discussion in the DDC level meeting." But, in other places within the same district, researchers found that some newly disabled PwD had already received their ID cards.

2.12 Intellectual Disabilities & Caregivers

The research confirmed prior assertions that intellectually disabled persons are perhaps the most marginalized group in Nepal, which is rooted in a significant lack of societal understanding and awareness about a) the causes of intellectual disability; b) the different types of intellectual disabilities and their various consequences; c) the ways in which intellectually disabled may be included or mainstreamed in social and economic life; and d) the experience of intellectual disability for PwDs and their families. All of these misunderstandings result in intense stigmatization.

A great deal of confusion exists in Nepal about the classification of intellectual disability, which is often mistaken for mental disability, or other conditions and conflated with developmental disabilities, which is not always the case.[14] Intellectual disabilities are characterized by "significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior, which covers a range of everyday social and practical skills. 'Intellectual disability' forms a subset within the larger universe of 'developmental disability,' but the boundaries are often blurred as many individuals fall into both categories to differing degrees and for different reasons"(Human Rights Watch 2013: 13). But, as a DPO representative in Kavre district said: 'Most people don't understand the levels of intellectual disabilities and dismiss it as being *pagal* or *dimag nabhayeko* (mad or 'having no mind').'

To counter these simplistic and negative perceptions, one DPO representative in Kathmandu told us that "in order to bring about a tangible and long term change, we need to foster a culture of tolerance and understanding within upbringing"—meaning that the idea of disability should be normalized for children starting from primary school.

Several of the study respondents indicated that intellectual disability presents a lifelong challenge for families and caregivers. Throughout the fieldwork, parents of the intellectually-disabled often expressed worry about the future of their children, even if their children were already adults, saying: Who is going to look after him/her after we are gone?' Another caregiver pointed out the fact the limited effects of the disability allowance: 'Intellectually disabled cannot support themselves, and they are given only NRs 1,000 per month allowance if they have a red card. What can they do with this amount?' Many of the larger problems related to livelihood that PwDs of all kinds face are further magnified for the intellectually disabled.

The study showed that the intellectually disabled are among the most vulnerable groups during the earthquake and its aftermath, for a variety of reasons including:

[14] For example Down Syndrome is both a developmental disability and an intellectual disability, while autism is also not technically an intellectual disability; other developmental disabilities that do not have a cognitive impairment component include cerebral palsy, epilepsy and other seizure disorders (Human Rights Watch 2013: 13).

Lack of Disaster Preparedness: Very little effort had been made to disseminate information or to devise DRR awareness campaigns tailored to the needs of persons with intellectual disabilities and their caregivers. Reports of the immediate response to the earthquakes by the intellectually disabled varied widely, ranging from being 'frozen,' to 'being difficult to control,' to 'laughing' due to unawareness of the danger.

Spatial Exclusion: Persons with intellectual disabilities in Nepal often occupy marginal living spaces, and some are even kept by families in locked rooms. The researchers heard reports of three different caregivers who lost their lives trying to assist the intellectually disabled during the earthquake.

Anxiety: As persons with intellectual disability do not like change, it was not easy for them to adopt in new places in the post-earthquake context, under the tents, and so many had to return home and regardless of the condition of the house. Several caregivers reported cases of intellectually disabled children 'getting lost'.

Vulnerability: Young women PwDs were particularly vulnerable to sexual abuse and trafficking in IDP camps and collective living situations.

Increased Alienation: Death of caregivers can place extreme pressure on families and further marginalize the intellectually disabled; and many adults are abandoned in the community and survive by begging. They have limited social networks to help them access help in the wake of a disaster.

Overall the study found that many caregivers had invested considerable effort to ensure the safety of intellectual disabled family members, but that they were exhausted from the exertion of trying to access relief materials while also taking care of their children/wards. This supports the findings of a post-earthquake survey conducted by Parents Federation of Persons with Intellectual Disability (PFPID)—covering 467 households of persons with intellectual disability in seven districts—that the majority of households had received only the first relief package, and that there were no specific programs targeted towards people with intellectual disabilities in these areas, other than the Federation's own efforts to distribute basic shelter materials and warm clothes to the survey households.

When asked about the roles of caregivers and what kind of support would be necessary for them, one parent of an intellectually disabled child told us that the financial and emotional burden on families can be overwhelming. Sadly, he informed us that the stress of providing constant care can trigger resentment and depression, with many sometimes thinking '*kahile marchha yo ra maile chutkara pauchhu*' or 'when will they die so that I can finally be free'. Societal pressure and stigmatization along with inadequate facilities only create additional stress or feelings of isolation, and pressures on caregivers are compounded in the wake of crisis or disaster.

2.13 Underreporting of Mental Disabilities

> Mental health problems should be viewed not only as a medical problem but as a complex area which includes politics, sociology, culture and economy. —Basu & Murthy 2003

The World Health Organizaton has estimated that 20% to 25% of the total population in developing countries like Nepal have mental health problems, and that five of the ten leading causes of disability globally are related to mental health (WHO 2006, Koshish Nepal 2010). In

Nepal, however, recognition, appropriate diagnosis, and treatment of mental health remains unfortunately limited. Though the CRPD includes mental illness as a psychosocial disability, Nepal has not created legislation to ensure the rights of persons with mental illness or psychosocial disability.

The Government of Nepal adopted a national mental health policy in 1997 that included mental health as an element in primary health care. But only 0.14 % of the national health budget is spent on mental health and that too only for hospital services.[15] Furthermore, mental health problems are poorly understood and under-recognized in Nepal for a variety of structural and attitudinal reasons. An overall lack of diagnostic capacity and institutions for supporting mental health (especially in underdeveloped and rural areas of Nepal) severely limits the recognition and appropriate treatment of mental disabilities. Further, awareness about mental health issues is severely limited in Nepal by certain beliefs that equate mental illness with sin or bad *karma*, or that dismiss or normalize mental health issues amongst the poor as a component of poverty.[16] As a result, mental health risks are unevenly distributed across different segments of the Nepali population due to a variety of social and cultural norms that categorize human value using hierarchical frameworks of gender, ethnicity, and caste—in short, certain risks and certain forms of mental suffering are deemed acceptable to some and not others. Open acknowledgement and conversation about mental health problems is rare, as is the reporting of mental health incidents. As a result, mental health issues remain largely invisible across Nepal, brought into public view only in the most extreme cases or in times of collective disaster—the issue of mental health itself is marginalized.

The study indicates that mental illness and mental disabilities are massively under-diagnosed in Nepal, due in part to the centralization of mental-health practitioners in Kathmandu, but also due to low levels of awareness and social stigmas attached to mental illness. Few Disability Cards have been given for mental disability across Nepal[17]—a product of lack of diagnostic capacity and referral mechanisms as well as unclear procedural guidelines for classification. A key informant from TPO-Nepal described the logistical issues as such: "To get the disability card you need to have psychiatrist referral and VDC recommendation letter. Since there is stigma attached to mental health, people are not likely to go to VDC to get their cards."

In the rural areas of Nepal where accredited psychiatrists are practically non-existent, there are spatial barriers to seeking treatment. In urban areas like Kathmandu, the costs of seeing a psychiatrist are inordinately expensive for most Nepalis. Further, the low likelihood of receiving a red disability card (indicating severe disability) that itself comes with a maximum allowance of NRs 1,000 per month may discourage people from making the effort.

Past research has indicated that many PwDs experience high rates of physical, emotional, and sexual abuse, both within the household and the broader communities where they live and work. In addition to direct patterns of discrimination and abuse, the increased strain on families and caregivers trying to support persons with disabilities, can also lead to indirect patterns of domestic abuse and gender-based violence that can foster both a sense of shame and mental health problems for PwDs. One international report focused on the intersectional aspects of discrimination of women and PwDs in Asia identifies the causal connections between disability and patterns of abuse, stating that, "violence against women is both a cause and consequence

[15]From http://mentalhealthworldwide.com/2010/08/Nepal/ -

[16]Though the concept of *dukha* (suffering or sadness) is understood as a fact of life for many Nepalis, it exists in - Nepali society perhaps in a way that limits discussion on chronic mental health issues that may arise from such - suffering. -

[17]According to TPO-Nepal, one of the leading organizations working on mental health issues in Nepal, only two - disability ID cards have been issued so far with Category D. -

of disability" (De Alwis 2010:19). Another study acknowledges that, "in a patriarchal society like Nepal, where prevalence of gender discrimination and domestic violence is very high, women with disabilities are even at higher risk." (Norad 2012)

A 2007 survey by the NDWA indicated that 35% of disabled women were the victims of physical violence, 55 % had suffered some form of sexual abuse or harassment, and 80% were subject to psychological abuse (Khanal 2007: 48-49). Unfortunately, these patterns of abuse often begin within the family unit in Nepal as '60% of disabled women expressed suffering different forms of violence from their family' (Khanal 2007: 38) To illustrate the severity of these interrelated patterns of physical, sexual, and psychological violence, one of the case studies from the 2007 study conducted by the NDWA is reproduced here in full:

> Lalita was low vision by birth. Her parents sent her to school, but she could not study properly due to lack of assistive devices. Being born in Hindu family, her parents regarded it as their duty to have her married off with a suitable boy. Being a low vision girl, she was not getting suitable proposals. Then one day, a schoolteacher nearby their home came to her home. He was 55 years old, already married. But the couple did not have any child. The wife of the teacher persuaded him to get married again. Thus, Lalita was married off. Her co-wife promised that she would be well provided for, the only thing she needed to do was produce a child. After she got married, she became an unpaid household laborer, doing all chores of house and also looking after the cows and goats. She did not have any interest in a sexual relationship with her husband, but she had to comply to his wishes. She became pregnant. But by then, her co-wife was very jealous of her. At a time when Lalita needed to take more rest and eat nutritious food, she was denied from both. Her chores increased more than ever. Her husband turned a blind eye to this treatment, because he considered Lalita just as his servant. Due to carrying heavy loads every day and lack of nutritional diet, the child died in her womb, when it was merely four months old. After that incident, she repeatedly faced violations from her husband in hope of another child. The second child she gave birth to was stillborn. This was because of the continued worse treatment from her co-wife and her husband. After this incident, she was told to go back to her parents. She has not received any compensation or financial support from her husband yet. She is depressed and psychologically disturbed.
>
> (Khanal 2007: 40)

2.14 The Post-Earthquake Mental Health Gap

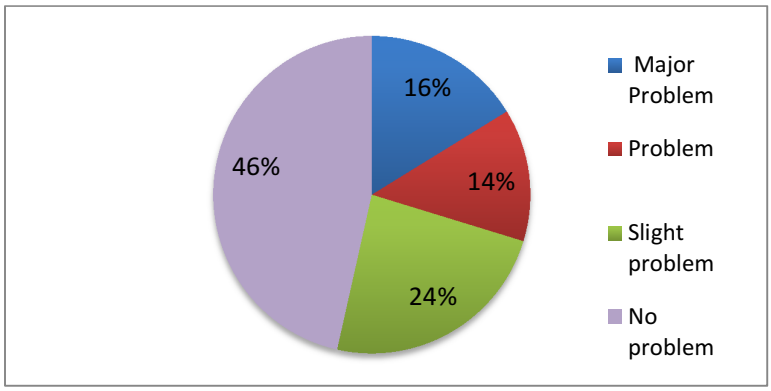
Mental health and psychosocial issues are an important aspect of public health, especially in a post-disaster situation. The mental wellbeing of a population especially after a disaster is crucial to the post disaster recovery efforts and should be a focus area within any recovery effort; and international frameworks for disaster risk management highlight the importance of specific measures for risk reduction, emergency response and recovery for socially isolated groups (Disaster Risk Management for Health Fact Sheets, Global Platform, May 2011). Similarly, An international study conducted by Handicap International found that 27% of persons with disabilities have experienced psychological, physical or sexual abuse, and that 38% of persons with disabilities reported increased psychological stress and/or disorientation following a disaster or crisis (Handicap International 2015: 8).

Despite recognition of these vulnerabilities and the existence of the Protection Cluster in post-earthquake Nepal, our research indicates the existence of a significant mental health gap in earthquake-affected areas of Nepal. Despite the fact that the majority of respondents reported

suffering from varying degrees of anxiety disorders that limited their everyday function,[18] only 5.9% had received psychosocial counseling after the earthquake (i.e., only 3.5% in Sindhupalchowk, and slightly higher in Nuwakot at 14.3%). Despite the fact that many people identified mental health issues as a need, with more than 50% indicating varying degrees of impact (Figure 2.14), almost half of survey respondents (49.7%) said they have not even heard about psychosocial programs in the wake of the earthquake (men and women; disabled and abled are equally underserved).

Despite the recognition that psychosocial issues can and have become a problem in the aftermath of the earthquake, only 6% of persons with disabilities, 15% of Dalits and 8% of Janajatis have received counseling. This situation exists in spite of the fact that approximately 13% of PwDs, 32% of Dalits and 26% of Janajatis indicated that they required such help.

Figure 17: Reported Prevalence of Mental Health Problems after the Earthquake



Vulnerable populations, however, face greater risks in the wake of disaster, including an increased risk of mental health problems. In the post-earthquake scenario in Nepal, the study indicates that vulnerable groups such as PwDs are at a higher risk of mental health problems, in part due to limited mobility but also feelings of helplessness and dependence. Among the survey respondents psychosocial issues are considered a major problem by 22% of PwD respondents compared to only 12% of the non-PwD respondents. For example, one physically disabled single woman from Dhulikhel said: 'My heart starts beating very fast and I feel paralyzed with fear whenever I think I feel aftershocks or even a slight tremor. I feel very scared when this happens as I can't walk or run fast like the others and I feel the house will crush me.' Such feelings of helplessness can be especially acute for those who have a decreased ability to communicate or verbalize problems, particularly those with intellectual disabilities or multiple disabilities.

Though there is currently a lot of activity in the 'psychosocial sector' it must be acknowledged that: a) most of this is short-term counseling programs; b) there is a lack of coordination between different NGOs offering piecemeal psychosocial support; and c) training of psychosocial counselors occurs in a relatively accelerated timeframe.

One of the exceptions to this rule is the work of the Transcultural Psychosocial Organization-Nepal (TPO-Nepal) was active in both the UN Protection Cluster and the mental health sub-cluster within the UN Health Cluster and continued advocacy programs focused on mental-health issues. TPO-Nepal also worked on a UNICEF funded 'emergency psychosocial project'

[18]Although not officially diagnosed, these reported symptoms indicate a pattern of anxiety disorders and Post Traumatic Stress Disorder (PTSD) that is common in the wake of natural disasters (Peykan Gökalp & Hacioğlu. 2004; Chou et al. 2004).

that trained and mobilized 70 community psychosocial workers (CPSWs) in six earthquake-affected districts, where they provided counseling and made referred serious cases to regional counselors and the Teaching Hospital in Kathmandu. Similarly TPO-Nepal also conducted a rapid training for Women Development Offices (WDOs), Mother's Groups, and women's savings groups, to enable them to provide psycho-social screening/counseling within their communities. Further, after the Koshi floods of 2008, TPO Nepal also helped to translate and contextualize the Inter-Agency Standing Committee (IASC) Guidelines that establish a minimum set of multi-sectoral guidelines for humanitarian actors to protect and improve people's mental health and psychosocial well-being in the midst of an emergency, which they said was used after the 2015 earthquakes by several organizations interested in psychosocial issues.

Despite these efforts, significant challenges remain to the effective deployment of appropriate psychosocial counseling and mental health programs in Nepal, central among them barriers of culture and language that are even more difficult when attempting to deal with mental health problems experienced by persons with disabilities. Despite widespread acknowledgement of massive trauma caused by the 2015 earthquakes (particularly in certain locations where mass casualties occurred, such as the Langtang Valley) the long term mental health implications of this tragedy are not yet fully understood.

3. STRATEGIC POLICY RECOMMENDATIONS

3.1 Reconstruction & Recovery: Incorporating the Principles of Universal and Accessible Design

In the wake of the 2015 earthquakes, there is both a critical need and a significant opportunity to improve the existing building codes of Nepal and to incorporate greater principles of accessibility and 'universal design' into the official process of post-disaster reconstruction. Firstly, the Reconstruction Phase is the perfect moment to raise awareness about disability in Nepal and to better account for the needs and capabilities of persons with disabilities during the process of rebuilding. Secondly, lessons learnt about earthquake-resistant construction techniques appropriate to the Nepal setting should be synthesized with international best practices to increase ease of access (and evacuation) for persons with disabilities, as per the Sendai Framework. Given the time his work needs to start immediately.

There is currently an incredible amount of discursive momentum focused on 'building back better,' and given the delays in the process of reconstruction, there is considerable risk of 'building back similar'. Hence, now is the moment to promote greater advocacy for the needs of persons with disabilities, before the window of opportunity closes. This can be accomplished in the following ways:

- Placing specialists with expertise in disability-friendly design as technical advisors in institutions like the NRA and the Department for Urban Development & Building Construction (DUDBC).
- Hiring personnel with expertise in disability studies to advise on appropriate strategies for consultation and communication with different kinds of disabled groups as well as facilitate greater inclusion of the voices of the most-marginalized populations (such as female Dalit PwDs) into account during the planning process.
- Working with DPOs to ensure that information on reconstruction policies and earthquake-resistant designs are sufficiently and appropriately disseminated to different kinds of PwDs in the appropriate formats to ensure that PwDs, too, are afforded the opportunity to improve the earthquake-resistance of their living spaces.
- Working with the relevant government authorities and local DPOs at the district level to ensure project monitoring and compliance.

Using the principles of disability-friendly design and the needs of persons with disability as lenses through which to focus reconstruction activities will improve the overall safety of private and public spaces in Nepal, which will ultimately benefit all sections of society. This study indicates that there is a significant opportunity to use district headquarters and municipalities as initial case studies that can be replicated or 'upscaled' in later reconstruction and urban/municipal planning efforts in Kathmandu. The natural geographic challenges of Nepal sometimes produce cynicism about initiatives to build 'a wheelchair ramp at 3,000 meters,' and admittedly it is not feasible to improve community infrastructure in all regions of rural Nepal. But the findings indicate that a significant number of PwDs tend to cluster around district headquarters and market towns precisely because these places are more navigable for PwDs. Hence, improving the accessibility of public spaces in certain strategic areas with a density of PwDs would actually yield significant benefits.

Lastly, it is critical to remind policymakers that this last round of seismic activity in Nepal was by no means the last. An investment in disaster preparedness and improved construction

technologies in the immediate can help to save millions of dollars and thousands of lives in the future when the next 'Big One' strikes.

3.2 Supporting the Pending Disability Rights Bill

Civil society and donor institutions should pay careful attention to the status of the Disability Rights Bill introduced in early 2016. The major goal of this Bill is to domesticate or contextualize the rights and provisions of the CRPD within the Nepali legal code, by creating an updated rights framework for persons with disabilities in Nepal and by assigning responsibility for the implementation of these rights in practice (Disability Rights Bill Draft 2016). The current draft includes language on fine-tuning the classification of disability, of creating disaggregated disability data, and creating a system for punishment/award for discriminatory practices, all of which will be achieved under the coordination of a National Direction Committee on Disability.

The proposed Disability Rights Bill also ensures Nepali persons with disabilities the right to protection during the time of conflict, emergency, or natural disasters. Under this proposed legislation, the state is responsible for providing necessary protection to the PWDs by investigating and keeping records of the events, fostering greater awareness about disaster and greater community disaster preparedness, protecting and rehabilitating victims, and undertaking disaster risk reduction measures to limit the occurrence of such events (Disability Rights Bill Draft 2016). This legislation builds on increased advocacy concerning the needs of PwDs both during and after the decade-long Maoist conflict, the Koshi Floods of 2008, and the earthquakes of 2015. This piece of legislation would begin the process of operationalizing some of the principles of inclusion embedded in the 2015 SDRRF—which would make Nepal one of the first countries to do so in the wake of a natural disaster.

Importantly, as recognized by other scholars on disability (De Alwis 2010), there is also a significant need to ensure that new legislation on disability is integrated with Nepal's commitments to other international conventions that promote the rights of persons with disabilities who face multiple forms of discrimination—such as the Convention on the Elimination of all Forms of Discrimination Against Women (CEDAW) for women with disabilities, and the United Nations Declaration of the Rights of Indigenous Peoples (UNDRIP) and International Labor Organization Convention-169 (ILO 169) for indigenous persons with disabilities.

3.3 Investment in Capacity Building within Nepal's Disability Sector

Research into the institutional landscape of disability indicates that issues of disability are relatively marginalized within Nepali civil society and that the disability sector is relatively underserved and underfunded compared to more robust programming focused on Gender Equality and Social Inclusion (GESI) and the needs of Dalit communities or other marginalized groups. The 2012 Norad report had recommended that "Competencies for effective advocacy need to be strengthened and strategic alliances developed with other civil society agencies for greater visibility and leverage: (Norad 2012: xii). Because disability is a cross-cutting issue there is a significant need to work with other NGOs and civil society institutions to promote a more holistic approach to social inclusion in development.

Importantly, several of the DPOs lamented both the extremely limited public resources allocated to the disability sector and a relative lack of support from international institutions. Unfortunately, the high demand from differently situated district-level PwD NGOs for a small budget (i.e., eight DPOs in Gorkha, seven in Nuwakot) leads to competition for government funds, which can promote both uneven political alliances and counterproductive social fractures. As one DPO representative told us: "We are doing advocacy on an empty stomach." There is therefore a significant need to invest in the capacity of disability sector, which can be accomplished by:

- Lobbying the Government of Nepal to increase the budget available to the disability sector, both at the national level where national DPOs seek funding and at the district level where local DPOs seek funding
- Direct investment in Nepali DPOs at the national level to increase advocacy capacities
- Improved coordination between INGOs with international expertise in the disability sector and Nepali DPOs, including the promotion of 'legitimate knowledge transfer' via workshops and technical trainings
- Greater emphasis on the inclusion of persons with disabilities across all the institutions of the Government of Nepal (i.e. not just the Ministry of Women Children and Social Welfare [MoWCSW]) so as to sensitize the government to the needs of PwDs and to improve coordination on disability-friendly programming across government silos
- Supporting capacity-building programs and outreach efforts for DPOs operating at the district level to help limit the effects of spatial exclusion
- Ensuring the meaningful inclusion of both national and local DPOs in all planning programs focused on disaster-risk reduction and disaster preparedness (see below)

All investments in the capacity of DPOs should be in coordination with the comprehensive systems of data management (see above) and monitoring and evaluation frameworks that can help promote real-time review of program outcomes, greater accountability in public and private sector programs, and evidence-based learning and knowledge sharing that will benefit the entire disability sector.

3.4 Improved Information Architecture: New Initiatives to Improve Data

There remains a significant need to improve both the quantity and quality of data on disability in Nepal, which is currently both inadequate and uncertain. Though the 2011 Census estimates that PwDs represent 1.94% of the total population of Nepal, this statistic is highly out of line with global averages of 10-12%—a gap that should prompt a serious reconsideration of the methods and criteria used to estimate disability in Nepal. DPOs have questioned the accuracy of existing national estimates for years, and have conducted several studies, albeit with a smaller sample size due to a lack of technical capacity and funding, that produced very different results. Further, though the earthquakes of 2015 have no doubt increased the number of PwDs in Nepal there is no indication of that scale. Further, disaggregated data on disability types is not yet fully available, and it is widely accepted that mental and intellectual disabilities are chronically underreported across Nepal. All of this uncertainty and confusion severely limits the possibilities for advocacy and intervention within the disability sector in Nepal.

This study strongly recommends strategic investment in the collection and management of data on disability in Nepal, both at the national and district levels. Importantly, this requires significant collaboration with Nepali DPOs embedded at the local level and can maintain a

long-term relationships as well as an investment in their technical capacity to manage and interpret disaggregated data on disabilities. Likewise, it is necessary to improve the methods of accounting for disability used in national censuses although this alone will not be sufficient. There is some precedent for this kind of information management system—namely, the Disability Database created by the NFDN launched in 2009-2010 but unevenly utilized. There is now a need for: a) renewed dialogue among stakeholders about the methods for creating a viable information architecture that can be efficiently maintained; b) improved coordination among different stakeholders to ensure collective buy-in; and c) a financial commitment to ensure the longevity of any given programme. As previously mentioned, the recent statistical survey focused on 'Living Conditions among People with Disability in Nepal' conducted by the SINTEF Group (Eide et al 2016) also represents an important resource for policymakers, and there is a need to 'put this data to work' in the coming years prior to the next National Census of Nepal in 2021.

The importance of geospatial tools in disaster response and crisis management has been highlighted by international scholars of disaster (Enders and Brandt 2007). Consultations with DPOs indicate that the MoWCSW has recently allocated some funds to develop a geospatial (GIS) data management system for PwDs that can help to address this data gap. It might be possible to synchronize this programme with the NFDN Disability Database but again effective coordination is critical. As indicated by the success of post-earthquake mapping initiatives (from the UNOCHA platform to the 'QuakeMap' developed by Kathmandu Living Labs, the value of geospatial tools to map the distribution and needs of PwDs across Nepal cannot be underestimated, particularly in terms of disaster risk reduction and crisis response.

3.5 Information Accessibility & Sharing

The 2030 Sustainable Development Goals explicitly state the need to "increase significantly the availability of high-quality, timely and reliable data disaggregated by disability" (Sustainable Development Goals, Target 17.18). And yet, reflecting a historical pattern, our research and consultations indicate: a) that information on disability in Nepal is highly fragmented and difficult to locate, b) that information sharing within government and civil society networks remains a major barrier to the inclusion of DPOs and persons with disabilities in Nepal. As a result, the rate of diffusion for new information is slow and limited to specific networks and organizations.

These problems are particularly important for small-scale organizations and are particularly acute for organizations that are based outside of Kathmandu—in effect, limited information sharing perpetuates patterns of inclusion within civil society. For example, many of the smaller DPOs complained a) that they were not well informed about new events and publications related to issues of disability, b) that they were either rarely included in broader discussions on disability or included only superficially at the later stages, and c) that larger or more centrally located organizations were much better informed. At the larger scale, many DPOs are not aware of larger institutional discussions on topics of gender and social inclusion (GESI) that should very much include them. Reflecting a common problem in Nepal's development sector, it seems that many international non-governmental organizations (INGOs) and national-level DPOs share information via distinct networks, often unaware of their own parallel efforts and interests. In short, an open-source information portal where multiple organizations can generate, contribute, and share content related to disability is sorely needed.

Therefore, to promote a greater level of mutual understanding and to support more coordinated advocacy and dialogue within Nepali civil society, we recommend the creation of a public and accessible information-sharing portal that can serve as an archive and clearinghouse for materials related to disability. While some umbrella-network organizations like the National Federation of Disabled-Nepal do attempt to collect and disseminate information[19], it is apparent that a more formal platform for information sharing is necessary. This platform would include a wide range of materials related to issues of disability, such as: policy documents, past publications and research, copies of international conventions on disability (including highlights from the SDGs and the SDRFF), orientation materials for people new to the topic of disability in Nepal, a centralized database with contact information for DPOs across Nepal, an event calendar, etc. Perhaps an information manager from the 'National Working Group on Disability' [recommended below] could moderate and maintain this information portal, but it is important that all organizations have equal opportunity to share and access information to ensure the representation and inclusion of all voices.

Importantly, this information portal and forum should be made 'accessible to all', with all documents translated into Nepali and made available in alternative formats for persons with visual disabilities. Wherever possible, pictorial language and infographics that are more accessible to people with intellectual and learning disabilities should be created to communicate key concepts—this will also help to reach illiterate users, who are often among the most excluded. Further, we suggest that a specific fund be created to support rapid translation of relevant documents into accessible forms.

This information-sharing portal could also be the official site for the release of accessible translations of relevant policy documents—such as those disseminated by the Ministry of Women Children & Social Welfare or the National Reconstruction Authority—ensuring that they reach a broader audience among persons with disabilities in Nepal.

3.6 Coordination: Forming Strategic Working Groups on Disability in Nepal

Given the cross-cutting nature of issues related to disability in Nepal and the need for coordination highlighted by the recent earthquake, this study recommends the formation of a multi-stakeholder 'National Working Group on Disability' with the central objective of operationalizing the multiple frameworks relevant to the inclusion of PwDs in Nepal—beginning with the CRPD which Nepal has already signed along with the SDGs and the SDRRF, and extending to the pending Disability Rights Bill.

Ideally, this Working Group should include representatives from the relevant institutions from the Government of Nepal, UN agencies, INGOs and donor institutions, the private sector, and national- and local-level DPOs—led perhaps by the MoWCSW and supported by the NFDN. Such an initiative can greatly increase the quality of coordination and information sharing between differently oriented organizations that can facilitate a shared process of evidence-based learning. Increased dialogue between differently oriented institutions could also facilitate the identification of collaborative initiatives and strategic partnerships to support the well being

[19] The National Federation of Disabled Nepal also maintains a comprehensive and accessible website which includes many of their past reports, links to official policies related to issues of disability in Nepal, and translations of international reports on disability, but there remains room for improvement. Conversations with NFDN indicate that traffic and downloads doubled once they made their own website fully accessible.

of PwDs in Nepal. Such a Working Group could help establish an important precedent for other countries seeking to operationalize the SDGs and SDRFF.

In order to ensure the relevance of policymaking and to prepare for eventual implementation, the Working Group should also periodically include district-level officers and local stakeholders. Most importantly, there is a critical need to ensure that these groups meaningfully include PwDs themselves; when discussing the idea of a technical working group during a roundtable with DPOs and disability-oriented NGOs one of the NGO representatives, himself a PwD, clearly stated: 'Nothing about us, without us.' The participation of PwDs will help increase accountability and the lived experience of PwDs is a valuable resource for policymaking that cannot and should not be overlooked.

Though this idea arose independently during the research process, a review of the literature on disability in Nepal shows there are precedents for such an idea. First, it seems that the Forum for Women Law and Development convened a 'Working Group on Advancing the Rights of Women and Children with Disabilities' in 2008 which 'comprised of 20 individuals representing the Constituent Assembly, and representatives from organizations of persons with disabilities including physical disability, hearing disability, visual disability, parents of persons with intellectual disabilities, speech disability, multiple disabilities; medical fraternity; women's rights and children's rights groups, international NGOs and public interest and legal aid lawyers' (De Alwis 2010: 22). Four years later, the Norad study provided a similar recommendation: 'Consider taking the initiative in forming a donor group for this purpose… Linking up with likeminded agencies and using arguments based on CRPD and the Millennium goals could be a way forward' (Norad 2012: xiii). It seems this recommendation was not taken forward but since the CRPD has not yet been operationalized in Nepal and because the SDGs provide significant leverage for PwD advocacy in Nepal, there is a pressing need to form such a group in the current historical moment.

To complement and support the National Working Group on Disability, the study also recommends the formation of two other groups focused on disability in the immediate:

1. A Committee to Support Nepalis Disabled by the Earthquake: There is currently a need to create an organization that can help provide support and services to newly disabled people struggling to adapt to their new situation. There is an existing precedent for this kind of activity, as the Ministry of Peace and Reconciliation agreed to provide specific rehabilitation services to persons disabled during the decade-long Maoist conflict. At that time, the Three-Year Plan (2013-2016) of the National Planning Commission stipulated specific Operating Policies for 'Peace, Reconstruction, and Rehabilitation' that mandated the initiation of 'programmes for the special treatment and living arrangements of persons injured and disabled in various movements and political conflicts will be implemented' (National Planning Commission 2013: 130). The Government of Nepal should form a series of concrete policies for the rehabilitation of persons suffering from chronic injuries and disabilities following the earthquake.
2. A UN Interagency Dialogue on Disability in Nepal: Given the centrality of the SDGs and the stated interest by the UN Secretary General in 'strengthening coherence and coordination on disability issues within the United Nations system,' the study also recommends the initiation of a UN Interagency Dialogue on Disability for improved coordination and knowledge sharing at the national level in Nepal. The involvement and input of UN agencies with different orientations to disability and post-earthquake recovery (i.e., UNICEF on children with disabilities, UNDP on Disaster Risk Management, UN Habitat on Reconstruction, UN Women on GESI issues, etc) and different levels of experience with disability programming would be extremely helpful

in ensuring complementary disability-oriented programming in the coming years. Importantly, however, this UN Interagency Dialogue should not replace the National Working Group on Disability—in fact, the UN Interagency Dialogue should be required to report into the National Working Group to ensure that the Government of Nepal takes the lead on these efforts.

Currently, the Association of International NGOs in Nepal also has its own 'Disability Working Group' which "calls on AIN member organizations, and also its boundary partners who we interact with, to take initiatives to effectively promote, protect and ensure the rights of persons with disabilities "(AIN 2014). The problem here, indicate during our institutional consultations and evident in the language used in its inception document, is that this group is defined in terms of international NGOs and does not meaningfully include a) Nepali Disabled Persons Organizations (DPOs) or b) the Government of Nepal in its activities. To build on the successes of the AIN Working Group and to promote broader coordination on disability issues in Nepal, we recommend that the AIN Working Group be incorporated into the larger framework of a "National Working Group" (similar to the UN Interagency Dialogue above).

3.7 'Disability is not Incapability': Targeted Livelihood Programs for PWDs

Specific programmes are needed to address the systematic lack of livelihood opportunities for persons with disabilities in Nepal, as economic autonomy is a critical component of the right to self-determination. To help address this opportunity gap, it is necessary to promote equitable inclusion of PwDs at both the macro and micro scale.

On the national scale, the Government of Nepal and its external partners need to provide genuine support to policy focused on 'mainstreaming' PwDs to promote broader economic inclusion into existing programmes and institutions via the promotion of a reservation system (which exists is some cases but are weakly enforced) or the implementation of preferential hiring systems. Large-scale livelihood programs being implemented by international NGOs, such as UNDP's Micro-Enterprise Development Programme (MEDEP), should also include targeted initiatives to support employment and entrepreneurship for PwDs.

On the local scale, there is a significant need for targeted analysis and creation of new sectors and employment opportunities that account for the different abilities of PwDs. One possible strategy is to learn from and build on the successes of existing programmes such as: a) the PwD-owned and operated incense production facility in Nuwakot (highlighted above); and b) the outpatient skill development and training programmes implemented by the Spinal Injury Rehabilitation Centre. These successful models of collective employment and skill development (and others such as women's handicraft cooperatives) can and should be replicated for PwDs across Nepal. Importantly, however, it is necessary to create partnerships with the private sector that can ensure the market linkages and product placement necessary to sustain these initiatives.

Lastly, in cases where severe disabilities limit the ability of PwDs to participate in these kind of programmes, it may also be helpful to promote new kinds of income-generating activities for the caregivers who support them as a complementary effort.

3.8 Supporting Caregivers

The majority of persons with disabilities in Nepal are dependent or at least partially dependent on family members for their care and livelihood. Caregivers range from children, siblings, parents, spouses and other relatives. The crucial caregiving role is often times lifelong and with little or no outside help at all, creating an environment where the level of care is as not where it is supposed to be. This is not to say that caregivers aren't doing what they can but with a lack of outside help, the level and quality will depend on the financial situation of the family and sustained level of care is difficult to maintain. This sort of strained relationship between the persons with disabilities and their caregivers also creates undue tension for the persons with disabilities themselves, as indicated by the following quote from a caregiver in Sindhupalchowk district:

> For someone whom you have to feed, put to sleep, clean up after, basically everything, the level of care and support might be okay one day but to do this continuously without any support will create a lot of stress for the family. This is something that the disabled person themselves understands but unfortunately is helpless to do anything about. My disability does not hamper my daily living but I can imagine how life is like for those who are severely disabled and their caregivers.

There is a distinct lack of an institutionalized support structure for caregivers of persons with disabilities and they are usually taken as an afterthought and their 'services' are taken for granted. Further, there is evidence that this kind of continued and high levels of stress that caregivers are under cause 'negative caregiver outcomes, including feelings of burden, social isolation, depression and health problems' (Haley et al. 1987). As our research indicates, stress levels are particularly high in the wake of disaster, especially for families who have lost a caregiver or for families that include a newly disabled person struggling with their own transition. Family counseling sessions and support groups should be established to help these people.

The current lack of policies and dialogue between the State, DPOs and aid agencies regarding the role and well being of care givers represents a type of short sightedness and prevents the mainstreaming of persons with disabilities issues in the national agenda. Caregivers can be an important source of information about issues of disability in Nepal, and should be consulted in the design and implementation of disability policies and programs for disaster risk reduction (see below). Providing support for family and caregivers can increase the possibilities of future autonomy for those they care for, supporting the self-determination of persons with disabilities.

3.9 Discussing Prevention

Chronic public health problems in Nepal increase the incidence and experience of disability. As mentioned above, the 2001 Situation Analysis of Disability in Nepal conducted by New Era (with NPC & UNICEF) indicated that 30.3% of the disabilities can be attributed to disease or lack of medical care, pointing to the fact that a significant percentage of disabilities in Nepal may be preventable. During our roundtable consultations, Dr. Bibek Banskota of the Hospital & Rehabilitation Center for Disabled Children (HRDC) also stated that around 30% of disabilities may be preventable and pointed out that just a handful of specific procedures can help to prevent a wide range of congenital disabilities, citing both World Health Organization data and his own organizational experience.

The concept of prevention, however, is a highly politicized topic within the global discourse on disability. On one hand it can signify active programmatic engagement with the systemic social-medical causes of disability, while on the other hand it can also reference outdated negative perceptions of disability as an 'affliction' which perpetuate patterns of discrimination and even selective abortion. Tellingly, while prevention is recognized as a priority in the 1982 World Programme of Action Concerning Disabled Persons, the concept of prevention is largely absent from the 2006 UN Convention on the Rights of Persons with Disabilities—reflecting the larger shift from a 'medical model' of disability to a 'social constructionist model' of disability[20].

Presenting a critical legal critique of the UN CRPD, Ribet (2011) argues that while it is certainly productive to move away from the problematic idea that disability is something that should be 'eliminated' (a major point of advocacy by PwDs seeking to reduce social stigmas and discrimination) it is also possible that a diminished focus on 'prevention' and understanding the structural causes of disability can be counterproductive, particularly in the developing world. In this vein, Ribet (2011) argues that "with the elimination of attention to disability prevention, international law has also simultaneously vacated any analysis of disability that acknowledges its social origins or enables recognition that power relations have anything to do with the production of disabilities" (Ribet 2011: 105). Ribet goes on to argue for greater recognition of 'emergent disability'—"a descriptive term for a pattern of burgeoning mental and physical conditions which correlate, often strongly, with poverty and various forms of social and political subordination"—a type of disability that emerges as a result of systemic social inequities and deprivation. (Ribet 2011: 107). Ultimately, Ribet makes the important argument that greater recognition of the reasons for 'emergent disability' is needed to incorporate larger questions of inequity, particularly in underdeveloped regions.

Similarly, our research focused on the different paths to recovery amongst the socially disadvantaged in post-earthquake Nepal indicates that the concept of prevention remains appropriate in discussing 'emergent disabilities' that are produced by systemic patterns of social, political, and economic exclusion in underdeveloped countries like Nepal. These questions are particularly relevant in the wake of conflicts or natural disasters that affect different populations unequally—consider those disabled by Nepal's Maoist Conflict or the 2015 earthquakes. As such, we recommend that civil society include the topic of prevention in all discussions on disability in Nepal.

3.10 Knowledge Production: Supporting Future Research

UNDP should provide support for further research that can increase the visibility of disability issues in the broader development agenda and improve the quality of the conversation on disability in Nepal. Though a handful of studies have been produced in the past, issues of disability in Nepal remain understudied overall, particularly in the context of DRR but also with regard to the specific challenges faced by PwDs from socially disadvantaged groups such as women and Dalits. In this regard, UNDP should seek to work with Nepali organizations with research experience in this space such as the National Federation of NFDN, the Disability Research Center at Kathmandu University, and Social Science Baha.

[20] However, the goal of "prevention," particularly "primary prevention," has been distinctly eliminated from the Convention, either in its original language as reflected in the World Programme, or in any explicit goal geared towards altering the context in which "impairments" initially occur. (Ribet 2011: 103)

Supporting the production and dissemination of research on disability in Nepal is in line with the UN Secretary General's strategic recommendations of 'the way forward' in mainstreaming disability. It is pertinent here to point out the upcoming 'Conference on Disability' being organized by the Disability Research Center at Kathmandu University on June 15th, 2016[21]— both a timely opportunity for knowledge sharing and a way of continuing the ongoing dialogue.

[21] 'Conference on Disability aims to bring together leading academic organizations, DPOs, and research scholars, and other stakeholders to exchange and share their experiences and research results about all aspects of Disability. It also provides the interdisciplinary cross-cutting forum for researchers, practitioners and educators to present and discuss the most recent innovations, trends, best practices, and challenges in the field of Disability in Nepal'.

4. DISABILITY AND DISASTER RISK REDUCTION: OPERATIONALIZING THE SENDAI FRAMEWORK

While most humanitarian actors pledge to target vulnerable persons in crisis time, few of them are putting in place specific mechanisms and procedures to effectively reach to, and taking into account, persons with disabilities in their programs.

(Handicap International 2015: 4).

An inclusive approach to disaster risk reduction (DRR) is critical to minimize the impacts of disaster on the most vulnerable segments of society—before, during, and after a disaster occurs. In Nepal, a chronically underdeveloped country in the seismically active Himalayan region (where future earthquakes are a certainty) where the uneven effects of disasters are exacerbated by limited infrastructure and intense socioeconomic inequalities, the need is particularly acute. However, our research indicates: a) that DRR activities in Nepal were weak overall prior to the 2015 earthquakes, b) that the DRR activities that did occur failed to meaningfully include vulnerable sections of society and reflected systematic social and spatial biases, c) that the majority of persons with disabilities were not included, engaged, or consulted in DRR activities, and d) that the majority of information and programs on disaster, DRR, and disaster preparedness were not accessible to persons with disability, further limiting their awareness about disasters.

Unfortunately, these findings reflect a global trend indicated by several international studies that describe how persons with disabilities often 'fall through the cracks' during disasters and other humanitarian crises (UNISDR 2013, Handicap International 2015, IFRC 2015). Despite both widespread recognition of the rights of persons with disabilities within the UN Convention on the Rights of Persons with Disabilities (CRPD)—which includes a section on specific rights within 'Situations of Risk and Humanitarian Emergencies'[22]—and repeated commitments to include vulnerable segments of society, both governmental agencies and humanitarian organizations fail to adequately include persons with disabilities in disaster preparedness and planning and disaster risk reduction activities.

In the current moment, however, there is a significant opportunity for the Government of Nepal to improve disaster risk reduction programs based on lessons learned in the wake of the earthquakes and to incorporate new internationally accepted policies and principles of disaster risk reduction into the process of reconstruction and recovery. Importantly, the Nepal earthquakes occurred less than a month after the Sendai Framework for Disaster Risk Reduction 2015-2030 (Sendai Framework) was adopted at the Third UN World Conference on Disaster Risk Reduction (WCDRR) in March 2015—a convention focused on inclusive disaster risk reduction. Therefore, as Nepal pursues its agenda of 'building back better', both government and civil society institutions are in a position to put the Sendai Framework into action and to establish a precedent for inclusive disaster risk reduction that will set a global example.

As previously discussed, the Sendai Framework historically recognizes the need to

[22] Article 11 of the UN CRPD concerning "Situations of Risk and Humanitarian Emergencies" states that: "States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters."

meaningfully engage persons with disabilities in all aspects of disaster risk reduction—highlighting issues of inclusion, accessibility and universal design in terms of disaster preparedness, information sharing in the process of recovery, rehabilitation, and reconstruction. The inclusion of these principles within this landmark convention can be understood as an important waypoint within the evolution of the global discourse on disaster—the product of increasing attention to and recognition of issues of disability in the context of disaster, evidenced by a series of international studies on issues of disability and disaster in recent years (UNISDR 2013; IFRC 2015; Handicap International 2015) and the inclusion of a dialogue focused on disability issues during the upcoming UN World Humanitarian Summit planned in May 2015. However, despite increasing recognition of these issues many of these principles have not yet been put into action[23] and national level policies and programs are needed to operationalize the Sendai Framework—again indicating an opportunity for Nepal to lead by example.

The most significant vector for the operationalization of the Sendai Framework is the Post-Disaster Recovery Framework (PDRF) currently being developed by the National Reconstruction Authority of the Government of Nepal. As this document will serve as a guide for the process of recovery and reconstruction and establish the strategic priorities for recovery over the upcoming five years, it is critical to ensure that it reflects a policy-level commitment to accessibility and inclusion. The inclusion of specific language and action points that recognizes the equal rights and specific needs of persons with disabilities will help greatly in defining a more inclusive pattern of recovery and reconstruction. Importantly, the recognition of disability issues within the PDRF can also help to set the tone for a more dynamic conversation on disability in Nepal—creating momentum that will support pending legislation like the Disability Rights Bill and other policy initiatives focused on the inclusion of persons with disabilities motivated by the Sustainable Development Goals. Importantly, however, the PDRF itself is just a framework, and careful attention to disability issues during its actual implementation is crucial to realize the overarching goal of 'building back better.'

With all of this in mind, this report concludes with a series of forward-looking recommendations based on our research and a review of the existing literature on disability and disaster. These recommendations seek to provide relevant guidelines for accounting for issues of disability before, during, and after disasters, for promoting the meaningful inclusion of persons with disabilities in all aspects of disaster risk reduction and disaster preparedness programs. Throughout these recommendations we emphasize the following four important conceptual points:

a) The meaningful recognition of issues of disability within disaster risk reduction activities requires *both* efforts to 'mainstream' persons with disabilities within the broader process of DRR and the mitigation of additional risks related to disability
b) Disability can be used as a lens to identify and understand larger structural and attitudinal barriers in society
c) Efforts to promote the inclusion of persons with disabilities in disaster risk reduction

[23] "Progress has recently been made in the way humanitarian frameworks and policies address the issue of inclusion: significant attention was paid to this challenge in the post-2015 Disaster Risk Reduction framework consultation process and the Sendai outcomes; several States such as the United Kingdom, Australia and Italy developed policies or guidelines on disability in emergency contexts; and disability in emergency contexts has been addressed as part of the monitoring process of the Convention on the Rights of Persons with Disabilities. But actors continue to face difficulties in translating those policies into action." (Handicap International 2015: 6)

activities should reflect the general shift from a medical model of disability to a 'social model' of disability informed by a greater recognition of human rights to equal opportunity (ECHO 2009)

d) Disaster risk reduction programs that account for the needs of the most vulnerable populations such as persons with disabilities will ultimately result in benefits for all Nepalis.

The following represents a brief overview of potential strategies for accounting for issues of disability within disaster risk reduction activities. For more detail on these topics, please review the 'Training Manual for Mainstreaming Disability into Disaster Risk Reduction' created specifically for Nepal by ECHO & Handicap International in 2009.

4.1 Meaningful Inclusion through Participation & Consultation

The meaningful inclusion of persons with disabilities begins by recognizing their voice and agency, by making a commitment to listening and acknowledging their ability to make meaningful contributions to the dialogue on disaster risk reduction. Risks, like disabilities, often remain invisible to the majority of society; making them visible is a collective effort informed by dialogue, and vulnerable groups who live with greater risks have a great deal to contribute to that dialogue. As indicated by Margareta Wahlstrom, Head of the UN Office for Disaster Risk Reduction, persons with disabilities "want to be consulted equally about their needs in order to face and prepare for disasters, as well as being able to contribute expertise and participate in planning and implementation. We need to keep in mind that disability is not inability" (UNISDR 2013).

The importance of equitable participation is clearly stated in Guiding Principle #4 of the Disaster Risk Reduction framework: "Disaster risk reduction requires an all-of-society engagement and partnership. It also requires empowerment and inclusive, accessible and non discriminatory participation, paying special attention to people disproportionately affected by disasters, especially the poorest. A gender, age, disability and cultural perspective should be integrated in all policies and practices." (SDRRF 2015)

To ensure that the experiences and concerns of persons with disability are accurately reflected in disaster risk reduction programs, it is critical to pursue a dual strategy for inclusion, as described below:

a) **Mainstream PwDs in broader DRR Activities:** To guarantee the participation and inclusion of persons with disabilities in conversations about disaster and disaster risk reduction at all scales (i.e. in the formation of national preparedness strategies, within Disaster Risk Management Committees at the district and VDC level, and in the context of community-based disaster response planning). To increase the overall level of awareness within communities it is important to "organize focus groups where a range of community members (children, elderly, pregnant women, persons with reduced mobility or visual impairments, etc.) can discuss barriers and share experiences, instead of having separate groups for persons with disabilities." (IFRC 2015: 26)

b) **Focused Engagement:** To explicitly solicit input from persons with disabilities by initiating targeted programs of consultation and assessment designed to understand their specific concerns, needs, and capabilities. Thus, in some situations, it may be appropriate to consult persons with disabilities separately, individually or in groups.

Importantly, all consultations and assessments should be flexible and adaptive rather than limited to pre-defined interests or expected results. Both disability and disaster risk reduction are complex topics; "When assessing the vulnerability of persons with disabilities, you are likely to discover issues that are not related to shelter and settlements, or to physical barriers. Be prepared to follow up, respond to or make referrals for these issues." (IFRC 2015: 27) Exclusion and risk exposure are the result of layered structural and attitudinal barriers, and all interactions should be conducted with a goal of recognizing, discussing, and mitigating barriers.[24]

When conducting consultations the following issues should be considered:

- Persons with disabilities should be adequately informed about meetings and consultations on DRR issues at all levels
- All meetings and consultations should be conducted in locations that are accessible for all participants and should occur in accessible format, with facilitation provided as needed
- Make specific efforts to include 'minorities within minorities' who face multiple forms of exclusion and unique risks – in Nepal this would include women with disabilities (WwDs), indigenous persons with disability (IPwDs), and Dalits with disabilities (DwDs)
- To ensure the meaningful participation of persons with mental and intellectual disabilities, which may also include consultations with their caregivers
- Consultations can be accompanied by public awareness campaigns that promote a greater understanding of disability concerns

When conducting assessments the following issues should be considered:

- All DRR assessments and data collection should include a disability component, and should attempt to resolve gaps in the data on disability that limit ability to plan and adequately prepare for disasters
- Questionnaires and assessment tools need be made fully accessible to persons with disabilities
- Assessments should collect disaggregated data on disability to promote a greater understanding of the relationship between risks and different types of disability
- Assessments should use internationally recognized tools for identifying and classifying disability, such as the Washington Group questions[25]
- Wherever possible assessments should collect geospatial data on disability, so as to assist with the mapping of vulnerable households, to establish community-level plans for evacuation, and to help identify function post-disaster safe zones
- Include embodied methods to elicit information, for example: "Accompany persons

[24] "Barriers refer to physical or invisible obstacles that prevent a person with disability from accessing or fully participating in 'life activities'. There are a number of different types of barriers which affect a person's ability to take full part in normal daily life activities. Some are visible and can be addressed through physical action e.g. building a ramp or removing an obstacle, others which are less obvious can require a more long-term approach to removing them, and involve the change of attitudes, beliefs and expectations." (Handicap International 2012: 2)

[25] For more information on the Washington Group's questions on disability please visit their website at: http://www.cdc.gov/nchs/washington_group/wg_questions.htm

with different types of disabilities on a 'transect walk' through the community or settlement to identify barriers and share observations " (IFRC 2015: 26):

- Sensitizing research or assessment methods to account for barriers faced by PwDs: meeting in accessible locations, using facilitation and multiple or alternative methods of communication as necessary, conducting home visits, respecting the privacy of persons with disabilities, maintaining standards for the ethical protection of research subjects
- Wherever possible, try to empower persons with disabilities by including them within assessment or monitoring activities as data collectors and contributors

4.2 Trainings to Promote Awareness

In cases like Nepal, it may be necessary to conduct additional trainings for government and civil society representatives working in the disaster response sector, to ensure that all DRR policymakers are adequately educated about issues of disability in the disaster context and to ensure that all formal and informal disaster response agencies in Nepal are adequately sensitized to issues of disability.

Our research indicates that some resources for these kinds of trainings exist, including a 'Training Manual for Mainstreaming Disability Into Disaster Risk Reduction' created by Handicap International-Nepal in 2009 (Handicap International-Nepal 2009) and an international report titled "All Under One Roof: Disability-Inclusive Shelter and Settlements in Emergencies" created by IFRC in partnership with CBM and Handicap International (IFRC 2015) that was recently published and used by the Shelter Cluster and the Camp Management Cluster following the Nepal Earthquakes.

Government institutions like the National Emergency Operation Center and organizations like the Nepal Red Cross Society should incorporate these materials into their trainings going forward. The first step may be focused trainings for risk reduction trainers themselves, so that information can be propagated throughout Nepal.

4.3 Information Sharing & Early Warning Systems

Our research indicates that information on disaster risk reduction and disaster preparedness is not adequately distributed and largely inaccessible to persons with disabilities in Nepal, especially persons with sensory and intellectual disabilities. Similarly, several international studies indicate that lack of information or inadequate access to information is a major problem for PwDs before, during, and after disaster, heightening their risk exposure. Importantly, clear and accessible communication in multiple formats will also benefit all: "Providing information through media in a manner that is more understandable to all means that protective actions can be taken more effectively and by a broader range of the population… Design of accessible technology has the potential to similarly provide equitable access to disaster risk reduction for other vulnerable populations. While the focus in the SFDRR is on technology that would make disaster notification more accessible for people with disabilities, such technology also serves people without disabilities (Stough & Kang 2015: 146).

The following recommendations, based on the 'Inclusive Disaster Preparedness Checklist' created by IFRC (2015), offer strategies for overcoming these informational barriers and ensuring equal access to information:

- **Ensure Information Accessibility**: Ensure that all information on disaster risk reduction, disaster preparedness, and disaster planning are made accessible to persons with disabilities. Make additional efforts to ensure that these materials are adequately distributed to marginalized and excluded groups. Ensure that all formal information featured in central forums such as the official Disaster Risk Reduction portal and all information provided to the public by the Government of Nepal is presented in a format or medium that is accessible to all.
- **Use Alternative & Complementary Information Technologies:** Radio broadcasts are an important and appropriate technology for dissemination of information in Nepal, yet these messages should also be complemented by other forms of communication. As mobile phone technology proliferates across Nepal, using text-based alerts through SMS may help to disseminate information to those who are not listening or able to listen to the radio. For example, the two major providers in Nepal are NCell and NTC and both provide text based alerts for elections, festivals, and other events; this system should be used for DRR and disaster response activities as well. The following case study from Japan shows the value of using complementary technologies that could possibly be developed in the future in Nepal: "Shortly after the disaster struck, a private company called *PLUSVoice* initiated a service to provide free sign language interpretation via videophones or smartphones for inhabitants of Iwate, Miyagi and Fukushima prefectures. This remote communications support has provided persons with hearing disabilities with new ways to access information and emergency warnings" (IFRC 2015: 31).
- **Establish Inclusive Chains of Communication:** Establish inclusive and targeted chains of communication that focus on alerting persons with disability to possible disaster risks and providing them with timely information on disaster risk reduction. This includes the need to "involve persons with disabilities in planning and managing inclusive and targeted early warning systems" and the need to ensure that "responsibilities and methods for informing, locating and assisting persons with disabilities in case of emergency have been identified" (IFRC 2015).
- **Include PwDs in the Design of Early Warning Systems & Evacuation Plans:** Engage persons with disabilities and their caregivers in the planning process to collect their feedback on the appropriateness of these programs and to ensure their understanding of how these systems function: "An inclusive early warning system will take into account the different communication needs of persons with disabilities. It will also consider the capacity of persons with disabilities to act on the early warning messages" (IFRC 2015). Planners should also ensure that ""Emergency evacuation shelters and evacuation routes have been mapped and categorised according to their level of accessibility" (IFRC 2015) and that PwDs take an active role in evacuation exercises and evacuation plans should be modified as per consultations and feedback.
- **Include PwDs in the Generation of DRR Information:** Wherever possible directly include PwDs in data collection and knowledge production about disaster and its risks: "Involve persons with disabilities in monitoring risks, such as measuring rainfall and water levels, or listening to radio reports" (IFRC 2015).

4.4 Building Disaster Preparedness Capacity with DPO Networks

"The capacity of disabled people's own organisations must be developed and used to inform humanitarian action and build resilient and inclusive communities."

(IFRC 2015: 4)

Nepali Disabled Persons Organizations (DPOs) are a major yet underutilized disaster risk reduction resource in Nepal—as they are under-recognized by the Government of Nepal, international development institutions, and even other GESI-oriented civil society groups. DPOs are well positioned to conduct localized advocacy efforts, to advise 'mainstream' humanitarian agencies on the needs of PwDs, to collect new data on disabilities, and conduct 'initial assessments.' "The participation of persons with disabilities themselves at the decision-making level and at all stages of the humanitarian response is considered a key issue by DPOs: 70% of the responding DPOs highlight this aspect as a necessity to ensure that the relevant authorities and stakeholders have a clear understanding of the requirements of people with disabilities during a humanitarian response" (Handicap International 2015: 21). Yet a recent international survey of DPOs conducted by Handicap International identified the following major challenges to response inclusive in the time of crisis: "the lack of access to funding (47%), the lack of coordination and information sharing among humanitarian actors (46%), and the lack of knowledge of the vulnerability factors of persons with disabilities (43%)" (Handicap International 2015: 20).

Additionally, our research indicates that Nepali DPOs were under-represented in the institutional architecture of disaster response, that they were not meaningfully engaged in District Disaster Recovery Committees or the Protection Cluster. This finding also contrasts with international recommendations that "Local DPOs should be invited to take part in a review of existing shelter and settlement preparedness plans from a disability perspective" (IFRC 2015: 38). To combat this kind of 'crowding out', which seems to occur repeatedly during the emergency phase, a recent report on 'Disability in Humanitarian Contexts' (Handicap International 2015: 27) recommends:

a) Creating a disability focal point in the response to mainstream disability within clusters and operational agencies, and support coordination between humanitarian organisations, the UN, DPOs and local authorities.
b) Providing capacity building to DPOs staff on humanitarian architecture including coordination mechanisms and response interventions to further supporting their capacities in developing response activities.

Our research also indicates that (with the exception of partnerships established by UNICEF, Handicap International, and CBM) coordination between international aid organizations and national DPOs was very weak in the wake of the 2015 earthquakes, for a variety of institutional, financial, geographic, and social reasons. This compares negatively with a greater pattern of international engagement where "50% of DPOs report having run at least one activity in partnership with humanitarian actors to support them in their activities and/or to provide technical expertise and guidance on inclusion" (Handicap International 2015: 20). Encouragingly, the same Handicap International study reports that **"**81% of DPOs report having continued to run activities during the crisis; 36% adapted their activities to respond to evolving situations; and 29% developed new activities in response to the crisis" (Handicap International 2015: 20) indicating that DPOs are acting as dynamic responders in times of crisis.

To address these gaps, a variety of efforts need to be undertaken to build the disaster risk reduction capacity of Nepali DPOs and to ensure that DPOs are recognized and meaningfully included as key stakeholders in a greater range of DRR and preparedness activities at the national and district level. For example, to increase coverage and coordination, the IFRC (2015) recommends creating an "inventory of existing organizational capacity and experience

with disability issues" that can be used as a resource map and a communication network in the wake of disaster. Similarly, a DPO representative from Sierra Leone recommended that: "humanitarian organizations have to develop a database of active DPOs, include them [in their work], and promote partnerships and networks with them." (Handicap International 2015: 21) This would also be an excellent recommendation in Nepal, which could be served by the clearinghouse and membership function of the Information Portal mentioned above. Unfortunately, however, our research and international studies indicate that efforts to include DPOs in disaster risk reduction or planning typically come only after the disaster, when valuable time and opportunity to improve DRR programs and disaster response activities has passed.

In short: it is critical to leverage the experience and evidence-based knowledge of DPOs in order to improve disaster risk reduction activities and post-disaster coordination.

4.5 Attention to Disability within Disaster Response

To provide the necessary support to persons with disabilities and persons newly disabled in the wake of disaster, issues of disability need to be formally incorporated into official disaster response strategies and disaster management plans. As our research and other international studies demonstrate, persons with disabilities are both exposed to greater risk during disasters and more likely to receive inadequate attention and coverage in the post-disaster context. In the wake of the 2015 earthquakes, it is crucial to re-initiate the planning process and to reevaluate the effectiveness of current disaster response systems so as to improve them. The following recommendations are meant to serve as basic guidelines for initiating what needs to be an ongoing conversation.

Increasing Awareness about Disability & Disaster: Provide periodic briefings and trainings to all institutional responders about disability issues, to ensure equal coverage of persons with disabilities during the immediate disaster response phase. Ensure that these trainings reflect current best-practices in the field of humanitarian response, that they incorporate the principles of the CRPD and the Sendai Framework and that they leverage existing resources such as the Nepal-specific training guidelines for "Mainstreaming Disability into Disaster Risk Reduction" developed by Handicap International-Nepal (Handicap International-Nepal 2009). It is also important to continue targeted advocacy efforts that raise issues of disability with the relevant disaster-risk reduction institutions within the Government of Nepal, such as the Ministry of Home Affairs and the National Emergency Operations Center, to ensure that the needs of persons with disabilities are recognized in formal disaster preparedness plans.

Now that the 2015 earthquakes have increased the level of attention and resources dedicated to disaster risk reduction, the larger goal should be to establish a formal platform for knowledge sharing [i.e. the recommended 'National Working Group on Disability'] that can "facilitate links, knowledge sharing and learning between humanitarian organisations, specialised organisations and DPOs through documentation and dissemination of good practices, lessons learned and recommendations on the delivery of inclusive response activities" (Handicap International 2015: 28).

Filling Gaps in Response Coverage: Recognize that primary healthcare services in Nepal are highly centralized and largely inaccessible to persons with disabilities living in remote areas. Create an emergency response system that increases the capacity of decentralized medical facilities across Nepal and "ensure that a system of referrals exists to leverage existing

rehabilitation services or services set-up by other humanitarian actors" (Handicap International 2015: 28). In order to reach persons with disabilities living in difficult to access areas of Nepal, it is also important to "develop facilities and mobile teams to ensure persons with disabilities who have difficulties in moving have access to essential health services" (ibid: 27). To ensure a timely and decentralized response in the wake of disaster, these mobile units should be established at both the national and district-level. To make these units effective and improve coordination, local Nepali DPOs should be included in emergency medicine trainings and response planning efforts.

Rehabilitation and Assistive Technology: Build greater capacity in rehabilitation services across Nepal, ensuring that these facilities are decentralized and accessible to all before, during, and after a disaster. Create a system of equipment depots to ensure that assistive devices and assistive technology are made locally available in the wake of disaster. Ensure that persons with disabilities and their caregivers are informed about the location of these depots and that they understand how to access them. These technologies include "emergency wheelchairs, crutches, walking frames, white canes and portable toilet seats. Consult with local DPOs for selection of items" (IFRC 2015). Given the fact that post-disaster access is severely limited by the geography and limited physical infrastructure of Nepal, it is crucial to ensure that these services and depots are spatially distributed in a decentralized manner, so that they are accessible to rural as well as urban populations. Similarly, it is critical to coordinate these programs with local DPOs and Government officials at the district level (i.e. District Disaster Management Committees and the Women's Development Office) and to ensure that information on this program is widely distributed[26].

Conversations with representatives from Handicap International-Nepal indicate that they have been working with the government to develop a program to provision assistive devices in the wake of disaster. The same respondent, however, identified a human resources gap in the rehabilitation sector, stating that there is need to train more physiotherapists and technicians who can fit assistive devices critical for persons with disabilities. Though equipment depots have been established in strategic locations to provide material resources (i.e. prosthetics and other assistive devices) for disaster response, the challenge is to allocate and deploy the needed human resources to these areas during a disaster.

Providing Long-Term Support for Recovery: In the wake of disaster it is critical to provide ongoing medical treatment, rehabilitation, counseling, and other kinds of services that support the long-term recovery of persons with disabilities. From a medical perspective, it is critical to "ensure follow-up on persons with disabilities and persons with injuries once they have been discharged from the health facility so that their health needs are met" and to "ensure services, including medical assistance and longer-term rehabilitation, are available for post-operative patients to avoid or reduce long-term impairment" (Handicap International 2015: 28). It is important to maintain the continuity of support programs well beyond the immediate phase of disaster relief.

Additionally, for newly-disabled persons struggling to transition into new lives, it is also important to provide counseling, training programs, and other kinds of services that will assist them with difficult social and economic transitions. In this regard, one great example of this kind of support program is the outpatient livelihoods training program offered by the Spinal

[26] Recent conversations with Secretary Madhu Prasad Regmi of the Ministry of Women Children and Social Welfare indicate a commitment by the Government of Nepal to establish a rehabilitation facility in each of the seven federalist states. This is a positive step in decentralizing disaster response, but it remains important to increase rehabilitation capacity in each of the 75 districts of Nepal.

Injury Rehabilitation Centre in Lalitpur, which helps persons with disabilities cultivate new capabilities and livelihood strategies. Another excellent program is the 'medical rehabilitation shelter' that the Nepal Healthcare Equipment Development Foundation (NHEDF) established in the wake of the earthquakes, a volunteer facility in Kathmandu which has provided accommodations, rehabilitation services, and social programs to over 300 persons who were disabled or severely injured by the earthquake. Successful programs like these should be supported, expanded, and replicated in other settings across Nepal.

Addressing Mental Health Issues: Ensure that psychosocial services and counseling are included as part of the response and that these services are accessible to persons with disabilities that limit their mobility or ability to communicate. Recognize that persons with disabilities and their caregivers may face a greater risk of mental health problems in the wake of a disaster and design programs specific to their needs. Use the disaster as a platform to increase public awareness about issues of mental health.

Accessibility & Universal Design: To counter significant limitations on mobility faced by persons with disabilities within the post-disaster environment, it is important to ensure that principles of accessibility and 'universal design' are incorporated into the planning and design of post-disaster humanitarian spaces, as per the Sendai Framework. To accomplish this, all planners and responders should reference the recent report by IFRC titled 'All Under One Roof: Disability-Inclusive Shelter & Settlements in Emergencies' (2015) which provides comprehensive guidelines for assuring that emergency shelters, humanitarian facilities, and other post-disaster infrastructures are accessible for persons with different kinds of disabilities. To be clear: "Shelter is a basic need for all. Targeting persons with disabilities in emergency shelter and settlement activities can save lives and offer vital protection to disaster-affected populations" (IFRC 2015: 39). This means, for example: a) siting emergency facilities and emergency settlements in accessible locations, b) creating specific spaces reserved for persons with disability within collective settlements, c) ensuring that facilities are accessible and navigable for persons with reduced mobility or visual impairments, by undertaking both 'temporary or permanent adaptations' and d) constructing toilets and sanitary facilities that are accessible to persons with all kinds of disabilities and which are gender-sensitive. Importantly, as persons with disabilities encounter significant challenges related to accessibility when living in collective settlements such as camps for internally-displaced persons (IDPs), it may also be productive to consider programs for 'assisted self settlement' (IFRC 2015: 39) that allow PwDs to live with greater dignity in their own space.

To reiterate, all of these issues should be considered and discussed in consultation with PwDs and DPOs well before a disaster occurs, so that these principles are carefully maintained during the chaotic emergency phase. Lastly, as discussed above, all efforts to 'build back better' in the wake of disaster need to incorporate the principles of accessibility and 'universal design' as per the Sendai Framework.

4.6 Social Inclusion & Benefits for All

Like disability, the risk of disaster remains largely invisible to the majority of society most of the time. When a disaster occurs, creating new disabilities and affecting sweeping changes in the mobility of the broader population, it can also make disability more visible, increasing awareness about the challenges faced by persons with disability. This increased visibility is an important resource, which can be leveraged to affect social and policy-level change and to create more inclusive systems of disaster preparedness and disaster risk reduction. Therefore,

in addition to these specific recommendations, we would also like to emphasize the value of using issues of disability 'to think with', arguing that disability can be used as a lens to recognize, discuss, and mitigate risks and barriers that typically remain hidden to society.

Importantly, the Sendai Framework on Disaster Risk Reduction 2015-2030 also highlights the fact that principles of accessibility and universal design reduce risks not only for persons with disabilities, but for all of society. Further, the Sendai Framework also specifically indicates the value of input from persons with disability within the larger goal of reducing risk before, during, and after disaster. "Persons with disabilities and their organizations are critical in the assessment of disaster risk and in designing and implementing plans tailored to specific requirements, taking into consideration, inter alia, the principles of universal design" (Sendai Framework 2015: 20). In more concrete terms, making an office building accessible to persons with disability will also make it easier for everyone to evacuate in the case of an emergency; ensuring that information on disasters is made accessible to persons with disabilities promotes greater clarity and creates an important redundancy in systems for information dissemination that will help reach others during a disaster. Thus, as argued by Stough & Kang (2015): "The concepts of inclusion, accessibility, and universal design are of use for all people, not just people with disabilities. In essence, including people with disabilities in planning and policy not only has the potential to make people with disabilities safer—it makes everyone a bit safer" (Stough & Kang 2015). An investment in inclusive disaster risk reduction is an investment in a safer and more equitable future for all.

5. LOOKING FORWARD: DISABILITY WITHIN THE SUSTAINABLE DEVELOPMENT GOALS

> Despite significant advancement in the international normative framework on disability during the last three decades, limited action has taken place on the ground. The lack of understanding of disability as a development issue, the lack of policy coherence and coordination in terms of addressing disability and development, and the absence of specific institutions and resources for action have been contributing factors.
>
> —UN General Assembly 2013: 15

The recognition of the needs and capabilities of persons with disabilities within the recently promulgated SDGs represents an important point of departure within the global discourse on disability, by clearly defining collective responsibilities to ensure the meaningful inclusion of PwDs within the global development agenda. This progressive engagement with issues of disability has emerged from decades of advocacy and widespread critique of the previous Millennium Development Goals, which failed to meaningfully account for disability (Mulligan 2009, Wapling 2012).

The 2030 Sustainable Development Agenda, by contrast, clearly states that disability cannot be a reason or criteria for lack of access to development programming and the realization of human rights, and provides several specific commitments to the inclusion of PwDs within the following Sustainable Development Goals (UN Enable 2015)[27]:

- Goal #4: Guaranteeing equal and accessible education by building inclusive learning environments and providing the needed assistance for persons with disabilities.
- Goal #8: Promoting inclusive economic growth, full and productive employment allowing persons with disabilities to fully access the job market.
- Goal #10: Emphasizing the social, economic, and political inclusion of persons with disabilities.
- Goal #11: Creating accessible cities and water resources; affordable, accessible, and sustainable transportation systems; providing universal access to safe, inclusive, accessible and green public spaces.
- Goal #17: Underlining the importance of data collection and monitoring of the SDGs, with emphasis on disability disaggregated data.

Importantly, the SDGs are intended to help operationalize the 2006 CRPD by creating a framework for the articulation of strategic action plans and specific developmental goals related to disability for each of the ratifying member states. Whereas the CRPD was a rights-based mechanism focused on compliance, the SDGs seek to promote greater accountability by promoting the creation of strategic targets related to sustainable development and the inclusion of PwDs.

The challenge now is to ensure that these principles are put into practice, which remains a significant challenge in countries like Nepal, which has ratified the CRPD but has yet to translate this commitment into formal legislation. As it has been argued throughout this report, the implementation of the SDGs is further complicated by high levels of social inequality and multivalent patterns of social exclusion that present additional challenges for persons with disability. Hence, the risks that PwDs will remain marginalized and excluded within uneven patterns of development are significant.

[27] Summary available at: http://www.un.org/disabilities/documents/sdgs/disability_inclusive_sdgs.pdf

The SDGs can serve as a point of leverage for PwDs and DPOs in Nepal and as a lens for development institutions to bring sorely needed attention to issues of disability—particularly in the wake of the 2015 earthquakes. As highlighted earlier, it is critical to recognize the uneven impacts of the earthquakes arising from structural inequalities, to understand the different trajectories and rates of post-earthquake recovery experienced by PwDs and other marginalized groups, and to recognize the voice of persons with disabilities within the process of recovery and reconstruction. The current historical moment, therefore, presents a timely opportunity to begin the work of operationalizing the SDGs in Nepal and to initiate a process of learning that can help to establish an important precedent for post-disaster recovery in other future contexts. This report, which seeks to promote meaningful and effective dialogue about the needs of PwDs in Nepal, is intended to initiate and inform this process.

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ANNEX I | THE EVOLUTION OF DISABILITY POLICY IN NEPAL

Persons with Disabilities in Nepal face numerous challenges in their everyday lives, imposed both by structural limitations and attitudinal barriers. The dimensions of these challenges depend on a network of factors, including the individual type of disability, differential social orientations, the socioeconomic status of the individual and/or caregivers, and constraints to mobility related to geography and lack of infrastructure. Understanding disability in Nepal requires recognition of the fact that disability is both a cause and consequence of subordination that social inequalities can produce and exacerbate disadvantages arising from disability, and that social conceptions of disability can create feedback loops that systematically exclude persons with disabilities from certain rights and opportunities. "Disability is often not only not discrete but also literally created by race, gender, class, sexuality, age, religion citizenship, and nationality. Disability can be, among other things, a (violent) production." (Ribet 2011: 149) In short, disability is both a cause and a consequence of social exclusion in Nepal, and persons with disability often face intersecting patterns of discrimination, that exacerbates conditions of vulnerability and lead to greater marginalization.

The 2001 'Situational Analysis of Disability in Nepal' conducted by the National Planning Commission and UNICEF found that 82.9% of Persons with disabilities in their sample (representing over 13,000 households) stated that they were aware of their rights within the framework of human rights for disabled persons but said that they were unable to take advantage of them, and 70.1% of Persons with disabilities reported that it was difficult to live in the community with self-respect (NPC 2001). The same report also found that in 28.4% of respondents from the over 13,000 households surveyed people believed that disability was a product of the fate of these individuals or their caregivers, and that many persons with disabilities remain discriminated against due to superstitious traditional beliefs about the cause of disability. In some cases "disability is still viewed as a sin of the previous life, and hence a shame to the family, which often results in concealing the family members from society and denying them a dignified life" (Norad 2012: 8). Though awareness about the medical causes of disability and the capabilities of differently abled people are spreading, these antiquated beliefs still manifest in the form of durable social stigmas.

The first formal set of policies focused on the rights of persons with disabilities in Nepal was the Disabled Protection and Welfare Act of 1982, which emerged largely in response to the promulgation of the UN World Programme for Action Concerning Disabled Persons in 1982. Envisioned as a comprehensive legislative measure, the PWDA sought to provide the following rights and facilities for persons with disabilities (UNESCAP 2010):

- Rights to free education, waiving fees for students with disability in government schools
- Rights to health care and health facilities including free medical examinations
- Opportunities for employment, including self-employment
- Eligibility for tax exemptions
- Special accommodations for public transportation
- Establishment of a 'disabled person device fund'
- A 5% employment reservation for persons with disabilities in public institutions
- Rights to free legal services
- Provisions for the issuance of 'identity cards' and initial efforts to "maintain inventory of disabled persons"

However, these provisions remained relatively weak for over a decade, until a set of implementing regulations were put in place in the form of the 1994 Protection and Welfare of the Disabled Persons Rules. Importantly, the 1994 Rules also defined the institutional structure for governance, which including the establishment of a high-level Disability Determination Committee within the Ministry of Women Children and Social Welfare (MoWCSW) and the definition of the "functions, duties and powers of the Social Welfare Officer in charge of formulating district level plan and programme with respect to persons with disabilities" (UNESCAP 2010).

This initial legislation was followed by additional measures for Persons with disabilities included in the 1992 Labor Act—which sought to promote both greater workplace safety and appropriate working conditions for persons with disabilities—and 1992 Children's Act—which included provisions for the Government to establish homes and educational facilities for orphaned and abandoned children with disabilities. Then in 1996, the Government of Nepal enacted the Disabled Service National Policy, which expanded existing provisions for the rights of Persons with disabilities, by pursuing the following ambitious agenda:

- Conduct disability prevention programs focused on maternal care, chronic malnutrition, and minimization of road-based accidents.
- Promote greater awareness about disability via a coordinated media campaign
- Provide free education for persons with disabilities up to higher degree and launch special education programme for persons with disabilities with special needs
- Provide free medical care to Persons with disabilities at certain facilities
- Improve the quality of official statistics on disability

In 1998, a National Coordination Committee for the welfare of disabled persons was formed led by the Ministry of Women Children and Social Welfare. However, despite the seeming comprehensive nature of these early policies, they are widely acknowledged as superficial—as a lack of commitment by the Government of Nepal, limited technical capacity, and ongoing political volatility led to weak implementation. "Many development laws in Nepal, including the Disabled Protection and Welfare Act, have remained only on paper. The law made in 1982 by the legislature of the time for the welfare and protection of persons with disability promised to deliver many things, but in actual practice has served very little purpose." (NPC 2001: 14)

In 2003, the Government of Nepal's Tenth Five Year Plan (2003-2008) formally initiated a 'community-based rehabilitation programme' that stipulated an integrated and localized approach to establishing special and inclusive schools, providing scholarships for disabled students, and sponsoring informational campaigns focused on awareness and disability prevention. In 2006, a Special Education Policy was established to promote inclusive education by creating disability-friendly education materials and providing teacher training—building on the recommendations for the 'special education' of children with visual, hearing, intellectual or mental disabilities included in the Education Act of 1971. Most significantly, in 2006 a National Policy and Plan of Action on Disability (NPPAD 2006) was implemented, in part as a reaction to the UN CRPD of 2006, which identified seventeen priority areas[28] for policy intervention, provided a legal basis for a renewed interest in PwD programs, and outlined a more comprehensive plan for monitoring and coordination mechanisms within a variety of

[28] These 17 priority areas are summarized in a 2010 UNSECAP policy brief as: "national coordination; law making; Information and research; awareness and advocacy; training and employment; access; communication; transportation; education; sports, cultural and recreational activities; prevention of disability; medical treatment; rehabilitation, empowerment and poverty alleviation; assistance materials and assistance services; self-dependent organizations; women and disability; international and regional assistance" (UNESCAP 2010).

implementing agencies. The 2007 Interim Constitution formed in wake of the Maoist Conflict (also identified as The People's War) also included provisions for the protection of the rights of persons with disabilities.

In December 2009, the Government of Nepal officially ratified the UN Convention on the Rights of Persons with Disabilities (CRPD and its optional protocol). The CRPD, which was designed to be legally equivalent to national statutory law once adopted, thus complements and strengthens the existing laws and policies set forth by the Disabled Protection and Welfare Act of 1982, which provides a baseline for recognizing the needs and rights of persons with disabilities in Nepal. Following the ratification, Nepal established a CRPD Monitoring Committee coordinated by the National Federation of the Disabled Nepal (NFDN), which includes a full range of disabled persons organizations (DPOs) and PwD-oriented civil society groups, to promote the full integration of persons with disabilities in Nepali societies. The National Human Rights Commission (NHRC) was also an early advocate for the promotion of PwD rights and the ratification of the CRPD in Nepal and maintains an active interest in promoting greater awareness about the rights of people with disability in Nepal. All this said, a recent study by Norad, however, found that "institutional structures for promoting rights of persons with disabilities do not necessarily result in effective mainstreaming"; and that "disability is confined only to the CRPD-specific activities as separate initiatives" (Norad 2012: 52).

As a result of the increased policy attention brought with the ratification of the CRPD in December 2009, the 2011 National Census reflected a greater commitment to collect comprehensive data on disability, and the annual program adopted by the parliament for 2011/12 included specific provision for rehabilitation for persons with disabilities who were disabled as a result of the Maoist conflict (Norad 2012). Alongside these domestic developments, the Third Asian and Pacific Decade of Disabled Persons was recently launched in 2012 during the ESCAP High-level Intergovernmental Conference in Incheon, Republic of Korea, in November 2012 (UNESCAP 2012) to which Nepal is also a signatory.

Building on the past issuance of disability identification cards, the Government of Nepal began distributing 'allowances' for persons with disabilities in May of 2013, as an extension of a recently enacted *Samajik Surakchhya Karyakram Sanchalan Karyabidhi B.S. 2069* (Social Protection Programme Working Procedures 2012-2013) that also included allowances for the elderly, Dalits, and single women. These distributions were made to persons with disabilities with severe disabilities holding red and white disability identification cards: 1,000 NRs (~$10 USD) to holders of red disability ID cards and 300 NRs (~$3 USD) to holders of white ID cards per month respectively

Institutionally, the Ministry of Women, Children and Social Welfare (MoWCSW) is the focal ministry, hence it is the responsible government body for formulating and reformulating proper policies, plans, acts and regulations and their effective implementation so as to address issues on disabilities across the country. Nonetheless, several ministries, lines agencies, civil society organizations, external development partners (EDPs) have been working on issues of disability in the country, via the Disabled Service National Coordination Committee that is operational under the aegis of MoWCSW—with representatives from Ministry of Finance (MoF), Social Welfare Council (SWC), National Planning Commission, and Nepal Industrial Development Corporation (NIDC). The National Coordination Committee is responsible for providing advice to government on plans, and policies coordinating policies plans and programmes as well as doing monitoring and evaluation of programmes regarding person with disability (JICA, 2002, NPPAD, 2006). Further, at the central level other ministries have separate section

to deal with issues of disability under the scope of each respective ministry, summarized as follows:

- The Ministry of Education has a 'Special Education Section' which has promoted special education programmes for students with disabilities, pursuant to the 2006 Special Education Policy. This unit works as a secretariat for special education council and is responsible for allocating funds to run special education programmes in special schools across the country (JICA, 2002).
- The Ministry of Health has a separate division to deal with preventive, curative and promotive services for persons with disabilities. Particularly Disability Prevention and Rehabilitation Focal Unit (DRFU) is functional under the support of Leprosy Control Division [LCD] which is mainly working for providing services to leprosy induced disability.
- The National Planning Commission Secretariat has its education unit to deal with issues of special education programmes and the social service division of the commission is also responsible for dealing with issues on disability (JICA, 2002).

At the district level, the Women's Development Office (which the MoWCSW looks after issues of social protection writ large) is the concerned government institution, overseeing the issuance of disability identity card and the distribution of disability allowances, in coordination with the District Development Committee and District Health Office. The District Development Committee is also responsible for the disbursement of the (very limited) annual budget provided by the central government to Disabled Persons Organizations (DPOs) in each district. Finally at the community level, the Village Development Committee Council is the point of contact for keeping records, enumerating total numbers of persons with disabilities across the VDC, and refer to the Women's Development Office for further processing of the cases. Currently the VDC Secretary works with local 'social mobilizers' to handle these tasks at the community level, which is highly problematic due to a) the ongoing vacuum of locally elected governments at the VDC level since 2002, and b) systemic absenteeism of VDC Secretaries in remote areas across Nepal. This relative absence of local government and failures of local governance limit the quality of data and severely complicates governance in Nepal's disability sector.

In the years following the promulgation of 2006 UN CRPD, attention to the issue of disability in Nepal has slowly been increasing, as evidenced by the handful of ongoing programs being implemented by some international agencies. Examples of these programs include support for medical treatment and rehabilitation for persons with disabilities in Nepal (Handicap International, Karuna Foundation), focusing on special education (UNICEF, Norad), livelihood programs and vocational development (Norad, Handicap International), support for people with physical disabilities (Handicap International) and visual disabilities (CBM Nepal), issues related to mental health (Koshish Nepal) and an attempt to increase the visibility of PwD issues through institutions like the Social Inclusion Research Fund. In addition to the National Federation of Disabled Nepal (NFDN) there are a variety of Nepali DPOs operational across Nepal, but the majority of these are focused on advocacy and social welfare work, rather than the direct provision of services. Prior to the earthquake, our research indicates that very few DPOs were collaborating with INGOs, and that the vast majority of these organizations remain significantly underfunded and unable to implement more comprehensive programs—signaling an opportunity for greater investment in these local DPOs.

Most recently, the newly promulgated Constitution of Nepal 2015 ensures a series of 'Fundamental Rights and Duties' (Part III) for all citizens of Nepal. This includes the 'Right to Live with Dignity' (Article 16.1) which is highly relevant to persons with disabilities in Nepal,

and the Right to Equality which guarantees that "there shall be no discrimination in the application of general laws on the grounds of origin, religion, race, caste, tribe, sex, physical conditions, disability, health condition, matrimonial status, pregnancy, economic condition, language or geographical region, or ideology or any other such grounds" (Constitution of Nepal 2015: Article 18.2).

In early 2016, a renewed Disability Rights Bill was introduced to the parliament for consideration, the major goal of which is to domesticate or contextualize the rights and provisions of the UN CRPD within the Nepalese legal code (Disability Rights Bill Draft 2016). This document creates an updated rights framework for persons with disabilities and assigns responsibility for *the implementation of these rights in practice* to a variety of different ministries under the coordination of the National Direction Committee on Disability. The current draft includes language on fine-tuning the classification of disability, of creating disaggregated disability data, and creating a system for punishment/award for discriminatory practices. Some relevant highlights of this pending legislation are as follows:

- Persons with disabilities have both equal citizenry rights and special rights (Section 3, Article 7)
- Persons with disabilities have rights against discrimination in all the sectors of the society including family, education, social institutions and property etc. (Section 3, Article 8)
- Persons with disabilities are guaranteed the right to protection against insult, physical and mental violence, gender based violence, domestic violence, and sexual violence (Section 3, Article 9)
- Persons with disabilities are ensured a 'right to social life' which includes the right to choose a place to live; stating that they shall not be compelled to live in a particular place because of their disability (Section 3, Article 9)
- Persons with disabilities shall also not be denied access to public infrastructures. (Section 3, Article 8)
- Persons with disabilities are ensured rights to political participation and equal access to voting facilities during elections (Section 3, Article 11)
- Section 4 of the Bill defines special rights to women and children with disability

Importantly, the pending Disability Rights Bill also ensures Nepali Persons with disabilities the right to protection during the time of conflict, emergency, or natural disasters. The state shall be responsible to provide necessary protection to the persons with disabilities during such events by investigating and keeping records of the events, implementing relevant laws, protect and rehabilitate the victims, provide measures so as not ensure that such events do not occur, create awareness in the community and local levels (Disability Rights Bill Draft 2016). This legislation builds on increased advocacy concerning the needs of Persons with disabilities both during and after the decade-long Maoist Conflict, during the Koshi floods of 2008, and the earthquakes of 2015, and this legislation would begin the process of operationalizing some of the principles of inclusion embedded in the 2015 Sendai Disaster Risk Reduction Framework—which would make Nepal one of the first countries to do so in the wake of a natural disaster.

Overall, however, this evolution of policies pertaining to disability has been accompanied by weak implementation and the persistence of social exclusion that disadvantages persons with disabilities in Nepal. Although various policies and provisions have been made regarding persons with disabilities in Nepal, the actual realities that PWDs are living with set of challenges in their everyday life is different. The Nepal Disabled Women Association critiqued the current situation in the following terms: "Government has signed and ratified the various

international treaties … such as CRPD and CEDAW but the implementation is virtually none. Domestic's laws were not amended in the line of CRPD. There is various policy but not strong monitoring mechanism made by government." (NDWA 2013: 9) Further research is needed to explore the reasons for this gulf between policy and practice and to understand the effects that weak implementation has at the ground level.

ANNEX II | ALTERNATIVE & ACCESSIBLE TABLES FOR FIGURES INCLUDED IN THE STUDY

Figure 1: Level of Earthquake Damages Incurred in Comparison to Others in the Community

	Same as Others	Better than Others	Worse than Others	Not Sure
Persons with Disabilities	25.9%	23.5%	49.4%	1.2%
Abled Persons	47.1%	23.1%	29.8%	0.0%
Dalit	23.8%	31.0%	45.2%	0.0%
Janajati	40.4%	19.1%	39.4%	1.1%
High-Caste	44.9%	24.5%	30.6%	0.0%
Total	37.8%	23.2%	38.4%	0.5%

Figure 2: Impact on Economic Activities/Sources of Livelihood -

	Yes	No
Persons with Disabilities	66.7%	33.3%
Abled Persons	58.7%	41.3%
Dalit	57.1%	42.9%
Janajati	63.8%	36.2%
High-Caste	63.3%	36.7%
Total	62.2%	37.8%

Figure 3: Post-Earthquake Challenges Identified by Persons with Disabilities -

Challenge Identified	Men with Disabilities	Women with Disabilities	Total
Daily Problems of Accessibility	15	13	28
Physical Vulnerability	9	9	18
Livelihood Issues	8	7	15
Psychological Issues	3	2	5
Lack of Health Services	2	1	3
Problems with Government Disability Allowance	1	2	3
Access to Information	2	0	2

Figure 4: Perceptions of Being Excluded from Public Life -

Demographic Group	Excluded	Not Excluded
Abled Persons	22.1%	77.9%
Persons with Disabilities	37.0%	63.0%
Dalit	40.5%	59.5%
Janajati	25.5%	74.5%
High-Caste	24.5%	75.5%
Total	28.6%	71.4%

Figure 5: Access of Different Categories of Persons with Disabilities to Public Facilities -

Demographic Group	SubGroup	Good	Adequate	Inadequate or Poor	Don t Know
	Male	5.0%	12.5%	72.5%	10.0%
Gender	**Female**	5.9%	14.7%	61.8%	17.7%
	Dalit	15.4%	7.7%	61.6%	15.4%
	Janajati	2.4%	11.9%	81.0%	4.8%
Caste Group	**High-Caste**	2.3%	21.1%	42.2%	31.6%
	Physical Disabilities	4.4%	13.3%	66.7%	15.6%
Type of Disability	**Other Disabilities**	6.9%	13.8%	69.0%	10.3%

Figure 6: Access of Different Categories of Persons with Disabilities to Government Services

Demographic Group	SubGroup	Good	Adequate	Inadequate or Poor	Don t Know
	Male	0.0%	22.5%	60.0%	17.5%
Gender	**Female**	0.0%	17.7%	61.8%	20.6%
	Dalit	7.7%	7.7%	84.6%	0.0%
	Janajati	0.0%	11.9%	73.9%	14.3%
Caste Group	**High-Caste**	0.0%	26.3%	52.6%	21.1%
	Physical Disabilities	0.0%	20.0%	57.7%	22.2%
Type of Disability	**Other Disabilities**	0.0%	20.7%	65.5%	13.8%

Figure 7: Access to Information in the Immediate Aftermath of the Earthquake -

Demographic Group	Easy	Average	Difficult	Don t Know
Persons with Disabilities	40.7%	22.2%	25.9%	11.1%
Abled Persons	54.8%	14.4%	21.2%	9.6%
Dalit	54.8%	14.3%	19.0%	11.9%
Janajati	42.6%	21.3%	24.5%	11.7%
High-Caste	55.1%	14.3%	24.5%	6.1%

Figure 8: Perceptions of the Relative Difficulty of Receiving Relief

Demographic Group	Easy	Average	Difficult	Don t Know
Persons with Disabilities	45.7%	19.8%	27.2%	7.4%
Abled Persons	59.6%	12.5%	19.2%	8.7%
Dalit	64.3%	4.8%	19.0%	11.9%
Janajati	48.9%	21.3%	22.3%	7.4%
High-Caste	53.1%	14.3%	26.5%	6.1%

Figure 9: Reasons Identified for Feeling Excluded in the Post-Earthquake Period

Reason Identified	# of Respondents
Disability	35
Caste/Ethnicity	26
Region	2
Gender	6
Other	31

Figure 10: Differences in Access to Post-Earthquake Support & Assistance

Form of Support or Assistance	Abled Persons	Persons with Disabilities
Tents/Tarps	90.0%	85.0%
Food Relief	89.0%	84.0%
CGI Sheets	72.0%	66.0%
Healthcare Support	48.0%	41.0%
WASH/Dignity Packs	82.0%	70.0%
Damage Assessments	61.0%	58.0%
Cash for Work Programs	56.0%	29.0%
Rehabilitation of Community Infrastructure	38.0%	30.0%
Rehabiliation of Schools or Temporary Learning Centers	54.0%	38.0%
Cash Transfer for Temporary Shelter	81.0%	70.0%
Winterization Support	77.0%	71.0%
Support for Demolition and Debris Management	46.0%	36.0%
Business or Microenterprise Support	4.0%	0.0%

Figure 11: School Attendance by Demographic Group

Demographic Group	Not Attending School	Local Government School	Boarding School	School in Kathmandu	School Abroad	Not Applicable
Abled Persons	9.5%	50.5%	15.2%	4.8%	1.0%	19.0%
PwDs	16.7%	32.1%	20.2%	4.8%	0.0%	26.2%
Dalit	14.0%	41.9%	20.9%	2.3%	0.0%	23.3%
Janajati	11.6%	44.2%	15.8%	6.3%	0.0%	22.1%
High-Caste	14.0%	40.0%	18.0%	4.0%	2.0%	22.0%
Overall	12.7%	42.3%	17.5%	4.8%	0.5%	22.2%

Figure 12: Changes in Employment & Livelihood Strategies Before & After the Earthquake

Category of Work	PwDs		Abled Persons		Dalit		Janajati		High Caste		Total	
	Pre EQ	Post EQ	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Agriculture - Self Employed	42.0%	30.9%	55.8%	45.2%	42.9%	31.0%	54.3%	41.5%	46.9%	40.8%	49.7%	38.9%
Agriculture - Wage	0.0%	0.0%	1.9%	1.9%	2.4%	2.4%	1.1%	1.1%	0.0%	0.0%	1.1%	1.1%
Non Agriculture - Wage	11.1%	9.9%	9.6%	13.5%	14.3%	14.3%	10.6%	10.6%	6.1%	12.2%	10.3%	11.9%
Remittance	3.7%	3.7%	6.7%	5.8%	7.1%	4.8%	3.2%	3.2%	8.2%	8.2%	5.4%	4.9%
Operating Own Business	17.3%	18.5%	14.4%	11.5%	23.8%	23.8%	11.7%	12.8%	16.3%	10.2%	15.7%	14.6%
Private Sector Employment	3.7%	3.7%	2.9%	1.0%	2.4%	2.4%	2.1%	2.1%	6.1%	2.0%	3.2%	2.2%
Public Sector Employment	6.2%	6.2%	3.8%	3.8%	2.4%	2.4%	5.3%	5.3%	6.1%	6.1%	4.9%	4.9%
Social Security Allowance	9.9%	4.9%	0.0%	0.0%	0.0%	2.4%	6.4%	2.1%	4.1%	2.0%	4.3%	2.2%
NGO Employment	2.5%	1.2%	1.9%	1.9%	2.4%	2.4%	3.2%	2.1%	0.0%	0.0%	2.2%	1.6%
Other Work Types	3.7%	11.1%	2.9%	4.8%	2.4%	7.1%	2.1%	7.4%	6.1%	8.2%	3.2%	7.6%
Not Applicable / Unemployed	0.0%	9.9%	0.0%	10.6%	0.0%	7.1%	0.0%	11.7%	0.0%	10.2%	0.0%	10.3%

Figure 13: Changes in Household Migration Trends Before and After the Earthquake

Demographic Group	Pre Earthquake	Post Earthquake
Persons with Disabilities	28.4%	12.3%
Abled Persons	45.2%	19.2%
Dalit	38.1%	19.0%
Janajati	36.2%	14.9%
High-Caste	40.8%	16.3%
Total	37.8%	16.2%

Migration Destinations	Pre Earthquake	Post Earthquake
Kathmandu	32.9%	43.3%
Gulf States	30.0%	26.7%
Malaysia	17.1%	16.7%
Other Places within Nepal	11.4%	6.7%
Other Countries	8.6%	6.7%

Figure 14: Percentage of Households with New Loans Following the Earthquake

Demographic Group	Percentage of Households
Persons with Disabilities	30.9%
Abled Persons	35.0%
Dalit	41.5%
Janajati	28.7%
High-Caste	34.7%
Total	33.2%

Figure 15: Sources of Loans or Credit after the Earthquake by Demographic Group

Demographic Group	Neighbour/ Friend	Moneylender/ Landlord	Community Groups	Savings Cooperatives	Banks
Persons with Disabilities	20.0%	4.0%	24.0%	28.0%	12.0%
Abled Persons	27.8%	11.1%	19.4%	30.6%	2.8%
Dalit	17.6%	11.8%	29.4%	29.4%	11.8%
Janajati	29.6%	11.1%	11.1%	18.5%	7.4%
High-Caste	23.5%	0.0%	29.4%	47.1%	0.0%
Total	24.6%	8.2%	21.3%	29.5%	6.6%

Figure 16: Type of Disability Identity Cards among Persons with Disabilities Surveyed

Disability ID Card Type	% of Respondents
Red	13.0%
Blue	27.0%
Yellow	20.0%
White	12.0%
No Disability Card	28.0%

Figure 17: Reported Prevalence of Mental Health Problems After the Earthquake

Identified as a Problem?	% of Respondents
Major Problem	16.0%
Problem	14.0%
Slight Problem	24.0%
No Problem	46.0%

ANNEX III | ETHNOGRAPHIC CASE STUDIES: STORIES FROM PWDS IN NEPAL

1. Amar Bahadur

Name	Age	Gender	Disability	District
Amar Bahadur	70	Male	Physical	Sindhupalchowk

I am an old man. I live alone in a temporary shelter. I only have one son who stays with his own family. My brother's family helps me out with the food. I have given my land on lease, and I give the grains to them. They cook for me. The only source of income is the old-age allowance that I get. I manage my other expenses by borrowing money from the property owners of the village and repay them in installments with the money that I receive from the old-age allowance.

One day, around 8 years ago, I fell down from my bed and broke my left leg. I went to the local hospital and the treatment did not go well. I could not afford to go to the government hospital as I did not have money. I need to walk with a stick. As I can walk around with the help of a stick, the VDC does not categorise me as a disabled. But I walk with a great difficulty.

Earlier, I also used to go to play in a band during marriage ceremonies of the other villagers and also worked as a wage labourer, but once my leg got broken, I have not been able to work as I did in the past. I feel very bad that I cannot work on my own now and need to depend on others. The only son I have treats me as a stranger now, neither does he comes during Dasain nor Tihar. I cry a lot thinking of him when I am alone. As we grow old, we start becoming a burden to our children. On top of that, I am a disabled; he did not want to take care of me. If he would have wanted, he could have taken me to Kathmandu. But why would he? He does not love me anymore.

Sometimes blood relations are not important. Does my brother's daughter-in-law have any responsibility towards me? But she has been helping me at least with the food.

I am happy with the debris management programme from UNDP, as I would not be able to afford this on my own. My house would have never been cleared in a lifetime if the organization would have not supported us.

I am disappointed as the VDC secretary refused to categorize me as a disabled. I have stopped taking part in any of the VDC activities. I think the VDC is a corrupt body and it does not do anything for the welfare of the Dalits.

I think I need a permanent shelter and some money. I am happy with the financial assistance that I have received after the quake as I could repay my loans to the moneylenders. I think that money is the best form of relief as we can spend it on whatever is required.

The same way I could not have demolished the house, I will not be able to reconstruct it again. I have a hope that you all will support us for the construction of the house.

2. Anusha

Name	Age	Gender	Disability	District
Anusha	16	Female	Physical (New)	Sindhupalchowk

Anusha from Ward no. 7, Phulpingdanda VDC in Sindhupalchowk, is a baby-faced 16-year-old new PwD (paraplegic); she sits in her makeshift bed that has been propped up by layered stones and a plywood sheet in her temporary shelter made of tin sheets. Nearby is a dying firewood makeshift stove that has presumably been used to cook breakfast for the family; I can see used pots and pans lying about on the hard mud floor. A biting cold wind comes in directly through the low doorway. She is shy and is not willing to talk. Her mum, Juna speaks on her behalf and tells us about the hardships they have had to face since the earthquake on April 25th (2015).

Juna: "My daughter, Anusha, she's 16. As you can see, she can't walk at all; her spinal cord was injured when the house collapsed around her. She has no feeling from the waist down and I have to look after her around the clock. She cannot sense when she needs to go the toilet; I have to watch her all the time. She hasn't been to school in a year; she missed out on this year's SLC exam as well, let's see maybe next year we'll manage something."

"The earthquake came when her father and I weren't home, she was alone here; I feel guilty when I think about that time. The neighbours pulled her out of the rubble, unconscious, and took her to the hospital." When asked about whether Anusha has received disability allowance, Juna says, "Yes, she does have the card, it's the red one that gives us 1000 rupees per month. In fact we applied for her citizenship and then the disability card." One of the few who received the disability card post-earthquake in Sindhupalchowk, it's a sad irony she received her card along with her citizenship card, which is issued at the age of 16, regarded as being on the cusp of adulthood.

Anusha and her mum spent seven months in Kathmandu at various hospitals, the last one being a hospital specialising in spinal-cord injuries. Juna tells us, "She was depressed for months and wouldn't speak to anyone including me and wasn't able to sit up at all, but the doctors and nurses were very encouraging and helped her with months of intensive physiotherapy, which has helped her a least to sit up like this." The earthquake not only took her daughter's mobility but took the sources of livelihood for the family, "We lost our house, one cow and one buffalo; I used to sell the milk here in the village and have a small income to buy vegetables for dinner, tarkari khane paisa aunthyo. My husband lives in Kathmandu, he has a job there, which he lost last year because we were so busy running around hospitals for our daughter. We're in trouble now, we've borrowed money and have been living off of that, I don't know how we'll continue like this."

As we come to the end, Juna asks us, "My real worry is for my daughter, do you know of any organisations that will help her to finish her studies. There were a few that offered help but they never materialised to anything."

There are numerous challenges yet to come for young Anusha, effectively trapped in her tin house on a hill completely inaccessible for a seriously disabled person and just one more statistic for the VDC office to add to their PwD roster; the shiny new wheelchair more of a hindrance than a boon in a hilly terrain like this one.

3. Bhupendra

Name	Age	Gender	Disability	District
Bhupendra	32	Male	Physical	Sindhupalchowk

I am Bhupendra, 32 years old from Kunchok-3, Sindhupalchowk, and I am physically disabled. I hold yellow card (disability identity card). I have five members in my family. I have a wife, three children, and my mother.

I was studying at the local government school. While I was unable to pass SLC examinations in the very first attempt, I quit studies and started to work in a hotel. Later my father again filled up the exam form for SLC examinations. But I again could not pass and returned to my previous job. After eight years, I passed the SLC examinations in the year 2063 BS. After passing SLC, I joined the three-month training for rural animal health workers conducted by the District Livestock Services at Chautara.

After completion of the training, I thought about starting an agro-vet service in the village because there were no technicians and agro-vet (dispensary) in this locality. I started the service investing a very low amount. My hard labour and dedication to work paid off. My agro-vet is now running very well and local people are very happy with my service. I provide treatment for their livestock.

The year 2063 BS was very good lucky for me. I got the job as a temporary letter distributor at the Additional Post Office at Kunchok. I am still working there. I have to deliver the letters within the VDC twice a week. Later I completed +2 level studies. I am able to meet the expenses for five members in the family very well and satisfied with the work. I am performing multiple tasks simultaneously but never feel any pressure.

As a PwD, I am very energetic and concerned about the rights of PWDs. I was nominated as the chair of Kunchok Disabled Organisation in 2063 BS and I still hold that post. People believe that I can raise voice for PwDs and do the work honestly. So I have been in the post continuously.

The earthquake destroyed my house. The very sad moment of the earthquake for me was that I lost my father. I was shocked very much. On that day, I was walking in the village with my three children. My father, mother, and wife were inside the house. Except me and my children, all of the members were buried under the debris. They were rescued by the neighbours and villagers, but they could not rescue my father.

I am very happy with the demolition done by UNDP. It was very safe. People got cash when they needed it most. I must say that there is politics in other organisations but here in UNDP, there isn't. Both engineers and overseers all of them worked equally.

4. Bhim Maya

Name	Age	Gender	Disability	District
Bhim Maya	50	Female	Physical	Sindhupalchowk

I met Bhim Maya on a sunny and warm winter's day. Dressed in a worn out but clean '*dhoti*' and '*cholo*', she's just finished combing her sparse hair and is smoking a '*beedi*'. As I approach

her with a 'Namaste', she seems embarrassed that she's smoking a *beedi* and hurriedly puts it out.

I ask her to introduce herself, "I'm around 62 years old, and I live here with my family". People around her say she is actually not 62. "I'll show you my citizenship and disability card, according to them, I'm 50 but I'm 62, some kind of mistake I there I think. This disability card doesn't give me any allowance; I wonder why that is when others get money from it? (It's a category D; seems disappointed)".

"As you can see, I can't walk very well, I walk with a limp. When I was a baby, I had an accident, and you know how it was in those days in the village, people didn't know how to take care properly, so my hip healed badly. I can walk around on my own but can't do too much work in the fields, look after cows or go to the jungle to get fuel wood, can't do much." "I think that's why my husband left me years ago, since then I've been living with my brother's family here." "But our house was destroyed and so I've living in this tin shed; my nephews built it for me; the VDC office gave those tin sheets, especially for people like me." I spot slivers of meat hanging in the corner and enquire about it; this elicits a cheeky grin out of her and a conspiratorial tone telling me it is "*ranga ko masu* (buffalo meat); *kaile kahi khana parcha*" (I eat once in a while).

When asked about her experiences on the earthquake, her jovial mood changes to one of sadness as she recounts her story. "Our house was there where the rubble has been cleared away. I lost my brother in the quake; he got crushed by the house and we were unable to get him out for two days; he was already long gone by the time we dug him out. He was my favourite; he looked after me and gave me food to eat and a place to stay. I have two other brothers in Kathmandu, I don't see them much."

When asked about whether she directly received any compensation for the earthquake-affected, she says no as she 'officially' lives with her brother's family. As I probe further about her current source of income and her livelihood, she says, "I was part of the group that cleared destroyed houses; I helped to move stones and mud. I also helped clear the roads for another group also" (Cash for Work crew for UNDP's Phase 1 debris management as well as the road clearance of World Food Programme). When asked how she got these jobs and how long she worked for, she says, "My relatives helped me get these jobs through a quota and I worked for 40 days and made around 20,000 rupees. This money is helping me live comfortably for now." When asked about her experience as Cash for Work labourer, she says, "I felt useless my entire life, but the job (CFW temporary employment) made me feel useful, and that I was actually able to contribute something (tangible) to my community even if it just meant clearing stones from the roads."

5. Chhima Devi

Name	Age	Gender	Disability	District
Chhima Devi	58	Female	Physical	Sindhupalchowk

It has been around five years since one-half of my upper body has been paralysed. One night, suddenly my blood pressure was high. I found it very difficult to move. My husband and my son took me to the Bahrabise Hospital early the next morning. However, the doctors there referred me to the Bir Hospital. The doctors at the Bir Hospital were also unable to completely cure me and provided me with medicines and told me that I will recover slowly. Now, I can walk slowly. However, I am not able to lift my legs high up.

My husband is very helpful; he helps me bathe, combs my hair, and even cooks for us when he does not have to go out for work. When he is not free, I can cook by sitting when all the cooking materials are around me. He washes all the dishes. I feel lucky to have a husband like him. If there was someone else in his place, he would have thrown me out. My son and daughter-in-law also take me as a burden and they got separated from us. I think I would not have been recovering this well if my husband did not show so much of love, care, and concern.

During the earthquake, I was alone inside the house and my husband was not there. I could not move. Our house was a two-storied house; the upper part of the house collapsed and the ground floor had cracks only. My husband came running thinking that I must be dead. But thank god, I was alive. He was happy to see me alive.

Other females can at least help their husband in income generation, but I cannot; I was also of no use while constructing the temporary shelter. It is difficult for us to recover as there is only one working member in the family who works as a wage labourer. It only helps in sustenance and not for us to do well.

I have not received any individual relief from the non-government organisations. The only relief that I have received as an individual is NPR 500 from the VDC after the earthquake.

Note: The family is aware that they can obtain a card from the District Development Committee (DDC). However, it is very difficult to take Chhima to the DDC. The husband stated, 'It would be good if she could get the person-with-disability identity card. I talked with the people in the VDC but they told me that she needs to go to the DDC to get the card. Only those people who are completely dependent on others get the card from the DDC with a recommendation from the VDC. But she cannot travel in a bus. She has been receiving NPR 300 per year from the VDC.'

6. Drupati

Name	Age	Gender	Disability	District
Drupati	54	Female	Multiple	Kavrepalanchowk

Note: Drupati was very happy that someone came to ask about her. She stayed with the interviewer for the whole interview though it was difficult for her to understand what was going on. One of her sisters-in-law told her story to the interviewer as follows:

She has had both impairment of speech and hearing from birth. Her parents died when she was around ten years old. Since then her brothers have taken care of her. Now, as the brothers are separated, she has been staying with us, the younger brother and his family. We run a small shop, made up of tarp and zinc sheets, where we sell *chana chatpate*. The shop, meanwhile, is on the public ground. Also, we have made a space to stay by separating the shop by a curtain as our house was destroyed in the earthquake.

The daily challenges we face is that she has difficulty in expressing what she wants. She gets angry when she feels hungry. After the earthquake, she needs to share the same space with us. It is difficult for her to maintain personal privacy in such a space. She had her own room before the quake. But now, she finds it difficult to change her clothes and feels uncomfortable. She is facing the same problems as the other family members are.

She has not received any assistance from the government except the allowance that she gets from the government for the blue card (disability identity card) she has. We are not aware about any programmes that are there for PWDs. Nor has there been any assistance from other organisations.

7. Hom Bahadur

Name	Age	Gender	Disability	District
Hom Bahadur	17	Male	Multiple	Gorkha

Hom Bahadur is a class nine student at Himalayan Higher Secondary School. He needs to walk 15 minutes, with apparent difficulty from his home. In addition to his noticeable physical disability, he has speech impairment as well, which makes it difficult for him to speak smoothly. For this reason, we asked written questions to him and requested him to write answers in a copy. We did so in his classroom during break time. As this method did not work effectively, we talked with his teachers who taught him, in the presence of Hom at the office of the school.

'I not only like to read a lot but also feel happy while reading,' Hom writes, when we interacted with him. We talked to a teacher, who has been teaching in the same school for the last 25 years, where Hom currently studies. The teacher mentioned that accessibility for people with disabilities (PwDs) like Hom in public spaces such as schools, health facilities is totally lacking in the community. There are the awareness-raising programmes regarding these issues in the locality by non-governmental organisations (NGOs) including Handicapped International (HI).

'Hom has not experienced any humiliation, discrimination, and stigma due to his physical condition at least in the school from the teachers and his fellow students. We treat him in the same way as everyone else in the school,' the teacher said. While we asked the same question to Hom, he smiled at us.

'We prioritised PwDs while distributing relief package as well, and CARE Nepal had provided NPR 7500 to the PwDs in the locality or had become disability due to the earthquake,' a teacher of Hom said. Apart from this, there is no specific program targeted to the PwDs in the community after the earthquake. The teacher mentioned that in this difficult period 'we are unable to think about the accessibility issues of PwDs'.

Hom has red colour (disability identity) card and receives NPR 1000 per month from the Government of Nepal as disability allowance. Hom said, 'I would like to open a stationery shop in the future' while discussing with us what he would like to do in the future.

'A boarding house which could easily accommodate PwDs according to their requirements and income-generating activities would help them to live a useful life in a relatively easy manner,' a teacher recommended. And access to public spaces such as schools, health facilities will be helpful for them in the future, the teacher suggested.

8. Kamala

Name	Age	Gender	Disability	District
Kamala	24	Female	Physical	Sindhupalchowk

I am Kamala, 24 years old, and a physically disabled woman. My disability is from birth. During my treatment, doctors said that in my body a minor vein is missing. Because of that, I am disabled. That vein could not be grafted. So this is a life-long problem for me. I have blue card (disability identity card). I am not satisfied with the NPR 300 provided by the government.

I have no experience of humiliation by the family and society. Family members always motivated me to study. I passed SLC in 2063 BS. I am an office assistant (peon) at a local government primary school. I joined the job in 2063 BS, after completion of SLC. There are two teachers in the school. Besides being the office assistant, I also perform the role of a teacher. I am an all-rounder teacher, teaching English, Nepali, sciences, and math. I do not get extra payment for this. The salary of the office assistant is NPR 3500. I take NPR 800 and contribute NPR 700 to the school. Every Friday I have to perform sanitation work in the school.

Various skill trainings are conducted for PwDs at Chautara. I went to Chautara to participate in candle-making training. I was unable to get in because of my disability. I was unable to join the computer training for the same reason. So I focus on PwD-friendly skill trainings.

I have confidence to do something. And I have proven my confidence and ability by being dedicated towards the school and students.

Earthquake destroyed my house. I was luckily safe. UNDP supported debris management. My father was deployed for Cash for Work (CFW) for UNDP. He was also involved in track-opening work for WFP. I am happy with the UNDP. I say that UNDP is very good. We were mentally shocked by the earthquake. We were like orphans. We were afraid of the cracked houses that were unsafe to live in. UNDP relieved our stress.'

9. Karmila

Name	Age	Gender	Disability	District
Karmila	15	Female	Intellectual	Kavrepalanchowk

'Pachi ma mare pachi ta magnu (referring to Karmila) *parcha ki kya ho, kya ho…aru kasle hercha, afno afno bachcha herna ta garho cha.'*

Karmila is a 13-year-old girl and suffers from a disability. According to her 77-year-old grandmother, Karmila had a sudden attack of disability after a few years of her birth. Initially until two years old, she used to say '*maa'* (mother), '*ba'* (father). After that, '*yeslai chhopyo'* (she got attacked) and she became how she is now. Nonetheless, her grandparents and her parents thought that she would recover soon and get back to her early behaviour but she did not recover after that. Her grandmother does not really know the reason behind the disability.

Karmila barely speaks, and she finds it hard to understand the language of other people too. Whenever there are not any people around her, Karmila goes outside and even ate '*disaa'* (faeces) too. *'Ufrera hindchha, nangai hindcha, barbaad garcha'* (She moves with bounding leaps, walks naked, and destroys everything). Because of such behaviour, according to her grandmother, she has always stayed close to her and does not let Karmila out of her sight. Karmila's mother passed away when she was around 10 years old. She was left alone with her father, a butcher, who later married a 'Chhetri' woman. Her father owns a meat shop, a 'traditional' business inherited from his father. According to her grandmother, the step-mom does not look after Karmila and instead, her father has said that if there is any organisation that would look after her then he will pay around NPR 20,000 to 30,000. Nonetheless, her father does not look after her now and Karmila is looked after by Pyare-lal, the second son and brother of Karmila's father who also owns a chicken meat shop. Karmila is also financially supported by her two cousin-sisters who are already married, mainly for *'chiya siya khana lai saya dui saya dincha'* (a few hundreds rupees for tea and light snacks). Her grandmother told me that it would be nearly impossible for her to look after her 'natini' if her two children would not have given any money to her whenever they visit her. In her food, Karmila is provided meat out of that money, according to her grandmother.

Talking about the business, her grandmother told me that her husband did not have anything when they first married. She came from Palanchowk. But her miseries were added on with more than ten children 'inside' her womb. Subsequently, she prevailed upon him to rear a pig and then start a meat shop and now because of their hard work as a wage labourer ('*ita bokera, mato bokera, baari khanera*' [carried bricks and soil, tilled the land]), they are pretty much sound in their economic status. They currently have two houses in Dhulikhel, close to the highway, passing through Kavre. Meanwhile, they have also not remained untouched by the quake. The *'purano'* house is affected by the quake. Also because of this, I met them outside nearby their house inside a tent. Inside the tent, I found Karmila's grandfather, grandmother, and Karmila. When I asked her grandmother that why she is kept outside (but inside in a tent) of their house, her grandmother said that it is much easier for her and her husband's mobility without any concern over them falling from stairs. '*Bhagnai sakdaina yo laati, khutta baliyo chhaina, hidnai sakdaina'* (She cannot run, her feet are not strong, and she can't walk properly). The tent was provided to them not by any organisation but by their 'naati' (their daughter's son). Inside that tent, food is served to them. For Karmila, according to her grandmother, her father gives food twice a day (in the morning and in the evening) without any lunch and for them. *'Diunso ko chhod dincha, hajur ke garne?'* (They do not give an afternoon lunch, what to do?) was her reaction when I asked her about lunch. *'Khaanu ta jatti pani khanchha'* (she can eat a lot) was her grandmother's affirmation when asked about Karmila's intake of food. For both grandparents, foods are provided by their second son. Karmila's father stays separately with his second wife, who, according to the grandmother, cannot stand the sight of Karmila. Also the grandmother stated that they are not really helped by their sons when asked about whether their sons looked after them or not. *'Herdaina hajur, bis rupaiya chiya la khau vanera pani didaina hajur, chiya khanu ta pari halyo…chiya khuwayeko chaina ahile'* (No, they do not look after us, they do not even give us twenty rupees for tea though we do like to have tea. I have not yet been able to give her tea now). During the whole of the interview, none of their sons showed up. It might be due to their involvement in their respective shops, which they did not shut down even after the quake. Also, it is their only source of income.

When asked about whether Karmila has a disability card or not, then her grandmother replied that she does not have one. Many people, like me, came and saw her and returned back after writing a note about Karmila. Her grandmother said that nobody has helped Karmila yet. Besides not getting any help from any organisations, including disability-related organisations,

she has not been sent to any school too. It's mainly because of her behaviour she is not sent to a school. They do not really know whether there is any school for her disability. *'Baa ama le wastaa gardaina'* (her father and step-mom do not really care). Karmila has three stepbrothers and stepsisters. They are admitted to a school. It seems that her father's re-marriage has absolved him from his care and responsibility towards his daughter Karmila. However, she is mainly looked after by her grandmother. '*Maya lagcha hajur, maya lagcha'* (I love her very much, I love her).

When asked about the well-being or what could be done best for Karmila, her grandmother's response expresses complete love for her. *'Hera bichar gare, teslai baani lagaye, teslai ke garera huncha, ramro cheez banayera, safa garera, garna sakyo vane*' (I cared for her, taught her manners, only if I could not teach her to keep and stay clean somehow). Yet her response also expressed pessimism as she complained that most of the people are finding it hard to look after their children and if she dies, Karmila might be forced to become a beggar. When asked about how villagers treat Karmila, her grandmother said that not even a grain of rice is given to her by outsiders. '*Eutai gharko le ta herdaina vane, pachi bahira ko le ke hercha*' was her poignant reply. Explaining further, she said that none of the other villagers knows about having a hungry stomach.

10. Milan

Name	Age	Gender	Disability	District
Milan	21	Male	Intellectual	Kavrepalanchowk

My name is Milan, and I am 21 years old. I have been categorised as an intellectually disabled person. I have a blue card (disability identity card). I started talking late, but I could not speak clearly. I went to school but soon my teachers realised that I would not be able to cope with class-works. I struggled hard to catch up with other students in the class. Though I could not reply to most of the questions asked by the teachers, my father said that I did my work well and I had the most beautiful handwriting. I even got the Best Handwriting Award in my school.

I live with my parents. I am the eldest of the three siblings in the family. As I grew older, I had to quit school because there was not any special school for people like me. Other schools did not take me in. According to my father, my disability was often confused with being mentally retarded by people and that created further problems in the understanding of my disability. As a parent, my father said that one of the challenges was to constantly be positive and smiling with me and any reaction other than this would often make me violent.

I usually work at my house. I do my work properly and help my family with everyday work. I even milk the cow in the morning, clean the cowshed, and dispose of the fertilisers in the proper place. I also go to the nearest market and whenever there is a meeting in the VDC office, or if I come to know there is something (event), I go. I also stay clean and take shower every day.

Meanwhile, I took part in skill-based training for making handcrafted bamboo furniture as well as making statues. Even though these trainings were good for people like me, it was not very useful. According to his father, training alone will not help. 'It doesn't bring any social or economic change. What can they do only with the training? Milan has skills but he is incapable of forming a team and work. Moreover, there is no market even if he is going to make such items. So, only giving training is not enough. What is needed is real economic change in the

lives of Milan.' Through his blue card, he gets NPR 300 monthly. His father has been saving that money in a local cooperative. 'I haven't used a single penny from his money,' he said, 'His saving must be around NPR 30,000 until now.'

11. Raj

Name	Age	Gender	Disability	District
Raj	23	Male	Multiple	Gorkha

Twenty year-old Raj lives with his father and step-mother in Baluwa VDC. He is in class seven at the local school. Raj has mobility difficulty as well as speech impairment. The interviewer spoke with his father in Raj's presence. He has a red card (disability identity card) and receives NPR 1000 per month as a disability allowance from the government. Raj has not received any incentive from the school where he studies. Teachers at his school treat him well. Before joining the present school, Raj had studied in a school for the deaf for two years in a nearby VDC, but as his condition was different from the rest of the other students in the school, the teachers asked his father to admit Raj elsewhere, according to his father.

'I help in Raj's everyday activities including changing dress, helping him in taking a bath and so forth; we have sought a number of treatments, consultation with physiotherapists, but his condition has not improved as expected,' the father informed. He added, Raj was born prematurely at seven months and he has been having problems since birth.

'When the earthquake moved occurred, Raj was not in the house. As the earthquake occurred, we were most concerned about him, what had happened to him. I walked around in search of him, and finally I found him uninjured. A person of Tarai origin helped him walk out of the house as he was watching television at a neighbour's house.'

He mentioned that he does not know of any projects and programmes working in his locality except that he was told that Goreto, an NGO, used to work on issues of disability but not in the village. And, CARE Nepal and CRS, a local NGO, provided NPR 7500 to Raj after the earthquake. He further mentioned that people with disabilities are highly neglected in the society; he recalled an incident when he and Raj went to National Federation of Disabled Nepal (NFDN), Kathmandu, to explore any suitable opportunity for Raj. When the father and son reached the office of NFDN and talked to the staff, the staff disturbingly said, '*Tapaile chhora ramro bhayeko bhaye, yeha lyaaunu hune thiyena tara naramro bhayara lyayeko*'' (you would not have brought your son here if he was normal, you have brought him here as he is abnormal). 'I felt so bad with such a response from the staff who works in such an organisation. Then, we returned to home.'

Raj's father is more concerned about the accessibility to the public spaces such as school, hospitals, health facilities, and even in the homes so that people like Raj can easily perform their everyday/regular activities without or less support from family members. He suggests that the state should pay adequate attentions to the accessibility and livelihood issues of PwDs in the communities. Otherwise, they will die without their parents/family members to support them. 'Who will take care of our son after our death? He will die as he will not be able to eat and perform everyday activities without other's support. One of the most worrisome issue for me is Raj's living condition after our death,' he added.

12. Shanti -

Name	Age	Gender	Disability	District
Shanti	26	Female	Physical	Kavrepalanchowk

My name is Shanti. I am 26 years old. I have been living here for 9 years. I came here as I got married from Manan Chanden village in Kavre. My family depends on agriculture. Besides, they are also involved in making bricks in a brick factory. Brickmaking, meanwhile, is seasonal as it is made only during a few months of the year.

On the 16th day of my birth, according to my parents, I got burnt when I was sleeping in the kitchen. My mother had gone to toilet for a few minutes. When she came back, she found me crying. Because of that fire, I nearly lost one of my legs as it was totally burnt though my parents took me to an emergency hospital for burns. Besides, my mother is also physically unwell. During my birth, she bled a lot.

My family could not afford operation on my leg due to our poor economic condition. Though the hospital check-up suggested a need to operate on my burnt leg, we (my parents) could not collect enough money. Consequently, they had to cut off my leg. Subsequently, my parents took me to a government hospital for the disabled, where I was provided an artificial leg to aid my walking. Only after that, I was able to walk. At the age of 16, I completed my class 8. Again, after 7 years, I am disabled now as I do not have enough money to maintain my prosthesis.

Many people rejected our proposal for my marriage when my family forced to marry me. It was primarily due to my disability. They became despondent and thought that now no one will marry me. I had many questions in my mind during those moments, and thankfully, my uncle suggested me to marry another disabled person who would understand me and my feelings. Later, he helped and provided me several photos and I found and chose one among them, who was also totally disabled. The decision has borne fruit as my husband helps me to put my artificial leg on and my life has become easy. I am, therefore, lucky to get such a helpful man who has been there in my every step. Now, we have two healthy and non-disabled kids.

Meanwhile, I do not really want to remember the day of 12 of Baisakh (2072 BS). My life has suddenly become harder. Due to the quake, I lost my house. I suffer from memory lapses. We stayed in a tent for nine months and nobody helped us though we heard that there are many organisations that help disabled people like us. Now, I don't have a job and my husband cannot work. Since the quake, we have been surviving only from his allowance. However, my children are studying. Some people have personally shown their interests and will pay the school fees till SLC. Amidst all this, I would still request the government to help disabled people like us and those who have completely lost their homes in the quake. Yes, we also remain dependent on government allowance.

13. Sukram

Name	Age	Gender	Disability	District
Sukram	35	Male	Physical (New)	Gorkha

I'm a local resident of Barpak, Gorkha, my name is Sukram. I run a small eatery-cum-guest house on rent. About my disability, I lost one of my hands during the April 25th earthquake this year (2015). While admitted to the Teaching Hospital in Kathmandu, two Japanese persons offered me help for a new artificial hand. I was trapped three feet under a pile of broken wall of two houses for more than six hours. Later my family and friends finally rescued me. I was sent to Pokhara for treatment, but the doctors there after a few weeks suggested me to go to a hospital in Kathmandu for better treatment. In Pokhara, people from 'Gurung Samaj' (Gurung Society) helped me by providing NPR 17,000 for further treatment. Only in Kathmandu, I found out that my wounds had started to affect my kidneys. As a result, I had problem with excretion. Finally after two-month-long treatment in the Teaching Hospital, Kathmandu, I was able to come back home but without a hand.

Though I have extremely low expectations of help from institutions or the government or even from my own VDC, but I expect to get it sooner or later. With this hope, I took this new profession for income generation. Earlier I worked as a mason there in Kathmandu. I was frequently accompanied by visitors who interviewed and photographed my disability. I want to share an incident where my father-in-law, when he came to Kathmandu, found people selling videos in the form of DVDs in which he is shown being interviewed by foreign faces. As for me, I face great difficulty even for daily chores, though I help my wife in washing utensils and washing clothes. I dream meanwhile that my children will help me cope with my disability in the future, so I have sent them to a boarding school for quality education in spite of my poor economic condition. I own a disability identity card, about which I came to know about through radio programmes and hope to receive NPR 300 per month from the VDC office.

In terms of infrastructural help, we wish for better roads. And I also hope for monetary help to start up a new business for our income generation on behalf of my fellow villagers as well. I also look forward to help other handicapped people (along with fellow earthquake survivors) either by collecting money or by constructing temporary homes for them or running a business. I am glad that my children were safe on the 5th April 2015 as they were in school for studies.

I despise the local Village Development Committee who sent my brother away empty-handed when he asked for help on my behalf. Furthermore, though there are boards of INGOs, namely CARE Nepal, which conducted WASH programmes in the area but have shown no concern for handicapped people like us.

14. Shushmita

Name	Age	Gender	Disability	District
Shushmita	17	Female	Multiple	Gorkha

Shusmita, a 17-year-old girl, lives with her parents in Baluwa VDC, on the way to Barpak, and studies in class six in the local school. She currently lives with her parents in a temporary house constructed nearby their earthquake-damaged house. Shushmita's father mentioned that he spent about NPR 150,000 to build this temporary house as the earthquake heavily damaged their house and it is not in a liveable condition. The family runs a shop in the temporary house. Two elder sisters of Shushmita are now abroad. During the initial conversation, when we asked Shushmita, 'Do you support your parents by working in your shop?' she replied, 'I do not,' and laughed. And Padam Bahadur, Shushmita's father added, 'She does not work at all, rather we

have to assist in conducting her regular daily activities, her mother [pointing to the mother] helps in changing dress while going to school and needs to support while taking bath'.

We talked with Shushmita's parents, mostly with her father in the presence of Shushmita and some other local persons, and a district representative of National Federation of Disabled Nepal (NFDN). Indeed, a local person helped us find Shushmita's house and her parents as we asked a young man in Baluwa if there were any persons with disabilities in the locality. Her house is located by the main roadside. When we were near her house, she was standing near the tap, and a person, who accompanied the interviewers, asked her to come and sit in a bench placed in front of the main door of her house. One could not only easily see her apparent physical/mobility difficulty but also could notice her psycho-social disability. It looked like she had cerebral palsy (CP). When we talked with her, she mentioned that she likes to go to school and she does not help her parents in her shop. Meanwhile, she got up from the bench, put on her dress, and went to school. Obvious mobility difficulty could be observed from her walking posture.

Her parents told us that when Shushmita was studying in class two in one of the private schools in Kathmandu, she suddenly fell sick and was admitted to the Kanti Children's Hospital, where she spent two months in Intensive Care Unit (ICU) and then the hospital discharged her, but she did not return to her previous normal condition. Prior to this, she was a normal school-going child. 'Since then, we have been spending a lot of time and money for her treatment and care and visited various possible places.' Shusmita was admitted in a rehabilitation centre in Chitwan, where she could do physiotherapy and study as well. 'By admitting her in the rehabilitation centre, we were expecting improvement in Shushmita's overall condition but it did not go as we expected,' they said. 'While Shushmita was staying in the rehabilitation centre in Chitwan, usually we, mostly she [mother], used to visit her once every five/six months, but her condition was not better in the expected way,' the parents emphasised. 'She spent about a year in the centre where we had to pay NPR 15,000 per month,' they stated.

While explaining further about Shushmita, her father said that she forgets things quickly and gets angry abruptly. She needs support and care to perform her regular dailies activities like changing dress. 'As she does not do anything at home, it is difficult for her to stay at home the entire day doing nothing, so we think it is better for her to go to school, which makes easier for her to spend time with friends and teachers. In terms of her study, she does even know simple English alphabets, ABCD….' The father said, *'Usko dimaaga nai chhaina, usko dimagale kam gardaina'* (She does not have brain, and her brain does not function properly). During our conversation, the father used these phrases many times.

Shushmita received NPR 300 from her school once. Her parents mentioned that she has a blue colour card (disability identity card) and the mother was trying to show that card to us but did not find it. If one has a blue card, then he/she receives NPR 300 per month from the Government of Nepal, but she has not received this allowance yet. By listening to the discussion between the mother and Amar, it looked like Shushmita's disability card was in the process of completion as they have submitted the necessary documents to the district headquarters for the card. She will begin to receive NPR 300 per month once she receives her card. Her father told us that it is not easy to go to the district headquarters frequently as Shushmita has difficulty in reaching the district office, 'so I did not continue submitting documents in the district office and finally when we submitted all the documents, even then it was difficult for us to carry Shushmita along to apply for the disability card'.

Considering the needs of Shushmita and people like her in the community, her parents are very worried about her life after their deaths. Even though there are not any programmes for PwDs

in the locality, it would be helpful for Shushmita and her friends who have similar physical condition if programmes can address the issues of livelihood, accessibility to the public space including schools, health facilities, and incentive for caretakers or management of caretakers.

15. Shanti

Name	Age	Gender	Disability	District
Shanti	43	Female	Physical (New)	Gorkha

I was injured severely in my lower parts in the April 25th, 2015 earthquake. I was trapped in a destroyed house while returning from the shed after giving fodder to my two buffaloes. I was alone in the house and had just woken up after taking a nap as I was not feeling well on that day. My name is Shanti and I am 43 years old from Barpak VDC. I usually spend my days by sitting on the bed in my temporary house constructed by my husband's brother. My house was damaged by the earthquake and is now unliveable. Prior to this, I used to live a normal life primarily by being involved in agriculture and household chores. I am also a mother of five children; all of them are studying in Kathmandu. My eldest son is 25 years old. I currently live with my husband in a temporary house.

On the day of the earthquake, my husband had gone to Kathmandu and a daughter had gone to a neighbour's house to watch television, so I was alone at home. When I had just returned from the shed, the earth began to shake, and as I felt the shaking, I was confused:

> All of a sudden, my house fell apart and I was badly trapped in it. For about 10 to 15 minutes, my condition was not that bad, but after that, I felt severe pain in the heart and a liquid started flowing in the lower part of my body, which I could not see but was in fact blood from my body. Later I was rescued by my *jethaju* (husband's elder brother) and a person from the community. I shouted to my *jethaju* to rescue me. After 15 to 20 minutes of that, he came to me and I asked him to rescue me but as his hand was broken last year, he was not able to drag me out. As he saw my condition, he ran around in the community to ask for help. But all the surviving persons from the community were not in the community as they had run to open spaces to keep themselves safe; however, my husband's brother came along with another person and they together pulled me from my trapped place. After that, I felt so thirsty and my mouth was so dry and I even lost my eyesight and hearing capacity, and as they went to search for their own family members, there was no one to give me water either. When the aftershocks occurred, I was alone and could not run to safety, so I just cried. In the evening, a group of young people came and they brought me out in the open space and provided me treatment as I was unconscious. I did not know what they did for my treatment, and the next morning, I was airlifted to Pokhara for further treatment. I returned to my home after about four months of treatment in Pokhara. Most of the treatment was free. In the course of treatment, various organizations provided us food, clothes, and some money.

As I recall, my life prior to the earthquake and post-quake is very different. Earlier, I was able to work and now I cannot anymore. I, therefore, wish that no other earthquake occur now onwards.

I do not have any disability identity card for now, but I received NPR 7500 provided by CARE Nepal as I become a long-term disabled from the earthquake, and my Dai (elder brother) registered my name as a newly disabled person when CARE Nepal was surveying PwDs in the community. I spend all of my time by sitting at home and do not contact people outside my family. I am not much aware about what has been going regarding PwDs in the communities.

'Kahile raamro hune ho, pahila ko jasto bhayeta ke kaama haru garna hunthyo, [in a quivering voice and tear-filled eyes*] aba jindagee yestai hola bhanera runchhu.*' (I do not know when I will get well, if I could return to my previous state, I would do many things, I cry thinking that rest of my life will have to be spent like this).

16. Serrong

Name	Age	Gender	Disability	District
Serrong	36	Female	Physical	Nuwakot

I am Serrong, 36 years old from Deurali-7, Nuwakot. I was born in a middle-class family. My father was a farmer. When I was studying in class 7, I dropped out of school and started to work as a porter in trekking business. I went to Kathmandu and worked for two years. I saw the difficulties while working and returned to the village to continue my studies. I passed the Test Exam but could not pass the SLC. I tried for five times and, at last, became hopeless and again left studies.

I am a physical disabled and have yellow card (disability identity card). My uncle was an army man and fond of hunting. One day I was trying to hunt, but unfortunately the gun exploded in my hand and I lost fingers at the age of 12. I started to work for PwDs in the year 2058 BS and established an organisation, PWD Service Organisation, and was its chair for 10 years. Receiving aid from the Deurali 'nagarpalika' (municipality) and from the central level, I and other members completed a three-month incense-making training. We started the business but it was at a loss. I am engaged in agriculture and now I am growing vegetables in five ropanis of my own land.

Beside agriculture, I started silk-farming in 2064 BS. I collected information from the agricultural office, and I participated in a 50-day silk-farming training. Fifty other people are also involved in this business. An organisation in Dhading is monitoring the silk-farming. It provides larvae and again comes to collect the silk. The silk is collected at NPR 250 per kg. A box contains 10 thousand larvae of silkworm and I have two boxes. Silk-farming can be done during three seasons of the year. I earn NPR 20,000 to 25,000 per season.

Though the earthquake destroyed my house, animal shed, and equipment for silk farming, I was not disheartened and started working hard. I would like to say that there is no loss after working hard, the result is very fruitful. And this is coming true. I am going to get NPR 40,000 from Youth Self-employment Programme to run my business. I am independent for household expenses. I am running the household well. In future, I am thinking of extending my business and provide employment to others.

17. Urmila

Name	Age	Gender	Disability	District
Urmila	48	Female	Physical	Kavrepalanchowk

My name is Urmila from Dhulikhel, Kavre. I am 48 years old. I have lived here all my life. My parents have businesses here. To run our family, my father used to go to China to buy goods.

We had a joint family and there were around 18 people staying in the same house. I have four brothers and two sisters. I think that we are the richest family in Dhulikhel but a few of my siblings are disabled. One of my brothers is deaf. Another has no hands, and I do not have both legs.

My family has many problems due to such disabilities. Except me, all my brothers and sisters are married. In addition, I have many problems in my life. I have had check-ups by doctors, but they failed to make me a normal person. I could not study or go to school, which was far, due to my disability. Furthermore, there is not any organisation for the disabled though the community-organised disability programmes helped me a lot.

Now I am like a frozen statue. I cannot do anything for my family though I have many plans for them. No one listens to my words due to my disability. So, I have cried all day many times. The tragedy further struck upon us when I lost both of my parents due to diseases such as heart attack and high blood pressure. A few brothers have already separated from this house. Therefore, I have been staying with my sister and I have made my disability identity card (red colour).

On 12 Baishak (2072 BS), I was watching TV in my room. When the earthquake shook my house, I could not run outside due to my disability. Then, I thought that was the last day in the house, made up of brick and mud, but the quake did not affect it. Later, my sister quickly came up shouting and rescued me. All the community people then stayed outside though our community was the least affected by the quake.

Earlier, disabled people were dominated everywhere. Our family hides the truth in our community. I don't know why people are so scared to say, 'My children are disabled'. In my view, money cannot buy everything; I have lots of money, land, gold, but I am still an unhappy person in this world. I want to marry and have children, but who is going to marry a person with disability in this country? The government should provide facilities, rules, programmes, and respect to disabled people.