



Monitoring the rights of persons with disabilities in Nepal

# HOLISTIC REPORT

# Prepared by

National Federation of the Disabled-Nepal

# In collaboration of

Disability Rights Promotion International and York University, Canada 2013

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Nepal Association of the Blind (NAB) National Deaf Federation (NDFN) Guardian Federation of People with Intellectual Disabilities (GFPID) National Association of Physical Disability (NAPD) Nepal Disabled Women Association (NDWA) Nepal Disabled Human Rights Center (DHRC) National Association of Deaf and Hard of Hearing (NADH) National Rehabilitation Center for Disability NRCD) Nepal Paralympics Committee (NPC) Nuwakot Women Association (NWA) Association of Psychiatric survivors (Koshish) Forum for Human Rights and Disabled, Dang (FHRD) Kaski Association of the Blind (KAB)

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# Preface

To agree internationally on provisions and standards for human rights is one thing. To live by them is another matter. The fact that the international community now has fully recognized that the exclusion and discrimination facing people with disabilities is a human rights concern for all nations in the world is of extreme importance for hundreds of millions of people living with a disability. It offers great opportunities to improve their living conditions.

However, real change can only be achieved, if we learn to identify, describe and report human rights violations against people with disabilities. We must use our efforts to develop our capacity in monitoring the situation through a sharp human rights lens. Persons with disabilities themselves must play the major role in this pioneering work. This is what we want to achieve through the Disability Rights Promotion International (DRPI) project and pilot projects with partners from the disability communities of several countries

This is also the reason why the Swedish International Development Cooperation Agency (Sida) has provided us with economic resources for this task.

We want to thank National Federation of the Disabled-Nepal and, in particular, Mr. Birendra Raj Pokharel, project Coordinator and all of the project personals including site coordinators, monitors, Data analysts and monitoring assistants who worked very hard to make this report possible. Heartfelt thanks also goes to our other collaborating DPOs: Nepal Association of the Blind, National Deaf Federation, Guardian Federation of People with Intellectual Disabilities, National Association of Physical Disability, Nepal Disabled Women Association, Nepal Disabled Human Rights Center, National Association of Deaf and Hard of Hearing, National Rehabilitation Center for Disability, Nepal Paralympics Committee, Nuwakot Women Association,

Association of Psychiatric survivors, Forum for Human Rights and Disabled, Dang and Kaski Association of the Blind.

This project provides a model for similar projects in other countries in which people with disabilities themselves take on the monitoring of their own rights. We hope that it is the beginning of a series of reports that will lead to social justice for people with disabilities in Nepal.

Bengt Lindqvist

Marcia Rioux

Co-Directors, Disability Rights Promotion International

Monitoring the Human Rights of People with Disabilities

# Acknowledgement

Monitoring the human rights situation of people with disabilities is a necessary step to evaluate whether the constitutional, legal and policy framework in place are adequate and effective on the ground, as well as to determine the degree of human rights violations affecting the lives of persons with disabilities in the country. It felt urgent need to develop a sustainable system to ensure that disability rights data collection to be carried out which is achieved by the implementation of DRPI tools and method and building monitoring capability within Nepalese disability rights movement through National Federation of the Disabled-Nepal.

The DRPI holistic monitoring project aims at monitoring the human rights situation of people with disabilities in Nepal. It scrutinize an evidence based information on implementation status of laws and policies within the country that protect and promote the human rights of persons with disabilities in conjunction with personal experiences, societal attitude with the information published in media outlets.

Accomplishing disability rights monitoring project has provided us the valuable experience of working on the monitoring of disability rights through the application of DRPI tools and method, with the active participation of persons with disabilities at all levels.

On behalf of National Federation of the Disabled -Nepal, I would like to express sincere gratitude to the DRPI specially Prof. Marcia Rioux, Co-Director, Disability Rights Promotion International and York University, Canada and Bengt Lindqvist, Co-Director, Disability Rights Promotion International for the trust bestowed for undertaking the Disability Rights Country Monitoring project in Nepal.

NFDN deeply beholden to the persons with disabilities participating in the individual experience interviews, site coordinators, monitors and monitoring assistants for their incredible engagement to share and document the personal experience of human rights violations of persons with disabilities. The active engagement of Systemic Monitors, Media Monitors and Data analysts indeed proved most valued amongst the effort undertaken in the disability rights country monitoring project and NFDN strongly feels this needs appreciation.

NFDN extends its gratitude to National Human Rights Commission, Ms. Rita Samson, former DRPI International Project Coordinator, Mr. Chris Lytle, former DRPI Research Associate, Ms. Heng Channtey of, Cambodian Disabled Peoples Organization (CDPO), Ms. Ashrafun Nahar Misti of Bangladesh Protibandhi Kallyan Somity (BPKS) and Ms. Saowalak Thongkuay, Regional Development Officer of Disabled Peoples' International-Asia Pacific (DPIAP) for participating in the country monitoring training, without whose presence and facilitation the monitoring would not have been possible.

NFDN is thankful to the committed work of Ms. Chona M. Sabo, DRPI Regional Coordinator for Asia Pacific, Ms. Paula Pinto, DRPI Research Associate and Ms. Paula Hearn, DRPI International Project Coordinator and appreciates them highly for their

critical and invaluable inputs in terms of ideas and creativity for the data analysis and completion of the report.

Furthermore, I would like to express our gratitude to the Government of Nepal, member organisations and chapters of NFDN for their invaluable support in the overall monitoring process.

My special thanks go to Mr. Birendra Raj Pokharel for coordinating the overall monitoring project, supporting for Data analysis and writing the systemic and individual experience report and translation in English language and moreover writing the holistic report.

Finally, NFDN hopes the report of the country monitoring project shall be invaluable resource as shadow report of human rights situation of persons with disabilities to be submitted in UNCRPD committee.

Sudarshon Subedi

National President, NFDN

Chairperson

Coalition of DPOs

**Disability Rights Monitoring Project** 

September, 2013

# **Executive Summary**

Every Human being is entitled for respecting self worth with identity, freedom of choice and non-discrimination. Interim Constitution of Nepal in its Article 13 prohibits discrimination which applies for persons with disabilities as well. The provision of Right to equality mention that the State shall not discriminate against citizens on grounds of religion, race, caste, tribe, sex, origin, language or ideological conviction or any of these. Provided that nothing shall be deemed to prevent the making of special provisions by law for the protection, empowerment or advancement of women, Dalits, indigenous peoples (Adibasi, Janajati), Madhesi or farmers, workers, economically, socially or culturally backward classes or children, the aged and the disabled or those who are physically or mentally incapacitated.

The development of socio-cultural phenomenon has always associated with Barrier-free environment where each individual can participate fully and effectively in the society. they are included in the community and respected with differences thus spend productive and comfortable life. A barrier free environment allows each individual for the enjoyment of equal opportunities, free and safe movement regardless of age, gender and functional impairment. The prevailing barriers restrict persons living with physical, mental, intellectual and sensory impairment -enjoying the human rights, as such Persons with disabilities in Nepal are facing higher incidence of human rights violations, discrimination and unequal treatment, disregard for difference, abrasion of dignity, denial of accessibility and exclusion, belonging to the educational status and poverty whether in urban or rural areas, the -victimization and human rights violations occur. The reporting to proper authorities of such victimization is insignificant due to lack of confidence that something positive will happen, lack of knowledge on how and where to report, avoidance of probable unnecessary trouble, and the fare of negative attitude of community by disclosing the incident. Hence the close observation is very essential for the people living in marginalization, their rights entitlement such as monitoring of human rights of persons with disabilities.

Monitoring the human rights situation of people with disabilities is a necessary step to evaluate whether the constitutional, legal and policy framework in place are adequate and effective on the ground, as well as to determine the extent of human rights violations affecting the disability sector in different parts of the country. It is felt urgent need to develop a sustainable system to ensure that disability rights data collection to be carried out in technical and financial enrichment of this particular and most essential initiative. This has been achieved by extension of collaboration with York University and DRPI to monitor disability rights and building monitoring capability within Nepalese disability rights movement through National Federation of the Disabled-Nepal. The DRPI holistic monitoring project aims at monitoring the human rights situation of people with disabilities in Nepal. It scrutinize an evidence based information on implementation status of laws and policies within the country that protect and promote the human rights

of persons with disabilities in conjunction with personal experiences collected through face-to-face in-depth interviews with persons with disabilities in the country. The elaboration and dissemination of monitoring reports is important purpose of this project. The reports also reflect societal attitude- with the information published in media outlets about the rights of people with disabilities, how much they cover existing breaching of disability rights and provide information to prevent future rights violations of people with disabilities. They can serve as the tangible evidence to support advocacy for changes in laws, policies, and programs to improve the lives of people with disabilities. Most importantly, the holistic reports provide a benchmark to monitor the Nepal government's progress in fulfilling the commitments it has made to people with disabilities after ratification of CRPD and other International human rights instruments.

The steering committee, coalition of specific and cross-disability organisations, established for providing policy guideline for this project identified four sites in Nepal with engagement of one country coordinator, four site coordinators, 18 individual monitors, 3 systemic monitors, 3 media monitors and 2 data analysts. The involvement of organizations of people with disabilities and persons with disabilities individually in all aspects of the monitoring projects which is a foundational principle of all DRPI projects. The monitors who conducted the interviews were persons with disabilities themselves who had received intensive training during country monitoring training on human rights principles and interview techniques in the context of this project. As in other liberation movement, the presence of monitors who are themselves people with disabilities helped interviewees to disclose their personal stories and to feel safe while describing very intimate and often painful experiences where 106 individual experiences interviews have been covered in the analysis.

A goal of monitoring is to be sustainable so that the population of persons with disabilities and disabled people's organizations are able to gather evidence-based information about disability rights through continuous process. Specifically, the holistic monitoring project endeavored to cover three major aspects of evaluating the enjoyment of rights by persons with disabilities;

1) The circumstances the persons with disabilities experiencing their civil, political, social, economic and cultural rights, affected by cross-sectional forms of deprivation such as gender, age, cross disability, education level and income level, geographic location etc;

2) The coherent execution of the constitution, laws, policy and program enacted to protect and advance the human rights of people with disabilities;

3) The media coverage on supporting persons with disabilities to exercise their rights and promote positively the societal attitude towards persons with disabilities.

The individual experiences have been considered as major source of information while

conducting the holistic analysis of enjoyment of rights by persons with disabilities. The information generated by the individual experience and the systemic monitoring of implementation status of the provisions in existing constitutional, legal, policy and program in the country have been mapped while conducting the analysis, at the same time, the identification of the challenges concerning enjoyment of the rights have identified and the relevant recommendation have been provided. The result of the media monitoring have also been applied for evaluating if the identified challenges of enjoyment of rights by persons with disabilities if being supported positively or negatively by societal attitude. In the analysis, five human rights indicators were considered (Dignity, Autonomy, Participation, Inclusion and Accessibility, Non-Discrimination and Equality, Respect for Difference).

All of the general human rights principles have been applied when collecting information and analyzing the human rights situation of persons with disabilities in Nepal. These human rights indicators have been considered in eight domains of disability rights issues such as privacy and family lives; education; work; social participation; information and communication; access to justice; income security and support services; health, habilitation and rehabilitation. Based on the responses and feedback received during consultation workshop while presenting the primary report of individual experience monitoring, there are four cross-sectional analysis included within the eight domains such as gender, employment, educational and distance of resident from the city.

The interviewees have expressed their experiences only in their concerned issue of human rights situation thus the different domains have different numbers and percentages. Only 7 per cent interviewees have responded concerning the issue of education, this indicates that 93 per cent of them have been excluded by education thus on the experience concerning educational opportunity been intensively covered. The analysis of individual experiences show that majority of respondents have expressed their concerns in social participation. 48 per cent of them have expressed that the social participation is one of major approach for including persons with disabilities in development discourse. 19 per cent respondents have expressed that the full and effective participation in family lives is also one of important aspect of overall development of persons with disabilities.

The human rights of persons with disabilities are at serious risk in every stage of their subsistence in the community, society, academic institutional, workplace, hospitals and even within family.

"My husband always ask me to abandon the house otherwise he would kill me. I am facing continuous violence by him. I feel lack of dignity while being violated, I am disregarded and humiliated in everyday lives only because of my disability" (APNPJPA14- Age 34 Women)

The interim constitution of Nepal (2063) in its article 12, right to freedom provide every

person shall have the right to live with a dignity, and no law shall be made which provides for the death penalty, that has ensured the rights to life for all human beings including persons with disabilities and article 10 of CRPD also has reaffirm that every human being has the inherent right to life and the state shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others. No one is entitled to threat the persons with disabilities for assassination; this conduct shall be taken as serious violation of human rights.

The existing constitutional, legal and rights protection mechanism in Nepal exhibit that there are significant state commitments including constitution, laws, institutions, programs, activities & self-help movement with strategic advocacy in National and local settings, organizations of persons with disabilities etc to promote the rights of persons with disabilities. It might give a impression that, there is already tremendous initiatives taken that persons with disabilities in Nepal have achieved a lot, and have nothing else to fight for. In fact, fortune exist in paper but unfortunate in execution, that –doesn't ensure tangible outcome in the lives of persons with disabilities. Nevertheless the development of a technical back-up to sustain the collection, analysis and storage of data to monitor the human rights of people with disabilities should be continuous process. Article 33 of the CRPD requires governments to establish a mechanism to monitor the implementation of the Convention, and urges State Parties to involve people with disabilities in this process. This project provides people with disabilities and their organizations with the necessary tools to undertake self-initiatives to watch Government commitments and Endeavour on protecting the rights of persons with disabilities.

After the ratification of CRPD, the monitoring of implementation and enforcement of the provisions of the legislation and other pertinent laws concerning persons with disability has been one of the major agenda of the DPOs with perseverance and determination so that further recommendation can be made to the Government, conspicuously through advocacy, awareness-raising campaigns directed to the society, institutions engaged in employment promotion, corporate sector, educational, health, etc. Given the wide gap found in this study between the direction of existing laws and policies and the ground reality of its execution, urgent measures should be taken;

Amendment and enforce the provisions of the DPWA in line with CRPD and antidiscriminative measures, mapping of the discriminative provisions in other pertinent laws against persons with disability and improvement and perseverance and determination, obviously, sensitization directed to the policy makers, general population, institutions, Government and concerned departments and local authorities, as well as to persons with disabilities themselves and their parents and representing organizations is the integral part of ensuring human rights of persons with disabilities.

Provide rights to livelihood through immediate economic empowerment to persons with disabilities and their families, as the respondent expressed that:

"I have attempted for the job in several agencies and organisations but due to my disability, I have not got any job. I was told that you can do nothing that require for this position, I can do I replied, but the job is not applicable for persons with disabilities, I was refused. I am now spending hardship life, have no earning" APNPKKA07 female age 25)

The article 10 of DPWA in the topic of service and benefit has mentioned the provision of providing land to the helpless persons with disabilities for starting their selfemployment and agriculture profession supporting livelihood however such provision has not been implemented, none of the individual living with disability has received a single piece of land from the Government scheme since there are many occasion the Government has provided such land to the persons living in hardship condition.

The CRPD in its article 28 obligate Nepal to recognize the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of disability, and shall take appropriate steps to safeguard and promote the realization of this right to ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes.

Many people acquired the disabilities due to a decade long armed conflict, the ministry of Peace and reconstruction has categorised the intensity of disability based on the functional limitation and loss of bodily part in percentage. The compensation has also been delivered in recommendation of ministry of health and population based on the percentage of the bodily part lost. This provision however covers the disability compensation but entirely driven from the medical perspective, the social aspect of the persons who acquired disabilities due to armed conflict has not been covered.

The reports on the evidence based monitoring, like this, will be disseminated to many diverse organizations of persons with disabilities, other individual persons, groups or organizations that are working to improve the lives of people with disabilities, groups who have prime interest in human rights for all people, the media, government agencies and legislators, policy makers and International community will have opportunity of enhance capability for further planning and collaboration.

# Chapter I

#### 1.1. Introduction

National Federation of the Disabled-Nepal (NFDN) has been established as crossdisability umbrella organization in 1993 and registered as a non-profitable and nongovernmental organization (Registration number: 67/050/51 in CDO and 1399/050/51 in SWC). It works to protect and promote the rights of Persons with Disabilities ensuring civil, political, economic, social and cultural rights of Persons With Disabilities. The inclusion and mainstreaming of disability issues in the national development process and to enhance the participation of Persons With Disabilities in the decision making process as objectives of this federation to be fulfilled by four major strategic intervention such as awareness and sensitization, advocacy and lobbying, capacity building, Networking and collaboration.

**Vision**: NFDN envisages an empowered person with disability who is educated, socially secure, economically productive, politically aware, and happily living with full realization of human right and dignity in an inclusive and a barrier free society.

**Mission**: NFDN will play an effective, gender sensible, leadership role to ensure that People with Disabilities have a decisive role in the development process in an organized way.

**Goals**: To get a positive and fully sensitized state, demand driven and inclusive program and activities, obligatory laws, policies, rules and their effective implementation ensuring dignified lives of Persons With Disabilities.

NFDN has a wide, recognised and locally rooted organisational set-up consisting more than 300 member DPOs comprising all types of disabilities (Physical, Visual, Hearing, Speech, Deafblind, Intellectual, Psychosocial and multiple) even undefined category such as hemophilic persons. NFDN has been mobilizing its regional and district chapters for the enjoyment of rights and benefits facilitating outreach services to the Persons With Disabilities. The member organizations expanded across the country have formed self-help groups of Persons With Disabilities in the community levels that have established the linkage through the deeply rooted mechanism to facilitate access to services and benefits provided by the state to ensure rights, meaningful inclusion and promoting democratic values.

The activities of NFDN under Ministry of Women, Children and Social Welfare covers the capacity Building for enjoyment of state services by Persons With Disabilities since 1998. NFDN has been working in cooperation of various National and International partners. such as DPOD Denmark, FFO-Norway, My Rights Sweden, Abilis Foundation-Finland, Handicap International, Plan Nepal, OHCHR, Action Aid-Nepal, International Foundation for Electoral System etc. Since its establishment, NFDN has been instrumental in coordinating, elevating and advocating for the rights of Persons with Disabilities in close collaboration with the Government of Nepal, DPOs and stakeholders. There is Representation of the President of NFDN in Government's high level committees such as, "National Development Forum" under the chairpersonship of Prime-minister, "Special Education Council" under the chairpersonship of Minister of Education and the "Disabled Service National Coordination Committee" under the Minister of Women, Children and Social Welfare. With the cooperation of parliament, NFDN has been succeed for the Ratification of Convention on the Rights of Persons With Disabilities (CRPD) and its optional Protocol by Nepal as such Nepal became state party since 7 May, 2010. The enactment of the National Policy and Plan of Action on Disability in 2006 and provision of classified Identity Card in coloring form. NFDN has established Inter-parliamentarian Disability Friendly Caucus comprising 16 parliamentarians for ensuring Disability Rights within the fundamental rights provisions. There was participation of NFDN in the election monitoring process during the Constitutional Election in Nepal in 2008.

As Nepal ratified the CRPD and its Optional Protocol and became state party since 7 May, 2010, it is important to make sure that the state obligation is fulfilled and rights guaranteed to persons with disabilities reflected in their real lives. For the CRPD to have a real and positive impact on the lives of persons with disabilities, Nepal should have baseline information so that they can identify gaps in the paper and practice and how persons with disabilities are exercising their rights. This information help to measure how the situation is improving by collecting, tracking and reporting on information about whether persons with disabilities are enjoying their rights that can be generated by the proper monitoring which plays an important role in the process of defacto implementation of the CRPD.

Advancement of the rights of persons with disabilities should be undertaken by twintrack approach, which is, recognizing the importance of ratification, implementation and monitoring of the CRPD to achieving the full enjoyment of rights by persons with disabilities also acknowledging the application of other human rights treaties that have been ratified by Nepal and apply to persons with disabilities. Provided that, Nepal has ratified seven core International Human Rights Instruments. For instance, International Covenant on Civil and Political Rights (14 May 1991) and Optional Protocol to International Covenant on Civil and Political Rights (14 may 1991). Second Optional Protocol to the International Covenant on Civil and Political Rights with Provision for the Elimination of Capital Punishment (4 June 1998). International Covenant on Economic, Social and Cultural Rights (14 May 1991). Convention on the Elimination of All Forms of Racial Discrimination (30 January 1971). Convention on the Elimination of All Forms of Discrimination against Women (22 April 1991). Convention on the Rights of the Child (14 September 1990). Optional Protocols to the Convention on the Rights of the Child on the involvement of children in armed conflict (31 October 2005) and Optional Protocols to the Convention on the Rights of the Child on the sale of children, child prostitution and child pornography (31 October 2005). Convention against Torture and Other Cruel, Inhuman and Degrading Treatment & Punishment (14 May 1991).

(Source: National Human Rights Commission, Nepal, www.nhrcnepal.org)

Persons with disabilities in Nepal often experience the violation of their basic human rights with the consequences of myth belief, negative attitudes, and pejorative language, social, legal and environmental barriers. After International Year of Disabled People 1981(IYDP) in Nepal, Some remarkable achievements has been accomplished. Enactment of DPWA-1982 (DPWA) is one of the major outcomes. The DPWA is considered as a comprehensive legal framework which incorporates the provisions that are essential for the enhancement of lives of Persons with Disabilities. There are various provisions in the act that reflect the essential measures for benefiting the Persons With disabilities by providing employment opportunity, educational rights, supply of the assistive devices, health facilities, micro-credit scheme and more over the social security. There are legal provisions addressing the disability rights such as, Special Children Act-1992, Disabled Protection and Welfare Rules (DPWR) - 1993, Special Education Policy - 1996, Disabled Service National Policy - 1996, Local Self-Governance Act - 1999, Labor Act -1999, Education Act Seventh Amendment - 2002 and National Policy and Plan of Action on Disability - 2006 have addressed the concerned issues of Persons with Disabilities. These acts and policies also address the provisions of the UN Standard Rules, Convention on Rights of Children and World Programs of Action concerning Persons with disabilities. The government has amended the Civil Service Act with has made provision for five percent quota to Persons With Disabilities through open competition in all public services under good governance policy.

Nevertheless the government has enacted the DPWA for ensuring rights of Persons with Disabilities; it has not been implemented so far. In the course of action on the writ application, the Supreme Court has issued the direction order in the name of the government for implementing the act fulfilling its deep sentiment. Still the provisions mentioned in the act has not been taken seriously because, all the provisions are voluntary not obligatory. Local Self-Governance Act -1999 authorizes the Village Development Committee and Ward Committee to help in activities relating to the protection and livelihood of Persons with Disabilities however there is not adequate programs executed in the community levels supported by the local government agencies.

The National Policy and Plan of Action has been enacted with the long term objective of establishing inclusive, Barriers free and rights-based society for people with disability, and to include them in the mainstream of national development. It was believed that the situation of Persons with Disabilities will be improved by the successful implementation of the policies and programs however the Government lacked in implementation of such policy and programs that couldn't contribute for achieving the target of poverty reduction strategy by the 3 years interim plan of the Government. Though some of the VDCs are allocating the budget for the disability sector but there is no comprehensive monitoring thus the gap couldn't be identified.

Since CRPD is ratified by Nepal, periodically reporting to the UN on its progress in implementing and enforcing the treaty obligations is mandatory. NFDN has now realized the need of further intervention to push for its implementation and enactment of the monitoring mechanism of CRPD implementation. At the same time, it is felt necessary

to identify the existing situation of persons with disabilities and the implementation status of existing legislations, policies and programs so that the gaps can be identified and the report of CRPD implementation can be realistic.

The monitoring of utilization of the local resources is important to improve the situation of persons with disabilities. Because of the gap in policy and practice for the allocation of the local resources in past, many of them are deprived from the services and benefits. In this instant, the disability rights monitoring is felt necessary in Nepal.

# 1.2. Methodology

Monitoring the rights of persons with disabilities has adopted the Holistic approach that follows the rights of persons with disabilities in several aspects and integrates the information as beads and pieces method. Such an approach gives a better insight into the experiences of persons with disabilities in real lives. It also allows to find out how different problems interlinked and affect each other, whether they are based in the laws and policies, practices, or social attitudes or coverage of the media towards persons with disabilities.

A steering committee formed comprising a Coalitions of organizations of persons with disabilities in leading role of NFDN including cross-disability organizations for hosting disability rights holistic country monitoring project. Within the steering committee, there were representation of NFDN, organizations working in single disability such as Nepal Association of the Blind, National Deaf Federation, National Association of Deaf and Hard of Hearing, National Association of Physical Disability, Nepal Disabled Women Association, Nuwakot Women Association, Association of Psychiatric survivors (Koshish), Nepal Disabled Human Rights Center, Guardian Federation of Intellectual Disabled Children, National Rehabilitation Center on Disabilities, Nepal Paralympics Committee etc.

The method applied a snowball sampling technique to identify key informant interviewees. In Statistical analysis, snowball sampling is a non-probability sampling procedure, most often used in qualitative research, that allows access to difficult to reach, marginalized groups such as persons with disabilities. Small groups (5-6 people) were identified as potential interviewees at the outset of the process through contacts in local organizations of people with disabilities in each monitoring sites. At the end of each interview, the monitors asked the interviewee if they would recommend someone else to be interviewed. The next people interviewed had been selected from these recommendations. There were 28 samples in each of Dang and Kaski sites were covered where as 15 sample in Jhapa and 48 in Kathmandu were identified. Out of 119 persons with disability were interviewed while 106 interviews were incorporated in the analysis based on the quality and relevancy of the interview text. The sample balanced for gender, age (18+), educational attainment, type of disability and social status. Detailed records of interviewees' demographic characteristics and experiences were also gathered at each site so that the proportional coverage of the diverse characteristic of sample could make more representative.

With the informed consent of the interviewees, interviews were digitally audio recorded and the recorded interviews were then collected by the site coordinators in flash drive for transcribing, translation to Nepali language and conduct further data processing and analysis. Data processing was done using NVivo 10, on the basis of a Coding Scheme in accordance to the DRPI tools.

The tool consists of a series of close-ended and semi-structured questions which were developed to ensure that people with disabilities have an opportunity to tell their own story and to identify those rights issues that are most important to them. Time reference of individual experiences was the last 5 years where as the interviews conducted during July and August 2012.

The Nepalese participants of Asia-Pacific Regional Disability Rights Monitoring Training conducted by DRPI are highly motivated to develop and take an active role in a disability rights monitoring project in Nepal. The responsibilities of National Coordinator of the project have been delivered to Mr. Birendra Raj Pokharel. The tasks for site coordinators have been delivered to Mr. Chintamani Paudel, Mr. Kumar Regmi, Ms. Rampyari Karki and Mr. Shishir Khanal. There were 18 Monitors among Persons with Disabilities, 4 in each of Dang and Kaski districts, 2 in Jhapa and 8 in Kathmandu valley.

There were 3 persons involved in Systemic Monitoring, 3 in Societal Monitoring and 3 as Data Analysts.

#### **1.2.1.Background of Monitoring Sites**

Nepal, the world's youngest republic state, lies to the north of the equator between 26°22' to 30o27' north latitude and 80o4' to 88o12' east Longitude. Nepal is the world's most steep staircase the frozen heights in the north and flat, checks plains of the low land Tarai. The shape of Nepal in the world map is little inclined rectangle, occupies 147,181 sq. kilometers of south Asian sub-continent. The length is almost uniform is 885 kilometers and the width varies to give an average of 193 kilometers. Nepal is the world's 93rd largest country by land mass and the 41st most populous country, squeezed between vastness of Peoples' Republic of China to the north and India to the south, east and west. Specifically, the Indian states of Uttarakhand, Uttar Pradesh, Bihar, West Bengal, and Sikkim surround Nepal while across the Himalayas lies the Tibetan Autonomous Region in the North. Nepal is separated from Bangladesh by the narrow Indian Siliguri corridor. Kathmandu is the nation's capital and largest metropolis.

Geographically, Nepal has been divided into three ranges (Mountain, Hills and Terai). The mountaineering region occupies more than 25% of Nepal's land area to be over 3,000 meters to 8848 meters from sea level. It also includes eight peaks higher than 8,000 meters. The Everest, highest peak of the world, named "Sagarmatha" is in Mahalangur mountain range and the third highest peak Kanchanjunga (8598M) is in Kumvakarna mountain range. Nepal, contains more than 240 peaks over 20,000 ft (6,096 m) above sea level.

Below the Himalayas, there is Hilly region, also known as Pahad, varies from 800 to 4,000 meters (2,625 to 13,123 ft) in altitude with progression from subtropical climates below 1,200 meters (3,937 ft) to alpine climates above 3,600 meters (11,811 ft). Two parallel ranges running in a similar west-northwest to east-southeast direction. One of them is Mahabharat Lake, rises to elevation between 1500 meters and 2700 meters.

Broad tropical valleys such as Kathmandu and Pokhara are enclosed in these ranges. The Mahabharat Range reaching 1,500 to 3,000 meters (4,921 to 9,843 ft) is the southern limit of this region, with subtropical river valleys and "hills" alternating to the north of this range. Population density is high in valleys but notably less above 2,000 meters (6,562 ft) and very low above 2,500 meters (8,202 ft) where snow occasionally falls in winter. Immediately south is the Siwalik Hills elevated between 600 to 1500 meters. Nepal's approximately 58% of lands are occupied by Hills.

From the south or Siwalik Hills to the boarder of India there is Madhesh/ Terai region. This has been extended from, east to west Nepal with the breadth of 25 to 32 kilometers and is elevated between 60 to 600 meters from the surface of sea. The Terai is formed and fed by three major Himalayan rivers, the Kosi, the Narayani, and the Karnali as well as smaller rivers rising below the permanent snowline. This region has a subtropical to tropical climate. The outermost range of foothills called Shiwalik or Churia Range cresting at 700 to 1,000 meters (2,297 to 3,281 ft) marks the limit of the steeply Plain, however broad, low valleys called Inner Tarai (Bhitri Madhes) lie north of these foothills in several places, Dang is largest valley in this region. The Terai covers 17% of Nepalese land and being plain it is most populous, agricultural and industrial region.

The southern Terai region is fertile and humid. Jhapa lies in the far eastern belt of this region. Lumbini, the birthplace of Lord Buddha, is located in this region. Lumbini is one of the holiest places of one of the world's great religions, and its remains contain important evidence about the nature of Buddhist pilgrimage centres from as early as the 3rd century BC. Hinduism is practiced by about 81.3 per cent of Nepalese, making it the country with the highest percentage of Hindus, Buddhism is linked historically with Nepal and is practiced by 9 per cent, Islam by 4.4 per cent, Kirat 3.1%, Christianity 1.4%, and animism 0.4%.

Nepal is landlocked country with ecological diversity. The development of different part of the Country depends upon the geographic deformities. Nepal has been divided in to five development regions, fourteen Zones and seventy five districts.

Nepal has five climatic zones, broadly corresponding to the altitudes. The tropical and subtropical zones lie below 1,200 meters (3,937 ft), the temperate zone 1,200 to 2,400 meters (3,937 to 7,874 ft), the cold zone 2,400 to 3,600 meters (7,874 to 11,811 ft), the subarctic zone 3,600 to 4,400 meters (11,811 to 14,436 ft), and the Arctic zone above 4,400 meters (14,436 ft).

Nepal experiences five seasons: summer, monsoon, autumn, winter and spring. The Himalaya blocks cold winds from Central Asia in the winter and forms the northern limit of the monsoon wind patterns. In a land once thickly forested, deforestation is a major problem in all regions, with resulting erosion and degradation of ecosystems.

The steering committee analyzed the local circumstances of various aspects of Geographic, socio-cultural phenomenon, refugee, rural and urban area to identify the project site. While executing the individual experience monitoring, such circumstances was mapped in whole country and identified four districts as DRPI country monitoring sites.



#### Jhapa

Jhapa is the easternmost district of Nepal and lies in the fertile Terai plains. It borders llam district in the north, Morang district in the west, the Indian state of Bihar in the south and east, and the Indian state of West Bengal in the east.

The district is divided into 47 Village Development Committees (VDC) and three municipalities, namely Bhadrapur, in the south, Mechinagar in the east and Damak in the west. In 2012, Birtamod was slated for municipality status, however, has not yet been functioning as a municipality. Other major centers are Dhulabari, Budhabare, Surunga, Charali, Baniyani, Kechana, Patharia, Balubadi, Gherabari, Pathamari, Prithvinagar, Halddibari, Maharanijhora, Lakhanpur, Gauradaha, Topgachhi, Gauradaha, Rajgadh, Ghailadubba, Charpane, Laxmipur.

Jhapa is one of the most developed districts of the country. Almost all the villages and towns are linked by roads. There are schools and colleges in many parts of the district. There is also an airport and a hospital in Chandragadhi. It has the highest literacy rate in the country after Kathmandu, Kaski and Chitwan districts. Airport is domestic and one can get regular flights from Kathmandu to Chadragadi to Kathmandu. It takes one hour flight. There is a hundred bedded Zonal hospital. It has different departments as Medicine, Surgery, Gynaecology & obstetrics, Paediatrics, and the 24 hours emergency facilities. AMDA Hospital Damak, established in 1992 as AMDA referral center of 15-bed capacity with the help of AMDA International, and Damak Municipality. There are some

private hospitals like Life Line Hospital, Damak, Mechi Model Hospital & Research Center Pvt.Ltd.Birtamod etc. The government hospital also provides the plastic surgery services occasionally.

Jhapa has a literacy rate of 66.93 percent. Chulla Chulli English Boarding School and Little Flowers School are some of the best schools in the country. There are also some good private schools like Suryodaya English School, Siddhartha Boarding School, Newtons Education Academy, Shree Pashupati Secondary School, Balmiki Academy, Gyanjyoti Higher Secondary School, Dipjan English Boarding School, Divya Jyoti Secondary School, Purwanchal Academy etc. The number of Colleges providing opportunity of higher studies has been increasing in Jhapa. Mechi Multiple Campus Bhadrapur and Damak Multiple Campus are the wings of Tribhuvan University. Kankai Adarsh Campus Birtamode, College for Higher Education (COHED) and Kanakai Multiple Campus Surunga are the other main Colleges Providing higher education up to Master's Degree in Management, Education and Humanities Stream.

In the disability rights monitoring, Jhapa district cover the people from refugee individuals and "Madhesee" community.

Based on the report of national population census 2011, total number of person with disability in Jhapa is 15,376 out of them, women with disability constitute 6910 followed by 8466 male. Out of the total population 812,650 where the number of woman population is 427,554 and male is 385,096.

#### Kathmandu Valley

This valley consists of Kathmandu, Lalitpur and Bhaktapur Districts an area of 220 square miles. The valley consists of the municipal areas of Kathmandu Metropolitan City, Lalitpur Submetropolitan City, Bhaktapur municipality, Kirtipur Municipality and Madhyapur Thimi Municipality; the remaining area is made up of a number of Village Development Committees. The valley is a cultural and political hub of Nepal. The Kathmandu valley was accorded the status of a World Heritage Site by UNESCO in the year 1979.

The Kathmandu Valley lies at the crossroads of ancient civilizations of Asia, and has at least 130 important monuments, including several pilgrimage sites for Hindus and Buddhists. There are seven UNESCO World Heritage Sites within this valley. Historically, only the Kathmandu Valley was referred to as "Nepal" by people who lived outside the valley. After the annexation of the valley by the Gorkha kingdom, and subsequent conversion of the valley as the capital of their empire, this designation of "Nepal" was extended to every land they conquered.

The Kathmandu valley has many nicknames like "K-Town", "City Of Event", "Cherry On The Cake". It is the most developed and populated place in Nepal. The majority of offices and headquarters are located in the valley making it the economic hub of Nepal. It is popular with tourists for its unique, rich, culture and architecture; including the highest number of jatras in Nepal. The valley itself was referred to as "Nepal Proper" by British historians.

The valley cover people representing urban, slum, economically rich and poor class

where the persons with disabilities of such class have been covered in the monitoring.

Based on the report of national population census 2011, the total number of person with disability in Kathmandu is 25,260, out of them women with disability constitute 11,843 followed by 13,417 male. Out of the total population 2,517,023 where the number of male population is 1,305,967 and female is 1,211,056.

#### Kaski

Kaski District, a part of Gandaki Zone, is one of the seventy-five districts of Nepal, a landlocked country of South Asia. The name is disambiguated from Kaskikot, the ancient Kaski Kingdom.

The district, with Pokhara as its district headquarters, covers an area of 2,017 km<sup>2</sup> and had a population in 2011 of 380,527.

The district covers parts of the Annapurna mountain range, and the picturesque scene of the mountains can be observed from most parts of the district. It is one of the best tourist destinations of Nepal.

The centroid of Nepal lies in this district. In this district the list of VDC is Arba Vijaya, Armala, Begnas, Bhachok, Bhadaure Tamagi, Bharat Pokhari, Chapakot, Dangsing, Deurali, Dhampus, Dhikur Pokhari, Dhital, Ghachok, Ghandruk, Hansapur, Hemaja, Kahun, Kalika, Kaskikot, Kritinachnechaur, Lahachok, Lamachaur, Lekhnath Lumle, Lwangghale, Machhapuchchhre, Majhthana, Mala, Mauja, Mijuredada, Namarjung, Nirmalpokhari, Parche, Pokhara, Pumdibhumdi, Puranchaur, Rakhi, Reevan, Rupakot, Saimarang, Salyan, Sarangkot, Sardikhola, Shisuwa, Siddha, Sildujure, Thumakodada, Thumki.

The people with disabilities represent from indigenous community and mountaineering geographic setting in the monitoring.

Based on the report of national population census 2011, the total number of person with disability in Kaski is 9219 out of them women with disability constitute 4237 followed by 4982 male. Out of the total population 492,098 where the number of male population is 236,385 and female is 255,713.

#### Dang

Dang Deukhuri District is an Inner Terai district some 280 km west of Kathmandu in Rapti Zone of Nepal's Mid-Western Region. Dang-Deukhuri covers an area of 2,955 km<sup>2</sup> with population (2011) of 552,583. Ghorahi is the district's administrative center and largest city lying on thew lap of chure range.

This district consists of the larger easterly and upstream portions of parallel Inner Terai valleys, Dang and Deukhuri, plus enclosing ranges of hills and mountains. Downsteam, both valleys cross into Banke District, Bheri Zone.

To the south, the district borders Uttar Pradesh, India—specifically Balarampur and Shravasti districts of Awadh. Because the international border follows the southern edge

of the outermost Siwalik foothills called the Dudhwa Range Outer Terai extending onto the main Ganges Plain in this district. The permeable geology of the Siwaliks does not support moisture retention or soil development so they are covered with unproductive scrub forest.

The Dudhwas rise steeply to a crest at about 700 meters then slope down gradually into Deukhuri Valley, to 250 meters at the Rapti River. The Dudhwas extend more than 100 km, causing the Rapti to detour west around them before turning SE down the overall trend of the plains into India. Deukhuri's climate is nearly tropical and it is well watered by the river as well as abundant groundwater.

North of Deukhuri Valley the Dang Range rises to peaks as high as 1,000 meters with passes at about 700 meters. Dang Valley lies north of these hills, at elevations from 600 meters along the Babai River with alluvial slopes gradually rising northward to 700 meters along the base of the Mahabharat Range. Then the district extends upslope to the crest of the Mahabharats at 1,500 to 1,700 meters elevation. Bordering districts to the north are Pyuthan, Rolpa and Salyan.

Mahendra Highway—the main east-west highway across Nepal—follows Deukhuri Valley, passing Bhalubang bazar at the upper end and Lamahi downstream. From Bhalubang, branch roads lead up the Rapti River into Pyuthan and Rolpa Districts. From Lahami there are roads north across the Dang Range to Ghorahi, and south over the Dudhwas to Koilabas bazaar on the international border where goods enter Rapti Zone from India. At Tarigaun VDC, all-weather TARIGAUN AIRPORT ABOUT 1.5 KM FAR FROM TULSIPUR AND 30 KM FROM GHORAHI] has scheduled connections to other cities in Nepal and a motorable road goes north into Salyan District. Further the roads from Ghorahi lead to Rolpa sistrict and Sworgadwari.

The monitoring covers the people with disabilities representing rural, bonded labour and conflict ridden area from this district.

Based on the national population census 2011, total number of person with disability in Dang is 12,881, out of them women with disability constitute 6,021 followed by 6,860 male. Out of the total population 552,583, the number of male population is 261,059 and female is 291,524.

# **1.2.2.** Population and Sample

The holistic monitoring project used a multi-method approach combining multiple research techniques and methodologies. Collection and analysis of individual human rights experiences of people with disabilities through fieldwork in four research sites. The fieldwork involved face to face interviews with people with disabilities in their actual places or location, conducted by trained monitors who are themselves people with disabilities. One hundred nineteen (119) interviews were conducted in the four identified sites where as only 106 interviews are considered for the analysis based on the quality and relevancy of the interview.

Based on the responses and feedback received during consultation workshop while presenting the primary report of individual experience monitoring, there are four cross-

sectional analysis carried out within the eight major domains such as gender, employment, educational and distance of resident from the city. The table below shows the sample size in each of domains.

Domains	Number of experience	Percent
Privacy and family life	66	19
Education	27	7
Work	15	6
Social participation	301	47
Information and communication	4	1
Access to justice	3	3
Income security and support services	4	4
Health, habilitation and rehabilitation	2	1

The interviewees have responded only in the issues concerning their own experiences of human rights situation thus the different domains have different numbers and percentages. Only 7 per cent interviewees have responded concerning the issue of education, this indicates that 93 per cent of them have been excluded by education thus no such experience. The analysis of individual experiences show that majority of respondents have expressed their concerns in social participation. 48 per cent of them have expressed that the social participation is one of major approach for including persons with disabilities in development discourse. 19 per cent respondents have expressed that the full and effective participation in family lives is also one of important aspect of overall development of persons with disabilities.

# **1.2.3. Monitoring Tools**

The DRPI holistic monitoring project aims at monitoring the human rights situation of persons with disabilities in Nepal. It involves the scan of defacto implementation of the laws and policies in place within Nepal that protect and promote the human rights of people with disabilities and existing provisions in the law policies and program as dejury measures taken by the government. It further encompasses the analysis of personal experiences generated through face-to-face in-depth interviews with people with disabilities in different parts of the country to capture their human rights situation. This process is a necessary step to understand whether the legal and policy instruments in place are adequate and effective on the ground, as well as to determine the extent of

human rights violations affecting the overall development of persons with disabilities in different parts of the country.

In the analysis, five human rights indicators (Dignity, Autonomy, Participation, Inclusion and Accessibility, Non-Discrimination and Equality, Respect for Difference) have been applied.

**Dignity**: Dignity refers to the self-respect of all persons which is about protecting and promoting human rights. Everyone is entitled to be respected in their community and society in everyday lives that ensure the inherent importance of every individuals.

**Autonomy** is about the enjoyment of right to make own choices independently or with support. Autonomy means that the person is placed at the centre of all decisions affecting ones lives.

#### Participation (Inclusion and Accessibility)

Inclusion is the right of all persons to have full and effective participation in decision making. It involves making sure that society is organized to be accessible and is without physical or social barriers including enjoyment of reasonable accommodation.

Non-discrimination and equality: Everyone is entitle with enjoyment of rights. If a person is denied enjoying rights based on disability, race, sex, language, religion, political or any other opinion, national or social origin, property, birth or age, this is the condition of discrimination.

If favoritism is shown to one group of people over another, this may be based on prejudice, this is discrimination. If law, policies, programs, actions or failures to act that result in denying persons with disabilities the ability to exercise their human rights, is discrimination.

Respect for difference involves recognizing and accepting persons with disabilities as part of human diversity. Difference is not about denial of one's rights and dignity. The responsibility to change does not fall on the individual but on the community and the government and society who must recognize diversity and find ways to be inclusive of the difference that disability represents.

#### 1.2.4. Socio-Political Context

The hatred perspective gradually shifted to the beginning of the charitable perspectives with the enactment of the "Muliki Ain" (Civil Code) in 1853. This model tend to view Persons with Disabilities are entitled for food and clothes as they are the beneficiaries of charity, and services for which they should be grateful. The consequences of such legal provision, Persons with Disabilities are viewed as tragic or suffering people, to be pitied and cared for. At the same time, they are supposed to have few choices, no means of accessing relevant advice, and no powers to decide how they could best be assisted. Services are designed for them and delivered to them, perhaps with the best of intentions, but with insufficient consultation to them.

Majority of disabilities are consequent by falling from trees and cliffs, herding live stocks, transport accidents, collecting fodder, grass, fires, poverty, lack of education, awareness, inadequate health services such as; immunization, early identification, timely interventions, less attention on mother and child health care, lack of appropriate health care instructions and genetics deformities.

In Nepal, it is a dispute regarding prevalence of disabilities. Various surveys and studies conducted by government agencies, NGOs and Self-help organizations have come up with different prevalence rate from 0.45 to 8.99. Over the past years, due to insurgency it is estimated that around 13000 people have died and thousands of them are injured and many more acquired disabilities.

In accordance the National population census report 2011 produced by Central Bureau of Statistics, among total population of 26,494,504 (Male 12,849,041 and Female 13,645,463) there are 1.94 per cent persons with disabilities reside in Nepal. Out of the prevalence of 513,321 (Male 2,80,086 and Female 2,33,235) persons with disabilities, the physical disability constitutes 36.3 per cent followed by visual disability of 18.5 per cent, Hearing Disability 15.4 per cent, Speech disability 11.5 per cent, Multiple Disability 7.5 per cent , Mental Disability 6 per cent, Intellectual Disabilities 2.9 per cent and Deafblind 1.8 per cent.

The National Civil Code (NCC) called Muluki Ain has made the legal provision of providing some stuff for livelihood as a measure of social security of Persons with Disabilities in Nepal in 1963. That provision of service was entirely based on the perspective of charity for those who are the part of compassionate or pity.

It was the first peoples' movement which restored democracy in 1991 that allowed Persons With Disabilities to begin establishing Self-Help Groups and to start to develop Disabled Peoples Organisations in Nepal. Though, these organizations put endeavor for the promotion of health, education and employment opportunity for the Persons With Disabilities under the Government policy and plan of action, it is not found to be realistic and result orientated. The prominent lacking of the line Ministry for looking after issues of Disabilities was realized. By the establishment of Ministry of Women, Children and Social Welfare (MWCSW) in 1995, the welfare and rehabilitation programs for Persons with Disabilities have been initiated. Since its establishment, MWCSW has been addressing the issues concerning policies and plans for the development of Persons with Disabilities and has been instrumental in taking stock of commitments made by Government. As a focal, Ministry MWCSW has been involved in implementing existing National and International legal framework and ensuring the facilities to Persons with Disabilities within the country. The MWCSW has tried to fulfill its obligations for ensuring rights of Persons with Disabilities by formulating policy and plan of action on Disability delivered by World Program of Action Concerning Persons with disabilities.

The National Human Rights Commission (NHRC) established in 2000 as an independent, autonomous and a statutory body under the Human Rights Commission Act 1997. The Interim Constitution of Nepal 2007 made the NHRC a constitutional body. It has a separate sphere of responsibilities in the constitutional legal system of the country. These responsibilities complement the responsibilities of the normal administration mechanism of Justice, the Supreme Court, the Office of the Attorney

General, the Commission for the Investigation of Abuse of Authority and other existing executive judicial bodies performing in the legal system of Nepal. The Commission has been established as a foundation and reference point for the monitoring of human rights situation of the people including vulnerable section of the society such as Women, scheduled cast people, indigenous people, children and Persons with Disabilities as well. There is disability focal point in the commission that looks after the complains made by the Persons With Disabilities in their human rights abuse and work closely in collaboration of NFDN, National Cross-disabilities organizations and DPOs.

These initiatives of the Government supported to enable Persons With Disabilities and their parents to achieve positive changes in their lives, and for general people to understand more about disability. The principles of rights, equal participation, and inclusion have now been recognized in some Government programmes.

A monarchy throughout most of its history, Nepal was ruled by the Shah dynasty of kings from 1768, when Prithvi Narayan Shah unified its many small kingdoms, until 2008; a decade-long armed conflict led by the Communist Party of Nepal (Maoist) presently known as the Unified Maoist, and 19 days of Peoples' movement led by all major political parties. The parliament was reinstated; Interim constitution enacted and held the constituent assembly election on 28 May 2008 overwhelmingly favored the abolition of the monarchy and the establishment of a multiparty representative democratic federal republic of Nepal.

When, the Peoples' movement in 2006 reinstated full democracy in Nepal, The Persons with Disabilities strongly advocated to the government for respecting Human Rights of Persons with Disabilities. The active role played by the Persons with Disabilities during Peoples' movement was highly acknowledged by political parties, government and relevant stakeholders, the MWCSW developed consciences for collaborating with the Self-help organizations for the promotion of Persons With Disabilities in all concerned areas by formulating Rules to implement DPWA-1982, defining disabilities through social perspectives, developing Policy and Plan of Action (NPPAD) to follow the guidelines of UN Standard Rules on Equalization of Opportunity for Persons With Disabilities and Biwako Millennium Framework of Action. Some of the remarkable outcomes have observed that has been appreciated by the SHOs and stakeholders. Consequently the Government ratified the Convention on the Rights of Persons with Disabilities in 2009 and has become the state party of the convention since 7 May 2010. The recent adoption of the Convention on the Rights of Persons with Disabilities represents a crucial opportunity to consolidate disability-related activities within the Government policy and plan of action. This paradigm shift has opened space to many Persons with Disabilities to regain control of their own lives and mainstreaming in the development discourse.

The active participation of Self-Help organisations and stakeholders has been showing positive impact on Persons with Disabilities in their community life, employment, education, cultural, social and recreational activities, transportation and housing. There are 110,000 children With Disabilities enrolled in the educational institutional. Out of them 65,000 Persons with Disabilities have received scholarship. The number of Persons with Disabilities 2037 enjoying employment in government agencies; private sectors and self-employment are the result of consolidated efforts made by Self-Help

organizations.

The state transformation process is very much concern to persons with disabilities in Nepal. The constitutional Assembly convened in April 10 and the representation of many vulnerable communities has been ensured including Women, Madhisee, Indigenous People, Dalits, and many more but the representation of persons with disabilities was not ensured except than representation of one Deaf People by CPN United party. In this instant, NFDN declared Agitation for ensuring nomination of at least one person by the government in the Constitutional Assembly to be nominated 26 members. Consequently the government nominated a wheel chair user Women with Disability in the recommendation of the NCP Unified Maoist in the Constitutional Assembly. This is one of remarkable outcomes of NFDN's advocacy during state transformation process. As much intervention made by the disability community in the present state transformation process , as effective for ensuring human rights of persons with disabilities in New Nepal.

The constituent assembly despite of its continuous effort for four years with extension of two years of tenure couldn't enact the constitution and suddenly dismissed. The recent developments, political parties of Nepal have agreed on forming an interim election government under the leadership of Chief Justice Khil Raj Regmi in order to hold Constituent Assembly elections by June 21, 2013 to end the political deadlock by announcing election dates for November. The Government has announced the date of second election of constituent Assembly for 19 November, 2013.

Nepal is still in transitional phase, the forthcoming second election of Constitutional Assembly is expected to enact the constitution of the country. The frequent change in the government, the implementation of CRPD and follow the provision mentioned in article 33 to designate one or more focal points within government has been delayed. The inter-parliamentarian disability friendly caucus also been terminated with the dismissal of parliament that has barriers to ensure the accommodation of rights based provisions in the constitution and endorsement of amendment of DPWA is overshadow.

# Chapter II

#### 2.1. Individual Experience Monitoring

The individual experiences have been considered as major source of information while conducting the holistic analysis of enjoyment of rights by persons with disabilities. The information generated by the individual experience and the implementation status of the provisions in existing constitutional, legal, policy and program in the country have been mapped while conducting the analysis, at the same time, the identification of the challenges concerning enjoyment of the rights have identified and the relevant recommendation have been provided. The result of the media monitoring have also been applied for evaluating if the identified challenges of enjoyment of rights by persons with disabilities if being supported positively or negatively by societal attitude.

The Country Monitoring Training was convened from 18 April to 24 April. The preparation was started from the beginning of January 2012 with the translation of the training documents. In the course of preparation of the CMT, various steps have been taken.

Based on the designing of the DRPI country holistic monitoring project, three major areas have been undertaken, Individual experience, Systemic and societal attitude monitoring. As per the nature of monitoring methodology, objectives and DPI tools, monitors have been identified to undertake the described tasks.

The individual experience monitors have been selected by the local DPOs in each monitoring sites by the recommendation of site-coordinator and consultation with DRPI country monitoring National Coordinator. There are 4 monitors from "Dang" comprising 2 men and 2 women, all are persons with physical disabilities. From Kaski, there are 4 monitors comprising 2 men and 2 women representing physical and visual disabilities 2 from each category. There are 2 monitors from Jhapa comprising 1 man and 1 woman comprising both Physical disabilities. Similarly, 8 monitors are selected in Kathmandu valley by NFDN comprising 3 men and 5 women representing 1 hearing disability, 1 hemophilic disability, 2 visual disability and 4 physical disabilities.

For the purpose of organizing, analyzing and producing report of individual experience monitoring using NVivo 10 based on the qualitative data collected through individual experiences monitoring interviews, two data analysts, lead by Mr. Dhurba Gnawali comprising Mr. Yubaraj Kattel were engaged.

All of the general human rights principles have been applied when collecting information and analyzing the human rights situation of persons with disabilities in Nepal. These human rights indicators have been considered in eight domains of disability rights issues such as privacy and family lives; education; work; social participation; information and communication; access to justice; income security and support services; health, habilitation and rehabilitation.

#### 2.2. Systemic Monitoring

After the National observation of International Year of Persons with Disabilities 1981(IYDP) in Nepal, some remarkable achievements has been accomplished. Enactment of DPWA-1982 (DPWA) is one of the major outcomes. There are various provisions in the comprehensive act that reflect the essential measures for benefiting the persons with disabilities by providing employment opportunity, educational rights and scholarship, supply of the assistive devices, health facilities, micro-credit scheme and more over the social security. However the government has materialize DPWA, it has not been implemented so far. In the course of action on the writ application against the government for implementing the act, the Supreme Court has issued the verdict in the name of the government for implementing the act and reporting the progress. Still the provisions mentioned in the act have not been taken seriously.

Disabled Protection and Welfare Rules (DPWR) - 1993, Special Education Policy - 1996, Disabled Service National Policy - 1996, Local Self-Governance Act - 1999, Labor Act -1999, Education Act Seventh Amendment - 2002 and National Policy and Plan of Action on Disability - 2006 have addressed the concerned issues of Persons with Disabilities. These acts and policies have also incorporated the basic points that are mentioned in the UN Standard Rules on Equalization of Opportunities for Persons with Disabilities, Convention on Rights of Children and World Programs of Action concerning Persons with disabilities (WPA).

Education Act 2028 is the main national act to regulate the whole education system of Nepal. In the 'definition' of this act only 'special education' has been defined as a separate education to be provided to Persons with disabilities. This has indirectly guided the state and society to provide education to Persons with disabilities in isolation or in specially organized places which is contrast from inclusive principles. The act and its relevant rules seems silence to enforce the state mechanism for removing all physical or other barriers that prevent the access of Children with disabilities in the mainstream education system. In the education rules 2059, (rules 60 to 66) has mentioned some provisions regarding the rights to education council, operation of special school and special facilities to be provided to interested organizations to run special school. The rules have not provided any directions and guidelines to concerned stakeholders to build disability friendly inclusive system.

Special Education Policy 2053 was brought by the government in 2053 with the objective of making Persons with disabilities self dependent. This policy paper has defined 'special education' as the specialized teaching methodology for the schooling of Persons with disabilities and categorized schools into two categories as special school and integrated school. As defined in the policy paper special schools are specially and separately made schools where Persons with disabilities from particular disability category such as blind, deaf, intellectual disabilities or physical disabilities, are schooled. Similarly the integrated schools are those where persons with disabilities having mild and moderate types of functional limitations are taught with the support of resource class and other essential facilities.

School Sectors Reform Plan (SSRP) 2009 – 2015 is the key strategic document related to the education brought by the government for achieving the goal of basic and secondary education and similarly for contributing to EFA and MDG by 2015.

Government has been implementing this document since 2009 which includes all appropriate policies, strategies, action plan, expected results and budget for completing the broader objectives of education for all. Promotion of inclusive and flexible schooling system with priority to underprivileged children and child friendly environment are the key strategic goal of this document however there is inadequate provision of mainstreaming children with disabilities in regular educational system.

The article 16.2 of DPWA mention No person with disabilities suffering from mental disease, save those against whom proceedings are being taken or who have been punished in a criminal offence under the prevailing law, shall not withstanding anything mentioned in the prevailing law, be kept in a jail except for treatment or security arrangements.

The DRPI Law & Policy Monitoring Template has been utilized which provide technical assistance to collect, assess, report and track information about protections of the rights of persons with disabilities found in national constitution, laws, policies, programs and judiciary decision, using the principles and rights entitled by the CRPD and other ratified international treaties as benchmarks.

The team engaged in the systemic monitoring identified and analyzed the critical gaps and lack in the contents and implementation of national constitution, legislative and policy frameworks, and- in which degree the persons with disabilities enjoy their rights in real lives.

The systemic monitors have selected based on the experiences in law, policies and program of the Government. The process was led by Mr. Mukunda Dahal, Legal Advocate, the parent of ID child, comprising Ms. Tika Dahal, the Secretary General and Mr. N.B. Limbu, President of Nepal Association of the Blind. The team consulted with many groups including organizations of persons with disabilities, relevant authorities of Nepal government, national human rights commission, service providers and other individual engaged in studies and research concerning disability issue. The monitoring used the DRPI law and policy template that include 44 specific issues along with one integrated concern of degree of implementation of existing laws, policies and program and its impact in the real lives of persons with disabilities. Each of the issue was mapped with the CRPD articles, existing provisions in the constitution, law, policy, program, court verdict, proposed bill and the information generated by the concerned individuals.

Finally, thorough analysis has been carried out and provided recommendation for areas of legal and policy reform, measure to be taken for ensuring improvement toward the full realization of the rights by persons with disabilities within progressive time frame.

The report has been considered the major part of the evidence based information for the holistic monitoring report to be submitted in UNCRPD committee as a shadow report on behalf of the DPOs in Nepal.

# 2.3. Societal Attitude Monitoring

The portrayal of disability in the media plays a vital role in forming public perception of

disability. The media monitoring helps to identify the different level of coverage according to the cross-cutting issues of disability. It can be use as a tool to support the attitude monitoring, perception of society towards disability rights through the content analysis of published and broadcasted stories on disability related issues.

Five national level newspapers were selected to analysis the content which covered one month time period. The study found that contribution of disabled human rights activist and the Disabled People's Organization (DPOs) has been reflected slightly in the media. Contribution of the government for the promotion and protection of disability rights has still been lacking rather they believe on charity instead of rights.

The citizen daily of 24th August, 2012 has covered news that reflects the behavior of the society towards persons with disabilities. The general people who occupies the reserved seat in the public bus. The bus doesn't stop if the persons with disabilities ask for stop. These reflect the Herat perspective towards persons with disabilities.

The Media Monitoring was more focused on human rights, rehabilitation, education, livelihood, CRPD concerns, discrimination, state responsibility, health and family life and social security.

*Gorkhapatra, Kantipur* Daily, *Nagarik* Daily, Nepal *Samachar Patra* in Nepali language and Himalayan Times in English were key outlets for the monitoring. The study period covered a month which started from 17th August 2012 to16th September 2012. All together 77 published stories related disabilities issues that had been taken as sample for the study. The stories were categorized by cross-cutting topics.

The Himalayan daily has covered most of the news concerning sports since the reference period was the commemoration of London paralympic, the outlet of 5th September 2012 has covered a picture news that reflect the athlete in Paralympics, London. This news has supported building positive attitude towards Blind and visual impaired persons that the sports and recreational activities are applicable to them as well.

The Himalayan daily of 5th September 2012 has covered picture news that reflects the athlete in Paralympics, London. This news has supported building positive attitude towards Blind and visual impaired persons that the sports and recreational activities are applicable to them as well.

The Himalayan daily of 6th September 2012 has covered sports news. The wheelchair Rugby match has build the societal perception positive as the wheelchair users also play and sports is a right for everyone including persons with disabilities.

In the present state transformation process, the media has been considered one of the important tools of shifting the societal attitude through the evidence based message of any events, evolution and any potential vulnerability of catastrophe among the communities. As such disability issues should be covered for developing an inclusive society that play vital role for human rights protection and promotion. It is found that the media plays major role to broaden disability issues so that civil society be positive together in disability rights. The monitoring indicated that the issues of persons with disabilities have not been covered satisfactorily by Nepali Media. It is now necessary to push for the media coverage on disability issues which has been kept behind and narrowed the attitude towards disability rights.

The Gorkhapatra daily of August 19, 2012 has covered a news that reflect that a child girl of age 4 has been fenced on her leg for protecting her by uncle and aunt. This news has pictures the real societal attitude that undertake disability as past sin commit and should tolerate every conduct of the society and family. The legal defense against such conduct has not been done thus it is very hard to change the societal attitude positively.

The societal attitude monitoring was led by Mr. Jagadish Prasad Adhikari the president

of National Human Rights Center.

Monitoring social attitudes involves looking at and finding patterns in the way that disability is described and covered in print media to uncover societal attitudes about disability and persons with disabilities. This information is then used to better understand individual rights experiences and systemic measures (constitution, laws, policies, programs and services) and determine what changes could be made to fight against negative stereotypes and prejudice.

# Chapter III

Human Rights implication of Persons with Disabilities

# 3.1. Participation

Mainstreaming the marginalized group of people has been recognized in Nepal by the adoption of good governance act 1998 that allows participation of vulnerable group of people through development and empowerment. The principal of inclusion of persons with disabilities has been agreed in Nepal by the Interim constitution 2007. Despite of commitments of the Government for promoting an inclusive, barriers free and rights based society for persons with disabilities by the enactment of National policy and plan of action on disability 2006, they are marginalized in all spheres of lives. The consequences of prevailing discriminations, isolations and denial of fundamental services, they are deprived from equal opportunity, resulting them deprivation in health services, access to quality education, economic activities and barriers in participation in social and cultural life.

In article 33 of the Interim constitution, the obligations of the State is to have participation of *Madhesi*, *dalit*, indigenous peoples, women, labors, farmers, disabled, backward classes and regions in all organs of the State structure on the basis of proportional inclusion. Despite of these commitments, the persons with disabilities in Nepal are daily confronted by systematic discrimination, pejorative terminology and visible and invisible barriers that hinder their equal and active participation in the lives of their communities. They are seeking equal opportunities for inclusion. Specific measures are necessary to ensure their full inclusion and participation.

Inclusion is the right of all persons to have full and effective participation in decision making. It involves making sure that society is organized to be accessible and is without physical or social barriers including enjoyment of reasonable accommodation.

# 3.1.1. Social Participation

The social participation of persons with disabilities in broader sense has been covered in this domain. The live experiences in social, political activities, sports, entertainment, leisure and rest are the broader part of social participation which has been taken in account for the context of persons with disabilities and covered in the analysis.

The majority of the respondents have expressed their life experiences in the broader sense of social participation through their engagement in the activities concerning social, political, sports, entertainment, leisure and rest. Around 65 per cent of the experiences show that persons with disabilities have no means of independent living participating in societal activities in contrast to that, 19 per cent reflects that the societal activities are inclusive to them. Likewise 54 per cent of the

experience shows that they are suppressed in societal participation and only 8 per cent experience show positive impression.

"The college students had organised a picnic program in the course of celebration of New year, where all my friends joined the program but I was abandoned"

M1: Why were you left back?

"They said that I cannot walk, the picnic spot was in the bank of the river and difficult, the mobility is difficult for me, I was discarded!"

M2: How did you feel then?

"I wish to participate when others involve in entertainment activities, when the friends left back to me, I felt very dishonor, I am really humiliated" (APNPKMA06 Female age 29)

Article 10.2 of DPWA mentioned that in case any person with disabilities desires to take part in sports, entertainment or cultural exhibition/show etc. he/she may be given priority in regard to the provision of appropriate training, teaching and the making of arrangements for the act in the concerned organization.

Article 30.5 of CRPD obligates Nepal to enabling persons with disabilities to participate on an equal basis with others in recreational, leisure and sporting activities, the country shall take appropriate measures to ensure that persons with disabilities have access to sporting, recreational and tourism venues.

The proposed draft bill for unification of disability related acts, in its article 30 mention that the persons with disabilities are entitled for equal participation in cultural activities, television program cinema, drama, theatre including cinema hall, library, tourism services to be accessible and enjoyable equally by persons with disabilities in equal basis to the others, however due to the prevailing barriers, they are being excluded from the social participation and enjoyment of this rights, at the same time, the bill has not been endorsed by the parliament.

72 per cent experiences of unemployed persons with disabilities show that they have no dignity in social participation and 56 per cent of employed persons with disabilities have same experience. In contrast to that, 35 per cent experiences show that unemployed persons with disabilities have dignity in social participation where as it is 10 per cent higher in case of employed persons with disabilities. It is found that the employment is one of the major factor for ensuring dignity and respect in the society for persons with disabilities.

Around 66 per cent experiences of unemployed persons with disabilities show that they are excluded in the social participation where as 57 per cent experiences of employed persons with disabilities are excluded from social participation. In contrast to that, 12 per cent experiences of unemployed persons with disabilities have been included in the social participation which is 21 per cent in case of employed persons with disabilities.

"I am not been included in various seminars and functions in the society because of my disability"

M1: Is this because of your disability?

"I am sure. I have been excluded in the ceremonies in my own community because I am a person with disability"

M2: Why is that?

"It is said that the disabled have nothing to do in the seminar and Ceremony in the community, I feel very bad, I am ignored" (APNPJPA01 Female age 30)

The Interim Constitution of Nepal in its section 4: responsibility of state article 33-sub article D1 mention that the proportional representation in the state mechanism based on cast, dalits, indigenous, madhesee or farmers, labor and Disability will be ensured. As such this provision is only the directives not the fundamental rights thus the inclusion of persons with disabilities in political and social activities has been overlooked. At the same time, the provision of inclusion in article 21 of the Interim Constitution has overlooked the inclusion of persons with disabilities in state mechanism thus the inclusion of persons with disabilities in social and political lives has been ignored.

51 per cent experience reflect that the barriers, discrimination and exclusion are persisting only because of disability where as only 5 per cent experiences show that the persons with disabilities arte enjoying the equal rights.

"When I was travelling from Kalanki to Thankot, the bus conductor pulled my hand and asked not to take the bus. Despite of my full effort, I was forced not getting into the bus"

M2: Why is that?

"The conductor said that I might not pay the fare. In the public transportation, we are being excluded for getting into the bus; I am really hurt by this incident" (APNPKMD04 Male age 29)

The Interim Constitution of Nepal (2007) has granted freedom of movement to all citizens that include persons with disabilities. No one should be deprived of this entitlement.

Based on the article 20 of UNCRPD, it is the obligation of Nepal to ensure the rights of persons with disabilities by taking effective measures to ensure personal mobility with the greatest possible independence by facilitating at the time of their choice, and at affordable cost.

The article 10.3 of DPWA provides concessions while traveling by bus, train, plane, any person with disabilities and in case he/she shall be in need of continuous help of any other person, such one other person as well as, may be granted concession of half of the passenger fare. This provision has been enjoyed by persons with disabilities only in the basis of the individual perception of the service provider however this provision has been adopted by the several public transport companies. The discrimination for the equal enjoyment of utilizing the public service only because of disabilities is the violation of human rights of persons with disabilities. The barriers of personal mobility have been

a prime factor for deprivation of persons with disabilities for social participation. The Government has a financial policy of tax exemption for the four wheeler scooter for persons with physical disabilities however the procedure is lengthy and hard to follow.

Further article 10.10 provides arrangements may be made to have reservations of some seats in the mean of public transportation for the person with disabilities.

Himalayan daily of 17th September 2012 covering the news about quota enforced in public buses. Metropolitan traffic police circle Jawalakhel together with civil police has started enforcing the existing law which makes it mandatory for transport entrepreneurs to reserve seats for women, the disabled and elderly. This news has support building positive attitude of society both in attitude and legal respect.

The persons with disabilities who have an opportunity to join the school have comparatively more experiences in social participation than the persons who never joined the school. It is found that around 98 per cent experiences of the respondents who joined school mentioned that their dignity has not been respected in the social participation where as only 20 per cent experiences of the persons who never joined school feel they have no dignity in the society. In contrast to that, only 7 per cent experiences of the respondents who joined school reflect that they have dignity in the social participation.

#### 3.1.2. Family Life

The individual experience of privacy and family life of persons with disabilities have been covered in the analysis in connection of articles 22 and 23 of CRPD and existing legislations in Nepal.

In the analysis of the participation in family lives, There are 28 per cent persons with disabilities expressed that they have been excluded in decision making where as only 3 per cent have expressed that they have been included in the decision making within the family. In general, the persons with disabilities are facing discrimination in the family lives.

"My elder brother and the sister in law blamed me that I am pretending of low vision; many times she mocked me as a blind person. I was even threatened with knife by the nephew that I should be killed, they treat me bad, and I am always threaten me of finishing my life" (APNPKKB10 – Age 43, Male)

"My husband always ask me to abandon the house otherwise he would kill me. I am facing violence by him. I feel lack of dignity while being violated, I am disregarded and humiliated in everyday lives only because of my disability" (APNPJPA14- Age 34 Women)

The interim constitution of Nepal (2063) has ensured the rights to life for all human beings including persons with disabilities and article 10 of CRPD also has reaffirm that every human being has the inherent right to life and the state shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others. No one is entitled to threat for assassination to the persons with disabilities, this conduct shall be taken as serious breach against persons with
disabilities.

Persons with disabilities in Nepal are facing higher incidence of human rights violations specially women in comparison with men. Discrimination and unequal treatment, disregard for difference, abrasion of dignity, denial of accessibility and exclusion. belonging to the educational status and poverty whether in urban or rural areas, the victimization and human rights violations occur, the incident of reporting to proper authorities is diminutive due to lack of confidence that something positive will happen, lack of knowledge on how and where to report, avoidance of unnecessary trouble, and the negative attitude of society to disclose the issue. The media also have negligible news coverage on the human rights violation of persons with disabilities.

## 3.1.3. Social Participation of Women with Disabilities

Comparatively, majority of male respondents have expressed their experiences in social participation than the women. Based on the social-cultural phenomenon in Nepal, the women are mostly engaged in household activities and male are entitled to participate in society, as a reflection of such practice, women with disabilities have very few engagement in societal activities.

"I am a Dalit woman; there is always a boundary of touch ability in any of the social activities for us. I was kept one yard beyond the border line, I feel very dishonor "(APNPKMB10 Female age 24)

In the social participation, around 99 per cent experiences of men and 58 per cent of women have no dignity in the society. Around 82 per cent experience of men and 41 per cent of women have been excluded from the societal activities only because of their disabilities.

"I used to be invited in several parties and ceremony in the society when I had eyesight, now they don't invite me because of my visual disability..."

M2: What prevent you participating?

" I wish to participate in the societal activities as equally as a non-persons with disabilities, I am treated like a childhood, I am supposed to have no common sense, I feel very dishonor when they avoided me" (APNPKMC03 Female age 25).

Around 21 per cent male and 13 per cent women have an experience of inclusion in the societal activities. Among those who participated in the societal activities, around 80 per cent experience of male and 48 per cent of women have no dignity. In contrast to that, around 52 per cent experience of male and 24 per cent of women have a feeling of respectful in the society.

Around 72 per cent experience of male and 37 per cent of women have faced discrimination in the societal participation where as only 2 per cent experience show that there is no discrimination.

The article 5 of the DPWA in Right to Equality and its regulation mention that no person with disabilities shall solely on the basis of his/her disability, be denied entry into any association or club or community or function providing education or training or launching

social or cultural programme within Nepal.

#### 3.2. Work and Employment

In the assessment of the human rights situation of employed and non-employed persons with disabilities, the employed persons have higher dignity and respect within the family live. Among the employed persons with disabilities, there is 24 per cent experiences show that they have no dignity in the family which is 28 per cent in case of unemployed persons with disabilities, 35 per cent experiences exhibit that they are frequently facing discrimination in the family where as this number is 10 per cent lower in case of employed persons with disabilities.

It is shown that the unemployed persons with disabilities have higher engagement in the familial activities rather than the employed persons with disabilities. 21 per cent experiences of unemployed persons with disabilities have expressed that they are being disrespected in the family where as this number is lesser than 2 per cent in case of employed individual. Likewise there are 5 per cent employed persons with disabilities have expressed that they are respected in the family where as only 2 per cent unemployed persons have expressed that feeling.

It can be justified by the analysis that the unemployed persons with disabilities have lesser attainment of dignity, autonomy and level of non-discrimination in the family. Hence the status of employment is one of the factors for respecting human rights of persons with disabilities.

#### **3.2.1. Public Employment**

The Interim Constitution has made the policy provisions to promote the quality of life of the marginalized and disadvantaged groups. The constitution has clearly mentioned "The State shall pursue a policy of making special provision based on positive discrimination to the minorities, landless, squatters, bonded laborers, disabled, backward communities and sections, and the victims of conflict, including women, dalits, indigenous, madhesees, Muslims and people from rural area. Based on this provision of the constitution, the civil service act has provided a reservation of 5 percent among the total reserved quota for persons with disabilities in civil service. This provision has also been adopted by the public, semi-public and academic institutions and has been considered affirmative action for the employment promotion of persons with disabilities however the provision has not been prioritized on the basis of severity of disability. The cross-sectional inclusion has not been ensured where the people with severe disabilities are still deprived by the enjoyment of these rights.

The experiences of persons with disabilities in work and labor market have been obtained in non-discrimination and equality. Almost 10 per cent of the experiences reveal that the persons with disabilities are facing discrimination, exclusion and barriers for participation only because of their disability where as only 2 per cent of the

experiences show that they have enjoyed equal opportunity.

"I like teaching profession, I applied in a school in a teacher job, I attended the written examination and got selected for interview, and I was finally refused"

M2: Why is so?

"It was said in the interview that I am incapable to work, then I was forcefully disqualified for the job because of my disability" (APNPKKA01 Male age 37)

In the workplace, 7 out of nine experiences exhibit that, the persons with disabilities are encountering humiliation where as only 2 of the experience have a positive feeling.

DPWA in its Article 5.3 has mentioned, no -discrimination, shall be made against any person with disabilities in the appointment of Government service or any other public service, and no person with disabilities shall be deprived of being appointed for any post or promoted or upgraded or having equal treatment, merely on the ground of their disability. Provided that, if it deems inappropriate to appoint, promote, upgrade or treat equally to a person with disabilities in the functioning of specific service based on the nature of the service or job, this Section shall not bar to act accordingly.

#### 3.2.2. Private Employment

Concerning the social participation, majority of unemployed persons have negative experiences rather than the employed persons with disabilities. It is obvious that the unemployed persons will have enough time available to be engaged in societal activities thus the experiences of such respondents is higher than that of the employed individuals. Around 81 per cent experiences of unemployed persons with disabilities have a feeling of discrimination in society where as this experience in case of employed individuals is around 76 per cent.

"Once in last five years, I had applied for the job in an organization where I also had succeeded in the recruitment test. Surprisingly I was not recruited by the chairperson of this organization..."

M1: Why is so?

"It is only because of my disability. He said that I can do nothing with my disability. I was sure that I could definitely do this work:

M2: Didn't they recruit you?

"Later I came to know that they recruited a non-persons with disabilities in the same position. I have been excluded from the job opportunity because of my disability, I couldn't complete my wish, I am deprived to fulfill my choice" (APNPKMB02 female age 22)

The DPWA in its article 5 and its regulation mention that the Disabled can be enrolled in open or sustainable employment opportunity in rural area according to the open labor policy. This provision is entirely voluntary and no force provision thus the execution of such provision cannot guarantee the rights of persons with disabilities for employment.

#### 3.2.3.Self-Employment

The unemployed persons with disabilities have expressed comparatively more experiences of rights violation than the employed persons, the consequences of reporting of such incidents have challenge their employment, and it is found that the scarcity of employment opportunity is one of the reasons behind suppression of persons with disabilities for livelihood or the small scale business.

"I opened a small tailoring shop and started work of sewing. Nearly, there are some other tailors opened by non-persons with disabilities. They didn't like that I am working similar as them, they started discouraging me.

M1: How did they discourage you?

"They used to use derogatory language, what a lame can do..."

M2: Why is so?

"I was considered an unwanted competitor. One day I was brutally bitten by these people, I felt dishonored and cried; I ran to the people in the community and complained about the degrading treatment, I even complaint in the village authority:

M1: Were they punished?

"No, my voice was not heard, No action was taken against my violation" (APNPJPA10 Female age 39)

DPWA in its article 2 define the persons with disabilities from medical aspect: "Persons with disabilities" means a Nepalese citizen who is physically or mentally unable or handicapped to do normal daily lifework. The expression also includes a blind, one eyed, deaf, dumb, dull, crippled, limb, lame, handicapped with one leg broken, handicapped with one hand broken or a feeble minded person. Such definition has addressed derogatory terminology and disrespect persons with disabilities. There is no such act that addresses non-discriminative principles and punishment against the use of such terminology despite of adoption of definition and classification from human rights perspective in the communication and physical accessibility guideline 2013 adopted by the Government that follows the perspective of CRPD.

The article 5.3 of DPWA tries to provide equality to persons with disabilities mentioning that no discrimination shall be made against any persons with disabilities in the appointment of Government service or any other public service, and no persons with disabilities shall be deprived of being appointed for any post or promoted or upgraded or having equal treatment, merely on the ground of their disability. Provided that, if it deems inappropriate to appoint, promote, upgrade or treat equally to a persons with disabilities in the functioning of specific service based on the nature of the service or job, this Section shall not bar to act accordingly. It is observed that the provision mentioned covered the voluntary provision of promoting entrepreneurship development of persons with disabilities however the enjoyment of such provisions has not been materialized because of soft statement in the act.

The respondents living in semi-urban setting are deprived in the work, 10 per cent of them expressed that discriminated where as this experience are 4 in urban and 3 per

cent in the remote setting. There is very few wage employment in rural area where the self-employment is most applicable in rural area thus the discrimination in workplace has been observed more in semi-urban setting.

6 per cent employed persons with disabilities in semi urban setting have expressed that they are excluded in decision making in the workplace where as 2 per cent respondents in urban and 3 per cent respondents in rural setting have the same experience.

"I am educated and can do something productive despite of my disability, I think; I should do something remarkable in the subject I learnt. But there is no opportunity in none of the industries in the village, if I get opportunity, I can prove myself a productive citizen, instead of providing opportunity, the villagers misbehave and misconduct to me" (APNPKMB02 Age 24, Female)

DPWA in its Article 8.5 have a provision of arrangements may be made to provide basic facilities, availability of raw materials, loans, market management etc. and protection so as to operate cottage and rural small scale industry for providing private employment to the person with disabilities only. Despite of this legal provision, the annual budget has not reflected such commitments of the Government.

# 3.2.4. Discrimination against Persons with Disabilities in the Workplace

The life experiences of persons with disabilities obtained in the workplace such as educational institutions, labor market, corporate business and self-employment have been cover in the analysis.

"I was totally ignored by my colleagues in the school while I was working as a teacher. I felt lonely and isolated then I could not continue the job" (APNPKMB02 Age 24, Female)

Around 5 out of seven of the experiences show that the persons with disabilities have been excluded for decision making in the workplace because of their disability, in contrast to that, only 2 out of seven have an experience of inclusion in the decision during work. In the workplace, around two-third of the experience have exhibit that persons with disabilities are not respected as their disability as human diversity.

The respondents who got opportunity acquiring education have been covered in this part of analysis thus very few responses have been analysed. Two out of two educated persons with disabilities have experienced lack of autonomy in workplace while 4 out of five unemployed respondents have the same experience. Likewise 8 per cent employed individuals have no dignity where as 11 per cent unemployed persons with disabilities have no dignity. This analysis indicates that despite of acquiring education, the unemployed individuals have no dignity in comparison of the employed individuals.

DPWA in its article 10.6 mention that Government of Nepal may exempt a factory which provides employment to the person with disabilities from income tax by the rate as prescribed in proportion to the person with disabilities appointed by that factory. The expenses incurred for the special replacement in the equipment of own factory or the

spare parts equipped therewith so as to appoint the person with disabilities may be permitted to be added to the sum exemptible from income tax, in such a quantum as prescribed.

Further article 8.4 of DPWA mention that a factory which appoints more than 25 labours may be so required that it should appoint the persons with disabilities in a number not less than five person of the total number of the labours to the appropriate works, to the extent available, on the basis of their physical capability, training, qualifications and experience. Such labourer shall receive such remuneration as is equal to that payable to other labours. Their terms of service and career development opportunities shall also be the same, as are of the labours. Provided that, where any factory, having shown the fact that in appointing a persons with disabilities by the factory there exists a possibility of injury to his/her health of other condition, has obtained prior approval of the Social Welfare Office, such factory may be granted exemption from the mandatory provision of this Sub-section.

Among the educated individuals, 6 per cent employed respondents have experience of discrimination where as 4 per cent unemployed individuals have the same experiences. The analysis clearly visualize that there is remarkable incidents of discrimination encountered by persons with disabilities in the workplace even by educated individuals.

"In the course of my teaching profession, I have been treated badly by the elite colleagues in the school"

M1: How did you feel that?

"They ignore me in every activities, we have same way to walk back home, I am abandoned because of my disability, I feel very bad and insulted" (APNPKKA03 Male- age 43)

Around 15 per cent experiences of persons with disabilities who are educated are capable to identify if they are being discriminated or not where as only 1 per cent uneducated employed persons have responded that they have been discriminated in workplace. Likewise the educated persons with disabilities have expressed that they have been excluded in decision making where as there's no responses obtained among the individuals who have not join the school.

"When I started teaching job in the school, everyone was positive but after seven months, I was gradually discriminated and faced ill-treatment:

M1: How is that?

"They commented that I cannot walk in slippery surface in the muddy pathway:

M1: What makes it difference?

"In assumption that I might get an accident, I create problem to them, they dismiss me from the job" (APNPKKA11 Male age 24).

Among the persons with disabilities who had attended educational institution, 7 per cent have expressed that they have been discriminated in the workplace where as 2 per cent of the uneducated respondents have the same experiences.

The Interim constitution of Nepal (2007) in its article 13 (1) Rights of equality has

expressed the special measures taken for the service and benefits for persons with disabilities shall not be considered as discrimination. The dignity, autonomy, participation with inclusion can be promoted however the execution of such provision has not been taken care by the Government. This has deprived the persons with disabilities for equalization of opportunity and affirmative action.

Nepal has an obligation to take measures which are necessary to accelerate or achieve

de facto equality of persons with disabilities which shall not be considered discrimination

under the terms of the CRPD which is mentioned in article 5.5.

#### 3.3. Education

The life experiences of persons with disabilities during the engagement in acquiring education in school or any educational institutions have been covered in this section of analysis. Among the respondents, 11 per cent experiences reveal that they have been facing discrimination and exclusion in acquiring education where as only 5 per cent of them expressed that they have opportunity and respect in the educational activities. The analysis clearly indicates that the discrimination is prevailing in acquiring education for persons with disabilities.

The autonomy of educated persons with disabilities in the family is found remarkably 17 percent higher than uneducated individuals. Both the positive and negative experiences on dignity, autonomy, participation, respect of difference have been experienced remarkably by the persons with disabilities who have a chance to attend the school. There is lesser experience in human rights implication by persons who had no opportunity of school attainment. These findings shows that the educated individual can express the views and understand the level of discrimination and marginalization thus have been expressed such incident.

"I want to be treated equally and positively like my brothers but my family treats differently, they have a feeling that I can do nothing due to my disability. I have been discriminated in various opportunities including education" (APNPKMB04-Men Age 24)

DPWA in its article 6 provides rights to education. Provision for education and training include any person with disabilities is to get admission to any educational institute to pursue education, he/she shall not be required to pay fees at such educational institute. In spite of such legal commitments, the private academic institutions have no policy of providing scholarship and affirmative action to persons with disabilities.

#### **3.3.1.Access to Education**

It is a remarkable reflection of 68 per cent experiences of the respondents who got education show that they are respected in the social participation where as only 10 per cent of the uneducated respondents reflect the same.

Around 96 per cent experiences of the persons with disabilities who had joined school reflect that they are humiliated where as only 20 per cent experiences of the respondents who never joined school are ignored by the social participation.

"There was one of my fast friends in my neighbor, near by the school, she was very closed to me but her mother and elder brother didn't want me to walk and chat with her..."

M2: Why is that?

"They used to prevent her to contact me only because of my disability, she was scolded in front of mine, not to be in touch with me, my disability will be transferred to her or she might be spoilt by my friendship"

M1: What did you feel with this?

"I became very sad, I felt ignored and humiliated by this behavior, I was bound to transfer to the school in Kathmandu, I am far from my own community" (APNPKMB10 Female age 22)

The Interim Constitution of Nepal (2007) in its article 13, the main provision of rights to equality, and the persons with disabilities are ignored. As such persons with disabilities are considered weak, worthless and object of pity, the autonomy and dignity cannot be preserved for persons with disabilities in such circumstances.

Around 95 per cent experiences of the respondents who got opportunity to join the school are excluded from the social participation where as only 13 per cent experiences of the uneducated respondents have the same feeling.

"I have been excluded for choosing my favorite subject in the college only because of my visual disability. After my higher secondary education, I had initially chosen the physical education which I continued for a year. After studying for first year I also attended theoretical exam, while I joined the practical exam, the external examiner excluded me to take part in the viva examination"

M1: How did he exclude you?

"He said me to stay away from the ground, he asked other students to play. I asked that I also can play but he replied that the physical education is not applicable for the students with visual disabilities"

M2: What was his argument behind excluding you?

"He argued that the dean office has not provided authority and have no policy of engaging such students in physical education, I am totally ignored and excluded from rights of choice, I lost my one year and I have no autonomy of selection"

M1: What did you do then?

"... I determined to complain in different authorities, I complained to the college authorities and NFDN..."

M2: What happened then?

"... I got a written reply upon the correspondence of NFDN to the Tribhuwan University for respecting my rights which is the obligation of the state. The

response of the university was that the policy doesn't allow them to engage a person with disability to enroll in the physical education. They suggested me to change the major subject that is quite easy for me, as a visual disability. Now I have enrolled in another campus in Kathmandu, I am deprived; I not only lost my money but also a potential year of my energetic lifetime..." (APNPJPA15 Male age 28)

The CRPD in its article 30, sub article 5 focus to enabling persons with disabilities to participate on an equal basis with others in recreational, leisure and sporting activities. To this end, Nepal shall take appropriate measures to ensure that children with disabilities have equal access with other children to participation in play, recreation and leisure and sporting activities, including those activities in the school system. Likewise, the special education policy 1994 has granted the rights to persons with disabilities to participate in the special sports and special measures to be taken however the autonomy of persons with disabilities is not respected for the selection of their favorite subject as physical education and equal participation in the sports. This does not respect persons with disabilities as human diversity and doesn't follow the principles of non-discrimination.

The Himalayan daily of 1st September, 2012 has covered picture news of Paralympics London. The swimmer has exhibited the physical capability despite of physical disability. This type of news has supported building societal attitude positive that support the dignity of persons with disabilities.

#### 3.3.2. Learning Environment and Reasonable Accommodation

In the academic field, 7 out of nine of the experiences have realized that the participation, inclusion and accessibility have not been equally enjoyed by the persons with disabilities where as only 2 of them have realized the equal participation in the academic institutions. The analysis shows that many students with disabilities are deprived for participation in educational activities.

"... In the course of acquiring education in the school, the teachers didn't take care of my concerns..."

M1: Why is so?

.. The teacher didn't allow me to sit in front desk of the classroom. I couldn't catch the lecture"

M2: What make this difference to you?

"I couldn't study well and continue my studies"

Article 6.2 of DPWA mention that necessary arrangements may be made for appropriate trainings to the teachers teaching the person with disabilities, but training to the teachers about the disability equality has not been provided as such the treatment of the teachers for the student with disabilities has been degrading.

The respondents among those attending school, 9 per cent have expressed that they have no dignity in the school in contrast to that, 7 per cent have feel dignity.

"In the music school, the teacher used to write in the board, it was very hard for me to catch-up.

M1: How did you follow the lecture?

"The sighted people could copy but I couldn't do so because of my visual impairment"

M2" What did you do then?

"I requested the teacher to provide me the lecture notes and repeat the text he wrote, but he ignored my request and didn't repeat the text he wrote in the board. I was deprived by participation in the classroom" (APNPKMB08, Age 25, Male)

The educational policy of the government allows human writers for persons with print disabilities or for those who cannot write by their own. The provision of providing fifty percent additional time for the Blind students who need writer's assistance is however positive aspect but this provision is not within the principles of reasonable accommodation.

The experiences show that 10 per cent men have encountered discrimination in education where as 1 per cent women have the same feeling. In the course of decision making for the educational activities, 10 per cent women have been excluded where as 4 per cent men have the similar experience. 7 per cent men have been humiliated while 3 per cent women have the same experience. The analysis shows that if women got opportunity of acquiring education, the level of deprivation might be reduced.

"... I asked one query that I was confused, Teacher ignored my query in the classroom, and I felt humiliated"

M1: what did you do then?

"In response on the level of humiliation, I complained in my family, my mother several times visited the school, requested my teachers to treat equally to me, a girl with visual disability"

M2: Did the teacher treat you equally?

"No, the teacher never treated equally as the other non-disabled students in the classroom"

M1: does this happening several times?

"Yes, I was continuously ignored while asking the questions during the lecture where as the teacher used to response to my non-disabled colleagues. I feel insulted in this situation" (APNPKMD12, Age 20, Female)

"I will be forced to sit in the last bench always when the lecture starts in the classroom. Other non-disabled students will not be forced like that, only because of my disability, I am deprived, I can't understand the lecture and interact with the teacher" (APNPKMB08 Age 25, Male)

Because of lack of the policy of reasonable accommodation, many persons with disabilities have been deprived for access to education.

#### 3.3.3.Accessibility

Among the respondents, four out of four experiences show that the persons with disabilities have no autonomy in education where as all the women have the same feeling. In contrast to that, there are no responses of having dignity in the education neither by women nor by men.

"I attended the school, could hardly join the school with big argument.

M1: Great, did you continue?

"No, after one year, I was abandoned by the school only because of my disability"

M2: Why is so?

"I needed assistance to go to classroom in upper stories and the toilets, the school could not provide such assistance. The teachers also ignored me and didn't tell what they wrote in the board since I also have low vision; I was discarded only because I needed assistance..." (APNPKMC10, Age 23, Male)

The special education policy (1996) has exclusively mentioned that the school infrastructure shall be accessible for ensuring easy mobility of the children with disabilities. The absence of execution of such provisions in the school, many children are deprived of joining schools and have remarkable high drop-out rates.

National Building Code 2060 is the standard guidelines issued by government for building construction. Addressing the voice of persons with disabilities, government included some provision concerning physical accessibility in public building including schools. Despite of its existence for promoting barriers free public places, the construction of school building have not been taken in account. The studies show that the accessibility related provisions are not implemented effectively. There is no provision of anti-discriminative measures and punishment system thus the execution of such provision is always in challenge.

The persons with disabilities who had an opportunity to join school have expressed their experience in the information and communication where as there no such experience of uneducated persons with disabilities. Around four out of seven experiences of persons with disabilities reflect that they have been excluded, two out of seven expressed that they are discriminated and one out of seven expressed there is no dignity. There are no positive responses at all.

"The audio books are not available in the college, the government doesn't provide Braille books in the higher secondary levels. I am deprived of learning materials and left back in the classroom, I have no opportunities to learn the text that I wish" (APNPKMA03 Male age 22)

The building code 2060 has not covered the perspective of accessibility of different

disability circumstances, thus should include many other requirements of accessibility related to visual, hearing and multiple disabilities. The implementation of this code should be obligatory and any kind of ignorance to implement the accessibility provisions should be penalized.

Nepal should take appropriate measures to enable persons with disabilities to live independently and participate fully in all aspects of life based on article 9 of UNCRPD, that ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems.

The National policy and plan of action on disability 2006 in its priority area 3 mention that that a center shall be established to conduct research on development and adoption of new technology for promoting access to information and communication for the persons with disabilities however the provision has not been implemented. Design, development, production and distribution of accessible information and communications technologies and systems should be taken in account at an early stage, so that these technologies and systems become accessible at minimum cost.

The analysis on the respondents living in urban, semi-urban and rural as a setting of resident show that majority of the respondents are found to be connected with semiurban setting of resident either the town house or the rented house thus the coverage of the experiences has been incorporated from the semi-urban setting. It is found that 24 per cent experiences of persons with disabilities in urban area have disrespect in the family where as it is 20 per cent in semi-urban and 4 per cent in the rural setting.

This analysis clearly indicate that the persons with disabilities living in urban and semiurban setting are empowered and are capable to understand the cases of human rights violation and lack of dignity, autonomy and respect of difference which they could expressed in society rather they are more deprived in the rural setting.

"... I have no accessibility for mobility, I use to crawl with four legs and arms, and it is hard for me to walk..."

M1: Don't you have support service in family?

"... My family never listen my limitation, they treat me badly for not being able to work in household activities..." (APNPKKA12- Male age 60)

The Local governance act (2055) has tried to protect the dignity of persons with disabilities in the local community. The civil society are not found much aware about the fundamental rights of mobility, the articles and news covered in the media have not promoted the respect of persons with disabilities and their importance. The news covered in some of media outlet have interpreted that the persons with disabilities are entitled of charity and should be treated differently. This type of media coverage will not promote the societal attitude positively.

The Citizen daily of 21st August, 2012 has covered news about access to education to the children with visual disability. This news has reflected positive perception of the media for ensuring educational rights of persons with disability. The education should

be equal rights which have been reflected in the news.

#### 3.4. Social Protection and Income Security

The experiences of persons with disabilities concerning acceptance or rejection of income security and support services have been included in this section of Analysis.

Major concerns of persons with disabilities based on two-third of experiences show that there is no autonomy in the income security and support services. In contrast to that, one third of experiences show that there is autonomy in income security.

Similarly two-third experiences exhibit that there is exclusion while rendering income security and support services where as one-third of the experience of interviewees reflect positive support in employment.

"When I was selling stuffs in a pity shop near the pavement in the street, the police from municipality scolded me with pejorative language; they called me, one arm! Go away from the pavement..."

M1: What did they do then?

"They scattered my stuffs. They apprehended my belongings. Instead of supporting a persons with disabilities for the livelihood and enhancing their financial capability, the Government has tortured me"

M2: How do you manage your livelihood?

"I have no means of earning, I am deprived and living in hardship" (APNPKMA05 Male age 42)

The DPWA in its article 8 has ensure the loan service to persons with disabilities for self employment establishing rural cottage industry providing raw materials, small scale business and market management in order to promote their livelihood and income security however such provision has not been executed. The Government had provided soft loan to persons with disabilities through the Social Welfare Council for income-generating program, with the mismanagement in past, the provision has been stopped. Several hundreds of Persons with Disabilities are left back by the opportunity of income security.

Around four out of five experiences of persons with disabilities reflect that they are not respected as human diversity in accessing income security and support services where as only out of five experiences reflect positively.

"I have attempted for the job in several agencies and organisations but due to my disability, I have not got any job...:

M1: Why is so?

"I was told that you can do nothing that require for this position, I can do I replied, but the job is not applicable for persons with disabilities, I was refused. I am now spending hardship life, have no earning" APNPKKA07 female age 25) Article 27.1 of CRPD provides Nepal a binding obligation to recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities.

DPWA in its article 10, tries to provide facilities and concessions to person with disabilities, who is homeless needs land to build his/her house or any person with disabilities needs land to engage him/her in agricultural occupation, Government of Nepal may subject to the terms and restrictions prescribed make available the land to be distributed or granted for cultivation at present under the prevailing law.

In case the employment opportunities are available, the article 10 of DPWA in the topic of service and benefit should be applied. This mentioned the provision of providing land to the helpless persons with disabilities for starting their self-employment and agriculture profession supporting livelihood however such provision has not been implemented, none of the individual living with disability has received a single piece of land from the Government scheme since there are many occasion the Government has provided such land to the persons living in hardship condition.

The experiences of women with disabilities show higher discrimination than the men in income security and support services. There are three out of five experience of women reflect that they have no dignity in the issue of income security and the same number of experiences of women with disabilities show that they have no autonomy for income security and support services. The same numbers of experiences of women with disabilities reflect that they are discriminated and excluded in participation in income security and support services where as three out of five experiences of men reflect that they are deprived from the participation in income security and two out of five experiences show they have no autonomy.

"I am trained in tailoring, I am fully confident that I can continue this profession but my family never believes me, I am not being supported"

M1: What do you want? from whom?

"I want to be a productive citizen and earn for the livelihood but my husband, father in law, mother in law don't support and provide information for establishing tailoring shop for me. I am in need of financial support and adequate information for establishing my tailoring business but I have no means of investment, I feel very bad and deprived" (APNPDGB04 Female age 28)

The DPWA in its article 8 mentions that the persons with disabilities can be provided Essential training and employment opportunity to make them self-sustained according to their health condition, the disabled friendly environment can be created to provide suitable return to their skill. The act further mention that persons with disabilities can be enrolled in open or sustainable employment opportunity in rural area according to the open labor policy, extra facility can be provided to lead ordinary life for persons with disabilities however such provisions are not executed because of weak provision in the act. Some of persons with disabilities are even more deprived after joining the labor market in absence of reasonable accommodation in the job placement, even without having disability identity card.

The Himalayan daily of August 29th 2012 has covered picture news that reflects the support of a staff of district administration office, Dhankuta for getting citizenship card. This news supports for building societal attitude for the enjoyment of civil and political rights of persons with disabilities.

"I am entitled for receiving red color disability identity card based on my severity however the authority didn't provide me that category. As my disability is visible and quite clear that I should get red card, I am deprived of acquiring this card. I feel humiliated and I have not been respected as human diversity"

Article 3 of DPWA in determination of disability mention that the definition of the persons with disabilities set forth in Clause (a) of Section 2 and the determination of disability shall be on the basis of the generally accepted principles of the medical Science and the criteria set in the context of Nepal. With regard to the matter whether any person is a disabled one or not under Sub-section (1), the decision of the medical practitioner or committee designated or constituted by the Government of Nepal for this purpose shall be authentic. Provided that, nothing in this section shall be deemed to bar Government of Nepal from making alternations to the decision made by such medical practitioner or committee designated or constituted, through an order published in the Nepal Gazette, by taking into consideration of international practice and the context of the Nepal.

The Himalayan daily of 16th August, 2012 covers with sports news. The news encompass the golf competition that was won by a persons with disabilities however the news used the terminology "Handicap" that put the society in dilemma for using the appropriate terminology.

The Government has adopted the definition and classification of Disability in 2006 September that define disability as the circumstances of participation restriction for a person having functional limitation of bodily part(s), sensory and mental organs and systems in compass of existing barriers including physical, social, cultural, environment and communication in carrying out daily activities normally and in participating in social life. The classification include four category based on severity and have a provision of providing different colour disability identity card. The Profound disability is a condition where there is difficulty in carrying out daily activities even with the continuous support of others and entitled receiving red colour Identity card. Despite of policy guideline, the distribution system is not fully capacitated. The persons permitted for one category have been mismatched, that led the disproportion of enjoyment of service and other entitlements.

The definition of disability has to be revised where not all the persons with disabilities have been accommodated. The information and accessibility guideline (2013) has defined disability from human rights perspectives however this document has yet to be executed through every Government mechanism. The newly drafted bill for the amendment of DPWA (1982) has tried to define the disability in line with CRPD, the bill yet to be passed by the cabinet ministries and endorsed by the parliament, which is absent since long due.

#### 3.4.1. Exercising the Right to Disability Allowance and Scholarship

There are majority of employed respondents have expressed their experiences in income security. The analysis encompasses the social security allowance and economic benefit.

"I was told that I can get the red color disability ID card based on my severity, I couldn't get the card of red category. I am deprived of receiving social security allowance, I felt lack in dignity and humiliation" (APNPKKA12, Age 60, Male)

Around 6 per cent employed persons with disabilities have expressed lack in participation in income security and support services where as there is none of the responses by the unemployed persons. It is relevant that the employed persons are not entitled for the social security allowance; only the unemployed persons can obtain such cash support however several persons with disabilities are being deprived of the disability allowance because of the quota system for the medium category of disability allowance.

"I claimed for the disability allowance in the village development committee, my claim is not taken in account, there is Government scheme under the annual budget that the persons with disabilities will be provided the allowance, I am deprived of this service, I am excluded" (APNPKKB04 Male age 47)

Article 10.9 of DPWA encompass unemployment allowances, living allowances, aged persons pension as prescribed for the person with disabilities and special allowance for the person with disabilities unable to earn and maintain themselves may be arranged.

The Supreme Court, in June 2012 has issued the verdict in the name of the Government for providing disability allowance of NPR 500 to 3000 and from 300 to 5000 for the profound disabilities who continuous need support services. The provision has been prioritized to those who have no employment and those who are living in profound condition. The Annual budget for 2013 couldn't follow the court verdict.

The Interim Constitution has made the policy provisions to promote the quality of life of the marginalized and disadvantaged groups. The constitution has clearly mentioned "The State shall pursue a policy of making special provision based on positive discrimination to the minorities, landless, squatters, bonded laborers, disabled, backward communities and sections, and the victims of conflict, including women, dalits, indigenous, madhesis and Muslims. The vision has not been fully executed in the spirit of the constitutional provision, there is very little quota system for the disability allowances and the amount is very low which is NPR. 1000 for the persons with profound disability (red colour disability identity card) and NPR. 300 for the severe (blue colour disability identity card).

Article 5.2 of DPWA mentions that no persons with disabilities shall be deprived of such political rights and the right to economic and social security, to spend life with dignity, employment, to have humanitarian dignity to engage in any useful, productive and meaningful occupation as others are entitled there; however their quota system for providing disability allowances and no employment guarantee for economic enhancement of persons with disabilities.

Article 28.2 (b) of CRPD obligates Nepal to ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes but the disability allowance has been inadequate for the daily subsistence.

Ministry of Local Development has directed the district development committees to ensure accommodation of persons with disabilities in the district coordination committee, so that the representatives of Disabled Peoples' Organisations might play effective role for the management of disability allowance however this circulation has not been executed across the country.

Both employed and unemployed persons with disabilities expressed that they have no dignity in rendering income security and support services.

The respondents who have attended educational institutions have expressed their experiences in support services. 4 per cent of such experiences reflect that the persons with disabilities have no dignity while obtaining assistive devices where as there is no positive experiences received. Likewise around 7 per cent experiences show that the persons with disabilities are excluded while rendering support services and around 3 per cent experiences show that they are humiliated in obtaining assistive devices, support services and scholarship as well.

The present provision of scholarship grants to the children with disabilities by government has been considered effective since it is not only centered on the ecological belts, covered four types of scholarship but also considered the remoteness and distance of the students from schools including poverty and diversity. The annual budget 2013/14 announced that the highest category of monthly scholarship shall be NPR. 3000 in the mountaineering belt while it is 2500 in hilly and Tarai belt which is considered the increment on the basis of recommendation of disability rights activists.

The Himalayan daily of august 31st, 2012 has covered a picture news that reflect the demonstration of persons with disabilities along with elderly aged and single women for the social security allowance in Khotang district. This news cover the lack of Government's initiatives to fulfill the legal obligation in timely manner. The societal attitude might be positive with the collective initiatives of the marginalized group of people.

## 3.4.2. Lack of property rights

The experiences show that women with disabilities in comparison of men have expressed their concerns concerning access to ancestor property where most of the experiences are negative. It is also found that the ignorance is one of the causes that persons with disabilities have not practiced judiciary mechanism.

Based on the social-cultural phenomenon of Nepalese society, the women are bound in the household activities. Their concerns might not be addressed even after complain thus very few experience in accessing justice have been obtained. The respondents have expressed that their complaints have gone in vain.

"I filed my case of property rights in consultation with disabled peoples

organizations. I had no one to support in the judiciary process, I couldn't hire solicitors, eventually the court decision couldn't favor me" (APNPDGB 03 Female age 31)

The interim constitution (2007) in its article 30 mentioned that equally the son and daughter are entitled for acquiring ancestor property however this provision has not been executed for ensuring rights of women with disabilities.

The disabled protection and welfare rules (1994) has mentioned a provision of providing Government solicitor to persons with disabilities in the judiciary process in order to ensure justice to persons with disabilities however due to ignorance and information, such provision has not been executed and benefitted persons with disabilities.

#### 3.5 General Health Service

Many experiences show that the persons with disabilities are not respected as human diversity, they are underestimated and have no autonomy in accessing health service, habilitation and rehabilitation services.

"I would have received the good quality health service if I am able to communicate with the doctors and other health professionals, since I can't hear, speak and communicate with them, I am not considered as human worth. I couldn't obtained quality health services, I feel self worthless" (APNPKMC11 Male age 28)

The article 4 of DPWA mention that for the Protection of the interest of the persons with disabilities, Government of Nepal may make appropriate provisions as required to make available necessary medicines and health services to the persons with disabilities for the treatment of their disability, to make them have such accessories, equipment and tools as are required to minimize, to the maximum extent possible, the adversaries likely to occur due to their disability, and to have acquisition of capacity to work, to provide them with welfare assistance and services to rehabilitate them educationally, professionally, economically, physically, mentally, socially and to make them fully participate in the community on the basis of equality.

Despite of Government's commitments, the hospitals are not aware about the provision. There is even no provisional arrangement of sign language interpreter for supporting the communication for the persons with hearing disabilities and the personal attendant services to the persons with profound disabilities and the persons with visual disability as well. Since there is no adequate support to the persons with disabilities in hospitals, many DPOs have frequently received the complaints and found solution in ad hoc basis, in fact, such arrangement should be provided within the system of the hospitals.

Citizen daily of 17th August 2012 has covered news about supply of the artificial limb to a girl by a hospital in Pokhara. The News has reflected that the girl has been luckiest one for receiving such an artificial leg without cost. The news missed to interpret that the assistive devices, orthotics and the prosthetics– are the rights of persons with disabilities. This type of article however cover the disability perspectives, can't support to develop the societal attitude from rights based perspectives. In the analysis of gender representation in accessing health services, habilitation and rehabilitation, the male respondents have higher experiences than that of women. The experiences show that persons with disabilities have no dignity and autonomy in the health services and rehabilitation.

"When I was abandoned by my husband, I have been disrespected both in my paternal and maternal house. I am not getting any support and treatment, I would have been prevented acquiring disabilities if timely health support was rendered, I am very sad and dishonored "(APNPDGB09 Female age 34)

The Kantipur daily of 24th August, 2012 has covered news that reflect the wrong attitude of the parents however the society exhibited charity to a disabled boy. In a hospital in Pokhara, the parents of a disabled boy abandoned him unclaimed in the courtyard of the hospital after they came to know that the boy has no treatment of disability. Such incident reflects the real picture of the societal attitude especially in the rural area and economically poor family.

The article 7 of DPWA incorporate the provision for health and medical treatment that mention Government of Nepal may make necessary arrangements to prevent and abolish the disability which is preventable or abolishable, and to find out the factors leading to disability and to prevent, abolish, control, eradicate and cure, but the intime intervention has not been done specially in the district hospitals.

The NPPAD has mentioned a provision of providing health service to persons with disabilities and possible rehabilitation services including minimizing the effect of disability. The rights to equality in the same act in its article one mention that the Government can provide health service and medical facilities to the persons with disabilities for the possible rehabilitation to minimize the effect of their disability, to provide essential assistive devices and tools to develop work efficiency of the persons with disabilities however the defacto implementation for the disability prevention program, habilitation and rehabilitation has not been found due to weak provision.

#### 3.5.1 Medical Rehabilitation and Habilitation

The experiences of the interviewees concerning their acceptance or denial in health services, habilitation and rehabilitation have been analyzed in this portion of the report.

The experiences of persons with disabilities show that around four out of five reflect that the provision of health service, habilitation and rehabilitation have not been effectively executed for ensuring inclusion of persons with disabilities, in contrast to that, one out of five experience show their inclusion in such services. Likewise, around three-fourth experience revealed that the concerns of persons with disabilities have not been addressed in enjoying health services for persons with disabilities where as only onefourth positive experiences have been obtained. Likewise around third-fourth experiences show that the persons with disabilities have lack in access and decision making capacity in acquiring health services where as only one-fourth experiences have been revealed positively. "There is no action from anywhere against the tripper driver who made an accident, I am bound to acquire disability. The proprietor of the company didn't fulfill the commitment of providing me the health services and rehabilitation..."

M1: How did you manage your treatment?

"I sold my new mobile set for the treatment. I am yet not habilitated in my disability, I have no sense of excretion, no control over bowling, and I am in catheter"

M2: Who is supporting you?

"My mother support for proper sanitation and hygiene in the evening, after she get back from the duty" (APNPDGB12, Male-age 23)

The article 12 of DPWA provide duty of guardians and medical practitioner for examining any person, who, in their opinion, has become disabled or been in a position to become disabled, to notify or take such person to the nearby hospital or the place prescribed by the Government of Nepal as soon as possible. It shall be the duty of such hospital or medical practitioner to treat such person on the priority basis and to recommend and send him/her to the place where his/her treatment can be done in case his/her treatment cannot be done there.

Further the DPWA in its article 4 highlight To reduce the negative health effect caused by disability, essential examination and treatment can be done by the Government, possible control of the situation of disability, Nutrition program, prevention and control of parasitic diseases and accident control management can be executed by Government so that the health services, habilitation and rehabilitation can be rendered to the persons with disabilities however such provision has not been implemented in practice due to the lack in executable provision in the act as such all the provisions are volunteer and no binding obligation.

Living independently is not living without any contact and support of others. This is more related to one's decisions made with respect and dignity. By human rights, every person has rights to decide about their life without violating other's rights and their decisions are respected in the society, community or family. In essence, the rights to live independently means the rights to choose how you live, where you live, with whom you live and to what degree you wish to interact with your community. It also means having access to any support you might need to realize those choices and to achieve an adequate standard of living. In this sense the accessibility is very essential component for ensuring the independent living of Persons with disabilities.

The experiences of employed persons with disabilities show that they have no dignity in getting health services where as the unemployed persons have expressed minimum experiences in this issue. The autonomy of employed persons with disabilities has not been ensured in absence of reasonable accommodation in hospitals and health posts. They expressed that it is hard for them to continue the job in lack of assistive devices and rehabilitation tools.

The persons with disabilities who have joined educational institutions have expressed that the lack in rehabilitative tools including assistive devices and orthotics and prosthetics they are deprived of continuation of education. They have no dignity and autonomy while rehabilitative services are rendered to them.

Due to the inaccessible school environment, their participation and inclusion has been restricted. The reasonable accommodation has not been respected in providing human writers in the assessment and no autonomy in selection of own writer, has limited their capability, they don't feel habilitated within their functional limitation.

"I feel that despite of my capability, I am not rehabilitated to acquire education. The people in my community discourage me to continue school, I am embarrassed" (APNPJPA02 Male age 28)

"When acquiring disability, I am bound to depart from my school, I discontinued my education. The classroom is situated in the upper floor, where accessibility using wheelchair is not possible, I couldn't continue my studies" (APNPKMB01 Age 26, Female)

The guideline for accessible physical infrastructure and communication service to persons with disabilities (2013) adopted by the Government has attempted to provide barrier free environment, dignity, autonomy and participation of persons with disabilities respecting them as human diversity however this guideline is in the beginning stage of its execution thus positive result have not been obtained in this earlier stage.

The Citizen daily of September 27th 2012 has covered a news concerning need of assistive devices of persons with disabilities. The news has however covered the disability perspectives, the rights entitled by the persons with visual disability has not been highlighted. The temporary measures for using eye-glass have been considered as appropriate solution, which is not the case. The societal attitude might be developed pathetically for persons with disabilities.

## 3.5.2. Community Based Rehabilitation

CBR programmes have been initiated in Nepal after the celebration of International Year of Disabled Peoples in 1981. In the early days, the CBR programmes were initiated by the service delivery organizations in cooperation of international funders. After the establishment of Ministry of Women, Children and Social Welfare in 1996, the CBR program was adopted by the Government since 1999. In collaboration with the organizations working in CBR and their National network, the Government developed a national strategy to enhance and implement CBR programmes in Nepal.

"Despite of my disability, with great enthusiasm, I wanted to acquire skill and empowerment so that I could provide service to the persons with disabilities like me..."

M2: why couldn't you fulfill your wish?

" ... I am deprived by the barriers created in the family"

M1: how?

"... I am restricted for learning computers or sewing and knitting" (APNPKMD07 - Age 44, Female

The provision mentioned in the execution manual of community based rehabilitation for persons with disability (2008) covers that the persons with disabilities are entitled to participate effectively in the family and community for their own concerns and issues, however their participation in the decision making levels both family and community is denial. The level of deprivation undermines their autonomy.

The CBR Guideline developed by the Ministry of Women, Children and Social Welfare is a core document that guides the implementation of the CBR program. The Women and Children Officer has been assigned as the focal person for the execution of CBR in each of the districts. There is CBR committee under the chairpersonship of Chief District Officer comprising district level government officers including health, education, local development and DPO representative that decide for the identification of the organization to assign for carrying out the Government's CBR program.

It is welcome initiatives of Government to expand CBR in all 75 districts however the geographical coverage has been observed only around 5% among the VDCs particular those surrounded by the district headquarters.

Comparatively the experiences of persons with disabilities living in community of urban and semi-urban setting have been reflected in the issue of community based rehabilitation through income security. There are 3 per cent experiences in each urban and semi-urban setting reflect that there is exclusion of persons with disabilities in income security and support services. Likewise there is one per cent experience show discriminative behavior. Around half of the experiences in urban setting reflect that persons with disabilities have no dignity where as similar experience found 1 out of six in semi-urban setting. Around one-third experiences in semi-urban setting reflect that persons with disabilities have faced humiliation which is one third in urban setting.

The experiences of persons with disabilities living in semi-urban setting reflect that they have no dignity and participation in accessing health service, habilitation and rehabilitation measures. Their autonomy is overshadowed while the community based rehabilitation program doesn't cover the whole district and village.

"I have no caliper for supporting me to walk, I My mobility has been restricted in absence of caliper and I am excluded for acquiring health service, compelled to stay within room..." (APNPKKA01 Male age 37)

The Gorkhapatra daily of August 19, 2012 has covered news that reflects that a child girl of age 4 has been fenced on her leg for protecting her by uncle and aunt. This news has pictures the real societal attitudes that undertake disability as past sin commit and should tolerate every conduct of the society and family. The legal defense against such conduct has not been done thus it is very hard to change the societal attitude positively.

People with physical disability experience range of different challenges which limits their access to various services due to lack of assistive devices such as wheelchairs, crutches, artificial limbs. Another challenge is the physical barriers within public places. Majority of public places in Nepal, even those situated in central levels do not have

ramps in toilets and other premises. The toilets and locks are not disabled friendly. Experience of little persons show that they experience problem due to lack of appropriate beds in hospitals.

The organisations working for the rehabilitation have no sufficient outreach services however the DPWA in its article 10.5 mention that Government of Nepal may exempt the person with disabilities or the organizations established for the rehabilitation of person with disabilities or used for the execution of that work, from income tax and all other types of taxes. After the person with disabilities and such organizations so exempted have submitted a certificate showing their engagement in the service of their own disability and in that service respectively, they shall not be required to submit the returns of income.

## 3.5.3. Right to Information and Communication

The analysis based on the experiences of persons with disabilities concerning the activities and function entitled by the rights to information and communication has been covered in this sub-section.

There are majority of the experiences of respondents among persons with hearing disabilities have been covered within this analysis. The lack of adequate support of sign language interpreters, the absence of knowledge to the general public on sign-language is the major factor that the persons with disabilities have been deprived of enjoyment of the rights to information and communication. The lack of knowledge in English language for most of the persons with hearing disabilities face barriers in information and communication specially while rendering health services in the hospitals.

"My wife, a deaf lady, I took her the hospital for the check-up when she was pregnant. I couldn't communicate with the doctor in sign language, along with that, I couldn't read the prescription which was written in English language. I am a deaf person, uneducated, I don't know English, I was completely beyond communication with the doctor and couldn't understand what measures to be taken in such a health condition of my wife..."

M2: What did you want in such a condition?

"If there was a sign-language interpreter in the hospital, I might have understand what is her health condition, I was deprived of my rights to information" (APNPKMA10 Male age 34)

Based on article 21 of CRPD, Nepal is obligated to take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice. The interim constitution of Nepal (2007) in its article 27 provides the rights to information to every individual. The act concerning rights to information (2007) has granted rights to information and expression to every person however this provision has not been fully executed in absence of appropriate format, module, means and technology, this has

deprived the persons with disabilities for the enjoyment of rights to information and communication.

The experiences of persons with disabilities concerning activities regarding information and communication show that around 3 per cent respondents have expressed that they have been deprived for participation and inclusion due to communication barriers where as only 1 per cent of the experience show that the persons with disabilities have obtained information in equal basis with others.

"Once travelling in bus, I showed my disability identity card in order to get discount in fare, the conductor grabbed the card and spoke something that I couldn't understand. I tried to explain him about my hearing disability and the value of my card, he didn't care of my sign and seized the card. There was no one to support me, I could not express what I mean, I might have communicated if there was sign-language interpreter along with, and I might not have missed my card. I have been faced such embarrassing situation and dishonored several times because of lack in communication" (APNPKKA07 Female age 25)

The experiences of women with disabilities have been comparatively lower than the men with disabilities in the practice of accessing information and communication. The majority of respondents have expressed that they have no dignity, autonomy and inclusion while making the decision of use of the means of information and communication. Because of their fewer experience, the respondents could provide small amount of information in the analysis. The inclusion of women with disabilities in decision making is overlooked where as men has some positive experience of participation. In general, the persons with disabilities are not considered as human diversity while enjoyment of rights of information and communication technology.

The experiences reflect that persons with disabilities have no capacity for decision making in the factors effecting information and communication is found similar numbers of experiences show the persons with disabilities have been participated in the decision making. All the experiences concerning information and communication exhibit that the barriers concerning access to information and communication for persons with disabilities have not been address by the concern authorities.

"Once I had gone to the Government office for some urgent work, in absence of sign-language interpreter, I tried to communicate with the officers writing in the paper, they denied..."

M1: Why is so?

"It takes unnecessarily lots of time for understanding your feelings by writing, bring your sign-language interpreter, they put the concerns"

M2: What did you do then?

"I couldn't manage the interpreter and it took around 10 days for my work to be done where as it was only a work of hardly 1 hour, I had no choice of communication, I was not taken as human diversity, I was dishonored" (APNPDGA13 male age 43)

The analysis shows that employed and unemployed persons with disabilities have

similar experiences in enjoying the means of information and communication. Around 2 per cent have expressed that they have been excluded practicing the information and communication. There are negative experiences in dignity and autonomy of persons with disabilities due to lack of means and appropriate format of information and communication technology.

"In the course of official work, which had to be accomplished urgently, due to the absence of sign-language interpreter, I had to hold the task for some days. I could not perform well and couldn't find the better result with my full dedication" (APNPKKB08 Male age 34).

Article 21 of CRPD obligates Nepal to take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, as defined in article 2 of the Convention by accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions. However the implementation plan of CRPD has not been enacted. The communication and physical accessibility guideline has been endorsed by the Government but the execution of such directive non-binding document has not been executed as per the expectation, the MOWCSW has no checklist for the implementation of such a recent document that follow the CRPD principles.

# Chapter IV

#### 4. Cross-Sectional Deprivation of Persons with Disabilities

#### 4.1. Women with Disabilities

In the analysis of gender based discrimination of persons with disabilities in privacy and family life, there are 36 per cent women with disabilities expressed they have no dignity in the family. This incident is 19 per cent higher than that of the men. Likewise 37 per cent women with disabilities are facing discrimination in one way another in the family which is 14 per cent higher than that of men with disabilities.

"... I was very much enthusiastic to attend the wedding ceremony of my elder brother however I was denial to attend the ceremony only because I can walk...

M1: Why is so?

"... I might harm the familial prominence..." (APNPKMB09- Female age 22

The article 20 of the interim constitution of Nepal (2063) exclusively grant the rights of non-discrimination to Women which is also applicable to the women with disabilities however they are facing numbers of discrimination in the family and society.

13 per cent women with disabilities have expressed that they have been excluded by the familial activities which is 5 per cent higher than that of the men with disabilities. Likewise there are 23 per cent women with disabilities have an experience of humiliation in the family life which is 7 per cent higher than that of men with disabilities.

"... I am not counted as a family member because of my disability,

M2: How can you say that?

"... I was even excluded in the family for execution of the death custom of my husband, that was my cultural rights..." (APNPKMC01 - Women age 43)

In this assessment, the incident of non-discrimination and respect of difference have been expressed by very few respondents, where 2 per cent experiences of men and 1 per cent of women with disabilities have non-discrimination and respect in the family.

The analysis of the responses of the individuals who have joined the academic institutions show that the male respondents have remarkable experiences of joining the academic institution rather than the women respondents. 12 per cent male responses have expressed that they have no dignity where as 7 per cent women have not feel dignity in the educational activities. This number is relatively lower in the case of women respondents because the rate of school enrollment of girls is lower than that of boys.

The responses covered in this analysis are the experiences of the individuals engaged in the workplace as wage employment or self-employment. This number is very few where as the overall respondents have been considered as the whole population thus the numbers of responses mentioned in the analysis is even low in number. The experiences show the remarkable discrepancy in the employment status based on gender while enjoying human rights.

In the analysis, two-third and one-third women have expressed that they have no autonomy in the workplace. The experiences of women is 2 per cent higher than men for not having dignity where as 7 per cent more women than men have expressed that they have been discriminated in work.

"When I joined the school as a teacher, I was very happy in the beginning, gradually, I was treated badly by the colleagues..."

M1: How did you feel that?

"I was humiliated; I was treated differently because of my disability:

M2: What made you feel that?

"The colleagues used to comment erroneously on my dress and hairstyle, they asked me to cut the hair, I was also asked to wear the hill shoes where as they know, normal shoes are not applicable for my feet"

M2: Why did they ask such a thing, Is this their concerns?

"I don't think that is their valid concern, I was sometimes mocked and teased looking at my figure, I felt very bad, embarrassment and couldn't continue the job there" (APNPKMB02 female age 24)

During the course of various work and employment, 5 per cent more women than men have experienced discriminated where as equally 4 per cent women and men have expressed that they are dishonored in the workplace.

Women and girls with disabilities encounter further discrimination as they are exposed to greater risk of physical and sexual abuse, denial of their reproductive rights, and reduced opportunity to enter marriage and family life. In rural areas girls and women are more disadvantaged, with higher rates of illiteracy, and lack of access to information and services. Stigmatized and rejected from earliest childhood and denied opportunities for development, girls with disabilities grow up lacking a sense of selfworth and self-esteem and are denied access to the roles of women in their communities.

The article 19 of DPWA provides binding obligation to the Government to be the plaintiff in the cases under this Act and the case shall be deemed to be included in Schedule-1 of the Government Cases Act, 2017 (1961). Despite of such a provision, many persons with disabilities especially the women with disabilities are deprived of rendering the government services while enjoying the legal rights from the court and lost the case.

## 4.2. Rights to Protection in the Situation of Emergency and Disaster:

The experiences of persons with disabilities who live in the urban area have been cover comparatively higher than in rural or semi-rural setting reflect that their participation in information and communication is overlooked in the situation of disasters and emergency. In the absence of appropriate mechanism of providing information and communication system to the persons with disabilities who are living in emergency situation are at high risk since the disaster risk management strategy has no priority in early warning system during the possible disaster.

"I am a person with hearing disability, the fire trapped my house in 2011, I didn't know what should be done is in this situation. When I informed to the municipality, they didn't understand me and ignored my request. When they understood, it was said that the fire-brigade is out of function, they couldn't support me. When I was suffering by the disaster, I didn't receive appropriate support, that is only because of my hearing disability" (APNPDGB13 Male age 43)

The CRPD highlight the treaty obligations in article 12, under international law, including international humanitarian law and international human rights law, all necessary measures to be taken by Nepal 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.

The Disasters Risk Management National Strategy (2010) however has covered the mainstream gender issue and inclusion of the highly risky community in every stage of disasters risk management, the measures for incorporating the issues of persons with disabilities has not been covered. As such the persons with disabilities are always exposed in the high risk of casualty during the disaster in absence of accessible early warning system, preparedness planning and rescue mechanism.

## 4.3. Geographic Remoteness

In the comparative analysis of the human rights implication of the respondents based on their resident, the distance from the city. In the rural area, most of persons with disabilities have no opportunity to join the educational institutional thus the experience of the individuals living in rural area has been covered very few in the analysis. Among the respondents living in urban and semi-urban area, 3 per cent in each setting have expressed lack of autonomy in the educational activities where as there is no response available from rural area. Likewise 4 per cent in urban and 15 per cent respondents in semi-urban area have experience of lack of dignity in education where as there is not a single response from the rural area.

The experience show that 5 per cent in urban, 4 per cent in semi urban and 1 per cent in rural area have facing discrimination.

"I asked for the Braille book for higher secondary level, I was told by the teacher that the Braille books are not available in higher education. I have no access to learning materials..."

M1: What do you use as learning materials?

"I have to get assistance of the friend who is willing to support, when the accessible materials is not available, the desired text cannot be studied, I am left back only because of lack of accessible books" (APNPKMA03 Male 22 years)

The experiences of the respondents living in semi urban setting are higher than that of the urban and rural setting. Around 31 per cent experiences of persons with disabilities in semi-urban setting reflect that the persons with disabilities have no autonomy in social participation where as 15 per cent in city and 7 per cent experiences in rural area have the same feelings. In contrast to that, 11 per cent experience in semi urban, 7 per cent in city and 3 per cent in rural setting reflect that the persons with disabilities have autonomy in social participation.

Likewise in semi urban setting, around 90 per cent experiences reflect that the persons with disabilities have no dignity in social participation where as 40 per cent in city and 15 per cent experiences in rural area have the same feeling. In contrast to that, 3 per cent in each city and semi-urban and 4 per cent in rural setting has the experiences that persons with disabilities have their dignity in social participation.

It is observed that the persons with disabilities have no dignity, autonomy and participation in social activities for employment promotion which is higher in semi-urban setting than in city and rural area.

Article 8.2 of DPWA mention that the arrangements may be made to engage the persons with disabilities by way of labour supply system, in labour or employment scheme such as open and self-help industry or rural employment; however the interim plan of the Government don't incorporate such provision accommodating persons with disabilities in the poverty reduction strategy.

Moreover, there is lack of comprehensive country level information or baseline data, unclear registration policy of persons with disabilities and lack of effective mechanisms at various levels (Village/Municipal, District and National level). The larger section of Nepali society from the rural and semi-urban areas, still view disability as a penance to the sins committed in the previous lives. The notion that Persons with disabilities have equal rights and duties, as any other individual, is largely absent from the popular mindset. In terms of marriage, participation in social activities, access to education, participation in community organisations and employment is harder for women with disabilities, gravely affects the extent of marginalisation faced by such individual. Despite the presence of strong movements for women's rights, dalit rights and indigenous rights in Nepal, the further marginalisation of the disabled within these marginalised communities is not highlighted.

## 4.4. Refugee Persons with Disabilities

In Nepal, there are both Refugees and displaced people due to their circumstances. The Bhutanese citizens have been forced to abandon their homes in 1991 because of fear in their homeland and are placed in various camps in eastern Nepal as refugee status. Because of physical and social barriers, they are unable to access mainstream assistance programs offered to other refugees in the camps and are even overlooked due to the communication and other physical barriers.

There were two persons with disabilities were interviewed among the Bhutanese refugees however the adequate information couldn't be delivered that they have faced

within the camp.

"I am a Bhutanese refugee, I was abandoned by the vehicle only because of my visual disability when I wanted to go to the camp. I signed my hand to stop the bus so that I can get into, but the driver didn't stop. I was ignored and compelled to miss the important event in the camp. I felt very sad and dishonored" (APNPJPA06 Male age 27)

Persons with Disabilities among Refugees reveals a disparity between refugee camps and urban areas: in camps there is a greater awareness about the needs of the disabled and better services than in urban environments, where refugees with disabilities are unable to access services offered by the government and virtually no one is providing special assistance to them.

"I applied for the placement along with other refugee for United States of America, my turn never came. I am contacting with the authority but they don't understand me. I use traditional sign language with them. I am still not getting any response upon my application to be migrated in US under the placement scheme. Most of my friends already migrated, I am discarded..."

(APNPJPA06 Male age 24)

People with disabilities remain among the most hidden, neglected and socially excluded in the refugee camps. They are often not prioritized in placement scheme or identified in providing social protection. Because of communication and social barriers, they are unable to access mainstream assistance programs offered to other refugees. Their potential is seldom recognized and they are often seen as a problem for their families and communities, rather than a resource, can leave them extremely vulnerable.

#### 4.5. Persons with Disabilities Affected by Armed Conflict

The twelve-year long war has affected the lives of many people all over Nepal and many have been internally displaced. Many have acquired disabilities, caught in ambush or in crossfire between general public, security personnel and Maoists. The situation of people with disabilities who are displaced during the armed conflict hasn't been adequately addressed, neither by the Nepal government nor by most of the External Development Partners. Hence, it is imperative that the new initiatives to be undertaken to address the concerns of persons with disabilities particularly women youth and children while the transformation towards democratic rules and respect for human rights of all.

The consolidation of peace building for rule of law and respect for all human rights and fundamental freedoms will be essential to promote a sustainable model of development in Nepal. The extreme levels of poverty and resulting malnutrition is a main factor in causing disabilities. The increasing rate of road accidents together with lack of infrastructural development and timely medical care has led to a large number of people are bound to acquire disability in Nepal. Hence, it is imperative that the new model of development should be significantly inclusive; persons with disabilities who acquired

disability due to armed conflict must be involved in charting the path of peace building and sustainable development.

The ministry of Peace and Reconstruction has been providing rehabilitation support to those who acquired disabilities during armed conflict. There is relief scheme based on intensity of disability however the process is too much bureaucratic and hard to follow thus many persons affected by the armed conflict have been denied acquiring relief amount.

# Chapter V

#### 5.1 Region for not reporting

In Nepal, especially in the rural communities, persons with disabilities do not think it will make a difference to report the ill-treatment or violence they experience. Sometimes people may fear that they might be neglected if they report about the miss-behave of others. In fact, documenting and reporting such individual cases of misbehave and abuse that happens both in society and within the family and other private settings, is important because it support people to be sensitized, developing awareness and can lead to changing the circumstances. The information may also uncover what is really going on and make it difficult for the authorities to claim that rights are being respected when they are not in reality.

The experiences of access to justice for persons with disabilities encompass the broader sense of legal capacity, access to the legal system, freedom, security and free from abuse and torture. Around 9 out of ten experiences reveal that persons with disabilities are deprived in access to judiciary mechanism, legal capacity, freedom and security from all kind of misbehave, violence and torture. In contrast to that only 1 out of ten experience show that the legal system has addressed access to justice to persons with disabilities.

"I reported the Government authority about the misbehave of the bus conductor, I was told that there will be immediate action against such misbehave of persons with disability, I waited several days but there was no proper action from the authorities" (APNPJPA07 Male age 30)

Around 5 out of six experiences show that the concerns of persons with disabilities are not taken in account however 1 out of six experience show that the concerns have been addressed in accessing justice.

"It is the regular deprivation I experience in the family. I also complained about the ill-treatment of my family, my concerns were not taken seriously by the police. There was not any action taken against, I think, my hearing disability is the cause the police didn't believe me and did nothing in providing justice to me like they listen to a non-persons with disabilities" (APNPKMD07 Female age 25)

The civil code (1964) and the DPWA (1982) have mentioned that the punishment against the violence to persons with disabilities shall be added in the regular punishment in the same crime against others however such provision has not been executed due to the weak enforcement and voluntary ideology of the act.

The experiences reflect that the persons with disabilities have no dignity and autonomy in justice mechanism where as there is no such experience that reflect dignity and positive autonomy in access to justice.

"I filed petition to many organisations against the misbehave of my husband against me, there is no hearing of my appeal, no action has been taken for providing justice to me. I might be the first person who lost eye by the physical violence of the husband. I wish for the lasting punishment to him" (APNPJPA14 Female age 32)

There are very few respondents have expressed their experiences concerning access to justice. Some of The respondents have expressed that they have no dignity since they have been frequently abused in the community and educational institution. The experiences of the respondent who never attended school have expressed that there is dignity while enjoying the legal capacity. There is no positive response among the educated interviewees. It is found that the case of violence and torture have been overshadow because the persons with disabilities are hesitant to disclose such incidents. In supplements to that, the complain will not been taken seriously by the concerned authorities thus even the educated individuals, they are reluctant to disclose such incident.

"I had complained in the concerned authority against the college decision to exclude me after one year for continuing physical education as major subject only because of my visual disability. The authority had communicated with Dean Office of education section of the university. Finally I was informed that the physical education is not applicable to the persons with disabilities, I was deprived of selecting my favorite subject, I was forced not only to lose the investment but also one energetic year of my lifetime" (APNPJPA15 Male age 30)

The article 10 (XIII) of Sports development Act (1991) has mentioned the provision of rights to sports and recreational activities for persons with disabilities and to allow them for the engagement in regular sporting activities and tournaments. The act also mentions that the publicity and awareness of the importance of such sporting activities of persons with disabilities shall be conducted. Despite of such legal provision, persons with disabilities are still excluded from the mainstream sports activities.

The experiences of the respondents living in urban and semi urban setting have the similar feeling that they have no dignity in accessing the justice. The respondents living in semi-urban setting have expressed that they have no autonomy and their participation in justice mechanism has been denial. It is found that the respondents living in rural setting have less access to the complain mechanism, due to the ignorant, they have no access to the justice even in the incident of torture and degrading treatment that deprive them to enjoy the rights entitled by the legislation.

## 5.2. Key Findings

The existing constitutional, legal and rights protection mechanism in Nepal exhibit that there are significant state commitments including constitution, laws, institutions, programs, activities & self-help movement with strategic advocacy in national and local settings, organizations of persons with disabilities etc to promote the rights of persons with disabilities. It might give an impression that, there is already tremendous initiatives taken that persons with disabilities in Nepal have achieved a lot, and have nothing else to campaign for. In fact, fortune exists in paper but unfortunate in execution, that doesn't ensure tangible outcome in the lives of persons with disabilities. Nevertheless the development of a technical back-up to sustain the collection, analysis and storage of data to monitor the human rights of people with disabilities should be continuous process.

Specific group of persons with disabilities in Nepal are more vulnerable to the risk of poverty. In most of the communities women with disabilities receive less care and hygiene, have less access to health care and rehabilitation services and fewer education and employment opportunities. They also tend to have lower marriage prospects than disabled men, and to be at a higher risk of physical, sexual and mental abuse.

Poverty has been considered both a cause and a consequence of disability, reinforcing each other, and contributing to increased vulnerability and exclusion in most of Nepali society. In general persons with disabilities have lower education and income levels than non-persons with disabilities. They are more likely to have incomes below poverty level, and less likely to have savings and other assets, this holds for both urban and rural settings.

The screen-reading software is available however is not within the purchasing capacity of persons with visual disability. It is essential for making availability of Braille books and talking books for ensuring access to blind students in education. The adoption of new technology is very much essential in everyday lives for blind and print disability. It is found that few sets of Digital talking books are available for blind students studying in schools in different districts in city areas. There is strong need for NAB in coordination of technical organizations to identify effective strategy and program to ensure blind students have textbooks according to their need. It is important for increasing the production of DAISY books. The attention to the need of persons with low vision (Partial sighted) in support system, large prints and magnifiers.

Literature show that higher disability rates are associated with higher rates of illiteracy, inadequate nutritional level, lower immunisation coverage, higher unemployment and underemployment rates, and lower mobility. Early marriages, when girls in their early teens become mothers before they are physically mature, may be another cause for disability prevalence.

The Government has adopted rehabilitation as a process aimed at enabling persons with disabilities to reach and maintain their optimal physical, mental, intellectual, sensory or social functional levels, thus providing them with the instruments to change their lives towards a higher level of independence. Rehabilitation may include measures to provide and/or restore functions, or compensate for the loss or absence of a function or for a functional limitation. The rehabilitation process does not involve primary medical care. It includes a wide range of measures and activities from more fundamental and general rehabilitation to socialization activities.

People with disabilities as a group are frequently not included in emergency humanitarian assistance Give access to and include people with disabilities into the assistance, aim at their participation in the planning process, focus on preventive measures in the humanitarian assistance and early warning system.

In the existing political transitional phase, the participation of persons with disabilities through human rights approach encompass their engagement in community development, democratic decision processes, and in reconciliation efforts during post-conflict societies.

Evidence suggests that the quality of life of persons with disabilities, and of the broader community, improves when persons with disabilities themselves actively voice their concerns and participate in decision-making. Self-help organizations are the most qualified, best informed and most motivated to speak on their own behalf concerning the proper design and implementation of policy, legislation and strategies which will ensure their full participation in social, economic, cultural and political life and enable them to contribute to the development of their communities.

There is Ministry of women, children and social welfare, the focal ministry to look after the disability issue and the children however the coordination within the institutional inter-coordination is lack. Likewise, the MOHP, MWCSW, MOLD and MOE have no coordinating action plan that create miss-communication and lack in coordination among inter ministerial activities and program consequently the persons with disabilities are deprived from the enjoyment of services and benefits.

This report support to push the Government for establishing a mechanism to monitor the implementation of the Convention, and urge Nepal to involve people with disabilities in this process as prescribed in the article 33 of the CRPD. This project provides people with disabilities and their organizations with the necessary tools to undertake selfinitiatives to watch Government commitments and Endeavour on protecting the rights of persons with disabilities.

Persons with disabilities in Nepal are facing higher incidence of human rights violations specially women in comparison with men. Discrimination and unequal treatment, disregard for difference, abrasion of dignity, denial of accessibility and exclusion. belonging to the educational status and poverty whether in urban or rural areas, the victimization and human rights violations occur, the incident of reporting to proper authorities is diminutive in number due to lack of confidence that something positive will happen, lack of knowledge on how and where to report, avoidance of unnecessary trouble, and the fear of having negative attitude of society by disclosing the issue. The media also have negligible news coverage on the human rights violation of persons with disabilities.

#### 5.3. Recommendation

#### Recommendation:

By the execution of Holistic Monitoring Project, the leading DPOs including NFDN in Nepal have gained immense experience of human rights situation and established evidence based information to advocate for disability related policy and program with the political parties, parliamentarians and government that might have positive impact on mainstreaming persons with disability in policy level in value of equality and justice. The recommendations also highlight the frequent commitments of the Government thus is expected to be fulfilled by the Government.

Comprehensive report developed by this project highlight the existing situation on the human rights of people with disabilities that makes an important contribution to understanding of their lives and daily situations. It is recommended to implement the recommendation for bridging the gaps between the policy and practice of Government, service providers and others based on their commitments towards people with disabilities. Ensuring improvements to the human rights situation of persons with disabilities is possible by the adoption of strategies to achieve tangible changes that should begin at the community and country level. The strategy of DPOs can be developed to attempt to influence people to ensure changes that will have positive impact for the persons with disabilities enjoy their rights.

Change in approach and policy: The statutory binding provisions are recommended in the consolidated act as an amendment of DPWA 1982 that is fail to recognized human rights of persons with disabilities.

**Enhance Capability of Self-Initiatives:** In order to promote the Social participation, it is imperative fostering self-initiatives of Persons with disabilities in development process through inclusion. This endeavor shall be targeted at 3 layers, the national level encompass initiatives of lobbying and advocacy for policy and programmes designed for the wider inclusion of Persons with disabilities, the regional level cover the capacity building of Persons with disabilities' and their organisations for monitoring activities to ensure effective implementation of provisions for the rights of persons with disabilities and the community level comprise action of advocacy and Enabling Environment for the enjoyment of state services and awareness building through self-initiatives of Persons with disabilities.

**Statistics and Defining Disability:** Lack of adequate data has been one of the most significant factors leading to the neglect of disability issues, including the development of policy and measures to monitor and evaluate its implementation; the data collected do not reflect the full extent of disability prevalence in Nepal. A common system of defining and classifying disability to be adopted by the amendment of the National definition and classification encompass of all categories of person with disabilities and establishing database in community levels.

Health services: The Environmental Health Programme of the Government should cover
the cause and consequences of disabilities as cross-cutting issue of comprehensive health service system. The Insurance Act does not provide anti-discrimination provisions that are related to life insurance, which should be binding obligation of the state.

**Rehabilitation**: The public health service system, both governmental and nongovernmental, should include rehabilitation services such as physiotherapy and occupational therapy as well as the provision of essential assistive devices services. Counseling services for traumatized Persons with disabilities need specific attention as a measure of habilitation. The existing program of CBR should be comprehensively elaborated reaching out to persons with disabilities in rural areas, raising awareness and advocacy for the inclusion in all activities in the community.

Assistive Devices: It is strongly realized that the assistive devices are fundamentals to overcome the barriers for mainstreaming Persons with disabilities, with such support; they are capable to participate actively in their own community. Inclusive mechanism fosters a disability friendly approach to development that ensures, all resources and support services are adapted to the need of persons with disabilities in the own community.

**Education**: Access to education should be enhanced for persons with disabilities by accommodating school sector reform program from disability inclusion strategy as a part of free and compulsory education for all levels.

**Livelihood:** Persons with disabilities should be respected as human diversity and their abilities to be utilized and they should have the right to choose what they want to do base on their capabilities to enjoy the equal opportunity of educational, vocational training, employment and entrepreneurship development available to all. Some may require individual support services, assistive devices and reasonable accommodation.

**Social Protection:** Establishment of appropriate social protection schemes, such as adequate disability allowance for those who have no employment opportunities and elderly as well as health insurance for all persons with disabilities. Government should Provide various forms of incentives, including exemption of duties for ICT devices used by persons with disabilities and subsidize the cost of assistive technology equipment to ensure that they are affordable for persons with disabilities in need.

Free from abuse and violence: Governments should implement measures to uphold the rights of Persons with disabilities and to protect them from discrimination, In particular, measures should be taken to ensure equal access to health services, education, sports and protection from sexual and other forms of abuse and violence.

**Information and Communication:** In Nepal, Sign Language, Braille and tactile communication have not yet been standardized. These and other forms of communication need to be developed, standardized and disseminated. Without access to such forms of communication, persons with visual, hearing impairments and deaf blindness cannot benefit from ICT developments. More importantly, they may be deprived of the basic human right to language and communication in their everyday lives.

Information and communication technology break down the barriers since the

accessible ICT is most essential for the Persons with disabilities for comprehensive development which is even more relevant in the remote geographic and low economic circumstances in Nepal, in this context, the Government should provide greater support in the area of accessible ICT development.

Recognition of specific cultural and linguistic identity of persons with disabilities or sign language, and culture of persons with hearing impairments.

**Empowerment:** It is imperative to recognize the right of persons with disabilities to self-representation and to strengthen their capacity to participate in the decision-making process.

The significant improvement in terms of providing cultural material and content in an accessible format, and the recognition of a specific cultural and linguistic identity of people with disabilities, particularly for persons with hearing impairments is needed. As analysed in the monitoring, persons with hearing impairments will experience in the health field should not bound to repeat the same problem when establishing communication with doctors.

It is essential to improve the communication system for accessing opportunities to the people with hearing disability through the availability of sign language and adequate vocabulary that help to enhance their higher attainment in society.

Eventually, the report of the holistic monitoring shall been used as shadow report to be submitted in the CRPD committee by the Coalitions of DPOs from Nepal. This report shall also be applied in preparation of CSO report under UPR of Nepal. Since the capacity of NFDN is enhanced by the experience of holistic country monitoring, the process shall to be continued beyond the scope of the DRPI project in the region.

# 6. Appendices

# 6.1. Abbreviation and Acronyms

CBR	Community Based Rehabilitation
CDO	Chief District Officer
CMT	Country Monitoring Training
COHED	College for Higher Education
CPN	Communist Party of Nepal
CRPD	Convention on the Rights of Person with Disability
CSO	Civil Society Organization
DPI	Disabled People International
DPOs	Disabled People's Organizations
DPWA	Persons with disabilities Protection and Welfare Act
DPWR	Disabled Protection and Welfare Rules
ICT	Information Communication Technology
IYDP	International Year of Disabled People
MWCSW	Ministry of Women Children and Social Welfare
NCC	National Civil Code
NFDN	National Federation of the Disabled-Nepal
NHRC	National Human Rights Commission
NPPAD	National Policy and Plan of Action on Disability
SSRP	School Sectors Reform Plan
SWC	Social Welfare Council
UN	United Nations
UNESCO	United Nations Economic and Social Council
VDC	Village Development Committee
WPA	World Programm of Action Concerning Disable People

### 6.2. Interview Guide

for Monitoring the Individual Human Rights Experiences of Persons with Disabilities in Nepal

#### A. Beginning the Interview

Introductions:

- [Introduce everyone present (e.g. monitors, aide(s) and anyone else attending the interview)]
- [Explain the equipment you have with you.]
   Request Written, Free and Informed Consent to Participate in Interview:
- [Review the *Information Sheet* with the interviewee.]

• [Ask the interviewee if she/he will consent to participate by signing the *Free and Informed Consent Form*.]

 [If the interviewee does not want to sign the consent to participate line on the Free and Informed Consent Form, thank him/her for his/her time and END the interview. Do not proceed any further.]

• [If the interviewee signs the consent to participate line on the *Free and Informed Consent Form*, proceed with the next step]

#### Request Written Permission to Audio Record the Interview:

- [Ask the interviewee if she/he will consent to having her/his interview audio recorded by signing the *Free and Informed Consent Form*.]
- [If the interviewee does not want to sign the consent to record line, thank him/her for her/his time and END the interview. Do not proceed any further.]
  - [If the interviewee signs the consent to record line on the Free and
  - Informed Consent Form, proceed to the next step.]

#### Write information on Identification Sheet:

[Write the interviewee's name on the *Identification Sheet*.]
 [BEGIN the digital AUDIO RECORDING NOW]

[MONITOR: Say into the digital audio recorder, "This is the beginning of Interview (insert Interview Code here)]

- B. Experiences faced by the Interviewee:
- (a) Please tell me a little about your life during the past five (5) years. What things do you do? Where do you go? Who do you meet?
- (b) What are the things in your life that are most satisfying?
  - (c) What are the most difficult barriers or challenges that you face in your life?

#### [1<sup>st</sup> EXPERIENCE]

1.1 Do you recall a particular time or event in the last five (5) years when you were

left out or treated badly or prevented from participating because of your disability?

- 1.2 WHAT happened? WHERE and HOW did it happen?
- 1.3 Is this still happening or did it just happen once?

1.4 Are there other details that you want to share with us about this experience? [Dignity]

1.5 HOW did this experience make you feel and WHY? (For example, did you feel respected/not respected, ignored/cared for, worthy/ unworthy?)

- 1.6 WHAT made you feel that way?
- 1.7 What do you think made people treat you that way?

### [Autonomy]

1.8 Did you feel that you had a choice about what happened to you?

WHY? or WHY NOT?

1.9 If you had a choice, would it have made a difference to what happened? In what way?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES RELATED TO CHOICE AND MAKING A DECISION YOURSELF (AUTONOMY) ASK:

(a) Did you want to make a different decision or did you want to do something else?

WHAT was the different decision or what did you want to do?

- (b) Did you have enough information to make that decision? If not, what prevented you from having enough information?
- (c) Did you feel pressured to act the way you did? WHO/WHAT was pressuring you? HOW did it make you feel?

#### [Participation, Inclusion & Accessibility]

1.10 Did people in your community who knew or saw what happened to you do anything about it?

lf yes, WHO?

[MONITOR: interviewee does not need to give someone's name here – can give general description of the person e.g. "neighbour", "sister", etc.]

WHAT did they do?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES RELATED TO PARTICIPATION, INCLUSION or ACCESSIBILITY ASK:

(a) Were you kept apart or left out?

- (b) Did you need a service or some assistance so that you could participate?
- If YES, what service(s) or assistance did you need? Did you receive it? If you did not receive it, HOW did that affect you?

[Non-Discrimination & Equality]

- 1.11 How do you think your disability affected what happened to you?
- 1.12 Do you think that persons without disabilities would be treated the same way you were? WHY or WHY NOT? HOW would they have been treated?
   FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES of DISCRIMINATION or INEQUALITY ASK:
  - (a) Do you know anyone else who was treated in the way you were?

#### [Respect for Difference]

1.13 Were you treated the way you were because people thought you were different?

In what ways do people see you differently?

- 1.14 Do you think that a person without a disability would have been treated in a similar way?
  - If not, how do you think he/she would be treated?
  - 1.15 Do you feel that people label you and then treat you differently because of the label?

If YES, what label do they use?

HOW does this label affect you?

# FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES RELATED TO RESPECT FOR DIFFERENCE ASK:

- (a) Would someone of a different ethnicity be treated that way? WHY? or WHY NOT? How are people from a different ethnicity treated in your community?
- (b) Would a woman be treated that way? WHY? or WHY NOT?
  - How are women in your community usually treated?
- (c) Would a poor person be treated that way?
   WHY? or WHY NOT?
   How are poor people treated in your community?

How are poor people treated in your community?

1.16 Did you report the experience to anyone?

□ yes □ no

- If you REPORTED the experience, what kind of person/
- organization did you report it to?

government official

police officer	NOTE: Par
<mark>□ army officer</mark>	Guide that
NGO employee	in yellow n
Political leader	particular l
Civil society leader	more infor
□ Social Activist	
National human rights commission	
disability organization (DPO)	
□ other:	
(explain)	
<ul> <li>How did that person react?</li> </ul>	
<ul> <li>What action was taken?</li> </ul>	

If you did NOT REPORT the experience to anyone:
 WHY did you not report it?

- 1.17 In your opinion, what action[s] should be taken to improve [or prevent] the experience in the future?
- 1.18 Is there anything else that you would like to tell us about that experience?

#### [MONITOR: HERE YOU WILL MOVE ON TO THE 2<sup>nd</sup> EXPERIENCE ...]

Do you recall another particular time or event <u>in the last five (5) years</u> when you were left out or treated badly or prevented from participating because of your disability?

- 2.2 WHAT happened? WHERE and HOW did it happen?
- 2.3 Is this still happening or did it just happen once?
- 2.4 Are there other details that you want to share with us about this experience? [ Dignity ]

HOW did this experience make you feel and WHY? (For example, did you feel respected/not respected, ignored/cared for, worthy/unworthy?)

- 2.6 WHAT made you feel that way?
- 2.7 What do you think made people treat you that way?

#### [Autonomy]

Did you feel that you had a choice about what happened to you?

WHY? or WHY NOT?

2.9 If you had a choice, would it have made a difference to what happened? FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES RELATED TO CHOICE AND MAKING A DECISION YOURSELF (AUTONOMY) ASK:

- (a) Did you want to make a different decision or did you want to do something else? WHAT was the different decision or did you want to do?
- (b) Did you have enough information to make that decision? If not, what prevented you from having enough information?
- (c) Did you feel pressured to act the way you did? WHO/WHAT was pressuring you? HOW did it make you feel?

NOTE: Parts of the Interview Guide that have been highlighted in yellow may be changed to suit particular local circumstances. See more information in Appendix B. [Participation, Inclusion and Accessibility]

2.10 Did people in your community who knew or saw what happened to you do anything about it?

If yes, WHO?

[MONITOR: interviewee does not need to give someone's name here - can give general description of the person e.g. "neighbour", "sister", etc.]

#### WHAT did they do?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES RELATED TO PARTICIPATION, INCLUSION or ACCESSIBILITY ASK:

- (a) Were you kept apart or left out?
- (b) Did you need a service or some assistance so that you could participate?
- If YES, what service(s) or assistance did you need?

Did you receive it?

If you did not receive it, how did that affect you?

#### [Non-Discrimination & Equality]

2.11 How do you think your disability affected what happened to you?

2.12 Do you think that persons without disabilities would be treated the same way you were?

WHY or WHY NOT?

HOW would they have been treated?

# FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES of DISCRIMINATION or INEQUALITY ASK:

(a) Do you know anyone else who was treated in the way you were?

#### [Respect for Difference]

2.13 Were you treated the way you were because people thought you were different?

If not, how do you think he/she would be treated?

- 2.14 Do you think that a person without a disability would have been treated in a similar way? If not, how do you think he/she would be treated?
- 2.15 Do you feel that people label you and then treat you differently because of the label?
   If YES, what label do they use?
   HOW does this label affect you?
   FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES RELATED TO RESPECT FOR DIFFERENCE ASK:
  - (a) Would someone of a different ethnicity be treated that way? WHY? or WHY NOT? How are people from a different ethnicity treated in your community?
  - (b) Would a woman be treated that way?

WHY? or WHY NOT?

How are women in your community usually treated?

- (c) Would a poor person be treated that way?
   WHY? or WHY NOT?
   How are poor people treated in your community?
- 2.16 Did you report the experience to anyone? □ yes □ no
- If you REPORTED the experience, what kind of person/ organization did you report it to?

#### government official

- police officer
- army officer
- NGO employee
- Political leader
- Civil society leader
- Social Activist

#### National human rights commission

- disability organization (DPO)
- other: \_

(explain)

- How did that person react?
- What action was taken?
- If you did NOT REPORT the experience to anyone:
  - WHY did you not report it?
- 2.17 In your opinion, what action[s] should be taken to improve [or prevent] the experience in the future?
- 2.18 Is there anything else that you would like to tell us about that experience?

# MONITOR: HERE YOU WILL MOVE ON TO THE 3<sup>rd</sup> EXPERIENCE ...]

- 3.1 Do you recall *another* particular time or event <u>in the last five (5) years</u> when you were left out or treated badly or prevented from participating because of your disability?
- 3.2 WHAT happened? WHERE and HOW did it happen?
- 3.3 Is this still happening or did it just happen once?
- 3.4 Are there other details that you want to share with us about this experience?

#### [Dignity]

HOW did this experience make you feel and WHY? (For example, did you feel respected/not respected, ignored/cared for, worthy/unworthy?)

- 3.6 WHAT made you feel that way?
- 3.7 What do you think made people treat you that way?

#### [Autonomy]

Did you feel that you had a choice about what happened to you?

WHY? or WHY NOT?

3.9 If you had a choice, would it have made a difference to what happened? FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES RELATED TO CHOICE AND MAKING A DECISION YOURSELF (AUTONOMY) ASK:

(a) Did you want to make a different decision or did you want to do something else?

WHAT was the different decision or did you want to do?

- (b) Did you have enough information to make that decision? If not, what prevented you from having enough information?
- (c) Did you feel pressured to act the way you did?
   WHO/WHAT was pressuring you? HOW did it make you feel?
   [Participation, Inclusion and Accessibility]
  - 3.10 Did people in your community who knew or saw what happened to you do anything about it?

If yes, WHO?

[MONITOR: interviewee does not need to give someone's name here – can give general description of the person e.g. "neighbour", "sister", etc.] WHAT did they do?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES RELATED TO PARTICIPATION, INCLUSION or ACCESSIBLITY ASK:

- (a) Were you kept apart or left out?
- (b) Did you need a service or some assistance so that you could participate?
- If YES, what service(s) or assistance did you need?

Did you receive it? If you did not receive it, how did that affect you?

[Non-Discrimination & Equality ]

3.11 How do you think your disability affected what happened to you?

3.12 Do you think that persons without disabilities would be treated the same way you were?

WHY or WHY NOT?

HOW would they have been treated?

# FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES of DISCRIMINATION or INEQUALITY ASK:

(a) Do you know anyone else who was treated in the way you were?

[Respect for Difference]

3.13 Were you treated the way you were because people thought you were different?

In what ways do people see you differently?

3.14 Do you think that a person without a disability would have been treated in a similar way?

If not, how do you think he/she would be treated?

3.15 Do you feel that people label you and then treat you differently because of the label?

If YES, what label do they use?

HOW does this label affect you?

# FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES RELATED TO RESPECT FOR DIFFERENCE ASK:

(a) Would someone of a different ethnicity be treated that way?

WHY? or WHY NOT? How are people from a different ethnicity treated in your community?

- (b) Would a woman be treated that way?WHY? or WHY NOT?How are women in your community usually treated?
- (c) Would a poor person be treated that way?
   WHY? or WHY NOT?
   How are poor people treated in your community?
- 3.16 Did you report the experience to anyone?

□ yes □ no

• If you REPORTED the experience, what kind of person/ organization did you report it to?

government official

□ police officer

army officer

NGO employee

Political leader

Civil society leader

Social Activist

National human rights commission

disability organization (DPO)

other:

### (explain)

- How did that person react?
- What action was taken?
- If you did NOT REPORT the experience to anyone:
  - WHY did you not report it?

3.17 In your opinion, what action[s] should be taken to improve [or prevent] the experience in the future?

3.18 Is there anything else that you would like to tell us about that experience?

# [TURN digital AUDIO RECORDER OFF NOW]

# C. Follow-up & Verification Information:

Is there anyone we could contact who saw what happened to you or who could provide us with more information about the experiences you talked about?

FOR 1<sup>st</sup> EXPERIENCE:

- What is their name? [write name on *Identification Sheet*]
- - If yes, what is the best way for us to contact him or her? [MONITOR: write details on *Identification Sheet*] *FOR 2<sup>nd</sup> EXPERIENCE:*

- What is their name? [write name on *Identification Sheet*]
- - If yes, what is the best way for us to contact him or her? [MONITOR: write details on *Identification Sheet*] *FOR 3<sup>rd</sup> EXPERIENCE:*
- What is their name? [write name on *Identification Sheet*]
- Can we contact this person? 
   – YES 
   – NO
  - If yes, what is the best way for us to contact him or her?
     [MONITOR: write details on *Identification Sheet*]
     [TURN digital AUDIO RECORDER BACK <u>ON</u>NOW]
     D. Background Information:

Now, if you don't mind, we would like to ask you a few questions about yourself.

- 4.1 What is your sex?
- 4.2 In what year were you born?
  - 4.3 How would you describe your disability? [choose as many as apply] □ mobility
  - $\Box$  sensory if so,  $\Box$  blind  $\Box$  low vision  $\Box$  deaf  $\Box$  hard of hearing
  - □ intellectual
  - psycho-social
  - □ other

(ask interviewee to describe)

- 4.4 How long have you had your disability?□ since birth
  - □ since \_\_\_\_\_ (ask interviewee to state the year)
- 4.5 Did you go to school?
  - □ yes □ no
  - If YES, what kind of school?

[MONITOR: interviewee should identify as many as apply]

- primary school
- secondary school
- Higher Secondary school
- college
- university

Religious school

- 4.6 Is there a specific place where you live?
  - □ yes □ no
  - If YES, do you <a>
     </a> own that place?
    - □ lease that place?
    - rent that place?
    - live with someone who owns, leases or rents the place?

```
Is the place in a permanent building?
```

```
□ yes □ no _
```

```
(explain)
```

If YES, what is the building made of? concrete Cemented □ wood Mud and straw □ other: (explain) 4.7 How far do you live from the City Centre? 4.8 Who lives with you? [MONITOR: interviewee should identify as many as apply] □ no one □ spouse □ children [if yes, how many children ?] □ parent(s) [if yes, how many parents ?] □ other family member(s) [if yes, how many family members ?] □ friend(s) [if yes, how many friends ?] □ other (explain) [if yes, how many?] 4.9 How far is the closest police station to where you live? 4.10 What do people use to cook with in your neighbourhood? [MONITOR: Interviewee should indicate as many as apply] electricity <mark>□ wood</mark> Straw brickets charcoal <mark>□ gas</mark> dust oven (ask interviewee to specify) □ other: 4.11 How do you get the water that you use? in the house Supply water nearby Roaher pumb collected from lake, river, stream or well (ask interviewee to specify) □ other: 4.12 Do you have toilets in your house? □ ves □ no, but centralized and accessible □ no, pit latrines Wooden temporary latrins □ other (ask interviewee to specify) 4.13 What kind of sewage system do you use for your home? open sewage system closed sewage system no sewage system 4.14 How far is the nearest health centre from your house? 4.15 What type of care is offered by the health centre?

	<ul> <li>homeopathic</li> <li>Aurvedic</li> <li>traditional Hillers</li> <li>Hemophetic medicine</li> </ul>		
	□ natural therapy		
	□ other		
	(ask interviewee to specify)		
4.16	Do you have a job?		
□ yes			
	no no		
	If yes, what is your job? (specify)		
Do you get paid?			
4.17	<ul> <li>no</li> <li>Do you belong to an organization of persons with disabilities?</li> <li>yes</li> <li>no</li> </ul>		

- 4.18 Would you say that the area where you live is accessible for persons with disabilities?
  - 🗆 yes
  - 🗆 no

4.19 What makes the area where you live accessible or not accessible?

#### E. Ending the Interview

- Do you have anything else that you would like to add?
- Do you have any final questions for us about the study?

#### [MONITOR: Answer these questions.]

[MONITOR: Review briefly what will happen with the information the interviewee has provided, the purpose of the project and the relevant time frames.] [MONITOR: Say into the digital audio recorder: "This is the end of Interview (insert Interview Code here)"]

[STOP digital AUDIO RECORDING THE INTERVIEW NOW] Identifying Another Person to Interview:

- Do you know someone with a disability who lives in your community who we could interview for this study?
- What is his or her name?
   What type of disability does he or she have?
   Is he or she a man or a woman?
- How old is he or she?
- How can we contact him or her?
   [MONITOR: Write this information on the *Identification Sheet*.]
   [MONITOR: Thank the interviewee very much for his/her time. Remember to leave the *Information Sheet* with the interviewee for his/her information.]

#### F. Completing Notes & Transferring Data

CHECKLIST:

<u>Digital Audio Recorder</u>: Secure the recording by turning OFF recorder immediately after the interview and downloading the interview file to a secure computer as soon as possible. Label the file with

the correct Interview Code (from Identification Sheet)

- As soon as possible after the interview, monitoring pairs should listen to the audio recording of the interview. If part of an audio recording is not clear, monitors should explain what is missing (if you remember) in the *Interview Notes*.
- The *Interview Notes* should also contain the following observations:
  - Provide your overall impression of the interview (e.g. interviewee seemed nervous or anxious over certain questions, the atmosphere was comfortable, etc.).
  - Provide details about the location of the interview (e.g. held indoors/outdoors, type of building, type of room, who else was around, etc.).
  - Provide information about who was present at the interview (number

of monitors, interpreters ...)

- Provide details about any challenges faced or interruptions that occurred during the interview (e.g. airplane flew overhead making it difficult to hear, lost electrical power so could not see, etc.), at what stage in the interview they occurred and what steps were taken to address them.
- If you have any concerns about the truthfulness and/or accuracy of statements by the interviewee, identify the statements and explain why you feel this way (e.g. answers were very inconsistent, answers seemed rehearsed, etc.)
- Be certain that one of the monitors has signed and dated the *Free and Informed Consent Form*.
- Provide the Project Coordinator or Site Coordinator with the following documents:
  - o audio recording of interview labeled with the correct Interview Code
    - o completed Interview Notes
    - o completed *Identification Sheet*
    - o signed Free and Informed Consent Form

[END]

#### 6.3. IDENTIFICATION SHEET

#### [KEEP SEPARATE FROM ALL OTHER RECORDS OF THE INTERVIEW]

Monitoring Site:

Interview Code<sup>1</sup>: \_\_\_\_\_\_ (Remember to also state Interview Code at beginning and end of audio recording) 

Interviewee Address: \_\_\_\_\_

SITUATION #1 - FOLLOW-UP CONTACT INF Name:	
Contact Details (Phone, Email or Address):	
 SITUATION #2 - FOLLOW-UP CONTACT INF	
Name:	
Contact Details (Phone, Email or Address):	
SITUATION #3 - FOLLOW-UP CONTACT INF	ORMATION
Contact Details (Phone, Email or Address):	
ANOTHER PERSON TO INTERVIEW: Name: Type of Disability: Contact Dataila (Dhana, Email or Address);	Sex: Male or Female (circle one)
Contact Details (Phone, Email or Address):	

<sup>&</sup>lt;sup>1</sup> A possible Interview Code would be APnNPKMB04. This code would be put together as follows: AP= first 2 characters for all interviews in the Asia Pacific Region; NP= country where the interview takes place (e.g. Nepal); KM= first two letters of the monitoring site where the interview takes place (e.g. Kathmandu); B = letter designating the pair of monitors who conducted this interview (e.g. Sarashoti and Yubaraj); 04 = means that it was the fourth interview conducted by monitoring Pair B.

## 6.4. Information Sheet

for the study called

Monitoring the Individual Human Rights Experiences of People with Disabilities in Nepal

This information is provided so that you can make a decision about whether or not you want to participate in this study. We are giving you a lot of information because we want you to be able to make the decision that is best for you. Sponsors:

The study is being sponsored by:

- National Federation of the Disabled-Nepal
- Swedish International Development Cooperation Agency (Sida)
- Disability Rights Promotion International (DRPI) which is a research project based at York University in Toronto, Canada (website: www.yorku.ca/drpi)

Why are we doing this study?

We are collecting information about the lives and experiences of people with disabilities by talking directly to people with disabilities. We want to see if their human rights are being respected. The information we collect will be studied and reports will be written. The names of participants will not be mentioned in the reports unless they have given us clear permission to do so. The reports will be available to organizations of people with disabilities, other groups working to improve the lives of people with disabilities, the media and Nepal government.

The reports made will be used to:

- let people know about violations of the rights of people with disabilities
- help stop human rights violations
- provide facts to back up arguments for changes in laws, policies, and programs to improve the lives of people with disabilities
- keep track of the steps that the government has taken or has failed to take in order to fulfill the promises it has made to people with disabilities when it signed agreements at the United Nations saying that it would protect, promote and fulfill the rights of people with disabilities

What will happen in this study and what will you be asked to do?

Our project is going to various countries around the world to talk to people with disabilities about their lives and their experiences.

If you agree to participate, you will be asked a series of questions about your life and your experiences. We will particularly want to know if your human rights have been violated and how they have been violated. In other words, we will want to know if there are unfair things that have happened to you which have stopped you from participating in society in the way that people without disabilities participate in society.

If you agree to participate, you will be interviewed by one or more people with disabilities who are members of a local organization run by people with disabilities. We call these people the "monitors". We know that, in the past, people with disabilities have often been left out of research about people with disabilities. We think that it is only fair that people with disabilities play an active role in any research about them.

During the interview, the monitors will take notes. They will also audio record the interview so that we can be sure to get all of the information you provide accurately. Depending on the methods of communication that are used, the complete interview should take approximately 2 to 3 hours to complete.

After the interview, the monitors will give all of their written and audio recordings to the person in charge of the project who we call the Project Coordinator. The monitors will not keep any copies and will not talk to anyone except for the Project Coordinator about what you said. The interview will be confidential.

The Project Coordinator will pass the written and audio recordings of your interview to the researchers who will study them. Your name will not be on any of the information given to the researchers, they will not know whose information they are studying. After looking at your information and the information from interviews with at least 50 other people with disabilities in your country, the researchers will write reports that will be given to organizations of people with disabilities, other groups working to improve the lives of people with disabilities, the media and governments. Your name will not be mentioned in the reports without your clear permission.

Are there possible negative things that might happen if you participate in the study? There are no negative things that will happen to you by participating in this study. However, you may feel uncomfortable when you start thinking about some of the questions that you are asked. For example, you may remember some things that have happened to you that are not pleasant to think about. If that happens, you can take a break from the interview or, if you want, you can stop the interview completely. If you want to continue to talk about these things, that's fine, too. If you feel upset about these things, you can ask the monitors for the name of someone you can talk to about your feelings after the interview is over.

Are there good things that might happen if you participate in this study? You may or may not receive any direct benefit from participation. You might find that it makes you feel better to talk about some of your experiences. Also, we hope that organizations of people with disabilities, the media and Nepalgovernment learn from the studies and reports that are made and take steps to improve the lives of people with disabilities in Nepal.

Can you decide if you want to participate in the study?

You are free to choose to participate or not to participate in the study and you may choose to stop participating at any time. Your participation is completely voluntary. Your decision not to participate in the study will not influence your ongoing relationship with any of the study sponsors, monitors or any other person or group associated with the project.

Can you stop participating if you don't want to continue participating?

If, at any time during the study, you want to stop participating, for any reason, just let the monitors know and they will stop asking you questions. If you want to answer some questions, but not others, you can do that, too. It is entirely your decision.

If you decide not to participate in the study, or if you decide to stop participating in the study, we will not use your information for our research. Any written or audio recordings made up to the point you decided to stop will be destroyed. Your decision to stop participating, or to refuse to answer particular questions, will not affect your relationship with any of the study sponsors, monitors or any other person or group associated with

the project. No one will treat you any differently if you decide that you do not want to participate in the study.

Will your information be kept confidential?

The information you provide will be kept confidential within the limits of the law. Unless you specifically provide your consent, your name will not appear in any report or publication of the research. The written and

audio recordings of your interview will be safely stored in a place that is locked and will be destroyed at the end of the project.

Costs and Compensation

You will be reimbursed for the cost of your transportation to the interview location and the cost of any disability-related supports or assistance that you will need in order to participate in the interview. You will receive these things even if you decide to stop participating in the project at some point during the interview and/or decide not to answer certain questions.

If you have questions about the study

If you have questions about the research in general or about your own role in the study, please feel free to contact:

Mr. Birendra Raj Pokharel

Disability rights monitoring project coordinator

National Federation of the Disabled-Nepal

Vrikutimandap, Kathmandu

Nepal

Mobile:

+977-9851043399

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OR

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### 6.5. Consent Form

#### FREE and INFORMED CONSENT FORM (Interviews)

I have read and understood the *Information Sheet*. The research procedures have been explained to me and all of my questions have been answered to my satisfaction. I have been informed that I can withdraw from the study at any time without penalty and that, if I choose to do so, any data collected as a result of my participation will be destroyed. The potential discomforts that I might experience because I have participated in the study have been explained to me. I also understand the potential benefits of being a part of this study.

I know that I may ask now, or at any time in the future, any questions I have about the study. I have been assured that the audio and written records related to this study will be kept confidential to the limits of the law. I have also been assured that no information will be released or printed or made public that would disclose my personal identity unless I give permission for that to happen.

I hereby consent to participate

Printed Name of Participant:
Date:
Signature of Participant:
I hereby consent to having my interview audio recorded
Signature of Participant: Date:
Printed Name of Monitor: Date:
Signature of Monitor:

#### PLEASE NOTE:

This research has been reviewed by the Human Participants in Research Committee, York University's Ethics Review Board, and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines and the York Senate Policy on research ethics. If you have any questions about this process, or about your rights as a participant in the study, please contact: Senior Manager & Policy Advisor for the Office of Research Ethics 4700 Keele Street, 5<sup>th</sup> Floor, York Research Tower, York University, Toronto, ON, Canada M3J 1P3; telephone: +1 416-736-5914; e-mail: <u>ore@yorku.ca</u>

6.5.

#### INTERVIEW NOTES

Interview Code:	Page of
(Remember to also state Interview Code at beginning and er	nd of audio recording)
Notes Written by:	Date:

NOTE: Please use as many sheets of paper as necessary to write your responses.

- (a) Provide your overall impression of the interview (e.g. interviewee seemed nervous or anxious over certain questions, the atmosphere was comfortable, etc.).
- (b) If any part of the audio recording of the interview is not clear, explain what is missing (if you remember).
- (c) Provide details about the location of the interview (e.g. held indoors/outdoors, type of building, type of room, who else was around, etc.).
- (d) Provide information about who was present at the interview (number of monitors, interpreters ...)
- (e) Provide details about any challenges faced or interruptions that occurred during the interview (e.g. airplane flew overhead making it difficult to hear, lost electrical power so could not see, etc.), at what stage in the interview they occurred and what steps were taken to address them.
- (f) If you have any concerns about the truthfulness and/or accuracy of statements by the interviewee, explain why you feel this way (e.g. answers were very inconsistent, answers seemed rehearsed, etc.)

Signatures:

MONITOR