SINTEF A27656- Unrestricted

Living conditions among people with disability in Nepal

Arne H. Eide, Shailes Neupane, Karl-Gerhard Hem

SINTEF Technology and Society
Department of Health Research
2016-04-28

Disclaimer

This study, "The National Survey on Living Condition among Individuals with Disabilities in Nepal", was designed and implemented based on the consultations of the Steering committee representing members from the Ministry of Women, Children and Social Welfare, National Planning Commission, Central Bureau of Statistics, Ministry of Education, Ministry of Health and Population, Department of Education, Valley Research Groups and National Federation of the Disabled, Nepal. The opinions expressed in the report are those of the researchers and do not necessarily reflect the views of the Government of Nepal, Ministry of Women, Children and Social Welfare.

SINTEF Teknologi og samfunn
SINTEF Technology and Society

Address:
Postboks 4760 Sluppen
NO-7465 Trondheim
NORWAY

Telephone:+47 73593000
Telefax:+47 93270500

ts@sintef.no
www.sintef.no
Enterprise /VAT No:

Report

Living conditions among people with disability in Nepal

VERSION
Version

DATE
2016-04-28

AUTHOR(S)

Arne H. Eide, Shailes Neupane, Karl-Gerhard Hem

CLIENT(S)
Norwegian Federation of Organisations of Disable People (FFO)

CLIENT'S REF.
Hanne Witsø

PROJECT NO.
102007659

NUMBER OF PAGES/APPENDICES:
157 + Appendices

ABSTRACT
This report is from the National study on living conditions among people with disabilities carried out in Nepal in 2014-2015. The study was carried out as a household survey with two-stage stratified sampling, including a screening/listing procedure using the Washington Group on Disability Statistics 6 questions, one Household questionnaire administered to households with (Case HHs) and without disabled members (Control HHs), one Individual Case questionnaire administered to individuals who were found to qualify as being disabled in the screening (Case individuals), and an Individual Control questionnaire administered to matched non-disabled individuals in the Control HHs (Control individuals). The study covers a range of indicators on level of living, such as socio-economic indicators, economic activity, income, ownership and infrastructure, health (including reproductive health), access to health information, access to services, education, access to information, social participation, and exposure to discrimination and abuse (see all questionnaires in Appendix).

PREPARED BY
Arne H. Eide, Research Manager

SIGNATURE

CHECKED BY
Karl-Gerhard Hem, Research Scientist

SIGNATURE

APPROVED BY
Randi E. Reinertsen, Research Director

SIGNATURE

REPORT NO.	ISBN	CLASSIFICATION	CLASSIFICATION THIS PAGE
SINTEF A27656	978-82-14-06036-2	Unrestricted	Unrestricted

Contents

Contents

Living conditions among people with disability in Nepal

A National Representative Study

1 Acknowledgements

This is a report from a National, representative household survey carried out in Nepal in 2014 – 2015. It is the first comprehensive disability survey in Nepal. The study was made possible through the collaboration between The National Federation of the Disabled in Nepal (NFDN) and The Norwegian Federation of Organizations of Disabled People (FFO). Funding was provided by the Norwegian Agency for Development Cooperation (NORAD) through the Atlas Alliance.

The accomplished study is first of all a credit to The National Federation of the Disabled in Nepal (NFDN) who initiated the study and had a coordinating role during its implementation. In particular, we want to thank the National President of NFDN, Mr. Shudarsan Subedi, for his continuous interest and support, and to Mr. Bimal Paudel for his enthusiastic and competent coordination of the study in addition to his important contribution to this report. We are happy to have experienced that the whole leadership of NFDN has strongly supported the generation of high quality data on disability in Nepal. We are convinced that NFDN will utilise the opportunity given by this report and the data that can be further utilised in the time to come, in their continuous advocacy for the interests of individuals with disability.

The Steering Committee for the survey comprised Mr. Sankar Pathak: Ministry of Women, Children and Social Welfare(MOWCSW), Mr. Nebinlal Shrestha: Central Bureau of Statistics (CBS), Mr. Tankanath Lamsal: National Planning Commission (NPC), Mr. Bhojraj Shrestha: Ministry of Education (MOE), Mr. Rudra Prasad Adhikari/Ganesh

Paudel: Department of Education (DOE), Mr. Bharat Sharma: MOWCSW, Mrs. Humkala Pandey: MOWCSW, Mr. Resham Kumar Khatri/Nim Prasad Bhattrai: MOWCSW, Mrs. Renu Lohani: FFO-Norway, Mr. Shudarson Subedi: National Federation of the Disabled Nepal (NFDN), Mr. Shailesh Neupane: Valley Research Group(VARG), Mr. Parva Prasad Sapkota: Ministry of Health (MOH) and Mr. Bimal Paudel: NFDN. They should all be thanked for their support and efforts to make this survey a useful tool for persons with disability in Nepal in the years to come. The strong interest and involvement from several ministries and the Planning Commission promises that the findings in the study will have impact on policy and practices on the ground.

Valley Research Group (VaRG) in Kathmandu has been responsible for all elements of the data collection; recruitment and training of research assistants, data collection, data entry and cleaning. We are happy to say that this has been done in a highly competent way and the result is data of very good quality. We thank in particular Mr. Shailes Neupane, Executive Director of VaRG, for his contribution to a conducive collaboration and an excellent result, which has led to further collaboration with SINTEF.

A number of individuals with disability have contributed in different roles. Not least has this been an exercise that has proven the capabilities of disabled people, either in the Steering Committee, in the coordinating role, or as research assistants. This study and the report had not been possible without their enthusiastic participation. You have all contributed tremendously, not least to change the role of disabled people from objectives for research to actors and decision makers in research. This is a remarkable achievement, given the difficult situation for many individuals with disabilities in Nepal.

We have experienced a strong interest in the research on living conditions among people with disabilities in Nepal, not only from those who have been directly involved, but also from a broad range of national and international stakeholders. With such a broad support for this project, it has been a pleasure being a part of this comprehensive exercise. We believe that the strong interest and the continued collaboration between NFDN and FFO will lead to some tangible results for individuals with disability.

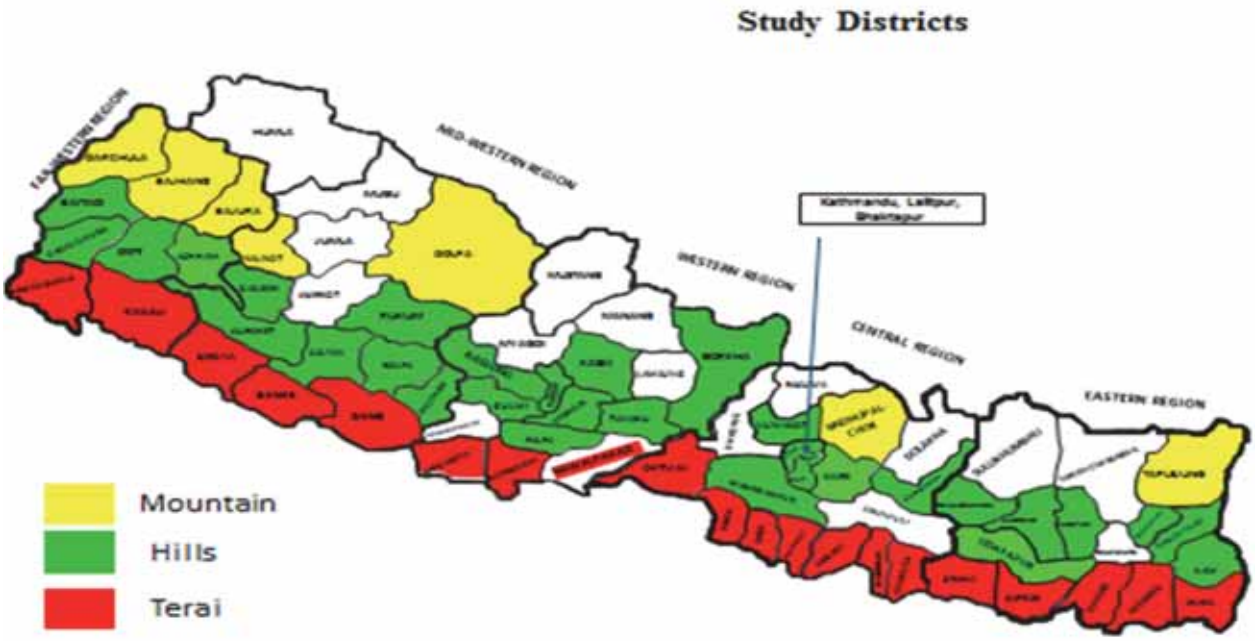
We congratulate all stakeholders involved in this field with the establishment of new knowledge about the situation for individuals with disability in Nepal.

Oslo, 22nd April 2016

Arne H. Eide
Chief Scientist

Karl-Gerhard Hem
Research Scientist

Map of Nepal



2 Executive summary

This study on living conditions among persons with disability in Nepal was carried out in 2014 - 2015. It follows similar studies in seven countries in the southern Africa Region and is thus part of a large database that can be utilized for international comparison. In Nepal, the study was carried out in a partnership between the National Federation of Disabled in Nepal (NFDN), the Norwegian Federation of Organizations for Disabled People (FFO) and SINTEF. Other key partners in the study have been Valley Research Group, the Ministry of Women, Children and Social Welfare (MOWCSW), National Planning Commission, Central Bureau of Statistics, Ministry of Education, Department of Education and Ministry of Health.

A chapter synthesizing existing relevant disability related publications and legal provisions forms a background for the current study. The chapter discusses the loopholes between

policy and practice and presents some recommendations for positive changes. The chapter concludes that many efforts are still floating to be completed particularly concerning the legislative framework and its execution.

The study in Nepal was carried out as a household survey with two-stage stratified sampling, including a screening/listing procedure using the Washington Group on Disability Statistics 6 questions, one Household questionnaire administered to households with (Case HHs) and without disabled members (Control HHs), one Individual Case questionnaire administered to individuals who were found to qualify as being disabled in the screening (Case individuals), and an Individual Control questionnaire administered to matched non-disabled individuals in the Control HHs (Control individuals).

The questionnaires cover a range of indicators on level of living, such as socio-economic indicators, economic activity, income, ownership and infrastructure, health (including reproductive health), access to health information, access to services, education, access to information, social participation, and exposure to discrimination and abuse (see all questionnaires in Appendix).

The study has demonstrated that households with at least one person with disability as member score lower on most indicators on level of living than control HHs. This is the case for the indicator comprising possessions in the household (possession or asset scale), dietary diversity, access to information as well as dependency ratio. It adds to this difference that case HHs have a higher mean number of members and thus more mouths to feed. With regards to infrastructure (housing facilities, type of houses, access to water, toilet facilities) and ownership of houses, a tendency was found for control households to be somewhat better off, but these differences are largely marginal within geographic locations. There are, on the other hand, substantial differences between locations, with poorer standard in rural areas as compared to urban areas.

At the individual level, persons with disability have generally more health problems, a higher proportion with poor physical and mental health, lower well-being, and less access to health information as compared to control individuals. Fewer individuals with disability access the formal education system, those who access the education system tend to spend shorter time in school, and there is a tendency that persons without disability achieve higher levels of education. This results in lower level of literacy among individuals with disability.

Unemployment is higher among persons with disability, and fewer have paid work and thus tend to depend more on others in their households. Somewhat more nondisabled report to have skills/skills training. Among those who reported a regular income, control individuals earn significantly more than case individuals.

Individuals with disability experience substantial gaps in services. The largest gaps in services in percentage points were found for vocational rehabilitation and legal advice, while the smallest gap was found for traditional healer and health services, followed by health information. For a range of other basic services, the gap was found to be between 70 – 90 percent.

Around one in eight of individuals with disability stated that they used an assistive device. This is clearly on the low side when comparing to what was found in similar studies in low-income contexts.

Involvement of the disabled respondents was considerably lower compared to the non-disabled respondents. However, taking these differences into account, it should be noted that the majority of the respondents felt that they were involved and part of the family. The largest differences were found with regards to taking part in their own traditional practices, and the difference in voting in last election was 12 percentage points.

The study has revealed some important gender differences. Most, although not all, of the indicators that were analyzed point towards somewhat less favorable results for females

as compared to males. Females had significantly lower school attendance, lower level of literacy, less involvement in working life, more limited access to assistive devices, and reported lower levels of participation. On the other side, fewer females reported to have chronic illness, fewer had experienced discrimination by public services, females spend more years in school as compared to males, and fewer had been refused entry to school due to their disability.

The study has confirmed clear differences in living conditions between urban and rural areas. The three main socio economic indicators (SES) all indicate that the living standard is lowest in rural areas. All infrastructure variables confirm the same. Two of the indicators on abuse are higher among individuals with disability living in rural areas. Discrimination by public service is however lower in rural areas, although this could just as well indicate lack of access to such services. School attendance, mean years in school, literacy, participation in the workforce, and access to assistive devices are all examples of indicators where individuals with disability are worse off. The case/control differences are however found also within the two locations, confirming that households without disabled members are better off than case households. For indicators at household level, it does add to the difference that case households are larger than controls (higher mean number of members).

Generally, the study reveals consistent differences between case/control households and case/control individuals. Level of living, measured by means of a range of different indicators, is higher among controls than among cases at both levels (household and individual), with a few exceptions. Altogether, the study thus provides evidence for differences in level of living that should be reduced and limited completely. This requires an active stand from the side of public authorities and a multi-sector strategy that deals with these differences. Measures to achieve this will be both general and sector specific and a thorough analysis of what can be done to reduce the documented differences and to address service gaps and inadequacy in assistive device services, etc.

Having established evidence for differences between disabled and non-disabled is an important step in the promotion of human rights and improved level of living among individuals with disability. The study offers an opportunity for boosting advocacy, for setting priorities, for assessing impact and developing policies, for monitoring the situation, and for increased knowledge among disabled and the public in general.

SUMMARY OF CASE/CONTROL COMPARISONS

Indicator	Household study		Individual study	
	Case	Control	Case	Control
N	10693[1]	10031	2123	2000
Mean age			40.0 years	40.1 years
Percentage males			51.8%	53.8%
Dependency ratio	0.78	0.74		
SES scale (0-22)	9.7	10.7		
Dietary diversity (0-12)	9.7	10.1		
Access to information scale (0-6)	2.7	3.0		
	Individuals in Household study			
Chronically ill last 12 months[2]	21.6%	7.0%	21.6%	15.2.0%
School attendance (>15)[3]	35.4%	62.5%	35.8%	52.3%
Studied as far as planned (>15 years)[2]			7.5%	
Mean years of education (15 years +)[2]	8.8%	9.7%	8.8years	.1years
Literacy (15 years +)[2]	39.4%	65.4%		
Paid work (=> 15 years)[3, 4]	10.8%	19.7%		

Indicator	Household study		Individual study	
	Case	Control	Case	Control
N	10693[1]	10031	2123	2000
Currently working (=> 15 years)			36.4%	54.6%
Unemployed (=> 15 years)[3]	29.7%	3.3%		
Have a skill (=> 15 years)[2]	6.6%	8.2%		
Environmental barriers (10 - 40)[3]			20.61	15.95
What is your income[3]			60.5%	44.2%
0 – 4999 NPR			23.5%	29.0%
5000 9999 NPR				
⇨ 10000 NPR			16.0%	26.8%
Voted in last election (=> 20 years)[3]			75.3%	89.2%
Wellbeing scale (12-52)[3,5]			23.70	19.75
Poor/not very good physical health[3]			81.4%	20.8%
Poor/not very good mental health[3]			61.3%	21.2%

[1] Number of individual members [2]Comparison between individuals with disability and all other respondents; not matched [3] Matched comparison (individual level questionnaire) [4] Excluding self-employed [5]Higher scale values = lower wellbeing

SUMMARY OF INDICATORS AMONG INDIVIDUALS WITH DISABILITY - MALE/FEMALE COMPARISON[1]

Indicator	Total	Male	Female
WG6 mean score[1] (0-16)	2.92	2.95	2.90
Environmental barriers (10-40)	17.41	17.70	17.08
Chronic illness last 12 months[2]	21.6%	22.3%	20.8%
Wellbeing scale (12-52)[3]	23.70	23.61	23.79
Discrimination and abuse:			
- Beaten or scolded	24.2%	23.8%	24.6%
- Beaten or scolded by family member	20.5%	20.2%	20.7%
- Discriminated by public service	9.9%	11.8%	7.8%
Service gap[4]			
- Medical rehabilitation	83.8	80.8	85.1
- Assistive devices	72.5	59.0	76.1
- Educational services	78.9	79.0	78.8
- Vocational rehabilitation	95.6	95.2	96.3
- Counselling pwd	89.3	89.8	88.8
- Counselling parents	79.1	77.2	83.2
- Welfare services	88.7	89.9	88.3
- Health services	29.2	29.1	29.3
- Health information	64.8	64.5	65.1
- Traditional healer	27.9	25.0	30.9
- Legal advise	94.3	95.5	92.7
School attendance (accessed primary education) (=> 15 years)	35.8	47.9	22.6
Mean years in school (=> 15 years)[2]	9.0 years	8.6 years	9.5 years

[1] The figures in this summary table may deviate marginally from the above summary table as the analyses have i) been done among the disabled sub-sample only, leading to small differences in N, [2] Individual data from household study, [3] Higher scale values indicate lower well-being, [4] Service gap = 100 – needed/received, [5] "No" includes also those who were "still studying", [6] "Yes" + "sometimes"

Indicator	Total	Male	Female
Literacy (=> 15 years)	39.6%	52.0%	26.1%
Currently paid work (=> 15 years)	10.9%	17.1%	4.1%
Unemployed (all reasons) (=> 15 years)[2]	29.4%	34.8%	23.9%
Use an assistive device	12.5%	15.0%	9.8%
Feel involved and part of the family/household (yes + sometimes)	92.0%	92.4%	91.6%
Participate in local community meetings[6] (yes + sometimes)	16.9%	22.8%	10.5%
Voted in the last election (20 + years)	75.3%	77.4%	73.1%
Poor/not very good physical health	81.4%	81.1%	81.7%
Poor/not very good mental health	61.3%	60.1%	62.6%

SUMMARY OF INDICATORS - URBAN/RURAL COMPARISON

Household study				
		Urban	Rural	Total
SES scale (0-22)[1,]	Case HHs	11.71	9.35	
ControlHHs		12.92	10.09	
Dietary scale (0-12)[2,]	Case HHs	10.48	9.57	
ControlHHs		10.92	9.88	
Access to information scale (0-5)	Case HHs	3.54	2.51	
ControlHHs		3.80	2.67	
Individual level study				
Environmental barriers (10 - 40)[4]	Case	18.29	17.21	
	Control	13.31	13.50	
Chronic illness last 12 months	Case	21.1%	21.7%	
	Control	14.8%	15.3%	
Wellbeing scale (12 - 52)[5]	Case	23.29	23.78	
	Control	19.35	19.86	

Household study				
		Urban	Rural	Total
Poor/very poor physical health	Case	78.3%	83.0%	
	Control	28.0%	18.5%	
Poor/very poor mental health	Case	62.2%	61.1%	
	Control	23.4%	20.6%	
Discrimination and abuse (disabled):				
-Beaten or scolded		16.4%	25.7%	
-Beaten or scolded by family member		12.9%	21.9%	
-Discriminated by public service		12.2%	9.5%	
School attendance (accessed primary education) (=> 15 years)	Case	52.4%	32.5%	
	Control	66.9%	48.0%	
Mean years in school (=> 15 years)[6,7]	Case	10.8 years	8.5 years	
	Control	10.4 years	8.2 years	
Literacy (=> 15 years)[7]	Case	55.2%	36.6%	
	Control	71.8%	52.4%	
Paid work (=> 15 years)[7]	Case	16.0%	15.0%	
	Control	23.3%	9.9%	
Unemployed (all reasons) (=> 15 years)[7]	Case	32.7%	28.7%	
	Control	5.6%	5.9%	
Use an assistive device (disabled)		16.7%	11.6%	
Voted in the last election (=> 20 years)		72.2%	75.9%	
	Case	87.3%	89.7%	
	Control			

[1]Higher values = higher socio-economic status, [2] Higher values = higher dietary diversity, [3] Higher values = higher access, [4] Higher values = increase environmental barriers, [5]Higher values = reduced wellbeing, [6] Of those who had accessed formal primary education, [7] Household data file – individual questions,

3 Preface

Mr. Shankar Prasad Pathak Joint Secretary, Ministry of Women, Children and Social Welfare

In the past, people accepted disability as a part of their fate or the punishment of the god for the sin committed in the past life. Now the concept of disabled people in the society is changed with the advancement of medical science as well as awareness of the people. The Government of Nepal, in collaboration with family members and different stakeholders, has for many yearsmade various efforts to support the rightsright of personsperson with disabilities. The efforts include policy reforms, rehabilitation of person with disability, partnership with Disabled PeoplesPersons Organizations etc. In this light, Nepal has already ratified the UNCRPD. Now the new Disability Rights Billdisability right bill is also tabled in parliament.

Now, a small numbers of people with disability started coming out of their houses, seeking for better opportunities, inclusion and social participation. Still the majority of people with disability are suffering due to layers of social barriers. In Nepal, the majority of disabled people are from the economically weak communities who have not been given the chance to attain education. The situation of personsperson with disabilities is not as enhanced as expected and is found poorer in the rural and illiterate communities.

The availability and accessibility of the data is a major instrument to address the issues of person with disabilities andfor policy formation and program implementation. At national level, very few studied have been done in this sector, and if done have been limited to head count or prevalence rates only. However, still the estimate of disability in Nepal is found varying from one study to another. According to the latest population census carried out in 2011, the prevalence of disability is 1.94% in Nepal.

The Ministryministry is pleased to be a part of this study, "the National Survey on Living Condition among Individuals with Disabilities in Nepal" carried out by SINTEF, an international research institute of Oslo, in collaboration with Valley Research Group in Nepal, andwith the financial support of FFO-Norway (Disabled People Organization-

Norway). The overall coordination role was carried out by National Federation of Disabled, Nepal (NFDN).

The study accesses household information and individual information of person with disabilities and compares the situation of person with and without disability. This report contains a lot of analytical information especially focused on socio economic condition of the person with disabilities. For a range of most of the basic services, the gap was found to be substantial: between 70 – 90 percent. The fact is evidently demonstrated by instances that aroundaround one in eight of individuals with disability only stated that they used an assistive device and the difference in voting in last election between people with and without disabilities was 12 percentage points. It thus needs more intervention in forth coming days.

The ministry is confident that the report will be shared among concerned stakeholders, which will be useful for policy makers, researchers and those working in the areas of persons with disabilities. On behalf of the Ministry, I would like to thank the members of the Steering Committeesteering committee for their valuable contribution. Finally, I would also like to thank all the agencies and individuals who have contributed in bringing this publication into the present form.

Mr. Shankar Prasad Pathak
Joint Secretary
Ministry of Women, Children and Social Welfare
March, 2016.

Mr. Shudarson Subedi, National President, NFDN

Currently, the whole nation is heading towards the execution of the newly adopted constitution. Most of the marginalized & traditionally excluded groups of people are raising their voices, demanding all their rights to be included into the mainstream of the development process with their full and effective participation in decision making. The persons with disabilities are also among them who are tirelessly fighting for the same.

A major chunk of the population of persons with disabilities is still invisible and segregated in the society due to stigma, discrimination and inaccessibility. Most of the people from rural areas and economically poor backgrounds are extremely in need of having their fundamental rights fulfilled. More than that, almost none of the developmental activities have indeed been reaching out to persons living with complete and severe types of disabilities. It perpetuates a vicious cycle of poverty, illiteracy and unemployment that consequently results into the low living standard of persons with disabilities. NFDN and all the stakeholders engaged in disability rights promotion have felt that the inadequacy of disability related data and information to describe the real situation of persons with disabilities ultimately has affected policy formulation and program planning on disability. The planning and budgeting of government and non-government agencies on disability issues used to suffer due to the lack of data and comprehensive information.

Nepal as the state party of the Convention on the Rights of Persons with Disabilities (UNCRPD-2006) is obliged to gather comprehensive data and information of persons with disabilities (article 31) to ensure that the services and facilities are provided according to their needs and based on priorities and diversity. Beside this, the Incheon Strategy 2012 (regional level 10 years strategy adopted by the governments of Asia and Pacific region) adopted by UNESCAP (United Nations Economic and Social Council for Asia Pacific Region), and also officially signed by Government of Nepal, has also highlighted the importance and need of quality statistics on disability.

Over the past years, NFDN had determinedly been seekingfunding partners to conduct the study on the living condition of persons with disabilities in Nepal and consequently the present research project has been carried out in Nepal with the financial cooperation of

FFO Norway and the Atlas Alliance. This research was carried out by the Oslo based internationally renowned research organization SINTEF in partnership with the Nepalese research company, Valley Research Group (VARG), and NFDN. NFDN has contributed as the coordinating partner, basically to ensure local coordination among the relevant stakeholders and monitoring of the whole survey. On top of that, the engagement of government agencies, the disability community and other relevant stakeholders achieved in this endeavourendeavour has built a wider ownership, ensured reliability and added value. NFDN is always proud of this joint effort.

I believe that the research has ultimately lessened the gap of statistical unavailability on the situation of the living s of persons with disabilities in Nepal. The findings of this research will be utilised not only to boost advocacy and awareness-raising activities on disability; all the prospective stakeholders including government shall also get certain clear cut & governing guidelines and direction on the different issues of people with disabilities which may support those who are in decision making and its execution level as well.

Coincidentally the new constitution of Nepal has recently been promulgated. The new disability Promotion Act 2072(2016) and a 10 years National Policy and Plan of Action on disability are about to be adopted by the state. Unsurprisingly, the execution of such legislations in a real sense will be in need of disability statistics. The Sustainable Development Goals (SDGs) have instantly been announced for the next ten years at the same time as the publication of our survey report. These recommendations would thus undoubtedly be prolific guidance for all individuals, groups, organizations, governmental agencies and developmental partners in policy formulation, priority setting and real execution processes.

On behalf of NFDN, it is my great privilege to announce the report of the living condition survey among individual with disabilities in Nepal. I would like to express my sincere thanks and gratitude to all of them who contributed directly or indirectly in the completion of this research work. I must always be indebted to FFO Norway and its country

representative Ms. Renu Lohani whose support only enabled us to accomplish this whole survey.

I express my sincere gratitude to the SINTEF Group, the Government of Nepal and Valley Research Group who have contributed in the implementation of the survey. I am always thankful to the team of the Disability Promotion Section, Ministry of Women Children and Social Welfare and specially to Mr. Sankar Prasad Pathak, Joint secretary, and all members of the Steering Committee for their valuable guidance in the present survey and active participation in the monitoring of the field work.

My special thanks goes to Mr. Manish Prasai, administrative manager of NFDN, for his excellent efforts in monitoring the whole project. My debt is beyond the reckoning to Mr. Bimal Paudel, Program Officer of NFDN, for coordinating this survey tirelessly and writing the qualitative survey report as a part of this report. In a nutshell, I am equally thankful to board members and staff members of NFDN, representatives of Disabled People's Organizations (DPOs), development partners and other stakeholders whose insightful comments/inputs and their persistent support have really been of inestimable value in bringing the survey report to this present form.

Mr. Shudarsan Subedi:
the National President
National Federation of the Disabled, Nepal (NFDN)
February, 2016

4 Introduction

Arne H. Eide

This report is one result of the long-term collaboration between the National Federation of the Disabled in Nepal (NFDN) and the Norwegian Federation of Organizations of Disabled People (FFO). Due to lack of comprehensive statistical data on disability in Nepal, the current study was initiated in 2012 and carried out by SINTEF in collaboration with Valley Research Group and with NFDN. Funding was provided by the Norwegian Agency for Development Cooperation (NORAD) through the Atlas Alliance and FFO.

An important intention with the current study has been to build capacity in NFDN to utilize and engage in research and with researchers. This study in Nepal draws on experiences from eight similar studies in southern Africa (Eide & Jele 2011; Kamaleri & Eide 2010; Eide &Kamaleri 2009; Eide & Loeb 2006; Loeb & Eide 2004; Eide et. al. 2003; Eide et al. 2003b) as well as the international development within the field of disability statistics. The study thus forms a part in a growing body of evidence about the living conditions of individuals with disability in low- and middle income contexts. It further responds to the requirement in the UN Convention on the Rights of Disabled People (CRPD) that all ratifying countries collect data that can be utilised to map and act on the situation of disabled persons. Such data is crucial for policy development, development of services, priority setting, poverty reduction, etc.

5 Disability policy and practice in the context of Nepal

Bimal Paudel, NFDN

Together with the quantitative data collection, a qualitative desk review on policies and practice in the disability field in Nepal was carried out in combination with a small number of telephone interviews and case studies to provide some background to the result of the survey. There is little academic research and study on disability preceding the current national study in Nepal, but there are some applicable legislatives, survey reports, reports of disability related organizations, publications and documents on disabilities which provide information that is useful to contextualise the results from the national survey. This review has attempted to excavate some important opportunities and gaps between policies and practices.

Objectives:

- To analyze the rights base for persons with disabilities in Nepal in the lights of some international and national legal provision on disability.
- To synthesize some already published disability related documents, reports, case studies with special focus on the living condition of persons with disabilities in Nepal.
- To explore the real gaps between legal provisions on disability and their execution by looking at the good practices and experiences of some individuals with disabilities.
- To put forward some recommendations as a framework for the future development.

Methodologies adopted

For this review, we obtained and analysed mainly data from secondary sources. The secondary sources were such as recently published survey reports, media reporting and various relevant documents on disabilities. Additionally, a small sample telephone survey, some case studies, feedback/recommendations from some national and regional workshops, and good practices of some Disabled People's Organizations (DPOs) were also included as key resources of information.

The review has covered four major life domains - education, general health care, livelihood and access to services including transportation, communication, information and assistive devices. Employment, self-employment and social security were analysed under livelihood. Access to information and facilities/services was the key dimension, prominently used in structuring the opinions in all four domains. National and international policy frameworks matching the four dimensions were extracted.

The sample telephone survey was conducted with 20 persons with different kinds of disabilities from all five development regions, covering different ages, sex, geographical location and educational status. They were interviewed using a semi-structured questionnaire. All the interviewees were selected on the basis of recommendations of district wings and regional offices of NFDN. The number of interviews may not be sufficient in depicting all the voices throughout the country, however, it will certainly provide the bird’s eye view in analysing the current situation of persons with disabilities.

5.1 Some legal provisions on disability

International provisions:

The Universal Declaration of Human Rights (1948) addressed the fundamental rights of human beings in general, but in the case of persons with disabilities they were not able to enjoy those human rights without addressing their special rights. Realizing this, the Declaration on the Rights of Persons with Mental Disabilities (1971) and the Declaration on the Rights of Persons with Disabilities (1975) are brought to guarantee and recognize the special human rights of the persons with disabilities. Over the past few decades, some legislative frameworks on disabilities have been issued at international, regional as well as national level in the spirit of these declarations.

The United Nations World Conference on 'Education for All - Meeting Basic Learning Needs' (1990), the 'Salamanca Statement and Framework for Action' of World Conference on 'Special Needs Education: Access and Quality' (1994), and the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities

(1992), are some of the prominent international legislative frameworks on disability. Also, some regional and national laws and policies, which will be shown below, are formulated/amended on the basis of these documents.

5.2 United Nations Convention on the Rights of Persons with Disability (CRPD, 2006):

Due to the lack of strong and legally binding international laws, the human rights of persons with disabilities did not come into the priority of governments' programs, policies and budgets. The discrimination of persons with disabilities did not decrease as desired. Taking this fact into account, United Nations General Assembly adopted the Convention on the Rights of Persons with Disabilities (CRPD) on 13th December, 2006. The CRPD is a legally binding document which has defined and described disability in a social perspective and rights based approach. Instead of viewing persons with disabilities as objects of charity, medical treatment and social protection, this document has recognized them as full and equal members of society, with human rights. The CRPD is considered as a strong human rights instrument with obligatory provisions to ensure, protect and promote the rights of persons with disabilities on an equal basis with others. Some of the provisions connected to the living conditions of persons with disabilities are as follows:

Article 9: Accessibility

To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure access of persons with disabilities, on an equal basis with others, to the physical environment, to transportation, to information and communication, including information and communication technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:

- Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;

- (b) Information, communications and other services, including electronic services and emergency services.

Article 20: Personal mobility

State Parties shall take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities, including by:

- Facilitating personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost;
- Facilitating access by persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost;
- Providing training in mobility skills to persons with disabilities and to specialist staff working with persons with disabilities;

Article 21: Freedom of expression and opinion, and access to information

State Parties shall 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 present Convention.

Article 24: Education

State Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, State Parties shall ensure an inclusive education system at all levels and lifelong learning, and that persons with disabilities are able to access general tertiary education, vocational training, adult education, and lifelong learning without discrimination and on an equal basis with others. To this end, State Parties shall take all appropriate measures.

Article 25: Health

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. State Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation.

Article 27: Work and employment

State Parties recognize the rights 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.

Incheon Strategy

In the Asia and Pacific region, the Dhaka Declaration(1997) and the Biwako Millennium Framework for Action (2002) previously contributed to the development of the disability rights movement at great extent. The United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP), in the celebration of the Asia and Pacific decade of 2013-22, prepared the Incheon Strategy in 2012 to the end of effective execution of CRPD in this region with its widely quoted slogan: “Make the rights real”. Some of the targets in this strategy are extracted here below:

Employment/self-employment:

Target 1.B.

Increase work and employment for persons of working age with disabilities who can and want to work

Target 1.C.

Increase the participation of persons with disabilities in vocational training and other employment-support programmes funded by governments

Access to services

Target 3.B.

Enhance the accessibility and usability of public transportation

Target 3.C.

Enhance the accessibility and usability of information and communications services

Target 3.D.

Halve the proportion of persons with disabilities who need but do not have appropriate assistive devices or products

Social protection

Target 4.A.

Increase access to all health services, including rehabilitation, for all persons with disabilities

Target 4.B.

Increase coverage of persons with disabilities within social protection programmes

Early childhood intervention and education

Target 5.A.

Enhance measures for early detection of, and intervention for, children with disabilities from birth to pre-school age

Target 5.B.

Halve the gap between children with disabilities and children without disabilities in enrolment rates for primary and secondary education

5.3 National provisions

Definition and classification of disability in Nepal

The definition and classification of disability has persistently been constructed and varied upon different developmental stages of the conceptual development. Disability can also be defined by time, place, nature and its severity. The Government of Nepal, beyond the definition in the Disabled Protection and Welfare Act (DPWA) (GoNMOWCSW1982), in 2006 defined disability as "..... the condition of difficulty in carrying out daily activities normally and in taking part in social life due to problems in parts of the body and the physical system as well as obstacles created by physical, social and cultural environments, and by communication". GoN further classified disability on the basis of nature and severity. According to the nature of the problem and difficulty in the parts of the body and in the physical system, disability was classified into the following seven categories:

Physical Disability is the problem that arises in operation of physical parts, use and movement in a person due to problems in nerves, muscles and composition and operation activities of bones and joints.

Disability related to vision is the condition where there is no knowledge about an object's figure, shape, form and colour in an individual due to problem with vision. This is of two types: blind and low vision.

Disability related to hearing: Problems arising in an individual related to discrimination of composition of the parts of hearing and voice, rise and fall of position, and level and quality of voice is a disability related to hearing. It is of two types: deaf and hard of hearing.

Deaf-Blind: An individual who is without both hearing and vision.

Disability related to voice and speech: Difficulty produced in parts related to voice and speech and difficulty in rise and fall of voice to speak, unclear speech, repetition of words and letters.

Mental Disability: The inability to behave in accordance with age and situation and delay in intellectual learning due to problems in performing intellectual activities like problems arising in the brain and mental parts and awareness, orientation, alertness, memory, language, and calculation. It is of three types: intellectual disability/mental retardation, mental illness and autism.

Multiple disability: Multiple disability is a problem of two or more than two types of disability mentioned above.

Moreover, disability is defined based upon severity. *Total (complete) disability* is a condition where there is difficulty in carrying out daily activities even with the continuous assistance of others. The condition of having to continuously take other people's assistance in order to carry out individual daily activities and to take part in social activities is *acute (severe) disability.* The condition of being able to perform daily activities by oneself with or without taking others' support, if the physical facilities are available, the physical barriers are removed and there are opportunities of training and education, is called *moderate disability*. The situation where taking part in regular daily activities and social activities by oneself is possible if there is no social and environmental obstacle is *ordinary (mild) disability*. These four categories are reflected in Nepal in four types of disability identity cards of red, blue, yellow and white colours that are being entitled to persons with disabilities.

5.4 Disabled Protection and Welfare Act 2039(1982):

The first and foremost legislation regarding the rights of Nepalese citizens with disability was the Disabled Protection and Welfare Act (1982). Its rules, in materializing the act in practice, were however formulated only after 12 years, in 1994. Some legal provisions enshrined in national legislations are mentioned below:

Education

- No fees shall be charged to disabled students.
- Five percent of places in Government organizations providing vocational training should be reserved for disabled people.

• NGOs or private organizations that provide education and training for disabled people can ask for assistance from the Government. The Disability Relief Fund (established in 1981) can allocate scholarships to disabled students.

Health

• Disabled people are entitled to free medical examination.

• All hospitals with more than 50 beds should allocate two beds for the use of disabled people.

• There should be free treatment for disabled people over the age of 65.

Employment and Self-employment

• It is prohibited to discriminate against disabled people in relation to employment.

• Individual businesses employing more than 25 people should give 5 % of their jobs to disabled people.

• There should be income tax exemption for employers who employ disabled people.

• There should be no duties on specialist equipment required by disabled employees

• Five percent of jobs in the Civil Service should be allocated to disabled people

• The Act directs the Government to provide programs which support disabled people into self-employment.

• The Disability Relief Fund should allocate loans of between NPR 5000 and NPR 20000 in order for disabled people to establish themselves as self-employed.

Social Welfare

• The Act allows for disability allowance to be paid to disabled people, but this is a 'power' rather than a 'duty' and is qualified by a statement that this is subject to available resources.

Transport

- The Act allows for transport companies to allow disabled people to travel at half the regular fare - but this can only be undertaken with the agreement of the particular company. At the present time all transport in Nepal is privately owned.

5.5 National Planning and Plan of Action on Disability in Nepal, 2063(NPPAD, 2007)

Since it was necessary to prepare and implement a timely national policy and action plan based on the Extended Asian and Pacific Decade of Disabled Persons (2003-2012) and the Biwako Millennium Framework of Action, Mandates for Action, the National Policy and Plan of Action on Disability (2063 B.S.) was prepared by including the opinion and suggestions of various ministries and associated bodies, the civil society, people with disability and their organizations. Some of the provisions are as follows:

- A policy for construction standards will be adopted that allows easy access of people with disability to physical infrastructure of public importance (large buildings, cinema halls, banks, schools, hospitals, offices, streets, pavements, traffic signs, bus etc.).
- The current policy of providing free fare, concessions, and seat reservations will be implemented in public transportation vehicles for people with disability and their assistants.
- Education will be provided to children with disability in a manner that is easily accessible and favourable for disability. A policy will be adopted to provide quality and free education from pre-primary to higher level for people with disability. Infrastructure of a medium school (integrated, inclusive or special) with residential facilities will gradually be developed in each district for such children. Textbooks will be reviewed and contents that develop positive attitudes to people with disability will be included.
- Provision of free basic health treatment in every government hospital and health center will be made by amending current acts and regulations in order to ensure the

rights of people with disability for medical treatment. Services will be provided by providing separate beds in central, regional and district level hospitals. Special provision will be made in health policy, program preparation and budgeting, for free treatment and medical investigation. Appropriate resources and means, in addition to policy measures, will be managed in order to provide medical treatment discounts in private and institutional health centers and nursing homes.

- Rehabilitation programs based on communities will be expanded for people with disability. In this regard, a policy will be adopted to expand and develop human resources. A policy related to rehabilitation of people with disability will be provided and effectively implemented by amending the Disability Protection and Welfare Act, 2039, and Regulation, 2051. For the empowerment of people with disability, provisions will be made for technical and vocational training by providing loans with concessional rates for machine, equipment, and infrastructure development. Appropriate programs for empowerment of people with disability (social, economic and political) will be determined and effectively implemented. A fund will be established at the national level for social security and economic uplifting of people with disability.
- Assistive devices will be constructed by utilizing local resources and means, and appropriate mechanisms will be developed for improvement and research in this regard. Provisions will be made for free production and distribution of assistance materials needed for people with disability. OrthopaedicOrthopaedic workshops will be established in affiliated hospitals. A program will be carried out for strengthening those institutions in the five development regions that produce and distribute assistive devices.

Some inclusive national legislation

- **The Education Act 2000** authorizes the Government to develop special rules for disabled people in education.
- **The Social Welfare Act 1992** established the Social Welfare Council and gave the Government powers to develop special programs for disabled people.

- **The Child Protection Act 1992**, which was introduced to address issues raised in the UN Convention on the Rights of the Child, states that disabled children cannot be discriminated against and gives a duty that disabled children who cannot be cared for by their family must be provided for in children's homes and receive necessary education.
- **The Local Self-Government Act 1999** authorizes VDCs and VDC Wards Committees to help protect disabled and other vulnerable people. It also gave them a duty to keep a record of disabled people in their area[2].
- **The Civil Service Act section 7** has made provision of a five percent quota to persons with disabilities through open competition in all public services along with other marginalized communities such as women, indigenous people, Dalit, Madhesi and people from poor communities.

[2] Report on Disability Policy in Nepal, 2006, Disabled Human Rights Center-Nepal (DHRC-Nepal).

6 The current situation for persons with disability in Nepal

To agree internationally on provisions and standards for human rights is one thing. To live by them is another matter[3]. As stated in the Holistic monitoring report (NFDN/DRPI 2013), it is, no doubt, important that the rights of persons with disabilities, for their full enjoyment, ought to be documented and agreed for its advancement internationally. But the most salient fact is in any way to scrutinize the real execution status of such agreements by looking at practice and accelerate further relevant steps.

Across the world, people with disabilities have poorer health outcomes, lower education achievements, less economic participation and higher rates of poverty than people without disabilities[4]. The monitoring report furthermore emphasizes that “these difficulties are exacerbated in less advantaged communities”. Nepal is no exception to this fact. This chapter attempts to use existing sources to explore the concrete living status of Nepalese people with disabilities.

6.1 Prevalence of disability in Nepal

The National Census 2011 conducted by GoN reported that 1.94% of the total population of Nepal is living with some kind of disabilities, whereas the National living standard survey report (NLSS) 2011 has claimed it to be 3.6%. However, both figures are quite low as compared to the 15% disability prevalence rate claimed by WHO and World Bank in the World Report on Disability (2011). These figures are in sharp contrast to studies carried out by specific impairment groups - for example a survey carried out in five districts in 1991 stated that 16.6% of children aged over five were deaf while a study by a mental health organization, Aasha Deep (2000), found that 10-12% of the population had experienced some form of mental health difficulties.[5]

[3] Holistic report: Monitoring the human rights of persons with disabilities in Nepal, 2013, NFDN/DRPI-Aware Project.

[4] The world report on disability, 2011, World Health Organization(WHO) and World Bank.

[5] Disability policy in Nepal, 2006-Disabled Human Rights Centre-Nepal(DHRC-Nepal).

NFDN as well as the other stakeholders working on disability rights promotion, through the different surveys/studies, has persistently blamed the government of Nepal of not being able to present the real status of people with disabilities. Various surveys and studies conducted by government agencies, NGOs and self-help organizations have come up with different prevalence rates from 0.45 to 8.99.[6] Besides that, the CBIDP report-2015 by RCRD-Nepal, and the report on challenges to measure and compare disability-2012 by Madhusudhan Subedi, have also recognized the discrepancy of disability statistics in Nepal.

According to these various reports, this sort of variation occurs due to various factors: different perspectives/conceptual frameworks in deciding the definition and classification of disability, different methodologies of data collection, and variation in the quality of study design. The result is that generating prevalence rates that are understandable and internationally comparable is a difficult enterprise. The prevailing poverty and illiteracy in the Nepali society, difficulties in accessing health services, increments for old aged people, more than 10 years of armed conflict, high rate of accidents, and the devastating earthquake-2015, are some of the factors that one could expect leading to high disability prevalence in the country, far distant from what previously conducted surveys/studies have given.

6.2 Educational status

All children with disabilities are entitled to have access to quality education on an equal basis with non-disabled children. The Flash Report of Department of Education (DOE) 2013-2014 stated that the total number of children with disabilities (5-18 years) is 179,000 throughout the nation. A total of 73,985, or only 41.3% of all children with disability are benefiting from some kind of educational opportunities. However, about 60% of children with disabilities, largely intellectual, psychosocial, deafblind and multiple disability, are still

[6] Holistic report: Monitoring the human rights of persons with disabilities in Nepal, 2013, NFDN/DRPI-Aware project.

deprived even the opportunity of basic education[7,8].These children are getting no opportunities of education which ultimately force them to live low-quality lives.

The newly adopted Constitution of Nepal, 2072 (September, 2015), in its article 31, clearly declared that every person with disability shall have the right to free education up to the higher-secondary level. Similarly, it is also clearly stated that persons with visual disability shall have access to Braille and persons with deaf and hard of hearing disability to sign language.

In case of persons with disabilities, in materializing this clause there are two types of education systems: special and integrated schools. There are 365 resource classes throughout the country to provide support for the education of children with disabilities. More than 4000 students with different kinds of disabilities: visually impaired, intellectual disability, and deafness, are supported in various mainstream schools by such resource classes. These students are also enjoying the scholarship provided by the government[9]. Some other, including children with physical disability, are also enrolled and benefit in their own community schools as well. According to our sample telephone survey, 12 out of 20 persons have taken or are taking the education whereas three of five children (5-18 years) are going to school at present.

In the telephone interview, a 32 year old blind man from Kailali expressed that:

> "I started my education from age of 12, since my parents didn't know I can study. Now, I am studying in grade 12"[10].

As stated in the above instance, most of the parents lack the information about what to do if they get a child with disability in the family. In the telephone survey, only 10 among 20 persons did have knowledge about free education and scholarships. One out of three

[7] A report from a feasibility study on CBID, 2015, RCRD-Nepal.

[8] Report on Barriers to the inclusive education for children with disabilities in Nepal-2011, Human Rights Watch Nepal).

[9] A feasibility study on Community Based Inclusive Development and Inclusive Education in Nepal, 2015, RCRD-Nepal.

[10] 32 year old visually impaired man from Kailali who is now studying in grade 12 with his little brother and sisters.

children had received a scholarship, while two out of three had been provided free accessible educational materials in their schools. The report on disability policy in Nepal by DHRC also recognizes the absence of knowledge on disability policy even in the management teams of different educational institutions. In our telephone survey, only eight educational institutions among 20 did have any knowledge on disability policy.

According to the parents that were interviewed, almost all the children with disabilities felt humiliated, ignored and discriminated within the school premises by either friends or teachers, whereas half of them experienced some kind of difficulties due to inaccessible environment for easy movement and to get access to education. The Holistic report of NFDN/DRPI-Aware (2012) also asserted that 95% of the respondents expressed to be experiencing the same kind of difficulties in their schools/colleges. The special education policy (1996) exclusively mentioned that the school infrastructure and teaching learning materials should be accessible for ensuring and promoting access to education of children with disabilities. Due to the absence of execution of such provisions, many children are bound not to be joining schools and having remarkably high drop-out rates. This is exemplified by a father of a child with intellectual disability who says:
“My child was denied to be admitted at school in my village. They told that they couldn’t teach his child putting him with other children at the same class.”[11]

This citation is an example that our inclusive educational institutions do not set up the appropriate environment to welcome children with disability, mostly intellectual, autism, deafblind and multiple disability. Nor have they established a comprehensive evaluation mechanism to identify and feed on students' learning achievements.

The disability rights activists and other stakeholders, therefore, are facing so many challenges in ensuring enrolment in institutions and ensuring quality education for children with diverse nature of disabilities. Such problems and challenges are prevailing in

[11] Parents of a 16 years child with intellectual disability in Rupandehi district.

particular in the most disadvantaged communities[12]. Based on our observations, lack of parental awareness on rights to education, prevailing poverty in most of the communities, inadequately trained teachers and educational personnel, and inaccessible infra-structure including means of transportation and roads, are the main problems in paving the way for improvement of the educational status of Nepalese citizens with disabilities.

No inclusive classroom environment, lack of disability friendly curriculum and teaching materials, insufficient assistive devices, no use of modern technology in classrooms, and negative attitudes on the capability of children with disabilities, are also some of the significant factors that have eventually resulted in low school enrolment and high dropout rates among children with disability in Nepal. This is the bitter truth that frequently has been highlighted in different surveys/studies published by national as well as international agencies. The educational status of Nepalese citizens, as a result, is considered as a mixed bag indeed.

6.3 General health services

In response to our questions: are you aware of the free health services and have you ever taken any?, a 19 year old blind girl from Sindupalchok replied:

> "I am certainly aware about the free medical treatment of governmental hospitals for persons with disabilities like me. The health post is at long distance from my village due to which, it is impossible to get there independently because of geographical difficulties. I am instead taking treatment from the private clinic in my village."

The Constitution of Nepal, 2072 (September, 2015) in its Article 35 stated that every citizen shall have the right to basic health services from the state free of cost as provided in the law. The state is also obliged to provide free health services including medication

[12] Opinions given by different disability rights activists in a regional workshop convened in Dhangadi, Kailali from 9 districts of Far-Western Developmental Region, which is the most underdeveloped area of the nation.

for persons having epilepsy and some other chronic diseases. However, so many people are either unknown to the services or do not access granted facilities and services, consequently, resulting in the extreme poor health condition of persons with disabilities.

In our sample telephone survey, 12 persons (out of 20) were found not to have any information about free health services. Three persons out of twenty benefitted from the provisions, however, they only experienced taking general type of treatments. Many of those who are aware still do not access governmental health clinics/hospitals for different reasons.

The Holistic report on monitoring the human rights of persons with disabilities in Nepal (2012) reveals the fact that around four out of five persons with disability asserted lack of effective execution of legislations in ensuring inclusive health services. The report on disability policy in Nepal, 2006, published by DHRC- Nepal revealed that 16 of 20 hospitals were totally ignorant on the issue of free health service, while 10 (out of 20) did have certain provisions for patients with disability. This apparently unveils the fact that even service providing hospitals/clinics are not aware of the legislations and policies regarding inclusive health treatment of persons with disabilities.

Most of the health posts/health clinics are not accessible and do not accept the presence of persons with severe disability, although attempts have been made to make newly established hospitals in national as well as district level accessible (at least having ramps). In the absence of trained human resources and necessary equipment, disability identification and early prevention programs have not been effectively executed, though some of the hospitals are trying to improve. Intellectual disability and multiple disabilities are truly felt difficult to be recognized and timely treated[13].
Similarly, many persons with disabilities need to use different types of medicine at a regular basis due to their health condition. They may also need regular counselling to

[13] Report: Feasibility Study on CBID in Nepal, 2015, RCRD-Nepal.

reduce the side effect of their disability in the future. Such services are also not available free of cost which NFDN has demanded from the government for the last few years.

Our hospitals neither make their information sharing materials available in accessible formats. Consequently, they are prone to having less information and more communication problems that reduce possibilities for counselling and instruction. A 34 years old deafblind man from Kaski in the telephone talk mentioned his bitter experience while getting health services:

> “I always ought to undergo through the hardship situation while approaching my doctors in hospitals as in other places. When I speak out, I hardly get their response properly, because of that I have been compelled to manage communication with the support of my friends/family members".

In this circumstance, most of the people with disabilities, especially in rural areas and among economically poor families, are still living hardship lives with highly insecure access to general health services.

6.4 Livelihood

Mentioning the rights in legislations and policies is not a guarantee for ensuring good quality of life for persons with disability. In spite of existing legislation, most of the persons with severe and complete disabilities are still prone to live penniless lives and being a burden to their own families. Even the employed persons with disabilities do have bitter experiences of being discriminated, humiliated and ignored in their working places. The Constitution of Nepal, 2072 (September, 2015) in its Article 33 continued the provision already mentioned in The Interim Constitution 2063 (2007) that every citizen shall have the right to employment. A specific livelihood policy has however not yet been adopted in the country.

Data is unavailable on how many people with disabilities are involved in employment and livelihood opportunities. A low number indeed are deployed in civil services, the teaching profession, companies/industries, NGOs/INGOs, private enterprises, and so on. Many

have benefited from self-employment activities. NGOs[14] carry out some vocational training such as handicrafts, farming/animal husbandry, candle/chalk production, mobile/bicycle repairing, training on computer software/hardware, and so on, targeting persons with rare possibility of education and a career. The Government has, however, taken only a few such initiatives[15]. Consequently, most of the youngsters with disability are in the same situation as a 28 years blind male from Rupandehi who expressed:

> "I have passed bachelor in education with good division. All the employers, whom I approached, denied to enrol me in their schools due to my disability. I have also taken some vocational training on candle production, mushroom farming, detergent powder production. But, due to the lack of seed money, I am deprived of earning no more at all."[16]

The above cited experience seems to be very common among persons with disability in Nepal, confirmed in our telephone survey. For instance, of 15 persons (15 years above) contacted, only five persons are now in their jobs. Even their experiences exhibit that the persons with disabilities are facing difficulties and a sense of discrimination and humiliation in their workplaces. The remaining 10 persons have no access to employment for various reasons. Eight persons have taken part in some kind of skills development/vocational training, but only five out of them have been using their skills in earning a livelihood. This fact is illustrated by the voice of a 45 year old blind woman from Surkhet who states:

> "I have not been provided any allowance from nowhere yet. I have taken some vocational trainings as well. But I can't continue my job in the absence of knowledge about raw materials and possible markets. So, I am compelled to totally be dependent on my family even in fulfilling my basic daily needs." [17]

[14] The annual progress reports of different member organizations of NFDN, Disabled people's organizations(DPOs).
[15] A report from a feasibility study on CBID in Nepal, 2015, RCRD, Nepal.
[16] 28 years old blind male, Rupandehi.
[17] 45 years old blind women from Surkhet.

GoN even provided NPR 1000 and 300 per month to people with complete (Red card holders) and severe disability (Blue card holders) respectively who cannot be addressed by the employment/self-employment programs[18]. While the constitution provisioned that women, labourers, the aged, disabled as well as incapacitated and helpless shall get social security from the state as provided for in the law, most of the people and in particular those from rural areas and with poor background, have neither knowledge nor access to such facilities. Moreover, persons with disabilities are not reaching to the schemes of loan given by GoN for the initiation of small businesses. Nor are they supported in searching the market for selling their products.

Ten of the respondents in the telephone survey had blue disability identity card. Of them, three had not received social security allowance, even though the annual policies and programs of GoN for the fiscal year 2071/72 B.S., dismissing the previous quota system, had declared to provide compulsory allowance to them. Further, only four of seven persons who receive the allowance reported that they were able to spend their money at their own choice, whereas the allowances of the remaining three were utilized for household expenses on other family members' decision.

In this way, many are out of reach of the livelihood opportunities that resulted in poor economic conditions. Inaccessible working places, no access to educational opportunities, inadequate skills development and vocational training, negative stereotypes regarding the persons with disability and their capacity, no provision of reasonable accommodation, are some of the obvious barriers to expanding livelihood opportunities for persons with disabilities. Traditional and useless methods on vocational activities, lack of seriousness in governmental offices in executing the programs effectively, and weak monitoring mechanism, are key factors that have hindered the legislations to be executed in practice.

[18] A Disability Resource Book, fourth addition, 2071(2014), NFDN/UNICEF/MOWCSW.

6.5 Access to facilities/services

Getting access to various services by targeted communities determines the execution of legislations, policies and programs in practice. Some legislations and policies are targeted to improving the living conditions of persons with disabilities through promoting access to various services/facilities. Most of the services/facilities are, however, beyond the reach of targeted groups, especially in rural areas and among economically poor families.

Disability friendly physical infrastructure and communication systems are keys to increase the access of persons with disabilities to different services. GoN adopted The Accessible Physical Structure and Communication Services directive in 2012, however, the recently established structures, at least roads, public buildings, and governmental websites, do not strictly follow the directive. Consequently, persons with disabilities experience hardships in accessing services such as transportation, information and communication, assistive devices, and so on.

GoN subsidizes public transport for individuals with disability with 50% and also require that seats are reserved. The execution of such provisions however depends upon the interest of particular travel companies or specific staff. Except in Kathmandu valley, the provision for reserved seats is totally ignored by staff as well as non-disabled passengers of public transport. The experience of a 35 year old male wheelchair user from Kailali clearly demonstrates this:

> "Most of the micro staffs don't become ready to take me in public vehicles due to my wheelchair. At that time I feel to be humiliated, abandoned and really discriminated. I usually have to quarrel for my fare concession too. Even they sometime dear to charge double fare from me[19]."

This voice is supported by the result of our telephone survey. Of 20 persons who responded, only 13 persons had experienced obtaining reduced fares or that seats were reserved for them. A father of a child with intellectual disability from Kaski told that he never got concession for his daughter even after showing her disability identity card

[19] A 35 aged wheelchair user man, Kailali.

because she cannot be identified easily as other persons with visible disabilities. Lack of proper monitoring, no punishment or reward system, and absence of a focal point for any complaints, are some of the key problems that needs to be addressed.

The Constitution in Article 27 mentions that every citizen shall have the right to demand and obtain information on any matters of concern to him/herself or to the public. According to this condition, persons with disabilities are also entitled to request, receive and impart the necessary information in the format they require. Except in some cases[20], none of the governmental agencies have provided their information in accessible formats. Nor have they appointed sign language interpreters at their front desks[21]. Nine persons among 20 in the telephone interview expressed to have no knowledge about the services/facilities of GoN targeted to the persons with disabilities. This clearly indicates that persons with disabilities are denied their right to information.

Enhancing access to modern technology ultimately becomes important to receiving information as well as getting access to different services/facilities. As indicated by the telephone survey, many persons with disabilities are still out of reach of modern technology. Only one-fourth of the respondents with disabilities in the telephone survey do have basic knowledge of computers, whereas three-fourths are independently operating mobile phones. Prevailing poverty, high rate of illiteracy, and no knowledge of reasonable accommodation, are some obvious challenges to be taken into consideration.

Access to assistive devices is also of importance to enhance access to different services and to participation in society more broadly. Except the production of some wheelchairs by the Independent Living Centre in partnership with GoN[22], the Government has taken no initiatives in manufacturing and distributing assistive devices. As a result, all the modern assistive devices are imported and distributed occasionally as charity objects. Although GoN via five physical rehabilitation centers established in the five developmental

[20] National Human Rights Commission (NHRC), Election Commission Nepal and some other agencies have initiated to produce a few materials in accessible format.
[21] The opinions of different deaf activists in various workshops and events.
[22] A feasibility study on CBID in Nepal, 2015, RCRD, Nepal.

regions are distributing a few number of assistive devices, INGOs/NGOs are the main supplier in Nepal. Disabled Rehabilitation Society-Nepal, for instance, separately distribute more than 1000 wheelchairs per year in various parts of Nepal.

Out of 20 interviewees, 12 required regular use of some kind of assistive devices. One third of these did not have any device. Seven out of eight persons having an assistive device benefited from the INGOs/NGOS, whereas only one person benefitted from the program of GoN. The limited survey indicates the gap in accessing assistive devices. A large number of persons with disabilities are still beyond the coverage of GoN's policies and programs.

6.6 Gap between policy and practice

The first disability exclusive act, DPWA-1982, seemed to grant many rights and privileges to persons with disabilities. Disability rights activists and other concerned stakeholders have, however, persistently asserted that the act was solely provisionary and optional rather than practical and binding. Consequently, such provisions are not enjoyed by targeted groups.

GoN tries to escape from the execution of different legislations in the name of inadequate resources and something else. For instance, as a response to the writ application, the Supreme Court in August 2012 issued a direction order in the name of GoN to the effective implementation of existing legislations on disability with their deep sentiments. GoN instead turns its back to this order and attempts to ignore it in the pretention of the transitional period (political deadlock of the country) and limited resources of the present situation. The fact is thus that there is lack of due commitments of GoN and its various agencies in the implementation of legal provisions in practice[23]. In a nutshell, most of the Nepalese people with disabilities are prone to face the consequence of loopholes between policy and practice.

[23] A situation analysis of persons with disability: report on disability sample survey, 2001, by New Era for National planning commission Nepal.

GoN has adopted disability promoting policies and programs along with other marginalized groups and allocated some limited amount in the budget. However, as yet there has been no overall strategy and national mechanism to support implementation and monitoring of existing legislation. In an event on the celebration of American Disability Act (ADA), 1990, convened by the American embassy in Nepal on 26th July-2015, a representative of the Ministry of Women, Children and Social Welfare (MOWCSW) presented the existing policy framework and endeavours by GoN for its execution in practice. The allocated resources were not only ridiculously insufficient but also did not have appropriate monitoring mechanisms. This necessities revision of the DPWA in line with current international legislative frameworks such as UNCRPD and many more.

GoN ratified UNCRPD and thus agreed to implement the full enjoyment of rights by citizens with disabilities in Nepal. As Nepal ratified the convention on 7th May 2010, the nation should have made sure the granted rights to be reflected in the lives of the people. No doubt, it has gradually contributed to generate public awareness and paved the ways to further development throughout the nation, though some of the people opine it is too early to ratify the convention without proper groundwork for the same.

Besides the execution process for enjoyment of different rights by persons with disabilities, GoN should have prepared a national framework and established a coordinating focal point in each governmental agency (at least ministries) for the implementation and monitoring of the convention (article 33) which is not found to be happening even six years after the ratification. GoN, furthermore, should have prepared a report to be submitted to the CRPD Committee on Monitoring of Implementation of the Convention to ensure the full and effective participation of civil society, specially persons with disability and their representative organizations. Since it instead secretly submitted the report in 2014 without any consultation, NFDN is now preparing a shadow report based on extensive consultations with relevant stakeholders on behalf of civil society.

The National Planning and Plan of Action on disability (NPPAD, -2006) became executed less in practice but more on paper due to the absence of seriousness of GoN in implementing the policy and programs. Since GoN lacked a comprehensive monitoring mechanism, disability is not accomplished as a cross-cutting issue in different sectors. It also needs to be updated in accordance with the current national as well as the international scenario[24]. NFDN, therefore, realizes the need of further intervention for the enactment of a comprehensive monitoring mechanism for the effective implementation of different legislations, policies and programs.

GoN (Council of Ministries) enacted The Accessible Physical Structure and Communication Services Directive (2013) in the localization process of CRPD in Nepal. The directive does have obligatory provisions to make public places accessible for all persons with disabilities, both physically and in case of communication. However, even recently set up structures from the government side are found to be inaccessible which is of very serious concern for the disability community[25]. Most of the GoN agencies do have their own rules, including The National Building Code for any construction. The directive is however not taken into account or carried out in practice.

Some other inclusive laws and policies have also addressed issues of disability. The execution status is however unsurprisingly low. For instance, The Local Self-Governance Act -1999 authorizes local governmental offices (DDC, VDC and Municipality) to help in activities relating to the protection and livelihood of persons with disabilities. There are no adequate programs executed at the community level supported by the local government agencies, even though some of the self-help groups are utilizing the budget for the betterment of the disability community efficiently[26]. A 53 year old physically disabled woman from Ilam expresses:

[24] Different opinions given by diverse participants about NPPAD implementation in different workshops (specially in NPPAD review workshop, 2015) organized in the facilitation of NFDN.
[25] The article: Is it also opportunity for us?-BimalPaudelBimal Paudel; published in Rupantaran-2072-issue 2-earthquake special.
[26] 4 Holistic report: Monitoring the human rights of persons with disabilities in Nepal, 2013, NFDN/DRPI-Aware project.

"I have, as other persons with disability in my village, been provided NPR 200 to 300 per year from the Village Development Committee (VDC) office. More than that, I am no longer benefitting from such office. "[27]

This citation illustrates that most of the budget allocated for empowerment and development on disability is either distributed as small allowances or spent in other developmental activities.

6.7 Way forward

Some visible recommendations for further development:

No doubt, the lives of people gradually develop simultaneously with our society in course of time. However, steps need to be moved ahead for changes so that some visible improvements in the living standard of persons with disabilities shall be achieved. Some recommendations to the route for future developments are listed below:

- Most of the existing legislations/policies are solely provisional/optional, so that authorities are reluctant to execute what they had previously committed to. Existing legislations/policies thus ought to be revised/amended from a rights based perspective. Moreover, other necessary legislations/policies must be adopted as they will be mandatory and will have binding provisions to the end of effective implementation with strong elements for enforcing them, if they are neglected.
- The new constitution has just been promulgated. Concerned agencies must accountably step ahead in executing the enshrined rights of people with disabilities. The political leaders must essentially be committed to materialize the rights of persons with disability in a real sense.

[27] Voice of a 53 years female with physical disability, Ilam district)

- Disability is a cross-cutting issue. So, it must be incorporated within every sphere of development, i.e. legislations and policy development, and its implementation level.
- Disability policies and programs should clearly be directed to the improvement of the living standard of persons with disabilities, in particular in the rural areas and poor communities of the nation.
- A clearly prioritized budget needs to be allocated. Due to which, intervention is centralized on the development and empowerment of people with complete and severe disability so that development may cover the whole community.
- Presently, there needs to be, as stated in the CRPD, a comprehensive monitoring mechanism for the effective execution of existing policies and laws in practice. As a focal point of disability in Nepal, the Ministry of Women, Children and Social Welfare (MOWCSW) has to take the leadership for the same.
- All the concerned stakeholders have to work jointly for the betterment of targeted groups in line with the national policy and plan of action on disability.

6.8 Conclusions

We discussed previously on the loopholes between policy and practice and also tried to supply some recommendations for positive changes. It does not mean that no stones have been turned for the execution of existing legislations by the side of GoN. The government itself and through the non-governmental sectors is gradually putting its efforts into improving the living standard of persons with disabilities as of others throughout the nation. Presently, we have many chances leading to the positive transformation ahead.

Firstly, the new constitution of Nepal, 2072 (2015) has just been promulgated. Various noteworthy rights of persons with disabilities, including the right to political participation, are enshrined in the new constitution. Different issues regarding disability have been incorporated such as the fundamental rights, social justice, state's obligations, policies and guiding principles. The transformation of the situation of persons with disabilities can

be expedited simultaneously with the state transformation process. It has created the light of hope for future development.

Secondly, the Disability Protection and Welfare Act, 1982, in line with the CRPD is to be revised and enacted by the legislature/parliament of Nepal in the near future. The state shall forcibly be obliged to execute the provisions unlike in previous times. The Act may further accelerate the development for the betterment of targeted communities.

Thirdly, the National Policy and Plan of Action on Disability in Nepal, 2063(2006) is also being revised on the grounds of the current national and international scenario.

Fourthly, different stakeholders are eager to work together on issues of disability to the improvement of the living standard of persons with disabilities, preserving the achievements up to this time throughout the nation.

In a nutshell, so many endeavours are still floating to be completed, especially for the legislative framework development and its execution. On the other side, current dynamic opportunities undeniably shall lead to genuine changes in the lives of persons with disabilities.

Bibliography:

1. United Nations Universal Declaration of Human Rights, 1948,.
2. United Nation Convention on the Rights of Children (CDC), 2089.
3. United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), 2006.
4. Incheon Strategy,United Nations Economic and Social Council for Asia and Pacific (UN ESCAP), 2012.
5. Disabled Protection and Welfare Act, 1982 (DPWA), Government of Nepal.
6. Education Act: 7th Amendment, Government of Nepal.
7. Disability Rights Holistic Monitoring Report (2013): NFDN/DRPI-Aware project.
8. Disability policy in Nepal, 2006: a qualitative study by Disabled Human Rights Centre, Nepal (DHRC, Nepal).
9. A Feasibility Study on Community Based Inclusive Development and Inclusive Education in Nepal, April 2015 (RCRD, Nepal).
10. Challenges to measure and compare disability: a methodological concern, Madhusudhan Subedi, Dhaulagiri Journal of Sociology and Anthropology, Vol-06, 2012.
11. Barriers to the inclusive education of children with disabilities in Nepal: Futures Stolen, Human Rights Watch- Nepal, 2011.
12. The world report on disability, World Health Organization (WHO) and World Bank, 2011.
13. National Policy and Plan of Action on Disability, 2063 (2006), Government of Nepal-Ministry of Women, Children and Social Welfare (MOWCSW).
14. Special Education Policy in Nepal, 2053(1996), Government of Nepal- Ministry of Education and Sports.
15. Local Self-Governance Act, 2055(1999), Government of Nepal-Ministry of Local Development.
16. Government of Nepal, Ministry of Women, Children and Social Welfare (MoWCSW), Nepal Gazette, August 2006
17. Interim Constitution of Nepal, 2063 (January2007).
18. First draft of New Constitution of Nepal, 2072(July 2015).

19. The constitution of Nepal 2072 (September, 2015).
20. Report on National Census program, 2011, GoN Central Bureau of Statistics.
21. Report of National Living Standard Survey in Nepal, 2011, GoN Central Bureau of Statistics.
22. A Disability Resource Book, fourth addition, 2071 (2014), NFDN/UNICEF/MOWCSW.
23. A situation analysis of persons with disability: report on disability sample survey, 2001, New Era/UNICEF/National Planning Commission (NPC).

7 Conceptual understanding

A. H. Eide & S. Neupane

Disability and living conditions are core concepts to the study presented in this report. Both concepts are open to interpretation and can be perceived in different ways. While the International Classification on Functioning, Disability and Health (ICF) (WHO 2001) seems to gain ground as the main model on disability, it is important to be aware that the understanding of disability will vary from one socio-cultural context to another (Whyte & Ingstad, 1998). Some clarification of the conceptual understanding inherent in the current study is necessary for the interpretation and utilization of the results.

7.1 Disability

During the 1970s there was a strong reaction among representatives of organisations of persons with disabilities and professionals in the field of disability against the then current terminology. The new emerging concept of disability was more focused on the interaction between the individual and his/her environment, and on the close connection between the limitations experienced by individuals with disabilities, the design and structure of their environments and the attitudes and practice of the general population. Recent development has seen a shift in terminology and an increasing tendency towards viewing the disability complex as a process (the disablement process), involving a number of different elements on individual, societal and contextual levels. The traditionally dominant medical model of disability was challenged by the social model (Finkelstein & French, 1993; Shakespeare, 2014), leading further to development of an interactional model on disability (WHO, 2001).

The recently adopted UN Convention on Rights of People with Disabilities (CRPD) (UN 2006) defines disability as:

"Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (Article 1)

7.2 International Classification of Functioning, Disability and Health (ICF)

The adoption of the World Health Organization's International Classification of Functioning, Disability and Health (WHO, 2001) represents a milestone in the development of the disability concept. From 1980 and the first classification (The International Classification of Impairments, Disabilities and Handicaps (ICIDH) (WHO, 1980), a process over two decades resulted in a shift in the WHO conceptual framework from a medical model (impairment based) to a new scheme that focuses on limitations in activities and social participation. Although not representing a shift from a strictly medical to a strictly social model, the development culminating with ICF may be understood as a merge of the social and the medical model into an interaction model that implies a much wider understanding of disability and the disablement process.

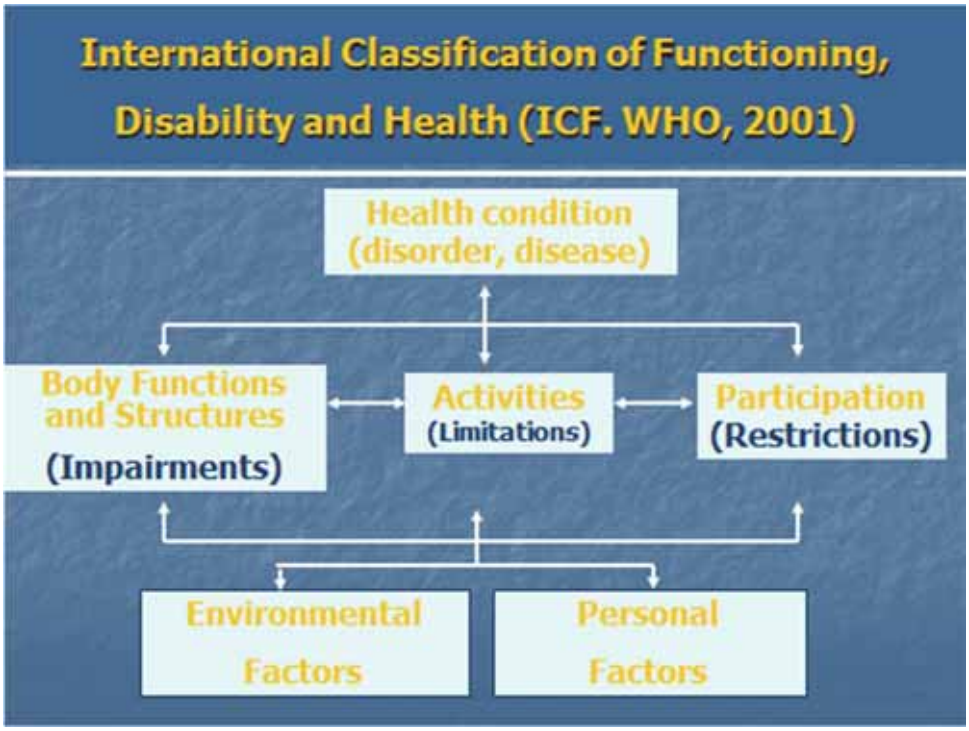


Figure B. The ICF model

7.3 Application of ICF in the current study

The development leading to the ICF is important as it has methodological implications and forms a new fundament for the collection of statistical data on disability. New

concepts and relationships between concepts influence how disability is measured. While the current study does not represent a full application of ICF, and it has not been the intention to test the new classification as such, the study has aimed to cover all elements of the model and in particular to approach disability as activity limitations and restrictions in social participation. This is pronounced in the screening procedure and in the inclusion of measures on activity limitations, participation restrictions and measurement of environmental barriers. The current study provides a unique possibility for applying some core concepts from the ICF and testing some aspects of the model statistically.

An understanding of disability as defined by activity limitations and restrictions in participation within a theoretical framework as described in Figure 1 underlies this study. The term “disability” is, with this in mind, a problematic concept since it refers to, or is associated with, an individualistic and impairment-based understanding. As a term, it is nevertheless applied throughout this text since it is regarded as a commonly accepted concept, and its usage is practical in the absence of any new, easy to use terminology in this sector.

Environmental factors are important elements in the ICF model, and it is fundamental to the present understanding of disability that activity limitations and restrictions in participation are formulated in the exchange between an individual and his/her environment. In the current study, environmental factors are included in separate section, utilizing an established research instrument. It is however acknowledged that studies like the current one traditionally focus on the individual and that this is also the case here.

7.4 Living conditions

The concepts of “level of living” or “living conditions” have developed from a relatively narrow economic and material definition to a current concern with human capabilities and how individuals utilise their capabilities (Heiberg & Øvensen, 1993). Although economic and material indicators play an important role in the tradition of level of living surveys in the industrialised countries, an individual’s level of living is currently defined not so much

by his or her economic possessions, but by the ability to exercise choice andto affect the course of his or her own life. Level of living studies have been more and more concerned with such questions and are currently attempting to examine the degree to which people can participate in social, political and economic decision-making and can work creatively and productively to shape their own future (UNDP, 1997).

A number of core items can be regarded as vital to any level of living study: demographics, health, education, housing, work and income. Other indicators may comprise use of time, social contact, sense of influence, sense of well-being, perceptions of social conflict, access to political resources, access to services, social participation, privacy and protection, etc. The choice of which indicators to include will vary according to the specific requirements of each study and the circumstances under which the studies are undertaken.

7.5 Disability and living conditions

Research on living conditions is comparative by nature. Comparison between groups or monitoring development over time within groups and populations are often the very reasons for carrying out such studies. The purpose is thus often to identify population groups with certain characteristics and to study whether there are systematic differences in living conditions between groups - or to study changes in living conditions within groups over time and to compare development over time between groups. Population sub-groups of interest in such studies are often defined by geography, gender, age - or the focus of the current research, i.e. people with disabilities vs. non-disabled. Research in high-income countries has demonstrated that people with disabilities are worse off along the whole specter of indicators concerning living conditions, and that this gap has also remained during times with steady improvement of conditions for all (Hem & Eide, 1998). This research-based information has been very useful for advocacy purposes, for education and attitude change in the population, as well as for planning and resource allocation purposes. These same patterns of systematic differences are also at work in low-income countries, as has been documented in our studies in other countries in the

region (op. cit.). When the stated purpose of the research is to study living conditions among people with disabilities, it is essential, at the onset, to decide upon a working definition of disability in order to identify who is disabled and who is not. This is a more complex issue than choosing between a “medical model” on one side and a “social model” on the other. How this is understood and carried out has major impact on the results of research, and consequently on the application of results (refer to chapter 3.1 on the disability concept).

The ICF may to some extent be viewed as an attempt to combine a broad range of factors that influence the “disability phenomena”. The authors behind this research report support the idea that disability or the disablement process is manifested in the exchange between the individual and his/her environment. Disability is thus present if an individual is (severely) restricted in his/her daily life activities due to a mismatch between functional abilities and demands of society. The role of the physical and social environment in disabling individuals has been very much in focus during the last 10 - 20 years with the adoption of the Standard Rules (UN 1994), the World Programme of Action (UN 1993), ICF (WHO 2001), and lately the UN Convention (CRPD) (UN 2006). It is logical that this development is followed by research on the mechanisms that produce disability in the meeting between the individual and his/her environment. It is true that studies of living conditions among people with disabilities in high-income countries have been criticised for not evolving from an individualistic perspective. Data are collected about individuals and functional limitations are still in focus. It is a dilemma that this research tradition has not yet been able to reflect the relational and relative view on disability that most researchers in this field would support today. While we agree to such viewpoints, we nevertheless argue that a “traditional” study is needed in low-income countries to allow for a description of the situation as well as comparing between groups and over time. In high-income countries such studies have shown themselves to be powerful tools in the continuous struggle for the improvement of living conditions among people with disabilities. In spite of an individualistic bias in the design of these studies, the results can still be applied in a critical perspective on contextual and relational aspects that represents important mechanisms in the disablement process.

7.6 Combining two traditions and ICF

The design that has been developed and tested here aims at combining two research traditions: studies on living conditions and disability studies. Pre-existing and validated questionnaires that had been used in Namibia (on general living conditions - NPC, 2000) and in South Africa (on disability - Schneider et. al., 1999) were combined and adapted for use in the surveys. A third element, on activities and participation, was included to incorporate the conceptual developments that have taken place in connection with development of ICF. By combining the two traditions, a broader set of variables that can describe the situation for people with disabilities are included as compared to traditional disability statistics. A possibility is established for a broad comparison of the conditions of disabled people (and households with disabled people) with non-disabled (and households without any disabled members). This comparative aspect is rather rare in disability statistics. In the current study comparison is made possible between case/control households and individuals. Further, the study is part of a long-term research activity with similar studies being carried out in southern Africa, creating a unique data base for comparison also across countries.

8 Design and Methodology

(S. Neupane & B. Suwal)

8.1 Introduction

The International Classification of Functioning, Disability and Health defines disability as "an umbrella term for impairments, activity limitations and participation restrictions (WHO 2011). According to the Population Census 2011, about two percent (1.94%; 513,321) of the total population reported to have some kind of disability in Nepal. Of them, physical disability constitutes 36.3% followed by blindness/low vision (18.5%), deaf/hard to hearing (15.4%), speech problem (11.5%), multiple disability (7.5%), mental disability (6%), intellectual disability (2.9%) and deaf-blind (1.8%).

Considering the need of addressing the problems of disabled, the Government of Nepal, through the Ministry of Women, Children and Social Welfare is launching various programs for the socioeconomic development of PWDs. The programs consist of various components like distribution of ID disability cards, community-based rehabilitation, production and distribution of support materials for PWDs and so on. The Government encourages involvement of NGOs and INGOs for implementation of various programs for the PWDs.

For viable planning and implementation of programs leading to upliftment of quality of lives of PWDs field-based data/information is needed. In this line, recently, the National Federation of Disabled in Nepal (NFDN) and the Norwegian Federation of Organizations of Disabled People (FFO), working under the umbrella of the Atlas Alliance, had agreed to carry out a National Study on Living Conditions among people with disabilities in Nepal. The planned study was part of an ongoing mapping of living conditions among individuals with disability in several countries.

The general objective of the study was to lay the groundwork for repeated long-term data collection on living conditions among PWDs in Nepal, seconded by the specific objectives of (a) carrying out a representative nation-wide study on physical, social, economic and

political participation among PWDs, and (b) generating a complete representative data set on living conditions among the PWDs.

8.2 Sampling design

To attain the aforesaid objectives, the study was carried out in 59 districts with representation of all the five development regions of Nepal – eastern, central, western, mid-western and far-western regions. The population for the study was both the persons with disabilities (PWDs) and without disabilities (non-PWDs) living in the household with and without disabled members. A total of 4000 sampled households (2000 households having PWD and 2000 households not having PWD) were included, and 4123 respondents (2123 PWDs and 2000 non-PWDs) were interviewed from these households. The list of study clusters by ecological regions with sampled VDCs is presented in Annex 1.

The prevalence of disability for Nepal may be assumed to be 10 per cent. A population with such a low prevalence rate of disability is generally considered to be statistically a case of “rare” phenomenon. Surveys of rare phenomenon generally require a different approach to sampling, particularly screening of target population[28]. It is mainly because if probability samples are drawn from total population, many ultimate sampling units (i.e. households) are likely to appear blank, meaning not containing target population under study. The screening design is generally recommended as a cost-effective and practical design whenever survey of rare phenomenon is carried out. The basic procedure of the screening design is “randomly select required number of primary sampling units (PSUs)[29], carry out screening of target units within each sampled PSU, and finally randomly select required number of ultimate target units”.

---

[28] Hard to see, harder to count: Survey guidelines to estimate forced labour of adults and children, International Programme on the Elimination of Child Labour (IPEC), Special Action Programme to Combat Forced Labour (SPA-FL), International Labour Office (ILO), Geneva, 2011. Also see, Sampling for household-based Child Labour Survey by Vijay Verma, International Programme on the Elimination of Child Labour (IPEC), International Labour Office (ILO), 2008, Geneva.

[29] “Wards” of the VDCs/municipalities which represent the smallest administrative and political units in Nepalwillbe treated as PSUs.

In this study, the screening design was employed as a two-stage stratified probability cluster sample design by selecting PSUs (PSU here is equivalent ward, also called as cluster) at the first stage, screening of target units (households with disabled members) in the PSUs, and selecting required number of ultimate target units within each PSU at the second stage. The sample design involved both the “target” (households with PWDs) and “control” (households without PWDs) groups

8.3 Sample size determination

a) Target group

Based on simple random sampling (SRS) at least 400 sample of “target group” and another 400 for “control group” are required for each region (region here refers to five development regions of Nepal – eastern, central, western, mid-western and far western). According to this estimate, a total of 4000 sample size was required for the present study – 2000 for target group (5 regions*400 households for each region) and 2000 for control group (5 regions*400 households for each region).

Assuming binomial distribution of variables, the minimum sample size required for a study like a cross-sectional study of this kind is generally estimated on the three statistical parameters: population variability measured as prevalence rate (proportion), **p**; desired level of precision measured in terms of standard error of proportion (**se$_{(p)}$**); and the level of confidence at 95%. In addition to this, it is essential to consider degree of response rate and analytical plan also while determining sample size. The formula for sample size estimate is given as,

$$n' = [\frac{1.96^2 * (p * q)}{s_e^2}]$$

$$n_{srs} = \frac{n'}{1+(n'/N)}$$

$$n_{clust} = (n_{srs} * deff)/0.90$$

where,

n'	=	*initial estimate of sample*
1.96	=	*normal standard deviation from t-distribution at 95 percent confidence level*
p	=	*population proportion (assumed to be 0.10)*
q	=	*(1-p)*
*p*q*	=	*indicator of population variability*
s_e^2	=	*desired level of precision measured in terms of standard error (assumed to be 5%)*
n_{srs}	=	*sample size for simple random sample (srs)*
N	=	*population size*
n_{clust}	=	*sample size for cluster design*
deff	=	*design effect (deff, assumed to be 2)*
0.90	=	*Response rate assuming non-response rate of 10 per cent.*

An exercise on the minimum sample required for the target group based on the above statistical assumptions for eastern region is shown below:

$$n' = [(\frac{1.96^2 * (0.10 * 0.90)}{0.05^2})]$$

$$= 138$$

$$n_{srs} = \frac{138}{1 + (138 / 5811555)} = 138$$

$$n_{clust} = (138 * 2.0) / 0.90$$

$$= 307$$

Under the above assumption, the minimum sample size came to 307 households for each region. When applied the sample size of 307 for all the regions, total sample size for target group at national level is 1535 (307*5 regions).

The sample size of 307 is minimum sample size only with consideration of statistical assumptions. In this respect, however, the plan for analyses should also be considered while estimating final size. In order to have more detail analysis of data, the minimum sample size has been increased to 400. Comparatively larger sample sizes are desirable in order to increase sampling efficiency and precision of the estimate by reducing the level of sampling error. A sample size of 400 appears to be more reasonable from a statistical as well as an analytical point of view for the present study. Assuming simple random sampling size of 400 for a region, we will estimate proportion (p) between 5 to 50 per cent of major survey variables under study with the standard error of 1-2.5 per cent.

b) Control group

Sample size for control group was the same as the target group. Accordingly, a sample size of 400 households for control group of each region was implemented, thus making a total of 2000 households from five development regions.

c) Sample stratification and allocation

The sample was equally allocated to five development regions namely Eastern, Central, Western, Mid-western and Far-western Development Regions which was followed by a two-stage stratified probability cluster sample design. Table 1 presents total sample size for each region according to target and control group. 800 households (400 for target and 400 for control group) were drawn from each region. The national sample size for each group was 2000 with the total sample size of 4000. The samples came from a total of 100 clusters all over the country. In each region, 20 clusters were selected.

Table A: Summary of sample size by region according to target and control group

S. No.	Development Region (stratum)	# of clusters to be sampled	# of households to be sampled per cluster	Total household sample from target group	Total household sample from control group	Total household sample from target and control group
(1)	**(2)**	**(3)**	**(4)**	**(5)=(3)x(4)**	**(6)=(3)x(4)**	**(7)= (5)+(6)**
1	Eastern	20	20	400	400	800
2	Central	20	20	400	400	800
3	Western	20	20	400	400	800
4	Mid-western	20	20	400	400	800
5	Far-western	20	20	400	400	800
	Total	**100**	**-**	**2000**	**2000**	**4000**

8.4 Selection of enumeration areas

In a cluster design like this, one cannot take too many households (HHs) from a cluster because it tends to increase clustering effect and reduce sampling efficiency. In this respect, samples of 20 households per cluster are generally recommended with an expected design effect of two[30]. Based on this, 20 clusters were selected from each region in order to attain the sample size of 400 households (400/20 HHs per cluster). In addition, 20 control households were selected from the same cluster selected for the target group.

8.5 Household listing and screening

Upon arrival in the sampled Ward (cluster) the field team first contacted the representative of VDC/municipality and briefed them about the purpose of the study and field plan along with the letter from Ministry of Women and Children, Government of Nepal. These letters were issued with a motive to inform that this research was taking

[30] A. G. Turner, *Master Sample for Multi-purpose Household Surveys in Nepal: Detailed Sample Design*, Submitted to National Planning Commission (NPC). Kathmandu: National Planning Commission, Government of Nepal, 1994.

place in the VDC/wards and to provide necessary support and cooperation in the process of conducting the research.

Prior to proceeding to the data collection activity, the survey team, in consultation with the local leaders and key informants of the sampled cluster, prepared a sketch map of the sampled ward(s). The maps were prepared carefully consisting of the most essential information including name of the places adjoining to the ward, roads and pathways, names of blocks, main public places, temples, schools, health facilities and estimated number of households. The purpose of preparing the sketch map was to locate the settlements within the ward in the sketch maps and make familiar the field teams with the geography of the sampled ward. Then the team enumerated list of families (households) currently residing in the sampled ward(s) using the household listing and screening forms specifically developed for the purpose of this study.

Where the selected ward had less than 150 households the adjoining ward was merged to make a single cluster. On the other hand, where the selected ward had more than 250 households it was divided into segments by distributing the total households equally into two parts and one cluster was selected by lottery technique for information collection. Similarly, where the selected ward had 550 households it was divided into three clusters following the procedure as mentioned above. The same procedure as mentioned above was adopted to divide the clusters into more numbers according to the proportion of increased number of households in the ward.

Upon preparation of sketch maps of the sampled ward(s), the field team filled up the ***household listing and screening form*** systematically beginning from a particular point of the cluster and listing the households according to the name of the village. Then required numbers of households were selected for interviews from this list. The field team recorded the location of the households clearly, including the name of the village which helped them identify the households later on for interview.

8.6 Selection of households

Selection of households having PWDs (Case households)

Upon completion of household listing, the field team prepared a new list of households which had person/s living with disability (PWD) giving a new serial number. Then 20 households with PDWs were selected systematically (by using random number sampling technique) from the list. After identifying the sample household, they first administered **Questionnaire for Head of Household** to collect household level information followed by interview with PWDs (3 to 80 years of age) of the sampled household using the **Individual Questionnaire for PWDs**. All PWDs (3 to 80 years of age) living in the sampled households at the time of survey were contacted for the interview.

Where the required number (n=20) of households with PWDs in the sampled ward was not available, the field team had to visit the adjoining ward and administer ***household listing and screening form*** to identify a sufficient number of eligible household. Once interview in 20 households were completed they stopped interviewing PWDs from that particular ward. If a household had more than one PWDs, all PWDs were selected for interview.

Selection of households without any PWD (Control households)

Households without PWD were selected from the same ward. For this purpose, the field team first interviewed the head of the household with a PWD member, and next the eligible PWD(s). After completion of the interview with the household head and the eligible PWD(s), the team continued with selecting the nearest household in which there were family members whose age and sex matched or nearly matched with the same age and sex of the interviewed PWD. The age of the non-PWD selected for the interview was 5 years more or less from the age of the interviewed PWD. Where there was more than one non-PWD in the household of which age and sex matched with the age and sex of interviewed PWDs included, only one non-PWD was selected randomly from that household.

8.7 Data collection tools

Development of questionnaires

Three sets of survey instruments were developed and used for data collection – one for household head, one for persons with disability (PWD) and one for persons without disability. In addition, a *household listing and screening form* was used to identify and select PWDs and non-PWDs in the sampled clusters.

Pre-testing of questionnaires

The Nepali version of the questionnaires was pretested in the rural areas of Kathmandu Valley. After the pre-test, a debriefing meeting was organized to get feedback on the questionnaires and their administration. The survey questionnaires were modified based on the pre-test findings

8.8 Disability screening in the context of the survey

In order to identify the PWDs for this survey a screening form consisting of six criteria was used. Those households meeting at least one of the six criteria (i.e. answering at least "some problems" to any of the six questions) were considered as a household with PWDs. The six criteria included in the screening form were person having:

- difficulty seeing, even if wearing glasses
- difficulty hearing, even if using a hearing aid
- difficulty walking or climbing steps
- difficulty remembering, concentrating, or both
- difficulty with self-care such as washing all over or dressing
- difficulty, using the usual (customary) language, communicating (understanding or being understood by others)
- For all six questions the follow answers were possible: (no difficulty (1), some difficulty (2), a lot of difficulty (3), cannot do at all (4)

8.9 Research team (field organization and data collection)

The data were collected by 62 data collectors consisting of both genders under the overall supervision of VaRG senior researchers. Of the 62 data collectors 31 were males and 31 were females. These data collectors were selected from among those who have previous knowledge and experiences in conducting field surveys in the rural and urban areas of the country.

Training of field staff

The training of the data collectors was conducted for six days in Kathmandu in November 2014. Training topics included description of study objectives, short presentations, role-play and field practices. In addition, all field staffs were given training on maintaining consistencies in administration of the questionnaires, research ethics and field management. The trainees were evaluated during and after the training. All of them performed well and, therefore, were selected for field work.

Data collection procedure

15 teams consisting of one supervisor and 3-4 interviewers in each team worked in the study areas to collect necessary information. All questionnaires were administered in Nepali language. Information was collected through face-to-face interview. The interviewers were made mainly responsible for interviewing the household level respondents. The field supervisors were made responsible primarily for rapport building with the community, preparing sketch maps of the sampled clusters, sampling, supervising the interviewers work and questionnaire scrutiny.

In order to ensure the thoroughness of the data collection work, the senior researchers also visited some of the study areas to supervise and monitor field work. In addition, frequent telephonic communication with the field teams was also maintained to monitor the data collection activity. Field work was conducted during December 2014 and February 2015.

8.10 Data processing and analysis

a) Data entry and software

All the filled-up questionnaires were manually edited and coded, and entered into computer by trained data entry personnel. Data was entered/processed using CSPro4.1 and SPSS software packages. Data entry was directly done from the filled up questionnaires. Numbers of quality check mechanisms such as range and consistency checks were adopted to minimize the data entry error. The computer programmer constantly supervised and monitored the data entry activities. The programmer also randomly checked entered data on a routine basis. Machine editing of the data was done by developing a computer program. The cleaned data set was then transferred to SPSS and a SPSS system file was prepared for output generation.

b) Weight calculation

The weight calculation was performed in the present study to adjust the effect of imbalance representation of estimation domains due to over and under sampling. As described above, five development regions constitute estimation domains for the present study which were represented with equal sample. Equal allocation of sample to the study domains had led to over sampling of some study domains while others being under sampled.

Weight calculation was done in two step processes. At the first step, raw weight was calculated as an inverse of combined probabilities of cluster and household. Combined selection probabilities in PPS method (P_{jh}) is given by

$$P_{jh} = \frac{(a_{h*}m_{jh})}{M_h} * \frac{n_{jh}}{N_{jh}}$$

where,

M_h = total number of households in the domain h

a_h = total number of clusters selected from the domain h

m_{ih} = total number of households in j^{th} sampled cluster of domain h

N_{jh} = total number of households from the household listing operation in j^{th} cluster of domain h

n_{jh} = total number of sample households selected from the j^{th} cluster of domain h.

Inverse of the combined probabilities (W'_{jh}) is given by

$$W'_{jh} = \frac{1}{P_{jh}}$$

Here, W'_{jh} represents raw weight which is generally known as multiplier or expansion factor. Raw weights can be used to extrapolate sample value to population value. But if findings are to be presented with sample cases, then raw weight should be normalized with its mean. Normalized weight is generally called as relative weight equivalent to sample cases with adjustment of unequal selection probabilities between the study domains. Raw weights are normalized with following process

$$W_{jh} = \frac{W'_{jh}}{\sum W'_{jh} / a}$$

Where,

W_{jh} = normalized weight (relative weight)

W'_{jh} = raw weight for j^{th} cluster of domain h

a = total number of cluster selected (100 clusters)

$\Sigma w'_{jh}/a$ = mean weight over all the sample clusters

Data for weight calculation was managed in excel with proper identification (ID) of the study domain and cluster. Weight are calculated in excel and transferred to a data file which is managed in SPSS/PC.

Annex 1 List of sampled wards, VDCs and districts by eco-development region

Mountain		Hills		Terai	
Districts and Development region	VDC/Muni-cipality and ward	Districts and Development region	VDC/Muni-cipality and ward	VDC/Muni-cipality and ward	
Taplejung (E)	Change - 9	Panchthar (E)	Subhang- 9	Jhapa (E)	DamakMun -11
Sindhupalchok (C)	Gloche -1	Ilam (E)	Shanti Danda – 3		Mahabhara – 3
Dolpa (MW)	Likhu -5	Terhathum (E)	Myanglung – 1		Taghandubba – 4
Kalikot(MW)	Marta -4	Bhojpur (E)	Dummana– 4	Morang (E)	Biratnagar Sub-Metro – 11
Bajura (FW)	Baddhu -8	Okhaldhunga (E)	Khijifalate – 3		Itahara – 9
Bajhang(FW)	Banjh - 3	Khotang (E)	Yamkha – 8		Sanischare – 9
	Melbisauni -	Udayapur (E)	TriyugaMun – 12	Sunsari (E)	Bhokraha - 2
Darchula (FW)	Dadakot - 5	Ramechhap (C)	Gelu – 1		InaruwaMun – 7
		Kavre (C)	UgrachandiNala – 5		RamnagarBhutaha – 9
		Lalitpur (C)	Lalitpur Sub-metro – 15	Saptari (E)	Kachan -7
		Bhaktapur (C)	MadhyapurThimi Mun– 17		Theliya – 3
		Kathmandu (C)	Jorpati– 8	Siraha (E)	KalyanpurJabadi - 8
			Kathmandu Metro – 10	Dhanusa (C)	JanakpurMun – 4
			Kathmandu Metro – 29	Mahottari (C)	Bijayalpura – 9
			Mahadevathan– 3	Sarlahi (C)	Bagdaha -8
		Nuwakot (C)	Ralukadevi– 8		Parwanipur – 3
		Makwanpur (C)	Agara– 4	Rautahat (C)	Bishrampur – 3
		Gorkha (W)	Aarupokhari – 1	Bara (C)	Amab – 9
			Sirdibas – 7		ShreenagarBairiya – 2
		Tanahu (W)	Anbukhaireni – 5	Parsa (C)	Thori – 5
			Khairenitar – 8	Chitawan (C)	Mangalpur – 7
		Syangja (W)	Malyangkot – 1	Nawalparasi (W)	Baidauli – 9
		Kaski (W)	Hansapur– 9		Makar – 4
			Pokhara Sub-Metro – 7		Sunwal - 3

Mountain		Hills		Terai	
Districts and Development region	VDC/Muni-cipality and ward	Districts and Development region	VDC/Muni-cipality and ward	VDC/Muni-cipality and ward	
		Parbat (W)	Sarangkot – 9 Khurkot– 6	Rupandehi (W)	ButwalMun - 13 LumbiniAadarsha – 7
		Baglung (W)	BaglungMun– 2		Siddharthanagar Mun – 8
		Gulmi (W)	Dohali – 7	Kapilbastu (W)	Hariharpur – 1
		Palpa (W)	Devinagar– 3		Tilaurakot – 2
		Pyuthan (MW)	Baraula – 1	Dang (MW)	Hapur – 3
			PythanKhalanga - 7		Rampur - 8
		Rolpa (MW)	Liwang – 6		TulsipurMun – 1
		Rukum (MW)	Kanda – 7	Banke (MW)	Hirminiya - 2
		Salyan (MW)	Darmakot– 6		NepalgunjMun – 1
			Tharmare– 1		Sonpur – 8
		Surkhet (MW)	BirendranagarMun– 10	Bardiya (MW)	GulariyaMun - 6
			Malarani – 3		Patabhar – 2
		Dailekh (MW)	Gamaudi – 5	Kailali (FW)	Chuha – 4
			Toli– 5		DhangadhiMun – 4
		Achham (FW)	Dhamali – 5		Godawari – 6
			Ramarosan– 2		Masuriya – 7
		Doti (FW)	DipayalSilgadhi Mun – 8		RamsikharJhala – 9
			Saraswotinagar– 2		TikapurMun – 9
		Dadeldhura (FW)	AmargadhiMun – 3	Kanchanpur (FW)	Dekhatbhuli – 6
		Baitadi (FW)	Amchaur – 8		BhimdattaMun – 3
			Mahadevsthan– 1		Pipaladi - 8

Note: (E): Eastern Development Region; (C): Central Development Region; (W): Western Development Region; (MW: Mid-Western Development Region; and FW: Far-Western Development Region

Mun= Municipality

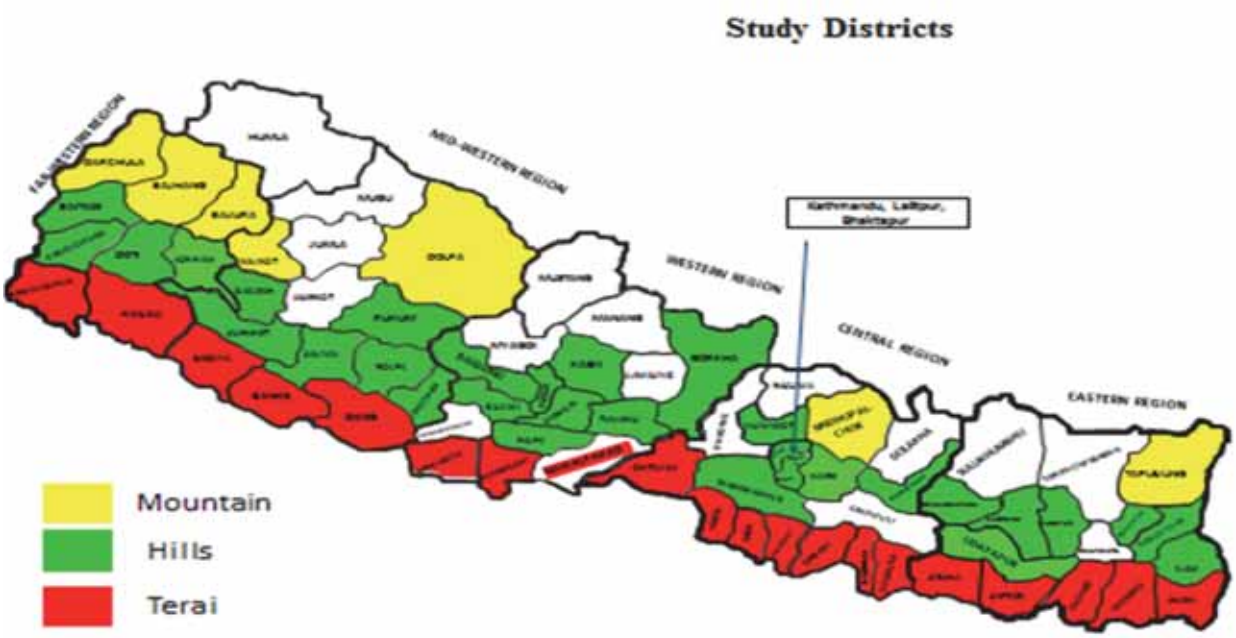


Figure A. Study districts

9 Results

The results are presented in two sub-sections:

1. **Household section:** Results from comparative analyses between households with at least one member with disability (case HHs) and households without a member with disability (control HHs) (household data). Head of household or someone knowledgeable about the household was the main informer.

- Data on every member in the household were also collected (household roster).

2. **Individual section:** The results are based on a detailed survey that specifically addresses the situation of persons identified with disability. The disabled person or a proxy was the informer (Individual data).

- This section also includes some comparisons on level of living conditions between persons with (case individuals) and without disability (control individuals).

Throughout this chapter, the term ‘Disability’ and ‘Control’ will be used interchangeably with household or individuals with or without disability. Here, the term ‘Disability’ refers to individuals with activity limitations (i.e. disabled person) or households with member(s) with activity limitations (i.e. disabled household). The term ‘Control’ refers to individuals without functional limitation (i.e. control person) or households without any member with functional limitation (i.e. control household). We will also use "individuals with disability", "person with disability" and the short form "pwd" to mean the same thing.

Sampling weight was implemented in the analyses to account for the differences in the population and households in the different provinces. The purpose of weight in the present study is to adjust the effect of imbalanced representation of estimation domains due to over and under sampling. Particular care has also been taken during the analyses to control for both gender and regional (districts) differences. Whenever these potential confounders have revealed significant differences, these are commented in the text, otherwise not.

9.1 Household section

(Source: Household data)

In general, a household consists of a man, his wife, and their children with or without other relatives, domestic servants, boarders and lodgers. In other words, it refers to persons who *live and eat together*. A person who lives alone and caters for herself/himself forms a one-person household. The main unit of the survey is the household as defined above. We are further interested in information about only the permanent members of the household – that is visitors were *excluded* and temporarily absent members were *included*. Those at boarding schools or those away for seasonal work are considered as members of the household while those in long-term institutions are not considered as members of the household. Family members living and/or working abroad are not considered as permanent household members.

A total of 18,223 households were screened using the Washington City Group (WCG) (CDC, 2010) questions on disability primarily to identify households with member(s) with disability for detailed interview. The head of the household or someone who were knowledgeable about the household was the key informer. The total number of households with persons with disability was 2,636, giving an overall prevalence of disability on 14.5% of households[31]. The total population in the screening was 90,461, giving an average household size among the screened households of 4.96 persons per household. As it is an average of 1.06 disabled persons in the case-households (households with PWD), our overall rough estimate of disability prevalence is 14.5 pct. / 4.96 * 1.06 = 3.1 pct.

Results from the household screening were used as population frame to select households and individuals with and without disability for detailed interview.

[31] See Annex 2 in the Survey Field Report, June 23 2015

9.1.1 Household characteristics

Number of households and individuals in the households is presented in Table 1.

Table 1. Total study sample: Households and Individuals in the households

	Number of:	
	Households	Individuals
Disabled	2000	2123
Control	2000	2000
Total	4000	4123

The table below presents the proportion of households included in the detailed interview according to the different development regions in Nepal.

Table 2. Sample of households by region

Region	Households			
	Disabled	Control	Total	
	n	*n*	*n*	(%)
Eastern	508	444	952	(23.8)
Central	813	707	1520	(38.0)
Western	293	412	705	(17.6)
Mid-western	219	263	482	(12.0)
Far western	167	174	341	(8.5)
Total	2000	2000	4000	(100.0)

The distribution of head of households and disability status is presented in the table below. A total of 16.0% of the household heads were persons with disability. A total of 20.8% of the households (both cases and controls) reported to have a female head, with slightly more female heads in the case households. There was further no significant difference in gender distribution between households with and without disabled member and marginal urban-rural differences.

Table 3. Head of household by gender and disability status

	Individual with disability	Individual without disability
Male household head	15.9	84.1
Female household head	16.1	83.9
Total	16.0	84.1

Table 4. Head of household by gender and location

Head of household	Urban %	Rural %
Male	78.5	79.9
Female	21.5	20.1
	2000	2000

9.1.2 Household size

Household size refers to the number of individuals living in a household. Household size in this study has a range from one person to 22 persons (Figure 1).

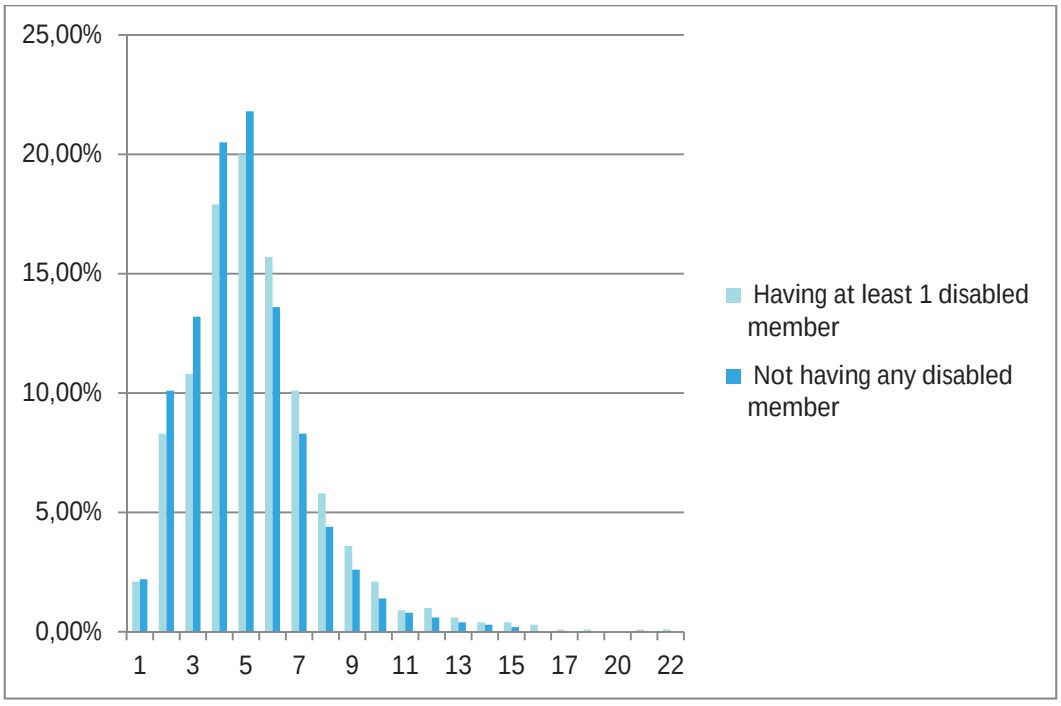


Figure 1. Number of persons in households by household type. Percent

In general, disabled households (with at least one disabled member) have significantly more household members than control households (5.4 vs. 4.9, p=0.000). However, despite the tendency that mean household size is higher in households with at least one member with disability compared to control household, detailed analyses revealed that the difference is only significant in Eastern, Central and Mid-western region, but not in Western or Far western region (Figure 2).

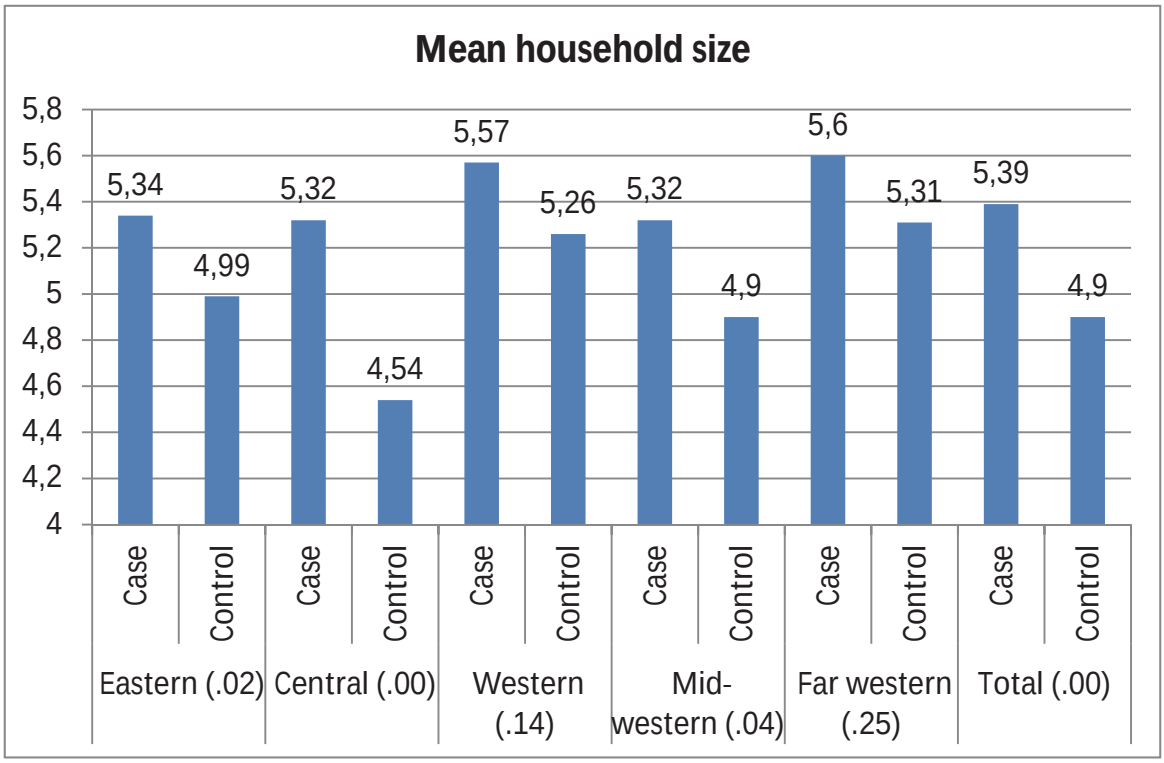


Figure 2. Average number of persons in households by household type and development region[32]. Percent. (N = 4000)

Some households comprised more than one disabled member. Therefore, the total number of disabled persons (case) in the households was 2123, giving an average number of 1.06 disabled persons in the 2000 case households.

[32] P-values in parenthesis

9.1.3 Age of members

The mean age in case households were marginally lower than in the controls, namely 28.8 and8and 29.0 years respectively. The age distribution do not differ much between the two household types (Table 5).

Table 5. Age by household type. All members in the household.

Age Group	Disabled HH	Control HH
	Percent	
0 – 10	21,6	20,6
11 – 20	23,2	24,1
21 – 30	15,9	15,3
31 – 40	11,6	12,7
41 – 50	10,2	10,0
51 – 60	7,7	8,6
61 – 70	6,6	5,9
71 and above	3,2	2,8
Total%	100	100
N	10 693	10 031

9.1.4 Dependency ratio

Another measure of the structure of households is the dependency ratio. This is a measure of the proportion of a population that is composed of dependents (people who are too young or too old to work). Here, we defined dependents as those who were below 15 years or over 65 years, while working-age is defined by those aged 15 to 65 years. Therefore, the dependency ratio is equal to the number of dependents divided by the number of individuals in working-age[33]. A rising dependency ratio is of concern to countries with quickly aging populations, since it becomes difficult for pensions systems to provide for this older, non-working population. A rapidly growing population with a high

[33] Dependency ratio (d) = $\frac{N_{\leq 14} + N_{\geq 65}}{N_{15-64}}$ $\frac{N_{\leq 14} + N_{\geq 65}}{N_{15-64}}$

fertility rate implies that a relatively large proportion of the population consists of children who are dependent on their families for sustenance.

A dependency ratio of 0 means that the household consists of only individuals between 15 to 64 years old (i.e. working-age), while dependency ratio of 1.0 means there is one working-age person for each dependent in the family (e.g. a family of four with two adults and two children). Dependency ratio under 1.0 is indicative of less burden on the wage earners in the family and dependency ratio over 1.0 indicates a burden. It illustrates the economic responsibility of those economically active in providing for those who are not.

Analysis of the overall data shows that there is a marginal and non-significant difference between disabled and control households; 0.78 and 0.74 respectively (p=0.087, Figure 3). The variation between regions is more pronounced than the variation between disabled and control, and the difference is only significant within the Central development region. (This region also has the largest number of observations).

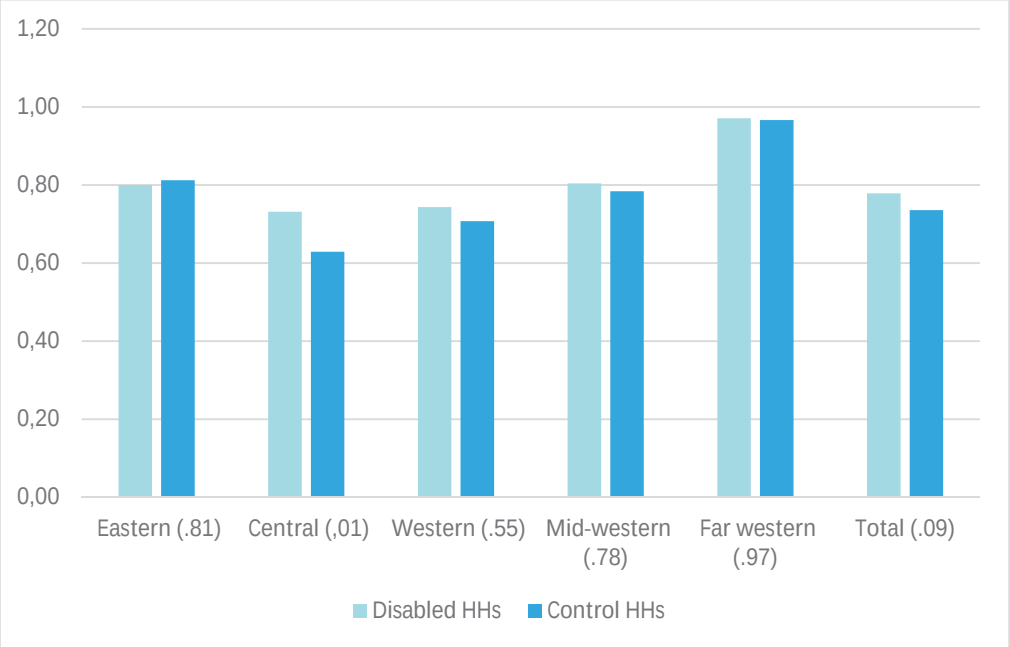


Figure 3. Dependency ratio by household type and region[34]. (N = 4000)

[34]P-values in parenthesis

9.1.5 Gender

There was no significant difference in the gender distribution between casebetweencase and control households (48.4% males in total survey). This pattern is found in all regions. There were a total of 10748 females and 9976males included in the sampled households. Mean age among females was 28.8 years and 28.2 years among males (difference not significant).

9.1.6 Socioeconomic status

Socioeconomic status (SES) was measured by asking questions on household possession of different items in the household. The questions ranged from items such as bed or radio to expensive items such as refrigerator, washing machine or car. There were 29 items being asked with “yes-no” answer. An aggregated score is the sum of all the items (fig 4). The figure shows that control households were more likely to have more items than case households ($p < .001$).

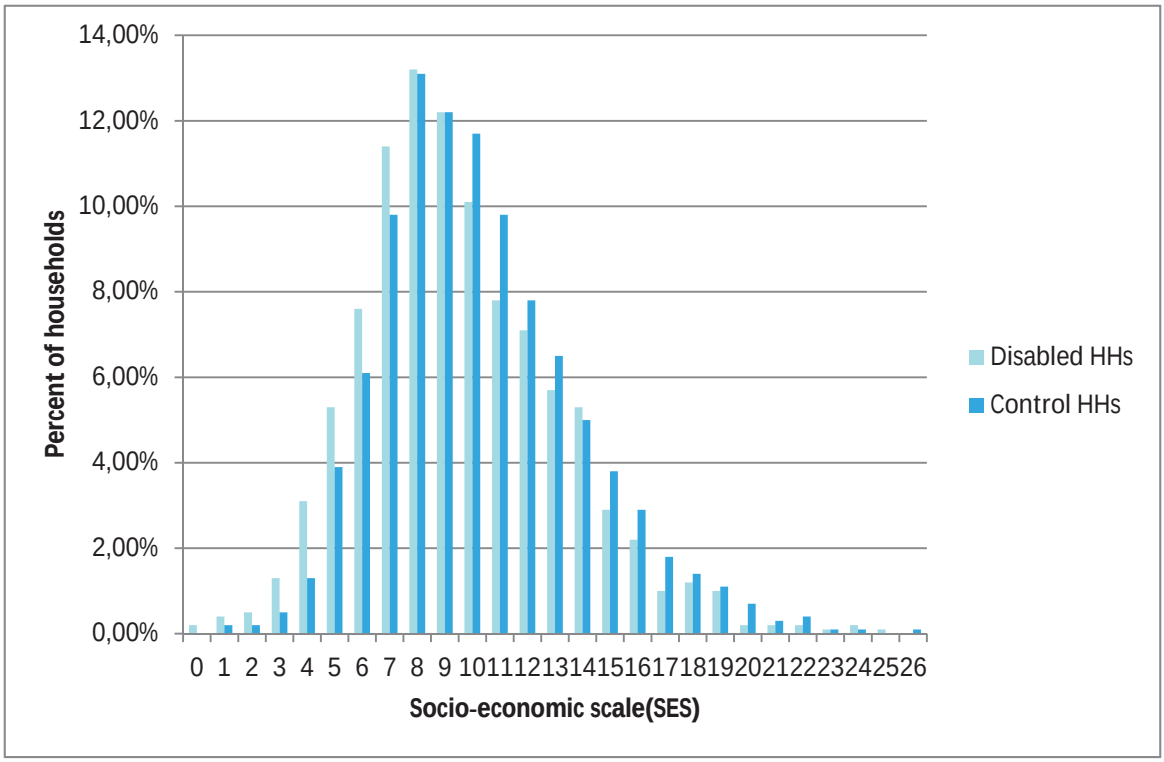


Figure 4. Socio-economic scale by household type. (N = 4000)

Adding the 29 items together produced an SES scales (asset scale) with mean value 10.18, range from 0 to 26, and standard deviation 3.63. The mean scale value among households with disabled members was 9.67, and 10.67 among control households. The mean values were 11.73 (disabled HHs) and 12.84 (Control HHs) in urban areas and 9.28 (disabled HHs) and 10.03 (control HHs). Thus, SES is higher in urban than in rural areas, and significantly higher among control households in both urban and rural areas.

Looking at the average SES for the different regions reveals that the difference between regions is larger than the difference between disabled and control (Figure 5). On average the difference is exactly one item, meaning that disabled households (even often larger than controls) have smaller resources than control households ($p < .001$).

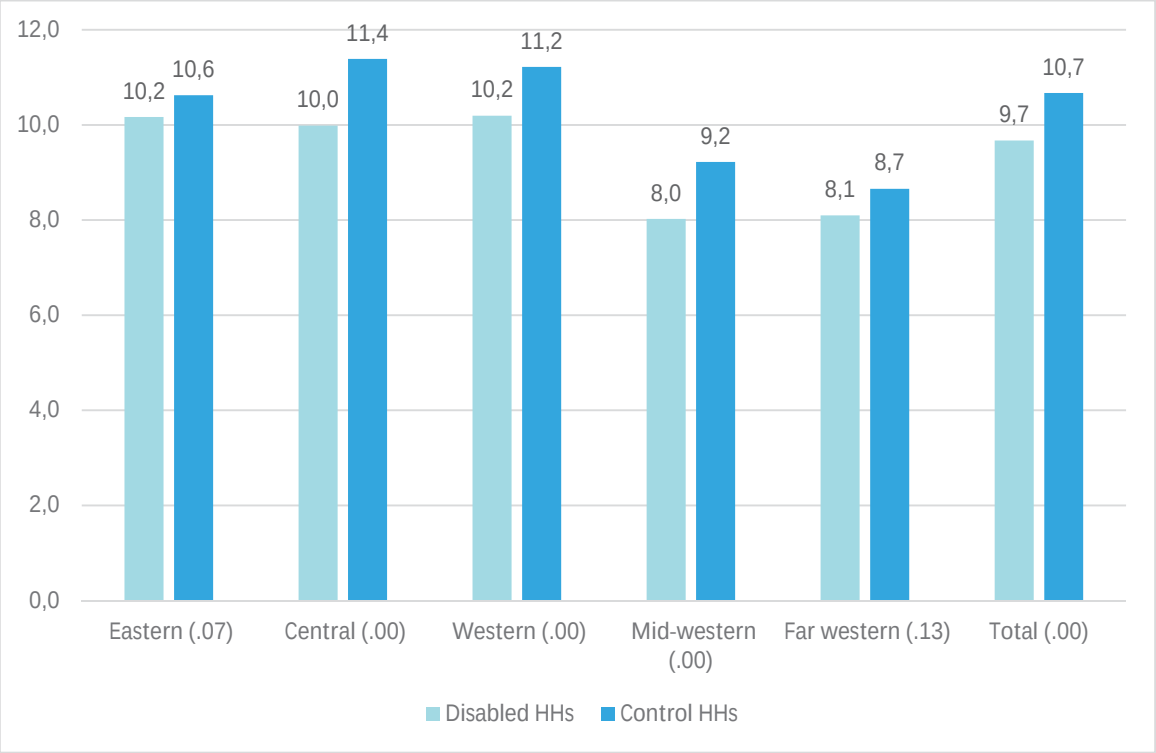


Figure 5. Average socio economic scale by household type and region. (N = 4000).

With regards to primary source of income in the households, 39.4% of the case households reported “wage or salary work” as the main household income compared to 41.4% among control households (Figure 6).

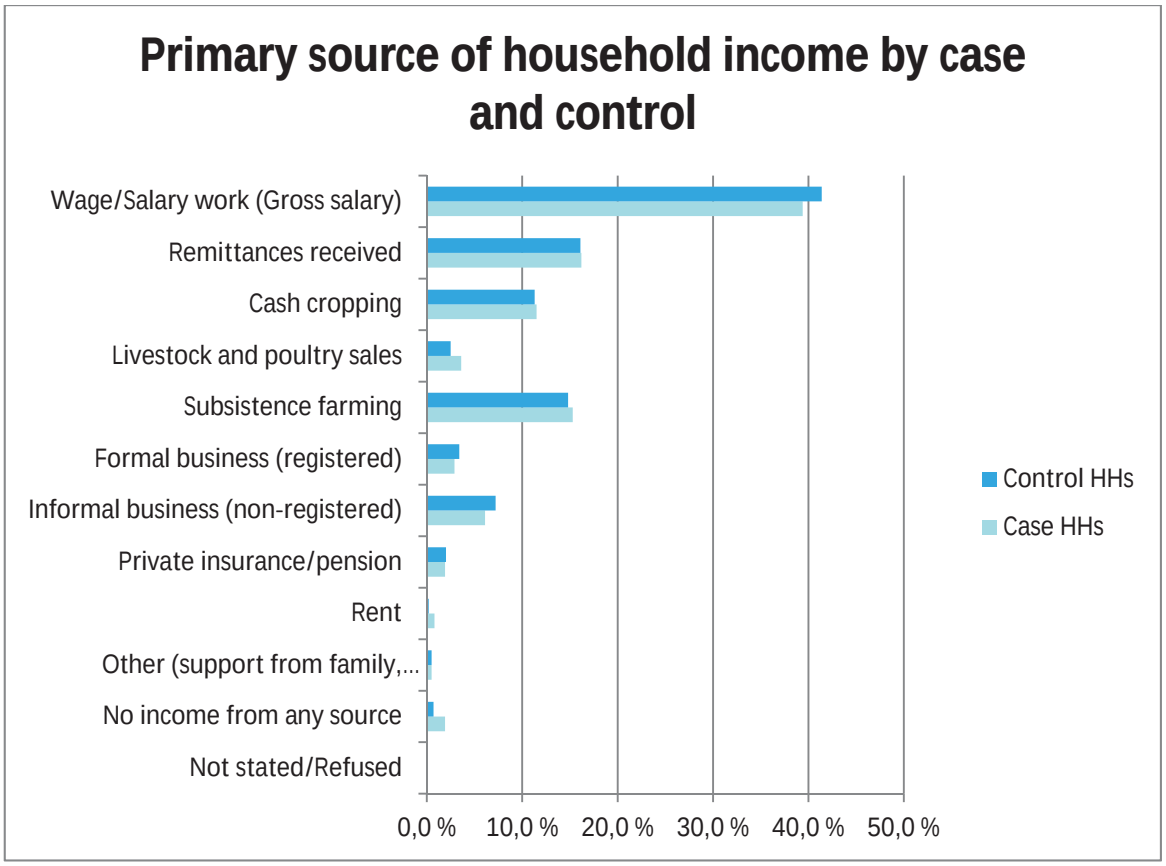


Figure 6. Primary source of household income by household type. Percent. N = 4000

Ranking of expense categories was measured on a six-point scale ranging from 0 to 5, where 5 indicated that most of the household income was spent on a particular category. As shown in Figure 7, Food and beverages had the highest score, i.e. ranked as highest among both household types. This was followed by culture and entertainment, clothing and footwear, and Medical care/health services. At the lower end we find Domestic servants, Rent and building materials, Tobacco and Alcohol. For nine of the items there was a significant difference between disabled and control households. Disabled households ranked Disability related expenses, Medical care/health services and Agricultural inputs higher than control households. On the other side, control households ranked Food, Rent, Fuel, Transport, Education, and Savings higher than disabled households.

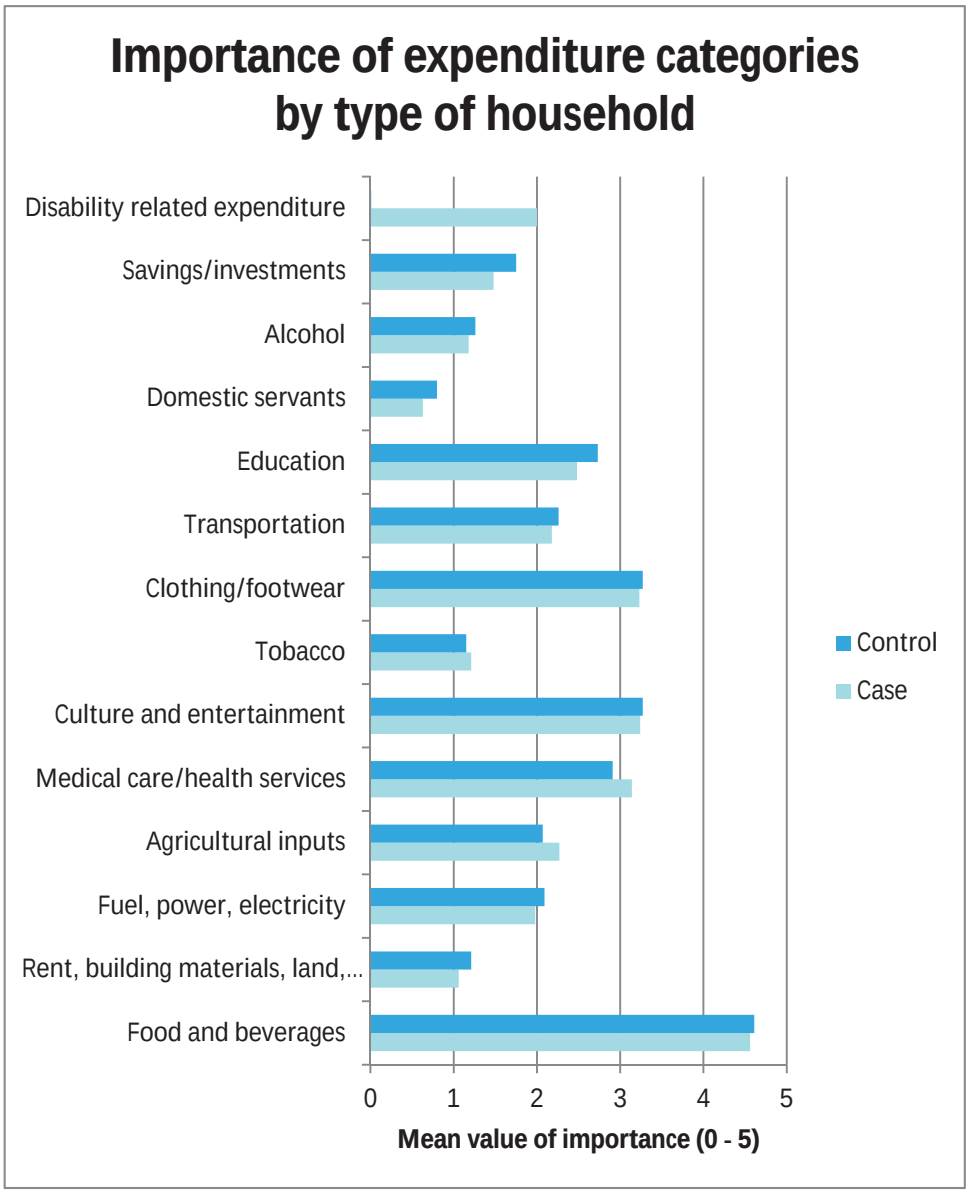


Figure 7. Importance of expenditure categories by household type. (N = 4000)

9.1.7 Dietary diversity

Household dietary was assessed by the Household Dietary Diversity Score (HDDS) (Swindale 2006). The assessment was based on 12 different food groups consumed in the household in the past two weeks (Figure 8).

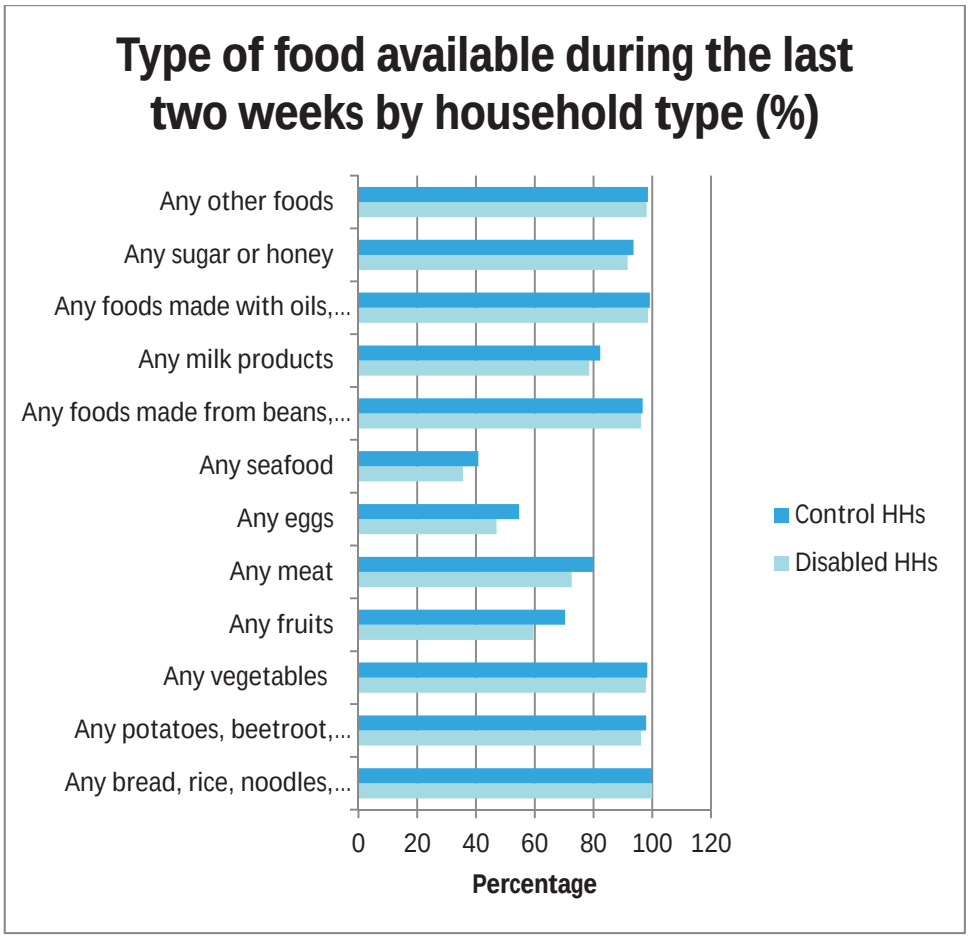


Figure 8. Type of food ate in the past two weeks by household type. Percent. (N = 4000).

For all the 12 different food items in Figure 9 except the first one (bread, rice, noodles, biscuits), control households score higher. While the difference is relatively small for several of the food items (five differences are non-significant), the largest differences were found for fruits (17.7 percentage points) and eggs (7.4 percentage points).

The twelve food items in Figure 8 were added together to form a Dietary diversity scale (mean value 9.88, range 0 – 12, standard deviation 1.70). Households with disabled members had a mean scale score of 9.72 and control households 10.12.

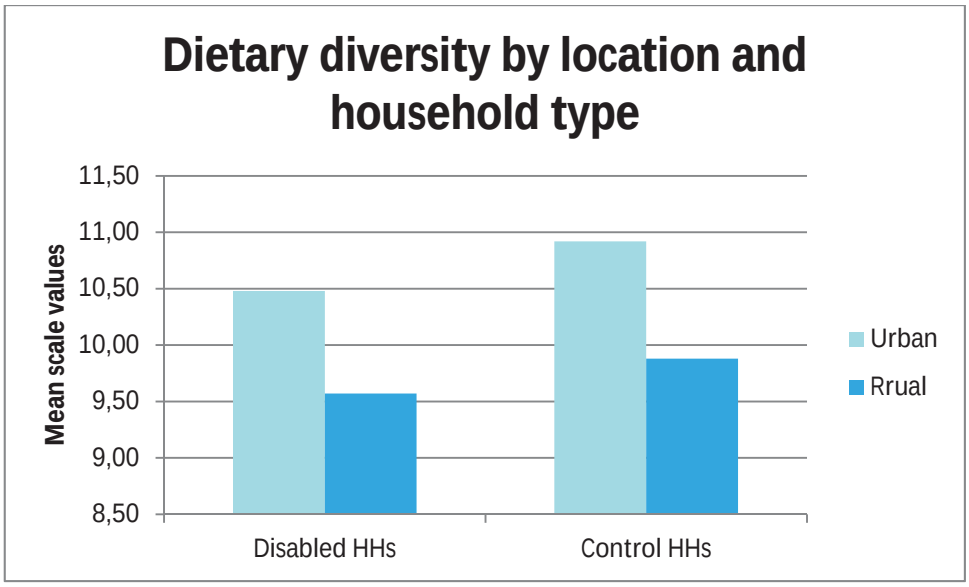


Figure 9. Dietary diversity scale mean values by location and HH type. (N = 4000).

Dietary diversity is significantly higher among control households both in urban and rural areas. Urban households have a more diverse diet as compared to rural households.

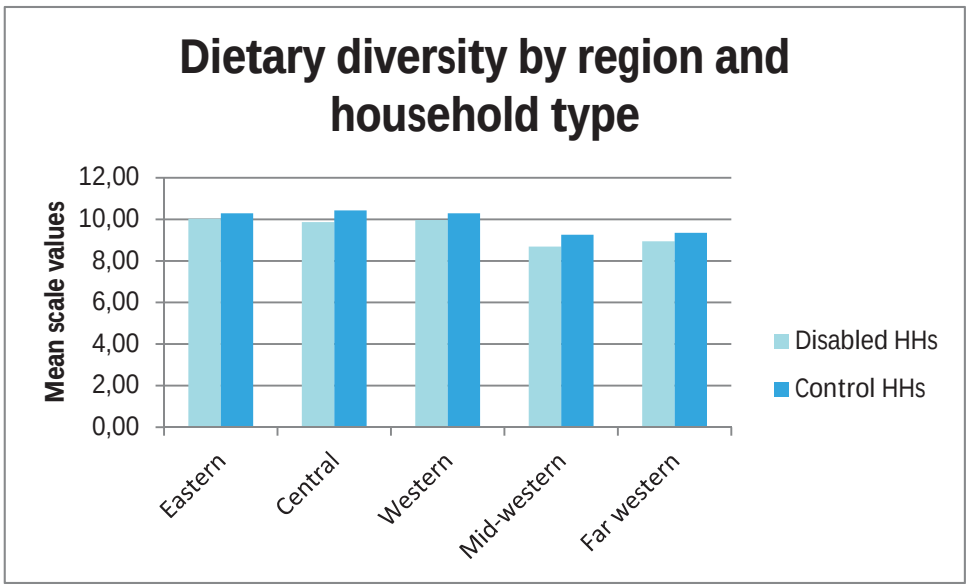


Figure 10. Dietary diversity scale mean values by region and household type. (N = 4000).

Dietary diversity is higher among control households in all five developmental regions of Nepal, and the dietary diversity is lower in the Mid-western and Far-western regions.

A question was also asked about incidents of no food at all during the last two weeks. While this had happened to relatively few, it was reported by somewhat more disabled households. Differences between urban and rural households were marginal (not significant), while the tendency for disabled households to report lack of food more often was found in both urban and rural areas.

Table 6. No food to eat during the last two weeks because of lack of resources (%)

	Urban		Rural	
	Disabled HHs	Control HHs	Disabled HHs	Control HHs
Never without food	92.7	97.6	92.0	95.8
Rarely without food (1-2 times)	5.5	2.4	5.5	3.6
Sometimes without food (3-5 times)	1.2	0.0	1.6	0.5
Often without food (> 5 times)	0.6	0.0	0.8	0.2

9.1.8 Access to information

Respondents were asked to report on their access to six different information channels/sources. In the below table, "own/use regularly" and "have access" are combined into "have access". Those who answered "no access" or "no use for" were coded as "no access".

Table 7. Percentage confirming that they own/use/access information sources N = 3495 - 4000

	Disabled HHs		Control HHs	
Telephone	90.6	1807	94.8	1892
Radio	67.7	1315	70.3	1424
Television	57.6	1108	65.8	1199
Internet	16.5	294	23.0	343
Newspaper	17.0	364	23.7	408
Library	16.9	329	17.4	322

For all six information source items in Table 7, control households score higher than disabled households. The difference is statistically significant for all information sources except library.

Based on the dichotomous variable used in Table 7 (No = 0, Yes = 1), an Information access scale was computed by adding the six items. This produces a scale with mean value 2.84, range 0 – 6, and standard deviation 1.57. The mean scale value for disabled households was 2.71 and 2.96 for control households, implying slightly better access for controls.

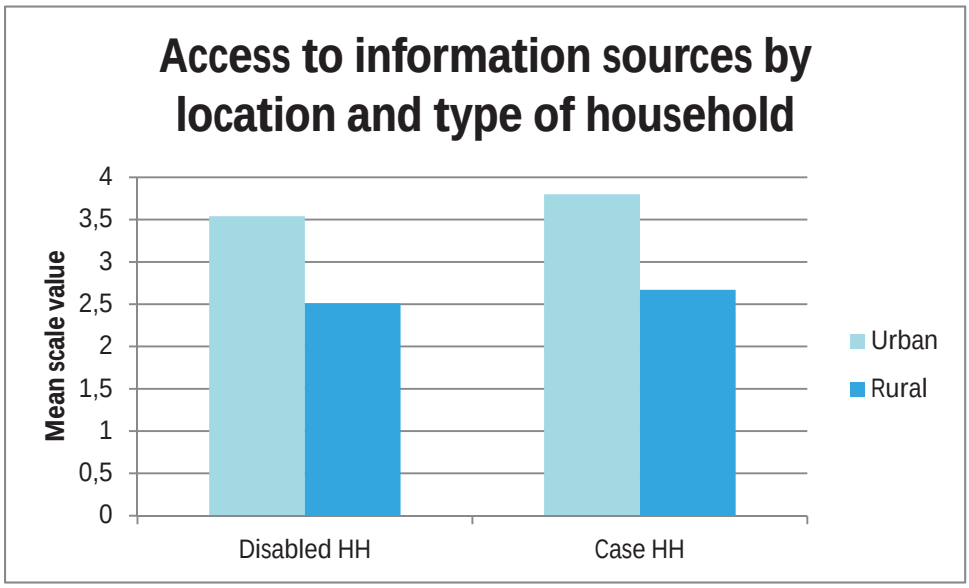


Figure 11. Access to information sources by location and household type

The urban – rural difference in access to information sources is pronounced among both household types, and the relatively small overall difference between disabled and control households is found also within each of the household types.

Analysing access to information sources by Development regions revealed that the difference between the two household types was confirmed in four of the five regions, the exception being Western region. While the difference in access between regions was pronounced, the difference between household types was however significant in Central and Far-western region only (Mid-western: $p = .055$).

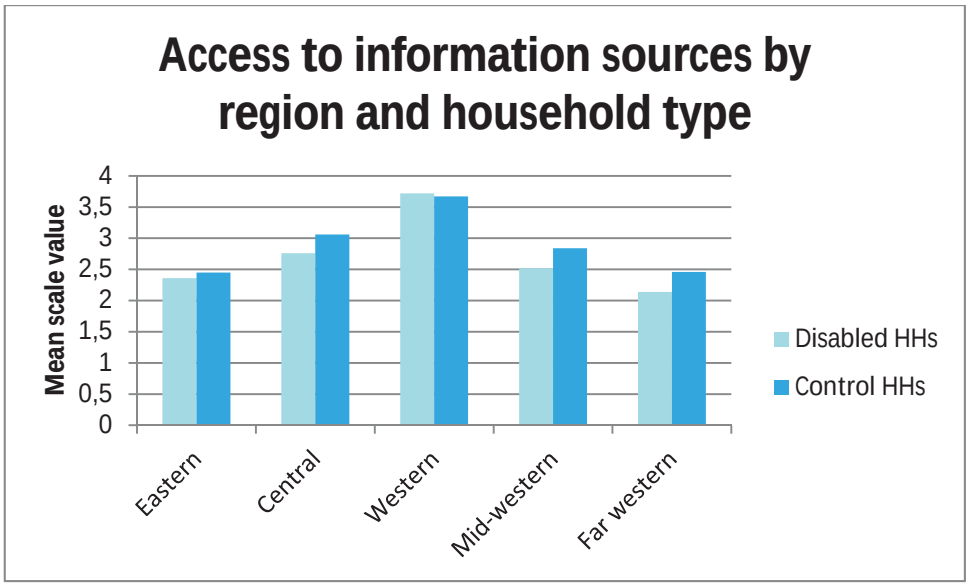


Figure 12. Access to information sources by location and household type. (N = 3092).

9.1.9 Buildings

The building material used for the roof differed between urban and rural locations, in that concrete was most common in urban areas whereas corrugated iron sheets, grass/leaves thatch and tiles/shingles were most common in rural areas. Smaller differences between the two household types in both urban and rural areas all points towards somewhat higher standard in control households (i.e. for instance fewer with grass/leaves thatch and more with concrete).

Table 8. Main type of roof by household type. (N = 4000).

Type of roof	Disabled households		Control households	
	Urban	Rural	Urban	Rural
Wood	0.3	3.2	0.0	1.4
Corrugated iron sheets	28.9	32.9	33.3	40.0
Grass/leaves thatch	5.2	14.7	1.5	12.3
Tiles/shingles	16.9	23.9	9.4	17.5
Concrete	46.5	10.3	53.6	14.1
Stone, slate	2.7	13.5	1.7	13.2
Other (med, bamboo)	0.3	1.6	0.4	1.4

The main type of floor in urban locations is concrete/cement, while most of the floors in rural areas are made out of mud. Comparing types of households, we find that more disabled households in both urban and rural areas is made out of mud, while more control households have floors made out of concrete/cement. This confirms somewhat higher standard in control households.

Table 9. Main type of floor by location and household type. (N = 4000).

	Disabled households		Control households	
Type of floor	Urban	Rural	Urban	Rural
Mud	32.6	81.3	27.5	77.2
Concrete/cement	65.9	17.3	71.5	21.3
Wood	1.5	1.3	0.6	1.4
Other (stone, tiles)	0.0	0.1	0.4	0.1

The most common type of walls in urban areas is concrete, while the most common in rural areas is stone with mud. Also, far more rural than urban households have floors that are made out of poles and mud. There are small differences between disabled and control households on this indicator.

Table 10. Main type of walls by location and household type. (N = 4000).

Type of wall	Disabled households		Control households	
	Urban	Rural	Urban	Rural
Poles and mud	5.8	21.7	4.9	17.3
Corrugated iron sheets	0.3	0.2	0.0	0.1
Grass/leaves	0.6	3.4	0.6	3.3
Bricks (burnt/sun dried)	28.0	11.9	24.2	11.8
Compact earth	1.8	2.0	2.1	2.4
Concrete	43.9	12.6	49.8	15.2
Stone with mud	11.3	42.2	10.3	44.1
Cement block	0.6	9.7	1.1	1.1
Thatched with mud	1.5	2.4	0.9	1.2
Other	6.1	2.9	6.0	3.5

There are small differences between urban and rural households concerning number of bedrooms in the house, and likewise between disabled and control households.

Table 11. Number of bedrooms in house by location and type of household (N = 4000).

Number of bedrooms	Disabled households		Control households	
	Urban	Rural	Urban	Rural
1	24.0	21.9	23.9	20.0
2	29.2	38.6	30.8	37.8
3	22.8	18.5	21.7	22.2
4	17.0	13.9	15.3	12.5
5 >	7.2	7.0	8.3	7.5

More households live in self-owned houses in rural than in urban areas. Somewhat more disabled households live in self-owned houses as compared to the control group, but this difference is statistically significant in urban areas only.

Table 12. Ownership of house by location and type of household (N = 4000).

	Disabled households		Control households	
	Urban	Rural	Urban	Rural
Rented	22.5	3.2	31.1	3.1
Owned	75.1	95.3	67.6	95.5
Rent free (not owned)	1.8	1.4	0.4	0.8
Provided by employer (government)	0.0	0.0	0.0	0.0
Provided by employer (private)	0.6	0.2	0.9	0.6

9.1.10 Drinking water, energy sources and sanitations

The most common source of drinking water in both urban and rural areas is tube well. In urban areas, this is followed by piped water inside the house and public pipe/tap, while in rural areas the second most common source is public pipe/tap followed by piped water outdoors, on property. More control households have piped water inside, while slightly more disabled households have tube well.

Table 13. Main source of drinking water by location and household type (N = 4000)

Main source	Disabled households		Control households	
	Urban	Rural	Urban	Rural
Piped water inside	17.9	4.5	28.1	7.4
Piped water outdoors, on property	12.2	11.5	15.6	13.6
Piped water outside the property	3.3	4.2	1.7	3.4
Public pipe/tap	13.1	30.6	12.	29.7
Borehole	1.8	0.5	1.1	0.4
Protected well	4.3	0.4	1.7	1.1
Unprotected well	0.0	0.5	1.7	0.2
River/stream/dam/spring/ lake	6.4	7.2	2.6	6.7
Water carrier/tanker	2.1	0.0	0.9	0.1
Tube well	38.9	40.6	34.7	37.4

In urban areas, the most common source of energy for cooking is gas, while the most common in rural areas is wood. Wood is the second most common in urban areas, while gas and dung/grass/stalks is the second most common in rural areas. More disabled households use wood and more control households use gas.

Table 14. Main source of energy for cooking by location and household type (N = 4000)

Energy for cooking	Disabled households		Control households	
	Urban	Rural	Urban	Rural
Kerosene	0.3	0.1	0.9	0.3
Gas	57.0	12.7	71.5	17.9
Wood	39.9	73.5	26.0	70.3
Coal/charcoal	0.3	0.2	0.0	0.1
Solar	0.0	0.2	0.2	0.0
Dung/grass/stalks	2.4	13.3	1.5	11.4
Other (husk; sugarcane leaf)	0.0	0.1	0.2	0.0

The main source of energy in both urban and rural areas is electricity, and in urban areas this is close to all. In rural areas, many report that they use solar energy and, somewhat fewer, kerosene. Disabled households in rural areas tend to use less electricity and more solar energy and kerosene. The difference between disabled and control households is statistically significant only among rural households.

Table 15. Main source of energy for lighting by location and household type (N = 4000)

Main source of energy	Disabled households		Control households	
	Urban	Rural	Urban	Rural
Electricity	97.0	69.3	98.3	76.4
Kerosene	2.7	11.4	1.3	7.1
Wood	0.0	1.3	0.0	0.5
Solar	0.3	18.1	0.4	16.0

In both urban and rural areas, ventilated improved pit latrine is the most common sanitation facility. Flush toilet is reported by around one out of four urban households. Many rural households have no facility at all, while this is the case for very few urban households. More rural disabled households have no facility as compared to control households, and pan is more common among urban than among urban households. The difference between household types is however statistically significant among rural households only.

Table 16. Main type of sanitation facility by location and household type (N = 4000)

Sanitation facility	Disabled households		Control households	
	Urban	Rural	Urban	Rural
Flush toilet	24.6	3.3	25.5	3.7
Traditional pit toilet	5.8	15.0	3.4	16.6
Ventilated improved pit toilet	49.5	41.0	49.0	41.9
No facility	8.2	32.6	6.2	22.2
Pan	11.9	8.1	15.8	15.6

Tables 8 – 16 above reveal first of all a pronounced difference between urban and rural areas, in that rural households have a higher standard on their infra structure than rural households. While less pronounced, there are however indications across most of these indicators that disabled households lag behind in terms of standard of infra structure as compared to control households.

9.1.11 Education

The percentage of school attendance among disabled members aged 5 years old and above was considerably lower than members without disability; 40.5% vs. 70.8%. The lower school attendance among individuals with disability is found in all age categories. There is a drop in school attendance among both individuals with and without disability with increasing age, reflecting increased school coverage over the years.

Among disabled persons aged 5 to 10 years, 35% were not attending school (Table 17). This was much higher than the proportion of non-disabled members of the same age group (5%). For disabled persons aged 11 to 20 years, 30% of them were not attending any educational institutions. More males than females are attending school, a pattern that is even more pronounced among people with a disability.

School attendance differs between the five Development regions. Among individuals with disability, highest attendance is found in Western region, and the lowest in Eastern region. Among non-disabled, the highest and lowest school attendance was found in Western region and in Eastern region. While the difference between groups (disabled/non-disabled) was found in all five regions, the gap between the two groups varies from 19 percentage points (Mid-western region) to 3.2 percentage points (Western region), most likely indicating variation in practices resulting in different levels of exclusion/inclusion of individuals with disability in the formal school system.

More males were attending or had attended school, college or university (Table 13) as compared to females. This trend was the same among both disabled and non-disabled persons, with the gender gap being more than 30 percentage points in both groups. School attendance is further shown to increase sharply with higher socio-economic status.

Table 17. School attendance by age, gender, region and economic group. Age 5 years and above. Percent. N = 18851.

		Disabled	**Control**
	Total	Percent	
		40.5	71.1
Age group	5-10	64.6	94.8
	11-20	69.7	95.3
	21-30	57.3	81.9
	31-40	43.2	60.2
	41-50	30.9	43.8

		Disabled	Control
	Total	Percent	
	51-60	25.9	33.3
	61-70	19.2	23.7
	71+	7.9	13.4
Gender	Male	50.6	81.5
	Female	29.8	61.7
Development region	Eastern	41.2	58.2
	Central	44.4	53.0
	Western	50.3	53.5
	Mid-western	33.3	52.3
	Far western	48.5	52.9
Economic group[2]	Low	27.2	31.9
	Medium	43.8	49.7
	High	60.7	68.8
Ecological zone	Mountain	25.9	44.6
	Hills	44.2	56.9
	Terai	40.4	72.9

Source: Household roster[1] School attendance = ever accessed formal primary education, *[2]SES scale divided into three, see text about socioeconomic status above*

As many as 59.5% of disabled aged five years old and above were recorded as “never attended school”, compared to 29% in the control group. The household head or main informer in the household was asked the reasons why household member(s) had never attended school, with lack of money being the main reason for not attending among both

individuals with disability and non-disabled. This explained almost half of the reasons for not attending school among people without disability. Among individuals with disability, shortage of money explained one fourth of the reasons. For more than 20% of people with disability aged five years old and above, the disability was attributed as the reason for not attending. Furthermore, 16.7% of persons with disability stated illness as a reason for non-attendance, as compared to 1.9% of non-disabled. Bearing in mind that health and disability often are associated, close to 40% of disabled non-attendees thus stated their own functional/health status as the reason.

Table 18. Reasons for never attending school by disability status

Reasons	Disabled %	Control %
Not enough money	40,7	47,9
Failing/underachiever	0,4	0,2
Illness	0,5	0,1
Lack of interest	8,6	12,2
Because of disability	21,0	0,0
School not accessible	13,9	14,9
Pregnancy (female only)	0,2	0,1
Discrepancy[1]	8,5	15,1
Other (not allowed; lack of knowledge about it; no practice; need to support family for household chores)	3,2	4,2
Do not know	3,1	5,3
Base percent (n)	1255	4819

[1] Discrimination in terms of caste, economic status and gender

Number of years at school is shown in Table 19. Firstly, number of years at school is reduced with increasing age among both cases and controls, indicating some positive development during recent years. Secondly, females with disability report substantially

more years in schools than their male counterparts, while the gender difference is marginal among controls. Thirdly, there is substantial difference between among cases by Development regions, with particularly high mean number of years in Central province. There is further substantial differences between the ecological zones with the lowest mean years in school found among both case and controls in the Mountain zone, and the highest in the Terrai zone. There is also a clear SES gradient in that higher socio-economic status is associated with higher mean number of school years, among both cases and controls. Overall, individuals with disability report lower number of years in school as compared to cases.

Table 19. Number of years at school by age, gender, region and socio-economic group. Age 5 years and above. N = 18851. Percent

		Disabled	Control
	Total (20 + years)	Mean years in school	
Age group	21-30	10.24	10.25
	31-40	8.73	9.69
	41-50	8.18	9.46
	51-60	8.10	8.82
	61-70	7.13	9.72
	71+	7.45	7.74
Gender	Male	8.24	9.35
	Female	10.10	9.44
Development region	Eastern	8.36	9.97
	Central	8.35	10.49
	Western	7.50	7.98
	Mid-western	8.39	8.14
	Far western	7.51	8.12
Economic group[2]	Low	6.75	7.61
	Medium	7.41	9.06
	High	9.97	10.60
Ecologicalzone	Mountain	5.41	8.77
	Hills	8.31	9.16
	Terai	9.08	9.42

Source: Household roster[1] School attendance = ever accessed formal primary education, [2]SES scale divided into three, see text about socioeconomic status above

Figure 13 shows firstly that many students drop out of school during primary and lower secondary school (Standard 1 – 9). Secondly, more non-disabled seem to drop out during the first years (Standard 1). There is a tendency among both males and females that individuals with disability drop out earlier than non-disabled. Gender difference is not very clear, although more females drop out during the first three years of education. The highest drop-out rates are found between Standard 2 and Standard 5 for all groups.

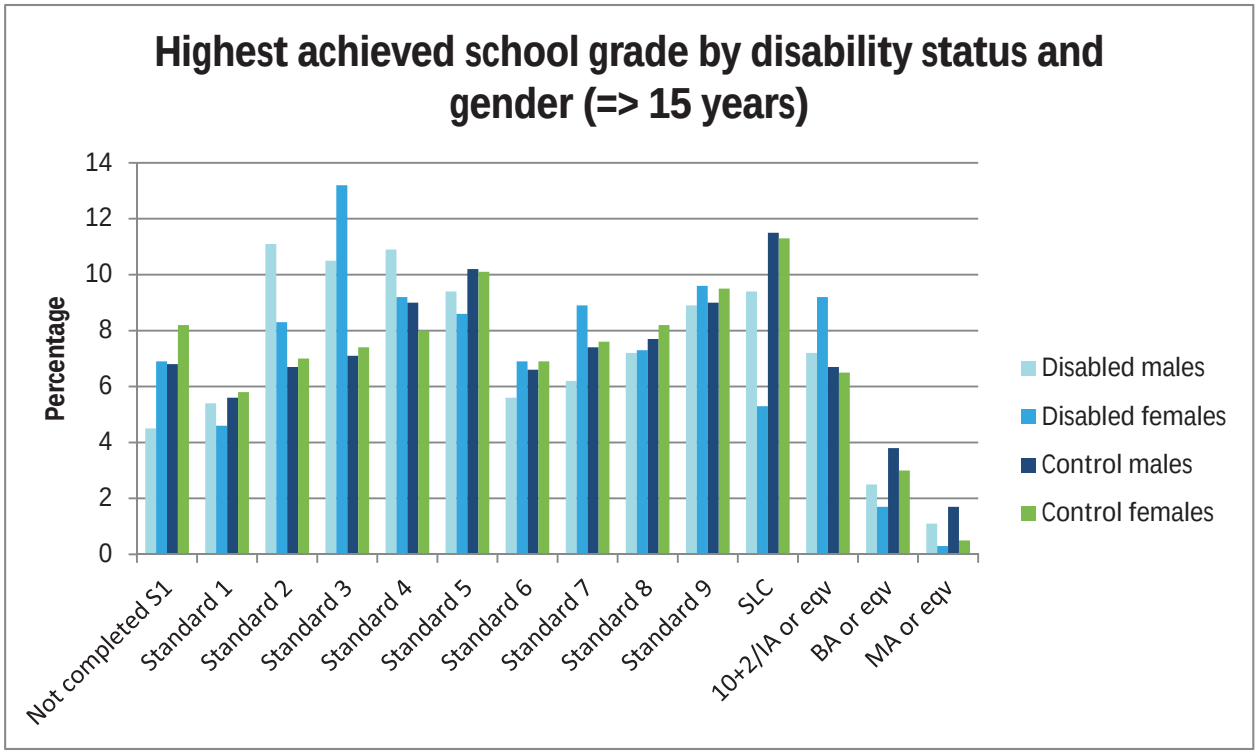


Figure 13. Highest grade achieved by disability status and gender. Age 15 years and above (N = 12724)

(The detailed numbers used in Figure 13 is shown in the table below for easier interpretation).

Table 20. Highest grade achieved by disability status and gender. Age 15 years and above (N = 12724)

	Disabled males	Disabled females	Control males	Control females
Not completed Standard 1	4.5	6.9	6.8	8.2
Standard 1	5.4	4.6	5.6	5.8
Standard 2	11.1	8.3	6.7	7.0
Standard 3	10.5	13.2	7.1	7.4
Standard 4	10.9	9.2	9.0	8.0
Standard 5	9.4	8.6	10.2	10.1
Standard 6	5.6	6.9	6.6	6.9
Standard 7	6.2	8.9	7.4	7.6
Standard 8	7.2	7.3	7.7	8.2
Standard 9	8.9	9.6	9.0	9.5
SLC	9.4	5.3	11.5	11.3
10 + 2/IA or eqv	7.2	9.2	6.7	6.5
BA or eqv	2.5	1.8	3.8	3.0
MA or eqv	1.1	0.3	1.7	0.5

Individuals with disability are overrepresented among those with highest achieved school grade at the low end of the scale. This pattern is more mixed and to some extent reversed in the higher grades. The difference is however not very pronounced/systematic except in the lower grades, indicating that many individuals with disability who enter the education system reach the same levels as non-disabled. The urban – rural difference is also reflected in the figure.

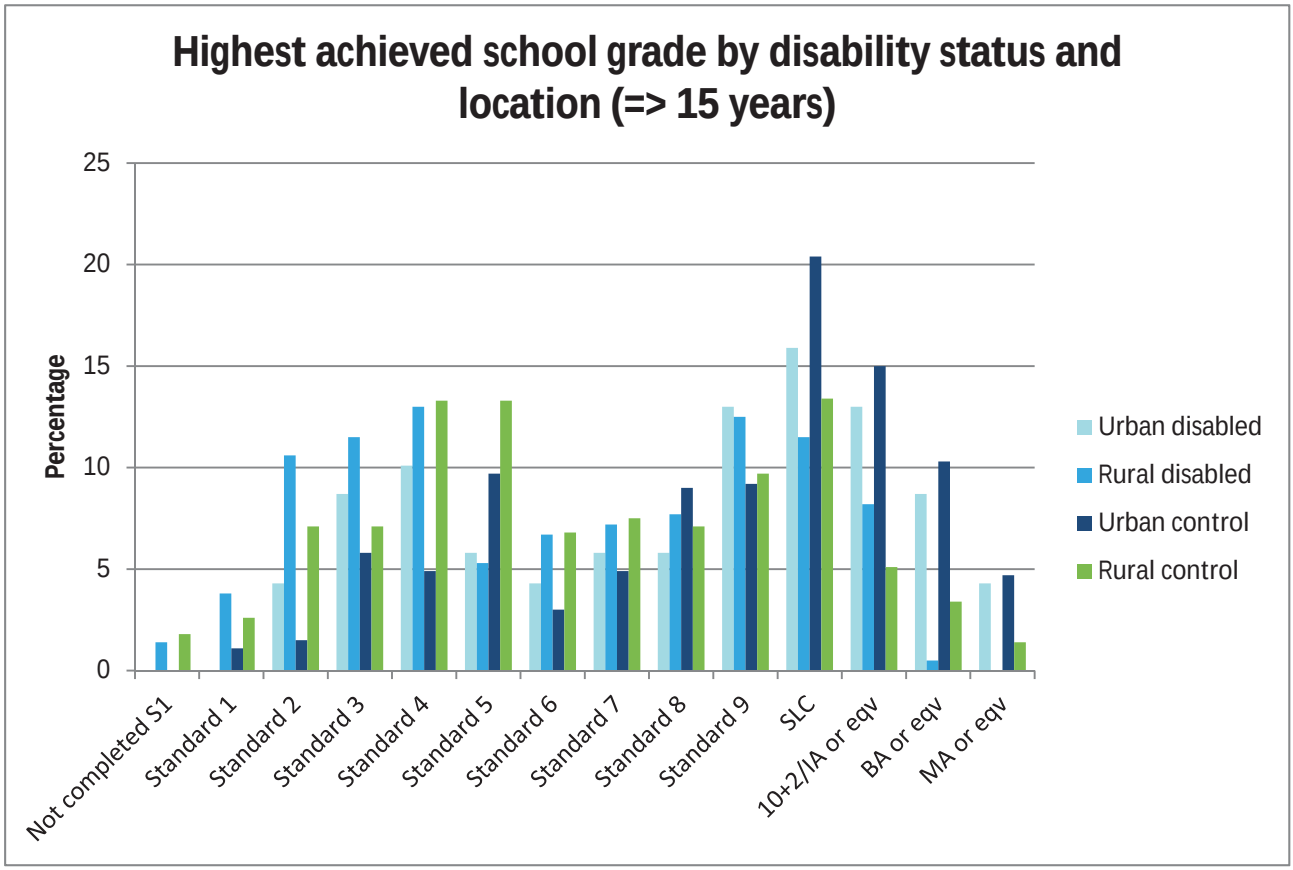


Figure 14. Highest grade achieved by disability status and location. Age 15

9.1.12 Literacy

The question on literacy addresses the issue of individual's ability to read and write in any language. The analyses include only members aged 10 years old and above. Among persons with disability, 42.1% was literate while the proportion was 61.1% among non-disabled. Literacy was much lower among females, with the difference between groups (disabled/not disabled). It is further shown (Table 21) that literacy is substantially higher in rural as compared to urban areas.

Table 21. Literacy rate by gender and disability status (10 + years) (N = 3867)

	Case	Control
Female	30.9%	46.5%
Male	52.6%	73.8%

Table 22. Literacy rate by location and disability status (10 + years) (N = 3885)

	Case	Control
Urban	57.7%	74.6%
Rural	39.0%	57.1%

Figures 15 and 16 shows that literacy rate varies between development regions as well as ecological zones, but also that the difference between cases and controls are found in all five districts and the three ecological zones. Literacy rate among individuals with disability is lowest in Mid-Western province and highest in Eastern and Western provinces. Concerning the ecological zones (Figure 16), literacy rate is lowest in the Mountain and Terai zones, and substantially higher in the Hill zone. Note that among non-disabled, literacy is highest in the Hills zone, followed by Terai and the lowest in the Mountain zone.

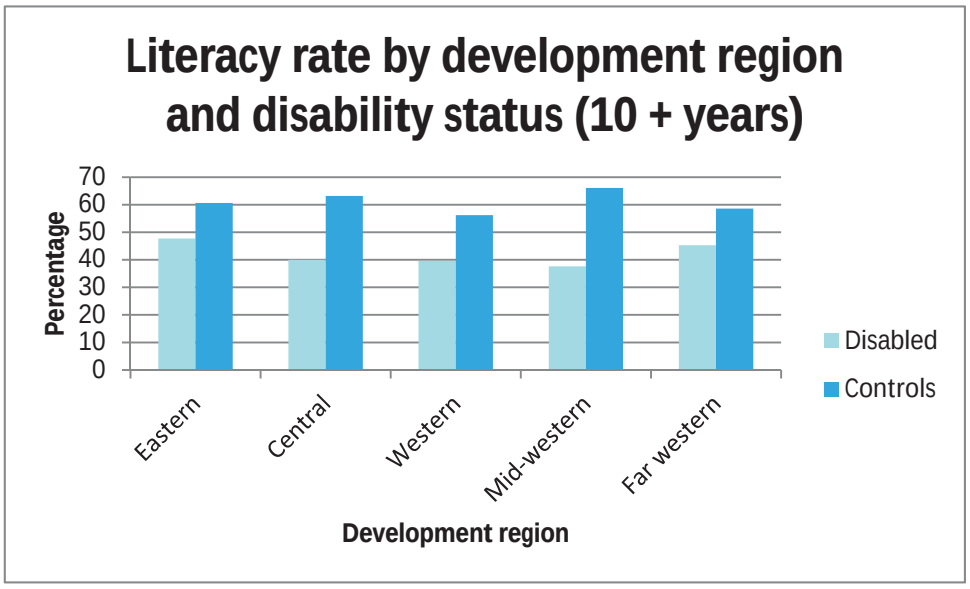


Figure 15 Literacy rate by development region and disability status (10 + years) (N = 3867)

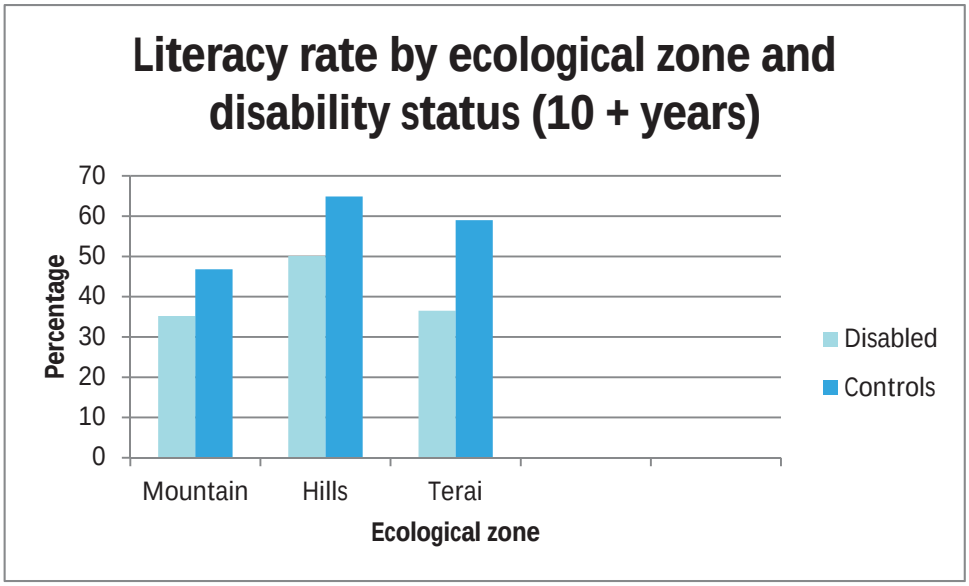


Figure 16. Literacy rate by ecological zone and disability status (10 + years) (N= 3867)

9.1.13 Employment

The figure below gives the distribution of employment status among economically active persons aged 15 to 65 years old. The results are not meant to provide a statement on unemployment rate in the country but indicate the situation of people with disability compared to people without disability on these four employment statuses.

The results presented in Figure 17 clearly demonstrate the difference between disabled and non-disabled. The proportion of individuals with paid work is more than 60% higher among controls as compared to cases. Also the proportion of self-employed is higher among non-disabled. Unemployment for health reasons is 24.0% among disabled and close to zero among controls. Three times more controls than cases report that they are students, while somewhat above 20% are homemakers in both groups.

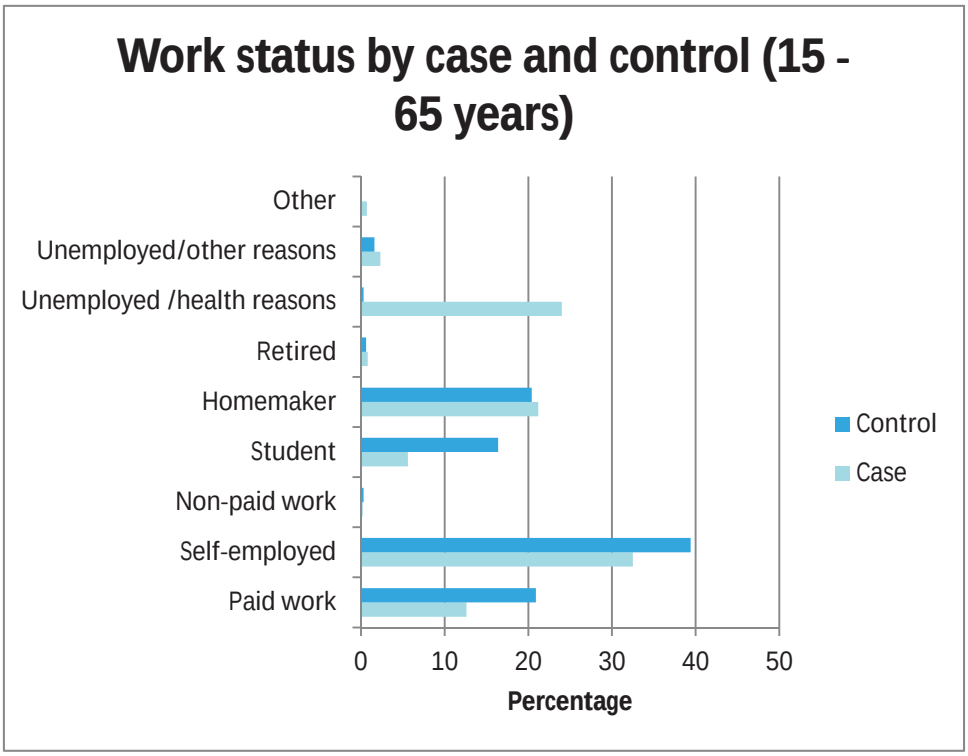


Figure 17. Employment status by disability status. Age 15+. Percent. N=12 970.
Source: Household roster

Table 23 shows that the difference in work status demonstrated in Figure 17 is more pronounced for females as compared to men when it comes to paid work, while it is the other way around for self-employment. This is especially true among the disabled household members. In addition, unemployment for health reasons is clearly higher among disabled men than disabled women, both in numbers and with regards to the ratio between disabled and non-disabled.

Table 23. Employment status by gender and disability status. Age 15 – 65 years (N = 12971) (%)

		Disabled	Control
Male	Paid work including remittance	19.9	39.6
	Self-employed, such as own business or farming	39.6	41.2
	Non-paid work such as volunteer or charity	0.1	0.2
	Student	5.0	17.2
	Keeping house/homemaker	1.0	0.6
	Retired	1.5	1.3
	Unemployed (health reasons	28.9	0.3
	Unemployed (security reasons)	0.3	0.0
	Unemployed (other reasons)	2.8	2.3
	Other (priest; landlord; renting house)	0.8	0.2
Total		100.0	100.0
Female	Paid work including remittance	4.8	7.3
	Self-employed, such as own business or farming	24.9	37.9
	Non-paid work such as volunteer or charity	0.3	0.4
	Student	6.3	15.7
	Keeping house/homemaker	42.7	37.4
	Retired	0.0	0.0
	Unemployed (health reasons)	18.8	0.3
	Unemployed (security reasons)	0.0	0,0
	Unemployed (other reasons)	1.5	0.9
	Other (priest; landlord; renting house)	0.7	0.0
Total		100.0	100.0

		Disabled	Control
What is the work status of (NAME)?	Paid work including remittance	12.6	20.9
	Self-employed, such as own business or farming	32.5	39.4
	Non-paid work such as volunteer or charity	0.2	0.3
	Student	5.7	16.4
	Keeping house/homemaker	21.2	20.4
	Retired	0.8	0.6
	Unemployed (health reasons	24.0	0.3
	Unemployed (security reasons)	0.1	0.0
	Unemployed (other reasons)	2.2	1.6
	Other (priest; landlord; renting house)	0.7	0.1
Total		100.0	100.0

9.2 Individual section

(Individual questionnaire)

Source: Individual questionnaires, case and controls

Every individual identified with disability during the household interview was invited to participate in the detailed individual interview. A total of 59.1% (N = 1250) of the individuals with disability responded themselves, whereas proxy reporters answered in 21.4% (N = 449) of the interviews. The remaining 19.1% (N = 402) was when the proxy responded together with the disabled persons.

9.2.1 Demographics

The table below presents demographic information about persons with and without disability. The information includes the proportion of disabled and non-disabled persons according to age group, gender and districts. There was no difference in mean age

between the two groups, and the combined mean age for both groups was 40.0 years (Std. dev: 20.65), and differences within different age categories were marginal. Moreover, no statistical significant difference was found in gender distribution according to districts. Due to the way sampling was carried out, both individuals with and without disability in the sample are evenly spread across the five Development regions.

Table 24. Demographic information by disability status. Percent. N = 4123

		Disabled	Control
Age	**3-10**	7.9	7.0
	11-20	16.9	18.1
	21-30	11.7	11.8
	31-40	13.1	12.4
	41-50	15.2	14.9
	51-60	14.5	16.9
	61-70	14.5	13.5
	71 and above	6.2	5.7
Gender	**Male**	51.8	53.8
	Female	48.2	46.2

9.2.2 Distribution of disability core domains

The levels of difficulty among individuals with disability in the sample on the six WG domains is shown in Figure 18. More than four out of ten individuals with disability in the sample reported at least some difficulty with walking or climbing steps. The least frequent was remembering/concentrating with 80.6% reporting no difficulty. Combining "a lot of difficulty" and "unable to do" to indicate severe disability, difficulty in walking or climbing steps reached 21.8%,% followed by self- care (17.5%),% communicating (16.1%),% hearing (13.6%),% remembering/ concentrating (9.1%),% and seeing (7.2%).% Gender difference was significant only for communicating, with fewer females reporting any difficulty.

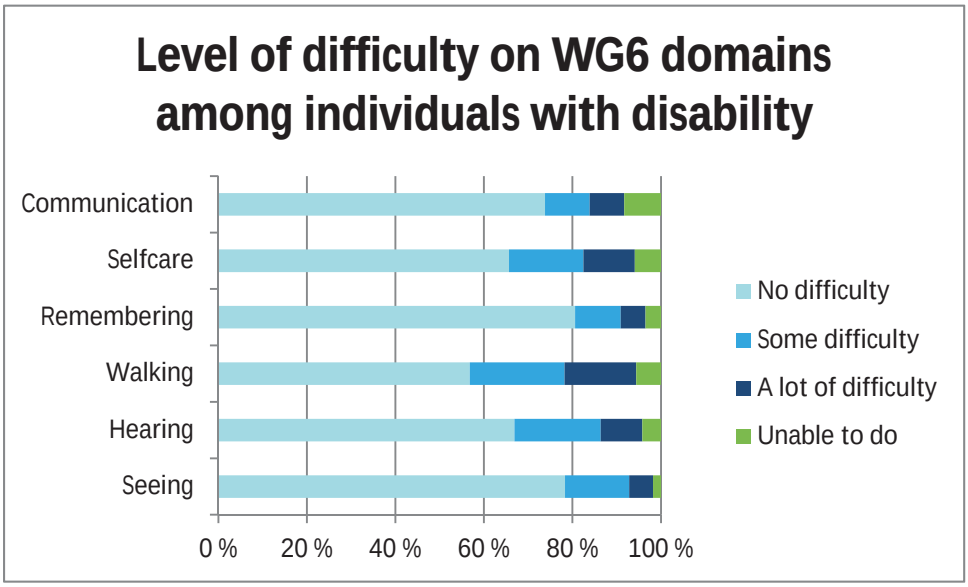


Figure 18. Level of difficulty on WG6 domains among individuals with disability. Percentage (N = 2123)

Among the individuals with disability in this study, the most common is to have "some difficulty" or more severe difficulty in one WG6 domains, and then the percentage is reduced with increasing number of difficulties. There were marginal gender differences in the distribution of number of difficulties.

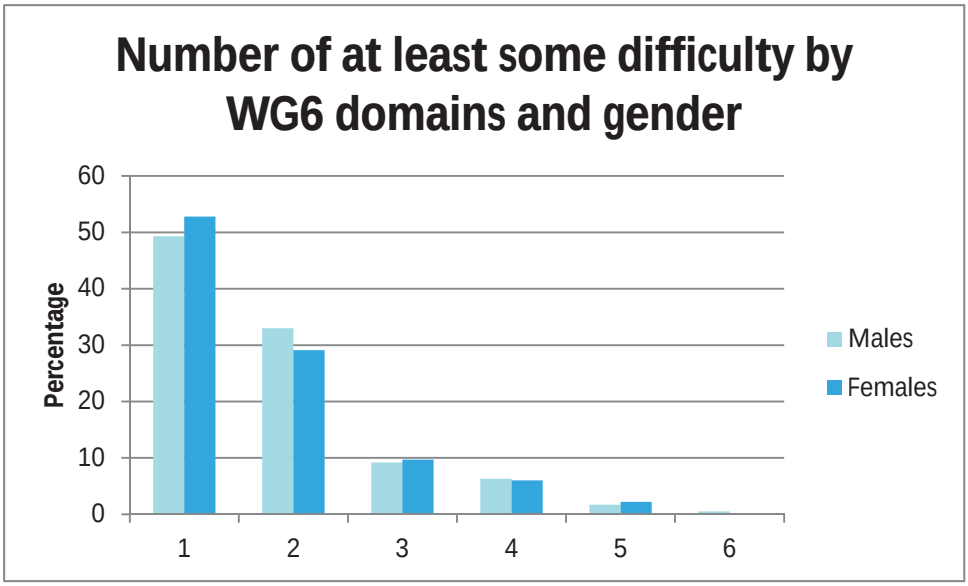


Figure 19. Number of at least some difficulty by WG6 domains and gender (N = 2123)

The six WG domains were added together to form an Activity limitations/Disability severity scale. The range of the scale was 6 – 24, mean value 8.92, and standard deviation 2.45. Among individuals with disability, we see that males score higher among urban respondents, and that rural females score higher than their urban counterparts.

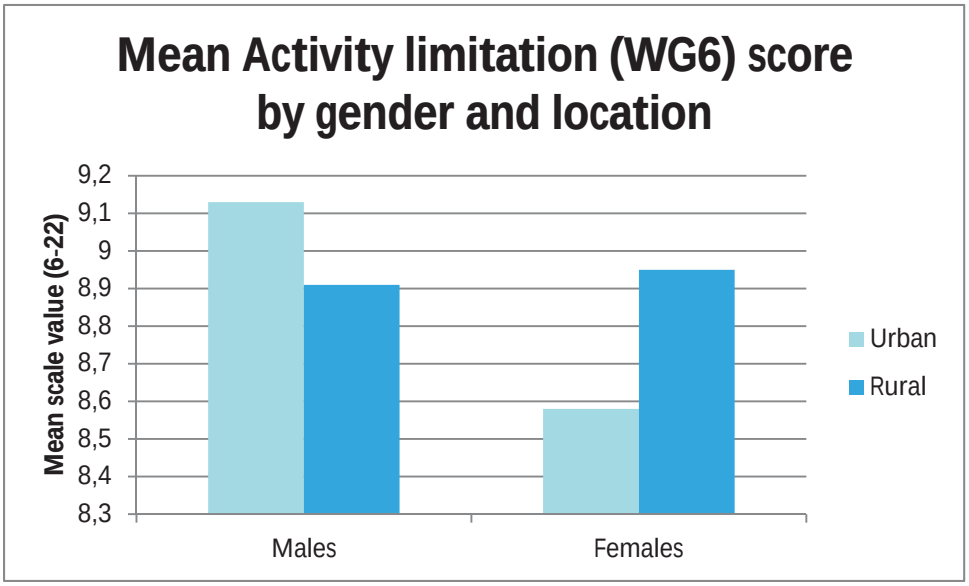


Figure 20. Mean Activity limitation (WG 6) score by gender and location (N = 2123)

In Figure 21 we see that women score higher in the Mountain zone and the other way around for Hills and Terai zones. Mean level (both men and women) is highest in the Hills zone, followed by Mountain and Terai zones.

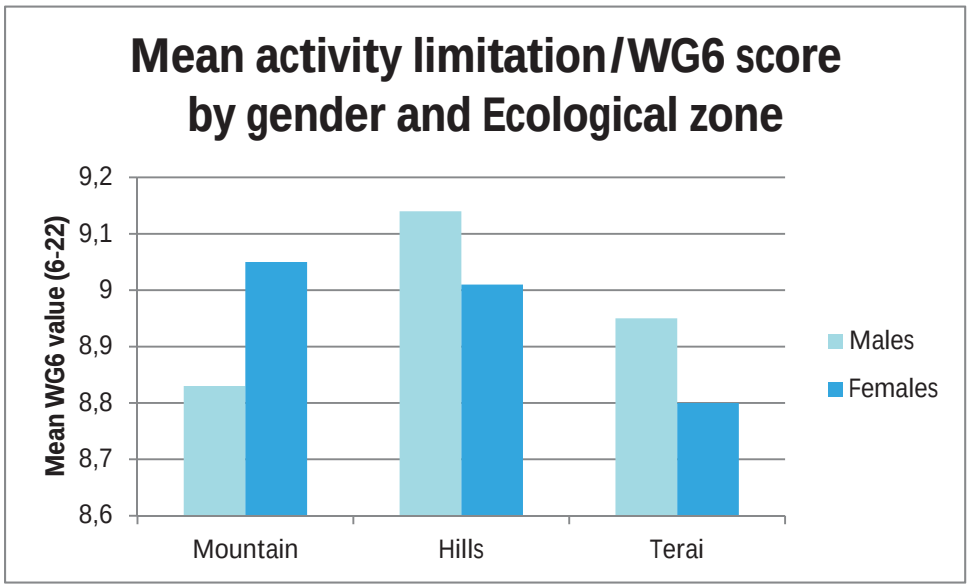


Figure 21. Mean Activity limitation (WG6) score by gender and ecological zone (N = 2123)

In Table 25 we see that there is some variation in proportion with severe disability (a lot of difficulty + unable to do) across age categories. Vision difficulty tend to increase with increasing age, difficulty with remembering and communication is reduced with increased age, and self-care difficulty is most common among the youngest and the oldest age groups. For hearing and walking difficulty there is no significant variation across the age categories, although there is an observable increase for walking difficulty in the oldest age group.

Table 25. Distribution of severe disability1 according to disability core domain and age groups (N = 2123)

Disability core domain	Age groups							
	3 – 10	11 – 20	21 – 30	31 – 40	41 – 50	51 – 60	61 – 70	> 70
	%	%	%	%	%	%	%	%
Vision	5.4	4.8	4.4	3.9	5.9	8.1	10.2	19.1
Hearing	14.3	12.3	13.0	15.5	15.2	14.7	12.0	13.8
Walking	20.5	20.9	18.8	18.8	18.9	24.7	23.2	32.3
Remembering	18.0	16.7	13.8	10.5	5.5	3.0	3.3	2.3
Self-care	27.4	21.2	15.0	15.5	12.1	16.0	16.7	23.1
Communicating	33.6	19.6	22.3	19.4	16.1	9.5	6.2	3.8

[1] Severe disability: at least a lot of difficulty

Severity was also operationalised by means of splitting the WG6 (Activity limitations) scale into three; Mild disability (value 7 on the scale; 32.0%), Moderate disability (values 8 and 9 on the scale; 38.6%) and Severe disability (values above 10 on the scale; 29.4%).

In Figure 22 we see that the distribution of the three severity categories (mild, moderate and severe) varies somewhat with gender and location. In the rural sub-sample, moderate disability is the most common category, followed by mild disability and severe disability. Among urban females the rank order is mild, moderate and severe. Among urban males, mild disability is particularly low and moderate correspondingly high. The distribution of the three categories is more even in rural areas as compared to urban.

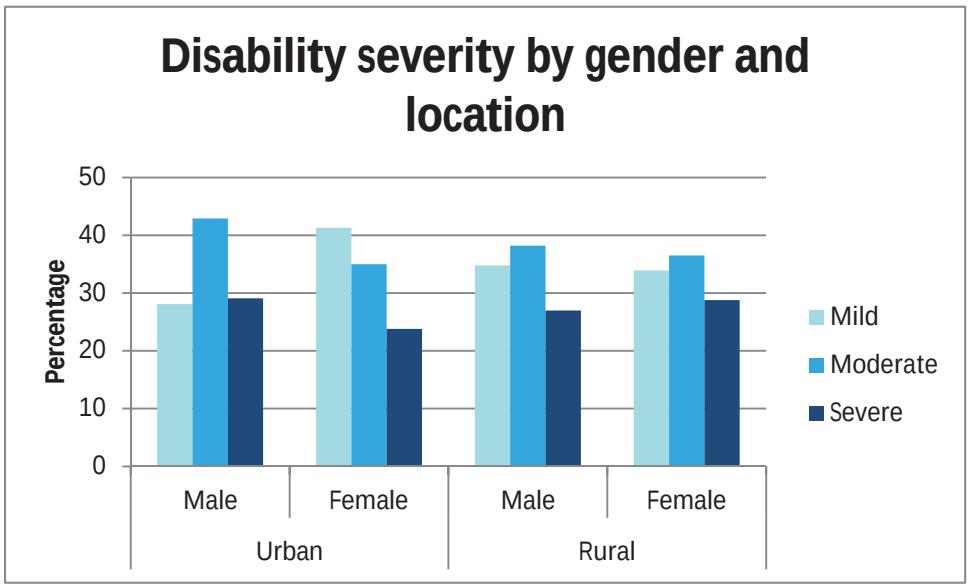


Figure 22. Disability severity by gender and location (N = 2123)

9.2.3 Cause of disability

Personal perception about the cause of their disability was also recorded. No attempt was made to acquire a medical verification of causes of disability. The different causes are listed in the table below. Disability because of disease was reported as the most frequent cause followed closely by congenital/from birth. They represent 38.3% and 33.6% of the disability causes respectively. Falls and accidents were stated as cause by 11.5% and 7.7% respectively.

Table 26. Causes of disability

Causes of disability	n	%
From birth/congenital	775	33.6
Accident	163	8,3
Fall	245	10.5
Burns	29	1.3
Disease/illness	758	38.3
Beaten by member in the family	8	0.3
Violence outside the house	6	0.3
War related	15	0.6
Animal related	13	0.6
Stress related	23	0.9
Witchcraft	9	0.4
Other (side effects from the use of medicine; experienced this problem after giving child birth; got injured while play	34	1.4
Do not know/refuse	45	3.6
Total	**2123**	**100**

Disability onset

Respondents were also asked about timing of the onset of the disability. Table xx show that most (50.6%) of disability onset took place within the age bracket 0 – 10 years, and with an additional 8.0% occurring between 11 – 20 years of age. As also shown above, one third (33.6%) of onset were reported to be at birth/congenital.

Table 27. Onset of disability

	N	%
From birth	773	33.6
First living year	26	1.2
1-5 years	179	8.6
6-10 years	142	7.2
11-20 years	158	8.0
21-30 years	153	7.5
31-40 years	150	7.1
41-50 years	193	9.5
51-60 years	191	9.8
61 – 70 years	132	6,6
71 + years	19	0.9
Total	**2116**	**100**

Source: Individual interviews (Case, i.e. persons with a disability)

Onset of disability was analysed with respect to severity and gender. Age of onset reduced with severity, indicating further the importance of addressing newborn and childhood disability causes. Gender differences were small and not statistically significant.

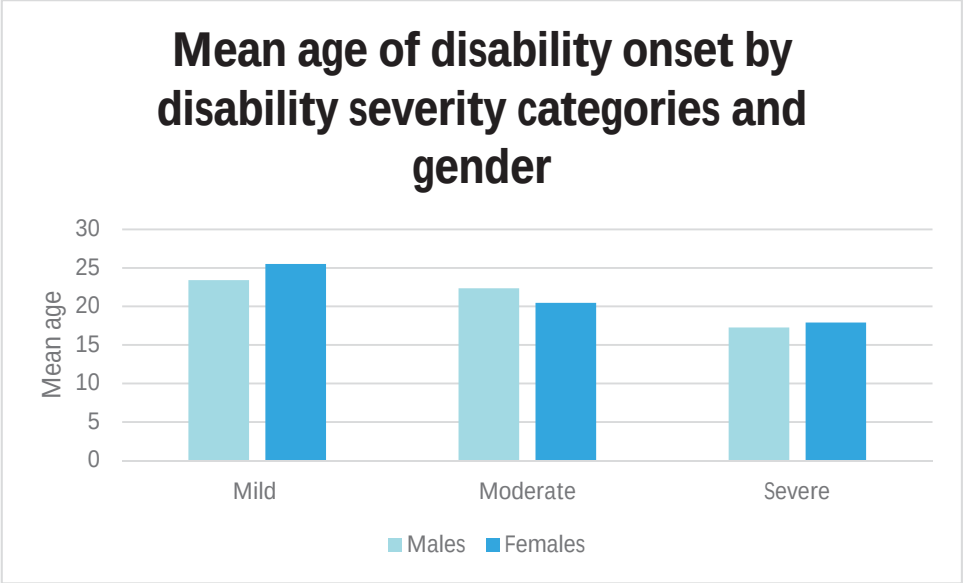


Figure 23. Mean age of disability onset by disability severity and gender (N = 2116)

9.2.4 Abuse and discrimination

An attempt was made to recode personal experience of being abused and discriminated both in the family and society among disabled respondents. Three questions were asked to assess the experience of being discriminated, with answer categories *yes*, *no* or *don't know.* These questions are:

Experience of being beaten or scolded by family members or relatives

Experience of being beaten or scolded by others

Experience of being discriminated in any public services i.e. hospital, clinic, police station, bank etc.

The analyses below are presented without the *don't know* answer category.

The most prevalent of the three indicators was *beaten or scolded by a family member*, reported by 24.2%. Some variation was observed between the different age groups with reduced reported abuse and discrimination for among the oldest age groups. The only significant gender difference was on discrimination by public services that was reported

by more males than females. With regards to regional differences, beating or scolding by family members are reported by more respondents in the Far-western and fewest in the Western region. Beating or scolding outside family is reported by more respondents in Central and Far western region, and fewest in Western region. Discrimination by public services seems to be more common in the Far-western region and less so in the Eastern and Western regions.

Table 28. Distribution of personal experience of being abused or discriminated, by age, gender and development region (N = 2105)

	Family	Society	Public services
Total	24.2	20.4	9.9
3-10	27.4	25.3	2.3
11-20	36.2	27.4	14.8
21-30	30.2	25.2	10.6
31-40	29.1	24.5	15.8
41-50	27.4	24.6	11.3
51-60	16.6	15.2	9.0
61-70	11.8	10.2	4.5
71 and above	4.7	3.8	3.1
Male	23.8	20.2	11.8
Female	24.6	20.7	7.8
Eastern region	22.5	15.7	7.4
Central region	26.3	26.5	10.1
Western region	11.3	8.7	8.4
Mid-western region	27.9	20.5	10.0
Far western region	35.6	24.4	19.3

The three abuse/discrimination questions were analysed with respect to severity of disability. For all three indicators, there is a clear pattern in that more severely disabled are exposed to more abuse and discrimination.

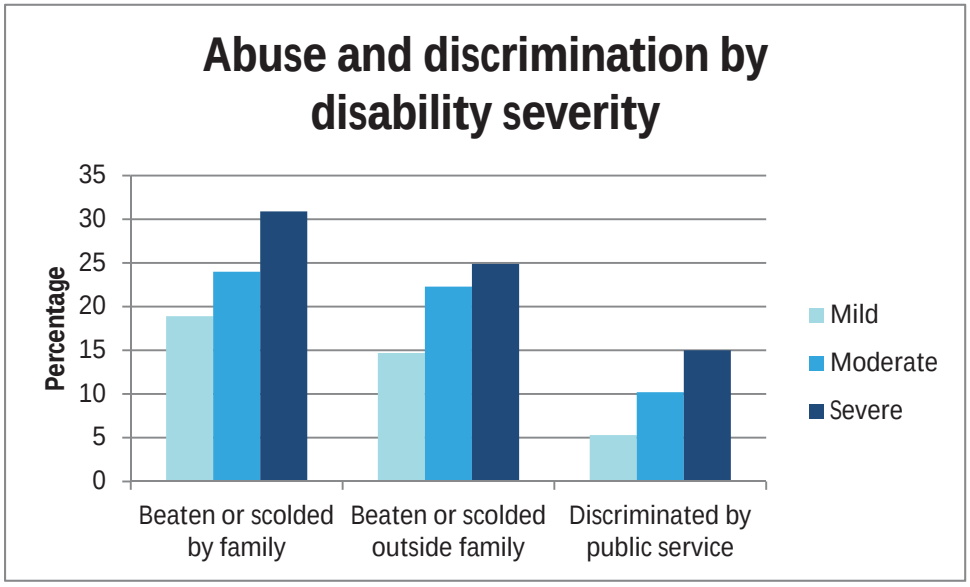


Figure 24. Abuse and discrimination by disability severity (N = 2020 – 2106)

9.2.5 Welfare and Health Services: Needed, Aware of or Received

An attempt was made to record the need of people with disability of several welfare and health services and at the same time determine whether they are aware of and have received the services. The table below lists the different welfare and health services and the proportion of people with disability who were in need of and aware of the services. The analyses included only people with disability.

Table 29. Proportion of persons with disability who needed, were aware of and had received services (N = 2123)

Type of services	Needed %	Aware of %	Received %
Medical rehabilitation	55.7	40.6	9.6
Assistive devices	56.0	61.8	15.4
Educational	32.3	40.0	6.8
Vocational	45.4	46.6	2.0
Counseling pwd	41.3	32.8	4.4
Counseling for parent/family	41.4	34.5	8.3
Welfare	79.9	73.5	9.0
Health	86.5	86.4	61.2
Health information	59.7	53.0	21.0
Traditional/faith healer	38.4	80.4	27.7
Legal	31.8	28.8	1.8

Source: Individual interviews (Case, i.e. persons with a disability)

The results show discrepancies between need of services and awareness of the services (Gap I). In six of the eleven services, the expressed need was greater than the awareness of the services. The biggest gap between the need and awareness of services was found in medical rehabilitation (15.1 percentage points), followed by counselling (9.5 percentage points), and welfare services (6.5 percentage points). For five services, it was the other way around with awareness being higher than needed and with traditional healer standing particularly out with a gap of 42.0 percentage points.

Gap 2 was calculated as the gap between need of the different welfare and health services and the actual access to the services. For six of the services, there were less than 20% of disabled respondents who actually received the services they needed. The largest gaps were found for vocational rehabilitation, legal advice, counseling for person

with disability, and welfare services. The smallest gaps were found for traditional healer and welfare services. The pattern of the gap was almost similar for respondents who did not receive the services despite that they needed as well as were aware of the services (Gap III). This is presented in the table below.

Table 30. Gap II & III: Proportion of people who needed but did not receive the services

Type of services	Received %	Gap II[1] %	Gap III[2] %
Medical rehabilitation	9.6	82.8	78.0
Assistive devices	15.4	72.5	77.6
Educational	6.8	78.9	83.8
Vocational	2.0	95.6	85.7
Counseling	4.4	89.3	80.4
Counseling for parent/family	8.3	80.0	67.1
Welfare	9.0	88.7	90.6
Health	61.2	19.2	36.9
Health information	21.0	64.8	43.7
Traditional/faith healer	27.7	17.9	54.7
Legal	1.8	94.3	90.9

[1]All disabled respondents who needed the service but did not receive: 100 – needed/received
[2]Disabled respondents who needed and were aware of the service but did not receive

9.2.6 Assistive devices

Of respondents with a disability, 11.7% report that they use an assistive device.

Figure 25 illustrates differences in access to assistive devices by gender and location. More males access such devices than females, and more urban than rural dwellers.

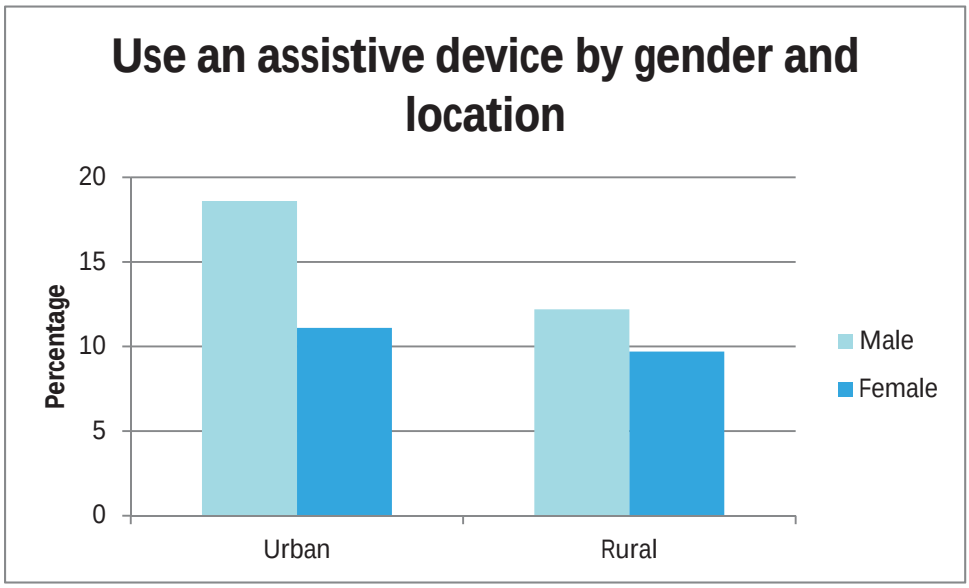


Figure 25. Use an assistive device by gender and location (N = 2123)

Figure 26 reveals differences between the three ecological zones in that fewer respondents from the Mountain zone report that they use an assistive device, while the Hills zone score somewhat higher than Terai zone.

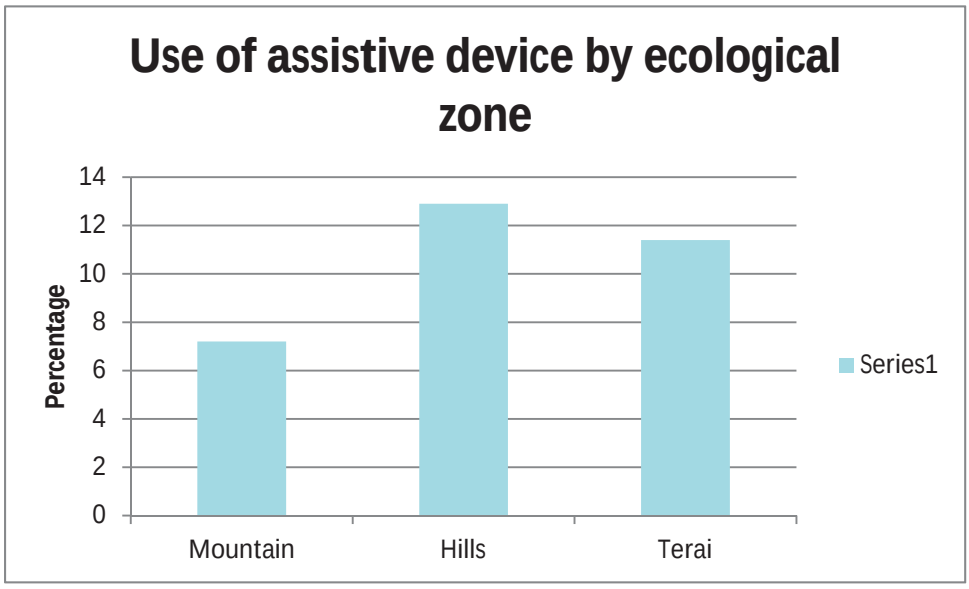


Figure 26. Use of assistive device by ecological zone (N = 2116)

Contrary to what could be expected, use of assistive devices is reduced with increased severity of disability (Figure 27).

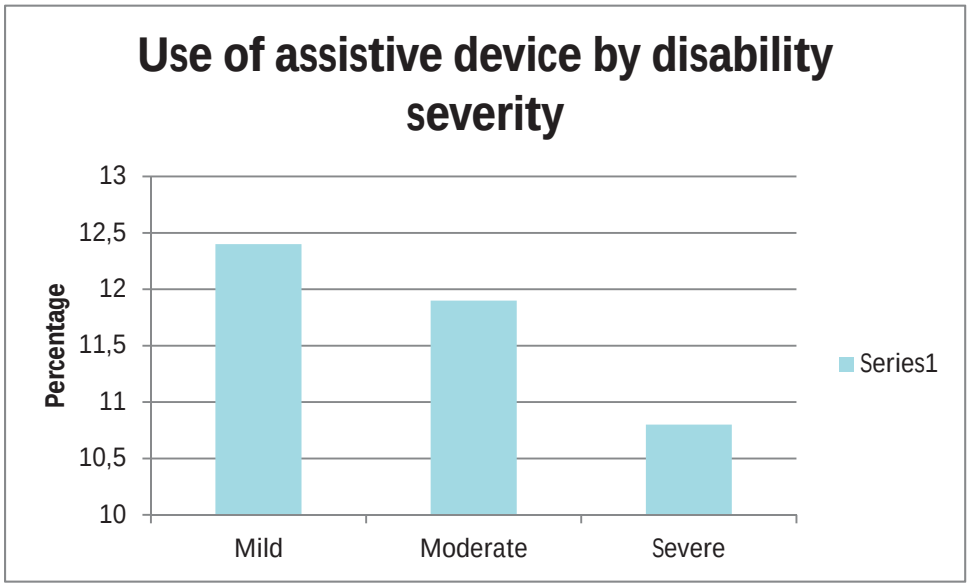


Figure 27. Use of assistive device by severity of disability (N = 2115)

Of those who confirmed that they used an assistive device, most reported using Household items (56.7%) (flashing light on doorbell, amplified telephone, vibrating alarm clock. A total of 55.7% used Information device (55.7%) (eye glasses, hearing aids, magnifying glass, telescopic lenses/glasses, enlarged print, Braille), while 48.4% used devices for handling products and goods (gripping tongues, aids for opening containers, tools for gardening), and 34.6% used devices for personal mobility (wheelchairs, crutches, walking sticks, white cane, guide, standing frame).

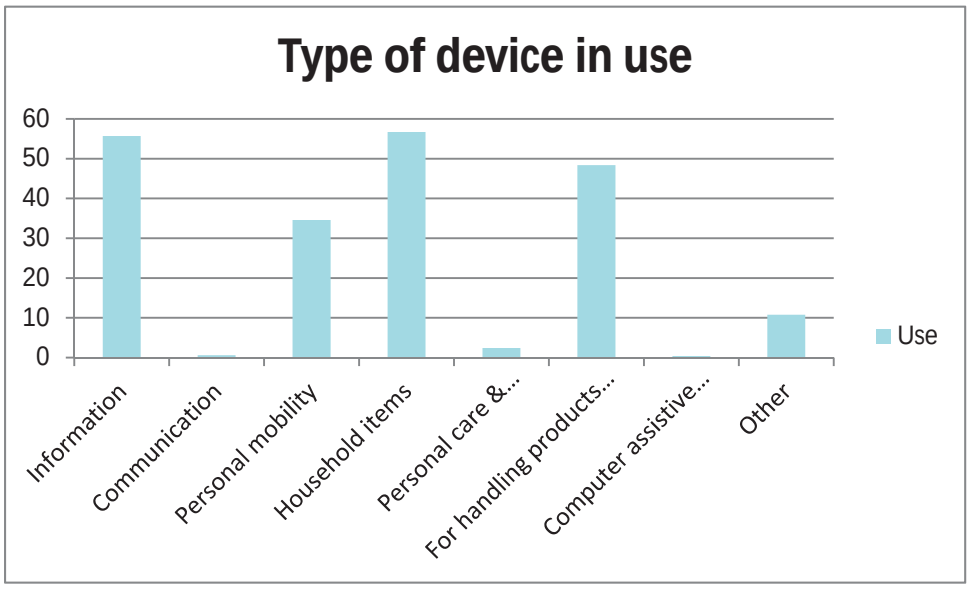


Figure 28. Distribution of assistive devices (N = 234)

Of the 234 who confirmed that they were using an assistive device, 93.2% reported on one devices, while 6.4% had two devices and 0.4% had three. The majority (51.1%) reported that the device they had was in good working order.

The large majority (81.1%) of the devices were stated to come from a private source, 8.7% came through an NGO, 6.4% from Government health services, and 3.8% from other Government services.

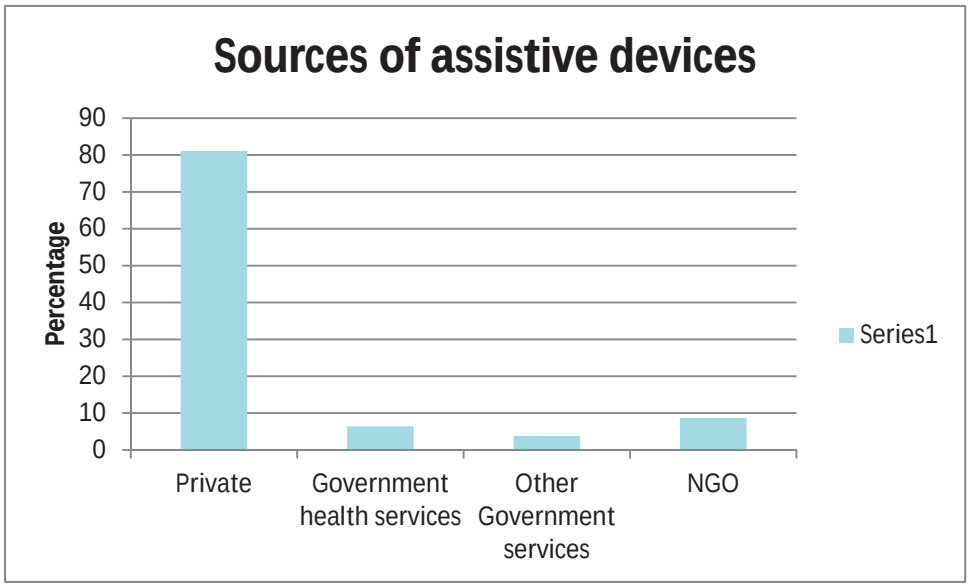


Figure 29. Sources of assistive devices (N = 264)

Most of the assistive devices (54%) are maintained by the user him/herself. The second most common is family members (24%), followed by not maintained (17.5%). Government is almost completely absent here, as are also NGOs and employers.

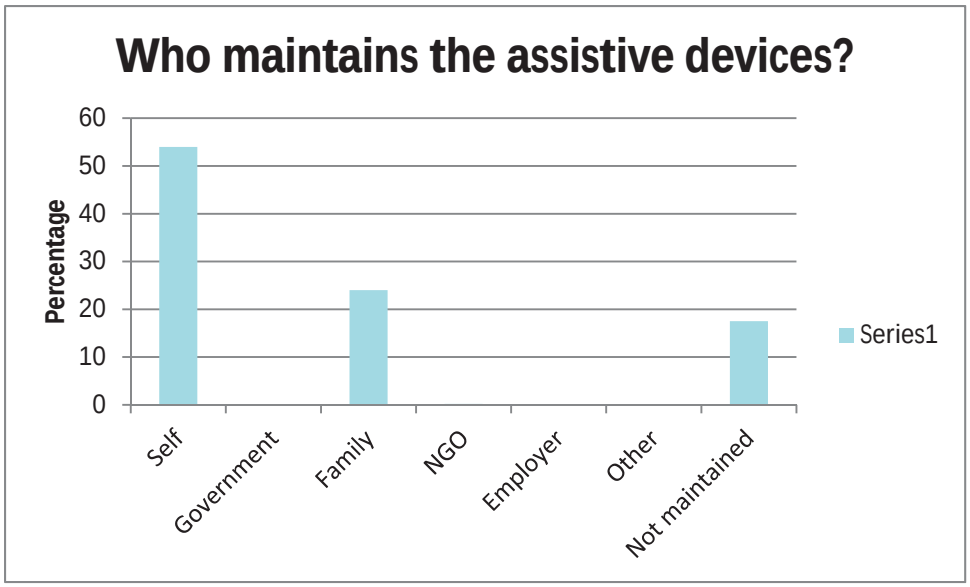


Figure 30. Who maintains the assistive devices (N = 263)

Almost half (48.8%) of those who use an assistive device report that they have received complete/full information in how to use the device. The remaining 51.2% have received some (22.5%) or no information (28.7%).

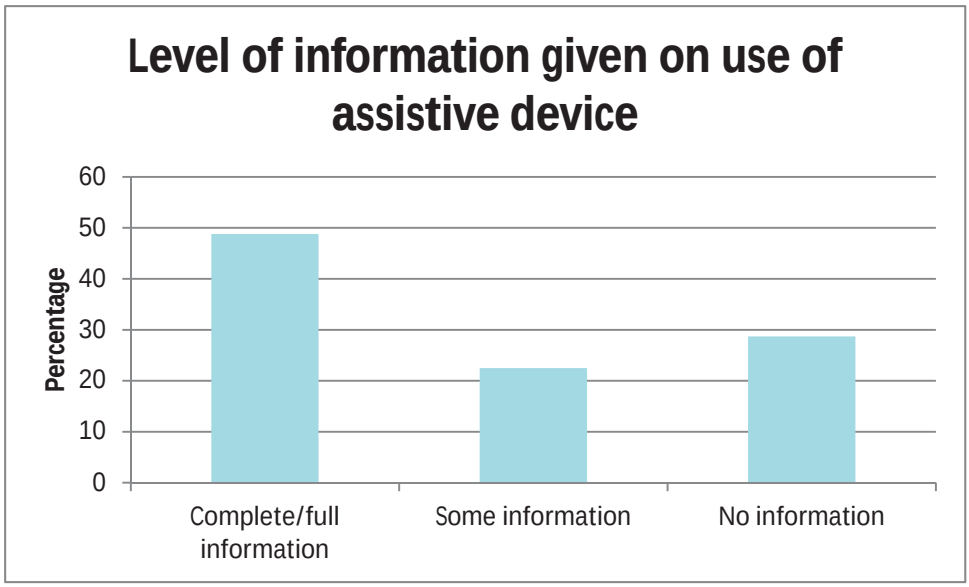


Figure 31. Level of information given on use of assistive device (N = 244)

Around two thirds (66.8%) of the individuals with disability using an assistive device state that they are either very content (36.8%) or content (30%) with their devices. Among the remaining, 9.8% are not content and 23.9% are content. There is some variation between urban and rural respondents, in that more rural respondents are not content and more urban respondents are very content, but the difference between the two groups (urban/rural) is not statistically significant. There are further marginal gender differences in level of satisfaction.

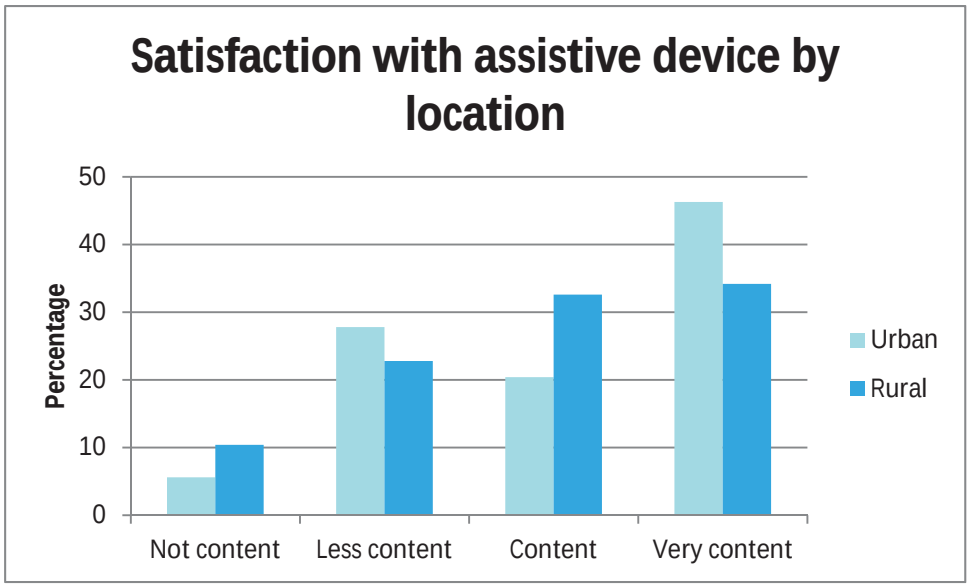


Figure 32. Satisfaction with assistive device by location (N =247)

9.2.7 Employment

Respondents with and without disability aged 15 years and above were asked if they were currently working. Currently working includes casual laborers, part-time work and those who were self-employed. A total of 41.7% of the respondents who were currently working. It is important to note that this rate should not be used as a national employment rate but, as below, in a comparison between disabled and non-disabled respondents.

The results in the table below show that the proportion of respondents with disability who were currently working was substantially less than the proportion of non-disabled respondents, with the difference being 22.2 percentage points. More individuals with disability have never been employed, and more control individuals are still studying, both indicating that individuals with disability are less integrated into working life.

Table 31. Current employment status, by disability status (15 + years)(N = 3457)

Currently working	Disabled %	Control %
Yes	36,4	54,6
No, but have been employed previously	20,7	11,0
No, never been employed	21,3	4,1
Homemaker	16,9	20,8
Still studying	4,7	9,5
Base = 100%	**1769**	**1688**

Detailed analyses according to gender revealed that among disabled respondents, 24.3% females and 47.5% males were currently working. Among non-disabled, 36.6% females and 70.3% males of the non-disabled respondents were currently working.

Among those who were unemployed, 31.0% of the non-disabled respondents stopped working because they had retired, 9.3% of the disabled respondent stopped working because of the same reason. The low percentage could be explained by the low employment rate among the disabled people. On the other hand, 72.0% of the disabled respondents stopped working due to illness or disability, while 19.0% of the non-disabled stated illness as a reason.

Table 32. Reason for unemployment by disability status (15 + years) (N = 548)

Reason	Disabled %	Control %
Retired	9.3	31.0
Retrenched	1.6	6.0
Fired	1.4	2.2
Injury/accident at work	8.2	0.0
Illness	24.7	19.0
Because of disability	47.3	0.0
Cannot work/too old	4.4	28.3
Other	2.5	10.9
Do not know	0.5	2.7
Base = 100%	**364**	**184**

Employment status was also analysed by location (urban/rural), as shown in Table33.The differences between individuals with and without disability is here demonstrated both in urban and rural areas. While there are some differences between urban and rural respondents, a general impression is that these differences are small

Table 33. Employment status by disability status and location (=> 15 years) (N = 3432)

	Urban		Rural	
Work status	Disabled	Controls	Disabled	Controls
Yes, currently working	32.6	52.1	37.1	55.4
No, but been employed previously	22.6	13.1	20.3	10.3
No, never been employed	20.1	3.3	21.4	4.3
I am a housewife/homemaker	16.0	18.2	17.1	21.6
Still studying	8.7	13.3	4.0	8.4

9.2.8 Accessibility

Disabled respondents were asked if their home has different rooms or facilities such as kitchen, bedroom, living room, dining room and toilet. They were also asked if these rooms were accessible to them and that they can get there easily and use the facility most of the time. Availability of these rooms or facilities and their accessibility are listed in the table below. Generally, it can be claimed from the data presented that the majority of those who had these facilities or rooms in their home could access them as well. Regarding ownership, less than half of the disabled respondents had a living room in their home (39.5%), while half of the respondents (50.6%) had a dining room in their home. Almost one-third of the disabled respondents claimed that they did not have their own toilet at home.

Table 34. Accessibility at home and ownership (N = 2123)

Room/facility	Accessible %	Have none %
Kitchen	95.1	4.9
Bedroom	95.4	4.4
Living room	39.5	2.5
Dining room	92.7	4.8
Toilet	87.5	7.0

The table below presents the distribution of accessibility of different places or facilities among disabled persons who had used them or where these places or facility were available in their area. Among all the places and facilities, it is interesting to note that offices of DPOs were the least accessible, followed by recreational facilities, the court system and banks, all within the range of 37% - 33% not accessible. The most accessible were places of worship (13% not accessible) and shops (17% not accessible). About 28% claimed that the hospitals were not accessible, while 19% stated that the primary health care clinics were not accessible. The table also shows the proportion of respondents who did not perceive the facilities as available or applicable. School comes out very high,

which is explained by the majority of the respondents being too old for ordinary schooling. The second least available/applicable was recreational facilities. Workplace is also quite high and reflecting the large number of individuals being outside of the formal labor market. Also, DPOs were quite high with 32.0% regarding them as either not available or not applicable, which may indicate that the organisations have a challenge in attracting the interest of their potential constituency.

Table 35. Accessibility outside the home

Place/facility	Accessible[1]	Total[2]	Not available/
	%	*n*	Not applicable[3]
Workplace	90.8	1108	47.8
School	95.0	379	82.1
Shops	86.8	2073	2.4
Place of worship	87.7	2042	3.8
Recreational facilities	64.6	749	64.7
Sports facilities	79.9	1600	24.6
Police station	72.1	1989	6.3
Magistrates office/traditional courts	65.4	1916	9.8
Post office	70.6	1908	10.1
Bank	66.3	1787	15.8
Hospital	71.8	2010	5.3
Primary health care clinic	80.9	2093	1.4
Public transportation	77.8	2019	4.9
Hotels	75.0	1985	6.5
DPOs, organizations for PWD	63.1	1443	32.0

[1]Percentage that did not use, or the places or facilities were not available

[2]Total number of respondents who used the places or facilities

[3] Percentage of all respondents

9.2.9 Assistance in daily life activity

The results presented under this topic are obviously dependent on numerous factors; among them the sex and age of the disabled persons and the severity of their disability. The analyses are based on the proportion of the sample that did not classify the activity as *not applicable*; the basis, or denominator, for the calculations is the number of persons with disability who answered either *yes*, *no,* or *sometimes* on the different types of assistance they needed in daily life activity. The results are presented in the figure below.

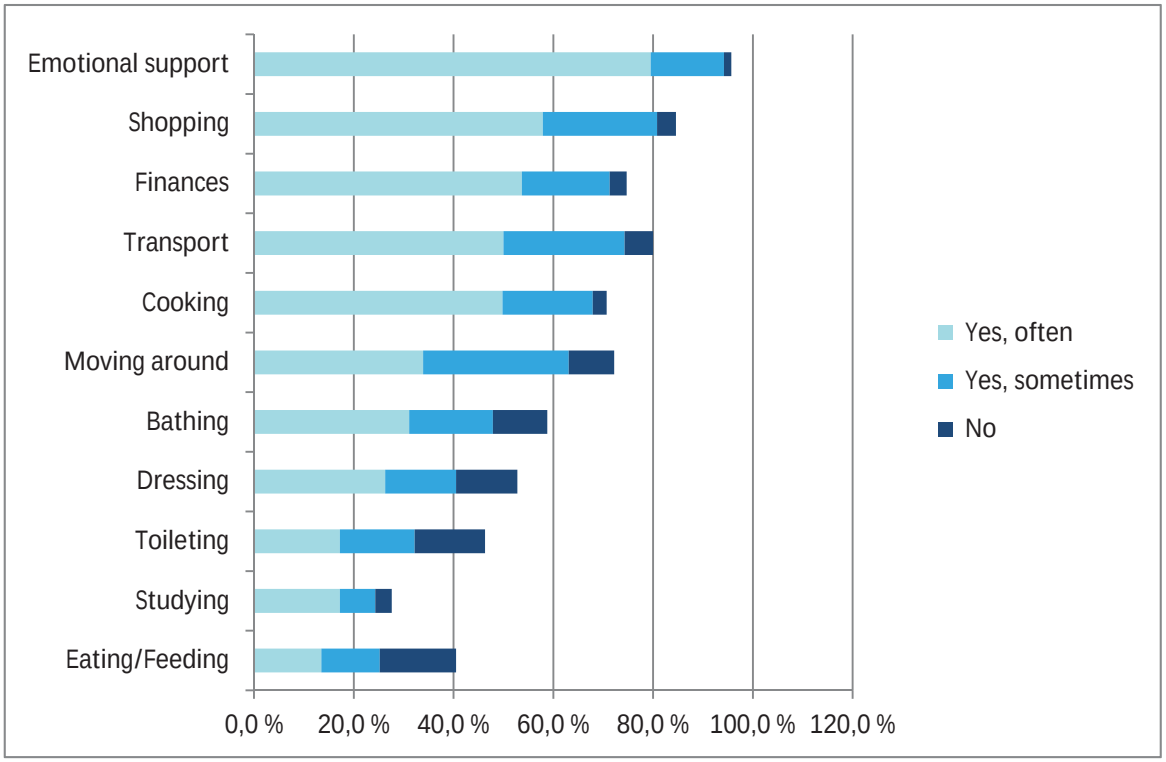


Figure 33. Assistance received by individuals with disability in daily life situations (N = 379 – 2093)

The range of percentages of assistance received for the different daily life activities lies between 13.5% - 79.5% for *yes* and 7.1% to 29.2% for *sometimes*. The majority (among those who did not respond "not applicable") of the disabled persons report that they received emotional support (79.5%). Assistance in shopping and finances were also reported by more than half of the respondents. Few reported assistance in feeding

(13.5%), studying (17.2%) and toileting (17.2%). Gender differences in assistance received were largely marginal.

9.2.10 Involvement in family, social life and social activities

Involvement in family life activities was also analyzed and results are presented in the tables below. While the majority of the questions involved activities that were not regular in the aspect of family life, it is worth noting that about 15 % of disabled respondents answered that they were not included with the family to events such as family gatherings or social events. In addition, about 14.6 % claimed that the family did not involve them in conversation compared to only 6.4 % among non-disabled respondents. This is presented in Table 36.

In general, comparison of involvement in family life between disabled and control respondents show that involvement of the disabled respondents in all five family life activities was considerably less compared to the non-disabled respondents. However, taking into account of these differences, it should be noted that the majority of the respondents felt that they were involved and part of the family.

Among respondents aged 15 years old and above, questions on involvement in making decision in the family and participation in local community meetings were also asked. The difference between disabled and non-disabled respondents on the involvement measures is presented in Table 36. When combining the proportions for the five family-related indicators who responded either "yes" or "yes, sometimes", the differences between individuals with disability and controls were between 7.9 and 16.9 percentage points. Largely, the combination of the two ("yes" or "sometimes") is confirmed by between 80% and 90% of individuals with disability and around 98 %% among controls. For the first questions on local community involvement/participation, four out of ten among individuals with disability state that they do not participate in local community meetings, while the corresponding figure for controls is close to seven out of ten. Among those who confirm such participation, most feel that their voice is being heard, but the proportion among

controls in 10 percentage points higher than among individuals with disability (for these two questions, "do not know" has been recoded to "no").

The difference between the two groups is also marked when it comes to voting, with more controls confirming and the difference is around 20 percentage points.

Table 36. Involvement in family life, by disability status

Measure of involvement	Disabled				Control			
	Yes %	Sometimes %	No %	Total n	Yes %	Sometimes %	No %	Total n
Family/household								
Consulted about household decisions	69.9	10.9	19.2	2012	92.2	4.6	3.3	1957
Go with the family to events such as family gatherings, social event etc.	64.3	20.7	15.0	2095	88.2	10.7	1.1	1993
Feel involved and part of the household or family	87.4	4.3	8.3	2037	98.9	0.7	0.4	1988
Family involves you in conversations	73.2	12.2	14.6	2035	93.6	5.0	1.4	1972
Take part in your own traditional practices	60.4	26.7	12.9	2109	84.0	15.2	0.8	1997

Measure of involvement	Disabled				Control			
	Yes %	Sometimes %	No %	Total n	Yes %	Sometimes %	No %	Total n
Local community								
Participate in local community meetings	20.1	11.4	68.5	1775	45.4	12.9	41.6	1688
If yes/sometimes, do you feel that your voice is being heard	76.8		23.2	560	88.6		11.4	985
Voted in the last election	69.0		31.0	1775	81.5		18.5	1688

Relationship with and knowledge about the disability movement was used as an additional indicator for involvement in society among individuals with disability. Only 7.7% reported to be a member of a disability organization (DPO, disabled peoples' organization), while 37% said that they were aware of such organizations. Among those who were aware, 18.5% reported to be member of a DPO.

Table 37. DPO awareness and membership. 21 years old and above (N = 1776)

Measure of involvement	Yes %	No %
Aware of any DPO	36.6	63.4
Member of a DPO	7.7	92.3

Persons with and without disability aged 21 years old and above were asked if they voted in the 2007 election. A total of 69.0% reported that they voted in the last election (68.8% of males and 65.8 %of females, no significant difference), as compared to 81.5 % among controls. Higher participation in election was reported among those who were aware of DPOs; 79.9% as compared to 74.0% among those who were not aware. Well over one third (38.7%) of individuals with disability who did not vote stated that disability was the reason.

9.2.11 Health

Of the respondents with a disability, 23.2% (N = 2117) stated that they used any medication or traditional medicine for pain that was caused by their disability. A small non-significant (p = .07) gender difference was found with 24.6% of females and 21.9% of males confirming use of any medication. More urban dwellers reported use as compared to rural dwellers. The urban/rural difference was however statistically significant only among males (30.4% vs. 20.0%).

Further analyses were done on distribution of the two types of medicine, revealing firstly an overall strong dominance of "modern" ("western") medicine, secondly a tendency that "modern" medicine was more often in use in urban areas while traditional medicine and a combination of the two was more common in rural than in urban areas. No significant gender difference was found.

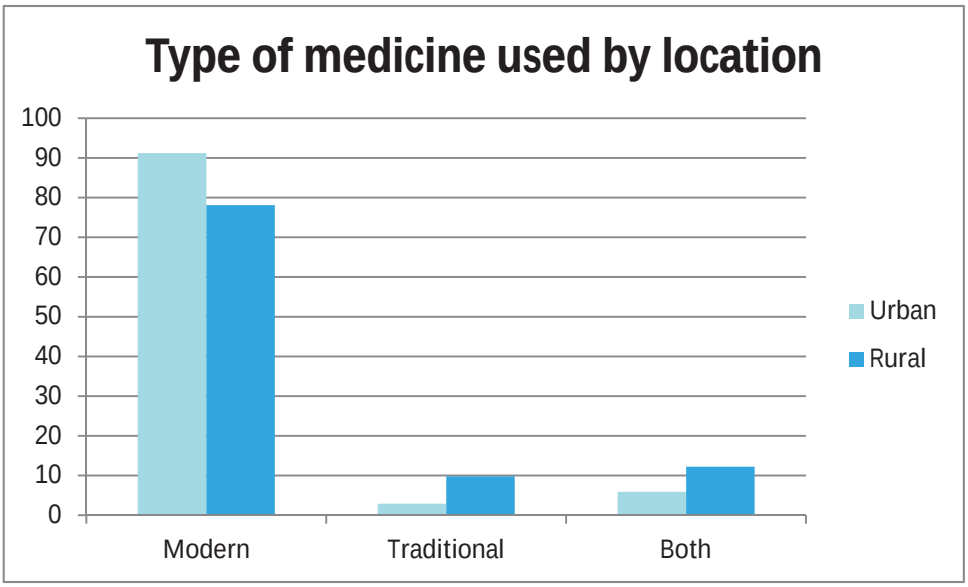


Figure 34. Type of medicine used by location (N = 467)

Variation in type of medication used was also done by ecological zone. The main finding was that the Mountain zone differ from the Hills and Terai zones with less use of modern medicine and more traditional and combination of modern and traditional.

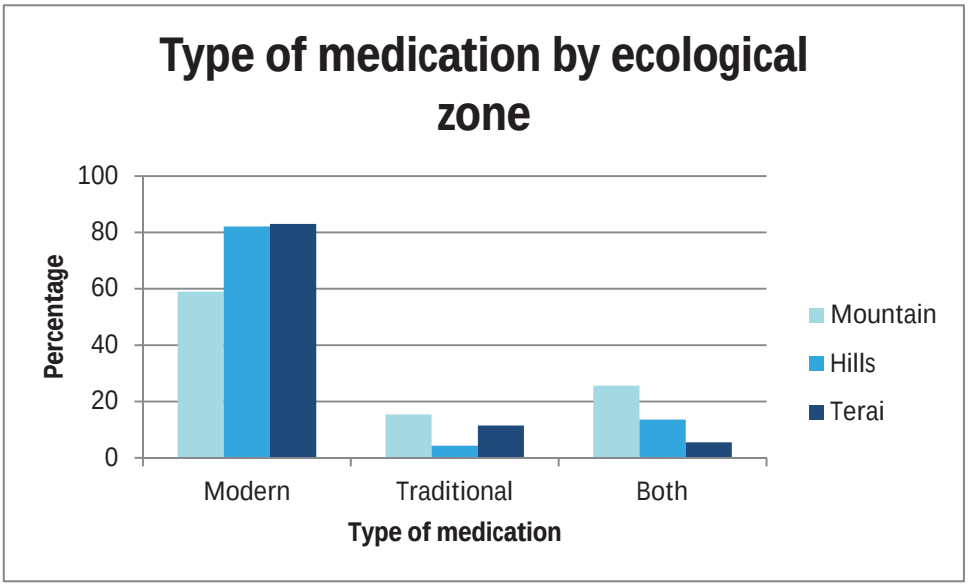


Figure 35. Type of medication by ecological zone (N = 492)

Respondents were asked to state whether they currently had any of 15 common health conditions.

Table 38. Health conditions by disability status (%) (N = 4123)

Health condition	Disabled	Controls
Heart condition	2.5	1.6
Respiratory condition	3.3	1.4
Asthma	4.3	3.9
Epilepsy	0.9	0.1
Cancer	0.3	0.1
Diabetes	1.4	1.2
Kidney/liver disease	0.9	0.3
Rheumatism (related)	4.7	2.1
Gynecological problem[1]	2.3	3.5
Occupational disease	0.4	0.3
High or low blood pressure	6.0	4.3
Gastrointestinal disease	4.9	2.7
Other	2.1	1.1

[1] Females only, N = 1945

For all the 14 different conditions in Table 38 except four, individuals with disability report higher incidence of the different health conditions. The difference was not statistically significant for Asthma, Cancer and Diabetes, and Gynecological problems were significantly higher among non-disabled females. Mostly, the identified differences are relatively small but statistically significant due to the large data material.

Assessment of general well-being was done using a standardized General Health Questionnaire 12-item (GHQ-12) (Goldberg & Williams, 1988). A standard Likert scoring procedure was implemented in GHQ-12, with scores for each question ranging from 1 to 4. Higher score represents higher psychological distress. All respondents aged 15 years old and above were asked these questions. Mean value on the scale was 21.78, range was 12 – 48, and standard deviation was 5.64.

Table 39. GHQ-12 score, by disability status

	Disabled	Control
	Mean	Mean
Female	23.6	19.4
Male	23.8	20.1
Total	23.7	19.8

Overall, disabled respondents scored higher in the GHQ-12 assessment compared to non-disabled respondents; 23.7 and 19.8 respectively. This illustrates that respondents with disability have lower general well-being status compared to respondents without disability. A significant gender difference was also found in that males reported to have lower general well-being (higher scores on GHQ) compared to females, but significance was reached only aong controls.

Figure 36 reveals that wellbeing is reduced with severity of disability. There is also a tendency that females report slightly lower wellbeing, except among the mildly disabled.

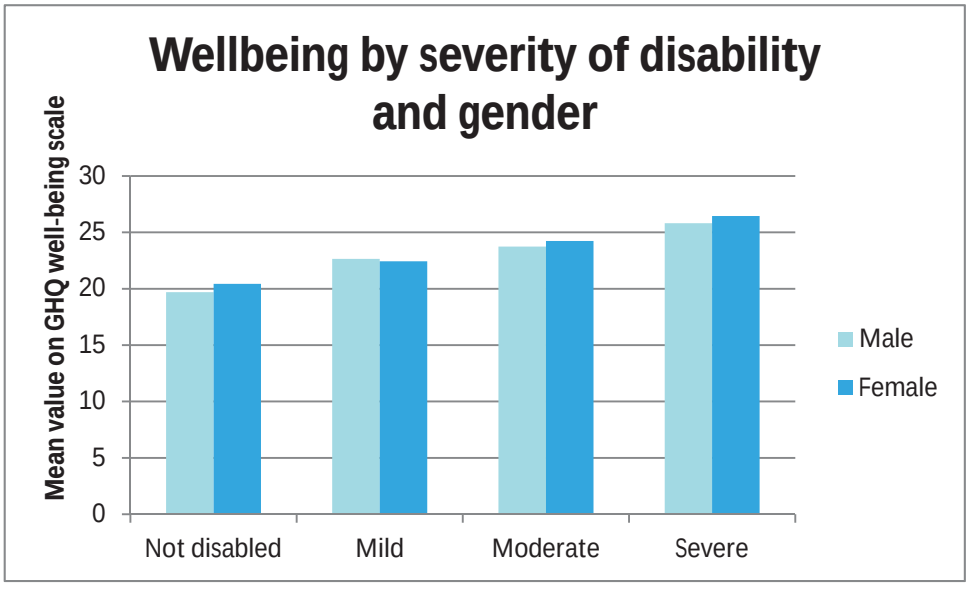


Figure 36. Wellbeing by severity of disability and gender (=> 15 years, N = 3434)

Small differences in wellbeing were found between urban and rural respondents, although the overall difference was found to be statistically significant. The tendency is slightly lower wellbeing among rural respondents.

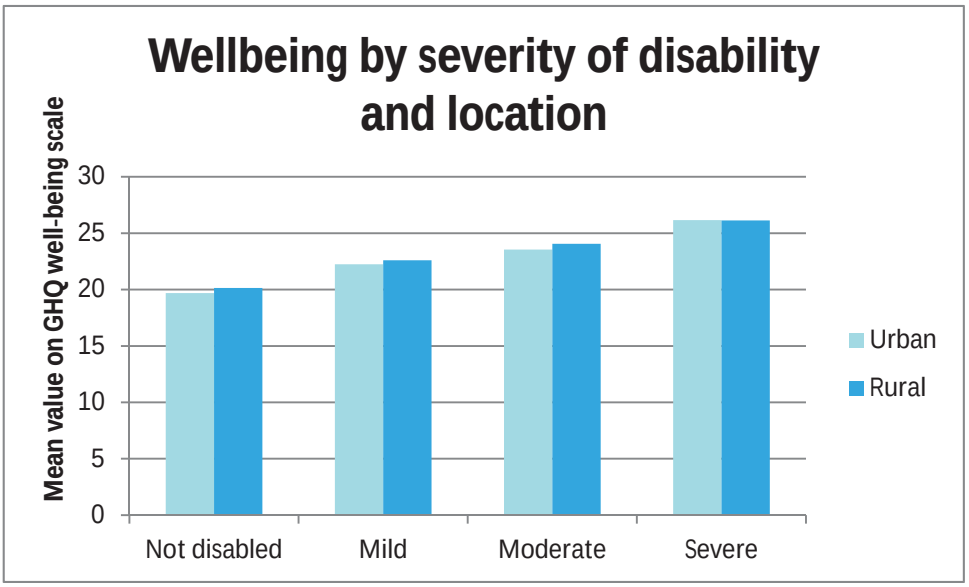


Figure 37.Wellbeing by severity of disability and location (=> 15 years, N = 3434)

The questionnaire also included two direct questions on current physical and mental health. As shown in Table 40, there is a pronounced difference between individuals with and without disability in that controls report better on both indicators.

Table 40. Overall physical and mental health at present, by disability status (%) (N = 4100 and 4078)

	Disabled		Control	
	Physical health	Mental health	Physical health	Mental health
Poor	42.4	26.9	7.6	7.2
Not very good	39.0	34.4	13.2	14.0
Good	16.4	36.4	69.7	68.9
Very good	2.2	2.3	9.5	9.9

Analysing mental and physical health by severity of disability revealed firstly the same as in the table above, that control individuals scored higher on both. Secondly, both mental

and physical health is reduced with increasing severity of disability.

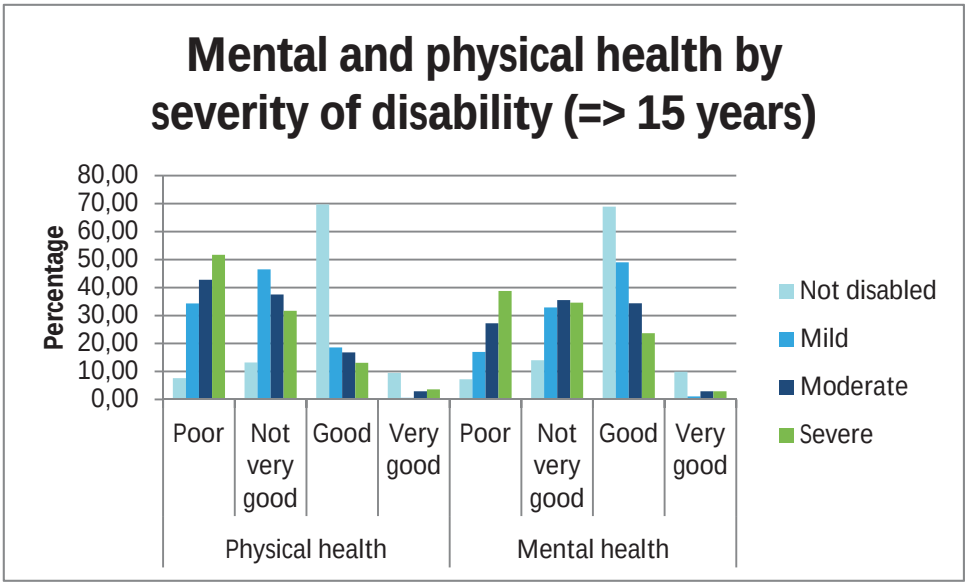


Figure 38. Mental and physical health by severity of disability (N = 4110 and 4083)

9.2.12 Knowledge, access to information and exposure to some common diseases

Significantly more control individuals report that they have knowledge about the four diseases in Table 41. In percentage points, the difference is around 20 percentage points, varying between 19.3 (TB) and 24.1 (Sexually transmitted infections, STI).

Table 41. Percentage confirming knowledge about four common diseases by disability status (N = 3839 - 3946)

Do you have any knowledge about	Disabled	Controls
HIV/AIDS	45.5	68.6
STI	37.3	61.4
Diabetes	58.2	77.9
TB	65.0	84.3

Knowledge about the four diseases was also analysed with respect to severity of disability. We see in Figure 39 that there is a clear drop in proportion of respondents who confirm knowledge by severity, for all four diseases. Fewer individuals with more severe disability claim to have knowledge about the diseases as compared to those with moderate, mild and no disability. The figure also reveals that it is more common to have knowledge about TB and least about STI.

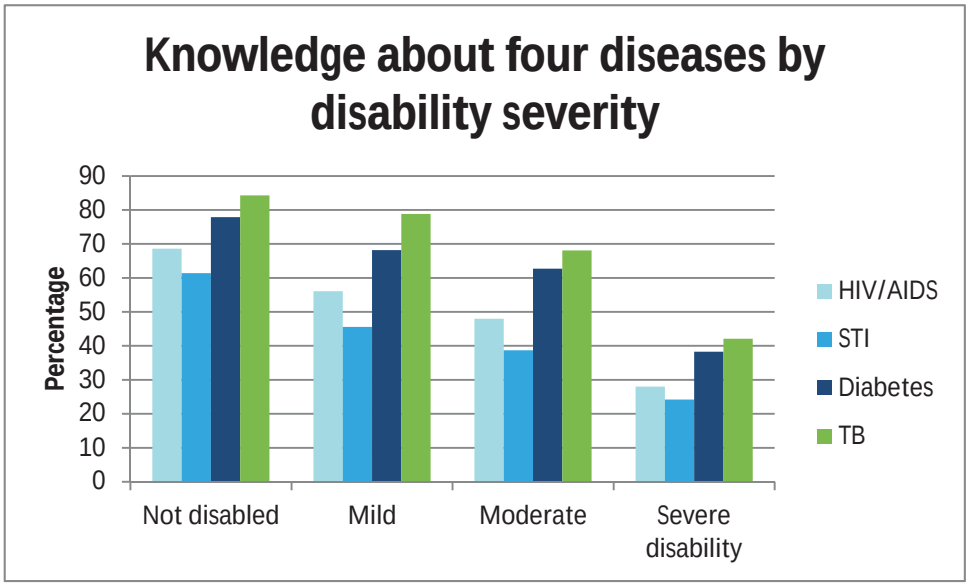


Figure 39. Knowledge about four diseases by disability severity (N = 3803 – 3928)

There are three main sources of information about the four diseases, but the rank order of the main sources differs somewhat between the diseases. For HIV/AIDS and STI, the main source is Radio/TV, followed by School and Friends. For Diabetes and TB, the most important source is Friends, followed by Family, Radio/TV and School. Family was clearly more important as a source for Diabetes and TB as compare to HIV/AIDS and STI. It can also be observed that Doctor is more important as a source for Diabetes and TB, but is still only reported by 5 – 6%. Statistically significant differences between disabled and controls could be observed for HIV/AIDS, largely due to higher importance of Friends and lower importance of School and Radio/TV among individuals with disability. The second significant difference was found for TB with Friends and Family being more often reported as a source among individuals with disability and the opposite for Radio/TV and School.

Table 42. Source of knowledge about four common diseases by disability status (=> 15 years, N = 1901 - 2833)

Where did you get most of the information?	HIV/AIDS		STI		Diabetes		TB	
	D	N	D	N	D	N	D	N
Health clinic	3.0	3.7	2.3	4.3	4.1	3.7	3.8	4.1
Doctor	1.6	1.9	2.5	2.0	5.6	4.6	5.7	5.0
At work	1.0	1.0	1.3	1.3	0.9	0.8	0.6	0.6
Magazines/newspapers	3.1	1.9	3.9	2.9	1.2	1.2	1.1	0.9
From friends	26.3	21.6	22.1	19.7	35.7	31.9	33.4	30.4
From family	4.6	3.8	3.8	2.8	19.1	16.6	19.2	12.2
Radio/TV	33.6	36.7	35.3	36.9	17.4	22.3	20.6	26.7
Posters and pamphlets	1.3	0.5	1.1	0.3	0.3	0.1	0.5	0.3
School	24.4	28.5	26.7	29.4	15.0	18.4	14.7	19.4
Other	1.1	0.3	1.0	0.3	0.7	0.3	0.4	0.4
Do not know	0.0	0.1	0.0	0.1	0.0	0.1	0.0	0.0

Around 20 – 25% of individuals with disability responded that they had problems understanding the information they had received about the four diseases, mostly HIV/AIDS information and least STI information. The corresponding figures for non-disabled were between 15 and 18%,% mostly HIV/AIDS information and least information about TB and Diabetes.

Table 43. Any problems in understanding information about four common diseases by disability status (=> 15 years, N = 1901 - 2833)

	HIV/AIDS		STI		Diabetes		TB	
	D	N	D	N	D	N	D	N
Any problems in under-standing information	24.7	18.0	19.5	16.6	24.2	14.8	22.9	14.7

10 Discussion

Arne H. Eide

A national, representative study on living conditions among people with disabilities has been carried out in Nepal in 2014- 2015. This report brings some of the key results from this study. NFDN, FFO, Valley Research Group, and SINTEF have, in collaboration with the MOWCSW, established a comprehensive data base about individuals withdisabilities and their households in the country. The data base also comprises a sample ofnon-disabled, which provides a basis for comparing between disabled and non-disabled.

Data on disability in low-income contexts is scarce, although currently growing and with several ongoing international initiatives to improve the knowledge base. The data that has been generated in this study provides opportunities for comparing between regions in Nepal and also with similar data from southern Africa. The data may in themselves be used by both the disability movement, Government agencies in Nepal and by international organisations involved in the disability sector in Nepal, and can bea vehicle for increasing awareness about disability and building capacity to improve thesituation for people with disabilities. In particular it is expected that the data is utilized by NFDN in their advocacy towards Government agencies and international organisations, and by MOWCSW as responsible Government agency for the livelihoods of individuals with disability in Nepal.

10.1 Comparing households

An interesting feature of household composition, which has been found also in previous studies, is that households with disabled members tend to be larger than controlhouseholds and with a higher mean age among the household members. This is of importance as it implies more mouths to feed, more school fees to pay, etc. While the Dependency ratio did not differ between case and control households, this indicates that the higher number of members in households with disabled members is among those in productive age groups, (between 15 and 64 years of age). This may imply that in some households, additional help is needed in the house and that the possible additional

burden on households with disabled members plays out in adult children staying home to cater for the individuals with disability. While the current study cannot confirm such an assumption, there is some support for this in the international literature on disability in low-income countries(Ingstad, Baider and Grut 2001; Grut, Olenja and Ingstad 2011)

While the Dependency ratio did not differ between the two household types, three different indicators on standard of living, i.e. a Possession scale, the Dietary diversity scale, and a scale on Access to information, all point in the same direction: control households are better off than case households. This implies higher burdens for households with disabled members as compared to controlhouseholds. Bearing in mind the differences in householdcomposition, the real difference between the two household types is in fact underestimated.

Although comparing housing situation and infrastructure revealed small and partly marginal differences between the two household types, there are some indications that households without disabled members are better off. Small differences could be expected as all/most households within a location share more or less the same standard, and that the variation is rather found between locations than within. Still, the data do indicate differentiation also within locations. Seen in a poverty perspective, and based on the international literature in the field (e.g. WHO 2011), higher prevalence of disability/households with disabled members in poorer areas with lower standard (housing and infrastructure) may be assumed. This can however not be deducted from the current data material (representative at regional level).

10.2 Activity limitations/disability

The concept of "activity limitation" as derived from the ICF (WHO 2001) invites an understanding of disability as a broad, continuous phenomenon of relevance for all. The profile of activity limitations in the current study does not deviate much from previous studies, with mobility (walking) as the most prevalent difficulty, and with sensory impairment (hearing difficulty + seeing difficulty) combined reaching the same level as

mobility. It is worth noting that the study applied a screening procedure that was "wide" in including everyone who reported "some difficulty" on one WG6 domain. This contributes to explain the high level of multiple scores in this study.

The results on disability onset reveal firstly that disability is age related, i.e. increasing disability with increasing age. This is as expected and part of natural development, but is clearly also an indication of need for intervention among the older age groups. It is however the relatively high incidence of early onset, i.e. among children, that gives reason for concern. This is further emphasized by the perceived causes of disability, strongly dominated by "By birth/Congenital" and "Disease/Illness. These findings have to be taken as indicating access and/or quality problems in prenatal and perinatal care for mother and child and should be an area of intervention, and also further studies in order to reveal more detailed knowledge on causes and critical factors. There is good reason to assume that a substantial proportion of child disability in Nepal is preventable.

10.3 Violence and abuse

A small proportion of the respondents (1 - 2%) have stated violence, including war related and witchcraft, as the cause of their disability. The figures are however considerably higher when asking for experiences of violence because of disability, up to 24% and 18.5% for violence/abuse within family and outside of the home respectively. This is slightly higher than in previous comparable studies. Slightly more females reported experience of being discriminated in any public service than males, but the main impression is that gender differences are small. Any experiences of being beaten, scolded or discriminated are unacceptable and a violation of human rights, and it may be of some concern that violence/abuse by family members is reported by one in four in spite of the context of this data collection that one can assume contributed to underestimate the phenomenon. The results indicate that many individuals with disability suffer under unacceptable treatment in particular in their home environment.

10.4 Health, well-being and health information

The comparison between case and controls with regards to chronic illness reveals a substantial difference with much higher incidence of chronic illness among cases. This is as expected, and although disability is created in the exchange between the individual and his/her social and physical surroundings, health is still an important explanatory component for disability within the ICF framework.

The relationship between health and disability is confirmed by both the household level and the individual level data, with lower levels of well-being, physical and mental health as assessed by the individuals with disability themselves. The study has further revealed that a large proportion of individuals with disability have no or limited knowledge and information about common diseases, and that the lack of knowledge of the four diseases included in this section of the questionnaire was more than 20 percentage points for three of the diseases. More than one in five of individuals with disability have problems understanding information given to them about these common diseases, which is significantly higher than among non-disabled for three out of the four diseases. This is clearly serious both in a preventive and treatment perspective and may indicate that vulnerable groups are not sufficiently targeted by prevention efforts. Radio/TV, friends and schools are the major sources of information for all four diseases included, while health clinics and doctors were reported by relatively few. The latter may be seen as rather surprising and possibly indicate that prevention is given low priority within the current health services.

Access problems and limited information may be regarded as barriers, and in particular for individuals with disability. Addressing health and disability is thus about more than the health service itself - additionally it is also about information and knowledge and securing that tailor made information is provided to individuals and groups that are harder to reach than the general population and that easily get sidelined. An information/ knowledge gap among individuals with disability also requires consciousness-raising among health workers and particular strategies to ensure inclusion of individuals with disability.

Individuals with disability have higher levels of anxiety and depression than non-disabled, and they rate both their physical and mental health lower. This is of importance as the status of being disabled may easily shadow for health problems. It is a prerequisite for equitable health services that service providers are conscious about the double burden of many individuals with disability, i.e. poorer mental and physical health in addition to the impairment/disability.

10.5 Services

Unlike many other countries that have been included in similar research, there appears to be a substantial gap in access to health services among individuals with disability, with more than 40% stating that they did not receive health services even though they needed it. On one hand, this is the service with the smallest gap among the services included in the study. On the other hand, the gap is very high for such a critical service and simply implies that health coverage can hardly be said to be universal in this population. Gaps in services are very high for many of the services included, and simply indicate that many of the basic services are not available for large proportions of the disabled population and that the current specter of basic services is not sufficient to cater for the needs of individuals with disability. This must be assumed to impact on the inclusion of individuals with disability in society and an evident area for improvements. This may partly be a capacity problem and partly a matter of exclusion. Further research will be necessary to reveal this. As these questions were not presented to non-disabled, we do not know to what extent access is lower among individuals with disability.

10.6 Daily life and social inclusion

The results on accessibility at home reflect the standard of housing which will vary between locations. In general, many respondents live in simple houses with weak infra structure and few facilities, i.e. without separate living rooms, dining rooms etc. Whereas the large majority of those who had the different facilities in their home did not report any

accessibility problems, mapping and adaptation where needed could be carried out by health and rehabilitation services at community level.

Concerning accessibility in the community, many of the facilities mentioned in the questionnaire were not applicable, i.e. assumed not to be available. Among those who responded to this question, the percentage stating not available ranged between 10% and 35%, in fact indicating major accessibility problems for individuals with disability who need to pay a visit to different public services. This can be assumed to lead to dependency and lack of inclusion. A mapping exercise of accessibility at public places/buildings/services could be a first step towards reducing such barriers.

Many individuals with disability report that the family supports them in their daily activities. There is a consistent pattern in that control individuals are more involved than case individuals. For various variables on involvement, there is a gap of 10 – 25 percentage points when comparing individuals with and without disability. The results clearly indicate inclusion as an area in need of intervention both at family/household and community level. It adds to this that awareness of DPOs and membership in DPOs among individuals with disability is low, leaving the large majority of individuals with disability without this potentially important source of support.

10.7 Education

The individual level data in the household section revealed a substantial difference between individuals with and without disability in school attendance and literacy. The difference in school attendance is more than 30 percentage points. Non-disabled reported (somewhat) more years of education, higher school achievement and more often stated that they studied as far as planned. All in all, the results reveal that many individuals with disability are excluded from the education system, and other indicators indicate lower school achievement among individuals with disability. Supported by the results of the study, the combination of many individuals with disability not accessing school and relatively small differences between school going cases and controls, indicates a

selection process whereby the most competent individuals with disability are included and the more severely disabled are excluded from education. This is thus a matter of both ensuring access to education for all and to improve the way students with disability are handled. While this study does not reveal the mechanisms whereby individuals with disability are excluded from their right to education, both competence and attitudes within the school system should be targeted to improve the situation.

10.8 Economic activity

The different socio-economic indicators (Possession scale, Dietary diversity, Dependency Ratio, Access to information, Income types) all point in the same direction: control households are in a better economic position than cases, with more secure and stable income.The individual level data (Individual section) reveals that substantially more control individuals are employed, and that more case individuals have previously or never been employed. This is also reflected in the mean salary level which is substantially higher among case individuals.

While there are differences in economic activity to the advantage of control households, the large majority of both individuals with and without disability do not have work that gives them regular income. Results on economic activity, however, show clearly that control individuals and households are more integrated into the formal labor market. This must be regarded as the major reason for the economic/SES differences between the two groups (HHs and individuals), and the difference between the groups is exacerbated by the difference in mean number of household members in that case households cater for more people.

10.9 Assistive devices

Relatively few individuals with disability confirm that they have an assistive device. Assistive devices are more common among males than females and among urban as compared to rural based individuals with disability. While we can expect that the need for assistive devices increase with increasing severity of disability, an interesting result is that

the use of assistive devices drops with increasing severity of disability. This may indicate that severely disabled are not properly serviced in Nepal. While there appears to be some diversity in the supply of devices, results further indicate that that private sources dominate and that maintenance is largely left to the owners of the devices or their families. Most users of assistive devices claim to have sufficient information, although a large group lacks information. The results indicate limited involvement from the authorities in supply and service delivery.

10.10 Gender

The study has revealed some important gender differences. Fewer males report chronic illness and more females have poor or very poor physical and mental health. The gap in services tends to be larger for females and in particular with regards to educational services and assistive devices. Somewhat more females report that they have been refused entry to school. Fewer females have paid work, and more females report that they are unemployed. All in all, most of the indicators that were analysed point towards clearly less favorable results for females as compared to males.

Slightly fewer females with disability have children as compared to non-disabled females, and the number of children did not vary much between the two groups of women. There is also a tendency that more females with disability report pregnancies that ended before term. These three indicators indicate small differences in reproductive life courses among females with and without disability.

10.11 The urban - rural dimension

The study distinguishes between urban and rural areas. Important differences in standard of living between the urban and rural areas are demonstrated by the indicators on infrastructure. Also, the contextual differences are reflected in the measure on environmental barriers.

The three SES indicators all indicate that the living standard is substantially lower in rural areas. This is supported by most individual level indicators.

11 Conclusion

Having established evidence for differences between disabled and non-disabled is an important step in the promotion of human rights and improved level of living among individuals with disability. The study offers an opportunity for boosting advocacy, for setting priorities, for assessing impact and developing policies, for monitoring the situation, and for increased knowledge among disabled and the public in general.

Generally, the study reveals consistent differences between case/control households and case/control individuals. Level of living, measured by means of a range of different indicators, is higher among controls than among cases at both levels (household and individual). All together, the study thus provides evidence for differences in level of living that should be reduced and limited completely. This requires an active stand from the side of public authorities and a multi-sector strategy that deals with these differences. Measures to achieve this will be both general and sector specific and a thorough analysis of what can be done to reduce the documented differences and to address service gaps and inadequacy in assistive device services, etc.

REFERENCES

Eide A H, Jele B (2011) Living Conditions among People with Disabilities in Swaziland. A National, Representative Study. SINTEF A 20047. Oslo; SINTEF Technology & Society.

Eide A H, Kamaleri Y (Eds.) (2009) Living conditions among people with disabilities in Mozambique. SINTEF Report No. A9348. Oslo; SINTEF Health Research.

Eide A H, Loeb M E (2006) Living conditions among people with disabilities in Zambia. A national representative survey.SINTEF Report No. A262. Oslo, SINTEF Health Research

Eide A H, Nhiwathiva S, Muderedzi J, Loeb ME (2003). Living Conditions among people with activity limitations in Zimbabwe. A representative regional study.STF78 A034512.SINTEFUnimed, Health & Rehabilitation, Oslo.

Eide A H, van Rooy G, Loeb M E (2003b). Living Conditions among people with disabilities in Namibia. A National, Representative Study. STF78 A034503.SINTEFUnimed Health & Rehabilitation, Oslo.

Finkelstein, V., & French, S. (1993). Towards a psychology of disability. In J. Swain, V. Finkelstein, S. French & M. Oliver (Eds.), Disabling barriers - enabling environments (pp. 26-33). London: Sage.

Grut L, Olenja J, Ingstad B (2011) Disability and barriers in Kenya. In: A H Eide and B Ingstad. Disability and Poverty. Bristol: The Policy Press.

Heiberg M, Øvensen G (1993) Palestinian Society in Gaza, West Bank and Arab Jerusalem. A Survey of Living Conditions. FAFO Report no. 151. Oslo, FAFO.

Hem, K.-G., Eide, A. H. (1998) Funksjonshemmedes levekår 1987-1995: Sakker akterut tross forbedringer. *Samfunnsspeilet*, 2, 20 - 25. (In Norwegian)

Ingstad B, Baider A, Grut L (2011) Where culture really matters: disability and well-being in Yemen. In: A H Eide and B Ingstad. Disability and Poverty. Bristol: The Policy Press.

NPC (2000) Level of Living Conditions Survey. Windhoek: National Planning Commission.

Kamaleri Y, Eide A H (Eds.) (2010) Living Conditions among People with Disabilities in Lesotho. A National, Representative Study. SINTEF Report No. A17239. Oslo: SINTEF Technology and Society

Loeb M, Eide A H (Eds.) (2004) Living Conditions among People with Activity Limitations in Malawi.SINTEF Report no.STF78 A044511. Oslo, SINTEF Health Research.

Schneider M, Claasens M, Kimmie Z, Morgan R, Naicker S, Roberts A, McLaren P. (1999) We also count! The extent of moderate and severe reported disability and the nature of disability experience in South Africa. Pretoria: Community Agency for Social Enquiry.

Shakespeare, T. (2014). Disability Rights and Wrongs Revisited (Second ed.). Oxon: Routledge, Taylor & Francis Ltd.

UN (2006).Convention on the Rights of Persons with Disabilities and Optional Protocol. New York: United Nations.

United Nations (1994) The Standard Rules on the Equalizationof Opportunities for Persons with Disabilities. New York:UnitedNations.

United Nations (1993) World Programme of Action ConcerningDisabled Persons. New York: United Nations.

United Nations Development Programme (1997) Human Development Report 1997. Oxford, Oxford University Press.

WHO (2001) International Classification of Functioning, Disability and Health. Geneva: World Health Organisation.

WHO (1980).International Classification of Impairments, Disability and Handicap. Geneva: World Health Organization.

Whyte SR, Ingstad B. (1998) Help for people with disabilities: do cultural differences matter? World Health Forum, 19, 1, 42 - 46.

HOUSEHOLD		CONFIDENTIAL

A Study on Living Conditions among People with Disabilities in Nepal 2014

Questionnaire for Household Head

(Conducted by SINTEF/VaRG/NFDN)

	Identification of person with disability	Code
1	Name and Code of District	
2	Nameof VDC/Municipality	
3	Location	1 = Urban 2 = Rural
4	WardNumber	
5	NameofVillage/Locality	
6	Cluster Number	
7	Household Number / ID	
8	Nameof Household Head	
9	Genderof HH Head	1= Male 3= Other 2= Female
10	Was this household screened as:	Having at least 1 disabled member……..…1 Not having any disabled member……2
11	Total Number of Persons in Household (should be the same as last Line Number filled in Section A)	
12	Total number of persons with disability	
13	Line number of primary respondent	
	To be completed by interviewer	**Date ofinterview**
	Time interview ☐☐ ☐☐ ☐☐ ☐☐	Day Month Year 2 0 1 4
	NameofInterviewer: Comments Signature	

Supervisor	**Interview Status**	**Enumerator has to return to the household**	**Checked by the Supervisor**
Name: Signature:	Complete…..….1 Incomplete…...2	Yes……..…1 No……...2	☐

Section A. Household Composition: For All Persons

Line Number	Who are Permanent Members of this Household?	Relationship to Head of Household	Sex	Age	Marital Status	BurdenofDisease	
	List the first names and first letter of the surname of all persons in this household, starting with the head of the household	What is the relationship of (NAME) to the head of the household? *	Is (NAME) male or female? 1=Male 2=Female 3= Third gender	How old was (NAME) at his/her last birthday? **Enter age in completed years** 99=Don't know	What is(NAME'S) maritalstatus?** **Only 12yrs andabove**	Has (NAME)been chronicallyill during thepast 12 months? 1=Yes 2=No 9=Don't know **If 2 or 9Q.9➔**	Whatwasthe illness?***
(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)
01		01	M 1 F 2	IN YEARS			
02			1 2				
03			1 2				
04			1 2				
05			1 2				
06			1 2				
07			1 2				
08			1 2				
09			1 2				
10			1 2				

*CODES FOR Q.3 RELATIONSHIP TO HEAD OF HOUSEHOLD	**CODES FOR Q.6 MARITAL STATUS	***CODES FOR Q.8 CRONIC ILLNESSES
1 = Head 2 = Husband/wife 3 = Son/Daughter 4 = Son/Daughter-in-law 5 = Grandchild of head/spose 6 = Parent of head/spose 7 = Brother/Sister of head/spose 8 = Other relatives 9 = Domestic worker/Non-relative 10 = Other non-relatives 98 = Don'tknow	1 = Never married 2 = Married with certificate 3 = Marriedtraditional 4 = Consensual union 5 = Divorced/separated 6 = Widowed 7 = Inter family marrige 8 = Don'tknow/refuse	1= Heart problem 2= Breathing problem 3=Asthma 4= Epilepsy 5= Cancer 6= Diabetes 7= Malfunction of kidney 8= Cirrhosis of liver 9= Occupational disease 10= High or low blood pressure 11 = Other disease 98 = Don'tknow

Section A. Household Composition: For All Persons

LINE NO.	Because of a HEALTH PROBLEM…						FILTER		
	Does (NAME) have difficulty seeing, even if wearing glasses?	Does (NAME) have difficulty hearing, even if using a hearing aid?	Does (NAME) have difficulty walking or climbing steps?	Does (NAME) have any difficulty remembering or concentrating?	Does (NAME) have difficulty with self-care such as washing all over or dressing?	Using the usual (customary) language, does (NAME) have difficulty communicating for example understanding or being understood?	Mark **X** with person disability	Is (NAME) **5 yrs old** or above? YES → Q.16 NO → STOP	
	1 = NO 2 = SOME 3 = A LOT 4 = UNABLE 9 = NA	1 = NO 2 = SOME 3 = A LOT 4 = UNABLE 9 = NA	1 = NO 2 = SOME 3 = A LOT 4 = UNABLE 9 = NA	1 = NO 2 = SOME 3 = A LOT 4 = UNABLE 9 = NA	1 = NO 2 = SOME 3 = A LOT 4 = UNABLE 9 = NA	1 = NO 2 = SOME 3 = A LOT 4 = UNABLE 9 = NA		**CHECK Q.5**	
(1)	(9)	(10)	(11)	(12)	(13)	(14)	(15A)	(15B)	
01	☐	☐	☐	☐	☐	☐	☐	YES 1	NO 2
02	☐	☐	☐	☐	☐	☐	☐	1	2
03	☐	☐	☐	☐	☐	☐	☐		
04	☐	☐	☐	☐	☐	☐	☐		
05	☐	☐	☐	☐	☐	☐	☐		
06	☐	☐	☐	☐	☐	☐	☐		
07	☐	☐	☐	☐	☐	☐	☐		
08	☐	☐	☐	☐	☐	☐	☐		
09	☐	☐	☐	☐	☐	☐	☐		
10	☐	☐	☐	☐	☐	☐	☐		

Section A. Household Composition: For All Persons – cont. for household member 11 -20

LINE NO.	WHO ARE PERMANENT MEMBERS OF THIS HOUSEHOLD?	RELATIONSHIP TO HEAD OF HOUSEHOLD	SEX	AGE	MARITAL STATUS	BURDEN OF DISEASE	
	List the first names and first letter of the surname of all persons in this household, starting with the head of the household.	What is the relationshipof (NAME) to the head ofthe household? *	Is (NAME) male or female? 1=Male 2=Female	How oldwas (NAME) at his/her last birthday? **Enter age in completed years** 99=Don'tknow	What is (NAME'S) marital status?** **Only 12 yrs and above**	Has (NAME) beenchronically ill during the past 12 months? 1=Yes 2=No 9=Don'tknow **If 2 or 9 → Q.9**	Whatwas the illness?***
(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)
			M **F**	IN YEARS			
11			1 2				
12			1 2				
13			1 2				
14			1 2				
15			1 2				
16			1 2				
17			1 2				
18			1 2				
19			1 2				
20			1 2				

IF THERE ARE MORE THAN 20 PERSONS IN THE HOUSEHOLD, PLEASE USE A CONTINUATION SHEET AND TICK THE BOX BELOW

☐

*CODES FOR Q.3 RELATIONSHIP TO HEAD OF HOUSEHOLD	**CODES FOR Q.6 MARITAL STATUS	***CODES FOR Q.8 CHRONIC ILLNESSES
1 = Head 2 = Husband/wife 3 = Son/Daughter 4 = Son/Daughter-in-law 5 = Grandchildof head/spouse 6 = Parentof head/spouse 7 = Brother/Sister of head/spouse 8 = Other relatives 9 = Domesticworker/Non-relative 10 = Other non-relatives 99 = Don'tknow	1 = Never married/single 2 = Marriedwithcertificate 3 = Marriedtraditional 4 = Consensual union 5 = Divorced/separated 6 = Widowed 9 = Don'tknow/refuse	1 = Cancer 2 = TB 3 = Malaria 4 = Diarrhoea 5 = Malnutrition 6 = Measles 7 = Pneumonia 8 = Heartdisease 9 = High bloodpressure 10 = HIV/AIDS (related) 11 = Otherdisease 99 = Don'tknow

Section A. Household Composition: For All Persons – cont. for household member 11 -20

LINE NO.	Because of a HEALTH PROBLEM…						FILTER	
	Does (NAME) have difficulty seeing, evenif wearing glasses?	Does (NAME) have difficulty hearing, even ifusing a hearingaid?	Does (NAME) have difficulty walking or climbing steps?	Does (NAME) have any difficulty remembering or concentrating?	Does (NAME) have difficulty withself-care such as washing all over or dressing?	Using theusual (customary) language, does (NAME) have difficulty communicating for example understanding or being understood?	Mark X with person disability	Is (NAME) **5 yrs old** or above? YES → Q.16 NO → STOP
	1 = NO 2 = SOME 3 = A LOT 4 = UNABLE 9 = NA	1 = NO 2 = SOME 3 = A LOT 4 = UNABLE 9 = NA	1 = NO 2 = SOME 3 = A LOT 4 = UNABLE 9 = NA	1 = NO 2 = SOME 3 = A LOT 4 = UNABLE 9 = NA	1 = NO 2 = SOME 3 = A LOT 4 = UNABLE 9 = NA	1 = NO 2 = SOME 3 = A LOT 4 = UNABLE 9 = NA		**CHECK Q.5**
(1)	(9)	(10)	(11)	(12)	(13)	(14)	(15A)	(15B)
11	☐	☐	☐	☐	☐	☐	☐	YES 1 / NO 2
12	☐	☐	☐	☐	☐	☐	☐	1 / 2
13	☐	☐	☐	☐	☐	☐	☐	
14	☐	☐	☐	☐	☐	☐	☐	
15	☐	☐	☐	☐	☐	☐	☐	
16	☐	☐	☐	☐	☐	☐	☐	
17	☐	☐	☐	☐	☐	☐	☐	
18	☐	☐	☐	☐	☐	☐	☐	
19	☐	☐	☐	☐	☐	☐	☐	
20	☐	☐	☐	☐	☐	☐	☐	

Section B. Levelof Education of Household Members – Aged 5 Years or above

Line Number	ATTENDING SCHOOL	YEARS OF EDUCATION	HIGHEST GRADE COMPLETED*	REASONS NEVER ATTTEND SCHOOL**		LITERACY	FILTER
Transfer the **LINE NO.** of persons as listed in Sect. A who are 5 yrs old or above	Has (NAME) attended any school, college or university? 1 = YES 2 = NO~~Q.19~~ 9 = DON'T KNOW	How many years in all did (NAME) spend studying in school, college or university? 99 = DON'T KNOW	What is (NAME'S) highest standard form or level of education completed?* SKIP Q19A & Q19B	If (NAME) never attend school, what is the reason?** **(Code up to 2 reasons)** **To be asked only if (NAME) answered NO in column (16)**		Can (NAME) read and write in any language? (incl. mother tongue) 1 = YES 2 = NO 9 = DON'T KNOW	Is (NAME) **15 years old** or above? YES~~Q.22~~ NO~~STOP~~ **CHECK Q.5**
(1)	(16)	(17)	(18)	(19A)	(19B)	(20)	(21)
							YES 1 NO 2
							1 2
							1 2
							1 2
							1 2
							1 2
							1 2
							1 2
							1 2
							1 2

*CODES FOR Q.18 HIGHEST GRADE COMPLETED	**CODES FOR Q.19A & 19B REASONS FOR NOT ATTENDING/LEFT SCHOOL/COLLEGE OR UNIVERSITY
0 = not completed Standard 1 1 - 9= Standard 1 - 9 10- SLC 911=10+2/IA or equivalent 12= BA or equivalent 13= MA or equivalent 14= Voctionalschool 98= Do not know/refuse	1=Not enoughmoney 2=Failing/underachiever 3=Illness 4=Lackofinterest 5=Becauseofdisability 6=School not accessible 7=Pregnancy 8=Other 98=Don'tknow

Section B. Level of Education of Household Members – Aged 5 Years or above – continue 11 to 20

LINE NO.	ATTENDING SCHOOL	YEARS OF EDUCATION	HIGHEST GRADE COMPLETED*	REASONS NEVER ATTTEND SCHOOL**		LITERACY	FILTER
Transfer the **LINE NO.** of persons as listed in Sect. A who are 5 yrs old or above	Has (NAME) attended anyschool, college or university? 1 =YES 2 =NO Q.19 9 =DON'T KNOW > Q.20	How many years in all did (NAME) spend studying in school, college or university? 99 =DON'T KNOW	What is (NAME'S) highest standard form or levelof education completed?* **SKIP Q19A & Q19B**	If (NAME) never attend school, what is the reason?** **(Code up to 2 reasons)** **To be asked only if (NAME) answered NO** **in column (16)**		Can (NAME) read and write in any language? 1 = YES 2 = NO 9 = DON'T KNOW	Is (NAME) **15 years old**or above? YES Q.22 NO STOP **CHECK Q.5**
(1)	(16)	(17)	(18)	(19A)	(19B)	(20)	(21)
							YES 1 NO 2
							1 2
							1 2
							1 2
							1 2
							1 2
							1 2
							1 2
							1 2
							1 2

*CODES FOR Q.18 HIGHEST GRADE COMPLETED		**CODES FOR Q.19A & 19B REASONS FOR NOT ATTENDING/LEFT SCHOOL/COLLEGE OR UNIVERSITY
0 = not completed Standard 1	13 = Vocationalschool	0=Not enough money
1 - 7 = Standard 1 - 7	14 = College/Diploma	1=Failing/underachiever
8 = Form 1	15 = University	2=Illness
9 = Form 2	16 = Post-graduates	3=Lackofinterest
10 = Form 3	99 = Don'tknow/refuse	4=Becauseofdisability
11 = Form 4		5=School not accessible
12 = Form 5		6=Pregnancy
		7=Other
		9=Don'tknow

Section C. Economic Activity of Household Members Aged 15 Years or above

LINE NO.	WORK STATUS*	POSSESS ANY SKILL?	TYPE OF TRAINING	FILTER
Transfer the **LINE NO.** of persons aslisted in Sect. Awho are 15 yrs old or above	What is the workstatus of (NAME)?*	Apart from formal education, has (NAME) received any formal or informal training that has resulted in his/her having aparticular skill e.g. carpentering, sewing, running business, farming etc.? 1 = YES 2 = NO → Q.25 8 = DON'T KNOW → Q.25	Did (NAME) receiveany formal or informal training to get the skill? 1= Formal 2= Informal 8= Don'tknow	Is (NAME) a **Female?** YES → ~~Q.26~~ NO ~~STOP~~ **CHECK Q.4**
(1)	(22)	(23)	(24)	(25)
				YES 1 / NO 2
				1 / 2
				1 / 2
				1 / 2
				1 / 2
				1 / 2
				1 / 2
				1 / 2
				1 / 2
				1 / 2
				1 / 2
				1 / 2
				1 / 2

***CODE FOR Q.22**
WORK STATUS

1 = Paidwork
2 = Self employed, such as own business or farming
3 = Non-paid work such as volunteer or charity
4 = Student
5 = Keeping house/homemaker
6 = Retired
7 = Unemployed (healthreasons
8 = Unemployed (securityreasons)
9 = Unemployed (otherreasons)
10 = Other
98 = Don'tknow/Refuse

Section D. Reproductive Health of Female Household Members aged 15 years or above

LINE NO.	CHILDRENmarriedonly??	NO. OF CHILDREN		STILLBIRTHS	NO. OF STILLBIRTS
Transfer the**LINE NO.** ofpersons aslisted in Sect. Awho are 15 yrsold or above	Does (NAME) have anychildren? 1 = YES 2 = NO → Q.28 8 = DON'T KNOW → Q.28	How many children do(NAME) have today? **Don't include those thathave died**		Does (NAME) havepregnancies ended beforeterm? 1= YES 2= NO → STOP 8= DON'T KNOW → STOP	How many did (NAME)have pregnancies endedbefore term?98 = DON'T KNOW
		BOYS	GIRLS		
(1)	(26)	(27a)	(27b)	(28)	(29)

NOTE: The following questions should be completed by the PRIMARY RESPONDENT/HEAD OF HOUSEHOLD

Section E: Income and Expenses

Q. #	Question	Codes		Go to Q
130	What is the PRIMARY source and SECONDARY source (if any) of income in your household?			
	Income Category	**Primary source** *[Circle one only]*	**Secondary source** *[Circle one only]*	
	1 Wage/Salary work (Gross salary)	1	1	
	2 Remittancesreceived	2	2	
	3 Cash cropping	3	3	
	4 Livestock and poultry sales	4	4	
	5 Subsistencefarming	5 → Q132	5	
	6 Formal business (registered)	7	7	
	7 Informal business (non-registered - see below*)	8	8	
	8 Private insurance/pension	9	9	
	9 Workman'sCompensation	10	10	
	10 Rent	11	11	
	11 Other (specify)	12	12	
	12 No income from any source	13 → Q132	13	
	13 Not stated/Refused	14 → Q132	14	
	* This includes payments received for handicrafts, knitting, sewing, repairing shoes, repairing punctures, for providing services (e.g. making thatch roofs for huts, cutting reeds etc.) Also includes income from selling e.g. charcoal, local gin, local beer etc.			
131	**Ranking of expense categories:** I'm going to ask you on your household expenses. On a scale of 1 to 5, please rank on the expense categories I'm going to read, where "1" = the least of the household income goes to and "5" = the most of household income goes to. If your household has no expense on a specific category, please say "NONE".			

	Least → Most					None
1 Food and beverages	1	2	3	4	5	8
2 Rent, building materials, land, house	1	2	3	4	5	8
3 Fuel, power, electricity	1	2	3	4	5	8
4 Agricultural inputs (fertilizer, labour, etc.)	1	2	3	4	5	8
5 Medical care/health services	1	2	3	4	5	8
6 Cultural and entertainment	1	2	3	4	5	8
7 Cigarettes/tobacco/snuff	1	2	3	4	5	8
8 Clothing/footwear	1	2	3	4	5	8
9 Transportation	1	2	3	4	5	8
10 Education	1	2	3	4	5	8
11 Domestic servants	1	2	3	4	5	8
12 Alcohol	1	2	3	4	5	8
13 Savings/investments	1	2	3	4	5	8
14 Disability related expenditure	1	2	3	4	5	8

132	Now I would like to ask you about the types of foods that you or anyone else in your household prepared and ate in the past **TWO** weeks during the day and night (food purchased and eaten outside of the home is not included)			
			Yes	No
	1	Any bread, rice, noodles, biscuits, or any other foods made from millet, maize, rice or wheat?	1	2
	2	Any potatoes, beetroot, yams, cassava, carrots or any other foods made from roots or tubers?	1	2
	3	Any vegetables? (cabbage, spinach, pumpkin leaves or any green leafy vegetables)	1	2
	4	Anyfruits?	1	2
	5	Any pork, lamb, goat, rabbit, chicken, duck, or other birds, liver, kidney, heart, or other organ meats?	1	2
	6	Any eggs?	1	2
	7	Any fresh or dried fish or any seafood?	1	2
	8	Any foods made from beans, peas, pulses, legumes or nuts?	1	2
	9	Any cheese, yogurt, milk or milk products?	1	2
	10	Any foods made with oil, fat, or butter?	1	2
	11	Anysugar or honey?	1	2
	12	Any other foods, such as condiments, coffee, tea?	1	2
133	In the past month did it happen that there was no food to eat of any kind in your household because of lack of resources?	No..... 1 Rarely (1 – 2 times)..... 2 Sometimes (3 – 5 times)..... 3 Often (more than 5 times)..... 4 Don't know/refuse 8		
	Section F: Ownership			
134	Does your household have any of the following? (Read All)			
			Yes	No
	1	Radio	1	2
	2	Hi-fi/music stereo	1	2
	3	Television	1	2
	4	DVD/VHS player	1	2
	5	Cell phone	1	2
	6	Telephone in the house	1	2
	7	Iron	1	2
	8	Fan	1	2
	9	Heater	1	2
	10	Air conditioner	1	2
	11	Stove with gas/electric	1	2
	12	Stove withparaffin	1	2
	13	Table and chairs	1	2
	14	Refrigerator	1	2
	15	Microwave	1	2
	16	Electricity	1	2
	17	Solar energy system	1	2
	18	Electrical generator	1	2
	19	Personal computer	1	2
	20	Bicycle	1	2
	21	Motorcycle	1	2
	22	Private car	1	2
	23	Bed(s)	1	2
	24	Livestock (cattle etc.)	1	2
	25	Washingmachine	1	2
	26	Satellitedish	1	2

	27 Bed sheets	1	2	
	28 Blankets	1	2	
	29 Warm clothes	1	2	
135	**Which of the following best describes your dwelling?** *[Circle ONE only under each heading]*			
1351	**Main type ofroof**	Wood ..... 1 Corrugated iron sheets ..... 2 Grass/leaves thatch ..... 3 Tiles/shingles ..... 4 Paper/plastic..... 5 Asbestos sheets ..... 6 Other(specify) 7		
1352	**Main type offloor**	Mud..... 1 Concrete/cement..... 2 Wood ..... 3 Other(specify) 4		
1353	**Main type ofwalls**	Poles & mud..... 1 Corrugated iron sheets ..... 2 Grass/leaves..... 3 Bricks (burnt or sun-dried)..... 4 Compacted earth (mdindo) ..... 5 Concrete ..... 6 Other(specify) 7		
136	**How many bedrooms does your main dwelling have?**	Numberof bed rooms:_____		
137	**Which of the following applies to your housing situation?** *[Circle ONE only]*	Rented ..... 1 Owned ..... 2 Rent Free (not owned)..... 3 Provided by employer (government) ..... 4 Provided by employer (private)..... 5 Other(specify) 6		
138	**What is the MAIN source of drinking water in your household at present?** *[Circle ONE only]*	Piped water inside ..... 1 Piped water outdoors, on property..... 2 Piped water outside the property ..... 3 Public pipe/tap..... 4 Borehole ..... 5 Protected well..... 6 Unprotected well..... 7 River/ stream/dam/spring/lake..... 8 Rain-water tank ..... 9 Water carrier/tanker ..... 10 Other(specify) ..... 11 Don't know/refuse..... 98		
139	**What is the MAIN source of energy that your household uses for cooking and lighting?**			

1391	**Source of energy for cooking** *[Circle ONE only]*	Electricity ..... 1 Paraffin ..... 2 Gas ..... 3 Wood ..... 4 Coal/charcoal ..... 5 Solar ..... 6 Dung/grass/stalks ..... 7 None ..... 8 Other (specify) ..... 9 Don't know/refuse 98
1392	**Source of energy for lighting** *[Circle ONE only]*	Electricity ..... 1 Paraffin ..... 2 Gas ..... 3 Wood ..... 4 Coal/charcoal ..... 5 Solar ..... 6 Candles ..... 7 Torch ..... 8 None ..... 9 Other (specify) ..... 10 Don'tknow/refuse 98
140	**What kind of sanitation facility does your household mainly use?**	Flush toilet ..... 1 Traditional pit toilet ..... 2 Ventilated improved pit toilet ..... 3 No facility ..... 4 Other(specify) ..... 5 Don't know/refuse 8

Section G: Transportand Communication

141 **How long (in time) does it take to WALK ONE WAY to each of these facilities? (Read All)**

	Service/Facility	Facility not available within walking distance	5 minutes or less	6-15 minutes	16-30 minutes	31-60 minutes	More than 60 minutes	DK/NA
1	Nearest school	1	2	3	4	5	6	8
2	Nearest health facility	1	2	3	4	5	6	8
3	Nearest market/shop	1	2	3	4	5	6	8
4	Nearest sports facility	1	2	3	4	5	6	8
5	Post office	1	2	3	4	5	6	8
6	Police station	1	2	3	4	5	6	8
7	Church/mosque/temple	1	2	3	4	5	6	8

142 **What is the MAIN MODE of transport that household members use when visiting each of these facilities?**

	Service/Facility*		**Codes:**	
1	Nearest school		1 = Walk/Wheelchair	8= Company car
2	Nearest health facility		2 = Bicycle	9 = Hike lift (car)
3	Nearest market/shop		3 = Motor bike	10= Cart
4	Nearest sports facility		4 = Bus	11= Horse/Donkey
5	Post office		5 = Taxi	12= Other
6	Police station		6 = Rickshaw	98Don'tknow / NA
7	Church/mosque/temple		7= Owncar	

143 **How available and affordable are the following services to your household?**

	Service	Availability					Affordability	
		Own/ usere gularl y	Have acces s to	Have nouse for	Have noacc ess to	DK/r efuse	Yes	No
1	Telephone/mobile phone	1	2	3	4	8	1	2
2	Radio	1	2	3	4	8	1	2
3	Television (TV)	1	2	3	4	8	1	2
4	Internet (includingInternet Café)	1	2	3	4	8	1	2
5	Newspaper (*purchaseregularly)	1	2	3	4	8	1	2
6	Library (*useregularly)	1	2	3	4	8	1	2

Section H: Other Information

144 **Has any household member passed away within the past twelve months? (Circleonlyone)**

Yes 1
No ..... 2 →Stop
Do not know/refuse ..... 8 →Stop

145 **If YES, could you please tell me:**

	What was deceased person's position in the household? 1= Head 2= Spouse 3= Son/Daughter of head/spouse 4= Spouse of child 5= Grandchild of head/spouse 6= Parent of head/spouse 7= Other relative 8= Domestic worker/non-relative 9= Other non-relatives 98= DK (Enter only one code)	**Was the deceased person female or male?** 1= Male 2= Female (Enter one code)	**How old was she/he at the time of death?** Enter age in completed years 98= DK	**Could you tell me what she/he died of?** 1= Accident (Car or other) 2= Violence/ Murder 3= Cancer 4= TB 5= Malaria 6= Diarrhoea 7= Malnutrition 8= Measles 9= Pneumonia 10= Heart disease 11= High blood pressure 12= HIV/AIDS (related) 13= Other disease 14= Old age 15= Witchcraft 16= Suicide 98=DK (Enter only one code)	**Was that person disabled?** 1= Yes 2= No 8= DK (Enter one code)
(a)	**(b)**	**(c)**	**(d)**	**(e)**	
Person 1					
Person 2					
Person 3					
Person 4					
Person 5					
Person 6					

END – Finished with Household Living Conditions Survey.

IF THIS IS A "CONTROL HOUSEHOLD", THANK THE PRIMARY RESPONDENT FOR THEIR TIME IN COMPLETEING THE QUESTIONNAIRE AND ASK TO SPEAK TO A PERSON (randomly selected) TO COMPLETE THE CONTROL QUESTIONANNAIRE.

IF THIS IS A HOUSEHOLD WITH A DISABLED FAMILY MEMBER – a circle in column 114A – , THANK THE PRIMARY RESPONDENT FOR THEIR TIME AND ASK TO SPEAK TO THAT PERSON IN ORDER TO COMPLETE THE DETAILED DISABILITY QUESTIONNAIRE.

Table 1: Conversion from Year of Birth to Age in Years

Yearof birth	Age	Year of birth	Age	Year of birth	Age	Year of birth	Age
2014	**0**	1988	**26**	1962	**52**	1936	**78**
2013	**1**	1987	**27**	1961	**53**	1935	**79**
2012	**2**	1986	**28**	1960	**54**	1934	**80**
2011	**3**	1985	**29**	1959	**55**	1933	**81**
2010	**4**	1984	**30**	1958	**56**	1932	**82**
2009	**5**	1983	**31**	1957	**57**	1931	**83**
2008	**6**	1982	**32**	1956	**58**	1930	**84**
2007	**7**	1981	**33**	1955	**59**	1929	**85**
2006	**8**	1980	**34**	1954	**60**	1928	**86**
2005	**9**	1979	**35**	1953	**61**	1927	**87**
2004	**10**	1978	**36**	1952	**62**	1926	**88**
2003	**11**	1977	**37**	1951	**63**	1925	**89**
2002	**12**	1976	**38**	1950	**64**	1924	**90**
2001	**13**	1975	**39**	1949	**65**	1923	**91**
2000	**14**	1974	**40**	1948	**66**	1922	**92**
1999	**15**	1973	**41**	1947	**67**	1921	**93**
1998	**16**	1972	**42**	1946	**68**	1920	**94**
1997	**17**	1971	**43**	1945	**69**	1919	**95**
1996	**18**	1970	**44**	1944	**70**	1918	**96**
1995	**19**	1969	**45**	1943	**71**	1917	**97**
1994	**20**	1968	**46**	1942	**72**	1916	**98**
1993	**21**	1967	**47**	1941	**73**	1915	**99**
1992	**22**	1966	**48**	1940	**74**	1904	**100**
1991	**23**	1965	**49**	1939	**75**	1903	**101**
1990	**24**	1964	**50**	1938	**76**	1902	**102**
1989	**25**	1963	**51**	1937	**77**	1901	**103**

A Study on Living Conditions among People with Disabilities in Nepal 2014

Questionnaire for People WITH Disabilities

(Conducted by SINTEF/VaRG/NFDN)

	Identification of person with disability	Code
1	Name and Code of District	
2	Name of VDC/Municipality	
3	Location	1 = Urban 2 = Rural
4	Ward Number	
5	Name of Village/Locality	
6	Cluster Number	
7	Household Number / ID	
8	Name of Household Head	
9	Gender of HH Head	1= Male 2= Female 3= Other
	Detail of Person with Disability (copy from household roster)	
10	Name	
11	Age (3 years +)	
12	Line Number in Household Listing	
	Is this face to face interview with the person with disability? [Do not read out. Code by observation] 1 = Yes (i.e. interview directly with the person with disability) 2 = No (i.e. someone else is reporting on behalf of the person with disability) 3 = Both (i.e. someone else is reporting together with the person with disability) 4=Interpreter Line number of person as proxy	
	To be completed by the interviewer	**Date of interview**
	Time interview	Day Month Year 2 0 1
	Name of Interviewer: Comments Signature	

Supervisor	Interview Status	Enumerator has to return to the household	Checked by the Supervisor
Name: Signature:	Complete…….1 Incomplete…..2	Yes……1 No…….2	

Q. #	Question	Codes	Go to Q
	Activity Limitation		

101 **How difficult it is for you to perform this activity WITHOUT any kind of assistance at all?**

[Without the use of any assistive devices – either technical or personal]
Read out the options

	Activity Limitation Items	No difficulty	Mid difficulty	Moderate difficulty	Severe difficulty	Unable to carry out the activity	Not specified/Not applicable
1	Watching/looking/seeing	0	1	2	3	4	8
2	Listening/hearing	0	1	2	3	4	8
3	Learning to read/write/count/calculate	0	1	2	3	4	8
4	Acquiring skills (manipulating tools, painting, carving etc.)	0	1	2	3	4	8
5	Thinking/concentrating	0	1	2	3	4	8
6	Reading/writing/counting/calculating	0	1	2	3	4	8
7	Solving problems	0	1	2	3	4	8
8	Understanding others (spoken, written or sign language)	0	1	2	3	4	8
9	Producing messages (spoken, written or sign language)	0	1	2	3	4	8
10	Communicating directly with others	0	1	2	3	4	8
11	Staying in one body position	0	1	2	3	4	8
12	Changing a body position (sitting/standing/bending/lying)	0	1	2	3	4	8
13	Transferring oneself (moving from one surface to another)	0	1	2	3	4	8
14	Lifting/carrying/moving/handling objects	0	1	2	3	4	8
15	Fine hand use (picking up/ grasping/manipulating/releasing)	0	1	2	3	4	8
16	Hand & arm use (pulling/pushing/ reaching/throwing/catching)	0	1	2	3	4	8
17	Walking	0	1	2	3	4	8
18	Moving around (crawling/climbing/ running/jumping)	0	1	2	3	4	8

	Participation Restriction		
102	**Do you have any difficulty performing this activity in your current environment?** *[Current environment where you live, work and play etc for the majority of your time, and with the use of any assistive devices, either technical or personal]* Read out the options		

	PARTICIPATION RESTRICTION ITEMS	No problem	Mild problem	Moderate problem	Severe problem	Complete problem (unable to perform)	Not specified/Not applicable
1	Washing oneself	0	1	2	3	4	8
2	Care of body parts, teeth, nails and hair	0	1	2	3	4	8
3	Toileting	0	1	2	3	4	8
4	Dressing and undressing	0	1	2	3	4	8
5	Eating and drinking	0	1	2	3	4	8
6	Shopping (getting goods and services)	0	1	2	3	4	8
7	Preparing meals (cooking)	0	1	2	3	4	8
8	Doing housework (washing/cleaning)	0	1	2	3	4	8
9	Taking care of personal objects (mending/repairing)	0	1	2	3	4	8
10	Taking care of others	0	1	2	3	4	8
11	Making friends and maintaining friendships	0	1	2	3	4	8
12	Interacting with persons in authority (officials, village chiefs)	0	1	2	3	4	8
13	Interacting with strangers	0	1	2	3	4	8
14	Creating and maintaining family relationships	0	1	2	3	4	8
15	Making and maintaining intimate relationships	0	1	2	3	4	8
16	Going to school and studying (education)	0	1	2	3	4	8
17	Getting and keeping a job (work & employment)	0	1	2	3	4	8
18	Handling income and payments (economic life)	0	1	2	3	4	8
19	Clubs/organisations (community life)	0	1	2	3	4	8
20	Recreation/leisure (sports/play/ crafts/hobbies/arts/culture)	0	1	2	3	4	8
21	Religious/spiritual activities	0	1	2	3	4	8
22	Political life and citizenship	0	1	2	3	4	8

103	**<u>Environmental Factors</u>** **Being an active, productive member of society includes participating in such things as working, going to school, taking care of your home, and being involved with family and friends in social, recreational and civic activities in the community. Many factors can help or improve a person's participation in these activities while other factors can act as barriers and limit participation.** First, please tell me how often each of the following has been a barrier to your own participation in the activities that matter to you. Think about the past year, and tell me whether each item on the list below has been a problem **daily, weekly, monthly, less than monthly, or never.** If the item occurs, then answer the question as to how big a problem the item is with regard to your participation in the activities that matter to you. (Note: if a question asks specifically about **school or work** and you neither work nor attend school, check not applicable) **Please CIRCLE only one.**		
1031	In the past 12 months, how often has the availability/accessibility of transportation been a problem for you?	Daily ..... 1 Weekly..... 2 Monthly ..... 3 Less than monthly..... 4 Never ..... 5 Not applicable..... 8	 →1033 →1033
1032	When this problem occurs has it been a big problem or a little problem?	Little problem ..... 1 Big problem 2	
1033	In the past 12 months, how often has the natural environment – temperature, terrain, climate – made it difficult to do what you want or need to do?	Daily ..... 1 Weekly..... 2 Monthly ..... 3 Less than monthly..... 4 Never ..... 5 Not applicable..... 8	 →1035 →1035
1034	When this problem occurs has it been a big problem or a little problem?	Little problem ..... 1 Big problem 2	
1035	In the past 12 months, how often have other aspects of your surroundings – lighting, noise, crowds, etc – made it difficult to do what you want or need to do?	Daily ..... 1 Weekly..... 2 Monthly ..... 3 Less than monthly..... 4 Never ..... 5 Not applicable..... 8	 →1037 →1037
1036	When this problem occurs has it been a big problem or a little problem?	Little problem ..... 1 Big problem 2	
1037	In the past 12 months, how often has the information you wanted or needed not been available in a format you can use or understand?	Daily ..... 1 Weekly..... 2 Monthly ..... 3 Less than monthly..... 4 Never ..... 5 Not applicable..... 8	 →1039 →1039

1038	When this problem occurs has it been a big problem or a little problem?	Little problem ..... 1 Big problem 2	
1039	In the past 12 months, how often has the availability of health care services and medical care been a problem for you?	Daily ..... 1 Weekly ..... 2 Monthly ..... 3 Less than monthly ..... 4 Never ..... 5 Not applicable 8	 →10311 →10311
10310	When this problem occurs has it been a big problem or a little problem?	Little problem ..... 1 Big problem 2	
10311	In the past 12 months, how often did you need someone else's (family member only or other persons also) help in your home and could not get it easily?	Daily ..... 1 Weekly ..... 2 Monthly ..... 3 Less than monthly ..... 4 Never ..... 5 Not applicable 8	 →10313 →10313
10312	When this problem occurs has it been a big problem or a little problem?	Little problem ..... 1 Big problem 2	
10313	In the past 12 months, how often did you need someone else's help at school or work and could not get it easily?	Daily ..... 1 Weekly ..... 2 Monthly ..... 3 Less than monthly ..... 4 Never ..... 5 Not applicable 8	 →10315 →10315
10314	When this problem occurs has it been a big problem or a little problem?	Little problem ..... 1 Big problem 2	
10315	In the past 12 months, how often have other people's attitudes toward you been a problem at home?	Daily ..... 1 Weekly ..... 2 Monthly ..... 3 Less than monthly ..... 4 Never ..... 5 Not applicable 8	 →1017 →1017
10316	When this problem occurs has it been a big problem or a little problem?	Little problem ..... 1 Big problem 2	
10317	In the past 12 months, how often have other people's attitudes toward you been a problem at school or work?	Daily ..... 1 Weekly ..... 2 Monthly ..... 3 Less than monthly ..... 4 Never ..... 5 Not applicable 8	 →10319 →10319
10318	When this problem occurs has it been a big problem or a little problem?	Little problem ..... 1 Big problem 2	

10319	In the past 12 months, how often did you experience prejudice or discrimination?	Daily ..... 1 Weekly..... 2 Monthly ..... 3 Less than monthly..... 4 Never ..... 5 Not applicable..... 8	 →10321 →10321
10320	When this problem occurs has it been a big problem or a little problem?	Little problem ..... 1 Big problem 2	
10321	In the past 12 months, how often did the policies and rules of businesses and organizations make problems for you?	Daily ..... 1 Weekly..... 2 Monthly ..... 3 Less than monthly..... 4 Never ..... 5 Not applicable..... 8	 →10323 →10323
10322	When this problem occurs has it been a big problem or a little problem?	Little problem ..... 1 Big problem 2	
10323	In the past 12 months, how often did government programs and policies make it difficult to do what you want or need to do?	Daily ..... 1 Weekly..... 2 Monthly ..... 3 Less than monthly..... 4 Never ..... 5 Not applicable..... 8	 →104 →104
10324	When this problem occurs has it been a big problem or a little problem?	Little problem ..... 1 Big problem 2	

104 **The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM: (Read All)**

		No	Some	A lot	Unable
1	Do you have difficulty seeing, even if wearing glasses?	1	2	3	4
2	Do you have difficulty hearing, even if using a hearing aid?	1	2	3	4
3	Do you have difficulty walking or climbing steps?	1	2	3	4
4	Do you have difficulty remembering or concentrating?	1	2	3	4
5	Do you have difficulty with self-care such as washing all over or dressing?	1	2	3	4
6	Using your usual (customary) language, do you have difficulty communicating for example understanding or being understood?	1	2	3	4

105 **<u>Check Q104 and circle below</u>**

Did the person answer ”A LOT” or “UNABLE” in ONE of the questions 1
Did the person answer “SOME” difficulty in TWO or more questions..... 2
None of the above (does this refer to Q104 or option 1 or 2 in Q105) ..... 3 →STOP

106	**What is the main cause of your difficulties doing the activities (disability)?** **(Single Response)**	From birth/congenital ..... 1 Accident..... 2 Fall..... 3 Burns ..... 4 Disease/illness ..... 5 Beaten by member in the family..... 6 Violence outside the house..... 7 War related ..... 8 Animal related ..... 9 Stress related..... 10 Witchcraft..... 11 Others(specify)_____ ..... 12 Don't know/refuse..... 98	
107	**How old were you when it started?**	Grade-…… ☐☐ From birth..... 97 Do not know/refuse 98	
108	**Have you ever been beaten or scolded because of your disability?**	Yes..... 1 No ..... 2 Do not know 8	
109	**Have you ever been beaten or scolded by any family member or relatives because of your disability?**	Yes..... 1 No ..... 2 Do not know 8	
110	**Have you ever experienced being discriminated in any public services? For example: hospital, clinic, police station, bank etc.**	Yes..... 1 No ..... 2 Do not know 8	
111	**Do you have any of the following health conditions? (Read All)**		

	Yes	No
1 Heart problem	1	2
2 Breathing problem	1	2
3 Asthma	1	2
4 Epilepsy	1	2
5 Cancer	1	2
6 Diabetes	1	2
7 Malfunction of kidney	1	2
8 Cirrhosis of liver	1	2
9 Occupational disease	1	2
10 High or low blood pressure	1	2
11 Other, specify:……..	1	2

112	**Have you ever lived in an institution or special home for people with disabilities?**	Yes..... 1 No ..... 2 Do not know 8	

113 **Which services, if any, are you *aware* of and have ever *needed/received*?**
[Read out; Enter the appropriate code for each column of each row]

		Q1131 Needed Service		**Q1131** Aware of Service		**Q1131** Received Service	
		Yes	No	Yes	No	Yes	No
1	**Medical rehabilitation** (e.g. physiotherapy, occupational therapy, speech and hearing therapy etc)	1	2	1	2	1	2
2	**Assistive devices service** (e.g. Sign language interpreter, wheelchair, hearing/visual aids, Braille etc.)	1	2	1	2	1	2
3	**Educational services** (e.g. remedial therapist, special school, early childhood stimulation, regular schooling, etc.)	1	2	1	2	1	2
4	**Vocational training** (e.g. employment skills training, etc)	1	2	1	2	1	2
5	**Counselling for person with disability** (e.g. psychologist, psychiatrist, social worker, school counsellor etc)	1	2	1	2	1	2
6	**Counselling for parent/family**	1	2	1	2	1	2
7	**Welfare services** (e.g. social worker, disability grant, etc)	1	2	1	2	1	2
8	**Health services** (e.g. at a primary health care clinic, hospital, home health care services etc.)	1	2	1	2	1	2
9	**Health information** (e.g. from media, at schools, clinics,hospital etc.)	1	2	1	2	1	2
10	**Traditional healer/faith healer**	1	2	1	2	1	2
11	**Legal advice**	1	2	1	2	1	2

CHKB X 1 Check Q113, and circle below
Circled at least one "Yes" or 1 in column 3 1
Circled all "No" or 2 in column 3 ..... 2 → **Section D**

114 **What can you characterised of the services you have received or still receiving? (Read All)**

[code only ONE main characteristic per service]

		Satisfy with the service	It is very helpful	It is too expensive	Has communication/language barriers	Not really helping me	Discriminating	Other	DK/refuse/never receive
1	**Medical rehabilitation** (e.g. physiotherapy, occupational therapy, speech and hearing therapy etc)	1	2	3	4	5	6	7	8
2	**Assistive devices service** (e.g. Sign language interpreter, wheelchair, hearing/visual aids, Braille etc.)	1	2	3	4	5	6	7	8

3	**Educational services** (e.g. remedial therapist, special school, early childhood stimulation, regular schooling, etc.)	1	2	3	4	5	6	7	8
4	**Vocational training** (e.g. employment skills training, etc)	1	2	3	4	5	6	7	8
5	**Counselling for person with disability** (e.g. psychologist, psychiatrist, social worker, school counsellor etc)	1	2	3	4	5	6	7	8
6	**Counselling for parent/family**	1	2	3	4	5	6	7	8
7	**Welfare services** (e.g. social worker, disability grant, etc)	1	2	3	4	5	6	7	8
8	**Health services** (e.g. at a primary health care clinic, hospital, home health care services etc.)	1	2	3	4	5	6	7	8
9	**Health information** (e.g. from media, at schools, clinics, hospital etc.)	1	2	3	4	5	6	7	8
10	**Traditional healer/faith healer**	1	2	3	4	5	6	7	8
11	**Legal advice**	1	2	3	4	5	6	7	8

115 **Think of ALL services you have received, if you are no longer getting the service, why did you stop? (Read All)**

[code only ONE main reason for stopping]

		Not satisfied with the service	It is too expensive	Too far or has no transport	Not really helping me	No longer available	Has communication/language barriers	Other	DK/refuse/never receive
1	**Medical rehabilitation** (e.g. physiotherapy, occupational therapy, speech and hearing therapy etc)	1	2	3	4	5	6	7	8
2	**Assistive devices service** (e.g. Sign language interpreter, wheelchair, hearing/visual aids, Braille etc.)	1	2	3	4	5	6	7	8
3	**Educational services** (e.g. remedial therapist, special school, early childhood stimulation, regular schooling, etc.)	1	2	3	4	5	6	7	8
4	**Vocational training** (e.g. employment skills training, etc)	1	2	3	4	5	6	7	8
5	**Counselling for person with disability** (e.g. psychologist, psychiatrist, social worker, school counsellor etc)	1	2	3	4	5	6	7	8
6	**Counselling for parent/family**	1	2	3	4	5	6	7	8

7	**Welfare services** (e.g. social worker, disability grant, etc)	1	2	3	4	5	6	7	8
8	**Health services** (e.g. at a primary health care clinic, hospital, home health care services etc.)	1	2	3	4	5	6	7	8
9	**Health information** (e.g. from media, at schools, clinics, hospital etc.)	1	2	3	4	5	6	7	8
10	**Traditional healer/faith healer**	1	2	3	4	5	6	7	8
11	**Legal advice**	1	2	3	4	5	6	7	8

<u>Education</u>

CHKBX2 **<u>Check respondent's age (Q11) and circle below</u>**
Respondent 15 years or above 1
Respondent below 15 years of age ..... 2 →127

116 **Have you received a formal primary education?**
Yes 1
No ..... 2 →123
Do not know/ do not remember 8

117 **Has your level of education helped you find any work at all?**

*[Do not read out; Circle only **one** answer]*
Yes 1
No 2
Do not know 8

118 **What type of school do or did you *mainly* attend in pre-school, primary, secondary or tertiary school?**
*[Do not read out; Circle only **one** answer for each line]*

		Mainstream/ Regular school	Special school	Special class in mainstream/ regular school	Did not go to school or N/A
1	Pre-school/early childhood development services	1	2	3	4
2	Primary school	1	2	3	4
3	Secondary school	1	2	3	4
4	Tertiary education	1	2	3	4
5	Vocational training	1	2	3	4

119 **Have you ever been refused entry into a school, pre-school or university because of your disability?**

*[Circle only **one** answer for each line]*

		Yes	No	Not applicable
1	Regular pre-school	1	2	9
2	Regular primary school	1	2	9
3	Regular secondary school	1	2	9
4	Special school (any level)	1	2	9
5	Special class (remedial)	1	2	9
6	University	1	2	9

120	**Have you ever been refused entry into a school, pre-school or university because of lack of money?** *[Circle only **one** answer for each line]*				
		Yes	No	Not applicable	
	1 Regular pre-school	1	2	9	
	2 Regular primary school	1	2	9	
	3 Regular secondary school	1	2	9	
	4 Special school (any level)	1	2	9	
	5 Special class (remedial)	1	2	9	
	6 University	1	2	9	
121	**Did you have a drop out from a school, pre-school or university any time in the past?** *[Circle only **one** answer for each line]*				
		Yes	No	Not applicable	
	1 Regular pre-school	1	2	9	
	2 Regular primary school	1	2	9	
	3 Regular secondary school	1	2	9	
	4 Special school (any level)	1	2	9	
	5 Special class (remedial)	1	2	9	
	6 University	1	2	9	
122	**Did you study as far as you planned?** *[Do not read out; Circle only **one** answer]*	Yes ..... 1 No ..... 2 Still studying ..... 3 Do not know 8			→124 →124 →127 →124
123	**If you have NOT received a formal primary education, have you ever attended classes to learn to read and write as an adult?**	Yes ..... 1 No ..... 2 Do not know/ do not remember 8			
	Employment and Income				
CHKBX4	**<u>Check Q11 and circle below</u>** 15 years or above ..... 1 Less than 15 years of age 2				 →127
124	Are you currently working? (include casual labour, part-time work and those who are self-employed).Circle only **one** answer.	Yes, currently working ..... 1 No, but have been employed previously .. 2 No, never been employed ..... 3 I am a housewife/homemaker 4			 →127 →127
125	What is your income per month from your job (if previously employed than from previous job)?	0-5000 ..... 1 5000-9999 ..... 2 10,000-14,999 ..... 3 15,000-19,999 ..... 4 20,000-24,999 ..... 5 More than 25,000 6			

126	If you are currently unemployed, why did you stop working? *To be answered ONLY if Q.124 is "**have been employed previously**". Circle only **one** answer.*	Retired ..... 1 Retrenched (due to cut backs) ..... 2 Fired..... 3 Injury/accident at work..... 4 Illness..... 5 Because of disability..... 6 Other ..... 7 Don't know..... 8	
127	Are you currently receiving social security, a disability grant or any other form of pension/grant?	Yes..... 1 No ..... 2 Do not know 8	→131 →131
128	What type of grant or pension do you receive? *[Do not read out; circle **ALL** that apply]*	Disability grant ..... 1 Social Security..... 2 Workman's Compensation ..... 3 Private insurance/pension..... 4 Old age pension ..... 5 Old age grant ..... 6 Other (specify)_____ ..... 7 Don't know..... 98	
129	What are the TWO MAIN THINGS that the money from your disability grant or pension is spent on? [*Do not read out; **circle only ONE in Choice A and ONE in Choice B** answers*]		

	Choice A	Choice B
1 Household necessities i.e. food, groceries, etc.	1	1
2 Clothing	2	2
3 Rent/accommodation	3	3
4 Recreation/entertainment	4	4
5 Transport	5	5
6 Education	6	6
7 Water and electricity	7	7
8 Rehabilitation and health care services	8	8
9 Assistive devices	9	9
10 Personal assistant/carer (care for self)	10	10
11 Other (specify)	11	11
98 Don't know	98	98

130	Are you the one who *mainly* decides how to spend your disability grant or pension?	Yes..... 1 No ..... 2 Do not know 8	
	Your surroundings and how easy it is for you to get around. If you use one or more assistive devices or someone is helping you, answer as if you are using them. **Ask both directive and proxy reporters. Please remember the information must be about the person with disability.**		
131	Let's look at your home first. Are the rooms and toilet accessible? By accessible we mean that you can get there <u>easily</u> and use the facility most of the time. *[Read out; Circle only **ONE** answer for each line]*		

			Yes (accessible)	No (not accessible)	Have none	
	1	Kitchen	1	2	3	
	2	Bedroom	1	2	3	
	3	Living room	1	2	3	
	4	Dining room	1	2	3	
	5	Toilet	1	2	3	

132 Now let's look at various places you might want go to. Think of getting in and out of the places, and tell me for each place whether it is generally accessible to you or not.
[*Read out; Circle only **one** answer for each line*]

		Yes (accessible)	No (not accessible)	Not available/ Not applicable
1	The place where you work	1	2	3
2	The school you attend	1	2	3
3	The shops that you go to most often	1	2	3
4	Place of worship	1	2	3
5	Recreational facilities (e.g. cinema, theatre, pubs, etc) – think of the last three months	1	2	3
6	Sports facilities	1	2	3
7	Police station	1	2	3
8	Magistrates office/Traditional courts	1	2	3
9	Post office	1	2	3
10	Bank	1	2	3
11	Hospital	1	2	3
12	Primary Health Care Clinic PHC/HP/SHP)	1	2	3
13	Public transportation (bus, taxi, train)	1	2	3
14	Hotels	1	2	3

<u>Assistive Devices:</u>

Ask both direct and proxy respondents: Please remember the information must be about the person with disability.

133 Do you use any medication or traditional medicine for pain that is caused by your disability?
Yes 1
No ..... 2 →135

134 If YES, what type of medication?
Modern 1
Traditional 2
Both 3

135 Do you use an assistive device?
[*For examples, see Q.136 below*]
Yes 1
No ..... 2 →142

136 **Please specify which assistive devices you use.**

*[Read out; Circle **one** answer for each row]*

	Device category	Example	Yes	No	NA (do not need)
1	**Information**	eye glasses, hearing aids, magnifying glass, telescopic lenses/glasses, enlarge print, Braille	1	2	3

2	**Communication**	sign language interpreter, fax, portable writer, computer	1	2	3
3	**Personal mobility**	wheelchairs, crutches, walking sticks, white cane, guide, standing frame	1	2	3
4	**Household items**	Flashing light on doorbell, amplified telephone, vibrating alarm clock	1	2	3
5	**Personal care &protection**	special fasteners, bath & shower seats, toilet seatraiser, commode chairs, safety rails, eating aids	1	2	3
6	**For handling products & goods**	gripping tongs, aids for opening containers, tools for gardening	1	2	3
7	**Computer assistive technology**	keyboard for the blind	1	2	3
8	**Other devices**	(specify)	1	2	3

137 Is the assistive device(s) mentioned above in good working condition/order?

*[If more than one device in one category, choose **most important** device - List device by **name**]*

Name of Device	Good working condition		
	Yes	No	Do not know
a	1	2	8
b	1	2	8
c	1	2	8

138 Where did you get the assistive device(s)?

*[Read out; Record only **one** answer for each line]*

*[If more than one device in one category, choose **most important** device - List device by **name**]*

Name of Device	Where did you get the device?					
	Private (it means bought onself ??)	Government helth services	Other government services (not health)	NGO	Other	Do not know
a	1	2	3	4	5	8
b	1	2	3	4	5	8
c	1	2	3	4	5	8

139 Who, if any, maintains or repairs your assistive device(s)?

*[Do not read out: record only **one** answer for each line]*

*[If more than one device in one category, choose **most important** device - List device by **name**]*

Name of Device	Maintenance/Repair								
	Self	Government	Family	Employer	NGO	Other	Not maintained	Cannot afford to maintain or repair	Do not know

a	1	2	3	4	5	6	7	8	9
b	1	2	3	4	5	6	7	8	9
c	1	2	3	4	5	6	7	8	9

140 Were you given any information or help/training on how to use your device(s) (mentioned in Q139 above)?

Name of Device	Information or help			
	Complete/full information	Some information	No informtion	Do not know/ can not remember
a	1	2	3	8
b	1	2	3	8
c	1	2	3	8

141 Think of the MAIN assistive device you are using – on a scale from 1 (not content) to 4 (very content) – How would you describe your level of content/satisfaction with the device that it meets your needs?

Not content 1
Less content 2
Content 3
Very content 4
Do not know 8

How do you feel and what do you think about being a person with a disability?

Let's start with your role within the household and your family.

Ask both direct and proxy respondents: Please remember the information must be about the person with disability.

142 **Which of the following, if any, do people in the household or family help you with?**

*[Read out; Circle **one** answer for each row]*

*[**NB: Do not include assistance provided by person paid to care for the person or things you would not normally do because of your age or your culture**]*

	Yes, often	Yes, sometimes	No	Not applicable or not necessary
1 Dressing	1	2	3	9
2 Toileting	1	2	3	9
3 Bathing	1	2	3	9
4 Eating/Feeding	1	2	3	9
5 Cooking	1	2	3	9
6 Shopping	1	2	3	9
7 Moving around	1	2	3	9
8 Finances	1	2	3	9
9 Transport	1	2	3	9
10 Studying	1	2	3	9
11 Emotional support	1	2	3	9
12 Other(specify)	1	2	3	9

143 I'm going to ask you some questions about your involvement in different aspects of family, social life and society. Please listen to each one and answer yes, no, sometimes or not applicable.

*[Read out and circle **one** answer for each row]*

		Yes	No	Sometimes	Not applicable	Do not know
1	Are you consulted about making household decisions?	1	2	3	4	8
2	Do you go with the family to events such as family gatherings, social events etc.	1	2	3	4	8
3	Do you feel involved and part of the household or family?	1	2	3	4	8
4	Does the family involve you in conversations?	1	2	3	4	8
5	Does the family help you with daily activities/tasks?	1	2	3	4	8
6	**IF YES (1) or SOMETIMES (3) in "5" above,** Do you appreciate it or like the fact that you get this help?	1	2	3	4	8
7	Do/did you take part in your own traditional practices (e.g. initiation ceremonies)	1	2	3	4	8
8	Are you aware of Organisations for people with disabilities (DPO)?	1	2	3	4	8
9	Are you a member of a DPO?	1	2	3	4	8
10	Do you participate in local community meeting?	1	2	3	4	8
11	**IF YES (1) or SOMETIMES (3) in "10" above,** Do you feel your voice is being heard?	1	2	3	4	8
12	Did you vote in the last election?	1	2	3	4	8
13	**IF NO (2) in "12" above,** Was it related to your disability that you didn't vote?	1	2	3	4	8

Only ask disabled respondents who are 15 years of age or older and reporting for themselves.

If the respondent is a Proxy reporter for a person with disability 15 years or older, then ask them to answer about the person with disability.

If person with disability is younger than 15 years then go to Section 9 or Q150.

144	**(INSTRUCTION TO THE NUMERATOR):** *[Don't read the control question out loud]* **FILTER QUESTION** **Is the person 15 years of age or older?** **Check Q13 and circle below** 15 years or above ..... 1 Less than 15 years of age 2		→150
145	Do you make important decisions about your own life? *[Read out; circle only **one** answer]*	All the time ..... 1 Sometimes ..... 2 Never ..... 3 Do not know 8	
146	Are you married or involved in a relationship?	Yes ..... 1 No ..... 2 Do not know 8	 →148 →148
147	Does your spouse/partner have a disability?	Yes ..... 1 No ..... 2 Do not know 8	
148	Do you have children?	Yes ..... 1 No ..... 2 Unmarried 3	 →150 →150
1494	If Yes, how many children?	Number of children:_____	
150	Has there any miscarriage occurred in your household in the last 12 months? If yes, how many?	Number of miscarriages:_____ None 7	
151	Did any women in your household abort in the last 12 months due to possibility of giving birth to a disabled baby?	Yes ..... 1 No 2	
152	How many children have died in your household before 9 months of age in the past?	Number of children:_____ None 7	
	Health and General Wellbeing		
153	**I would like to ask you how your health has been in general, over the past few weeks**		
	For the past few weeks have you ……		
	1 Been able to concentrate on what you're doing	Better than usual ..... 1 Same as usual ..... 2 Less than usual ..... 3 Much less than usual 4	
	2 Lost much sleep over worry	Not at all ..... 1 No more than usual ..... 2 Rather more than usual ..... 3 Much more than usual 4	
	3 Felt you were playing a useful part in things	More so than usual ..... 1 Same as usual ..... 2 Less so than usual ..... 3 Much less than usual 4	
	4 Felt capable of making decisions about things	More so than usual ..... 1 Same as usual ..... 2 Less so than usual ..... 3 Much less than usual 4	

	5	Felt constantly under strain	Not at all ..... 1 No more than usual ..... 2 Rather more than usual ..... 3 Much more than usual 4
	6	Felt you couldn't overcome your difficulties	Not at all ..... 1 No more than usual ..... 2 Rather more than usual ..... 3 Much more than usual 4
	7	Been able to enjoy your normal day-to-day activities	More so than usual ..... 1 Same as usual ..... 2 Less so than usual ..... 3 Much less than usual 4
	8	Been able to face up to your problems	More so than usual ..... 1 Same as usual ..... 2 Less so than usual ..... 3 Much less than usual 4
	9	Been feeling unhappy and depressed	Not at all ..... 1 No more than usual ..... 2 Rather more than usual ..... 3 Much more than usual 4
	10	Been losing confidence in yourself	Not at all ..... 1 No more than usual ..... 2 Rather more than usual ..... 3 Much more than usual 4
	11	Been thinking of yourself as a worthless person	Not at all ..... 1 No more than usual ..... 2 Rather more than usual ..... 3 Much more than usual 4
	12	Been feeling reasonably happy, all things considered	More so than usual ..... 1 Same as usual ..... 2 Less so than usual ..... 3 Much less than usual 4
154	Thinking about your general <u>physical health</u> (things like: sickness, illness, injury, disease etc.) – on a scale from 1 (poor) to 4 (very good) – How would you describe your overall physical health today?		Poor ..... 1 Not very good ..... 2 Good ..... 3 Very good ..... 4 Do not know 8
155	Thinking about your general <u>mental health</u> (things like: anxiety, depression, fear, fatigue, tiredness, hopelessness etc.) – on a scale from 1 (poor) to 4 (very good) – How would you describe your overall mental health today?		Poor ..... 1 Not very good ..... 2 Good ..... 3 Very good ..... 4 Do not know 8

156 **We would like to know about your understanding of some common diseases and whether you have access to information about them.**

	Do you have any knowledge about [Name of Disease]?	Where did you get most of the information about this disease from?**	Did you experience any problems in obtaining/understanding information about this disease?			Have you ever had this disease?		
			Yes	No	DK	Yes	No	DK
1 HIV/AIDS	Yes ..... 1 No..... 2 Do not know. 8		1	2	8	1	2	8

2 STI	Yes ..... 1 No..... 2 Do not know. 8		1	2	8	1	2	8	
3 Diabetes	Yes ..... 1 No..... 2 Do not know. 8		1	2	8	1	2	8	
4 TB	Yes ..... 1 No..... 2 Do not know. 8		1	2	8	1	2	8	

**CODES		
1 = Health Clinic	5 = From friends	9 = School
2 = Doctor	6 = From Family	10 = Other
3 = At work	7= Radio/TV	98 = Don't know
4 = Magazines/Newspapers	8 = Poster and pamphlets	

END – Finished with the questionnaire.

THANK THE RESPONDENT FOR THEIR TIME AND WILLINGNESS TO PARTICIPATE IN THE STUDY.

Technology for a better society

www.sintef.no