SINTEF

2020:01387- Unrestricted

# Report

## Living conditions among persons with disabilities in Uganda

**Author(s)**
Arne Henning Eide
Nulu Nanono
Julius Omona

**SINTEF Digital**
Dept. of Health Research
2021-01-20

SINTEF Digital
**SINTEF Digital**
Address:
Postboks 4760 Torgarden
NO-7465 Trondheim
NORWAY
Switchboard: +47 40005100

info@sintef.no

Enterprise /VAT No:
NO 919 303 808 MVA

# Report

# Living conditions among persons with disabilities in Uganda

KEYWORDS:
Living conditions
Persons with disabilities
Uganda

**VERSION**
1.0

**DATE**
2021-01-20

**AUTHOR(S)**
Arne H. Eide
Nulu Nanono
Julius Omona

**CLIENT(S)**
Atlas Alliance

**CLIENT'S REF.**
Morten Eriksen

**PROJECT NO.**
102016933

**NUMBER OF PAGES/APPENDICES:**
121 + Appendices

**ABSTRACT**

The national, representative study on living conditions among people with disabilities was carried out in Uganda in 2018 - 2019. The data also includes a sample of non-disabled people, providing a basis for comparison between disabled and non-disabled. The partners who implemented the study were the National Union of Disabled Persons of Uganda (NUDIPU), Makerere University, School of Social Science and SINTEF Digital. Important collaborating partners have been Ministry of Gender, Labour and Social Development, the responsible ministry for disability in Uganda, and the Ministry of Education and Sports. The study was funded by the Atlas Alliance on behalf of Norwegian Agency for Development Cooperation (NORAD). The study is part of a series of similar studies that have been implemented in southern Africa and Nepal, characterized by a strong involvement of the disability movement and relevant ministries in the respective countries. The current study adds to a comprehensive data base about individuals with disabilities and their households in sub-Saharan Africa that provides unique insights into the level of living among persons with disabilities and an opportunity for comparison between countries and between regions.

**PREPARED BY**
Arne H. Eide

SIGNATURE
Arne H Eide (Feb 4, 2021 16:14 GMT+1)

**CHECKED BY**
Stine Hellum Braathen

SIGNATURE
Stine Hellum Braathen (Feb 5, 2021 07:28 GMT+1)

**APPROVED BY**
Jon Harald Kaspersen

SIGNATURE
Jon Harald Kaspersen (Feb 5, 2021 07:39 GMT+1)

**REPORT NO.** 2020:01387
**ISBN** 978-82-14-06414-8
**CLASSIFICATION** Unrestricted
**CLASSIFICATION THIS PAGE** Unrestricted

# Document history

| VERSION | DATE | VERSION DESCRIPTION |
|---|---|---|
| 1.0 | 2021-01-20 | Final version |

SINTEF

# Table of contents

**APPENDICES**

1. Consent form
2. Household listing and screening form
3. Household questionnaire
4. Individual level questionnaire for persons with disabilities
5. Individual level questionnaire for persons without disabilities

# PREFACE

It is my great pleasure to present the Living conditions among persons with disabilities in Uganda Survey report. The basis for this study stemmed from the need of understanding the living conditions of persons with disabilities in Uganda henceforth closing the existing gap regarding disability data. NUDIPU's commitment to addressing diverse disability related issues requires empirical data and information to inform policy actions. Globally there is increased use of evidence-based advocacy and designing of policies and interventions based on relevant and timely data and information. Therefore, there is greater need for quality disability data and information this research study has produced.

The study on Living conditions among persons with disabilities in Uganda has expanded the understanding of the context and various socio-economic status indicators among persons with disabilities in comparison with the non-disabled in Uganda. We hope that this data and information from 12 sub-regions will be used to contribute to improvement of living conditions of Persons with Disabilities in Uganda.

National Union of Disabled Persons of Uganda would like to acknowledge the contribution and invaluable input of the study reference group during implementation of the research study. The reference group was comprised of representatives from Ministry of Gender, Labour and Social Development, Ministry of Education and Sports, Uganda Bureau of Statistics and Makerere University.

Our efforts would have been unsuccessful without the financial support from Atlas Alliance/NORAD and the technical support from SINTEF to whom we are much grateful.

Our sincere gratitude is extended to the board, management and NUDIPU staff for the coordination of the study. I would also like to thank the research assistants and team of supervisors who tirelessly worked to ensure the research study is executed successfully. The district and leaders, in their respective capacities, in the sub-regions where the data collection took place are equally appreciated for their support and cooperation in this regard.

Ngirabakunzi Edson
Chief Executive Officer
National Union of Disabled Persons of Uganda

# 1 EXECUTIVE SUMMARY

The national, representative study on living conditions among people with disabilities was carried out in Uganda in 2018-2019. The data also includes a sample of non-disabled people, which provides a basis for comparison between disabled and non-disabled. The partners who implemented the study were the National Union of Disabled Persons of Uganda (NUDIPU), Makerere University, School of Social Science and SINTEF Digital. Important collaborating partners have been Ministry of Gender, Labour and Social Development, the responsible ministry for disability in Uganda, and the Ministry of Education and Sports. The study was funded by the Atlas Alliance on behalf of Norwegian Agency for Development Cooperation (NORAD). The study is part of a series of similar studies that have been implemented in southern Africa and Nepal, characterized by a strong involvement of the disability movement and relevant ministries in the respective countries. This also includes Southern Africa Federation of the Disabled (SAFOD). The current study adds to a comprehensive data base about individuals with disabilities and their households in sub-Saharan Africa that provides unique insights into the level of living among persons with disabilities and an opportunity for comparison between countries and between regions.

The study draws on the understanding of disability in the International Classification of Functioning, Disability and Health (ICF) (WHO 2001), i.e., disability resulting from the interaction between an individual and his/her environment. The questionnaires applied in the study have been developed over many years and utilized in similar studies in nine other low-income countries. Changes in the research instrument over time is due partly to adaptation to different contexts, partly to development in the field of disability research, and partly based on experiences in the utilization of results. The questionnaires combine a broad range of common indicators on living conditions and with all elements of the ICF included.

The study is a two-stage and cross-sectional household survey combining data collection at household and individual level. The National Sampling Frame provided by Uganda Bureau of Statistics (UBOS) forms the basis for selection of a representative number of Enumeration Areas (EAs) in which a listing and screening procedure utilizing the Washington Group Short Set and the Washington Group/UNICEF Module on Child Functioning was implemented. The listing has been used to estimate prevalence of disability in Uganda, found to be 14.8 % among adults aged 18 years or more, 4.7 % among children 4 years old or less, and 8.4 % among children below 18 years. The overall prevalence was found to be 11.7 %.

Random sampling among the listed/screened households identified with or without disabled members yielded a sample that is representative at National and Regional (Province) level. Household interviews were carried out in 5207 households with members with disabilities and 5401 households without members with disabilities. A total of 11511 individuals were interviewed, of which 6112 were individuals with disabilities and 5399 matched individuals without disabilities.

In addition to the screening instruments/questionnaires, the study utilized a household level questionnaire responded to by heads of households that also included some information about individuals in the households. Further, an individual level questionnaire was utilized for the data collection among individuals with disabilities and another individual level questionnaire was utilized for data collection among individuals without disabilities.

The study has demonstrated that households with disabled members are worse off than households without disabled members on several indicators on level of living. Comparison of socio-economic status, dietary diversity, access to information, and to some extent housing standard and infra structure – all point in the same direction and to the disadvantage of households with disabled members.

At the individual level, the general picture is that individuals with disabilities are worse off than non-disabled on a range of indicators on level of living. A higher proportion of individuals with disabilities have been chronically ill during the last 12 months and have poor or not very good mental and physical health. Lower proportions of individuals with disabilities have ever attended school, are in paid work, and voted in the last election. More individuals with disabilities drop out of primary or secondary school. Individuals with disabilities score lower on well-being, social participation, health literacy, and income as compared to non-disabled, but higher on environmental barriers. More individuals with disabilities report a service needs gap across a range of services.

Both at household and individual levels, the broad picture is that rural households and individuals with disabilities are worse of on most of the indicators on level of living included in the study. Females are worse off than males on many indicators even though this picture is somewhat mixed. For instance, females with disabilities score higher on activity limitations (daily life activities) than males, lower on well-being, substantially lower on school attendance, being in paid jobs, salary among persons with paid jobs, and accessing assistive technology. There are on the other hand small male-female differences among persons with disabilities with regards to environmental barriers and health literacy and a more complex picture concerning involvement in the family/household.

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 households with and without disabled members and individuals with and without disabilities in Uganda. Level of living, measured by means of a range of different indicators, is higher among non-disabled than among disabled at both levels (household and individual). The gender and urban/rural dimensions also play out among persons with disabilities, with the general finding being that living in rural areas and being female are associated with lower levels on most indicators.

All together the study provides evidence for differences in level of living that have been found in similar studies in the region and which should be reduced and eliminated. 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 is called for to reduce the documented differences and to address service gaps and inadequacy in service delivery. The editors of this report recommend a close collaboration among researchers, DPOs and the Government of Uganda in translating the results from the current study into practice.

**Table 1. Summary of some main results**

| Indicator | Household study | | Individual study | |
|---|---|---|---|---|
| | HHs with disabilities | HHs without disabilities | With disabilities | Without disabilities |
| N Individuals | | | 6112 | 5399 |
| N Households | 5333 | 10710 | | |
| Mean age | | | 37.4 years | 34.3 years |
| Percentage males<br>Rural ratio | 51.4<br>86.9 | 51.5<br>87.0 | 50.5%<br>86.7% | 51.5%<br>87.0% |
| SES scale (0-29) | 6.4 | 6.7 | | |
| Dietary diversity (0-12) | 7.2 | 7.5 | | |
| Access to information scale (0-6) | 1.5 | 1.6 | | |
| | **Individuals in Household study** | | | |
| Chronically ill last 12 months | 31.4% | 13.7% | | |
| School attendance (>5) | 74.6% | 87.3% | | |
| | | | | |
| Mean years of education (5 years +) | 5.8 years | 6.0 years | | |
| Literacy (10 years +) | 56.9% | 73.1% | | |
| Paid work (15 -65 years) | 8.4% | 10.1% | | |
| Currently working (=> 15 years) | | | 26.4% | 35.5% |
| | | | | |
| | | | | |
| Environmental barriers (12 - 60) | | | 22.6 | 18.2 |
| Voted last election (20 +) | | | 55.8% | 62.8% |
| Wellbeing scale (12-46)[1] | | | 25.4 | 20.8 |
| Poor/not very good physical health | | | 59.7% | 12.0% |
| Poor/not very good mental health | | | 69.4% | 7.4% |
| Number of health conditions | | | 0.7 | 0.5 |
| Accessed primary education | | | 60.8% | 69..8 |
| Drop-out of primary school[2] | | | 37.6% | 12.8% |
| Drop-out of secondary school[2] | | | 23.4% | 2.4% |

[1] Higher scale values = lower wellbeing, [2] Percentage of those who accessed primary/secondary education

**Table 1 Cont. Summary of indicators among individuals with disabilities – male/female comparison**

| Indicator | Total | Male | Female |
|---|---|---|---|
| Activity limitations mean score (0-72) | 11.15 | 10.49 | 12.18 |
| Environmental barriers (11-55) | 22.53 | 22.53 | 22.54 |
| Wellbeing scale (12-52) | 25.38 | 25.06 | 25.69 |
| School attendance (accessed primary education) (=> 15 years) | 57.7 | 69.1 | 46.6 |
| | | | |
| Confirmed primary school dropout | 37.9% | 38.0% | 37.9% |
| Confirmed secondary school dropout | 23.8% | 29.3% | 17.0% |
| Currently working (=> 15 years) | 26.8% | 30.6% | 23.0% |
| Use an assistive device | 6.9% | 8.6% | 5.2% |
| Feel involved and part of the family/household (yes + sometimes) | 94.1% | 93.7% | 94.5% |
| Participate in local community meetings (yes + sometimes) | 61.7% | 64.0% | 59.4% |
| Voted in the last election | 82.5% | 84.8% | 80.4% |
| Physical health poor or not very good | 59.2% | 62.2% | 56.3% |
| Mental health poor or not very good | 69.0% | 70.5% | 67.3% |
| Wellbeing (GHQ12) (12-46) | | | |

**Table 1 cont. Summary of indicators among individuals with disabilities – Urban/rural comparison**

| Indicator | Total | Urban | Rural |
|---|---|---|---|
| Activity limitations mean score (0-72) | 10.96 | 9.95 | 11.12 |
| Environmental barriers (11-55) | 22.61 | 21.34 | 22.80 |
| Wellbeing scale (12-46) | 25.50 | 25.73 | 25.46 |
| School attendance (accessed primary education) (=> 15 years) | 61.1 | 72.0 | 59.4 |
| | | | |
| Confirmed primary school dropout | 37.9% | 34.8% | 38.4% |
| Confirmed secondary school dropout | 23.8% | 24.8% | 23.7% |
| Currently working (=> 15 years) | 26.2% | 38.8% | 24.2% |
| Use an assistive device | 6.9% | 9.4% | 6.5% |
| Feel involved and part of the family/household (yes + sometimes) | 94.1% | 95.7% | 93.9% |
| Participate in local community meetings (yes + sometimes) | 61.7% | 58.4% | 62.2% |
| Voted in the last election | 82.5% | 81.0% | 82.8% |
| Physical health poor or not very good | 59.2% | 54.4% | 60.0% |
| Mental health poor or not very good | 69.0% | 65.3% | 69.6% |

# 2 LIST OF MAPS, TABLES AND FIGURES

# 3 ABBREVIATIONS

| | |
|---|---|
| CRPD | United Nations Convention on the Rights of Disabled People |
| EA | Enumeration Area |
| HH | Household |
| ICF | International Classification on Functioning, Disability and Health |
| MGLSD | Ministry of Gender, Labour and Social Development |
| NORAD | The Norwegian Agency for Development Cooperation |
| NUDIPU | National Union of Disabled People of Uganda |
| SAFOD | Southern Africa Federation of the Disabled |
| UDHS | Uganda Demographic and Health Survey |
| UNICEF | United Nations Children's Fund |
| WHO | World Health Organization |

# 4 INTRODUCTION

This study is the result of joint efforts by the National Union of Disabled People of Uganda (NUDIPU), Makerere University, School of Social Science, and SINTEF Digital. The study has been supported by the Ministry of Gender, Labour and Social Development. The Ministry of Education and Sports has also been supportive through membership in the reference group for the study. Funding was granted by Atlas Alliance (Norway) on behalf of the Norwegian Agency for Development Cooperation (NORAD). This study in Uganda is the last one in a long series of similar studies in southern Africa and in Nepal (www.sintef.no/login), representing a first generation of comprehensive mapping of the living conditions among persons with disabilities in low- and middle-income countries.

The study 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 monitoring living conditions among persons with disabilities, feeding into policy development, tailoring service development, setting priorities, and creating awareness. While drawing on experiences from a series of similar studies in southern Africa (Eide & Mmatli 2015; Eide & Jele 2011; Kamaleri & Eide 2010; Eide & Kamaleri 2009; Eide & Loeb 2006; Loeb & Eide 2004; Eide et. al. 2003; Eide et al. 2003b) and in Nepal (Eide, Neupane and Hem 2015), the study also incorporates international development within the field of disability statistics through the utilisation of up-to-date measurement of disability among both adults and children.

The study provides a rich data base covering a wide range of indicators on level of living and also includes data on living conditions among persons and households without disabilities. The data collection was complex and involved a large number of people including around 60 enumerators (research assistants) covering all corners of Uganda. While the data collection was successful and was carried out without major problems, translating the results into practice remains. This requires that the fruitful collaboration leading up to this report continues between the disability movement, government and researchers in Uganda. We have suggested specific follow-up points (see Recommendations) to guide the coming process. It is sincerely hoped that the involved stakeholders use the results and identify realistic action points to produce tangible positive changes for persons with disabilities in Uganda. While research can be critical in the development of an inclusive society, it is the ability of decision makers to pave the ground for positive changes that in the end will determine how useful this exercise has been.

# 5 BACKGROUND TO THE STUDY

This project presents a continuation of the project on "Living conditions among persons with disabilities in Southern Africa" that has been carried out by SINTEF Technology and Society (now: SINTEF Digital) of Norway on the instructions of the Atlas Alliance (until 2017: Norwegian Federation of Organisations of Disabled People (FFO) and in collaboration with the Southern African Federation of Disabled People (SAFOD). Funded by the Atlas Alliance and NORAD (The Norwegian Agency for Development Cooperation), the previous phases aimed at developing a culturally sensitive design for the collection of data on living conditions among persons with disabilities in Southern Africa and to carry out National representative studies in Namibia (2003), Zimbabwe (2003), Malawi (2004), Zambia (2006, 2015), Mozambique (2009), Lesotho (2010), Swaziland (2011) and Botswana (2016), and follow-up studies in Zambia (2015), Zimbabwe (2015) and Malawi (2018). A similar study has also been carried out in Nepal (2016). In all the afore mentioned studies, it was established that there was a significant gap between the living conditions of persons with disabilities compared to those without disabilities. The current project for Uganda aimed at utilising the developed design in a representative study on living conditions among people with disabilities and to build capacity to utilise and disseminate research results in Uganda. As for the previous studies, a comprehensive contextual adaptation process was undertaken before implementing the study in Uganda in 2018-2019.

## 5.1 Problem statement

The recent 2014 census and other research show that disability in Uganda cannot be ignored. According to recent estimates, persons with disabilities constitute up to 12.5 percent of the 34.6 million people in Uganda (UBOS, 2014a). The 2014 census results show that more females (15%) have a disability compared to males (10%). Disability was also found to be higher in urban areas (15%) compared to the rural areas (12%). There is also regional variation in the disability prevalence. Further analysis of the Census 2014 data under the Bridging the Gap (BtG) study (2018) show that the Northern region had more disabled persons (15 %) than the other regions of the country, followed by the Eastern region as shown in Table 2 below. These two regions also exhibit high levels of poverty compared to other regions of the country as per the Uganda National Household Survey of 2012. Northern Uganda has just emerged from almost two decades of the Lord's Resistance Army (LRA) insurgency.

**Table 2: Type of Disability by Region (age 2+ years)**

| Region | Any Disability | Hearing | Remembering | Seeing | Walking | Without | Total Percentage | Population |
|---|---|---|---|---|---|---|---|---|
| Central | 9.8 | 2.3 | 3.9 | 5.4 | 3.8 | 90.2 | 100.0 | 8,934,381 |
| East | 14.0 | 3.6 | 6.5 | 7.0 | 5.2 | 86.0 | 100.0 | 8,557,214 |
| North | 14.5 | 4.3 | 5.6 | 7.2 | 4.8 | 85.5 | 100.0 | 6,793,785 |
| West | 12.3 | 3.2 | 5.8 | 6.7 | 4.4 | 87.7 | 100.0 | 8,421,337 |
| Total | 12.5 | 3.3 | 5.4 | 6.5 | 4.5 | 87.5 | 100.0 | 32,706,717 |

*Source: UBOS2016 (re-analysis of the Census 2014 data)*

The recent BgT study (BtG, 2018) reveals that there is a wide gap between people with disability and those without in access to services such as education, health, employment, income, housing conditions and many others. Though policy makers and practitioners have worked to improve the lives of people with disabilities through specific interventions and measures, results still show limited geographical coverage, inconsistent quality and unsustainability. Other challenges effecting the disability subsector includes limited budgets, policy incoherence and conditionality of some programs such as the social assistance grant for empowerment (SAGE) which is awarded to persons with disability above a certain age, and in specific areas of the country. Some grants, such as the disability grant is only accessed if the person with disabilities belongs to specific impairment categories. Disability issues are not explicitly included or stated in national development plans such as the Uganda Vision 2040 and the National Development Plans (NDPs), but vaguely covered under the concept "vulnerability". This sub-sector still needs evidence-based data to inform the stakeholders to take informed actions to address the anomalies in this sector. It is for this very reason this current research has been undertaken.

## 5.2 Objectives of the research

The developmental objective of the project is:

- To contribute to the improvement of disabled people's living conditions and inclusion in the development process in Uganda

## 5.3 Specific objectives are:

- To identify what barriers to inclusion in the development process for persons with disabilities exist that affect their living conditions
- To identify why barriers to inclusion in the development process for persons with disabilities exist, that affect their living conditions
- To identify ways in which these barriers can be overcome, so that persons with disabilities enjoy the benefits of development on the same basis as others

## 5.4 Research questions

- What are the existent barriers to inclusion in the development process for persons with disabilities that affect their living conditions and thus welfare? Are they in the education, health, employment and other sectors?
- Why do these barriers to inclusion in the development process for persons with disabilities exist, that affect their welfare? Is it due to exclusion, discrimination, poor prioritisation of the development in their favour, abuse of their rights or what else?
- How can these barriers be overcome by all actors? Through policy reforms, advocacy, lobbying, direct service provision, affirmative action or other measures?

### 5.4.1 Rationale and justification of the study

According to the background information already encountered, disability in Uganda can't be ignored, it is a reality that should be acknowledged by stakeholders. The current study is therefore not to contest the findings

of previous studies on the same but rather to complement and consolidate their findings. The current study is intended to provide more data to help overcome the identified challenges aforementioned, amongst others; to build capacity to utilise and disseminate similar research results in Uganda; to provide quality, adequate, reliable and readily available data on disability that can be used by politicians and practitioners especially as issues of disability are explicitly mentioned in the global development agenda, the SDGs, the UN Convention of the Rights of Persons with Disabilities (CRPD), and vaguely in national planning frameworks such as the National Development Plan and the Uganda Vision 2040 and other sectoral development plans.

# 6 CURRENT KNOWLEDGE ON DISABILITY AND POLICY IN UGANDA: A SCOPING REVIEW ON DISABILITY IN UGANDA 2000-2019 (by Nulu Nanono)

Disability data and information is limited globally especially in developing countries. The goal of this scoping review is to complement the findings from the survey of living conditions among people with disabilities in Uganda, as well as to show the extent of the data and information gap in relation to disability in Uganda**.**

A scoping review is usually carried out to develop an overview and understanding of the research landscape by examining the extent, range and nature of existing evidence (Matter et al. 2016) and typically comprise five steps:

(a) identifying the research questions, (b) accessing all pertinent studies, (c) determining which studies to keep for detailed analysis, (d) chart the data iteratively according to criteria established by the authors, and (e) organize and summarize the findings (McColl, Short and Goodwin 2009). This review follows the principles of scoping reviews but not to a full extent due to limitations in time and resources. A full scoping review is expected to be published at a later stage.

The objective of this scoping review is to explore and find available research information on disability in Uganda, restricted to the time period between 2000 and 2019. The scoping review question is: what is the available research that has been conducted on disability in Uganda between 2000 and 2019?

The information included is limited to published literature available in different peer-reviewed journals on the search data bases of Google Scholar, Scopus and Web of Science. This scoping review contains articles looking at people with disabilities of all ages, genders and all types of studies; both quantitative and qualitative.

The first step in the search strategy included a limited search on Google Scholar by the NUDIPU team with the search words “disability in Uganda”. Retrieved papers from Google Scholar included papers from different disability related journals and other journals with papers about disability in Uganda. Additional papers added in this scoping review were availed from SINTEF. Some of the papers availed by SINTEF were new papers not found in Google Scholar, but also full retrieved versions of papers that the NUDIPU research team did not have full access to. The second step was scrutinizing the titles and abstracts of the retrieved papers. Thirdly, the reference lists of identified and retrieved research papers were searched for additional studies. Studies that were included were selected at various stages; the first stage of selection was based on the title. The title was checked for inclusion of any key words for disability in Uganda relevant to this scoping review. The second stage of selection was at abstract and full text examination to check for relevance to the scoping review.

Data extraction entailed charting of the results and in addition a descriptive summary of each of the selected papers. The draft charting table below records details of the included papers; reference/citation, aim, methodology, sample size, results/findings, key words and the scoping review researchers’ comments.
The results are presented as data extracted from the included retrieved papers in a tabular form and in a descriptive format that aligns with the scope and research question of review (See Table 3).

The summary table below (Table 3) shows results of; type of study (qualitative, quantitative, other such as theoretical, policy analyses, year of publication, origin of journal (Europe/North American/Australia, Japan, generally industrialised countries versus Africa), nationality of first author, topic (typical topics: poverty, gender, health, children), conclusions and distribution of studies by year or period of publication, disability topic, and research methods. This is supplemented by a narrative summary of how these results communicate with the review objective and question, what are the key findings and gaps in research.

The review is limited to few data bases and we would very likely have been able to identify more papers if other data bases were searched. Additionally, the search terms were limited to "disability in Uganda" and more papers could have been identified if we used other search words, for instance "impairments", "mobility impairment", etc. Further, in this chapter we have not included information about the search history. Finally, and due to costs, for some papers we have only accessed the abstract.

**Table 3. Summary table scoping review**

| No | Type of study | Year of publication | Name/ Origin of Journal | Name/ Nationality of first author | Topic |
|---|---|---|---|---|---|
| 1 | Quantitative | 2005 | Journal of African economies, Africa | Johannes G. Hoogeven, Dutch | Poverty |
| 2 | Qualitative | 2003 | Cornell University publication, USA | Charles Lwanga Ntale, Ugandan | Poverty |
| 3 | Qualitative | 2015 | The Quarterly review of economics and finance, USA | Mark Labie, Belgium | Micro finance and credit |
| 4 | Qualitative | 2008 | Scandinavian journal of disability research, Sweden | Hisayo Katsui, Finland | Human rights |
| 5 | Qualitative | 2013 | International Journal of Speech Language Pathology, UK | Hellen Barret, Uganda | Disability |
| 6 | Quantitative | 2009 | Clinical orthopaedics and related research, UK | Shafique Pirani, Canad | Club foot |
| 7 | Quantitative | 2013 | Global Health Action, UK | Makandwe Nyirenda, South Africa | Health |
| 8 | Quantitative | 2014 | Global Health Action, UK | Stephen.O.Wandera, Uganda | Prevalence |
| 9 | Qualitative | 2009 | BMC International Health and Human rights, UK | Joshua Ssebunya, Uganda | Mental health and stigma |
| 10 | Quantitative | 2006 | African Health sciences, Africa | M Galukande, Uganda | Disability due to injury |
| 11 | Qualitative | 2014 | African Journal of disability, Africa | Julie Abimanyi Ochom, Australia | Uganda's disability journey |
| | Qualitative | 2015 | Sexuality and disability, USA | MIhoko Tanabe, USA | Sexual and reproductive health and disability in humanitarian settings |
| | Quantitative | 2014 | BMC Public health, UK | Karen M Devries, UK | Violence against children with disabilities |
| | Theoretical | 2013 | International Journal of speech language pathology, UK | Karen Wylie, Australia | Communication disability |
| | Quantitative | 2016 | Global Health Action, UK | Joseph O Mugisha, Uganda | Disability and HIV/AIDS |

| No | Type of study | Year of publication | Name/ Origin of Journal | Name/ Nationality of first author | Topic |
|---|---|---|---|---|---|
| | Qualitative | 2005 | African journal of disability, Africa | Paul Emong, Uganda | Disability and Higher education |
| | Quantitative | 2016 | Journal of Development Studies, UK | Trudy Owens, UK | Disability and Human rights |
| | Quantitative | 2014 | BMJ Global health, UK | Abdulgafoor M Bachani, USA | Disability measurement |
| | Quantitative | 2004 | Social psychiatry and psychiatric epidemiology, Germany | Paul Bolton, USA | Depression prevalence |
| | Qualitative | 2013 | International Journal of speech language pathology, UK | Isla Jones, UK | Communication disability |
| | Qualitative | 2014 | International Journal for Equity in Health, UK | Moses Mulumba, Uganda | Health of older persons with disabilities |
| | Qualitative | 2011 | Third World Quarterly, UK | Susie Miles, UK | Inclusive education |
| | Mixed method | 2005 | Development Policy review, UK | Kate Bird, UK | Poverty and disability |
| | Mixed method | 2012 | Journal of Disability and Society, UK | Ephraim Lenny Nuwagaba, Uganda | Micro finance and Disability |
| | Qualitative | 2002 | International Journal of Disability, development and education, UK | Susanne Arbeiter, Germany | Inclusive/Integrated education |
| | Mixed method | 2016 | African Journal of Disability, Africa | Femke Bannink& Geert Van Hove, Uganda/Belgium | Parental care for persons with disabilities |
| | Qualitative | 2003 | Folia Phoniatrica et. Logopaedia, Switzerland | Robinson H., Uganda | Communication disability |
| | Quantitative | 2016 | Journal of Disability and Rehabilitation, UK | Abdulgafoor M Bachani, USA | Disability measurement |
| | Quantitative | 2012 | Enterprise Development and Micro finance, UK | Leif Alte Beisland, Norway | Micro finance and disability |
| | Qualitative | 2014 | Labor Law Journal, USA | Nyombi Chrispas, Uganda | Employment and disability |
| | Quantitative | 2004 | International review of psychiatry, USA | Sheila Nydanabangi, Ugandn | Mental health |
| | Report from a pilot project describing an intervention | 2009 | Disability Studies Quarterly, USA | Mersland R, Norway | Microfinance and disability |
| | Quantitative | 2012 | Journal of International Education and Leadership, USA | PeterMoyi , Kenya | Education and disability |
| | Quantitative | 2003 | JAMA, USA | P Bolton, USA | Mental disability |
| | Quantitative | 2012 | Journal of International Development, UK | Leif Atle Beisland, Norway | Micro finance and disability |
| | Qualitative | 2007 | Journal of disability and rehabilitation, UK | T. McElroy, Canada | Club foot treatment and adherence |
| | Qualitative | 2014 | BMC Reproductive Health, UK | Sharon Eva Ahumuza, Uganda | Sexual and reproductive health and disability |
| | Qualitative | 2015 | Journal of disability and rehabilitation, UK | Sarah Nakamanya, Uganda | Neurological impairment |
| | Qualitative | 2015 | Social Inclusion, Portugal | Femke, Bannink, Belgium | Children with Spina Bifida |
| | Quantitative | 2010 | BMC Psychiatry, UK | Noeline Nakasujja, Uganda | Mental Health |
| | Qualitative | 2014 | International Journal of Social Psychiatry, UK | N Quinn, UK | Mental Health |

| No | Type of study | Year of publication | Name/ Origin of Journal | Name/ Nationality of first author | Topic |
|---|---|---|---|---|---|
| | Practice note: reflections | 2012 | Journal of Human Rights Practice, UK | R James, Uganda | Disability movement |
| | Discussion paper | 2003 | British Medical Bulletin, UK | James Mclntyre, South Africa | Maternal health and disability |
| | Qualitative | 2007 | SSRN, USA | Moses Mulumba, Uganda | Mental Health |
| | Mixed method | 2010 | Journal of social aspects of HIV/AIDs, South African | Regis Chireshe, South Africa | HIV/AIDs and Persons with disabilities |
| | Quantitative | 2003 | World Psychiatry: official journal of the World Psychiatric Association, Switzerland | Verdeli H, USA | Mental Health |
| | Qualitative | 2016 | Journal of Third World Thematics, UK | Dyan Mazaruna, USA | Disability and War |
| | Quantitative | 2013 | Journal of Inclusive education, UK | Patrick Ojok, Uganda | Inclusive education |
| | Qualitative | 2006 | British Journal of Special Education, UK | Kristen Kristensen, Uganda | Inclusive education |
| | Quantitative | 2017 | Annals of Global Health, US | Lukia Namaganda, Uganda | Community based rehabilitation |
| | Quantitative | 2014 | Disability and Society, UK | Leif Alte Beisland, Norway | Micro finance, employment and disability |
| | Qualitative | 2016 | Internal Journal of Migration and Border Studies, Switzerland | Smith-Khan, Australia | Refugees and disability |
| | Quantitative | 2006 | British Journal of Psychiatry, UK | Judith Bass, USA | Mental Health |
| | Quantitative | 2014 | SAGE Journals, UK | Angela Kakooza Mwesige, Uganda | Autism |
| | Qualitative | 2010 | International Journal of mental health systems, Australia | Maye A Omar, UK | Mental Health |
| | Mixed method | 2013 | Loughborough University Institutional repository, UK | Jane Wilbur, UK | WASH and disability |
| | Qualitative | 2016 | Journal of International AIDS Society, Switzerland | Tun Waimar, USA | HIV/AIDS and disability |
| | Quantitative | 2013 | Global Public Health, USA | Loida Erhard, USA | WASH and disability |
| | Qualitative | 2017 | Global Public Health, USA | Malcolm MacLachlan, South Africa | Poverty and disability |
| | Qualitative | 2018 | Journal of disability and rehabilitation, UK | Katie D Schenk, USA | HIV/AIDS and disability |

## 6.1 Summary of findings – scoping review

Sixty of the studies that were reviewed were found to meet the inclusion criteria. Of these, 24 were categorised as quantitative, 27 were qualitative, five were mixed method, and the remaining four were a descriptive report from a pilot project, one theoretical paper, one practice note and one discussion paper.

The quantitative studies comprised a variety of topics, of which some were:

- Several studies om access to credit and microfinance, showing a mixed picture where some studies revealed better access for persons with disabilities than assumed, while others indicated discrimination in access
- Studies about specific impairments; extent, nature and consequences
- Health problems in old age; chronic conditions and disability among elderly persons

- One study about violence, demonstrating small differences between persons with and without disabilities and that risk factors are the same
- Studies on education; access to and level of education is lower among persons with disabilities, leading also to lower income. A mixed picture of both negative and positive attitudes towards disabled learners
- Several studies on mental health; lower level of education and higher age associated with depression; inadequate number of mental health professionals and funding; interpersonal psychotherapy has positive effects
- Limitations in life activities and participation among persons with disabilities; disability negatively associated with social and economic indicators

The qualitative studies touch upon a range of different topics, of which some are:

- Poverty and stigma as cause of exclusion; poverty and disability in a reciprocal relationship
- Marginalisation in the community reduces access to health services
- Alarming shortage of resources in schools hit children with disabilities hard; still, many teachers show positive attitudes towards integration of disabled children in school. Some positive results of government commitment to teacher education are indicated. Discrimination of students with disabilities in higher education.
- Huge gap between policy and practice in the field of disability
- Burden of caring for disabled children is high among mothers

The quantitative studies varied a lot in scope and sample size varied from 204 to 57247. Likewise, the qualitative studies are very dispersed when it comes to specific topic and purpose. There is also large variation in the quality of the papers and the studies. While the studies to a large extent demonstrate the problematic situation for persons with disabilities and their families within different life domains, the picture drawn by the studies in this review also contain some more positive results for instance in the field of microfinance and concerning teachers' attitudes towards children with disabilities.

# 7 CONCEPTUAL UNDERSTANDING

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) has gained ground in the 19 years since its adoption, 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 conceptual understanding of disability. The new emerging concept of disability 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 an increasing tendency in viewing disability as a complex process (the disablement process), involving a number of interacting elements at individual, societal and contextual levels. The traditionally dominant medical model of disability was challenged by the social model (Finkelstein & French, 1993; Shakespeare, 2014), and further developed into an interactional model on disability (WHO, 2001).

The UN Convention on the 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 (Figure 1). Although not representing a shift from a strictly medical to a strictly social model, the development culminating with ICF may be understood as a merger of the social and the medical model into an interaction model that implies a much wider understanding of disability and the disablement process.

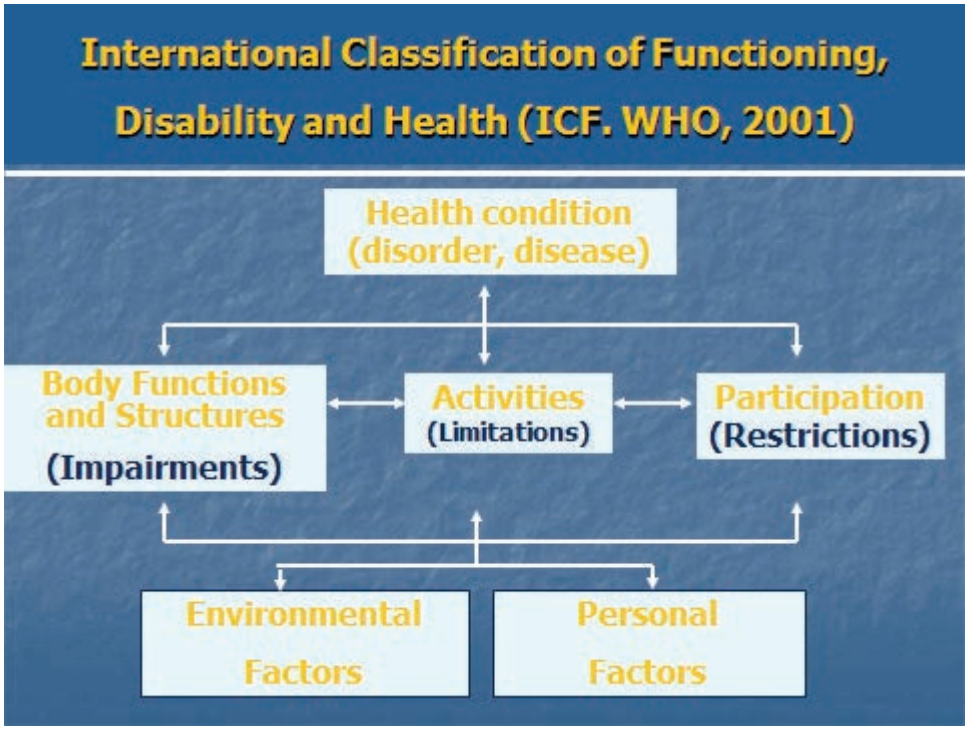



**Figure 1. The ICF model**

## 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 basis 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 ICF "model" 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 defined as activity limitations and/or restrictions in participation within a theoretical framework as described in Figure 1 underlies this study. With this in mind, the term “disability” is 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 occur in the exchange between an individual and his/her environment. In the current study, environmental factors are included in a separate section, utilizing an established research instrument.

## 7.4 Identification of disability/persons with disabilities; the WG6 and the Child Module

The Washington Group on Disability Statistics (http://www.washingtongroup-disability.com/) developed the Short Set for screening of disability (https://www.cdc.gov/nchs/washington_group/ wg_questions.htm). The six questions (WG Short Set), based on ICF, has been used in living conditions studies in Botswana (Eide and Mmatli 2015), Lesotho (Kamaleri and Eide 2010), Swaziland (Eide and Jele 2011), Mozambique (Eide, Loeb and Kamaleri 2009), and Zambia (Eide and Loeb 2006). Increasingly, the Short Set is accepted as the current standard for screening of disability in censuses and surveys (Madans, Loeb and Eide 2017). It was also used during Uganda's last census (UBOS, 2014a).

As experience has been gained with the WG Short Set, shortcomings have become clear and particularly the problems faced in using the instrument for screening of disability among children. Among children, and in particular very young children, it may be difficult to distinguish between slow but still within "normal" development and lasting disability. There was therefore a need for an instrument better (than WG Short Set) able to capture child disability in all its different facets. Consequently, the module on Child Functioning ("The Child Module") was developed jointly by the Washington Group and the United Nations Children's Fund (UNICEF)
(http://www.washingtongroup-disability.com/washington-group-question-sets/child-disability/).
Further information about the use of WG6 and the Child Module is found in the Methods chapter.

## 7.5 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 research tradition in 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 and to 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 such as sex, age and place, health, education, housing, work and income. Other indicators may comprise use of time, social contact, sense of influence, sense of well-being, perception 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.

## 7.6 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 in such studies are often defined by geography, gender, age - or the focus of the current research, i.e., persons 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 living conditions for all (Hem & Eide, 2009). In developing countries, apart from people with disabilities being worse off, this gap has widened in some cases (cf: BtG, 2018, Groce et al., 2011; Eide and Ingstad, 2013; McConkey, 2012; Mitra, 2013: Palmer, 2011; Mizunoya and Mitra, 2013; Munsaka and Charnley, 2013). 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 African 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 (ref. Methods section, page 40; Identification of individuals with disability).

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 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. However, studies of living conditions among people with disabilities in high-income countries have not evolved from an individualistic perspective. Data 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. Despite 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.

## 7.7 Combining two traditions and ICF

The design that has been used 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. An opportunity 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.

Disability and development have been understood through many conceptual lenses. The commonest and widely acknowledged models are as displayed in the figure hereunder:

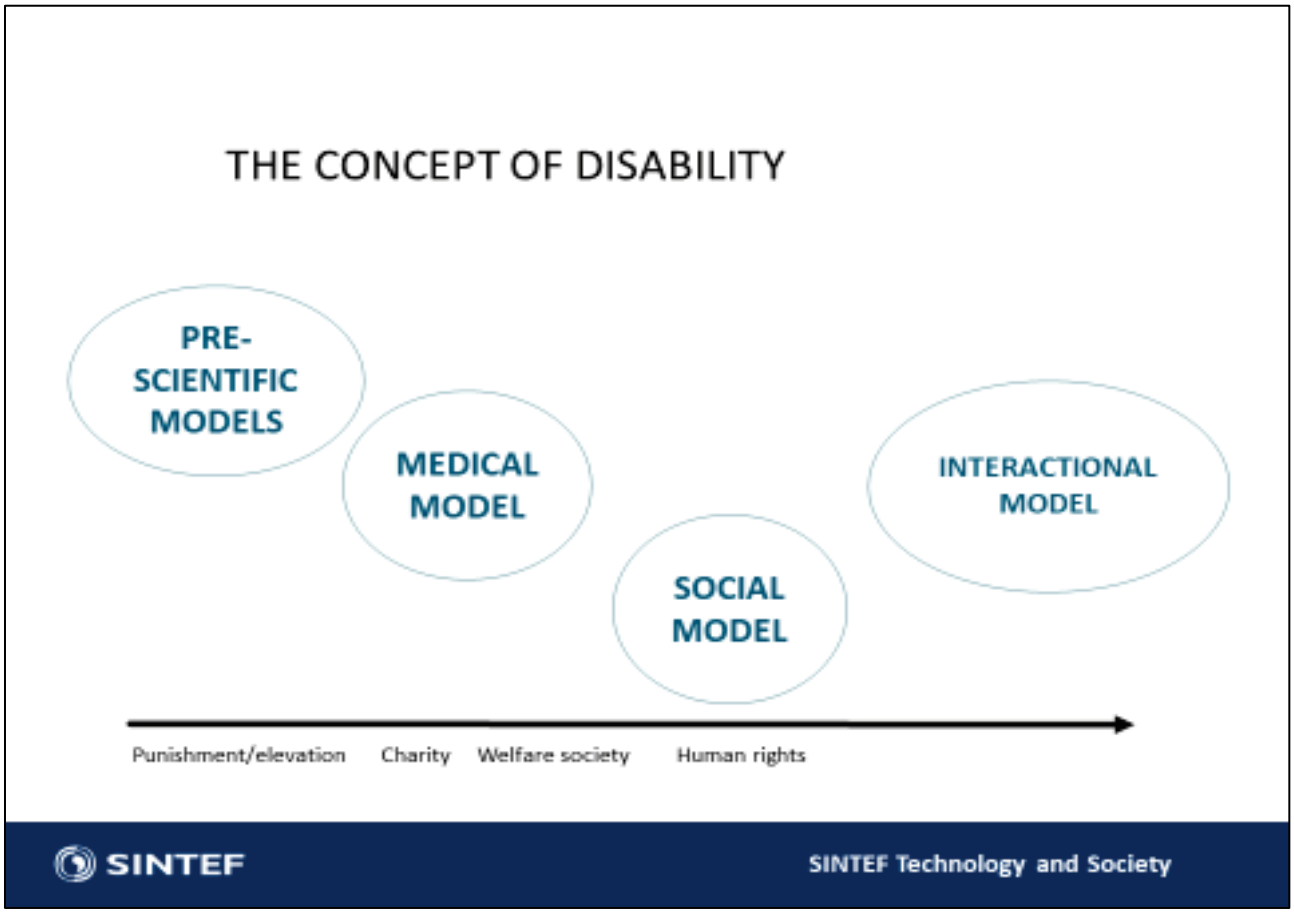



**Figure 2 The concept of disability – some common models**

The pre-scientific models are linked to religious or animistic belief systems and may be explained as a result of moral failure (Retief & Letsose 2018). These are largely regarded as primitive models of disability which consider people with disabilities as objects of pity, handicapped and unable to function fully. This view is still prevalent globally, and in developing countries including Uganda.

The medical model posits that disability is caused by conditions such as injury, sickness or other health conditions (Brucker and Helms, 2017). Hence, persons with any impairments are considered to have a disability, regardless of whether or not the impairment has been associated with limitations in their daily lives (Brucker

and Helms, ibid.). The medical model on disability indicates that people are disabled by their impairments or differences and these differences or impairments need to be "fixed" or changed by medical treatment, even when the impairment or difference does not cause pain or illness since it looks as if there is something wrong with the person.

The social model of disability defines disability as a limitation rather than a health condition and it particularly highlights the limitations of the social and technological context (environment) of an individual (Currie and Kahn, 2012). This model posits that the environment is not inclusive for all persons and it limits the participation of persons with impairments and this exclusion results into disability (Shakespeare and Watson, 2001). This model argues that barriers are not just physical. This is because, attitudes found in society, based on prejudice and stereotype disables people from having equal opportunities and deters them from becoming an integral part of their society. Accordingly, the social model places emphasis on promoting social change that empowers and incorporates the experiences of persons with disabilities, asking society itself to adopt and change.

On the basis of the exclusion identified under the social model, the model that attempts to include all aspects of persons with disabilities in society is the human rights-based model (Interactional model). The model has taken a global dimension and it is expressed through the CRPD (2006), which Uganda signed in 2007 and ratified in 2008. The CRPD is intended as a human rights instrument with an explicit social development dimension. It adopts a broad categorization of persons with disabilities and reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms. It clarifies and qualifies how all categories of rights apply to persons with disabilities and identifies areas where adaptations have to be made for persons with disabilities to effectively exercise their rights and areas where their rights have been violated, and where protection of rights must be reinforced.

It is on the basis of the interactional model (human rights-based model) that there is increasing search by stakeholders to come up with human rights-based model that ensure a comprehensive integration of vulnerable groups in development interventions. The emergence of *EquiFrame* (Mutamad, 2011; Mannan, 2011) is attributed to this. EquiFrame is an analytical framework for assessing the degree to which social inclusion and human rights feature in policy and policy-related documents. The framework was initially developed with regard to health policy documents with the motivation to contribute to enhancing equity in healthcare. It is now widely being used in other sectors. *EquiFrame* identifies the degree of commitment of a given policy to specified Vulnerable Groups and to Core Concepts of Human Rights. It treats social inclusion and human rights as key components of equity in the context of service provision. Under this *EquiFrame,* vulnerable groups, as described above, are "social groups who experience limited resources and consequent high relative risk for morbidity and premature mortality" (Flaskerud & Winslow, 1998, p. 69) and this may include people with disabilities, categorised into physical, sensory, intellectual or mental health conditions, and including synonyms of disability. The 21core concepts of human rights enshrined in the EquiFrame are: Non-discrimination, Individualised services, entitlement, capability-based services, participation, coordination of services, protection from harm, liberty and autonomy. Others are privacy, integration, contribution, family resource, family support, cultural responsiveness, accountability, capacity building, access, quality and efficiency. Most of these are contained in the Convention for the rights of persons with disabilities, and other Uganda national documents such as the 1995 (Amended 2005) Constitution especially Chapter 4, Article 20; Chapter 4, Articles 21-31 and Chapter 4, Article 41 contain provisions relevant to people with disabilities. The disability policies, namely the Disability

Policy, 2006; the Disability Act, 2006 and the National Council of Disability Act, 2003 are all emphatic on disability issues.

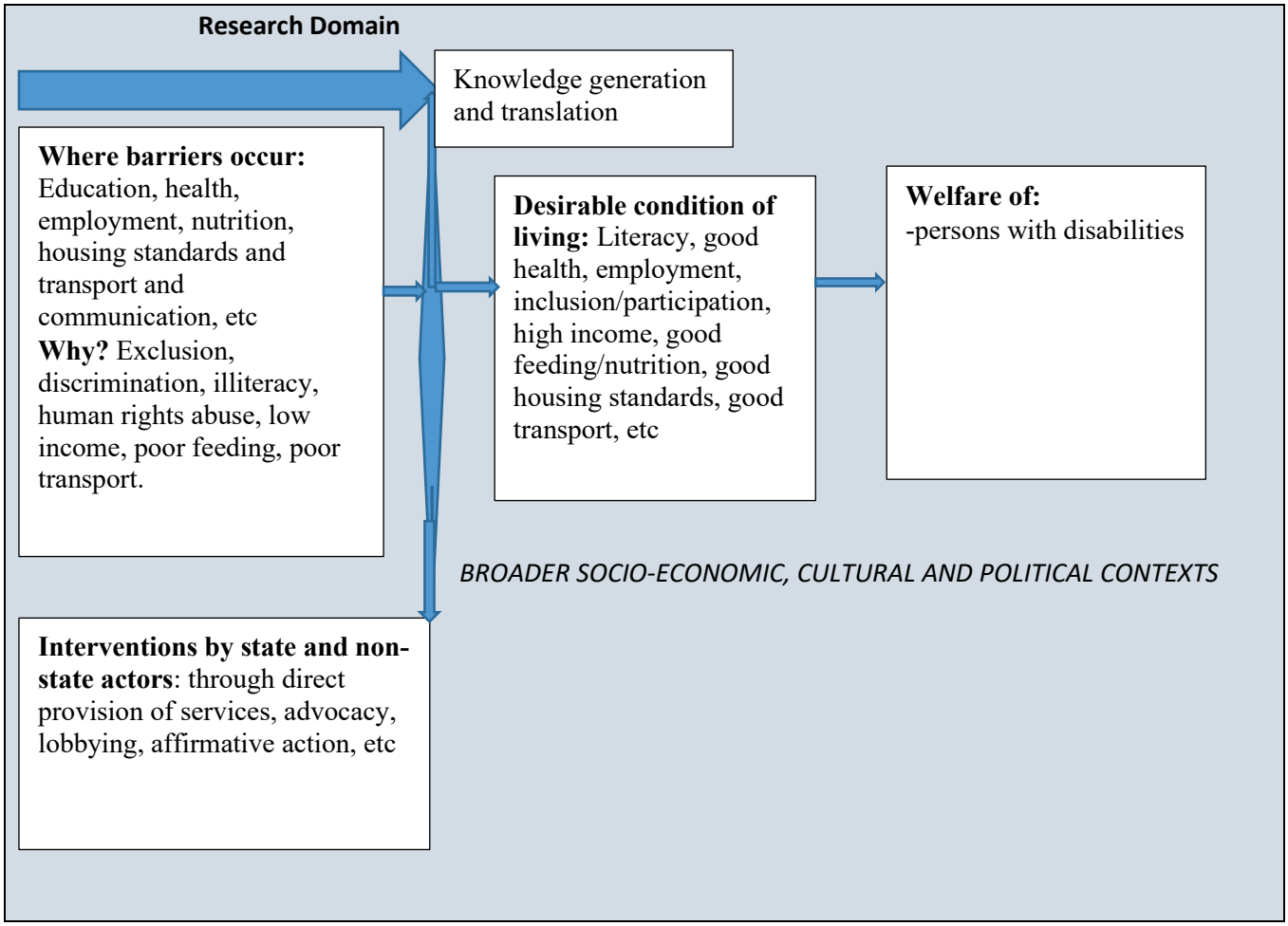



**Figure 3 Conceptual framework and definitions**

Figure 3 shows the relationship between and amongst research, actors and welfare of persons with disabilities. Source: Research Team

The conceptual framework shows the relationship between research, actors and final consumers of research outcomes, in this case persons with disabilities. The outcomes of the research will then provide evidence-based data that can be used by actors to improve the living conditions of the households with disability and in doing this their standards of living (welfare) will be improved.

## 7.8 Operational definitions

Key concepts that are worth defining are living conditions and disability. The definition of disability is enshrined within the International Classification of Functioning developed by World Health Organisations and combine three aspects: impairments, functional limitations (such as difficulty of walking), and participation restrictions (such as restrictions in employment) to define disability (Altman, 2001; WHO, 2001).

The details of ICF model are summarized below:

**Table 4. ICF definitions. Source: (Brucker and Helms, 2017)**

| Limitation type | Questions |
|---|---|
| Activity limitations | •Do you have difficulty dressing or bathing? |
| | •Because of physical, mental or emotional condition, do have difficulty doing errands alone such as visiting a doctor alone or shopping? |
| Functional limitations | •Do you have serious difficulty walking or climbing stairs? |
| | • Because of physical, mental or emotional condition, do have serious difficulty remembering, concentrating or making decisions? |
| Sensory limitations | • Do you have difficulty hearing? |
| | •Are you blind or do you have serious difficulty seeing even when wearing on glasses? |

The definition of disability is enshrined in the universal models of disability applied in this research: the Washington/UNICEF group of six questions, developed along the three limitation types identified by ICF that identify disability among adults in terms of difficulty in seeing, hearing, walking, remembering or concentrating, self-care and communicating. These three functionality types have been selected for identifying persons with disabilities at the aggregate level and serve the following goals:

- To monitor the level of functioning within the given population
- To provide services, including the development of programs and policies for service provision and evaluation of these programs and services
- To assess equalisation of opportunities (Washington group of disability statistics, 2018).

The children's models capture disability in the adult category but also include difficulty in learning new things, playing, biting, anxiety, depression and making new friends. This global tool thus measures disability, in the physical and psychomotor aspects.

Living conditions refers to the welfare status of the households or individuals. The welfare of an individual or household is determined by level of, or access to education, health, income, employment, inclusion/exclusion, living conditions of home, sanitation, transport and communication, all of which are used in this research to operationalise living conditions.

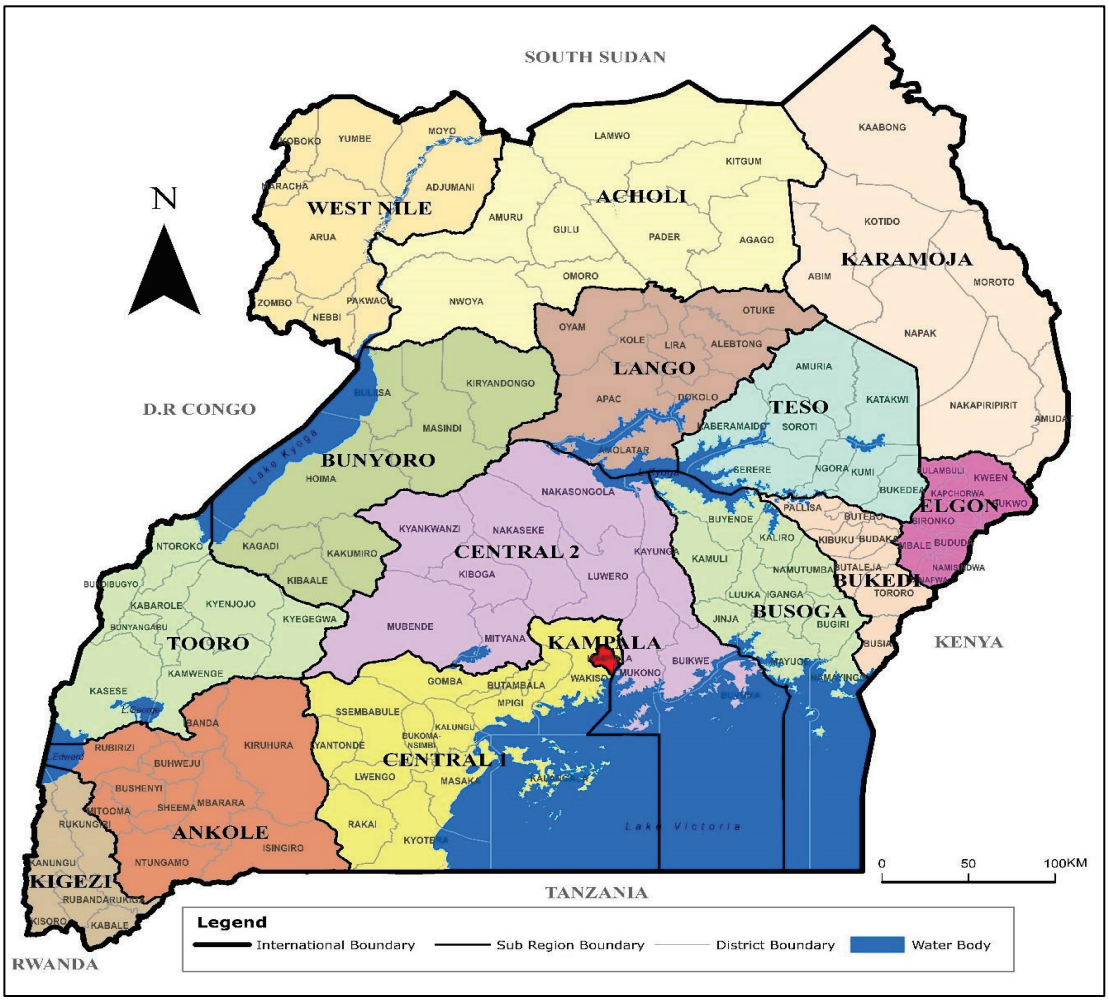
# 8 METHODS

## 8.1 Study design and content

The study was a cross-sectional household survey with two-stage cluster sampling.

## 8.2 Description of the study sites

The following sub-regions were covered: West Nile, Acholi, Lango, Teso, Karamoja, Bugisu (Elgon), Busoga, Bukedi, Bunyoro, Tooro, Ankole and Kigezi. The sub-regions were generated from a list of sub-regions used during the last census, 2014 (UBOS, 2014a). For the survey, only central and Kampala sub-regions were not selected. This was because these areas were known to have experienced sufficient disability research coverage in the past and are not as marginalised as the other sub-regions of the country. Besides, the 12 sub-regions were considered to be more representative of the national population, since they covered more than 2/3 of the population size of the country. The sub-regions excluded are Central 1, Central 2 and Kampala. Details are shown in the Map below.




Map A: Sub-regions covered in the study. Source: (UBOS, 2014b)

The district groupings within the 12 sub-regions are as indicated below:

- **Busoga:** Bugiri, Namutumba, Buyende, Iganga, Jinja, Kaliro, Kamuli, Luuka, Mayuge, Namayingo
- **Bukedi:** Budaka, Butaleja, Kibuku, Pallisa, Tororo, Busia, Butebo
- **Bugisu (Elgon):** Bulambuli, Kapchorwa, Kween, Bududa, Manafwa, Mbale, Sironko, Bukwo, Namisindwa
- **Teso:** Amuria, Bukedea, Katakwi, Kumi, Ngora, Soroti, Kaberamaido, Serere
- **Karamoja:** Abim, Amudat, Kaabong, Kotido, Moroto, Nakapiripirit, Napak
- **Lango:** Alebtong, Amolatar, Dokolo, Lira, Otuke, Apac, Kole, Oyam
- **Acholi:** Agago, Amuru, Gulu, Lamwo, Pader, Kitgum, Nwoya, Omoro
- **West Nile:** Adjumani, Arua, Koboko, Maracha, Moyo, Nebbi, Yumbe, Zombo, Pakwach
- **Bunyoro:** Buliisa, Hoima, Kibaale, Kiryandongo, Masindi, Kagadi, Kakumiro
- **Tooro:** Bundibugyo, Kabarole, Kasese, Ntoroko, Kyenjojo, Kamwenge, Kyegegwa, Bunyangabu
- **Kigezi:** Kabale, Kisoro, Kanungu, Rukungiri, Rubanda, Rukiga
- **Ankole:** Buhweju, Bushenyi, Ibanda, Isingiro, Kiruhura, Mbarara, Mitooma, Ntungamo,
- Rubirizi,Sheema

## 8.3 Household survey (quantitative)

This comprised of a two-stage cluster sampling as follows:

- Selection of Enumeration Areas (EAs) based on the National Sampling Frame (UBOS).
- 1st stage data collection: listing and screening procedure covering all households in the sampled EAs to identify households with and without disabled members.
- 2nd stage data collection: full interview of identified households with and without disabled members. At individual level: matching of persons with and without disabilities by gender and age.

### 8.3.1 Questionnaires

- Screening instrument: Washington Group Short Set for adults (18 + years) and UNICEF/WG Child Module for children (2 – 17 years) (Appendix ii)
- Household level questionnaire (households with and without disabled members) (Appendix iii)

Summary of content of household questionnaire (not exhaustive):

| | | |
|---|---|---|
| Demographics | Socio-economic status | Employment |
| Health | Dependency ratio | Income and expenditure |
| Education | Dietary diversity | Access to information |
| Infra structure and housing | Reproductive health | |

- Individual level questionnaire (individuals with and without disabilities) (Appendix iv and v)

Summary of content of individual level questionnaire (not exhaustive):

| | | |
|---|---|---|
| Activity limitations | Health literacy | Wellbeing |
| Participation restrictions | Assistive devices | Access to services |
| Environmental barriers | Education | Physical and mental health |
| Cause and onset of disability | Employment | Accessibility |
| Discrimination and abuse | Social participation | |

### 8.3.2 Sampling and sample size

The recent UDHS2016 shows that about 7% of the persons aged 5 years and above are disabled[1]. . Uganda was estimated to have a population of about 38.8 million by 2016. The population aged 5 years and above was about 82.1% implying those in this age category were about 31.9 million people. These figures therefore provide an estimated total number of persons with disability in Uganda to 2.2 million people. Note that this figure could be different if 2 years + are factored in the study. The country has an average household size of 4.7 (UBOS, 2014a) and we estimate that the total number of households with disabled persons is about 476,596. This study covered both households where there are persons with disabilities and households without. The study covered the 12 sub-regions and involved a total of 10,472 households. We adopted some of the approaches used in other countries on a similar study e.g. Botswana (Eide & Mmatli, 2016). A total of 528 enumeration areas (EAs) were sampled across Uganda. To determine the sample size needed, the following assumptions were made:

- Desired level of confidence of the survey results (95 percent)
- Acceptable margin of error of the survey results (1.5 percent)
- Estimated baseline indicator (7% percent)

Additionally, the sample size was adjusted for:

- Anticipated non-response (5 percent)
- Design effect of the sampling methodology (2)

Taking the above parameters into consideration, the formula below was used for sample size calculation.

$n=Z^2 [P(1-P)/e^2]$
Where z=level of confidence (z-score of 5 percent = 1.96 in a normal distribution)
p=baseline level of indicators
e=margin of error

[1] The UDHS2016 used Washington Group Short Set and "a lot of difficulty or more" as qualifier for disability. See section on Washington Group Short Set.

**Table 5. Calculation of sample of households with persons with disabilities**

| Z | $Z^2$ | P | 1 - p | e | $e^2$ | N | (*)Design effect | (/)Response rate | =Final N |
|---|---|---|---|---|---|---|---|---|---|
| **1.96** | 3.8416 | 0.109 | 0.891 | 0.015 | 0.000225 | 1,658 | 2 | 0.90 | 3,685 |

In computing the sample size, we utilised the Yamane's formulae (1967) that takes into account the population parameters and is given as:

This implies that the sample size, *n* is:

$$n = \left( \frac{N}{1 + Ne^2} \right) * \frac{100}{r} * deff$$

Where *N* is the population value, *e* is the desired error margin (fixed preferably between 1 – 5%) and *r* is the response rate and *deff* is the design effect. We set e to 4% and r to 90%.

This implies that the sample size, n is:

$$n = \left( \frac{476{,}596}{1 + 476{,}596 * 0.04^2} \right) * \frac{100}{90} * 2 * 2 \approx 10{,}472$$

The total number of households expected were thus 10,472. This translated into 528 Enumeration Areas countrywide out of a total of 79,303 EAs and the EAs were allocated to the12 sub-regions using proportional allocation, based on total number of households- bigger EAs had 44 and smaller EAs had 43 EAs.

The survey used a two-stage stratified cluster sample design, with enumeration areas (small geographical units) selected during the first stage and households selected during the second stage. A representative sample of the total number of Enumeration Areas was drawn from the 2014 Population and Housing Census Frame using Probability Proportion to Estimated Size (PPES) procedure.

In each selected EA, all households were mapped during the household listing exercise prior to enumeration, to provide a comprehensive sampling frame for the selection of households. In all the sub-regions, a total 145,146 households were listed. The listing is simply a complete listing of households or complete count of households in the enumeration area.

The identification of individuals with disabilities was done at individual level after the households were randomly selected. All individuals in the selected households were interviewed to determine whether the

household would be classified as with or without a disabled member. An average of (20) households were selected in each enumeration area on a 50-50 basis, with and without disabilities. In all, 6112 individuals with disabilities were interviewed against 5399 without disabilities.

### 8.3.3 Research Assistants, Translation and Capacity building

Before the start of the project, a call for applications for 60 slots of equal opportunity research assistants was made. The advertisement was made in both Makerere and NUDIPU on-line and on the notice board of the respective institution. A total of 2700 applications were received from all the research sub-regions. Selection of the 60 research assistants was based on these key attributes: ability to speak the local language in one of the sub-regions selected for the research, a minimum of a degree in social sciences, some experience in disability research or social sciences in general, and experience in translation of tools from English to a local language. On the basis of these criteria, 5 research assistants were selected for each of the 12 sub-regions. For contingency purpose, one extra research assistant was selected and placed on reserve but invited for the training. The selection was followed by translation of the tools to the local languages. Each sub-region had two translators- one for forward and then for backward translation. The translation period was followed by the training period that lasted for a week. The training was facilitated by SINTEF and staff from both Makerere University and NUDIPU. The key themes covered were background and purpose of the research, checking the accuracy of the translated tools against the English tools, getting acquainted with the application of the Washington Short Set and the Washington Group/UNICEF Child Module, use of tablet, techniques of data collection, and research ethics. Through this, we ensured a sufficient capacity level of the research assistants and the participating institutions. We took the GPS (Global positioning system) coordinates of all households in the survey to confirm that they indeed participated in the research after being sampled.

### 8.3.4 Administering the questionnaires

Resulting from previous phases, a tested and adapted design for data collection on living conditions among people with disabilities was finalised and used. In each selected household, screening was undertaken by means of WG6 and three short sets of selected questions from the Child Module (2-17 years, 2 – 4 years and 5 – 17 years), covering all the domains in the module. All individuals responded on their own behalf (main caretaker for children <= 12 years and for those > 12 if unable to respond or together with the main caretaker if that was found to be the right way).

In households with disabled members, the questionnaire was administered to the household head and the individual questionnaire to all individuals having qualified as being disabled (individual interviews or by proxy as explained above). In sampled households without disabled individuals, household questionnaire was administered to the household head and the individual questionnaire to one non-disabled person randomly selected from the household using the Kish Grid Revision method[2]. Care was taken to have the services of sign language interpreters present in all sub-regions.

### 8.3.5 Identification of individuals with disability

A wide definition of disability is applied in order to adequately capture also individuals with mild disabilities. Among adults (18 + years), the six Washington Group questions were applied. Anyone who responded "some

[2] https://www.statisticshowto.datasciencecentral.com/kish-grid/

difficulty" to one of the questions was included as a person with disability. Among children (2 – 17 years), questions 17 – 30 in the Child Module was used to identify children with disabilities. Any child responding "some difficulty" to one of the questions was included as a child with disability.

### 8.3.6 Households with at least one person with disability

All persons with disabilities were eligible for an individual interview. Persons with disabilities aged 2-17 were interviewed using the Child Module and the Disability questionnaire. For children below 12 years with a difficulty (identified as disabled according to the explanation above), the caregiver or the parent to the child was asked to respond to the questions. Children between 12 – 17 years respond by themselves if they were able to answer on their own. If they were unable to, they needed a care giver with them, or the care giver would respond on their behalf.

All adults (18+ years) were asked the six Washington Group questions on their own if they were available during the household interview. For those who were not available, an appointment was made so that an interview could be done later. If they were not available and for some reason an appointment could not be made, the household head, main respondent or care giver who was knowledgeable of the household members responded on their behalf. It took a maximum of one hour to have this tool completed.

### 8.3.7 Households without a person with disability

Households without a person with a disability were interviewed using the same household questionnaire as for households with disabled members. Following a matching procedure, matched individual controls were interviewed using the individual control questionnaire. The matching was by age (+or – 5 years) and gender.

The questionnaire for individuals without disabilities collects information similar to the individual with disability questionnaire but did not include disability specific questions, such as questions on assistive devices, discrimination and abuse, accessibility etc. It took between 30 to 45 minutes to complete this questionnaire.

**Table 6. Sub-Regions, households covered and Enumeration Areas (source: Field Data)**

| Sub-region | HH with disabilities | HH without disabilities | Total households covered | EA completed |
|---|---|---|---|---|
| Acholi | 448 | 881 | 1329 | 44 |
| Ankole | 417 | 895 | 1312 | 43 |
| Bugisu | 427 | 954 | 1381 | 44 |
| Bukedi | 451 | 876 | 1327 | 43 |
| Bunyoro | 451 | 869 | 1320 | 44 |
| Busoga | 453 | 867 | 1320 | 44 |
| Karamoja | 431 | 897 | 1328 | 44 |
| Kigezi | 466 | 892 | 1358 | 45 |
| Lango | 458 | 890 | 1348 | 44 |
| Teso | 446 | 872 | 1318 | 44 |
| Tooro | 444 | 916 | 1360 | 44 |
| West Nile | 441 | 901 | 1342 | 42 |
| **Total** | **5333** | **10710** | **16043** | **524** |

### 8.3.8 Data Cleaning

Data cleaning was done in two phases

*Phase 1*

During this phase, the main task was to ensure that the households and their members that were sampled from the listing master file were the ones that were, actually, interviewed. This was ascertained by linking the data in (i) the HHs with disability file, and (ii) the HHs without disability file, with the data in (iii) the listing master file.

The preoccupation here was to synchronize the data in files (i) and (ii), with the data in the Master file (iii). Whenever any discrepancies were discovered, especially with regards to the HH No. and the respective HH Member_ ID, these were synchronized and corrected. After the cleaning, attaching weights to each of the 528 Enumeration Areas (EAs) was done.

(a) HHs with Disabilities

In the cleaning phase 1, files (**i**) and (**iii**) were handled simultaneously, and apart from doing the above, the unique cases as highlighted below were identified and rectified.

In working on the following EAs, it was discovered that during the listing phase, the Research Assistants that worked in these EAs, assigned the same HH member to each HH member of a particular Household, yet these IDs are meant to be unique.

| | EA Name | | | EA Name |
|---|---|---|---|---|
| 1. | ADIPALA | | 10. | KAURIKAKINE 'C' |
| 2. | ALIR | | 11. | LOPUTUK |
| 3. | CHERELACHKOUM | | 12. | NACHUKUT |
| 4. | ENTEBBE AREA 'A' | | 13. | NADOMEIT |
| 5. | KAEKAB | | 14. | NAITAKWAI |
| 6. | KANAAN | | 15. | NANGOLEKURUK |
| 7. | KASIKIROI | | 16. | NASINYONOIT |
| 8. | KATANGA 'C' | | 17. | TRADING CENTRE |
| 9. | KATAPARALEM 'B' | | 18. | KYENSHAMA II |

Additionally, there were some cases in which it was found that an entire EA was assigned the same HH No. Such EAs include: Igabiro, Kyenshama II, Upper Bibia, etc.

There were other cases where several members of the same HH were assigned the same HH number. Examples of these are outlined in the table below.

| | **EA name** | **Affected HHs** |
|---|---|---|
| 1. | KONGGORO | HH1, HH3, HH4, HH6, etc |
| 2. | LUNYANGO 'F' | HH2, HH5, HH20, HH30, HH45, HH66, etc |
| 3. | MATIMIAMOR 'A' | HH1, HH5, HH6, HH7, HH8, HH10, HH11, HH12, etc. |
| 4. | MICIRI 'A' | HH1, HH2, HH3, HH4, HH5, HH6, HH7, etc. |

(b) HHs Without Disabilities

Even in these HHs without disabled members, similar mistakes were made by enumerators.

There were also a number of cases of Research Assistants assigning a similar HH No. to multiple households. Examples of EAs with this anomaly include: ABERIDWOGO, ABILONENI, ABUDAMA, ADOK 'A', AGONGA A 'B', AKAGYERA II, AKUNGUR 'A', ELUPE, KACHURU 'A', etc. All these mistakes were corrected.

Similar to what happened with the Disabled HHs, after cleaning file (**ii**), weights were assigned to each of the 528 Enumeration Areas (EAs).

*Phase 2*

This cleaning phase was more comprehensive and elaborate than the first phase because, in this, mistakes that could not be detected in the first phase were addressed. Here, the major task was cleaning the entire master listing file – which had a total of 145, 146 records, by synchronizing it with both files (i) and (ii).

Generally, the more dominant anomaly was that of assigning a similar HH No. to multiple households. This occurred in more than 100 EAs, but it was worked on. Some of the over 100 EAs include the following:

BUKATIKOKO 'A', GOTOTAL, HARUTOOTO, IBANDA 1 'B', IREDA CENTRAL 'C', ITAKAIBOLU A 'C', IWAWU, KABONERO B, KACHURU 'A', YWAYA and many others. Results of the quantitative data are presented in the findings section.

### 8.3.9 Data Management and analyses

Data was collected using tablets under the technical supervision of Makerere, in collaboration with the rest of the key stakeholders. The SurveyCTO (www.dobility.com) was used for data transfer and storage. Data was exported from the server to be cleaned and analyzed using Stata and Excel statistical packages.

Analyses were handled by SINTEF in conjunction with Makerere University. The analyses were performed by use of IBM SPSS Statistics, version 25. The main focus of the analysis was to i) analyse differences between households with and without disabled members and between individuals with and without disabilities, ii) analyse disability specific phenomena among individuals with disabilities.

There was a combination of univariate, bivariate and multivariate analyses – and both parametric and non-parametric statistics according to the measurement level of variables involved. The most common types of analyses were:

- Frequencies; simple distribution on single variables
- T-tests of differences in mean value on a continuous measure of a phenomenon between two groups
- Chi-square tests for testing relationships between categorical variables
- Analysis of variance (ANOVA) to analyse the differences among groups
- Linear and logistic regressions (bi-variate and multi-variate) for estimating the relationships among variables
- Constructing scales: scalability and factor analyses

Appropriate figures and tables are used to present the findings.

### 8.3.10 Ethical considerations

*Approval from ethical committees and public authorities*

This project followed ethical standards and guidelines set out by both Norwegian and Ugandan laws and upheld by national ethics committees. The project was assessed for ethical approval from both the Mildmay and Uganda National Council of Science and Technology vide REC ref 0105-2019 and SS5031 respectively. The Ministry of Gender, Labour and Social Development, NUDIPU and Makerere University facilitated access to relevant public authorities. Local gatekeepers were also approached, including local councils, district and community-based social welfare officers, and community-based leaders dealing with disability. The study was also approved by the Norwegian Center for Research Data (reference number 346746).

*Informed Consent*

Before each interview commenced, every participant was informed of the purpose of the study, and informed consent was obtained (Appendix i). Direct consent was obtained from respondents above the legal age (18 years), while guardians/caretakers provided consent for children below 18 years of age or with reduced ability to consent. However, participants still had to assent to the interview.

*Voluntarism*

Participation in this project was voluntary in the sense that participants could withdraw at any time and could decline to answer any question during the interview. Participants did not receive payment for their participation. However, in Karamoja sub-region, which is a highly marginalised community, every household was given cash as a token of motivation and appreciation for participating in the research.

*Confidentiality*

The confidentiality of the participants was ensured by using household and individual and unique codes. Even where names were used, this was done for formality but not used in the analyses. During the FGDs and KIIs, interviews were recorded only if informants consented, and the recordings were deleted after transcription.

*Participant Protection*

Persons with disabilities are among the most vulnerable and marginalized of any population. This project was thus particularly sensitive to how they were interviewed. Extreme care was taken to avoid disrupting the daily lives of participants (practically, financially and emotionally) by, for example, conducting the interview in a manner that is most convenient to the interviewees, to ensure that sensitive issues were brought up properly and contextually, and to avoid creating false expectations.

### 8.3.11 Data storage

Data will be stored for a maximum of 5 years, to give time for revisiting the tools should there be any need to do so. In case this revisiting of the tools will be found necessary, MUREC will be informed accordingly.

### 8.3.12 Communication

The data was collected in a language best understood to the respondent. In this case, one major language was used in each of the 12 sub-regions. In addition, a translator was involved in a rare situation where the research

assistant could not communicate well with the interviewee. Effective communication was considered important to yield accurate data and thus output.

### 8.3.13 Competence of Senior researchers

It was important that the senior researchers -Julius, Nulu and Arne were competent to lead the research in different aspects and at different stages. To ensure this, they had to first undergo a senior researcher's course for which each obtained a certificate of research before the onset of the research. This was important in contributing to the quality of research output.

### 8.3.14 Organisation and responsibility distribution chart

SINTEF Digital was the Technical Expert responsible for the research quality. NUDIPU was responsible for managing and coordinating all the steps in the research process in Uganda, including establishing working relationships with stakeholders and in particular Makerere University (research partner in Uganda), Uganda Bureau of Statistics (UBOS) and the Ministry of Gender, Labour and Social Development (MGLDS). The project was anchored within NUDIPU, but the specific organization of the study was considered in dialogue with key partners in Uganda, and specifically organised with a Research Team and a Reference Group.

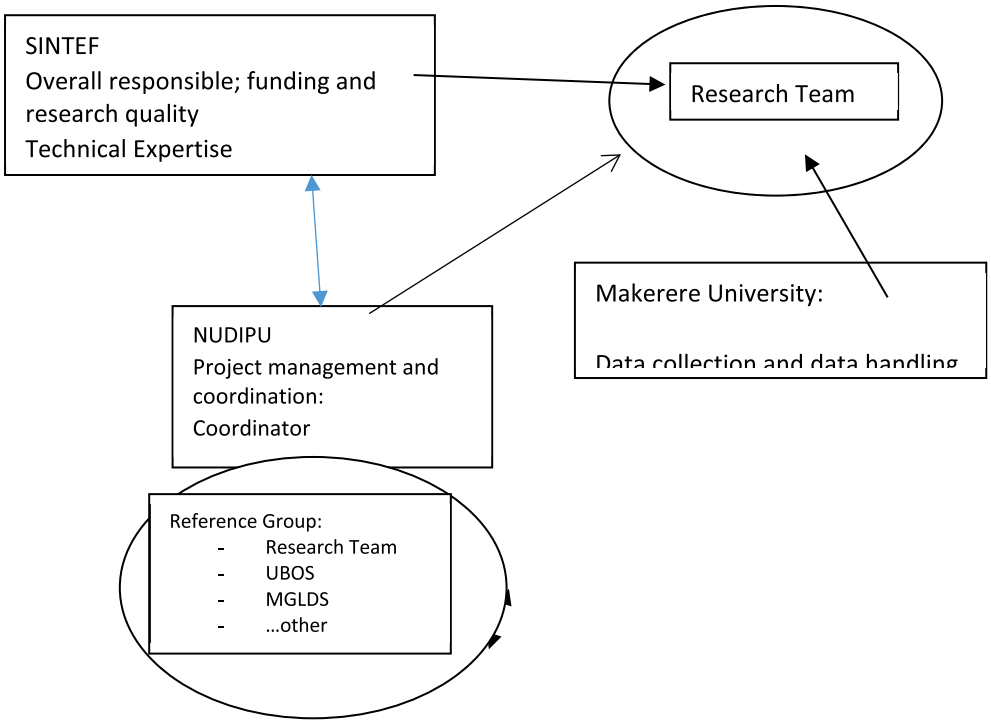



**Figure 4 Project Organisation**

The key people in the research were: Julius Omona, Nanono Nulu and Arne H Eide who worked with others within the systems above to ensure the success of the research.

*Responsibility distribution flow chart*

The following chart shows the responsibility distribution of the research among the three key persons.

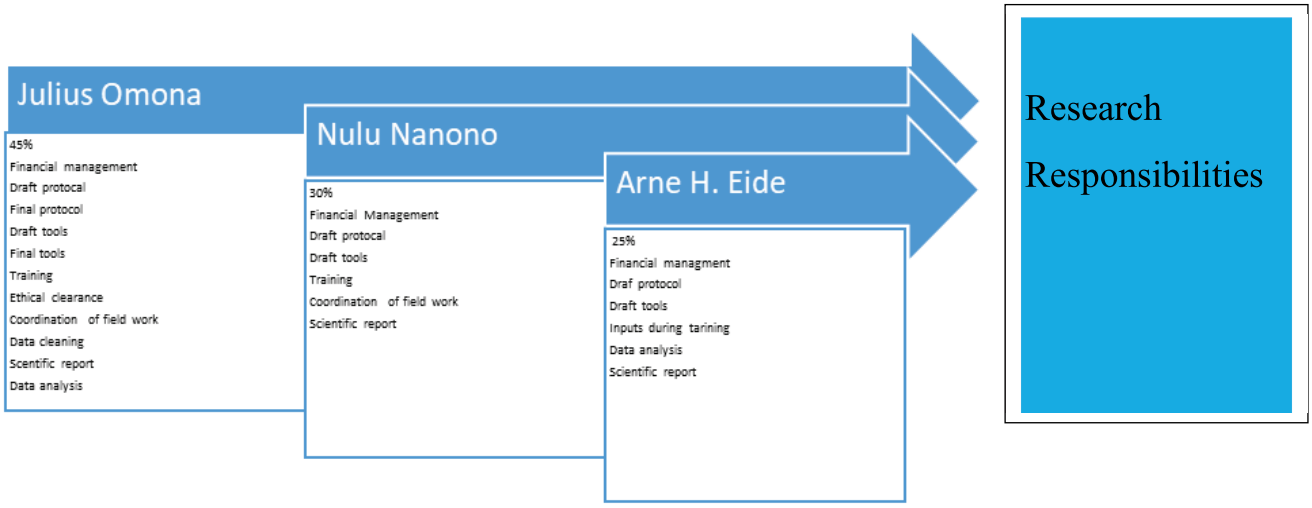



**Figure 5 Responsibility distribution flow chart**

### 8.3.15 Challenges

Many challenges were faced during the data collection. Some of the challenges were unique to some sub-regions, while most were common to all the sub-regions

*Accommodation and transport*

Since the selection of the EAs was randomly done, many remote areas were selected. Because of poor facilities and infrastructure in most rural settings, in some remote EAs it was not very easy for research assistants, supervisor or coordinators to find accommodation or access transport. In some instances, one had to travel long distances (30Kms or more) after a long search for any available transport and late in the night in order to get a decent accommodation.

*Language barriers*

In some areas, especially in border sub-regions such as *Bunyoro, Bundibugyo, Kigezi, West Nile and Bukedi,* communication became a problem because of language barriers. As was planned, in each sub-region one major language was used, but in border areas with mixed ethnicities, this became a challenge. For example, in West Nile, though *Alur and Lugbara* were the officially translated languages for the research because they are the most predominantly spoken languages, in practice, some of the selected households were found to be speaking other languages such as *Lendu, Kakwa, Kebu, and Madi.* However, this was overcome by either reverting to English, or engaging someone else in the community who could help in the translation.

*High and false community expectations*

As is known, most of the rural communities are impoverished. Many therefore expected that participation in the research would give them the opportunity to gain some tangible benefits, mainly financial. Local guides, in some places in particular and in almost all sub-regions, asked for much more money than what was budgeted for them as a token of appreciation for guiding research assistants in their communities. Some households conceived that the interview was an opportunity to register all the persons with disabilities in order to receive some benefits form government. Because of these, some "fake" or exaggerated disabilities in families were reported in order to benefit from the study. Some even accused the research assistants of hiding their share of the benefits, imagining that the organisers could have budgeted more for them, but that the research assistants were not giving them the money meant for them. To mitigate this, research assistants were asked to thoroughly explain the purpose of the research to the participants and to make sure to present them with realistic expectations. In other cases, research assistants were asked to make household heads or local leaders talk directly to supervisors or coordinators to clarify on aspects of the research that the community members were not clear about. For ensuring that the real disabled people were included, researchers were advised to strictly stick to the disability parameters as prescribed by the Washington Group Short Set and the Washington Group/ UNICEF Child Module questions.

*Precedence and culture*

In some communities, especially in Karamoja, it was established that NGOs operating in the area have made it a habit or culture to give some token of appreciation to households involved in such a research due to their extreme vulnerability and being a hard-to-reach area. Because of this, we had to make a special provision of committing some cash payment to all households involved in the research from this sub-region.

*Listing of households and selection of respondents*

In some communities, especially in Karamoja, most people did not have a surname, and a Christian name as was expected to be used during listing and interview. Even the surname used was found to be shared by most, if not all members of the family. This then became a problem in the selection of the respondents within the same household for interview. Research assistants were asked therefore to stick to giving a unique identification number to each household member even if they had the same surname.

*Different concept of disability in many communities*

It was found that in some communities, people had a more exaggerated conception of disability. Any condition that the community perceived as out of the normal was considered a disability. Consequently, in some communities, people with bald head, long unkempt beards, more than five fingers or toes, the impotent, those with hydroceles, and those with HIV/Aids, were considered to be disabled. Again, research assistants were asked to stick to parameters of disability as agreed for the study.

*Local politicking*

In some areas, local leaders took advantage of the research to consolidate their political aspirations or positions. In some cases, the local leaders were rightly moving with the research assistants as local guides. In the process, they would warn the households involved that whoever will not vote him/her next time, will not benefit from any subsequent government programs for which a research was being conducted. Others were bragging that the selection of the EAs in the community where they have jurisdiction instead of the those in the neighbouring

communities was a clear indication of the trust in them by the central government as local leaders because of their achievements compared with other leaders in the EAs who were not selected for the study. In some communities, local leaders did not want those known to belong to the opposition political parties to be interviewed, even when they were randomly selected. Research assistants were asked to steer clear of political waters and stand their grounds against being lured by local leaders.

*Geography of the communities and natural forces*

Some districts, and thus the EAs within these districts, were so sparsely populated that, coupled with poor road network, rainy season and hilly terrain, made accessibility of the research sites difficult in some areas. Sparse population was especially experienced in Karamoja and Acholi sub-regions. Too much rain was experienced in the northern Uganda and Kigezi. Kigezi, Tooro, Bududda and Kwen are hilly areas of the country, alongside Bugisu (Elgon) area.

*Clearance*

In some sub-regions, local leaders did not clear the research teams as fast as they (the teams) would have liked. This was because either the right person- the Chief Administrative Officer, Resident District Commissioner or Community Development Officer - was either out of station on official duty or was within but occupied with the community. This delay on the clearance also delayed the onset and eventual completion of the research. The Busoga team experienced these delays, including the research assistant who worked in Amuru district, in northern Uganda.

*Power supply and connectivity*

Since this was an electronically based research by the use of tablets, in some places with poor power supply, this was a major challenge to the research assistants and the entire team. This was common in remote places such as *Lamwo, Kagadi, Bulisa, Pahida, Alebtong,* etc. Coupled with poor connectivity, mobile phone communication was difficult among and between the research assistants and the rest of the research teams. Some learnt the hard way and had to individually purchase power banks. Many had to move to the nearest spots where network connection could be available.

*Performance below expectations*

Despite the training done, some research assistants were found to perform below expectations, especially in the first week of the exercise. For example, in the first week while some research assistants had covered up to the 2 EAs, others were still doing the listings in the first EAs. Some of the extremely slow performers were replaced immediately. This happened in Busoga and West Nile. Due to such marginal performance, it is suspected that some research assistants did not capture all the data in every households as expected. For example, a perusal of the completed data indicated that some respondents interviewed only one household member with disability and which they matched with a respondent from a non-disabled family.

*Content of the tools*

It was discovered that the comprehensive tools for collection of household data, data on persons with and without disabilities and covering a wide scope of sectors, brought a lot of strain on the respondents, who

struggled to respond to all the questions. In most homes, one interview lasted for more than two hours. It is hoped that the information they provided were not compromised because of fatigue.

*Data hosting/server*

The data collected was hosted on Survey CTO. However, this brought us some challenges. For example, since the renewal of data was done online and piece meal as per their requirements, sometimes when the deadline expired and renewal was not instant, data submitted by RAs would bounce back since there would be no space. This was made even worse by the connectively problem we already alluded to earlier. Managing the server also became so demanding since the senior programmer in Kampala had to be alert all the time to communicate with the field programmers and the research assistants.

*Administrative changes*

In some sub-regions, it was discovered that the EAs provided by UBOS was different from that on the ground. This is because over time since the demarcation of boundaries for the census, new districts were created and because of this, one would find that an EA that originally belonged to a particular district, was now divided into two, with one half belonging to a newly created EA under a new political and administrative jurisdiction. In this case, we asked our RAs to stick to the new development on the ground as directed by the local leaders. Omoro district was a typical example, which was curved out of Gulu district and became operational in 2016, long after the Census[3].

### 8.3.16 Lessons learnt during data collection

- One lesson learnt from this field experience is that future selection of research assistants should be multistage, involving both paper selection and actual face to face interviewing. This would be necessary to cross check the information stated in the application against the applicant physically. We experienced cases where some RAs applications were very colourful, yet when it came to training, piloting and actual field exercise, the performances were below expectations.

- The other lesson learnt was that where random selection of study sites and respondents is involved, the research team should be able to have a contingency plan in terms of resources- to cover any issues that may not have been planned for such as the type of respondents selected, unforeseen weather challenges, differences in culture etc. It is also important to have adequate resources at hand in order to meet any emerging challenges. For example, if the plan was to include 50 RAs, it is better to have this number plus some more on standby to cater for any eventuality such as sickness, inability to cope with the work, etc.

- It is also imperative to have adequate time for the research, and allowances should be given for the delays such as administrative clearance, public holidays, breakdown in field equipment, and slow learners. It is extremely risky to plan for a research say for 40 days and commit all resources for those days only. A properly planed research of 40 days should have an additional allowance of 4 or 5 days.

[3]The district was created by Parliament on 3rd September 2015 and became operational on 1 July 2016 (https://en.wikipedia.org/omoro_district. 19th August 2019.

- Before the onset of data collection, it is important to explicitly explain the purpose of the research, its immediate benefits, long term benefits, and also being clear on the expectations of the research team. Doing this helps to avoid misunderstandings and misrepresentation of facts by the respondents for the sole purpose of unnecessarily gaining some benefits or favour from the research.

- It was observed that there were many people in the communities with different forms of disabilities, and there is fear that the limited scope of parameters used during the last census (2014) could have given a false prevalence of national disability statistics. It is also doubtful whether the parameters used in the current research actually captured all forms of disabilities as understood by the communities. What was evidently learnt from the different parts of Uganda was that there was discrimination in the communities against persons with disabilities. It was even found to be worse against females with disabilities. For example, it was found that most persons with disabilities did not have access to the basic services that would be evidently accessible by non-disabled community or family members.

# 9 RESULTS

## 9.1 Disability prevalence and profile

A total of 145 146 individuals were included in the listing. Of the total number of individuals in the data collected, 17031 qualified as being a person with disability according to the set criteria, using the Washington Group/UNICEF set of short questions and the Child Module tool (WHO, 2001). This means that the overall disability prevalence in this study was 11.7 %.

Among 63825 children in the listing data, 5828 qualified as being disabled. Disability prevalence among children was thus 8.4 %. Among the 75468 individuals of 18 years or more, 11190 were persons with disabilities, yielding a disability prevalence of 14.8 % among adults.

**Table 7. Disability prevalence[4]**

| Item | N total | N disabled | Prevalence (%) |
|---|---|---|---|
| All individuals | 145 145 | 17 031 | 11.7 |
| Children (< = 4) | 14 839 | 704 | 4.7 |
| Children (5 – 17) | 54 814 | 5 124 | 9.3 |
| Children (<= 17) | 69 653 | 5 828 | 8.4 |
| Adults (18 +) | 75 492 | 11 203 | 14.8 |
| Males | 70087 | 8361 | 11.9 |
| Females | 75058 | 8670 | 11.6 |

Figure 6 shows the "disability profile" among adults, using the six domains of the Washington Group/UNICEF Short Set (WHO 2001). While the highest score on a single item is for "some difficulty seeing" (5.2 %), total prevalence, combining the three degrees of disability, is highest for "difficulty walking" (7.2 %) and lowest for "difficulty communicating" (1.2 %).

[4] All figures including estimated prevalence in Table 7 are drawn from the listing file containing all individuals in the sampled EAs

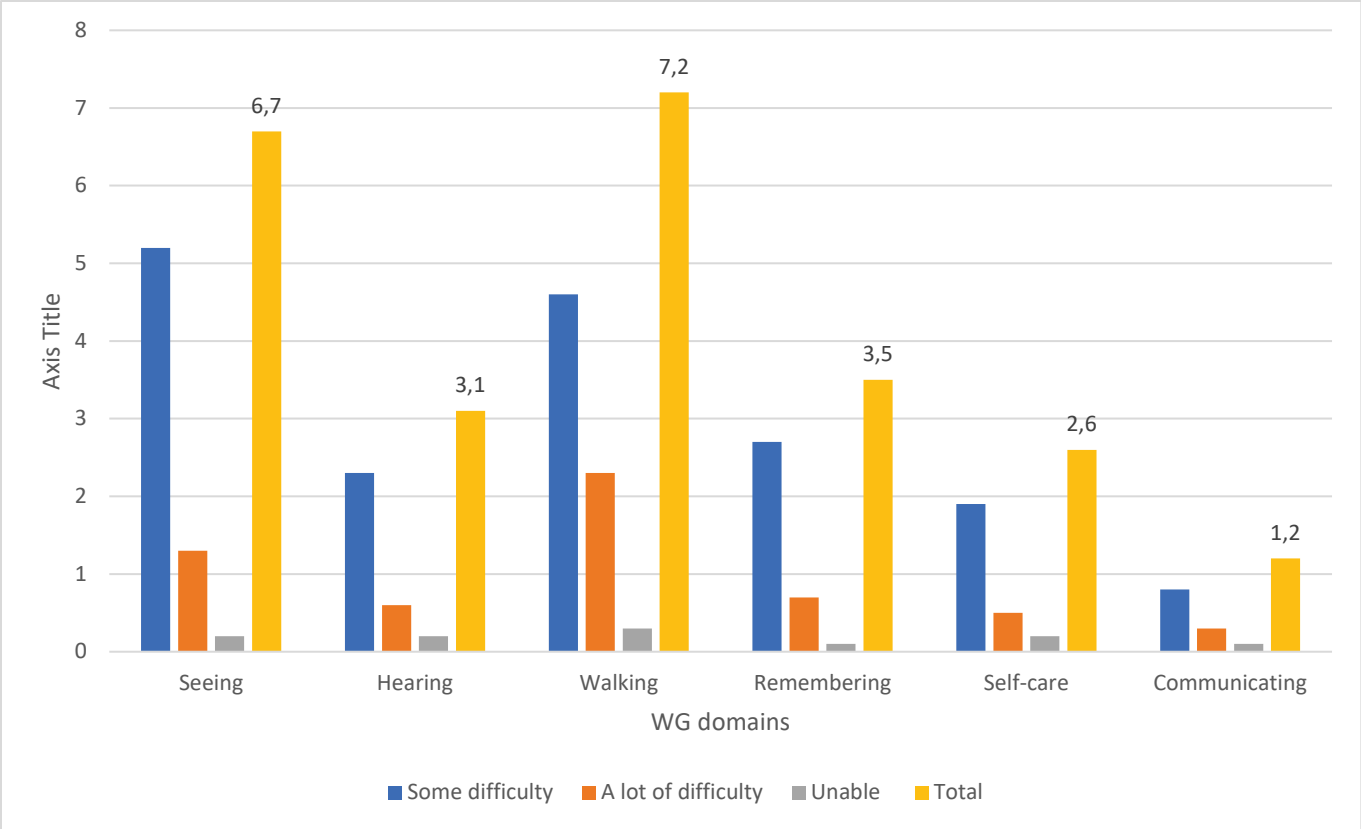



**Figure 6 Prevalence by WG domains among adults (18 +) N = 11190**

## 9.2 Household section

This section uses household level data from the household questionnaire.

### 9.2.1 Indicators of socio-economic status Asset scale (possession scale/SES).

A list of 29 common household items were included in the questionnaire, and the respondents (heads of households) reported which items were found in their respective households.

Table 8 shows that with two exceptions (Stove with gas or electric and Personal computer), it is only two household items that are more common in HHs with disabled members. For these two items, the difference between the two household types are marginal and not to be regarded as differences statistically. All other items are more common among households without disabled members. However, the difference is statistically significant (< .05) only for 10 items. The overall picture is nevertheless a clear tendency for households without disabled members to score higher on possessions than households with disabled members, but that the difference are relatively small.

**Table 8. Ownership of common household items by HH type (%)**

| Household item | HH with disabled (N = 5333) | HH without disabled (N = 10710) | $X^2$ | p |
|---|---|---|---|---|
| Radio | 53.1 | 57.4 | 25.92 | < .001 |
| HiFi Music stereo | 3.4 | 4.2 | 6.42 | .011 |
| TV | 6.7 | 7.9 | 6.67 | .010 |
| DVD/VHS | 4.1 | 4.3 | .65 | .420 |
| Cell phone | 60.2 | 68.3 | 105.70 | < .001 |
| Telephone in house | 1.7 | 1.8 | .41 | .521 |
| Flat iron | 12.1 | 13.6 | 6.86 | .009 |
| Fan | 1.1 | 1.2 | .50 | .480 |
| Stereo | 0.3 | 0.3 | .00 | .990 |
| Air conditioner | 0.1 | 0.1 | .74 | .390 |
| Stove with gas or electric | 0.4 | 0.3 | .35 | .553 |
| Stove with paraffin | 2.3 | 2.6 | 1.56 | .212 |
| Table and chairs | 65.0 | 68.0 | 14.14 | < .001 |
| Refrigerator | 1.1 | 1.2 | .16 | .692 |
| Microwave | 0.2 | 0.1 | .10 | .756 |
| Electricity | 6.5 | 7.1 | 2.11 | .147 |
| Solar energy system | 29.7 | 32.4 | 11.27 | .001 |
| Electrical generator | 0.2 | 0.3 | 1.00 | .318 |
| Personal computer | 0.9 | 0.8 | .01 | .933 |
| Bicycle | 25.6 | 26.7 | 2.00 | .158 |
| Motorcycle | 5.4 | 7.1 | 16.94 | < .001 |
| Private car | 1.3 | 1.5 | 1.12 | .290 |
| Bed(s) | 70.7 | 74.6 | 27.58 | < .001 |
| Livestock cattle | 39.9 | 41.2 | 2.72 | .099 |
| Washing machine | 0.4 | 0.5 | .31 | .581 |
| Satellite dish | 3.4 | 3.7 | .54 | .463 |
| Bed sheets | 92.5 | 94.3 | 20.11 | < .001 |
| Blankets | 79.9 | 81.7 | 8.26 | .004 |
| Warm clothes | 68.0 | 71.1 | 17.02 | < .001 |

The 29 items were added together (yes = 1, no = 0) to form an asset/possession scale and used here as an indicator of socio-economic status (SES). The range of the SES scale was 0 – 29, mean value 6.62 and standard deviation 3.00.

As shown in Figure 7 below, SES is higher among households without than with disabled members (total: $F = 58.35$, $p < .001$) and higher among urban than rural households ($F = 425.78$, $p < .001$). In both rural and urban areas, SES is higher among households without disabled members. This is also the case for eight of the twelve sub-regions.

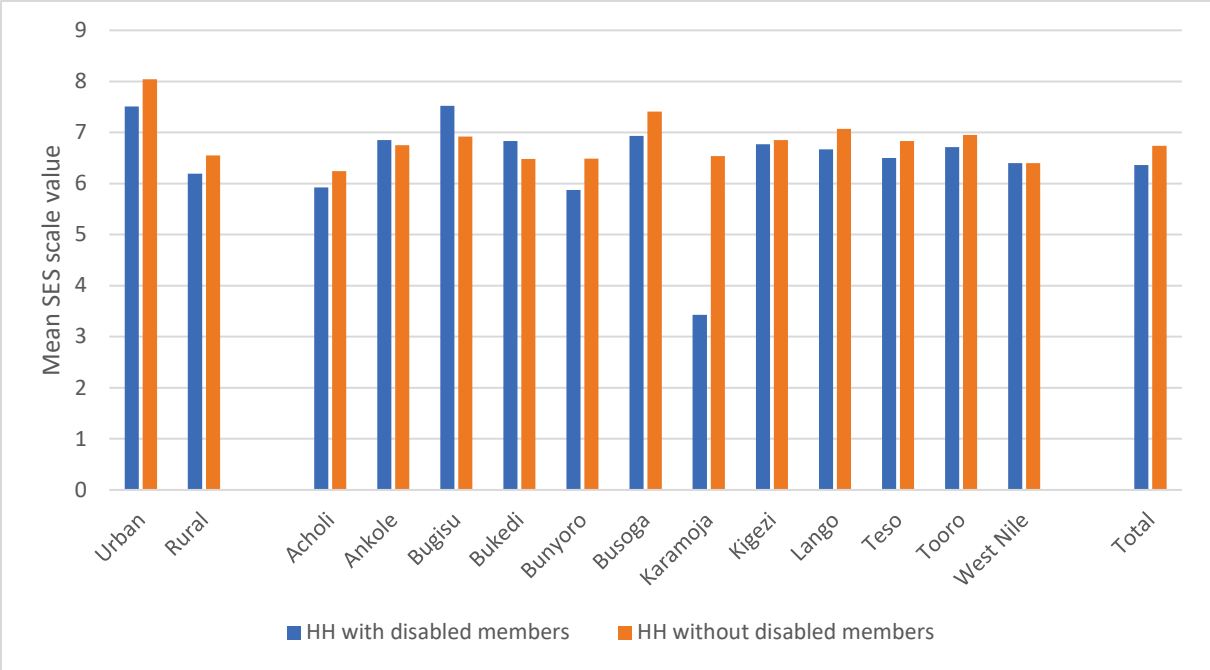



**Figure 7 SES by sub-region and urban/rural (N = 5333 and 10710)**

### 9.2.2 Dietary diversity and food in the household

A list of twelve different food items/food categories were included. Respondents were asked if the household had prepared and consumed the different foods during the past two weeks. For eleven of the food categories, more households without disabled members confirm consumption within the given time period. More households with disabled members have consumed fruits, which may be explained by fruits being cheap and readily available in the current context. While the difference is marginal for three food categories (potatoes etc., vegetables and beans etc.) and the mentioned reverse difference regarding fruit, the main picture is that of households with disabled members reporting less dietary diversity than households without disabled members.

**Table 9. Consumption of different food categories in households last two weeks (%)**

| Food item/food category | HH with disabled (N = 5333) | HH without disabled (N = 10710) | $X^2$ | p |
|---|---|---|---|---|
| Bread, rice, noodles, biscuits, etc. | 78.8 | 81.4 | 15.90 | < .001 |
| Potatoes, beetroot, yams, cassava, carrots, etc. | 89.5 | 89.9 | .53 | .467 |
| Vegetables | 89.1 | 89.4 | .54 | .462 |
| Fruits | 79.4 | 72.3 | 6.17 | .013 |
| Pork, lamb, goat, rabbit, chicken, duck, etc. | 47.8 | 50.9 | 13.68 | < .001 |
| Eggs | 27.5 | 30.8 | 18.84 | < .001 |
| Fish or any seafood | 41.9 | 44.5 | 9.51 | .002 |
| Beans, peas, pulses, legumes, nuts, etc. | 86.7 | 87.2 | .89 | .348 |
| Cheese, yoghurt, milk, any milk products | 36.0 | 38.7 | 10.36 | .001 |
| Foods made with oil, fat or butter | 47.1 | 51.1 | 22.77 | < .001 |
| Sugar or honey | 57.1 | 61.0 | 21.78 | < .001 |

| Food item/food category | HH with disabled (N = 5333) | HH without disabled (N = 10710) | $X^2$ p |
|---|---|---|---|
| Other foods such as condiments, coffee, tea | 50.4 | 53.5 | 14.04 < .001 |

The twelve food items were added together (yes = 1, no = 0) to form a dietary diversity scale (Swindale and Bilinsky 2006). The range of the scale was 0 – 12, mean value 7.41 and standard deviation 2.49.

Dietary diversity is higher among households without than with disabled members ($F = 36.84$, $p < .001$). It is also higher among urban vs. rural households ($F = 136.28$, $p < .001$). In both urban and rural areas, households without disabled members report higher dietary diversity than households without disabled members. Comparing between the two household types across the sub-regions reveals a somewhat mixed picture with households with disabled members reporting higher dietary diversity in four sub-regions, the reverse is found in 6 sub-regions, and in the remaining two hardly any difference is revealed.

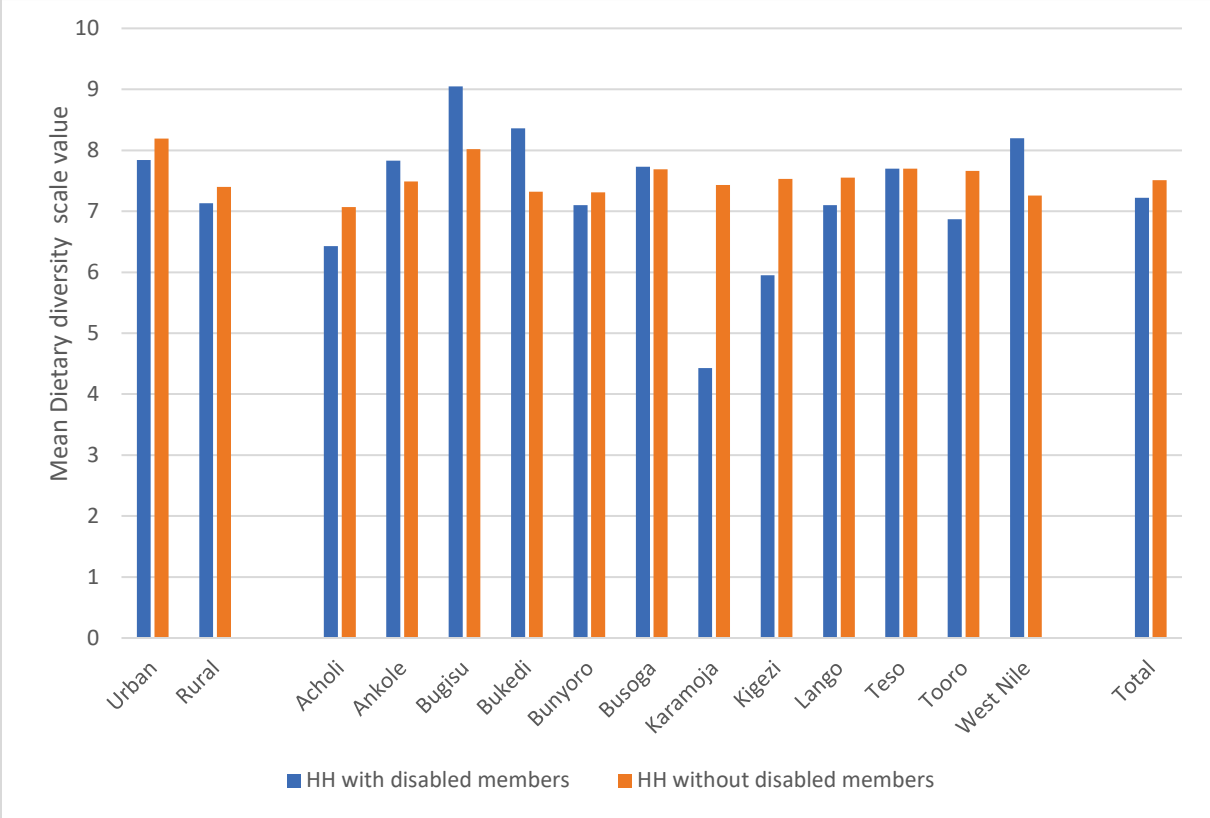



**Figure 8 Dietary diversity by sub-region and urban/rural (N = 5333 and 10710)**

Households with disabled members have fewer meals per day as compared to households without disabled members ($\chi^2 = 46.06$, $p < .001$). The majority of rural households both with and without disabled members report that they have two meals per day. While two meals per day is also most common among urban households of both types, considerable fewer urban households have two meals and more have three meals per day. Four meals per day is not very common, still more common in urban than in rural areas among both household types. More households with than without disabled members have only one meal per day both in urban ($\chi^2 = 13.65$, $p = .003$) and in rural areas ($\chi^2 = 37.92$, $p = .003$).

**Table 10. Number of meals per day by household type and location (%)**

| Number of meals normally per day | Households with disabled members (N = 5333) | | Households without disabled members (N = 10710) | | Total HHs with disabled members | Total HHs without disabled members |
|---|---|---|---|---|---|---|
| | Urban | Rural | Urban | Rural | | |
| One meal | 16.9 | 16.3 | 11.8 | 14.1 | 16.4 | 13.8 |
| Two meals | 49.2 | 63.4 | 49.7 | 61.3 | 61.6 | 59.8 |
| Three meals | 31.7 | 19.8 | 36.9 | 24.0 | 21.4 | 25.7 |
| Four meals | 2.2 | 0.5 | 1.6 | 0.6 | 0.7 | 0.8 |

Fewer households with than without disabled members have never experienced having no food on the table, while more have experienced this sometimes of often ($\chi^2 = 65.04$, $p < .001$). We further see in Table 11 that this overall pattern is reflected both in urban and rural areas ($\chi^2 = 20.94$, $p < .001$ and $\chi^2 = 49.06$, $p < .001$). Urban households have less experience with lack of food than rural households among most households with and without disabilities ($\chi^2 = 26.19$, $p < .001$ and $\chi^2 = 91.46$, $p < .001$.

**Table 11. No food to eat in the household in the past month**

| Food to eat | Households with disabled members (N = 5333) | | Households without disabled members (N = 10710) | | Total HHs with disabled members | Total HHs without disabled members |
|---|---|---|---|---|---|---|
| | Urban | Rural | Urban | Rural | | |
| No, never | 58.7 | 48.4 | 66.1 | 53.1 | 49.7 | 54.8 |
| Rarely, 1–2 times | 25.2 | 30.1 | 23.8 | 29.8 | 29.5 | 29.0 |
| Sometimes, 3–5 times | 12.6 | 16.6 | 8.6 | 13.6 | 16.1 | 13.0 |
| Often. More than 5 times | 3.5 | 4.9 | 1.4 | 3.4 | 4.7 | 3.2 |

### 9.2.3 Information access

Access to information was measured by means of two questions on availability and affordability of six different sources of information. Table 12 shows that all six sources of information were more common in urban than in rural areas. Households without disabled members more often report availability. The difference was statistically significant for four of the information sources, but not for newspaper and library. The difference between household types was also found when analysing urban and rural households separately, but mostly the differences were small and not significant. The difference between household types was statistically significant for radio (urban: $\chi^2 = 3.83$, $p = .05$, Rural: $\chi^2 = 14.20$, $p < .001$), telephone (urban: $\chi^2 = 18.12$, $p < .001$, Rural: $\chi^2 = 63.73$, $p < .001$) and television (urban: $\chi^2 = 3.87$, $p = .049$, rural: $\chi^2 = 3.86$, $p = .050$), but not for the three remaining sources.

**Table 12. Access to information sources by household type and location (%)**

| Information source | Households with disabled members (N = 5315-4367) | | Households without disabled members (N = 10704-8811) | | Total HHs with disabled members | Total HHs without disabled members | Total difference $X^2$ p |
|---|---|---|---|---|---|---|---|
| Own/have access to/use regularly | Urban | Rural | Urban | Rural | | | |
| Telephone | 80.1 | 65.9 | 87.2 | 72.5 | 67.7 | 74.4 | 78.22 < .001 |
| Radio | 60.1 | 57.1 | 64.5 | 60.4 | 57.5 | 60.9 | 17.81 < .001 |
| Television | 27.9 | 8.3 | 32.2 | 9.3 | 10.8 | 12.3 | 7.40 .004 |
| Internet | 10.2 | 2.2 | 12.6 | 2.6 | 3.2 | 3.9 | 4.72 .030 |
| Newspaper | 11.2 | 2.7 | 12.1 | 3.0 | 3.8 | 4.2 | 1.34 .247 |
| Library | 7.0 | 1.3 | 5.3 | 1.6 | 2.1 | 2.1 | .00 .964 |

The six information items in Table 12 were added together - for an Information access scale, with range 0 – 6, mean value 1.56 and standard deviation 1.12. The differences between urban/rural and household type are shown in Figure 9. More households have access to information in urban areas ($F = 520.38$, $p < .001$). In both urban and rural areas, we further see in Figure 9 that more households without disabled members access information ($F_{Total} = 45.38$, $p < .001$).

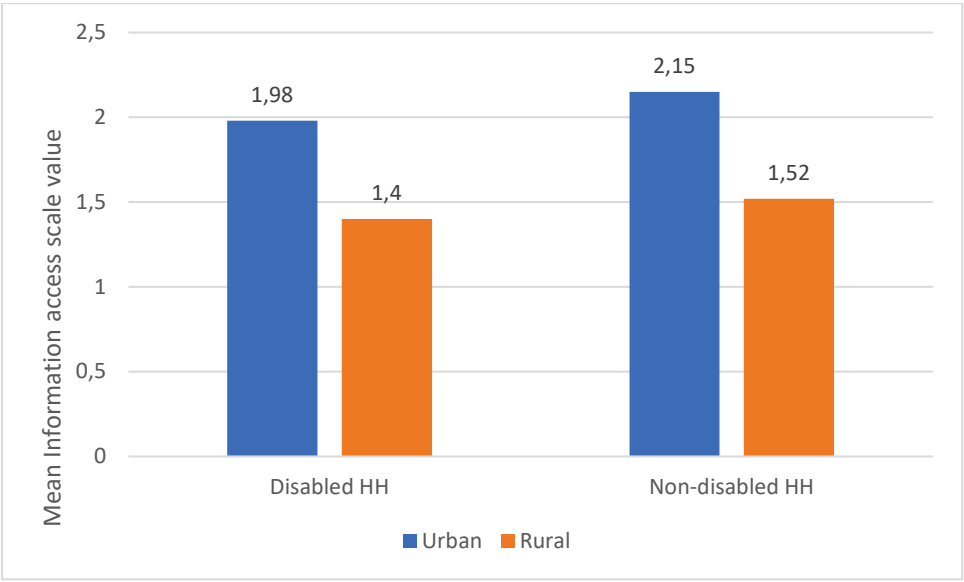



**Figure 9 Access to information (scale) by household type and location (N = 4836 and 9754)**

### 9.2.4 Dwelling – building materials

A series of questions were asked about the standard of dwellings and sources of drinking water and energy. Generally, pronounced differences were found as expected between urban and rural dwellings, but the results indicate small differences between the two household types (with and without disabled members). Table 13. shows that corrugated iron sheets were the most common type of roof material in particular in urban but also in rural areas. Well over one third in rural areas reported that their roof was made of grass/leaves thatch, while

this was reported by less than one in five in urban areas. Mud was by far the most common type of floor in rural areas while concrete/cement was the most common in urban areas. Still, around 45 % in urban areas also reported mud as material of their floor. In rural areas, more than half of the houses use poles and mud as material for walls, while well over one third reported bricks. In urban areas it is the other way around with the majority reporting bricks and around one in four used poles and mud. Somewhat more disabled households report poles and mud and more non-disabled households in urban areas have floor made of concrete. The differences in floor material between urban and rural dwellings were sufficient to indicate real differences between the household types, to the disadvantage of households with disabled members.

**Table 13. Type of roof by household type (%)**

| **Type of roof** | **Households with disabled members (N=4642-5253)** | | **Households without disabled members (N = 9310-10554)** | | **HH with vs. without disabled members** $X^2$ **p** |
|---|---|---|---|---|---|
| | Urban | Rural | Urban | Rural | |
| **Type of roof** | | | | | 7.90 .245 |
| Wood | 0.7 | 4.7 | 0.7 | 4.8 | |
| Corrugated iron sheets | 79.4 | 51.6 | 79.5 | 51.7 | |
| Grass/leaves thatch | 17.8 | 39.0 | 18.6 | 39.3 | |
| Tiles/shingles | 0.4 | 0.3 | 0.3 | 0.1 | |
| Paper/plastics | 0.0 | 0.0 | 0.0 | 0.1 | |
| Asbestos sheets | 1.6 | 4.3 | 0.9 | 3.9 | |
| Other | 0.0 | 0.2 | 0.0 | 0.1 | |
| **Type of floor** | | | | | 3.74 .797 |
| Mud | 46.6 | 80.5 | 44.8 | 80.8 | |
| Concrete/cement | 52.2 | 18.9 | 53.9 | 18.3 | |
| Wood | 0.3 | 0.4 | 0.1 | 0.6 | |
| Tiles | 0.7 | 0.1 | 0.1 | 0.2 | |
| Other | 0.1 | 0.1 | 0.1 | 0.1 | |
| **Type of walls** | | | | | 19.14 .004 |
| Poles and mud | 27.2 | 52.0 | 23.3 | 53.1 | |
| Corrugated iron sheets | 3.2 | 1.5 | 2.4 | 1.7 | |
| Bricks | 54.0 | 38.2 | 54.5 | 38.0 | |
| Compacted earth | 2.5 | 4.6 | 3.3 | 4,3 | |
| Concrete | 12.6 | 2.8 | 16.5 | 2.4 | |
| Other | 0.6 | 0.3 | 0.0 | 0.1 | |

More than four out of ten households have one bedroom and most of the remaining houses have two or more. There are small differences between household types and also small differences between urban and rural dwellings.

**Table 14. Number of bedrooms in main dwelling by household type (%)**

| Number of bedrooms | Households with disabled members (N = 5329) | | Households without disabled members (N = 10708) | | HHs with vs. without disabled members $X^2$ p |
|---|---|---|---|---|---|
| | Urban | Rural | Urban | Rural | 6.82 0.149 |
| 0 | 1.3 | 3.6 | 1.6 | 3.2 | |
| 1 | 41.6 | 40.7 | 42.1 | 40.4 | |
| 2 | 28.3 | 27.1 | 26.9 | 28.5 | |
| 3 | 16.5 | 19.3 | 18.9 | 19.4 | |
| => 4 | 12.3 | 9.3 | 10.6 | 8.4 | |

About half of the households in urban areas describe their dwelling as "permanent", while this is close to ten percentage points lower in rural areas. More households with than without disabled members are reported to be permanent.

**Table 15. Dwelling status by household type (%)**

| Dwelling | Households with disabled members (N = 5333) | | Households without disabled members (N = 10710) | | HHs with vs. without disabled members $X^2$ p |
|---|---|---|---|---|---|
| Dwelling status | Urban | Rural | Urban | Rural | 8.03 0.018 |
| Permanent | 50.2 | 43.2 | 49.0 | 40.6 | |
| Semi-permanent | 25.6 | 33.3 | 25.6 | 34.9 | |
| Temporary | 24.2 | 23.6 | 25.4 | 25.4 | |

### 9.2.5 Dwelling - water and energy

A majority of rural household's report that their source of drinking water is a borehole, while this is also most common, but ten percentage points lower among urban households. More rural than urban households use a public pipe/tap while more rural households use protected and unprotected wells and sources like river/stream/dam/spring/lake.

**Table 16. Main source of drinking water by household type (%)**

| Source | Households with disabled members (N = 5333) | | Households without disabled members (N = 10710) | | HHs with vs. without disabled members $X^2$ p |
|---|---|---|---|---|---|
| **Source** | **Urban** | **Rural** | **Urban** | **Rural** | **7.34 0.501** |
| Piped water inside | 2.6 | 0.3 | 5.3 | 0.3 | |
| Piped water outside, on property | 7.9 | 1.3 | 6.1 | 1.3 | |
| Piped water outside the property | 6.4 | 1.9 | 6.9 | 1.6 | |
| Public pipe/tap | 22.2 | 7.7 | 20.1 | 8.4 | |
| Borehole | 40.2 | 52.1 | 40.9 | 52.0 | |
| Protected well | 5.0 | 9.0 | 5.0 | 9.1 | |
| Unprotected well | 5.4 | 10.1 | 4.8 | 10.1 | |

| Source | Households with disabled members (N = 5333) | | Households without disabled members (N = 10710) | | HHs with vs. without disabled members $X^2$ p |
|---|---|---|---|---|---|
| River/stream/dam/spring/lake | 10.2 | 16.9 | 10.1 | 16.7 | |
| Rainwater tank | 0.1 | 0.6 | 0.9 | 0.6 | |

The large majority of rural households use wood as source of energy for cooking while urban households use either wood or coal/charcoal.

**Table 17. Main source of energy for cooking by household type (%)**

| Source | Households with disabled members (N = 5309) | | Households without disabled members (N = 10670) | | HHs with vs. without disabled members $X^2$ p |
|---|---|---|---|---|---|
| **Source** | **Urban** | **Rural** | **Urban** | **Rural** | **4.83 0.566** |
| Electricity | 1.6 | 0.1 | 1.6 | 0.0 | |
| Paraffin | 1.5 | 0.7 | 1.4 | 0.6 | |
| Gas | 0.0 | 0.2 | 0.1 | 0.3 | |
| Wood | 47.9 | 88.6 | 46.3 | 87.8 | |
| Coal/charcoal | 42.8 | 4.0 | 43.8 | 4.8 | |
| Solar | 0.4 | 0.5 | 0.3 | 0.4 | |
| Dung/grass/stalks | 5.8 | 6.0 | 6.3 | 6.0 | |

Electricity is a source of energy for lighting among one third of urban households, while few rural households use electricity. Paraffin is used by nearly one third in rural areas and around one in five in urban areas. Solar energy is also relatively common, but more so in rural areas. Somewhat more disabled households use paraffin, wood and torch, while more non-disabled households use electricity and solar energy.

**Table 18. Main source of energy for lighting by household type (%)**

| Source | Households with disabled members (N = 5242) | | Households without disabled members (N = 10564) | | HHs with vs. without disabled members $X^2$ p |
|---|---|---|---|---|---|
| Source | Urban | Rural | Urban | Rural | 25.06 0.001 |
| Electricity | 32.0 | 3.4 | 34.2 | 4.1 | |
| Paraffin | 20.9 | 32.2 | 17.4 | 30.8 | |
| Wood | 3.0 | 0.1 | 2.2 | 0.2 | |
| Coal/charcoal | 0.1 | 0.4 | 0.8 | 0.3 | |
| Solar | 20.6 | 29.4 | 21.9 | 32.4 | |
| Candles | 6.2 | 2.3 | 5.9 | 1.9 | |
| Torch | 17.3 | 25.3 | 17.7 | 24.0 | |

## 9.3 Individual section

This section uses individual data from the Household questionnaires and from the Individual questionnaires (disabled and non-disabled individuals). N will vary depending on which data file was used.

This section analyses

i) *Individual level and disability-specific variables* at the individual level, including only persons who were identified as a person with disability and included in the sample to be interviewed

ii) *Individual level variables that are not disability specific*, comparing persons with and without disabilities who were selected for full interview (see methods section)

### 9.3.1 Demographics

The difference in number of males and females in the study sample is small and non-significant, and there is also a marginal difference in urban/rural distribution with the large majority being rural dwellers both among persons with and without disabilities. Individuals with disabilities however tend to be older than their non-disabled counterparts, reflecting the age gradient in disability to be demonstrated further down.

**Table 19. Sex, age, and location by disability status**

| Sex, age and location | Disabled N = 6112 | Non-disabled N = 5399 | Total N = 11511 | p level |
|---|---|---|---|---|
| Sex (males) | 50.5 | 51.5 | 50.9 | $\chi^2 = 1.13$ n.s |
| Mean age (years) | 37.4 | 34.3 | 35.9 | F= 51.82 p < .001 |
| Location | | | | $\chi^2 = .22$ n.s. |
| Urban | 13.3 | 13.0 | 13.2 | |
| Rural | 86.7 | 87.0 | 86.8 | |

The majority of the interviews with persons with disabilities were performed directly with the disabled person him/herself. In one third of the interviews, someone else reported on behalf of the person with disabilities. One in ten was interviewed together with someone else/caretaker, and a translator was used in a few of the interviews. As shown in Table 20, mean age of persons with disabilities who were interviewed directly were significantly higher than among those who had someone reporting on their behalf or together with a caretaker (F = 596.10, p < .001).

**Table 20. Mode of interview among persons with disabilities**

| Mode of interview | N | % | Mean age | St.D. |
|---|---|---|---|---|
| The interview was directly with the disabled person | 3435 | 56.2 | 48.3 | 22.99 |
| Someone else reporting on behalf of the disabled person | 2031 | 33.2 | 23.9 | 21.53 |
| Someone else reporting together with the disabled person | 618 | 10.1 | 22.8 | 23.42 |
| Interview was performed with translator | 28 | 0.5 | 42.3 | 27.87 |
| Total | 6112 | 100.0 | 37.6 | 25.67 |

### 9.3.2 Activity limitations

A set of 18 items were used to determine level of activity limitations (the ICF matrix). The question was: How difficult is it for you to perform this activity WITHOUT any kind of assistance at all? Answer categories: No difficulty (0), slight difficulty (1), moderate difficulty (2), severe difficulty (3) and cannot do the activity at all (4). Fewest have any difficulties with staying in one body position (83.1 %) and Communicating directly with others (80.1 %), while the proportion who cannot do the activity at all is highest for Reading/writing/-counting/calculating (15.8 %) and Learning to read/write/count/calculate (13.2 %).

**Table 21. Activity limitations among individuals with disabilities (%) (N = 5703 – 6103)**

| Activity | No difficulty | Slight difficulty | Moderate difficulty | Severe difficulty | Cannot do at all |
|---|---|---|---|---|---|
| a. Watching/looking/seeing | 58.5 | 18.3 | 12.2 | 9.3 | 1.6 |
| b. Listening/hearing | 73.2 | 11.6 | 6.9 | 6.3 | 2.1 |
| c. Learning to read/write/ count/ calculate | 55.2 | 17.6 | 7.3 | 6.5 | 13.5 |
| d. Acquiring skills | 62.0 | 15.2 | 6.3 | 5.5 | 11.1 |
| e. Thinking/concentrating | 72.3 | 14.2 | 5.2 | 5.6 | 2.8 |
| f. Reading/writing/counting/calculating | 51.6 | 18.4 | 7.6 | 6.5 | 15.8 |
| g. Solving problems | 71.1 | 14.8 | 4.8 | 4.0 | 5.3 |
| h. Understanding others | 76.6 | 11.2 | 4.3 | 3.9 | 4.0 |
| i. Producing messages | 75.0 | 11.3 | 4.4 | 3.9 | 5.4 |
| j. Communicating directly with others | 80.4 | 9.5 | 3.5 | 3.8 | 2.8 |
| k. Staying in one body position | 83.1 | 10.1 | 3.2 | 2.6 | 1.0 |
| l. Changing a body position | 76.4 | 13.2 | 4.9 | 4.1 | 1.4 |
| m. Transferring oneself | 75.5 | 12.9 | 5.3 | 4.5 | 1.8 |
| n. Lifting/carrying/moving/handling objects | 68.1 | 14,1 | 6.9 | 6.9 | 4.1 |
| o. Fine hand use | 77.8 | 11.2 | 4.6 | 4.1 | 2.3 |
| p. Hand and arm use | 75.8 | 11.8 | 5.2 | 4.8 | 2.5 |
| q. Walking | 56.3 | 14.2 | 12.0 | 14.2 | 3.3 |
| r. Moving around | 57.9 | 14.2 | 10.6 | 12.6 | 4.6 |

In the next step, missing values were replaced with mean value for each single item and then added together to form an Activity Limitation Scale that will be used as a measure of disability severity in below analyses. The scale, including both persons with and without disabilities, ranged from 0 to 72, mean value 11.35, Standard deviation 10.93. In Figure 10 it is shown that Activity limitations score higher among females with disabilities than males with disabilities ($F = 36.92$, $p < .001$). While the overall urban – rural difference is significant ($F = 4.18$, $p = .041$), the urban – rural difference among males and females respectively are not large enough to reach statistical significance.

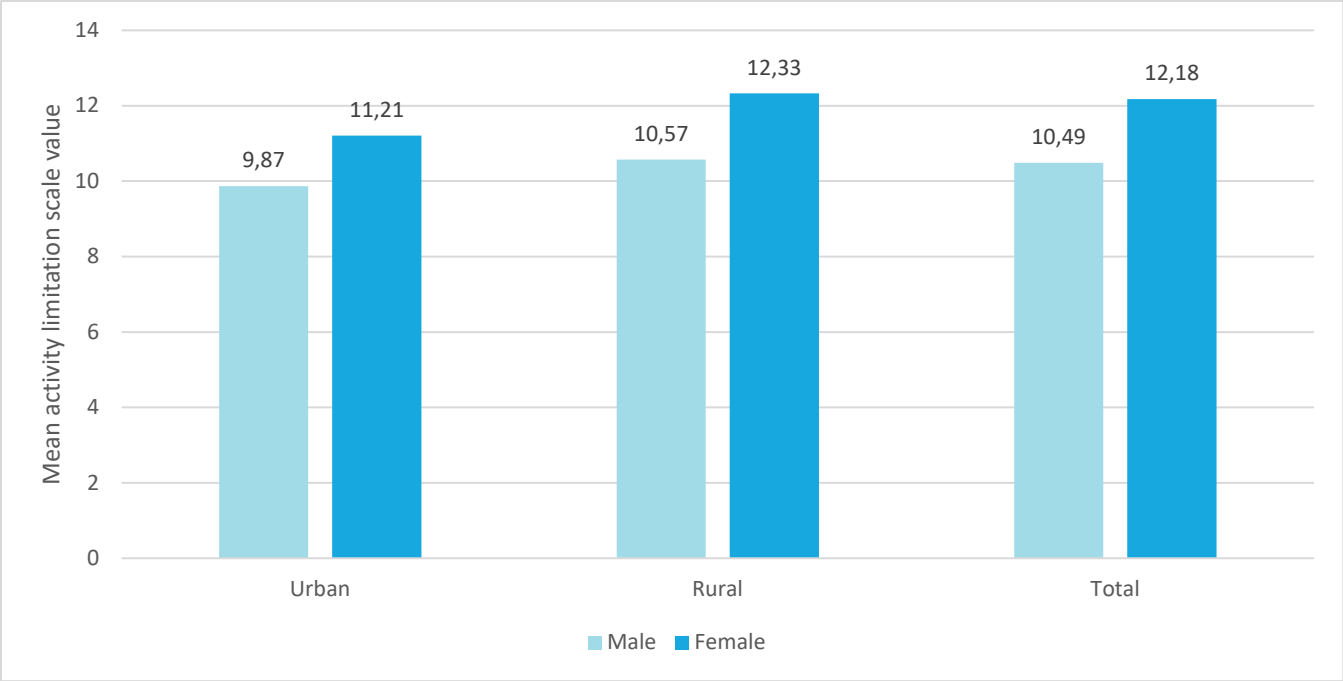



**Figure 10 Activity limitations by location and sex among persons with disabilities (N = 6058)**

Figure 11 below shows Activity limitation mean scale values by sub-region and for both persons with and without disabilities. As expected, there is a marked difference between persons with and without disabilities across the sub-regions. There is variation among persons with disabilities across the sub-regions, with Teso scoring highest on activity limitations and Lango, Bukedi and Busoga lowest ($F = 8.90$. $p < .001$). There is also variation in participation restrictions among non-disabled with Busogo scoring highest (3.08) and Lango lowest (2.09) ($F = 2.74$, $p < .01$)

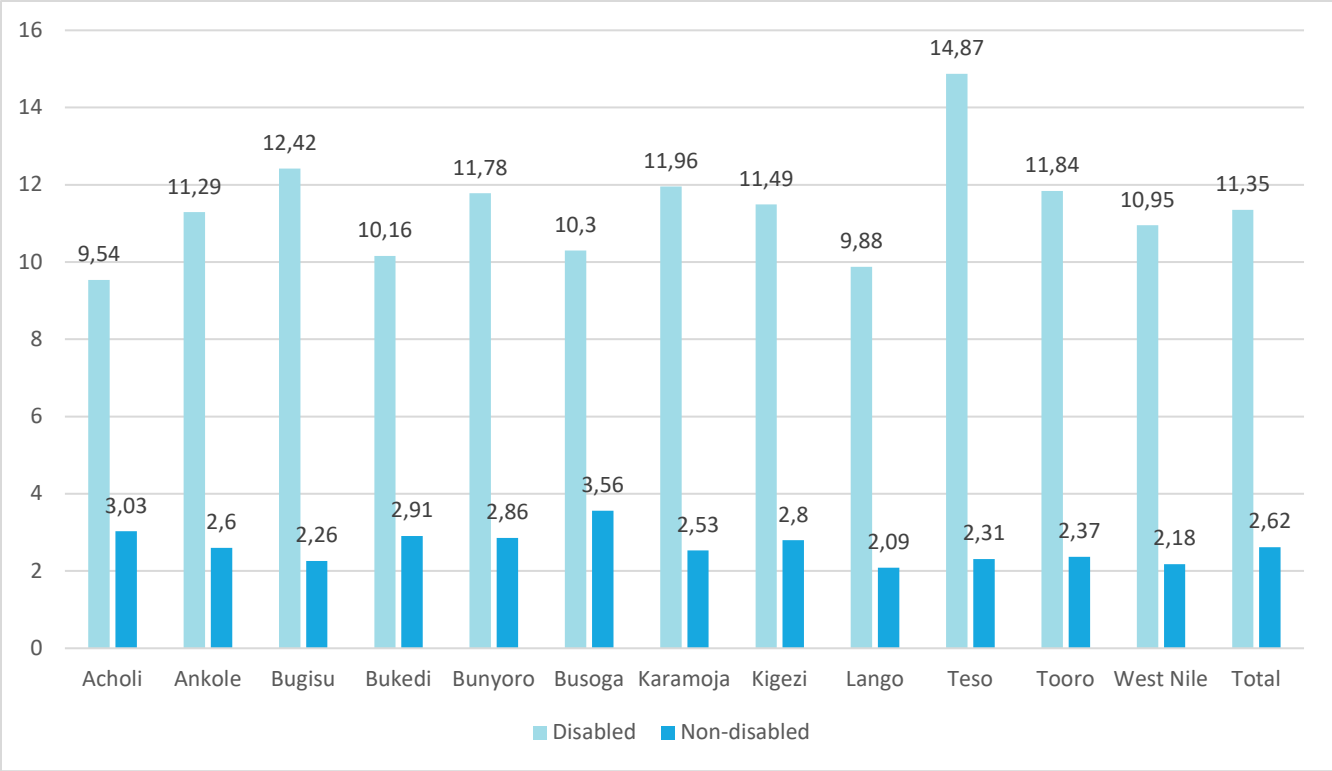



**Figure 11 Activity limitations by sub-region among individuals with and without disabilities (N = 11511)**

The Activity Limitation scale was recoded into four values: No disability (0), Mild disability (0,17 – 1,98), Moderate disability (2 – 5.86) and Severe disability (6 +). This was a pragmatic categorisation to ensure that the non-disabled sample were included in the first category (No disability: 57.1 %), while the remaining three categories were split in three (approximately) equally large (in frequency) categories (Mild disability: 12.9 %; Moderate disability: N = 15.0 %; Severe disability: N = 15.1 %). This categorised variable is used in some of the analyses below.

### 9.3.3 Participation

A set of 18 items were used to determine level of restrictions in social participation (the ICF matrix). The question was: Do you have any difficulty performing this activity in your current environment? Answer categories: No problem (0), slight problem (1), moderate problem (2), severe problem (3) and complete problem (unable to perform) (4). Fewest have any problems with Eating and drinking (93.2 %) and Religious and spiritual activities (86.1 %), while the proportion who had complete problems (unable to perform) was highest for Getting and keeping a job (18.9 %) and Going to school/studying (18.7 %).

**Table 22. Participation restrictions among individuals with disabilities (%) (N = 3192 - 6079)**

| Participation item | No problem | Slight problem | Moderate problem | Severe problem | Complete problem |
|---|---|---|---|---|---|
| a. Washing oneself | 79.2 | 11.3 | 3.0 | 2.2 | 4.3 |
| b. Care of body parts | 81.1 | 11.1 | 2.5 | 1.8 | 3.5 |
| c. Toileting | 85.0 | 7.9 | 2.3 | 2.6 | 2.2 |
| d. Dressing and undressing | 84.9 | 7.8 | 2.6 | 1.8 | 2.9 |

| Participation item | No problem | Slight problem | Moderate problem | Severe problem | Complete problem |
|---|---|---|---|---|---|
| e. Eating and drinking | 93.2 | 4.2 | 1.0 | 1.8 | 0.9 |
| f. Shopping | 68.9 | 13.9 | 5.7 | 3.3 | 8.2 |
| g. Cooking | 64.3 | 13.0 | 6.0 | 4.2 | 12.5 |
| h. Washing and cleaning | 63.6 | 14.8 | 7.3 | 4.9 | 9.4 |
| i. Mending and repairing things | 71.1 | 13.7 | 4.5 | 3.4 | 7.3 |
| j. Taking care of others | 72.6 | 12.7 | 4.5 | 3.2 | 7.0 |
| k. Making and maintaining friends | 83.8 | 8.8 | 2.5 | 2.1 | 2.8 |
| l. Interacting with persons in authority | 80.8 | 9.0 | 3.2 | 2.5 | 4.4 |
| m. Interacting with strangers | 79.7 | 9.7 | 3.2 | 3.4 | 3.9 |
| n. Creating and maintaining family relationships | 85.8 | 7.6 | 2.2 | 2.0 | 2.4 |
| o. Making and maintaining intimate relationship | 78.6 | 7.5 | 3.5 | 2.6 | 7.8 |
| p. Going to school, studying | 60.6 | 9.8 | 5.0 | 5.9 | 18.7 |
| q Getting and keeping a job | 61.2 | 9.6 | 4.9 | 5.4 | 18.9 |
| r. Handling income and payments | 74.9 | 9.0 | 3.5 | 3.0 | 9.6 |
| s. Community life | 75.0 | 10.4 | 4.1 | 3.1 | 7.5 |
| t. Recreation and leisure | 69.6 | 11.3 | 5.1 | 4.6 | 9.4 |
| u. Religious and spiritual activities | 86.1 | 6.6 | 1.8 | 1.5 | 4.1 |
| v. Political life and citizenship | 78.9 | 8.0 | 2.5 | 2.4 | 8.2 |

In the next step, missing values were replaced with mean value for each single item and then added together to form a Participation Restriction Scale that are used is some of the analyses below. The scale, including both persons with and without disabilities, ranged from 0 to 86, mean value 11.40, Standard deviation 15.70.

In Figure 12 below it is shown that Participation restrictions score higher among females with disabilities than males with disabilities in rural areas and the other way around in urban areas. The differences between males and females are however not statistically significant. at there is an opposite ($F = 36.92$, $p < .001$). There is an urban – rural difference among females ($F = 4.03$, $p = .045$) but not among males. The overall difference between urban and rural individuals with disabilities is 0.43 on the Participation restriction scale ($F = 3.94$, $p = .047$).

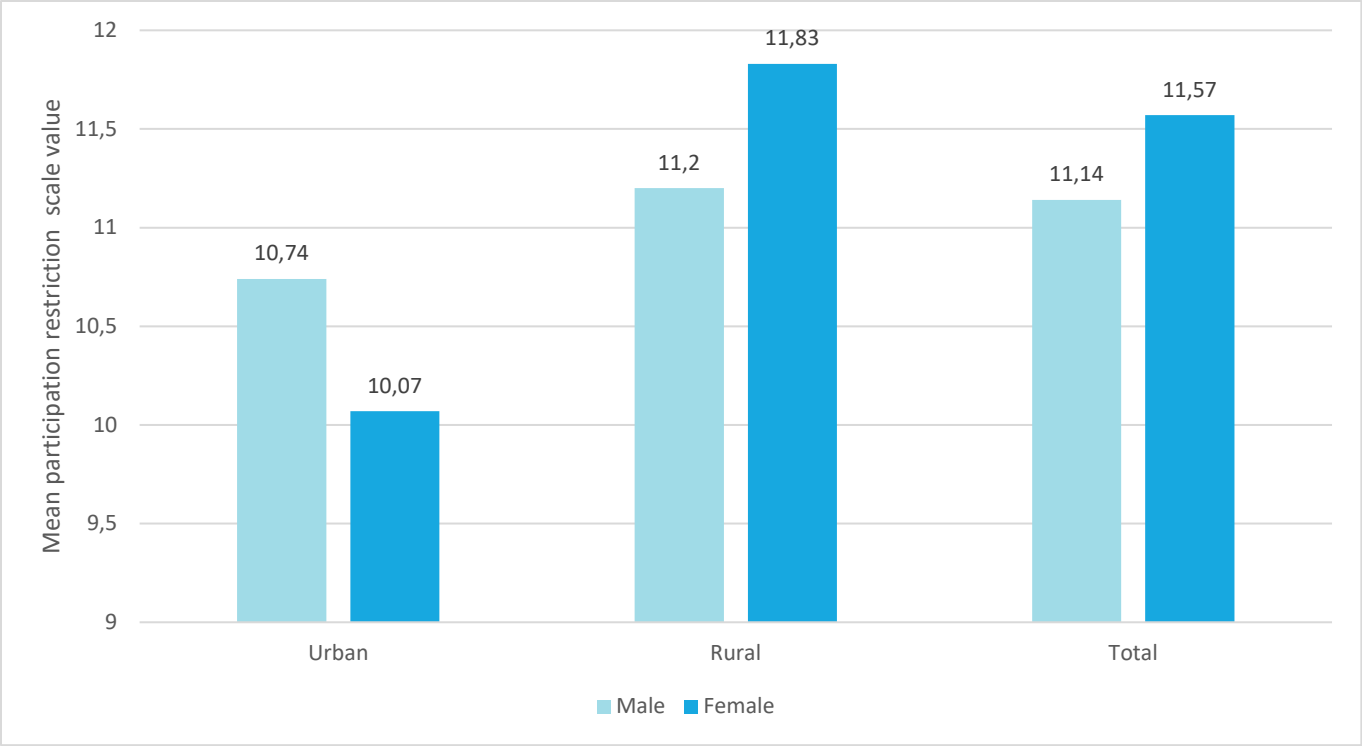



**Figure 12 Participation restrictions among persons with disabilities by location and sex (N = 6058)**

Figure 13 below shows Participation restrictions mean scale values by sub-region and for both persons with and without disabilities. As expected, there is a marked difference between persons with and without disabilities across the sub-regions There is variation among persons with disabilities across the sub-regions, with Bugiso scoring highest on activity limitations and Busoga lowest ($F = 10.29$, $p < .001$). There is also variation in participation restrictions among non-disabled with Busogo scoring highest (6.77) and Tooro lowest (2.98) ($F = 3.81$, $p < .001$). While Busoga is a sub-region with the highest prevalence of poverty and the Tooro area is among the most economically productive parts of the country, socio-economic differences may provide part of the reason for variation in participation restrictions as shown in Figure 13.

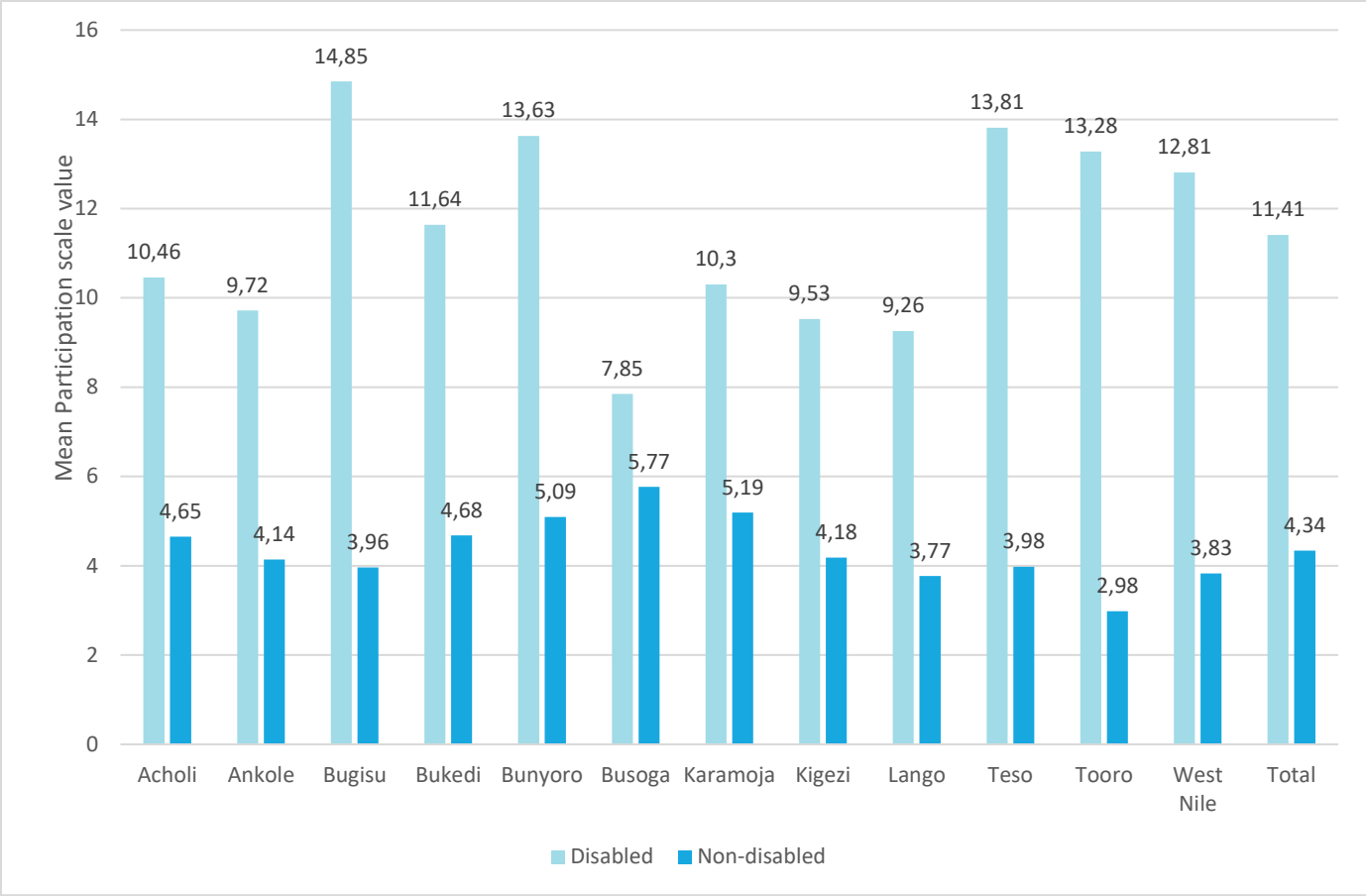



**Figure 13 Mean Participation restrictions by sub-region and disability status (N = 11511)**

### 9.3.4 Impairments

In addition to measuring disability as either *Activity limitations* or *Restrictions in social participation*, respondents were also asked to describe their type of impairment according to 10 pre-defined categories (Table 23). Respondents were allowed to report more than one type of impairment (multiple impairments). The most common impairment is Physical (mobility and movement), followed by Visual (36.6 %) and Hard of Hearing (19.4 %) and Mental disorder (8.6 %). For the three most prevalent impairment types, more females than males confirmed, while more males reported Epilepsy. For the less prevalent impairments, gender differences were not statistically significant.

**Table 23. Impairment type by sex among persons with disabilities (%)**

| Impairment type | Males (N = 3057) | Females (N = 3001) | Total (N = 6058) | $\chi^2$ | p |
|---|---|---|---|---|---|
| Visual | 34.2 | 39.0 | 36.6 | 15.06 | < .001 |
| Hard of hearing | 17.6 | 21.3 | 19.4 | 12.96 | < .001 |
| Deaf | 4.5 | 4.3 | 4.4 | 0.12 | n.s. |
| Blind | 2.8 | 2.6 | 2.7 | 0.26 | n.s. |
| Epilepsy | 3.5 | 2.1 | 2.8 | 10.33 | < .001 |
| Physical (mobility and movement) | 44.0 | 47.3 | 45.6 | 6.60 | .010 |

| Impairment type | Males (N = 3057) | Females (N = 3001) | Total (N = 6058) | $\chi^2$ | p |
|---|---|---|---|---|---|
| Intellectual | 8.0 | 7.5 | 7.8 | 0.64 | n.s. |
| Autism | 0.8 | 0.7 | 0.8 | 0.05 | n.s. |
| Mental disorder | 9.2 | 8.0 | 8.6 | 2.75 | n.s. |
| Albinism | 0.1 | 0.1 | 0.1 | 0.00 | n.s. |
| Other | 8.8 | 8.8 | 8.8 | 0.01 | n.s. |

Mean age varies substantially between the different types of impairments (Table 24). Individuals with visual or physical impairments or who are blind or hard of hearing, mean age is significantly higher than among individuals with other impairment types. There is no age difference between individuals with or without albinism among persons with disabilities (due to low N). For the remaining impairment types, individuals confirming the different impairments are younger than individuals with other impairment types. Highest mean age is found among individuals who are blind, who have visual impairment or physical impairment. Lowest mean age is found among individuals with epilepsy, albinism, mental disorder or intellectual impairment. Age differences indicate that some of the major impairment types such as physical and visual impairment increase with age, while lowest mean age is found for individuals with autism, epilepsy and albinism.

**Table 24. Mean age by impairment type**

| Impairment type | Confirm impairment type (age) | Not confirmed (age) | F | p |
|---|---|---|---|---|
| Visual | 46.9 | 32.0 | 571.94 | < .001 |
| Hard of hearing | 38.9 | 37.1 | 5.33 | .021 |
| Deaf | 28.5 | 37.8 | 37.07 | < .001 |
| Blind | 48.2 | 37.1 | 32.63 | < .001 |
| Epilepsy | 23.0 | 37.9 | 62.25 | < .001 |
| Physical (mobility and movement) | 43.8 | 32.1 | 364.66 | < .001 |
| Intellectual | 25.9 | 38.4 | 115.97 | < .001 |
| Autism | 16.4 | 37.6 | 34.59 | < .001 |
| Mental disorder | 25.8 | 38.5 | 131.13 | < .001 |
| Albinism | 23.8 | 37.4 | 1.85 | n.s. |
| Other | 28.9 | 38.3 | 72.03 | < .001 |

### 9.3.5 Activity limitation by impairment type

Figure 14 shows the scores on the Activity limitation scale by impairment type. Individuals with autism score highest on the scale, followed by individuals with mental disorders and blindness. Individuals with visual impairments (and who are not blind) report lowest mean value on the Activity limitation scale, followed by Albinism and Hard of hearing.

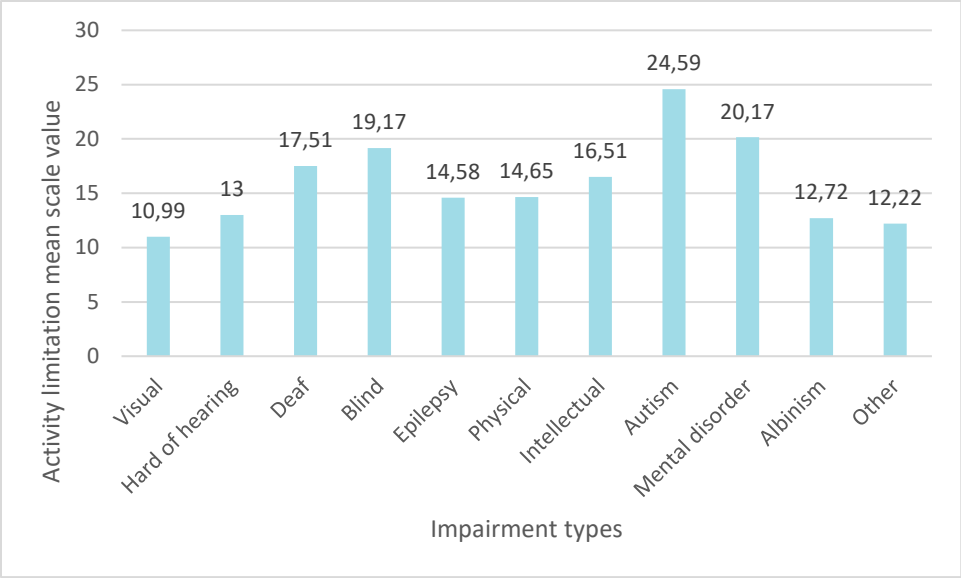



**Figure 14 Activity limitation (0 – 72) by impairment type (N = 6112)**

The majority (69.7 %) of individuals with disabilities have one impairment, while one in five (18.7 %) report two impairments and 6.7 % three or more. More males report one impairment, while more females report two and three ($\chi^2 = 32.62$, $p < .001$) (Table 25).

**Table 25. Number of impairments by sex (%)**

| Number of impairments | Males (N = 3057) | Females (N = 3001) | Total (N = 6058) |
|---|---|---|---|
| 0 | 5.0 | 4.7 | 4.8 |
| 1 | 72.5 | 67.0 | 69.8 |
| 2 | 16.9 | 20.5 | 18.7 |
| 3 | 4.4 | 6.7 | 5.5 |
| 4 | 0.8 | 0.8 | 0.8 |
| 5 | 0.3 | 0.3 | 0.3 |
| 6 | 0.1 | 0.0 | 0.1 |

### 9.3.6 Cause of disability

Disease/illness was reported as cause of the disability by 40.0 % of the respondents, followed by birth/congenital with 27.8 % (Table 26). Together, this is two thirds of the sample, and indicates firstly the exposure to ill health in this population as well as the potential for reducing disability as these high figures at least partly reflect a potential for improvement of health services. Even the accident-related disabilities reported by 11.7 % may indicate a health service-related potential for reduced disability. The difference between males and females ($X^2 = 90.22$, $p < .001$) comprise more reporting from birth/congenital and Accident and fewer Disease/illness and Other reasons among males.

**Table 26. Cause of disability**

| Cause | N | Total % | Male % | Female % |
|---|---|---|---|---|
| From birth/congenital | 1683 | 27.8 | 28.9 | 26.6 |
| Accident including fall, burns and animal related | 720 | 11.7 | 15.3 | 9.2 |
| Disease/illness | 2424 | 40.0 | 37.7 | 42.4 |
| Violence not war-related | 54 | 0.8 | 1.1 | 0.7 |
| War related | 56 | 0.9 | 1.1 | 0.7 |
| Stress related | 19 | 0.3 | 0.3 | 0.4 |
| Witchcraft | 100 | 1.7 | 1.6 | 1.7 |
| Other reasons or do not know | 1002 | 16.5 | 15.0 | 18.2 |
| Total | 6058 | 100.0 | 100.0 | 100.0 |

### 9.3.7 Disability onset

Respondents were asked when their disability started. As can be seen in Table 27, most (46.2 %) stated that it started before 10 years of age, reflecting the high score on "from birth/congenital" on cause of disability (Table 27). Reason for high number of missing values is assumed to be due to respondents not knowing the answer. Missing values were evenly spread between age categories and thus do not affect the percentages much. Except for the high figures for the 0 – 10 years age category, disability onset is spread relatively evenly across the other age categories. The difference between males and females ($\chi^2 = 33.13$, $p < .001$) is due to higher percentage of males reporting 0 – 10 years and 11 – 20 years and higher percentage of females in the age categories above 21 years.

**Table 27. Age of disability onset (N = 4714)**

| Age category | N | Total % | Male % | Female % |
|---|---|---|---|---|
| 0 – 10 years | 2203 | 46.2 | 46.9 | 42.7 |
| 11 – 20 years | 529 | 11.1 | 11.5 | 10.8 |
| 21 – 30 years | 419 | 8.8 | 8.6 | 9.0 |
| 31 – 40 years | 432 | 9.1 | 8.6 | 9.7 |
| 41 – 50 years | 477 | 10-0 | 9.0 | 11.0 |
| 51 – 60 years | 324 | 6.8 | 6.1 | 7.5 |
| 61 + years | 371 | 7.8 | 6.6 | 9.2 |
| Total | 4755 | 100.0 | 100.0 | 100.0 |

Figure 15 reveals a marked increase in mean age with increasing severity ($F = 149.28$, $p < .001$). The increase in impact of disability with age may indicates that older individuals have different types of disabilities, and/or that the impact of disability simply increases with increasing age.

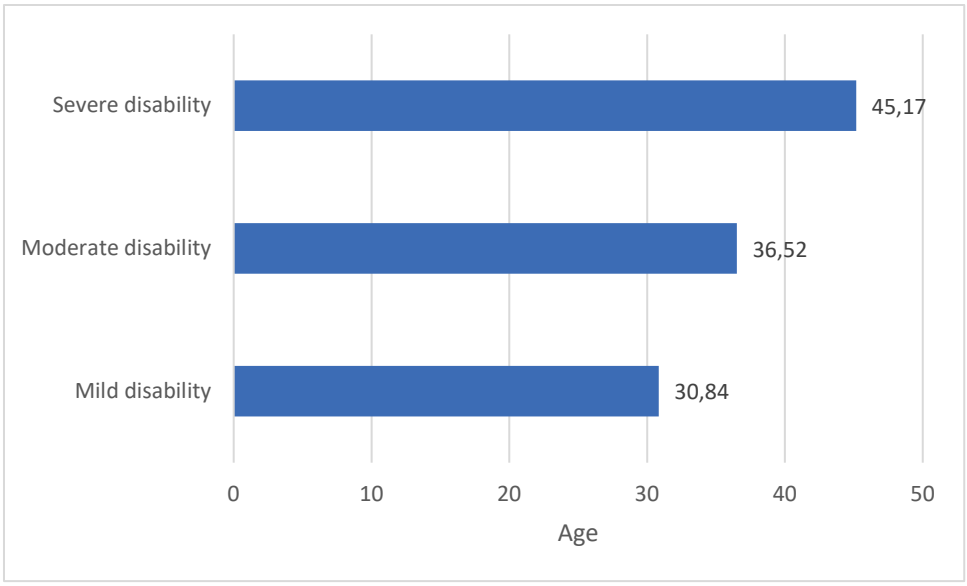



**Figure 15 Mean age by disability severity (N = 5849)**

### 9.3.8 Environmental barriers

Table 28 shows that the most common barriers among individuals with disabilities are Availability and accessibility of transportation, Availability of health care services and medical care and Natural environment. Policies and rules of businesses and organisations, Government programmes and policies and Other people's attitudes at home are the least common barriers. For all items in Table 28, more problems are reported among individuals with disabilities as compared to non-disabled.

**Table 28. Environmental variables by disability status (%) (N = 7817 – 11102)**

| In the past 12 months, how often has ,,,,,, been a problem to you? | | Daily | Weekly | Monthly | Less than monthly | Never | $\chi^2$ p |
|---|---|---|---|---|---|---|---|
| Availability and accessibility of transportation | D[1]<br>ND[2] | 24.5<br>14.6 | 7.5<br>6.8 | 12.9<br>8.2 | 13.0<br>9.1 | 42.0<br>61.3 | 436.02 < .001 |
| Natural environment – temperature, terrain, climate | D<br>ND | 16.7<br>9.5 | 7.4<br>5.5 | 14.1<br>11.6 | 14.1<br>10.8 | 47.7<br>62.6 | 273.35 < .001 |
| Aspects of the surroundings – lightning, noise, crowds | D<br>ND | 11.1<br>5.0 | 4.3<br>3.6 | 9.1<br>4.5 | 9.9<br>7.8 | 65.5<br>79.1 | 299.34 < .001 |
| Information you wanted/needed but could not get | D<br>ND | 12.9<br>5.7 | 4.9<br>2.8 | 8.0<br>5.2 | 11.7<br>9.0 | 62,5<br>77.4 | 314.55 < .001 |
| Availability of health care services and medical care | D<br>ND | 13.9<br>6.2 | 7.6<br>5.5 | 17.3<br>10.5 | 16.4<br>13,4 | 44.8<br>64.3 | 472.70 < .001 |
| Needed someone's help in your home and could not get it | D<br>ND | 11.8<br>4.2 | 5.3<br>3.0 | 10.1<br>5.6 | 12.9<br>8.3 | 59.9<br>70.0 | 495,39 < .001 |

| In the past 12 months, how often has ,,,,,, been a problem to you? | | Daily | Weekly | Monthly | Less than monthly | Never | $\chi^2$ p |
|---|---|---|---|---|---|---|---|
| Needed someone else's help at school/work and could not get it | D<br>ND | 8.9<br>2.9 | 4.7<br>2.8 | 9.7<br>4.8 | 10.3<br>8.8 | 66.6<br>80.8 | 260.77 < .001 |
| Other people's attitudes at home | D<br>ND | 9.9<br>2.4 | 3.5<br>1.7 | 5.6<br>3.1 | 8.5<br>4.6 | 72.5<br>88.2 | 447.62 < .001 |
| Other people's attitudes at school/work | D<br>ND | 10.0<br>2.2 | 4.1<br>2.3 | 7.2<br>3.4 | 9.3<br>6.4 | 69.4<br>85.8 | 372.61 < .001 |
| Prejudice or discrimination | D<br>ND | 9.9<br>1.4 | 3.1<br>1.2 | 7.0<br>2.6 | 10.1<br>6.5 | 69.8<br>88.3 | 617.60 < .001 |
| Policies and rules of businesses and organisations | D<br>ND | 4.8<br>2.5 | 2.2<br>1.3 | 5.2<br>3.3 | 8.3<br>7.9 | 79.5<br>85.0 | 65.15 < .001 |
| Government programs and policies | D<br>ND | 5.1<br>3.3 | 2.5<br>1.5 | 4.8<br>3.1 | 10.3<br>11.0 | 77.3<br>81.1 | 51.95 < .001 |

[1] = Disabled, [2] = Non-disabled

The 12 items in Table 28 were added together (after replacing missing with mean) to form the Environmental Barrier Scale. The range of the scale was from 12 – 60, mean value 20.51 and standard deviation 9.18. Figure 16 shows a breakdown of mean scale values by disability status, location and sex. Firstly, Environmental barriers is, as expected, substantially higher among persons with disabilities as compared to non-disabled individuals ($F = 680.07$, $p < .001$). Secondly, rural respondents report higher level of environmental barriers than urban respondents among both individuals with disabilities ($F = 15.21$, $p < .001$) and individuals without disabilities ($F = 46.96$, $p < .001$). Finally, differences between males and females are generally small and not statistically significant.

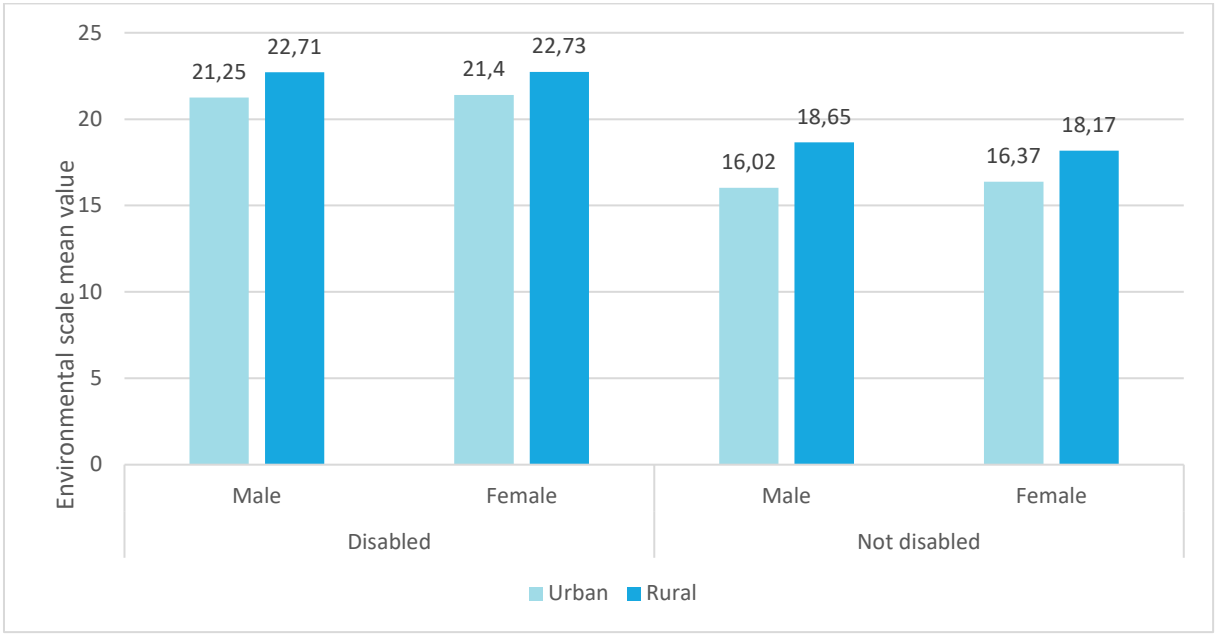



**Figure 16 Environmental barriers by disability status, location and sex (N = 11099)**

As shown in Figure 17, Environmental barriers increase as expected with increasing disability severity (F = 229.03, p < .001), among both rural and urban individuals, with and without disabilities. The somewhat higher level of barriers in rural areas are found at every level of disability severity.

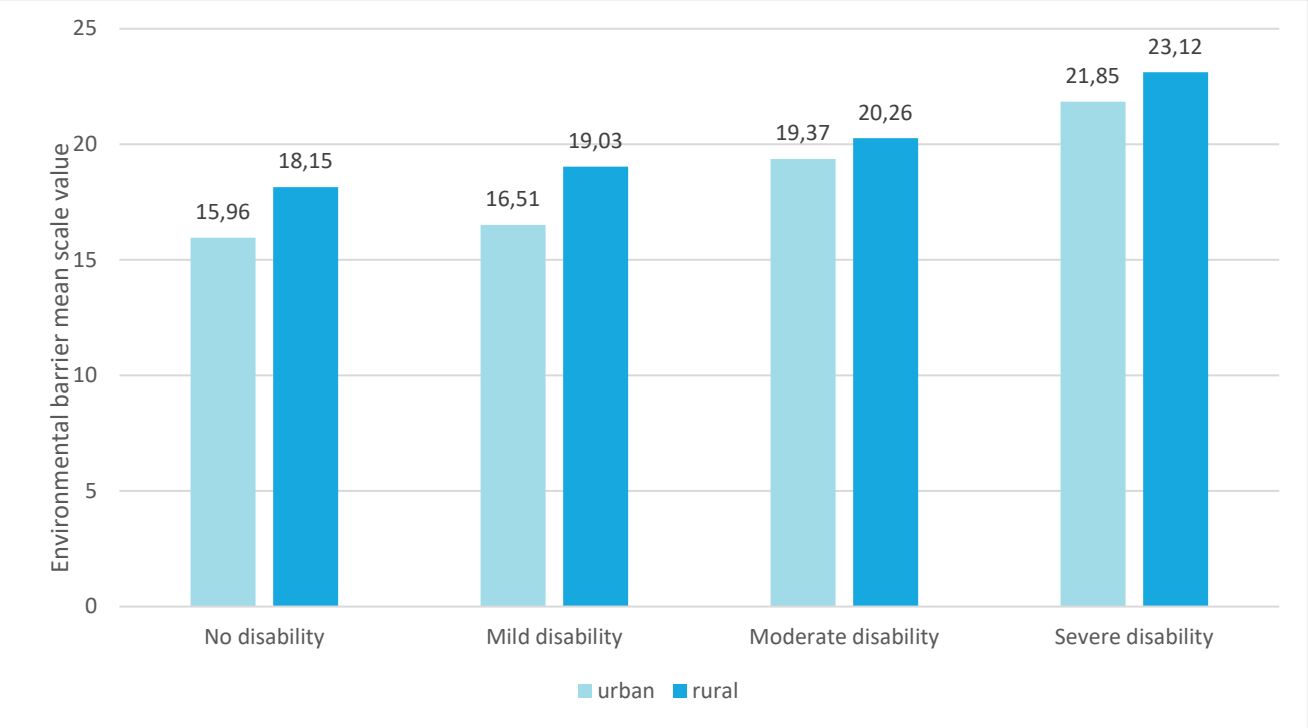



**Figure 17 Environmental barriers by disability severity and location (N = 11503)**

### 9.3.9 Education

Figure 18 below shows that while the majority has accessed formal primary education, there is also a substantial proportion who has never been to school, particularly among rural females where only half of females with disabilities had ever accessed formal primary education. School attendance is highest in urban areas and the urban – rural difference is significant for both individuals with and without disabilities ($\chi^2 = 44.31$, $p < .001$ and $\chi^2 = 19.67$, $p < 001$) and for both males and females ($\chi^2 = 24.08$, $p < .001$ and $\chi^2 = 27.72$, $p < 001$).

The male-female difference is found among persons with disabilities both in urban ($\chi^2 = 26.08$, $p < .001$) and in rural areas ($\chi^2 = 166.95$, $p < .001$), but not among persons without disabilities.

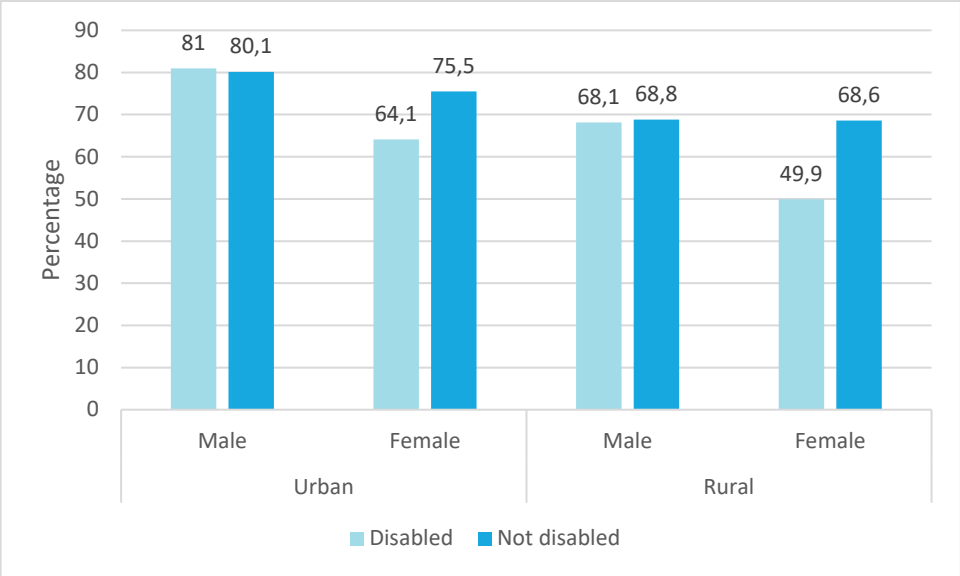



**Figure 18 Accessed formal primary education by disability status, sex and location (age => 5 years) (N = 10034)**

A total of 2.9 % of respondents who had not attended formal primary education reported that they had attended classes to learn how to read and write as an adult. Figure 19 shows that this is more common among non-disabled as compared to individuals with disabilities (total: $\chi^2 = 5.96$, $p = .015$). More rural than urban males with disabilities and more urban than rural females with disabilities have attended adult literacy classes (Figure 19).

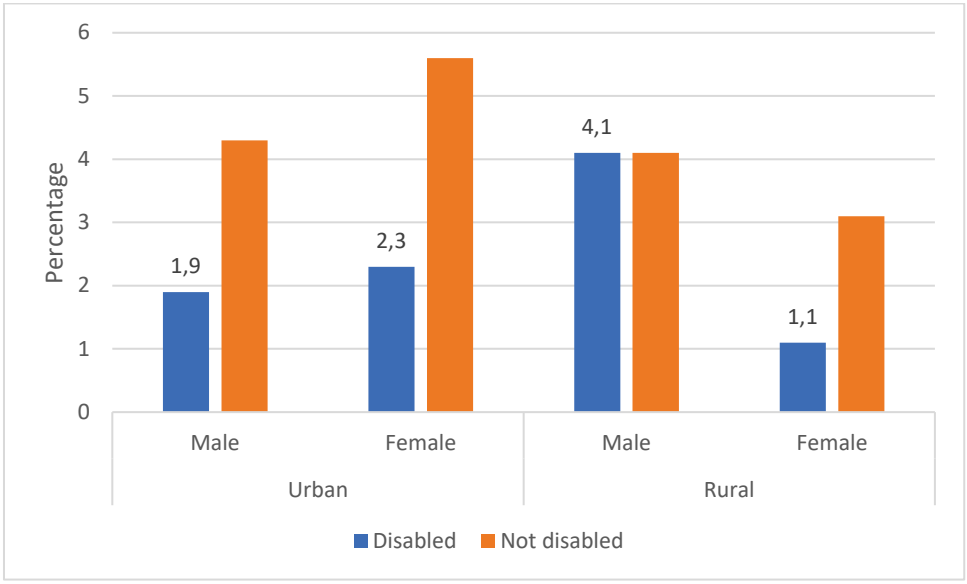



**Figure 19 Attended classes to learn how to read and write as an adult by disability status, sex and location (age => 18 years) (N = 2789)**

School drop-out rates are substantially higher among individuals with than without disabilities (Figure 20). This is particularly dramatic in Primary school and Secondary school. In Primary school, the average drop-out rate for individuals with disabilities is 37.9 % among individuals with disabilities and 13.6 % among non-disabled ($\chi^2 = 235.27$, $p < .001$). In Secondary school, the average drop-out rates for individuals with and without disabilities

are 23.8 % and 2.3 % respectively ($\chi^2$ = 232.47, p < .001). The average drop-out rates for the other school levels/types are Pre-school: 8.5 % vs. 6.3 % ($\chi^2$ = 5.66, p 0 .017), Special class: 3.6 % vs. 1.5 % ($\chi^2$ = 10.08, p = .001) and Tertiary education: 5.9 % vs. 2.9 % ($\chi^2$ = 10.54, p = .001). Drop-out rates are lower among urban males in primary school and among rural females in secondary school. Drop-out rates are higher among rural males in special classes and among urban males in tertiary education.

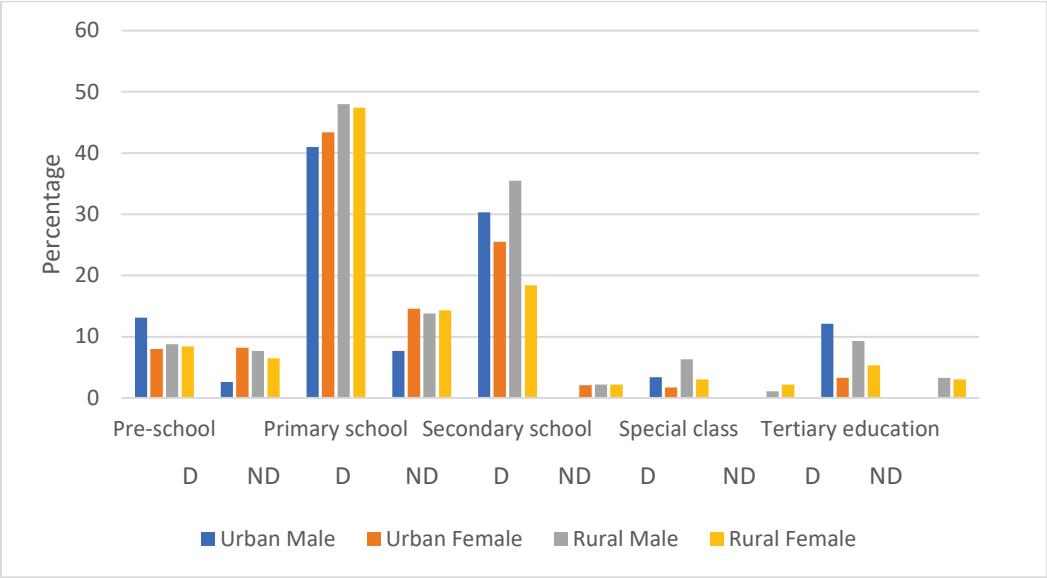



**Figure 20 Drop-out from school by school level, disability status, sex and location (age > 5) ($N_{Pre\text{-}school}$ = 4109, $N_{Primary\ school}$ = 5360, $N_{Secondary\ school}$ = 2777, $N_{Special\ class}$ = 2237, $N_{Tertiary\ education}$ = 1999)**

The main reason for dropping out of school is lack of money (for school fees). This is stated by well over two thirds of the respondents. The second most important reason among persons with disabilities is the disability and among non-disabled it is that getting to school was difficult. Around 5 % of individuals with disabilities state illness as the reason, but this is marginal among non-disabled. Table 29 also reveal that more females with than without disabilities report that they dropped out of school because they got pregnant (Total difference between disabled and non-disabled: $\chi^2$ = 344.58, p < .001); Males with and without disabilities: $\chi^2$ = 208.50, p < .001; Females with and without disabilities: $\chi^2$ = 143.77, p < .001).

**Table 29. Reason for drop out by disability status and sex (%) (N = 2881)**

| | Disabled | | Not disabled | |
|---|---|---|---|---|
| **Stated reason** | **Males** | **Females** | **Males** | **Females** |
| Not enough money | 72.4 | 70.8 | 67.8 | 73.5 |
| Failed school | 3.1 | 2.4 | 3.7 | 2.4 |
| Illness | 5.5 | 5.0 | 0.7 | 0.2 |
| Not interested | 4.2 | 5.4 | 5.3 | 5.3 |
| Disability | 11.9 | 10.0 | 0.6 | 0.5 |
| Difficult to get to school | 2.8 | 2.3 | 21.8 | 16.7 |
| Pregnant | | 4.1 | | 1.2 |

Among individuals with disabilities, more urban respondents state that the reason for drop-out had to do with lack of money, while more rural respondents blamed illness or they were not interested ($\chi^2$ = 17.89, p = .007).

Also, among non-disabled, more urban respondents report lack of money as the reason for drop-out and more rural respondents were not interested. Additionally, substantially more rural respondents found it difficult to get to school and pregnancy was more common in urban than in rural areas as the reason for drop-out (urban-rural difference among non-disabled: $\chi^2 = 22.26$, $p = .001$).

**Table 30. Reasons for drop out by disability status and location (%) (N = 2881)**

| Stated reason | Disabled | | Not disabled | |
|---|---|---|---|---|
| | Urban | Rural | Urban | Rural |
| Not enough money | 77.4 | 71.7 | 82.9 | 71.4 |
| Failed school | 2.3 | 2.9 | 2.6 | 3.0 |
| Illness | 2.6 | 5.9 | 0.0 | 0.6 |
| Not interested | 1.5 | 5.2 | 2.6 | 5.4 |
| Disability | 10.9 | 11.1 | 0.0 | 0.5 |
| Difficult to get to school | 1.9 | 2.6 | 7.9 | 19.8 |
| Pregnant | 3.4 | 1.5 | 3.9 | 0.4 |

Among respondents who had accessed formal primary education, more individuals without disabilities stated that they had not studied as far as planned and more individuals with disabilities were still studying ($\chi^2 = 219.55$, $p < .001$). The same pattern was found among both males ($\chi^2 = 116.21$, $p < .001$) and females ($\chi^2 = 103.51$, $p < .001$).

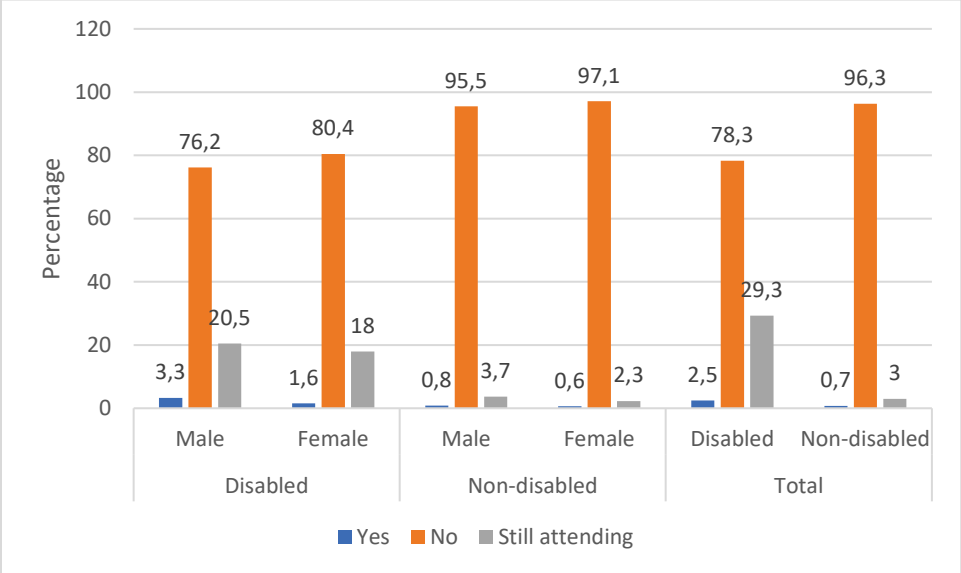



**Figure 21 Studied as far as planned by disability status and sex (%) (N = 6703)**

More individuals with disabilities in rural than in urban areas did not study as far as planned and more urban respondents with disabilities were still studying ($\chi^2 = 22.30$, $p < .001$). The urban – rural difference among non-disabled is marginal (Figure 22).

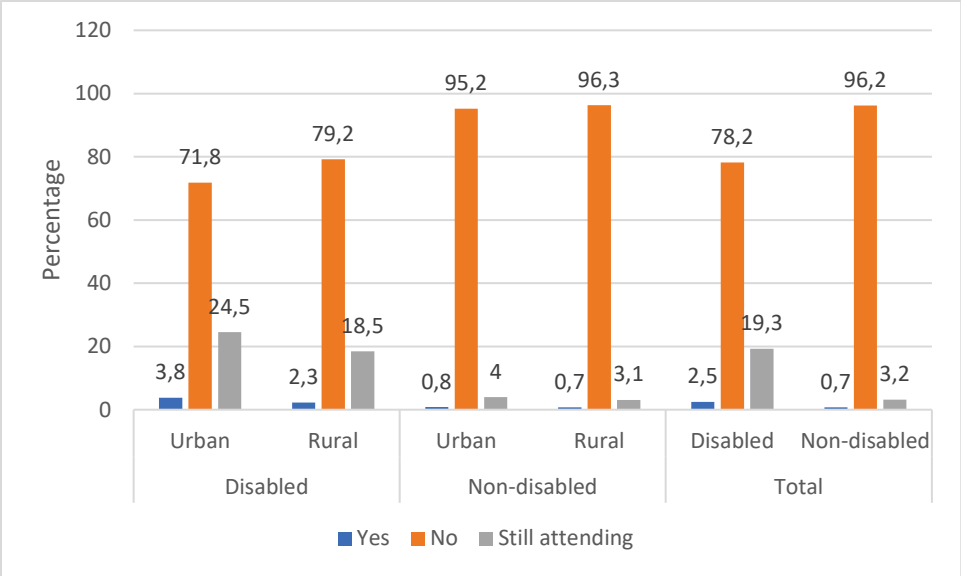



**Figure 22 Studied as far as planned by disability status and location (N = 6846)**

More persons with than without disabilities confirm that their level of education has helped them in getting a job ($\chi^2 = 63.61$, $p < .001$). This is the case among both males ($\chi^2 = 47.27$, $p < .001$) and females ($\chi^2 = 15.81$, $p < .001$). The highest proportion is found among males with disabilities (11.3 %) and lowest among non-disabled females (1.6 %). While a total of 9.3 % of males and 4.5 % of females have been helped by their level of education to get a job ($\chi^2 = 46.48$, $p < .001$), the sex difference is statistically significant only among males ($\chi^2 = 45.32$, $p < .001$) (Figure 23).

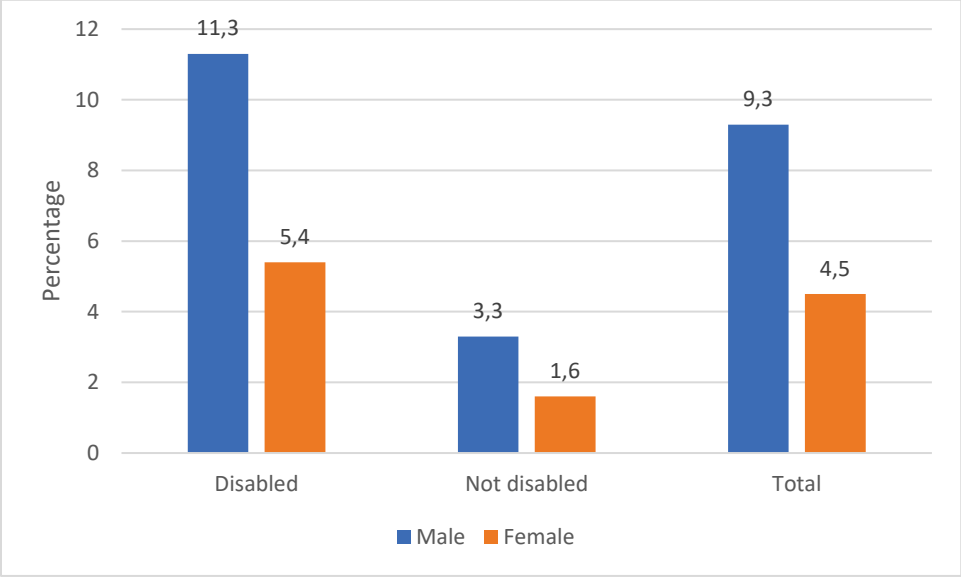



**Figure 23 Education helped in finding work by disability status and sex (N = 5319)**

### 9.3.10 Work

Among individuals with disabilities, more males than females confirm that they are working (including formal employment, casual labour, part-time work and those who are self-employed) ($\chi^2 = 65.75$, $p < .001$). There is

no male-female difference among non-disabled. More individuals with disabilities have never worked (disabled – non-disabled: $\chi^2 = 197.18$, $p < .001$).

**Table 31. Currently work status (%) (N = 8364)**

| Work status | Disabled | | Not disabled | |
|---|---|---|---|---|
| | Male | Female | Male | Female |
| Currently working | 29.7 | 22.7 | 35.5 | 35.5 |
| Worked previously | 11.4 | 8.4 | 6.0 | 4.8 |
| Never worked | 53.5 | 65.2 | 49.4 | 51.7 |
| Still studying | 5.4 | 3.7 | 9.1 | 8.1 |

Respondents who were either working or who had worked previously were asked to state their income per month, which was reported to be UGX 176656 and UGX 176810[5] for individuals with and without disabilities respectively (n.s.). Males with disabilities reported higher income per month than males without disabilities, but the difference was not statistically significant. Females without disabilities have a higher monthly income than females with disabilities and urban respondents without disabilities earn more per month than their rural counterparts.

**Table 32. Income per month (N = 3098)**

| Subject | Mean income in UGX | F | p |
|---|---|---|---|
| Individuals with disabilities | 176 856 | .01 | n.s. |
| Non-disabled | 176 810 | | |
| Males with disabilities | 222 229 | .94 | n.s. |
| Males without disabilities | 179 309 | | |
| Females with disabilities | 124 106 | 11.31 | .001 |
| Females without disabilities | 173 481 | | |
| Urban with disabilities | 247 581 | 2.56 | n.s. |
| Rural with disabilities | 161 786 | | |
| Urban without disabilities | 285 295 | 49.05 | < .001 |
| Rural without disabilities | 176 810 | | |

Among individuals who perceived themselves as being unemployed, most (27.8 %) stated that this was because they had retired, and with illness (24.9 %) as the second most common reason. More individuals without disabilities are retired or state other reasons. Of persons with disabilities, 26.1 % stated that the disability was the reason (disabled vs. non-disabled: $\chi^2 = 90.50$, $p < .001$).

[5] 1 US dollar = 3600 Shillings at the time of the data collection.

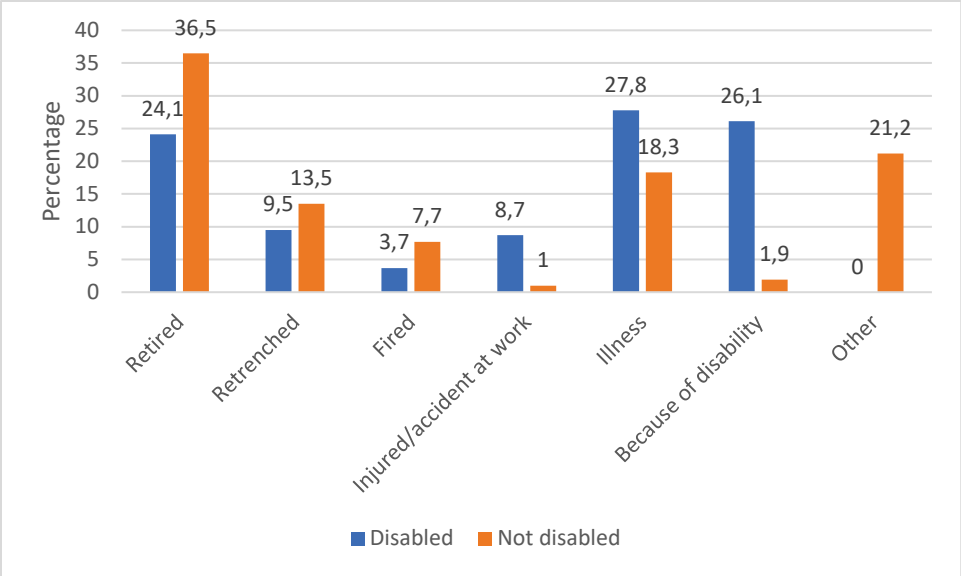



**Figure 24 Reason for being currently unemployed by disability status (N = 345)**

## 9.3.11 Assistive devices

**Table 34. Use of assistive device by sex and location (%) (N = 6058)**

| Location | Male | Female | Total |
|---|---|---|---|
| Do you use an assistive device? | | | |
| Urban | 11,9 | 7.1 | 9.4 |
| Rural | 8.1 | 4.8 | 6.5 |
| Total | 8.6 | 5,2 | 6.9 |

In Figure 25 it is demonstrated that use of assistive devices increases with increasing disability severity ($\chi^2$ = 103.22, p < .001).

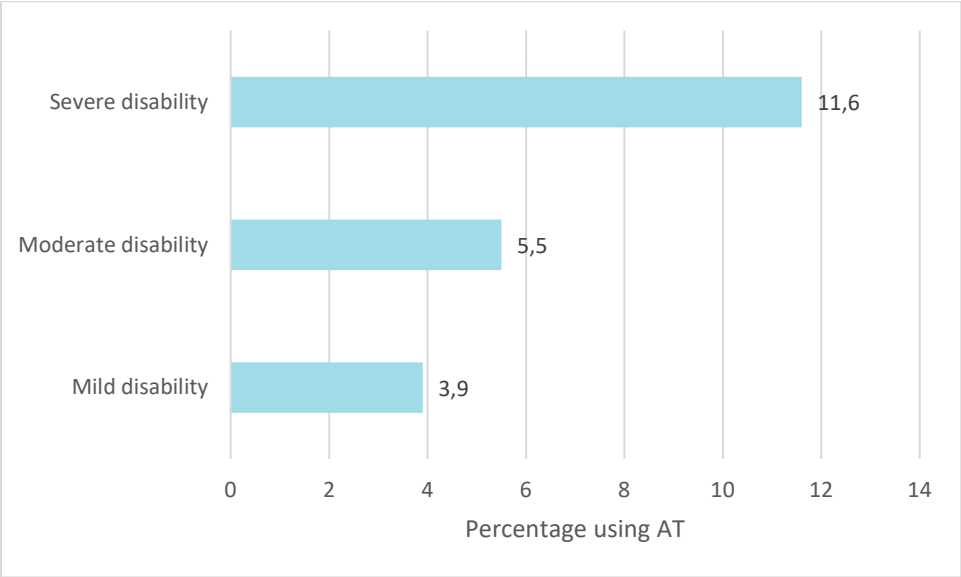



**Figure 25 Use of assistive device by disability severity (N = 405)**

Use of assistive devices increases with increasing age (Males: $\chi^2 = 113.67$, $p < .001$; Females: ($\chi^2 = 52.67$, $p < .001$). Use of assistive devices is more often reported among males than females for six of the seven age categories.

**Table 35. Use of assistive device by age category and sex (%))**

| Age category | Male (N = 3057) | Female (N = 3001) | Total (N = 6058) |
|---|---|---|---|
| 0- 10 years | 2.9 | 1.6 | 2.3 |
| 11-20 years | 3.1 | 3.4 | 3.3 |
| 21–30 years | 5.4 | 2.9 | 4.3 |
| 31-40 years | 9.7 | 2.6 | 6.4 |
| 41-50 years | 13.7 | 7.1 | 10.5 |
| 51-60 years | 10.6 | 5.7 | 8.0 |
| 61 + years | 17.0 | 9.6 | 12.8 |

Table 36 shows that the type of assistive device is dominated by communication and mobility devices. The most common device is Enlarged print, followed by Walking stick and Eyeglasses. Very few report devices within the categories Household items, Personal care and protection and Handling products and goods.

**Table 36. Specified assistive devices among persons who use assistive device (%) (N = 425)**

| Type of device | N | % |
|---|---|---|
| Communication | | |
| Eyeglasses | 105 | 24.7 |
| Hearing aids | 16 | 3.8 |
| Magnifying glass | 5 | 1.2 |
| Telescopic lenses/glasses | 3 | 0.7 |
| Enlarge print | 205 | 48.2 |
| Braille | 4 | 0.9 |
| Sign language interpreter | 13 | 3.1 |
| Personal mobility | | |
| Wheelchair | 49 | 11.5 |
| Crutches | 60 | 14.1 |
| Walking stick | 183 | 43.1 |
| White cane | 15 | 3.5 |
| Guide | 16 | 3.8 |
| Standing frame | 10 | 2.4 |
| Household items | | |
| Flashing light on doorbell | 0 | 0.0 |
| Amplified telephone | 2 | 0.5 |
| Vibrating alarm clock | 1 | 0.2 |
| Personal care and protection | | |
| Special fasteners | 3 | 0.7 |
| Bath and shower seat | 8 | 1.9 |
| Toilet seat raiser | 4 | 0.7 |

| Type of device | N | % |
|---|---|---|
| Commode chair | 3 | 0.7 |
| Safety rails | 1 | 0.2 |
| Eating aid | 1 | 0.2 |
| Handling products and goods | | |
| Gripping tong | 0 | 0.0 |
| Aids for opening containers | 0 | 0.0 |
| Tools for gardening | 1 | 0.2 |
| Computer assistive technology | | |
| Keyboard for the blind | 1 | 0.2 |

Slightly over half of the assistive devices are reported to be in good working condition. The difference between urban and rural respondents is marginal.

**Table 37. Working condition of main device by location (%) (N = 413)**

| Working condition | Urban (N = 76) | Rural (N = 349) | Total (N = 425) |
|---|---|---|---|
| Good | 50.0 | 54.0 | 53.5 |
| Not good | 50.0 | 46.0 | 46.7 |

Most respondents who confirm that they use an assistive device state "Private" as source of the device. This category covers when the person with disability has bought the device him/herself, it has been bought privately or donated/given by someone else in the family or a person who are not member of the family. Government services have provided around one in ten of the devices in question, and NGOs even less. The "Other" category is the second largest, indicating most likely that individuals often do not know where the device comes from. There are some minor differences between urban and rural respondents on this question, but not sufficient to reach statistical significance.

**Table 38. Source of assistive device by location (%)**

| Source | Urban (N = 76) | Rural (N = 349) | Total (N = 425) |
|---|---|---|---|
| Private | 64.5 | 67.0 | 66.6 |
| Government health services | 7.9 | 9.5 | 9.2 |
| Other Government services | 3.9 | 0.9 | 1.4 |
| NGO | 9.2 | 6.0 | 6.6 |
| Other or do not know | 14.5 | 16.6 | 16.2 |

The large majority report that they maintain the assistive device themselves, while quite a number (17.2 %) say that the device is not maintained. More than one in ten state that a family member does the maintenance. Government services and NGOs are marginal when it comes to maintenance. There are some differences between urban and rural respondents, most notable that maintenance by a family member is clearly more common in rural areas ($\chi^2 = 12.54$, $p = .084$).

**Table 39. Maintenance of assistive device by location (%)**

| Who maintains the device | Urban (N = 76) | Rural (N = 349) | Total (N = 425) |
|---|---|---|---|
| Self | 65.8 | 64.5 | 64.7 |
| Government | 1.3 | 1.7 | 1.6 |
| Family | 3.9 | 13.5 | 11.8 |
| NGO | 2.6 | 0.6 | 0.9 |
| Not maintained | 19.7 | 16.7 | 17.2 |
| Other or do not know | 6.6 | 3.1 | 3.6 |

Close to half of the respondents say that they have received no information or training in how to use their assistive device, while slightly more than one in four have received some information (26.3 %) or complete/full information (23.9 %). More urban than rural respondents have received complete/full information and more rural than urban respondents have received no information ($\chi^2 = 14.87$, $p = .002$).

**Table 40. Information and training in use of assistive device by location (%)**

| Level of information/training | Urban (N = 76) | Rural (N = 349) | Total (N = 425) |
|---|---|---|---|
| Complete/full information | 41.1 | 20.2 | 23.9 |
| Some information | 23.3 | 27.0 | 26.3 |
| No information | 35.6 | 52.8 | 49.8 |

More than half of the respondents are either not content or less content with their assistive device (22.5 % and 33.1 %), while as few as 17 % are very content. More respondents in urban than in rural areas are very content (28.0 % vs. 14.6 %) and more rural than urban respondents are less content (35.1 % vs. 24.0 %). Taken together, rural respondents are less content than their urban counterparts ($\chi^2 = 9.80$, $p = .020$). The difference between males and females was marginal.

**Table 41. Satisfaction with assistive device by location (%)**

| Level of satisfaction | Urban (N = 75) | Rural (N = 342) | Total (N = 417) |
|---|---|---|---|
| Not content | 25.3 | 21.9 | 22.5 |
| Less content | 24.0 | 35.1 | 33.1 |
| Content | 22.7 | 28.4 | 27.3 |
| Very content | 28.0 | 14.6 | 17.0 |

The more satisfied persons with disabilities are with their assistive device, the lower the score on Acitivity limitations (disability severity) ($F = 2.73$, $p = .044$). This association is however only significant for females ($F = 2.98$, $p = .034$).

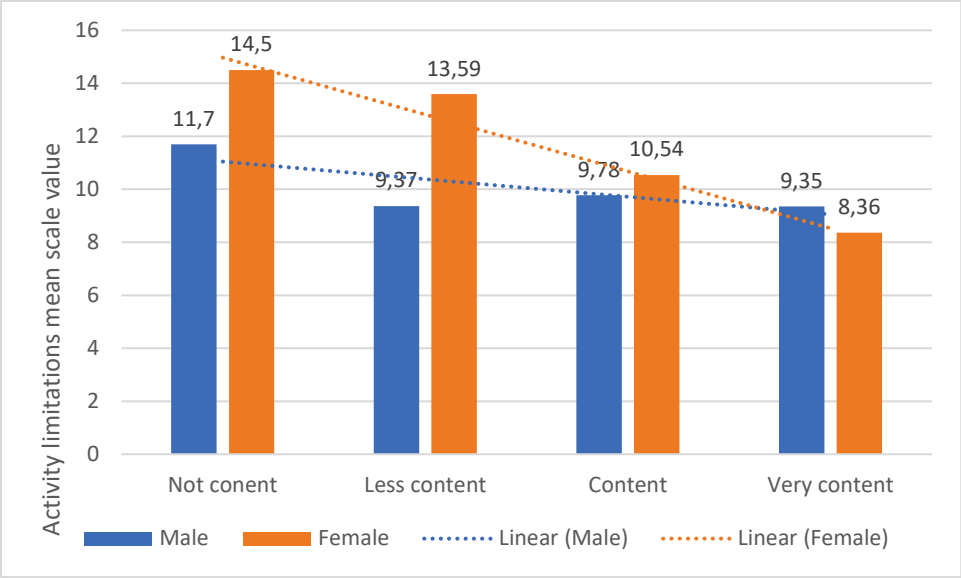



**Figure 26 Satisfaction with main assistive device by activity limitation and sex (N = 405)**

### 9.3.12 Abuse and violence

A total of 12.4 % of disabled persons in urban areas and 7.1 % in rural areas have experienced being beaten by a family member due to their disability ($\chi^2 = 24.31$, $p < .001$). The urban – rural difference is 6.1 percentage points among males ($\chi^2 = 15.58$, $p < .001$) and 7.6 percentage points among females ($\chi^2 = 10.66$, $p < .001$). The difference between males and females is marginal and not statistically significant.

More persons with disabilities report that they have been beaten and scolded by a non-family member: 19.7 % in urban areas and 12.5 % in rural areas ($\chi^2 = 29.58$, $p < .001$). The difference in percentage points between urban and rural respondents is 11.6 among males ($\chi^2 = 28.38$, $p < .001$) and 4.8 among females ($\chi^2 = 7.66$, $p = .005$). More males than females have experienced being beaten or scolded by a non-family member in urban areas ($\chi^2 = 5.66$, $p = .022$) but not in rural areas. Overall difference between males and females in this question (urban and rural combined) is 8.3 percentage points ($\chi^2 = 3.76$, $p = .05$).

In urban areas, 15.5 % of respondents say that they have experienced being discriminated by public services due to their disability, while the corresponding figure for rural areas is 14.5 % (n.s.). There are small and non-significant difference between urban and rural areas among both males and females. Difference between males and females is marginal in both urban and rural areas.

**Table 42. Abuse and discrimination due to the disability (%)**

| Form of abuse | Males | | Females | | Total | |
|---|---|---|---|---|---|---|
| | Urban | Rural | Urban | Rural | Urban | Rural |
| Beaten or scolded by a family member (N=5746) | 13.3 | 7.2 | 11.6 | 7.0 | 12.4 | 7.3 |
| Beaten or scolded by a non-family member (N=5675) | 23.4 | 12.8 | 16.5 | 11.7 | 19.7 | 12.5 |
| Discriminated in any public service (N=5618) | 16.3 | 15.5 | 14.8 | 13.2 | 15.5 | 14.5 |

Figure 27 reveals that the disability is more severe among those who confirm that they have been exposed to abuse/discrimination (Abused by family member: $F = 28.97$, $p < .001$; Abused by non-family member: $F = 17.26$, $p < .001$; Discriminated by public service: $F = 71.76$, $p < .001$).

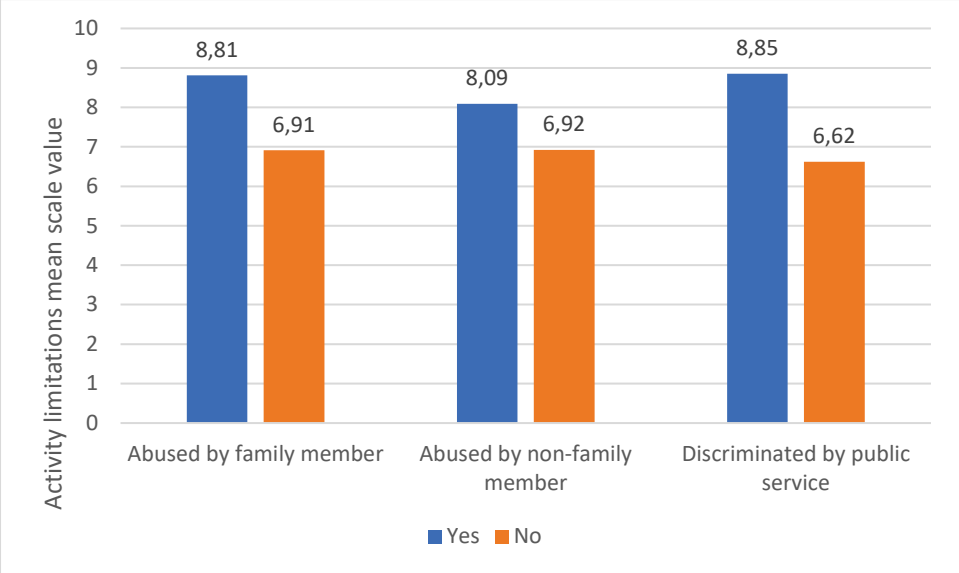



**Figure 27 Abuse and discrimination by disability severity (N = 5569, 5501 and 5456)**

## 9.3.13 Accessibility

Accessibility to different rooms within a house at home is a problem for relatively few persons with disabilities, ranging from 4.1 % to 5.9 % for the different rooms/facilities. For 8.2 % of the respondents, toilet is not available. Urban – rural differences were relatively small, but fewer rural dweller reported living room to be accessible.

**Table 43. Accessibility of rooms/facilities in the home (%) (N = 6112)**

| Room | Yes, accessible | | Not accessible | | Not available | |
|---|---|---|---|---|---|---|
| | Urban | Rural | Urban | Rural | Urban | Rural |
| Kitchen | 87.5 | 89.6 | 4.4 | 6.0 | 8.1 | 4.4 |
| Bedroom | 94.7 | 92.2 | 3.8 | 4.2 | 1.5 | 3.6 |
| Living room | 74.2 | 65-8 | 4.0 | 5.2 | 21.7 | 29.0 |
| Dining room | 40.9 | 41.5 | 5.4 | 5.7 | 53.7 | 52.8 |
| Toilet | 88.3 | 85.5 | 5.2 | 6.0 | 6.5 | 8.5 |

Accessibility and availability are more problematic outside the home, as shown in Table 44. Most of the facilities are not accessible for 14 – 20 % of the respondents, with Police station, Recreational facilities, and Magistrate courts as most inaccessible. For most of the facilities, more rural respondents report that the facilities are not accessible. For all facilities, more rural than urban respondents report that the facility is not available, with the largest difference in percentage points found for recreational facilities, magistrates office and hotels.

**Table 44. Accessibility of facilities in the community (%) (N = 6112)**

| Facility | Yes, accessible | | Not accessible | | Not available | |
|---|---|---|---|---|---|---|
| | Urban | Rural | Urban | Rural | Urban | Rural |
| Workplace | 42.4 | 37.9 | 6.6 | 8.0 | 51.2 | 54.0 |
| School | 41.1 | 34.9 | 7.2 | 9.3 | 51.7 | 55.7 |
| Shops | 85.6 | 79.5 | 10.4 | 14.3 | 3.9 | 6.2 |
| Place of worship | 89.9 | 88.6 | 8.5 | 8.9 | 1.6 | 2.5 |
| Recreational facilities | 66.1 | 49.1 | 19.3 | 21.3 | 14.6 | 29.6 |
| Sports facilities | 74.7 | 61.6 | 15.7 | 19.5 | 9.6 | 18.9 |
| Police station | 84.3 | 65.3 | 11.3 | 23.4 | 4.4 | 16.3 |
| Magistrates office | 55.5 | 41.8 | 19.0 | 21.4 | 26.5 | 36.8 |
| Post office | 36.1 | 23.5 | 18.2 | 17.1 | 45.8 | 59.3 |
| Bank | 56.9 | 32.1 | 18.5 | 19.3 | 24,5 | 48.6 |
| Hospital | 84.9 | 68.5 | 9.6 | 16.1 | 5.5 | 15.3 |
| Primary health care | 80.6 | 78.3 | 9.3 | 14.6 | 10.1 | 7.1 |
| Public transport | 86.5 | 74.7 | 10.9 | 17.7 | 2.6 | 7.6 |
| Hotels | 55.7 | 38.7 | 16.9 | 16.7 | 27.4 | 44.7 |

### 9.3.14 Health

More individuals with disabilities report that they have 10 out of 13 health conditions. More non-disabled confirm one of the 13 conditions, while there is no difference for two of the health conditions.

**Table 45. Health conditions among individuals with and without disabilities (N = 11511)**

| Health condition | Disabled | Non-disabled | Total | Disabled - Nondisabled $\chi^2$ | p |
|---|---|---|---|---|---|
| Heart problem | 7.6 | 4.1 | 6.0 | 60.46 | < .001 |
| Acute respiratory infection | 3.0 | 2.0 | 2.5 | 12.31 | < .001 |
| Asthma | 1.8 | 1,5 | 1.6 | .95 | n.s. |
| Epilepsy | 3.3 | 0.3 | 1.9 | 141.13 | < .001 |
| Cancer | 0.9 | 0.3 | 0.6 | 13.82 | < .001 |
| Diabetes | 2.6 | 1.5 | 2.1 | 19.25 | < .001 |
| Malfunction of kidney | 2.6 | 1.1 | 1.9 | 34.11 | < .001 |
| Cirrhosis of liver | 0.4 | 0.9 | 0.6 | 10.89 | .001 |
| High or low blood pressure | 9.9 | 5.3 | 7.7 | 83.71 | < .001 |
| HIV/AIDS | 4.7 | 3.2 | 4.0 | 16.41 | < .001 |
| Malaria | 20.1 | 20.2 | 20.1 | .01 | n.s. |
| Tuberculosis | 1.8 | 1.1 | 1.5 | 12.39 | < .001 |
| Mental illness | 5.8 | 0.4 | 3.3 | 263.03 | < .001 |

Among individuals with disabilities, more females report that they have five of the 13 health conditions (Table 46). Among individuals without disabilities, more males report three of the listed conditions, while females are higher on one condition. Thus, while morbidity is generally higher among persons with disabilities, it is higher among females vs. males with disabilities and higher among males vs. females without disabilities.

**Table 46. Health conditions among individuals with and without disabilities by sex (N = 11099)**

| Health condition | Disabled | | Non-disabled | | Male-female difference | | | |
|---|---|---|---|---|---|---|---|---|
| | | | | | Disabled | | Non-disabled | |
| | Males | Females | Males | Females | $X^2$ | p | $X^2$ | p |
| Heart problem | 5.5 | 9.7 | 4.2 | 4.2 | 38.03 | < .001 | 0.00 | n.s. |
| Acute respiratory infection | 2.1 | 3.9 | 1,6 | 2.4 | 17.57 | < .001 | 3.88 | .049 |
| Asthma | 1.5 | 2.0 | 1.4 | 1.6 | 2.77 | n.s. | 0.33 | n.s. |
| Epilepsy | 3.5 | 3.0 | 0.2 | 0.3 | 1.55 | n.s. | 0.86 | n.s. |
| Cancer | 0.7 | 1.0 | 0.4 | 0.2 | 1.40 | n.s. | 0.81 | n.s. |
| Diabetes | 1.8 | 3.5 | 1.8 | 1.3 | 16.45 | < .001 | 2.56 | .068 |
| Malfunction of kidney | 2.8 | 2.4 | 1.1 | 1.1 | 1.37 | n.s. | 0.05 | n.s. |
| Cirrhosis of liver | 0.3 | 0.4 | 0.7 | 1.0 | 0.45 | n.s. | 1.20 | n.s. |
| High or low blood pressure | 5.8 | 14.1 | 6.0 | 4.8 | 116.30 | < .001 | 3.53 | .061 |
| HIV/AIDS | 4.8 | 4.6 | 3.6 | 2.4 | 0.07 | n.s. | 5.36 | .021 |
| Malaria | 18.6 | 21.8 | 20.4 | 19.9 | 9.70 | .002 | 0.18 | n.s. |
| Tuberculosis | 1.9 | 1.8 | 1.0 | 1.2 | 0.08 | n.s. | 0.21 | n.s. |
| Mental illness | 6.0 | 5.3 | 0.3 | 0.5 | 1.22 | n.s. | 1.47 | n.s. |

For five of the 13 health conditions, morbidity is higher among individuals with than without disabilities in urban areas, while for one condition (malaria), morbidity is higher in rural areas. Among non-disabled individuals, morbidity is higher in urban areas while for malaria, it is higher in rural areas.

**Table 47. Health conditions among individuals with and without disabilities by location (N = 11511)**

| Health condition | Disabled | | Non-disabled | | Urban-rural difference | | | |
|---|---|---|---|---|---|---|---|---|
| | | | | | Disabled | | Non-disabled | |
| | Urban | Rural | Urban | Rural | $X^2$ | p | $X^2$ | p |
| Heart problem | 9.6 | 7.3 | 3.8 | 4.2 | 5.25 | .027 | 0.20 | n.s. |
| Acute respiratory infection | 4.3 | 2.8 | 2.1 | 2.0 | 5.31 | .027 | 0.09 | n.s. |
| Asthma | 2.1 | 1.7 | 2.1 | 1.4 | 0.61 | n.s. | 2.03 | n.s. |
| Epilepsy | 2.6 | 3.4 | 0.1 | 0.3 | 1.50 | n.s. | 0.54 | n.s. |
| Cancer | 1.2 | 0.8 | 0.0 | 0.4 | 1.58 | n.s. | 2.56 | n.s. |
| Diabetes | 5.0 | 2.3 | 2.3 | 1.3 | 21.06 | < .001 | 3.68 | .063 |
| Malfunction of kidney | 2.1 | 2.7 | 1.0 | 1.1 | 0.99 | n.s. | 0.10 | n.s. |
| Cirrhosis of liver | 1.3 | 0.2 | 0.1 | 1.0 | 23.77 | < .001 | 4.83 | .025 |
| High or low blood pressure | 13.1 | 9.4 | 7.1 | 5.0 | 11.13 | .001 | 5.13 | .030 |

| Health condition | Disabled | | Non-disabled | | Urban-rural difference | | | |
|---|---|---|---|---|---|---|---|---|
| | | | | | Disabled | | Non-disabled | |
| | Urban | Rural | Urban | Rural | $X^2$ | p | $X^2$ | p |
| HIV/AIDS | 5.3 | 4.6 | 3.3 | 3.2 | 0.80 | n.s. | 0.17 | n.s. |
| Malaria | 16.7 | 20.7 | 15.3 | 20.9 | 7.22 | .007 | 11.56 | .001 |
| Tuberculosis | 2.5 | 1.8 | 1.4 | 1.0 | 1.90 | n.s. | 1.03 | n.s. |
| Mental illness | 4.9 | 5.9 | 0.1 | 0.4 | 1.35 | n.s. | 1.41 | n.s. |

The 13 health conditions in Tables 45 - 47 were recoded (0 = no, 1 = yes) and added together to a variable on the number of health conditions. In Figure 26 it is shown a clear difference between the two groups in that more individuals without disabilities report no health conditions, while more individuals with disabilities report that they have one health condition or more ($\chi^2 = 228.78$, $p < .001$).

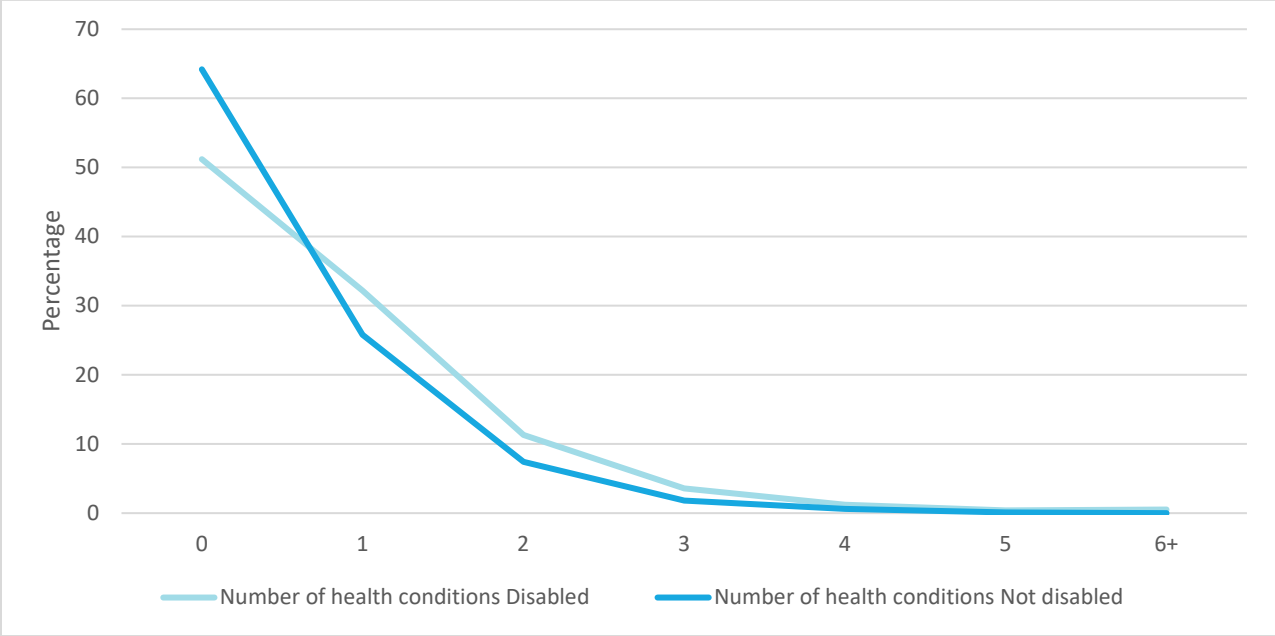



**Figure 28 Number of health conditions by disability status (N = 11511)**

## 9.3.15 Anxiety and depression

The General Health Questionnaire (GHQ) (Goldberg 1970) is a well-known instrument for measuring minor psychological distress. The version with 12 items was included in the current study. The questions asked were: Over the past few weeks – have you ……(item), all with four answer categories as shown in Table 48. For all 12 items, persons with disabilities report clearly more negative experiences, thus revealing more psychological distress than non-disabled.

**Table 48. GHQ12 items among individuals with and without disabilities (%) (N = 11511)**

| Item | Categories | Disabled | Non-disabled | $\chi^2$ | p |
|---|---|---|---|---|---|
| Been able to concentrate on what you are doing? | More so than usual | 11.0 | 23.4 | 860.80 | < .001 |
| | Same as usual | 64.3 | 70.0 | | |
| | Less so than usual | 18.4 | 5.7 | | |
| | Much less than usual | 6.2 | 0.9 | | |

| Item | Categories | Disabled | Non-disabled | $\chi^2$ | p |
|---|---|---|---|---|---|
| Lost much sleep over worry? | Not at all | 42.1 | 58.5 | 511.87 | < .001 |
| | Same as usual | 28.1 | 27.9 | | |
| | Less so than usual | 20.1 | 10.6 | | |
| | Much more than usual | 9.7 | 3.0 | | |
| Felt you were playing a useful part in things? | More so than usual | 10.8 | 20.9 | 717.92 | < .001 |
| | Same as usual | 61.1 | 69.3 | | |
| | Less so than usual | 20.7 | 8.0 | | |
| | Much less than usual | 7.4 | 1.8 | | |
| Felt capable of making decisions about things? | More so than usual | 11.7 | 21.1 | 639,38 | < .001 |
| | Same as usual | 60.1 | 68.3 | | |
| | Less so than usual | 20.3 | 8.4 | | |
| | Much less than usual | 7.9 | 2.2 | | |
| Felt constantly under strain? | Not at all | 37.7 | 55.8 | 658.89 | < .001 |
| | No more than usual | 28.7 | 29.8 | | |
| | Rather more than usual | 21.9 | 11.3 | | |
| | Much more than usual | 11.6 | 3.2 | | |
| Felt you couldn't overcome your difficulties? | Not at all | 37.2 | 54.9 | 635.43 | < .001 |
| | No more than usual | 31.1 | 31.6 | | |
| | Rather more than usual | 20.7 | 10.6 | | |
| | Much more than usual | 11.0 | 3.0 | | |
| Been able to enjoy your day today activities? | More so than usual | 8.8 | 18.1 | 803.71 | < .001 |
| | Same as usual | 60.0 | 70.9 | | |
| | Less so than usual | 22.4 | 9.2 | | |
| | Much less than usual | 8.7 | 1.8 | | |
| Been able to face up to your problems? | More so than usual | 8.0 | 16.7 | 718.47 | < .001 |
| | Same as usual | 58.0 | 69.5 | | |
| | Less so than usual | 24.9 | 10.9 | | |
| | Much less than usual | 9.1 | 2.9 | | |
| Been feeling unhappy and depressed? | Not at all | 37.7 | 56.9 | 694.91 | < .001 |
| | No more than usual | 30.5 | 30.2 | | |
| | Rather more than usual | 21.7 | 10.3 | | |
| | Much more than usual | 10.1 | 2.6 | | |
| Been losing confidence in yourself? | Not at all | 48.4 | 67.5 | 637.12 | < .001 |
| | No more than usual | 25.3 | 22.9 | | |
| | Rather more than usual | 17.2 | 7.5 | | |
| | Much more than usual | 9.1 | 2.1 | | |
| Been thinking of yourself as worthless? | Not at all | 50.9 | 69.0 | 608.33 | < .001 |
| | No more than usual | 23.2 | 21.5 | | |
| | Rather more than usual | 17.2 | 7.6 | | |
| | Much more than usual | 8.6 | 1.9 | | |
| Been feeling reasonably happy? | More so than usual | 12.3 | 20.8 | 604.72 | < .001 |
| | Same as usual | 62.5 | 70.4 | | |
| | Less so than usual | 17.3 | 7.1 | | |
| | Much less than usual | 7.8 | 1.8 | | |

The 12 items in Table 48 were added together to form a Psychological distress scale. Range of the scale was 12 – 46, mean value 23.24 and standard deviation 6.97. Figure 29 shows that females score somewhat higher on Psychological distress than males (F = 5.52, p = .019). The urban – rural difference is marginal (not significant). Individuals with disabilities score substantially higher (more psychological distress) than their non-disabled counterparts (F = 1414.21, p < .0019.

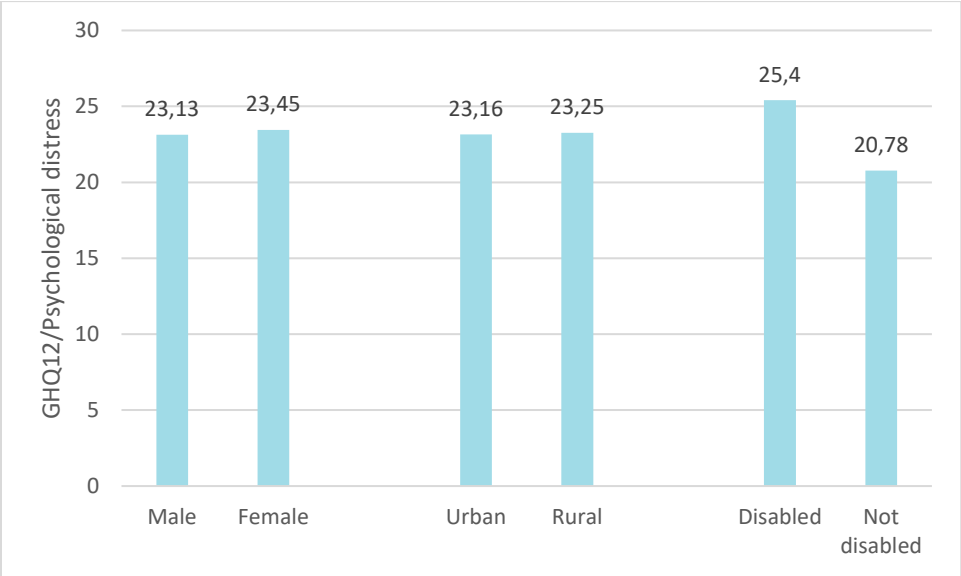



**Figure 29 Psychological distress (GHQ12) by sex, location and disability status (N = 11511, 11099, 11511)**

Psychological distress increases with disability severity (Figure 30) ($\chi^2$ = 534,04, p < .001). While this pattern is the same for males and females, the small difference in level of psychological distress between males and females shown in Figure 30 is also demonstrated at each level of disability severity in Figure 28.

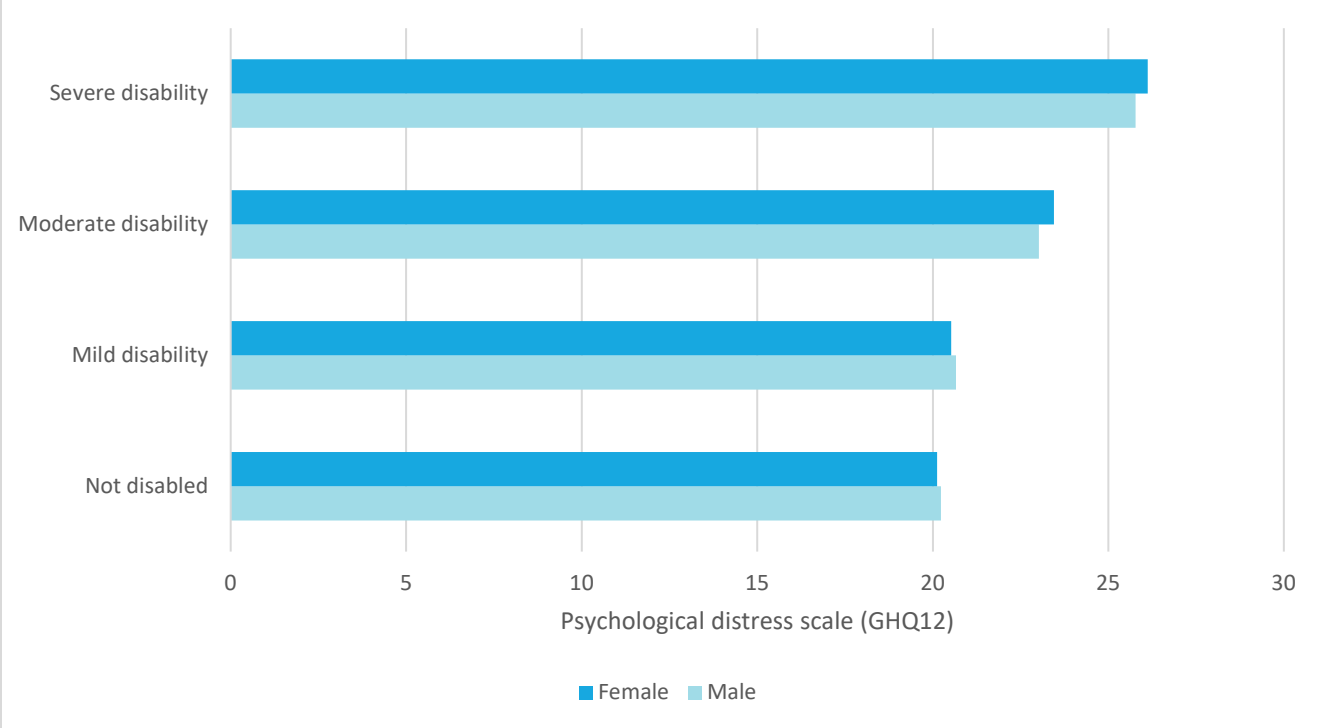


**Figure 30 Psychological distress by disability severity and sex (N = 11091)**

The large majority of non-disabled individuals report either good or very good health, while more than half of individuals with disabilities report either not very good or poor health. Individuals with disabilities report clearly worse physical health than non-disabled ($\chi^2 = 2641.98$, $p < .001$), among both males ($\chi^2 = 1476.09$, $p < .001$) and females ($\chi^2 = 1175.15$, $p < .001$). Disabled women report somewhat better physical health than disabled males ($\chi^2 = 20.81$, $p < .001$), while the sex difference is marginal among non-disabled.

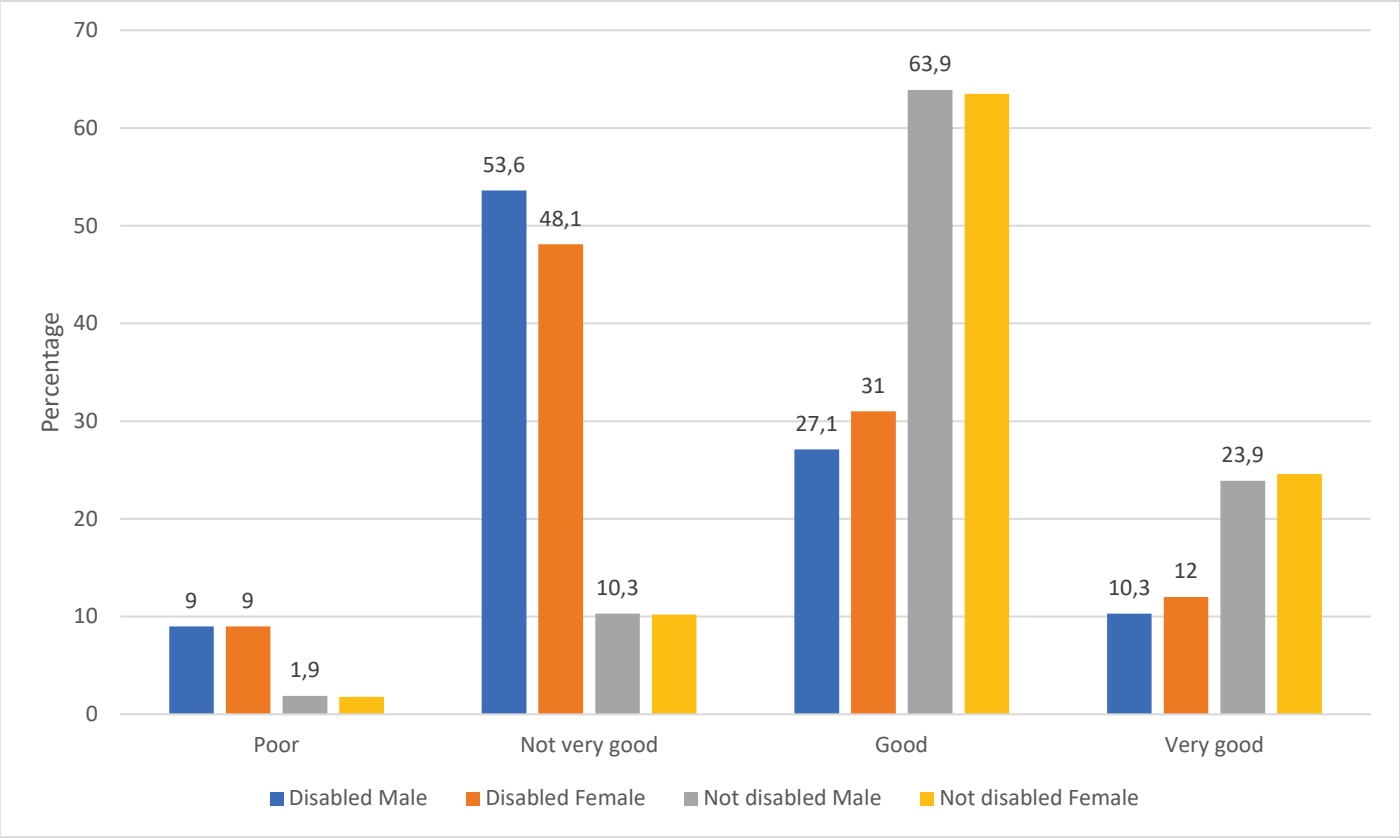



**Figure 31 General physical health by disability status and sex (N = 11049)**

Individuals with disabilities report clearly worse mental health than non-disabled ($\chi^2 = 4334.38$, $p < .001$), among both males ($\chi^2 = 2318.33$, $p < .001$) and females ($\chi^2 = 2022.33$, $p < .001$). Among persons with disabilities, males report slightly worse mental health than females ($\chi^2 = 8.77$, $p = .032$).

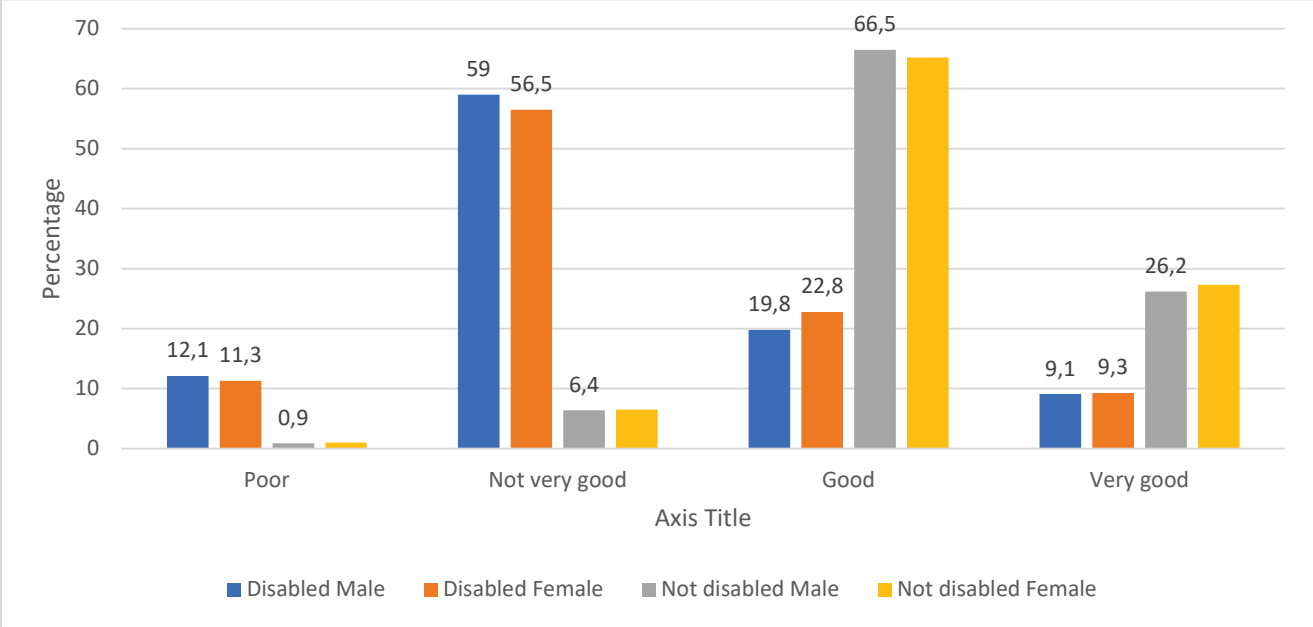



**Figure 32 General mental health by disability status and sex (N = 11005)**

### 9.3.16 Use of medication

Respondents with disabilities were asked whether they use any type of medicine (modern or traditional) for pain that was caused by their disability. All-together, 43.6 % of the respondents (males and females combined) confirmed. There were small and insignificant overall differences between males and females and between urban and rural respondents. However, the difference between urban and rural males was more marked ($\chi^2$ = 3.92, p = .052).

Concerning type of medicine, the large majority reported to use modern medicine only, few used traditional medicine only, while close to one in four combined the two. In urban areas, more males used modern medicines only, while more females combined modern and traditional medicine ($\chi^2$ = 13.42, p < .001). In rural areas and for the total sample, gender differences were marginal. Overall (males and females combined), more rural respondents reported to combine types of medicine while more urban respondents used modern medicine only ($\chi^2$ = 11.08, p = .004). A more or less similar difference was found both among males ($\chi^2$ = 13.83, p = .001) and females ($\chi^2$ = 9.41, p = .009), although Table 33 reveals lower use of traditional medicine among urban males only.

**Table 33. Use of medicine for pain that is caused by the disability by sex (%)**

| Location | Male | Female | Total |
|---|---|---|---|
| Use any type of medicine (N = 6058) | | | |
| Urban | 48,3 | 43,5 | 45.7 |
| Rural | 42.9 | 43.6 | 43.2 |

| Location | Male | Female | Total |
|---|---|---|---|
| If yes, type of medicine use (N = 2639) | | | |
| Urban | | | |
| Modern medicine | 79.1 | 74.1 | 76.5 |
| Traditional medicine | 8.2 | 8.2 | 5.1 |
| Both | 12.6 | 23.8 | 18.3 |
| Rural | | | |
| Modern medicine | 68.8 | 67.1 | 67.6 |
| Traditional medicine | 6.2 | 8.2 | 7.2 |
| Both | 25.1 | 24.7 | 24.9' |
| Total | | | |
| Modern medicine | 70.2 | 68.1 | 69.2 |
| Traditional medicine | 6.5 | 7.3 | 6.9 |
| Both | 23.4 | 24.5 | 23.9 |

A total of 6.9 % of persons with disabilities confirm that they use an assistive device. The proportion of persons using a device is significantly higher among urban than rural respondents ($\chi^2 = 3.92$, $p = .048$), both among males ($\chi^2 = 6.08$, $p = .014$) and females ($\chi^2 = 4.05$, $p = .044$). More males than females use an assistive device both in urban ($\chi^2 = 5.46$, $p = .019$) and in rural areas ($\chi^2 = 23.49$, $p < .001$).

### 9.3.17 Health literacy

Respondents were asked if they had any information about HIV/AIDS, Sexually transmitted infections (STIs), Diabetes and Tuberculosis (TB). HIV/AIDS stands out as the disease known by most. However, more non-disabled respondents confirmed any knowledge ($\chi^2 = 33.89$, $p < .001$). The same pattern of more knowledge among non-disabled was found among both males ($\chi^2 = 22.59$, $p < .001$) and females ($\chi^2 = 12.03$, $p < .001$). The difference between persons with and without disabilities were found also for STIs (Total: $\chi^2 = 47.60$, $p < .001$, males: $\chi^2 = 20.97$, $p < .001$ and females: $\chi^2 = 26.56$, $p < .001$), Diabetes (Total: $\chi^2 = 29.26$, $p < .001$, males: $\chi^2 = 20.97$, $p < .001$ and females: $\chi^2 = 26.56$, $p < .001$) and TB (Total: $\chi^2 = 24.71$, $p < .001$, males: $\chi^2 = 14.68$, $p < .001$ and females: $\chi^2 = 10.19$, $p < .001$). Gender differences were generally small and not statistically significant.

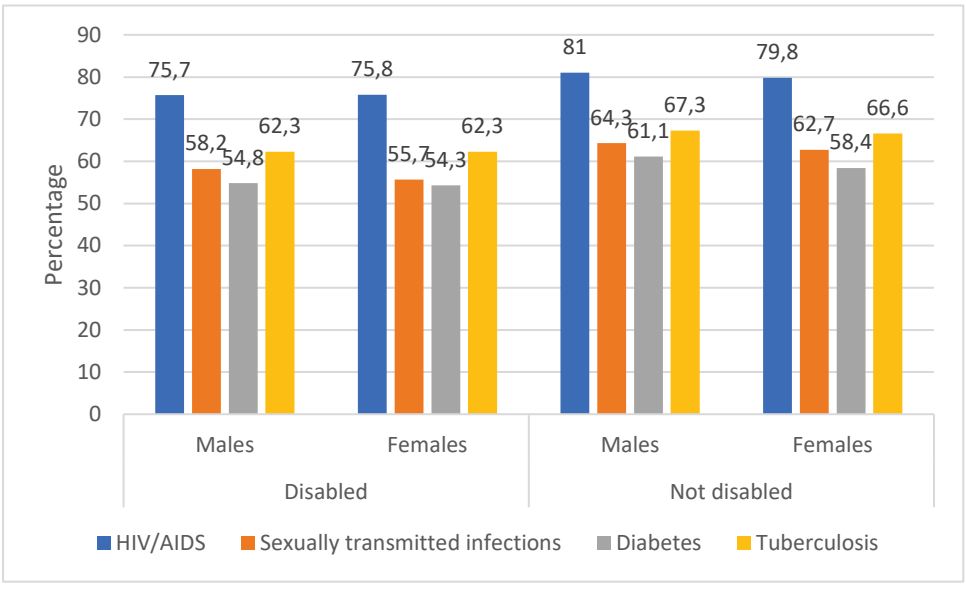


**Figure 33 Knowledge about four diseases by disability status and sex (N = 10568 – 10738)**

The overall picture is a clear rank order of information sources for the four diseases in Table 47. Health clinic is the main source of information and combined with doctor/nurse, information from health workers is stated by around half of the respondents. Four sources are stated by more than 10 %, with the following rank order: friends, school, family and radio/tv.

While there is some variation in the distribution of sources between individuals with and without disabilities, this is largely marginal and can hardly be understood as distinct patterns.

**Table 49. Source of information about four diseases by disability status (%)**

| Source of information | HIV/AIDS N = 8251 | | STI N = 6272 | | Diabetes N = 5942 | | TB N = 6767 | |
|---|---|---|---|---|---|---|---|---|
| | D[1] | ND[2] | D[1] | ND[2] | D[1] | ND[2] | D[1] | ND[2] |
| Health clinic | 37.4 | 37.6 | 40.9 | 41.3 | 34.1 | 34.4 | 36.5 | 36.0 |
| Doctor/nurse | 10.2 | 10.5 | 15.7 | 15.1 | 16.1 | 14.8 | 15.0 | 13.3 |
| At work | 0.6 | 0.5 | 0.9 | 1.0 | 0.7 | 1.0 | 0.6 | 1.1 |
| Magazines/Newspapers | 0.2 | 0.2 | 0.3 | 0.2 | 0.3 | 0.2 | 0.1 | 0.2 |
| From friends | 15.2 | 14.9 | 13.1 | 12.2 | 15.9 | 14.1 | 12.6 | 12.2 |
| From family | 10.6 | 9.3 | 6.7 | 6.7 | 11.3 | 11.1 | 10.5 | 8.8 |
| Radio/TV | 13.6 | 12.5 | 10.9 | 9.6 | 13.9 | 14.6 | 13.5 | 14.8 |
| Posters and pamphlets | 0.0 | 0.1 | 0.1 | 0.2 | 0.1 | 0.2 | 0.4 | 0.7 |
| School | 12.2 | 13.8 | 11.3 | 13.8 | 7.7 | 9.5 | 11.0 | 13.0 |

[1] D = Disabled, [2] ND = Non-disabled

Respondents who reported that they had any information about the four diseases were asked if they had any problems in understanding the information (Figure 35). Around 15 % confirmed that they had problems, varying marginally between the different diseases. For STIs, slightly more individuals without disabilities report that this was problematic ($\chi^2 = 3.52$, $p = .061$) and we can observe in Figure 35 the same tendency for both Diabetes and TB, although these differences are not near significant as is the case for STIs.

Differences between males and females are also generally small (Figure 36); More urban females than urban males with disabilities confirm STIs ($\chi^2 = 4.63$, $p = .031$) and likewise with diabetes ($\chi^2 = 4.82$, $p = .032$)

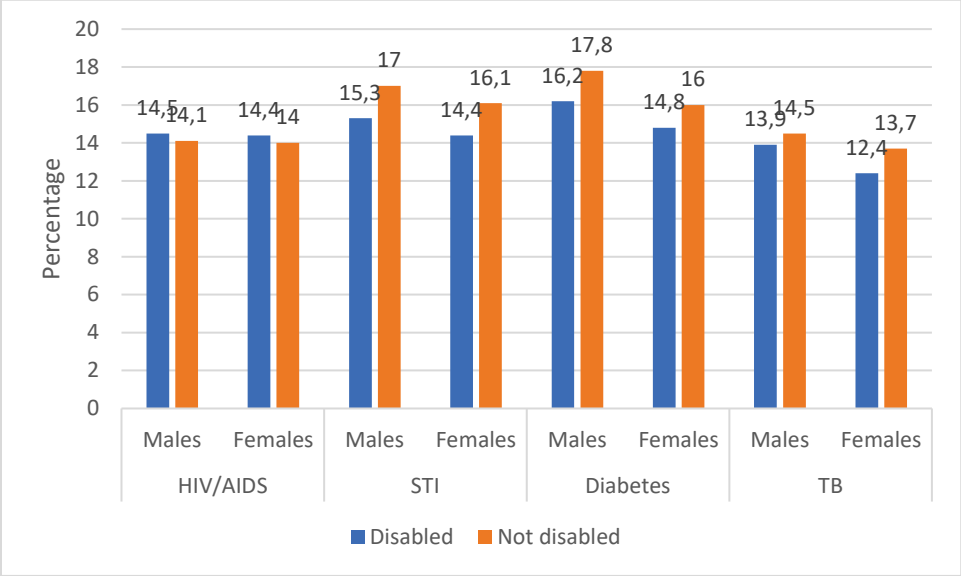



**Figure 34 Problems in understanding information about four diseases by disability status and sex (N = 5917 – 8197)**

A total of 14.8 % state that they have had STIs, 8.8 % HIV/AIDS, 8.6 % diabetes, and 7.2 % TB. For all four diseases and among both males and females, more individuals with than without disabilities confirm that they have had the four diseases (Figure 35). Differences are however relatively small and real differences in a statistical sense (significant) are found only for HIV/AIDS among females ($\chi^2 = 4.63$, $p = .031$) and diabetes among females ($\chi^2 = 4.40$, $p = .038$).

Differences between males and females are also generally small (Figure 36); More urban females than urban males with disabilities confirm STIs ($\chi^2 = 4.63$, $p = .031$) and likewise with diabetes ($\chi^2 = 4.82$, $p = .032$)

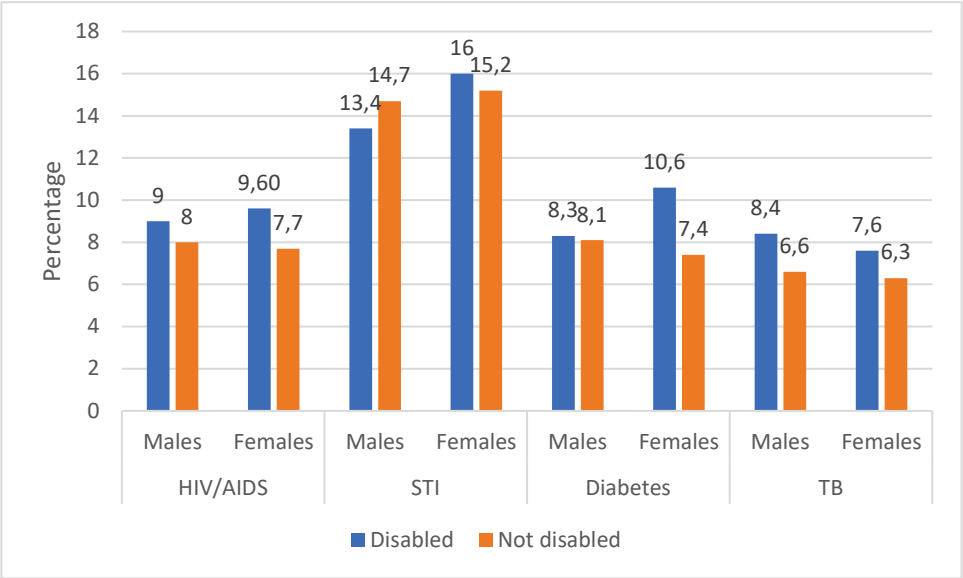



**Figure 35 Ever had the disease by disability status and sex (N = 5620 – 7962)**

Urban – rural differences are also generally small and marginal (Figure 37). The differences that reach statistical significance are more reported diabetes and TB among individuals with disabilities in rural areas (diabetes total: $\chi^2 = 4.81$, p = .028; TB total: $\chi^2 = 5.62$, p = .018).

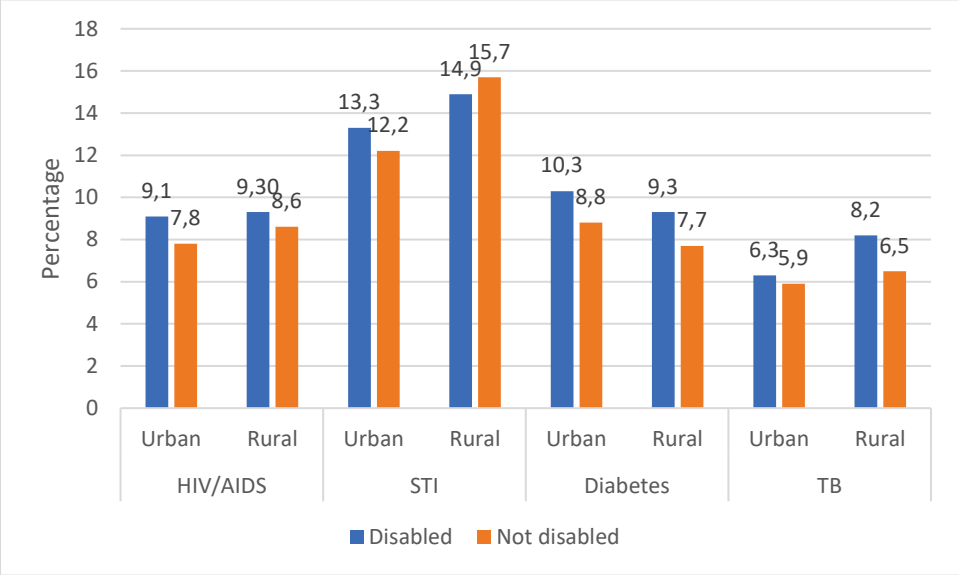



**Figure 36 Ever had the disease by disability status and location (N = 5842 – 8277)**

### 9.3.18 Services

Awareness of services is here understood as knowing about a service that is available. Table 50 shows that most respondents are aware of Health services, Health information, Faith healer, and Traditional healer. Lowest of awareness are Medical rehabilitation, Counselling for persons with disabilities and Welfare services. While more persons with disabilities are aware of Welfare services and more non-disabled are aware of Faith healer, awareness of services is generally similar among persons with and without disabilities.

The most needed services are Health services (86.4 % and 85 %) and Health information (80.1 % and 80.3 %), and the least is Traditional healer. For the seven services where there is information for both individuals with and without services, confirmed need is higher for individuals with disabilities. However, the differences are rather small and statistically significant only for three of the services; Counselling for parent/family, Welfare services and Traditional healer. The five services with only information from individuals with disabilities are in the 40 – 50 % range.

Services that are most often confirmed to be received are Health services (72.0 % and 72.8 %) and Health information, and the least among services that are relevant for both disabled and non-disabled is Welfare services (7.3 % and 6.8 %). Differences between disabled and non-disabled are generally small and statistically significant only for Traditional healer (16.6 % and 14.3 %). The five services with information only for individuals with disabilities are generally received by very few (4.1 % to 24.0 %).

Gap in a service is defined as follows: 100 minus the proportion of received services of needed services. Among the services with information for both disabled and non-disabled, the gap is larger among individuals with disabilities for six of the services, while the gap is larger among non-disabled for Traditional healer. The difference in gap between disabled and non-disabled vary between 7.5 percentage points (Welfare services) and 2 percentage points (Health information). As shown in Table 50 below, the largest gaps are reported for Vocational training, Assistive device services and Welfare services.

**Table 50. Gaps in services by disability status ($N_{i-vi}$ = 11511, $N_{vii-xi}$ = 6112)**

| Service | Aware of | | Needed | | Received | | Gap in services | |
|---|---|---|---|---|---|---|---|---|
| | D | ND | D | ND | D | ND | D | ND |
| i) Counselling for parent/family | 53.8 | 53.8 | 51.2 | 46.0[1] | 30.3 | 29.1 | 40.8 | 36.8 |
| ii) Welfare services | 47.8 | 41.0[1] | 50.6 | 31.0[1] | 7.3 | 6.8 | 85.6 | 78.1 |
| ii) Health services | 85.8 | 85.5 | 86.4 | 85.0 | 72.0 | 72.8 | 16.7 | 14.4 |
| iii) Health information | 79.9 | 80.7 | 80.1 | 80.3 | 65.4 | 67.2 | 18.4 | 16.4 |
| iv) Traditional healer | 61.1 | 62.2 | 23,3 | 21,1[3] | 16.6 | 14.3[2] | 28.8 | 36.3 |
| v) Faith healer | 75.9 | 77.8[3] | 57.5 | 56.9 | 47.2 | 48.1 | 17.9 | 15.5 |
| vi) Legal advice | 45.8 | 47.5 | 22.2 | 23.5 | 8.6 | 9.9 | 61.3 | 57.9 |
| vii) Medical rehabilitation | 39.4 | | 42.1 | | 9.2 | | 78.2 | |
| viii) Assistive device services | 50.2 | | 42.4 | | 6.1 | | 85.7 | |
| ix) Educational services | 57.1 | | 51.4 | | 24.0 | | 53.4 | |
| x) Vocational training | 50.2 | | 36.6 | | 4.1 | | 88.8 | |
| xi) Counselling for person with disabilities | 45.0 | | 47.1 | | 14.6 | | 69.1 | |

[1] $p < .001$, [2] $p < .01$, [3] $p < .05$

## 9.3.19 Satisfaction with services

The majority of respondents who had received Counselling for parents and family are either very satisfied or satisfied with this service (total: 53.1 %) (Figure 37). Although differences are small, somewhat more individuals with disabilities are very dissatisfied or somewhat dissatisfied (14.4 % vs. 11.2 %; $\chi^2 = 21.58$, $p < .001$).

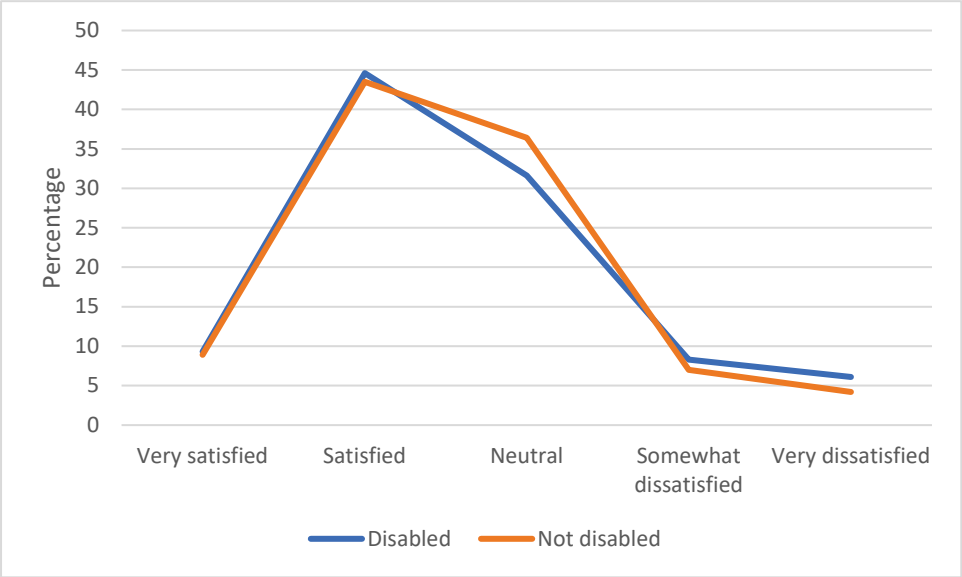



**Figure 37 Satisfaction with Counselling for parents and family by disability status (N = 3719)**

While 38.4 % of respondents who had experience with Welfare services said they were neutral to the question about satisfaction with this service, 41.4 % were either very dissatisfied or somewhat satisfied. More individuals with than without disabilities were dissatisfied (45.6 % vs. 37.5 %; $\chi^2 = 35.90$, $p < .001$).

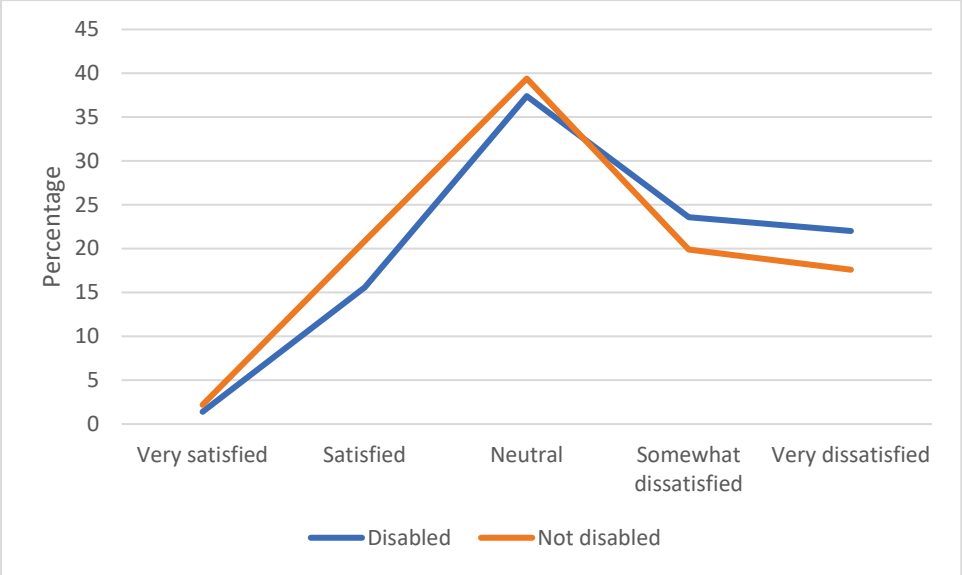



**Figure 38 Satisfaction with Welfare services by disability status (N = 3937)**

Somewhat more non-disabled are somewhat satisfied or satisfied with Health services (55.7 % vs. 50.2 %). More individuals with than without disabilities were either very dissatisfied or somewhat dissatisfied (23.7 % vs. 18.8 %) ($\chi^2 = 77.95$, $p < .001$).

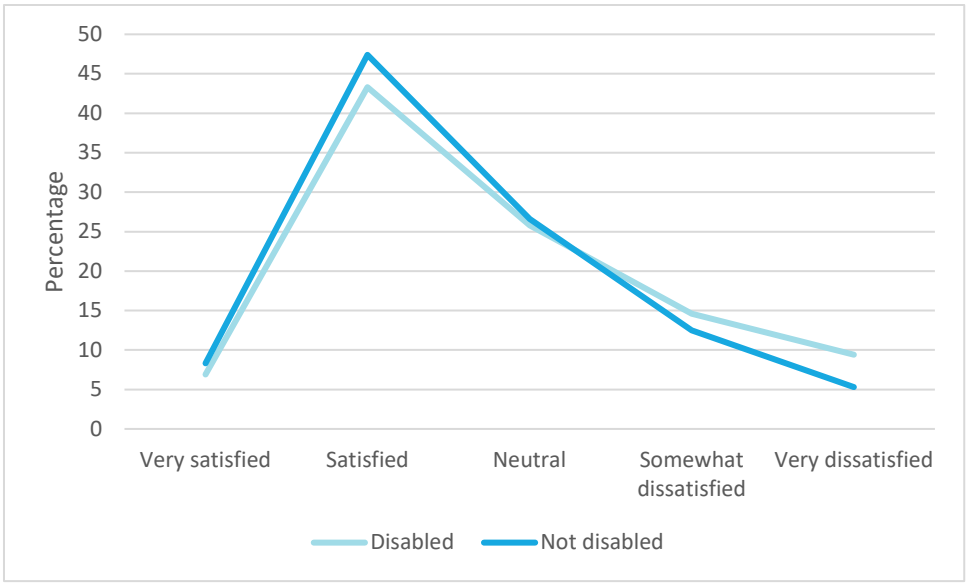



**Figure 39 Satisfaction with Health services by disability status (N = 9745)**

Almost half of the respondents are satisfied with the Health information they have received (47.5 % and 49.8 %). Somewhat more individuals with disabilities are either somewhat dissatisfied or very dissatisfied (17.7 % vs. 13.2 %) ($\chi^2 = 77.95$, $p < .001$).

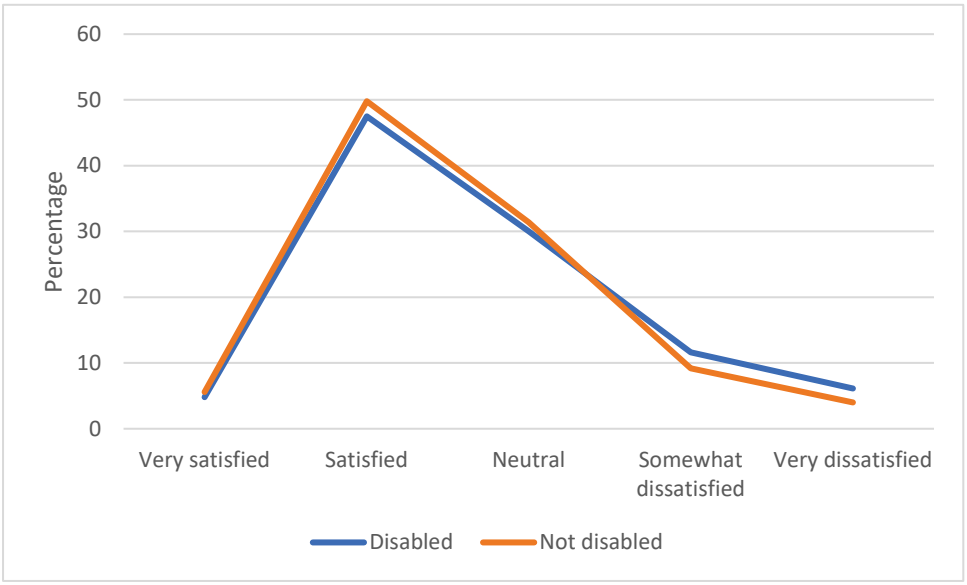



**Figure 40 Satisfaction with Health information by disability status (N = 8834)**

More than one third of the respondents report that they are neutral in their assessment of services given to them by Traditional healers (34.2 % and 38.6 %). More individuals with disabilities are either very or somewhat dissatisfied (42.7 % vs. 40.2 %) ($\chi^2 = 10.31$, $p = .036$).

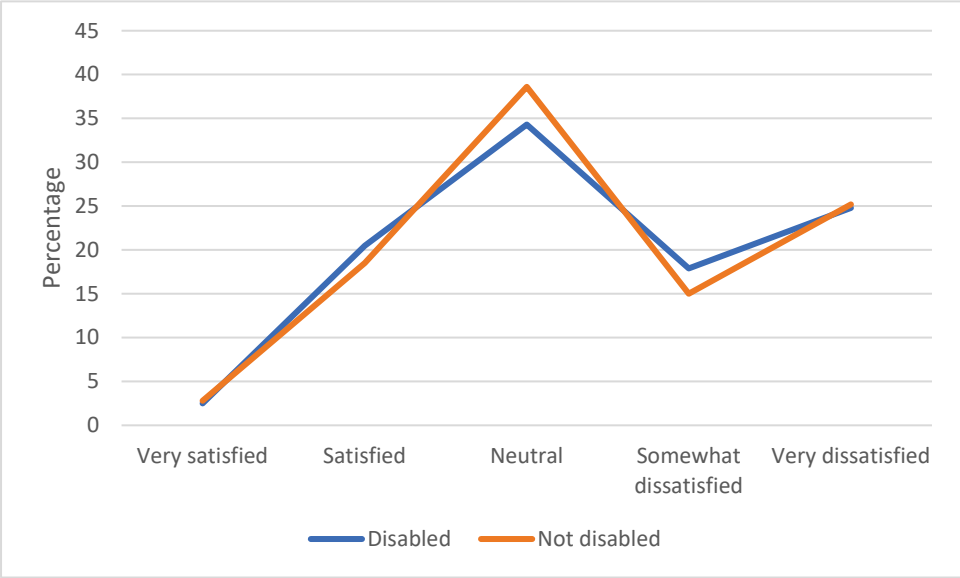



**Figure 41 Satisfaction with Traditional healer by disability status (N = 3323)**

The majority are either very satisfied or satisfied with the Faith healer (56.5 % and 58.5 %). Differences between disabled and non-disabled are marginal (n.s.).

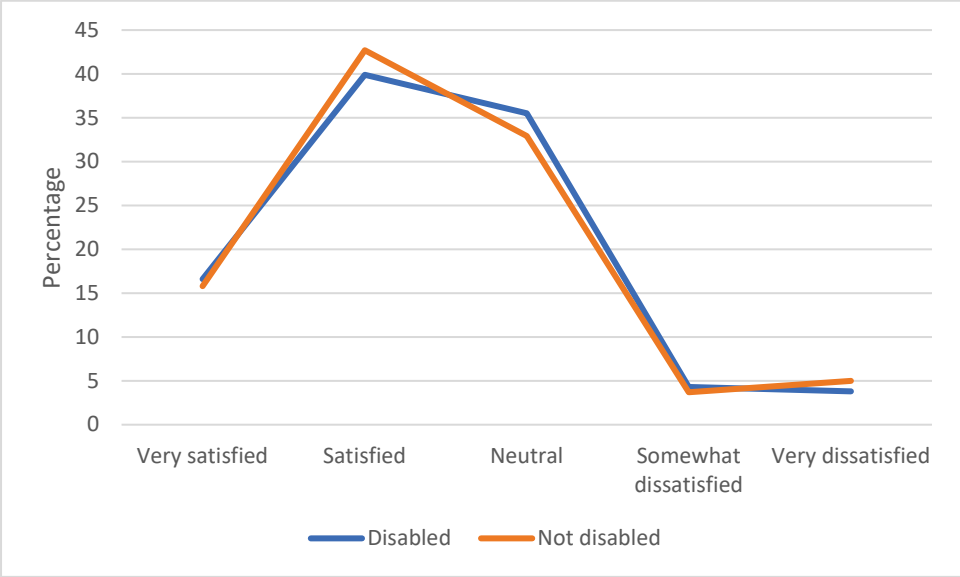



**Figure 42 Satisfaction with Faith healer by disability status (N = 6475)**

The largest proportion of respondents are neutral in their assessment of the Legal advice they had received. More individuals with disabilities are either very dissatisfied or somewhat dissatisfied with the Legal advice (32.3 % vs. 27.0 %) ($\chi^2 = 16.16$, $p = .003$).

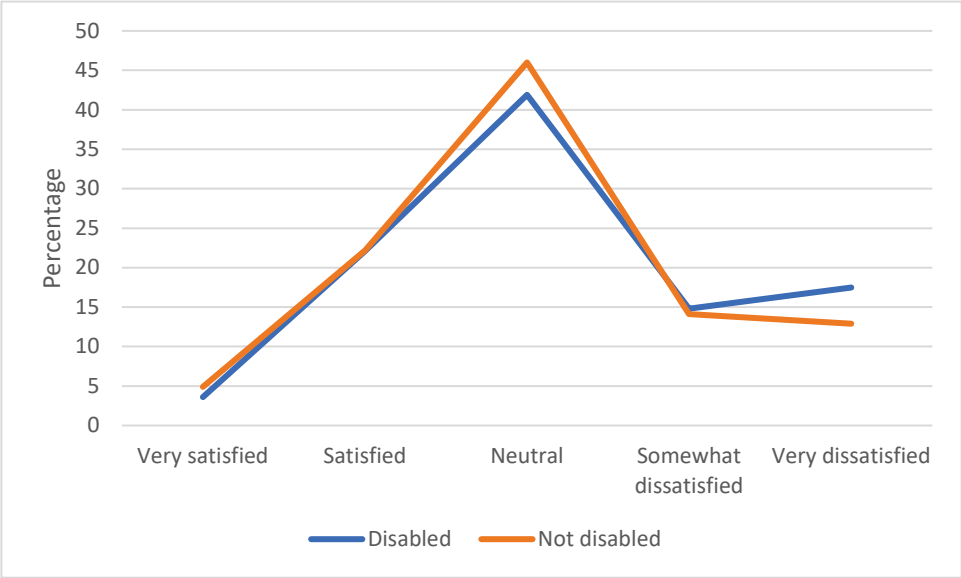



**Figure 43 Satisfaction with Legal advice by disability status (N = 6475)**

Summing up the comparison in Figures 37-43 above, while individuals with and without disabilities tend to assess the different services similarly, individuals with disabilities are somewhat less satisfied and more dissatisfied. Overall, respondents are most satisfied (very satisfied or satisfied) with Faith healer (57.5 %), Health information (53.8 %), Counselling for parents and family (53.1 %), and Health services (52.9 %). They are on the other hand least satisfied with Welfare service (20.1 %), Traditional healer (22.0 %) and Legal advice (26.5 %).

Figure 44 shows the distribution of responses to the five services that were only assessed by individuals with disabilities. Response pattern is somewhat similar for the five services, with neutral as the most common response for all, ranging from 37 % (Assistive devices) to 44.1 % (Counselling for persons with disabilities). The rank order of the most negative answer category (very dissatisfied) is Assistive devices (23.3 %), Vocational training (18.5 %), Counselling for persons with disabilities (13.1 %), Educational services (12,9 %), and Medical rehabilitation (12.5 %). The highest proportion who are satisfied is for Educational services (27,2 %), followed by Counselling for person with disabilities (23.8 %), Medical rehabilitation (21.2 %), Vocational training (14.8 %), and Assistive device services (14.3 %).

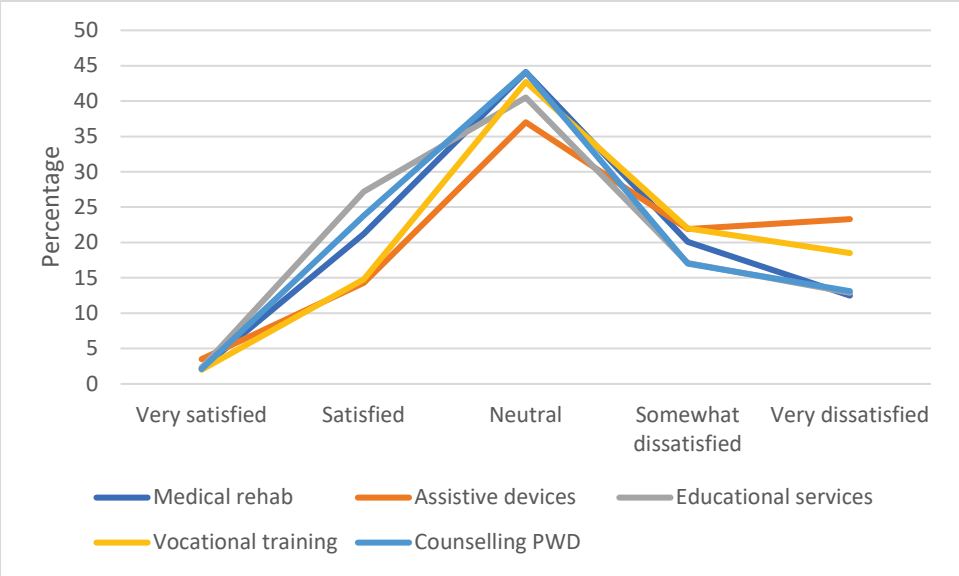



**Figure 44 Comparing satisfaction with five services among persons with disabilities (N = 1402 – 2150)**

### 9.3.20 Family and community participation

For all the variables A to I in Table 51, more individuals with than without disabilities confirm participation. While all these differences are statistically significant, the difference is largest for F, "Participate in local community meetings (17.0 percentage points difference) and E, "Take part in own traditional practice (9.9 percentage points difference)". Smallest differences are found for H,"Is your voice being heard (1.5 percentage points difference)" and G, "Make important decisions about one's own life (1.9 percentage points difference)".

**Table 51. Participation and involvement by disability status**

| Involvement | N | Disabled | Non-disabled | $\chi^2$ | p |
|---|---|---|---|---|---|
| A, Consulted about household decisions | 10918 | 78.3 | 86.1 | 112.64 | < .001 |
| B. Go to family events | 11228 | 86.8 | 94.1 | 169.66 | < .001 |
| C. Feel involved and part of the family | 11121 | 93.6 | 97.3 | 87.92 | < .001 |
| D. Does the family involve you in conversations | 11195 | 92.8 | 96.0 | 53.74 | < .001 |
| E. Take part in own traditional practice | 10326 | 70.9 | 80.8 | 136.55 | < .001 |
| F. Participate in local community meetings | 10754 | 59.6 | 76.6 | 352.28 | < .001 |
| G. Make important decisions about one's own life | 9990 | 68.4 | 70.3 | 4.17 | .041 |
| H. If yes to previous question, is your voice being heard | 5461 | 95.2 | 96.7 | 8.49 | .004 |
| I. Voted in the last election (=> 20 years) | 11151 | 55.8 | 62.8 | 58.02 | < .001 |

Questions A to I in Table 51 were recoded to 0 (No) and 1 (Yes) and then added together to form a Family and Community Participation Scale; Range: 0 – 9, mean value 8.48, standard deviation 0.81. Firstly, participation measured by means of this scale is gradually reduced with increased level of disability severity ($F = 9.15$, $p < .001$). The difference in level of participation is larger among females ($F = 11.59$, $p < .001$) than among males (n.s.), and the level of participation among females is higher than males among persons without disability or with mild disability and lower among persons with moderate and severe disability ($F = 6.97$, $p = .008$).

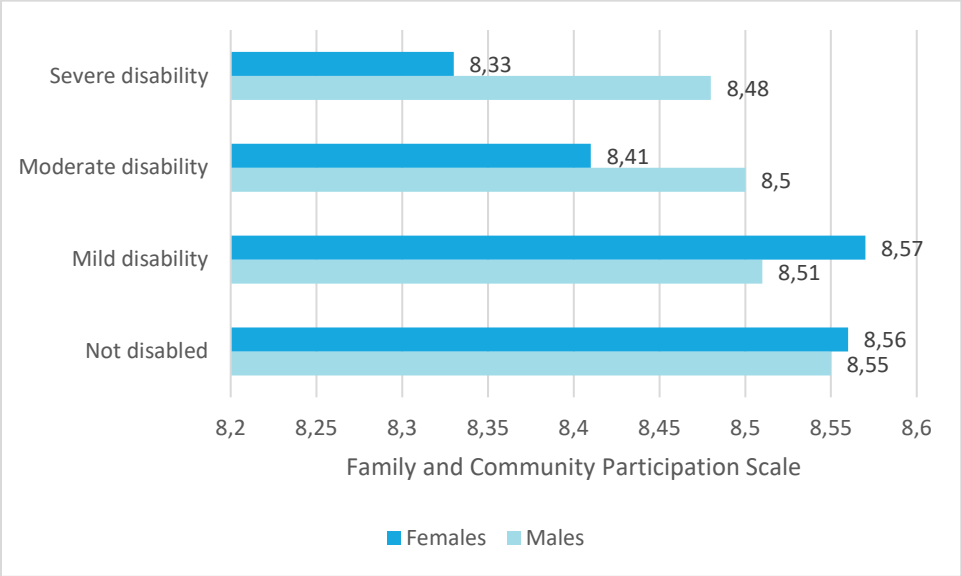



**Figure 45 Family and community participation scale by disability severity and sex (N = 4725)**

Individuals with disabilities were asked if they were aware of disabled people's organisations (DPOs) and if they were members. Awareness of DPOs was higher among males, while there was no difference in rate of membership between males and females. Both awareness and membership were also more prevalent among urban than rural respondents.

**Table 52. Awareness of and membership in DPOs (N = 5640 – 5747) (%)**

| | **Males** | **Females** | **$X^2$ p** | **Urban** | **Rural** | **$X^2$ p** |
|---|---|---|---|---|---|---|
| Aware of DPOs | 23.4 | 19.7 | 11.50 .001 | 25.8 | 20.8 | 9.64 .002 |
| Member of DPO | 5.4 | 4.5 | 2.49 .115 | 6.7 | 4.8 | 5.09 .024 |

In Figure 46 it is shown that those who are members of DPOs report higher level of activity limitations, i.e., more severe disabilities. Further that environmental barriers are higher among those who are not DPO members.

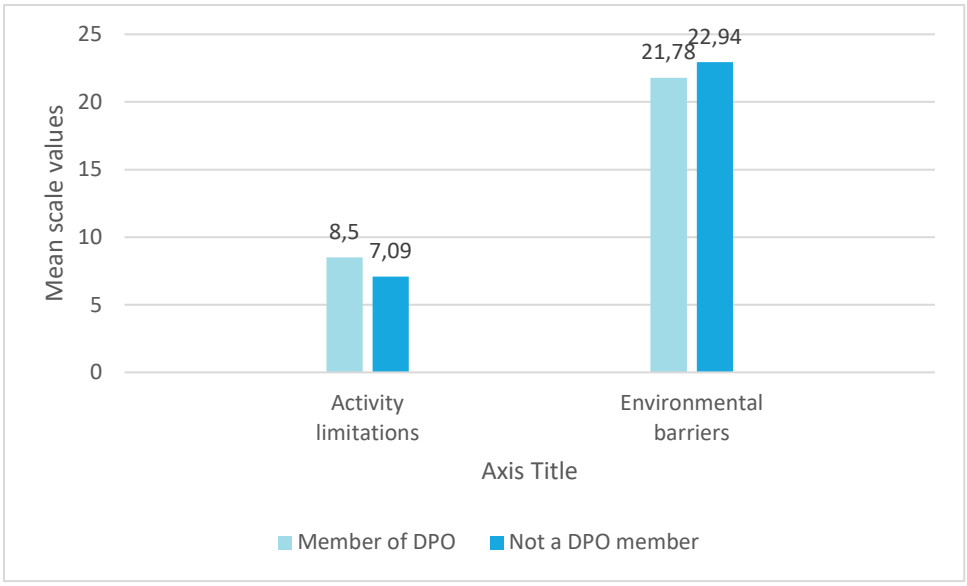



**Figure 46 Membership of DPO by activity limitations and environmental barriers (N = 5461 – 5686)**

### 9.3.21 Child functioning

A total of 24 questions in the WG/UNICEF Child Module were asked. Responses to these 24 questions among children aged between 2 – 4 (9 questions) and 5 – 17 (15 questions) are shown below.

Among children aged 2 – 4 years, the most common difficulty is difficulty walking, of which 5.6 % are reported not to be able to walk at all. As many as 36.3 % have difficulty being understood when speaking, of which 2.6 % are not understood at all.  Around one third have difficulty in learning things and in playing. Around one in five kick, bite or hit other children and adults more than children of the same age.

**Table 53: Distribution of difficulties among children with disabilities aged 2 – 4 years (%) (N = 233)**

| WG/UNICEF Child model question | No difficulty | Some difficulty | A lot of difficulty | Cannot do |
|---|---|---|---|---|
| CFD3.Does … have difficulty seeing | 79.8 | 16.3 | 3.4 | 0.0 |
| CFD5.Does ….have difficulty hearing? | 82.0 | 12.9 | 3.4 | 1.3 |
| CFD8.Does ….have difficulty walking? | 61.4 | 20.2 | 12.4 | 5.6 |
| CFD11 Compared to children of the same age, does ….. have difficulty picking up small objects? | 82.8 | 11.6 | 4.7 | 0.9 |
| CFD12 Does ….. have difficulty understanding you? | 82.3 | 12.9 | 4.7 | 0.0 |
| CFD13 When …. Speaks, does he/she have difficulty being understood? | 73.7 | 16.8 | 6.9 | 2.6 |
| CFD14 Compared with children of the same age, does …… have difficulty learning things? | 76.3 | 16.4 | 6.0 | 1.3 |
| CFD15 Compared with children of the same age, does ….. have difficulty playing? | 76.7 | 16.4 | 4.3 | 2.6 |
| | Not at all | The same or less | More | A lot more |
| CFD16 Compared with children of the same age, how much does ……kick, bite or hit other children and adults? | 62.1 | 18.1 | 9.1 | 10.8 |

Among children aged 5 – 17, around one in four have at least some difficulty in walking a distance (100 and 500 meters), learning and remembering things. We further see in Table 54 that 24 % have at least some difficulty hearing and 20.3 % have at least some problems being understood by people outside his/her household. It is further shown that 30.4 % and 28.8 % of children in this age group are reported to be sad (or depressed) or anxious (or nervous or worried) at least a few times per year. While most with such difficulties are sad or anxious a few times per year, 5.6 % and 4.6 % respectively are sad or anxious on a daily basis.

**Table 54 Distribution of difficulties among children with disabilities aged 5 – 17 years (%) (N = 1560)**

| | No difficulty | Some difficulty | A lot of difficulty | Cannot do |
|---|---|---|---|---|
| Does ….. have difficulty seeing? | 81.5 | 13.9 | 3.8 | 0.7 |
| Does ….. have difficulty hearing? | 76.0 | 17.1 | 4.4 | 2.4 |
| Does ….. have difficulty walking 100 meters on level ground? | 75.1 | 15.1 | 7.7 | 2.2 |
| Does ….. have difficulty walking 500 meters on level ground? | 73.4 | 15.1 | 8.8 | 2.6 |

| | | No difficulty | Some difficulty | A lot of difficulty | Cannot do |
|---|---|---|---|---|---|
| Does ….. have difficulty with selfcare such as feeding or dressing him/herself? | | 84.6 | 11.2 | 2.5 | 1.8 |
| When ….. speaks, does he/she have difficulty being understood by people inside this household? | | 83.3 | 10.3 | 3.7 | 2.8 |
| When ….. speaks, does he/she have difficulty being understood by people outside this household? | | 79.7 | 13.4 | 4.2 | 2.7 |
| Compared with children of the same age, does ….. have difficulty learning things? | | 74.1 | 17.2 | 6.3 | 2.4 |
| Compared with children of the same age, does ….. have difficulty remembering things? | | 74.3 | 17.0 | 6.5 | 2.2 |
| Does ….. have difficulty focussing on an activity he/she enjoys doing? | | 82.1 | 10.6 | 4.7 | 2.6 |
| Does ….. have difficulty accepting changes in his/her routines? | | 86.7 | 9.8 | 1.9 | 1.7 |
| Does ….. have difficulty making friends? | | 88.6 | 7.8 | 1.7 | 1.9 |
| | | No difficulty | The same or less | More | A lot more |
| Compared to children of the same age, how much difficulty does ….. have controlling his/her behaviour? | | 83.8 | 11.3 | 3.2 | 1,7 |
| | Never | A few times per year | Monthly | Weekly | Daily |
| How often does ….. seem anxious, nervous or worried? | 71.2 | 15.2 | 4.6 | 3.5 | 5.6 |
| How often does ,,,,,, seem sad or depressed? | 69.6 | 17.7 | 4.4 | 3.7 | 4.6 |
| | | | | | |

# 10 DISCUSSION

Data on disability in low-income contexts is scarce, although currently growing and with several ongoing international initiatives to improve the knowledge base. One such recent initiative in Uganda is the Disability Situational Analysis in Uganda undertaken by the Ministry of Gender, Labour and Social Development (UBOS 2020). While limited research on disability is also the case in Uganda, the scoping review identified a large number of small- and medium size studies of mixed quality and on a range of different topics. A main conclusion of the scoping review is that disability is negatively associated with social and economic factors, which concurs with the results in the current study that brings analyses of a large number of different indicators on level of living.

The national, representative study on living conditions among people with disabilities was carried out in Uganda in 2018 - 2019. This report brings some of the main results from this study. Further results from this rich data material will be published in the time to come. Makerere University, Department of Social Work, the National Union of Disabled Persons of Uganda (NUDIPU) and SINTEF have established a comprehensive data base about individuals with disabilities and their households in the country. The data base also comprises a sample of the non-disabled population, which provides a basis for comparing between disabled and non-disabled individuals and households with and without disabled members. The study follows a series of similar studies carried out in southern Africa between 1998 and 2018. All-together, 12 studies have been carried out in nine different countries, since the first studies on living conditions among persons with disabilities in Namibia and Zimbabwe during 2001 – 2003. These data form a unique data base on disability in low-income contexts that have been utilized by researchers, policy makers, DPOs and international organisations. This study is thus part of a larger data base on disability in sub-Saharan Africa allowing for comparison between countries. In this and the previous studies, the disability movement has played a central role in planning, design development and data collection as well as the immediate dissemination and future use of the data.

The data from this study may be used by both the disability movement, Government agencies in Uganda and by international organisations operating in Uganda and can be a vehicle for increasing awareness about disability and building capacity to improve the situation for people with disabilities. It is particularly expected that the data will be utilized by NUDIPU in their advocacy towards Government agencies and international organisations, and by Makerere University as a stronghold for disability research in the country. It is further expected that both NUDIPU and Makerere University utilizes the data in their collaboration with relevant government bodies in Uganda, and in particular with the Ministry of Gender, Labour and Social Development, Ministry of Education and Sports and Uganda Bureau of Statistics who have all supported the study.

## 10.1 Comparing households

In the previous similar studies, an interesting feature of household composition has been that households with disabled members tend to be larger than control households and with a higher mean age among the household members. In the current study in Uganda, this difference is smaller than in the comparable studies. However, 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.

Although comparing housing situation and infrastructure revealed small and partly non-significant differences between the two household types, there are some indications that households without disabled members are better off in the sense that they tend to have more modern/ sophisticated facilities than households with disabilities. Small differences could be expected as all/most households within a location share more or less the same standard, and that variation is found between locations rather than within. The urban-rural difference is clearly demonstrated by indicators on infrastructure. Still, the data do indicate differentiation also within locations (within urban and rural respectively). 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 Disability

The Washington Group Short Set was used in the initial screening during data collection. However, this report uses a longer set of activity questions (18 items) to determine level of disability, and also includes a similar longer set of participation questions (22 items). Both have been referred to as "the ICF matrix". The downside of this is that this reduces comparability with studies using the Short Set. On the other hand, these longer sets of questions are used to construct scales on disability severity (activity limitations) that have better statistical properties than the 6 – item measure.

The WG Short Set was however used for estimating prevalence, using a low threshold (at least some difficulty) to determine disability/activity limitations. The prevalence estimate for the adult population was 14.8 %, which is aligned with the WHO estimate of 15 % (WHO 2011). This position is consistent with a recent study on the same, which concluded that disability is most prevalent among older persons in Uganda, for as people age and grow frailer, their health decreases and they are more likely to experience age-related impairments (UBOS, 2020). Prevalence among children under 18 was much lower, down to 8.4 %, which is as expected and similar to other comparable studies (e.g., CSO & MMCDSS 2018; ZimStat & MHCC 2015), and 4.7 % among children below 4 years. Uganda Bureau of Statistics (UBOS) published statistics from the 2016 Demographic Health Survey in Uganda, estimating prevalence of disability among adults (18 +) to be 16.5 % among adults, 7.5 % among children between 15 – 17 years and 3.5 % among children between 2 – 4 % (UBOS 2018). The results from this recent and the current study in Uganda and the two recent studies referred to above are very similar, providing good support to the crude estimate by WHO (WHO 2011). The GoU (2019) report, based on other data sources put the national prevalence of disability at 44 percent of the households, with 12 percent of the households with severe forms of disabilities. However, some national documents in Uganda though rich in data, are not disability disaggregated and are thus not helpful for disability planning. For example, the GoU (2015) report on national service delivery critically looked at topical issues such as water and sanitation; Justice, law and order; Transport; Agriculture; Housing conditions; Environmental management; Health and education but without being disability disaggregated.

Activity limitations and restrictions in social participation are higher among rural than urban residents and generally also higher among females than males, the exception being more participation restrictions for males in urban areas. A somewhat more complex picture is drawn by analysing family and community participation, where we have seen (Figure 45) that among non-disabled and mildly disabled individuals, females report more

participation than males, while this is the opposite among males with moderate or severe disability. Clearly, this is more complex than leaning on classical gender and urban/rural differences and may indicate other mediating explanatory factors in the social and cultural sphere.

Environmental barriers are key elements in increasing activity limitations and restrictions in social participation, ref. the ICF model on disabling processes (WHO 2011). While the study indicates that lack of support from others constitute an important type of barriers, negative attitudes and the physical environment are also important. Higher score on environmental barriers among rural respondents as could be expected due to both physical environment and higher levels of poverty. It is further worth noting that females do not report higher levels of barriers than males as could be expected in a male-dominant socio-cultural context.

The distribution of impairment categories (Table 23) corresponds to several previous studies in sub-Saharan Africa (e.g. Eide & Munthali 2018), including Uganda 2014 Census data (UBOS, 2016). Physical impairments is the most prevalent, followed by sensory impairment (visual followed by hearing), mental disorder, and intellectual (developmental) impairment. The mean age differences between the different impairment types (Table 23) reflect that some impairments are more common in younger age groups and some are more closely related to aging. While this is as expected, the results confirm that different measures are needed for children/youths and the older age groups. Further, individuals within the different impairment categories score differently on activity limitations, implying that some impairment categories, such as autism and mental disorders are more disabling than others (Figure 14) and thus require more attention from health care and rehabilitation services.

Nearly half of the reported disabilities in this study started between 0 – 10 years of age, with "congenital" dominating as a cause, combined with "disease and illness" reported as a cause by four out of ten. The high level of congenital disabilities is an indication of an interplay between high levels of child morbidity and under-performing or not easily accessible health services for mother and child. Prolonged war in Uganda has also been responsible for causing disability in Uganda, where for example the nodding disease syndrome, common in northern Uganda, is attributed to this (BtG, 2018). Very likely, much of the disabilities appearing at birth or in the first year of life could be prevented. Improving health services for mother and child should be a top priority for health services in Uganda as this could reduce avoidable disability and health problems substantially.

## 10.3 Comparing individuals

Individuals with disabilities are generally older than non-disabled individuals. While some impairment categories are associated with younger age, there is nevertheless and overall age gradient in disability. It is of importance to keep this in mind when interpreting differences between individuals with and without disabilities.

### 10.3.1 Education

More males than females and more urban than rural respondents have accessed primary education. The same pattern emerges when looking at who is benefitting from adult literacy classes. While drop-out rates are higher among individuals with than without disabilities, the picture is mixed when comparing urban/rural and male/female. Drop-out rates among individuals with disabilities are quite dramatic, in particular in primary school (Figure 20). Bearing in mind that many individuals with disabilities have not access school at all, we can

assume that those attending are better equipped for primary education. Still, the high drop-out rate indicates that education is far from inclusive and there is a strong need for knowledge and research on what is actually taking place in the classroom. The causes for the high drop-out rate among individuals with disabilities may be found in lack of competence and awareness among teachers, negative attitudes and physical barriers. Drop out is also attributed to many factors, accordingly to the UBOS (2020). These include limited budget for disability, at 0.1 percent of the overall budget for education. Others relates to the additional costs of disability, in particular the use of additional resources in the classroom, including classroom assistants or support teachers. In Uganda, the permitted ratio of students to teachers in mainstream schools is currently 45:1. Unfortunately, classrooms often exceed this, making inclusion of children with disabilities even more difficult. However, when reporting on causes for drop-out in the current study, the majority of both individuals with and without disabilities state that this has to do with costs (school fees). Only one out of ten state the reason to be disability related.

The disadvantage of children with disabilities when it comes to access and drop-out indicate that many do not get the basic education that they are entitled to and that they need to become fully participating adult citizens. This is a matter of both ensuring access to education for all and to improve the way students with disabilities are included in school. 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. The BtG (2018) findings on education was also consistent with the current findings, where a widening gap in educational attainment among children and young adults with and without disabilities was established, and greater share of children with disabilities were out of school compared to children without disabilities.

### 10.3.2 Employment

Fewer individuals with than without disabilities reported to be currently working, more disabled had worked previously (but not now), and more individuals without disabilities were still studying. Generally, individuals with disabilities are less integrated in the labor market, and females with disabilities less so than males. Similar work experience was noted in the UBOS (2020) study, where persons with disabilities are found to be less likely to have ever worked than their peers without disabilities, with women less likely to have worked than men. Indeed, the report indicated more than three quarters of women aged 30-60 years who cannot perform functional activities at all have never worked. However, when comparing income between individuals with and without disabilities, there were hardly any difference to be observed. Further breakdown by gender and location revealed however some expected differences: higher income in urban areas and lower income among females than among males. The surprising results was that urban males with disabilities reported highest income, and higher than their non-disabled male counterparts. While non-disabled females earned more than females with disabilities, as could be assumed, the reversed difference (among males) cannot be explained by this study, but we probably have a highly selected group of males with disabilities who are given career chances in urban contexts.

A higher proportion of individuals with disabilities considered themselves as unemployed, compared to non-disabled individuals. More individuals with disabilities were retired, reflecting the age difference between the groups (disabled – non-disabled), and more individuals with disabilities were unemployed because of illness or disability. The first reflects to some extent age differences between disabled and non-disabled, while the latter indicates that disability and ill health are excluding individuals from the labor market.

### 10.3.3 Activity limitations, restrictions in social participation and environmental barriers

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. Figure 10 and 11 shows how activity limitation varies with socio-demographic variables, Table 21 shows activity limitations with a more refined 18-item scale in the sub-sample of individuals with disabilities, and Tables 53 and 54 show the activity limitations/disability profile for children by means of 20 items in the Washington Group/UNICEF Child Module on Functioning.

In the current sample, comprising individuals with and without disabilities, difficulty with walking is the most prevalent among the WG6 domains /7.2 %), followed by seeing (6.7 %), remembering (3.5 %), hearing (3.1 %), self-care (2.6 %), and communicating (1.2 %). The more refined question set applied to individuals with disabilities only, reveals that cognitive skills (reading/writing/counting/calculating) score highest, reflecting illiteracy and lack of basic education. This is followed by mobility (walking/moving around) and sensory limitations. When analysing the data on children (2 – 17 years) only, we see (Figure 44) that the most prevalent functional problems (difficulties) when using a low threshold for qualifying as being disabled (at least some problems), are walking, learning and remembering, while the least prevalent difficulties are making friends, accepting changes and controlling behavior. All in all, Table 54 demonstrates the broad specter of functional problems/difficulties that defines the disability profile of children in Uganda. This is thus much more complex than identifying single impairments.

More participation restrictions were reported concerning schooling and work and domestic chores (shopping, cooking, washing). While the different approaches to disability (activity limitations, participation restrictions, WG6 domains) present different profiles, it is important to understand that they do not measure the same phenomenon, and that they complement each other to provide a fuller picture of disability than through one type of measurement. Disability is complex and is intertwined with social/environmental factors. While there is a specter of different environmental barriers, lack of help/support and negative attitudes are among the most prominent, implying that activity limitations/participation restrictions (disability) may be reduced in particular if awareness about the situation of individuals with disabilities, their rights and potential for participation and contribution is increased. The higher level of environmental barriers in rural areas may be the result of poor infrastructure.

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. With this wide definition, prevalence among adults (18+) almost reached the WHO estimate of 15 % in any population (WHO 2011). As found in other studies, prevalence among children was lower, also as expected and found in other studies. Higher prevalence among rural as compared to urban populations and variation across geographical areas was as expected. An interesting finding is the reverse difference between males and females in rural vs. urban areas with regards to participation restrictions. This may indicate more favorable conditions for females in urban areas.

The results on disability onset reveal firstly that disability is age related, i.e., both increasing with age as well as a relatively high proportion of disability onset very early in life. The first is part of natural development, but also an indication of the need for intervention among the older age groups. It is however the relatively early onset of disability, i.e. among children, that gives reason for concern. This is further emphasized by the perceived causes of disability, strongly dominated by "Disease/Illness" and "By birth/Congenital". These findings indicate

access and/or quality problems in prenatal and perinatal care for mother and child and should be an area of intervention, and 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 Uganda is preventable.

While the distinction between persons with and without disabilities is central to this report, it is also important to distinguish between levels of disability. The broad screening procedure in this study leads to the inclusion of many individuals with mild disabilities. Consequently, differences between persons with and without disabilities may be underestimated. Distinguishing between mild, moderate and severe disability contributes to reveal the differences in living conditions between the most vulnerable and non-disabled, as well as between persons with different levels of disability.

The profile of impairment categories in the current study largely resembles the results from previous studies (BtG, 2018). Physical impairments (movement, mobility) are the most common, followed by difficulties with seeing (visual and blind) and hearing (hard of hearing and deaf). In fact, the combined sensory impairments affect more than half of the individuals with disabilities, while physical impairment is reported by somewhat less than half. Intellectual (developmental) impairments and mental problems (Mental disorder and Autism in Table 23) make up 17.2 %. of all respondents with disabilities,

### 10.3.4 Violence and abuse

Very few of the respondents (< 1 %) stated violence as the cause of their disability. The figure is low also when including witchcraft and war related cause. While violence as a cause may be partly hidden in the larger "other" category, the figures are however clearly higher when asking for experiences of violence (physical and verbal) because of disability. For instance, 19.7 % of urban males had been beaten or scolded by a non-family member and 12.7 % by a family member due to the disability. This is similar to previous comparable studies in southern Africa. Discrimination was also reported to be more or less at the same level as similar studies (8.1 %). While gender differences are small, there is a tendency for more males to report beating/scolding, and likewise, more urban than rural respondents.

Any experiences of being beaten, scolded or discriminated are unacceptable and a violation of human rights. Even though the results here do not stand out negatively compared to other similar studies, it may be of some concern that close to one in five in urban areas have experienced being beaten by a non-family member due to their disability, bearing in mind that the figures are assumed to be under reported. The results indicate that quite a number of individuals with disability suffer under unacceptable treatment.

### 10.3.5 Welfare and health services

The large majority of persons with disabilities are aware of health services, health information, faith healers and traditional healers. For most other basic services, only around 50 % of disabled informants were aware, and less than 40 % were aware of legal aid. What this means is that, for many persons with disabilities, important services that could have contributed to reducing negative implications of impairments, are simply not known, and/or not available. The potential for reducing the negative impact of disability and impairments is thus quite substantial. The generally small differences in awareness about services among persons with disabilities compared to non-disabled, may be regarded as a positive sign of equitable dissemination of information.

However, bearing in mind that persons with disabilities generally need more services than non-disabled, this result indicates that persons with disabilities are disadvantaged also in having more limited knowledge about the relevance of various services to them. To underline this further, for six of the seven services where we have data for both disabled and non-disabled, the service gap is larger among persons with disabilities. In other words, less awareness about services and about their own needs among persons with disabilities adds to the additional health needs and contributes to inequity in health.

There appears to be relatively small gaps between need and provision of health services, health information and faith healers. Large gaps are registered for vocational training, assistive devices, welfare services, and medical rehabilitation. There are also substantial gaps in counselling for persons with disabilities and legal advice. Generally, the results show health services and health information as well as faith and traditional healers are largely available to the population under study, but that other types of basic services are unavailable or inaccessible for the large majority. Gaps in services must be assumed to impact on the inclusion of individuals with disability in society and this provides an evident area for improvement. This may partly be a capacity problem and partly a matter of exclusion. The results on satisfaction with services further indicates that there is room for improvement, as the overall picture is that respondents, both with and without disabilities, tend to be neutral. Few are very satisfied, and quite a number are very dissatisfied, with health services and traditional healers reaching around 25 % and welfare services around 20 %. For several of the services, more individuals with than without disabilities are very dissatisfied.

### 10.3.6 Assistive devices

A low proportion of individuals with disabilities confirm that they have an assistive device. The prevalence of 6.9 % is lower than in most other countries in sub-Saharan Africa where similar studies have been undertaken (Eide, Mji and Chiwaula, 2019) and below any reasonable estimate of actual need. According to Table 50, more than four out of ten individuals with disabilities need an assistive device, and the gap between need and provision is 85.7 %. The findings on assistive devices in this study are consistent with those in the UBOS (2020) which established that the overall use of assistive products is low among persons with disabilities. Only 13 per cent of persons with at least a lot of difficulty with functional activities report using devices. This is simply an area that calls for attention from both national authorities and international organisations.

Assistive devices are more common in urban than in rural areas, and among males compared to females and among the older age groups. An expected increase in the need for assistive devices with increased severity of disability was confirmed as the proportion of assistive device users was more than double (11.6 %) among individuals with severe as compared to moderate disabilities. Further, disability severity was also found to be associated with reduced satisfaction with the assistive device. As in previous similar studies, the results further confirm that the selection of assistive devices available is narrow and mostly confined to mobility and information devices. This means that Uganda is unable to meet the needs of a diverse population of disabled. A fragmented supply chain, lack of maintenance and training as shown in this study all confirm that this is an area in need of substantial input and development.

### 10.3.7 Health, well-being and health information

More than four out of ten persons with disabilities reported that they use medication for pain caused by their disability. This may seem to be on the high side, and most likely, a lot of this medication is non-prescriptive pain

killers. Higher proportion of persons with disabilities reporting chronic illness 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. This however also contributes to underline that individuals with disability have more health care needs than non-disabled, and its provision is necessary for equity in health to be more than a slogan. In the oft-cited UBOS (2020) research, it was however found that persons with disabilities face many of the same health challenges as their counterparts without disabilities, including HIV/AIDS, but often experience less access to healthcare and treatment, and less good health overall. Costs of healthcare, including transport to health centres, can also be a barrier to accessing services for persons with disabilities. A major reason why persons with disabilities experience less access to healthcare is that they are often not considered a priority area for funding purposes. A significant proportion of the Ministry of Health's funding derives from international donors who may not prioritise disability issues, and often have a disease-specific agenda (for example, HIV/AIDs, neglected tropical diseases, and malaria).

The relationship between health and disability is confirmed by both the household level individual data and the individual level data, with lower levels of well-being, physical and mental health as assessed by the individuals with disability themselves. An additional aspect of this is that illness increases with severity of disability. It is particularly important to be aware of increased prevalence of mental health problems among persons with disabilities and more so among those with severe disabilities. In most poor countries, mental health services tend to be grossly under-dimensioned if they exist at all. Untreated mental health problems are disabling in themselves and can aggravate the situation for persons living with disabilities.

The study has further revealed that a number of respondents report not to have knowledge about four common diseases. While this seems to be less of a problem with HIV/AIDS, the knowledge gap among individuals with disabilities is around 38 – 46 % for the STDs, Diabetes and TB and between 33 – 42 % for non-disabled. More females report no knowledge, and the gender difference is between 3 – 8 percentage points for the different diseases for both groups (disabled and non-disabled). Around 15 % (varying from 12.4 % to 17.8 %) confirmed that they had problems in understanding information given on the different diseases. There were small differences between the different diseases and between males and females although around 1 – 2 percentage points more females than males reported problems in understanding three of the diseases. The main source of information about common diseases for both disabled and non-disabled was a health clinic (34 – 41 %), which can be considered as a good sign as we can expect health professionals at health clinics to provide correct information. It adds to this that 10 – 16 % states doctor/nurse as the source. Friends, Radio/TV, schools and family are also important sources of information for all four diseases. Small differences between disabled and non-disabled may be seen as a positive sign and indicating that persons with disabilities are not particularly excluded from health information in this context.

Inaccessible and/or limited information are barriers, particularly for individuals with disability. Thus, addressing health and disability also includes 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 awareness-raising among health workers and particularly strategies to ensure inclusion of individuals with disability.

Most (14.8 %) confirmed that they had ever had an STI, followed by HIV/Aids (8.8 %), diabetes (8.6 %) and TB (7.2 %). While more females with and without disabilities confirmed having or having had diabetes, more males with than without disabilities had TB and HIV/AIDS, these and other differences were small. The relatively small differences between disabled and non-disabled still is sufficient to confirm the broader picture of higher morbidity among individuals with disabilities.

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 overshadow health problems. It is a prerequisite for equitable health services that service providers are conscious about the double burden faced by many individuals with disabilities, i.e. poorer mental and physical health in addition to the impairment/disability. In all, the findings in this research on health are consistent with those by BtG (2018) which established, among other things, that a significantly higher proportion (77%) of women with disabilities were not using family planning methods compared to non-disabled women (67%). The difference is that it appears the current study never investigated use of family planning in details.

### 10.3.8 Accessibility

The results on accessibility at home reflect the standard of housing which will vary between locations. The majority of respondents have accessible kitchen, bedroom, toilet and living room, while fewer reported to have a dining room in the home. Only around 4 – 5 % reported that the different facilities were inaccessible, while more than half reported not to have (not available) a dining room and more than one in four did not have a living room. More urban dwellers reported to have a living room and a toilet. Even though these facilities were mostly accessible, inaccessibility can be a serious problem for those who are faced with such challenges and thus reduce participation and the quality of life of many individuals. Mapping and adaptation, where needed, could be carried out by health and rehabilitation services at community level.

Many of the facilities mentioned in the questionnaire were not applicable to the community, i.e., assumed to be mostly unavailable. Mostly, available services were accessible. Accessibility ranged from 36.1 % (school) to 88.8 % (banks). Quite a number stated that services were not available, with the highest figure found for post office, school and workplace. As could be expected most of the facilities are more available in urban than in rural areas.

### 10.3.9 Daily life and social inclusion

Many individuals with disability report that the family supports them in their daily activities. It is interesting to note that emotional support is the most frequent type of support together with economic support. Least frequent was found to be support to basic functions, which reflects the profile of our sample of persons with disabilities with relatively low numbers being unable to care for themselves. Indeed, the UBOS (2020) study established that, a person's informal safety net in Uganda has traditionally been their family as well as their community, with these networks offering financial, physical and emotional support. However, a number of factors, including land fragmentation, high levels of poverty and unemployment, migration, increasing living costs, and the HIV/AIDs crisis, have contributed to an increasing nuclearization of networks, with Ugandans now more likely to receive support from a smaller, more tight-knit group of family members. Consequently, although households and care structures can be blurred across a compound, living arrangements can provide a good indication of a person's care networks. Depending on age, impairment type and level of severity, this has

implications both for the support that a person with a disability provides, and the support that they receive. The same research revealed that in Uganda, persons with disabilities are more likely to live in larger households than their peers without disabilities and this kind of family structure can complicate the support system, to the disadvantage of the person with disability. Moreover, the research further revealed that households with persons with disabilities are also more likely to be headed by a woman. The reasons for this are complex, but gender is a significant factor concerning caring responsibilities and social norms, which in turn can increase vulnerability and lower living standards for the household. It also points to the fact that older persons with disabilities are most likely to be widowed women.

There is a consistent pattern in that control individuals are more involved than individuals with disability, in the family/household as well as in the community. For various variables on involvement, there is a gap of 4 – 10 percentage points when comparing individuals with and without disability, with the exception being 17 percentage points for participation in local community meetings. Further, involvement/participation decreases with increased severity, and there appears to be a complex relationship between sex, participation and disability severity. The results clearly indicate inclusion as an area in need of intervention both at family/household and community level.

It adds to the inclusion/participation gap shown above that awareness of DPOs and particularly membership in DPOs among individuals with disability is low, leaving the large majority of individuals with disability without this potentially important source of support and information.

# 11 CONCLUSIONS

Having established evidence for differences between the disabled and non-disabled population 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 people and the public in general.

Generally, the study reveals consistent differences between households with and without disabled members and between individuals with and without disabilities in Uganda. Level of living, measured by means of a range of different indicators, is higher among non-disabled than among disabled at both levels (household and individual). The gender and urban/rural dimension also play out among persons with disabilities, with the general finding being that living in rural areas and being female are associated with lower levels on most indicators. Over all, the findings in this current research indicate that although Uganda has put in place the requisite policy and legal framework aimed at strengthening the social security system, there are still issues to do with coverage, adequacy, efficiency and sustainability (GoU, 2019). As already indicated, the findings are consistent with the GoU (2019) report that reiterates that people with disabilities and their households have a lower standard of living than the non-disabled and are more likely to fall into poverty. This is attributed to the systemic institutional, attitudinal, and environmental barriers that affect disabled people's opportunities to participate in economic and social activities, resulting in reduced access to, for example, education, employment, and healthcare. It also further limits their effective incorporation within social, economic, and political networks (Yoe and More, 2003; Groce et al, 2011 and Trani & Loeb, 2012). In such a problematic environment, it is obvious that persons with disabilities, therefore, face greater challenges in acquiring the human and social capital needed to convert capabilities into functioning, thereby impacting on their capacity to access adequate incomes.

All together the study provides evidence for differences in level of living which should be reduced. 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 is called for to reduce the documented differences and to address service gaps and inadequacy in service delivery.

# 12 RECOMMENDATIONS

The editors of this report suggest a close collaboration among researchers, DPOs and the Government of Uganda in translating the results from the current study into practice. It is recommended that NUDIPU, relevant ministries and other key stakeholders, use this report to boost awareness about disability and disability rights in the country. The same stakeholders should work together to identify a long list and a short list of areas in need of improvement and then draw up an action plan on how to rectify the problems defined by the short list. They should ensure that disability is mainstreamed in their national budgets and program priorities.

Specifically, stakeholders are asked to prioritise the following:

- Through its Annual plan, National Development Plan and Vision 2040, government should continue to be committed in fighting poverty and deprivation in Uganda by implementing the existing disability inclusive policies, programs and a new legislation such as the Persons with Diability Act 2020. Doing this will strengthen the social protection system and help to alleviate the deplorable state of welfare of persons with disabilities since they constitute a good proportion of the vulnerable population in the country, both in the rural and urban areas.
- In the health sector, stakeholders should increase access to resources, such as assistive devices, to facilitate inclusion. Improving of health services for mother to child is also important as this could reduce avoidable disability and health problems that are found in this study to be substantial among the children.
- Extending the eligibility of the ongoing Senior Citizen's grant by lowering the age limit for coverage. The gist of this matter is to ensure that older persons with disabilities are explicitly and deliberately included in government social programs, as disability was found to be substantial among the older age groups. A good starting point could be in the current SAGE (social assistance grant), run by the Ministry of Gender, Labour and Social Development, by deliberately including all older persons with disabilities in the programs. Although the program is supposed to be universal and includes the elderly from 80 years and above, this could be deliberately lowered to 60 for persons with disabilities.
- Fully meeting the costs of education of persons with disabilities at all levels since the cost of attending school has been established to be a major reason for poor access and dropout from school. Though the current UPE and USE are expected to be free, there are certain costs that parents and caregivers still provide and these are the costs obstructing the education of persons with disabilities in poor families.
- Ensuring that persons with disabilities are integrated in the labour market. Though there are disability favourable labour market policies (e.g Uganda National Employment Policy, 2011, National Trade Policy, 2007, etc), enforcement, compliance, commitment and awareness seem to be the problem.
- Confronting the complex and integrated social and environmental barriers to services and activities for person with disabilities. Lack of social support and negative attitudes should be the primary targets. Stakeholders should device or invigorate strategies of awareness creation about persons with disabilities, their rights and potential to participate and contribute at all levels. This will have pay offs on their welfare and that of society in general.
- Infrastructure development, especially in the rural areas, such as building roads, bridges, schools, clean water, and health centres should be tackled since these currently constitute major environmental barrier in the rural areas.
- Families should unequivocally continue to give emotional and economic support to their members with disabilities. This is the first line of defence against discrimination and exclusion.

- NUDIPU in particular and other DPOs should expand their program of national awareness creation and membership for their members. This is a huge potential for information and source of support that can ward off discrimination, exploitation and exclusion.
- Academia, in partnership with donors and the local civil society fraternity should continue to partner on disability research in order to produce timely evidence-based data to inform policies and programming. In order to effectively deliver programmes and policies that support the promotion and protection of the rights of persons with disabilities, it is important for such research outputs to be disaggregated to the extent that allows implementors to know how many persons with disabilities there are in Uganda, their age distribution and where they live, and their type of impairment.
- Efforts should be made at all levels and in all sectors by all stakeholders to professionalise social work in the country. This can be achieved through strategically professionalise social work courses in all institution, recognising social work as a distinct profession in the civil service and creation of a prelesional social work body that ensure that social work is ethically practiced on the basis of its core values and principles.

# 13 REFERENCES

Altman, B. M. (2001) Definitions of disability and their operationalisation, measurement in survey data: An update. *Exploring Theories and Expanding Methodologies: Where we are and where we need to go*, 77-100.

Amin M, MacLachlan M, Mannan H, El Tayeb S, El Khatim A, Swartz L, Munthali A, Van Rooy G, McVeigh J, Eide A H, and Schneider M (2011) EquiFrame: A framework for analysis of the inclusion of human rights and vulnerable groups in health policies. *Health and Human Rights,* Vol 13 (2), December.

Brucker, D.L., & Helms, V.E. (2017). Measuring Disability. *Cityscape*, 19, 257-266.

BtG (2018). Bridging the gap: Examining disability and development in four African Countries- A Uganda Report. A project coordinated by Leonard Cheshire Disability Centre, University of London.

Currie, J., & Kahn, R. (2012) Children with Disabilities: Introducing the Issue. *The Future of Children,* 3-11.

Eide, A. H., Ingstad, B., (2013). Disability and poverty – Reflections on research experiences in Africa and beyond. African Journal of Disability, 2(1), pp.1–7.

Eide A H, Mji G, Chiawula M (2019) Need for, access to and quality of assistive technology in low- and middle-income countries. In: Global perspectives on assistive technology. Proceedings of the GReAT Consultation 2019, Vol 1. Geneva: World Health Organization.

Eide A H, Munthali A (2018) Living conditions among persons with disabilities in Malawi. A National, representative survey, 2017. SINTEF Report No. 20180065. Oslo: SINTEF Digital, Department of Health. DOI: 10.13140/RG.2.2.19303.09128

Eide A H, Mmatli T (2016) Living conditions among people with disability in Botswana. SINTEF Report No. A27196. Oslo: SINTEF Technology and Society.

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, Loeb M E, Kamaleri Y (2010) Vol. 5. Living conditions among people with disabilities in Mozambique. A national representative and comparative household survey among individuals with disabilities in Mozambique. Saarbrücken; Lambert Academic Publishing.

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

Finkelstein, V., & French, S. (1993). *Towards a psychology of disability.* In J. Swain, V. Finkelstein, S. French, & M. Oliver (Eds.), *Disabling barriers—Enabling environments* (p. 26–33). Sage Publications, Inc; Open University Press.

Flaskerud, J.H., & Winslow, B. J. (1998) *Conceptualizing Vulnerable Populations Health-Related Research. Nursing Research.* 47, 69-78.

GoU(2015) National Service Delivery Survey. A report. Ministry of Finance, Planning and Economic Development.

GoU (2019) State of Uganda Population Report. Promote Social Protection: Ensure Equity and Equality in harnessing the Demographic Dividend. Ministry of Planning Finance and Economic Development.

Groce, N., Kett, M., Lang, R., Trani, J. F. (2011). Disability and Poverty: The Need for a More Nuanced Understanding of Implications for Development Policy and Practice. Third World Quarterly, 32(8), pp.1493-1513.

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 KG, Eide AH (2009) Levekår blant personer med KOLS. *Tidsskrift for den norske lægeforening*, 15, 129, 146-8.

Johnson, B. & Christensen, L. (2004). Educational Research: Quantitative, Qualitative, and Mixed approaches ( 2nd ed). Needham Heights, MA: Allyn & Bacon.

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 & Society.

Krueger, R.A. (2000). Focus groups: A practical guide for applied research (3rd ed.). Thousand Oak, CA: Sage.

Langford, B. E., Schoenfeld, G. & Izzo, G. (2002). Nominal grouping sessions vs. focus groups. Qualitative Market Research 5: 58-70.

Madans J, Loeb M E, Eide A H (2017) Measuring Disability and Inclusion in relation to the 2030 Agenda on Sustainable Development. *Disability and the Global South*, 4, 1, 1164 – 1179.

Mannan, H., Amin M. & MacLachlan M., El Tayeb, S., El Khatim, A., Bedri, N. & McVeigh, J. & Swartz, L., Munthali, A., Van Rooy, G., Eide, A., & Schneider M. (2011) The EquiFrame Manual: A tool for Evaluating and Promoting the Inclusion of Vulnerable Groups and Core Concepts of Human Rights in Health Policy Documents. The Global Health Press, Dublin.

Matter B, Harniss M, Oderud T, Borg J, Eide A H (2016) Assistive Technology in Resource Limited Environments: A Scoping Review. *Disability and Rehabilitation: Assistive Technology*. DOI: 10.1080/17483107.2016.1188170. URL: http://dx.doi.org/10.1080/17483107.2016.1188170

McColl MA, Shortt S, Godwin M, et al. Models for integrating rehabilitation and primary care: a scoping study. *Arch Phys Med Rehabil*. 2009; 90:1523–1531.

McConkey, R. (2012). Disability, Illness and Poverty: Can the winter of despair lead to a springtime of hope? International Journal of Disability, Development and Education, 59(3), pp. 321–323.

Mitra, S. (2013). Data revolution for Disability-inclusive Development. Lancet Global Health, 1(4), pp. e178 - e179.

Mizunoya, S., Mitra, S. (2013). Is there a Disability Gap in Employment Rates in Developing Countries? World Development, 42, pp.28-43.

Morgan, D. L. (1997). Focus groups as qualitative research. Qualitative Research Methods Series, 16. Thousand Oaks, CA: Sage.

Munsaka, E., Charnley, H. (2013). "We do not have chiefs who are disabled": disability, development and culture in a continuing complex emergency. Disability and Society, 28(6), pp. 37–41.

Ojha, G. (ed.) (2018) Disability in Nepal: Taking stock and forging a way forward. A Report.

Omona, J. (2013) Sampling in Qualitative Research: Improving the Quality of Research Outcomes in Higher Education. Makerere Journal of Higher Education. ISSN 1816-6822 4(2) 2013, 169-185
DOI: http://dx.doi.org/10.4314/majohe.v4i2.4

Palmer, M. (2011). Disability and poverty: a conceptual review. Journal of Disability Policy Studies, 21(4), pp.210-18.

Retief M, Letsosa R (2018) Models of disability: A brief overview. HTS Theological Studies, 74, 1, a4738. https://doi.org/10.4102/hts.v74i14738

Shakespeare T (2014) Disability Rights and Wrongs Revisited. London: Routledge.

Shakespeare, T., & Watson, N. (2001). The Social Model of Disability: An outdated ideology? *Exploring Theories and Expanding Methodologies: Where we are and where we need to go*, 9-28.

Swindale, A. and Bilinsky, P. (2006) Household Dietary Diversity Score (HDDS) for Measurement of Household Food Access: Indictor Guid (v.2). Washington, D.C.: Food and Nutrition Technical Assistance Project, Academy for Educational Development.

Trani, J.F & Loeb, M (2012) Poverty and Disability: A vicious cycle? Evidence from Afghanistan and Zambia. *Journal of International Development*, 24 (1) S19-S52.DOI:10.1002/jid.1709

UBOS (2020). The Situational Analysis of Persons with Disabilities in Uganda. Ministry of Gender, Labour and Social Development

UBOS (2018) Uganda Functional Difficulties Survey 2017. Kampala: Uganda Bureau of Statistics.

UBOS (2014a) Uganda Population and Housing Census. A Report.

UBOS (2014b) Uganda Population and Housing Census. National Analytical Report.

UBS & MCHSS (2018) Zambia National Disability Survey 2015. Lusaka: Central Bureau of Statistics and Ministry of Community Development and Social Services.

UN (2006) Convention on the rights of persons with disabilities and optional protocol. New York: United Nations.

UN (1997) Human Development Report. Human Development to Eradicate Poverty. New York: United Nations.

UN (1994) The Standard Rules on the Equalization of Opportunities for Persons with Disabilities. New York: United Nations.

UN (1993) World Programme of Action Concerning Disabled Persons. New York: United Nations.

WHO, (2011) *World Report on Disability*. World Health Organisation.

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

WHO (1980) International Classification of Impairments, Disabilities and Handicaps. Geneva: World Health Organisation.

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

Yoe, R. & Moore, K. (2003) Including Disabled People in Poverty Reduction work: Nothing about us, without us. *World Development*, 31 (3): 571-590. DOI: 10.1016/S0305-750X (02) 00218.8

ZimStat and MHCC (2015) Living conditions among people with disability in Zimbabwe. A national representative household survey among individuals with and without disabilities. Harare: Zimbabwe National Statistics Agency and Ministry of Health and Child Care.

# 14 APPENDICES

## Appendix 1. Consent form

MAKERERE UNIVERSITY COLLEGE OF HEALTH SCIENCES
MILDMAY

INFORMED CONSENT TEMPLATE FOR INTENDING RESEARCHERS

Title of the proposed study: Living conditions of persons with disability in Uganda.

Investigators :
Give the names, contacts and institutions of the investigators.

Julius Omona, Makerere University, Department of Social Work and Social Administration, P.O Box 7062 Kampala, Ph 0782452618
Nanono Nulu, NUDIPU, Plot 530 Kisasi, Bukoto Road, P.O Box 8567 Kampala, Ph 0789357940

Background and rationale for the study:
Give a brief background and rationale for the proposed research.
The rationale for this study is that the large majority of people with disabilities live in developing countries, very often living under poor conditions and lacking basic support that could have improved their lives considerably. Disabled people are often marginalised and belong to the poorest segments of society further adding to a situation of powerlessness and lack of political influence. Many global documents, including the Convention on the Rights of Persons with Disabilities and it's Optional Protocol to which Uganda is a signatory, emphasise addressing the plight of persons with disabilities. The Convention marked a major milestone in the effort to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms of persons with disabilities, and to promote respect for their inherent dignity. Specific requirements for undertaking relevant research are included in the Convention. The current research is thus a move in this global direction and is a continuation of previous phases that have been undertaken on living conditions among disabled people in Southern Africa.

A description of sponsors of the research project and the organizational affiliation of the researchers:

The current research is a continuation of the project on "Living conditions among disabled people in Southern Africa" that have been carried out by SINTEF with funding from Atlas Alliance and NORAD. Arne H. Eide is the Chief Scientist in this study and is affiliated to SINTEF. The research project was initiated and is supervised by the National Union of Disabled Persons of Uganda (NUDIPU). The collection of data will be carried out by Makerere University. Uganda Bureau of Statistics and the Ministry of Gender, Labor and Social Development are key partners in the study

Purpose:
The objective for this project is to contribute to the improvement of Uganda disabled people's living conditions including the improvement of degree of activity and level of participation in society.
Specifically, it is aimed at the following:
- To carry out a representative nation-wide study on living conditions among people with disabilities in Uganda
- To lay the groundwork for repeated and long-term data collection on living conditions among people with disabilities in Uganda
- To assist in capacity building among disabled peoples' organisations and relevant professionals at ministerial level

The study is not experimental; rather the method is an interview-based household survey where participants will respond to a set of questionnaires.

Participants will be asked to respond to a survey that will last between 30 minutes and one hour.

Procedures:
The study will be conducted in 12 sub-regions of the country - Busoga, Bukedi, Bugisu, Teso, Karamoja , Lango, Acholi, West Nile, Bunyoro , Tooro, Kigezi and Ankole, and these are thought to represent the disability population and characteristics in the country. In each sub-region, the Enumeration areas will be randomly selected until a total number of 175 households are selected and interviewed by an enumerator. Out of these about 116 hhs (2/3) shall constitute households with at least one person with a disability and the remaining hhs without disabilities for comparison purpose. In each household, the head of the household will be interviewed to respond to the hh questionnaires, and other specific questionnaires will be responded to by the appropriate respondents. The survey will consider all household members from 2 years and above.

Who will participate in the study:
(Brief description of the intended participants, the expected total number and how long each will be required to be active in the study).

The study will cover the 12 sub-regions involving a total of 10,472 households and the research will take a total of 45 days, including training and screening. Each selected household is expected to be active only within the time of interview. However, the hh can ask questions about the research up to the end of the project in 2019. Participants will be both people with a disability and those without. It will also involve children 2-17 years.

Risks/Discomforts and Benefits:

- A disclosure of appropriate alternative procedures or courses of treatment, if any, that might be advantageous to the research participant

There will be minimal risks to the participants as a result of taking part in the study. You may feel a bit sad, if you remember some difficult or traumatic events in your past. We will offer you support if this happens. If you want further support or advice, we will put you in touch with your local disabled people's organisation or other support. We will give you the internet address of the programme so that you can read updates about the research. If you want a copy of the final report of this project, or the programme as a whole, we will keep your contact details on a list to receive these. We will delete your contact details after we have sent these out to you.

The research will be beneficial to the participants in the long run, when policies and programs begin to be implemented in communities and at national level in a manner that will ensure quality, equity, inclusiveness, and adequacy. The communities and households with persons with disabilities will have enhanced welfare and a better society for all. The outcome of the research will also help to build capacity to utilise and disseminate research results in Uganda. It will contribute through providing evidence on which to base disability related advocacy, policy planning, monitoring and effective resource utilisation.

Confidentiality:
Your confidentiality will be protected in this research. Nobody will know if you have taken part in the project. Your interview will be transcribed, and translated into English if necessary. Your name and any other details will be removed from the transcript. We will keep the transcript for 10 years, and then destroy it. We may quote from you what you say, but you will not be identified. However, I should inform you that the SPH-REC and Uganda National Council of Science and Technology (UNCST) are entities which may have access to private information that identifies the research participants by name.

Alternatives/Voluntary participation
It is not compulsory that you have to take part in this project. It is entirely voluntary. If you decide not to participate, this will not affect any services you may be receiving wherever you are. You can stop the interview at any stage. You can also withdraw from the study after the interview is finished. You do not have to give a reason. But after the interviews are completed and we have started analysing the data, it will be too late to remove your data from the project.

Cost:
You don't need to meet any costs in the process of this interview. The interview will be conducted within your household- so you don't need to incur any cost such as transport, airtime or meals. In case the interviewer asks you to meet at a different venue, the costs of the transport and communication will be borne by him/her.

Compensation for participation in the study:
Since the interview will be conducted at participant's home, there will be no need for compensation.

Reimbursement:
Since investigators will meet interviewees from their homes, costs related to transport, time and meals are not catered for.

Questions about the study:
If the respondent has any study related questions, he/she should immediately ask the investigator to answer such question(s). If s/he is not satisfied with the response from the investigator on site, he/she should contact: Julius Omona on 0782452618 or Nanono Nulu on 0789357940.

Questions about participants rights:

If you have any questions about your rights as a research subject, you can call the Chair of the Higher Degrees, Research and Ethics Committee (HDREC) (Dr: Suzanne Kiwanuka on 0772886377.

Dissemination of results:
A statement that research participants will get feedback on findings and progress of the study and that any new information that affects the study or data that has clinical relevance to research participants (including incidental findings) will be made available to research participants and/or their health care providers.

Since this is a national research, dissemination will be done at national and local level before the closure of the project. Participants in the research are potential invitees to the dissemination workshops.

Ethical approval:
The study has been approved by MAKERERE UNIVERSITY COLLEGE OF HEALTH SCIENCES SCHOOL OF PUBLIC HEALTH RESEARCH AND ETHICS COMMITTEE (SPH-REC)

Consent:

STATEMENT OF CONSENT/ASSENT
..... has described to me what is going to be done, the risks, the benefits involved and my rights regarding this study. I understand that my decision to participate in this study will not alter my usual medical care. In the use of this information, my identity will be concealed. I am aware that I may withdraw at any time. I understand that by signing this form, I do not

waive any of my legal rights but merely indicate that I have been informed about the research study in which I am voluntarily agreeing to participate. A copy of this form will be provided to me.

Name ……Signature/thumb print of participant ……Date ……

Name ……Signature of parent/guardian for minors (If applicable)…Date ……...

Name……Signature of witness (if applicable)……Date…….

Name ……..Signature of interviewer/Person obtaining informed consent ……Date ……

**Appendix 2**

# Screening No…..

**HOUSEHOLD LISTING AND SCREENING FORM**

**Name of Enumeration zone:**

Name of District:_____

Sub-county…….. Name of RA:_____

Name of village/locality:_____ Cluster number:_____ Name of Head of Household

| HH No. | Name of HH member | Age | Sex | Marital status | Considering your health status do you: | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | have difficulty seeing, even if wearing glasses? | have difficulty hearing, even if using a hearing aid? | have difficulty walking or climbing steps? | have difficulty remembering, concentrating, or both? | have difficulty with self-care such as washing all over or dressing? | have difficulty, using the usual (customary) language, communicating (understanding or being understood by others)? | Is this HH member a person with a disability? |
| | | | | 1. Single<br>2. Married<br>3. Divorced<br>4. Separated<br>5. Widowed | 1 = NO 2 = SOME3 = A LOT4 = UNABLE TO DO IT | | | | | | 1=Yes, 2=No |
| | | | | | | | | | | | |
| | | | | | | | | | | | |
| | | | | | | | | | | | |
| | | | | | | | | | | | |
| | | | | | | | | | | | |
| | | | | | | | | | | | |
| | | | | | | | | | | | |
| | | | | | | | | | | | |

Supervisor: …… Checked ☐ Signature: ……

Day……. Month…… Year 2019 Started (time) ……. Completed (time) …….

# Screening 2 – 4 years Qualifies for being identified as a person with disability: At least one "Some difficulty" Or: At least "more" on CFD 16

| Screening code | Domain | CFM question | Response categories |
|---|---|---|---|
| CFD 11 | Seeing | **CFD3.** Does (child's name) have difficulty seeing? | 1) No difficulty<br>2) Some difficulty<br>3) A lot of difficulty<br>4) Cannot do at all |
| | Hearing | **CFD5**. Does (child's name) have difficulty hearing? | |
| | Walking | **CFD8**. Does (child's name) have difficulty walking? | |
| | Picking up things | **CFD11**. Compared to children of the same age, does (name) have difficulty picking up small things with his/her hand? | |
| | Understanding | **CFD12**. Compared with children of the same age, does (name) have difficulty in understanding you?<br><br>**CFD13**. When (name) speaks, does he/she have difficulty being understood by you? | |
| | Learning | **CFD14**. Compared with children of the same age, does (name) have difficulty learning things? | |
| | Playing | **CFD15**. Compared with children of the same age, does (name) have difficulty playing? | |
| | Kick, bite or hit | **CFD16**. Compared with children of the same age, how much does (name) kick, bite or hit other children or adults? | 1) A lot more<br>2) More<br>3) The same or less<br>4) Not at all |
| | | | |

| **Name of Child** | CFD3 | CFD5 | **CFD8** | **CFD11** | **CFD12** | **CFD13** | **CFD14** | **CFD15** | **CFD16** | | Disability Status 1=Yes, 2= No |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | | | | |
| | | | | | | | | | | | |
| | | | | | | | | | | | |

# Screening 5 – 17 years Qualifies for being identified as a person with disability: At least "Some difficulty" or At least "few times a year" Or At least "More"

| Screening code | | Domain | CFM question | Response categories |
|---|---|---|---|---|
| CFM-13 | CFM-7 | Seeing | **CFD3.** Does (child's name) have difficulty seeing? | 1)No difficulty<br>2)Some difficulty<br>3)A lot of difficulty<br>4)Cannot do at all |
| | | Hearing | **CFD5**. Does (child's name) have difficulty hearing? | |
| | | Walking | **CFD8**. Does (child's name) have difficulty walking 100 meters on level ground?<br>**CFD9**. Does (child's name) have difficulty walking 500 meters on level ground? | |
| | | Self-care | **CFD14**. Does (name) have difficulty with self-care such as feeding or dressing him/herself? | |
| | | Speaking | When (child's name) speaks does he/she have any difficulty being understood by:<br>• **CFD 15**. People inside the household?<br>• **CFD 16**. People outside the household? | |
| | | Learning | **CFD17**. Compared with children of the same age, does (name) have difficulty learning things? | |
| | | Remembering | **CFD18**. Compared with children of the same age, does (name) have difficulty remembering things? | |
| | | Anxiety/worry | **CFD19**. How often does (name) seem anxious, nervous or worried? | 1)Daily<br>2)Weekly<br>3)Monthly<br>4)A few times a year<br>5)Never |
| | | Depression/sadness | **CFD20**. How often does (name) seem sad or depressed? | |
| | | Controlling behaviour | **CFD21**. Compared with children of the same age, how much difficulty does (name) have controlling his/her behavior? | 1) No difficulty<br>2) The same or less<br>3) More<br>4) A lot more |
| | | Focusing attention | **CFD22**. Does (name) have difficulty focusing on an activity that he/she enjoys doing? | |
| | | Accepting change to routine | **CFD23**. Does (name) have difficulty accepting changes in his/her routine? | |
| | | Making friends | **CFD24**. Does (name) have difficulty making friends? | |

**Appendix 3**

| HOUSEHOLD | | CONFIDENTIAL |
|---|---|---|

# A Study on Living Conditions among People with Disabilities in Uganda 2018/19

## Questionnaire for Household Head

### (Conducted by NUDIPU/MAKERERE UNIVERSITY/SINTEF)

INFORMATION TO RESPONDENTS (READ OUT):

This is an inquiry about participation in a research project where the main purpose is to collect information about the level of living among households and individuals across Uganda.

We are particularly interested in information about persons struggling with daily life activities and participation. The project aims to map the level of living and compare between different groups. The information from the project will be useful in understanding who needs support from Government and civil society and how people can be helped to improve their level of living.

The research project was initiated and is supervised by the National Union of Disabled Persons of Uganda (NUDIPU). The collection of data is carried out by Makerere University. Uganda Bureau of Statistics and the Ministry of Gender, Labor and Social Development are key partners in the study.

This household has been randomly sampled. In each household we need to interview the head of the household, all persons with difficulties in performing daily life activities and possibly persons without such problems.

This is an interview-based survey, meaning that a research assistant will ask you questions and record the answers on his/her computer. Completing an interview will take approximately 30 minutes – 1 hour.

Participation is voluntary. If you choose to participate, you can withdraw your consent at any time without giving a reason. There will be no negative consequences for you if you chose not to participate or later decide to withdraw. All information provided by you will be anonymous, meaning that it will be impossible to identify who has answered what.

We will use the data for mapping of living conditions in Uganda, with particular focus on persons with limitations in their daily life activities. The result will be a report that is going to be used by NUDIPU, Makerere University, the Government of Uganda and international partners to address the plight of persons living with disabilities. The results will also be used in other publication formats.

Any questions about the study can be directed at: Julius Omona (Team Leader)/TELEPHONE 0782452618/0708386363 OR Nanono Nulu 0789357940/0704281033

**TO BE FILLED IN BY THE INTERVIEWER:**

**Ask the respondent if he/she consents to participate in the study – after reading the above statement.**

**Does the respondent consent to participate in the study?** **Yes** □ **No** □

| | | Code |
|---|---|---|
| 1. | Name and code of zone…… | |
| 1b | Name and Code of District | |
| 2 | Name of RA | |
| 3 | Location | 1 = Urban<br>2 = Rural |
| 4 | Ward Number | |
| 5 | Name of Village/Locality | |
| 6 | Cluster Number | |
| 7 | Household Number / ID | |
| 8 | Name of Household Head | |
| 8b: | Tribe of HH head | 1= Basoga<br>2= Jap<br>3= Bagisu<br>4= Muteso<br>5= Karamajong<br>6= Langi<br>7= Acholi<br>8= Alur<br>9= Lugbara<br>10= Banyoro<br>11= Batoro<br>12= Mukiga<br>13= Banyankole<br>96= Others specify .. |
| 9 | Gender of HH Head | 1= Male<br>2= Female |
| 10 | Was this household screened as: (Interviewer to observe) | Having at least 1 disabled member?……..…1<br>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 of interview |
|---|---|
| Time interview started ☐☐ ☐☐ Time ended ☐☐ ☐☐ | Day ☐☐<br>Month ☐☐<br>Year 2019 |
| Name of Interviewer:<br>Comments<br>Signature | |

| Supervisor | Interview Status | Enumerator has to return to the household | Checked by the Supervisor |
|---|---|---|---|
| Name:<br>Signature: | Complete…..….1<br>Incomplete…...2 | Yes……..…1<br>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 | Burden of Disease | |
|---|---|---|---|---|---|---|---|
| | Q14: List the first names and first letter of the surname of all persons in this household, starting with the head of the household | Q15: What is the relationship of (NAME) to the head of the household? * | Q16: What is (NAME) male or female?<br>1=Male<br>2=Female | Q17: How old was (NAME) at his/her last birthday?<br>**Enter age in completed years**<br>98=Don't know | Q18: What is (NAME'S) marital status? **<br>**Only 12yrs and above** | Q19: Has (NAME)been chronically ill during the past 12 months?<br>1=Yes<br>2=No → 21<br>98=Don't know → 21 | Q20: What was the illness? *** |
| (1) | 14 | 15 | 16 | 17 | 18 | 19 | 20 |
| 01 | | 0 1 | 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 | | | | |

| *CODES FOR Q.15 RELATIONSHIP TO HEAD OF HOUSEHOLD | **CODES FOR Q.18 MARITAL STATUS | ***CODES FOR Q.20 CHRONIC ILLNESSES |
|---|---|---|
| 1 = Head<br>2 = Husband/wife<br>3 = Son/Daughter<br>4 = Son/Daughter-in-law<br>5 = Grandchild of head<br>6 = Parent of head<br>7 = Brother/Sister of head<br>8 = Other relatives<br>9 = Domestic worker/Non-relative<br>10 = Other non-relatives<br><br>98 = Don't know | 1 = Never married<br>2 = Married with certificate<br>3 = Married traditional<br>4 = Consensual union<br>5 = Divorced/separated<br>6 = Widowed<br>7 = Inter family marriage<br>98 = Don't know/refuse | 1= Heart problem<br>2= Breathing problem<br>3=Asthma<br>4= Epilepsy<br>5= Cancer<br>6= Diabetes<br>7= Malfunction of kidney<br>8= High or low blood pressure<br>9= Acute respiratory infection<br>10= HIV/AIDS<br>11 = Malaria<br>12=Tuberculosis<br>13=Mental illness<br>96= Other specify |

## Section B. Level of 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 | Q21: Has (NAME) attended any school, college or university?<br>1 = YES<br>2 = NO Q→ 24<br>98 = DON'T KNOW →25 | Q22: How many years in all did (NAME) spend studying in school, college or university?<br>98 = DON'T KNOW | Q23: What is (NAME'S) highest standard form or level of education completed? * | Q24: If (NAME) never attend school, what is the reason? **<br>**(Code up to 2 reasons) To be asked only if (NAME) answered NO to Q 21** | Q25: Can (NAME) read and write in any language? (incl. mother tongue)<br>1 = YES<br>2 = NO<br>98 = DON'T KNOW | Q26: Is (NAME) **15 years old** or above?<br>YES→ Q.27?<br>NO → STOP<br>**CHECK Q.5** |
| (1) | 21 | 22 | 23 | 24 | 25 | 26 |
| | | | | | | YES NO<br>1 2 |
| | | | | | | 1 2 |
| | | | | | | 1 2 |
| | | | | | | 1 2 |
| | | | | | | 1 2 |
| | | | | | | 1 2 |
| | | | | | | 1 2 |
| | | | | | | 1 2 |

***CODES FOR Q.11**
**HIGHEST GRADE COMPLETED**

0 = Not completed Standard 1
1 = Standard 1
2 = Standard 2
3 = Standard 3
4 = Standard 4
5 = Standard 5
6 = Standard 6
7 = Standard 7
8 = Standard 8
9 = Form 1
10 = Form 2
11 = Form 3
12 = Form 4
13 = BA or equivalent
14 = MA or equivalent
15 = Vocational school
98 = Do not know/refuse

****CODES FOR Q.12**
**REASONS FOR NOT ATTENDING/LEFT SCHOOL/COLLEGE OR UNIVERSITY**

1 = Not enough money
2 = Failing/underachiever
3 = Illness
4 = Lack of interest
5 = Because of disability
6 = School not accessible
7 = Pregnancy
96 = Other
98 = Do not know/refuse

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

| LINE NO. | WORK STATUS* | POSSESS ANY SKILL? | | FILTER |
|---|---|---|---|---|
| Transfer the **LINE NO.** of persons as listed in Sect. A who are 15 yrs old or above | Q27: What is the work status of (NAME)? * | Q28: Apart from formal education, has (NAME) received any formal or informal training that has resulted in his/her having a particular skill e.g. carpentering, sewing, running business, farming etc.?<br><br>1 = YES formal<br>2 = YES informal<br>3 = NO<br>98 = DON'T KNOW | | Q29: Is (NAME) a **Female?**<br><br>YES → Q.30<br>NO → SECTION E<br>**CHECK Q.16** |
| (1) | 27 | 28 | | 29 |
| | | | | YES 1 / NO 2 |
| | | | | 1 / 2 |
| | | | | 1 / 2 |
| | | | | 1 / 2 |
| | | | | 1 / 2 |
| | | | | 1 / 2 |
| | | | | 1 / 2 |
| | | | | 1 / 2 |
| | | | | 1 / 2 |

***CODE FOR Q.27 WORK STATUS**

1 = Paid work
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 (health reasons)
= Unemployed (security reasons)
8 Unemployed (Can't find work)
9 = Unemployed (other reasons)
96 = Other specify
98 = Don't know/Refuse

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

| LINE NO. | CHILDREN married only? | NO. OF CHILDREN | | STILLBIRTHS | NO. OF STILLBIRTHS |
|---|---|---|---|---|---|
| Transfer the **LINE NO.** of persons as listed in Sect. A who are 15 yrs old or above | Q30: Does (NAME) have any children?<br>1 = YES<br>2 = NO → Q.32<br>98 = DON'T KNOW → Q.32 | Q31a: How many children do (NAME) have today?<br>**Don't include those that have died** | | Q32: Does (NAME) have pregnancies ended before term?<br>1= YES → Q 33<br>2= NO → SECT: E<br>98= DON'T KNOW → SECT: E | |
| | | BOYS | GIRLS | | |
| (1) | 30 | 31a | 31b | 32 | 33 |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |

**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 |
|---|---|---|---|---|
| 34 | 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 Remittances received | 2 | 2 | |
| | 3 Cash cropping | 3 | 3 | |
| | 4 Livestock and poultry sales | 4 | 4 | |
| | 5 Subsistence farming | 5 | 5 | |
| | 6 Formal business (registered) | 6 | 6 → | |
| | 7 Informal business (non-registered - see below*) | 7 | → 7 | |
| | 8 Private insurance/pension | 8 | 8 | |
| | 9 Workman's Compensation | 9 | 9 | |
| | 10 Rent | 10 | 10 | |
| | 11 Other (specify) | 11 | 11 | |
| | 12 No income from any source | 12→ Q37 | 12 | |
| | 13 Not stated/Refused | 13→ Q37 | 13 | |
| | * 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. | | | |
| 35 | How would you describe the level of income in the household | Much lower than average .....1<br>Lower than average .....2<br>Average .....3<br>Higher than average .....4<br>Much higher than average .....5 | | |

| Q. # | Question | Codes | | | | | | Go to Q |
|---|---|---|---|---|---|---|---|---|
| 36 | **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 | 88 | |
| | 2 Rent, building materials, land, house | 1 | 2 | 3 | 4 | 5 | 88 | |
| | 3 Fuel, power, electricity | 1 | 2 | 3 | 4 | 5 | 88 | |
| | 4 Agricultural inputs (fertilizer, labour, etc.) | 1 | 2 | 3 | 4 | 5 | 88 | |
| | 5 Medical care/health services | 1 | 2 | 3 | 4 | 5 | 88 | |
| | 6 Cultural and entertainment | 1 | 2 | 3 | 4 | 5 | 88 | |
| | 7 Cigarettes/tobacco/snuff | 1 | 2 | 3 | 4 | 5 | 88 | |
| | 8 Clothing/footwear | 1 | 2 | 3 | 4 | 5 | 88 | |
| | 9 Transportation | 1 | 2 | 3 | 4 | 5 | 88 | |
| | 10 Education | 1 | 2 | 3 | 4 | 5 | 88 | |
| | 11 Domestic servants | 1 | 2 | 3 | 4 | 5 | 88 | |
| | 12 Alcohol | 1 | 2 | 3 | 4 | 5 | 88 | |
| | 13 Savings/investments | 1 | 2 | 3 | 4 | 5 | 88 | |
| | 14 Disability related expenditure | 1 | 2 | 3 | 4 | 5 | 88 | |

**SECTION F. Dietary diversity and food intake**

| | | | |
|---|---|---|---|
| 37 | 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 Any fruits? | 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 Any sugar or honey? | 1 | 2 |
| | 12 Any other foods, such as condiments, coffee, tea? | 1 | 2 |
| 38 | How many meals does the household have normally per day? | ……..1<br>……..2<br>……..3<br>…… 4 | |
| 39 | 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<br>Rarely (1 – 2 times)..... 2<br>Sometimes (3 – 5 times)..... 3<br>Often (more than 5 times)..... 4<br>Don't know/refuse ..... 98 | |

**Section G: Ownership**

40 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 with paraffin | 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 | Washing machine | 1 | 2 |
| 26 | Satellite dish/ Aerial | 1 | 2 |
| 27 | Bed sheets | 1 | 2 |
| 28 | Blankets | 1 | 2 |
| 29 | Warm clothes | 1 | 2 |

| | | | |
|---|---|---|---|
| | **SECTION H. Information about dwelling**<br><br>**Which of the following best describes your dwelling?** *[Circle **ONE** only under each* | | |
| 41 | **Main type of roof** | Wood ..... 1<br>Corrugated iron sheets ..... 2<br>Grass/leaves thatch ..... 3<br>Tiles/shingles ..... 4<br>Paper/plastic..... 5<br>Asbestos sheets ..... 6<br>Other(specify) ..... 96 | |
| 42 | **Main type of floor** | Mud..... 1<br>Concrete/cement..... 2<br>Wood ..... 3<br>Tiles……4<br>Other(specify) ..... 96 | |
| 43 | **Main type of walls** | Poles & mud..... 1<br>Corrugated iron sheets ..... 2<br>Grass/leaves..... 3<br>Bricks (burnt or sun-dried)..... 4<br>Compacted earth ..... 5<br>Concrete ..... 6<br>Other(specify) ..... 96 | |
| 44 | **How many bedrooms does your main dwelling have?** | Number of bed rooms:_____ | |
| | | | |
| 45 | **Which of the following applies to your housing situation?** *[Circle ONE only]* | Rented ..... 1<br>Owned ..... 2<br>Rent Free (not owned)..... 3<br>Provided by employer (government) ..... 4<br>Provided by employer (private)..... 5<br>Other(specify) ..... 96 | |
| 46 | **Would you say that your dwelling is permanent?** | Yes, permanent .....1<br>Semi-permanent.....2<br>No, temporary.....3 | |
| 47 | **Does the household have access to land for cultivation purposes?** | Yes .....1<br>No .....2 | |

| | | | |
|---|---|---|---|
| 48 | **What is the MAIN source of drinking water in your household at present?** *[Circle ONE only]* | Piped water inside ..... 1<br>Piped water outdoors, on property..... 2<br>Piped water outside the property ..... 3<br>Public pipe/tap..... 4<br>Borehole ..... 5<br>Protected well..... 6<br>Unprotected well..... 7<br>River/ stream/dam/spring/lake..... 8<br>Rain-water tank ..... 9<br>Water carrier/tanker ..... 10<br>Other(specify) ..... 96<br>Don't know/refuse..... 98 | |
| 49 | **What is the distance to the household's source of drinking water?** | 0 (inside or on building).....1<br>0 – 50 meter .....2<br>51 – 100 meters.....3<br>101 – 500 meters.....4<br>501 meters – 1 km .....5<br>1 km + .....6 | |
| 50 | **What is the MAIN source of energy that your household uses for cooking and lighting?** | | |
| 51 | **Main source of energy for cooking** *[Circle ONE only]* | Electricity ..... 1<br>Paraffin ..... 2<br>Gas ..... 3<br>Wood ..... 4<br>Coal/charcoal..... 5<br>Solar..... 6<br>Dung/grass/stalks ..... 7<br>None ..... 88<br>Other (specify) ..... 96<br>Don't know/refuse..... 98 | |
| 52 | **Main source of energy for lighting** *[Circle ONE only]* | Electricity ..... 1<br>Paraffin ..... 2<br>Gas ..... 3<br>Wood ..... 4<br>Coal/charcoal..... 5<br>Solar..... 6<br>Candles ..... 7<br>Torch..... 8<br>None ..... 88<br>Other (specify) ..... 96<br>Don't know/refuse..... 98 | |
| 53 | **What kind of sanitation facility does your household mainly use?** | Flush toilet ..... 1<br>Traditional pit toilet..... 2<br>Ventilated improved pit toilet ..... 3<br>No facility..... 4<br>Other(specify) ..... 96<br>Don't know/refuse..... 98 | |

## Section I: Transport and Communication

54 **How long (in time) does it take to WALK ONE WAY to <u>each</u> 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/Ref used |
|---|---|---|---|---|---|---|---|---|
| 1 | Nearest primary school | 1 | 2 | 3 | 4 | 5 | 6 | 98 |
| 2 | Nearest secondary school | 1 | 2 | 3 | 4 | 5 | 6 | 98 |
| 3 | Nearest health facility | 1 | 2 | 3 | 4 | 5 | 6 | 98 |
| 4 | Nearest market/shop | 1 | 2 | 3 | 4 | 5 | 6 | 98 |
| 5 | Nearest sports facility | 1 | 2 | 3 | 4 | 5 | 6 | 98 |
| 6 | Post office | 1 | 2 | 3 | 4 | 5 | 6 | 98 |
| 7 | Police station | 1 | 2 | 3 | 4 | 5 | 6 | 98 |
| 8 | Church/mosque/temple | 1 | 2 | 3 | 4 | 5 | 6 | 98 |

55 **What is the MAIN MODE of transport that household members use when visiting <u>each</u> of these facilities?**

| | **Service/Facility*** | |
|---|---|---|
| 1 | Nearest primary school | |
| 2 | Nearest secondary school | |
| 3 | Nearest health facility | |
| 4 | Nearest market/shop | |
| 5 | Nearest sports facility | |
| 6 | Post office | |
| 7 | Police station | |
| 8 | Church/mosque/temple | |

**<u>Codes:</u>**

1 = Walk
2 = Bicycle
3 = Motor bike
4 = Bus
5 = Taxi
6 = Rickshaw/ tri cycle
7= Own car
8= Company car/
9 =Hike lift (car)
96= Other (specify) …..
98Don'tknow / NA

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

| | **Service** | Availability | | | | | Affordability | |
|---|---|---|---|---|---|---|---|---|
| | | Own/ use regularly | Have access to | Have no use for | Have no access to | DK/refuse | Yes | No |
| **1** | Telephone/mobile phone | 1 | 2 | 3 | 4 | 98 | 1 | 2 |
| **2** | Radio | 1 | 2 | 3 | 4 | 98 | 1 | 2 |
| **3** | Television (TV) | 1 | 2 | 3 | 4 | 98 | 1 | 2 |
| **4** | Internet (including Internet Café) | 1 | 2 | 3 | 4 | 98 | 1 | 2 |
| **5** | Newspaper (*purchase regularly) | 1 | 2 | 3 | 4 | 98 | 1 | 2 |
| **6** | Library (*use regularly) | 1 | 2 | 3 | 4 | 98 | 1 | 2 |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | **Section J: Other Information** | | | | | | |
| 57 | **Has any household member passed away within the past twelve months? (Circle only one)** | | | Yes ..... 1<br>No ..... 2<br>Do not know/refuse ..... 98 | | | →Stop<br>→Stop |
| 58 | **If YES, could you please tell me:** | | | | | | |
| | | **What was deceased person's position in the household?**<br>1= Head<br>2= Spouse<br>3= Son/Daughter of head<br>4= Spouse of child<br>5= Grandchild of head/spouse<br>6= Parent of head<br>7= Other relative<br>8= Domestic worker<br>9= Other non-relatives<br>98= DK<br>(Enter only one code) | **Was the deceased person female or male?**<br>1= Male<br>2= Female<br>(Enter one code) | **How old was she/he at the time of death?**<br>Enter age in completed years<br>98= DK | **Could you tell me what she/he died of?**<br>1= Accident (Car or other)<br>2= Violence/ Murder<br>3= Cancer<br>4= TB<br>5= Malaria<br>6= Diarrhea<br>7= Malnutrition<br>8= Measles<br>9= Pneumonia<br>10= Heart disease<br>11= High blood pressure<br>12= HIV/AIDS (related)<br>13= Other disease<br>14= Old age<br>15= Witchcraft<br>16= Suicide<br>98=DK<br>(Enter only one code) | **Was that person disabled?**<br>1= Yes<br>2= No<br>8= DK<br>(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 COMPLETING THE QUESTIONNAIRE AND ASK TO SPEAK TO A PERSON (randomly selected) TO COMPLETE THE CONTROL QUESTIONANNAIRE.**
**THANK THE PRIMARY RESPONDENT FOR THEIR TIME AND ASK TO SPEAK TO THAT PERSON IN ORDER TO COMPLETE THE DETAILED DISABILITY QUESTIONNAIRE.**

**Appendix 4.**
**Questionnaire for individuals with disabilities**

# A Study on Living Conditions among People with Disabilities in Uganda 2018/19

## Questionnaire for People WITH Disabilities

**(Conducted by NUDIPU/MAKERERE/SINTEF)**

**READ OUT BEFORE INTERVIEW**:

This is an inquiry about participation in a research project where the main purpose is to collect information about the level of living among households and individuals across Uganda.

We are particularly interested in information about persons struggling with daily life activities and participation. The project aims to map the level of living and compare between different groups. The information from the project will be useful in understanding who needs support from Government and civil society and how people can be helped to improve their level of living.

The research project was initiated and is supervised by the National Union of Disabled Persons of Uganda (NUDIPU). The collection of data is carried out by Makerere University. Uganda Bureau of Statistics and the Ministry of Gender, Labor and Social Development are key partners in the study.

This household has been randomly sampled. In each household we need to interview the head of the household, all persons with difficulties in performing daily life activities and possibly persons without such problems.

This is an interview-based survey, meaning that a research assistant will ask you questions and record the answers on his/her computer. Completing an interview will take approximately 30 minutes – 1 hour.

Participation is voluntary. If you choose to participate, you can withdraw your consent at any time without giving a reason. There will be no negative consequences for you if you chose not to participate or later decide to withdraw. All information provided by you will be anonymous, meaning that it will be impossible to identify who has answered what.

We will use the data for mapping of living conditions in Uganda, with particular focus on persons with limitations in their daily life activities. The result will be a report that is going to be used by NUDIPU, Makerere University, the Government of Uganda and international partners to address the plight of persons with disbilities. The results will also be used in other publication formats.

Any questions about the study can be directed to: Julius Omona (Team Leader) 0782452618 and Nanono Nulu 0789357940/0704281033

**To be filled in by the interviewer:**
**Ask the respondent if he/she consents to participate in the study.**
**Does the respondent consent to participate in the study?** **Yes** □ **No** □

| | | **Code** |
|---|---|---|
| 1 Name and Code of District | | |
| 2 Name of Sub county | | |
| 3 Location | 1 = Urban<br>2 = Rural | |
| 4 Ward name | | |
| 5 Name of Village | | |
| 6 EA Number | | |
| 7 Household Number / ID | | |
| 8 Name of Household Head | | |
| 8b Tribe of HH Head | 1 = Basoga<br>2 = Jap<br>3 = Bagisu<br>4 = Bateso | |

| | |
|---|---|
| | 5 = Karamajong<br>6 = Langi<br>7 = Acholi<br>8 = Alur<br>9 = Lugbara<br>10= Banyoro<br>11= Batoro<br>12= Bakiga<br>13= Banyangkole<br>96= Other, specify: |
| 9 Gender of HH Head | 1= Male<br>2= Female |
| **Detail of Person with Disability (copy from household roster)** | |
| 10 Name | |
| 11 Age (2 years +) | |
| 12 Line Number in Household Listing | |
| | |
| **Is this face to face interview with the person with disability?**<br>[Do not read out. Code by observation]<br>1 = Yes (i.e. interview directly with the person with disability)<br>2 = No (i.e. someone else is reporting on behalf of the person with disability)<br>3 = Both (i.e. someone else is reporting together with the person with disability)<br>4=Interpreter<br>Line number of person as proxy | |
| **To be completed by the interviewer**<br>Time interview started ☐☐ ☐☐ Time ended ☐☐ ☐☐ | **Date of interview**<br>Day<br>Month<br>Year 2 0 1 9 |
| Name of Interviewer:<br>Comments<br>Signature | |

| Supervisor | Interview Status | Enumerator has to return to the household | Checked by the Supervisor |
|---|---|---|---|
| Name:<br>Signature: | Complete…….1<br>Incomplete…..2 | Yes……1<br>No…….2 | ☐ |

| Q. # | Question | Codes | Go to Q |
|---|---|---|---|
| | **SECTION A: Activity Limitation and Participation Restrictions** | | |

13 **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 | Slight difficulty | Moderate difficulty | Severe difficulty | Unable to carry out the activity | Not specified/Not applicable |
|---|---|---|---|---|---|---|---|
| 1 | Watching/looking/seeing | 0 | 1 | 2 | 3 | 4 | 99 |
| 2 | Listening/hearing | 0 | 1 | 2 | 3 | 4 | 99 |
| 3 | Learning to read/write/count/calculate | 0 | 1 | 2 | 3 | 4 | 99 |
| 4 | Acquiring skills (manipulating tools, painting, carving etc.) | 0 | 1 | 2 | 3 | 4 | 99 |
| 5 | Thinking/concentrating | 0 | 1 | 2 | 3 | 4 | 99 |
| 6 | Reading/writing/counting/calculating | 0 | 1 | 2 | 3 | 4 | 99 |
| 7 | Solving problems | 0 | 1 | 2 | 3 | 4 | 99 |
| 8 | Understanding others (spoken, written or sign language) | 0 | 1 | 2 | 3 | 4 | 99 |
| 9 | Producing messages (spoken, written or sign language) | 0 | 1 | 2 | 3 | 4 | 99 |
| 10 | Communicating directly with others | 0 | 1 | 2 | 3 | 4 | 99 |
| 11 | Staying in one body position | 0 | 1 | 2 | 3 | 4 | 99 |
| 12 | Changing a body position sitting/standing/bending/lying) | 0 | 1 | 2 | 3 | 4 | 99 |
| 13 | Transferring oneself (moving from one surface to another) | 0 | 1 | 2 | 3 | 4 | 99 |
| 14 | Lifting/carrying/moving/handling objects | 0 | 1 | 2 | 3 | 4 | 99 |
| 15 | Fine hand use (picking up/ grasping/manipulating/releasing) | 0 | 1 | 2 | 3 | 4 | 99 |
| 16 | Hand & arm use (pulling/pushing/ reaching/throwing/catching) | 0 | 1 | 2 | 3 | 4 | 99 |
| 17 | Walking | 0 | 1 | 2 | 3 | 4 | 99 |
| 18 | Moving around (crawling/climbing/running/jumping) | 0 | 1 | 2 | 3 | 4 | 99 |

| | | | |
|---|---|---|---|
| | **Participation Restriction** | | |

14 **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 | Slight problem | Moderate problem | Severe problem | Complete problem (unable to perform) | Not specified/Not applicable |
|---|---|---|---|---|---|---|---|
| 1 | Washing oneself | 0 | 1 | 2 | 3 | 4 | 99 |
| 2 | Care of body parts, teeth, nails and hair | 0 | 1 | 2 | 3 | 4 | 99 |
| 3 | Toileting | 0 | 1 | 2 | 3 | 4 | 99 |
| 4 | Dressing and undressing | 0 | 1 | 2 | 3 | 4 | 99 |
| 5 | Eating and drinking | 0 | 1 | 2 | 3 | 4 | 99 |
| 6 | Shopping (getting goods and services) | 0 | 1 | 2 | 3 | 4 | 99 |
| 7 | Preparing meals (cooking) | 0 | 1 | 2 | 3 | 4 | 99 |
| 8 | Doing housework (washing/cleaning) | 0 | 1 | 2 | 3 | 4 | 99 |
| 9 | Taking care of personal objects mending/repairing) | 0 | 1 | 2 | 3 | 4 | 99 |
| 10 | Taking care of others | 0 | 1 | 2 | 3 | 4 | 99 |
| 11 | Making friends and maintaining friendships | 0 | 1 | 2 | 3 | 4 | 99 |
| 12 | Interacting with persons in authority (officials, village chiefs) | 0 | 1 | 2 | 3 | 4 | 99 |
| 13 | Interacting with strangers | 0 | 1 | 2 | 3 | 4 | 99 |
| 14 | Creating and maintaining family relationships | 0 | 1 | 2 | 3 | 4 | 99 |
| 15 | Making and maintaining intimate relationships | 0 | 1 | 2 | 3 | 4 | 99 |
| 16 | Going to school and studying (education) | 0 | 1 | 2 | 3 | 4 | 99 |
| 17 | Getting and keeping a job (work & employment) | 0 | 1 | 2 | 3 | 4 | 99 |
| 18 | Handling income and payments (economic life) | 0 | 1 | 2 | 3 | 4 | 99 |
| 19 | Clubs/organisations (community life) | 0 | 1 | 2 | 3 | 4 | 99 |
| 20 | Recreation/leisure (sports/play/ crafts/hobbies/arts/culture) | 0 | 1 | 2 | 3 | 4 | 99 |
| 21 | Religious/spiritual activities | 0 | 1 | 2 | 3 | 4 | 99 |
| 22 | Political life and citizenship | 0 | 1 | 2 | 3 | 4 | 99 |

| | | | |
|---|---|---|---|
| 15 | **<u>SECTION B: Environmental Factors</u>**<br><br>**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.**<br><br>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.<br><br>(Note: if a question asks specifically about **school or work** and you neither work nor attend school, check not applicable)<br><br>**Please CIRCLE only one.** | | |
| 16 | In the past 12 months, how often has the availability/accessibility of transportation been a problem for you? | Daily .....1<br>Weekly.....2<br>Monthly .....3<br>Less than monthly .....4<br>Never .....5<br>Not applicable.....99 | <br><br><br><br>→18<br>→18 |
| 17 | When this problem occurs has it been a big problem or a little problem? | Little problem .....1<br>Big problem .....2 | |
| 18 | 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<br>Weekly.....2<br>Monthly .....3<br>Less than monthly .....4<br>Never .....5<br>Not applicable.....99 | <br><br><br><br>→20<br>→20 |
| 19 | When this problem occurs has it been a big problem or a little problem? | Little problem .....1<br>Big problem .....2 | |
| 20 | 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<br>Weekly.....2<br>Monthly .....3<br>Less than monthly .....4<br>Never .....5<br>Not applicable.....99 | <br><br><br><br>→22<br>→22 |
| 21 | When this problem occurs has it been a big problem or a little problem? | Little problem .....1<br>Big problem .....2 | |

| | | | |
|---|---|---|---|
| 22 | 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<br>Weekly.....2<br>Monthly .....3<br>Less than monthly .....4<br>Never .....5<br>Not applicable.....99 | <br><br><br><br>→24<br>→24 |
| 23 | When this problem occurs has it been a big problem or a little problem? | Little problem.....1<br>Big problem.....2 | |
| 24 | In the past 12 months, how often has the availability of health care services and medical care been a problem for you? | Daily .....1<br>Weekly.....2<br>Monthly .....3<br>Less than monthly .....4<br>Never .....5<br>Not applicable.....99 | <br><br><br><br>→26<br>→26 |
| 25 | When this problem occurs has it been a big problem or a little problem? | Little problem.....1<br>Big problem.....2 | |
| 26 | 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<br>Weekly.....2<br>Monthly .....3<br>Less than monthly .....4<br>Never .....5<br>Not applicable.....99 | <br><br><br><br>→28<br>→28 |
| 27 | When this problem occurs has it been a big problem or a little problem? | Little problem.....1<br>Big problem.....2 | |
| 28 | 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<br>Weekly.....2<br>Monthly .....3<br>Less than monthly .....4<br>Never .....5<br>Not applicable.....99 | <br><br><br><br>→30<br>→30 |
| 29 | When this problem occurs has it been a big problem or a little problem? | Little problem.....1<br>Big problem.....2 | |
| 30 | In the past 12 months, how often have other people's attitudes toward you been a problem at home? | Daily .....1<br>Weekly.....2<br>Monthly .....3<br>Less than monthly .....4<br>Never .....5<br>Not applicable.....99 | <br><br><br><br>→32<br>→32 |
| 31 | When this problem occurs has it been a big problem or a little problem? | Little problem.....1<br>Big problem.....2 | |

| | | | |
|---|---|---|---|
| 32 | In the past 12 months, how often have other people's attitudes toward you been a problem at school or work? | Daily .....1<br>Weekly.....2<br>Monthly .....3<br>Less than monthly .....4<br>Never .....5<br>Not applicable.....99 | <br><br><br><br>→34<br>→34 |
| 33 | When this problem occurs has it been a big problem or a little problem? | Little problem .....1<br>Big problem .....2 | |
| 34 | In the past 12 months, how often did you experience prejudice or discrimination? | Daily .....1<br>Weekly.....2<br>Monthly .....3<br>Less than monthly .....4<br>Never .....5<br>Not applicable.....99 | <br><br><br><br>→36<br>→36 |
| 35 | When this problem occurs has it been a big problem or a little problem? | Little problem .....1<br>Big problem .....2 | |
| 36 | In the past 12 months, how often did the policies and rules of businesses and organizations make problems for you? | Daily .....1<br>Weekly.....2<br>Monthly .....3<br>Less than monthly .....4<br>Never .....5<br>Not applicable.....99 | <br><br><br><br>→38<br>→38 |
| 37 | When this problem occurs has it been a big problem or a little problem? | Little problem .....1<br>Big problem .....2 | |
| 38 | 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<br>Weekly.....2<br>Monthly .....3<br>Less than monthly .....4<br>Never .....5<br>Not applicable.....99 | <br><br><br><br>→40<br>→40 |
| 39 | When this problem occurs has it been a big problem or a little problem? | Little problem .....1<br>Big problem .....2 | |
| | **SECTION C: Cause and onset of difficulty** | | |
| 40 | To which category of impairment does the respondent belong? (Tick as applicable?) | Visual.....1<br>Hard of hearing.....2<br>Deaf .....3<br>Blind .....4<br>Epilepsy .....5<br>Physical (mobility and movement).....6<br>Intellectual .....7<br>Autism .....8<br>Mental disorder.....9<br>Albinism .....10<br>(Others) Specify?? 99 | |

| | | | |
|---|---|---|---|
| 41 | What is the main cause of your difficulties doing the activities (disability)?<br><br>(Single Response) | From birth/congenital .....1<br>Accident .....2<br>Fall .....3<br>Burns .....4<br>Disease/illness .....5<br>Beaten by members in the family.....6<br>Violence outside the house.....7<br>War related .....8<br>Animal related .....9<br>Stress related.....10<br>Witchcraft .....11<br>Other: _____.....12<br>Do not know .....98 | |
| 42 | How old were you when it started? | Age……. ☐☐<br><br>Do not know/refuse .....98 | |
| 43 | Have you ever been beaten or scolded by a family member because of your disability? | Yes .....1<br>No .....2<br>Do not know.....98 | |
| | **SECTION D: Abuse and discrimitation** | | |
| 44 | Have you ever been beaten or scolded by a non family member because of your disability? | Yes .....1<br>No .....2<br>Do not know.....98 | |
| 45 | Have you ever experienced being discriminated in any public services? For example: hospital, clinic, police station, bank, schools etc. | Yes .....1<br>No .....2<br>Do not know.....98 | |
| | | | |
| | **SECTION E: Health conditions** | | |
| 46 | Do you have any of the following health conditions? (Read All) | | |

| | | Yes | No |
|---|---|---|---|
| 1 | Heart problem | 1 | 2 |
| 2 | Accute respiratory infection | 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 | High or low blood pressure | 1 | 2 | |
| | 10 | HIV/AIDS | 1 | 2 | |
| | 11 | Malaria | 1 | 2 | |
| | 12 | Tuberculosis | 1 | 2 | |
| | 13 | Mental illness | 1 | 2 | |
| | 14 | Other specify | 1 | 2 | |
| | | | | | |
| 47 | **Have you ever lived in an institution or special home for people with disabilities?** | | Yes .....1<br>No .....2<br>Do not know .....98 | | |

**SECTION F: SERVICES**

48 **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]*

| | **Q481** Aware of Service | | **Q482** Needed Service | | **Q483** 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** | 1 | 2 | 1 | 2 | 1 | 2 |
| 11 **Faith healer** | 1 | 2 | 1 | 2 | 1 | 2 |
| 12 **Legal advice** | 1 | 2 | 1 | 2 | 1 | 2 |

CHKB X 1 Check Q48, and circle below
Circled at least one "Yes" or 1 to Q48.....
Circled all "No" or 2 to Q48.....

49 **How satisfied are you with the services you have received or are still receiving?**

*[code only ONE main characteristic per service]*

| | | Very satisfied | Satisfied | Neutral | Somewhat disatisfied | Very disatisfied | DK/refuse/ never | **Not appli cable** | |
|---|---|---|---|---|---|---|---|---|---|
| 1 | **Medical rehabilitation** (e.g. physiotherapy, occupational therapy, speech and hearing therapy etc) | 1 | 2 | 3 | 4 | 5 | 6 | 99 | |
| 2 | **Assistive devices service** (e.g. Sign language interpreter, wheelchair, hearing/visual aids, Braille etc.) | 1 | 2 | 3 | 4 | 5 | 6 | 99 | |
| 3 | **Educational services** (e.g. remedial therapist, special school, early childhood stimulation, regular schooling, etc.) | 1 | 2 | 3 | 4 | 5 | 6 | 99 | |
| 4 | **Vocational training** (e.g. employment skills training, etc) | 1 | 2 | 3 | 4 | 5 | 6 | 99 | |
| 5 | **Counselling for person with disability** (e.g. psychologist, psychiatrist, social worker, school counsellor etc) | 1 | 2 | 3 | 4 | 5 | 6 | 99 | |
| 6 | **Counselling for parent/family** | 1 | 2 | 3 | 4 | 5 | 6 | 99 | |
| 7 | **Welfare services** (e.g. social worker, disability grant, etc) | 1 | 2 | 3 | 4 | 5 | 6 | 99 | |
| 8 | **Health services** (e.g. at a primary health care clinic, hospital, home health care services etc.) | 1 | 2 | 3 | 4 | 5 | 6 | 99 | |
| 9 | **Health information** (e.g. from media, at schools, clinics, hospital etc.) | 1 | 2 | 3 | 4 | 5 | 6 | 99 | |
| 10 | **Traditional healer** | 1 | 2 | 3 | 4 | 5 | 6 | 99 | |
| 11 | **Faith healer** | 1 | 2 | 3 | 4 | 5 | 6 | 99 | |
| 12 | **Legal advice** | 1 | 2 | 3 | 4 | 5 | 6 | 99 | |

## SECTION G: EDUCATION

| | | | | | | |
|---|---|---|---|---|---|---|
| CHKB X2 | **Check respondent's age (Q11) and circle below**<br>Respondent 5 years or above ..... 1<br>Respondent below 5 years of age..... 2 | | | | | →SECT F……. |
| 50 | **Have you received a formal primary education?** | Yes .....1<br>No .....2<br>Not applicable .....99 | | | | →52 |
| 51 | **What type of school do or did you *mainly* attend in pre-school, primary, secondary or tertiary school?** | | | | | **→53** |
| | | Mainstream/ Regular school | Special school | Special class in mainstream/ regular | 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 | |
| 52 | 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<br>No .....2<br>Do not know/refuse.....98 | | | | |
| 53 | **Have you ever been refused entry into a pre-school, primary school, secondary school, or university because of your disability?**<br>*[Circle only **one** answer for each line]* | | | | | |
| | | Yes | No | Do not know | | |
| | 1 Regular pre-school | 1 | 2 | 98 | | |
| | 2 Regular primary school | 1 | 2 | 98 | | |
| | 3 Regular secondary school | 1 | 2 | 98 | | |
| | 4 Special school (any level) | 1 | 2 | 98 | | |
| | 5 Special class (remedial) | 1 | 2 | 98 | | |
| | 6 University | 1 | 2 | 98 | | |
| 54 | **Have you ever been refused entry into a pre-school, primary school, secondary school, or university because of lack of money?**<br>*[Circle only **one** answer for each line]* | | | | | |
| | | Yes | No | Do not know | | |
| | 1 Regular pre-school | 1 | 2 | 98 | | |
| | 2 Regular primary school | 1 | 2 | 98 | | |
| | 3 Regular secondary school | 1 | 2 | 98 | | |
| | 4 Special school (any level) | 1 | 2 | 98 | | |
| | 5 Special class (remedial) | 1 | 2 | 98 | | |
| | 6 University | 1 | 2 | 98 | | |
| 55 | **Did you have to drop out from a pre- school, primary school, secondary school or university any time in the past?**<br>*(Circle only **one** answer for each line]* | | | | | |
| | | Yes | No | Do not know | | |
| | 1 Regular pre-school | 1 | 2 | 98 | | |

| | | | | | |
|---|---|---|---|---|---|
| | 2 Regular primary school | 1 | 2 | 98 | |
| | 3 Regular secondary school | 1 | 2 | 98 | |
| | 4 Special school (any level) | 1 | 2 | 98 | |
| | 5 Special class (remedial) | 1 | 2 | 98 | |
| | 6 University | 1 | 2 | 98 | |
| 56 | **Why did you drop out of school?** | Not enough money/could not afford .....1<br>Failed school .....2<br>Because of illness .....3<br>Not interested .....4<br>Because of disability .....5<br>Difficult to get to school.....6<br>I was pregnant .....7<br>Do not know.....98 | | | |
| 57 | **Did you study as far as you planned?**<br><br>*[Do not read out; Circle only **one** answer]* | Yes .....1<br>No .....2<br>Still studying .....3<br>Do not know .....98 | | | |
| 58 | **Has your level of education helped you find any work at all?** | Yes .....1<br>No .....2<br>Do not know .....98<br>Not applicable .....99 | | | |
| | **SECTION H: Employment and Income** | | | | |
| CHKBX4 | **<u>Check Q11 and circle below</u>**<br>15 years or above ..... 1<br>Less than 15 years of age ..... 2 | | | | <br><br>→73 |
| 59 | Are you currently working?<br>(include casual labour, part-time work and those who are self-employed). Circle only **one** answer. | Yes, working ..... 1<br>No, but worked previously ..... 2<br>No, never worked ..... 3<br>Still studying ..... 4 | | | <br><br>→67<br>→67 |
| 60 | What is your income per month from your job (if previously employed than from previous job)? | **……in UGX** | | | |
| 61 | If you are currently unemployed, why did you stop working?<br><br>*To be answered ONLY if Q.59 is "**have been employed previously**". Circle only **one** answer.* | Retired.....1<br>Retrenched (due to cutbacks) .....2<br>Fired .....3<br>Injury/accident at work.....4<br>Illness .....5<br>Because of disability .....6<br>Other .....7<br>Do not know .....98<br>Not applicable .....99 | | | |
| 62 | Are you currently receiving social security, a disability grant or any other form of pension/grant? | Yes.....1<br>No .....2<br>Do not know .....98 | | | <br>→71<br>→71 |

| | | | |
|---|---|---|---|
| 63 | What type of grant or pension do you receive?<br><br>*[Do not read,/Circle **ALL** that apply]* | Disability grant .....1<br>Social cash transfer .....2<br>Workman's Compensation .....3<br>Private insurance .....4<br>Pension .....5<br>Other, specify _____ .....96<br>Do not know .....98 | |

64 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 (Most importortant) | Choice B (Second most important) |
|---|---|---|---|
| 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 assistance/carer (carer for self) | 10 | 10 |
| 11 | Other (specify) | 11 | 11 |
| 12 | Do not know | 98 | 98 |

| | | | |
|---|---|---|---|
| 65 | Are you the one who *mainly* decides how to spend your disability grant or pension? | Yes .....1<br>No .....2<br>Do not know .....98 | |

**SECTION I: Accessibility**

**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.**

66 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) | Not Available |
|---|---|---|---|---|
| 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 |

67 Now let's look at various places you might want to 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 |
|---|---|---|---|---|
| 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 (including bicycle taxi), train) | 1 | 2 | 3 |
| 14 | Hotels | 1 | 2 | 3 |

## SECTION J: ASSISTIVE DEVICES

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

68 Do you use any medication or traditional medicine for pain that is caused by your disability?
Yes .....1
No .....2 →75

69 If YES, what type of medication?
Modern medicine.....1
Traditional medicine .....2
Both .....3

70 Do you use an assistive device?
Yes .....1
No .....2 →82

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

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

| | Device category | Example | Yes | No | Not applicable (do not need it) |
|---|---|---|---|---|---|
| 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, toolsfor gardening | 1 | 2 | 3 |
| 7 | **Computer assistive technology** | keyboard for the blind | 1 | 2 | 3 |
| 8 | **Other** | Specify: | 1 | 2 | 3 |

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

*[If more than one device in one category, choose **most important** device*

| Type of device | Yes | No | Do not know |
|---|---|---|---|
| a | 1 | 2 | 98 |

73 Where did you get the main assistive device?

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

*[If more than one device in one category, choose **most important** device.*

| Name of Device | **Where did you get the main assistive device?** | | | | | |
|---|---|---|---|---|---|---|
| | Private | Government health services | Other government services | NGO | Other | Do not know |
| a | 1 | 2 | 3 | 4 | 5 | 98 |

74 Who, if any, maintains or repairs your main 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 | Who maintains/repairs your main assistive device(s) | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | 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 | 98 |

75 Were you given any information or help/training on how to use your main device (mentioned in Q76 above)?

| | Name of device | Given any information or help/training | | | |
|---|---|---|---|---|---|
| | | Complete/full information | Some information | No information | Do not know/ can not remember |
| | a | 1 | 2 | 3 | 98 |
| | c | 1 | 2 | 3 | 98 |

| | | |
|---|---|---|
| 76 | 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<br>Less content……. ……2<br>Content ……3<br>Very content…….……4<br>Do not know.....……..98 |

**SECTION K: Daily life and participation**

**Now we would like to hear how other people feel and what 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**

77 **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 | 99 |
| 2 | Toileting | 1 | 2 | 3 | 99 |
| 3 | Bathing | 1 | 2 | 3 | 99 |
| 4 | Eating/Feeding | 1 | 2 | 3 | 99 |
| 5 | Cooking | 1 | 2 | 3 | 99 |
| 6 | Shopping | 1 | 2 | 3 | 99 |
| 7 | Moving around | 1 | 2 | 3 | 99 |
| 8 | Finances | 1 | 2 | 3 | 99 |
| 9 | Transport | 1 | 2 | 3 | 99 |
| 10 | Studying | 1 | 2 | 3 | 99 |
| 11 | Emotional support | 1 | 2 | 3 | 99 |
| 12 | Other(specify) | 1 | 2 | 3 | 99 |

78 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 | 99 | 98 |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | 2 | Do you go with the family to events such as family gatherings, social events etc. | 1 | 2 | 3 | 99 | 98 | |
| | 3 | Do you feel involved and part of the household or family? | 1 | 2 | 3 | 99 | 98 | |
| | 4 | Does the family involve you in conversations? | 1 | 2 | 3 | 99 | 98 | |
| | 5 | Does the family help you with daily activities/tasks? | 1 | 2 | 3 | 99 | 98 | |
| | 6 | Do/did you take part in your own traditional practices (e.g. initiation ceremonies) | 1 | 2 | 3 | 99 | 98 | |
| | 7 | Are you aware of Organisations for people with disabilities (DPO)? | 1 | 2 | 3 | 99 | 98 | |
| | 8 | Are you a member of a DPO? | 1 | 2 | 3 | 99 | 98 | |
| | 9 | Do you participate in local community meetings? | 1 | 2 | 3 | 99 | 98 | |
| | 10 | **IF YES (1) in "9" above,**Do you feel your voice is being heard? | 1 | 2 | 3 | 99 | 98 | |
| | 11 | Did you vote in the last election? | 1 | 2 | | | | |
| | 12 | **IF NO (2) in "11" above,** was it related to your disability that you didn't vote? | 1 | 2 | | | | |

| | | |
|---|---|---|
| | **Only ask respondents with disability who are 15 years of age or older and reporting for themselves.**<br><br>**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.**<br><br>**If the person with disability is younger than 15 years then go to Section L or Q 85.** | |
| 79 | **(INSTRUCTION TO THE RA/NUMERATOR):**<br><br>*[Don't read the control question out loud]*<br><br>**FILTER QUESTION**<br>**Is the person 15 years of age or older?**<br><br>**Check Q11 and circle below**<br>15 years or above ..... 1<br>Less than 15 years of age ..... 2 | →90 |

| | | | |
|---|---|---|---|
| 80 | Do you make important decisions about your own life?<br><br>*[Read out; circle only **one** answer]* | All the time.....1<br>Sometimes.....2<br>Never.....3<br>Do not know.....98 | |
| 81 | Are you married or involved in a relationship? | Yes .....1<br>No .....2 | →88 |
| 82 | Does your spouse/partner have a disability? | Yes .....1<br>No .....2 | |
| 83 | Do you have children? | Yes .....1<br>No .....2 | →90 |
| 84 | If Yes, how many children? | _____ | |

| | | |
|---|---|---|
| | **SECTION L: Health and General Wellbeing** | |
| 85 | **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? | More so than usual .....1<br>Same as usual .....2<br>Less so than usual.....3<br>Much less than usual .....4 |
| 2 | Lost much sleep over worry? | Not at all .....1<br>No more than usual .....2<br>Rather more than usual .....3<br>Much more than usual .....4 |
| 3 | Felt you were playing a useful part in things? | More so than usual .....1<br>Same as usual .....2<br>Less so than usual.....3<br>Much less than usual .....4 |
| 4 | Felt capable of making decisions about things? | More so than usual .....1<br>Same as usual .....2<br>Less so than usual.....3<br>Much less than usual .....4 |
| 5 | Felt constantly under strain? | Not at all .....1<br>No more than usual .....2<br>Rather more than usual .....3<br>Much more than usual .....4 |
| 6 | Felt you couldn't overcome your difficulties? | Not at all .....1<br>No more than usual .....2<br>Rather more than usual .....3<br>Much more than usual .....4 |
| 7 | Been able to enjoy your normal day-to-day activities? | More so than usual .....1<br>Same as usual .....2<br>Less so than usual.....3<br>Much less than usual .....4 |
| 8 | Been able to face up to your Problems? | More so than usual .....1<br>Same as usual .....2<br>Less so than usual.....3<br>Much less than usual .....4 |
| 9 | Been feeling unhappy and Depressed? | Not at all .....1<br>No more than usual .....2<br>Rather more than usual .....3<br>Much more than usual .....4 |
| 10 | Been losing confidence in Yourself? | Not at all .....1<br>No more than usual .....2<br>Rather more than usual .....3<br>Much more than usual .....4 |
| 11 | Been thinking of yourself as a worthless person? | Not at all .....1<br>No more than usual .....2<br>Rather more than usual .....3<br>Much more than usual .....4 |

| | | | |
|---|---|---|---|
| | 12 Been feeling reasonably happy, all things considered? | More so than usual .....1<br>Same as usual .....2<br>Less so than usual.....3<br>Much less than usual .....4 | |
| 86 | 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? | Better than usual.....1<br>Same as usual .....2<br>Less than usual .....3<br>Much less than usual .....4<br>Do not know .....98 | |
| 87 | 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? | Better than usual.....1<br>Same as usual .....2<br>Less than usual .....3<br>Much less than usual .....4<br>Do not know .....98 | |
| | | | |
| | **SECTION M: Health literacy** | | |

88 **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 | Do not know | Yes | No | Do not know |
| 1 HIV/AIDS | Yes .....1<br>No .....2<br>Do not know 98 | | 1 | 2 | 98 | 1 | 2 | 98 |
| 2 STI | Yes .....1<br>No .....2<br>Do not know 98 | | 1 | 2 | 98 | 1 | 2 | 98 |
| 3 Diabetes | Yes .....1<br>No .....2<br>Do not know 98 | | 1 | 2 | 98 | 1 | 2 | 98 |
| 4 TB | Yes .....1<br>No .....2<br>Do not know 98 | | 1 | 2 | 98 | 1 | 2 | 98 |

| **CODES | | |
|---|---|---|
| 1 = Health Clinic | 5 = From friends | 9 = School |
| 2 = Doctor/Nurse | 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.**

**Appendix 5**

Individual – Control Confidential

# A Study on Living Conditions among People with Disabilities in Uganda 2018/19

## Questionnaire for People WITHOUT Disabilities

**(Conducted by NUDIPU/MAKERERER UNIVERSITY/SINTEF )**

**READ OUT BEFORE INTERVIEW**:

This is an inquiry about participation in a research project where the main purpose is to collect information about the level of living among households and individuals across Uganda.

We are particularly interested in information about persons struggling with daily life activities and participation. The project aims to map the level of living and compare between different groups. The information from the project will be useful in understanding who needs support from Government and civil society and how people can be helped to improve their level of living.

The research project was initiated and is supervised by the National Union of Disabled Persons of Uganda (NUDIPU). The collection of data is carried out by Makerere University. Uganda Bureau of Statistics and the Ministry of Gender, Labor and Social Development are key partners in the study.

This household has been randomly sampled. In each household we need to interview the head of the household, all persons with difficulties in performing daily life activities and possibly persons without such problems.

This is an interview-based survey, meaning that a research assistant will ask you questions and record the answers on his/her computer. Completing an interview will take approximately 30 minutes – 1 hour.

Participation is voluntary. If you choose to participate, you can withdraw your consent at any time without giving a reason. There will be no negative consequences for you if you chose not to participate or later decide to withdraw. All information provided by you will be anonymous, meaning that it will be impossible to identify who has answered what.

We will use the data for mapping of living conditions in Uganda, with particular focus on persons with limitations in their daily life activities. The result will be a report that is going to be used by NUDIPU, Makerere University, the Government of Uganda and international partners. The results will also be used in other publication formats.

Any questions about the study can be directed to: Julius Omona (Team Leader), Ph 0782452618/0708386363 or Nanono Nulu 0789357940/0704281033

**To be filled in by the interviewer:**

**Ask the respondent if he/she consents to participate in the study.**

**Does the respondent consent to participate in the study?** **Yes** □ **No** □

| | Code |
|---|---|
| 1 NAME AND CODE OF DISTRICT | |
| 2 NAME OF Sub county | |
| 3 LOCATION | 1= Urban 2=Rural |
| 4 NAME OF VILLAGE | |
| 5 EA NUMBER | |
| 6 HOUSEHOLD NUMBER/ID | |
| 7 NAME OF HOUSEHOLD HEAD | |
| 8 GENDER OF HH HEAD 1= Male 2= Female | |
| 8b Tribe of hh head | 1= Basoga<br>2= Jap<br>3= Bagisu<br>4= Bateso<br>5= Karamajong<br>6= Langi<br>7= Acholi<br>8= Alur<br>9= Lugbara<br>10= Banyoro<br>11= Batoro<br>12= Mukiga<br>13= Banyankole<br>96= Other specify<br>… |
| 9 Gender of HH head | 1 = Male<br>2 = Female |
| **DETAILS OF PERSON WITHOUT DISABILITY (copy from household roster)** | |
| 10 NAME | |
| 11 AGE (full years) | |
| 12 LINE NUMBER IN HOUSEHOLD LISTING | |
| | |
| TO BE COMPLETED BY THE INTERVIEWER | Date of interview |
| Time interview started ☐☐ ☐☐ Time ended ☐☐ ☐☐ | Day<br>Month<br>Year 0 1 9 |
| Name of Interviewer:<br>Comments<br>Signature | |

| SUPERVISOR | Interview Status | Enumerator has to return to the household | Checked by the Supervisor |
|---|---|---|---|
| Name:<br>Signature: | Complete…….1<br>Incomplete…..2 | Yes……1<br>No…….2 | ☐ |

| Q. # | Question | Codes | Go to Q |
|---|---|---|---|
| | **SECTION A: ACTIVITY LIMITATION AND PARTICIPATION RESTRICTIONS** | | |

13 **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 | Slight difficulty | Moderate difficulty | Severe difficult | Unable to carry out the activity | Not specified/Not |
|---|---|---|---|---|---|---|---|
| 1 | Watching/looking/seeing | 0 | 1 | 2 | 3 | 4 | 99 |
| 2 | Listening/hearing | 0 | 1 | 2 | 3 | 4 | 99 |
| 3 | Learning to read/write/count/calculate | 0 | 1 | 2 | 3 | 4 | 99 |
| 4 | Acquiring skills (manipulating tools, painting, carving etc.) | 0 | 1 | 2 | 3 | 4 | 99 |
| 5 | Thinking/concentrating | 0 | 1 | 2 | 3 | 4 | 99 |
| 6 | Reading/writing/counting/calculating | 0 | 1 | 2 | 3 | 4 | 99 |
| 7 | Solving problems | 0 | 1 | 2 | 3 | 4 | 99 |
| 8 | Understanding others (spoken, written or sign language) | 0 | 1 | 2 | 3 | 4 | 99 |
| 9 | Producing messages (spoken, written or sign language) | 0 | 1 | 2 | 3 | 4 | 99 |
| 10 | Communicating directly with others | 0 | 1 | 2 | 3 | 4 | 99 |
| 11 | Staying in one body position | 0 | 1 | 2 | 3 | 4 | 99 |
| 12 | Changing a body position (sitting/standing/bending/lying) | 0 | 1 | 2 | 3 | 4 | 99 |
| 13 | Transferring oneself (moving from one surface to another) | 0 | 1 | 2 | 3 | 4 | 99 |
| 14 | Lifting/carrying/moving/handling objects | 0 | 1 | 2 | 3 | 4 | 99 |
| 15 | Fine hand use (picking up/ grasping/manipulating/releasing) | 0 | 1 | 2 | 3 | 4 | 99 |
| 16 | Hand & arm use (pulling/pushing/reaching/throwing/catching) | 0 | 1 | 2 | 3 | 4 | 99 |
| 17 | Walking | 0 | 1 | 2 | 3 | 4 | 99 |

| Q. # | Question | Codes | | | | | | Go to Q |
|---|---|---|---|---|---|---|---|---|
| | 18 Moving around (crawling/climbing/running/jumping) | 0 | 1 | 2 | 3 | 4 | 99 | |
| | **PARTICIPATION RESTRICTION** | | | | | | | |
| 14 | **Do you have any difficulty performing this activity in your current environment?**<br><br>*[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]*<br><br>Read out the options | | | | | | | |
| | **PARTICIPATION RESTRICTION ITEMS** | No problem | Slight problem | Moderate problem | Severe problem | Complete problem (unable to perform) | Not specified/Not applicable | |
| | 1 Washing oneself | 0 | 1 | 2 | 3 | 4 | 99 | |
| | 2 Care of body parts, teeth, nails and hair | 0 | 1 | 2 | 3 | 4 | 99 | |
| | 3 Toileting | 0 | 1 | 2 | 3 | 4 | 99 | |
| | 4 Dressing and undressing | 0 | 1 | 2 | 3 | 4 | 99 | |
| | 5 Eating and drinking | 0 | 1 | 2 | 3 | 4 | 99 | |
| | 6 shopping (getting goods and services) | 0 | 1 | 2 | 3 | 4 | 99 | |
| | 7 Preparing meals (cooking) | 0 | 1 | 2 | 3 | 4 | 99 | |
| | 8 Doing housework (washing/cleaning) | 0 | 1 | 2 | 3 | 4 | 99 | |
| | 9 Taking care of personal objects (mending/repairing) | 0 | 1 | 2 | 3 | 4 | 99 | |
| | 10 Taking care of others | 0 | 1 | 2 | 3 | 4 | 99 | |
| | 11 Making friends and maintaining friendships | 0 | 1 | 2 | 3 | 4 | 99 | |
| | 12 Interacting with persons in authority (officials, village chiefs) | 0 | 1 | 2 | 3 | 4 | 99 | |
| | 13 Interacting with strangers | 0 | 1 | 2 | 3 | 4 | 99 | |
| | 14 Creating and maintaining family relationships | 0 | 1 | 2 | 3 | 4 | 99 | |
| | 15 Making and maintaining intimate relationships | 0 | 1 | 2 | 3 | 4 | 99 | |
| | 16 Going to school and studying (education) | 0 | 1 | 2 | 3 | 4 | 99 | |

| Q. # | Question | Codes | | | | | | Go to Q |
|---|---|---|---|---|---|---|---|---|
| | 17 Getting and keeping a job (work & employment) | 0 | 1 | 2 | 3 | 4 | 99 | |
| | 18 Handling income and payments (economic life) | 0 | 1 | 2 | 3 | 4 | 99 | |
| | 19 Clubs/organisations (community life) | 0 | 1 | 2 | 3 | 4 | 99 | |
| | 20 Recreation/leisure (sports/play/ crafts/hobbies/arts/culture) | 0 | 1 | 2 | 3 | 4 | 99 | |
| | 21 Religious/spiritual activities | 0 | 1 | 2 | 3 | 4 | 99 | |
| | 22 Political life and citizenship | 0 | 1 | 2 | 3 | 4 | 99 | |
| | | | | | | | | |
| 15 | **SECTION B - INVENTORY OF ENVIRONMENTAL FACTORS**<br><br>**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.**<br><br>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.<br><br>(Note: if a question asks specifically about **school or work** and you neither work nor attend school, check not applicable)<br><br>**Please CIRCLE only one.** | | | | | | | |
| 16 | In the past 12 months, how often has the availability/accessibility of transportation been a problem for you? | Daily ..... 1<br>Weekly..... 2<br>Monthly ..... 3<br>Less than monthly..... 4<br>Never ..... 5<br>Not applicable..... 99 | | | | | | <br><br><br><br>→18<br>→18 |
| 17 | When this problem occurs has it been a big problem or a little problem? | Big problem ..... 1<br>Little problem ..... 2 | | | | | | |
| 18 | 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<br>Weekly..... 2<br>Monthly ..... 3<br>Less than monthly..... 4<br>Never ..... 5<br>Not applicable..... 99 | | | | | | <br><br><br><br>→20<br>→20 |
| 19 | When this problem occurs has it been a big problem or a little problem? | Big problem ..... 1<br>Little problem ..... 2 | | | | | | |
| 20 | 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<br>Weekly..... 2<br>Monthly ..... 3<br>Less than monthly..... 4<br>Never ..... 5<br>Not applicable..... 99 | | | | | | <br><br><br><br>→22<br>→22 |
| 21 | When this problem occurs has it been a big problem or a little problem? | Big problem ..... 1<br>Little problem ..... 2 | | | | | | |

| Q. # | Question | Codes | Go to Q |
|---|---|---|---|
| 22 | 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<br>Weekly..... 2<br>Monthly ..... 3<br>Less than monthly..... 4<br>Never ..... 5<br>Not applicable..... 99 | <br><br><br><br><br>→24<br>→24 |
| 23 | When this problem occurs has it been a big problem or a little problem? | Big problem ..... 1<br>Little problem ..... 2 | |
| 24 | In the past 12 months, how often has the availability of health care services and medical care been a problem for you? | Daily ..... 1<br>Weekly..... 2<br>Monthly ..... 3<br>Less than monthly..... 4<br>Never ..... 5<br>Not applicable..... 99 | <br><br><br><br>→26<br>→26 |
| 25 | When this problem occurs does it become a big problem or a little problem? | Big problem ..... 1<br>Little problem ..... 2 | |
| 26 | In the past 12 months, how often did you need someone else's help in your home and could not get it easily? | Daily ..... 1<br>Weekly..... 2<br>Monthly ..... 3<br>Less than monthly..... 4<br>Never ..... 5<br>Not applicable..... 99 | <br><br><br><br>→28<br>→28 |
| 27 | When this problem occurs it been a big problem or a little problem? | Big problem ..... 1<br>Little problem ..... 2 | |
| 28 | 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<br>Weekly..... 2<br>Monthly ..... 3<br>Less than monthly..... 4<br>Never ..... 5<br>Not applicable..... 99 | <br><br><br><br>→30<br>→30 |
| 29 | When this problem occurs, has it been a big problem or a little problem? | Big problem ..... 1<br>Little problem ..... 2 | |
| 30 | In the past 12 months, how often have other people's attitudes toward you been a problem at home? | Daily ..... 1<br>Weekly..... 2<br>Monthly ..... 3<br>Less than monthly..... 4<br>Never ..... 5<br>Not applicable..... 99 | <br><br><br><br>→32<br>→32 |
| 31 | When this problem occurs it been a big problem or a little problem? | Big problem ..... 1<br>Little problem ..... 2 | |
| 32 | In the past 12 months, how often have other people's attitudes toward you been a problem at school or work? | Daily ..... 1<br>Weekly..... 2<br>Monthly ..... 3<br>Less than monthly..... 4<br>Never ..... 5<br>Not applicable..... 99 | <br><br><br><br>→34<br>→34 |
| 33 | When this problem occurs it been a big problem or a little problem? | Big problem ..... 1<br>Little problem ..... 2 | |
| 34 | In the past 12 months, how often did you experience prejudice or discrimination? | Daily ..... 1<br>Weekly..... 2<br>Monthly ..... 3<br>Less than monthly..... 4<br>Never ..... 5<br>Not applicable..... 99 | <br><br><br><br>→36<br>→36 |
| 35 | When this problem occurs it been a big problem or a little problem? | Big problem ..... 1<br>Little problem ..... 2 | |

| Q. # | Question | Codes | | | Go to Q |
|---|---|---|---|---|---|
| 36 | In the past 12 months, how often did the policies and rules of businesses and organizations make problems for you? | Daily ..... 1<br>Weekly..... 2<br>Monthly ..... 3<br>Less than monthly..... 4<br>Never ..... 5<br>Not applicable..... 99 | | | <br><br><br><br>→38<br>→38 |
| 37 | When this problem occurs it been a big problem or a little problem? | Big problem ..... 1<br>Little problem ..... 2 | | | |
| 38 | 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<br>Weekly..... 2<br>Monthly ..... 3<br>Less than monthly..... 4<br>Never ..... 5<br>Not applicable..... 99 | | | <br><br><br><br>→40<br>→40 |
| 39 | When this problem occurs, has it been a big problem or a little problem? | Big problem ..... 1<br>Little problem..... 2 | | | |
| | | | | | |
| | **SECTION C – EDUCATION**<br><br>**Check Page 1, age of person without disability- and ask only people who are 5 years or older** | | | | |
| CHKB 40 (CHKBX2) | **Check respondent's age and circle below**<br>Respondent 5 years or above ..... 1<br>Respondent below 5years of age..... 2 | | | | <br><br>→54 |
| 41 | **Have you received a formal primary education?** | Yes ..... 1<br>No ..... 2<br>Don't know/do not remember ..... 98 | | | →47<br><br>→47 |
| 42 | **If you have NOT received a formal primary education, have you ever attended classes to learn to read and write as an adult?** | | | | →47 |
| 43 | **Did you drop out from school?**<br>(circle only one answer for each line) | Yes ..... 1<br>No ..... 2<br>Do not know ..... 98 | | | |
| | | Yes | No | Don't know | |
| 1 | Regular pre-school | 1 | 2 | 98 | |
| 2 | Regular primary school | 1 | 2 | 98 | |
| 3 | Regular secondary school | 1 | 2 | 98 | |
| 4 | Special school (any level) | 1 | 2 | 98 | |
| 5 | University | 1 | 2 | 98 | |
| | | | | | |

| Q. # | Question | Codes | Go to Q |
|---|---|---|---|
| 44 | **Why did you drop out of school?** | Lack of money ..... 1<br>Failed ..... 2<br>Health problem ..... 3<br>Could not concentrate ..... 4<br>Because of disability ..... 5<br>Difficult to get to school ..... 6<br>Pregnancy ..... 7<br>Other ..... 98 | |
| 45 | **Did you study as far as you planned?**<br><br>*[Do not read; Circle only **one** answer]* | Yes ..... 1<br>No ..... 2<br>Still studying ..... 3<br>Don't know ..... 98 | → |
| 46 | **Have your level of education helped you find any work at all?**<br><br>*[Do not read out; Circle only **one** answer]* | Yes ..... 1<br>No ..... 2<br>Don't know ..... 98 | |
| | **SECTION D: EMPLOYMENT AND INCOME** | | |
| CHKB 47 | **Check Q11and circle below (ASK ONLY PERSONS 15 YEARS OLD OR ABOVE.)**<br>15 years or above ..... 1<br>Less than 15 years of age ..... 2 | | <br><br>→48 |
| 48 | Are you currently working? (include casual laborers, part-time work and those who are self-employed). Circle only **one** answer. | Yes, currently working ..... 1<br>No, but previously employed ..... 2<br>No, never been employed ..... 3<br>Housewife/homemaker ..... 4 | <br><br>→48<br>→48 |
| 49 | What is your income per month from your job (if previously employed than from previous job)? | **…….in UGX** | |
| 50 | If you are currently unemployed, why did you stop working?<br><br>*To be answered ONLY if Q45 is "**have been employed previously**". Circle only **one** answer.* | Retired ..... 1<br>Retrenched (due to cutbacks) ..... 2<br>Fired ..... 3<br>Injury/accident at work ..... 4<br>Illness ..... 5<br>Because of disability ..... 6<br>Other ..... 7<br>Do not know ..... 8<br>Not applicable ..... 99 | |

| Q. # | Question | Codes | Go to Q |
|---|---|---|---|
| | **SECTION E: HOW YOU FEEL AND WHAT YOU THINK ABOUT YOUR SURROUNDING**<br><br>**LET'S START WITH YOUR ROLE WITHIN THE HOUSEHOLD AND YOUR FAMILY** | | |
| 51 | 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.<br><br>*[Read out and circle **one** answer for each row]* | | |

| | | Yes | No | Sometimes | Not applicable | Don't Know |
|---|---|---|---|---|---|---|
| 1 | Are you consulted about making household decisions? | 1 | 2 | 3 | 99 | 98 |
| 2 | Do you go with the family to events such as family gatherings, social events etc. | 1 | 2 | 3 | 99 | 98 |
| 3 | Do you feel involved and part of the household or family? | 1 | 2 | 3 | 99 | 98 |
| 4 | Does the family involve you in conversations? | 1 | 2 | 3 | 99 | 98 |
| 5 | Do/did you take part in your own traditional practices (e.g. initiation ceremonies) | 1 | 2 | 3 | 99 | 98 |
| 6 | Do you participate in local community meeting? | 1 | 2 | 3 | 99 | 98 |
| 7 | **IF YES (1) in "6" above,** Do you feel your voice is being heard | 1 | 2 | 3 | 99 | 98 |
| 8 | Did you vote in the last election? | 1 | 2 | | | |

| | | | |
|---|---|---|---|
| 52 | Do you make important decisions about your own life?<br><br>*[Read out; circle only **one** answer]* | All the time ..... 1<br>Sometimes ..... 2<br>Never ..... 3<br>Don't know..... 98 | |
| | | | |

| Q. # | Question | Codes | Go to Q |
|---|---|---|---|
| | **SECTION F: HEALTH AND GENERAL WELL-BEING** | | |
| 53 | **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<br>Same as usual ..... 2<br>Less than usual..... 3<br>Much less than usual..... 4 | |
| | 2 Lost much sleep over worry? | Not at all ..... 1<br>No more than usual ..... 2<br>Rather more than usual ..... 3<br>Much more than usual ..... 4 | |
| | 3 Felt you were playing a useful part in things? | More so than usual ..... 1<br>Same as usual ..... 2<br>Less so than usual..... 3<br>Much less than usual..... 4 | |
| | 4 Felt capable of making decisions about things? | More so than usual ..... 1<br>Same as usual ..... 2<br>Less so than usual..... 3<br>Much less than usual..... 4 | |
| | 5 Felt constantly under strain? | Not at all ..... 1<br>No more than usual ..... 2<br>Rather more than usual ..... 3<br>Much more than usual ..... 4 | |
| | 6 Felt you couldn't overcome your difficulties? | Not at all ..... 1<br>No more than usual ..... 2<br>Rather more than usual ..... 3<br>Much more than usual ..... 4 | |
| | 7 Been able to enjoy your normal day-to-day activities? | More so than usual ..... 1<br>Same as usual ..... 2<br>Less so than usual..... 3<br>Much less than usual..... 4 | |
| | 8 Been able to face up to your Problems? | More so than usual ..... 1<br>Same as usual ..... 2<br>Less so than usual..... 3<br>Much less than usual..... 4 | |
| | 9 Been feeling unhappy and Depressed? | Not at all ..... 1<br>No more than usual ..... 2<br>Rather more than usual ..... 3<br>Much more than usual ..... 4 | |
| | 10 Been losing confidence in Yourself? | Not at all ..... 1<br>No more than usual ..... 2<br>Rather more than usual ..... 3<br>Much more than usual ..... 4 | |
| | 11 Been thinking of yourself as a worthless person? | Not at all ..... 1<br>No more than usual ..... 2<br>Rather more than usual ..... 3<br>Much more than usual ..... 4 | |
| | 12 Been feeling reasonably happy, all things considered? | More so than usual ..... 1<br>Same as usual ..... 2<br>Less so than usual..... 3<br>Much less than usual..... 4 | |

| Q. # | Question | Codes | Go to Q |
|---|---|---|---|
| 54 | 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<br>Not very good ..... 2<br>Good ..... 3<br>Very good ..... 4<br>Don't know ..... 98 | |
| 55 | 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<br>Not very good ..... 2<br>Good ..... 3<br>Very good ..... 4<br>Don't know ..... 98 | |
| | **SECTION G: Services** | | |
| 56 | **Which services, if any, are you *aware* of and have ever *needed/received*?**<br>*[Read out; Enter the appropriate code for each column of each row]* | | |

| | | **<u>Q531</u>** Aware of Service | | **<u>Q532</u>** Needed Service | | **<u>Q533</u>** Received Service | | |
|---|---|---|---|---|---|---|---|---|
| | | Yes | No | Yes | No | Yes | No | |
| 1 | **Counseling for parent/family** | 1 | 2 | 1 | 2 | 1 | 2 | |
| 2 | **Welfare services** (e.g. social worker, disability grant, etc) | 1 | 2 | 1 | 2 | 1 | 2 | |
| 3 | **Health services** (e.g. at a primary health care clinic, hospital, home health care services etc.) | 1 | 2 | 1 | 2 | 1 | 2 | |
| 4 | **Health information** (e.g. from media, at schools, clinics, hospital etc.) | 1 | 2 | 1 | 2 | 1 | 2 | |
| 5 | **Traditional healer** | 1 | 2 | 1 | 2 | 1 | 2 | |
| 6 | **Faith healer** | 1 | 2 | 1 | 2 | 1 | 2 | |
| 7 | **Legal advice** | 1 | 2 | 1 | 2 | 1 | 2 | |

| Q. # | Question | Codes | Go to Q |
|---|---|---|---|
| | | | |

57 **How satisfied are you with the services you have received or are still receiving?**

*[code only ONE main characteristic per service]*

| | | Very [illegible] | Satisified with | Neutral | Somewhat disatisfied | Very disatisfied | DK/refuse/ never | **Not appli cable** | |
|---|---|---|---|---|---|---|---|---|---|
| 1 | **Medical rehabilitation** (e.g. physiotherapy, occupational therapy, speech and hearing therapy etc) | 1 | 2 | 3 | 4 | 5 | 6 | 99 | |
| 2 | **Assistive devices service** (e.g. Sign language interpreter, wheelchair, hearing/visual aids, Braille etc.) | 1 | 2 | 3 | 4 | 5 | 6 | 99 | |
| 3 | **Educational services** (e.g. remedial therapist, special school, early childhood stimulation, regular schooling, etc.) | 1 | 2 | 3 | 4 | 5 | 6 | 99 | |
| 4 | **Vocational training** (e.g. employment skills training, etc) | 1 | 2 | 3 | 4 | 5 | 6 | 99 | |
| 5 | **Counselling for person with disability** (e.g. psychologist, psychiatrist, social worker, school counsellor etc) | 1 | 2 | 3 | 4 | 5 | 6 | 99 | |
| 6 | **Counselling for parent/family** | 1 | 2 | 3 | 4 | 5 | 6 | 99 | |
| 7 | **Welfare services** (e.g. social worker, disability grant, etc) | 1 | 2 | 3 | 4 | 5 | 6 | 99 | |
| 8 | **Health services** (e.g. at a primary health care clinic, hospital, home health care services etc.) | 1 | 2 | 3 | 4 | 5 | 6 | 99 | |
| 9 | **Health information** (e.g. from media, at schools, clinics, hospital etc.) | 1 | 2 | 3 | 4 | 5 | 6 | 99 | |
| 10 | **Traditional healer** | 1 | 2 | 3 | 4 | 5 | 6 | 99 | |
| 11 | **Faith healer** | 1 | 2 | 3 | 4 | 5 | 6 | 99 | |
| 12 | **Legal advice** | 1 | 2 | 3 | 4 | 5 | 6 | 99 | |

| | |
|---|---|
| | |

| Q. # | Question | Codes | Go to Q |
|---|---|---|---|

58

**SECTION H: Health literacy**

**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<br>No .....2<br>Don't know...98 | | 1 | 2 | 98 | 1 | 2 | 98 |
| 2 | STI | Yes .....1<br>No .....2<br>Don't know...98 | | 1 | 2 | 98 | 1 | 2 | 98 |
| 3 | Diabetes | Yes .....1<br>No.....2<br>Don't know...98 | | 1 | 2 | 98 | 1 | 2 | 98 |
| 4 | TB | Yes .....1<br>No.....2<br>Don't know...98 | | 1 | 2 | 98 | 1 | 2 | 98 |

| **CODES | | |
|---|---|---|
| 1 = Health Clinic | 5 = From friends | 9 = School |
| 2 = Doctor | 6 = From Family | 96 = Other |
| 3 = At work | 7= Radio/TV | 98 = Don't know |
| 4 = Magazines/Newspapers | 8 = Poster and pamphlets | |

| 59 | **Do you have any of the following health conditions? (Read All)** | | |
|---|---|---|---|
| | | Yes | No |
| 1 | Heart problem | 1 | 2 |
| 2 | Acute respiratory infection | 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 | High or low blood pressure | 1 | 2 |
| 10 | HIV/AIDS | 1 | 2 |
| 11 | Malaria | 1 | 2 |
| 12 | Tuberculosis | 1 | 2 |
| 13 | Mental illness | 1 | 2 |
| 96 | Other specify | 1 | 2 |

**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**