BASELINE SURVEY ON SOCIAL INCLUSION OF PERSONS WITH DISABILITIES INTO SOCIAL SERVICES

Report

Rwanda, July 2012

Umbrella of Persons with Disabilities in the Fight against HIV&AIDS

PO Box 1493 Kigali – Rwanda, Tel: +250 788344552/ +250 788344553, Website: www.uphls.org, Email: infos@uphls.org

Disclaimer

This survey was commissioned by UPHLS; but the findings, interpretations, and conclusions expressed in this paper are entirely those of the authors and should not be attributed in any manner to Board of Directors, its affiliated organizations, or to any other entity.

Preamble

UPHLS as the umbrella organization for Disabled People Organizations in Rwanda plays a very significant and heightened role in the empowerment and promotion of equal opportunities, rights and full participation of persons with disabilities in Rwanda. Within the context of a global and national disability policy and program, UPHLS aspires constantly towards being in a position to predict the implications of the various policies and programs in terms of DPO-government-donor partner relations and to assess the potential impact on the work of DPOs and their partners on the improvement of the living conditions of persons with disabilities. This has also involved realization of the rights and strengthening of institutional framework for implementation of disability related programs as well as balancing the roles between influencing the DPO relations with government and donor-partner through the facilitation of dialogues among DPOs on the future direction of DPO operations in Rwanda in line with their individual agendas.

UPHLS foster and promote the consolidation of DPO service delivery work, experiences and achievements, and ensure that DPOs have clarity of mission and strategic direction in service provision. It encourages DPOs and Association of persons with disabilities to focus on their mission within the framework of government's national policies, plans and programs geared towards the improvement of the living conditions of persons with disabilities and the general enhancement of the lives of the people in Rwanda. In this process, UPHLS deals with tremendous challenges in the operating environment.

Primarily, UPHLS will address the issue of being relevant and responsive to the demands of individual DPO members, and demands from government, donors and other community based, national and international partners.

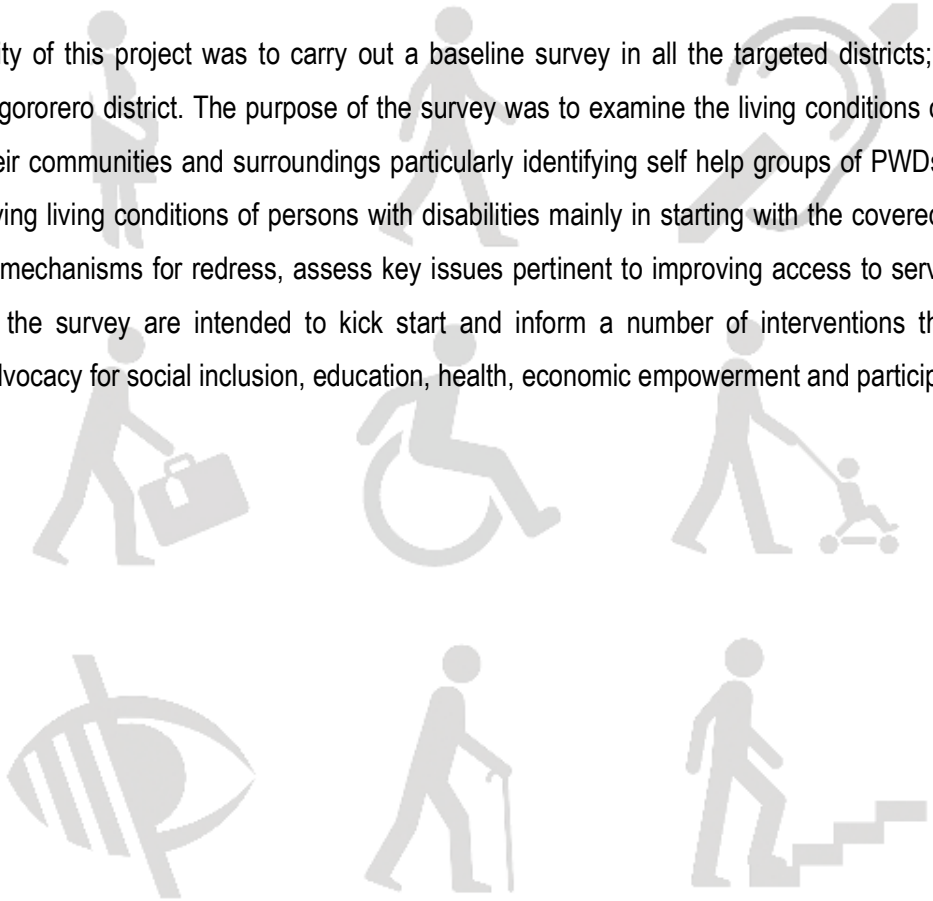
The operating concept for UPHLS has been in HIV/AIDS prevention, which clearly implies that UPHLS does not see its most important priority or its end-goal as policy development, but rather to ensure a barrier-free service delivery for persons with disabilities in Rwanda. Despite the very clear definition of the end-goal being centered on HIV/AIDS prevention, members strongly believe that the enjoyment of these services will only be possible if there is constant policy development and monitoring. Policy development and implementation therefore, will be used in an instrumental way and in the strategic view of UPHLS-members, as constituent element of and, essential means to an enabling service delivery environment for persons with disabilities.

FOREWORD

UPHLS is a Nonprofit and non-government organization working for the effective promotion of rights of persons with disabilities in health sector in Rwanda.

UPHLS in partnership with Light for the World-Netherlands implemented a baseline survey on social inclusion of persons with disability into social services in ten selected districts of Rwanda: Ngororero, Rusizi, Kicukiro, Kirehe, Nyagatare, Gakenke, Gasabo, Gicumbi, Nyamagabe and Muhanga.

The major activity of this project was to carry out a baseline survey in all the targeted districts; the first being undertaken in Ngororero district. The purpose of the survey was to examine the living conditions of persons with disabilities in their communities and surroundings particularly identifying self help groups of PWDs that might be helpful in improving living conditions of persons with disabilities mainly in starting with the covered districts, map out the existing mechanisms for redress, assess key issues pertinent to improving access to services of PWDs. The findings of the survey are intended to kick start and inform a number of interventions that will include Lobbying and advocacy for social inclusion, education, health, economic empowerment and participation.



Contents

Abbreviations and acronyms

AGHR	Association Générale des Handicapées au Rwanda
BPR	Banque Populaire du Rwanda
CBM	Christian Blind Mission
CBR	Community-based rehabilitation
CWDs	Child/children with disabilities
DPO	Disabled people's organization
ESSP	Education Sector Strategic Plan
FGD	Focus Group Discussion
HF	Health Facilities
HSSP	Health Sector Strategic Plan
MFI	Microfinance Institutions
MOH	Ministry of Health
NCPD	National council of persons with disability
P&O	Prosthetics and orthotics
RNUD	Rwandan National Union of the Deaf
RUB	Rwandan Union of the Blind
SACCO	Savings and Credit Co-operative
SEN	Special educational needs
THT	Troupe des Personnes handicapées Twuzuzanye
UPHLS	Umbrella of persons with disabilities in the fight against HIV/AIDS (UPHLS)
VSO	Voluntary Services Overseas

Glossary of Selected terms

Audiology - provides hearing assessments for persons who have difficulties hearing sounds and speech. They also fit and look after hearing aids for those who need them

Centre de santé - This is community health center staffed by a group of general practitioners and nurses

Disability- Disability summarizes a great number of different functional limitations occurring in any population in any country of the world. People may be disabled by physical, intellectual or sensory impairment, medical conditions or mental illness such impairments, conditions or illnesses may be permanent or transitory in nature.

Eye care services - Diagnosis and treatment of eye diseases and refractive and low vision services

Inclusion-Inclusion measures how persons with disabilities are taken into account in the design, implementation and evaluation of strategies, policies, programs, and projects.

Groupe scolaire - This includes The Nine Year Basic Education Program (9YBE) that is offering nine years of education to all Rwandan children free of charge and other public educational institutions like secondary school.

Handicap - The loss or limitation of opportunities to take part in the life of the community on an equal level with others it describes the encounter between the person with a disability and the environment.

Impairment - Impairment is a physical, intellectual, mental or sensory characteristic or condition, which places limitations on an individual's personal or social functioning in comparison with someone who does not have that characteristic condition.

Mutuelle de santé - is a community health based insurance that provides health coverage through voluntary and affordable local insurance

Njyanama - Group of elected community leaders representing different social groups within the community among others Women, Disabled, private sector, etc.

Occupational therapy – assists persons with temporary or permanent disability in activities of daily living (washing, dressing, seating, vocational, leisure) through therapy or adaptive devices.

Physiotherapy - treatment that uses physical means to relieve pain, regain range of movement, restore muscle strength and return patients to normal activities of daily living

Sector/umurenge - are the third level administrative subdivision in Rwanda. The Provinces of Rwanda are subdivided into 30 districts. Each district is in turn divided into sectors. There are 416 Sectors. This entire administrative structure is undergoing a process of decentralization - devolving greater authority to local governments and Municipalities.

Self help groups - refers to a system of behaviors and psychological processes occurring within a social group (*intra*self help groups).

Speech and Language Therapy – Supports children and adults who have difficulties in understanding or using language.

Acknowledgement:

It has been a pleasure to work with the whole UPHLS team and especially 9 District coordinators who vigorously mobilized self help groups from the grassroots, namely, MUGIRE KAGABA Jeannette, GATUSI NDAGWIJE Justin, MUKESHIMANA Claudine, UWINGABIRE Alphonsine, MUGEMANYI Augustin, UWUMUKIZA Providence, NDAGIJIMANA Olivier, NTWALI Antoine and MUNEZEREO Marie Mediatrice.

We greatly appreciate the support of our driver (HABARUREMA Jean Paul) who braved long hours of driving through terrible terrain. Many thanks go to all executive officials who gave their time to welcome us and also to participate in interviews, complete questionnaires and respond to numerous queries.

We are very grateful to Light for the World Netherlands for the financial and technical support they provided to us throughout the baseline survey.

Finally, and most importantly, we thank the persons with disabilities within the covered districts who participated directly in this study in focus groups discussion, in-depth interviews or indirectly by pressing their community leaders to include disabled people in development activities. We hope that, by listening to your voices and words, this report will bring positive changes in your lives.

Eric Mwanje, Blaise Shyirambere and Mathilde Umuraza (Research team Leaders)

Executive Summary

The UPHLS baseline survey was carried out in ten districts of Rwanda, from March to May 2012, gathering information through interviews using structured questionnaires, focus group discussion and observation. The aim of the survey was to gather baseline information on social inclusion of PWDs in social services. The sample of 561 participants, 208 females and 353 Males was drawn from those surveyed districts, plus 80 community leaders and 29 service providers interviewed.

The focus of this survey was on four thematic areas: social inclusion, health, education, economic empowerment and participation to determine the status of PWDs in those areas.

This Baseline survey will assist UPHLS in its planning and its core activities for instance advocacy and lobbying for the inclusion of persons with disabilities into social and health services. Persons with disabilities in Rwanda are among the poorest of the poor. Their numbers rose due war, genocide, AIDS&HIV and other diseases, etc. With disabled people invisible in development initiatives, hundreds of thousands of people who see themselves as potential and willing contributors to family and national economic activities are instead relegated to the margins of society where they are a perceived as actual burden. The result can be devastating, both to the individuals and to the economy.

This report provides disability movement in Rwanda with an assessment of current efforts to lobby for social inclusion of PWDs in the above four key areas. At the same time, it offers information and recommendations to UPHLS Secretariat and stakeholders on how best to move forward to improve the amount and quality of strategies that includes persons with disabilities.

KARANGWA Francois Xavier
Executive Director
UPHLS

ADMINISTRATIVE MAP OF RWANDA

CHAPTER 1: INTRODUCTION

Study background & terminology

GLOBAL CONTEXT

After the declaration of Universal Human Rights by U.N. in 1948, a lot of other proclamations, resolutions, declarations and adoptions emerged for persons with disabilities, notably:

- The International Year of the Disabled Persons (IYDP), which was proclaimed by General Assembly resolution 31/123 (1976)
- World Program of Action concerning Disabled Persons adopted by the General Assembly by its resolution 37/52 of (3 December 1982)
- Standard Rules for the Equalization of Opportunities and Full Participation of Persons with Disabilities
- International Convention on the Elimination of all Forms of Discrimination against Persons with Disabilities
- Convention on the Rights of Persons with Disabilities and Its Optional Protocol, adopted by the General Assembly by its resolution 61/106 in December 2006, and on 3 April 2008 triggering the entry into force of the Convention and its Optional Protocol 30 days later. This marks 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 of their inherent dignity
- African Plan of Action for Persons with Disabilities

All the above provisions constitute political obligations and moral foundation for the plight and support of Persons with Disabilities by all U.N. member nations.

MILLENNIUM DEVELOPMENT GOALS

Persons with disabilities (PWDs) in developing countries are disproportionately represented among the poorest people[1]. They have largely been overlooked in the development agenda so far, but the recent focus on poverty reduction strategies is a unique chance to rethink and rewrite the agenda. One of the Millennium Development Goals (MDGs) is the eradication of extreme poverty and hunger, a goal that cannot be achieved without taking into consideration the plight of PWDs.

Persons with disabilities are likely to become poorer because impairment or disability places heavy demand on limited resources and reduces access to opportunities for education and livelihood as the case. To prevent the disabilities that result from poverty, big changes are needed in the social order, government policies, allocation of resources and all planning process for developmental efforts.

NATIONAL CONTEXT

Basic Rights in the Constitution

Rwanda has confirmed its commitment to the U.N. Standard Rules on Disability by ratifying the UN Convention on the Rights of PWDs (UNCRPD) on 15/12/2008 and is a signatory to all major international human rights conventions.

The constitution states that the human person is sacred and inviolable (article 10) the State and all public administration organs have the absolute obligation to respect, protect and defend him or her. Furthermore, the constitution stresses that discrimination of whatever kind based on physical or mental disability or any other form of discrimination is prohibited and punishable by law (article 11). Therefore the State has the duty to take special measures to facilitate the education of disabled people (article 40) moreover the disability act of 2006 states that they are entitled to protection against discrimination especially with regard to health, employment and education (article 11, 13, 14, 15, 18, 19 &20). But while the constitutional framework and legal framework for the promotion of rights of persons with disabilities exist, the implementation remains an issue. This means that persons with disabilities have little access to what they are entitled to according to the national constitution.

Persons with disabilities are therefore unable to realize the majority of their basic human rights. They need strong organizations which are able to provide specific services for persons with disabilities and which are capable of representing them and advocating for changes at the national level. They also need opportunities to campaign for their own rights and influence changes in their immediate environments, which will enable them to improve the quality of their lives.

Poverty and Disability

Rwanda has begun to emphasize poverty reduction in their statement on disability. The joint position document of the famous incorporated Vision 2020, EPDRS and the MDGs components recommend poverty reduction as a key strategy in policies and services.

Scope of the Survey

The baseline survey was carried out in 10 districts drawing participants from twenty (20) sectors. The target groups were District authorities, welfare departments, Sectors, Njyanama, community health centers/district hospitals, educational institutes, SACCOs/Banks and grass root communities. The survey examined perceptions, forms, causes, level of awareness of general disability issues within the community. The survey further assessed means of redress and existing community interventions towards disability issues. Areas visited were 8 health centers; 5 hospitals, 1 referral hospital, 3 specialized centers, 10 schools, 3 banks, and 20 households. A total number of 561 respondents participated in the baseline survey.

Baseline Survey Objectives

The following objectives were to be achieved by the end of the study

- To review the involvement of persons with disabilities and their families in self help groups initiatives;
- To examine the living conditions of persons with disabilities in their communities and surroundings;
- To identify self help groups initiatives that might be helpful in improving living conditions of persons with disabilities;
- To understand the role of state and non-state actors on the rights of PWDs and come out with strategies for improvement of access to services.

Target Institutions and Target Respondents

The study was conducted in both government aided primary and secondary schools, health centers, district hospitals, referral hospital, district/sectors (Umurenge/Akarere) and SACCO or micro finance. The informants for whom the study targeted were the local authorities, head teachers, head of health facilities, head of financial institutions, community leaders and persons with disabilities as well as parents of PWDs.

Districts Profile

The baseline survey covered ten districts from four provinces plus Kigali City and from these provinces two Districts were selected based on the report on the mapping of associations & cooperatives of PWDs (2009). Findings from that report show that the following districts had the high prevalence of PWDs groups: Gakenke, Gasabo, Gicumbi, Kicukiro, Kirehe, Muhanga, Ngororero, Nyamagabe, Nyagatare and Rusizi. The table gives the summary about cooperatives and associations per district in the selected districts according to the mapping report of 2009[2].

Table 1: Associations/cooperatives/group dynamics in 10 selected districts

#	District	# of associations/cooperatives	# of members	# sectors
1	Gakenke,	30	1771*	19
2	Gasabo,	21	992*	15
3	Gicumbi,	32	62*	21
4	Kicukiro,	14	296*	10
5	Kirehe,	11	199*	12
6	Muhanga	16	846	12
7	Ngororero	33	415*	13
8	Nyamagabe	16	1249*	17
9	Nyagatare.	12	940	14
10	Rusizi	23	4335	18
Grand total		208	11,105	151

Note: * Some missing data on the exact number of members of the associations/districts, only figures collected are shown in the table.

From this table, we approximately targeted 11,105 people from 208 associations/cooperatives in 151 sectors.

Structure of report

The report is presented in four parts including the Introduction, the Methodology, Survey Findings and; Conclusions and Recommendations to inform future project activities.

CHAPTER 2: METHODOLOGY

2.1 Primary Data Sources

Two staff from the central office and nine district coordinators assisted by VSO volunteer conducted the study. The data collected using a questionnaire through either focus group discussion and interviews with key informant interviews described above as well as field visits conducted in the above mentioned districts constituted the primary data sources.

2.2 Secondary Data Sources

The desk review of policies, programs and reports of the relevant public and private organizations like Local Government reports, and district health centers/hospitals in the districts, mainly reports from Umurenge (sectors) in the covered districts among others gave insights on the situation of PWDs countrywide. Furthermore the observations of the venues and testimonies of PWDs talked more about the inclusion of PWDs in Rwanda

2.3 Data collection methods and tools

The UPHLS Baseline Survey Data Collection Instruments

An initial review carried out by the research team who were also charged with creation of the data collection tools based on desk review of the relevant literature and the situational analysis. The tool set for this baseline study comprises observation, undertaken by the research team, five different questionnaires, on different themes on social inclusion developed by the team; the questionnaires were administered by the research team.

The data collection instruments used for the Baseline Survey were as follows:

- Focus group discussion
- Situational analysis
- Face to Face interview with services providers
- Household's questionnaire

The research comprised a desk review of documents, followed by field visits to collect data. The key research techniques include observations, semi-structured interviews, focus group discussions and home-based interviews with person with disability and parents of disabled persons. This chapter presents information on data sources, methods of data collections and challenges faced during the collection of information. UPHLS decided it needed an independent assessment of how well it was doing at the grass root level, beginning with a baseline assessment. This report is the result. It uses criteria of Qualitative and quantitative data gathered from a survey of randomly selected

districts. The baseline assessment provided in this report can be used in the future to monitor progress on social inclusion and disability in UPHLS program activities.

The Focus Group Discussion

The focus group discussion was the main technique used to collect data. We had two types of focus groups discussions and the focus group members across the ten selected districts included:

1. One group discussion guide was for the self help groups leaders: two representatives per grass root association/cooperative/center of the PWDs participated into the discussion which lasted for 3 hours. The facilitator together with a note taker would guide the participants through 37 questions which go from the disability definition to the needs in capacities building of the organization to have access to equal opportunities to social services in the communities. The answers to the questionnaire formed the basis for the analysis.
2. Another questionnaire was structured for the members of the community advisory councils-sectors &cell-(Njyanama) with 12 questions through the focus group discussions we assessed the knowledge of the authorities on disabilities and how they do include them with their specific needs into the community development.

In-depth interviews

1. Care takers of PWDs/ Parents: We visited the PWDs' families where we held some discussions with the head of the families and the members of the families who are disabled if necessary to assess how families with PWDs do include them in the daily lives. The researchers went together with the family members through a guide of interview of … questions and access the acceptability of the disability as a diversity of the human nature and the burden of the disabilities on the whole family.
2. The service providers: They were divided into two main groups:
    a. The healthcare professionals: the interview to health service providers aimed at capturing their skills and knowledge towards disabilities and how they adjust their regular activities to include PWDs.
    b. Educations and the other service providers (education& banks/Micro finance Institutions): Based on the laws any public institutions should adjust to accommodate PWDs. The objective was to assess whether such institutions are including PWDs and what the challenges the do face to be inclusive.

Data Entry Guidelines

Data entry guidelines were agreed as follows:

- Design and develop a database using Microsoft Access

- An orientation of the data entry team
- Receiving and systematically entering the data into the database

Constraints

There were few constraints in carrying out this research:

- Persons with disabilities who participated in focus group discussions cannot be said to be representative of the majority of disabled people in Rwanda. This is because of the baseline survey only covered 10 districts out of 30 districts in Rwanda and most of the majority of participants are beneficiaries of UPHLS Global fund activities or they were all members of associations of persons with disability formed by community groups at sector level. Where possible, efforts were made to ensure that the participants were of different ages, sexes and had a range of impairments.
- The baseline survey sample size was small; more participants desired to be enlisted but were constrained by the budget provisions.

Mitigating Interventions:

- The survey team deeply explained the survey objectives, activities and expected results and benefits particularly to covered districts. This helped to enlighten and improve greatly the participants' perception and attitude towards the project and its outcome;
- Probing and prompting of the respondents was highly employed to enable the interviewers produce more correct information. The team further assured the key informants of the importance of the information given into future UPHLS programme planning;
- After the discussions and drawing from the participants' own experiences we took time to education the community on the rights of PWDs and explained further

Chapter 3: PRESENTATION AND DISCUSSION OF FINDINGS

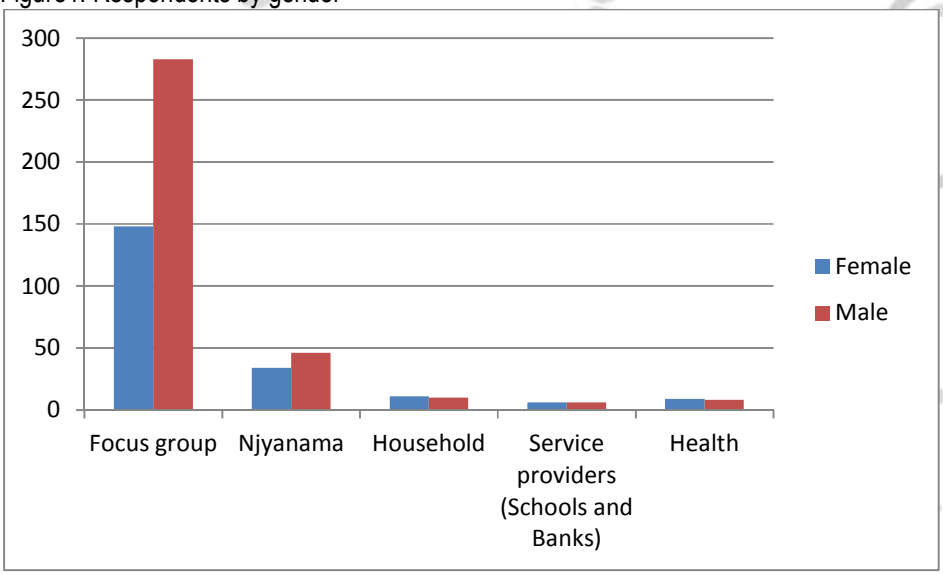
3.0. Introduction

This chapter is a presentation and discussion of findings on social inclusion of persons with disabilities into social services in 10 districts of Rwanda.

3.1. Characteristics of respondents

A total of 561 respondents participated in the baseline survey. The characteristics of the respondents are as shown below:

Figure1: Respondents by gender



3.2. Social exclusion & human rights

3.2.1. Defining Disability

There is much information in our collection on how disability was defined by the community. The data collected show a variety of definitions of disability is available show that disability is defined differently among the PWDs.

From the quote below, the community defines disability as impairment and vulnerability.

"Disability is defined as any condition which prevents a person from living normal social and working life." "Persons with disabilities are vulnerable", "Disability more defined based on functionalities and more related to physical deficiencies rather than environmental barriers" FGD of PWDs from Ngororero.

On the other hand, disability is defined as poverty thus some PWDs who are wealthy do not consider themselves as disabled neither does the community.

"*PWD are poor and have limited opportunities to development programs like VUP, Ubudehe & Girinka. Not all the people with are poor but those who are not poor do not join cooperatives/associations."* FGD of PWDs from Rusizi. The communities leaders do acknowledge that some PWDs are amongst the poorest but do not agree that PWDs are the poorest. They are aware that PWDs have some limitations towards development but deplore that the community are not rich to support them enough.

3.2.2. Human rights and social exclusion

3.2.2.1. Human rights

Table 2

Code	Label	Frequency on average
1	Health/Medical issue	80%
2	Poverty	85%
3	Human rights	90%

From the findings, human right issues were highlighted as the major issues PWDs do face. They are the poorest (85%) and have no or limited access to health and medical services (80%).

Analysis

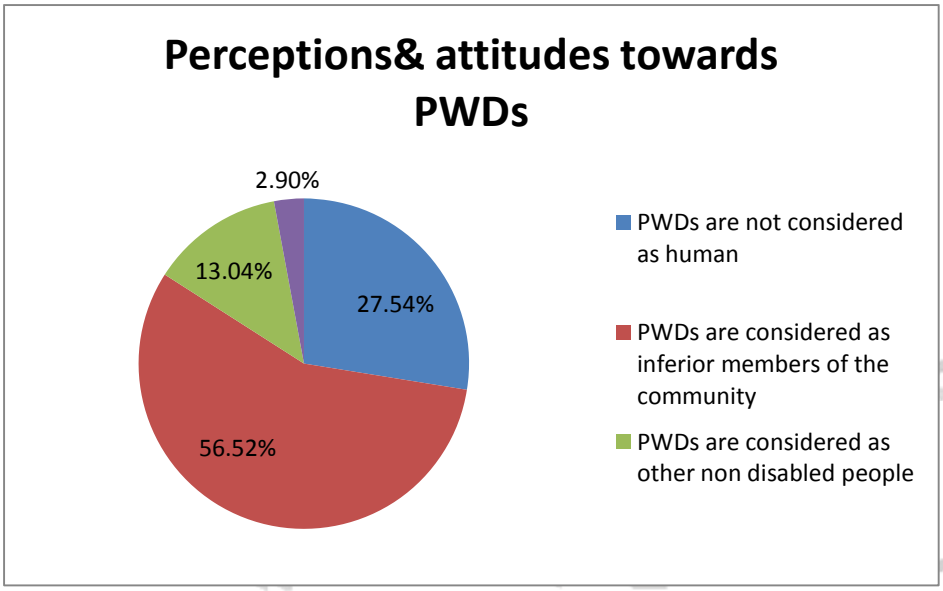
"*We are excluded in any decision making, whenever we try to raise our voice, people do not listen to us pretending that we are asking too much or there are other partners working with us to who we should go for any support"* Gicumbi FGD. *We hear that there are many organizations of PWDs, what do they do? The sectors are poor and cannot alone handle the problems of PWDs.* Community leaders from Kirehe

Stigmatization and discrimination, lack of knowledge on how to handle disability cases are the major causes of discrimination and isolation within the community, PWDs are considered or seen as a problem in their families and communities.

"*It is hard to live in the community when you are disabled, people look at you as abnormal and they think you are a curse think or you do suffer. They decide on anything about you without asking for your consent*" confessed CWD in a household.

On the other hand, PWDs are not counted and ignored in the community.
"*We only have some persons with disabilities! We do not see many, only this guy who is disturbing us asking for support for the roof*" Community leaders from Ngororero

❖ Perceptions & attitudes towards PWDs



56.52 % of respondents feel that they are considered as inferior people within the society. They live in and are among the poorest of the poor in their communities. 27% of PWDs feel that the community considers them as non human and only few members of the community (2.9%) do interact with them.

Analysis:

First, the common language refers to PWDs as objects rather than human beings. Some of the derogated names of PWDs referred to defect objects of daily use "*ikimuga"* (which can be literally translated as a defected pot).

Most of the time, they are commonly addressed by their types of disability rather than their real names. This reflects the stigmatization and discrimination towards PWDs within the community. This is exacerbated by some religious and traditional beliefs.

"Yes *we are always called by our disabilities! We are 'ibimuga'"* FGD in Nyamagabe.

Defected pots are kept in the backyard, they are of no use or neglected. "*Of course we are ibimuga! Family members are ashamed of us and when visitors come in we are asked not to come in the living room."* Household A from Gasabo

"Family *members are also referred to as parents, brothers/sisters of the defected! The household is called the family of or with the defected. It is a pity that people do consider us as abnormal. Some people especially children are afraid me thinking that I will contaminate them or eat them as I am a beast"* Household B in Kicukiro.

On the other hand, PWDs are excluded because some people due to ignorance are afraid that disabilities is communicable A single mother in household A in Kicukiro District confessed: "I *was born with the disabilities and when I got married my family in-law harassed my husband to divorce me saying that I would give birth to a defected family. Unfortunately that what happened when I gave birth to my first child, she was disabled. My husband abandoned me and my husband's family threw me out of the family house!"*

Some PWDs due to the stigma & discrimination they've been subjected to, at long run they are not confident and cannot push the community for change to include them into the development programs thus they are left out.

"Whenever you raise an issue on disabilities and inclusion, people including community leaders, they pretend to listen but take no actions… they simply shut you up. We've preferred to keep silent. " FGD in Gakenke

On the other hand, PWDs are seen as not normal; they are illiterate and not visible that the community members who have not been in regular contact with them or with negative mindset would say they are useless and or not mentally fit.

"*Disabled are sick and need to be protected and cured. If not it affects also their intellect"* Community leaders in Ngororero. *"I think some PWDs like psychosocial impaired and mentally ill are very dangerous and have to be kept in the special institutions to prevent the harm"* Community leaders from Gicumbi

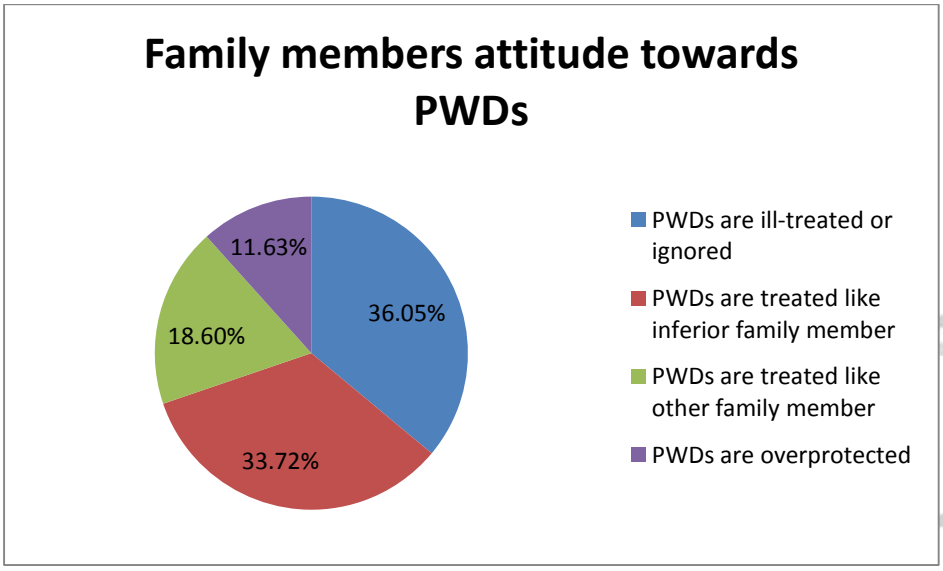
"I became blind when I was working with the Nyagatare District! I am lawyer by professional! I went for rehabilitation services at Masaka resource center but when I came back I was fired from my post of labor inspection" Household C in Nyagatare District

"Employing somebody who is visually impaired is not possible. How will he read, write or sign?" Local authorities Nyagatare District

Despite the prevalent negative attitudes towards PWDs, slight changes were identified with the government and non government initiatives targeting PWDs but still some categories of PWDs are likely not enjoying the changes some categories of impairments like visual, intellectual, mental and hearing disabilities are left behind).
"*Our district (Nyamagabe) is working with Gatagara rehabilitation center to provide services to our community members who are disabled. But it is at the beginning and we found very expensive"* Social affairs Rutare Sector in Nyamagabe District.

PWDs are rarely considered in development programs (One cow per poor family, decent housing, etc.)
"We *are not included in any development programs because people do say that we are not capable to deliver*" FGD from Rusizi District.

❖ Family members attitude towards PWDs



From the graph, respondents reported that 36.05% of them are ill-treated/ignored by the family members and 33.72 are treated like inferior members by their relatives. Only 18.60% of respondents recognized that in their families are treated equal.

3.2.2.2. Social exclusion

Most of the respondents who recognized they are treated equal are married men who head the families.

"There is no difference, we are all treated equal" Males from FGD Ngororero

Unfortunately, the situation of the WWDs & CWDs is not the same "*Most of the CWDs are usually cared for by the family members and it depends on the financial situation of the family. In poor families, the children are likely to be accused to be the root causes of their financial deficiencies*" Household B in Kirehe

"Still due to the traditional mindset, some families think that a PWD cannot have a bright future thus they shall not invest in him/her at all: schooling, health, etc." FGD of local leader in Gatumba, Ngororero District.

Most of the Psychiatric users and survivors are not believed to get healed and are seen as threats in the society. Therefore they are always excluded. *"When I do have some money, people do acknowledge that I am a pastor but when I run out money, they say that I am a fool"* confessed a psychiatric survivor in Gicumbi district

3.2.3. AWARENESS & ACCESS TO HEALTH SERVICES

3.2.3.1. Awareness on the services

Table 3

Code	Label	Frequency on average
1	Physiotherapy	95%
2	Occupational therapy	65%
3	Speech and language therapy	85%
4	Audiology	50%
5	Eye care services	90%

As captured in table 1.6, there is a significant discrepancy on the awareness of services provided in the 10 districts of Rwanda with 95% of respondents knowing where to go for physiotherapy services , 90% for eye care services, 85% for speech and language therapy and 50% know where to go when need Audiology services.

The biggest percentages of PWDs are much aware of Physiotherapy service and less aware of Occupational therapy and other rehabilitation services.

"*Yeah we know that Gatagara is offering such services. We've heard that there are such services Musanze, Rilima, CHUB and CHUK but when we go for the services they either refuse our MUSA or they've run out of materials"* FGD Kirehe

3.2.3.2. Rehabilitation services

The rehabilitation services are very scarce and Rwanda has not got enough specialists in the domains. For instance Rwanda appoints only 1 to 3 physiotherapists at the District hospitals. The estimates from the Rwandan Association of Physiotherapists in Rwanda, we have 150 physiotherapists countrywide (http://www.wcpt.org/node/24429). The geographical accessibility of the services remains a concern as they are only available from the district hospitals. The physiotherapy services from the district hospitals surveyed are not well equipped to provide the services. The observations from the respondents are that in most cases, the current physiotherapists have limited knowledge and skills on disability issues, there is a rigid referral system for such services from the health centers to District hospital. , and the financial accessibility of the physiotherapy services from the specialized centers which are better in terms of quality is very expensive.

"*I've been using physiotherapy of Ruli district hospital for some three months in vain. At some extent it even worsens my conditions that finally I abandoned"* confessed a participant from Ngororero District.

For more than 3 years, we've been using the physiotherapy from Byumba hospital but at the end they said that they can no longer continue to provide such services to my son. They ask me to do him the exercises while they did not train me how" Confessed a mother in Household A, Gicumbi district.

There are only 3 famous rehabilitation centres countrywide namely: Gahini, HVP Gatagara and Rilima. HVP Gatagara is the oldest rehabilitation center in Rwanda started by Father Fraipont Ndagijimana in 1960s. This center

provides mobility appliances (orthotics and prostheses) and CBR services at Ruhango District where they are carrying out a pilot program to address disability cases from the villages which mainly do not carry other activities except outreach activities.

Other services offered by the center include physiotherapy, rehabilitation, audiology services, repair of wheel chairs and early detection of disability in the infants.

Rehabilitation Center "HVP Gatagara" Workshop

3.2.3.3. Occupational, speech and language therapy

Occupational, speech and language therapy: these services are very new and found in a few number of specialized centers e.g. HVP Gatagara, Masaka resource centers and Rwanda Military Hospital.

"What? Speech & language therapy? No. I've never heard of that" Confessed a woman who's deaf in Nyarugunga, Kicukiro district.

Moreover, those special centers (Gatagara, Rilima and Masaka) are private owned and their services are not paid through the community based Insurance thus very expensive.

"*I went to Gatagara for prosthetics and I was asked to pay 200.000 RWF, where shall I get such amount? And they refuse to accept my MUSA saying that they do not have any contract with them!"* A participant in the FGD in Kigarama, Kicukiro District.

"We do provide many services including physiotherapy, audiology, occupational therapy and it is paying (…) We do have some contact with national insurances like RSSB but we are not working with MUSA. We ask people who are enrolled in the latter to pay themselves (…) we do not plan to work with MUSA except they improve their

reimbursement scheme because it takes too long i.e 6 months while we need the money to renew our stock" Director of HVP Gatagara Kigali Branch

Some hearing aids provided through charity organizations from abroad are not based on individual test results, not maintained or repaired.

"I *received the hearing aids from a South African charity organization last year but it was itching in ears and gave up. It is of no help"* Testified on participants who's deaf at the FGD in Kicukiro

3.2.3.4. Services for the blind and visually impaired

Kabgayi hospital is specialized in eye care services nationalwide. Those services are mainly supported by Light for the world/Belgium together with the Rwandan government. It is estimated that 100 to 150 visually impaired and blind people visit this center on a daily basis and the hospital carry out 20 to 25 operations per day from Monday to Friday according to the Director of the hospital. He continued

"*The major cause of blindness is due to cataracts and old age. Services offered include outreach clinics for district health centers for eye care treatment."*

3.2.3.5. Mainstream PWDs in the general health services

Eye care specialist attending to a patient at Kabgayi Hospital

Persons with Disability and mainstream Education

Education for disabled children and adults

The rights and needs of disabled people are recognized in the *Education Sector Strategic Plan 2004–08* (MINEDUC 2003). The plan commits the Ministry of Education, Science, Technology and Scientific Research (MINEDUC) to develop a policy on special educational needs (SEN). This includes, at primary level, to:

- train 20 SEN teachers by 2008
- open two new SEN centers
- Include a SEN component in teacher training colleges.

In order to promote *Education for All*, the strategy states that the educational sector should embark on adapting the initial and in-service training of both regular and specialized teachers in response to the new roles in the inclusive school, as well as ensure that classrooms, facilities and educational materials are accessible. Moreover, the strategy continues, the education sector must take responsibility for the quality of education and for the educational assessment of children with disabilities.

In 2007, the Rwandan government adopted the first ever SNE policy unfortunately only slight changes has happened up to now. We see that the educational provision for disabled children always being carried out in separate special institutions provided by private organizations, charities and the church in Rwanda. The disabled child is still excluded from the ordinary primary level.

"*I kept on sending my daughter to the ordinary primary school but the sent her back saying that she cannot cope with the normal schooling. When I went to Shyira for special school, they asked me to pay 45,000 RWF per quarter which I cannot afford then I abandoned. She is at home, what can I do*" Parent in household A in Ngororero.

"I desperately want to go to school but I don't have a wheelchair. When I was young like seven my mom used to carry me at her back but the school teacher sent me away… I've grown bigger and the I do not know whether the school teacher will accept me" 15 years daughter with cerebral palsy in household A in Ngororero

Currently, there is limited understanding of, or interest in, promoting and developing a system based on the principles of inclusive education within ministry of education. The importance of special needs education provision has been recognized by the Ministry of Education, most notably through the existence of special needs Policy. However, infrastructural challenges of access exist on a large scale within the country school environments. Whilst knowledge about special needs is still low amongst teachers.

Non accessible school

Accessible school

"*Some years back ago we began receiving some children with disabilities despite the inadequate infrastructures to accommodate such students. Unfortunately many children with severe disabilities could not cope and abandoned. On the other hand due to the lack of skills and knowledge of handling children with mental disabilities, visual impairments and hearing impairments, teachers found it very difficult to bring on the same level children with disabilities*" Headmaster of Nyagatare school in Nyagatare

The big number of children in class is also another challenge when it comes to inclusive education.
"We *are very willing to include CWD in our classrooms but the question is 'will we have time for them in a class of 45-60?' I am afraid no.*" Headmaster Mulindi Primary school in Gicumbi District

"Yes, we are encouraging children with disabilities to attend schools but still we see it is likely impossible. How will a student who is blind or in a wheelchair will reach here? Though the new schools of twelve years are provided with ramps and low blackboards, the toilets are still an issue for such learners" Headmistress of GS Nyange in Ngororero

During the survey in the schools visited, the headmaster/mistresses recognize they have to include CWDs but deplored that they lack of resources in as far as human, technical and financial concerned

SOCIAL-ECONOMIC & PARTICIPATION

Livelihood

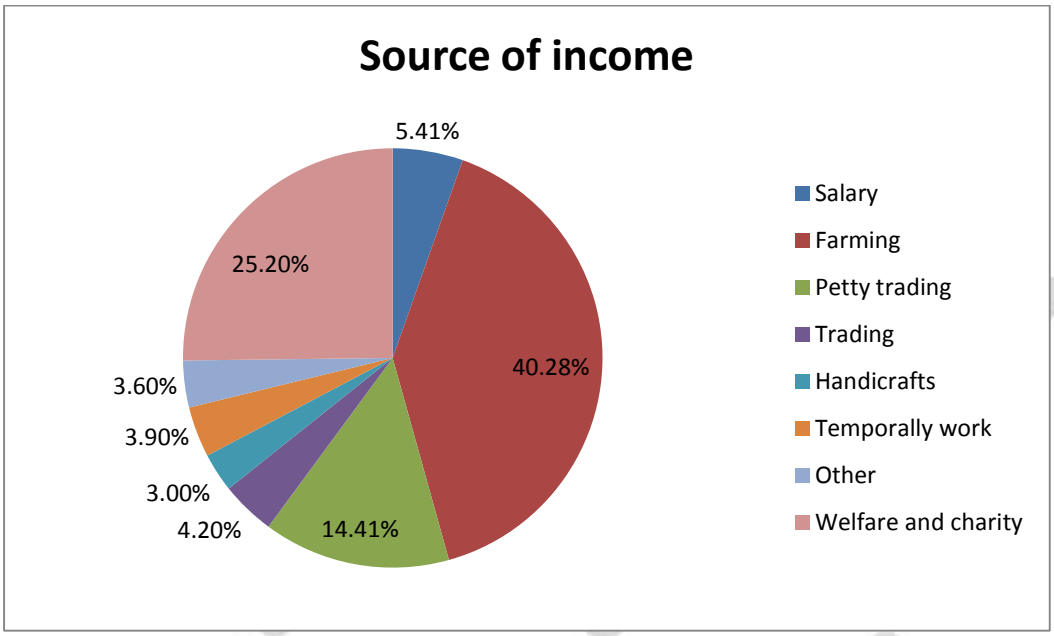


Table 2.2 shows the highest percentage of respondents involved mainly in farming 40% followed by petty trading with 14%, despite the obvious welfare and employment policy implications, very little is done on the labor market experience of persons with disabilities in Rwanda. The primary objectives of the research are to answer questions to what extent PWDs are employed in Rwanda?

Analysis:

Though the biggest percentage shows that PWDs are engaged in agriculture (40%), there is lack of needed assistive devices to help them involve fully in agriculture.

The problem of unemployment of PWDs in public sector requires coordinated efforts on social and economic levels, because poverty is the cause as well as the consequence of disability. A small percentage of PWDs have received trainings from some development agencies in vocational training but they lack startup capital or materials; (e.g. artists, Song writers, Barbers, bricks makers, Technicians, etc.);

SELF HELP GROUPS

Since late 1990s, there has been a movement of community based organization of PWDs. The mapping survey of the associations and organizations of PWDs carried out by UPHLS identified 1,978. The focus groups discussion primarily targeted those community based organizations as follows:

Networking

Table 1.8

Code	Label	Frequency on average
1	Member of DPO	85.00%
2	Member of Youth group	30.00%
3	Member of Sports group	40.00%
4	Member of Women group	30.00%
5	Member of any other social group	10.00%

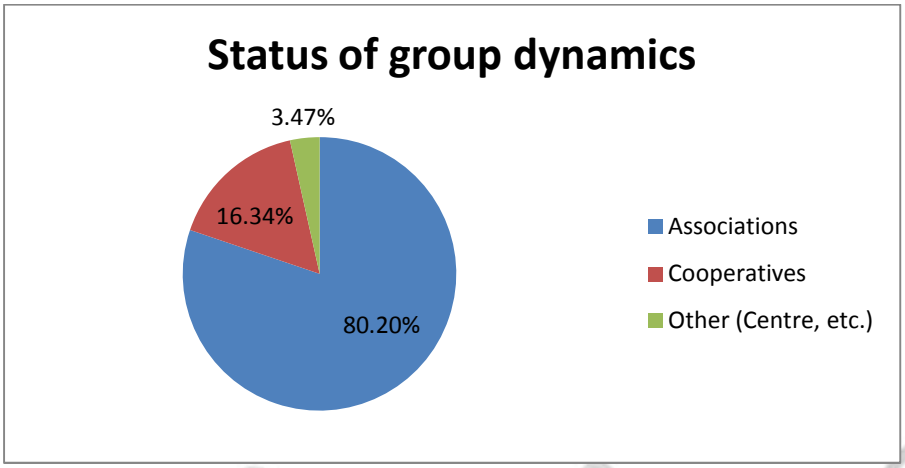
As shown in table 1.8 that 85% of respondents involved in the baseline survey are members of a certain DPO operating in Rwanda and another 40% at least have once engaged in sports for PWDs, this shows the willingness of networking among persons with disabilities despite non friendly facilities.

Some identified organizations are recognized at national level and are working with community based organizations like cooperatives and association. Those include AGHR, NPC, RUB, Collective TUBAKUNDE, NOUSPR Ubumuntu and RNUD. Other groups are somehow initiated through forums like youth forums namely ABADAHOGORA, Rwandan Youth Association for Culture Development INDAHIGWA, RIGHT TO PLAY FORUM; Sports groups like NGANGE GOAL BALL, NYAMAGABE GOAL BALL, ABADAHIGWA Sports Club, INTWARI, ABANA BAKINA BOCCIA, KABEZA FC; women groups: DUSABIRANE, DUTERIMBERE, NGIRANKUGIRE, URUMURI, ICYUZUZO, PROFEMME, TUMUKUNDE and other social groups : HIGA UBEHO, MUSICIANS, THT

Despite this big networks, People with disabilities experience restricted access to social and cultural events and to economic opportunities as identified they are more connected to organization working with PWDs and the inclusion in other groups like women and youth are very low (30%) as well as other social groups (10%) like religious groups and others is more limited.

Respondents reported they are likely not included in the main stream groups due to the prevalent negative attitudes of the community members, poverty, limited or no physical accessibility of the venues and lack/limited of access to information on what is happening in the community.

Status of self help groups



80.2% of self help groups surveyed are not registered or registered as associations; only 16% are registered as cooperatives while 3% are centers offering rehabilitation and education to CWDs.

As many of these self help groups surveyed are not strong enough in governance, leadership and management constitute a big hindrance to their development.

Analysis

Case study

The Association "Abantunkabandi" (People like others) from Gakenke District, Northern Province was created in 2010 by 85 PWDs members comprising every category. In 2011 they had collected up to 700,000 Rwf (1,200 USD) from different activities like bricks making, growing vegetables and pig rearing. They were saving this money as a revolving fund to help their members. But there were risks associated to the governance, leadership and *financial management of the association because the group members lack the capacity on above mentioned topics. As the money was increasing from the group activities, it involves regular financial book keeping, credit and loan management, etc. The group lacks the skills to implement the activities putting the association at the risk of losing its entire savings.*

Faustin NSABIMANA (Chairperson of the Association)

Active participation in self help groups

Table 2.0

Code	Label	Frequency on average
1	Daily	0.0%
2	Weekly	37.43%
3	Monthly	47.36%

4	Quarterly	13.04%
5	Semester	2.17%

Table 2.0 shows the level of participation of self help groups in planning, 47.36% meet on a monthly basis followed by 37.43% of respondents who meet on a weekly basis for the planning of their associations or cooperatives.

Analysis:

There is a big movement of disability and PWDs into self help groups meet regularly. They meet either for activities implementation or for administrative reasons. It represents an opportunity if mentored that they can bring in changes. The responsibility for changing attitudes and responses begins with persons with disability themselves. This Strategy articulates the values and principles needed to underpin policies and programs for people with disability. It helps provide leadership to build awareness and understanding of what needs to change so that people with disability fulfill their potential as equal citizens within the community they live in. However they do have many challenges which should be dealt with to bring the change as expected for inclusion.

Main common challenges

Table

Code	Label	Frequency on average
1	Limited capacity on group management, IGAs, etc.	95%
2	Very limited startup capital, needs of financial support	99%
3	Secure livelihoods	65%
4	Lack of funding partners& exchange programmes	50%

Most of the associations are meeting over an economic activity: Agriculture, animal husbandry, etc. From the table above, the groups face 4 major challenges first being limited access to start up capital with 99%, limited knowledge on group management, IGAs, governance (95%) to run these associations effectively, need to a secure livelihood 65% and limited funders (50%)

If we analyze better, we realize that most of the people with disabilities are coming together in self help groups to receive the support from both the government and its partners. Nevertheless, they lack trainings on disability rights and how to engage community leaders and service providers to receive such support. On the other hand, due to the challenges PWDs face in health especially for special services like lack to affordable and assistive devices (prosthetics, orthotics, white canes, hearing aids, wheelchairs, etc.). There is a need to strengthen the association to be effective and engage in income generating activities rather than waiting for the support which may not come at all.

Voluntary communal work involvement/frequency

Table 2.3

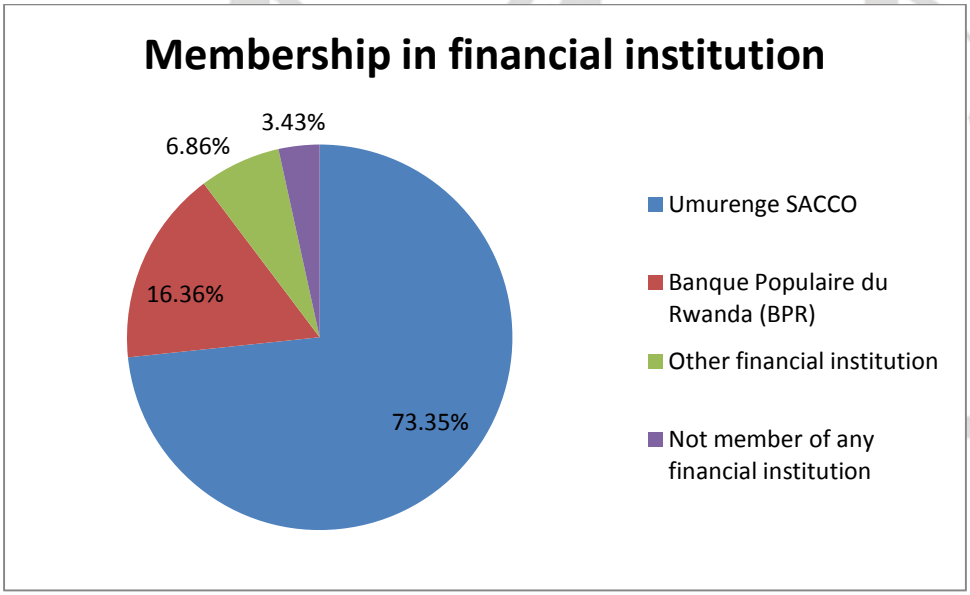
Code	Label	Frequency on average
1	Involved in voluntary communal works	81.68%
2	Not involved in voluntary communal works	18.32%

Table 2.3 shows the involvement of PWDs in communal work with 82% taking part and 18% not taking part due to severe disability.

Analysis:

This is because of public sensitization on voluntary work carried out by community officials (Umuganda) and UPHLS Peer education programs, coordination activities of the National Council of Persons with Disabilities (NCPD), and Community health campaigns. Beside the "Umuganda", the participation of PWDs in other community work is still low because of marginalization by the community.

Membership in financial institution



The biggest number of surveyed self help groups (73%) belongs to SACCOs at district sector level; this helps PWDs to have access to mainstream microfinance services. Lessons learned from the FGD: (entrepreneurs with disabilities are an untapped market opportunity for Micro Finance Institutions) but micro finance institute have negative attitude towards PWDs.16% belong to BPR were they have bank accounts, while 3% are not members of any financial institute.

Analysis

Even though the biggest number belong to SACCOs, but it requires to keep savings (deposit) in the micro finance institute but due to poverty, lack of collaterals, little activities and unemployment faced by PWDs, makes they accounts not operational. There is a lack of awareness, access to information among PWDs on one hand and financial institutions on the other hand to access loans provided by MFI at community level. However there is a need on training on the management of cooperative and income generating activities.

Access to Health Services

Persons with disabilities generally require more health services than non-disabled people. The nature of their impairments often leaves them more vulnerable to complications requiring medical treatment. PWDs share the same difficulties that non-disabled Rwandan face in accessing health care, but there are some differential factors.

First, PWDs need assistance to reach health facilities, and those with mobility problems find accessibility features in most facilities. Unfortunately, there is limited accessibility to all surveyed health centers except the district hospitals. Second, persons with disabilities are deterred to seeking medical help because of the nature of the government policy on health insurance called "mutuelle de santé" because PWDs can`t afford pay their premiums of 3,000 Rwf/year per person, thus they are left out of general services. Furthermore, the community health insurance does not cover the cost of rehabilitation services like assistive devices, etc.

Major needs identified includes:

1. Training of health official at community level on disability issues that includes early detection of disability in the early stages of pregnancy and birth.
2. Support by the government in establishment of medical rehabilitation centers at district level.
3. Provision of appliances (orthotics, prostheses and hearing aids) by health centers at a cheap price.
4. National prevention programs against certain illnesses must be promoted by ministry of health.
5. Include PWDs in community health committees at sector level

Access to Employment and vocational skills training:

Persons with Disability in Rwanda still face discrimination while trying to access employment coupled with low education standard attained by a big percentage of them. There are few programs provided by certain NGOs like JICA on ordinary vocational training programs but there still need for these programs to cover the grassroots PWDs and Provision of training places adjusted to the needs of individuals with disabilities at district level.

Although Rwandan employment policy mention employment of PWDs, little has been done, there is a need to elimination of all forms of discrimination against persons with disabilities in employment; introduction of disability-related issues into the general framework of economic and social regulations (Labor laws.), including regulations

concerning information accessibility requirements of training and work places, regulations concerning standards for workplace adjustment; accessibility of the legal system, and affirmative action measures in Rwanda. Identified need by the survey respondent that there is a need to re-design, implement and monitor the employment policy that will involve fully participation of all stakeholders.

Strengthening of the capacities of PWD self-help groups

1. Collective, analysis of statistical data on disability issues, as well as the participation of persons with disabilities in the national development programs.
2. Need for training in leadership, financial management and governance issues to strengthen these self help groups.
3. There was great demand of CBR services and training groups leaders on how to advocate for their rights.
4. Establishment of a revolving fund among members for the sustainability of these self help groups.

Conclusion and recommendations

Despite the recent development in the disability, PWDs in Rwanda still are subjected to isolation and social exclusion. For the last decade, Rwandans knew a disability movement than ever before. Rwanda enacted laws protecting PWDs in 2006, signed and ratified UN convention in the rights of PWDS (CRPD) in 2008 and recently in 2011; it instituted the first ever monitoring organ on disability: the National Council of PWDs (NCPD). From then on structures to represent PWDs have been put in place at all the decision making body from community level to Central government.

The research highlighted 4 main areas where PWDs do face challenges:

1. **Social exclusion and human rights:** All the respondents acknowledge that there is an improvement on disability rights. Nevertheless PWDs are still marginalized and not considered in the community. The findings from the survey highlighted that prevalent negative attitudes play a big role on the social exclusion PWDs especially children and women are subjected to.

   Social inclusion and community engagement should be the priority areas for the near future if we want to see the realization of the rights of PWDs into social services.

2. **Access to health and special services in health:** from the research, we found out that PWDs and their family are less likely to have access to the community based insurance (MUSA) due to financial limitations. Worse, PWDs who need special service like rehabilitation and others cannot get it through the health insurance schemes.

   Moreover, most of the special services are very expensive (assistive devices) and other are quasi inexistent in Rwanda (audiology, speech therapy).

   We'd recommend that health policy should be reviewed to be more inclusive. On the other hand, there should be a minimum package of services of PWDs in the health to guide the service providers in the domain. Furthermore, there is need of capacity building of the staff in the health facilities like pre service and in service trainings on the special service of PWDs as well as institutional capacity building to make those services affordable and accessible to PWDs all categories included.

3. **Access to inclusive education:** Rwanda special needs education policy is as old as 6 years now unfortunately, there is no much done in to include CWD. From the field visits, we observed that despite new law on public places accessibility, there is still much to be done to achieve the universal standards in physical accessibility. On the other hand the human capacity in inclusive education is very low despite the policy. MINEDUC and its partners have to include the special learning education on their agenda to achieve the MDG 2 as well as reviewing the curriculum of teacher training school to be disability inclusive.

4. **Livelihood and economic empowerment:** PWDs still live in extreme poverty. The research results show that only 5% of PWDs are employed and have a sustainable source of income. More than 80% of PWDs depend on informal sector or traditional agriculture for income with no hope for improved livelihood.

Households with disabled relatives do struggle to support the person both for health, education and any other social services. Additional expenses related to impairments are remaining a big issue for the family to cater for thus a big number (more than 80% of the families) cannot take care of it. The social protection should take into consideration of such people and give a hand to the family to alleviate the burden of the disability.

PWDs are mobilized to come together into self help groups as well as in big NGO. Unfortunately the latter are not supported by both government and development partners. There is a need for inclusive development agenda, much more advocacy should focus of the inclusion of PWDS in development.

The research also revealed limited capacity of the cooperatives thus most of the cooperative need to be mentored and empowered to be able to bring the change in the socio economic lives of its membership.

To conclude, we would like to say that though this is an exploratory study it has revealed many gaps especially in the above mentioned areas. There is still a need for a deeper research for each of the topics to understand more the parameters and factors influencing the social exclusion of PWDS. By the way, the survey sets benchmarks for disability movement in Rwanda.

References

1. Philippa Thomas, Disability Policy Officer / DFID, *Mainstreaming Disability in Development: Country-level research - Rwanda Country Report*, April 2005;
2. UPHLS, *Mapping des Associations des Personnes Handicapées et des intervenants dans le domaine du Handicap*, Rwanda, Février 2009;
3. Government of Rwanda, Ministry of Health, *Health sector strategic plan July 2009 – June 2012*, Rwanda, July 2009;
4. Republic of Rwanda, Ministry of Education, Science, Technology and Scientific Research, *Education Sector Policy*, Rwanda, July 2003;
5. Republic of Rwanda, Ministry of Local government, *National Social Protection strategy*, Rwanda, January 2011;
6. Republic of Rwanda, *Maternal, Neonatal and Child Health Assessment*, Rwanda, March 2006;
7. Republic of Rwanda, Ministry of Public Service and Labor, *National employment policy*, Rwanda, December 2007;
8. Republic of Rwanda, Ministry of Health, Mutual Health Insurance Policy in Rwanda, Rwanda, December 2004;
9. Kigali Institute of Education, *Draft Proposal for the National Equality and Diversity policy for higher Education*, Rwanda, April 2007;
10. Republic of Rwanda, Ministry of Finance and Economic Planning, *Rwanda Vision 2020*, Kigali, Rwanda, July 2000;
11. Government of Rwanda, Health Sector policy, Rwanda, February 2005

Appendixes

Appendix 1: Terms of reference for the study

Objective

The main aim of the survey is to identify the needs of UPHLS dynamic groups and come out with solutions to strengthen the learning capacities of the groups as part of their broader group's development. This survey is to give UPHLS and partners access to information and recommendations that can guide in programme and implementation practice to achieve higher levels of social inclusion for disabled people. In particular, the information gathered will be used to help formulate social inclusion of persons with disability into society.

Scope of work

The baseline survey will cover four provinces plus Kigali City and from these provinces two Districts will be selected for the study based on convenience sampling bringing to a total of 10 Districts. Two dynamic groups comprising of 20 members will be involved in each district, this will bring a total of 20 dynamic groups involving 400 Persons with Disabilities (PWDs) in the study and this is based on the following criteria:

a) All members groups dynamics with activities at a regional level and will have to identify the need to improve their learning processes;
b) Are willing to have a group leader responsible for organizing them collectively in decision making and daily management of the activities of their groups respectively;
c) All are willing to engage in activities in the areas of education, including skills training, income generation, welfare assistance, and advocacy and awareness rising;
d) Examining the main providers of support for disabled people and the group dynamic arrangements that make this possible
e) Identifying some of the causes or reasons for disability, and whether any of these are addressable
f) Identify and examine channels for advocacy and how UPHLS can improve on its effectiveness within the communities;
g) To analyze the meaning of social inclusion for disabled people within the communities of Rwanda and describe what is known of their aspirations for inclusion to map current disability-focused activities in Rwanda;
h) To analyze the opportunities and constraints facing these self help groups , particularly focusing on key sectors of Education, Health, income generating activities and Rehabilitation within the new policies on disability, social protection etc.

Methodology

The research will be carried out in four provinces and Kigali City, and will include 10 districts. The selection of the 10 Districts was based on convenience sampling. Thus the following criteria have been considered:

- High prevalence of PWDs from 2009 Mapping report;
- Districts with border crossing;
- Urban Districts;
- Rural Districts;
- Districts along Kivu Lake;

:

The UPHLS team at National level will carry out the research and will be assisted by UPHLS District coordinators within the selected Districts.

UPHLS TEAM

Will be responsible for:

- Identifying and reviewing key documents, come out with draft field questionnaires
- Identify key respondents;
- Test questionnaires
- Finalize data collection tools (interview and observation guide)
- Developing Baseline work plan and managing it
- Conducting in-country research, involving reviewing documents and carrying out semi-structured interviews with key focus groups, in deep interviews with key stakeholders, and field visits.
- Data entry and analysis;
- Prepare the base line report and identify means to take recommendations forward.

Specific activities

- Literature review;
- Facilitating meetings with key informants (such as service providers, community leaders and Focus groups);
- Conducting in deep interviews with selected key informants and observations;
- Making all logistical arrangements (such as travel to and within the communities and accommodation)

Outputs

Compiling a Research report containing:

- ✓ A summary of the current situation of self help groups (disabled people) within the communities and initiatives addressing disability

- ✓ An analysis of opportunities and constraints to take forward work on disability within wider work on social inclusion and in the key sectors of health, education and economic empowerments.
- ✓ Identification of a network of support partners for Dynamic groups

Duration

The first week (March 2012) will be for literature review to gather all relevant available information.
The following 4 weeks (April 2nd to May10th,, 2012) will be for data collection in the 10 selected Districts.
During the National mourning period (April 7 to 14, 2012), no field activities will be conducted.
Desk studies of secondary sources will be made within the last week of May 2012 and the report will be presented in draft form to stakeholders

Requirements (Logistics)

To be able to conduct this baseline study, the following are needed:

- Avail the supervision vehicles;
- Print data collection tools and materials (questionnaires, interview and observation guides);
- Bags and pens;
- Voice recorders;
- Digital cameras;
- Contact DPOs on their members: NPC, RUB, RNUD, NUDOR, ANFSMR, NOUSPR, AGHR, THT, ACPJNV

Key stakeholders in interviews and focus group discussion:

In each district, the researchers shall meet the following people:

Focus group discussions:

- Representatives of associations and cooperatives or centers for persons with disabilities (2 people per each)
- Coordinators of women, Youth the bureau of Njyamana of 2 cells
- Coordinators of women, Youth the bureau of Njyamana of 2 sectors

Interview:

- Head of 2 HF per district
- Headmasters of 2 schools per districts
- In charge of social affairs at Sectors
- In charge of social affairs at District

Visits

- Visit 2 households with a person with disability

Day and Time	Location of Group Dynamic/Area	Contact Person
2-3/04/2012	Ngororero	MUGIRE KAGABA Jeannette
04-05/2012	Rusizi	GATUSI NDAGWIJE Justin
06 & 20/04/2012	Kicukiro	MUKESHIMANA Claudine
16-17/04/2012	Nyagatare	MUGEMANYI Augustin
18-19/04/2012	Kirehe	UWINGABIRE Alphonsine
23 & 24/04/2012	Gakenke	MUNEZERO Marie Mediatrice
25-26/04/2012	Gicumbi	UWUMUKIZA Providence
27/04 and 04/05/2012	Gasabo	UWUMUKIZA Providence
30/04-01/05/2012	Nyamagabe	NDAGIJIMANA Olivier
02-03/05/2012	Muhanga	NTWALI Antoine

Appendix 2: Interview questions for FGD

Focus Group Discussion Guides for Use with Dynamic Groups

Questionnaire

Date of Interview: __/__/__ Interviewer: ……..

Home Address of respondents: district…….....Sector.....

Cell..... Village……..

Telephone No of Group Leader: ……..

Section A: Personal details

1. What is your group Dynamic name (optional)? ……

2. Number of your group membership?

3. Sex? a) ☐ Male b) ☐ Female

4. When was the group established? _____ in completed years

5. What is the group members marital status?

a) ☐ Single b) ☐ Living with partner c) ☐ Married
d) ☐ Divorced e) ☐ N/A

6. Who do you live with?

a) ☐ Alone b) ☐ Partner c) ☐ Immediate family
d) ☐ Extended family e) ☐ Institution
f) ☐ Other (please specify) ……

7. What is the nature of group members' disability?

a) ☐ Visual/seeing b) ☐ Hearing/communication
c) ☐ Mental health d) ☐ Physical mobility
e) ☐ Learning/cognitive f) ☐ other (please specify)……

Section B: Awareness, Perception and Attitude towards disability

11. What do you understand by the term disability?

11b. How do your community generally categorize disability?

Health/Medical issue ☐
Poverty ☐
Human right ☐
Don't know ☐
Others (Specify) ……

11c As a disabled person, what is your general impression about others' attitudes and behavior towards you?

……

11d Why do you think they behave in such a way towards you?

……

12. What do you think are the causes of disabilities?

a) ☐ Diseases b) ☐ God's will
c) ☐ Punishment d) ☐ Don't know
e) ☐ Other (please specify)……

13. What is the reaction of your family to your disability?

a) ☐ Treat me like other family members b) ☐ Overprotect me
c) ☐ Treat me like an inferior family member d) ☐ Ignore me
e) ☐ Other (please specify)……...
……
……

14. Why do they treat you that way?

……

……

……

14. Have you experienced any of the following in the last 6 months?

Please tick the box that best describes how you feel.	Always	Often	Sometimes	Never	Don't Know
Staring	☐	☐	☐	☐	☐
Dislike	☐	☐	☐	☐	☐
Name calling/mockery	☐	☐	☐	☐	☐
People not asking my opinion	☐	☐	☐	☐	☐
People feeling sorry for me	☐	☐	☐	☐	☐
Encouraging	☐	☐	☐	☐	☐
Others (please state)					
……	☐	☐	☐	☐	☐
……	☐	☐	☐	☐	☐
……	☐	☐	☐	☐	☐

15. Why did the people treat you the way they did?

……

……

……

15b what could be done to avoid or minimize negative attitudes/behavior of people towards the disabled persons?

……

……

……

……

Section C: Awareness and Access to Services

---

16. Are you aware of the following rehabilitation services?

Description	Aware of it	Never heard of it before
Physiotherapy - treatment that uses physical means to relieve pain, regain range of movement, restore muscle strength and return patients to normal activities of daily living	☐	☐
Occupational therapy – assists persons with temporary or permanent disability in activities of daily living (washing, dressing, seating, vocational, leisure) through therapy or adaptive devices.	☐	☐
Speech and Language Therapy – Supports children and adults who have difficulties in understanding or using language.	☐	☐
Audiology - provides hearing assessments for persons who have difficulties hearing sounds and speech. They also fit and look after hearing aids for those who need them	☐	☐
Eye care services – diagnosis and treatment of eye diseases and refractive and low vision services.	☐	☐

17. Do you know where to go if you need the following rehabilitation services?

Please tick the box that best describes how you feel.	Physio-therapy	Occupa-tional Therapy	Speech and Language Therapy	Audiology	Eye care services

Yes, I know where the service is provided	☐	☐	☐	☐	☐
I think so, I would be able to find out the nearest service in case I should need it	☐	☐	☐	☐	☐
I'm unsure where and how to find out about the nearest service provided	☐	☐	☐	☐	☐
No, I don't know where to go	☐	☐	☐	☐	☐

18. Are there rehabilitation services available close to where you live, please specify which ones

Please tick the box that best describes how you feel.	Physio-therapy	Occupa-tional Therapy	Speech and Language Therapy	Audiology	Eye care services
0 - 30 mins traveling	☐	☐	☐	☐	☐
30 mins – 1 hr traveling	☐	☐	☐	☐	☐
1 –2 hr traveling	☐	☐	☐	☐	☐
2-3 hrs traveling	☐	☐	☐	☐	☐
More than 3 hours traveling	☐	☐	☐	☐	☐
Don't know	☐	☐	☐	☐	☐

19. Do you currently receive the medical help that you need?

a) ☐ Yes, all that I need – **go to question 21** b) ☐ Most of it

c) ☐ A little bit d) ☐ None

20. If you do not receive the medical help that you need, why not? (Tick as many as apply to you)

a) ☐ Non-existent in Rwanda b) ☐ Don't know where to go

c) ☐ Transportation is too expensive d) ☐ other (specify)

……

……

21. Which service do you make use of, if any?

a) ☐ Physiotherapy
b) ☐ Occupational Therapy
c) ☐ Speech and language therapy
d) ☐ Audiology
e) ☐ Eye care services through low vision Units, Eye Care Services
f) ☐ Services for the Blind and Visually Impaired by Adjustment to blind technicians, Eye Care
g) ☐ Special Needs School
h) ☐ Sports facilities
i) ☐ None
j) ☐ Other

22. Are you satisfied with the services provided by service providers?

Please tick the box that best describes how you feel.	Very satisfied	Fairly satisfied	Fairly dissatisfied	Very dissatisfied	Don't need/use the service
Physiotherapists	☐	☐	☐	☐	☐
Occupational Therapists	☐	☐	☐	☐	☐
Speech and Language Therapists	☐	☐	☐	☐	☐
Rehabilitation assistants	☐	☐	☐	☐	☐
Audiologist	☐	☐	☐	☐	☐
Audiological assistants	☐	☐	☐	☐	☐
Refractionists	☐	☐	☐	☐	☐

Adjustment to blind technicians	☐	☐	☐	☐	☐
Sports Facilities	☐	☐	☐	☐	☐
CBR volunteers	☐	☐	☐	☐	☐
Others Specify----------	☐	☐	☐	☐	☐

23. If you are not satisfied, what is the reason for this?

Please tick the box that best describes how you feel.	Don't need the service	Services not available	services difficult to access	poor quality of services offered	poor attitude of service providers
Physiotherapists	☐	☐	☐	☐	☐
Occupational Therapists	☐	☐	☐	☐	☐
Speech and Language Therapists	☐	☐	☐	☐	☐
Rehabilitation assistants	☐	☐	☐	☐	☐
Audiologist	☐	☐	☐	☐	☐
Audiological assistants	☐	☐	☐	☐	☐
Refractionists	☐	☐	☐	☐	☐
Adjustment to blind technicians	☐	☐	☐	☐	☐
Sports Facilities	☐	☐	☐	☐	☐

CBR volunteers	☐	☐	☐	☐	☐

24. What would you suggest for improving the services?

……

……

……

25. How do service providers (rehabilitation workers, refractionists etc) react to your disability?

(Please tick the option that best suits how you feel)

a) ☐ Treat me with respect
b) ☐ Are willing but not very knowledgeable about my specific needs
c) ☐ Don't seem to be interested in and considerate about my specific needs
d) ☐ Treat me disrespectfully

Section D: Membership of a DPO

22. Which organization(s) do you belong to? Please specify names of organisations

a) ☐ DPO……
b) ☐ Youth Group……
c) ☐ Sports……
d) ☐ Women ……
e) ☐ Social Group……
f) ☐ Religious……
g) ☐ Other……
h) ☐ None……

23. What role do you have in your Group Dynamic or DPO?

a) ☐ Occasional participant in activities
b) ☐ Frequent participant in activities
c) ☐ Organize activities
d) ☐ Official role in the organization (e.g. board member, treasurer)
e) ☐ Other, ……..

24. How often are you involved in activities in your Group Dynamic?

a) ☐ Daily b) ☐ Weekly c) ☐ Every other week
d) ☐ Monthly e) ☐ Quarterly f) ☐ Yearly
g) ☐ Other ……

25. Are you satisfied with the activities organized/services provided by your group dynamic?

a) ☐ Very satisfied b) ☐ Fairly satisfied c) ☐ Fairly unsatisfied

d) ☐ Very unsatisfied

Why?

……

……

26. What would you like to see changed about your Group Dynamic?

……

……

27. What services/training/activities would you like your Group dynamic/DPO to offer to disabled person that they currently don't offer?

……

……

……

Section E. Socio-economic and participation

28 How do you currently earn your living?

a) Paid employment?

b) Farming

c) Petty trading

d) Others specify……

29. If paid employment, what is your sector of employment?

a) ☐ Public sector b) ☐ Private sector

c) ☐ NGO f) ☐ Other ……

30. Are you involved in work in and around the house? (E.g. shopping, cooking, cleaning, child caring, etc)

a) ☐ Yes b) ☐ No

If yes, please specify

……

……

31. Are you involved in voluntary communal work?

a) ☐ Yes b) ☐ No

32. If yes, what type of voluntary work?

……

33. How frequently are you invited to family meetings/social occasions gatherings?

a) ☐ Always b) ☐ Usually c) ☐ Sometimes

d) ☐ Rarely f) ☐ Never

34. How often did you visit other family members or friends in the past three months on the average?

a) ☐ Every week b) ☐ Twice a month c) ☐ Once a month,

d) ☐ Once every 3 months f) ☐ Never

35. How frequently do your family and friends come to visit you in your house (average over the last three months)?

a) ☐ Every week b) ☐ Twice a month c) ☐ Once a month,

d) ☐ Once every 3 months f) ☐ Never

36. Is there anything that stops you participating in activities that you would like to? ……..……How do you think these could be overcome?

.....

37.Are you a member of any micro finance institute within your community/How do you earn a living?……

……

Thanks

Appendix 3: Household Questionnaire

Province …… District …… Sector……Cell……..
Village……..
Interviewer …… Date of Interview __/__/__
Name of Respondent (optional) ……
Position in Region/District/Town/ or in village……
Sex _ (F or M) Age ____ in years
Relation to the household head (if not the head) ……..

Awareness, Perception and Attitude towards disability

1. What do you understand by the term disability?

……

……

2. How do community generally categories disability?

Health/Medical issue ☐
Poverty ☐
Human right ☐
Don't know ☐
Others (Specify) ……

3. What do you think are the causes of disabilities?

a) ☐ Diseases b) ☐ God's will
c) ☐ Punishment d) ☐ Don't know

4 What is your general impression about others' attitudes and behaviour towards you?

……

……

……

5 Why do you think they behave in such a way towards you?

……

……

……

6. How do your family members usually react to you?

a) ☐ Treat me like other family members b) ☐ Overprotect me

c) ☐ Treat me like inferior family members d) ☐ Ignore me

e) ☐ Other (please specify……...

……

7. Why do they treat you that way?

……

……

8. How can the negative attitudes towards you be minimized?

……

……

9. Some people think that the disables have the all the right types of services they need, do you agree?

☐ Yes b) ☐ No

9. Why?

……

……

10. What do you think should be done to improve services for the disabled?

……

……

11. Do you have a person with disability in the household or compound?

☐ Yes (Request to have interview with the person, if possible, and use the right questionnaire)

b) ☐ No

12. What more would like to tell about disabled people and how they are treated?

……

……

End of Interview

Thank you for the time you have taken

Appendix 4: Interview Guide for sector level (Chairperson of Njyanama, Women and Youth representatives).

Names:
Position:
Location: Town/Village……Cell ……..
Sector…… District ……
Interviewer…… Date ……

1. Do you have evidence of PWDs within your community?
Probe if necessary

……

2. Who is described as a PWD in this community? (Probe)

……

3. Do PWDs face difficulties in this community?
……
Mention them (Probe)
……

4. Where do these PWDs live and do they get any kind of care/support they need?
( ) Yes…… ( ) No……..
What kind of care or support {probe}

……

6. Do you think there are changes in the families these PWDs live?
Do such families have the abilities to take care of their relatives 'PWDs? {Probe}.

……

7. Does the community provide support to PWDs? {Probe what type of support, how often}
Where else apart from community do PWDs get support? {Probe government, religious leaders, and organizations what type of support, how often and in what quantity}

……

8. Has the number of PWDs in this community changed in the last two years? Probe for estimated number and direction of change.

……

10. Apart from PWDs, which other groups of people need support in the community? (e.g.,Orphans,beggars, prostitutes, child laborers and give reasons. Probe)

11. Is the community doing anything to address PWDs needs? If yes, explain (e.g., fostering, education, apprenticeship training, free food programs. Probe).

……

12. List the three or more most important things you would like to be done for PWDs within your community or district.

(1)…….

(2)……..

Appendix 5: Service Providers Checklist

Name of Institution……
Location: Town/Village……Cell ……..
Sector…… District ……
Address ……..
Name of Head of Institution …….
Name of person interviewed (if not head)……..
Interviewer …… Date ……
Status of organization (e.g. School, Sector administration, SACCO, Government department etc) ……

Q1. Please give me a brief summary of the mission and objectives of your organization?
……
……
……

Q2. How relevant is disability to the overall goal and work of your organization (why, how etc)?
……
……
……

Q3. What policy statements have been initiated or implemented by your organization or agency on disability issues?

……
……
……

Q4. How have you sought to address disability issues?
……
……
……

Q5 What specific initiatives, programs or projects are your organization supporting that specifically target PWD?
……
……
……

Q6 What type(s) of disability (ies) does your organisation support?

……
……
……

Q7 What types of services does your institution provide for the PWD?

……
……
……

Q8 How would you rate the quality of the services?

Very Good	Quite Good	Not so Good	Not Good at all
☐	☐	☐	☐

Q9 Please give reasons for your rating
……
……
……

Q10 If it is not Very Good, how could the quality of services be improved?
……
……
……

Q11 How would you rate the level of response of PWD to the services you provide?

Very Good	Quite Good	Not so Good	Not Good at all
☐	☐	☐	☐

Q12 Why do you think they respond in such ways?

……
……
……

Q13 What can you do or suggest to improve the quality of the services your institution provides to PWD?
……
……
……

Q14 What challenges/difficulties/constraints do you face in addressing disability issues or in providing these services for the disabled?

……
……
……

Q15 What plans are you making to address the challenges?

……
……
……

Q16 In what areas would you like more help?

……
……
……

Q17 What progresses do you think have generally been made in addressing the needs of PWDs within this district?

……
……
……

Q18 What more do you think needs to be done in addressing the needs of PWDs within your community?

……
……
……

Q19 What more would you like to tell me about disability and service provision within your community?

……
……
……
……
……

Thank you very much

Appendix 6: Interview Guide for Use with Key Informants -Healthcare Workers

Name of Institution……
Location: Town/Village……Cell ……..
Sector…… District ……
Address ……..
Name of Head of Institution …….
Name of person interviewed (if not head)……..
Interviewer …… Date ……

Status of health facility……

1. Are there disability cases within your community/district? (Probe-causes?)
   ……..
   ……
2. Have you noticed an increase/decrease in the number of PWDs in the area for which you are providing care? (last 6 months)

……

3. Why do you think there is an increase or decrease in the number of disability?

…….

b).Are there any measures taken to address this problem {probe}?

……..

c).Give example if any {probe}.

……

4. What are the major health problems {PWDs} face within the community/District?
   ……
   d) Mention them {probe}
   ……
   e).What causes them {probe}
   ……..
5. Who is responsible for paying for their clinical care and treatment?

   ……
   Where do they get the money to meet the costs {probe}?
6. Is there a social welfare department in the hospital/at the district/health center/ sub-county?
   ……..
   What are some of welfare services given out here {probe}
7. Who do they cater for and what are the criteria for eligibility?

   …….
8. Are PWDs engaged in District health planning processes?
   ……
   If **yes** (probe)……

   …….
9. Have you been able to influence government policy-making and planning on PWDs issues?

   …….
   Mention them {probe}
   ……..

10. Are there policies/practices in the hospital/health centers to detect early disability? If yes, specify. If no, why? {probe}

    ……..

11. Do you have a referral system for PWDs to other services?

    ……

    Which other services? {probe}

    ……

12. In what ways can you be involved in providing care and treatment services to PWDs? {probe what services, how, etc}

    ……..

13. Do you get any support to care or treat PWDs? Mention them.

    ……..

    What other assistance would you require to provide care and treatment to PWDs? {Probe}

    ……..

14. Have you had any training on disability issues?.....

    If yes, what specific training have you had?

    ……..

15. Is there anything else you would like to add? What is your view of the future?

    ……