UMBRELLA DES ORGANISATIONS DE PERSONNES EN SITUATION DE HANDICAP LUTTANT CONTRE LE VIH/SIDAET LA PROMOTION DE LA SANTE (UPHLS)

NEEDS ASSESSMENT OF PEOPLE WITH DISABILITIES IN HIV AND AIDS SERVICES AND STRATEGIES TO MEET THEM FOR EQUAL AND EQUITABLE HIV SERVICES

DRAFT REPORT

Kigali, August 2015

EXECUTIVE SUMMARY

People with Disabilities share the same difficulties that non-disabled Rwandan face in accessing health care, but there are some differential factors including assistance to reach health facilities, and those with mobility problems find accessibility features in most facilities. It is in this framework that during the period of July to August 2015, the Umbrella of organizations of Persons with Disabilities in the fight against HIV and AIDS and health promotion, UPHLS has conducted an assessment on *needs in HIV&AIDS services for PLWDs by types of disability and has developed an action plan laying out strategies and prioritization to address the identified HIV&AIDS needs of PLWDs by types***.** The overall objective of the assessment was to identify and appreciate the barriers faced by PWDs by types in accessing HIV&AIDS and design strategies to address those barriers by type of disability. The assessment was conducted in Gasabo, Kicukiro, Nyarugenge Districts in Kigali City, Gakenke District in Nothern Province, Gatsibo District in Eastern Province, Ngororero District in Western Province and Nyaruguru District in Southern. Key informants were selected from the sampled districts targeting all types of disabilities, services providers and DPOs.

The assessment has shown that the crucial challenges faced by PWDs in accessing HIV and AIDS services include some that can be applied to all types of disabilities while others are specific to different types of disability. The common challenges to all types of disability include the extreme poverty, sexual violence faced by physical severe disability, persons with mental disability, deaf and blind persons. They also include false beliefs for the services providers that PWDs are not at risk of HIV infection, self-discrimination made by PWDs to themselves and double discrimination made by the family member and community.

The specific challenges to specific types of disabilities include inter alia, communications barriers to deaf and blind persons with lack of sign language interpretation and lack IEC materials in accessible format to blind persons. The identified challenges were translated into needs and actions have been formulated to

address them. From the identified needs, an action plan laying out key priorities was developed.

Among the key recommendations UPHLS shall lobby Government to promote and decentralize disability sensitive VCT services and health centers to all districts, strengthen networking with other organizations working in the area of HIV and AIDS and human rights, to conduct a baseline study to know HIV prevalence among PWDs by types.

The districts have strongly recommended UPHLS to work closely with stakeholders and districts to issue common guidelines to health facilities allowing the monitoring of efficiency of HIV and AIDS to PWDs, organize stakeholders meeting to raise their awareness on HIV and AIDS mainstreaming in their activities/programs , to support cooperatives in integrating HIV and AIDS activities especially for voluntary counseling and testing and eventually put in place the clubs to fight against HIV infection among PWDs.

Services providers shall have IEC accessible materials to different types of disability; take into consideration the degree of disability when delivering HIV and AIDS services to PWDs when providing services.

National Council of Persons with Disabilities advocates for the implementation of the law protecting PWDs against violence**,** continue advocating for the existence of Rwanda Sign Language and conduct trainings for services providers, conduct family member training to equip knowledge at least one member from a PWD family to take care of him/her. Through NCPD organs and cooperatives of PWDs who are HIV positive shall be encouraged PWDs to give testimonies on the importance of getting tested and take drugs on time as instructed.

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ACRONYMS AND ABBREVIATIONS

AIDS: Acquired Immuno-Deficiency Syndrome

ART: Anti Retro Viral

CD4: Cluster of Differentiation type 4

CDLS: Commission de District de Lutte contre le SIDA

DPO: Disabled People Organizations

HIV: Human Immuno-deficiency virus

IEC: Information, Education and Communication

MOH: Ministry of Health

NCPD: National Council of Persons with Disabilities

NOUSPR: National Organization of Users and Survivors of Psychiatry in *Rwanda*

PLWD: People Living With Disability

PMTCT: Prevention of HIV Mother to Child Transmission

PWD: People with Disability

PWDs LWHA: People with Disabilities Living with HIV/AIDS

RNUD: Rwanda National Union of Deaf

TOT: Training of Trainers

UPHLS: Umbrella des organisations de Personnes en situation de Handicap Luttant contre le VIH/SIDA et pour la promotion de la Sante

VCT: Voluntary Counseling and Testing

VUP: Vision 2020 Umurenge Program

CHAPTER ONE: GENERAL INTRODUCTION

1.1. Background: Persons with disabilities needs in HIV &AIDS services

For several years now the international community has committed significant resources to respond to the HIV epidemic. However, despite these efforts, HIV and AIDS continue to spread in many resource-limited settings, especially in Sub-Saharan Africa where more than two- thirds of the world's HIV-infected people live (UNAIDS, 2012).

Social inequalities have been identified as potentially important mechanisms that fuel the epidemic (Magadi, 2013; Mayer et al., 2012; Parker, 2002). HIV infections can be concentrated in key populations resulting in the important heterogeneity of the HIV epidemic (Buvé, 2006; OHCHR & UNAIDS, 2003). Efforts must therefore target these groups to protect their health and more generally their rights (UNAIDS, 2012).

A good number of countries have achieved their targets in terms of the millenum development goals (MDG) especially Goal 6, which targets the spread of HIV infections and an AIDS-free generation.

People with disabilities who represent around 15% of the world's population are potentially vulnerable to HIV infection because they are also more likely to be poor, excluded from their communities and suffering

from violence factors which have been shown to be associated with increased HIV infection risk (Braithwaite & Mont, 2009; Brownridge, 2006; N. Groce & Trasi, 2004; Hanass-Hancock, 2009; Hughes et al., 2012; The World Bank, 2008; Trani & Loeb, 2012; WHO & The World Bank, 2011).

Despite a wide spread recognition of the likely equal or increased risk of HV among Persons with Disabilities, they are less likely to have equal and equitable access to HIV care and treatment services in their communities. [1] Factors of limited access include negative attitude of the service providers and the society in general and the double discrimination based on disability and HIV, the physical accessibility of the health facilities and the venues where the services are provided leave a lot to be desired and the limited accessible communication and information on HIV in general and HIV services in particular[2].

Persons with disabilities in Rwanda experience similar issues in HIV services access. A pilot study carried out by former SHIA showed the infection of HIV among Persons with disabilities within two selected districts was 1% higher than the general population.[3] However Persons with disabilities who are HIV positive who were interviewed by Hilda and Sophia reported that they are likely to be discriminated in HIV related services. Handicap international report mentioned cases of denial of medications because either they are blind or because they are deaf.[4]

Other cases were documented where persons have limited access due to architectural barriers of the places where the services are delivered. The government of Rwanda reports that Persons with disabilities face a number of barriers including environmental barriers when accessing public services. [5]

All those challenges as well as the others which are not mentioned are due to the fact that most likely the services providers lack or have a limited of the understanding of

[1] Check reference
[2] Hilda and Sophia, 2012, p. please check
[3] SHIA, HIV/AIDS, 2006, and disability: including persons with disability in HIV/AIDS programmes
[4] Handicap international, 2012 please check details
[5] Governemnt of Rwanda, 2015, p.35

disability and persons with disabilities in their complexity.Disability is human diversity[6] therefore is no likely one solution for all. There are a number of categories of disabilities. The Rwandan law recognizes five categories of disabilities: physical impairment, visual impairments, hearing impairment, mental and intellectual impairment and others[7]. However within one category there are subcategories. The WHO talks about levels of classification[8].

Although there are a number of challenges and needs which are common to persons with disabilities in general, it is indeed to recall that each category of disability remains unique and might face a number of specific challenges and needs. Thus, when interacting with persons with disabilities one needs to know and understand each individual into his or her uniqueness. WHO defines the needs of each category of disability based on the following items: body functions, body structures, impairments, activity limitations, participation restrictions and environmental factors.[9]

Applying that to HIV service provision, Persons with disabilities who are HIV positive are likely to have a diversified number of needs which are to be catered for to access equitable and equal services.

[6] UNCRPD, 2006, page. please consult
[7] Rwanda government, 2007, page please consult
[8] WHO, International classification of Functioning, Disability and Health, 2001, p. 23
[9] WHO, International classification of Functioning, Disability and Health, 2001, p. 8

1.2. Objective of the study

1.2.1. Overall Objective

Persons with disabilities have got a number of needs which are not taken care of by the HIV&AIDS service providers thus the study aims at:
To identify and design strategies to address the needs of PWDs by types disabilities in accessing HIV&AIDS services.

1.2.2. Specific Objectives

In order to achieve the overall objective, specific objectives were identified as follows:

Persons with disabilities have got a number of needs which are not taken care of by the HIV&AIDS service providers thes study aims at:

a. To assessing barriers/gaps in HIV&AIDS care and treatment service provision y types of disability
b. To identifying of PWDs needs for quality HIV&AIDS care and treatment services provision in Rwanda by types
c. Developing an action plan laying out strategies and prioritization to address the identified HIV&AIDS needs of PLWDs by types

People with disabilities generally require more health services than non-disabled people and their need as well as unmet needs exist across the spectrum of health services including promotion, prevention, and treatment (4).

Disability is associated with a diverse range of primary health conditions: some may result in poor health and high health care needs; others do not keep people with disabilities from achieving good health (5).

While little information is available, it is widely thought that people with disabilities have significant unmet needs (6)

CHAPTER II: CONCEPTUAL AND THEORETICAL FRAMEWORKS OF THE NEEDS OF DISABILITY IN HIV&AIDS SERVICE PROVISION

2.1. Definitions of Concepts

2.1.1. Who is Person with disability in Rwandan context?

There is a variety of definitions of disability in Rwanda. So far, none is shared by both the government and the civil society organisations led by PWD. Despite the controversy around who is disabled and who is not, the most popular definition in Rwanda is one used in the disability law of 2007.

According to the Rwandan law protecting PWD in general, in article 4 “disability” is defined as: “The condition of a person’s impairment or health status limiting the essential abilities he or she should have been in possession, and consequently leading to deficiency compared to others.”[10]

Hence, “a disabled person is any individual who was born without congenital abilities like those of others or one who was deprived of such abilities due to diseases, accident, conflict or any other reasons which may cause disability.”[11]In Rwanda, PWD are classified into five basic categories as follows: Physically disabled, visually, hearing, intellectual and other disabled[12]

This definition falls short of the conventional definition of disability. It places the problematic of disability on individuals. Looking at it closely it focuses more on limitations, inabilities and other medical details[13] which are very contested by PWD and their advocates who claimy that the issue is not about the individuals rather about the social barriers which prevent PWD to enjoy equal and equitable rights and opportunities.

To palliate to that weakness within the local legal framework, throughout this research, the definition provided by the United Nations Convention on the rights of

[10] Office of the prime Minister, p. 2
[11] Office of the prime Minister, p. 2
[12]Office of the prime Minister N° 20/18 du 27/07/2009, p. 77
[13] Reisdorf 2013, p.6

PWD (UNCRPD) is used. “PWD include those people with long-term physical, intellectual, mental and sensory impairments which in interactions with barriers will hinder their full and effective participation equal to others”[14]

2.1.2. The conceptualisation of the needs

2.2. Theoretical framework of disability in HIV&AIDS

Today, more than one billion people in the world live with some form of disability, of whom nearly 200 million experience considerable difficulties in functioning. In the years ahead, disability will be an even greater concern because its prevalence is on the rise (4).

Article 25 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) reinforces the right of persons with disabilities to attain the highest standard of health care, without discrimination (7).

Disability being a human rights issue mostly in inequalities to health care access, employment, education or political participation, a range of international documents including the World Programme of Action Concerning Disabled People (1982), the Convention on the Rights of the Child (1989), and the Standard Rules on the Equalization of Opportunities for People with Disabilities (1993) have highlighted key issues related to people with disabilities (4).

Since then, more than 40 nations adopted disability discrimination legislation during the 1990s and the CRPD – the most recent, and the most extensive recognition of the human rights of persons with disabilities – outlines the civil, cultural, political, social, and economic rights of persons with disabilities (7).

The major purpose of these international laws is to “promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by people with disabilities and to promote respect for their inherent dignity” with focus on the following general principles:

1. **Accessibility** – stop discrimination against people with disabilities when accessing health care, health services, food or fluid, health insurance, and life

[14] United Nations 13/12/2006, p. 4

insurance.

2. **Affordability** – ensure that people with disabilities get the same variety, quality, and standard of free and affordable health care as other people.
3. **Availability** – put early intervention and treatment services as close as possible to where people live in their communities.
4. **Quality –** ensure that health workers give the same quality care to people with disabilities as to others(4,7)).

In this line, the World Report on Disability suggests steps for all stakeholders – including governments, civil society organizations and disabled people's organizations – to create enabling environments, develop rehabilitation and support services, ensure adequate social protection, create inclusive policies and programmes, and enforce new and existing standards and legislation, to the benefit of people with disabilities and the wider community (4)The vulnerability of PWDs to HIV was first recognized in 2004 with Germany Symposium on Disability and the Global Survey on HIV&AIDS and disability, and 2008 with Kampala Declaration on Disability and HIV&AIDS, which outlined the roles, international and national stakeholders required to play (8).

The World Bank (WB) and UNAIDS have also recognized t-he importance of addressing the HIV epidemic among PWDs by including these population in their strategic plans for Africa (9)

While the Millennium Development Goals 1 and 6 aim at eradicating extreme poverty and hunger, and combating HIV&AIDS, evidence suggests that AIDS may lower GDP growth by up to 1.5% per year (10) (and that these major goals cannot be achieved without taking into consideration the plight of PWDs since they have largely been overlooked in the development agenda so far (11).

1.2.3. National Justification

People With Disabilities share the same difficulties that non-disabled Rwandan face in accessing health care, but there are some differential factors including assistance to reach health facilities, and those with mobility limitations find accessibility features in most facilities. Moreover, the nature of their impairments often leaves PWDs more

vulnerable to complications requiring medical treatment (11).

Key guiding national strategic documents including the Rwanda Vision 2020, EDPRS2 (2013-2018), the National HIV Strategic Plan 2013-2018 clearly indicate that achieving the long term national development needs to address HIV, AIDS issues (Vision 2020), and that disability, HIV and AIDS constitute major cross cutting heath issues to be taken into account in all programmatic areas in order not to leave any of Rwandan citizens behind in its development (EDPRS2). Furthermore, specific HIV related interventions such as mobile services and outreach activities should be implemented to reach isolated and marginalized populations, particularly hard-to-reach key populations such as FSW and MSM as well as to other vulnerable groups with specific needs including youth and people with disabilities (12).

In addition, Rwanda has confirmed its commitment to the U.N. Standard Rules on Disability by ratifying the UN Convention on the Rights of PWDs(11).

In this context, the Rwanda constitution states that the human person is sacred and inviolable (article 10) with the State and all public administration organs' absolute obligation to respect, protect and defend him or her, prohibiting any kind of discrimination, be it physical or mental disability that is punishable by law (article 11).

In the last decade, a number of efforts have been put in the comprehensive HIV services provision at different levels with regards to the constitutional and legal framework for the promotion of rights of persons with disabilities(12,13)), however, some gaps still exist in providing appropriate quality services to PWDs as reported by the Umbrella of Persons with Disabilities in the Fight against HIV&AIDS in Rwanda(11)

In fact, HIV and AIDS management being socially, psychologically and medically complex, it can generate fear, stigma to PWDs and challenges to healthcare providers. This can have implications on the HIV epidemic response in Rwanda where challenges to provide HIV services to PWDs poorly understood and not well documented to inform policy and strategies with regard to these marginalized social categories (11)

Therefore, a well-documented needs assessment of HIV services provision among PWDs is required to identify strategies as well as action plan to implement key interventions/programs addressing gaps in HIV services delivery to PWDs in Rwanda.

1.2.4. Success in HIV Services Provision in Rwanda

In Rwanda, the HIV response employs combinations of and achieves synergy between different HIV strategies and services in order to offer a comprehensive package of services adapted to different target groups and the HIV NSP (2013-2018) serves as a great reference to the Government efforts to response to HIV and AIDS epidemic.

To achieve its goals, the NSP has three main levels of intervention for the comprehensive HIV services provision including:

a. Prevention of new HIV infections
b. HIV care and treatment
c. Social Impact Mitigation

During the last five years, the global standards of geographic universal access to HIV services have increased to reach people in need with national coverage over 93% (12) This significant increase in geographic coverage was coupled with improvements in the quality of services being delivered. For example, high enrolment and retention rates have permitted Rwanda to reach universal access for ART with a coverage of 91.6 percent of the estimated number of eligible adults currently receiving treatment, compared to 63 percent in 2009(14)

These successes of the HIV response are to a large extent due to strengthening of the national health system. The network of health facilities is well decentralized, with almost all administrative sectors equipped with a health center (only 20 out of 416 sectors do not yet have a health center), and health posts are now being developed or upgraded to bring primary healthcare closer to isolated areas. Mobile services and outreach activities are implemented to reach isolated and marginalized populations, particularly hard-to-reach key populations such as FSW and MSM. Health care providers in health facilities are trained to provide adapted and respectful services to these key populations as well as to other vulnerable groups with specific needs such

as youth and people with disabilities(12).

In terms of financial accessibility, the community-based health insurance scheme (called Mutuelle de santé) now covers 85 percent of the general population. With other health insurance programs, it is estimated that 91 percent of all Rwandans are covered health insurance (1).

In spite of the strong results achieved by Rwanda in the last decade in addressing the HIV epidemic, issues of stigma and discrimination relating to the HIV epidemic are still persistent. Great strides have been taken to ensure geographic and financial accessibility to health and HIV services to all citizens, yet some marginalized groups such as individuals with disability still experience barriers to accessing appropriate and adapted services with reported inequities though one of the guiding principles of HIV services provision is equity and human rights (12).
As per the HIV national strategic plan (2013-2018), one of the overarching results framework state that people infected and/or affected by HIV have the same opportunities as the general population.

1.2.5. Challenges for PWDs in HIV Services

Currently, many countries report that HIV centers and clinics are physically inaccessible, lack sign language interpretation, and do not address the needs of the individuals with intellectual or mental health impairments (15). Furthermore, among those living in extreme poverty, persons with disabilities are often unable to afford transportation to HIV services sites, let alone the cost of testing or medical care and many health professionals, unaware that individuals with disability may be sexually active, do not offer to test them or provide services, under the assumption that they are not at risk (16).

It also reported that persons with disabilities may not benefit fully from HIV and related sexual and reproductive health services for the following reasons (15):

a. Service providers may lack knowledge about disability issues, or have misinformed or stigmatizing attitudes towards persons with disabilities
b. Services offered at clinics, hospitals andin other locations may be physically

inaccessible, lack sign language facilities or fail to provide information in alternative formats such as Braille, audio or plain language

c. Confidentiality for persons with disabilities in HIV testing and counselling may be compromised, for example, by the need for a personal assistant or a sign language interpreter to be present in order to access HIV-related services. The decision to use support services rests with the person with a disability and should be respected by the relevant health service provider
d. In settings with limited access to antiretroviral therapy and post-exposure prophylaxis, persons with disabilities may be considered a low priority for treatment. Where persons with disabilities are receiving HIV treatment, health professionals may not pay enough attention to potentially negative drug interactions between HIV treatment and the medications that persons with disabilities are taking. Some medications may actually worsen the health status of persons with mental health conditions, including depression.

Furthermore, failure to communicate in appropriate formats can lead to problems with adherence and observance(17).

According to a survey conducted by the Zimbabwe Parents of Handicapped Children's Association, people with disabilities are excluded from general HIV&AIDS services because counseling and testing are not offered in sign language for people with hearing impairments, and education and communication materials are not offered in Braille for people with visual impairments(18).

The result is that many individuals with disability are not reached with HIV and AIDS messages, are unaware of the symptoms of HIV&AIDS, and do not understand the implications of these symptoms, should they appear.

Today, little is known about needs and challenges that PWDs are facing in HIV services provision in Rwanda.

Persons with disability include people who have long term physical, mental, intellectual or sensory impairments which, in interaction with attitudinal and environmental barriers, may hinder their full and effective participation in society on equal basis with others'' (United Nations, 2006).

According to the Ministerial order N° 20/18 of 27/7/2009 determining the modalities of classifying persons with disabilities into basic categories based on the degree of

disability. In Rwanda context, people with disabilities are classified under the following categories (19):

A. Physically disability;
B. Blind persons;
C. Deaf-and-dumb persons or persons with either of these disabilities;
D. Persons with mentally disability;
E. Persons with disabilities not specified in the above categories approved by the Medical committee

Can we know which definition you are using during the study

1.2.6. Mental Disability

A state of arrested or incomplete development of mind, which includes significant impairment of intelligence and social functioning and is associated with abnormally aggressive or seriously irresponsible conduct

1.2.7. Hearing Disability

Deafness, or hearing impairment, is a partial or total inability to hear and speak where the ability would usually be expected.

1.2.8. Physical Disabilities

It is any impairment, which limits the physical function of one or more limbs or fine or gross motor ability. Other physical disabilities include impairments, which limit other facets of daily living, such as respiratory disorders and epilepsy.

1.2.9. Visual Disabilities

It is the condition of lacking visual perception due to physiological or neurological factors.

1.2.10. Others

Including people with albinism, little people, people with multiple disability

However, even though the law does include several types under ‘others’ category, the study will outline the specific needs for each of them.
This will allow developing a relevant action plan laying out strategies and prioritization to address the identified HIV&AIDS needs of PLWDS by types **(**UPHLS, Inclusion Guide of Peoples Living with Disabilities in HIV and AIDS Response, pp9-10)

CHAPTER III: METHODOLOGY

3.1 Desk Review

For a better understanding of the real needs of PLWDs, a deep review of key international and national documents was undertaken to have a clear picture of the current situation of legal framework and HIV services provision related to people with disabilities and pave the way to appropriate needs assessment for informed action plan.

3.2 Approach

Qualitative data was generated through a combination of several participatory techniques such as key informants interviews, focus group discussions, observation (especially at health services provision sites), case stories and testimonies. Checklists outlining guiding questions per theme were developed and used during data collection.

The inception report including data collection tools were prepared prior data collection and presented to the client for approval. After the presentation and approval of the inception report, the following steps were undertaken:

- Data collection,
- Data cleaning,
- Data entry,
- Data analysis (using thematic approach) and interpretation
- Compilation and draft report

These actions will be completed by final report writing, development of action plan with priorities and strategies

3.2.1 Sample Size Determination

The purposive sampling method was used for the selection of key informants. This sampling technique “also called judgment sampling” is the deliberate choice of an informant due to the qualities the informant possesses.

Referring to the information to be collected, the selection targeted people who could provide the information by virtue of knowledge or experience and inclusion criteria described below.

Based on this sampling justification, respondents were selected from:

- Rwanda Biomedical Center,
- National Council of persons with disabilities,
- UNICEF,
- Handicap International,
- The network of persons living with HIV&AIDS and,
- Organizations of Persons with Disabilities.

For service providers, the following health facilities were sampled:

- Three district hospitals: Kibagabaga in Gasabo District, Nemba in Gakenke District and Munini in Nyaruguru District.
- Seven (7) health centers were selected: Kacyiru and Remera in Gasabo District Nemba in Gakenke District, Kabarore in Gatsibo District, Cyahinda and Muganza in Nyaruguru District , Rususa in Ngororero District

At district level (10 people participated in the survey):

- District Disability Officers
- Director of health in five selected Districts (Gasabo in Kigali City, Gakenke in Nothern Province, Gatsibo in Eastern Province, Ngororero in Western Province and Nyaruguru in Southern Province)

From DPOs level the information was collected from:

- AGHR (representing persons with physical disabilities),
- RNUD (representing persons who are deaf),
- RUB (representing persons who are blind),
- NOUSPR (representing persons with mental disabilities,
- Collectif TUBAKUNDE (representing children with intellectual disabilities.

At community level: 136 PWDs (all types of disabilities considered), around 20 from each of the seven selected district: Gasabo, Kicukiro, Nyarugenge in Kigali City, Gakenke in Nothern Province, Gatsibo in Eastern Province, Ngororero in Western Province and Nyaruguru in Southern Province.

3.2.2 Inclusion and exclusion criteria

- At national level: were included the organizations that have been intervening in HIV&AIDS among PWDs and that have some experience to share.
- Districts
    - Urban districts: to have the picture from the respondents from different corners of Kigali City, PWDs were selected from all three Kigali City districts
    - Rural districts: to have a picture of the situation, four rural districts were selected to compliment the information from urban districts.
    - Either in urban or in rural, the staff in charge of persons with disabilities and the Director of health provided information on district commitments in integrating HIV and disability in district response.

a) Respondents from DPOs staff were either the Program Manager and or the social worker that were in the right position to provide reliable information.

b) Respondents from health facilities were in charge VCT, ART, PMTCT, psychosocial support, nutrition services.

- PWDs: the selection criteria include inter alia: having a responsibility in NCPD organs, DPO organ, in cooperatives or in associations, which motivated the relevancy of the information to be shared to the consultant. In additional to that, the respondents were selected on voluntary basis, and before any session a consent form was signed. PWDs that have experience HIV&AIDS issues to provide testimonies, such as persons with mental disability that have had trauma

due to HIV infection. For children with disability, parents or tutors had to sign a consent form on their behalf.

Therefore, was excluded from the sample:

- Any institution/organization not working directly or indirectly in health or disability related domains;
- Any service provider who was found not having HIV&AIDS services background,
- Persons with severe disability not able to express themselves appropriately

3.2.3 Data Collection techniques

A series of interviews with semi-structured questionnaires was conducted with selected respondents as described below.

- **Semi structured interview to ten people at district level:** The District Disability Officer (DDO) and the Director of health in five selected Districts, Gasabo in Kigali City, Gakenke in Nothern Province, Gatsibo in Eastern Province, Ngororero in Western Province and Nyaruguru in Southern Province.
- **Semi structured interview to DPOs**: AGHR, RNUD, RUB, NOUSPR, Collectif TUBAKUNDE, UWEZO Youth empowerment
- **Semi structured questionnaire to PWDs** from Gasabo, Kicukiro, Nyarugenge Districts in Kigali City, Gakenke District in Nothern Province, Gatsibo District in Eastern Province, Ngororero District in Western Province and Nyaruguru District in Southern Province.

Data Collection through Focus Group Discussions (FGD)

Ten Focus group discussions were organized at different places: DPOs offices in Kigali City and District office in rural area.

3.3 Ethical considerations

ETHICAL CONSIDERATIONS FOLLOWED BY THE STUDY TEAM

Ethical Considerations	Remarks
Confidentiality	All research team members were trained to understand issues around confidentiality and anonymity and committed to honor promises made to respondents about confidentiality. Consent form were signed the respondents. Prior to data collection study respondents were informed about the background to the exercise, as well as research processes to be followed (data collection, data storage, and data use)
Protection and privacy	The research team ensured that interviews and discussions are conducted in safe and secure environments in which respondents can discuss sensitive issues. The team assigned codes to respondents when needed.
Informed consent	Consent was sought from respondents before starting interviews and focus group discussions and all necessary national approvals were obtained prior data collection.
Potential side effects of the exercise	Being aware of the potential side effects of the assessment especially among the beneficiaries whose expectations may be raised study respondents were given detailed explanations on the background to the exercise before the interviews or focus group discussions.
Dissemination and presentation of the findings	During our official involvement in disseminating the findings of each phase of this consultancy, we shall present findings in a manner that respects people and honor promises of confidentiality.

CHAPTER IV: PRESENTATION OF RESULTS

4.0. INTRODUCTION

This chapter presents results from the needs assessment of people with disabilities in HIV and AIDS services aiming at identifying and designing strategies to provide equal and equitable HIV services to this specific group of people.

Key findings presented in this chapter result from (1) the desk review of the national HIV program, (2) interview with key informants, and (3) focus group discussions which are outlined below:

- Description of key informants
- HIV services provision to PWD in Rwanda
- Current needs for HIV services provision per type of disability
- Strategies to address needs of PWDs in HIV service

4.1. Description of Key Informants

During the data collection, different categories of respondents have been approached. These include primary respondents, secondary respondents and tertiary respondents as here described.

1. **Primary respondents**

As the assessments was to identify the needs in accessing HIV and AIDS services for persons with disabilities, they were the primary respondents to provide relevant information and share their experience in accessing HIV and AIDS services. One hundred thirty six persons (**136**) with disabilities have been involved in data collection through focus group discussions, interviews, and questionnaires.

2. **Secondary respondents**

The secondary respondents involved mainly ones from the institutions and organizations working for and with PWDs. They include the staff from NCPD, managers and social workers from DPOs and were 10 in total.

3. **Tertiary respondents**

The eighteen tertiary respondents include the District staff such District Disability Mainstreaming Officer, the in charge of health, the staff of health centers and hospitals.

4.1.1. Distribution of Respondents by Sex

Figure 1: Distribution of Respondents by Sex

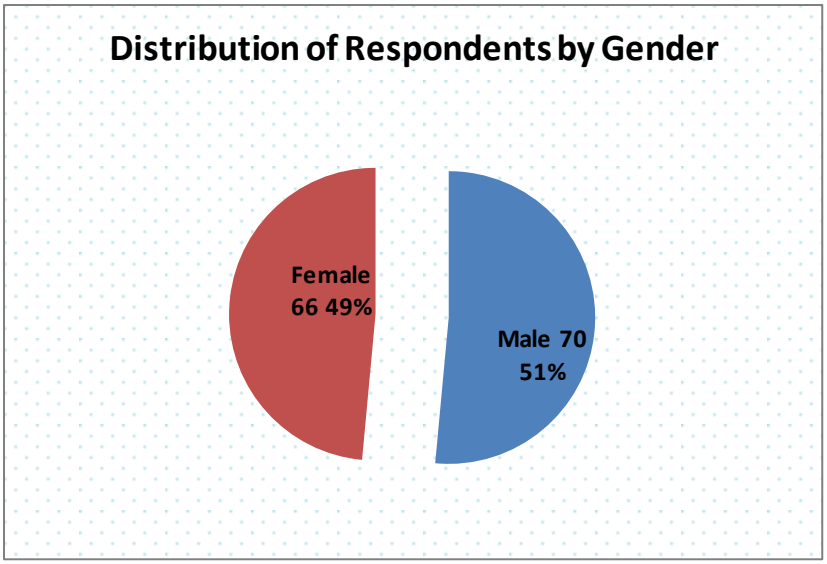


Figure 2: Number of Respondents by District

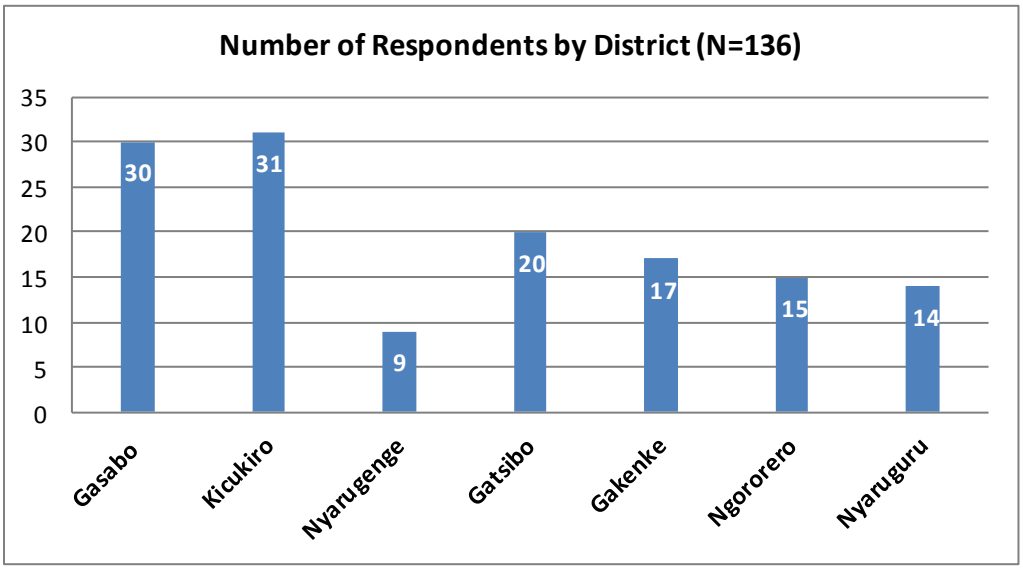
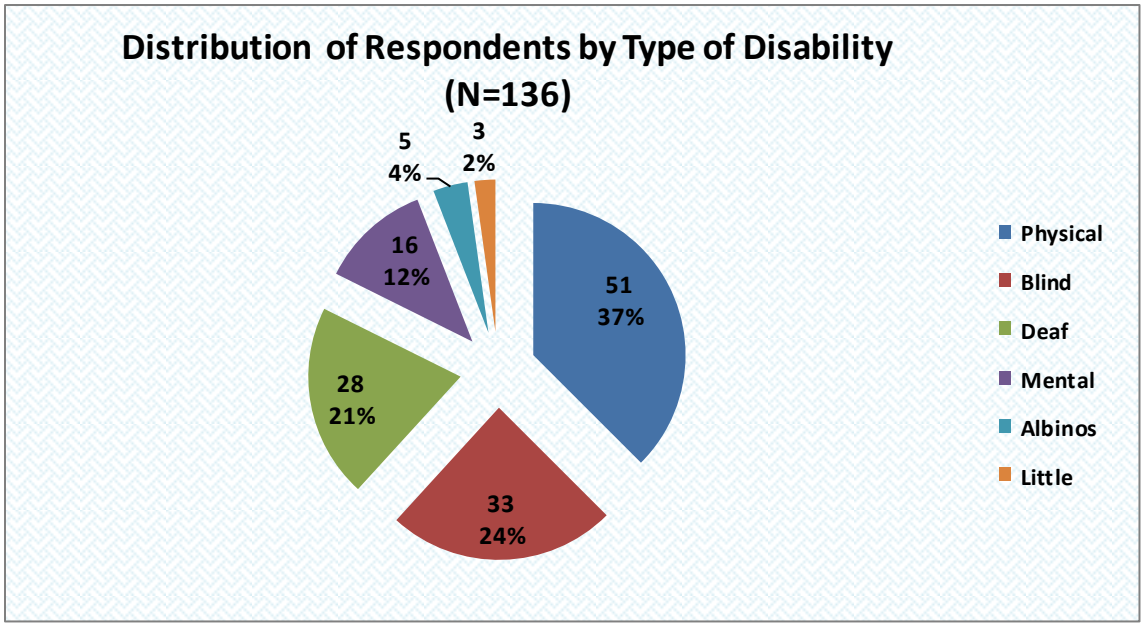


Figure 3: Distribution of Participants by Types of Disability



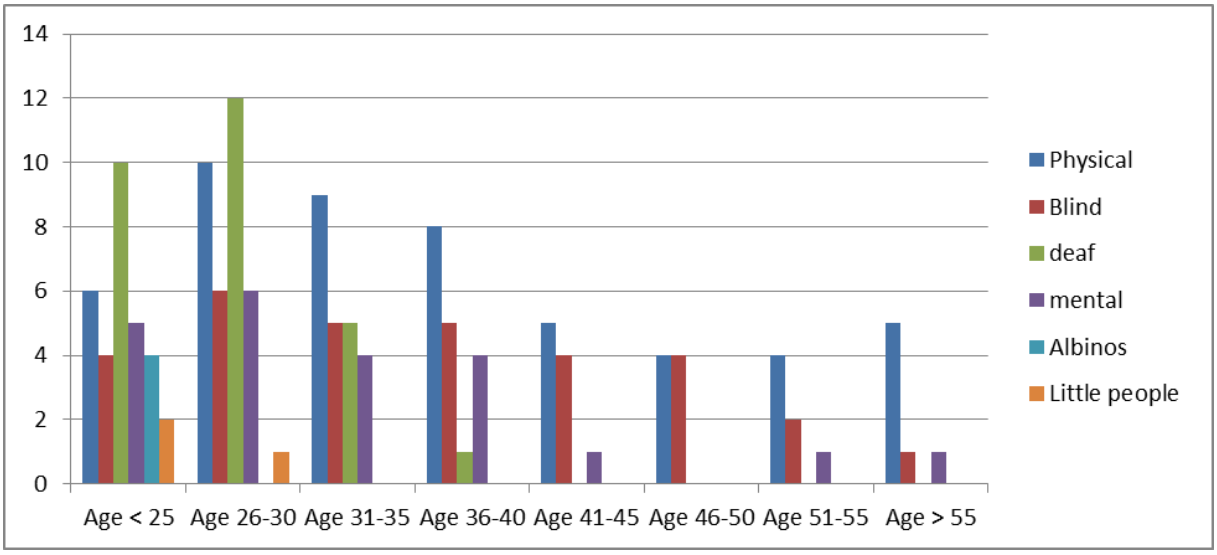
Source: Collected data

The graph above shows that our information was collected from 136 PWDs with 51 (37%) presenting physical disabilities, 33 (24%) with blindness, 28 (21%) deaf, 16 (12%) with mental disabilities, 5 (4%) albinos and 3 (2%) little people.

Figure 4: **Distribution of respondents by disability and age**

No	Age Disability	-25	26-30	31-35	36-40	41-45	46-50	51-55	+55
1	Physical	6	10	9	8	5	4	4	5
2	Blind	4	6	5	5	4	4	2	1
3	deaf	10	12	5	1	0	0	0	0
4	mental	5	6	4	4	1	0	1	1
5	Albinos	4	0	0	0	0	0	0	0
6	Little people	2	1	0	0	0	0	0	0
	Total	31	37	23	18	10	8	7	7

Source: collected data



As resulted from the table below describing the distribution of the age of respondents by age, thirty one were under twenty five, thirty seven were between twenty six and thirty, 23 between thirty one and thirty five, 18 between thirty six and forty, 10 between forty one and forty five, 8 between forty six and fifty, 7 between fifty one and fifty five while 7 were above fifty five.

4.1.2. Distribution of Respondents by Disability and Level of Education

Table 1: Distribution of Respondents by Disability and Level of Education

No	Disability	Primary	Secondary	Tertiary	VTC	Illiterate
1	Physical	16	20	7	5	3
2	Blind	8	10	12	0	3
3	Deaf	3	14	8	0	3
4	Mental	10	5	1	0	0
5	Little people	0	2	1	0	0
6	Albinos	2	2	0	0	1
	Total	**39**	**53**	**29**	**5**	**10**
	%	**29%**	**39%**	**21%**	**4%**	**7%**

Source: collected data

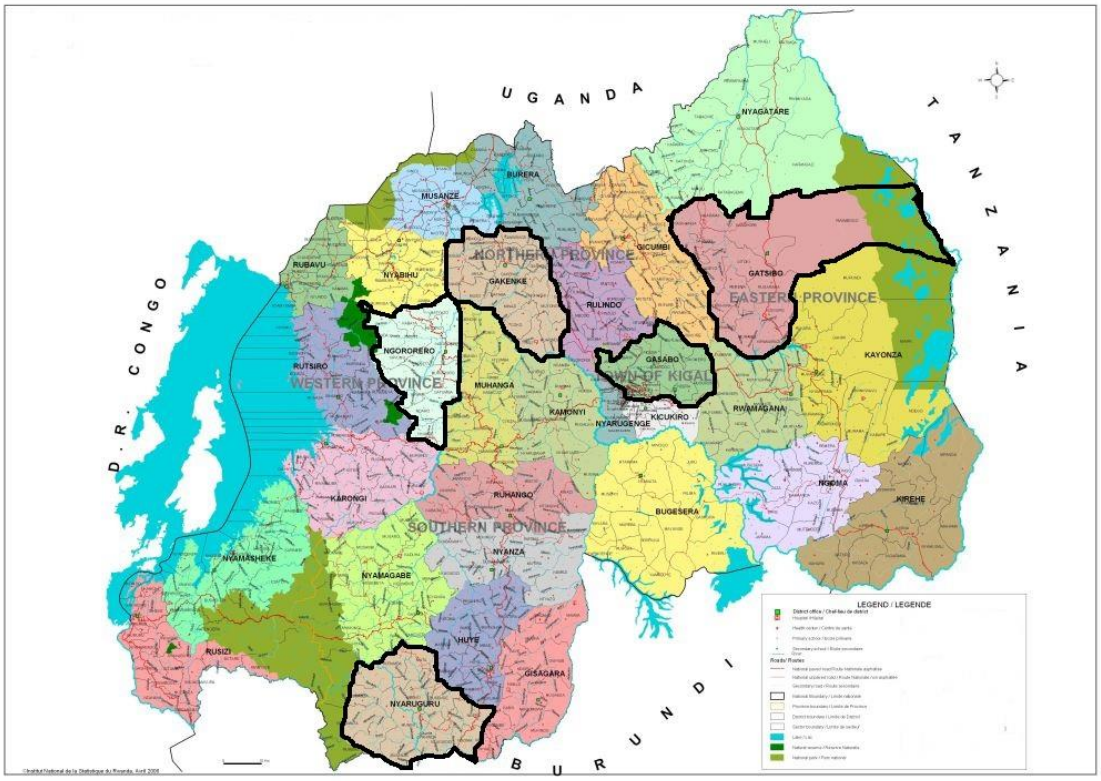
Referring to level of education, it is revealed from the table above that the 39 respondents have the primary (29%), 53 secondary (39%), 29 tertiary (21%), 5 (4%) vocational training level while 10 (7%) are illiterate.

4.2. Status of Existing HIV Services Provision to PWD in Rwanda

4.2.1 Response of District in HIV&AIDS Services

a) Sampled Districts

The information was collected from five districts of Kigali City: Gasabo, Kicukiro and Nyarugenge, Gakenke in Northern Province, Gatsibo in Eastern Province, Ngororero in Western Province and Nyaruguru in Southern Province.



The key respondents at district level were the District Disability Officers and Directors of health at District level.

b) Role of Districts in HIV and AIDS Services provision.

The District has the mandate of coordinating and monitoring all stakeholders' health interventions including ones provided by health centers and hospitals. HIV and AIDS come as health component among others. In line with HIV and AIDS, our consultations with districts Health Directors revealed that all health centers are supposed to provide the following services: voluntary counseling and testing VCT, PMTCT, and ART provision while few of them have nutrition services.

However, some districts like Gatsibo conducted awareness campaigns through cooperatives and associations working with PWDs for VCT services to know their status and get treatment once HIV+ as can be instructed by the professional. Support to cooperatives is provided to PWDs to improve life conditions, case of Ngororero District. The channel of peer educators seems being a strong and effective strategy to mobilize PWDs to VCT services. These peer educators should also play a role of counselors among their fellows.

c) Limitations in Mainstreaming Disability, HIV and AIDS Services

Either through districts planning or monitoring of HIV and AIDS interventions within stakeholders, no specific attention is paid to PWDs. At health facilities, PWDs are received like other citizens. In VCT service, the register has to mention whether the client has or disability, though it is not done on all health facilities.

d) Collaboration with Districts and UPHLS

Having the mandate of advocating for the access to HIV and AIDS services for PWDs, its collaboration with districts should be enhanced at all levels: from community to district.

Since UPHLS has no longer the districts coordinators, it isn't visible in districts interventions. Though, there is a gap in monitoring HIV and AIDS interventions as the health office at district level can't cover all the geographical area to ensure all stakeholders are doing effectively what they have planned to do.

e) Challenges

The consultations with districts have revealed some crucial challenges that still hamper the effectiveness of HIV and AIDS among PWDs.

- **Weak strategies to monitor the HIV and AIDS interventions targeting PWDs**: while this appears as the important task of the districts, there are still limited resources of to monitor the interventions with a specific attention to PWDs.

- **Weak collaboration of districts and UPHLS to monitor** the effective implementation of HIV and AIDS related interventions: although the monitoring belongs to districts, they cannot perform this task alone. Since UPHLS has the

mandate to advocate for the access to HIV and AIDS services to PWDs, its collaboration should be more visible that it is currently.

- **Lack of specific data specific on PWDs that benefit from HIV and AIDS services** within health facilities: this is linked to weak strategies of monitoring previously reported. Since there aren't clear and reliable data, there shouldn't be appropriate plans to improve the access to HIV and AIDS for PWDs.
- **Lack of tangible interventions in impact mitigation**: Many stakeholders within districts are reported to be more involved in HIV prevention than in impact mitigation. Though the interventions in HIV prevention are not enough, the life conditions of PWDs with HIV infection are still very poor and it requires strong strategies to empower PWDs to improve the living conditions.

2.1.1. HIV Service Provisions in Health Facilities

a) Description of Health Facilities Providing HIV Services

Health care providers were defined as any professional working in HIV and AIDS services at selected health facilities. The following health facilities have been consulted:

Table 2: Description of Health Facilities Providing HIV Services

No	HF	Type	District	Category
1	Kibagabaga DH	District Hospital	Gasabo	Public
2	Nemba DH	District Hospita	Gakenke	Government supported
3	Kacyiru HC	Health Center	Gasabo	Public
4	Remera HC	Health Center	Gasabo	Public
5	Nemba HC	Health Center	Gakenke	Government supported
6	Cyahinda HC	Health Center	Nyaruguru	Government supported
7	Muganza HC	Health Center	Nyaruguru	Government supported
8	Kabarore HC	Health Center	Gatsibo	Public
9	Rususa HC	Health Center	Ngororero	Government supported

Source: collected data

As described in the table above, the visited health facilities include two district hospitals and seven health centers.

b) Package of HIV and AIDS Services Offered in Health Facilities

The package of HIV services provided in Rwanda includes HIV prevention, HIV care and treatment and social impact mitigation (12,20). With regards to HIV prevention, interventions are mainly focusing on provision of prevention message, prevention of mother to child HIV transmission (PMTCT), voluntary medical male circumcision (VMMC) and follow up of serodiscordant couples**.**

The Care, support, and treatment component of the HIV National Program aim to provide services to PLHIV that will enable them to lead a normal life. These services include clinical and biological assessment for ART eligibility and disease progression, and prevention and treatment of opportunistic infections (OI) that include TB, STIs, cervical cancer, Cryptococcus, Viral hepatitis and other blood borne infections (12)

The last component of HIV related services package is the mitigation of the socio-economic impact of HIV on the people infected with and affected by HIV. The impact mitigation component of the national HIV response continues to be linked with and benefit from several Government of Rwanda social protection programs such as socio-economic support provided to the orphans and vulnerable children and PLHIV. This helps ensuring the economic viability of associations and cooperatives of PLHIV through training on income generating activities as well as financial management. PLHIV also receive training and support in human rights and legal issues to fight against stigma and discrimination and ensuring that PLHIV can actually claim them (12).

The package of HIV services varies depending on the level of implementing health facility (Hospital or Health Center)

- **District Hospitals**

The district hospitals mainly provide HIV care and treatment including patients enrolment, clinical evaluation, psychosocial and nutritional support, treatment initiation as well as clinical and biological follow up.

District hospitals also offer Provider Initiated Testing (PIT) for clients from admission and outpatient consultations.

For the purpose of efficiency, the HTC and PMTCT services are mainly offered at health centers in the catchment areas though in some specific cases hospitals can offer PMTCT in maternity for pregnant women referred from health centers.

- **Health Centers**

The health centers provide voluntary counseling and testing, VCT, care and treatment, nutrition, psychosocial support, prevention from mother to child transmission (PMTCT).

41.2 Access to HIV and AIDS by PWDs in Health Centers

During the period of data collection in July 2015, the consultant has captured the frequentation of PWDs in VCT (HTC) and ART services considering the period from January to June 2015. That frequentation is detailed in the table below:

Table 3: Access to HIV and AIDS by PWDs in Health Centers

No	Health Center	VCT	ART
1	Kibagabaga	N/A	4
2	Nemba	N/A	3
3	Kacyiru HC	3	N/A
4	Remera HC	2	3
5	Nemba HC	5	4

6	Cyahinda HC	4	3
7	Muganza HC	4	4
8	Kabarore HC	6	5
9	Rususa HC	4	3

Source: collected data

Where marked N/A it is because the service is not offered like at hospitals or no available information on PWDs that benefit from it.

Model of visited inaccessible health center

Model of visited accessible health center

4.1.3 Knowledge on HIV and AIDS

The consultants have assessed the knowledge of PWDs on HIV/AIDS and in 80% of respondents PWDs have knowledge on the pandemic. They know clearly the different between HIV and AID as the first means the presence of the virus in human body while the AIDS is stage when the HIV+ has started developed diseases related to the infection. Ninety 90% of the respondents know the ways of contamination of the virus while 10% still lack knowledge on that matter.

In general, blind communities have knowledge on HIV/AIDS: how HIV is different from AIDS, the ways of contracting HIV.

4.2 Group at High Risk of Contracting HIV

The consultations on groups at risk of contracting have ranked as follows:

- PWDs in general: 85 % have ranked this category and under this ranking, girls and women with disabilities were declared the most exposed. Within this category, girls and women with disabilities were declared the most vulnerable to HIV infection.
- Youth in general and in particular youth with disabilities. Sixty (60 %) of the respondents have declared this category being at high risk of contracting HIV.
- Sex workers: 55% of the respondents have declared this category being at high risk of HIV infection
- Men having sex with men: 30% of respondents have declared this category having at high risk of HIV infection

4.3 Needs in HIV and AIDS Services to PWDs by Type of disability

4.3.3 I**ntroduction**

This section highlights the crucial challenges faced by PWDs in accessing HIV and AIDS services, some of them apply to all types of disabilities while there are some that are specific to specific types of disability. The common challenges to all types of disability include the extreme poverty, sexual violence faced by physical severe disability, persons with mental disability, deaf and blind persons. They also include false beliefs for the services providers that PWDs are not at risk of HIV infection, self-discrimination made by PWDs to themselves and double discrimination made by the family member and community. The specific challenges to specific types of disabilities include inter alia, communications barriers to deaf and blind persons with lack of sign language interpretation and lack IEC materials in accessible format to blind persons. There are special false beliefs to little people and persons with albinism that they are source of lack once having sexual intercourse with them, this leads to sexual violence with risk of contracting HIV infection. The identified challenges were translated into needs and actions have been formulated to address them. (Source: From the respondents during the assessment)

4.3.4 Common Challenges to all types of disabilities

The collected information has helped to classify the challenges and needs by type of disability. Though some of them are specific to specific types of disability while others are specific to specific type of disability.

a) Extreme poverty

A big of number of PWD's live in extreme poverty and when associated to HIV + status, this hinders nutrition and affects the improvement of feeding instructions especially for PWDs HIV+ under ART. Therefore, the consequence is that certain PWD's do not respect the instructions of taking treatments as it is required due to lack of balanced diet.

Need: Economic empowerment of PWDs through income generating activities to equip them of means to improve their living conditions

b) The double discrimination

Disability associated with HIV infection creates the lack of integration of PWDs in family and society in general

Need: Smooth integration of PWDs with HIV infection in family and society through intensive counselling sessions using the community health workers and peer educators to build PWDs self esteem

c) Self-discrimination of PWDs and false beliefs of HCPs

PWD's rarely join community activities and AIDS campaign. PWDs to be considered as other human being as they are sexual active and consequently being at risk of HIV infection

False beliefs among certain health service providers that PWD's aren't at high risk of being infected by HIV and AIDS by assuming that PWD's are not sexually active.

Need: To address that challenge, PWDs need to be ensured the protection from sexual violence either by family members and community or by legal organs and grassroots leaders that need to be aware on the violence faced by PWDs.

d) Victim of sexual violence

Certain people infected with HIV believe that they could be cured from HIV if they have sexual intercourse with PWDs, especially those with severe disability, that are falsely believed they are not sexually active.

Need: There is a need in education to PWDs and HIV positive people about HIV prevention and treatment.

e) Ignorance

A big number of PWDs are illiterate and cannot access easily prevention message

Needs: Specific education to PWDs to reduce illiteracy

f) Lack of independence and freedom to love and loved

This makes many PWDs accepting any demand without even knowing whether or not the person is HIV infected. Young PWDs explore sexual experience and have unprotected sexual intercourse

Need: Education on human rights and freedom to chose a partner as well as on reproductive health.

4.3.5 Testimonies and Cases Study

The following testimonies were issued by PWDs to share the challenges they face in accessing to HIV and AIDS services.

Some PWDs with HIV infection on ART often lack nutrition support with an impact on treatment adherence. She is 45 woman years old and she is HIV+ and said: ‘’When you have disability and then you are HIV+, then you are renting house, nutrition conditions become also poor and it is not easy to take the treatment. In such circumstances, we are forced to abandon treatment. ‘’

How can HIV infect a PWD? In one health center, a data collector wanted to know the reasons behind a small number of PWDs in ART service, and the in charge of the service said that it should be because they are not infected by HIV. Asking why he thought they are not infected, he said no person can fall in love with a PWD.

4.3.6 Challenges and Needs of Specific PWDs

a) Deaf Persons

A part of common challenges to all PWDs, deaf persons encounter communication barrier that limit the access to HIV and AIDS services. Knowledge on sign language within community/family members and services providers is still limited.

- **Communication barrier** due to limited number of sign language interpreters. When they go for VCT they are tested without any prior counseling and they sometimes are frustrated and are denied the service and told to go away. And when they are the queue waiting for service, others are called on their names while the deaf people can’t hear. Consequently, they go back without having the needed service, and they take the whole day on queue. Sign language not

understood by HIV service providers. This leads to lack of confidentiality during the HIV and AIDS services provision that leads to violation of privacy when there is required to have intermediary to interpret with risk of not keeping.

Need: Access to friendly communication with sign language interpretation.

- **Lack of information on prevention** as some prevention campaigns done though radio channels. This becomes crucial in rural area where some deaf women become pregnant without knowing their HIV status, with prenatal consultations that aren't accessible to them. Some are married without knowing their status.

Need: Access to prevention campaigns done through the radios.

- **Literacy among deaf community** where the majority of people with hearing disability are literate with limitation information to access on HIV and AIDS

Need: Education to deaf persons to equip them with necessary skills allowing to access updated information. Specific education to deaf community to reduce illiteracy rate within this community and promote their rights to privacy

b) Blind Persons

Blind persons are still facing communication barrier in accessing HIV and AIDS services. Prevention messages made on billboards and on printed formats are not accessible to them. Lack of integration in society when HIV+ is still being very crucial. Blind persons face sexual violence, as they can't even see the perpetrator to report accordingly. Women with visual disabilities are forced by their families to get married without any consent and sometimes are infected with HIV. Services providers still have false beliefs behind blind persons where they think being blind can affect the hearing capacities and this makes them uncomfortable in attending counseling sessions.

- **Communication barriers:** Tools and modes of dissemination of information are not adapted to specific needs of blind persons since there are no Braille or audio IEC tools on HIV and AIDS to facilitate understanding. For instance there aren't any specific approaches on the sensitization on the use of the condom among blind persons. IEC to blind community should be used at schools, centers that take care of PWDs. For instance, RUB shall work with the branches to encourage them integrate HIV and AIDS in their day-to-day activities.

Need: Access to friendly communication to access to HIV and AIDS services

Being educated on the use of prevention materials such as condom. A blind person should be for instance be able to read all instructions on the use of condom such the expiration date, and have right to choose any kind wanted

- **Dependence** on guides and on other family members either from the community or the family when the person needs HIV and AIDS service such as VCT and ART. The services providers do not believe on dependency of the blind person and sometimes want to associate the guides to the counseling sessions.

Need: Being dependent when receiving HIV and AIDS service, such as VCT and ART.

- **Sexual Violence** and not possible to report as the victim hasn't seen the perpetrator

Need: Protection by family members and community

- **No liberty to decision:** some blind women are forced to be married and seek child to guide them and this union without consent can consequently lead to HIV infection.

Need: Right to choose the partner and being able to make the own decision.

Testimonies and Case Studies

- **Discrimination**: Name Sifa Prisca was interviewed at on July 8, 2015, revealed us the following: "*A 24-years young girl was born HIV+, with mental disability , and all her parents died from HIV AIDS. The young girl used to live with her HIV-negative grand sister who didn't take care of her. She was taking drugs but due to lack of support and care, she recently passed away. The lack of care frustrated her and abandoned the drugs". This shows how family of infected PWDs is sometimes careless.*

  Need: Care, integration in the family, adherence support

- **False beliefs of services providers**. She is 47 years and she is blind, met . "*One day, I went for testing with a group of friends, I knew I was HIV+. I only wanted to encourage my fellows to know their status. When the time of being given results came, I was as usually found HIV+ but the nurse asked to be taken the blood for a second time. The nurse wasn't expecting me to be HIV+. As I knew I was HIV+, it took much time to convince her, she couldn't believe*

how a blind person should be HIV+. The time came and *I enrolled on Anti Retroviral Therapy (ART), I was at the first time denied taking them myself, saying as the blind couldn't respect the instructions. I was obliged to buy a watch to convince her I was able to use it and know the exact time of taking drugs. Good news for me I was the first to be awarded among the persons who have been selected to respect instructions of taking drugs".*

Need: ???

- **Lack of acceptance and integration**. *One blind man, aged 45 was HIV+ and his wife abandoned him, although she was also HIV+. After being trained on doing income-generating activities, he started earning some money and the wife came back home. The man went back to thank the center that had trained him for the fact that her wife was back home. This shows being HIV + and live in poor conditions create a double stigma.*

  Need: *Need for economical empowerment through* income generating activities.

c) Persons with physical disabilities

Persons with physical disabilities face the challenge of long distance to make to reach health facilities. In up hills locations, the health facilities built up hills, which make them inaccessible. Mobility associated to lack of rehabilitation materials such as prosthetics and orthesis doesn't allow them to reach the health facilities for VCT and ART services.

- **Inaccessible health facilities**: long distance to reach places where HIV and AIDS are offered. Some location health facilities located on top of hills and at more than 2 Kilometers from the residence.

Need: Having all necessary facilities to access HIV and AIDS services at nearest places

- **Lack of appropriate materials**, such as weight measurers, for instance for the wheelchair user whose weigh can't be measured when needs to benefit from nutrition orientations

Need: Health facilities to have appropriate materials and equipment to offer services to PWDs in equal circumstances like to other clients.

d) Persons with mental disability

Our consultations have revealed that persons with mental are at high of contracting HIV. The following are the reasons for justification: they are victims of sexual violence when they in crisis as they are running at different places and can pass the nights in unsecured places. Some of women/girls are raped by their relatives. There are some beliefs saying that persons with mental disability are source of luck once having sexual intercourse with people.

- I**gnorance**: Very low level of education/ understanding: people with mental disabilities rarely access formal and informal education due to non-adapted material policies.

Need: Education to persons with mental disability that takes into consideration their needs.

- **Mindset**: The Rwandan community has the tendency to isolate/reject people with mental disabilities, and overprotect them, which makes them potential victims to sexual abuse and to the HIV and AIDS infection. Their families don't take care of their persons with mental disability, saying they are possessed by demon forces.

Need: Right to appropriate life with smooth integration in society.

- **The myths behind persons with mental disability** stipulate that having sexual intercourse with PWD's can cure HIV and AIDS, this being a source of HIV infection, some are violated by their relatives.

Need: Consideration with dignity and humanity and being accommodated appropriately

- **Lack of knowledge on disability issues**: service providers and stakeholders don't understand the mental disability.

Need: Having access to appropriate services line other citizens.

Our consultations with the organizations working with persons with mental disability have revealed that a big number of persons with mental disability have got trauma due to HIV+ and start discriminate themselves with lose of hope into their future.

The same organizations have also revealed that among the sex women workers, some have mental disability and this practice comes as a consequence of mental crisis and leads that can lead to HIV infection. Some persons with mental disability aren't aware on existence of HIV with very low level of thinking due to the nature of their disability. The following are some testimonies from persons with mental disabilities:

- Taking drugs for mental crisis and anti-retroviral treatment is a big challenge for persons with mental disability. She is 34 years old and is saying: '' *I have been violated and got HIV, at a certain period I started taking ART. Taking them simultaneously with drugs for mental disability was a very challenge for me. Fortunately, my CD4 recently increased and I stopped taking ART. And it several times happen to me to miss something to eat and in such situation I can't take drugs appropriately.*

- *A mother having a girl with mental disability lost her husband and got married to another man. The girl was violated by her mother's husband and got HIV and pregnancy. The girl is now under drugs. Fortunately, due to PMTCT service, she gave birth to a child free of HIV. Until now the perpetrator has disappeared*.
- A parent having a 15 years child boy with mental disability testifies: *My child has been violated by a man. I knew this when it had happened three times. I couldn't imagine how a man could have a sex with a boy. Going for a test it was found that he had been infected with gonorrhea. As the test shouldn't reveal results for VIH infection, the child was administrated preventive medicine for three months.*

e) Little people and people with albinism

- Self-discrimination that leads to not go for HIV and AIDS services

Need: Build little people self-esteem for smooth integration in society

- False beliefs that little people can be source of luck

Need: Consideration as human being like any other person without disability

Testimony

She is a little people and is 22 years old: I was attending a meeting in one neighboring and one man came to me and said: ‘I know little people can be source of luck, can you do me a favor of coming and start a business with me? I shall be seeking men to have sex with you and give you some money. I was very nervous and said I shall never attend such meetings’’

4.4 Challenges Identified at National Level

Lack of harmonization in HIV and AIDS Interventions: Impact mitigation activities are still very weak: PWDs are sensitized to VCT and found VIH+, not real intervention is done

Silence of NSP: The National Strategic plan on HIV/AIDS is silent on disability; this creates doubt on its smooth implementation and has an impact/change on access to HIV/AIDS services by PWDs.

Group at High Risk of Contracting HIV

The consultations on groups at risk of contracting have ranked as follows:

- PWDs in general: 85 % have ranked this category and under this ranking, girls and women with disabilities were declared the most exposed. Within this category, girls and women with disabilities were declared the most vulnerable to HIV infection.
- Youth in general and in particular youth with disabilities. Sixty (60 %) of the respondents have declared this category being at high risk of contracting HIV.
- Sex workers: 55% of the respondents have declared this category being at high risk of HIV infection
- Men having sex with men: 30% of respondents have declared this category having at high risk of HIV infection

4.5 Needs in HIV and AIDS Services to PWDs by Type of disability

4.5.3 Introduction

This section highlights the crucial challenges faced by PWDs in accessing HIV and AIDS services, some of them apply to all types of disabilities while there are some that are specific to specific types of disability. The common challenges to all types of disability include the extreme poverty, sexual violence faced by physical severe disability, persons with mental disability, deaf and blind persons. They also include false beliefs for the services providers that PWDs are not at risk of HIV infection, self-discrimination made by PWDs to themselves and double discrimination made by the family member and community. The specific challenges to specific types of disabilities include inter alia, communications barriers to deaf and blind persons with lack of sign language interpretation and lack IEC materials in accessible format to blind persons. There are special false beliefs to little people and persons with albinism that they are source of lack once having sexual intercourse with them, this leads to sexual violence with risk of contracting HIV infection. The identified challenges were translated into needs and actions have been formulated to address them

Source: From the respondents during the assessment

2.4.2 Common Challenges to all types of disabilities

- The collected information has helped to classify the challenges and needs by type of disability. Though some of them are specific to specific types of disability while others are specific to specific type of disability. **Extreme poverty:** in which a big of number of PWD's live and when associated to HIV + status, this hinders nutritional support and affects the improvement of feeding instructions especially for PWDs HIV+ under ART. Therefore, the consequence is that certain PWD's do not respect the instructions of taking treatments as it is required due to lack of balanced diet.

To address this challenge PWDs need to be economically empowered through income generating activities to equip them of means to improve their living conditions

- <u>The double discrimination</u> due to the fact of being PWD and being HIV+ at the same time. This creates the lack of integration of PWDs in family and society in general

  To fight that discrimination , there is a need of smooth integration of PWDs in family and society though being HIV+. Building self esteem through intensive counselling sessions using the community health workers and peer educators
- Self-discrimination of infected PWD's: due to lack of self esteem, PWD's rarely join community activities and AIDS campaign.

PWDs to be considered as other human being as they are sexual active and consequently being at risk of HIV infection

- False beliefs among certain health service providers that thank PWD's aren't at high risk of being infected by HIV and AIDS by assuming that PWD's are not sexually active.

To address that challenge, PWDs need to be ensured the protection from sexual violence either by family members and community or by legal organs and grassroots leaders that need to be aware on the violence faced by PWDs.

- **Victim of sexual violence**, especially those with severe disability. Certain people infected with HIV believe that they could be cured from HIV if they have

sexual intercourse with PWDs that are falsely believed that they are not sexually active.

There is a need in education to PWDs through literate initiatives to equip basis knowledge to allow them accessing prevention messages

- **Ignorance**: there is a big number of literate PWDs that can't access easily prevention message
- **Lack of independence and freedom to love and loved**. This makes many PWDs accepting any demand without even knowing whether or not the person is HIV infected

- Youth to explore sexual experience and have unprotected sexual intercourse

Need of freedom to chose a partner

Education on reproductive health to be aware on gender of having sex at early age.

Testimonies and cases study

The following testimonies were issued by PWDs to share the challenges they face in accessing to HIV and AIDS services.

Some PWDs that are HIV+ and that are under treatment face nutrition problem that requires enough means to overcome them. *'' She is 45 woman years old and is HIV+ and said: ''When you have disability and then you are HIV+, then you are renting house, nutrition conditions become also poor and it is not easy to take the treatment. In such circumstances, we are forced to abandon treatment. ''*

How can HIV infect a PWD? *In one health center, a data collector wanted to know the reasons behind a small number of PWDs in ART service, and the in charge of the service said that it should be because they aren't infected by HIV. Asking why he thought they aren't infected, he said no person can fall in love with a PWD.*

CHAPTER III: Action plan laying out strategies to address HIV/AIDS needs of Persons with disabilities

One of the objectives of the assessment was to produce an action plan laying key priorities to address the needs of PWDs in accessing HIV and AIDs quality services. Based on the needs developed above, the following action plan is built on four program objective: Reduce HIV new infection in PWDs, HIV positive PWDs have the same opportunities with like the general population, Reduce morbidity and mortality in PWDs with HIV, HIV positive have the same opportunities like others PLHIV. From the identified barrier/gap, strategies and activities were drawn.

Program Objective *:* Reduce HIV New Infection in PWDs			
Gap/ barrier	***Strategy***	***Activities***	***Target group***
Victim of sexual violence, and lack of liberty to decide of sexual and reproductive life	Increase the knowledge of PWDs in HIV prevention	To conduct education sessions on reproductive health and HIV transmission, refer and assist SGBV victims for the continuum of services.	General public
Lack of friendly environment to PWDs	Increase knowledge of health professionals on health special needs	Conduct awareness campaigns for HCPs with regards to PWDs	HCPs
Inadequate skills and knowledge of HCPs in the comprehensive management of HIV in PWDs	Increase knowledge of PWDs on HIV prevention	Organize specific trainings for HCPs on PWDs specific needs and their living conditions: sexuality, reproductive health and behavioral changes	HCPs
Insufficient prevention messages due to Communication barriers: Tools and modes of dissemination of information are not adapted to specific needs of blind persons since there are no Braille or audio IEC tools on HIV and AIDS to facilitate understanding	Increase knowledge, attitudes and behavior for HIV Prevention to all PWDs	Design and develop IEC materials specific to each type of disability	PWDs

Lack of knowledge on HIV and AIDS prevention among PWDs		Organize awareness campaigns on HIV Prevention	PWDs
Lack of appropriate Prevention messages		Organize sensitization of PWDs using appropriate channels specific to targeted disability	PWDs
lack of reliable data on HIV prevalence among PWDs	Promote evidence based policy making, interventions and programming	To conduct a baseline study to know HIV prevalence among PWDs by types of disabilities	PWDs HCPs MoH Stakeholders
Lack of independence in accessing HIV and AIDS services	Increase access to friendly prevention services	Educate and sensitize PWD's and the community in general on the human rights and the law repressing sexual and gender based violence.	Health services providers
Lack of access to appropriate information on HIV prevention	Increase knowledge, attitudes and behavior for HIV Prevention to all PWDs	Organize awareness campaigns on HIV Prevention	General Population
		Using appropriate prevention messages and IEC Materials	All PWDs
Double discrimination	Empower family members of PWDs for improved knowledge in HIV prevention	Train family members of PWDs on appropriate prevention messages specific to the type disability	Community
Lack of awareness on the rights of PWDs	Increase the public knowledge on the rights of PWDs	Train and counsel PWDs on positive living with HIV and AIDS and individual behavioral change	PWDs
		Educate PWDs and encourage them to join associations of PLWH	All PWDs

	Increase the knowledge on accommodating PWDs	Train family members of PWDs on appropriate prevention messages specific to the type disability	PWDs
Lack of information on prevention as some prevention campaigns done though radio channels. This becomes crucial in rural area where some deaf women become pregnant without knowing their HIV status, with prenatal consultations that aren't accessible to them. Some are married without knowing their status	Increase knowledge of HCPs in PWDs risk of HIV infection	Train HCPs on the specific needs of PWD's (SRH, SGBV, behavior change, etc.)	HCPs
Self-discrimination of infected PWDs and false beliefs of HCPs	Empower family members of PWDs for improved knowledge in HIV prevention	Train reproductive health peer educators from PWD communities/groups to assist in training PWDs	All PWDs
Communication barrier for persons with hearing impairment	Awareness campaign on HIV Prevention	Train service providers on the basic sign language in the area of HIV and AIDS	HCPs
Communication barrier for persons with hearing impairment	Increase access to friendly HIV prevention services	Train service providers on the basic sign language in the area of HIV and AIDS	HCPs
Programme objective : HIV Positive PWDs have the same opportunities like the General Population			
Gap/ barrier	***Strategy***	***Activities***	***Target group***
Discrimination for PWDs in general and PWDs HIV+ in particular	Reduce stigma and discrimination	Organize awareness campaigns on PWDs rights	General Population, PWDs
Discrimination for PWDs in general and PWDs HIV+ in particular	Reduce stigma and self discrimination	Organize Support groups for PWDs	All PWDs

Lack of harmonized guidelines and tools for HIV and AIDS among PWDs	Reduce stigma and self discrimination	Continue advocating for policy makers to consider disability in different policies, guidelines and tools	Decisions and policy makers
		Continue promoting sport and cultural activities for PWDs to help them getting out of the isolation and living positively with HIV	PWDs
Lack of independence in accessing HIV and AIDS services	Reduce dependence of PWDs to guide/accompanist	Promote IGA for PWDs	PWDs
Communication barriers	Increase access to HIV quality care services	Develop friendly materials IEC for different types of disabilities	PWDs HCPs
		Design specific guidelines and tools for HIV in PWDs	PWDs HCPs
		Design and set up centers of excellency for Special services to PWDs	PWDs HCPs
Communication barrier for persons visual impairment		To advocate for transcription in Braille handwriting the drug labels	PWDs HCPs
Limited resource for DPOs to integrate HIV and AIDS in their services	Advocacy for PWDs to improve their living conditions	Link DPOs to potential donors for resource mobilization to integrate and implement some HIV and AIDS related interventions to PWDs	PWDs
		Lobby the GoR and policy makers to mainstream poverty reduction programs in other socioeconomic	Decison and policy makers

		development national programs (Ubudehe, VUP, Gira Inka Munyarwanda,etc.)	
	Reduce extreme poverty among PWDs	Provide startup capital to PWDs to run IGA	PWDs
	Promote collaboration and networking of PWDs	Strengthen networking with other organizations working in the area of HIV and AIDS and human rights.	Stakeholders
	Ensure coordination of national programs related to PWDs	Strengthen the coordination of all districts with regards to PWDs action plans implementation	Stakeholders (Districts)
		Disseminate this assessment's findings at large scale and request support from different stakeholders to implement the developed action laying out the priorities to address the identified needs.	General public
	Reduce illiteracy among PWDs	Promote specific education for PWDs per type of disabilities	***PWDs***
	Increase access to HIV services	Increase the number of friendly services for PWDs	PWDs
	Avail friendly and appropriate infrastructures and equipment for PWDs at all health facilities	Adapt basic infrastructures and equipment to meet PWDs needs (stairs, chairs, weighing machines, toilets, examination tables, patients files, etc.)	PWDs HCPs

Program Objective : Reduce morbidity and Mortality in PWDs living with HIV			
Gap/ barrier	***Strategy***	***Activities***	***Target group***
Lack access to HIV and AIDS quality care services	Increase access to HIV quality care services	Avail specific guidelines and tools for HIV in PWDs	HCPs
		Conduct training of PWDs family members to equip them with knowledge and skills to provide home based care to PWDs	Community
		Design, develop and use specific national guidelines and tools for HIV in PWDs	PWDs
Communication barriers for persons with visual impairment		To work closely with the Ministry of health so that drugs manufacturers should ensure bottles/pills of different sizes specify the drugs and their dose in Braille	PWDs
Inadequate skills and knowledge of HCPs in the comprehensive management of HIV in PWDs	Increase skills and knowledge of HCPs in the comprehensive management of HIV in PWDs	Organized specific training of HCPs on the comprehensive prevention, management of HIV in PWDs	HCPs
Program Objective : HIV Positive PWDs have the same opportunities with PLHIV			
Gap/ barrier	***Strategy***	***Activities***	***Target group***
Lack of friendly environment to PWDs	Introduce home based care for PWDs living with HIV	Design and implement home based care for PWDs	PWDs
Lack of friendly environment to PWDs	Ensure appropriate enabling environment for PWDs	Develop Policy briefs to targerted institutions	Policy makers
Ignorance with very low level of education/	Increase skills and knowledge of HCPs in the	Design and implement special	PWDs

understanding: people with mental disabilities rarely access formal and informal education due to non adapted material policies	comprehensive management of HIV in PWDs	HIV and AIDS programs targeting adult PWDs and young people with disabilities	
Extreme poverty	Empower PWDs for IGA	Initiate IGA activities to empower PWDs	PWDs
Lack of access to appropriate information on HIV prevention	Increase knowledge of PWDs on HIV prevention	Provide the PWDs with radios to enable them access messages on HIV and AIDS and follow sensitisation programmes Support PWDs drama groups to disseminate information on HIV and AIDS and reproductive health.	PWDs
Extreme poverty for a big number of PWDs.	Reduce extreme poverty among PWDs	To initiate IGA activities to empower PWDs to help improve their living conditions and especially improve nutrition conditions for poor HIV+.	PWDs
Lack of harmonization in HIV and AIDS Interventions	Ensure the implementation of NSP on HIV with regards to PWDs	Advocate for the implementation of the The National Strategic plan on HIV/AIDS	Decision makers
	Empowerment PWDs to improve their living conditions	Train peer educators from PWD communities/groups (for instance leaders of DPOs and cooperatives) to assist in training PWDs in life planning skills	PWDs
	Ensuring economic opportunity and food security to PWDs living with HIV	To support cooperatives of PWDs for self-reliance toward food security	PWDs
Inaccessible health	Improve infrastructures and equipments at all	Put in place friendly infrastructures and	HCPs

facilities: long distance to reach places where HIV and AIDS are offered Some location health facilities located on top of hills and at more than 2 Kilometers from the residence.	health facilities	materials at all health facilities	
Lack of appropriate materials, (such as weight measurers, for instance for the wheelchair user whose weigh can't be measured when needs to benefit from nutrition orientations)		Organize mobile VCT to meet PWDs at their nearest community	PWDs
	Advocacy for PWDs	Develop clear advocacy plans & build relationships with key allies	PWDs Stakeholders Decision makers

CHPATER V: CONCLUSION AND RECOMMENDATIONS

Though, there have been important achievements in prevention, care and treatment, impact mitigation in lines with HIV and AIDS response, the assessment of needs in HIV and AIDS services for PWDs has revealed there is still a long way to go as they still face a big number of crucial challenges in accessing HIV and AIDS services. The action plan laying strategies to address the identified needs can't be implemented by UPHLS alone, joint efforts and collaboration are very needed. To make this happen, the findings from this assessment shall be disseminated at a large scale to raise the awareness of key stakeholders on their contribution to improve the access to HIV and AIDs services for PWDs.

Suggestions and recommendations should be inserted after conclusion

As a consequence of the assessment of needs in HIV and AIDS services to PWDs, a plan of intervention that is geared towards addressing the identified gaps and causing a positive change in the lives of PWDs with regard to access to information and services on HIV and AIDS, care and treatment, continuous psychosocial support and improving nutrition conditions, has been drawn up. However, there are important some recommendations that UPHLS shall later translate into practical actions based on achieved outcomes resulted to them.

In light of the findings of this assessment, the consultant recommends the following with the hope and expectation that they will lead to the empowerment of PWDs as change agents in this area of HIV and AIDS:

To UPHLS

By the consultant to UPHLS

- Lobby Government and other service providers to support Brailing and/or recording of messages/information on condoms, leaflets and other HIV and AIDS-related literature.
- Lobby Government to promote and decentralize disability sensitive VCT services and health centres to all districts
- Strengthen networking with other organizations working in the area of HIV and AIDS and human rights.

- Lobby Government and policy makers to incorporate disability issues into the mainstream poverty reduction programs such as ubudehe, VUP
- Ensure full participation of PWDs in HIV/AIDS control and sensitisation activities.
- To conduct a baseline study to know HIV prevalence among PWDs by types. And to allow this happen, special VCT can be organized by types of disabilities and some data can be captured.

By DPOs managers and PWDs to UPHLS

- Disseminate this assessment's findings at large scale and request support from different stakeholders to implement the developed action laying out the priorities to address the identified needs.
- Work closely with stakeholders and districts to issue common guidelines to health facilities allowing the monitoring of efficiency of HIV and AIDS to PWDs
- Follow up the trained TOTs as they can be resourceful people to disseminate relevant messages on HIV prevention among PWDs.
- Recruit a staff in charge of IEC materials and communication that can be in charge of disseminating messages among PWDs through different channels such as DPOs. This comes from the complain that *UPHLS is charge of advocating for* the access to HIV and AIDS services to different types of disability, but for instance deaf and blind persons can't access information on HIV and AIDS in accessible formats to since no one can communicate with deaf persons.
- Link DPOs to eventual donors for resource mobilization to integrate and implement some HIV and AIDS related interventions to PWDs.

- Support in training the patients experts that are trained to identify and take care of persons with mental disability and link them to services providers. NOUSPR has already initiated this program and need support to extend it.
- Organize stakeholders meeting to raise their awareness on HIV and AIDS mainstreaming in their activities/programs where possible it can be.
- Be strongly involved in visits to DPOs branches/cooperatives to give messages on HIV and AIDS with a focus on impact mitigation.

By the districts to UPHLS

- Submit action plans to districts on regular basis to allow making a follow up and coordination
- Work with cooperatives within districts to integrate HIV and AIDS activities especially for voluntary counseling and testing and eventually put in place the clubs to fight against HIV infection among PWDs.
- Be strongly involved in monitoring of the access to HIV and AIDS services for PWDs
- Set up mechanisms of working appropriately with trained TOTs to equip them knowledge of sensitizing PWDs to go for testing.

To stakeholders and DPOs

- Adopt appropriate and disability sensitive channels of communication to disseminate HIV and AIDS messages/information to the community of PWDs.
- Make HIV and AIDS cross cutting (transversal) in DPOs organizations, some sensitizations messages shall be included in project activities
- Train families members having children with special needs such as deaf, person with visual

Services providers

- Develop IEC accessible materials to different types of disability**:** multiply some images to deaf community, distribute condom with information in Braille,
- Take into consideration the degree of disability when delivering HIV and AIDS services to PWDs because their needs should vary according to that degree.

Community/families

- Help their PWDs for VCT to know their HIV status. Some are violated and get infected until they get to AIDS stage. The self group shall sensitize their members to go for VCT.

NCPD

- Put in place strong mechanisms of having the exact figures on PWDs by types. It has been revealed that many PWDs have missed categorization, as they are many that are hidden by the families, especially persons with mental disability (for instance RNUD declares having 1228 members while it is estimated that deaf persons are around 30,000 in the whole country)
- Advocate for the implementation of the law protecting PWDs against violence. The existing one is not respected. When PWDs, especially persons with mental disability are giving testimonies about violence they have faced, they are called 'crazy people' and the source of information is completely missed.
- Continue advocating for the existence of Rwanda Sign language and conduct trainings for services providers.
- Serve as model institution in making accessible the communication to deaf persons (it is not easy to think other institutions will improve the access to information while NCPD and DPOs are not acting exemplary)
- Promote adult literacy programmes for PWDs to enable them to read, write and interpret disseminated HIV and AIDS messages
- Continue advocating for policy makers to capture disability in different policy
- Conduct family member training to equip knowledge at least one member from a PWD family to take care of him/her.
- Encourage PWDs infected to give testimonies on the importance of getting tested and take drugs on time as instructed. This should help some PWDs that don't feel yet the importance of having such services accordingly.
- Continue promoting sport and cultural activities for PWDs to help them getting out of the isolation and help them HIV+ living positively.

MoH

- Work closely with drugs providers to put instructions in accessible communication such as Braille.
- Establish the mechanism of coordinating and monitoring HIV and AIDS since the CDLS coordinators no longer exist at district level.
- Support health facilities to use common tools to capture figures on PWDs that frequent HIV and AIDS services.

ANNEXES

QUESTIONNAIRE TO PWDs

This questionnaire aims at obtaining information on the needs in HIV&AIDS services for PLWDs by types of disability and to develop an action plan laying out strategies and prioritization to address the identified HIV&AIDS needs of PLWDs by types.

The information collected will only be used for the purpose of this assessment and therefore will be held confidential. (Please do not write your name).
Instruction: Tick the appropriate answer provided and where applicable writes the required responses in the spaces provided.

STRICTLY CONFIDENTIAL

Time of interview – start _____ Date: _____

Interviewee initials: _____ Age: _____ ☐ Sex M/F

District_____ Sector_____
Ward/Cell_____

Village_____

Introduction

I. Greet the respondent appropriately
II. Ask proper social questions
III. Explain the purpose of the interview

This interview is conducted in order:

1- To assess the needs in HIV&AIDS services for PLWDs by types of disability and
2- To help in developing an action plan laying out strategies and prioritization to address the identified HIV&AIDS needs of PLWDs by types

Section 1: N*EEDS IN HIV&AIDS SERVICES FOR PLWDS BY TYPES OF DISABILITY*		
S/No.	**Questions**	**Answers**
	a) PERSONAL INFORMATION	
1	Highest education background	(a) None ☐ (b) Upper Primary ☐ (c) Secondary ☐ (d) Tertiary ☐ (e) Others specify……
2	▪ Types of disability	(a) Physical impairment ☐ (b) Visual impairment ☐ (c) Hearing impairment ☐ (d) Mental ☐ (e) Others: albinos, little person, and multiple
	When have you got disability?	
3	Current position/occupation	(a) Government employee ☐ (b) CSOs employee ☐ (c) Private business ☐ (d) Others (specific) ☐ (e) None
4	Marital status	(a) Married (b) Single ☐ (c) Widow/widower ☐
	b) GENERAL INFORMATION ON HIV&AIDS	
5	Have you ever heard about HIV&AIDS?	1= Yes ☐ 2= No ☐
6	Do you know the ways of contracting HIV&AIDS?	(a) Sexual intercourse (b) Blood transmission ☐ (c) Mother to child transmission ☐ (e) Doesn't know
7	How do you access HIV&AIDS related information?	1. Health care facility 2. Radio 3. TV

		4. Bill boards ☐ 5. News paper 6. Campaigns ☐ 7. Others (specify)
8	Which category of persons do you think is at high risk of contracting HIV?	1= Youth ☐ 2= Women and girls ☐ 3= PWDs ☐ 4= Other (specify) ☐
9	Why do you think it is the first ranked category at high risk of contracting HIV?	1— 2— 3—
10	If PWDs are the first ranked, why do you think they are?	1— 2— 3—
11	Which type of disability is the most exposed to HIV?	1- Phyisical 2- Visual 3- Deaf 4- Mental 5- Other, specify
12	Select among the following statement why do you think that type of disability is the most exposed?	1.Lack of information on HIV&AIDS prevention 2.Poverty 3.Victim of Sexual violence due to extent of disability 4.Inaccessible VCT services 5- Failure of parents to provide sexual education to their children 6. Lack of unfaithulness to his/her partner 7. Inaccessible information education communication (IEC) materials 8. Engagement in risk behaviurs 5. Others (specify)
c) NEEDS OF PWDs IN HIV&AIDS SERVICES		

13	As PWDs, what challenges do you face to access HIV&AIDS services?	
	Have you ever faced the following challenges?	**1)** Self discrimination **2)** Commununity discrimination **3)** False beliefs of services providers (attitudes) **4)** Inaccessible infrastuctures where services are provided **5)** Ignorance (low level of education) **6)** Myths behind PWDs (having sexual intercouse with PWDs to be healed from HIVAIDS **7)** Lack of knowledge on disability issues **8)** Lack of friendly services (to specifiy)------ **9)** Other, specify
14	Which do you think is the most crucial among the highlighted challenges?	(a) Self discrimination (b) Commununity discrimination (c) False beliefs of services providers (attitudes) (d) Inaccessible infrastuctures where services are provided (e) Ignorance (low level of education) (f) Myths behind PWDs (having sexual intercouse with PWDs to be healed from HIVAIDS (g) Lack of knowledge on disability issues (h) Other, specify
15	Explain why you think is the most crucial among others?	
16	Do you think it is important to have HIV voluntary testing?	Yes No
17	Is there any nearest place where such services can be obtained?	Yes No
18	Have you ever heard about UPHLS?	Yes No

19	Have you ever heard about a DPO representing your type of disability? (If yes what is the name of that DPO?)	Yes No
20	Have you ever participated to the activity organized by the Umbrella (UPHLS)?	Yes No
21	How effective has this activity been for you?	(a) Very Helpful ☐ (b) Helpful ☐ (c) Not helpful ☐ (d) Not sure ☐
22	Do you think it is easy for a PWD to be integrated in society when is HIV positive?	Easy Not easy
23	If not easy, what are the challenges she/he faces that prevent that integration?	- - -
SECTION 2: STRATEGIES TO ADRESS THE IDENTIFIED CHALLENGES		
24	Are there specific challenges you are facing to access HIV services? If yes, how do you think they can be addressed?	Yes ☐ No ☐
25	What would you recommend to the policy makers and key stakeholders in HIV services to increase the access to HIV&AIDS services to PWDs?	
26	In your opinion what should be done to improve the	1. Putting in place relevant policy 2. Elaboration of programs that integrate

	access to HIV&AIDS services by PWDs?	HIV&AIDS and disability 3. Extend the awareness and education campaigns 4. To conduct researches to avail data on HIV/prevalence 5. Train HIV&AIDS services providers to PWDs 6. Others (specify)

QUESTIONNAIRE TO SERVICES PROVIDERS

This questionnaire aims at obtaining information on the **needs in HIV&AIDS services for PLWDs by types of disability and to develop an action plan laying out strategies and prioritization to address the identified HIV&AIDS needs of PLWDs by types**

The information attained will only be used for the purpose of this assessment and therefore will be held confidential. (Please do not write your name).

Instruction: Tick the appropriate answer provided and where applicable writes the required responses in the spaces provided.

STRICTLY CONFIDENTIAL

Time of interview – start _____ Date: _____

Health facility : _____District_____

Sector_____ Cell_____ Village _____

Date of creation_____ Initiator / Owner

Position of the interviewee:

Introduction

IV. Greet the respondent appropriately

V. Ask proper social questions

VI. Explain the purpose of the interview

This interview is conducted in order:

(a) To assess the needs in HIV&AIDS services for PLWDs by types of disability and

(b) To Develop an action plan laying out strategies and prioritization to address the identified HIV&AIDS needs of PLWDs by types

Section 1: N*EEDS IN HIV&AIDS SERVICES FOR PLWDS BY TYPES OF DISABILITY*		
S/No.	**Questions**	**Answers**
	d) GENERAL INFORMATION	
1	Status of the health facility	Private Public Gouvernement aided FBO (d) Others specify……
	Type of facility	Referral Hospital District Hospital Health Center Other specify
2	Services provided related to HIV&AIDS	(a) Voluntary counseling testing ☐ (b) Psychosocial support ☐ (c) Nutrition (d) Care and treatment (e) PMTCT ☐ (f) Others services
3	Source of resources	• Gouvernement ☐ • Own ressources • Donors • Others (specify)
	e) GENERAL INFORMATION ON HIV&AIDS PROVIDED SERVICES	
4	How many people do you receive in HIV&AIDS services?	1-Daily ☐ 2- Weekly ☐ 3- Monthly ☐

5	How many of them are PWDs? (Put Number)	
6	How many PWDs per type?	1. Phyisical 2. Visual 3. Deaf 4. Mental 5. Others, specify
7	Why do you think (ranked disability in 7)-is the first ranked category to be received in your HIV&AIDS services?	
8	Do you think PWDs are at high risk of contracting HIV compared to the general population?	Yes No
9	Why do you think PWDs are at high risk of contracting HIV	
f) NEEDS OF PWDs IN HIV&AIDS SERVICES		
10	Which type of disability is the most exposed to HIV?	✓ Phyisical ✓ Visual ✓ Deaf ✓ Mental ✓ Other, specify
11	Why do you think that type of disability is the most exposed?	
12	Based on the following statements, are the following	1—Lack of information on HIV&AIDS prevention 2—Poverty

	challenges faced by PWDs?	3—Victim of Sexual violence due to extent of disability 4—Inaccessible VCT services 5- Failure of parents to provide sexual education to their children 6. Lack of unfaithulness to his/her partner 7. Inaccessible information education communication (IEC) materials 8. Engagement in risk behaviurs 5. Others (specify)
14	What are the main challenges faced by PWDs in accessing HIV&AIDS services?	a) Self discrimination b) Commununity discrimination c) False beliefs of services providers (attitudes) d) Inaccessible infrastuctures where services are provided e) Ignorance (low level of education) f) Myths behind PWDs (having sexual intercouse with PWDs to be healed from HIVAIDS g) Lack of knowledge on disability issues h) Inappropriate clinical settings and facilities i) Lack of appropriate skills for providers j) Other, specify
15	Which do you think is the most crucial among the highlighted challenges?	1. Self discrimination 2. Commununity discrimination 3. False beliefs of services providers (attitudes) 4. Inaccessible infrastuctures where services are provided 5. Ignorance (low level of education) 6. Myths behind PWDs (having sexual intercouse with PWDs to be healed from HIVAIDS 7. Inappropriate clinical settings and facilities 8. Lack of appropriate skills for providers 9. Lack of knowledge on disability issues 10. Other, specify
16	Explain why you think is the most crucial among others?	

17	What challenges do you face as HIV&AIDS services providers?	
18	Do you have any collaboration with UPHLS?	Yes No
19	If No, what would you suggest to be done to build that collaboration	
20	Do you think it is easy for a PWD to be integrated in society when is HIV positive?	Easy Not easy
21	If not easy, what are the challenges she/he faces that prevent that integration?	- - -
SECTION 2: STRAGEGIES TO ADRESS THE IDENTIFIED CHALLENGES		
22	If yes, how do you think they can be addressed?	a) b) c) d)
23	Would you mostly recommend increasing the access to HIV&AIDS services to PWDs?	(1) (2)
20	In your opinion what should be done to improve the access to HIV&AIDS services by PWDs?	✓ Putting in place relevant policy ✓ Elaboration of programs that integrate HIV&AIDS and disability ✓ Extend the awareness and education campaigns ✓ To conduct researches to avail data on HIV/prevalence ✓ Train HIV&AIDS services providers to PWDs

		✓ Others (specify)

INTERVIEW GUIDE TO PWDs ORGANIZATIONS MANAGERS/SOCIAL WORKERS

This guide aims at obtaining information on the **needs in HIV&AIDS services for PLWDs by types of disability and to develop an action plan laying out strategies and prioritization to address the identified HIV&AIDS needs of PLWDs by types** and has to be used during the discussions with the managers/social worker within the PWDs organizations

The information attained will only be used for the purpose of this assessment and therefore will be held confidential.

Instruction: Tick the appropriate option

<u>This interview is conducted in order:</u>

- **To assess the needs in HIV&AIDS services for PLWDs by types of disability and**
- **To Develop an action plan laying out strategies and prioritization to address the identified HIV&AIDS needs of PLWDs by types**

QUESTIONS AND POINTS OF DISCUSSIONS

- Can you tell us about your organization: mission, vision, target group, area of coverage
- What are your recent achievements (the last three years) in line of **HIV&AIDS** interventions targeting PWDs?

1. In prevention
2. Care and treatment
3. Impact mitigation

- What about the ongoing interventions and plans in line with **HIV&AIDS** interventions?
- Are your beneficiaries aware of the HIV pandemic?

- How do you rate/measure the awareness
- What are the main challenges faced by PWDs (your target group) in accessing

1. Prevention messages

2. Voluntary counseling and testing

3. Access to care and treatment

- What are the most crucial and why are they?
- What do you think can be done to make:

1. Prevention messages more accessible
2. More accessible Health Care and Treatment services
3. Effective impact mitigation

- What can you recommend to improve the access to **HIV&AIDS** services to PWDs (be specific to different stakeholders such as GoR, MoH, RBC, Implementing partners, donors, health facilities, healthcare providers, PWDs)

Is there any other relevant information/comment you can provide in line with this assessment?

CHECKLIST FOR FOCUS GROUP DISCUSSIONS

This guide aims at obtaining information on the **needs in HIV&AIDS services for PLWDs by types of disability and to develop an action plan laying out strategies and prioritization to address the identified HIV&AIDS needs of PLWDs by types** and has to be used during the discussions with the managers/social worker within the PWDs organizations

The information attained will only be used for the purpose of this assessment and therefore will be held confidential.

<u>This FGD is conducted in order:</u>

- **To assess the needs in HIV&AIDS services for PLWDs by types of disability and**

- **To Develop an action plan laying out strategies and prioritization to address the identified HIV&AIDS needs of PLWDs by types**

QUESTIONS AND POINTS OF DISCUSSIONS

1. What is your understanding on
- HIV?
- AIDS?
2. How are they different?
3. Can you tell us some groups of persons that are at high risk of being infecting by HIV?
4. Why do you thing those category at high risk?
5. Have ever been involved in UPHLS activity?
6. What have you gained in terms of prevention of HIV among PWDs?
7. What are the main challenges faced by PWDs (your target group) in accessing
- Prevention messages
- Voluntary counseling and testing
- Access to care and treatment
8. What are the most crucial and why are they?
9. Which type of disability is at high risk of infection of HIV?
10. Are PWDs are of being at high risk of infection of HIV?
11. What do you think can be done to make:
- Prevention messages more accessible
- More accessible VCT services
- Effective impact mitigation
12. What can you recommend to improve the access to HIV&AIDS services to PWDs
13. Is there any other relevant information/comment you can provide in line with this assessment?

SPECIFIC QUESTIONS TO NCPD

1. Can you tell us about your organization: mission, vision, target group, area of coverage

- As an institution that coordinates all interventions related to PWDs, how do you contribute to HIV&AIDS services?
- What about your strategic plan, in terms of these interventions
- What are your achievements in line of HIV&AIDS interventions targeting PWDs since NCPD is created?

2. In prevention
3. Care and treatment
4. Impact mitigation
    - What about the ongoing interventions and plans in line with HIV&AIDS interventions?
    - What are the main challenges faced by PWDs (your target group) in accessing
5. Prevention messages
6. Voluntary counseling and testing
7. Access to care and treatment
    - What are the most crucial and why are they?
    - What do you think can be done to make:
4. Prevention messages more accessible
5. More accessible Health Care and Treatment services
6. Effective impact mitigation
    - What can you recommend to improve the access to HIV&AIDS services to PWDs (be specific to different stakeholders such as GoR, MoH, RBC, Implementing partners, donors, health facilities, healthcare providers, PWDs)
    - Any other relevant comment!

SPECIFIC QUESTIONS TO DISTRICTS

a) Is there any specific intervention on HIV&AIDS related to PWDs in your district?
b) As a district, how do you contribute to HIV&AIDS services among PWDs?
c) What are your achievements in line of HIV&AIDS interventions targeting PWDs since NCPD is created?

8. In prevention
9. Care and treatment
10. Impact mitigation

d) What about the ongoing interventions and plans in line with HIV&AIDS interventions?
e) Is there any collaboration with UPHLS? If not, why?
f) According to your experience, what are the main challenges faced by PWDs in accessing:
    11. Prevention messages
    12. Voluntary counseling and testing
    13. Access to care and treatment
g) What are the most crucial and why are they?
h) What do you think can be done to make:
7. Prevention messages more accessible
8. More accessible Health Care and Treatment services
9. Effective impact mitigation

i) What can you recommend to improve the access to HIV&AIDS services to PWDs (be specific to different stakeholders such as
    GoR, MoH, RBC,
    UPHLS
    Implementing partners, donors,
    Health facilities,
    Healthcare providers, PWDs)
j) Any other relevant comment?

LIST OF RESPONDENTS

No	INSTITUTION/ORGANIZATIONS	POSITION
NATIONAL LEVEL		
1	National Council of Persons with disabilities	Health and Counseling Officer
2	Handicap International	Project Manager
3	Rwanda Biomedical Center, RBC	Head of disability and injuries
DPOs		
4	AGHR	Legal representative and Executive Secretary
5	AGHR	Project Officer
6	RUB	Executive Director
7	RNUD	Communication and advocacy Officer
8	NOUSPR	Chairperson
9	RNUD	Executive Director
10	Collectif TUBAKUNDE	Executive Secretary
11	UWEZO Youth Empowerment	Project Manager
DISTRICT AND SERVICE PROVIDERS		
12	Gasabo District	District Disability Officer
13	Gasabo District	In charge of HIV integration
14	Kibagabaga District hospital	In charge of ART
15	Kacyiru health center	In charge of VCT and PMTCT
16	Kacyiru health center	In charge of ART
17	Remera health center	In charge of ART
18	Remera health center	In charge of VCT
19	Remera health center	In charge of PMTCT
20	Gatsibo District	District Disability Officer
21	Gatsibo District	Director of health
22	Kabarore health center	In charge of ART
23	Gakenke District	NCPD Coordinator
24	Nemba District hospital	Nurse in charge of ART
25	Nemba health center	Head of health center

26	Ngororero	District Disability Officer
27	Rususa health center	In charge of ART
28	Nyaruguru District	District Disability Officer
29	Cyahinda health center	In charge of ART
30	Muganza health center	In charge of ART and PMTCT
31	Muganza health center	In charge of VCT

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