TABLE OF CONTENTS

FIGURES

TABLES

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ABBREVIATIONS & ACRONYMS

AGHR: General Association of Disabled People in Rwanda

AIDS: Acquired Immune Deficiency Syndrome

CNLS(NACC): National AIDS Control Commission (Commission Nationale de Lutte Contre le SIDA)

DFID: Department for International Development

DPO: Disabled People's Organization

FACHR: Federation of Associations and Centres of the Handicapped in Rwanda

FERHANDIS: Federation Rwandaise de Handisport

HIV: Human Immunodeficiency Virus

I.E.C: Information Education for Communication

IMPACT: Implementing Aids Prevention and Care Project

IST/ STI: Infections Sexuellement Transmissible /Sexually Transmitted Infection

MOH: Ministry of Health

NGO: Non-Government Organisation

OVC: Orphans and vulnerable Children

PHR: Partners for Health Reform *plus*

PLWHV: People Living With HIV/AIDS

PNLS: Programme National de Lutte Contras le Siva (National AIDS Control Programme)

PWDs: Persons with Disabilities

RADW: Rwanda Association of Deaf Women

RNAD: Rwanda National Association of the Deaf

RUB: Rwanda Union of the Blind

SHIA: The Swedish Organisations of Disabled persons International Aid

TRAC: Treatment and Research AIDS Centre

UNAIDS: Joint United Nations Programme on AIDS

VCT: Voluntary Counselling and Testing

VSO: Voluntary Services Oversees

WHO: Word Health Organisation

Executive summary

It has been estimated that globally there are 335 million people living with different types of disabilities; physical, sensory (deafness, blindness), or intellectual disabilities. 70 per cent of whom live in developing countries. They are incorrectly believed to be sexually inactive and at less risk of violence or rape than their non-disabled peers. Concerns about the lack of access that this marginalized group has to HIV/AIDS programmes have been raised by organizations working for and with disabled people. It is evident that disabled people are less likely that their non-disabled peer to access HIV/AIDS prevention and care services.

In addition, studies on HIV & AIDS and young disabled people in Rwanda found that most were aware of the disease but their knowledge on prevention and transmission was weak. There was a general assumption in Rwandan society that disabled people did not have sex, or at least less sex than others, this led a minority to believe that sex was safer with a disabled partner. Disabled people were found to be particularly vulnerable because of their poverty, their difficulty in forming stable relationships and that many, particularly girls and women were at high risk of sexual abuse. Disabled people experience a double burden in relation to HIV/AIDS: increased risk of infection and reduced access to prevention and care service.

Findings

The findings in this project showed that People with disabilities are vulnerable to HIV/AIDS because they are marginalised, discriminated, illiterate and relatively poor and less attention has been taken by HIV/AIDS Organisations and centres to include disabled people in their work. Women with disabilities especially blind mental and deaf are more likely to be sexually abused or raped and find it very difficult to access information and services about HIV/AIDS in their respective communities.

Including disabled people in the work of HIV/AIDS Organisations requires disabled people should be able to effectively participate in programmes of prevention, monitoring and research that relates to HIV/AIDS. This requires the general disability awareness for different groups in society concerning disabled people: the role of the family, churches, the role of education and the State. This needs contextualised programmes and a new language, which avoids stigmatisation and marginalisation. Dialogue has to be increased about HIV/AIDS in general and disabled people and HIV/AIDS in specific.

Finally, to reach People with disabilities will depend on the individual disability, but ramps, sign language interpretation, and more verbal presentation and demonstration for blind people are some common measures that can easily be taken.

1 INTRODUCTION

"Some people think that people living with disabilities are not sexually active, but they're as active as everyone else,"

"Judy Heuman."

1.1 Background on Rwanda

Rwanda is a central country of Africa, located in the area of the great lakes. It has a surface of 26 388 km^2. It is a landlocked country and surrounded of Uganda in North, Burundi in the South, of Tanzania in the East and Democratic Republic of Congo in the West. At the demographic level, its population is 8 128 553 according to the General Census of Population and the Habitat of 2002.

Rwanda is among the ten most heavily affected African countries by the HIV/AIDS epidemic. AIDS has emerged as the most important public health issue. Data from the late 1990s indicate that up to 30 percent of pregnant women in antenatal clinics in Kigali and 15 percent in rural areas tested positive. HIV prevalence rates among male STD clinic attendees were as high as 55 percent in various surveys. The global prevalence of HIV found among patients in VCT Sites in 2004 was 11.3%, being women vulnerable with prevalence of 13.3% against 9.6% for men. Data of July 2005 showed that this prevalence was 10.2% that is 11.2% for women and 9.2% for men (CNLS,2005) .The major causes of the epidemic are the high rates of multiple sex partners, early onset of sexual activity, and the overall crisis of the 1990s and 1994 war and genocide. With a staggering one-third of households in Rwanda headed by females, the epidemic is exerting a disproportionate impact on women and persons with disabilities who are economically, socially and sexually vulnerability. Young people (i.e. under 20 years of age), who comprise 60 percent of the population, are also highly vulnerable with prevalence rates estimated at 10 percent in 1997. The youngest age group (12-14 years) was found to have a prevalence rate of about 4 percent, indicating a high proportion of new infections.

As elsewhere in Sub-Saharan Africa, adolescent women are more likely to be infected than their male counterparts. Roughly 500,000 Rwandans are estimated to live with HIV, of which roughly half are believed to have developed AIDS. Of those who are infected, roughly 50 percent are women and about 13 percent are

Table1: HIV/AIDS in Rwanda

Total population	8.1 million
Adult HIV Prevalence	8.9%
Adults and children Living with HIV/AIDS	500,000
Life Expectancy at Birth	39 years

Source: PHR*plus,* April 2004

Children under fifteen. Then the life expectancy which was 53.7 in 1991 shifted to 49years in 2000 and 39 years in 2005 with Maternal mortality rate(per100,000 live births) of 1400 (WHO (WHR2004)/UNICEF).

Despite the effort of offering mother-to-child transmission programs in more than 30 hospitals and health centers in Rwanda, by the year 2015, AIDS is expected to increase country's already high infant mortality rate of 107 per 1000 live births: Most likely, this will disproportionately affect infant from poor families who already report a significantly higher mortality rate than infant from richest households.

1.2 Project Objectives

The project intends to sensitize and educate HIV/AIDS Organisations in Rwanda on the needs and actions necessary in relation to persons with disabilities in the HIV/AIDS epidemic. This manual contains strategies on how to include persons with disabilities in the work of HIV/AIDS Organisations. It should be used as a handbook on how to reach per-

sons with disabilities, where to find them, what their different needs and the appropriate means of communication.
This manual should also be used to develop specific programmes by HIV/AIDS Organisations in HIV prevention to different types of disabilities.

1.3 Methodology

In this project the collection of the data involved the following methodologies:

All relevant articles and literature on HIV/AIDS was collected and searched from HIV/AIDS Organizations and centers in Rwanda as well as scientific articles on HIV/AIDS and disability.

1) All relevant literature and Internet sources were searched to identify resources, training manuals, and researchers currently working on HIV/AIDS issues within people with disability.
2) Existing HIV/AIDS Organizations were contacted and the questionnaires have been addressed to them to find out if any measures have been taken to reach disabled people in Rwanda and how they can be reached.
3) Some Disabled Organisations were contacted in Southern, Central and Eastern regions and focus group discussions in Kigali City on the questionnaire were held with about 12 representatives of disabled people associations.

2 BASIC INFORMATION ABOUT HIV/AIDS/STI

2.1 What is HIV? What is AIDS?

The term **"HIV"** stands for *Human Immunodeficiency Virus*. This virus weakens the body's immune system, the system responsible for defending the body from diseases. Although an HIV infection cannot be cured, it can be treated with a combination of medication called **'Antiretrovirals'** (ARVs).

An **HIV-positive person** (i. e. someone living with HIV) can live for many years without major health problems. However, if remained untreated, HIV can weaken the immune system so severely that it cannot fight certain diseases, and the HIV-positive person may eventually develop **AIDS** - *Acquired Immune Deficiency Syndrome.*

AIDS is a syndrome. In other words, it may be a collection of one or more (uncommon and rare) illnesses that are specifically associated with a deficient immune system. They are often referred to as *'AIDS-defining illnesses'*.

HIV and AIDS do not mean the same thing.

- HIV is the virus that weakens the immune system.
- AIDS is the syndrome that results from a very weak immune system.

Worldwide, AIDS has taken some 20 million lives, created 15 million AIDS orphans and caused enormous personal, social and economic losses. HIV infection is now a major cause of disease and death among persons aged 25-44. Among young people aged 15 to 24, some 10 million are currently living with HIV/AIDS, and every day, some 6,500 new infections – *half of all new infections* - occur among people in this age group. Also, only a fraction of the young people currently living with HIV is aware of their HIV-positive status.

The lack of information and/or misinformation about HIV and AIDS, in particular about modes of transmission of HIV, fuel a great deal of prejudice, causing individuals to fear contact with people living with HIV - whether those are strangers, members of their community, friends or relatives.

The stigma and discrimination attached to HIV and those living with it, not only raise questions of human rights, but they also discourage people from being tested and knowing their HIV status. This contributes to the spread of the virus, and delays treatment that can reduce the suffering of persons living with HIV or AIDS.

2.2 What are STIs?

Sexually Transmitted Infection, or "**STI**", is a general term for infectious diseases that are spread through sexual contact. HIV/AIDS can be regarded as a STI. Other major STIs are syphilis, gonorrhea and Chlamydia. Worldwide, the highest rates of STIs are usually found in the 20-24 age groups, followed by the 15-19 age groups.

STIs spread rapidly, in great part because the majority of infections either do not produce any symptoms or signs, especially in females, or produce symptoms so mild that they are often disregarded. Some STI symptoms even disappear over time, creating the false impression that the disease, too, has disappeared. Finally, many adolescents do not know the difference between normal and abnormal conditions and therefore do not know when to seek medical care. Even when they suspect they have an infection, many young people do not seek the medical care they need. This is especially true when services are too far away or too expensive, or when teens fear they will be judged, punished or exposed.

Over 100 million new sexually transmitted infections, excluding HIV, occur each year among young people under 25 years of age. STIs greatly facilitate HIV transmission between sexual partners, so treating and preventing them is an important step in breaking the HIV chain of infection.

- **How quickly do people infected with HIV develop AIDS?**

In some people, the T-cell decline and opportunistic infections that signal AIDS develop soon after infection with HIV. Most people remain asymptomatic for 10 to 12 years, and a few for much longer. As with most diseases, early medical care can help prolong a person's life.

2.3 How is HIV transmitted?

A person who is HIV-infected carries the virus in certain body fluids, including blood, semen, vaginal secretions, and breast milk. The virus can be transmitted only if such HIV-infected fluids enter the bloodstream of another person. This kind of direct entry can occur;

(1) Through the linings of the vagina, rectum, mouth, and the opening at the tip of the penis;

(2) Through intravenous injection with a syringe; or

(3) Through a break in the skin, such as a cut or sore.

Usually, HIV is transmitted through:

2.3.1 Unprotected sexual intercourse (either vaginal or anal) with someone who is HIV infected.

Women are at greater risk of HIV infection through vaginal sex than men, although the virus can also be transmitted from women to men. Anal sex (whether male-male or male-female) poses a high risk mainly to the receptive partner, because the lining of the anus and rectum are extremely thin and filled with small blood vessels that can be easily injured during intercourse.

2.3.2 Unprotected oral sex with someone who is HIV infected.

There are far fewer cases of HIV transmission attributed to oral sex than to either vaginal or anal intercourse, but oral-genital contact poses a clear risk of HIV-infection, particularly when ejaculation occurs in the mouth. This risk is increased when either partner has cuts or sores, such as those caused by sexually transmitted diseases (STDs), recent tooth-brushing, or canker sores, which can allow the virus to enter the bloodstream.

2.3.3 Sharing needles or syringes with someone who is HIV infected.

Laboratory studies show that infectious HIV can survive in used needles for a month or more. That is why people who inject drugs should never reuse or share syringes, water, or drug preparation equipment. This includes needles or syringes used to inject illegal drugs such as heroin, as well as steroids. Other types of needles, such as those used for body piercing and tattoos, can also carry HIV.

2.3.4 Infection during pregnancy, childbirth, or breast-feeding (mother-to-child transmission).

Any woman who is pregnant or considering becoming pregnant and thinks she may have been exposed to HIV even if the exposure occurred years ago should seek testing and counseling. Mother-to-child transmission has been reduced to just a few cases each year in Rwanda., where pregnant women are tested for HIV, and those who test positive are provided with drugs to prevent transmission and counseled not to breast-feed.

2.4 HIV/AIDS Test and counseling

According to the WHO, the VCT (voluntary counseling and testing) is widely used in reference to HIV testing and counseling services. However, HIV testing and counseling is a term that covers a variety of interventions in different service settings:

1. Testing and counseling in clinical treatment settings, where sick people are being offered HIV testing that may possibly aid their clinical diagnosis and management. This process of offering testing and counseling - with the option of "opting out" of testing - is the standard of care in tuberculosis treatment, and hospital/medical in-patient and out-patient services,

2. Testing and counseling in services for antenatal care for prevention of mother-to-child transmission, and in STI and targeted interventions for vulnerable and marginalized populations, sex workers and injecting drug users
3. Voluntary testing and counseling services for people who are asymptomatic and wish to learn their status.

3 DISABILITY IN RWANDA

3.1 Defining Disability

There is no universally agreed definition of disability because it is a multi-dimensional concept with both objective and subjective characteristics. When interpreted as an illness or impairment, disability is seen as fixed in an individual's body or mind. When interpreted as a social construct, disability is seen in terms of the socio-economic, cultural and political disadvantages resulting from an individual's exclusion.

Historically disability was seen primarily as a medical condition, with the problem located within the individual. This medical or individual model was challenged by disability activ-

ists who reconceptualised disability has primarily a social phenomenon. This *social model of disability* draws a clear distinction between impairments and disability. Society disables people with impairments by its failure to recognise and accommodate difference and through the attitudinal, environmental and institutional barriers it erects towards people with impairments. Disability thus arises from a complex interaction between health conditions and the context where they exist. This social understanding and human rights perspectives of disability has gained widespread acceptance and is reflected in UN World Programme of Action for Disabled Persons and the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities and in the WHO International Classification of Functioning Disability and Health (ICF) and by the World Bank, DFID and others.(PHILIPPA T.2004)

The disabled persons in Rwanda were historically excluded from the Rwandan society. Disabled children were hidden in their house or simply abandonned by their parents in the bush. Numerous negative expressions were used by the society to describe disabled persons. The disabled movement started after the Rwanda independence. It was greatly influence by the “Father” of disability in Rwanda, Abbé Fraipont with the creation of the HVP Gatagara center. It was the first time that disabled persons could receive basic rehabilitation services. Since that time, disabled persons who went to HVP Gatagara started disabled persons organizations (DPOs). The most known is General Association of handicapped people of Rwanda (AGHR) created in 1979.

All the DPOs were destroyed during the tragic event of 1994 genocide and a large number of people became disabled. Since then, the movement is slowly recreating itself. Note that the Federation of Associations and Centers of Handicapped people of Rwanda (FACHR) that is acting as an umbrella organization, was created in 2001 with the initiative of the government and some Disabled People Association and centers that existed that time.

3.2 HIV/AIDS and disabilities in Rwanda

"Abuse against disabled women is quite high and so it's common that they have multiple sex partners and are acquiring AIDS."

"Judy Heuman"

According to the World Health Organization (WHO), there are over 600 million disabled people throughout the world; and of these 180 million are children; 4000 million live in developing countries; and 80 million live in Africa. In Rwanda, the 2002 Census finds that about 3.8% of the population is disabled; however it is likely that this figure is too low, this figure seems to be underestimation. They are among the most stigmatized, poorest, and least educated of all the world's citizens. There is no accurate data on prevalence of different types of disabilities, but physical disabilities are the most common, followed by deafness, mental deficiencies, blindness and trauma according to the Census. The main causes of disability were: genocide and war; poverty (malnutrition, lack of adequate and appropriate medical care); ignorance (use of traditional healers, poor care in pregnancy etc); disease, accidents and congenital causes.

In Rwanda, like most developing countries, poverty is a major cause of disability and usually its consequence. Disabled people are over represented amongst the poor; they are often amongst the very poorest. Communities usually identify disabled people are one of the most vulnerable groups, along with widows and orphans. Disabled people share the same problems as the non-disabled poor but they experience poverty more intensely and their disabilities limit their opportunities to escape poverty.

A recent report (Yousafzi & Edwards 2004) on HIV & AIDS and young disabled people in Rwanda found that most were aware of the disease but their knowledge on prevention and transmission was weak. Most relied on the radio for information. There was a general assumption in Rwandan society that disabled people did not have sex, or at least less sex than others, this led a minority to believe that sex was safer with a disabled partner. Disabled people were found to be particularly vulnerable because of their pov-

erty, their difficulty in forming stable relationships and that many, particularly girls and women were at high risk of sexual abuse.

During the project, an informant said that some blind women were asked by their parents to have sexual intercourse in order to get a child that will take care of them.

Table2: The percentage of PWD infected or affected with/ by HIV/AIDS in Rwanda

PWD	But	Kig	Byu	Git	Umut	Kibun	Kibuy	Cya	Gik	Gis	Ruh	KN	Tot	%
Infected	0	2	1	2	1	0	2	3	1	3	2	8	25	13
Affected	16	14	15	14	15	16	14	13	15	13	14	8	167	84.3
Tot	16	16	16	16	16	16	16	16	16	16	16	16	192	

Source: FACHR, 2003(unpublished)

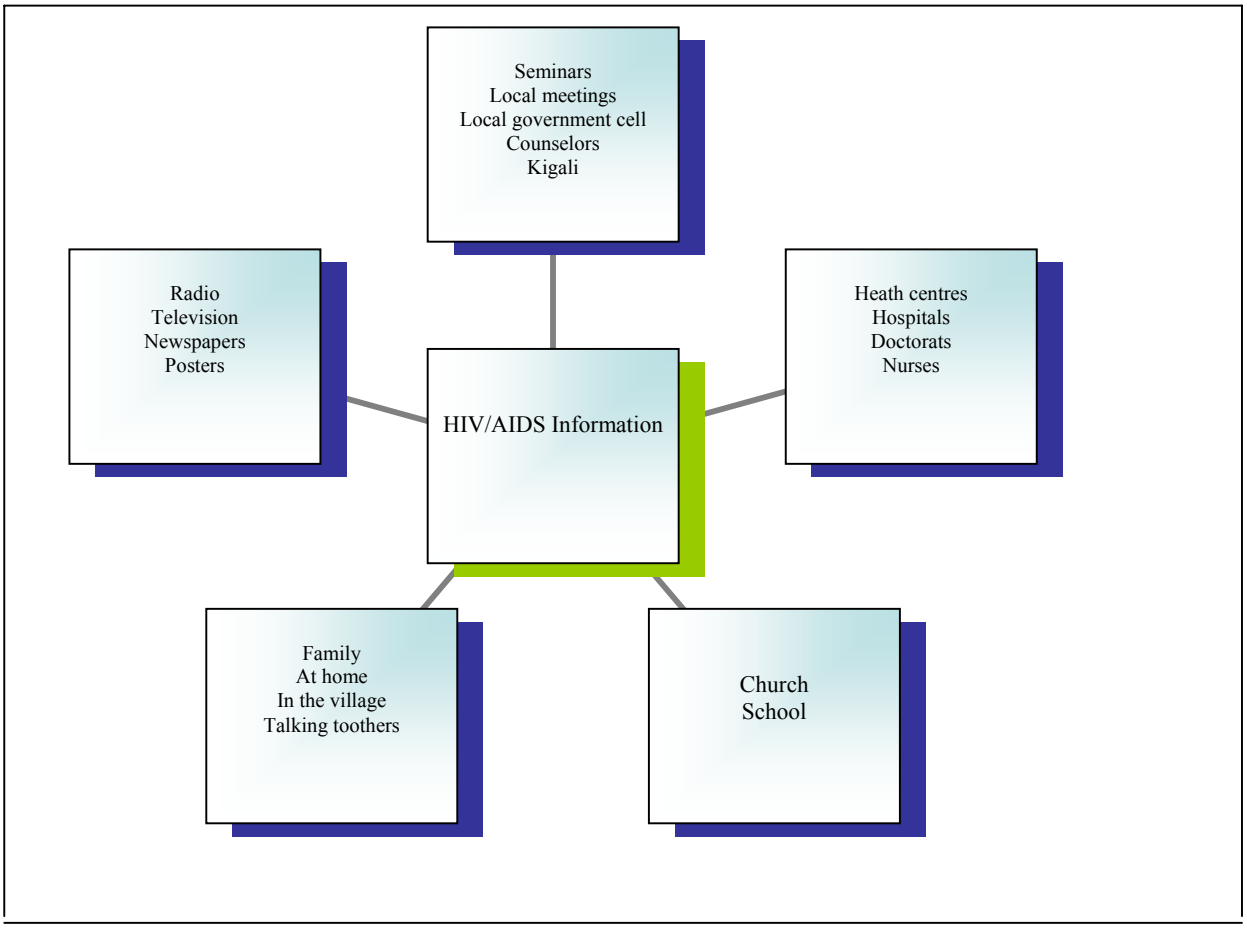
The table shows that 13% of people with disabilities in Rwanda have been infected with HIV/AIDS. This has been confirmed by disabled informants during the survey got Voluntary Counseling and Testing. In addition 84.3% of respondents were affected by the pandemic. They confirmed of having lost either a brother, parents, a friend, a spouse or living with an HIV positive in the family. Most of respondents in this survey were the physically handicapped.

According to Dr A. Yousafzi and K.Edouards (2004) most of disabled children had heard of HIV/AIDS and the exception were a few children with multiple/severe disabilities whose parents spoke on their behalf and said that the children had not heard of HIV/ AIDS due to the severity of their problems.

The Sources of Information about HIV/AIDS come from a number of sources. By far the most popular source was the radio ((Figure 1). Although radios were the most commonly cited source of information, poorer and particularly people with disabilities (i.e. deaf people) had no access to radios.

FIGURE 1 RANGE OF INFORMATION SOURCES ABOUT HIV/AIDS QUOTED BY YOUNG

People with disabilities, Parents and organization members



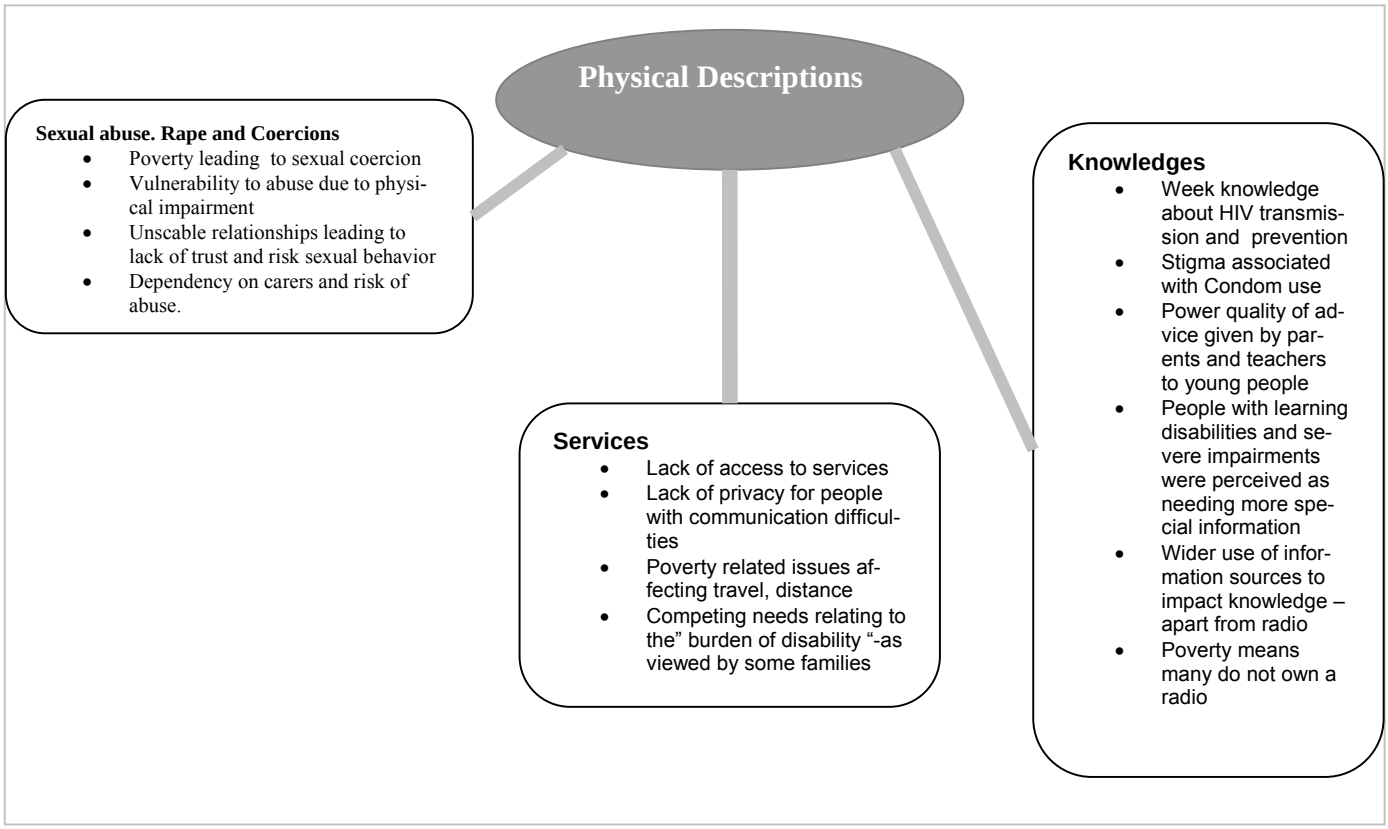
Source. Dr A. Yousafzi and K.Edouards (2004), Double Burden, p.54

Disabled youths did not use HIV services because of the difficulty in reaching them and because of the lack of privacy, most needed someone to assist them to access such services. They consistently highlighted the need for better information on HIV/AIDS for disabled people, particularly those who are deaf or blind.

Disabled people especially disabled women are Victims of sexual abuse (fig.2) because if

"*If person has a disability it is difficulty for her to defend herself as she has lower energy levels and is weaker*" said Marry

FIGURE 2: SUMMARY OF FINDINGS HIGHLIGHTING KEY ISSUES FOR PEOPLE WITH DISABILITIES



Source: Dr A. Yousafzi and K.Edouards (2004), Op. cit, p.63

Knowledge (fig. 2) about the HIV Prevention in young disabled people is still weak and few misconceptions about HIV transmission. The lack of access to testing centre and privacy for people with communication difficulties makes the services very poor.

4 TEACHING DISABLED PEOPLE ABOUT HIV/AIDS

There are several types of disabilities. In HIV/AIDS pandemic the communication for one type of disability may be different from another; Disability may then be divided into 4 main types:

- **Deaf or hard –of-hearing people**: this type of disability suffers of lack of materials. Those are for instance advertisements on TV are not suitable. Training interpreters is not easy because sign language is demanding. Interpreters should have the responsibility to either interpret when the person is being counseled or to counsel the person. When the person's HIV status is revealed then the question arises on the confidentiality of the interpreter which is an issue of professionalism.
- **Visually impaired**: People with visual impairment indicated that visually impaired community is being shut out: No Braille, no audio, no appropriate video or audio cassettes in local language (Kinyarwanda). The availability of services and public attitudes cause concern. Information necessary for saving lives needs to be translated into Braille (example, the expiry date of condom packaging). The visually impaired as well as all disabled people are "disabled but not unable" (to have sex).
- **Learning and mentally disabled people**: Different types of learning disabilities must be treated accordingly. There is a lack of tailored information. Information should be simplified, translated into local language and distributed. Material should be disseminated through schools and special attention should be given to disability sensitive media presentations.
- **Physically disabled people:** Access to information is a stumbling block for physically disabled people. They get information mainly through the radio but versatile ways must be introduced to make it interesting, e.g. drama. Disabled actors or disabled people can be used instead. There are not nearly enough human resources, as there is a lack of qualified professionals and the scarcity of funds to run and maintain the necessary programmes are shortcomings that effect the operations of organizations of disabled people.

Respondents came up with some reasons that prevent disabled people to be reached: Those different reasons are stated in the paragraph below.

4.1 Reasons People with Disability are not being reached

Disabled people in one way or another are not reached by the existing programs because:

- The Lack of education inhibits ability to obtain and process information.
- Information is in inaccessible formats.
    a) Radio campaigns miss the deaf.
    b) Billboards do not reach the blind.
    c) Complex or vague messages do not reach those with intellectual impairments.
    d) Clinics/services are inaccessible.

- A lot of myths and misconceptions that sex with a disabled female child cleanses HIV, The common assumption is that disabled individuals are not at risk. . They are incorrectly thought to be sexually inactive, unlikely to use drugs, and at less risk for violence or rape than their non-disabled peers.

- Limited access to HIV&AIDS information and utilization of services like VCT and OVC by parents and disabled children due to lack of information.
- Defilement of disabled children especially the girl child by care givers and relatives,
- People with disability are not being included either implicitly or explicitly in most HIV/AIDS outreach efforts. Lack of knowledge of disability and awareness of disability issues among AIDS workers, government ministers, NGOs, etc., is the primary barrier. Unfamiliar with disabled populations, they are unaware that individuals with disability are sexually active or otherwise at risk. Most view individuals with disability largely as a medically dependent, childlike population, isolated from the real world.

It was assumed that little attention has been given to the risk of HIV/AIDS for individuals who have a physical, sensory, intellectual, or mental health disability before becoming infected.

HIV/AIDS Organizations in Rwanda carry out HIV/AIDS general awareness interventions in a wide range or approaches and models but not specifically to people living with disabilities. This is the case of CARE INTERNATIONAL; Concern worldwide, PSI, etc. But, a large number of studies indicate that they are actually at increased risk for every known risk factor for HIV/AIDS. Despite the assumption that disabled people are sexually inactive, those with disability and disabled women in particular are likely to have more sexual partners than their non-disabled peers. Extreme poverty and social sanctions against marrying disabled women mean that they are likely to become involved in a series of unstable relationships.

Disabled individuals (both male and female) around the world are more likely to be victims of sexual abuse and rape than their non-disabled peers. Factors such as increased physical vulnerability, the need for attendant care, life in institutions, and the almost

universal belief that disabled people cannot be a reliable witness on their own behalf makes them targets for predators.

Individuals with disability are at increased risk of substance abuse and less likely to have access to interventions. It is estimated that 30% of all street children have some type of disability and these young people are rarely reached by safe sex campaigns. (NORA ELLEN GROCE, 2003).

Yet, the literacy rates of people with disabilities are very low (it is estimated an adult literacy rate of only 3%globally, as consequence making communication of messages about HIV/AIDS, safe sex, sexually Transmitted Infections, drug use and abuse become more difficult .

4.2 Means of communication to People with Disabilities

Most HIV/AIDS Organizations in Rwanda have not set up any HIV/AIDS program in disability dimension because: lack of political good-will; each organization desires to work in this domain must follow the main trends established by the government through the National AIDS Control Commission (CNLS). Some organizations think that other organizations are better able to handle it; it is not a specific target under HIV program.
People with learning disabilities may present more difficulties than others to some HIV/Organisations when included into their work of HIV/AIDS Organisations. For others, there is no particular difficulty in giving out messages when HIV lessons precede their initial reanimation, rehabilitation and entertainment would be neither effective nor efficient. HIV is to be an absolute cross-cutting issue to another wide package of services to them.
The information concerning HIV/AIDS that is reaching the disability community is less accurate than that reaching the general population.

The large HIV/AIDS campaigns on Television programs, education sessions in which no sign language or captioning was available for those who are deaf, other written materials, Documents written in Braille, No demonstration to people with visual impaired (e.g. Use of Condom), Training /education cessions in locations not accessible by wheelchair are inaccessible, Complex materials not appropriate for the intellectually disabled,

On the other hand they are some organizations such as Handicap International that are trying to set up a “centre d’encadrement” (center framing) but the project is still in paper.

4.2.1 To reach disabled people

People with disabilities should be reached through several ways, but it is recommended to:

- Contact local disability advocacy Organizations for guidance and help
- Make sure that local disability organizations are on your distribution list so that they receive the same materials that are sent to local HIV and AIDS Organizations.
- Invite disabled individuals to join HIV and AIDS training group and have materials ready in an accessible format.
- Make sure that disabled people are depicted as member of the general population in posters, billboards or other materials about HIV and AIDS.
- Make sure HIV testing centers and AIDS care services are accessible. Different types of adaptations will be needed for different types of disabilities, but most of adaptations can be easily anticipated. For instance, ramps for those with physical impairments, sign language interpreters for those who are deaf, AIDS talks those with intellectual impairments that are simple, straightforward and that emphasize repetition of key themes, talk for those who are blind that allow them to actually feel condoms rather than simply having someone in the front of the room hold one up.

- The nature of these services will depend on the individual disability, but ramps, sign language interpretation, and more verbal presentation and demonstration for blind people are some common measures that can easily be taken.
- Keep in mind that people with disabilities also engage in behaviors such as unprotected sex with contaminated needles that place them in traditional groups at higher risk of HIV exposure.
- Train AIDS educators, outreach workers, clinic and social service staff in disability issues. When recruiting volunteers and paid employees, make sure that disabled are considered and hired for these positions.
- Train police, lawyers and judges on disability issues related to protecting the safety and human rights of disabled people.
- Actually, there is no data on the impact of HIV and AIDS on disabled people. This means there is little information on the impact of the AIDS epidemic on the 10% of the Rwandan population and their families. Make sure to include a disability component when collecting data on HIV and AIDS.
- in day centers, or hospices where they brought to stay so as to receive required services (people with learning difficulties, intellectual, or mental health disability)

4.2.2 Appropriate means of communication:

1. **Visually impaired or Blind**: HIV/AIDS Organizations have to develop Audio/sound materials that have been well elaborated in collaboration with visual impaired organizations, Produce Audio cassettes tapes containing HIV/AIDS education in Kinyarwanda and make available Tapes players in rural area.

   People with visual impairments have no access to printed materials; there is a huge need for audio tapes and good Braille information for people who know Braille. No Braille materials are currently available in Rwanda. Audio tapes have to be developed.

2. **Hearing difficulties or Deaf:** IEC techniques, Visual, written and posters materials that have been well elaborated, sign language interpreters, in collaboration with Deaf Organization.

   Deaf people in Rwanda are at risk and there is still very little information on HIV and deafness. Sign language is not well-suited to explaining some issues surrounding HIV/AIDS and many sign language interpreters do not feel comfortable to participate in IEC efforts because they feel the signs used are too sexually explicit and rude. A lack of deaf counselors means that deaf people do not have any privacy when receiving counseling.

2 **Moving difficulties (physically disabled people):** Audio visual materials should be developed.

3 **Learning difficulties/ Feeling difficulties multiple/ disabilities** (Deaf -blind): IEC techniques that have been tested by Special Educationists. Experts are required in Rwanda

People with mental retardation/developmental disabilities are sexually active like other people. Some have poor judgment and poor impulse control, some has social skill deficit and most have cognitive problems and some difficulty in making decision. Their disabilities make them vulnerable to sexual abuse.

Trainers to deliver AIDS Education program must be prepared for obstacles that will accouter in delivery of AIDS education programs:

i. Professionals working with persons who have developmental disabilities should note that an HIV/AIDS infection represents an educational challenge for all population.
ii. AIDS is a sexual transmitted disease. That means in order to teach people with mental retardation/developmental disabilities how to avoid HIV infection, professionals must discuss sex. This discussion can be difficult for both educators and the trainees.

iii. AIDS is also transmitted through intravenous drug use, another topic that can be difficult to discuss. Most Professionals working with people who are developmentally disabled in Rwanda are not trained about IV.

iv. Much is not known about HIV infection and available information is frequently confusing, especially to people with developmental disabilities. I.e. HIV infection has an incubation period of several years between the time of exposure and the appearance of symptoms. This factor is complicated by widespread misconception about AIDS? Especially the modes of transmission and difference among various levels of HIV infection and confusion about the HIV antibody test.

v. AIDS are associated with stigmatized groups. Trainers must avoid attributing HIV infection to discrete" Risk groups". Instead, they must emphasize risk behaviors: anyone, regardless of their "group", is capable of these behaviors.

Principles for Developing a Program to Protect People Who Have a Developmental Disability from HIV Infection

1. To make the trainers and participants comfortable
2. Decide where the discussion should take place (e.g. in the individual's room, the educator's office) and whether a group or individual session would be most appropriate for the specific person; if a group is formed, persons with similar levels of functioning should be grouped together.
3. Educator must ensure confidentiality and build trust. They must be non-judgmental as possible avoiding value-laden words (Remember, someone may consider promiscuity to be sex with two persons in 20 years. Others

may feel very differently. Also, what is dirty to one person may be quite came to another)

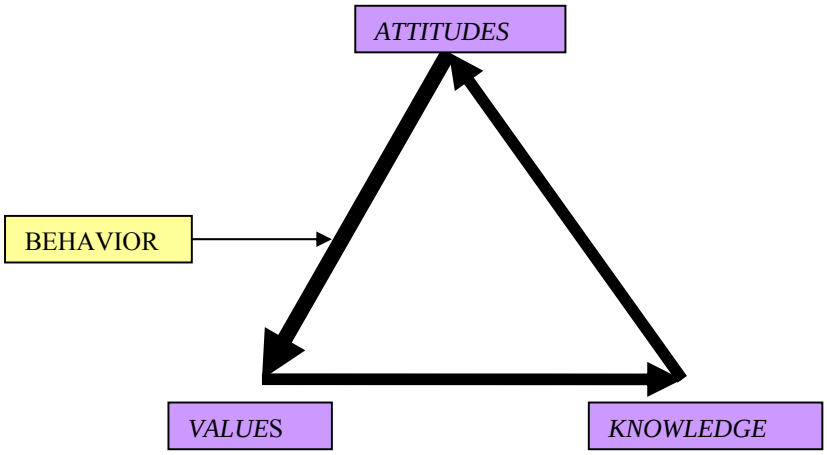
4. When teaching people who have developmental disability, it is especially important to prepare them for the session. Distribute an agenda and tell them what the topics and what are going to happen. Make sure the participants understand what is going to be discussed. Use the person's vocabulary and encourage questions and discussions.

   It is also important not to go too fast; all the relevant information will probably have to be covered over a series of sessions.

   Visuals are essentials to helping the trainees to understand and remember. When using visuals, however, keep in mind the importance of being as concrete as possible. If you put a condom on a banana, so might the person with a developmental disability! Use Video training program

5. Information alone is not enough to change behaviors (see Figure 2). Programs must also change the participant's attitudes and values(Jacobs&Martich, 1988;Mc Cusick et al, 1985).A*ttitudes* here means the sum total of a person's inclinations, prejudices, ideas, fears, and convictions on a specific topic(following Thurston's, 1928, definitions). *Values* refer to that which the individual's desire.

Figure 3. AIDS prevention behavior change model



Source: Raymond J., Perry Samowitz, Joel M. Levy, and Philip H.Levy (1989), p. 235

One of the most successful models adapted for AIDS education has been the ***HEALTH BELIEF MODEL***. Variations of this model for AIDS prevention and Education have been developed by several authors (McGussick et al, 1985; Morin, Charles, &Malyon, 1984, Prewitt, 1988).

Principles of this model are:

i. *People must perceive HIV infection as a personal threat.* People with Mental retardation/developmental disabilities must see themselves as susceptible. It is advised here to use Video and ask viewer who is at risk for AIDS. The technique of using Video helps people with Developmental disabilities make the connection between themselves and the people in video.
ii. *To emphasize that HIV is preventable:* People with Developmental disabilities, like the population at large, must feel empowered. They can realize that people are able to control whether they get the virus.
iii. *Individuals must be convinced that they can manage the behavioral changes that may be necessary(*Prewitt, 1988, called this concept" self efficacy", defined as the

degree to which an individual believes that one is capable of executing recommended preventive health behaviors.)

In the case of People with Developmental Disabilities, self efficacy necessitates that they learn everything they need to know in a manner that it is as simple and concrete as possible. Trainers need to sacrifice some accuracy. For example, an explanation of the difference between AIDS and other levels of HIV infection will confuse most people with a developmental disability. In some cases, trainers may choose to discuss these issues in later training sessions with people who have more advanced cognitive abilities.

iv. It is important to reassure individuals that *they can still be sexually satisfied*. Educators need to present their information with a positive approach. Giving up unprotected sex is perceived by many trainees as a loss? Safer sex is therefore, best presented as again that can replace this loss. People must be reassured they can continue to have good sex safely.

Materials should be clear and presented sensitively by trained individuals who are comfortable dealing with this information in an open and non-judgmental manner. Safer sex training should never be forced upon someone who is unwilling to participate. Because of the sensitive nature of the information, training is best offered in small groups or in individual sessions.

5 CARE PROVISION AND SUPPORT FOR PERSONS INFECTED/AFFECTED BY HIV

Very few disabled people get themselves tested for HIV because of:

- Fear of being more stigmatized
- Lack of awareness
- Inaccessibility
- Lack of effective ”encadrement”
- No sign language interpreters

Sometimes people who are disabled are diagnosed with HIV/AIDS much later than non disabled people, either because;

1. They do not recognize the symptoms
2. No one tells them the symptoms
3. Not go to clinics because of poverty

The Table below shows some types of actions that should be used to include people with disabilities in the work of HIV/AIDS Organizations in Rwanda.

Table 3 Types of actions to include disabled people in HIV/AIDS prevention and care

Type of Action	Methods	cost	Examples
Type I: Individuals with disability are reached by the same AIDS Education messages and services as members the general public	Ensure that AIDS educational outreach and services available to the general population include individuals with disability Use materials already available to general public, incorporating simple adaptations to ensure accessibility by all. Train AIDS educators, outreach workers, clinical and social service staff on disability issues. Train individuals with disability to be AIDS educators. Include outreach to the Disability community to recruit into these programs.	Little or no additional cost but keep in mind cost will rise with the level of tailoring to individual disabilities)	AIDS posters and billboards depict individuals with disability (i.e. wheelchair users, blind and deaf individuals) as part of group scenes. Move AIDS education, testing and care service delivery programs, as well as drug, alcohol and domestic violence programs to accessible meetings places. Make simple adaptations such as allowing blind individuals to feel a condom, rather than just talking to them about it. Make simple and straightforward HIV messages to allow intellectually disabled individuals to understand and memorize the words.
Type II: Adaptations are made to	Adapt already existing HIV materials to ensure inclusion of disabled people	Low to moderate additional cost	Caption AIDS public service announcements on TV for deaf people

AIDS outreach campaigns to ensure that individuals with disability are included as members of the general public	Make simple alternations to facilities to increase inclusion. During general training programs, train HIV and AIDS educators and clinicians about disability in general, and that there are differences in needs of individuals with different types of disabilities Tran individuals with disability to AIDS educators		Make AIDS materials available for blind people in inexpensive cassette formats and in Braille. Build ramps into meeting halls or clinics (ramps can be made of mud, stone, bamboo, wood, etc). Ensure that HIV/AIDS information is disseminated in a variety of formats: Radio, billboards, to ensure that specific groups (deaf, blind) do not miss out.
Type III: Disability specific adaptations of existing materials and development of new materials to reach individuals with disability outside the bounds of the general public, targeting harder to reach individuals and populations	Develop disability specific outreach efforts. Develop new materials to use in outreach efforts. Train AIDS educators, hire staff specializing in the issues related serving the specific disabled population targeted; train disability advocates to be AIDS educators within the disability community as well as the overall community.	Moderate to higher added cost	Videos in Sign language for the deaf Target schools, institutions and organisations serving populations of disabled people for special programs to ensure that students, residents or participating members have been informed. Rewrite training materials in simpler language/easy to understand format for those with intellectual impairments, or for disabled individuals who are illiterate or low literacy. Have a sign language inter-

	preter available at clinics/hospitals to explain complicated regimes of AIDS drugs and follow –up.
	Train HIV educators and service providers about disability issues.

* This table is based on a similar table in the Yale/World Bank Global Survey on HIV/AIDS and Disability report, 2004

CONCLUSIONS AND RECOMMANDATIONS

a) Conclusions

Including Disabled people in the work of HIV/AIDS requires the necessity of specially trained personnel and decentralized personnel. Indeed the rural as well as urban areas need to be sensitized about the disability awareness and social workers must be made more aware of disabled people. In addition, disabled persons have to access to resources, egg materials, training, facilities and they must make themselves visible if they want to make serious changes.

Communication and organizational structures must be established to reach all people with disabilities training for disabled people on sexual negotiation skills and assertiveness. Disabled people must be included as trainers as well as Participants.
Access to services, e.g. counseling and health services as well as lobbying and sensitizing government officials to HIV/AIDS and disability are further needed.

b) Recommandations

1) CNLS as the coordinating body should elaborate specific Policy and specific programs about HIV/AIDS and disability and Disabled people should be involved in all stages, from planning and design to distribution, of information/awareness Campaigns on HIV & AIDS. - All the different organizations of disabled people (representing different types of disabilities) should be included (both as planners and as recipients) in HIV & AIDS related programmes,
2) All programmes should include training disabled people by considering different types of disabilities. We strongly recommend that for the sustainability of the project a designated person in the FACHR or Rwanda National Decade Steering committee for the African Decade of Persons with Disabilities is tasked with developing and coordinating an HIV & AIDS programme that other organizations can lead into and that each Organization of People with Disabilities develops their own needs assessment regarding HIV & AIDS plus an action plan.
3) HIV & AIDS should be part of an educational curriculum either in ordinary schools or special schools by considering the needs of disabled people.
4) HIV/AIDS Organizations have to develop appropriate IEC materials for all types of disabilities.

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ANNEXE

ANNEXE 1

List of some HIV/AIDS Organizations and centers

No	Name of Organization	Phone& Fax	E-mail	Address	Contact Person
1	Africare	(+250)577484 (+250)585196	africarerw@yahoo.fr	Po Box 307 Kigali	Ntakirutimana Jean Baptiste
2	Association of Support for People Living with HIV/AIDS(ANSP+)	(+250)583646 (+250) 08687499 (president)	ansprwanda@yahoo.fr Vinbay2002@yahoo.fr	Po Box 6384 Kigali	Vincent Bayiganwa
3	Action Aid	(+250)530043/ 586800 (+250)08306250	aea@aarwanda.org.rw johna@aaburundi.org	Po Box 3707 Kigali	John Abuya
4	CARE International au Rwanda	(+250)583147/8/9 520038 (+250)08302267	care@care.org.rw	Po Box 550	Anne Morris
5	Commission Nationale de Lutte Contre le SIDA (CNLS)	(+250)503985/80 (+250)503979 (+250)08305561 08766212	abinagwaho@yahoo.fr cnls@rwanda1.com	Kigali	Rev.Past.Gasatura Nathan(President) Dr Binagwaho Agnès(SE) Dr Kitoko(mobilisation)
6	Comitè International de la Croix	572781/577344/5 572783	kigali.kig@icrc.org	Po Box 735 Ki-	Alain Ribleur Diana Couf-

	Rouge(CICR)			gali	feau
7	Concern Worldwide: HIV/AIDS PPMG	(+250)08439412	cdrwa@rwanda1.com sanaliou@yahoo.fr	Kigali	Sani ALIOU
8	Pro-femmes Twese-hamwe	(+250)518480 (+250)08500321 (+250)574832	pro-femme@rwanda1.com	Po Box 2758 Kigali	Jacqueline Rusilibya
9	Society of Women Against AIDS in Africa(SWAA Rwanda)	+250 562027 +250 501 303 +25008560698	swaar@rwanda1.com	Po Box 5196 Kigali	Rose GAHIRE
10	Forum des ONGs sur le SIDA au Rwanda	+250 587240 +250 08307775 +250 08307449 +250 08466151	ngofo-rum@rwanda1.com	Po Box 456 Ki-gali	Regis Ru-hanga
11	Implementation AIDS prevention and Care Project(FHI/IMPACT)	(+250)57619393/51 7186 574038 (+250)08302583	iprice@wayne.ed info@fhirw.org	Po Box 3146 Kigali	Dr Jessica Marco
12	Population Service International(PSI Rwanda)	503481/2/3/4 503478	info@psirwanda.org staci@psirwanda.org	Po Box 3040	Staci Leuschner
13	Réseau Rwandaise des Personnes vivant avec le VIH (RRP+)	+250 588151 + 250 08308191	rrp@rwanda1.com	Po Box 6031 Kigali	S. UMUTONI Shakilla
14	Voluntary Service Overseas(VSO)	(+250)513642/ 514643	Alex.Bisanukuli@vsoint.org	Po Box 4599	Alex Bisanu-kuri

		(+250)08301772 51364		Kigali	Irena Pearse(HIV/AIDS mainis-treaming coordinator)
15	Handicap Interna-tional	584206/517056	handint@hi.org.rw	Po Box 474 Ki-gali	Jacques Buhi-giro
16	Association Rwan-daise pour le Bien Etre Familial(ARBEF)	(+250)513138 (+250)08307449 (+250)572828	arbef@rwanda1.com nyabyenda@yahoo.fr	Po Box 1588 Kigali	Dr Octavien Nyabyenda
17	World Vision Rwanda	(+250)517072/ 511775 (+250)515327	kofi_hayan@wvi.org	Po Box 1419 Kigali	Kofi Hayan
18	Right To Play Remera	(+250)08741302	r2pkigali@yoo.ca	Po Box 5239 Kigali	Jean Philippe Marcoux
19	Solidarité Dans l'Action Contre le SIDA(SOLIDAC)	(+250)546080 546232 (+250)08412046	Soli-dac2002@hotmail.co m vicen-tie2000@yahoo.fr	Po Box 380 Ru-hengeri	Akimanizanye Vicentie
20	UYISENGA N'IMANZI	(+250)565462 (+250)08305007	uyis-enga@rwanda1.com	Po Box 7257 Kigali	Nyiratamba Annonciatta
21	Wikwiheba Associa-tion /EPR	(+250)08842989	-	Po Box 56 Kigali	Nyiramajyam-bere Fran-çoise
22	Garuringufu Associa-	(+250)08865217	Vinbay@yahoo.fr	Po Box	Mukareta

	tion			56 Kigali	Denyse
23	Women's Equity Access(WE-ACTx)	08303399	acd@we_actx.org	Kigali	Anne Christine
24	Protection and Care of Families Against HIV/AIDS (PACFA)	+250 59062048 +250 511 620	info@pacfa.rw	Kigali	-
25	Treatment and Research Aids Centre (TRAC)	+2505782 +2505787 3	lab-hiv@rwandatel1.rwanda1.com assim-wea@tracrwanda.org	Kigali	: Dr Anita Assimwe
26	Joint United Nations Program on Aids(UNAIDS)	+250 510 623 +250 510 622	dirk.vanhove@undp.org	Kigali	Dirk Van Hove (Country co-ordinator)
27	Caritas Rwanda	574295/574254	Caritas1@rwanda1.com	Po Box 124 Kigali	Abbé Gérard Habumugabe
28	UN Theme Group on HIV/AIDS	+250 590 405 +250 573 024	bkeita@unicef.org	Kigali	Bintou Keita
29	Catholic Relief Service	+250)582114/582109 +250)582126/582127	crs@crs.org.rw	Po Box 65 Kigali	Sean T.Gallagher

ANNEXE2

Some Disabled Person's Organizations in Rwanda

No	ORGANISATION	CONTACT PERSON	ADDRESS
1	FACHR	Rusiha Gastone	Phone: (+250)08302982 Email: rwandafachr@yahoo.com
2	AGHR	Nkundiye Zacharie	Phone: (+250)08430345 (+250)548713 Email: aghrw@yahoo.fr
3	RUB	Donatila KANIMBA	Tel: 250 576 097 / 576 233 Fax: 250 577 543 / 571 925 / 572 338 Mob: 250 08 856 671 E-mail: kdonatilla@yahoo.com; rub@rwanda1.com
4	RNAD	Francois TWAHIRWA	Phone:(+250)0842417 Email: rnad2003@hotmail.com
5	ACPJNV	Peter Nyankiko	Phone:(+250)08876915 E-mail:
6	AAAF	Innocent TWAGIRAYEZU	Phone(+250)08434085 Email: intwagira@yahoo.fr
7	AHUR	Patrick GATWAZA	Phone:(+250)08486508

			Email: ahuunr@yahoo.fr
8	ALPH/SIDA	Froribert	Phone: Email: arphlsida@yahoo.com
9	FDPR-URUFATIRO	Sam BADEGE	Phone:(+250)08777666 Email: badegesam@yahoo.fr
10	FERHANDIS	Dominique BIZIMANA	Phone:(+250)08618220 Email: sporthand@yahoo.fr
11	ADDP/RWANDA	Dr James NDAHIRO	Phone: E-mail:(+250)59142205
12	Troup Handicap Twu-zuzanye	Augustin Ngezahayo (Philosophe)	Phone(+250)08580810 Email: twuzuzanyetht@yahoo.fr
13	Amizero Aveugle	Kazamarande Vedaste	Kigali
14	ATOR	Mudaheranwa Emile	Kigali
15	Twisungane	Twagiramungu Jean Bosco	Konombe
16	Foi et Lumiere	Mukashyaka Agnes	E-mail: mukashyakaagnes@yahoo.fr
17	Amizero Centre	Muhayimana Jamuel	Phone: 08410349 E-mail:
18	HVP/Gatagara	Ngendahimana Celestin	Phone: 08309666 E-mail: celengend@yaoo.fr
19	Cooperative SOCORWA	Zacharie Nkundiye	Phone: 548713 E-mail: aghrrw@yahoo.fr

ANNEXE3.

QUESTIONNAIRE ON INCLUSIVE OF PERSONS WITH DISABILITIES IN THE WORK OF HIV/AIDS ORGANISATIONS AND CENTRES IN RWANDA

About the questionnaire

This questionnaire is to facilitate the collection of data from HIV/AIDS organizations and centers in Rwanda. The research project to which this questionnaire relates aims to sensitise and educate HIV/AIDS organizations and canters in Rwanda on the needs and actions necessary in relation to persons with disabilities in the HIV/AIDS epidemic. A part from this, this questionnaire will enable us to develop a very practical manual on how to include persons with disabilities in the work of HIV/AIDS Organizations. The manual will also be used as handbook on how to reach persons with disabilities, where to find them, what their different needs, how to find appropriate means of communication and how to develop inclusive strategies for their work.

Name of Organization	
Your position	
Organisation's address	
Domain of intervention	

Part I. teaching disabled people about HIV/AIDS through existing HIV/AIDS Organizations and centers

1. Is your Organization involved in teaching disabled people about:

☐ .HIV/AIDS

☐ Safe sex

☐ Sexually Transmitted Diseases

☐ Drug use and abuse

☐ Other topics relevant to HIV/AIDS (please describe)

a) If your Organization is involved in these activities, please describe the program(s) in more details here.

b) If your organization has not set up an HIV/AIDS program in disability dimension, what are the reasons?

☐ It is not the type of thing your organization does

☐ Other organizations are better able to handle it

If so, which organizations?

☐ You do not think it is a significant problem for the population you serve

☐ You worry about making disabled people ever more stigmatized

☐ Lack of resources and/or money

☐ Other (please explain)

2. . According to your experience, is it possible to include all types of disabilities into your work?

☐ Yes ☐ No

What kind of disabilities may present more difficulties than others when included into your work?

☐ People with seeing difficulties (**blind**, optic nerve damage, …)

☐ People with hearing difficulties (**deaf**, earless person, ear without ear drum(s)…)

☐ People with speaking difficulties (**speaking impaired person**, cleft lip and cleft palate, mute…)

☐ People with moving difficulties (amputee arm(s)/leg(s), polio, cerebral palsy, hemiplegia, paraplegia, paralysis…)

☐ People with feeling difficulties (3rd degree of leprosy, parahemiplegia…)

☐ People with learning difficulties (intellectual disability, slow learner…)

☐ People who have fits (epilepsy …)

☐ Other (describe)

Why?

What kind of disabilities can be most successfully included into your work?

☐ People with seeing difficulties (blind, optic nerve damage, ptosis…)

☐ People with hearing difficulties (deaf, earless person, ear without ear drum(s)…)

☐ People with speaking difficulties (speaking impaired person, cleft lip and cleft palate, mute…)

☐ People with moving difficulties (amputee arm(s)/le(s), polio, cerebral palsy, hemiplegia, paraplegia, paralysis…)

☐ People with feeling difficulties (3rd degree of leprosy, parahemiplegia…)

☐ People with learning difficulties (intellectual disability, slow learner…)

☐ People who have fits (epilepsy …)

☐ People with multiple disabilities(Deaf -blind)

Why?

3. Do you find any difficulties in teaching persons with disabilities about HIV/AIDS?

☐ Yes ☐ No

Explain

4. Are there any other HIV/AIDS organizations or centers in your area that are reaching or trying to reach people with disabilities about HIV/AIDS prevention information?

☐ Yes ☐ No

If yes, which ones?

5. Have you been asked for help by any disabled peoples' organization to reach people with disabilities in the Community?

☐ Yes ☐ No

If yes, which type of disability have you helped?

☐ People with seeing difficulties (blind, optic nerve damage, ptosis…)

☐ People with hearing difficulties (deaf, earless person, ear without ear drum(s)…)

☐ People with speaking difficulties (speaking impaired person, cleft lip and cleft palate, mute…)

☐ People with moving difficulties (amputee arm(s)/le(s), polio, cerebral palsy, hemiplegia, paraplegia, paralysis…)

☐ People with feeling difficulties (3rd degree of leprosy, parahemiplegia…)

☐ People with learning difficulties (intellectual disability, slow learner…)

☐ People who have fit (epilepsy …)

☐ Multiple disabilities (Deaf -blind)

6. Are there any measures that have been taken by your organization to reach people with disabilities?

☐ YES ☐ NO

If yes, which type of disability have you reached?

☐ People with seeing difficulties (blind, optic nerve damage, ptosis…)

☐ People with hearing difficulties (deaf, earless person, ear without ear drum(s)…)

☐ People with speaking difficulties (speaking impaired person, cleft lip and cleft palate, mute…)

☐ People with moving difficulties (amputee arm(s)/le(s), polio, cerebral palsy, hemiplegia, paraplegia, paralysis…)

☐ People with feeling difficulties (3rd degree of leprosy, parahemiplegia…)

☐ People with learning difficulties (intellectual disability, slow learner…)

☐ People who have fit (epilepsy …)

☐ Multiple disabilities (Deaf Blind)

If No, why

7. Do you think that the information concerning HIV/AIDS that is reaching the disability community is:

☐ Less accurate than that reaching the general population?

☐ Equal to that reaching the general population?

☐ More accurate than that reaching the general population?

8. Have there been large HIV/AIDS campaigns (by HIV/AIDS organizations and centers) that were inaccessible to the people with disabilities in the following formats:

☐ Radio programs

☐ Television programs

☐ Other written materials

☐ Complex materials not appropriate for the intellectually disabled

☐ Training /education cessions in locations not accessible by wheelchair

☐ Training /education sessions in which no sign language or captioning was available for those who are deaf

☐ Documents written in Braille

☐ No demonstration to people with visual impaired (e.g. Use of Condom)

☐ Other ways please explain

9. Where do you think disabled persons should be reached to be taught about HIV/AIDS epidemic?

☐ In their organizations

☐ In their families

☐ To their localities

☐ Schools

☐ Churches

☐ Seminars

☐ Others (describe)

10. How do you think disabled people should be taught about HIV/AIDS :

☐ Training trainers depending on each type of disabilities

☐ Build a center in Rwanda where all people with disabilities can get health care

☐ Peer Education

☐ Extra needs and strategies (Imfashanyigisho zijyanye n'ubumuga bw'umuntu)

11. What is the appropriate means of communication should be used in teaching HIV/AIDS people with:

a) Seeing difficulties such as blind, optic nerve damage, ptosis…?

b) Hearing difficulties such as deaf, earless person, ear without ear drum(s)…?

c) Speaking difficulties such as speaking impaired person, cleft lip and cleft palate, mute…?

d) Moving difficulties such as amputee arm(s)/le(s), polio, cerebral palsy, hemiplegia, paraplegia, paralysis…?

e) Learning difficulties such as intellectual disability, slow learner…?

f) Feeling difficulties (3rd degree of leprosy, parahemiplegia…)?

g) People who have fits such as epileptic…?

h) Multiple disabilities (Deaf -blind)?

Part II. **Help and support for Disabled people who are infected with HIV and suffering from AIDS.**

12. Why very few disabled people get themselves tested for HIV?

☐ Fear of being more stigmatized

☐ Lack of awareness

☐ Inaccessibility

☐ Others (describe)

13. Do you know any disabled person who could not be able to be tasted for HIV/AIDS or had trouble getting tested because of:

☐ Inaccessibility clinics

☐ No one willing to treat him

☐ No sign language translations

☐ Other difficulties (please explain)

14. Do you know any disabled person who could not access health care programs for people with HIV/AIDS or obtain treatment for HIV/AIDS because of their disability?

☐ Yes ☐ No

If yes, please explain

15. Sometimes people who are disabled are diagnosed with HIV/AIDS much later than non disabled people, either because :

☐ They do not recognize the symptoms,

☐ No one tells them the symptoms,

☐ No AIDS clinics welcomes disabled people or they are afraid and do not know much about HIV/AIDS.

☐ Not go to clinics because of poverty

Have people you know had any experience with this?

16. Sometimes people who are disabled do not get as good medical care as people who are not disabled. This is particularly true when people who are disabled need expensive drugs, or extra care or hospitalization. Have you ever seen this happen when someone with disability is diagnosed with HIV/AIDS?
17. What strategies should be used so that people with disabilities should be included in your work?