



A Healthy People. A Wealthy Nation



TRAINING MANUAL ON DISABILITY AND HIV & AIDS

*Manual for Health Professionals
in HIV & AIDS*

February 2015



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Abbreviations and acronyms

AIDS:	Acquired Immune Deficiency Syndrome or Acquired Immunodeficiency Syndrome
ART:	Anti retroviral Treatment
CHCS:	Center for Health Care Strategies
CHF:	California Healthcare Foundation
DPO:	Disabled People Organisation
FGD:	Focus Group Discussion
GF:	Global Fund
HI:	Federation Handicap International Program Rwanda
HIV:	Human Immunodeficiency Virus
HSSP III:	Health Sector Strategic Plan III
IEC:	Information, Education and Communication
JAWS:	Job Access with Speech
KPF	Kaiser Permanente Foundation
MoH:	Ministry of Health
MOV:	Means of Verification
NCPD:	National Council of Persons with Disabilities
NISR:	National Institute of Statistics of Rwanda
PMO:	Prime Minister Office
PMTCT:	Prevention Mother to Child Transmission
PWDs:	Persons with Disabilities
RPHC 2012:	Rwanda Population and Housing Census 2012
SSF:	Single Stream of Funding
UNCRPD:	United Nations Convention on the Rights of Persons with Disabilities
UPHLS:	Umbrella of Organizations of Persons with disabilities in the Fight against HIV&AIDS and for Health Promotion
VCT:	Voluntary Counseling and Testing
VSO:	Voluntary Services overseas
WID:	World institute disability
WWDs:	Women with Disabilities
YWDs:	Youth with Disabilities



Foreword



Despite many advances in HIV/AIDS response in the last decades, HIV still remain among major causes of death and disability in developing countries. This manual intends to provide guidelines for the accessible health service provision to persons with disabilities in HIV/AIDS response.

Health care services are among the basic services that should be available and accessible to all persons. Inaccessibility is the main reason for low utilization of health care services. The consequences could be detrimental to persons, families, communities and nations.

Persons with disabilities have equal or greater needs for Health care services. Most often in health care facilities, physical and environmental accessibility are poor and, health care providers do not have skills to communicate with persons with hearing or intellectual impairments.

This manual has been commissioned by the Umbrella of Organizations of Persons with disabilities in the fight against HIV/AIDS and for Health Promotion under the financial support of the Global Fund through the Ministry of Health.

The main objective is to provide guidance to Health service providers responsible for HIV prevention, treatment, care and support services on how to accommodate the needs of persons with disabilities.

We hope that the manual will contribute to current efforts targeting the reduction of HIV incidence as well as initiatives that are trying to make HIV services accessible to persons with disabilities.

*NIYOMUGABO Romalis
UPHLS Legal Representative*

Acknowledgement

We would like to thank the Ministry of Health which funded the development of this training manual through the Single Stream Funding on HIV&AIDS project. We are also grateful to the DPO, government institutions especially NCPD, Rwanda Biomedical Center, disability specific organizations in Rwanda like Handicap international, VSO and participants who were involved into the validation workshop for their valuable inputs into development of the manual.

Further, we would like to acknowledge the knowledge and skills of Rwanda Health Communication Center for their contribution on health promotion and communication expertise which was imparted to the development of the document.

We would like also to thank Kibondo Editions for the design and compilation all the information and comments from all the platforms to develop and produce this manual.

We hope that this manual will contribute to improved access to HIV and AIDS services for Persons with disabilities.

KARANGWA Francois Xavier
UPHLS Executive Director



Definitions of key words and concepts

HIV:

Human immunodeficiency virus; HIV is the virus that causes AIDS.

AIDS:

Acquired Immune Deficiency Syndrome or Acquired Immunodeficiency Syndrome. A group of diseases caused by the Human Immunodeficiency Virus or HIV.

Disability:

A disability is the result of interactions of individual impairments they be physical, sensory, mental, intellectual and or psychosocial with the environmental barriers: Physical, attitudinal, social and institutional barriers.

Gender:

Gender refers to the socially constructed roles, behaviors, activities and attributes that are considered by a society to be appropriate for its men and women.

- Gender is the social concept used to distinguish between women and men,
- Gender is based on society's assigned roles, social status, and acceptable ways that men and women are expected to express themselves,
- Thus, gender is socially constructed while sex is biologically determined,
- Gender roles can change from time to time e.g. during war or conflicts women are expected to take up less risky roles than women, women may take up leadership of families when men are out to fight, and forced to go back to their former passive positions when men return after the war.

Sex:

Sex refers to the biologically determined characteristics that define humans as female or male.



Sexuality:

- Referring to the interplay of physical, psychological, social, emotional, and spiritual makeup of an individual,
- It also encompasses gender, gender role, gender identity, sexual orientation, sexual preference, and social norms as they affect physical, emotional, and spiritual life.

Sexual assault:

- Sexual assault means: Any type of sexual activity that you do not agree to, including inappropriate touching, vaginal, anal or oral penetration,
- Sexual intercourse that you say no to,
- Rape, attempted rape,
- Child molestation.
- Sexual assault can be verbal, visual, or anything that forces a person to join in unwanted sexual contact or attention.

Rape:

- Forcing someone to have sex against their will,
- A more specific definition is, vaginal or anal penetration against the will and without the consent of the victim.

Accessibility:

Accessibility refers to facilities to physical environment, to transportation, to information and communications, including information and communications technologies and systems that enable persons with disabilities to live independently and participate fully in all aspects of life.



Communication:

Communication includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology.

Language:

Language includes spoken and signed languages and other forms of non-spoken languages;

Discrimination:

Discrimination on the basis of disability means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.



Part I: Introduction

1. 1. Background

According to 2012 Rwanda Population and Housing Census (RPHC) 446,453 out of which 221,150 are male and 225, 303 are female live with Disabilities. The risk of acquiring disability increases with age with 25% prevalence among those who are 80 and above. The most common type of disability is difficulty walking or climbing, with a prevalence rate of 3% among the resident population aged five and above. Other activity limitations have a prevalence rate below 1%. For instance, 0.9% experience difficulties learning concentrating and 0.6% have difficulties with their eyesight. More than 93% of all persons aged five and above who live with a disability have only one disability, and around 6% have two disabilities¹.

PWD in Rwanda are less privileged than in any group. The 2012 Census data show that PWD have got less access to education and more than 41% of them have no education, and particularly more than 50% of women with disabilities have no education at all Children with disabilities have less access to primary education than children without disabilities. People with hearing impairment are the least educated and less likely to go to school. The PWD are less likely to have access to information on sexual and reproductive health including HIV&AIDS.

In terms of labor and employment PWD are less likely to be employed. And the small numbers of those who are employed are in the agriculture, forestry and fishing sectors thus they have a reduced access to a sustainable source of income predisposing them to poverty of other driving factors of getting HIV&AIDS.

In terms of health and healthcare access, the majority of PWD has got disability due to an illness or disease. So, prevention of diseases should be the prevention of disability and the priorities on disability interventions. Injuries and accidents rank second, with one in five persons with a disability declaring this to be the cause. In addition, 13% have a congenital condition and for 8% the reported cause is war/mines or the genocide against the Tutsi.

¹ National Institute of Statistics of Rwanda (NISR), Rwanda Population and Housing Census, 2012



Though the access to health care is particularly important for persons with disabilities, fewer PWD are covered through health insurance compared to the counterparts without disabilities. The coverage is slightly lower than among the population without a disability (87%). And the large majority of insured persons with disabilities are members of the “Mutuelle de santé”, the public health insurance scheme (95%) which does not cover most of the rehabilitation and special services related to disability.

As far as sexual and reproductive health concerned, in Rwanda, the percentage of people who have never married among persons with a disability exceeds the percentage among non-disabled persons at all ages.

1. 2. Presentation of UPHLS

The Umbrella of Organizations of PWDs in the fight against HIV&AIDS and for Health Promotion “UPHLS” formerly known as UAHLS was created on 21st September, 2006 with the technical and financial support of the National Commission in the Fight against AIDS (CNLS). It consisted of 70 associations working in the field of HIV&AIDS plus the Rwandan DPOs.

Since June 2014, UPHLS membership is made by 8 National Organizations of Persons with Disabilities namely: Abadahigwa Blind Veterans, Association Générale des Personnes Handicapés au Rwanda (AGHR), Collectif Tubakunde, National Organization of Users and Survivors of Psychiatry in Rwanda (NOUSPR), National Paralympics Committee (NPC), Rwanda National Union of the Deaf (RNUD), Rwanda Union of the Blind (RUB) and Troupe des Handicapés Twuzuzanye (THT).

UPHLS Mandate is to empower Disabled People’s Organizations (DPOs) based on identified specific needs such as capacity building, planning, advocacy, coordination, monitoring and evaluation of PWDs HIV/ AIDS program activities.

UPHLS Vision is a society free of HIV and AIDS, in which PWDs are meaningfully involved in the response against HIV and AIDS.



1.3. UPHLS/SSF Project background

The “Scaling up Access to HIV&AIDS services with focus on Prevention in Rwanda (RWN-607-G08-H); Single Source of Funding (SSF) for HIV” is a government project funded by Global Fund under the National Strategic Plan on HIV&AIDS. UPLHS is sub grantee of the Ministry of Health to implement the interventions targeting PWDs.

In this Project, UPHLS role is to provide technical assistance and capacity building to different actors in the field of HIV to mainstream PWDs in their activities and improve access to HIV information and services for people with various types of disabilities.

This training manual is designed and developed to improve the knowledge and skills of Health Professionals who are working into HIV and AIDS services.

1.4. Objectives of the training manual

The production of this manual intends mainly to improve the accessibility of Health services especially HIV&AIDS related services to persons with disabilities through capacity building on disability needs in Health.

1.5. How to use this manual

This training manual has been designed to be guides to providers of HIV prevention, treatment and care services on making such services disability-inclusive. As the training is designed for health professionals who are daily involved in HIV&AIDS, bigger part of the training focused on disability and knowledge to deal with PWD assuming that trainers and trainees have got basic on HIV&AIDS services.

The manual will be useful to health workers who provide HIV prevention, treatment and care as well as other providers who may find parts of the contents relevant to their services. The part on disability awareness and inclusion is general to all service providers, community members, and development workers to raise their awareness of and sensitize them to disability issues.

In addition, disability awareness training and disability inclusion are both key to any intervention geared towards providing accessible basic services to persons with disabilities. Due to this reason, we encourage that disability awareness training and disability inclusion should always precede all efforts to remove barriers that persons with disabilities face in accessing services. So, whether you want to use this document to






train for disability-inclusive HIV services, it is expected that you first go through disability awareness training and inclusion.

And lastly, the introductory part is the integral aspect of any training of trainers' procedure. Hence, it is common to and forms the foundation for anyone who wants to train as a trainer. In the light of the above, the whole document is divided into five parts, each of which is made up of a number of sessions. Each session typically comprises specific objectives, time, facilitator's notes, participant's notes, recapitulation and evaluation.

The suggested training period is five days for the entire content. Due to the intensity of this five days training of trainers, it is strongly recommended that this is made a residential training in order to avoid people dropping out of the training exercise. Healthcare providers at both lower and higher levels and settings could find the training content applicable to their services. However, some of the content may be more applicable to providers at higher levels of care. But such content is also useful to alert health providers at lower level of care to the needs for referral.

This is a working document. We encourage users of these manuals to get back to us with feedbacks that will help us revise them on a regular basis.

In order to aid navigation through the document, the following icons are used:

Icon	Legend
	Time
	Guidance to the Facilitator
	Note to participants
	Tips
	Exercises
	Recapitulation

1. 6. Opening session



Time: 30 minutes

Preliminaries:

- Arrival and registration,
- Pre-training questionnaire – To be handed over to participants as they register,
- Welcome address,
- Who is here? – The following exercise should be undertaken to help participants set the climate for the training.



Guidance:

Have the group members stand in a semi-circle.

Have each participant come out and introduce him/herself – name, organization, position. Allow participants to greet two other persons that they have never met before and ask few questions about the person.

After participants gather back together on their seats, encourage them to share something they have known about the new person that they have just met (not name, organization and position).

Introduce the session after this exercise, then:

- Go around the group to let each individual mention what s/he hopes to achieve during the training
- Clarify issues by addressing the fears and ensure that the hopes are not dashed by referring and tackling them as need arises

Setting Ground-rules:

- Ask participants to name those rules that they think will enable the workshop proceed smoothly and create a safe environment/ space for everyone during the training
- Make a list based on their inputs. Ensure that the following are dealt with:
 - Confidentiality,
 - Listening with respect,
- Use of language that participants are comfortable with,
- Interrupt the process to confront oppression,
- Feelings are okay i.e. we agree to give people the space they need to laugh, cry and/or express their feelings,
- We agree to try on new ideas, feelings etc
- Each person has a right to self-identity,

1.7. Reminder on facilitation skills



Time: 30 minutes



Exercise:

Ask if there are participants who had facilitated sessions before.



Guidance:

Encourage them to share their experiences with others regarding the skills needed to facilitate sessions.

Discuss verbal and non-verbal methods of facilitation using participants' responses and facilitator's notes.

Facilitation skills

There are 2 types of facilitation skills. They usually go together, and a good facilitator must use a combination of the two. They are non-verbal and verbal.

Non-verbal communication/facilitation:

- Maintain eye contact with everybody in the group as you speak. Do not appear to favour certain people in the group;
- Move around the room without distracting the group. Avoid addressing the group from a place where you cannot be easily seen;
- React to what people say by nodding, smiling, or other actions that show that you are listening;
- Stand in front of the group; do not sit – particularly at the beginning of the session. It's important to appear relaxed and at the same time be direct and confident.

Verbal communication/facilitation

- Do not ask questions that elicit yes/no responses. Open-ended questions help: e.g., 'what do you think about...', 'why...', 'how...', 'what if...', etc. If a participant responds with a simple 'yes/no', ask 'why do you say that?';
- Ask the other participants if they agree with a statement someone makes,
- Be aware of your tone of voice, and speak slowly and clearly;
- Be sure the participants talk more than you do;
- Encourage participation from all by ensuring that not only a few participants dominate discussions;
- Do not dominate the sessions;

- Do not answer all the questions yourself. Participants can answer each other's questions. Say, "does anyone have an answer to that question?";
- Paraphrase by repeating statements in your own words. You can check your understanding and reinforce statements;
- Summarize the discussion. Be sure everyone understands it and keep it going in the direction you want. See if there are disagreements and draw conclusions;
- Reinforce statements by sharing a relevant personal experience. You might say, "that reminds me of something that happened last year...";

1.8. Overview of the training cycle



Time: 30 minutes



Exercise:

Ask participants if they had been involved in training before.



Guidance:

Encourage them to bring their previous knowledge to bear and help others.



Exercise:

Ask participants to differentiate between training by teaching and training by facilitation. Ask trainees to list the steps in training.



Guidance:

Lead a discussion on the order of steps in training and the key issues in each of the steps.

Training by TEACHING

- Teaching is the transfer of information from the 'teacher' to the 'student' with the hope that the 'student' will improve in knowledge and will apply the knowledge gained at some future time;
- It assumes that the learner does not know;
- It assumes that the teacher knows more than the learner;
- It is teacher-centered;
- Teaching is evaluated through examinations.

Training by FACILITATION

- Training using facilitation is the process whereby an individual is guided and helped to become able to learn and do things;
- Training by facilitation is all about skills development ;
- Information given or knowledge gained is expected to be displayed almost immediately post-learning ;
- It is learner-centered;
- It is not evaluated through examinations but through demonstration of skills gained.

Steps in training

Training needs assessment

- Asking trainees of their training needs;
- Conduct task analysis – steps involved in carrying out a task;
- Develop job descriptions/set expected performance standards;
- Measure current performance;
- Compare current performance to expected performance;
- Identify performance gaps.

Training goals and objectives

- Develop training goals and objectives by answering the question: what knowledge, attitudes and skills are required to fill the performance gaps identified?;
- Training goal is a statement of the overall purpose that the training intends to achieve;
- Objectives are the measurable learning outcomes of the training stated in terms of the knowledge, attitudes and skills that participants would have acquired by the end of the training;
- Your objectives must be SMART i.e. Specific, Measurable, Attainable, Relevant or Result-oriented and Time bound.

Designing a training (by answering the following questions)

- What content will help to meet the identified gaps of trainees, and in what order should the content be delivered?;
- What training methods & techniques will lead to effective delivery of the content?;
- What relevant/available materials & resources will be needed?;
- How will learning be evaluated?;
- How long should the sessions and the training take?;
- What style of documentation is required? e.g., modular/course system, manual/guide.

Planning a training (five Ws and one H of planning training)

- Who: participants, facilitators, funding source;
- What: training title, content ;
- Why: goal and objectives;
- When: duration, timing;
- Where: venue/location;
- How: facilitation methods, logistics.

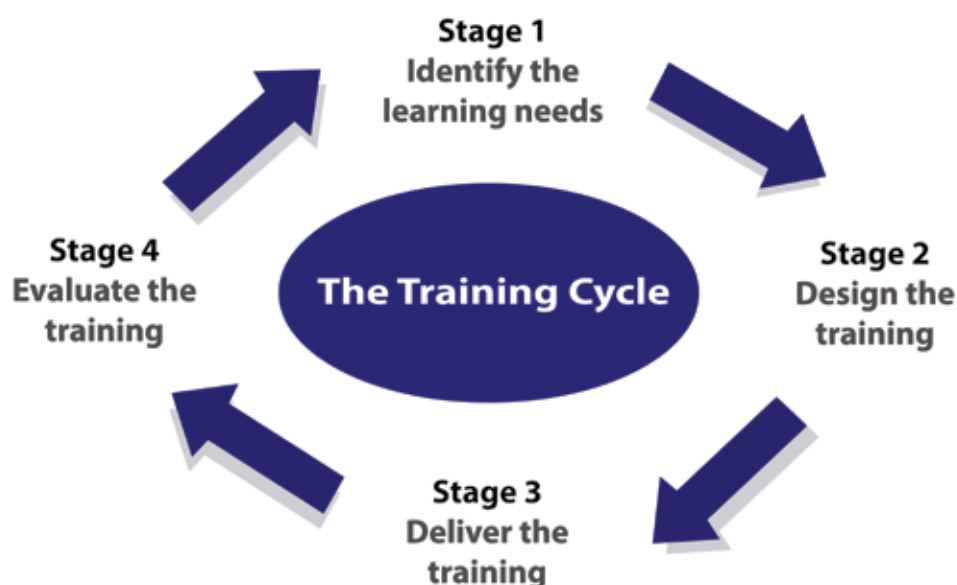
Training implementation (with appropriate learning methodologies and facilitation techniques)

- Brainstorming – asking questions and allowing participants to reflect and/or think about the topic or question. It allows for deep thought about the topic;
- Group work – exercises are given to participants in group setting. The group decides who is to lead it. They work together to come up with views or perspectives about the topic;
- Role play – participants are assigned roles or characters to be played to illustrate a topic, behavior, attitude etc. This can encourage people to reevaluate their stand on issues. Participants learn by doing;
- Gallery walk – a list of ideas written on cards by participants. These cards are displayed on a wall or flip chart. Participants walk through to read the ideas or points. It gives a wider picture of the topic at once, and participants are able to analyze the topic better. It allows for better interaction between participants;
- Lecture – facilitators deliver lecture to the participants. It could afford participants of information from expert’s view. But it is a passive method;
- Flip charts – ideas could be illustrated in sequence and it allows for analysis. Can be stopped at will for analysis. It is a simple and cheap, as well as reusable method. Can be difficult to illustrate complex ideas;
- Presentation (video, pictures, slides) – provides more interactive, visual session that encourages discussion. Can be used in series to illustrate a concept. Makes learning of complex procedures easier;
- Plenary – participants work in groups and groups choose representatives to present their ideas to all groups. It allows for better interaction. Other groups apart from the presenting one can criticize, add to or object to ideas;
- Games – ideas can be presented in simple ways and be enjoyed with fun. It provided a relaxed learning environment. Not ideal for complex issues;
- Drama – groups can be active ‘learning by doing’. Can attract attention and stimulate thinking if situations are effectively dramatized. Require adequate practice time which may not be suitable in training;
- Case study – can illustrate a situation and provides participants the opportunity to provide suggestions. It allows for deep analysis of the topic or scenario;
- Demonstration – participants can learn by practicing. Ideal for skills acquisition.

Training evaluation (involving answering the following questions)

- What were the entry knowledge, attitudes and skills? (Training needs assessment e.g., pre-test);
- What changes are taking place or have taken place? (Continuous and final evaluation);
- What changes failed to take place? (Continuous and final evaluation);
- What are the future plans to follow-up participants and support them in the application of new knowledge, attitudes and skills? (Plans for supportive supervision and monitoring);
- What are the means of verification (MOVs) / accounting for the training? (Training reports, photographs, participants' list etc.);

The Training Cycle



Recapitulation

Training could be achieved through teaching or facilitation. Training by facilitation is better because it is more participatory and recognizes the previous skills and/or knowledge of the trainees. There are steps in training and these steps must be followed accordingly in a cycle.

1. 9. Scope of training



Time: 10 minutes



Exercise:

Ask participants if there is anyone who knows or has used the concept of 'scope of training' in the past.



Guidance:

If participants are not familiar with the concept ask that they could guess what the concept means by considering the meaning behind the words

Facilitator clarifications:

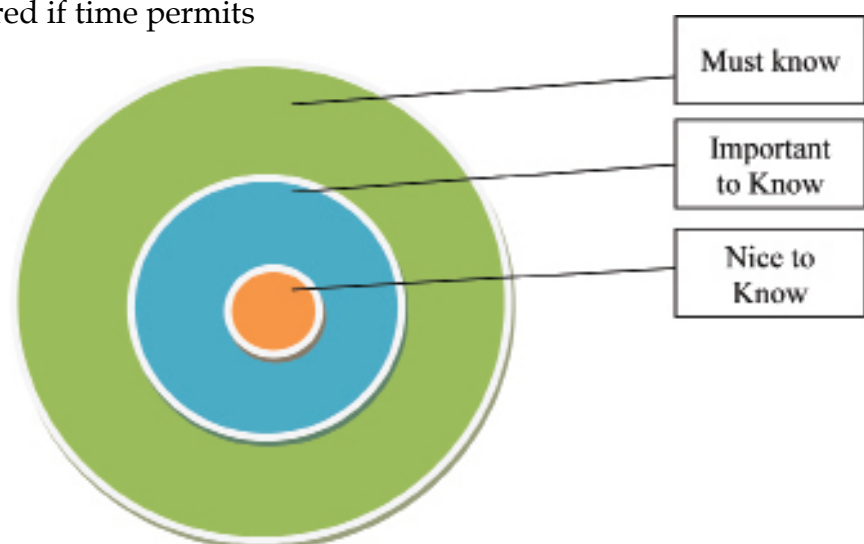
One of the key roles of a facilitator/trainer is to ensure that s/he covers the training content within the allotted time. The training design and plan involves many content. During the implementation, many issues will emerge that need clarifications. However, because there is always a limited time, the facilitator has to map out how to cover the most essential content. This is the basis of the concept of training scope.

Thus, the scope of training describes the priority that should be given to the training/session content. Every session must deal adequately with the 'must know' content areas, followed by the 'important or good to know' areas and finally the 'nice to know'. An effective facilitator must be guided by this scope of training to ensure that more important contents are not sacrificed for less important areas².

Therefore, in order of priority:

- The 'must know' is the very essential things which are to be shared with participants thoroughly
- The 'good to know' can be mentioned or listed for use
- The 'nice to know' is covered if time permits

Scope of Training



Recapitulation:

Inform participants that the scope of training is an essential tool for a trainer so as to accomplish a task within available time. They should also note that this concept should guide them in the preparation of their micro-training sessions.

2 Handicap International (HI), Training of trainers manual on disability-inclusive HIV and sexual and reproductive health for health workers, 2011

Part II: Disability

2.1. Understanding disability



Exercises:

- Ask participants to reflect on the term 'disability'.
- Ask participants to distinguish between impairment and disability.
- Ask participants to list the types of impairments that they are aware of.

2.2. Concept of Disability (including Definition of Disability)



Time: 30 minutes



Exercises:

- Ask participants that if given a chance to have a child with disability, what kind of disability will they prefer, and why?

Impairment

Impairment is a limited or total loss of functioning in parts of the body or organ of the body

Disability

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. In The Rwandan law protecting PWD in general, 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."³

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." In Rwanda, PWD are classified into five basic categories as follows: Physically disabled, visually, hearing, intellectual and other disabled⁴.

3 Rwanda Prime Minister Office (PMO), Law n° 01/2007 of 20/01/2007 relating to protection of disabled persons in general, 2007

4 Rwanda Prime Minister Office (PMO), Ministerial order n°20/19 of 27/7/2009 determining the modalities of facilitating persons with disabilities access medical care, 2009



Disability is a long-term physical, mental, intellectual or sensory (vision & hearing) impairment which in interaction with various barriers may hinder full and effective participation in society on an equal basis with others (UNCRPD, 2006).

- Impairments are not the same as disabilities;
- Disability results when impairments interact with barriers (attitudinal, environmental, institutional);
- Consequence is a lack of social participation on an equal basis with non-disabled persons .

Case study: Karikumana had polio infection as a child. The infection caused paralysis of both his lower limbs. As a result, he cannot walk and uses a wheelchair. He was interviewed for a job on telephone and succeeded. On the first day at work, he discovered that the office is on the second floor of a building. The building has no lifts and the office is not ready to explore any solutions. Eventually he lost that job.

Questions: From the case study, identify Karikumana impairment? Explain what his disability is in this case study.

Answers:

Karikumana's impairment: paralysis of both lower limbs.

Karikumana's disability: the interaction between his paralyzed limbs and lack of lifts (barrier) to the second floor where his office is.

2.3. Global and national trend on Disability



Time: 10 minutes



Exercise:

Ask participants to give estimates of how many (in percentage) persons with disabilities they think we have worldwide

Disability statistics

In 2011, PWD were estimated to more than one billion of the world population. Despite the magnitude of the issue, the global understanding of disability and its impact on individuals and society is lacking. PWD experience many socio-economic and socio-political barriers that prevent them from achieving full participation in their communities due to their invisibility. There are different barriers that people with disabilities face – attitudinal, physical, and financial preventing them to access to equal rights and opportunities.

According to 2012 Rwanda Population and Housing Census (RPHC) 446, 453 (out of which 221, 150 are male and 225, 303 are female) are PWDs with Disabilities. The risk of acquiring disability increases with age with 25% prevalence among those who are 80 and above. The most common type of disability is difficulty walking or climbing, with a prevalence rate of 3% among the resident population aged five and above. Other activity limitations have a prevalence rate below 1%. For instance, 0.9% experience difficulties learning concentrating and 0.6% have difficulties with their eyesight. More than 93% of all persons aged five and above who live with a disability have only one disability, and around 6% have two disabilities¹.

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Though the access to health care is particularly important for persons with disabilities, fewer PWD are covered through health insurance compared to the counterparts without disabilities. The coverage is slightly lower than among the population without a disability (87%). And the large majority of insured persons with disabilities are members of the “Mutuelle de santé”, the public health insurance scheme (95%) which does not cover most of the rehabilitation and special services related to disability.

As far as sexual and reproductive health concerned, in Rwanda, the percentage of people who have never married among persons with a disability exceeds the percentage among non-disabled persons at all ages. Various report show that PWD are less likely to have equal and equitable access to HIV&AIDS services due to prevalent attitude, stigma, discrimination, limited knowledge and skills of both health practitioners and PWD on either HIV &AIDS and or disability.

2. 4. Misconceptions about disabilities and persons with disabilities



Time: 20 minutes



Exercise:

Encourage participants to reflect on the most common causes of disabilities in Rwanda.



Guidance:

Use their responses to disprove traditional beliefs about causes of impairments and reinforce the true causes of impairments.



Guidance:

Lead a discussion on the visibility of persons with disabilities, and how wrong beliefs, negative attitudes, misconceptions, stigma and discrimination are making persons with disabilities invisible by being denied social participation. Build on that to disprove some common myths and misconceptions about persons with disabilities.



Guidance:

Divide participants into five groups. Assign each of these domains to each group: attitudinal, communication, environmental, institutional and physical.



Exercise:

Ask each group to come up with barriers and facilitators for the domain assigned to it.



Guidance:

Representative from each group should share their ideas by presenting in a plenary.

Myths/misconceptions	Facts
A pregnant woman will give birth to a child with impairment if she relates with persons with disabilities	You cannot get impairment by personal contacts with persons with disabilities during pregnancy or at anytime. Impairments are not contagious!
A woman with impairment will give birth to a child with impairment	Causes of most impairments are not hereditary.

Persons with disabilities are sick and dependent	Most persons with disabilities are very healthy and independent e.g., Beethoven is a person who is deaf and a great classical music composer, Steve Wonder is a famous musician who cannot see, Franklin Roosevelt was the only American president who served for three consecutive terms from a wheelchair, Honorable James NDAHIRO who cannot see, he is representative of PWDs in the East African Legislative Assembly, Chair Person of the Rwandan Capital Market and President of the Board of the Cooperative of Credit and Saving (CSS). However, some whose disabilities are caused by chronic illnesses could be sick at one time or the other.
Persons with disabilities are “childlike”	Persons with disabilities function according to their ages. Persons with intellectual impairments may have lower mental age compared to their chronological age, but they are physiologically adults. Also, they have richer life experiences than children
Persons with disabilities are asexual	Disability does not take away sexual feelings. Persons with disabilities do engage in sexual intercourses/activities and reproduce if they choose to
Persons with disabilities are few, so disability is not really an issue	Persons with disabilities are many but they are invisible due to social stigma. They may also be unable to participate in social activities due to attitudinal, physical, communication, environmental and institutional barriers
Persons with disabilities are an employment risk because they cannot meet performance standards	At work, persons with disabilities are as efficient or more efficient than some non-disabled persons
Accessibility is only about persons with disabilities	Accessibility applies to everybody regardless of disability status. It comprises signage to know one’s ways, to cross the roads etc. Most of the features that are designated for persons with disabilities are also more comfortable for and used by non-disabled persons e.g., pregnant women, elderly, children, persons who are sick
Inclusion is only about persons with disabilities	Inclusion applies to everybody and it ensures equity and fairness e.g., gender inclusion

It is costly to provide “reasonable accommodation” (measures put in place to make persons with disabilities work on the same basis with non-disabled persons) for persons with disabilities at work	Most persons with disabilities do not require any adjustments, and when they do, the cost is not usually as much as employers think. Universal design ¹ ensures that issues of access are taken care of from the beginning and this is less costly because it is planned well ahead of time
Persons with disabilities are aggressive	Persons with disabilities do not differ from the general population in their emotions. It is normal for persons to react when you discriminate against them.

2.5. Disability barriers and participation



Time: 45 minutes



Exercise:

Ask participants to mention what people in their different communities believe about mental impairments e.g., causes, symptoms etc (remember to stress the fact that mental impairment is not the same as intellectual impairment).



Guidance:

Link wrong beliefs about causes of mental impairments to stigma and difficult social interactions for persons with mental impairment

2.5.1. Types of barriers

Attitudinal barriers

- Myths/misconceptions about disability e.g., disability is as a result of past sins of the person or his/her parents
- Negative portrayal of persons with disabilities in the mass media;
- Inappropriate disability terminology use by the community and the mass media;
- Stigmatization and/or discrimination of persons with disabilities e.g., denying them the opportunity to be members of a community association because of disability, refusing to associate with families that have children with disabilities;
- Beliefs that they are unworthy members of the society;
- Negative attitudes that relegate persons with disabilities to the background e.g., a health worker declining HIV test to a person with disability, denying education to a child on the ground of disability.

Communication barriers

- Lack of information and communication in formats accessible to persons with disabilities e.g., sign language interpretation for persons who are deaf, Braille materials for persons who are blind, easy-to-understand information for persons with intellectual impairments, lack of adequate signage for persons who are blind or deaf;
- Lack of disability sensitive interpersonal skills among service providers.



Note: This applies to any form of information and communication.

For example, job advertisements, the mass media, health information, education, information on doors

Institutional barriers

- Lack of policies that are inclusive of women and men with disabilities;
- Lack of disability legislation;
- Lack of implementation of existing disability-inclusive policies;
- Lack of implementation of existing disability legislation.

Physical barriers

A high examination bed that is difficult for a wheelchair-user without assistance

- Lack of ramps in buildings with steps;
- Slippery and/or steep ramps;
- Lack of Braille lettering in lifts/elevators;
- Physically inaccessible meeting venues;
- Toilets that are not accessible to persons who use wheelchairs or have physical impairments.



The door of this toilet is too narrow for a wheelchair

- Doors that are too heavy for persons with physical impairments, particularly those with little use of their hands to open;
- Door handles that are higher than the level of average wheelchair-users;
- Hospital examination tables that are too high for women and men with physical impairments to use without assistance.



Environmental barriers

- Inadequate signage to guide persons who are blind;
- Inadequate lighting of a room to allow for easy sign language interpretation;
- Inadequate lighting of a room/venue for persons with vision impairment;
- Noisy environment in venues for programs including persons with low hearing;
- Reception tables in offices that makes it difficult for wheelchair-users to have eye-contact with receptionists;
- Lack of designated accessible car parking for persons with disabilities;
- Pasting of information at levels higher than what wheelchair-users can see conveniently.

2.5.2 Fostering participation of persons with disabilities



Exercise:

Ask for two volunteers. One should be blindfolded while the other serves as the Health center counselor. A woman who is blind visits the Health center to take HIV test. She is without any assistance. When it is her turn, the Counselor guides her into the counseling room and makes her take a seat.

Facilitating participation by removing attitudinal barriers

- Creating awareness about the causes of disabilities at the community level
- Disability awareness training of professionals and organisations
- Public enlightenment to disprove myths and misconceptions around disabilities
- Engage the mass media on disability awareness with focus on development of programs that portray positive images of persons with disabilities, as well as appropriate disability terminology
- Emphasizing that disability is something that can happen to anybody at any time
- Emphasizing that persons with disabilities are human beings that should be respected just like any other persons
- Showcasing persons with disabilities who are doing well or better than some non-disabled in spite of their disabilities

Facilitating participation by removing Communication barriers

- Engage communication Professional in accessible communication;
- Make information available in sign language;
- Provide printed information in Braille and/or audio formats;
- Development of information materials in formats that require little or no literacy;
- Training on disability-specific interpersonal skills and general disability awareness training for service providers e.g., basic sign language, use of simple language with persons with intellectual impairments.

Facilitating participation by removing Institutional barriers

- Advocating for policies that are inclusive of women and men with disabilities;
- Advocating and/or facilitating development of disability legislation;
- Developing organizational disability policy;
- Creating awareness about existing disability-inclusive policies and legal frameworks;
- Implementing existing disability-inclusive policies in programs and activities;
- Implementing existing national and international legal frameworks for persons with disabilities in all programs e.g., the UNCRPD.

Environmental barriers can be removed by:

- Adequate signage to guide persons who have impairments e.g., change in texture of the floor for persons who are blind, dedicated paint color for staircases to guide persons who have low vision, signage for accessible toilets;
- Adequate/appropriate lightning of meeting or activity venues suitable for persons who are blind or deaf;
- Hold meetings or activities in venues with reduced noise level;
- Reception desks in organisations and offices should be at the level of wheelchair-users to ensure eye contact;
- Provision and enforcement of designated accessible parking for persons with disabilities;
- Information should be pasted at levels accessible to wheelchair-users.

2.6. Disability Terminology



Exercise:

Ask trainees to write in meta-cards, the names given to these in their communities:

- a. The naked man on the road who goes about gathering paper and talking to himself;
- b. Your colleague at work who cannot see;
- c. He is an African man but has the complexion of an European man;
- d. An 18 year-old girl in your neighborhood whose intelligence is that of a 4 year-old;
- e. She crawls because she cannot walk;
- f. The parking space dedicated to persons with disabilities;
- g. Toilet designated for persons with disabilities;



Guidance:

Write down participants' responses under 2 columns (right, wrong, euphemism).
Do not put titles on the columns yet until you are done.



Exercise: Ask participants to give the word(s) used for the term 'disability' in their local language.



Guidance:

Explore together if the word(s) is/are derogatory in nature or not. Facilitate a discussion on appropriate disability terminology, with emphasis on why euphemisms are not encouraged. Use facilitator's notes and responses in items 3 and 4 above on PowerPoint slides



Recapitulation: The right based terminology of person with disabilities

Avoid/Offensive	Accepted
Victim of disabilities	Person with disability Person who has disability
Crippled/Lame	Person who has physical disability Person with physical disability Person who has physical impairment Person with physical impairment
Suffering from...	Person who has impairment Person with impairment
Afflicted by...	Person who has disability Person with disability
Wheelchair bound	Person who uses a wheelchair or wheelchair user
Invalid (= not valid)	Person with disability
Mental	Person with mental disability Person with mental impairment
Handicapped/ The handicapped	Person with disability Person with impairment
The disabled	Person with disability Person with impairment
Spastic	Person with Cerebral Palsy Person who has cerebral Palsy
Deaf and dumb	Person who has hearing impairment Person who is deaf Person who is hearing impaired
Blind	Person who has visual impairment Person who is blind Person who is visually impaired

Part III: Physical accessibility, communication and accessible information



Time: 45 minutes



Exercise

Ask for three/four volunteers to be either blindfolded, use a wheelchair or to act as a person with hearing impairment for 10 minutes while the training session continues.



Guidance:

After 10 minutes encourage the volunteers to share their experiences of what it feels like to be a person with disability.

3.1. Barrier free environment in Rwanda

Rwanda is committed to ensure the accessibility of healthcare services to the whole population including PWD. These efforts have resulted in laws and policies promoting equality, inclusion and participation of persons with disabilities in society. The article 245 of the law n° 01/2007 of 20/01/2007 relating to protection of disabled persons in general provides that all public building should be physically accessible to PWD of all types of disabilities. In 2009, the Ministry of Infrastructure enacted a ministerial decree on determines the modalities of constructing buildings providing various public services to ease the access of persons with disabilities. Thereafter Rwanda Housing Authority in 2011 published the standards of accessibility in public buildings.

3.1.1 Physical accessibility

Accessibility remains a key component in disability inclusion especially for access and utilization on health services and HIV&AIDS services in particular.

Various components must be addressed in order to ensure access to the physical environment. Contrary to popular beliefs, much more is required beyond a ramp and an elevator to make



a barrier-free environment. Other components that must be addressed include door and passage with, floor surfaces, counter heights, door handles, signage, auditory signals, and tactile guides. Accessibility entails understanding its relation to areas of life beyond just the physical environment. Areas that are often overlooked are access to services, information and communication which are an integral part of making a barrier-free society and address the accessibility needs of persons with sensory, intellectual and psychosocial disabilities as well.

To facilitate participation of persons with physical impairments, one can:

- Engage building professionals and building owners on the essentials of physical accessibility;
- Applying universal design to all buildings and constructions;
- Altering existing buildings to allow accessibility to persons with physical impairments;
- Providing non-slip and non-steep ramps where there are steps;
- Hold meetings or activities in accessible venues;
- Toilets should be wide enough to allow easy maneuverings for wheelchair-users;
- Toilets should be provided with support bars for persons with physical disabilities;
- Doors should be made of light materials that are easy to open;
- Door handles at the level of wheelchair-users; and such handles should be easy to open with a closed fist by persons who have limited use of their hands;
- Hospital examination tables that are at the level of a wheelchair;

3.1.2. Who needs physical accessibility

Contrary to the belief that accessibility concerns only people with physical impairments most of the people require accessibility or partial accessibility:

- People who use wheelchairs;
- People with limited walking/movement abilities;
- People with visual impairment or low vision;
- People with hearing impairment;
- People with intellectual disabilities;
- People with psychosocial disabilities;
- Elderly persons;
- Pregnant women;
- People with temporary disabilities;
- People carrying heavy or cumbersome luggage;
- Etc.

3.1. .3. Trip Chain concept

An important concept of the accessibility is the “Trip Chain”. A typical Trip Chain is the sum of all parts of movement from one place to another which must be accessible in order to ensure a barrier-free environment. For example, to be able to go from home to health facility a person must be able to:

- Exit the home to a sidewalk or pathway;
- Enter a vehicle;
- Alight from the vehicle to a sidewalk;
- Pathway near the health facility;
- Reach the entrance of the building;
- Enter the building;
- Maneuver within the building;
- Enter the health facilities or specific place in the building (waiting room, consultation room, cashier, laboratory, toilets, pharmacy);
- Getting out the health facility on the way back home.



Tip:

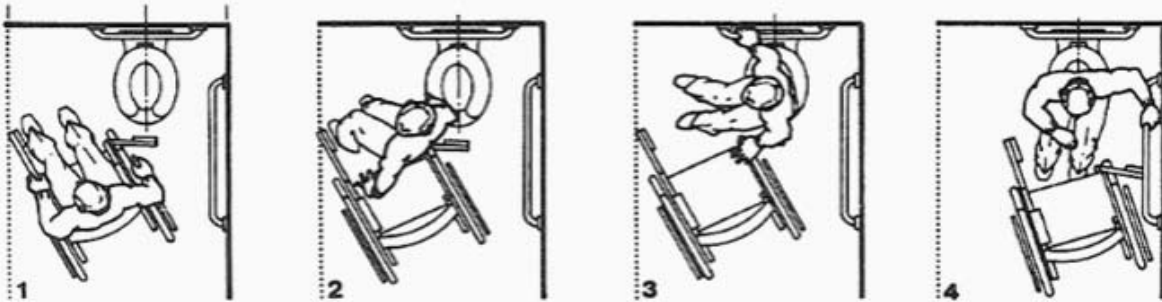
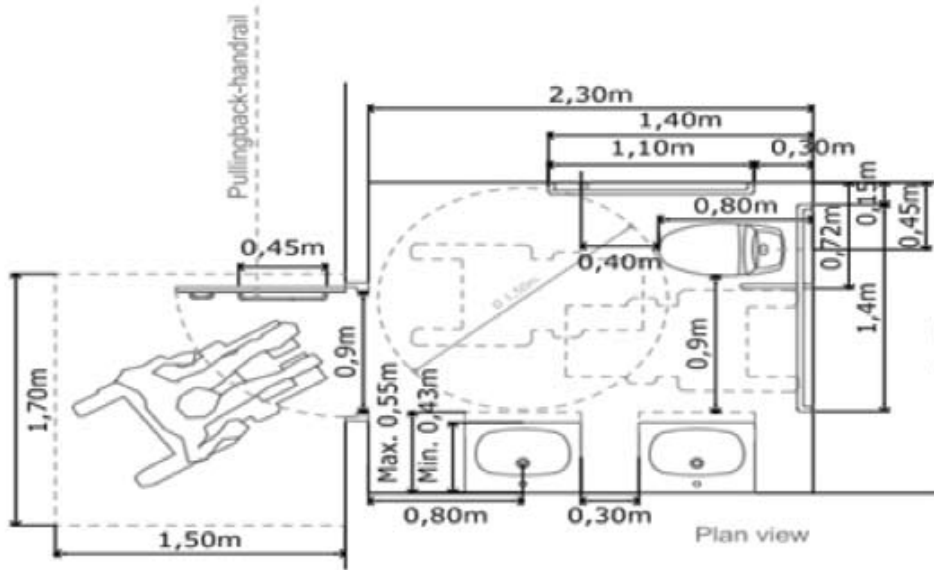
It takes only one inaccessible link in the Trip Chain to make the journey impossible. Therefore, each link must be considered and improved upon to foster a barrier-free environment.

3.1.4. Some features of physical accessibility

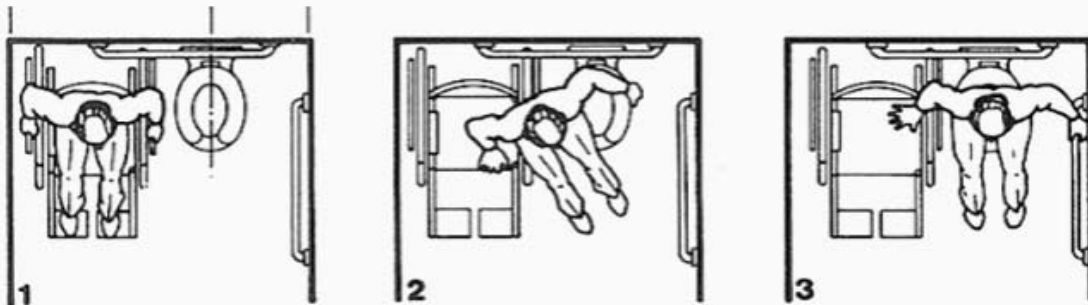
Many accessibility requirements relate to dimensions and other aspects of wheelchairs. In order to achieve a complete turn with the wheelchair, it is necessary to provide an unobstructed circle with a minimum diameter of 1.50m. Considerable energy is required to propel a wheelchair manually up ramps, over changes in level and over soft or uneven surfaces.

Some characteristics of physical accessibility are featured below:

Toilets



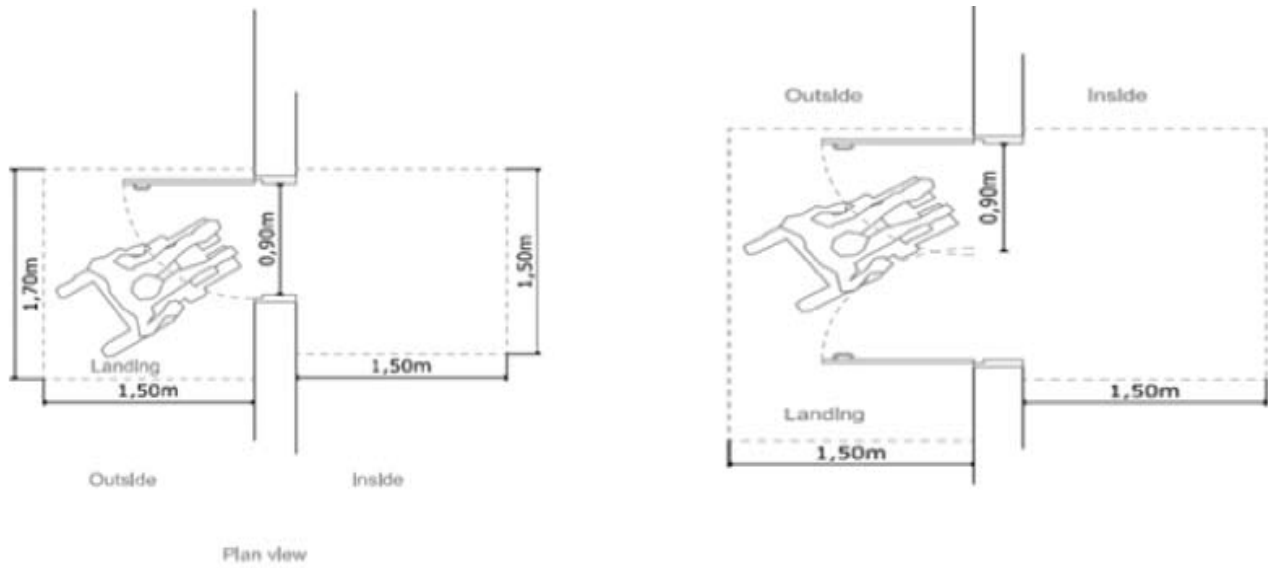
How a wheelchair user gets from the wheelchair to a toilet-seat (1-4)



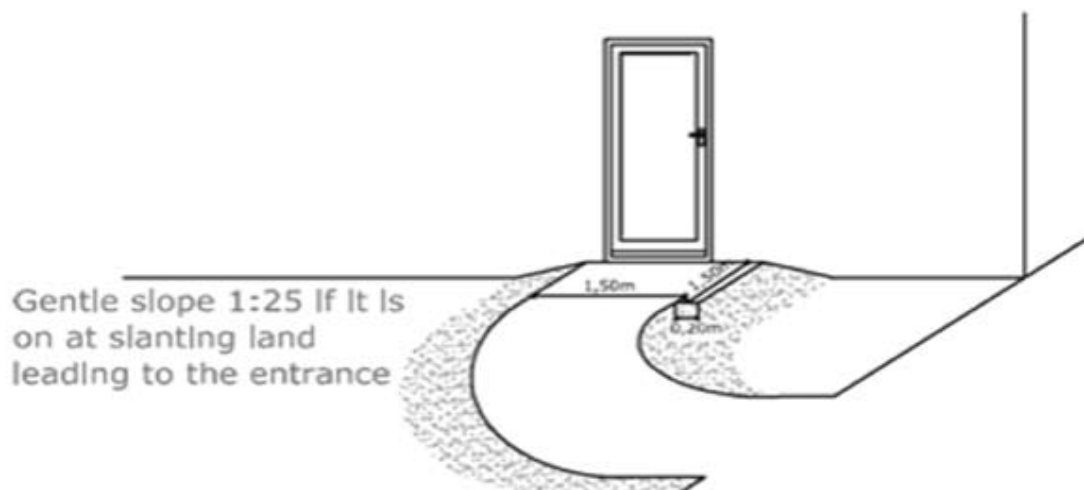
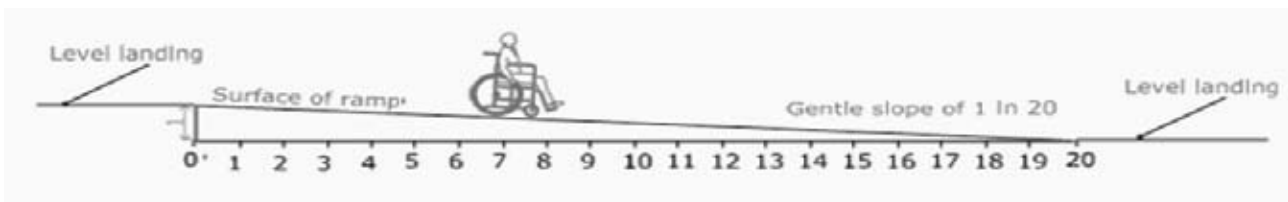
How a wheelchair user gets off from the toilet-seat back to the wheelchair (3-1)



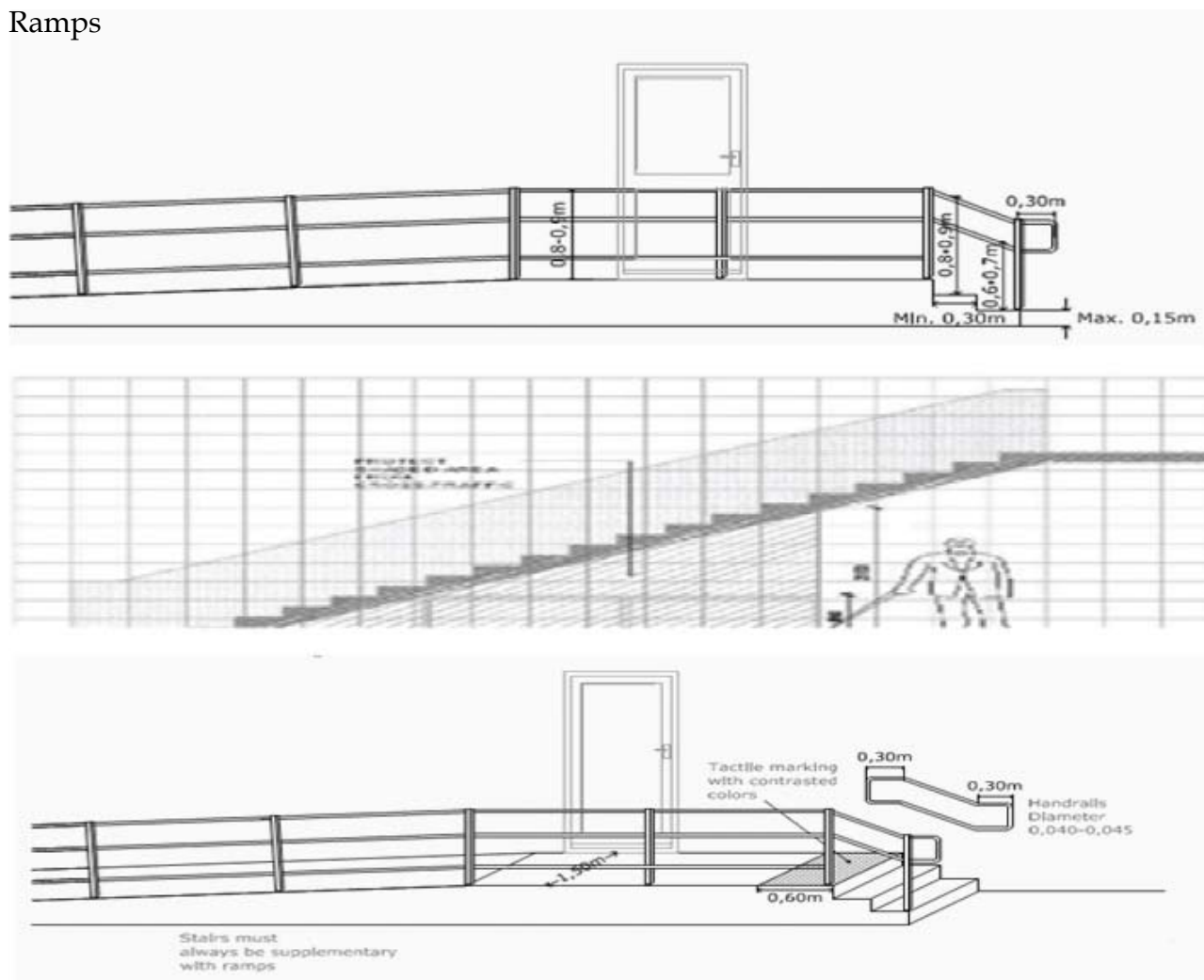
The entrance



Accessible stairs



Ramps



3.2. Interpersonal skills needed to relate with persons with disabilities

Persons with disabilities are diverse with different features and characteristics. Relating with them requires learning about the things that are unique to each of the impairments. It is easier to relate with many persons with disabilities than what many people think. Moreover, they are human beings and desire to be associated and/or related with like any other persons.

3.2.1. Meeting persons with disabilities generally

When meeting persons with disabilities:

- Do not stare at them. They are humans like you;
- Be careful NOT to ask for the cause of the impairment. S/he may not want to discuss such, particularly if it is a progressive condition;
- They do not need your pity. Pity is a negative approach. Rather, be willing to be of help/assistance if needed;



- Communicate directly with the person even when accompanied by a non-disabled person;
- Ask before you render assistance. Unsolicited help threatens the person's dignity and sense of independence. At times, it could constitute a security threat;
- Avoid 'heroic' praises. It signifies that you expect lower performances from persons with disabilities. Moreover, it is unhealthy if done in the presence of other persons with disabilities who may not have achieved that much. Even without disabilities, we have different capabilities. However, there is nothing wrong in persons with disabilities being role models to others.

3.2.2. Meeting a person who is blind or has visual impairment

When meeting a person who has vision impairment:

- It is good to introduce yourself. If you do not mind, describe yourself;
- S/he may attempt to feel your body shapes/parts for proper identification;
- When conversing in a group, address persons by names;
- When assisting, pay attention to person's response and take cues from him/her guidance;
- Avoid comments like 'over there...' when giving directions. Be specific to direct him/her to his/her right or left – not yours;
- The lighting needs of persons with low vision differ and may be significant. Many see better with stronger light while others do not;
- When preparing printed information for persons with low vision, ask the person his/her preferred formats for personal documents. General information is usually given in Arial 18 point bold;
- In case you are doing presentation, have simple, non-busy backgrounds on projected slides;
- Do not provide email attachments or files to be read on a computer in PDF or PowerPoint formats. Use Word document or html. Presently, accessible PDF files are emerging but still uncommon;
- Do not be surprised to hear phrases like 'I will see you', people who cannot see use such too;
- If you are at a table together for a meal, give a description of the food;
- Do not play with or remove the white cane of a person who is blind from where s/he places it. If it is unavoidable for you to place the white cane elsewhere, remember to inform the person. S/he needs the white cane for mobility purpose;
- Do not play with a guide dog without the owner's permission. It is a distraction. The dog is on duty!;
- Avoid revolving doors. On stairs or escalators, assist by putting his/her hand on the railing. Let the person know whether the stairs/escalators are going up or down. Allow him/her a choice between stairs, escalators or lifts;

- Never leave a person with vision impairment in an open area or leave without informing him/her. Lead the person to a landmark e.g., the reception for him/her to feel secure and orient to the environment;
- Do not relocate objects or furniture without informing a person with vision impairment;
- Do not leave doors half-open. Close or open them completely;
- When in a session that includes demonstration, allow the person to touch materials being used and practice the activity.



Tip when seating a person who is blind

- When seating a person who is blind, put the person's hand on the back of his/her chair. S/he will then be able to sit;
- If the chair is backless, put the person's hand on the seat for him/her to be able to sit.

3.2.3. Meeting a person with speech impairment

When meeting a person with speech impairment:

- Allow time for the person to speak. S/he may speak slower than you are used to;
- Avoid the urge to interrupt or complete the sentence for the person;
- If you do not understand what the person said, ask for repetition;
- Do not take over the conversation;
- Do not pretend you have understood if you haven't;
- Ask if there is somebody close by who may be able to interpret;
- If despite all you are unsuccessful, ask if the message is urgent;
- Make the message manuscripts available to people before the session (counseling, IEC session, ART, Opportunistic infections, Family Planning and PMTCT);
- Ensure that the sound system is in good working order;
- Consider installing a hearing loop system ;
- Arrange for sign-language interpretation if you know that someone with hearing is attending in advance.

3.2.3.1. Communication with Person with hearing impairment

When communicating with a person with hearing impairment:

- To get a person's attention, position yourself where s/he can see you;
- Face him/her when you talk. It allows for lip-reading for those who have learned to do that;
- Talk slowly with someone who has partial hearing;
- Ask short and clear questions that require short answers;
- Do not shout when talking to persons with low hearing; it could be embarrassing;

- Reword instead of repeating your sentence if s/he does not get you right;
- If s/he uses a sign language interpreter, talk slowly to allow for interpretation;
- Speak clearly because some people who are deaf can read your lip or someone who is hard of hearing can follow along;
- Face the person, not the interpreter;
- Do not call him/her even when s/he gives you a cell phone number rather, send text messages;
- You can use a paper and pencil/pen, computer to communicate if it is necessary;
- Reduce unnecessary background noise that can interfere with hearing aids;
- Feel free to use phrases like 'did you hear about.....'



Tips

- When communicating with somebody with hearing impairment, be aware of room lighting or window and position yourself where there is enough light on your face



3.2.4. Meeting a person who is deaf-blind

“Deaf-blindness” means concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness (Helen Adams Keller, 1880-1968).

“People with deaf-blindness or ‘dual sensory loss’ are people with a varying degree of vision and hearing loss which, in combination, causes difficulties with communication, access to information and mobility. This includes people with progressive sight and hearing loss

and those for whom, if taken separately, each single sensory impairment appears relatively mild”.

In Rwanda, children and youth having auditory and visual impairments, the combination of which creates such severe communication and other developmental and learning needs that they cannot be appropriately educated in special education programs solely for children and youth with hearing impairments, visual impairments, or severe disabilities, without supplementary assistance to address their educational needs due to these dual, concurrent disabilities.

3.2.4.1. Simple guidelines to assist you in interacting with a person who is deaf-blind

1. When you approach a person who is deaf-blind, let them know – by a simple touch on the shoulder or arm – that you are there. Reassure them of your continued presence in the same manner;
2. Immediately identify yourself by name or a sign name;
3. Communicate directly with the person who is deaf-blind, even when using an interpreter;
4. Make every effort to learn and use whatever method of communication the individual prefers, such as print-on-palm, finger-spelling, American Sign Language or writing with a bold, black pen, to name a few. Some individuals may have enough hearing to carry on conversations in quiet surroundings;
5. Use the words “see,” “hear,” “deaf,” and “blind” naturally, without hesitation, if your conversation calls for them;
6. Inform the person who is deaf-blind of their surroundings, including people and activities in the area;
7. When involved in group discussions, let the person who is deaf-blind know when it is their turn to speak;
8. Always tell the person when you are leaving, even if it is only for a brief period. See that s/he is comfortably and safely situated. If standing, make sure they have something to place their hand on, like a wall, a chair or table;
9. When guiding a person who is deaf-blind, never place him/her ahead of you. Instead, let the person hold your arm above the elbow. In this manner, the person can usually sense any change in pace or direction. When ascending or descending stairs, pause and then continue on. When walking through a doorway, let the person who is deaf-blind follow directly behind you;
10. Treat a person who is deaf-blind as you would treat anyone else. Be courteous, considerate and use common sense.

3.2.4.2. Print-On-Palm (POP) method

Print-on-Palm (POP) is a simple method of communicating with a person who is deaf-blind and familiar with printed English.

To use POP: With your index finger, print your message in the palm of the hand of the person who is deaf-blind. To make each letter, follow the diagram below, which indicates the recommended direction, sequence and number of strokes for each letter.

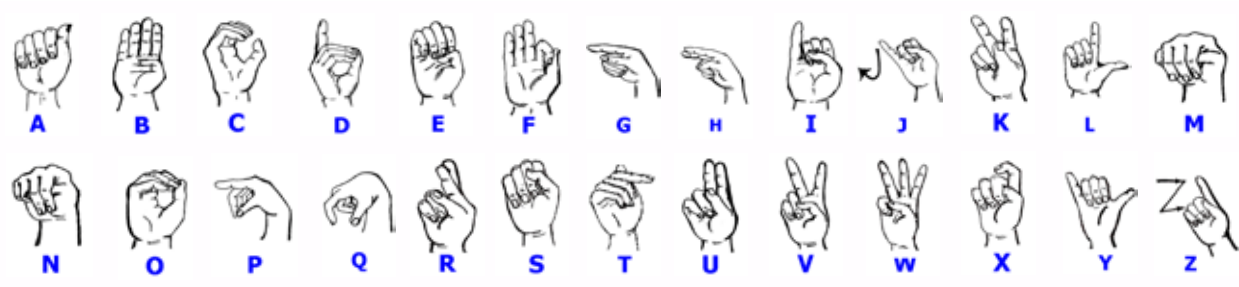
Use capital letters only, except for the letter “i” which is lower case. Print only in the palm area. Do not connect letters. Pause after each word. If you make a mistake, “wipe” the palm, then print the correct letter.

If the person has speech, he or she may say each letter and word aloud as you spell it. This is a good way to know that your message is being understood.



3.2.4.3. One Hand Manual Alphabet

The one-hand manual alphabet, also known as finger spelling, is a visual code for the English alphabet. It can be used to spell words to a person who is deaf-blind. If the person is totally deaf-blind, you will need to fingerspell the words into the palm of the person’s hand. This is called “tactual finger spelling.” You may recognize this as the method of communication used by Annie Sullivan with her famous student, Helen Keller.



3.2.3.3 Meeting a person with mental impairment/intellectual disability/ learning difficulties

3.2.3.4 Communication and interacting with a persons with mental

- Social interaction may be difficult. Be non-judgmental; allow time for interaction and decision-making
- If s/he appears unfocussed or speaks slowly – the person may be experiencing side-effects of medications or sleep disturbance
- If the person is responding to events/perceptions that you do not share – s/he has lost touch with reality

- If the person is anxious/frightened to the extent that s/he feels threatened- s/he is paranoid;
- If s/he is displaying an unusual/inappropriate behavior - be calm and patient;
- Read the body language to assess the situation;
- Allow the person his/her space and avoid both direct eye contacts and touch;
- Empathize with his/her feeling without necessarily agreeing with what is being said e.g., 'I understand that you are frightened by your experiences....';
- Do not take things personal. The person may not have insight into his/her behavior or how it impacts on others. Even if the person does s/he may not have control over it;
- Ask how you may help;
- To minimize confusion, use short, clear and direct sentences. Keep your voice tone low and unhurried.



Tips

- Next time you meet talk to the person. Remember that mental impairments are not present at all times;
- Don't refer to what happened the last time. Relate with the person normally;



Note:

These explain the stigma on mental impairments and why social interactions may be difficult for persons with mental impairments.

3.2.3.5. Meeting a person with intellectual impairment

When meeting a person with intellectual impairment:

- Keep in mind that there are different degrees of intellectual impairments, and some persons function at higher levels than others;
- They worry about the way you treat them or think of them. So, never treat them as if they are children or persons that do not understand anything. Everybody deserves respect!;
- Use simple and direct language when in a conversation;
- Be patient if the person also has speech impairment;
- You can ask if s/he understands what you have just said. If not, repeat yourself or reword your sentence and check if your language is simple enough;

3.2.3.6. Meeting a person with specific learning impairment

When meeting a person with specific learning impairment:

- Some people have difficulties with writing, others with reading etc. These are specific learning impairments, not intellectual impairments;
- Such persons may be of average or above average intelligence;
- If a person reacts to situations in an unconventional manner, keep in mind that s/he may have processing skills which affect social skills;
- Allow him/her time to respond.

3.2.4. Meeting a wheelchair-user

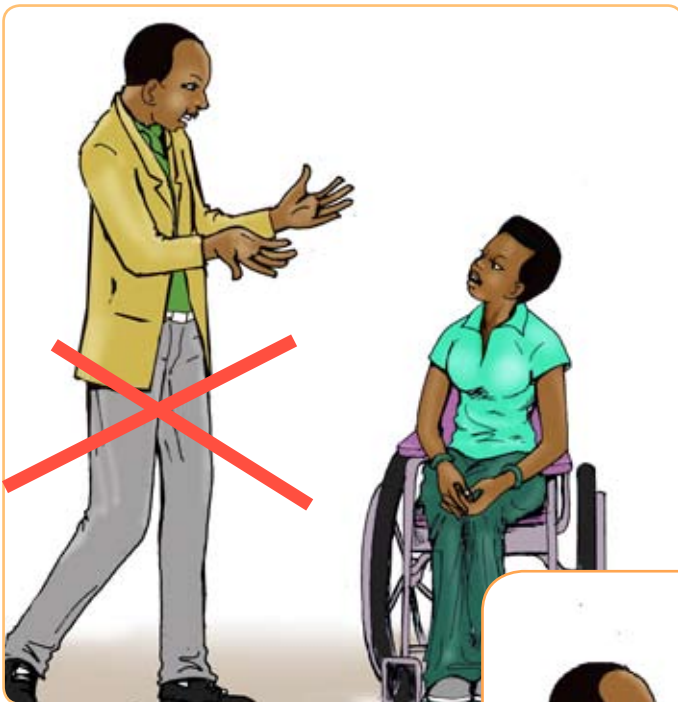
When meeting a wheelchair-user:

- Do not sit or lean on the person's wheelchair. Treat the wheelchair as part of his/her body space;
- Do not avoid words like 'run' or 'walk', wheelchair-users use them too;
- Do not give him/her items to carry for you;
- Never pat a wheelchair-user on the head or shoulder;
- Ensure a clear pathway to intended destinations, and at meetings and restaurants, make a chair-free space at tables for him/her to sit;

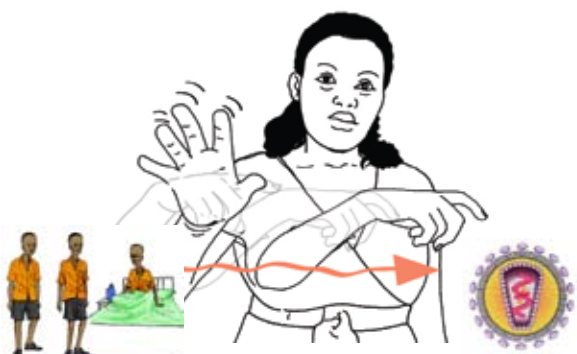


Tips:

- When going up/down a stair, ask if s/he prefers going forwards/backwards
- If engaged in a long conversation try to position yourself at the same eye level by sitting or stooping down.



Some communication tools for persons with hearing impairment



HIV/ Virusi itera SIDA/ VIH



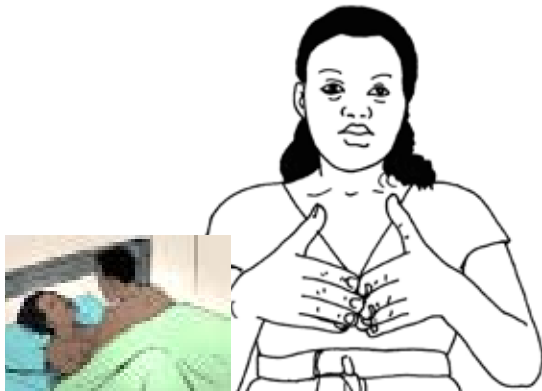
Abstinence/Kwifata
Abstinence



AIDS / SIDA/ SIDA



Fidelity/Ubudahemuka
Fidelité



Sexual intercourse
Imibonano mpuzabitisina
Relations sexuelles



Counselling
Ubujuanama/Counselling



PMTCT

Kurinda Umubeyi kwanduza Umwana we
PTME



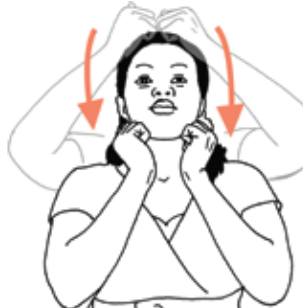
ARVs

Imiti igabanya ubukana
ARV



VCT

Ikigo gipima ku bushake
Virusi itera SIDA
CDV



Condom/ Agakingirizo
Préservatif



Circumcision/ Kwisiramuzo/
Circoncision



Tested positive/
Waranduye/
Testé Positif



Negative
Ntiwanduye
Négatif



Recapitulation

Working with people involves establishment of good relationships which only comes about through good interpersonal skills. One good way you could carry persons with disabilities along in works or programs that include them is to have a good knowledge of interpersonal skills that are sensitive to disability issues. Like any other persons, persons with disabilities are glad and ready to work with persons who have a good knowledge of disability. Moreover, a good understanding of disability is essential for addressing stigma which is the root of social exclusion of persons with disabilities in all facets of life.



Exercise:

Demonstrate how you will guide a person who is blind to his/her seat
What things are you to remember when you meet a client who is deaf?

Party IV: Disability Inclusion

Time: 45 minutes



Exercise:

- Ask trainees what the word 'inclusion' suggests to them;
- Facilitate a discussion on inclusion using participants' responses and facilitator's notes;
- Ask participants if they had ever met or related with persons with disabilities before.

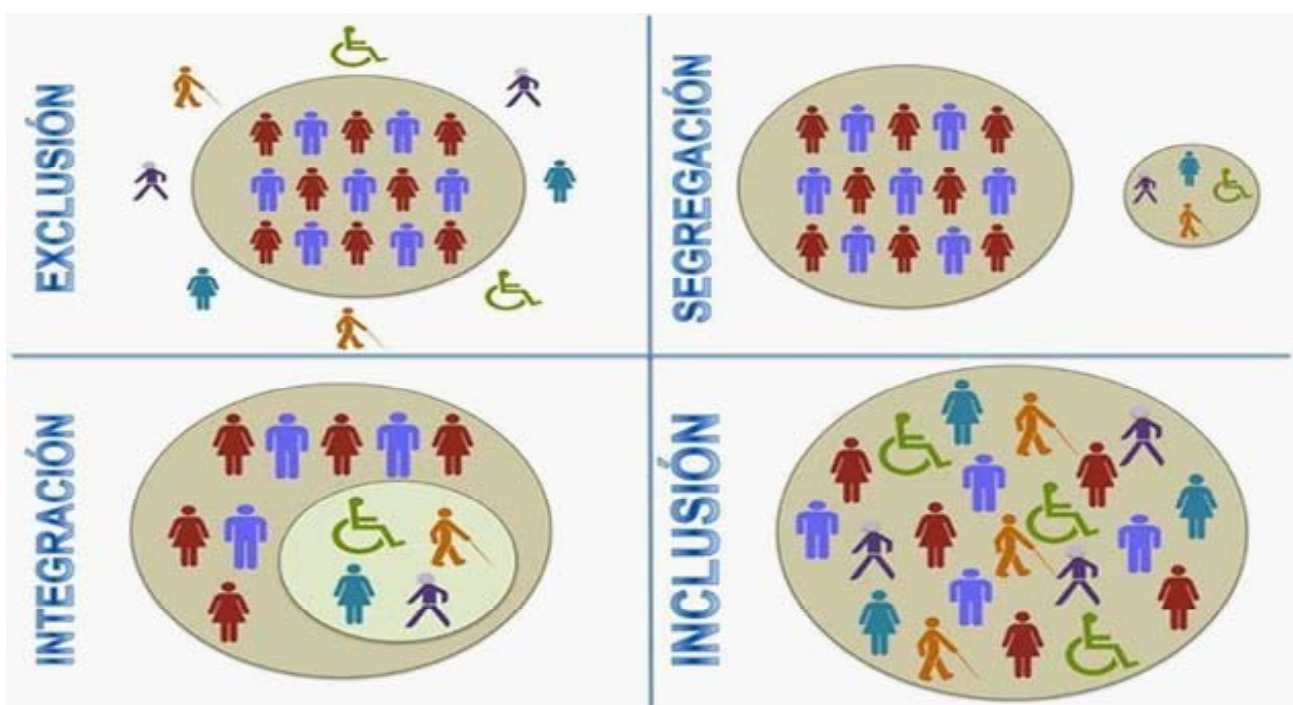


Guidance:

Give a card to each participant. Encourage participants to write their beliefs, feelings, reactions, thoughts the first time they met persons with:

- a. Intellectual impairments;
- b. Mental impairments;
- c. Physical impairments;
- d. Vision impairments;
- e. Hearing impairments.

Post the cards on the wall under each type of impairments and let participants take a look as if it were in a gallery.





Exercise:

Ask participants to distinguish between disability mainstreaming and disability inclusion



Guidance:

Encourage participants to come up with reasons why disability mainstreaming and/or inclusion efforts may fail



Exercise:

Ask each participant to mention one example each of a mainstreaming activity and a tailored activity.



Guidance: Write responses in flip chart for participants to see

4. 1. Inclusion

Inclusion is:

- Ensuring that everybody is involved i.e. no person is left out for any reasons
- Equality of opportunities;
- The needs of everybody is taken care of irrespective of age, gender, disability, religion, race, sexual orientation etc;
- The rights of all persons, particularly groups that face discrimination and exclusion are recognized.

Inclusion is about everybody. So, it is not unique to persons with disabilities. But disability inclusion implies equal opportunities for all persons in spite of disabilities. It means persons with different impairments should be able to participate in every aspect of life e.g., education, employment, health, basic services regardless of their impairments.

Therefore, inclusive development ensures that persons with disabilities are recognized as rights-holding equal members of society, whose needs and concerns are addressed in the design, implementation and evaluation of all policies, projects/programs at all levels.

4. 2. Models of disability

- These are frameworks that explain the lenses with which we view and understand disabilities;
- They also give us an understanding of how persons with impairments experience disabilities in their day to day activities;

- In addition, they provide a reference for society as laws, regulations and structures are developed that impact on the lives of persons with disabilities;

There are four principal models:

- Charity model;
- Medical/individual model;
- Social model;
- Right based model;

However, it is possible to find variants of these four models such as the charity, religious, and rights model. The ‘rights model’ is derived from the social model, whereas the first two are derived from the medical model of disability.

Charity model



This so-called charity approach sees people with disabilities as victims of their impairment. People with disabilities are to be pitied and need our help, sympathy, charity and welfare in order to be looked after. This old approach solved the problem of disability by creating special schools and special welfare programs for persons with disabilities. Sometimes people with disabilities themselves adopt this concept, in which case they usually feel ‘unable’ and have a low sense of self-esteem.

This guide will show what it means for organisations to work from a rights-based perspective on disability. We will explain how the medical and charity approaches, deeply rooted in our thinking, can be overcome.

Medical/individual model



Under the medical model, disability is seen as:

- A problem with the individual;
- It is as a result of the impairment;
- The person is considered to be sick;
- A personal tragedy;
- A life not worth of living;

As a result, the medical professionals decide what kind of life is fit for the person. Medical diagnoses are used to decide access and rights to:

- Housing/living conditions e.g., institutional life;
- Education e.g., special schools placement;
- Employment;
- Leisure;
- Transport;
- Parenthood e.g., forced sterilization, child custody;

Ultimately, the individuals are not allowed to participate in decisions that affect their lives. Others make the decisions for them. The individuals are DISEMPOWERED!

So, activities are directed towards making persons with disabilities conform to the socially constructed 'normalcy' by 'fixing' them. They must be cured or rehabilitated to function like non-disabled persons e.g., a polio-survivor may be forced to use crutches and calipers so that s/he can climb steps like non-disabled when actually s/he feels more comfortable or safer using a wheelchair, forced psychotherapy for a person with mental impairment against his/her will. In summary, the individual has to ADAPT to the society.



Tips:

Any views of disability that emphasize: impairments, sickness, weakness, pity, dependence, a life not worth living, persons with disabilities have to adapt to society, persons with disabilities are a burden is adopting the medical model of disability or its variants. This is UNACCEPTABLE!

Social model



The social model attributes disability to attitudinal, environmental and institutional barriers that persons living with impairments face in society e.g.

- Prejudices and/or discriminations against persons with disabilities;
- Lack of printed information in Braille;
- Lack of ramps and/or elevators where there are steps;
- Lack of sign language interpreters;
- Lack of inclusive policies.

Using the social model promotes:

- Access to basic services and rights are not under the control of the medical professions;
- Persons with disabilities are consulted by service providers to know how to meet their needs at all stages of project;
- Persons with disabilities are 'subjects' and 'drivers' of issues related to them;
- The principles of 'nothing for us without us' and EMPOWERMENT are upheld.

As a result, activities focus on removal of barriers that exclude persons with disabilities from the mainstream of life. The society adapts to persons with disabilities by putting inclusive policies in place, mainstreaming disabilities in programs/projects, providing tailored interventions. By adopting the principle of universal design for all, creation of new barriers could be avoided.

Is the social model completely against medical model?

No! Persons with disabilities recognize the fact that medical treatment/services or rehabilitation may be needed at one time or the other. But such should not be forced on them. Persons with disabilities should have freedom of choosing medical or rehabilitation services or not.

Right based model



The new rights-based perspective on disability emphasizes that persons with disabilities are often prevented from reaching their full potential not because of their impairment, but as a result of legal, attitudinal, architectural, communication and other discriminatory barriers. Persons with disabilities should be recognized and accepted as full and equal members of society who have important contributions to make to their families and communities, and have a right to access all basic needs – including schooling, health services and rehabilitation services. This new approach aims to give people with disabilities access to regular development programs, rather than organizing special programs exclusively for persons with disabilities.

The new understanding about disability challenges the more traditional viewpoint that disability is a strictly medical problem that needs to be addressed. In this medical approach the only focus is on ‘curing’ the disabled individuals to fit them into society. The issue of

disability is limited to the individual in question: the disabled person has to be changed, not society or the surrounding environment.

According to the medical approach, persons with disabilities need special services, such as special transport systems and welfare social services. For this purpose, special institutions exist: for example, special schools or sheltered employment places where professionals such as social workers, medical professionals, therapists and special education teachers determine and provide special treatment, education and occupations.

The new rights-based approach also challenges the viewpoint that persons with disabilities should be objects of charity, unable to lead their own lives.

4. 4. Achieving disability inclusion

To achieve disability inclusion we need:

- Removing barriers that exclude people from social participation (through mainstreaming and disability-specific interventions);
- Legislation (national and international) on disability inclusion;
- Formulating inclusive policies;
- Promoting facilitators e.g. ;
- Networking with DPOs and disability organisations;
- Putting disability policies in place;
- Implementing existing disability policies and laws;
- Using gendered and disability (disaggregated) indicators in all phases of Programs / projects;
- Disability monitoring and evaluation;
- Disability budgeting;

4. 5. Differences between disability mainstreaming and disability inclusion

The main differences between disability inclusion and disability mainstreaming includes but not limited to:

- Disability inclusion is a goal to ensure that persons with disabilities are not left out. It is a purpose that we set to achieve by putting mainstreaming activities/process in place and tailored interventions when necessary;
- Disability mainstreaming is a process that is continuous in order to reach a goal (i.e. inclusion). This process entails assessing the implications for persons with disability of any planned action, including legislation, policies and programs, in all areas and at all levels;
- Disability mainstreaming is one of the strategies for achieving disability inclusion. It involves making the concerns and experiences of persons with disabilities an integral

part of the design, implementation, monitoring and evaluation of policies and programs in all political, economic and societal spheres so that persons with disabilities benefit equally and inequality is not perpetuated.

Mainstreaming and/or disability inclusion may fail due to:

- Lack of institutional support for mainstreaming and/or inclusion;
- Failure to communicate policies;
- Failure to break down traditional attitudes to disability;
- Lack of practical guidance;
- Inadequate resourcing e.g., budget, trained staff.

International and national legal instruments for disability inclusion

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

The UNCRPD is the most recent and comprehensive international legal instrument for ensuring equality of rights and opportunities for persons with disabilities.

About the UNCRPD

- Adopted in December 2006;
- Opened for signature in March 2007;
- It is legally binding on countries that ratified it;
- Violation of any aspects of the instrument by any countries that ratified it can be challenged at the International Court of Law;
- It identifies the rights of persons with disabilities;
- It is based on the social model of disability.

The UNCRPD is anchored on 8 principles:

- Respect for inherent dignity, individual autonomy, including the freedom to make one's own choices, and independence of persons;
- Non-discrimination;
- Full and effective participation and inclusion in society;
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- Equality of opportunity;
- Accessibility;
- Equality between men and women;
- Respect for the evident capacities of children with disability and respect for the right of children with disability to preserve their identities.

It has 50 articles in Convention and 18 articles in Optional Protocol e.g.

- Article 5 on equality and non-discrimination;
- Article 6 on women with disabilities;
- Article 7 on children with disabilities ;
- Article 8 on awareness-raising;
- Article 9 on accessibility;
- Article 25 on health;

Particularly, for the sake of this manual we will introduce the main components of the article 25 of the UNCRP as far as the sexual and reproductive health of PWDs is concerned:

- (a) Provide PWDs with the same range, quality and standard of free or affordable health care and programs as provided to other persons, including in the area of sexual and reproductive health and population-based public health programs;
- (b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
- (c) Provide these health services as close as possible to people's own communities, including in rural areas;
- (d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;
- (e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
- (f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

Rwanda, disability and health

In 2007, Rwanda enacted a law protecting persons with disability in general where it provides:

- Article 14: The Government shall facilitate a disabled person in getting medical care and prosthesis and orthosis appliances if required;
- Article 15: The Government has an obligation to provide medical care to a needy disabled person and it shall provide prosthesis and orthosis appliances if required;
- Article 17: An order of the Minister in charge of Health shall determine the modalities of facilitating the disabled persons in matters related to receiving medical care and getting prosthesis and orthosis appliances.

In 2009, the decree of the Ministry of Health determines the modalities of facilitating persons with disabilities access Medical care. So far in the Health Sector, PWDs are considered in the following policies and strategies:

- Disability is considered in the Health Sector Strategic Plan III (HSSP III);
- Health Sector Policy recognizes disability needs;
- National Strategic Plan on HIV&AIDS (NSP) acknowledges that PWDs are among vulnerable groups to HIV&AIDS;
- Health Promotion Policy and Strategy;



Recapitulation

In this session, we have taken a look at the concept of inclusive development; models or framework for explaining how persons with impairments can experience disabilities; how disability inclusion can be achieved; difference between mainstreaming and inclusion and reasons why mainstreaming and/or disability inclusion efforts can fail. We also examined international and national legal frameworks for achieving disability inclusion.



Exercises:

Mention at least three things that you know about inclusive development

Distinguish between the medical and social models of disability

State the strategies for achieving disability inclusion

What is the difference between disability mainstreaming and disability inclusion?

Mention three principles of the UNCRPD

Party V: Disability and HIV&AIDS



Time: 40 minutes



Guidance:

Ask one participant to read the story and act the story while other participants to list key themes in the stories

First, let us introduce Robert a man who was disabled by polio at a young age and now walks with crutches and works at a protective workshop sewing cloth bags, clothes and other orders. He is involved in a love relationship with his girlfriend Nadia who is deaf from birth.

Our story will help guide you through this book. We hope that it will make learning about HIV/AIDS a bit easier for you. But if there's ever a part that you don't understand, don't feel shy to ask someone to explain it more. You should never feel shy to ask questions!

If you think about it, the fact that I use crutches, might only mean that I have very strong arms and big muscles, and Nadia's deafness could only mean she feels music instead of hearing it! This might just make us especially interesting people! But instead, a label of disability often makes others think they know how we are; they think we are somehow less valuable than non-disabled people. They are so wrong. People have all kinds of bodies, and what we label as disabilities can be just ordinary ways for human bodies to be. In fact, the way we treat each other can cause many disabilities and the way we build our communities can be disabling for all kinds of bodies!

I'm waiting in a queue at my local day hospital, listening to a health worker making a presentation on HIV/AIDS. This is so important to me, because I'm tired of prejudice directed at me just because I'm disabled. I need to fight against discrimination that we face around economic, health, sexuality issues – even around issues concerning HIV/AIDS. I have a lot of questions.

Robert (Surprised): “Madam/Sir, I am now 27 years old, 20 years being disabled. I have so many questions when it comes to the issues of disability and HIV/AIDS because since its discovery here in Rwanda many educational programs were scaled up to prevent the

spread of this virus, yet, I never heard anything or anyone speaking to the disabled, let alone having materials for people to read if they are visually impaired! This brought me to a conclusion that, only non-disabled people can get infected with this virus and, as for the disabled, we are immune to it. In fact the community believes that because we are disabled we can't be at risk of getting infected, is that so? I'm sorry to cut you short in your session; I just need some clarity there. Are we at risk of getting infected with HIV/AIDS? Can you give me those risk factors? Can I share this with you? Me and my girlfriend we are both disabled, she is Deaf and I'm on crutches but we do make love to each other what chances are there that we can get infections? Now think about other forms of disabilities..."



Exercise:

Are disabled people at risk of HIV infection?

5.1. Disability and HIV&AIDS: What is the Link?

- PWDs are among the poorest, most stigmatized and most marginalized of all the world's citizens;
- Disability and poverty form a vicious circle;
- Conditions of poverty such as poor nutrition and lack of access to health services or safe living and working conditions create disabilities that can occur from birth to old age;
- After the onset of a disability, barriers to health and rehabilitation services, education, employment, and other aspects of economic and social life can trap people in a cycle of poverty⁵ (Elwan 1999);
- Too often, individuals with disability have not been included in HIV prevention and AIDS outreach efforts because it is assumed that they are not sexually active and are at little or no risk for HIV infection;
- Individuals with disability have equal or greater exposure to all known risk factors for HIV infection;
- HIV messages and communication are often inaccessible to people who are blind or deaf;
- And health service facilities are often not accessible to people with physical disabilities;
- PWD in many countries, report being turned away when they are able to reach HIV testing centers or health facilities;
- Frequently, PWD report that they are told to go home by health staff, who assures them that disabled people "cannot get AIDS";
- Due to lack of life skills PWD especially WWD to discuss our sexuality with partners or caregivers, negotiating for safer sexual practices or getting information on sexual health from health care facilities;

5 Ann Elwan, Poverty and Disability: A survey of the literature, December 1999

- YWD and WWD lack particularly information on HIV&AIDS;
- Parents of YWD think they don't develop sexually;
- Special schools and centers lack of adequate information and skills on sexuality and reproductive health programs;
- PWD especially YWD, those with severe disability live in isolation exposing them to rape and sexual assault;
- Dependence for YWD, WWD, Mental, Deaf and Blind may lead to rape and sexual assault⁶;

5.2. Disability, gender and HIV& AIDS



Exercises:

Ask participants to distinguish between sex and gender.



Guidance:

Each person should be given two meta-cards of different colors and asked to write what s/he understand by the term 'sex' in one card and the term 'gender' in the second card. Display participants' responses on 'sex' on one side of a wall and responses on 'gender' on the other side of a wall.

With the participants, discuss the differences between sex and gender.

Exercises:

Ask each participant to mention the roles that are expected of men/women in communities.



Guidance:

Men should focus on roles expected of them while women focus on roles expected of women.



Exercises:

Ask participants to reflect on why it is necessary to have gender perspectives within HIV and disability programming.



Guidance:

Lead a discussion to highlight the importance of gender perspectives using participants' responses and facilitator's notes.

⁶ WID in collaboration with CHCS/KPF/CHF, Treating Adults with Physical Disabilities: Access and Communication - A Training Curriculum for Medical Professionals on Improving the Quality of Care for People with Disabilities, 2005

5.3. Gender and disability (Disadvantages and double discrimination)

- Many cultures in Africa place less value on girls, and in the face of limited family resources girls with disabilities are more likely to suffer the effects of poverty more than non-disabled girls and boys with disabilities;
- Boys often viewed as potential breadwinners and hence given more priority in resource allocation than girls;
- In cultures where the only value placed on girls is that she will get married, girls with disabilities are less valued because they are perceived as non-marriageable;
- Girls with disabilities have the lowest participation in education globally and less knowledge of science, technology, engineering and mathematics subjects, the skills and knowledge of which can provide significant employment opportunities for girls with disabilities;
- Women with disabilities are almost twice more likely to be unemployed than men with disabilities. This can be traced to low literacy levels and negative attitudes of employers;
- Due to unemployment, women with disabilities are disproportionately poor as compared with non-disabled persons and men with disabilities;
- Persons with disabilities, particularly women and girls are viewed either as asexual, not in need of sex or hypersexual, which results in low self-esteem and also increases their vulnerability to sexual violence;
- Often perceived as sick, dependent, helpless, child-like and in need of constant care, women with disabilities are more likely than men with disabilities to be unmarried, married later or divorced earlier;
- Women with disabilities are often sterilized due to the fears that they will give birth to children with disabilities. This is not the case for men with disabilities;
- Women with disabilities are twice discriminated against - for being women and for living with disabilities;
- Lack of policies and programs for women and girls with disabilities;
- Lack of data on women with disabilities;
- Lack of research on the lives of women with disabilities;

5.4. Women with disabilities and HIV and AIDS

While both men and women can become HIV positive if they have unsafe sex, this section focuses on women for these reasons:

- More Rwandan women than Rwandan men are HIV positive;
- HIV is spread mostly through sex between men and women;
- Women can only have safe sex (sex with a condom) if their partner agrees to it;
- Many women are unable to influence their partner to use a condom;
- In many cultures, women are seen as less important than men. They are not able to make demands on men. For example, they may not be able to ask men to use condoms;
- Women usually have less money than men. This means that they have less independence;

- When people are sick with AIDS, it is usually women who care for them. Caring for a very sick person is stressful and means that women have even more work to do;
- Women face the threat of rape and sexual abuse. This means that they are at greater risk of getting HIV and AIDS;
- Women often find out they are HIV positive when they are pregnant. This is very hard for them as the HIV germ can be passed on to the baby during pregnancy, birth or breast-feeding;
- Because they find out this way, women are often unfairly blamed for “bringing” HIV and AIDS into the family.



Recapitulation

The session has helped us to understand the fact that gender is socially constructed while sex is biologically determined. We also looked at the consequences of gender roles on the lives of women. Additionally, the double disadvantage of women with disabilities is highlighted. Being female and disability are both discriminated against by our society. This added disadvantage has implication for higher risk of HIV infection among women with disabilities compared with their male peers and non-disabled women. HIV and disability programming, therefore have to be sensitive to issues of women with disabilities.



Exercise:

1. Differentiate between sex and gender;
2. What are the consequences of gender on the lives of women?;
3. Mention five issues relating to gender and disability;
4. Mention five reasons why you think it is necessary to have gender perspectives in HIV and disability programming;

References

1. National Institute of Statistics of Rwanda (NISR), Rwanda Population and Housing Census, 2012;
2. Handicap International (HI), Training of trainers manual on disability-inclusive HIV and sexual and reproductive health for health workers, 2011;
3. Rwanda Prime Minister Office (PMO), Law n° 01/2007 of 20/01/2007 relating to protection of disabled persons in general, 2007;
4. Rwanda Prime Minister Office (PMO), Ministerial order n°20/19 of 27/7/2009 determining the modalities of facilitating persons with disabilities access medical care, 2009;
5. WID in collaboration with CHCS/KPF/CHF, Treating Adults with Physical Disabilities: Access and Communication - A Training Curriculum for Medical Professionals on Improving the Quality of Care for People with Disabilities, 2005.



Appendices

EVALUATION FORM

1. After completing the training, did you gain a better understanding of the health care needs of people with disabilities?

_____ Yes _____ Somewhat _____ No

Comments:

2. Do you think the training adequately addressed essential issues and barriers to serving this population?

_____ Yes _____ Somewhat _____ No

Comments:

3. Do you feel more confident in addressing medical issues for patients with disabilities (select one)?

_____ Very confident

_____ Somewhat confident

_____ Not confident

_____ Have difficult working with this population

_____ Other (please explain) _____

4. After this training, do you think you have improved knowledge to facilitate the following:

(select “yes” or “no”)?

