HIV/AIDS AWARENESS AND DISABILITY RIGHTS TRAINING MANUAL

PREPARED BY
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and
MIRACLES IN MOZAMBIQUE

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FOREWORD

This manual provides information on disabilities, HIV/AIDS, disability rights, HIV/AIDS advocacy and leadership skills. It is intended to facilitate more inclusive training, outreach and practices on these issues. The information contained here is specifically intended to broaden the knowledge of emerging leaders in the disability community and young people with disabilities. It is also intended to be used by HIV outreach workers to improve the dignity and well being of those to whom they provide services. I trust that this manual will be helpful to individuals who work in both the fields of disability and HIV/AIDS advocacy and prevention in every society throughout the world, especially since until now, few AIDS organizations have reached out to the disability community on the issue of HIV/AIDS.

With the adoption of the new UN Convention on the Rights of Persons with Disabilities, it is important that all persons know their rights and have equal access to information about their health and other facets of life. We hope this manual will help encourage greater understanding of disability rights and broader implementation of the Convention.

In order to ensure wider application of this manual to persons with disabilities who have special communication needs, it is hoped that it will be put into different accessible formats and be translated into different languages. I trust the manual will make a positive contribution not only to people with disabilities but also to the general population.

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Gidion Kaino Mandesi
December 2007
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This manual is intended as a guideline only and the authors and contributors are not legally responsible for any errors or omissions.
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LIST OF ABBREVIATIONS

AIDS    Acquired Immunodeficiency Syndrome
DOLASED Disabled Organization for Legal Affairs and Social Economic Development
DPOs    Disabled Peoples’ Organizations
HIV     Human Immunodeficiency Virus
PLWA    People Living with AIDS
PWDS    People with Disabilities
STIs    Sexually Transmitted Illnesses
UN      United Nations
WHO     World Health Organization
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INTRODUCTION

i. Overview of the Manual

This manual provides information on the steps to effectively train people with disabilities (PWDs) as well as non-disabled people in three areas: information about disability and HIV/AIDS, the impact of HIV/AIDS on the disability community, and disability rights and leadership skills. This guide seeks to provide a framework in which the trainer can learn more about disability issues and highlights useful techniques and tools to train individuals and Disabled Peoples’ Organizations (DPOs) on HIV/AIDS. It does not give all the answers to participants’ concerns, but it should serve as a guide toward finding a better way of introducing HIV/AIDS related issues to the target audience, especially emerging leaders and young people with disabilities.

The conception of this manual is based on the recent baseline survey on Disability and HIV/AIDS conducted by DOLASED (Disabled Organization for Legal Affairs and Social Economic Development) in Mozambique and Tanzania, which assessed the extent to which people with a disability are aware of the risk of getting HIV/AIDS and how they view the societal attitude towards disability concerning human rights, education, health and other social rights.

This manual is divided into two parts and would ideally be presented in a two-day training session. Part one presents materials for training on issues related to disability and HIV/AIDS and part two deals with issues related to advocacy on disability rights and strengthening disability leadership skills. At the end, participants should be able to answer the following questions:

1. What is disability and what are some common types of disabilities?
2. What are some effective ways to communicate with people with different types of disabilities?
3. What is the difference between HIV and AIDS?
4. How is HIV/AIDS transmitted?
5. What are some risks factors surrounding persons with disabilities in relation to HIV/AIDS?
6. What are the most effective ways of preventing HIV/AIDS?
7. Why is it important to have HIV/AIDS testing and counseling?
8. What are the effects of stigma and disability-based discrimination on people living with HIV/AIDS?
9. How can we reduce the social stigma associated with HIV/AIDS and disability?
10. What rights do persons with disabilities have at the international and regional levels?
11. What is advocacy?
12. What are the suggested steps in carrying out a successful advocacy campaign?
13. What are some basic principles of leadership?
14. What are some facilitation tips to assist in conducting training?

ii. How to use this Manual

This manual is intended for trainers who are focusing on the capacity building and leadership of DPOs and raising awareness among HIV/AIDS outreach organizations. These materials are based on the experiences of two countries, Tanzania and Mozambique, and the disability organizations therein, but may be adapted to the circumstances in other countries in Africa and worldwide. You may need additional teaching materials in accessible formats for different categories of persons with disabilities as well as flipcharts with colored markers, a blackboard with colored chalk (if possible) or, if available, projectors for power point presentations. Illustrations might be useful especially when the training is intended for illiterate groups and/or individuals with limited literacy skills.

The trainer is encouraged to use this manual in the most interactive way possible to make the contents understandable to participants or trainees. Instructions for
the trainer are included in a textbox for ease of reference. Suggested time frames are also provided in Annex C to help guide the schedule of the training.

iii. Who should use this Manual?
This manual is intended to impart useful information to people in the disability community, government officials involved in disability and HIV, community leaders, and persons working for HIV organizations. The format of this manual was developed to provide a comprehensive guideline for conducting simple but clear capacity building on HIV/AIDS advocacy and leadership development. The terminology used here was developed to suit the needs of individuals with little or no basic literacy skills. It is especially important since many persons with disabilities are often educationally underprivileged.

This version of the manual is designed for the trainer. It guides the trainer/facilitator(s) to prepare training materials for the participants.

iv. Preparation for the Training
It is important to become familiar with this manual before conducting training and to consider how it should be modified to most effectively reach the target audience, keeping in mind cultural sensitivities and education levels. The core point is not the manual itself, but the way you will make use of this manual by adapting it into an understandable tool for your trainees.

Here are some other ways to prepare in advance of the training:
1. Learn about who the participants will be –including their backgrounds, age, disabilities and current knowledge of HIV/AIDS and disability issues.

2. Review the proposed training program in Annex C and modify the schedule depending on the participants, culture and other factors.
3. If the participants do not know each other, consider some exercises to get the participants to know each other better, so they will be more comfortable speaking and sharing their opinions. Some ideas are included in Annex D.

4. Learn about local and national legislation relevant to persons with disabilities – this will help in explaining part two of the manual.

5. Learn about the location of HIV/AIDS clinics in the area and whether they are accessible for persons with different disabilities. When possible, find out about clinics that provide free or low cost services.

6. Arrive at the training site at least one hour before the training will begin, to allow time to set up the room and organize the documents.

   - If possible, the participants should be seated in a circle or U-shape so that they can see each other as well as the facilitator.
   - Each participant should have a copy of the program as well the information in the manual (the participant’s version) so they can follow along and make notes.
   - Make every effort to provide the training materials in alternative formats (Braille, large print, CD, etc) and provide sign language interpretation, depending on the participants.
   - If possible, all participants should receive a notepad, pen/pencil and glass or small bottle of water.
   - The facilitator should have several flip charts or a chalkboard, and markers or chalk, as appropriate.
   - Write the goals of the training session on the flipchart or chalkboard. Also consider preparing flipcharts in advance of the questions to be answered at the end of each section and other important facts.
v. Introduction to the Training

- To start the training, introduce yourself as the trainer(s) and give an overview of the goals and the overall program – outlined in Annex C.
- If the participants are not known to each other, ask them to introduce themselves and their affiliation (organization) or other relevant information.
- To encourage the participants to speak freely and feel comfortable in the group, begin with an exercise such as the following:
  - Ask each participant to say two true things about themselves and one false thing – and ask the other participants to guess which statement is false.
  - Ask all participants to find a partner and interview them; then each participant must introduce their partner to the group.
    (Other exercises can be found in Annex D.)
- If the group is literate, prepare a sign up sheet with name and contact information, and circulate this list among participants.
- Give an overview of the goals of the training – you can also refer to the 12 questions that the participants will be able to answer by the end of the training.

Goals of the training:

1. To better understand the concepts of disability
2. To learn about HIV/AIDS and its impact on the disability community
3. To gain knowledge of disability rights, particularly the UN Convention on the Rights of Persons with Disabilities
4. To gain leadership skills to be a more active member of the disability community
PART ONE
RAISING AWARENESS
ABOUT HIV/AIDS
CHAPTER ONE

BASIC CONCEPTS ON DISABILITY INTRODUCTION

Ask one of the participants to read the objectives of this chapter. If the group is illiterate or unable to access the materials, read the objectives to the group. (5 minutes)

Objectives

By the end of this chapter, the participants will understand the following concepts:

• disability
• common types of disabilities
• challenges faced by people with different types of disabilities
• effective ways to communicate with people with different types of disabilities

1.1 Definition of Disability

Ask the participants how they define disability – write some of the ideas on the flip chart, if available. After hearing some responses, explain the definition of disability and where the definitions come from. Explain that you will go into more detail about the UN Convention and other laws relevant to persons with disabilities in Chapter 4 of the training. (20 minutes)

According to the international definition of disability developed by the World Health Organization (WHO), disability is a condition which makes an individual unable to function normally in a particular social-cultural context.

Currently, the United Nations (UN) Convention on the Rights of Persons with Disabilities, which was adopted by the UN General Assembly on December 13, 2006, expands the definition of disability to include those who have a long term
physical, mental, intellectual or sensory impairment which together with different social, economic or political barriers may make it difficult to participate in society like everyone else.

People with disabilities face numerous challenges to equal opportunities in day to day life. Environmental, physical, legal and institutional barriers are found throughout society, and people’s negative attitudes towards persons with disabilities often cause social exclusion and are the hardest to overcome. Persons with disabilities are often assigned a low social status and in some cases are considered worthless, viewed by those around them with feelings of shame, fear and rejection. There is also the common belief that people with disabilities are cursed or may place a curse on others. For people with disabilities to be treated equally, physical barriers AND attitudes need to change.

1.2 Access to Information for People with Different Disabilities

Ask participants about the different types of disability that they are familiar with. Then describe the seven (7) groups of disability that are addressed in this manual (in bold below) as well as effective communication strategies for each group. Be sure to explain the appropriate terms used to describe disability from a rights-based approach. (45 minutes)

In general, persons with disabilities are not reached through HIV/AIDS outreach for a number of reasons. First, there is also an issue with lack of accessible public transport facilities as well as access to health services when not accompanied by a family member. Also, since many people with disabilities do not attend school, campaign information needs to have a strong visual component in the case of limited literacy skills. One of the major challenges in sharing information about HIV/AIDS with persons with disabilities is to know how to communicate with them most effectively. There are several types of disabilities and the means of disseminating information differs from one group to another. In the context of HIV/AIDS, disability rights and leadership training, this manual
provides guidelines for effective communication with the following: people who are deaf or hard of hearing, people who are blind or have low vision, people who are deaf-blind, people with intellectual or developmental disabilities\(^1\), people with psycho-social disabilities\(^2\) and people with physical disabilities. In Tanzania and Mozambique, as well as throughout most of Sub-Saharan Africa (SSA), individuals who are Albinos are also considered a distinct disability group, and they will also be considered in this manual.

Challenges in reaching these groups include the following:

(i) People who are deaf or hard of hearing
- Deaf people do not have access to radio campaigns and TV advertisements on HIV/AIDS since these media often lack sign language interpretation.
- Lack of privacy and confidentiality is another challenge that this group faces, as sign language interpreters or family members who sign, have to be around when deaf persons are being counseled.
- Sign language interpretation can be very expensive and often there are few or no sign language interpreters available.
- It is difficult to ask for or buy condoms when there is no interpreter.
- Because of difficulties in communicating with others, this may make them more vulnerable to verbal and sexual abuse.

(ii) Persons with visual impairments
- Audio tapes are rarely available to help visually impaired persons to access information.
- Information on ink print is not translated into Braille.

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\(^1\) The term “mentally retarded persons” is no longer used by the international disability movement. Nowadays, the preferred term is “a person with an intellectual or developmental disability”. These new terms are also found in the text of the International Convention of the Rights of Persons with Disabilities adopted by the UN in December 2006.

\(^2\) The term “psycho-social disability” is the human rights approach to what has previously been called “mental illness”.

Many people do not even have access to learning Braille in the first place due to limited education opportunities.

Billboards do not reach visually impaired people.

(iii) People who are deaf-blind

- More vulnerable to outside dangers, including physical and sexual abuse, because cannot perceive most visual or auditory cues—i.e. a person coming up behind them.
- More vulnerable to abuse, as it is harder to defend oneself without visual or auditory assistance.
- More dependent on outside factors (i.e. guide dog, interpreter, human guide) to get around in the outside world and society.
- Braille is the most efficient way of communicating and many texts are not translated into Braille.
- Cannot take advantage of most information campaigns because such campaigns usually use approaches that are not accessible to the deaf-blind, i.e. radio announcements or television ads
- Difficulty communicating often isolates people who are deaf-blind from others
- Traveling alone poses many more obstacles and problems, making it harder to get to health centers

(iv) Persons with intellectual or development disabilities

- Lack of simplified language often makes it difficult for members of this group to understand HIV/AIDS related issues.
- Complex or vague messages, as well as lack of simplified discussions about HIV/AIDS often does not allow this group to understand the issues involved and how this directly effects them.
- Persons with intellectual or developmental disabilities may not be allowed to travel by themselves, leading to a lack of freedom and privacy.
- More vulnerable to verbal and sexual abuse.
(v) **People with psycho-social disabilities**
- May feel more isolated because they feel as though they cannot connect with other individuals, making them more vulnerable to verbal and sexual abuse.
- Fear of ostracism may discourage them from seeking help in a public place.
- People with certain psycho-social disabilities (i.e. depression) may suffer from inactivity, making it harder for them to seek help outside their home.
- Some individuals with psycho-social disabilities have a more limited ability to handle social situations, placing more stress on the individual and possibly leading to withdrawal from social activity.
- Is often the least “visible” form of disability, which can cause problems in terms of societal recognition that the individual is suffering from a disability, as well as allowing people with these disabilities to avoid seeking assistance.

(vi) **People with physical disabilities**
- Inaccessibility of health facilities is the main problem.
- There is often a lack of mobility aids such as wheelchairs, canes, walkers, etc. to allow people to travel to community clinics and HIV/AIDS testing centers, as well as to places where public talks on HIV/AIDS are being given.
- Long distances and lack of accessible transportation or the ability to walk to health facilities purchase condoms on their own, are another problem.

(vii) **Albinos**
- Poor eyesight often makes reading difficult and small print is a particular problem for this group.
- Direct sunlight affects the skin and eyes of albinos, making it difficult to take prolonged travel to health facilities or public gatherings where AIDS is being discussed.
Albinos also face significant social stigma in some communities.

1.3 Communication Strategies for Persons with Different Disabilities

There are different ways in which you can effectively communicate with different groups of people with disabilities. These include the following:

(i) **People who are deaf or hard of hearing**
- Prepare visual, written and poster material with well trained sign language interpreters.
- Ensure that video and television advertisements are accompanied by sign language interpretations or captioning.
- Train some counselors to master sign language in order to foster privacy in health services facilities.

(ii) **Persons with visual impairments**
- Develop audio materials with HIV/AIDS information.
- Translate information on disability and HIV/AIDS from ink or typed print to Braille.
- Facilitate human readers to assist blind people to read ink or typed writing.

(iii) **People who are deaf-blind**
- Translate information on disability and HIV/AIDS into Braille.
- Create a network of human readers to interpret information to deaf blind.
- Create more interactive lessons based on things that can be touched to further involve them.

(iv) **People with an intellectual or developmental disabilities**
- Simplify information on disability and HIV/AIDS.
- Develop information on disability and HIV/AIDS in picture form.
- Provide information on HIV/AIDS in places other than health centers.
(v) **People with psycho-social disabilities**
- Conduct individual counseling or trainings rather than larger group sessions.
- Create smaller, more intimate, non-threatening environments.
- Adapt the learning environment to the specific needs of individuals who are otherwise hard to reach.
- Distribute information through many different types of media in order to reach those suffering from depression or people who have not looked for medical care.
- Conduct smaller group training sessions with persons suffering from the same or similar psycho-social disabilities.

(vi) **People with physical disabilities**
- Build ramps to enter testing centers, seminar rooms and other relevant places or move such activities to more accessible locations, such as a lower floor in the same building or a room in a nearby building.
- Provide bigger treatment rooms, training classrooms, etc and restrooms that are wheelchair accessible.
- Provide information on HIV/AIDS in places other than health centers.

(vii) **Albinos**
- Print information on disability and HIV/AIDS in large fonts.
- Develop audio tapes on disability and HIV/AIDS.
- Provide training venues which are not exposed to direct sunlight.
- Hold clinics in early evening to allow individuals to travel without walking for long periods or standing for a long time in sunlight in the middle of the day.

To conclude this chapter, ask the participants to answer the questions below.
*(15 minutes)*
End of Session

1. What is disability?
2. What are some common types of disabilities?
3. What are some effective ways to communicate with people with different types of disabilities?
CHAPTER TWO

UNDERSTANDING THE TRUTH ABOUT HIV/AIDS

Ask one of the participants to read the objectives of this chapter. If the group is illiterate or unable to access the materials, read the objectives to the group. (5 minutes)

Objectives

By the end of this chapter, the participants will understand the following concepts:

- the difference between HIV and AIDS
- how HIV/AIDS is transmitted
- risks factors surrounding persons with disabilities in relation to HIV/AIDS
- effective ways of preventing HIV/AIDS
- why it is important to have HIV/AIDS testing and counseling

2.1 The meaning of HIV

Ask the participants to discuss what they know about HIV/AIDS. (10 minutes)
Then explain the meaning of HIV and AIDS and allow participants to ask questions if the difference is unclear. (30 minutes)

HIV stands for Human Immunodeficiency Virus. This virus attacks important blood cells (known as CD4T lymphocyte or T cells), which help the body to fight sickness. As these cells die, the body becomes more and more likely to get diseases. The infection progresses over the course of time and once the rate of T cells becomes low enough, the name that health care workers give to the disease changes from HIV to Acquired Immune Deficiency Syndrome or AIDS.

Most people are unaware that they have been infected with the HIV virus. Although a certain number of people report flu-like symptoms for several weeks
after the infection has occurred, they will often feel fine for several years or longer. The HIV virus is very slow to progress in some people and it may be a number of years before they begin to feel sick. In other people, the virus moves much more rapidly and they may begin to feel sick within a year or two of being infected.

Once a person gets the infection, the person is said to be ‘HIV+’ or ‘HIV-positive’ and it is possible for the person to spread the infection to others. Therefore, it is important for ALL people to get a blood test for HIV/AIDS to check for possible infection. Only blood tests can tell if someone with or without a disability is infected with HIV. It is important not only for others but also for yourself, because if you know you are sick, there are ways to keep yourself as healthy as possible, and there are now medicines that can help prolong life. It is important to remember that the virus may take some time to show up in your bloodstream, so a test right after possible exposure will not necessarily accurately show whether the virus has been contracted.

2.2 The meaning of AIDS
AIDS is a disease caused directly by the HIV virus and it is the last stage of the HIV infection. The disease affects the body’s ability to fight off sickness, leaving the individual vulnerable to a wide range of infections. In one person, the virus may cause them to be more likely to catch tuberculosis (TB). In another case, an individual may have to battle various types of infections of the mouth and throat, brain or stomach. While the virus is the same in all these individuals, AIDS is called a syndrome because it affects different people in different ways. People living with AIDS (PLWA) are those who are infected either with HIV or AIDS.
2.3 Incorrect Beliefs about HIV/AIDS

There are common misunderstandings about HIV/AIDS, which are difficult to get correct because they are widespread in society. Some of these misunderstandings come from traditional beliefs, including:

- Belief that the HIV virus is the result of sin
- Belief that white people brought HIV/AIDS to Africa
- Belief that HIV is in condoms
- Belief that God is punishing you so there is no cure
- Belief that Muslims do not get HIV
- Belief that persons with disabilities are safe from HIV/AIDS infection
- Belief that sex with persons with disabilities (who everyone thinks are virgins) can cure HIV/AIDS

It is very hard to face the fact that you or someone you love is infected with a very serious disease. Some people respond by saying that the HIV virus is different from the AIDS virus and that HIV does not lead to AIDS. Unfortunately, while different people will take different amounts of time to go from being infected with HIV to having AIDS, there is clear evidence that the two diseases are caused by the same virus and that HIV turns into AIDS.
2.4 Common Ways of Transmitting HIV/AIDS

Ask the trainees to discuss ways through which HIV/AIDS is transmitted. (5 minutes). Then review the common ways that HIV/AIDS is transmitted. (30 minutes)

According to the HIV/AIDS and Disability Manual prepared by Solidarity, Human Inclusion and Accessibility (SHIA) and the Government of Tanzania (2006), a person who is HIV-infected carries the virus in body fluids, including blood, semen, vaginal secretions and breast milk. The virus can be transmitted only if such HIV-infected fluids enter the bloodstream of another person. This can occur:

- During sexual intercourse through the linings of the vagina, rectum, mouth, and the opening at the tip of the penis;
- Through intravenous injection with a syringe;
- Through the transfusion of blood if the blood donor is infected.
- A baby may get the HIV infection from his or her mother either while in the womb, during delivery or after birth, or through breast milk.
- Through a break in the skin, such as a cut or sore;

- **Unprotected sexual intercourse (either vaginal or anal) with someone who is HIV infected**

Both men and women are at risk of getting the HIV virus through unprotected sex. Women are at somewhat greater risk of HIV infection through vaginal sex. However, the virus can also readily be transmitted from women to men. Anal sex (whether male-male or male-female) poses a high risk mainly to the receptive partner, because the lining of the anus and rectum are extremely thin and are filled with small blood vessels that can be easily torn during intercourse, thus allowing the other person’s bodily fluids to enter the bloodstream. If the condom breaks, you can be at risk of HIV and other infections. You should contact a doctor right away about emergency medicine.
- **Unprotected oral sex with someone who is HIV infected**
  Oral-genital contact also poses a clear risk of HIV infection, particularly when ejaculation occurs in the mouth. This risk is increased when one partner has cuts or sores, such as those caused by sexually transmitted diseases (STDs), recent tooth-brushing or canker sores. These sores can allow the virus to more easily enter through the bloodstream.

- **Sharing needles or syringes with someone who is HIV infected**
  Laboratory studies show that infectious HIV can survive in used syringes for a month or more. That is why people who inject drugs should never re-use syringes used by other people or share syringes or drug preparation equipment. This includes syringes used to inject illegal drugs such as heroin, as well as syringes used for the injection of steroids, vitamins or other medical uses. Syringes, such as those used for body piercing and tattoos, can also carry HIV.

- **Unsafe blood transfusion**
  When someone is sick, doctors sometimes give them a transfusion (blood from another person) to help them get well. In some places, a transfusion is also given to newborn children who look sick. The blood being given must first be checked to make sure that the person who donated this blood is not infected. If blood has any infections, it should never be used.

- **Infection during pregnancy, childbirth, or breast-feeding (Mother-to-child transmission)**
  Any woman who is pregnant or considering becoming pregnant and thinks she may have been exposed to HIV (even if the exposure occurred many years ago) should seek testing and counseling. Because of new medicines, mother-to-child transmission has been reduced to fewer cases each year in the Sub-Saharan region in Africa when pregnant women are tested for HIV and given the medication before or soon after the child is born. Unfortunately, the new medications will not rid the mother of the HIV virus, however, her child may be
saved from the disease and the new medications will also help the new mother remain healthy so that she can live to see her child grow.

When a woman has the HIV virus, there is also a concern that the virus may be passed along to her infant through breast milk when the child is breast-fed. However, poor women sometimes do not have the money to provide other types of food for their infants and many new mothers with the virus – poor or rich – worry that if they do not breast feed, others in their family or community will know that they are HIV-positive. This is a hard decision to make, but if you have the HIV-virus and give birth, it is important to talk to a health care provider to decide what is best of you and your baby.

➢ **Through a break in the skin, such as a cut or sore**

When someone who is HIV positive has an accident and has a cut or scrape in the skin, they are at risk of spreading the virus if their blood comes in contact with another person. Many times people can have very, very small cuts or scrapes on their own skin, which will allow the infected blood to come into their system. This can happen through many activities – helping someone who is injured (in sport, in car accident or child who falls down), or during a fist fight, among other ways. If you want to help someone who is injured, try to use plastic gloves. If these are not available, use a plastic bag or other protection that is available.

2.5 **Why the Disabled Population is at risk of getting or spreading HIV**

Ask the trainees to discuss factors that suggest why people with disabilities may be vulnerable to the HIV/AIDS epidemic. (10 minutes). Then inform the participants of some of the risk factors below. (20 minutes)

The following are some of the factors that have led to the vulnerability of persons with disabilities to the HIV/AIDS epidemic:

- **Practice unsafe sex**
Some persons with disabilities have sex without using condoms with their partners. This practice greatly contributes to the transmission of HIV/AIDS. In addition, having multiple sexual partners adds to the risks of getting HIV or other sexually-transmitted illnesses (STIs).

- **Lack of knowledge/education**

The baseline survey conducted by DOLASED in Tanzania and Mozambique in 2006 indicated that the majority of people with a disability lack substantial knowledge on HIV/AIDS. Many have not had the opportunity to go to school at all and many others have only been allowed to finish primary school. Therefore, reading and understanding complicated explanations about how HIV/AIDS is caught and spread can be very confusing. Information on condom packages may also be difficult to understand if not in accessible formats. This situation puts persons with disabilities at risk of getting HIV since they do not fully understand HIV/AIDS and are less likely to get tested or seek counselling.

- **Lack of accessibility**

Movement from one place to another may be difficult and for people with physical disabilities, it is not possible to travel by foot to the health facility and find transport, especially in rural areas. People who are
blind or are Albinos may also face challenges in accessing health facilities.

It may also be difficult for persons with disabilities to reach the testing and counselling centres for HIV/AIDS because those health centres are often not accessible (for example, with steps and high verandas).

Persons who are deaf face problems because of the lack of confidentiality and lack of information about HIV/AIDS in accessible formats (such as video with closed captioning). Most people working in the health centres or hospitals do not know sign language so it is difficult to communicate and explain how one feels. If the deaf person brings a family member or friend who can assist with communication, the deaf person loses some of his/her privacy and may not be able to speak about all of his/her problems openly and honestly.

- Poverty

Poverty makes it very difficult for persons with disabilities to fight against the pandemic, especially since they often cannot afford education, and even buying condoms is too expensive for some – putting both themselves and their sexual partners at continuing risk. If infected with the HIV virus, poverty also limits access by people with disabilities to medications, healthy diet and other measures that enables them to keep them healthy once they are infected.

A young male student had sex in the toilet with a fellow student. After learning about this, the young woman’s parents asked the young man about what had happened. He explained that he was convinced by the lady to have sex after she had regularly touched his penis and that the sex was consensual – both partners were willing. The male student was asked if they had used a condom to prevent HIV or other Sexual Transmitted Diseases (STIs). The boy said he did not use a condom since condoms were not available and even if the condom were made available he had no money to buy them.
- Societal perceptions
Many persons with disabilities are highly at risk of being raped because they are seen as powerless, especially those with physical and intellectual disabilities as well as deafness and blindness.

HIV can also be transmitted to persons with disabilities because of beliefs that having sexual intercourse with a person with disability may lead non-disabled people to become rich or get jobs. Of particular concern is the belief that if a person has the HIV virus, having sex with a disabled person will cure them of the disease. Of course, this is absolutely NOT true, but it makes little difference to those who would abuse or take advantage of people with disabilities.

- Stigma
Stigmatization of persons with disabilities in most societies, especially in African societies, is very high. Persons with disabilities who have HIV/AIDS face double discrimination: first, because of their disability and second, due to HIV. The discrimination may be even worse where the person is a member of another disadvantaged or marginalized group. Therefore they are being isolated by other societal members and have little power to negotiate use of a condom or other forms of ‘safer sex.’ This is discussed further in Chapter 3. In addition, there is a common belief, even among those who work in the HIV/AIDS field, that disabled people are not involved in sexual relationships and therefore do not require testing or care.

“What I know is that HIV/AIDS is there and it is very dangerous. It can face every person without considering whether he/she has a disability or not. What we could do to escape HIV is to take care of (ourselves) by escaping other guys who pretend to be with us because they believe that girls with a disability are safe. I know that some guys have no true love for us.”
- Young deaf woman in Tanzania
- **Lack of necessary information**

Most persons with disabilities are not the target of HIV/AIDS outreach because many non-disabled people, including health care professionals, do not realize that persons with disabilities may be sexually active. As a result, public health efforts and mass media campaigns, as well seminars and lectures about HIV/AIDS, are often not accessible for people with disabilities.

Often, medical professionals and counsellors cannot communicate with individuals who are deaf, blind or deaf-blind because they do not know how to communicate effectively with people with different disabilities. They are also not aware that DPOs and other organizations are available to help them learn how to communicate more effectively. It should be understood that people with disabilities have a right to get education in accessible formats on the facts about HIV and AIDS since they are also vulnerable to the problem.

- **Poor laws and policies related to HIV**

Most policies do not favour persons with disabilities. Thus, laws should be enacted to promote awareness about the epidemic and encourage safer sex strategies and provision of treatment, care, and counselling specifically for persons with disabilities.

- **Lack of confidentiality**

People with disabilities often need assistance, which means they have little privacy particularly when getting information about HIV/AIDS or seeking testing. Deaf people need to have sign language interpreters and blind people need guides, whereas people with mobility problems need personal assistance when going to clinics and health centres. The people who assist persons with disabilities often are family members or friends from the community, who do not always keep what they hear confidential. Persons with disabilities, fearing such breaches of confidentiality, may be more reluctant to learn about HIV/AIDS or get testing or care.
The following groups are also very vulnerable to HIV/AIDS infections:

- Adolescents who have sex with older infected partners, including adolescents with disabilities.

- Men and women (including men and women with disabilities) who have sex with people who have untreated sexually transmitted diseases (STIs), such as syphilis.

- Women are at greater risk of physical exposure to bodily fluids during vaginal intercourse. Women are also at greater risk due to gender imbalances in the society. For example, women are often not allowed to insist that their sexual partner use condoms. This is particularly true for married women, even if they know their husbands are sexually active outside of the marriage. (And of course, women with a disability in these types of relationships are even less likely to be able to ask their partners to use condoms).

2.6 Voluntary Testing

Ask the participants if they know why they should get tested for HIV. (10 minutes) Then explain the reasons listed below, including what is the “window period”. (10 minutes)

HIV/AIDS counselling and testing is an important service to all individuals with or without disability in the community. Persons with disabilities in the community should benefit from all services provided to any other person.

A test is very important for finding out whether a person with or without disability has HIV. When the HIV virus enters the body, the body produces antibodies and
a simple test can show if a person has antibodies in his or her system. It is also important to remember that there is a period between the day the virus enters the body and the day the body starts to produce the antibodies,. This period is called the “window period” and it lasts for about 3 months. During this three month period, no HIV test can confirm if a person is HIV positive, but if the body is infected with the virus, the infected person can transmit the virus to others. In all cases of HIV testing, a second blood test should be performed in order to confirm the first test result after six months.

Ask the participants if they know where to go for voluntary HIV testing. Let them know about clinics for testing in the area (preferably free clinics). (5 minutes)

2.7 Counselling For Persons with Disabilities and HIV

Ask the participants to mention what they know about counseling for HIV and why it is important. (5 minutes) Then explain the reasons for counseling listed below. (10 minutes)

Counselling is face to face communication through a process of interaction between two or more people, during which the counsellor helps the person(s) to make decisions. It involves listening to people talk about their problems, giving them comfort and helping them work out what they want to do about their problems.

Counselling services should be provided in health settings in order to,

- Give support and advocacy
- Assist people to cope with problems (emotional, psychological, physical and social)
- Assist in solving problems, when possible
• Prevent or control problems
• Encourage change when it is needed
• Assist people to accept and act on information about health and well-being.

➢ Pre-conditions for successful counselling

Explain the three main conditions necessary for counselling to be effective, as described below. (5 minutes) Ask participants what they think about these conditions and if there are other conditions they would want for counseling. (10 minutes)

Counselling techniques will vary between social groups according to resources available and traditional ways of how help is sought and who is asked for help. However, there are a number of universal pre-conditions of successful counselling, influenced by culture, traditions and beliefs. These include:

(a) Acceptance - Everyone who is counselled in connection with HIV infection and AIDS should always be and feel fully accepted irrespective of lifestyle, past or current behaviour, or other characteristics.

(b) Consistency - All basic information about infection, transmission, risk of infection and risk reduction must be consistent and accurate.

(c) Trust and confidentiality - Confidentiality is a basic principle of counselling and trust is a crucial element of the relationship with the counsellor.

➢ Major types of HIV/AIDS counselling

Explain that there are two types of counselling – pre and post-test counselling – and what each of these involve. (15 minutes)
(i) Pre-Test Counselling

- Pre-test counselling is the counselling provided before the test is done
- What does pre-test counselling involve?
  (a) Establishing a positive relationship with the client and assuring him or her of confidentiality
  (b) Finding out information about the client
  - Why the person wants to be tested for HIV/AIDS
  - Behaviour and symptoms of concern to the client
  - Background of the client (sexual history as well as possible exposure through shared needles, blood transfusions and so forth)
  - What the client knows about HIV/AIDS and its ways of transmission, etc.
  (c) Giving basic information on HIV/AIDS and testing, for example:
    - HIV is not AIDS, but it does mean that you may eventually become sick with AIDS
    - A person with the HIV virus can still help keep himself or herself healthy for a long time by following medical advice and taking care
    - The “window period” means the time between infections and the production of antibodies
    - What a negative test result means and what a positive test result means
    - In case the client agrees to do the test, the councillor will also explain the procedure of post-test counselling

- What is most important is that pre-test counselling should always have a preventive character and motivate changes of behaviour.

(ii) HIV Test
• There are several types of HIV tests – some make uses of blood samples, others use a small scraper to take cells from the inside of a person’s mouth.
• None of these tests are painful.
• Some tests allow the health care worker to let the person know if they are infected during the same visit to the clinic and Post-Test Counselling will be given in the same visit. Other tests require that the blood sample be sent to a laboratory for analysis, and the results may not come back for several weeks. In these cases, the person who is being tested will be asked to come back to the office for Post-Test Counselling.

(ii) Post – Test Counselling
Post – test counselling is the counselling which is done when the test results are out, and the result may be positive or negative.

• What does post-test counselling involve?
  - Repeat basic information on HIV/AIDS again – this is a good opportunity to remind people how to keep themselves safer
  - Give the client time to prepare for the fact that being HIV infected or affected is possible
  - If the client is HIV negative, share the happiness and encourage him/her to change behaviour to keep himself or herself safe from the future possibility of infection (ie: use of condoms during sex, no reuse of needles if client uses injection drugs or other injected medications).
  - If the client is HIV positive (HIV+) don’t discourage him/her about the problem or convince your client that it is no problem. Advise him/her to live with hope and to follow the recommended means of living with HIV/AIDS
  - Have as much information on hand as possible about locally available resources and supports
2. 8  What to do after testing HIV positive

Over the past several years, a series of new medications have become available to help manage HIV/AIDS and to improve both the quality and length of life for individuals who are infected. These drugs, as a group, are called anti-retro viral drugs (ARVs). They should be provided to those persons with disabilities who have tested positive for HIV with a doctor’s prescription and permission. This will reduce the many types of infectious illness that persons with disabilities who are HIV positive may now get. It will also help lessen the chances of mother to child transmission. Scientists all over the world are working on new drugs and vaccines to lessen or eliminate the HIV virus and the health problems that are linked to it, but at this point, there is no cure for the disease.

If a person is tested and learns that he/she is HIV-positive, there is still much that a person can do to stay healthy and active for as long as possible:

- Seek out good health care and go to the doctor regularly.
- Insist that any anti-retroviral medications being made available to others who are not disabled, are also made available to you. Make sure that the health care providers understand that a person with a disability values remaining healthy and active as much as any other person who is HIV-positive.
- Try to eat good food and get enough rest.
- Establish a network of family and friends who can help you if you become sick due to the virus. In addition, see if you can set up a
support network with other persons with disabilities to help each other.

- Make sure that you do not spread the virus further, so use condoms with sexual partners, do not share needles if you use them and – should you become pregnant – seek out medications to help prevent your newborn from getting the virus.

2.9 Preventive measures

Ask the participants to mention how they can make sure to not get HIV or spread the disease (10 minutes). Then review the suggested ways to prevent getting HIV listed below. (15 minutes)

The following are some ways a person can protect against getting the HIV virus:

- **Using condoms**

  As is true for all people, condoms should be used EVERY time a person with a disability has sexual intercourse. Couples should also routinely use condoms unless both partners have been tested, both have been found NOT to have the virus and then both partners continue to have sexual relations ONLY with each other.

  Condoms should be provided to all people with disabilities, regardless of what type of disability, and they should be encouraged to use them whenever they have sexual intercourse with their partners.

- **Creating awareness among persons with disabilities**

  Governments, international organisations and civil society organisations should conduct workshops and training for persons with disabilities on issues related to HIV/AIDS so that they can learn about HIV/AIDS transmission and use this information to protect themselves and their partners. To promote inclusion, people with disabilities should also be invited to join HIV/AIDS trainings and
seminars available to all members of the community and such meetings should routinely have material ready in accessible formats, such as Braille, audio cassettes in local languages, written materials in large print and well-elaborated sign language interpreters. Disability advocacy groups should take on this challenge as well, creating awareness among their members.

- **Seeking voluntary testing**
  People with disabilities should be informed about the importance of being tested for HIV and such testing should be provided at minimal or no cost. Testing centres should be easily accessible for all people with disabilities.

- **Creating awareness among professionals**
  Governments, international organisations and NGOs should provide training to professionals, counsellors, social service staff, and HIV/AIDS educators on disability issues. Furthermore, special training should be conducted for deaf counsellors so that deaf people can benefit from privacy and confidentiality when receiving HIV counselling.

- **Reducing personal risks**
  People with or without disabilities can take steps to reduce their chances of getting HIV/AIDS by remaining faithful to their sexual partner who is faithful to them. For some couples, delaying having sex until marriage is one strategy as long as BOTH husband and wife have no other sexual partners. If either member of a married couple is not faithful, then the couple should also use condoms all the time.

- **Challenging perceptions of the relationship between disability and HIV/AIDS**
  Different societies have different ways of treating persons with disabilities in relation to disability and HIV/AIDS. Most societies ignore persons with disabilities and discriminate against them, often limiting their independence. It is important
that societies understand that HIV is a virus that can affect anyone – people with or without disabilities. People must also learn to support people with disabilities in their communities and recognise their potential and abilities.

To conclude this chapter, ask the participants to answer the questions below.
(20 minutes)

End of session
1. What is the difference between HIV and AIDS?
2. How is HIV/AIDS transmitted?
3. Are you at risk of getting HIV/AIDS?
4. Can you prevent the risk?
5. What are some suggested practices related to safer sex?
6. Do you think that HIV/AIDS is a serious problem in your community?
7. Have you ever thought of learning about your HIV/AIDS status?
8. What are the advantages and disadvantages of getting HIV/AIDS testing and counseling?
9. What can you do if you test positive for HIV/AIDS?

At the end of the day, ask one of the participants to facilitate a discussion of the group to evaluate the positive and negative aspects of the day. If you have a flipchart, make two columns – one with a smiley face on top and one with a frowning face. (10 minutes)
CHAPTER THREE

UNDERSTANDING AND CHALLENGING THE STIGMA FACING PERSONS WITH DISABILITIES WITH HIV/AIDS

Objectives

By the end of this chapter, the participants will understand the following concepts:

- the multiple discrimination faced by persons with disabilities with HIV/AIDS
- the causes and effects of stigma faced by persons with disabilities with HIV/AIDS
- strategies for reducing stigma

3.1 The nature of stigma and discrimination against people with disabilities

Explain what is stigma and ask the participants to discuss some forms of stigma in the community. Also explain that persons with disabilities who are affected by HIV/AIDS often experience double discrimination i.e. for being disabled and then for having HIV/AIDS, leading to neglect and social exclusion.

Some people think that people with disabilities are not sexually active, but the reality is that people with disabilities are as active as everyone else. They are also equally affected by the HIV/AIDS pandemic. Unfortunately, awareness campaigns and programs that are designed to fight against the spread of
HIV/AIDS often exclude disabled persons. For example, all written information is in ordinary print and little is in Braille for the visually impaired. Likewise, spoken information is not simultaneously translated into sign language for the benefit of the hearing impaired. Because of this situation, persons with disabilities are at the highest risk of getting HIV/AIDS and if infected with HIV/AIDS, they experience the double impact of stigmas related to having a disability and living with HIV/AIDS in the society. In the African context, many people face a triple stigma: disability, HIV/AIDS and poverty.

Stigma is described as a social process of devaluation of people who do not seem to conform to societal standards, such as either living with or being associated with disability or HIV/AIDS.

- Having a disability can reinforce outdated notions that it is proof of a former sin, or that people with disabilities should be outcast and ostracized.
- Having a disability can also lead to the incorrect notion that the person is simply “sick”, that he need only to be “fixed” or “cured” in order to reenter society. This suggests that people with disabilities are somehow abnormal or that a person living with a disability should not be a part of society.
- People with disabilities are often lumped into a group that many assume have the same goals, fears, and needs.
- HIV/AIDS builds upon and reinforces existing prejudices, or negative opinions or judgments.
- HIV/AIDS also strengthens existing social inequalities, especially discrimination on the basis of disability, gender, sexuality and race.
- HIV/AIDS and disability related stigma and discrimination play a key role in producing unequal relations of power and control. Some groups are devalued and others feel that they are superior. It can prevent those living with disability and/or HIV/AIDS from leading an enjoyable and productive life. It can also lead to lowered self-esteem as well as prevent those with
disabilities and/or with HIV/AIDS from seeking help because they are afraid of society’s reaction.

There are different forms/types of stigma towards disabled persons and towards people who have HIV or AIDS, ranging from name calling, finger pointing, labeling, blaming, judging, gossiping, making assumptions, suspecting, neglecting, rejecting, isolating, separation, to not sharing utensils, hiding, staying at a distance, harassment, all the way to physical violence and abuse. In reaction to this, people with disability or people who have HIV or AIDS may respond with self stigma and by isolating themselves.

3.2 The causes of stigma

Ask the participants to mention some factors which lead to stigma of persons with disabilities with HIV/AIDS in the community. (5 minutes) Then review the following causes of stigma with the participants. (10 minutes)

Some of the main causes of stigma against people with disabilities who have HIV/AIDS include:

- Lack of knowledge about HIV/AIDS and how it is transmitted (Some people believe that casual contact with people living with HIV/AIDS can result in infection.)
- Lack of knowledge of disabilities and how they occur; including the belief that a congenital disability is caused by a sin or is a sign of a curse
- Persons with disabilities’ difficulty in communicating with others
- Disbelief that people with disabilities feel and think the same way as others
- Unwillingness to put in extra effort (such as building ramps or translating literature into Braille) in order to reach out to those with disabilities
- Fear of HIV/AIDS
- General disbelief that people with disabilities are sexually active.
- Negative media about people with HIV/AIDS
- Gender compounds such stereotypes. For example, women with disabilities are both more stigmatized than men and less likely to be literate, find a job or live in a stable relationship.
- Poverty – For example, poor women are forced by poverty to do transactional or commercial sex, and poor people who are malnourished are stigmatized by their looks)
- General disbelief that HIV/AIDS exists.

3.3 Effects of stigma

Ask the participants to mention some effects of stigma on persons with disabilities and their family. (5 minutes) Then explain the following impact of stigma. (10 minutes)

People with disabilities with HIV/AIDS often face the following effects of social stigma:

- Shame, denial, loneliness, loss of hope, depression, isolation, self-rejection, self-blame, self-hatred, and self-inflicted violence – including suicide
- Withdrawal from public activities (e.g. church or mosque membership)
- Being forced to leave the community, kicked out of the family, fired from work
- Discrimination from social events
- An attempt to hide their disability, making it harder for them to obtain help
- A lowered self-esteem, belief that no one else will befriend or hire them because of their disability
- Declining school performance or dropping out of school
- Neglecting care or rejecting care which will hasten their deaths.
Stigma may also have immediate effects on the family, including:

- Shock, anger, disappointment, worry, grief, sorrow, fear of caring for people living with disabilities and/or HIV/AIDS
- Fear of neighbors finding out and being stigmatized
- Family denial and refusal to accept results
- Blame
- Resentment of member with disability, especially if others feel that he or she is not contributing to the family’s welfare
- Isolation – putting an infected family member in a separate bedroom, not allowing him or her to use the same dishes, bathrooms or eating places.

In the longer term, the family may also be impacted in the following way:

- Conflicts within the family, divorce or separation
- Heavy burden on the care givers (usually women)
- Loss of income
- A lowered quality of life for all family members
- Children drop out of school because of lack of money or the need to help care for an infected family member with a disability.
- Children may become orphans

3.4 Strategies/Solutions to address stigma and discrimination against persons with disabilities living with HIV/AIDS

Ask the participants to give examples of successful efforts to minimize or reduce the stigma. Below is one example of a successful story which can be shared with the participants. (10 minutes) Then review the list of strategies below (15 minutes)

Below is a list of some suggested strategies to reduce stigma and discrimination:

- Encouraging setting up of associations for people with disabilities who are living with HIV/AIDS
♦ Creating more outreach programs and efforts to reach those with disabilities to educate them about HIV/AIDS
♦ Promoting dialogue and exchanges between groups of people living with HIV/AIDS to share ideas and experiences
♦ Informing persons with disabilities with HIV/AIDS about the availability of care and services for people living with AIDS
♦ Educating the community about the lives of those with disabilities and those living with AIDS
♦ Undertaking advocacy to improve services and reduce discrimination in health and other services to persons with disabilities
♦ Informing and showing of educational films on HIV/AIDS and persons with disabilities and the stigma that exists in the community towards persons with disabilities
♦ Involving the whole community in discussing and identifying forms of stigma and discrimination to persons with disabilities
♦ Monitoring breaches of rights upheld in legislation and/or international conventions about HIV/AIDS
♦ Working with the media to play an active role in combating disability-based stigma and discrimination in the society
♦ Working with the media to encourage positive portrayals of people with disabilities and/or HIV/AIDS
♦ Bringing together people living with HIV/AIDS, with religious and traditional leaders to discuss stigma and discrimination

An Example:
One organization based in an African country has formulated a workplace policy promoting equal opportunity for employment for those infected and not infected with HIV/AIDS. In implementing this policy, the chairperson decided to hire a person with a disability living with HIV, who volunteered for a long time in the organization. This person was employed as a receptionist and has proven capable of performing his task with high efficiency. The organization has since gone on to welcome several persons living with HIV as volunteers, who work in raising awareness, home-based care, and also serve as receptionists at the information centre in the Organization’s head office.
Increasing self-esteem through provision of micro credit to people living with HIV/AIDS, especially people with disabilities

Increasing self esteem by teaching a skill to those living in poverty with disability and HIV/AIDS

Educating those living with disability and/or HIV/AIDS and ensuring that they have a voice and can communicate with others through writing or other forms of communication

To conclude this chapter, ask the participants to answer the questions below. (10 minutes)

End of session

1. What are the causes of stigma and disability-based discrimination on people living with HIV/AIDS?
2. What are some of the effects of stigma on persons with disabilities and their families?
3. What do you think are possible solutions to solve or minimize stigma caused by the HIV/AIDS epidemic and disability-based discrimination against people in your community?
PART TWO

ADVOCACY ON DISABILITY RIGHTS AND STRENGTHENING LEADERSHIP SKILLS
CHAPTER FOUR

ADVOCACY ON DISABILITY RIGHTS

Objectives

By the end of this chapter, the participants will understand the following concepts:

- international and regional disability laws, including the UN Convention on the Rights of Persons with Disabilities and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities
- advocacy for your rights
- suggested steps in carrying out a successful advocacy campaign

4.1 Overview of international disability rights

Begin by explaining that there are different international and regional laws on disability as listed below. Ask the participants if they have ever heard of these laws. (5 minutes)

There are important changes occurring at both local and global levels for the development of human rights for persons with disabilities. These are based on the following international and regional agreements or declarations:

The UN Convention on the Rights of Persons with Disabilities (CRPD) is the first international human rights law of the 21st century and represents an important legal document to stop discrimination against persons with disabilities in all areas of life. The Convention explains the rights to education, rehabilitation, health and access to information, public facilities and services. Another key part of the Convention is the setting up of a committee of experts, including people with disabilities, to make sure that the governments that adopt the treaty are fulfilling their legal requirements.

The Convention was the result of five years of negotiations which involved a very high level of input from persons with disabilities and their representative organizations. The Convention was unanimously adopted by all governments in the UN General Assembly on December 13, 2006. Countries began signing and ratifying this treaty on March 30, 2007.

**Signature** of the Convention means that the government is committed to the principles and goals of the international law, and will not act against those principles. It also means that that government plans to take the necessary steps
so that the Convention becomes national law. Signing a treaty does not mean that the government is legally required to follow all the specific provisions of the Convention.

**Ratification** means that the Convention is approved through a national process (which usually includes approval by the Parliament) and applies to all citizens of that country as national law. This national process of ratification may take years to complete because, in some cases, governments need to change their existing laws to the standard of the Convention. It is therefore very important to encourage all governments to ratify the treaty as soon as possible, so the laws will benefit all people with disabilities in all countries.

A full list of countries which have signed and/or ratified the Convention is available at: [www.riglobal.org](http://www.riglobal.org)

A full list of the rights in the Convention is included in Annex B.

Eight general principles form the basis for the legal rights in the Convention. These principles are:

- 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 evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.
One of the important outcomes of the Convention is the “paradigm shift” in thinking about protecting the human rights of persons, instead of providing charity for persons with disabilities. This rights-based approach means that society has a whole has to change its attitudes and behaviours toward persons with disabilities, because persons with disabilities have the same rights as all others but may face extra challenges in enjoying these rights.

**Key Relevant Articles in the CRPD**

**Children with Disabilities (Article 7)**

Young people with disabilities have the same human rights as all other children, but in practice, many young people experience discrimination in their homes, schools, hospitals, and other areas of life. Even though the Convention applies to all children and adults, there is a separate article for children with disabilities since they often face extra challenges. Article 7 of the Convention explains that children with disabilities have the same rights as all other children, such as the right to go to school and the right to play. Governments must also take steps to prevent or stop violence, abuse and isolation of young people with disabilities. Governments also cannot take away the right of a person with a disability to have a baby. In all actions concerning children with disabilities, it is most important to see what is best for the young person, but children with disabilities have a right to say what they want.

**Accessibility (Article 9)**
Accessibility is a widely used term to refer to the removal of barriers to buildings; the outdoors; transport; information and communication, and to other public facilities and services. Accessibility is an important part of achieving the full participation of persons with disabilities, and it is society’s responsibility to reduce the barriers that currently prevent this access. Accessibility also refers to information – whether it is audio, visual or in print -- when it is available in formats that can be used by persons with all types of disabilities. Some examples of making information accessible are to put text in Braille or large print, or adding subtitles for videos. Also, many computer screen readers, used by persons who are blind, cannot read documents in certain formats such as PDF – therefore, all efforts should be made to provide documents in Word or equivalent formats. In addition, accessible information must be in easy to read and understand forms. Arial, Century Schoolbook, Garamond and Verdana are among the generally desired fonts, with Arial and Verdana considered best for screens and Garamond and Century Schoolbook for printed materials. (Access by Design: A Guide to Universal Usability for Web Sites, Sarah Horton) In addition, large print should be made in at least 16 point font.

Article 9 of the Convention focuses on accessibility as one of the chief areas of responsibility for governments. In order to make accessibility a reality, it is necessary to identify and eliminate barriers that exist in society, particularly with regard to the physical environment, public services, emergency services and information and communications systems. Access can be achieved in various ways, including the development of standards and conducting training.

- **Education (Article 24)**

The right to education applies to everybody, regardless if a person has a disability or has HIV/AIDS. The reality is that there is a very small minority of children with disabilities that are currently receiving an education in most developing countries. Young people with disabilities deserve an education, and
they have a right to an education in the same facilities as other young people in their community.

The Convention clearly outlines education as a priority area. As it says in Article 24 of the CRPD, education is a right that all people should be able to enjoy without discrimination and at an equal level. Education is a tool whereby people with disabilities can reach their full potential, develop their personal talents and enable their full participation in society. Education really does have the potential to enable millions of children with disabilities to break free of the cycle of exclusion and poverty in which many of them find themselves. It is time these children’s voices were heard.

It is the government’s responsibility to make sure that all barriers to education are removed, and that children with disabilities are able to access education at the same rate as their non-disabled peers. This includes access to school buildings, special materials and equipment, training of regular teachers and support workers, different curricula and assessment strategies that suit the child’s individual needs. This education needs to be inclusive, meaning that children with disabilities are not separated from others in the education system, with supportive, individual structures in place to help the child to access the curriculum. This could include the use of inclusive communication techniques such as Braille, sign language and others, as well as making sure that education providers are appropriately trained. Finally, education does not end with childhood, and States are also responsible for the inclusion of people with disabilities in adult and tertiary education schemes.

- **Health (Article 25)**

Since HIV/AIDS is a big health issue, particularly in Africa, it is very important to understand this article in the CPRD and use strong arguments to make sure that
persons with disabilities receive the care and services they need and have a right to.

Article 25 provides that people with disabilities should have the same access to the highest possible quality of health care and the same choices and standards as others without disabilities in their country. More specifically, government officials must take action to make services accessible with attention to the different needs of men and women specifically in health-related rehabilitation and sexual and reproductive health. This includes:

- Particular attention to the specific health needs and necessary services of persons with disabilities.
- Providing health services as close as possible to the person’s home, even if the person lives outside a city area.
- Requiring health care professionals (doctors, nurses, social workers, physical therapists, etc.) to provide the same quality of care to persons with disabilities as they do for others with specific attention to free and informed consent: Consent means that a person has the right to have all of the information about their health conditions and possible solutions before making their own decision to accept or reject treatments.
- Requiring health care professionals to increase public understanding of human rights, dignity and autonomy for people with disabilities through trainings and by setting public standards for fair health care treatment. As a result, people with disabilities will be knowledgeable about their rights and will be supported to determine their own health care in a self respecting manner.
- Where health and life insurance are permitted by law, people with disabilities will be able to get insurance without discrimination. Public or private entities will then provide this insurance fairly.
- Decisions about access to health care, health services or food and fluids will not be made based on an individual’s disability. This means that
health care professionals cannot stop services based on their assumptions about the person’s quality of life because of their disability.

- **Habilitation and Rehabilitation (Article 26)**

Most of the world’s population have limited or no access to adequate habilitation and rehabilitation services. In fact, many persons with disabilities are denied access to regular health services because they have a disability. (World Health Organization) Habilitation and rehabilitation services that fully respect the individual’s dignity and autonomy can empower persons with disabilities to be as independent as possible in their mobility, communication, learning and self-care. In the past, rehabilitation services could be imposed without the individual’s consent. As reflected in the UN Convention, however, habilitation and rehabilitation is now viewed as a process in which persons with disabilities are the decision-makers about which services and skills they need to improve their lives.

Community-based rehabilitation brings together health professionals, disability service providers, families, carers and persons with disabilities to promote equality within the community so that persons with disabilities can participate in educational, economic, social, cultural, religious and political activities of interest. Many persons with disabilities do not currently have access to community-based rehabilitation services. It is important that persons with disabilities and disabled peoples’ organizations – along with professionals, carers and community members – help shape the development and improvement of community-based rehabilitation.

The Convention outlines the need for habilitation and rehabilitation services so that persons with disabilities exercise independence in all aspects of life. Article 26 of the CRPD explains the importance of these services in enabling the full participation of persons with disabilities in the community. This Article also
stresses the need for services to be voluntary, available as soon as required, individually tailored and located close to the person’s own home. States are also required to promote ongoing training for professionals and the use of assistive technology.

Conclude the session by explaining that all persons with disabilities have the right to participate fully in society. Young people should be encouraged to become active in their communities to raise awareness of disability rights and the discrimination facing persons with disabilities. (20 minutes)

4.1.2 UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities

Describe the purpose of the Standard Rules and when they were created. Also explain the main difference between the Convention and the Standard Rules. (5 minutes)

The UN Standard Rules were adopted by the UN General Assembly in 1993. The Standard Rules were intended to help summarize the message of the UN’s World Programme of Action Concerning Disabled Persons and provide guidance to governments on how to better address the equalization of opportunities for persons with disabilities. Unlike the Convention, the Standard Rules are not a legally-binding document: that is, governments are not legally required to follow the recommendations in the Standard Rules. The UN Standard Rules address 22 different rules on issues such as awareness-raising, medical care, rehabilitation, accessibility, education, employment, family life and personal integrity, culture, recreation and sports, religion, policy-making and planning, and national monitoring.

If you are familiar with national or local legislation on the rights of persons with disabilities, ask the participants if they know about these local or national laws on disability and explain the main laws. (5 minutes)
4.2 What is Advocacy?

Ask the participants to explain what they know about the idea of advocacy. (10 minutes) Ask them to give examples of different types of advocacy they have been involved in or have witnessed. (10 minutes)

Advocacy can mean many things depending on the issue you are tackling and the environment in which such an issue is being addressed. But in this specific case, advocacy means strategies, actions and solutions to influence decision-making at local, provincial, national and international levels to create positive (behavioral, attitudinal & political) change for people and their environment.

Furthermore, advocacy requires strong and effective organization as well as information gathering and dissemination. Research is needed to develop strong arguments, efficient communication within the group of persons with disabilities and strong support from within and outside the community.

For example,

Information campaigns usually play an important role included in implementing laws, promoting disability rights. Some examples include:

- In the year 2001 DOLASED in collaboration with DPOs in Tanzania identified a serious need for Tanzania to have in place national disability policy and legislation to guarantee access to basic social services to persons with disabilities and to guide different actors in the government and civil society to support persons with disabilities. To achieve this, the following steps have been undertaken. First, advocacy materials were prepared with the messages on the importance of having a national disability policy and legislation. Secondly, persons with different kinds of disabilities met and discussed key issues to be included in the national disability policy and legislation. Third, meetings/seminars involving leaders of DPOs and other policy makers have been held to address Tanzania’s
need for disability policy and legislation. Fourth, the media has been used to portray these messages to the general population. Fifth, parliamentarians have been encouraged to raise questions in the parliament asking about when the government will formulate disability policies and bring bills on disability to the floor for enactment or amendment of existing disabled statutes or for encouraging action on alternative legislative provisions.

As a result of this advocacy campaign, in 2004, Tanzania formulated the national disability policy that same year. Currently, the draft bill of the comprehensive national disability legislation has been tabled in the government for consideration and thereafter will be moved to parliament for passage.

Finally, DOLASED has also been active in drafting the above mentioned advocacy strategy to formulate disability policies and legislation in Zanzibar, part of the United Republic of Tanzania. In the year 2004 Zanzibar put in place disability policy and in the year 2006 for the first time in the history of Zanzibar, disability legislation has been enacted.

- The International Labor Organization (ILO) legislation guidelines “Achieving Employment Opportunities for Persons with Disabilities” are another example of effective advocacy which can be adapted here. It provides that if you want to promote the employment of people with disabilities and encourage good employment practices, advocacy materials can be prepared and sent to key stakeholders in the workplace. Much emphasis should be placed on highlighting the working capabilities of disabled persons and the fact that many employers find their disabled employees to be excellent workers and an asset to the company. Such advocacy tools could further aim to inform people with disabilities about their rights under the employment legislation, or inform trade unions about their role in ensuring that disabled workers access their rights.
There are many options to choose from, ranging from general campaigns involving radio, newspaper and television advertisements, to targeted campaigns focusing on specific groups, including peer educators (such as employers, or persons with disabilities). Consideration should be given in such campaigns to drawing up legislation and regulations to give effect to these. Ideally, media representatives should be involved in the design and implementation of these campaigns.

In addition to general information campaigns, provision should be made at the planning stage for technical advisory services targeted at employers, persons with disabilities and other stakeholders. Such services should include information and advice on technical aids and adaptations, job placement, financial grants and incentives, benefits in kind as well as career guidance and related services.

4.3 Steps in the Advocacy process

Review the nine steps in organizing an advocacy campaign as described below. After describing each phase in the advocacy campaign, give time for participants to explore how this relates to HIV/AIDS advocacy and/or the rights of persons with disabilities. (60 minutes total, including discussion) OPTIONAL: Tell the participants that they will have an exercise after the steps are reviewed, in which they develop their own advocacy campaign so they should think of ideas as the steps are presented.

i. Goals

Explain what are goals. Then ask participants to identify problems facing persons with disabilities with regard to HIV/AIDS and some goals to be achieved by the disability community.

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3 Nine Questions” Advocacy Institute, adapted from “Strategy Planning Tool for Advocacy Campaigns” Jim Shultz, Democracy Center
Groups wanting to conduct advocacy campaigns should ask themselves what they want to achieve. To reach stated goals, you need to recognize what are the problems warranting such goals. You may ask yourself what are your problems in terms of accessibility, services provision, policy making and/or participation in different social structures. After understanding these problems, you can ask yourself if your goal relates to policy, behavioral change and/or improved delivery of quality services in a given community. Remember that “Failing to plan is planning to fail”. You need to always plan right at the beginning before you begin to take action.

ii. Audience

*Explain the different target groups for advocacy. Ask participants to suggest target audiences for an advocacy campaign on HIV/AIDS and disability rights.*

The type of advocacy will always be determined by the type of target group you are planning to reach. For example, if your problem is lack of access to ARV therapy your targeted audience will be ARV providers, administrators or even policy makers in order to persuade them to create binding policies that allow persons with disabilities affordable and accessible ARV therapy. This can mean, apart from having free ARVs, places where these drugs are administered should also be user-friendly for persons with disabilities. In another example, DPOs and their partners targeted the legislators (MP) in their advocacy efforts to encourage Mozambique to sign the UN
Convention on the Rights of Persons with Disabilities. DPOs approached parliamentarians before their next session so when the session started, this point was on agenda and the Convention was finally signed. It is extremely important to identify the key players who can easily make things change once you reach them. Key players include government representatives, parliamentarians, legislators, lawyers, NGOs, and the media who have the power to influence decision-makers. Remember that you are also the key player in this action for you have the leading role in making change happen.

### iii. Type of Messages

*Describe the different types of messages, messengers and delivery. Ask the participants to consider possible messages, messengers and ways of advocating for greater accessibility to HIV/AIDS clinics.*

Although advocacy is about giving a message and expressing yourself, it is very important to find out exactly what message will get the attention of and ultimately convince your audiences. Reaching these different audiences requires crafting and framing a set of messages that will be persuasive. Although these messages must always be based on the same basic truth, they also need to be tailored differently depending on what members are ready to hear. In most cases, advocacy messages will have two basic components: an appeal to what is right and an appeal to the audience’s self-interest. For example, when advocating for affordable and accessible health centres, you can persuade the health centre to make the building accessible because they will have more customers paying for the services and a healthier community. You can also convince the government to make sure that all health centers are accessible and affordable because this benefits the public health and because persons with disabilities are at least 10-20% of the voting population. In the end, you can reach your desired goal with different messages for different audiences.
iv. Messengers/Conveyors

Remember that not all people with disabilities can speak in the same way or have the same credibility. In other words the same message has a very different impact depending on who communicates it. Who are the most credible messengers for different audiences? In some cases, these messengers are “experts on disability issues” whose credibility is largely technical. In other cases, we need to engage the “authentic voices,” those who can speak from personal disability experiences.

v. Delivery methodology

There are many ways to advocate the disability message. These range from simply talking (e.g. lobbying) to direct action. Messages can be conveyed in form of meetings, march, protest, strike, participation in events etc. You will need to assess thoroughly what you need your audience to hear from you and how. However, a good advocate will always evaluate messages and apply them appropriately, weaving them together in a winning mix. The example below illustrates one of the best methods of advocating for equal participation in ARV therapy:

An Example:

“During the week of ARV Treatment for ALL Campaign, we organized several activities within Maputo city and other provincial capitals. What we didn’t think of planning for the possible participation of persons with disabilities in the march. As we were preparing for our parade to the Ministry of Health in Maputo, a group of persons in wheelchairs joined the march. The first thing I thought was they came to beg and all of a sudden, I saw one of them taking out a banner from the back of his wheelchair written ‘ARV TREATMENT FOR ALL’. My next reaction was to organize a vehicle for them during the march, but I realized that their problem was not transport…it was ARV treatment; and they joined the parade with all others. This is when I realized that the concept of ‘ALL’ was not fully complied
and/or respected in our advocacy; now I make sure to include persons with disabilities in all of our activities.”

vi. Resources

Explain the importance of resources. Ask participants to list resources needed for an advocacy campaign for example, for introduction of sign language on TV news or for free medical treatment of people with disabilities.

An effective advocate will only succeed in his/her advocacy campaign if he/she has gathered all necessary resources. As disabled persons, you need to explore as much as possible what information is available in your country about disability, as well as know what regulations, policies, and plans for disability are available. Resources can vary from one advocacy issue to another. For instance, if you are planning to demand rights for people with disabilities or free access to ARV treatment for PWDs, you will first and foremost need to gather all legal elements that guarantee these rights such as international declarations, conventions, charters, protocols and domestic legislation like constitutions, national laws, resolutions and/or regulations that guarantee access to these social services.

It is also important to review past advocacy campaigns and look at what it took in order to achieve its goals, be it financial, human or material resources. You might also consider looking at alliances, information and political capacity, the media and other relevant staff to back your advocacy. In summary, you do not need to start from scratch; you can build upon what already exists.

vii. Gaps

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4 This was an extract of testimony from the Coordinator of MATRAM (Movement for ARV treatment for ALL) during an after march evaluation meeting with different HIV/AIDS service organizations in Maputo organized by MIM (Miracles In Mozambique)
After mapping out all necessary resources to undertake an advocacy campaign, now it is time to consider weaknesses that you have and the challenges you may face.

**CASE STUDY**
During the revision of the Plan of Action for Poverty Reduction (PARPA), disabled peoples’ organizations (DPOs) met together to talk about possible advocacy activities for the inclusion of persons with disabilities in the second Plan of Action. However, the majority of persons with disabilities didn't have a clear understanding of the Plan of Action. Also, DPOs represented different disabilities wanted to act separately. During the discussions, the DPOs came up with good but not consistent ideas to convince the government representatives about the need to include disability as a top priority in the government's development programs. As a result of this weakness, the second Plan of Action has very little to say about disability. Where disability is mentioned, there is not even a budget allocated within the government expenditure for disability development programs.

Some challenges may include:
- Discrimination against people with disabilities
- Lack of consultation with people with disabilities or their representative organizations when developing and carrying out programs and policies
- No special efforts to share information about programs and policies with people with disabilities
- Information materials not being provided in accessible formats such as Braille, large print and easy to read
viii. Tactics

*Explain what are some tactics for advocacy campaigns. Ask participants to share some ideas for tactics in a HIV/AIDS and disability rights campaign.*

In most cases disability advocacy campaigns have failed because they start with large scale activities. Many people begin with strategies instead of tactics to start advocacy campaigns. You need to understand that after the problem has been identified and the strategy adopted, you need to continue your advocacy by developing tactics such as circulating petitions (specific actions), staging a protest or writing letters to your target groups expressing your feelings.

ix. Evaluation

*Explain the importance of evaluating campaigns. Ask participants to share some ways they can evaluate a campaign or project.*

Many disability organizations have struggled to understand the concept of M&E (Monitoring and Evaluation). Some think that it is a “watchdog” instrument used by donor organizations to scrutinize partner activities. Evaluation is very important because it helps to assess the effectiveness of the activities. You need to know what went right or wrong, if there were any problems caused as a result of the activities or if your activities were greeted with enthusiasm and support. Such information can be collected through discussion with members, questionnaires posted to your audience etc. Other ways of evaluating progress is to make a survey at the beginning of the project and again at the end of the project to see if anything has changed. You can also evaluate success by counting the number of people reached through the project.
GROUP EXERCISE (Optional)

If you have time for a third day or at least half day, you can consider doing the group exercise.

Divide the participants into groups of 5-6 participants and ask each group to develop an advocacy campaign using the steps we reviewed. Give time for participants to freely discuss the steps towards structuring a good advocacy process. Let participants know that they will present their advocacy campaigns to the entire group at the end and others will be allowed to ask questions. (2 hours for planning, 1 hour for presentations) At the end of the time, (30 minutes) Reinforce the fact that young people and adults with disabilities should educate themselves on how best to run an advocacy campaign or disability organization and are capable of helping to improve the rights of persons with disabilities. As a facilitator, be sure to recognize the strong points in each campaign and make constructive comments on how the campaign ideas can be strengthened.

To conclude this chapter, ask the participants to answer the questions below.
(15 minutes)

End of session

1. What is the UN Convention on the Rights of Persons with Disabilities?
2. What is the difference between the UN Convention and the Standard Rules?
3. What is advocacy?
4. What are the suggested steps in carrying out a successful advocacy campaign?
5. What advocacy campaigns would be most important in your community?
CHAPTER FIVE

STRENGTHENING DISABILITY LEADERSHIP SKILLS

Ask one of the participants to read the objectives of this chapter. If the group is illiterate or unable to access the materials, read the objectives to the group. (5 minutes)

Objectives

By the end of this chapter, the participants will understand the following concepts:

- Leadership
- ways to become a good leader
- characteristics of good leadership
- elements of good governance
- the importance of disability rights and advocacy

Ask the group to share their ideas about what is a leader. (10 minutes). Then explain what is leadership, who is a leader and how to strengthen your leadership skills. (40 minutes)

5.1 What is Leadership

Leadership means many different things to many people so it is important for you to figure out what is best for you. When you learn leadership skills, you will be able to run a group or be a part of a board or committee. You will also be better able to speak up for yourself. Learning to be a leader also means learning how you can work together as a TEAM. Leadership skills also help in setting goals, creating agreement and maintaining commitment in a group of people who share common work. Therefore, leadership is less about your formal position and more about your actions and attitude.
A leader is a person who has the ability to influence, motivate, and enable others to contribute to a common goal. Leaders also know how to listen to people and know when a person might need support. Leadership is an attitude that influences the environment around us. According to Bass' (1989 & 1990) theory of leadership, there are three basic ways to explain how people become leaders. The first two explain the leadership development for a small number of people. These theories are:

- Some personality qualities may lead people naturally into leadership roles. This is the Trait Theory.
- A crisis or important event may cause a person to rise to the occasion, which brings out extraordinary leadership qualities in an ordinary person. This is the Great Events Theory.
- People can choose to become leaders. People can learn leadership skills. This is the Transformational Leadership Theory. It is the most widely accepted theory today and the principle on which this guide is based.

The basis of good leadership is an honorable character and selfless service to your organization. In your followers’ eyes, your leadership is everything you do that effects the organization's objectives and their own well being. Respected leaders concentrate on what they are (such as beliefs and character), what they know (such as job, tasks, and human nature), and what they do (such as implementing, motivating, and provide direction).

The following are some qualities of a good leadership:

- Trust
- Ability to lead peoples’ participation in social life and development
- Commitment to govern the organization in accordance with prescribed customs, practice, regulation and laws
- Ability to consult others and respect the majority opinions and concerns prior to taking action
- Ability to motivate through appreciation of individuals’ contributions to the success or performance of organization or by way of providing incentives
- Ability to influence quality management in carrying out the organization’s core functions
- Ability to communicate well
- Ability to respect principles of good governance

5.2. Strengthening your Leadership skills

There are many skills which a person can learn to be a good leader. For example, a person with good communication skills will have an easier time understanding community needs, getting information, having counseling skills and raising awareness of the rights and needs of his/her community. It is fundamental that young people with disabilities learn leadership skills to advocate for their own rights and the rights of others with disabilities.

Good leadership skills can help young leaders in preparing good planning, implementing and evaluating projects, mobilizing resources, coordinating people, understanding practical and strategic needs of people, and understanding human rights issues and how to share information. Leadership also increases confidence and helps to break barriers such as the discriminatory attitudes against people with disabilities that still prevail in society. Leadership skills also provide opportunities for young, emerging, and/or potential leaders to excel in education and in the workplace.

As an emerging leader, you’ll need to strengthen your skills to bring about positive change, lead your organizations, and also influence others to bring positive and/or effective change in your community.

i. Self Motivation/determination – As a leader, you need to explore your potential. Remember - you can be as good a leader as any non-disabled person. But you also need to keep in mind that being a person with a
disability, people or communities might look at all disabled people as less capable., Therefore you need as much self motivation as you can get to prove them wrong.

ii. **Education** - Education is probably the number one competency requirement for any leader. Education is the primary vehicle by which economically and socially marginalized persons with disabilities can build their skills and abilities and obtain means to participate fully in the community. Education plays a vital role in empowering young persons with disabilities and helping them access information, communicate effectively and promote human rights and democracy.

Education is fundamental because:

- Education is both a human right in itself and an indispensable means of realizing other human rights and skills
- Education is empowerment

iii. **Effective Communication** - As a leader, you must ensure effective and efficient flow of information to and from your members. Information flow will always depend on the type of disability and environment within the organization. You will always need to be flexible and adapt with the style of information given and received within the organization. It is important to share accurate and easily understandable information, which will serve as a model for how all of society should communicate. Remember that by communicating well, you can change the myth that people with disabilities

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When I discovered that my right leg could not move like my left leg, I thought that was the end of my life. But when I looked at my head I said to myself: ‘education is not about my leg, it is about my head’, I started going to school like other children. I faced many difficult times. For example, my friends often used to imitate my walking style because it was fun to them. Even though I faced these challenges, I decided not to give up until I succeeded and today I am glad that some of my school mates can watch the effects of my leadership skills.

– University Graduate & DPO Forum President-Mozambique
are difficult to communicate with. You can lead through two-way communication. Some communication is non-verbal. For instance, when you "set the example," by taking part in tasks and chores, thus communicating to your people that you would not ask them to perform anything that you would not be willing to do yourself. When dealing with disability, as a leader you will need to:

- Speak clearly, simply and straightforwardly.
- Use sign language and interpreter for deaf people or Braille writings for blind.
- Emphasize the point you want to deliver.
- Move from the general to the specific
- When needed, use visuals — charts, maps, and diagrams to explain your point.

This will also enable the leader to demonstrate an issue or explain a problem clearly because she/he is speaking slowly and clearly.

iv. **Be a Good Listener** – In many cases, leadership is easily confused with patronage and/or ownership which often means leaders do more speaking than listening. As a leader, you need to be a good listener. People will come to you with personal problems, human rights concerns and questions. You will need to listen carefully so you can give them good advice or information on where they can get advice.

Understanding human rights is not enough. Leaders need to understand multi-discrimination – the combination of rights, gender issues, poverty and lack of education that can affect the well-being of many individuals with disabilities. This can be achieved by listening to different perspectives of people with disabilities.
v. **Be Aware of Group Needs and Characteristics** - It is important for every leader to understand and have knowledge of different disability needs and characteristics in order to meet the practical and strategic needs of a particular group. Awareness of group needs and characteristics has five major areas of concern:

- Understand people’s needs
- Understand values
- Learn personal characteristics of group members

**a. Understand people’s needs**
Every leader should differentiate between practical and strategic needs. Practical needs can be strictly interpreted as those elements essential for human survival: shelter, food, water and health services. Strategic needs are the desire to remove forms of discrimination existing in the society and establish spheres of equality and improve the lives of persons with disabilities.

**b. Understand people’s value**
Values cannot be ignored if we are to know ourselves and others. Leaders should understand people’s values in order to find the best way to promote the rights of persons with disabilities. For example, the religions, traditions and customs of different tribes in Tanzania promote negative attitudes about children with disabilities. As a result, the children are often locked in the home, lose their opportunity to go to school or are even killed shortly after birth. Leaders need to understand social attitudes and find ways to speak to elders in the different tribes to change their attitudes toward persons with disabilities.
c. Learning personal characteristics
By knowing the strengths and weaknesses of individuals in a group, a leader can tailor its efforts and activities to take advantage of member's given talents and interests.

vi. Two-way Communication

a. Recognizing Achievement
Give individuals feedback and give particular attention to those who are doing well. Publicly praise those who are on track during the task and when they are done. One general rule is to praise in public, criticize in private.

b. Observing Closely
At various times while observing work in progress, the leader acknowledges everyone's contribution, no matter how slight. He pays more attention to those doing particularly well, and gives extra guidance to those unfamiliar with their work and those who need more assistance.

c. Setting task deadlines
As the leader, he or she watches to see that the job is performed on time. He or she makes sure group members are appropriately dressed and equipped, encourages everyone to do their best, sees that work is properly delegated, and sets positive examples at all times.

d. Being respectful
The leader gives instructions in an appropriate tone and manner. He/she should treat others as he/she would like to be treated. This is the Golden Rule.
e. Taking appropriate action

While the group works, the leader helps by giving encouragement and praise, lending assistance as required (when not in conflict with the leader's primary role), using a positive and confident manner and tone, avoiding threats and yelling; and by giving reasons for extra effort.

vi. Set the example – There is a myth that disability is a complex area, and DPOs often have internal conflicts. Whatever the stresses on you and your organization, as a leader, you need to be exemplary not only with your followers, but also with other societal groups. Remember that ‘actions speak louder than words’.

5.3 Principles of Good Governance

Any strong organization or advocacy campaign must also integrate good governance principles to make sure that the program is run effectively and appropriately. (For example, see the organizational manual and code of conduct of the Disabled Organisation for Legal Affairs and Social Economic Development (DOLASED) DPOs should have leaders who are accountable; honest and transparent; leaders who accept criticism and are ready to reform themselves; leaders who will be made accountable in accordance with the organization’s rules if they do not perform as required. Some aspects of good governance include:

- Accountability of leader
- Transparency and honesty
- Tolerance and acceptance
  - Rule of law
  - Human rights
- Obeying the constitution
- Proper use of funds and reporting expenditure
5.4 Importance of Emerging Disability Leaders

Ask the participants to tell you why they should gain leadership skills – what are the benefits. (10 minutes) Then review the qualities described below. (10 minutes)

It is important for persons with disabilities to gain advocacy and leadership skills to raise awareness of their rights and promote greater inclusion. These skills can also contribute to empowering persons with disabilities and ensuring their effective participation in all aspects of social life. Much emphasis should be given to preparing young people with disabilities to take a leading role in promoting and protecting a rights-based approach to guarantee access to basic social services to all persons with disabilities. In order to achieve this goal, persons with disabilities must acquire training on disability rights advocacy and leadership skills to build their capacities.

To conclude this chapter, ask the participants to answer the questions below. (15 minutes)

End of session

1. What are some qualities in a good leader?
2. What are some things you can do to strengthen your leadership skills?
3. What are some principles of good governance?
4. Why is it important for young people with disabilities to become leaders?
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Annex A

Definitions

**AIDS:** Acquired Immune Deficiency Syndrome, which is the last stage of the HIV infection. The body becomes weak and is more likely to get infections.

**ART:** Anti-Retroviral Therapy includes drugs which help stop the HIV from spreading. When antiretroviral drugs are given, HIV replication and its impact on the immune system can be delayed, and survival and quality of life improved.

**Disabled Peoples’ Organizations (DPOs):** Civil society organizations led by people with disabilities.

**Disability:** According to the international definition of disability developed by the World Health Organization, disability is a condition which makes an individual unable to function normally in a particular social-cultural context. Human rights and disability rights activists define disability as the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others of similar age and sex due to physical, intellectual or social factors.

**Discrimination:** According to the UN Convention on the Rights of Persons with Disabilities, discrimination is treating someone with a disability differently because they have a disability. Discrimination may be in the form of words, gestures or caricatures that embarrass persons with a disabilities or actions which stop persons with disabilities from doing something that every person is allowed to do.
HIV: Human Immunodeficiency Virus, which attacks important blood cells and destroys the immune system which causes AIDS. HIV negative means there is no HIV or HIV antibodies, which can be found out through HIV testing. HIV positive means there is an HIV infection. HIV testing needs a laboratory procedure done on a person to find out whether there is an HIV infection.

Stigma: An attitude of disrespect towards another person because someone thinks that person has certain characteristic. For example, people with disabilities and persons living with HIV/AIDS face stigma from society.
Annex B

List of Articles in the UN Convention on the Rights of Persons with Disabilities

Preamble
Article 1: Purpose
Article 2: Definitions
Article 3: General Principles
Article 4: General Obligations
Article 5: Equality and Non-Discrimination
Article 6: Women with Disabilities
Article 7: Children with Disabilities
Article 8: Awareness Raising
Article 9: Accessibility
Article 10: Right to Life
Article 11: Situations of Risk and Humanitarian Emergencies
Article 12: Equal Recognition Before the Law
Article 13: Access to Justice
Article 14: Liberty and Security of the Person
Article 15: Freedom from Torture or Cruel, Inhuman or Degrading Treatment or Punishment
Article 16: Freedom from Exploitation, Violence, and Abuse
Article 17: Protecting the Integrity of the Person
Article 18: Liberty of Movement and Nationality
Article 19: Living Independently and Being Included in the Community
Article 20: Personal Mobility
Article 21: Freedom of Expression and Opinion, and Access to Information
Article 22: Respect for Privacy
Article 23: Respect for the Home and Family
Article 24: Education
Article 25: Health
Article 26: Habilitation and Rehabilitation
Article 27: Work and Employment
Article 28: Adequate Standard of Living and Social Protection
Article 29: Participation in Political and Public Life
Article 30: Participation in Cultural Life, Recreation, Leisure and Sport
Article 31: Statistics and Data Collection
Article 32: International Cooperation
Article 33: National Implementation and Monitoring
Article 34: Committee on the Rights of Persons with Disabilities
Article 35: Reports by States Parties
Article 36: Consideration of Reports
Article 37: Cooperation between States Parties and the Committee
Article 38: Relationship of the Committee with other Bodies
Article 39: Report of the Committee
Article 40: Conference of States Parties
Article 41: Depositary
Article 42: Signature
Article 43: Consent to be Bound
Article 44: Regional Integration Organizations
Article 45: Entry into Force
Article 46: Reservations
Article 47: Amendments
Article 48: Denunciation
Article 49: Accessible Format
Article 50: Authentic Texts
## Annex C

### Training Program

#### DAY ONE

**Opening and Introductions**

<table>
<thead>
<tr>
<th>09.00-09.15</th>
<th>Welcome, Introduction of Facilitation Team</th>
<th>Name of Facilitator</th>
</tr>
</thead>
<tbody>
<tr>
<td>09.15-10.00</td>
<td>Introductions of participants and overview of training goals</td>
<td></td>
</tr>
</tbody>
</table>

**Chapter One: Basic Concepts on Disability**

<table>
<thead>
<tr>
<th>10.00-10.05</th>
<th>Objectives for Chapter One</th>
</tr>
</thead>
</table>
| 10.05-11.30 | • Definition of Disability  
              • Access to information  
              • Communication strategies |

**Chapter Two: Understanding the Truth about HIV/AIDS**

<table>
<thead>
<tr>
<th>11.30-11.35</th>
<th>Objectives for Chapter Two</th>
</tr>
</thead>
<tbody>
<tr>
<td>11.35-12.30</td>
<td>• Meaning of HIV/AIDS</td>
</tr>
<tr>
<td>12.30-13.30</td>
<td>Lunch</td>
</tr>
</tbody>
</table>
| 13.30-15.30 | • HIV/AIDS, myths and facts  
              • Transmission  
              • Disability and HIV/AIDS  
              • Testing |
| 15.30-16.00 | Coffee Break                |
| 16.00-17.50 | • Counseling and prevention |
| 17.50-18.00 | Evaluation                  |
**DAY TWO**

Chapter Three: Understanding and Challenging the Stigma Facing Persons with Disabilities

<table>
<thead>
<tr>
<th>Time</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>09.00-09.15</td>
<td>Review of the Previous Day</td>
</tr>
<tr>
<td>9.15-9.20</td>
<td>Objectives for Chapter Three</td>
</tr>
<tr>
<td>09.20-10.45</td>
<td>• Disability &amp; HIV/AIDS Vs Stigma</td>
</tr>
<tr>
<td></td>
<td>• Strategies</td>
</tr>
<tr>
<td>10.45-11.15</td>
<td>Coffee Break</td>
</tr>
</tbody>
</table>

Chapter Four: Advocacy for Disability Rights

<table>
<thead>
<tr>
<th>Time</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>11.15-11.20</td>
<td>Objectives for Chapter Four</td>
</tr>
<tr>
<td>11.20-13.00</td>
<td>• UN Convention on the Rights of Persons with Disabilities</td>
</tr>
<tr>
<td></td>
<td>• UN Standard Rules</td>
</tr>
<tr>
<td>13.00-14.00</td>
<td>Lunch</td>
</tr>
<tr>
<td>14.00-15.30</td>
<td>• What is advocacy</td>
</tr>
<tr>
<td></td>
<td>• Steps in advocacy process</td>
</tr>
<tr>
<td>15.30-16.00</td>
<td>Coffee break</td>
</tr>
</tbody>
</table>

Chapter Five: Strengthening Leadership Skills

<table>
<thead>
<tr>
<th>Time</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>16.00-16.05</td>
<td>Objectives of Chapter Five</td>
</tr>
<tr>
<td>16.05-18.00</td>
<td>• Leadership characteristics</td>
</tr>
<tr>
<td></td>
<td>• Skills</td>
</tr>
<tr>
<td></td>
<td>• Good governance</td>
</tr>
<tr>
<td></td>
<td>• Emerging disability leaders</td>
</tr>
</tbody>
</table>

Conclusion

<table>
<thead>
<tr>
<th>Time</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>18.00-19.00</td>
<td>Wrap Up, Evaluation and Certificates</td>
</tr>
</tbody>
</table>
Annex D

Suggested Introductory Exercises

1. Ask each participant to say two true things about themselves and one false thing – and ask the other participants to guess which statement is false.

2. Ask all participants to find a partner and interview them; then each participant must introduce their partner to the group.

3. Divide participants into groups of 5-7 people. Provide each group with a long string/rope and ask them to draw a square on the floor with their eyes closed.

4. Divide participants into pairs and ask each pair to use gestures to imitate an animal of his/her choice and the other member should name the animal.

5. Give each participant a name tag and pen or pencil. Ask them to print their names on the upper portion of the name tag and then draw three objects that represent who they are on the bottom portion of the tag. After completing the activity, participants share their names and drawings. (i.e. My name is Michael. I drew a sailboat, a dolphin, and a paint brush.)

6. Go around the room and have each person complete one of these sentences:
   - “One of the key questions I would like to discuss during this training is….”
   - “One strategy or resource that I have successfully used recently in the HIV/AIDS outreach or disability rights education is…”
   - “I am attending this training because…”

7. Tell participants to pretend that they have just found a magic wand that allows them to change one work-related activity (or things about their organization, country, etc). Have a discussion about why they would like to change these things.