

UNDERSTANDING AND CHALLENGING

# HIV STIGMA

Toolkit For Action



change

ICRW  
International Center for  
Research On Women

UNDERSTANDING AND CHALLENGING  
**HIV STIGMA**

Toolkit For Action

**Trainers Guide**

Developed by  
**Ross Kidd and Sue Clay**

Illustrations by  
**Petra Röhr-Rouendaal**

September 2003

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The toolkit has been developed by the CHANGE Project in partnership with these research institutions and AIDS related NGOs in Ethiopia, Tanzania, and Zambia. The NGOs participated in workshops to design the structure and contents of the toolkit; and have started to use and test out some of the modules in their work.

Development of the toolkit was coordinated by Ross Kidd (Botswana) with assistance from Sue Clay (Zambia). Others who have helped facilitate the toolkit workshops and develop the toolkit include: Hailom Bantenyerga (Ethiopia), Virginia Bond (Zambia), Levy Chilikwela (Zambia), Rudo Chingobe (Zambia), Martin Chisulo (Zambia), Lucy Davis (Zambia), Debbie Gachuhi (Kenya), Titus Kafuma (Zambia), Aklilu Kidanu (Ethiopia), Oratile Kidd (Botswana), Gad Kilonzo (Tanzania), Pfiriael Kiwia (Tanzania), Peter Kopoka (Tanzania), Neater Malambo (Zambia), Willbroad Manyama (Tanzania), Estella Mbewe (Zambia), Jessie Mbwambo (Tanzania), Clement Mufuzi (Zambia), Roy Mwilu (Zambia), Laura Nyblade (USA), Anton Schneider (USA).

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**Ethiopia:** Edao Abdi (Save The Children-USA), Amuluwork Abebe (Vision Ethiopia), Negussie Alemayehu (Ethiopian Employers Association), Getachew Alemu (Orphans' & Street Children's Organisation), Dawit Asseregidew (Medical Missionaries of Mary Counselling and Social Services Centre for PLHAs), Ayenew Damte (CARE International Ethiopia), Zerihun Demissie (Family Guidance Association of Ethiopia), Sara Emini (Bethzatha VCT Project), Hailegnaw Eshete (Policy Project Ethiopia), Gizachew Haile (Orphans' & Street Children's Organisation), Ali Hassen (National Committee on Traditional Practices, Bekure Herouy (Policy Project Ethiopia), Elfaggid Lemma (DSW Ethiopia), Michael Mamuye (MEKDIM HIV Positive Persons and AIDS Orphans National Association), Hagos Massa (Addis Ababa HIV AND AIDS Secretariat), Yohannes Mekonnen (Rohoboth Love Ministry), Aklilu Nega (Integrated Service for AIDS Prevention & Support Organisation), Dagmarwi Selamssa (HIWOT Ethiopia), Seyoum G. Selassie (Policy Project Ethiopia), Getachew Simie (Admas Newspaper), Masresha Teferi (Ethiopian Red Cross Society), Ethiopia Tilahun (Save Your Generation), Agumas Wudie (Ministry of National Defence HIV AND AIDS P/C Bureau), Berhanu Zenbere (Action Aid Ethiopia)

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## **Copies of the Toolkit are available from:**

The CHANGE project  
Academy for Educational Development  
1825 Connecticut Ave NW  
Washington DC 20009-5921  
[www.changeproject.org](http://www.changeproject.org)  
email: [changeinfo@aed.org](mailto:changeinfo@aed.org)

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# Introduction

This toolkit was written by AIDS activists from over 50 non-governmental organizations in Ethiopia, Tanzania and Zambia. They participated in workshops where they explored the implications of stigma and designed the exercises on different aspects of stigma.

## **What is the Toolkit?**

The Toolkit is a resource collection of participatory educational exercises for use in raising awareness and promoting action to challenge HIV stigma. Trainers can select from the exercises to plan their own courses for different target groups—both AIDS professionals and community groups.

## **Why was the Toolkit Developed?**

The Toolkit was developed to provide people working in the AIDS field—especially the “front-line” workers—with a set of flexible educational materials to raise their own understanding and help them facilitate awareness raising with community groups. The aim is to help people at all levels understand stigma—what it means, why it is an important issue, what are its root causes—and develop strategies to challenge stigma and discrimination.

The idea behind the toolkit is to create a safe space where AIDS professionals and community members can talk about their own fears and concerns about AIDS, look at the roots of stigma and how it affects PLHAs, families, children and communities and develop strategies and skills to confront stigma and discrimination.

## **How was the Toolkit Developed?**

The toolkit developed out of a three country research project on HIV stigma.\* At the start of the research project, workshops were organized for research assistants and AIDS NGOs to familiarize them with HIV-related stigma and build support for action against stigma. Participants liked the participatory exercises created for these workshops and asked for copies so they could use them. Out of this grew the idea of creating a “toolkit” of participatory training materials on HIV stigma.

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\* A summary of the stigma research findings is in Annex 1.



# How to Use the Toolkit

## **Use the Toolkit for Participatory Learning**

The toolkit is designed for participatory learning. The idea is to get participants learning through **doing**—sharing feelings, concerns, and experience, discussing and analyzing issues, solving problems, planning and taking action. So don't try to use it as a bunch of lectures. It just won't work! Changing attitudes on stigma can only be done through a participant-centered learning process, not through listening to lectures.

## **Pick and Choose Exercises to Make Your Own Training Program**

The toolkit is **not** a standardized package for a single training course or program. You are not expected to work your way through all of the modules. Use it selectively. Pick out exercises which suit the needs of your group to create your own custom training or integrate these exercises into an existing training program. The Annex includes sample workshops, timetables and exercises.

## **Help Participants Move From Awareness to Action**

The toolkit is designed to build awareness about and action against stigma—so help participants move to action. Participants should be encouraged to put their new learning into action, to start challenging stigma in their own lives.

The toolkit is designed for collective learning and action. The aim is to get people to meet with their peers, discuss stigma issues and work together to bring about change. Working with others makes it possible for people to learn together about stigma, develop common ideas about what needs to be done, set group or community norms for new attitudes and behavior, and support each other in working for change.

## **Start With Yourself**

You should first use the toolkit yourself to reflect on your own attitudes, values, language and behavior towards PLHAs—before you try to educate others.



## How to Use the Toolkit

### **Integrate Stigma Awareness Into Other AIDS Education Activities**

The toolkit focuses solely on stigma and workshops can be organized on this theme alone. But we would also encourage you to integrate these sessions into other AIDS education activities. The aim should be to “mainstream” stigma—to make it a regular part of all educational activities for AIDS educators and communities.

### **Next Steps**

The next step is for NGOs and other AIDS organizations to start using the materials to train their own staff and through them reach out to community groups. We would like to hear how you are using the toolkit. Please tell us the exercises you have used—what worked and didn’t work—and how we can improve them. We would be interested in any new exercises you develop. We hope to produce regular updates to the toolkit and your feedback will help us improve future versions.

**A feedback form for you to fill-out is in Annex 8.**

If you are like many trainers, once you have used the exercises in this toolkit you will be ready to try other exercises or variations of these exercises. Only 57 exercises were included in this version although 126 exercises were developed. The other 69 exercises can be used in addition to or to replace exercises in the shorter version. All of the exercises (126) are available on the CHANGE project website: [www.changeproject.org](http://www.changeproject.org) or contact us at: [changeinfo@aed.org](mailto:changeinfo@aed.org).

“ We often do the same old things in our workshops—brainstorm and discuss, brainstorm and discuss—and participants get bored. What I liked about this approach is the methods kept changing. We had no time to be bored! ”

*Participant, Ethiopian Toolkit Workshop, May 2003*

## Toolkit Methods and Materials

The toolkit uses a wide variety of participatory training methods and materials:

..... **Discussion** is the core method—the activity through which participants reflect on their own experience, share with others, analyze issues and plan for action together. All of the sessions are built around discussion.

..... **Presentations** are kept to a minimum and only used in summarizing sessions, or explaining some of the HIV and AIDS facts where participants are confused. If technical experts are available, use their expertise!

..... **Small groups** are used to maximize participation in discussions. Some trainees feel shy in a large group but in a small group they find it easier to talk. Small groups can also be used to do “task group” work—different groups exploring different topics.

..... **Buzz groups**—two people sitting beside each other—are a trainer’s secret weapon! They help get instant participation. It is hard to remain silent in a group of two people!

..... **Report backs** are used to bring ideas together after small or buzz groups. Often “round robin” reporting will be used—one new point from each group going round the circle. This ensures that all groups get a chance to contribute equally.

..... **Cardstorming** is a quick way of getting out ideas and getting everyone involved. Participants, working individually or in pairs, write single points on cards and tape them on the wall, creating a quick brainstorm of ideas. Once everyone is finished, the cards are organized into categories and discussed.

..... **Rotational brainstorming** is another form of brainstorming done in small groups. Participants break into groups and each group is given a starting topic.

## Toolkit Methods and Materials

Each group records points on its topic on a flipchart and after 2-3 minutes moves to a new topic and adds points. During the exercise groups contribute ideas to all topics.

**Pictures—Annex 3** includes pictures which are to be used in different exercises. Some of the pictures show various aspects of stigma (Picture Codes) as a focus for discussion. Other pictures show different types of people (Character Cards) or events in the lives of PHLAs (PLHA Story or PLHA's Rights cards) and participants make up their own stories around them.

**Stories and Case Studies** are provided in many of the exercises as a way of describing how stigma looks like in a real situation and providing a focus for discussion. In other exercises participants are asked to write their own stories about stigma.

**Stop-start drama** is a form of drama-making combined with discussion. The drama “starts” and then “stops” for discussion (to analyze the issues) and then the drama “starts” again.

**Drama or Role plays** are an option to Stories. Participants act out the stories in the module or their own stories, or they act out their analysis of an issue as a way of reporting back what they have discussed. Drama helps to make things real.

**Skill practice with feedback**—the workshop process can be used to practice some of the skills needed to mobilize action against stigma: facilitating discussion and giving presentations. Some of the report back sessions can be used to practice presentations—group reporters present their reports and then are given feedback on their performance.

**Warm up games and Songs**—trainers are encouraged to use their own games and songs to break the ice, build group spirit, and create energy for sessions. Some games are provided in the Annex.

## Working with Feelings

Many of the exercises in the Toolkit, involve working with feelings. An important component in anti-stigma training involves working with attitudes towards, experiences of and beliefs about traditionally taboo subjects like sex and death. To do this, many exercises are designed to help participants to express the feelings which often lie behind these attitudes.

An example of this is in the initial exercise of “Naming the Problem.” We ask participants to reflect on their own experiences of being stigmatized or of stigmatizing. Experiences of being isolated, rejected, mocked inevitably invoke strong feelings. These feelings help participants to see how hurtful- and powerful- stigma can be.

As trainers, it is important to create a safe, non-threatening space where feelings, fears and taboos can be discussed and explored openly. The following tips may help:

- Setting clear ground rules and expectations around confidentiality, listening and support are essential.
- Awareness of your own feelings and fears about the topics you are going to cover will also help you to feel more confident during the exercise. (Try out the exercises yourself)
- Participants are more likely to trust you if you can share your feelings openly and by doing this, you lead by example.
- Remember to always leave enough time for participants to share their feelings and help the group to create an atmosphere where participants know they will be listened to.
- Remember that no feeling is wrong—but some participants may find it difficult to accept certain feelings.
- Offer participants “time-out” if they need to take a break.
- Feelings are a powerful tool—use them with the group to develop drama and role-plays, to build on stories, and as examples for the future.
- If there are any exercises you do not feel comfortable leading, find a co-trainer who can help out. If you have counseling skills, you are more likely to be confident in working with feelings.

### **SPECIAL NOTE RE: “PLHA”**

We have used the acronym “PLHA” for “people living with HIV and AIDS” in order to shorten the text and make reading easier. We would, however, discourage the use of this acronym in workshops and instead promote use of the full phrase. In workshops where there are people who are openly positive, ask them how they would like to be addressed.

# MODULE

# A

## Naming the Problem

This chapter gets participants to **name the problem**, to see that:

- Stigma exists and takes many forms—rejecting, isolating, blaming and shaming, etc
- We are all involved in stigmatizing, even if we don't realize it.
- Stigma hurts people living with HIV and AIDS and those suspected of having HIV.
- Stigma is harmful to ourselves, our families, and communities
- We can make a difference by changing our own thinking and actions.

This chapter also gets participants to **own the problem**—to recognize that we are all involved in stigmatizing people living with HIV and AIDS. It is not someone else's problem. We are all **part of the problem**, even if at first we don't recognize it.

“A man who is isolated and alone can be regarded as a sort of discarded person. He is a man cast out of society, and that type of man, in the old days would have been killed. Let me say this—and I say it very seriously: there is nothing worse than being isolated.”

*Dinizulu, King of the Zulus, 1910.*

*Quoted in: Malan, Rian (1970) My Traitor's Heart. London: Vintage Books.*

“In our African idiom we say, “A person is a person through other persons.” None of us comes into the world fully formed. We would not know how to think, or walk, or speak, or behave as human beings unless we learned it from other human beings. We need other humans in order to be human. The solitary, isolated human being is really a contradiction in terms.”

*Archbishop Desmond Tutu, 2000.*

# MODULE

# A

## Naming the Problem

The chapter starts with people's own experience of and feelings about being stigmatized and stigmatizing others. The aim is to get people to connect to the issue on a personal, emotional level, rather than a theoretical level (through a definition). People can see how stigma affects people through their own experience of being isolated or excluded—and how it hurts.

Then the rest of this chapter looks at what stigma means for people:

- a) What are the forms of stigma? What does it look like—in our attitudes, language, and behavior?
- b) What are the effects of stigma—on PLHAs, families, communities, people's access to health services, etc.?
- c) What are the root causes of stigma?

The forms, effects and root causes are explored through a series of optional exercises.

### We ALL stigmatize

We stigmatize when:

- We say things like “she was promiscuous” and “he deserves it”; and
- We do things such as isolating PLHAs, excluding them from decision-making, etc.

### The MAIN CAUSES of stigma include:

- Insufficient knowledge, misbeliefs and fears about a) how HIV is transmitted; and b) the life potential/capacity of PLHAs (no immediate death);
- Moral judgements about people who we assume have been sexually promiscuous
- Fears about death and disease
- Lack of recognition of stigma

### The main FORMS of stigma include:

- Physical and social isolation from family, friends, and community
- Gossip, name calling, and condemnation
- Loss of rights and decision-making power.

### Other forms of stigma include:

- Self-stigma—PLHAs blaming and isolating themselves
- Stigma by association—the whole family affected by stigma
- Stigma by looks/appearance/type of occupation

### The EFFECTS of stigma include:

- Kicked out of family, house, work, rented accommodation, organization, etc
- Dropout from school (resulting from peer pressure—insults)
- Depression, suicide, alcoholism

# NAMING STIGMA THROUGH PICTURES

1  
EXERCISE

This is a good starter activity to get participants talking about stigma



## OBJECTIVES

Participants will be able to:

- Identify different forms of stigma in different contexts
- Identify how stigma affects people with HIV



## TIME

1 hour



## MATERIALS

Selection from stigma pictures (A1 to A41) in Annex

## ACTIVITIES

### *Picture-Discussion*

### **SPOTTING STIGMA**

Divide into groups of 2-3 people. Ask each group to select one of the pictures. Ask them to discuss—“What do you see in the picture? How does this picture show stigma?”

### **Report back**

Put up one picture at a time and ask the group to present their analysis. Record points on flipchart sheets. One other recorder should make a running list of common issues, which should be presented at the end.

### **EXAMPLE FROM ETHIOPIA NGO WORKSHOP (March 2002)**

#### **Man seated all alone on a bed (A14)**

No one is caring for him. Utensils under bed—shows that people are not sharing utensils with him. Looks lonely and worried—seems to have lost all hope.

#### **Parents pushing pregnant daughter out of house (A9)**

Unwanted pregnancy. Is she HIV positive? Maybe she will get abortion, drop out of school, or become a sex worker to survive.

#### **Woman sitting all alone crying (A27)**

Maybe she has just learned that she is HIV positive and people are rejecting her. Depressed, hopeless, anxious. No one to share her problems with.

#### **Sick man in bed with children visiting (A38)**

Looks depressed. Worried about future for his children once he dies. His children look worried—they don't know what to do if their father dies.



## ACTION IDEAS

Take the pictures home and discuss them with family members and friends. Help others see what HIV stigma means in our lives.



## Summary

### Forms of stigma

- Isolation, insults, judging, blaming
- Self-stigma—PLHAs blaming and isolating themselves
- Stigma by association—whole family affected by stigma
- Stigma by looks/appearance/type of occupation

### Effects

- PLHAs feeling isolated, rejected, condemned, forgotten, useless
- Kicked out of family, house, work, rented accommodation, organization, etc.
- Dropout from school (resulting from peer pressure—insults)
- Depression, suicide, alcoholism



## MODULE A Naming the Problem

# OUR EXPERIENCE AS STIGMATIZER AND STIGMATIZED

EXERCISE  
2

HIGH PRIORITY ACTIVITY—we encourage all groups to use this exercise



### OBJECTIVES

Participants will be able to:

- Describe some of their own personal experiences concerning stigma
- Identify some of the feelings involved in being stigmatized or stigmatizing others



### TIME

1-2 hours

This exercise was the energizer for the whole workshop. Getting people to think about their own experience of “being isolated or rejected for being seen to be different” helped them see how it really feels to be stigmatized. People could see how HIV stigma hurts people. This was when the workshop took off!

*(Trainer—Ethiopia Toolkit Workshop, May 2003)*

### ACTIVITIES

#### *Individual Reflection*

#### **OUR OWN EXPERIENCE OF BEING STIGMATIZED**

Ask participants to sit on their own at a distance from other participants. Then say: “Think about a time in your life when you felt isolated or rejected for being seen to be different from others—or when you saw other people treated this way.” Explain that this does not need to be examples of HIV stigma—it could be any form of “isolation or rejection for being seen to be different.” Ask them to think about—“What happened? How did it feel? What impact did it have on you?”

#### **Sharing in Pairs**

Say—“Share with someone with whom you feel comfortable.”

#### **Report Back**

Invite participants to share their stories in the large group. There is no compulsion—people will share if they feel comfortable

#### **Stop-Start Drama**

Invite some of the story tellers to act out their stories in short role plays (with other participants playing the other roles). This activity helps to make the stories come alive and to see the feelings involved—the pain in being rejected, isolated, or condemned. At the end of each scene ask the role players - “How did you feel to be stigmatized?”

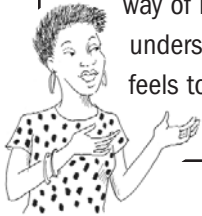
#### *Individual Reflection*

#### **OUR OWN EXPERIENCE OF STIGMATIZING OTHERS**

Ask participants to sit on their own. Then say—“Think about a time in your life when you isolated or rejected other people

### ACTION IDEAS

Talk with friends or family members about what you have learned about stigma. Get them to talk about their own experience of being isolated or rejected for being seen to be different—as a way of helping them understand how it feels to be stigmatized.



because they were different.” Ask them to think about—“What happened? How did you feel? What was your attitude? How did you behave?”

Then ask participants to write down any thoughts, feelings, or words that they associate with stigma.

### Report back

Ask each participant to read their list out loud and record the points.

Then discuss—“What feelings are associated with stigma?”

### Summary

Everybody has felt ostracized or treated like a minority at different times in their lives. And it is okay to feel like that because you are not alone—we have all experienced this sense of social exclusion.

### EXAMPLES FROM WORKSHOPS IN ETHIOPIA AND ZAMBIA

#### Experiences of Being Stigmatized

- Being fired from a job without any clear reasons for being dismissed and then laughed at or shunned by fellow workers.
- Going to another region of the country and not being able to speak the local language - as a result feeling isolated and lonely and thinking that people are making fun of me.
- Being left handed—“As a child my left hand was tied up in a cloth to stop me using this hand. This made me feel different from other people—like an outcast—children laughed at me.”

#### Experiences of Stigmatizing Others

- Using abusive language to street children or orphans
- Avoiding shaking hands with people who are suspected to have HIV
- Refusing to speak up for an HIV positive friend at the hospital

#### How did you feel when you were stigmatized?

Depressed. Rejected. Feeling judged. Feeling discredited. Outcast. Isolated. Alone/Loneliness. Second class citizen. Pushed down. Dehumanized—“people no longer take me seriously.” Unaccepted. Useless. Failure. Hated. Degraded. Misunderstood. Teased. Insulted

**STORY FROM ZAMBIA ABOUT BEING STIGMATIZED (September 2002)****Mary**

One couple had four girls and two boys. When they died, they left their children four houses. The houses were not distributed equally. One sister got two houses, one sister one house and one brother one house. The other brother—the oldest in the family—and two sisters got nothing. Those who took over the houses are renting out rooms to make money.

The older brother was forced to stay in a shanty compound. He was given money by his siblings for food and rental payments. After a while he became sick and his wife abandoned him. He was taken to the hospital, where he was told he had TB and placed in the TB ward. This news disturbed his siblings who quarreled over who should look after him. His brother agreed to buy food for him and his sister (the youngest) agreed to take the food to the hospital.

Eventually he was discharged and sent to stay with his brother. This brought confusion again—the siblings wanted to send him back to the shanty compound.

The older brother, however, refused. He said, “Who will look after me, since my wife has run away? I want to stay with you.”

They all refused to help but one sister offered to look after him. After two days she kicked him out saying that she could not care for him, since “he is a man and needs to be looked after by another man.” So he moved into his brother’s house and was given one of the rental rooms. His brother told him, “Since you are using the room which I would have rented to make money to buy you food, you will have to find your own money for food.” And he told his wife not to cook for his older brother.

The older brother is now struggling to find money to buy food, working as a tailor. He has very little contact with his brother who tries to avoid him. The three siblings continue to earn money from rentals, but the income is not shared with their siblings.



## STORIES FROM ETHIOPIA TOOLKIT WORKSHOP (May 2003)

### Evil Eye People

In Ethiopia the most heavily stigmatized group are craftsmen—pot-makers, blacksmiths and weavers—who have been stigmatized for centuries as “Evil Eyes”. People believe that contact with the “Evil Eye” can lead to harm, so they avoid eye contact with them and warn their children against them. As a result, “Evil Eye” people are forced to live a separate existence, living in separate colonies. People don’t mix with them, eat with them or marry them.

There have also been various attempts historically to defend these groups against stigma and discrimination. In the Bible and Koran there are passages appealing for the protection of stigmatized people and setting punishments against those who discriminate. In 1908, Emperor Menelik II made a proclamation to stop the persecution of the craft makers. He said:

*Don’t discriminate against the pot makers and blacksmiths. You brand these people as outcasts out of ignorance. These people produce useful things which we all have in our homes—cups, baskets, ploughs, leather goods, etc. We use these things to make our lives better. These people are very productive so they should be accepted and respected. Those who discriminate will be punished.*

The stigma against “Evil Eye” people has even been accepted by “Evil Eye” people as a form of self-stigma. Some “Evil Eye” people deliberately cover (or hide) themselves to make it easier for other people to avoid eye contact. They have accepted the view that they are “Evil Eye” or a danger to other people. Hiding their eyes or turning their backs stops eye contact with other people. This act removes the fear and the sense of threat.

### Lepers

*“My wife stopped us from moving into a new area when she learned that our neighbors would be lepers.”*

*“I saw the daughter of a leper beaten at the market because the traders feared getting infected through contact with her.”*



# NAMING STIGMA IN DIFFERENT CONTEXTS

3  
EXERCISE

This exercise works well in a workshop with many participants or in a community setting



## OBJECTIVES

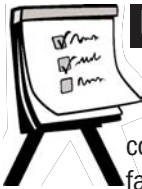
Participants will be able to:

- Identify different forms of stigma in different contexts
- Identify how stigma affects people with HIV
- Begin to identify some of the root causes of stigma



## TIME

2-3 hours



## PREPARATION

Tape up CONTEXT CARDS (family, community, health facilities, school, workplace, church/faith group, market, bar, funeral, media) on different walls of the room—G1 to G10

## ACTIVITIES

### Topic Groups

### STIGMA IN DIFFERENT CONTEXTS

Ask people to “vote with their feet”—to join the context group they want to join. Then ask groups to:

- Identify forms of stigma which occur in that context - write on flipchart
- Make a role play to show how the stigma occurs.

### Report Back

Ask each group to present their flip charted report and the role play. For each role play discuss:

- What happened? Why?
- What are the attitudes here?
- What are the contributing factors?

### Processing

Discuss some of the following questions:

- What are some of the common features across the different contexts?
- What are the attitudes/feelings in all contexts towards PLHAs?
- What are the effects on people who have been stigmatized?
- What are the root causes of stigma and discrimination?

## EXAMPLES FROM NGO WORKSHOP IN ETHIOPIA (March 2002)

**Home:** Family tries to hide PLHA at back of house so that neighbors don't know. Shame - honor/reputation of family destroyed - lose face. Stigma reinforces existing power relations: husband - concerned about protecting family honor; wife - more concerned about practical issues (e.g. care, etc). Wife blamed for not raising child properly. More tolerance/sympathy for men getting AIDS; no tolerance for women. Associated stigma—family stigmatized for having PLHA in their house—often assumed that they are all HIV positive. Family breakdown—children dumped with relatives, abandoned and become street children

**Community:** Gossip. Neighbors visit as voyeurs to see how thin PLHA is. Stop PLHAs using communal bucket at well. Stop PLHAs holding children. Show disgust when they shake hands.

**Market:** People stop buying from market seller suspected to have HIV. Isolation and gossip about their health status. Market a very public space— problems are raised in public—lots of shame.

**Workplace:** Workers shun and make comments about person suspected to have HIV. PLHA viewed as unreliable. Boss blocks promotion or further studies and tries to get rid of PLHA worker.

**School:** PLHAs' children treated badly. Rejection and name calling—not sharing seats & books. Teasing - "Your father died because of immoral behavior." Result—feel isolated/depressed, concentration declines, leads to dropout. Some communities force school to fire teacher with HIV.

**Clinic:** Nurses minimize contact with HIV patients. Some nurses insist on the use of gloves. Some people are denied drugs because this is viewed as waste of resources—"This person will die soon." Blaming and judging—"You have had too many partners—you deserve to die."

**Media:** Negative messages ("AIDS kills") promote fear and panic. Image of PLHAs as people who are about to die—nothing to live for. Constant repeating of negative messages.

**Faith Groups:** PLHAs have sinned—promiscuity, adultery, breaking moral laws. Curse—"You are punished for not following God's laws."

**Bar:** Source of initial infection but no stigma. No sanctions against casual sex—"spicing up our life." Sometimes people talk more freely in bars and stigmatize more.

### EXAMPLE OF TYPE OF ANALYSIS—HOME/FAMILY

**Analysis:** Forms of stigma—isolate and hide HIV infected family members so that neighbors cannot see what is happening and stigmatize. Denial to public that there is a problem. Associated stigma—the whole family is stigmatized by the community. Competitiveness and jealousy—neighbors use rumors about HIV status of family members as a weapon to put the family down.

**Drama:** A teenage girl learns she is HIV positive. She tells her sister but they are scared to tell the father. They tell their mother, who tells their father. The father gets angry, shouts at the girl and raves about the shame to the family. The family hide her and prevent people from seeing her.

### Discussion:

- Family has judged their daughter to be bad—father assumes the worst
- Father fears the loss of their family's reputation—disgrace and shame
- He wants to protect the family's reputation by kicking his daughter out of house
- He wants the daughter to die quickly to get rid of the problem
- Mother is worried about what the community will say about them
- Mother wants to hide the daughter in back room out of sight to prevent people from seeing her
- Men (father and son) are angry and focused on the shame and morality
- Women are more concerned about practical issues of survival
- Daughter—self-stigma—self-hatred and blame—feels her life is over

# WHAT IS THE MEANING OF STIGMA?

4  
EXERCISE

This exercise can be used to explain the definitions and theories on stigma



## OBJECTIVES

Participants will be able to:  
Define the meaning of stigma  
and give examples



## TIME

30 minutes

## ACTIVITIES

### Cardstorm

#### **WHAT IS THE MEANING OF STIGMA?**

Hand out cards and ask participants to write on cards:  
“What do you think is the meaning of ‘stigma’?”

Encourage people to give examples of stigma or define it. Then explain the definition below or give it out as a handout.

#### **PARTICIPANTS IDEAS AT A WORKSHOP IN ZAMBIA (September 2002)**

- Deep feeling one can have, which makes one feels disrespected or unloved
- I feel stigmatized in my work as an AIDS educator—people tease me about distributing condoms and call me “Mama Condom”
- PLHAs being blamed for their infection and told they deserve it
- People running away from you because of a disease you have
- Feeling ashamed because one has HIV/AIDS or TB
- Fear of disclosing one’s disease to others.
- Self-stigma—PLHAs react to and begin to accept negative judgements of society





## TEXTBOOK DEFINITIONS

Stigma is a spoiled identity. To stigmatize is to label someone, to see them as inferior because of an attribute they have

### Three types of stigma:

- **Self-Stigma** – self-hatred, shame, blame—people feel they are being judged by others so they isolate themselves—PLHAs practice “self-stigma”—isolate themselves from their families and communities
- **Felt Stigma** – perceptions or feelings towards PLHAs
- **Enacted Stigma or Discrimination**

### Stigma is a process:

1. **Point out or label differences** – He is different from us—he coughs a lot.
2. **Attribute differences to negative behavior** – His sickness is caused by his sinful and promiscuous behavior.
3. **Separate “us” and “them”** – e.g., shunning, isolation, rejection
4. **Loss of status and discrimination** (loss of respect, isolation).

### Other Important Dimensions

- Often people do not understand the word “stigma” in English.
- Difficult to find a word in other languages which is equivalent. Use a phrase
- Differs in intensity—sometimes blatant, sometimes subtle
- Targeted mostly at people who are assumed to be HIV positive
- Targeted at stereotyped and scapegoated groups (women, sex workers)
- Other diseases (TB) are stigmatized because of HIV.
- AIDS disfigures so stigma changes according to the stage of the disease. Stigma increases as the symptoms of the disease become more visible.
- HIV, sex, and death—value laden
- Motives for stigma change according to the setting
- Disrupts social relations
- People fear that HIV is very contagious.
- People hide their stigmatizing attitudes
- Discrimination and human rights



# EFFECTS OF STIGMA ON DIFFERENT PLAYERS

## 5 EXERCISE



### OBJECTIVES

Participants will be able to:  
Identify the effects of stigma on  
different players and institutions



### TIME

1 hour



### PREPARATION

Put up blank sheets  
of flipchart paper on  
different walls of the  
room, with a target  
group written at the top  
of each sheet—PLHAs,  
family, community,  
women, men, children,  
stigmatizers, health  
services, workplace,  
education, social  
relations.

### ACTIVITIES

#### *Rotational Brainstorming*

#### **HOW STIGMA AFFECTS DIFFERENT GROUPS**

Divide into groups and assign one group to each topic. Ask groups to brainstorm, “How does stigma affect your target group?” and record. [Ask participants to look for both immediate effects—shame, isolation, depression, hiding one's status; and spin-off or larger effects—loss of jobs, dropping out of school, suicide, etc.] After 3 minutes shout “Change!” and ask groups to move to the next topic and add points. Continue until groups have contributed to all topics.

#### **Report Back**

Ask the original group to present each topic—the main points—and then ask for clarifications and additions. Note common or unusual points.

#### **Ask**

“How does HIV stigma affect the take-up of HIV and AIDS services or programs?”

#### **Summary**

Explain how stigma blocks both prevention and treatment of HIV and AIDS:

- Stigma keeps people from learning their HIV status through testing and discourages them from telling their partners and as a result they infect them.
- Stigma keeps people who suspect they are positive from accessing treatment and counselling services. For example, a TB patient hides his diagnosis.

### ACTION IDEAS

Try out this activity in your own group—faith group, women’s group, youth group or workplace. Get the group to discuss the effect of stigma on group members or their families.



- Stigma discourages people from using other services (pregnant woman from taking ARVs)
- Stigma prevents people from caring for people living with HIV and AIDS.

### EXAMPLE FROM BARCELONA WORKSHOP (July 2002)

**PLHAs:** Rejection—chased away by family and friends. Dumped at back of house or village. No longer contribute to family’s income so feel useless. Resort to secrecy—hide status. Lose privacy. “Secrets” known by community. Low self-esteem. Scared to seek help and get services. Blamed and judged for past “immoral” behavior—“promiscuous”, “careless,” “sleeping around.” Guilt and shame. Self-blame and depression. Self-stigma. Loss of hope: HIV viewed as instant death—no hope for future. Not caring anymore—take risks and become reckless, i.e., not stigmatized safe sex.

**Family:** Shame, disgrace, loss of face—family’s reputation, status, and honor destroyed. Rejection by community. Secrecy—hide PLHA at back of house or in village so neighbors can’t see. Deny that there is a problem. Family conflicts—blame each other for loss of family reputation. Stigma reinforces existing power relations—wife blamed for not raising child properly. Marriage collapses. Children dumped with relatives. Loss of income when breadwinner dies. Property grabbing. Family can benefit from special resources for PLHAs; or lose out on services due to fear of stigma.

**Community:** Fear—community know but they keep the secret. Jealousy. Competitiveness. Finger pointing. Gossip. Rumor. Rumors about AIDS used as a weapon to condemn families. Mistrust: speculate about other families. Isolate families perceived to have AIDS. Creates two opposing groups within community—stigmatizers and stigmatized. Conflict and disunity—blame each other for bringing problem to village. Community organization weakens—result: fail to respond or prevent infection. Loss of breadwinners—collapse of production, migration, and infection. Positive effect—potential for peer support and solidarity among stigmatized—uniting force.

**Women:** Perceived as vectors of illness—AIDS seen as women’s disease. Women’s image devalued. Self-blame. Low self-esteem. Loss of income/support system—partner, family, friends. Extra burden of caring for PLHAs. Blamed by partners for not raising HIV+ son/daughter properly. Breakup of marital relations—separation or divorce. Avoid getting tested or seeking treatment.

**Men:** Loss of employment. Loss of face. Feel useless. Rejection by women. Loss of manhood. Associated with homosexuality or promiscuity. Withdrawal from social contact. Self-stigma.

**Children:** Stigmatized by association. Perceived as “innocent victims.” Made to feel guilty. Loss of support and care. Dumped with relatives. Neglected/abused by new “parents.” Grow up without trust and love. Become street kids. Self-isolation. Introverted. Difficulty handling grief. Depression. Loss of hope and sense of future. Isolated by friends. Some children carry the burden of becoming care-givers and breadwinners. Loss of childhood—forced to accept adult responsibilities

**Health Services:** PLHAs stop using services—testing, counseling, treatment, ARVs, MTCT. Lack of resources and heavy workloads. Burnout and fears—health workers desert AIDS work. Climate of silence around health care.

**Stigmatizers:** Sense of power. Double standard—stigmatization may cover up their own fears about HIV infection. Culturally acceptable—others are doing it—deep rooted.



## OBJECTIVES

Participants will be able to:

- Identify different forms of stigma and how stigma affects people
- Identify some of the root causes of stigma



## TIME

1-2 hours

## ACTIVITIES

### PROBLEM TREE

Participants write points on cards and tape them on a wall diagram to make a “problem tree”, showing forms of stigma (main trunk), effects (branches) and causes (roots). Then points are reviewed—and more analysis is done on the causes.

### **Card-Storming**

Divide into pairs. Hand out cards and markers. Ask pairs to record each point on a different card and tape at the appropriate level of the diagram. Cluster common points and eliminate repetition.

### **Debriefing**

Review one level at a time. Cluster similar points and add extra points. Help participants see the two levels of effects—immediate impact on PLHA (isolation) and spin-off effects (loss of jobs).

### Optional Extra Activities

If there is time, add two card-storming exercises:

- What are the effects on the family, the community, the nation?
- What things do people say about PLHAs? [This question should be used after participants have identified Name Calling as one of the forms of stigma.]

### **Extra Analysis on Causes**

Identify a list of key causes of stigma: morality, low knowledge, fear of disease, poor health care, poverty, fatalism, media, gender, government policy.

Set up a topic group for each cause. Ask groups to do a detailed analysis.



### Option

Use the “But why?” method. Assign each group one of the causes and then ask them to do a deeper analysis, using “But why?” to look for root causes.

#### Effects or Consequences

Shame. Denial. Self-isolation. Loneliness. Neglect. Loss of hope. Depression. Death. Alcoholism. Isolation. Self-rejection—give up on yourself. Self-blame. Self-pity. Self-hatred. Anger. Violence. Withdraw from public activities (church membership). Become very quiet. Commit suicide or start thinking about suicide. Die alone—without love. Feel unproductive/useless/not contributing. Forced to leave community. Family disruption. Divorce or separation. Kicked out of family. Fired from work. Loss of promotion, scholarship opportunities, rented accommodation. Decline in school performance or dropout from school. AIDS orphans and street kids. Abuse or poor treatment by relatives. Deprived of medical care—health staff argue that this is a “waste of resources.” Sent back to the village and property grabbing. Quarrels within the family—argue over who is responsible for this situation and who will take care of the sick PLHA. Stop making use of clinics, VCT program, and HBC program. Reluctance to take medication. No treatment. Spread of infection.

#### Forms of Stigma

Name calling. Scapegoating. Finger pointing. Teasing. Ridicule. Labelling. Blaming. Shaming. Judging. Back biting. Rumor. Gossiping. Making assumptions. Suspecting. Neglecting. Rejecting. Isolating. Separating. Not sharing utensils. Hiding. Staying at a distance. Harassment. Physical violence. Abuse. Self-stigma—blaming and isolating oneself. Stigma by association—whole family or friends also affected by

stigma. Stigma by looks/appearance. Associated stigma—family and friends also affected by stigma

#### Causes

Morality—view that PLHAS are sinners, promiscuous, unfaithful, “sleeping around.” People’s beliefs about pollution, contagion, impurity. Fear—fear of infection, fear of the unknown, fear of death. Ignorance—lack of knowledge and misconceptions makes people fear physical contact with PLHAs. Misconceptions. Inferiority and superiority complex. Gender and poverty—women and poor people more stigmatized than men/rich people. Prejudice. Tendency to judge others.

#### EXTRA ANALYSIS ON CAUSES

##### Poverty

- Poverty can lead people to stigmatize.
- Poor women are forced by poverty to do transactional or commercial sex.
- Poor people, who are malnourished, are stigmatized by looks. Cannot hide their HIV condition in the way that a rich person can—no walls—easily seen by neighbors. Already stigmatized as poor people.

##### Ignorance

- Lack of knowledge on how HIV is transmitted.
- Believe that casual contact with PLHA can result in infection
- Some have the knowledge but don’t believe it—think that they can still get HIV through casual contact.

# MODULE B

## More Understanding and Less Fear

HIV stigma is rooted in both fear and ignorance. Research has shown that everyone has some information about HIV and AIDS but few have enough information to overcome irrational fears associated with HIV and its transmission. Most people know that HIV can be transmitted through sex, but few are convinced that they are not also at risk through non-sexual “casual contact”. As a result they may fail to distinguish real risks from imagined risks. For instance, they may avoid a fellow (bus) passenger thought to be HIV positive for fear of coming into contact with his blood in the event of an accident or cleaning the bed sores of a PLHA in the home. Their fear of “casual contact” will often lead to isolation and segregation of PLHAs—isolating them from others, giving them separate plates and cups and a separate room.

**Attitudes toward PLHAs** are also affected by incorrect and incomplete knowledge. Many believe that a person who tests HIV positive will get sick and die immediately. Many assume that secondary infections (such as TB) cannot be cured in an HIV+ individual. Not knowing that a PLHA can lead a productive and long life, they stigmatize and de-humanize PLHAs, calling them “walking corpses” (people who are about to die) and treat them as “useless”, “unproductive” and “burdens on the family.”



On the last day of a six week AIDS course, which included many sessions on AIDS facts, a man said,

“I don’t believe this HIV business. The real reason people are getting sick is “kufunga” (sickness attributed to a man sleeping with a woman who has had a miscarriage).” The trainer threw up her hands and said, “How can you say this after all of the things I’ve taught you?” The man replied, “Okay, if you want me to say HIV is the cause of the sickness, I’ll say it, but I don’t really believe it.” (Zambia)

So lack of knowledge leads to stigma. But knowing facts is only half the story! People may know the basic HIV and AIDS messages, but often don’t believe them.

- People’s knowledge about HIV and AIDS is often rote knowledge—information which they have received, but not internalized. They know them as simple slogans or rules—“You can’t get AIDS from shaking hands” which they are expected to follow without any real understanding. The rote knowledge does not stop people fearing getting infected through casual contact. People are not willing to gamble their lives on an untested piece of rote knowledge, which they hardly believe.
- For full understanding people need to compare, test and question the information they have heard with their own experience, beliefs and common sense.
- The correct information people have received may be contradicted by other beliefs—what

they have learned from the family, clan, tribe, church, school, media as well as their own life experiences. Often these popular beliefs (e.g. that HIV is caused by sleeping with a woman who has aborted), are more persuasive than the facts provided by AIDS educators.

The HIV Stigma Study identified knowledge gaps in the following areas:

- How HIV is transmitted and is not transmitted
- The difference between HIV and AIDS
- What it means to live with HIV—opportunistic infections can be treated
- HIV positive test result does not mean instant death
- PLHAs can be as productive as any other members of society

All of these reasons contribute to MISCONCEPTIONS AND FEARS about

- HOW HIV IS TRANSMITTED THROUGH NON-SEXUAL CONTACT; and
- WHAT IT MEANS TO BE HIV POSITIVE (potential for long and productive lives if one takes proper care, rather than instant death).

So a NEW APPROACH is needed which provides more than raw facts, but instead helps people to own or internalize the knowledge and overcome their fears.

More Understanding and Less Fear



**Educational Process**

- Create safe opportunities for participants to raise all the fears, concerns, and questions they have about HIV/AIDS
- Assess participants' knowledge level about HIV/AIDS: Find out what they know and what they don't know about HIV and AIDS, beliefs and misconceptions.
- Provide information geared directly to people's fears and misperceptions about getting HIV through casual contact. Provide information to challenge misperceptions and help participants fully understand HIV transmission and make informed decisions about different risk situations (accidents).
- Provide information on progression of the illness and treatment for PLHAs in order to counter views that people who are HIV positive will die immediately.

Provide the information in a practical and participatory learning process which allows people to internalize the information—to discuss

it with their peers, connect it to their own ideas and experience and apply it to the situations they regard as risky in their daily lives

- Analyze and challenge incorrect popular beliefs. “Every time you have sex with a woman your viral load goes down.” “Sleeping with a virgin cures AIDS.” “AIDS is caused by sleeping with a woman who has had a miscarriage.”
- Emphasize common sense around hygiene. Example: we would not share razors with other people; and we would not drink from a cup or eat from a plate which has blood on it. This is common sense.
- Emphasize that sex is the main route for HIV. Explain that even though we are discussing non-sexual (casual) contact, people's biggest risk in getting HIV is having unprotected sex. **HIV IS TRANSMITTED MAINLY THROUGH SEX.** If appropriate, ask participants whether persistent belief in casual transmission somehow makes it easier to justify unsafe sex.



## OBJECTIVES

Participants will be able to:  
Identify what things they know  
and what they don't know about  
HIV and AIDS



## TIME

1 hour



## MATERIALS

HIV/AIDS Quiz  
(Annex 5)

## ACTIVITIES

### *Warm-up game*

### **ONE STEP FORWARD**

Ask participants to stand with their backs against one wall of the training room. Then say—"All those who know the three routes of transmission of HIV and AIDS take one step forward."

Continue this process, adding new statements each time. For each topic raised, ask one person who stepped forward to explain what he knows on that topic.

After a while stop and get participants to discuss how much they know/don't know.

### **FOUR OPTIONAL METHODS TO ASSESS KNOWLEDGE**

Choose one of these exercises only. Use the **Fact Sheets** (Annex) as a resource for answering questions or areas of confusion.

### **Brainstorming on the Move**

#### **Preparation**

Put up flipchart paper on different walls of room and put a question at the top of each sheet—a) What is HIV? b) What is AIDS? c) How can you get HIV? d) What are the signs/symptoms of HIV? e) What are the signs/symptoms of AIDS? f) How can you prevent HIV/AIDS? g) How can you live best with HIV?

Ask participants in pairs to walk around and write down: a) what they know about the topic; b) any questions; c) concerns or fears. Then review each sheet and respond to questions, concerns, or misinformation.



### **All the Things We Want to Know About Aids**

Divide into pairs. Hand out 5 blank cards to each pair. Ask pairs to write on each card questions or something they want to know about HIV and AIDS and tape the cards on the wall. Eliminate repetition. Then discuss each of the questions with participants contributing their ideas. Help to sort out fact from misinformation. If any question is unclear to both trainers and participants, ask the group to research this question for homework.

### **Risk Continuum**

#### **Preparation**

Write on cards different ways in which HIV may be transmitted (see examples below).

#### **Risk Continuum**

Tape up the continuum across the front wall—"HIGH RISK," "LOW RISK," "NO RISK," "DON'T KNOW." Hand out 2-3 cards to each participant (the cards are listed in the box below) and ask participants to tape their cards under the chosen category. Then discuss their choices.

Risk level	Ways in which HIV maybe transmitted
High Risk	Many sexual partners. Sex without condom. Blood transfusion. Using unsterilized needles/razor blades. Dry sex (herbs to make vagina dry)
Low Risk	Mother to child transmission. Breastfeeding. Using condoms.
No Risk	Non-penetrative sex. Kissing. Shaking hands or touching. Cleaning or bathing HIV+ person. Cleaning up spilled blood. Sharing cups. Sharing food. Sharing sheets, towels, clothing. Using toilets. Sleeping in room of HIV+ person. Bites from mosquitoes or fleas.
Don't Know	

# ASSESSING FEARS ABOUT HIV/AIDS

## 2 EXERCISE



### OBJECTIVES

Participants will be able to:

- Articulate their fears about HIV/AIDS
- Explain how these fears affect how they respond to PLHAs



### TIME

2 hours

### ACTIVITIES

#### *Cardstorming*

#### **FEARS ABOUT AIDS?**

Hand out cards and ask participants to think about their three greatest fears about AIDS. Ask them to record each fear on a card and tape on the wall. Cluster common points.

#### **FEARS ABOUT AIDS**

Getting infected. Dying slowly and painfully. Blame, shame, isolation by others. Shame—people talking about us. The unknown. Infecting my partner. Divorce or separation. Losing friends. Losing jobs. Neglect. A friend getting sick and dying. Loss of hope. No chance to have children. Helplessness. Having to take responsibility if a parent dies. Getting HIV from nursing someone else. Leaving children as orphans. Burden to my parents if I get sick. Getting pregnant and then discovering I am HIV positive. Being scared for my teenage children.



#### *Sharing in Pairs*

#### **HOW DO FEARS AFFECT OUR ATTITUDES TO PLHAs?**

Divide into pairs. Ask pairs to discuss—“How do your fears affect the way you feel about and treat PLHAs?”

#### **FEARS ABOUT AIDS**

I worry about getting HIV from contact with a PLHA during an accident so I am very careful who I sit beside when I am travelling in a bus. I always tell my mother to separate out the dishes used by my sister in law who is sick. I've seen all my brothers die of this illness so I am extra careful about contact with anyone who looks thin.

## **Summary**

Thank participants about being open about their fears and how they affect their attitudes to PLHAs. Explain that these fears are natural and we all have them (they are rooted in basic fears of “contagion”), but that the fears are a major part of stigma. Because of these fears, we instinctively put PLHAs at a distance and this is stigma.

*Fear leads to stigma. Fear can stop us being rational and finding out the correct information; or it can lead us to accept incorrect information: thinking that blood will get 'exchanged' and get into our bodies; or thinking that HIV is on top of the skin like a skin disease/fungus and can jump inside; or thinking that a PLHA who is preparing food may have blood on his hands, the blood may get into the food and people may eat the food and get HIV.*

# FEARS ABOUT NON-SEXUAL (CASUAL) CONTACT

3  
EXERCISE

HIGH PRIORITY ACTIVITY



## OBJECTIVES

Participants will be able to:

- Name their fears in relation to specific forms of non-sexual contact with PLHAs
- Identify why they think that HIV can be transmitted through those activities



## TIME

1 hour



## MATERIALS

“QQR” Fact Sheet  
(Annex 4d)

## ACTIVITIES

### Cardstorm

### FEARS ABOUT NON-SEXUAL (CASUAL) CONTACT

Divide into pairs and ask—“What fears do you think people have about non-sexual casual contact with PLHAs at home or at work?” Ask pairs to write single points on cards and tape on the wall. Our aim is to find out **indirectly** what participants’ **own** fears are.

### EXAMPLE FROM ETHIOPIA TOOLKIT WORKSHOP

- Accidents—PLHA getting cut; coming into contact with PLHA’s blood
- Contact with PLHA’s blood when I am helping to wash him at home
- While preparing food, PLHA cuts herself by accident—blood gets on food
- Helping to lift the PLHA when s/he has deep sores
- Carrying the body of a dead PLHA to the church or cemetery
- Eating a communal meal in a common pot with PLHA family member
- PLHA holding or playing with children
- Sharing toilets—virus from inside the toilet
- Shaking hands—HIV in sweat
- Sharing utensils—spoons, cups hold HIV virus from infected person
- Kissing when the PLHA has cuts in his mouth or on his lips



Then ask participants to prioritize—“What do you think are the biggest fears?”

### Role Play

Then ask each pair to select one of the high priority fears and make a role play to show how people stigmatize because of fear of this form of contact.



Ask pairs to present their plays. After each role play ask:

- “What happened?”
- Why do people think those forms of contact will lead to HIV infection?”

### EXAMPLE FROM ETHIOPIA TOOLKIT WORKSHOP

#### **Shaking Hands**

Friend avoids shaking hands by pulling his hand away. Why? HIV will spread through body contact so I don't want to touch him.

#### **Kissing On Cheek**

Person avoids kiss on cheek, using as an excuse “I can't hug you because I have a bad/cold.” Why? PLHA may have cuts on the face and I may contract the virus through kissing the cheek.

#### **Injured Person**

Person avoids contact with injured person who he suspects is HIV positive. Why? Blood might get on me if I touch him and I would get HIV.

#### **Sharing Toilet**

PLHA goes to toilet. Another person avoids using the toilet after him. Fears that HIV can be transmitted through the toilet seat.

#### **Sharing Utensils**

PLHA is a family member. Puts plates into a separate pile and writes the name on each plate so that they can be kept separately. Fears that he will be affected through "germs" left on the plate.

### **Processing**

Take each example and review WHY people think that HIV can be transmitted in that way. Then review the FACT SHEET and discuss why HIV cannot be transmitted through casual contact.

### **Option (more participatory)**

Divide into groups and assign each group one of the priority situations in which people fear casual contact. Ask the group to use the QQR Fact Sheet to develop a presentation to challenge this misperception.

### **Summary**

Hand out and discuss the Fact Sheet on Quality, Quantity, and Route of transmission (QQR).

# FEARS ABOUT CARING FOR PLHAS AT HOME

## 4 EXERCISE



### OBJECTIVES

Participants will be able to:  
Identify the places in the home  
where they fear non-sexual  
contact with PLHAs



### TIME

1 hour

### ACTIVITIES

#### *Household Mapping*

#### **FEAR AND STIGMA IN THE HOME**

Divide the participants into groups.

#### **Group Task**

- Make a drawing of a typical house in your community on a flipchart sheet.
- Mark on the drawing “points in the house where people might be scared of getting HIV through non-sexual contact with PLHAs and this leads them to stigmatize (e.g. isolate) PLHAs.”

#### **Report back**

Ask each group to present their drawing and explain why each area that they have marked makes them scared and results in stigma.

#### **Group work**

Divide into the same groups. Ask each group to identify what for them is the biggest fear or concern about casual contact in the home and then explore:

- Why do people think that this activity may lead to HIV infection?
- How do these fears lead to stigma?
- What are the facts which counter this fear or knowledge gap?

**EXAMPLE FROM ETHIOPIA TOOLKIT WORKSHOP (May 2003)**

<b>Bathroom</b>	<b>Small Bedroom</b>		
X1	X3	X4	X5
X2	X6	X7	X8

<b>Kitchen</b>	<b>Main Bedroom</b>	
X9	X10	X11
<b>Sitting Room</b>		<b>Small Bedroom</b>
X13		

**Code: Possible Points of Fear and Stigma in the Household**

**Bathroom**

- X1 Fear of getting HIV while helping to wash/clean PLHA
- X2 Uses these facilities alone—fear of sharing of facilities

**Backroom**

- X3 Told to stay in the backroom away from visitors
- X4 This area is prevented from getting visitors
- X5 Family prevents their children from playing with PLHA
- X6 No sharing of blankets and clothing
- X7 Given separate plate and utensils and asked to eat here alone
- X8 Left out of family discussions and decision-making

**Kitchen**

- X9 Prevented from cooking for the family or himself
- X10 Fear of accidents/cuts while cutting meat—fear of HIV transmission through blood
- X11 Family eats together without PLHA—no sharing of food

**Main Bedroom**

- X12 No sharing of blankets

**Sitting Room**

- X13 Minimal contact with visitors—kept in hiding





## OBJECTIVES

Participants will be able to:  
Have a clearer understanding of  
the practical realities of living  
with HIV and AIDS



## TIME

1 hour

## ACTIVITIES

### *Cardstorm*

#### **MYTHS**

Divide into pairs and hand out cards. Ask pairs to write on cards all the things they have heard about the lives of PLHAs after they have learned they are HIV positive—myths, misconceptions, do's and don'ts.

Cluster common points and review the list. Explore the thinking behind the myths and misconceptions, and the effect the myths/misconceptions have on PLHAs. Clarify any questions and uncertainties.

#### **TESTIMONY**

Invite a PLHA to come and talk to the group about their own experience—and answer group questions. Ask the PLHA to address some of the myths identified in Step 1.

### *Case Study*

#### **LIFE GOES ON**

Divide into groups and hand out a copy of the case study. Ask groups to make a list of things they learned from the case study.



## DOROTHY'S STORY

Dorothy is 28 years old. Three years ago she was tested for HIV. She was a member of one of the evangelical churches, which had planned a mass wedding ceremony for its members. All those taking part had to take a test. After her test, Dorothy was simply told that she would not be taking part. She was given no counseling or support. She only guessed that she was positive.

Dorothy did not tell anyone for two months. She stopped going to church and felt very alone.

Then she asked one of her close friends for advice. Her friend suggested that she go to Kara Counseling

Centre to check the result. She offered to go with her. Dorothy took the test again, but this time talked for a long time to a counselor. The test came back positive. Dorothy continued to see the counselor, and eventually told her Auntie whom she stays with.

Dorothy joined a skills-training scheme for people living with HIV and learned tailoring skills. Two years later she is running a successful tailoring business. She has married and is expecting her first baby. In her spare time, Dorothy gives talks to schools and workplaces about HIV and AIDS.



# WHY PEOPLE DON'T BELIEVE AIDS FACTS

**6**  
EXERCISE



## OBJECTIVES

Participants will be able to:  
Describe a number of beliefs which affect people's attitudes towards HIV/AIDS



## TIME

1 hour

## ACTIVITIES

### Cardstorm

### INTRODUCTION

Divide into pairs and ask pairs to brainstorm beliefs around HIV/AIDS.

### Task Groups

Divide into task groups. Ask each group to select one of the beliefs and try to explain it.

- Where does this belief come from?
- What are some of the reasons or thinking behind the belief?

## EXAMPLES OF POPULAR BELIEFS

- Condoms transmit HIV
- Using contraceptives such as the pill or loop can prevent a woman from getting HIV.
- HIV is caused by sleeping with a woman who has had a miscarriage.
- HIV is caused by witchcraft.
- The partner who falls sick first is the person who got infected with HIV first—who “brought HIV into the family.”
- Sex with a virgin/young girl cleanses you of HIV.
- Every time you have sex with another person your viral load goes down.
- If one partner is HIV positive, the other must also be HIV positive.
- Holy water can cure you of AIDS (Ethiopia).



### FACTORS AFFECTING BELIEFS

Day to day experience and survival learning. Common sense understanding of other illnesses. Teachings of the family, clan, tribe, church. Ideas from our peers. Facts learned at school. Media messages. Popular beliefs and sayings. Level of trust in AIDS educators or health workers.



#### *Cardstorm*

### **FACTORS AFFECTING OUR BELIEFS**

Hand out cards and ask participants to write: "What factors affect what we believe about diseases such as HIV/AIDS?"

#### *Cardstorm*

### **FACTS WE DON'T BELIEVE**

Divide into pairs to discuss:

- What do you know already about how HIV is transmitted?
- Which of those facts do you misbelieve and why?
- Who gives you information on AIDS? Do you trust people who give you information on AIDS? Do you trust their information? If not why not?

(Probe for traditional beliefs which would make people distrust what they get through AIDS educators or health workers.)

#### **Reasons why people may not trust factual information provided on AIDS**

- Educators give contradictory, confusing, or incomplete information
- Audience may not believe educator because of own beliefs, life experience, knowledge

#### **Traditional beliefs which make people distrust facts on HIV/AIDS**

- Faith groups—no sex before marriage
- Religious groups—virus is the result of sin
- White people brought AIDS to Africa
- HIV is in the condom
- God is punishing you so there is no cure
- Muslims don't get HIV

# MODULE

# C

## Sex, Morality, Shame and Blame

Many diseases are associated with shame and blame. Because HIV is sexually transmitted it is heavily associated with sex and “bad behavior” on the part of the affected individuals. In the stigma research study<sup>1</sup> many people reported that they believe that people living with HIV get it through sexual activity that goes against the social norms or religious teachings. The link between sex, religion and stigma is also crucial where there is strong belief that HIV is a punishment from God.

This module aims to tackle the difficult subjects of sex and morality in our daily lives and explore these issues in relation to HIV-related stigma.

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<sup>1</sup> Disentangling HIV and AIDS stigma in Ethiopia, Tanzania and Zambia, ICRW, 2003.

# WE ARE ALL IN THE SAME BOAT

1  
EXERCISE

Warm-up game



## OBJECTIVES

Participants will be able to:  
Recognize that all people are at risk of getting HIV so there is no point stigmatizing those who already have HIV



## TIME

15 minutes

## ACTIVITIES

### *Game and Discussion*

## WE ARE ALL IN THE SAME BOAT

Facilitate the game described below.

Then discuss, “What does the game mean?”

## GAME

### **“In the river, On the bank”**

Ask players to stand in a line all facing same direction. Then explain the game.

“Where you are standing is the bank. When I say, “In the river”, you should take one step forward. If, however, I say “On the river”, you should not move.

When I then say, “On the bank”, you should take one step back to the starting point “On the bank”. If, however, I say “In the bank”, you should not move. If anyone makes a mistake, they will be eliminated from the game.”

Start the game. Give the commands quickly. If anyone makes a mistake, ask them to leave the game. After a few minutes, stop and debrief.



### ZAMBIAN SAYINGS

“Whatever misfortune befalls me, tomorrow it may be YOU! Your friend's misfortune can become your misfortune.

*(Chaona muzaka chapita mawa chili pa iwe).*

Your funeral is my funeral. When I have a funeral, you will come to comfort me. We will take care of each other's burdens.”  
*(Malilo nikulilana)*

### Debriefing

Note that everyone laughed when the first person made a mistake. Ask the person who made the mistake—“How did that make you feel?” [*embarrassed, angry, stigmatized, the laughter made me feel bad!....*]

Then explain that this game shows us that “We are all in the same boat.” There is no separation between “us and them.” We are all facing and living with this epidemic together. We are all affected—we have all taken risks at one time in our lives and many of us still do and we all have family members and friends who have died of AIDS. Lots of people like to laugh at, blame and judge others, but one day they may also “fall into the river”—and others will laugh at them. **Remember:** HIV affects everyone.

All of us are at risk of getting HIV so there is no point in stigmatizing or blaming those who are already affected. We could join them any day!



## OBJECTIVES

Participants will be able to:

- Identify labels used by people to stigmatize PLHAs and other stigmatized groups
- See that these words hurt



## TIME

2 hours

## ACTIVITIES

### Warm Up

### SWITCHING CHAIRS GAME

Set up chairs beforehand in a circle or square around the walls of the room. Allocate roles to each person going round the circle—“PLHA, Sex Worker, Teenage Girl, Gay Man, Street Child, Widows.” Continue until everyone has been assigned a role. Then explain how the game works.

I am the **caller** and I do not have a chair. When I call out two roles, “PLHAs” and “Sex Workers,” all the “PLHAs” and “Sex Workers” have to stand up and run to find a new chair. I will try to grab a chair. The person left without a chair becomes the caller - and the game continues. The **caller** may also shout “**revolution**”—and when this happens, everyone has to stand up and run to find a new chair.

Then shout: “PLHAs and Sex Workers” and get the “PLHAs” and “Sex Workers” to run to a new chair. This starts the game.

### Debriefing

Ask: “How did it feel to be called a PLHA or sex worker?”

### Rotational Brainstorm

### THINGS PEOPLE SAY ABOUT

Divide into six groups based on the roles assigned for the game—all the sex workers together, all the street kids in one group, etc. Ask each group to go to its flipchart station. Hand out markers and ask each group to write on the flipchart all the things people



say about those in the group.” After two minutes, shout “Change” and ask groups to rotate. Continue until groups have contributed to all five flipcharts and end up back at their original list.

### SOME EXAMPLES OF THINGS PEOPLE SAY ABOUT

#### PLHAs

Promiscuous. Sinners. Put their hands where they shouldn't. Naughty. Careless. Reckless. Cursed. Not lucky. Bewitched. Useless. Foolish. They didn't listen. Good for nothing. Deserve to die. It's their own fault. Punished by God. Death sentence. Walking dead. Walking skeleton. Submarine. Already dead—we are just waiting for the funeral. Who cares if they die. Good riddance. No future. Life has ended. Hard to take care of. Say goodbye to your mother. A burden. Waste lots of money. Candle in the wind. You can get infected by touching them.

#### Sex Workers

Immoral. Evil. Sinners. Promiscuous. No shame. Sandras. Lazy to work. Irresponsible. Steal husbands. Break marriages. Sex maniacs. Don't practice safe sex. Don't respect their bodies. Sexually expired. Selling your bottom to feed your mouth. Making money by lying down. Poor—need money. Business. Want money for things they need. Burden to family and society. Drain on national resources. Spread AIDS and STDs.

#### Teenage Girls

Naughty. Mischievous. Like money and gifts. Fashion conscious. Sluts. Sex objects. T-bone meat. Love sex. Cheap to get. Give them money and they are yours. Depend on anyone. Medicine for AIDS. Fresh from the farm. Husband stealers. Hard working.

#### Gay Men

Immoral. Sinners. Unacceptable. Abnormal. Sex maniacs. Sick in the mind. Misfits. Insane. Need therapy. No feelings for the opposite sex. Sexual organs don't function. It's a phase—need to grow out of the phase. Don't want to change because of the fast money they can earn. Spread HIV because they are HIV carriers. Will erode our morals. Should not get married. Should not be allowed to adopt children. Should be castrated. Should be segregated. Take them far away and dump them.

#### Street Kids

Beggars. Rogues. Thugs. Homeless. No manners. Rejects from poor families. No respect for people. Stubborn. Dirty and stink—they don't bathe. Eat dirty foods. Sleep anywhere. Steal money or grab food. Lazy. Don't want to go to school. Glue sniffers. Nasty. Violent. Murderers. Rapists. Illiteracy. Sex workers. Make our streets dirty. Disturb our peace. Parents died of AIDS. Abusive language. Pretend to be street kids but they have homes. Abused. Illegitimate. They need love and positive support.

#### Widows

Husband killers. HIV carriers. Husband stealers. Dangerous—source of evil and trouble. Witches. Evil people.



### Report back: Gallery Review

Walk as a group around the room looking briefly at each of the flipcharts. At each flipchart ask:

- How do you, "the Orphans" (PLHAs/etc), feel if you are called these names? (Ask those who were assigned this label to react to these names.)
- In what situations do these comments hurt the most?
- What are the judgements or assumptions behind some of these labels?

### Group Work

## IMAGES OF PLHAs AND CONSEQUENCES

Review the lists of characteristics (see above). Ask groups to discuss:

- If these images of PLHAs are commonly believed, what are the consequences for PLHAs?
- What are the effects of these images?
- If the effects are negative, what can we do to help change these effects?

Image	Effects	How to Change
Promiscuous. Sinners. Foolish. Careless/reckless	Judged, blamed, and condemned by society	Advocate to others that we are "all in the same boat" –that we all put ourselves at risk at times in our lives
Useless. No longer productive. Waiting to die. Burden.	Treated as no longer able to contribute.	Educate society that PLHAs can contribute. Empower PLHAs to lead full, active lives. Create opportunities for PLHAs to use talents
Dangerous: they can infect other people through touch	Isolated and excluded and "quarantined"	Educate people about HIV transmission so they stop fearing casual contact with PLHAs



“ We are not victims, we are not patients, and we are not sufferers. These names are both derogatory and disempowering. We are people living with HIV. We laugh, we cry, we dance, we sing, we play, we argue, we pay tax, we are parents and children. We belong to families. We are all in communities. Above all these things we are part of human nature. That is the second challenge: destigmatizing ourselves and HIV/AIDS.”

**Thanduxolo Doro,**  
*speaking at the First National Summit for People Living with HIV/AIDS, held at the Eskom Conference Centre in Midrand, South Africa, October 2002.*

*Source: SafAIDS.*

# DOUBLE STANDARDS

## 3 EXERCISE



### OBJECTIVES

Participants will be able to:

- Explain the meaning and give examples of double standards in their lives
- Explain what can be done to reduce double standards in our communities



### TIME

30 minutes



### MATERIALS

Cards

### ACTIVITIES

#### *Cardstorm*

#### **INTRODUCTION**

Divide into pairs and ask pairs to write on cards

"What are some examples of double standards that we see around us?"

#### **GAME**

- We stigmatize others for "promiscuous" behavior which we are doing ourselves.
- We tell others to "Abstain, Be faithful and Condomize" and then go out and have unsafe sex with someone else's spouse.
- Pastor who preaches about sex and sin and then has an affair with his parishioner.
- The extended family advises a man to divorce his wife if she is HIV positive, but if the husband is HIV positive, they expect the wife to look after her husband.

Stick cards on wall and ask one of the participants to read through and summarize.

#### **Reflection**

Ask participants to sit on their own and think of a time in their lives when they didn't "practice what they preach." After 5 minutes ask them to find a partner and discuss: "Why is there often a big gap between what we say and what we do?"

#### **Summary**

- Some people use double standards to stigmatize others
- Sometimes people who stigmatize others are hiding something or are fearful about something in their own life



## OBJECTIVES

Participants will be able to:  
Identify the effects of stigma on  
different players and institutions



## TIME

1 hour



## MATERIALS

Character cards, e.g.,  
farmer, soldier, sex  
worker, housewife,  
businessman.

Three categories along  
the wall—HIGH RISK,  
LOW RISK, NO RISK

## ACTIVITIES

### Character Cards

#### SELECTION

Ask each person to select a character. In pairs, discuss the lifestyle of your character with your partner:

- What do they do for a living?
- Your perceived HIV risk status of this person and why

#### Sharing

Ask each participant to introduce their character—what they do and their perceived health risk—and then put the picture under one category.

#### Changes

Invite other participants to make any changes and explain why.

#### Discussion

- What did we learn from this exercise?
- How does the community perceive or judge high-risk people? What words do they use? What are the attitudes behind the words?
- What assumptions do we make about people?
- How do we judge/misjudge people? How do we resist judging people?

## EXAMPLES (FROM ETHIOPIA NGO WORKSHOP, March 2002)

**Businessmen:** Difference between businessmen who travel and those who remain at home. Mobile businessmen—high risk—free to have many partners in the towns on their route. Businessmen are often in positions of power—they may abuse their power in order to have sex with employees.

**Soldiers:** High risk. "Mobile men with money." Lots of freedom. Many partners. Long separation from regular partners. Negative behavior: forcing women to have sex.

**Farmers:** High risk. Illiterate and limited access to information about AIDS. Go to town to sell their crop - afterwards have drink in bar and have sex. No strong sanctions about this behavior

**Drunkards:** High risk. Because of heavy drinking, engage in sex with many partners and/or unsafe sex (i.e. without condoms), or maybe they are too drunk to have sex!

**Female Students:** High risk. Vulnerable to sexual demands by "sugar daddies", teachers and businessmen. Some dress/walk in a provocative way to get attention.

**Children:** May be high risk - vulnerable to sexual abuse or rape. Youth want to experiment with sex.

### ***Story + Cardstorming***

## **JUDGING OTHERS**

Ask participants (in pairs) to read the story below and write down their immediate thoughts, feelings and gut reactions. Tape all the cards on the wall and ask participants to read them.

### **Discuss**

- Do we judge people “who should know better” (counselors, nurses, doctors, etc.) more harshly?
- Research about stigma found that nurses were more stigmatized if they got HIV and often wanted to hide their status for as long as possible. Why do you think this is?

### ***Reflection***

## **JUDGING OURSELVES**

Ask participants to spend 10 minutes alone and reflect about: What have you done in your life that is culturally unacceptable? What judgments could be made against you by others? How would they make you feel?

### **Sharing**

Ask participants to pair up with someone they feel comfortable with. Discuss how it felt to do the reflection (NOT the “unacceptable behavior,” but the feelings).

*Option:* Come into a large group for sharing.

## **Summary**

- We are all capable of misjudging people based on their occupation, dress, age or gender.
- We make assumptions about people—and this is a source of stigma. Example: barmaid is assumed to be sexually active because she works in a bar but this assumption may be wrong.
- We have all done things in our lives which others would “judge badly.”

### Stigmatization involves

- **Judging or blaming** people.
- The judging is based on **assumptions** about people's sexual behavior.
- As humans we often believe or assume the **WORST** about other people.
- We assume that certain categories of people because of their occupation are at risk: sex workers, truck drivers, soldiers, or mobile businessmen.
- **We are all at risk**—so we should stop judging others
- HIV is not limited to groups or occupations—it is in every community

**Source:** Adapted by Dr. Gad Kilonzo from *The Fleet of Hope* (Bernard Joinet and Theodore Mugolola, 1994).



“Let he who is without sin cast the first stone.”

# BREAKING THE "SEX" ICE

## 5 EXERCISE



### OBJECTIVES

Participants will be able to:

- Talk more openly about sex and their feelings about sex and sin
- Recognize that the view that "SEX = SIN" is one of the roots of stigma



### TIME

1-2 hours

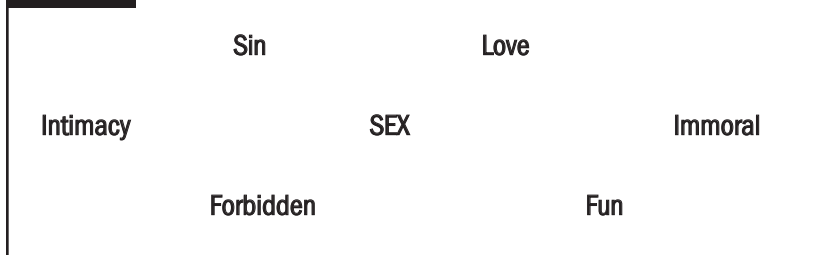
### ACTIVITIES

#### *Cardstorm*

#### **BREAKING THE "SEX" ICE 1 — (OUR IMAGES OF SEX)**

Put up the word "SEX" on a card at the centre of the wall. Hand out cards and markers to participants and ask them to write the first things they think of when they hear the word "sex" and tape on the wall around the central card.

#### EXAMPLE



#### **Debrief**

Ask: "What does this tell us about how people think about sex?"

#### *Gender Group Discussion*

#### **BREAKING THE "SEX" ICE 2 — WHY DO WOMEN OR MEN HAVE SEX?**

Divide into same sex groups. Ask groups to do a quick brainstorm on two questions and record on flipchart.

- Why do women have sex?
- Why do men have sex?

Put up the flipcharts (the women's lists and the men's lists alongside each other) and compare the views of women and men.

**Discuss**

- Some of the reasons will be similar, some may be very different. What does this tell us about attitudes to sex?
- How are men and women different?
- Do the answers show any links to sin?

**Cardstorm in pairs**

**GOOD (SINLESS) SEX vs BAD (SINFUL) SEX**

Hand out cards to pairs and ask them to write examples of the "good" sex and "bad" sex. One example per card. Tape the cards on the wall in two columns beside each other. Example below.

Good (Sinless Sex)	Bad (Sinful) Sex
Sex with one's spouse	Sex with sex worker
Sex for procreation	Sex for pleasure
Sex after you get married	Sex before you get married
Sex in a bed	Sex in the bush
Sex at night	Sex any time of the day
Sex without a condom	Sex with a condom
Sex with the opposite sex	Sex with the same sex (gay sex)

**Summary**

Although we are aware of these judgments, many of us do have "sinful" sex, even though we may keep it hidden. Sometimes this links to the "double standards." Sometimes we feel ashamed. Not being able to discuss sex more openly may lead to people taking more risks. These judgments about sex and sin can fuel stigma against PLHAs.



When PLHAs get sick, some people say that "they cannot hide anymore"—they are exposed. In Zambia a common word for PLHAs is "Kanayaka" which has many meanings, such as "the light is on," "you can be seen," "the warning light shows you are finishing," etc. These attitudes often link to the way we feel about sex, that it should be hidden, secret, not discussed. Thus the shame of HIV/AIDS is that your past sexual behavior can now be seen.

### Embarrassment is an Opportunistic Infection

I am embarrassed to talk about SEX  
So I avoid talking to my children  
I giggle and laugh nervously  
Whenever the word SEX is mentioned  
I am too embarrassed to look up

In the age of HIV/AIDS  
My embarrassment continues  
About SEX, AIDS and CONDOMS  
I am even afraid to read about the disease  
I am so embarrassed

Now I am at a loss  
My daughter, my son  
My husband and I have AIDS  
We have never talked about SEX and AIDS  
Even when we knew better  
We were too embarrassed  
Too embarrassed to protect ourselves  
Too embarrassed to keep DEATH at bay

Now I am too embarrassed  
To let anyone know about us  
My family and AIDS  
Then one day  
My mother opened my eyes  
She said "Your family is not dying of AIDS  
It is dying of embarrassment,  
A deadly OPPORTUNISTIC INFECTION"

Today we are no longer sick with embarrassment  
We know better  
That no one ever died of embarrassment  
But DAILY a loved one dies of AIDS



*By Mwaganu wa Kaggia*



## MODULE C

Sex, Morality,  
Shame and Blame

### 6 EXERCISE

# WHERE DID YOU GET IT?



## OBJECTIVES

Participants will be able to:

- See that asking PLHAs "where did you get it" can be judging or stigmatizing
- Analyze why people always ask this question when they meet PLHAs
- Explain how this question makes PLHAs feel
- Formulate arguments to counter this type of question when it occurs



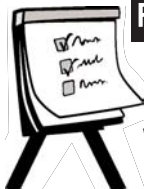
## TIME

30 minutes



## MATERIALS

Character Cards.  
Finger Pointing Pictures  
(A2 & A3)



## PREPARATION

Make up a simple song or chant with the words "WHERE DID YOU GET IT?" in English or a local language. Ask participants to help you.

## ACTIVITIES

### *Game and Song*

### **INTRODUCTION**

Explain that this session will look at why the first thing people always ask PLHAs is "Where did you get it!"

Introduce the song or chant and get everyone singing/chanting it, walking around in a circle. Then ask people to stop and explain the game.

Pass the object (masking tape) around the circle. When the leader claps, the person holding the object at that time has to step into the center of the circle. The whole group points their fingers at him/her and chants 3 times, "**Where did you get it?**" The person in the centre responds to the same beat as the chant—"I got it from my husband." Record on flipchart and continue the game.

### *Buzz Groups*

### **WHY DO WE ASK THIS QUESTION?**

- How did you feel when asked this question with everyone pointing fingers?
- Why do we ask this question: "Where did you get it?"
- Does the answer make a difference to how we respond to that person?

### **Report back**

Help the group to see that:

- This question is judging—we want to know how people have "sinned."
- The question makes PLHAs feel bad or condemned.

### ACTION IDEA

Try out these new ways of challenging stigma, in your community whenever you hear or see someone stigmatizing.



- Maybe it reassures us if we find out that the person got it by doing something that we have not done!

### *Stop-Start Drama*

## **HOW TO COUNTER THIS RESPONSE**

### **Discuss**

“How can we counter this stigmatizing behavior when it occurs in a social situation?” Play it out—a few actors in the circle.

Discuss after each drama and invite others to take over the roles and try out different ways of challenging this behavior.

# CARRYING CONDOMS CARRIES STIGMA

## 7 EXERCISE



### OBJECTIVES

Participants will be able to:

- Understand how carrying condoms carries stigma
- Think about different ways to challenge this form of stigma when talking about HIV/AIDS



### TIME

1 hour



### MATERIALS

Package of condoms

### ACTIVITIES

#### *Cardstorm*

#### **WHY ARE CONDOMS STIGMATIZED?**

Tape a condom pack on the wall. Divide into pairs and ask - "Why do condoms carry stigma?" Ask pairs to write their points on cards and tape on the wall. Discuss.

#### *Role Playing*

#### **ASSESSING CONDOM USE**

Ask the group if anyone has a condom with them. Tell them you need one for the next exercise. Check out if people are free to ask each other, feel embarrassed etc.

- Divide into small groups and hand out the role-play scenarios below. Ask participants to prepare a role-play to show the whole group.

Use "Stop-start Drama" to explore the issues at a deeper level. Make your own scenarios to fit your group.

### GAME

**Dropping condoms (1):** A mother asks her son to borrow some money. As he brings out his wallet, a packet of condoms falls out.

**Dropping condoms (2):** A Father asks his daughter to borrow some money. As she brings out her purse, she drops a packet of condoms.

Girlfriend and boyfriend are talking about having sex for the first time. The girl brings out a packet of condoms.

Two male friends chatting together about HIV/AIDS in their country. One starts to discuss using condoms.

A group of girl friends chatting together at home. One is very religious. One brings out a packet of condoms.

Husband and wife have recently tested HIV positive. They discuss their future. The husband brings out a packet of condoms.



### HAGOS STORY

We had all met the girl my son was going out with. When he was packing to go to university, he accidentally dropped a packet of condoms out of his bag in front of me. He seemed embarrassed, but I just picked them up and handed them back to him. I told him I was glad he was practicing safe sex. (Because of my job, I have taught him about gender issues and sex education and condoms). I felt proud of him.

*Ethiopia 2003*

### Discuss

- How can we challenge the stigma around condoms?
- How can we show support for the idea that they show someone is being responsible?

### Summary

- Condoms link to sex and so to sin and assumptions about someone's behavior and carry stigma.
- We need to change things so that condoms are linked to being responsible.



## OBJECTIVES

Participants will be able to:

- Discuss and explore HIV stigma in relation to gender
- Develop ways of looking at perceptions of risk behavior in relation to gender
- Explain the factors that contribute to women being more stigmatized than men



## TIME

1-2 hours



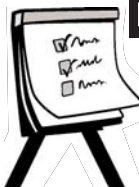
## MATERIALS

Character pictures or character descriptions on cards (below).

### Character Descriptions

Married working woman. Male bar owner. Female bar owner. Truck driver. Wife who sells goods in the next town. Daughter who meets her friends every week in the nightclub. Business executive. HIV counselor who attends a lot of workshops.

**Note:** Some characters are not defined as a man or woman. This can be used to challenge assumptions, if appropriate.



## PREPARATION

Set up a "BLAME" CONTINUUM on the front wall—with GUILTY at one end and INNOCENT at the other

## ACTIVITIES

### Blame Continuum

#### WHO IS TO BLAME?

Hand out one picture/card to each participant. Ask each participant to describe his/her character and place the card on the continuum:

- Who is the character? What does s/he do?
- Where would this person be on the BLAME CONTINUUM? (Ranging from most likely to least likely to bring HIV into the family)

### Discuss

- Why are the cards placed where they are?
- What makes someone more likely to be blamed?
- How does the blame link to gender?
- Are women blamed more than men?

### Small Group Brainstorming

#### ATTITUDES TO SEX WORKERS

Divide into small groups. Ask participants to brainstorm all the words/labels/insults used by people to describe commercial sex workers.

### Report back

Display the flipcharts. Ask participants to read the lists. Ask participants to explain words that are not clear.

If you have already done this exercise (C1), use the flipchart for sex workers.

### Sharing (pairs)

Ask pairs to share how they feel about these names.

**TRAINER'S NOTE**

You can do the same exercise, but focus on “teenage girls” instead of sex workers.



**Large group: Analysis**

- What are the feelings behind these names?
- How do these judgments link to attitudes and beliefs about women and sex?

# MODULE

# D

## Caring for PLHAs in the Family

Stigma and caring in the family are closely linked—some forms of stigma are triggered by family members not knowing what to do or how to care for HIV affected members. This, coupled with poverty and economic stress, creates conditions where frustrations can easily lead to stigma, with PLHAs being blamed for “being a burden” or neglected because families feel overwhelmed by the duty of care and support. Caring for PLHAs is something new and many family members have little idea how they can best look after PLHAs.

This is a new area of practical knowledge that people need to learn. Many family members have the basic equipment—the love for one’s close relatives—but they need other knowledge and skills: how to provide emotional support effectively, how to respond to health crises and how to share the burden of care. To manage HIV better in the household people need skills, understanding, compassion and external support (access to free treatment).

We hope that through this chapter, families will be able to explore the challenges of caring for a PLHA and that through more knowledge and sharing, stigma will be reduced.

# HOW HIV AFFECTS THE FAMILY

## 1 EXERCISE



### OBJECTIVES

Participants will be able to:

- Discuss more openly how AIDS affects the family
- Identify some of the critical issues related to living with, caring for and not stigmatizing PLHAs in the family/home
- Agree on the specific issues they would like to discuss in more detail



### TIME

1 hour



### MATERIALS

Selection from Stigma pictures (A23, A25, A26, A27, A28, A29, A42)  
Alternatively this could be done with a role-play, which stops at the point where the family finds that one family member has HIV

### ACTIVITIES

#### *Picture-Discussion*

#### **AFFECTS OF HIV ON THE FAMILY**

Put the picture(s) on the wall or organize a role-play based on one of the themes in the picture. Then discuss in small groups

- What is happening in this picture (or role play)?
- What happens when the family finds that one family member has HIV:
  - What are the IMMEDIATE EFFECTS?
  - What are the LONGER TERM EFFECTS?
  - What are the EFFECTS ON THE PLHA?
- What are families already doing to provide care and support for PLHAs?
- What is blocking families from helping PLHAs?
- What practical things can we do as families to support PLHA family members?

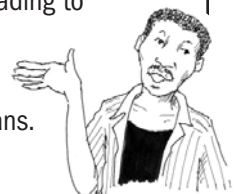
### EXAMPLES

#### **Immediate effects on the family**

Shock. Anger. Disappointment. Worry. Grief. Sorrow. Fear of caring for PLHA—why? Burden and fear of infection. Put him in an isolated bedroom. Fear of neighbors finding out and being stigmatized. Family denial—refuse to accept results. Family inaction—don't know what to do. Hatred within family. Blaming and shaming—"I told him not to go out at night."

#### **Longer term effects on the family**

- Conflicts within the family. Divorce or separation.
- Heavy burden on the caregivers (usually women) leading to burnout.
- Loss of income and money problems.
- Children drop out of school and may become orphans.
- Widows. Sexual cleansing. Property grabbing.





### ACTION IDEAS

Take a few of the pictures home and discuss the issues raised with other family members.



### EXAMPLES

#### Effects on PLHA

- Lose job, friends and self-confidence.
- Become withdrawn and depressed—may resort to drinking.
- Lots of worry, isolation and self-isolation.

#### What are families doing already to provide care and support for PLHAs?

- Taking PLHA family members for medical treatment from hospitals, faith groups or faith healers (traditional doctors)
- Raising funds for medical treatment.
- Getting help from faith groups.
- Trying to provide good food and nutrition
- Informal counseling.

#### What is blocking families from helping PLHAs?

- Lack of knowledge on how to care for PLHAs.
- Fear of infection due to lack of knowledge about HIV transmission.
- Blaming and judging attitudes.
- Poverty, fatigue, burnout

#### What practical things can we do to support PLHA family members?

- Encourage PLHAs to talk openly about their feelings and listen.
- Don't decrease interaction— treat them as you treat other family members.
- Chat and spend time with them. Make them feel wanted.
- Encourage them to identify and get treated for opportunistic infections.
- Create a fund for family emergencies related to HIV/AIDS.
- Connect them with other PLHAs for sharing experience and feelings.
- Encourage the PLHA's friends to visit.
- Encourage PLHAs to practice safe sex to avoid getting more HIV.
- Get help from and participate in Home Based Care program
- Get help from Hospice
- Support from church
- Arrange schooling and support for orphans.
- Organize the sharing of “caring work” among all family members.
- Resolving conflicts between partners.

*Ethiopia Toolkit Workshop, May 2003*

# STIGMA IN THE FAMILY AND HOUSEHOLD

## 2 EXERCISE



### OBJECTIVES

Participants will be able to:  
Identify various forms of stigma  
in a household with a PLHA.



### TIME

1 hour



### MATERIALS

Set of pictures  
showing stigma  
towards PLHAs in the  
family - A6, A7, A8, A9,  
A14, A15, A16, A17,  
A20, A23

### ACTIVITIES

#### *Picture-Discussion*

#### **STIGMA IN THE FAMILY**

Divide into groups and give each group a picture. Ask them to discuss:

- What do you see? What do you think is happening?
- Does this kind of thing happen in your family/household?
- How does it affect you? How does it affect the PLHA in your house?
- What can you do to solve this problem?



### GAME

- Separation of utensils—plates, cups, spoons.
- Burn or discard clothing and other things used by PLHA
- Physical isolation—Forced to sleep alone or in a separate room.
- Minimum physical contact. No hugging. Told not to touch/play with children.
- Hidden from neighbors so they can't see what is happening and stigmatize.
- PLHA feels passive and helpless. No role in house. Treated as if invisible. No longer economically valuable to the family so made to feel useless.
- Treated as a burden—extra money needed for food and treatment
- No input into family decision-making—all decisions made by other members.
- Judging. Blaming. Condemning. Made to feel s/he has disgraced family.
- Family members are not honest about their feelings towards PLHAs.
- PLHA is moved from house to house by different family members.
- When PLHA becomes very sick, dumped back in the village.
- Family members stop providing treatment, saying this is a waste of resources
- Women face violence, separation/divorce, and loss of income.
- Partners/spouses of PLHAs are assumed to be HIV positive
- In-laws blame spouse for HIV (HIV exaggerates tensions with in-laws)

### ACTION IDEAS

Take your story or one of the pictures home and discuss it with family or friends.



### Report back to large group

#### *Buzz Groups*

### **EXPERIENCES WITH STIGMA**

Divide into pairs and ask:

- What personal experiences have you had with HIV?
- How did those experiences affect you and your family?

Ask pairs to write a short story incorporating all the different experiences. Then in the large group ask each group to read its story.

### **Summary**

Explain how stigma in the family takes many forms: isolation, blaming, and judging PLHAs and the first step towards changing it is to identify it.

# STIGMA TOWARDS THE FAMILY



## OBJECTIVES

Participants will be able to:

- Describe how a community stigmatizes families who are caring for PLHAs
- Develop strategies on how to address this form of stigma and discrimination



## TIME

1 hours

## ACTIVITIES

### Story

### **STIGMA TOWARDS HIV AFFECTED FAMILIES**

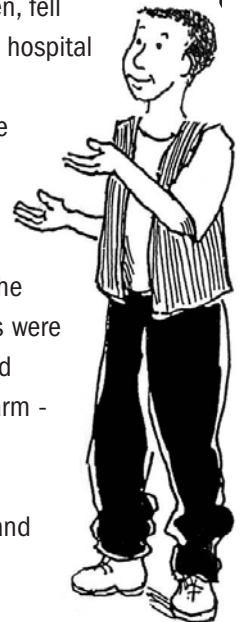
Ask one participant to read the story below.

#### STORY

Mr. Kalyabantu, a farm worker married with two children, fell sick. He was admitted at a hospital. During the stay in hospital he took an HIV test and tested positive. During the counseling session Mr. Kalyabantu decided to have the Home Based Care (HBC) team visit his home for continued care and support.

One month later Mr. Kalyabantu was discharged and the HBC team visited him at home. The other farm workers were very upset when they heard he had HIV and demanded that Mr. Kalyabantu and his family be kicked off the farm - or else they would resign.

The farm owner, under pressure, fired Mr. Kalyabantu and kicked him and his family off the farm.



*From Zambia Toolkit Workshop, February 2003*

### Discuss

- What happened in this story? Why?
- Has something like this happened in your community? What happened?
- How do neighbors generally treat households they think have HIV?
- What can we do to prevent or act against stigma and discrimination towards families living with HIV?

### ACTION IDEAS

Select one of the ideas which you have identified to prevent stigma, and discuss with your community or group to see if you can begin to put it into action.



### EXAMPLES

Forms of Stigma towards Families living with HIV:

- Isolation and rejection towards families suspected to have HIV/AIDS.
- Name-calling. Finger pointing. Gossip. Rumor. Backbiting. Jealousy.
- Rumors about HIV/AIDS used as a weapon to denounce families.
- Suspicion—speculate about other people based on observed symptoms
- Stigma triggered by visits/food relief provided by Home Based Care workers
- Shame—loss of family honor—“You have discredited/shamed our family.”
- Snooping—people visit to see the condition of the PLHA—“Is she finished?”
- Not allowing children to play with neighbor’s children.

# NEIGHBORS STIGMATIZING NEIGHBORS

## 4 EXERCISE



### OBJECTIVES

Participants will be able to:

- Describe how neighbors react to a suspected PLHA family
- Develop strategies to deal with problem of neighbors stigmatizing neighbors



### TIME

2 hours



### MATERIALS

Stigma Pictures—A4, A5, A43

### ACTIVITIES

#### *Buzz Groups*

#### **STIGMATIZING NEIGHBORS**

Divide into pairs and ask: “How do neighbors treat households they think have HIV? Why?”

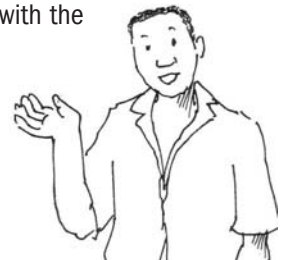
#### **EXAMPLE FROM ETHIOPIA TOOLKIT WORKSHOP (May 2003)**

##### **How do neighbors treat households they think have HIV?**

- Tell the landlord to kick the family out of rental accommodation.
- Stop the PLHA family or the PLHA using the communal toilet.
- Stop visiting PLHA family but worry about being blamed for not visiting.
- Stop exchanging foodstuffs with the PLHA family.
- Gossip about anyone who uses the communal toilet frequently.
- Openly talk and joke about PLHA dying—“He won't live until Christmas!”

##### **Why do neighbors behave this way?**

- Fear of infection through sharing the same toilet.
- Fear of children being infected through contact with the HIV affected family.
- Sympathy about heavy burden for the family of caring for the PLHA.
- Feel they are stigmatized through association—shame affects them



#### *Task groups—role playing*

#### **WHAT WILL THE NEIGHBORS SAY?**

Divide into two groups of equal sizes: Group A is the PLHA family, Group B is the neighbor. Organize two short role plays showing the two groups talking separately.

### ACTION IDEAS

Select one of the ideas which you have identified to change stigma and discuss with your community or group to see if you can begin to put it into action.



**Neighbors**—What are your fears about the family? Why?

**HIV Family**—What are you afraid that the neighbors will say about you?

### Discuss

- What kind of stigma is going on here?
- What can we do to change things?

### EXAMPLES FROM ETHIOPIA TOOLKIT WORKSHOP (May 2003)

#### Neighbors

Fear our children will get infected so we stop them playing with our children. If the family is a member of a community group, we kick them out. Family brings loss of honor to community/village. We visit for a while, then at intervals, and finally we stop altogether. Sympathy that they are spending all their money on medicine. Judging—she was unfaithful so she is “reaping what she sowed.”

#### Family

Fear of isolation. Fear of losing honor. Lose contact with neighbors. Keep to ourselves because we fear they are calling us names behind our backs. They pretend to be nice, when behind our backs they are judging us. If they ask about the PLHA, we say she is fine to stop them judging us. We discourage people visiting and if they come we keep them in the sitting room—and keep the PLHA in the back bedroom. We even discourage visits in the hospital—if someone comes to visit, we say, “Sorry, she is sleeping.”



## OBJECTIVES

Participants will be able to:

- Identify forms of stigma and discrimination practiced in the community
- Develop strategies for building community support for HIV affected households



## TIME

1 hour



## MATERIALS

Three pictures:  
Picture A1 – Group of people giving their backs to a female PLHA  
Picture A2 – Group of people pointing fingers at a male PLHA  
Picture A3 – Community pointing fingers at PLHA

## ACTIVITIES

### *Picture Discussion*

### **STIGMA IN THE COMMUNITY**

Display the three pictures and ask participants to discuss:

- What do you see in the pictures? How does this make the PLHAs feel?
- What other forms of stigma and discrimination are practiced by the community?

### *Group Discussion*

### **MOBILIZING COMMUNITY SUPPORT FOR HIV AFFECTED HOUSEHOLDS**

Divide into trios and ask—“What can we do to build more support for HIV affected households in our community?”

Report back—round robin. Then review the list of proposed actions and select one or two that the group wants to work on.

### **Summary**

Discuss the importance of getting the whole community and not just those families who are immediately affected to mobilize against HIV/AIDS. Addressing the problem of AIDS is the responsibility of the whole community. Emphasize that we are all at risk of getting HIV so we should all work to support those who are already affected by HIV. Explain that community mobilization will help to “normalize” HIV/AIDS and this will help to reduce stigma.



### ACTION IDEAS

In your group or community look at the list and see what you can do to build support in the community.



### POSSIBLE ACTIONS

- Organize community meeting to discuss what to do about AIDS in community.
- Form associations of families, neighbors and church groups to deal with HIV
- Identify the most vulnerable households (e.g. child/orphan headed households, grandparent headed households) and provide support
- Provide exemptions for HIV affected families from water fees, school fees, etc
- Provide neutral persons to help mediate disclosure or conflicts in families
- Facilitate the sharing of “AIDS survival knowledge” among community members
- Organize a regular system of visits to HIV affected households
- Donate food, clothing and agricultural inputs to destitute households
- Carry out repairs to houses or help cultivate the fields of vulnerable households
- Provide piece work for adolescent orphans working in others’ fields
- Organize income generating activities to support vulnerable households
- Provide communal fields for vegetable gardening
- Form burial associations and rotating credit and loan clubs



## OBJECTIVES

Participants will be able to:

- Analyze some of the financial problems facing HIV affected households
- Develop practical strategies for mobilizing and managing money effectively
- Develop strategies to combat stigma which is fueled by money problems



## TIME

2 hours



## MATERIALS

Cards - green and orange cards (for Income & Expenditure Tree)

## ACTIVITIES

### *Income and Expenditure Tree*

#### **FINANCING CARE FOR PLHAS**

Divide into trios and hand out cards. Ask trios to make **income and expenditure tree** for a family on the wall, using orange cards for roots and green cards for leaves:

**Roots**—the different ways the family earn money: selling crops, piece work, selling things, income from wage workers, etc

**Leaves**—things that the family spends their money on e.g. food, clothes, rent, transport, soap, school fees, clinic fees, medicine, etc.

### **Then discuss**

What changes when a family has to care for a PLHA?

Which items of expenditure go up significantly?

### **Role Play**

**Money problems**—Ask participants to perform a role play using the scenario below.



## ROLE PLAY

Joseph has just started TB medicine at the clinic. A few days later his appetite improves and he wants to eat more. When he asks Martha for meat and eggs in addition to what she has cooked, she shouts at him, “This is not a restaurant, you know. We can’t afford this kind of food? You’ve become a real parasite!”

### ACTION IDEAS

- Make a budget with your family
- Discuss ideas at home or in your community about how families can help each other with money problems such as rotating credit unions



### Discuss

- What happened in the role-play? Was this realistic?
- Do we face similar issues in our own homes, when we look after PLHAs?
- What can we do to deal with the real money problems we all face?



## OBJECTIVES

Participants will be able to:

- Recognize that PLHAs have rights and responsibilities just like other people
- Recognize that PLHAs' rights are often denied
- Agree on how the family and community can reaffirm those rights



## TIME

1 hour



## MATERIALS

Rights Cards D1-D18  
Picture A20 (PLHA left out of decision-making)

## ACTIVITIES

### Card storm

### PLHAS' RIGHTS

Divide into pairs and hand out blank cards. Ask pairs to brainstorm a list of PLHA rights and responsibilities—writing 1 point per card and sticking them on the wall.

### Then discuss

- Which of these rights do families try to remove? Why?
- Which of these responsibilities do PLHAs not always fulfill?
- What are the effects on the PLHA of being denied these rights?
- What can be done to reaffirm and reinstate those rights?

### PICTURE—ROLE PLAY

Divide into small groups. Ask each group to select a “Rights Card” and perform a short role-play to demonstrate this right.

### Discuss

How can we as families ensure these rights are met?

### EXAMPLES OF RIGHTS AND RESPONSIBILITIES

#### Rights

To be respected. To be hugged. To contribute to family decisions. To say NO! To have friends. To have food. To have sex. To get pregnant. Have a child. Have medical care. Have clothing.

#### Responsibilities

Be open to advice. Help out in the house when you can. Listen to others. Help with finding money when you are well. Talk to younger family members about protecting themselves. Practice safe sex.

### ACTION IDEAS

- Talk at home with other family members about their ideas on rights and responsibilities
- Ensure that you do not exclude any PLHAs in your family from family decisions



### Summary

- We need to ensure that PLHAs are involved in decisions about their lives, even when they get sick
- PLHAs need to understand the stresses on a family which might mean that all their needs cannot be met
- As communities we can look for ways to support families which will then enable rights and responsibilities to be respected

# PLHAS CAN LEAD LONG AND FULL LIVES

## 8 EXERCISE



### OBJECTIVES

Participants will be able to:

- Recognize that PLHAs can lead long and productive lives
- Identify the main features of living positively with HIV [emotional health, successful disclosure, treatment, food and nutrition and safe sex]



### TIME

2 hours



### MATERIALS

- Life Stories Exercise: Instructions
- Copies of Case-studies on PLHAs not being allowed to do things
- Case Study—"Life Goes On"

### ACTIVITIES

#### *Collective-Story*

### **PLHAS CAN LEAD LONG AND PRODUCTIVE LIVES**

Start a story about a person living with HIV. Set the scene and then 'pass' the story to a participant. Each participant makes up a couple of lines to develop the story - and then the next person takes over the story.

#### **Note to Trainer**

See how the story develops. At any point, the trainer can change the direction of the story. Make sure you cover some ideas about the PLHA being productive ( working, building a house, helping someone) and being involved in decision-making.

#### **Discuss**

- What happened in the story?
- What did we learn about the way we think about PLHAs lives?
- What can PLHAs do to lead long and productive lives?

### EXAMPLES

What PLHAs can do to lead long, productive lives:

- Care and emotional support in a supportive atmosphere.
- Successful disclosure with family members and others who are close.
- Treatment of infections. ARVs. Alternative therapies.
- Avoiding re-infection/practicing safe sex.
- Good food and nutrition.

### ACTION IDEAS

At home discuss with family and friends how you can support PLHAs in the family to be active and contribute to the family.



### Stories + Discussion

## **PLHAS NOT GIVEN CHANCE TO CONTRIBUTE**

Hand out copies of case studies below. Ask participants to read them.

### Discuss

- What happened in each of the stories? Why?
- What does this say about PLHAs' capacity to contribute?

### CASE STUDIES

**Anne** has been staying at her sister's house for the last 6 months, since she got sick. For the last couple of weeks she has been feeling better and decides to surprise her sister by cooking a special supper. When her sister returns from work, she is shocked to see Anne cooking. She tells her she is too sick to be in the kitchen and she would prefer to make her own meals.

**Emmanuel** works in a printing factory. For the last few months he has had time off work for sickness. When he returns, the manager tells him that he has been moved to work in a different department where the work will be less challenging physically and mentally. Emmanuel feels disappointed.

**Haile** is a person living with HIV. He wants to build a house for his family and goes to a credit agency to get a loan. When the credit agency suspects he is HIV positive, his application is turned down.

**Robert** is a keen footballer and plays for his company's team every week. Recently he has been sick, but since starting ARV treatment is beginning to feel better. He turns up for football training one evening and the coach tells him that he thinks it is better that he does not play since he has been so sick. His place in the team has been taken by a younger man.

### Case Study and Discussion

## **LIFE GOES ON!**

Ask participants to read the case study below. Then discuss:

- What happened to the husband and the wife?
- Why did the wife live a long life?

### **CASE STUDY—LIFE GOES ON!**

A long distance truck driver got sick in 1991 and died in early 1992. When he first became sick, there was lots of gossip by family and neighbors. People said he acquired HIV on the road. People at first visited him and then the visiting stopped. His sister came to stay for a while to look after her brother. When she saw that he wasn't getting better and was not dying, she left.

When the sister-in-law left, the driver's wife, who worked as a tailor in a factory, took over the caring of her husband. Because of the heavy burden, she often arrived late at work and was fired. After leaving her job she set up her own small tailoring business on the veranda of her house. She loved tailoring and many women came to her for chitenge outfits. She then discovered she was HIV positive. She accepted her situation and did all she could to stay healthy, including using Chinese medicine. Although her husband died, her own health improved and she became fatter. The neighbors, who originally said her husband died from AIDS, started to forget the earlier situation. They said her husband had been bewitched. She is still alive today.

*Case Study written by Tanzania Toolkit Workshop, December 2002*

## **Summary**

Emphasize that:

- PLHAs can lead long and productive lives.
- PLHAs can make a big contribution to their families, jobs, and communities. Their ability to do, to contribute should be recognized and valued.
- Things they can do to lead long and productive lives include:
  - Getting love and care from those around them
  - Successful disclosure to partners, family members, and friends
  - Getting treatment for their infections as early as possible
  - Getting Anti Retroviral Treatment, if it is provided or they can afford it
  - Practicing safe sex to avoid getting more HIV into their bodies
  - Getting good food, avoiding too much alcohol and avoiding stress
  - Carry on working and normal life



**9**  
EXERCISE



## OBJECTIVES

- Participants will be able to:
- Recognize the importance of emotional well-being for PLHAs in order to lead long and productive lives
  - Identify how we can help PLHAs stay healthy emotionally
  - Identify ways that we can challenge stigma and help PLHAs to cope with the effects of stigma



## TIME

1-2 hours



## MATERIALS

Paper, crayons, paints, magazines if possible

## ACTIVITIES

### **WHAT MAKES YOU FEEL GOOD ABOUT LIFE?**

Draw a picture, make a collage, write a poem, make a song, find a way to express 'what makes you feel good'.

In pairs, share your work.

In the same pairs, discuss:

- What do PLHAs need to feel good about themselves?
- Why is “feeling good” (emotional well-being) important for PLHAs to lead long lives?
- What might prevent PLHAs from feeling good?



## GAME

### **What do PLHAs need to feel good about themselves?**

To be loved. Cared for. Listened to. Given information about HIV/AIDS. Good food and nutrition. Involved in family decision-making. Access to proper medical services. Legal protection to stop them from being fired from jobs. Prayer and encouragement from spiritual leaders. Considered to be productive, contributing to the family like others.

### **Why is “feeling good” important for PLHAs living a long life?**

If our mind feels good, so does our body. Less likely to fall sick. More likely to share problems.

### **What prevents PLHAs from feeling good?**

Stigma—lack of attention, isolation, lack of care and support.  
Self-stigma—feeling guilty. Loss of friends. Stigma by neighbors.

**Role Play + Discussion**

**STIGMA, SELF-STIGMA, AND SELF-ESTEEM**

Ask participants to act out the role-play below.

**GAME**

At the market a PLHA is refused service and shunned by the traders, who gossip about him being “promiscuous.” He returns home, where he pours out his heart to his brother, talking about his frustration and feeling of rejection. He blames himself, saying he was “reckless and therefore deserves to be treated like this.”

**Discuss in pairs and then share**

- What happened? Who is stigmatizing? Why?
- How does the way he has been treated affect his emotional health?
- What are the indicators of “self-stigma?”

**Discuss with the whole group**

“How can we support PLHAs to cope with stigma?”

**EXAMPLES**

- Encourage PLHAs to talk openly with friends and family about their feelings and their situation and be listened to with empathy.
- Encourage them to get supportive counseling—family, friends, or health professionals.
- Encourage them to join a support group. Share feelings and experiences with other PLHAs.
- Allow them to continue being productive. Do things which build confidence and self-esteem.
- Help them to focus on the positives—“I want to stay alive for my children.”
- Talk together about feelings of anger.
- Use positive anger to fight back—join campaigns /lobby for human rights
- If family members gossip, we should say “We have already told you about our son’s status and you’re still talking!!! What’s new?”
- We can challenge stigma ourselves and show stigmatizers that they are wrong to judge.
- Recognize that PLHAs have rights to have sex, get married, have children, have work, have friends—and demand their rights.

*Tanzania Toolkit Workshop, December 2002*

**WHAT HAPPENED**

Stigmatization by traders—shunning, refusing service, gossiping

**Effects on PLHA’s Emotional Health**

Feeling of rejection.  
Hopelessness. Self-blame.  
Loss of face in community.  
Loss of self-esteem and confidence.

**Indicator of self-stigma**

Feels guilty—blames himself for his situation. Regret—“I shouldn’t have.” Accepts that he “deserves to be treated like this.” Self-isolation.



### ACTION IDEAS

If you are caring for someone who is living with HIV/AIDS, ask how you can help support them to “feel good.”



### Summary

- Looking after our emotional health is an important part of positive living. Sometimes stigma can really affect PLHAs emotional health
- Stigma by other people can lead PLHAs to self-stigmatize
- We can all play an important role in challenging stigma, and supporting PLHAs to cope with the effects of stigma

# DISCLOSING TO THE FAMILY

## 10 EXERCISE



### OBJECTIVES

Participants will be able to:

- Describe some of the issues involved in supporting PLHAs to disclose their status to other family members
- Understand some of the difficulties involved in disclosure



### TIME

1 hour



### MATERIALS

Pictures A29 and A42

### ACTIVITIES

#### *Brainstorm*

#### **INTRODUCTION**

Why is it important for PLHAs to disclose their status to other family members?

#### *Picture-Discussion*

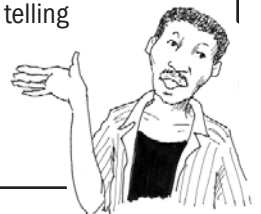
#### **HOW TO DISCLOSE**

Show picture and discuss in pairs:

- What do you think is happening in the picture?
- What are the difficulties in disclosing to other family members?
- If one of your family has told you about having HIV, how did you react?
- Have you told anyone else in your family?

#### **EXAMPLES OF DIFFICULTIES IN TELLING OTHERS**

Worries about negative, judgmental reaction. Fear of telling others—the shame in telling people that you have the virus in the family. Worries about a violent reaction. Fears of isolation and rejection.



#### *Paired Role Playing*

#### **PRACTICE**

The aim is to help participants practice how to disclose the status of a loved one to other family members or friends.

Divide into small groups and read the scenario. Take turns in the different roles.

### SCENARIO

Kamangala is a widow and a mother of five children. Last month her son returned from university and told her that he was HIV positive. He is still healthy, but he wanted his mother to know so that he can talk openly about it. He asked his mother if she would tell his brothers and sisters. His older sister is visiting today and Kamangala has decided that she will try to tell her.



### Debriefing

Kamangala: How did you feel about telling your daughter?

Daughter: How did you feel?

What techniques worked to tell the story?

### Summary

- A strong feeling of unity in some families makes disclosure slightly easier
- If your relationship with someone is strong, it will probably withstand the disclosure
- Old conflicts within families are reinforced with HIV. Due to past relationships HIV gives people an excuse to confirm their prejudices
- Always check with the PLHA first if you are going to tell a third person

### DISCLOSURE PRACTICE: EXAMPLES FROM ETHIOPIA TOOLKIT WORKSHOP (May 2003)

#### Woman telling her husband

- Selected a suitable place and time e.g. children asleep
- Put him in a good mood. Talked about his trip first.
- Broke the news slowly—started off saying she had gone to the clinic for a check-up; then said her friend had been tested for HIV; then said she decided to get tested too
- At each point in story she stopped to check on the awareness and reaction of the partner—before proceeding.

#### Brother telling his sister

Chose the right time. Evening after children asleep.  
Starting statement—“The reason I wanted to talk to you is because I know you can support and help me.”  
Why select sister? She already knows about HIV. She would be sympathetic.

#### Son talking to father

Best timing—early Monday morning at home. Why?  
Want to keep it short and let him think about it.  
Second session—father blames son for his behavior.  
Denial—father suggests he get another test. This shows the potential stigma towards the father—he will get blamed for not raising the boy properly.

#### Strategies

Go slowly. Ask for help and advice. Stay humble.  
Remember it is hard news to tell and hard news to hear.



## OBJECTIVES

Participants will be able to:

- Understand the importance of positive living
- Identify some of the main features of positive living in order to support PLHAs



## TIME

4 hours



## MATERIALS

As many leaflets, brochures, resources on aspects of positive living as you can find (nutrition, hygiene, safe sex, etc.)

## ACTIVITIES

### *Card storm and presentations*

#### **POSITIVE LIVING**

Divide into pairs and ask pairs to brainstorm (on cards) all the things they know are involved in positive living on cards. Cluster the cards according to categories.

### **Task Group Work**

Assign each category to a group of participants to do research. Ask groups to prepare a short (5 minute) presentation on their topic. (Give them enough time to prepare (2 hours or overnight homework?) Tell them to try to present new information that the group may not know about. Show them the resources you have.

### **EXAMPLE OF POSSIBLE TOPICS ON POSITIVE LIVING**

Food  
Hygiene  
Safe sex  
Emotional well-being  
Exercise  
Early medical care  
Treating OIs  
Alcohol intake





## OBJECTIVES

Participants will be able to:

- Identify the root causes of the workload or burnout problem affecting caregiver
- Identify inequalities who the burden of care falls upon
- Develop strategies to reduce the workload/burden



## TIME

4 hours



## MATERIALS

SILHOUETTES - grandfather, grandmother, father, mother, teenage boy, teenage girl, smaller children

## ACTIVITIES

### Card storm

### **BURDENS OF PLHA CARE**

Brainstorm a list of the tasks involved in caring for a PLHA in the home. Stick them on wall. Arrange according to who carries out the tasks.

### Discuss in pairs

- How is caring organized in your household?
- Who does what? When? How?

In large group ask anyone if they want to share.

### Circle

### **WORST JOBS AS A CAREGIVER**

Go around the circle asking each person to describe—"What are the worst things you have done as someone caring for a PLHA?"

Record these on flipchart. Then ask the whole group to read out the whole list, shouting out each item on the list.

## EXAMPLES

- Cleaning up after someone has diarrhea
- Cleaning the patient on a daily basis
- Dealing with nosy neighbors
- Dealing with kids complaints when you are tired from looking after PLHA
- Cooking extra meals for the PLHA to get him/her to eat
- Dealing with his anger when he refuses to take his medicine



**Debriefing**

Ask “How did this make you feel? What can you do when your work as a caregiver becomes too much?”

**Buzz Groups****WHO DOES THE WORK?**

Divide into pairs. Ask pairs to discuss—“What would happen if all the women in the family went away for a month.”

**Report back—Round robin**

Then ask:

- If one person is doing all of the work, is this a problem? Why?
- If so, what can be done to share burden?

**Stop Start Drama****CHANGING THE WORKLOAD**

Set up a drama to show the person in the house who is doing the most work. Ask her to share how she is feeling: burned-out, etc.

Then add extra scenes.

- What happens if a person comes in and helps her?
- What happens at a family meeting where the family discusses caring for the PLHA? Can they help the over-burdened carer?

**Summary**

- Women are viewed as homemakers so any caring activity usually falls to them. Caregivers are often older women who are asked to do the caring with very limited resources. This produces a huge strain on their shoulders.
- BURNOUT is a common problem for many caregivers. The workload becomes too much. They begin to resent this job and this can lead to poorer quality of care and stigmatizing the PLHA.
- It is important that caregivers are able to talk about their workload and look for support if they are overburdened
- Families and governments need to care for the caregivers.

**ACTION IDEAS**

- Discuss in your family who carries the greatest burden of care and how you can share the burden more
- Discuss with fellow caregivers ways of supporting each other
- Set up a caregivers support group





# MODULE

# E

## PLHAs Coping with Stigma

In any community initiative that aims to combat stigma, it is important to include strategies for supporting people living with HIV and AIDS to cope with the effects of stigma. PLHAs play a crucial role in helping to identify the many different types of stigma and raising community awareness about the damage and pain that stigma and discrimination bring.

This module was written with a team of people living with HIV and AIDS and is designed for use with PLHA training courses and support groups. The aim is to strengthen people living with HIV and AIDS as individuals in order to cope with stigma and to build up leadership ability to help and support others. The activities allow PLHAs to share experiences and strategies, develop communication and assertiveness skills and build self-esteem.

# TARGET OF STIGMA AND DISCRIMINATION

## 1 EXERCISE



### OBJECTIVES

Participants will be able to:

- Share experiences of being stigmatized and discriminated against
- Assess how these experiences affect them
- Begin to develop strategies for confronting stigma and discrimination



### TIME

1-2hours

### ACTIVITIES

#### *Individual Reflection and Group Work*

#### **STIGMA STORIES**

Ask participants to think about “an occasion when you were treated badly as a person living with HIV and AIDS by other people.” Allow 5 minutes of quiet reflection.

In pairs share your experience.

In large group, ask if anyone wants to share their story.

Ask group to select three of the stories and role-play them.

After each role-play discuss:

- What happened? How did the person feel? How did s/he react?
- Describe the power relations between stigmatizer and stigmatized.
- What are the root causes of this stigma or discrimination?

#### *Group Discussion*

#### **ANTI-STIGMA ACTION**

In small groups, discuss—“What can PLHAs do to counter stigma and discrimination?”

Write list on flip charts.

# HOW TO PROTECT OURSELVES

## 2 EXERCISE



### OBJECTIVES

Participants will be able to:

- Describe how they protect themselves against stigma and discrimination
- Analyze the effect of the different methods used to protect themselves



### TIME

1 hour

### ACTION IDEAS



Share with your friends and family other ideas for coping with stigma.

### ACTIVITIES

#### *Cardstorm in Pairs*

#### **COPING WITH STIGMA**

Think of all the personal strategies that you use to cope with stigma and discrimination. Write one per card.

Arrange cards in similar categories. Discuss, “Which of these strategies are most effective? Why?”

#### **In small groups**

Discuss some of the ways that we cope with stigma with the help of others. How do we support each other as PLHAs? Write on flipchart.

#### *Buzz Groups*

#### **CUSHIONS\***

Divide into pairs and ask—“How do we cushion or protect ourselves against the effects of stigma and discrimination?”

Record points on flipchart.

Combine pairs to form groups of 4 people to discuss:

- What are the effects of such behavior?
- What are the positive and negative outcomes of these personal strategies?

### EXAMPLES OF STRATEGIES

Withdrawing. Ignoring stigmatizers. Avoiding situations. Joking.  
Answering back. Fighting back. Support group. Trying to explain.  
Talking to stigmatizers. Going public. Denial. Talking to friends about what happened.

\* **Source:** Adapted from Exercise on “Cushions” in *Training for Transformation: Handbook for Community Workers, Hope and Timmel (Book 4)*, page 145-146.



## OBJECTIVES

Participants will be able to:  
Recognize that “keeping quiet” is a coping mechanism to deal with stigma



## TIME

30 minutes



## MATERIALS

Cards

“E” does not share information with her stepmother since she feels if she told her that she was HIV-positive, her stepmother would stigmatize her and use the information against her.

Extract from “E’s story,”  
Zambia



## ACTIVITIES

### Card storm

### FEARS

Discuss—“Situations where you might choose to keep quiet” (about your status, about stigma, etc.). Role-Plays



## EXAMPLES

You don’t want to draw attention to yourself. Stigma in front of many people. Fearing rejection from your family. Looking different from other people. At work, in case you lose your job. Wanting to protect someone from our worries. It may not be safe. Choosing carefully who we talk to. Reflecting on what being positive means to us. Taking time for it to sink in. Waiting for the right moment.

In small groups, choose one of the situations and role-play the situation to show the effects of keeping quiet.

In large group, discuss

- What happened in the role-play
- How did the strategy of keeping quiet work?
- How do the characters feel?
- Are there any other strategies you could use in this situation?

Try these ideas out in the role-play.

# DISCLOSURE: TELLING YOUR FAMILY

## EXERCISE 4



### OBJECTIVES

Participants will be able to:

- Share experiences about telling family members about their status
- Describe some basic strategies for disclosing to members of the family



### TIME

2 hours

### ACTIVITIES

#### *Case Study and Discussion*

#### **FEARS ABOUT DISCLOSURE**

Ask participants to read the case study below.

#### **CASE STUDY**

The funeral took place a week after her husband's death, followed by a week of being insulted by her in-laws for bewitching their only son and brother.

As she watched the coffin being lowered into the grave, she whispered to herself, "If you had only listened to me, you would still be alive. I would not have to take so many insults from your family."

As she tried to stand up to throw soil into the grave, she fainted. Her husband's family would say that it was her guilty conscience for killing her husband so that she could inherit the big house he had just finished building.

While she knew her husband had died of AIDS, Naledi decided to keep it to herself. Even if she told them they would never believe her. If anything they would say she had infected him with it.

Her problem started two years earlier when she decided to go for an HIV test. Her husband refused to go with her. When her test results were positive, her husband would not accept it.

"He kept denying the fact that I had the virus and that he might also have it. He even insisted that we should not use condoms, until it reached a point where we fought over condom use. He still refused to go for a test when he started to lose weight, claiming that he was on a diet. He finally agreed on his deathbed that he could be tested for AIDS. He died knowing that he had the virus, and that he was beyond redemption. But he was my husband, and I will love him always. That is why I will keep his secret."

*Source of Case Study:* Article "Me Go for a Test? No Way!" by Gregory Kelebonye in Mmegi Monitor (Botswana) 29 April to 5 May 2003

### Discuss

- What happened to Naledi when she told her results to her husband?
- What are your own biggest fears about sharing your status with partners, family members, or friends?

### *In Pairs*

## **DISCLOSING TO DIFFERENT FAMILY MEMBERS**

### Discuss

- Who in your family have you told about being HIV positive?
- How did you do it?
- What happened?

### *Paired role-play*

## **DECIDING ABOUT DISCLOSURE**

This exercise is designed to give people practice in disclosing to family members. Discuss in pairs:

- Who would you like to tell?
- What are some of your concerns about telling them?

### Role-play

Practice telling the person (take the role of the person you want to tell first of all, then swap)

After 5 minutes, ask one or two pairs to volunteer to come into the centre and show their role plays to the whole group.

### Debriefing

Partner A - How did you feel about disclosing your status?

Partner B - How did you feel about your role as the listener?

Partner A - What techniques did you use to tell your story?



### **FEARS ABOUT DISCLOSING**

People may use this information against you. Rejection. Guilt. Gossip. In-law relationships are fragile. Withdrawal of material support (“You are going to die anyway, so why should we waste our money on you?”) Relatives neglecting you (when sick, not taking you to the hospital). Vulnerable when sick or unproductive. Disappointment—shattered expectations. Past sexual relationships being raised. Your role as a guardian is undermined.

## DISCLOSURE PRACTICE—EXAMPLES FROM ETHIOPIA WORKSHOP 2003

### Woman telling her husband

- Selected a suitable place and time (children asleep)
- Put him in a good mood. Talked about his trip first.
- Broke the news slowly—started off saying she had gone to the clinic for a checkup; then said her friend had been tested for HIV; then said she decided to get tested, too.
- At each point in story she stopped to check on the awareness and reaction of the partner—before proceeding.

### Brother telling his sister

Best timing? Evening after children asleep. Starting statement—“The reason I wanted to talk to you is because I know you can support and help me.”

Why select sister? She already knows about HIV. She would be sympathetic.

### Son talking to father

Best timing—early Monday morning at home. Why?

Want to keep it short and let him think about it.

Second session - father blames son for his behavior.

Denial—father suggests he get another test. This shows the potential stigma towards the father—he will get blamed for not raising the boy properly.

### Who is it easier to disclose to?

Someone of the same sex. Sibling (same status in the family.)

### Strategies

Go slowly. Ask for help and advice. Stay humble  
Disclosing is a series of steps Go slowly and see how people respond. Brainstorm a set of strategies for disclosing successfully.

### Examples

- Start with relatives whom you are already close to.
- Find a time when it is easier for people to concentrate.
- Find a place where there will be no interruptions.
- Establish a good relationship and trust.
- Use your own status to encourage others to be careful with their own lives.
- If some relatives know your status and are sick, they may come and seek advice—this will show how valuable you are (they can lean on you for help).
- Share your burden. Be aware that it is a struggle, not easy, stressful.
- Do it gradually—if you get a supportive response from the first person, you can try a second, it gives you the courage to continue.
- If people respond well you may want to tell others; if the response is poor, it is hurtful and you may decide not to tell others



### Option 1

Draw concentric circles on the flipchart. Write “ME” at the center of the inner circle. Then in the next circle write for example, my older sister, mother—the closer relationships are located closer to the center of the circle. Use this to show how to disclose your status on a gradual basis, starting with close family members (siblings) and then gradually moving out to other people. Use the first supportive person to help you talk to the rest of the family.

### Circles of disclosure

Make a diagram with you in the middle. Show the important people in your life—mark them on inner circles. People who you know less well are placed on the outer circles. This can help you plan your disclosure, i.e., who to disclose to first.

### Option 2

#### JOHARI'S WINDOW

Explain “Johari’s Window.”

*Johari’s Window is a tool that helps us look at things about ourselves that we may want to share with others—or keep secret from others. Johari’s Window represents the whole person.*

	Known to self	Unknown to self
Known to others	<b>FREE</b>	<b>BLIND</b>
Unknown to others	<b>HIDDEN</b>	<b>MYSTERY</b>

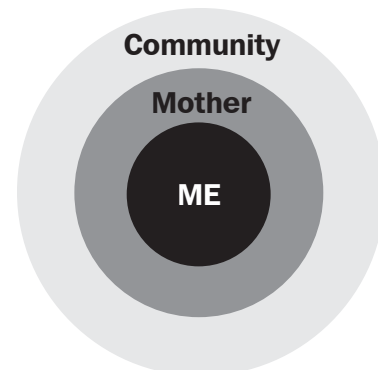
The four panes of the window can be described as:

**Free**  
That part of yourself which is known to you and to others. You are comfortable that people know these things about you.

**Hidden**  
That part which is known to you, but not to others—“secrets” which you know about yourself, but don’t want others to know.

**Blind**  
That part which is known to others but unknown to you. You learn about these things through feedback from others. Getting feedback about your good qualities from others builds up self-esteem.

**Mystery**  
That part of you which is unknown to you and to others. These are talents which you may not know about.



The first person she told was her cousin—her father’s sister’s daughter. She is a very close and understanding relative and her response was very encouraging. Her cousin thought her so courageous to have tested and remarked how most people do not know their status. At this stage, E is not sure if her cousin ever told others. It really helped E to tell her cousin—it was “one load lifted.”

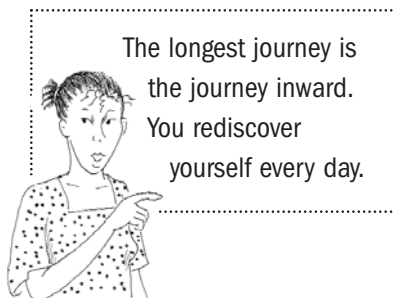
*Extract from E’s story, Zambia*



### Draw your own Joharis Window

Think first of all, what kind of things you would put in the different windows. Everyone’s Johari is a different shape. If you are someone who is very open, shares a lot, does not keep much hidden, then your FREE window will be big and your HIDDEN window small.





You do not have to share your window with anyone, but it can be a useful self-awareness tool.

### **Individual reflection**

Ask participants to sit on their own in the room. Ask them to think about things about themselves (or their families) which they have kept secret. Explain that these things are the HIDDEN WINDOW. If we decide to disclose our HIV status to partners or family members, we are reducing the HIDDEN WINDOW -others will get to know things which up until now have been secret and we increase the FREE window

### **Examples of HIDDEN Window**

Former relationships. Experience of having STDs. Family members who have HIV. Symptoms of HIV. Things we consider failures in our lives.

In going for testing we may be entering the MYSTERY WINDOW - finding out if we really have HIV. We may have had some symptoms which make us feel we may have HIV, but we are not sure until we have taken the test.

BLIND SPOTS are things which others know about you. The only way to discover our "blind spots" is to share with other people and get feedback on how they look at you. Otherwise these things will still remain hidden. Getting feedback from others will help us see that we have "hidden strengths" (e.g., leadership, counseling skills) which we didn't know about. This will help to build up our self-esteem.

### **Summary**

- Who, when and where to tell someone about your status is a personal decision. You should never be put under pressure to tell someone you do not want to.
- Practicing telling someone can be a useful way to develop personal strategies.
- Avoid telling people who might use it against you.
- Fear of stigma and blame are the main reasons that stop people from telling others about their HIV status.



## OBJECTIVES

Participants will be able to:

- Identify PLHAs rights and responsibilities
- Identify situations in which they may be denied their rights in the family, workplace or community
- Understand the importance of being assertive to maintain their rights



## TIME

2 hours



## MATERIALS

Picture of nurse talking to family members but excluding PLHA from the conversation and decision-making A20; PLHA Rights Cards D1-D18

## ACTIVITIES

### *Picture-Discussion*

#### **NAMING THE PROBLEM**

Put up the picture (A20) and ask participants to discuss in pairs:

- What is happening in the picture?
- How do family members treat someone once they know s/he is HIV positive?
- Do families consult them about decisions that affect their lives?
- Do families include them in activities of the home?

### *Cardstorm*

#### **NEEDS**

Divide into pairs. Hand out cards. Ask pairs to brainstorm a list of PLHA needs/rights and responsibilities—writing single points on cards and taping on the wall.

## EXAMPLES

### **Needs/Rights**

Food. Shelter. Clothing. Medical care. Respect. Love. Friends. Someone to listen to them. Have sex. Get pregnant. Have a child. Contribute to family decisions. To have a role in society.

### **Responsibilities**

To contribute to family welfare. Be open to advice. Help out in the house when you can. Listen to others. Help with finding money when you are well. Talk to younger family members about protecting themselves. Practice safe sex.



In small groups, discuss:

- Which of these needs/rights are met easily?
- Which are affected by poverty and economic factors?
- Which are affected by stigma?
- Which of these responsibilities are sometimes difficult to fulfill?

# UNDERSTANDING ASSERTIVENESS

## EXERCISE



### OBJECTIVES

Participants will be able to:

- Define and understand assertiveness
- Practice some assertiveness skills



### TIME

1-2 hours



### MATERIALS

Copies of case-studies

### ACTIVITIES

#### Discussion

#### WHAT IS ASSERTIVENESS

Read out the following statement:

*One reason why PLHAs are treated as “victims” is that they allow themselves to be treated as “victims.” They remain passive, allow others to think and decide for them and keep their own feelings and ideas hidden. PLHAs need to be more **assertive** if they are to gain more control over their lives and defend their rights.*

Discuss in small groups:

- What do think about this view?
- What does it mean to be assertive?
- Why does being assertive help?

#### DEFINITION OF ASSERTIVENESS

Saying what you think, feel, and want in a clear and honest way that is good for yourself and others. It is not being aggressive or showing anger. It is simply telling people in a clear and honest way what you a) think, b) feel and c) want.

#### Why be assertive?

Increase your confidence. Stand up for your rights. Gain more respect from others. Improve your relationships. Gain more control over your life.



## EXAMPLES

*PLHA:* I want to go see my friend.

*Family:* No, you should stay in the house and rest.

*PLHA:* I'll rest when I get home. I want to go see my friend.

*Family:* The neighbors will see you.

*PLHA:* I'm not worried. What is there to see? I want to see my friend.

*Family:* You don't have time for friends. You need to focus on your health.

*PLHA:* I'm getting stronger every day. This friendship is helping. So I am going to see my friend.

*Mother:* What are you doing?

*PLHA:* I am sweeping the yard.

*Mother:* But this work is too heavy for you.

*PLHA:* No, this is good for me—and I am taking rests from time to time.

*Mother:* No, you should rest.

*PLHA:* No, I want to continue sweeping. I'd like to help you.

*Mother:* But this work will make you sick.

*PLHA:* No, it is lifting my spirits and making me feel involved and helping out. I promise that if I start to feel sick, I will stop.

### *Paired Role Playing*

## **PRACTICING ASSERTIVENESS**

Divide into pairs and ask pairs to stand facing each other. Ask each pair to decide who the PLHA is and who the other person is. Give out the case studies, one per pair.

Then ask all the pairs to play (at the same time). After a few minutes, shout “stop” and ask to see a few of the plays. After a few demonstration plays, stop and ask: What happened? How did you feel? How can you assert your rights to contribute in different settings and keep control over your life?

When people suggest solutions, ask one of the pairs to play it out. Then discuss what made a difference—voice level? Language? Body posture? Confidence?

## **REPEAT IT AGAIN or BROKEN RECORD**

Explain that this is technique for assertiveness. It is so called because the person repeats herself several times. Explain that this technique can be used to stand up for your rights.

### **Paired Role Playing**

Divide into pairs and ask pairs to stand facing each other. Ask each pair to decide who the PLHA is and who is the family member. Then explain the situation:

*Scene 1.* The PLHA has found a new friend—a neighbor. A family member objects to this friendship and wants to stop it.  
OR

*Scene 2.* The PLHA is sweeping the yard when her mother returns from the Market

Then explain the PLHA's role—Your role is to

- Decide what you want to say and to say it clearly
- Stick to this statement, repeating it over and over, if necessary.
- Brush off the other person's excuses—and then repeat your demand.

Then explain the family member's role—"Your role is to refuse the PLHA's request and give all kinds of reasons why you think this friendship should stop."

Then ask all the pairs to play (at the same time). After a few minutes, shout 'stop' and ask to see a few of the plays.

### Discuss

Did you succeed? How? What did you do that forced the person to agree?

## Summary of Assertiveness Techniques

- Tell people what you think, feel, and want clearly and forcefully
- Say "I" feel or think or would like.
- Don't apologize for saying what you think or put yourself down.
- Stand or sit straight in a relaxed way.
- Hold your head up and look the other person in the eye.
- Speak so that people can hear you clearly.
- Stick with your own ideas and stand up for yourself.
- Don't be afraid to disagree with people.
- Accept other people's right to say "No" and learn how to say "No" yourself.

*Adapted from Gordon, Gill. 1999. Choices: A Guide for Young People. Macmillan Education, London, 1999. Pages 33-35.*

### ACTION IDEAS

Try these techniques out at home and report back!



# BUILDING SELF-ESTEEM

## 7 EXERCISE



### OBJECTIVES

Participants will be able to:

- Build up their self-esteem so that they can cope with stigma
- Be more aware of their personal coping strategies and strengths



### TIME

1-2 hours



### MATERIALS

Copies of word lists  
(Make your own word lists)

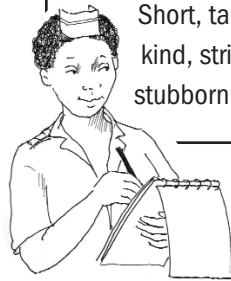
### ACTIVITIES

#### *Wordlist*

#### **WHAT KIND OF A PERSON AM I?**

Handout the word lists and asks each participant to draw circles around the words that best describe her or him.

#### EXAMPLES FOR WORD LIST



Short, tall, funny, serious, clumsy, attractive, slow, fast, generous, kind, strict, proud, friendly, warm, aggressive, hard-working, shy, stubborn, humorous, cheerful, playful, etc.

Discuss:

- How did you feel during the exercise
- Did you recognize anything new about yourself?
- Were there any words that you wanted to choose but felt that they were not you?

#### *Visualization Exercise*

#### **SEEKING COMFORT**

Ask participants to find their own space to sit or lie on the floor. Put on soft music. Once they are relaxed and comfortable, read out the exercise below. Read very slowly and pause between sentences. The exercise should take at least 15 minutes.

Close your eyes, get comfortable and focus on your breathing for a few moments .....Take some deep breaths and feel your body relax.....  
 Now imagine a place you would like to be where you feel totally comfortable with yourself..... It could be somewhere you know or a place in your imagination.....(long pause) How does it look? Look all around you- what do you see?..... Notice the weather..... any colors..... the atmosphere.....

Now imagine that you can bring anyone you want to meet you in this place. It could be a friend, someone in your family, a stranger, even someone who has died.....Take time to get a sense of who you want this person to be .....

You may want to talk to this person about your life, or you may want to share the silence....You might want to ask questions, tell them about yourself, maybe ask them for help...Take some time to be with this person.....(long pause).

Now it is time to leave.....take a look around you.....remember your beautiful place..... and slowly, when you are ready, come back to the room.

### Debriefing

Let participants share their experiences if they wish. Emphasize that if they found a peaceful place to be in the exercise, then that place will always be there for them. When they are feeling low or full of self-pity, they can remember that place in their mind, as a place of rest, free from judgments.

### Writing messages

#### **A MESSAGE TO YOU**

This exercise works best in a group who have known each other for a while.

### Materials needed

Sheets of colored paper or card, if possible



#### NOTE

In any group there is often one or two people who will not like visualization exercises. In the debriefing let these participants talk about what happened for them during the exercise or why they were not able to find their "place." Everyone will have his/her own experience.



Give everyone a piece of paper and ask them to write their name at the top, and on the back of the paper. Then ask them to pass paper to person on their right.

Then ask participants to write “One thing I really appreciate about you is....” about that person whose paper they hold. Then fold the paper down to cover the message and pass again to the person on the right. Complete the message for each participant, so that finally the paper comes back to the owner. Participants read their messages (aloud or to themselves).

### **WALKABOUT**

Give the following instructions in the form of a story:

“Close your eyes and imagine it is 05.00 in the morning. Feel the freshness and coolness of the morning before the heat of the day comes. Now - open your eyes. Start walking in any direction you feel like, making sure not to bump into anyone else. Focus on your own thoughts and actions. It is still early in the morning and you are feeling strong and fresh. Show how good you are feeling in the way you walk.....Now imagine you have been walking a long time and you are beginning to feel tired. The path is getting steeper - in fact it is going straight up a mountain! Reach out to grab hold of trees and pull yourself up. You have to work hard now to get to the top. Pull yourself up - pull! Pull!.....You've made it! Stop and take a break - look down the mountain. Can you see where you started? Now - start walking again. Show the tiredness in your body. You come to a river - cross it carefully - the water is up to your waist. When you reach the other side, you come to an area full of tall grass. Be careful where you walk - watch out for snakes! You finally come to a road and start to walk along it. All of a sudden you see an old friend. Rush to him/her and tell him/her about your journey.”

### ***Web of String***

### **BUILDING COMMUNITY**

Ask the group to sit in a circle and give one person in the group a ball of string. Ask him/her to say one quality that s/he has for

helping others and then throw the ball to someone else, holding on to the end of the string. Repeat until everyone has caught the ball and said a helping quality. Ask—“What does the web represent? [togetherness, unity, links between us, etc.] What would happen if someone did not participate?”

### ***Individual Reflection***

## **BUILDING SELF-ESTEEM**

Ask participants to sit on their own and answer the following questions:

- Make a list of things that make you proud of yourself and your achievements.
- How do other people see you? How do you want other people to see you?
- What do they expect you to do?
- How do these expectations and the way people see you affect how you feel about yourself?

Then ask participants to pair off and share what they written.

### ***Mime in Circle***

## **BODY SELF-ESTEEM EXERCISE**

Ask participants to think of three things that they like about themselves: appearance, mannerisms, thinking, relationships, spirituality, etc.

Go round the circle, asking each person to say, “One thing I like about myself is ....”. Show what s/he likes (if you like your hair, you might shake your head; if it is your body, you might wiggle your hips).

After each person does the mime, ask the group to guess what it is the person likes about herself. Make sure the group guesses what it is. Continue going round until everyone has had three turns.



When spider webs  
unite, they can tie up  
a lion.

*Ethiopian proverb*

## Summary

Our family and friends sometimes forget to praise us, they only criticize us. And if they stigmatize us, this lowers our sense of identity and self-esteem and this affects our ability to take action to improve things.

We can change the way we feel about ourselves and develop confidence and self-esteem in the following ways:

- Encourage people to praise us by praising them. Tell others what they have done well, the things we like about them, their strengths.
- Give ourselves positive messages. Sometimes we say good things about ourselves and sometimes bad. Sometimes our conscience tells us we have done wrong. Sometimes we are too hard on ourselves.
- We all make mistakes—that’s how we learn. But we don’t need to feel bad every time we make a mistake.
- Being good at something helps us gain confidence so focus on your strengths. Then when you are feeling bad, say to yourself, “Yes, but I’m very good at ...”

**Adapted from:** Gordon, Gill (1999) *Choices: A Guide for Young People*. Macmillan Education, London, 1999. Page 29



## OBJECTIVES

Participants will be able to:

- Understand their own feelings and fears about death and dying
- Talk to others about this topic. In our culture it is difficult to talk about death. People believe that the minute you start to talk about death, you will make death a reality. This exercise provides a safe space and hopefully less fearful way of getting people to talk about death



## TIME

2 hours



## MATERIALS

Description of Visualisation Exercise.

Tape recorder and soft music.

## ACTIVITIES

### *Brainstorm*

### **TALKING ABOUT DEATH**

Ask participants “How do we feel talking about death?”

### *Visualization Exercise*

### **MY FUNERAL**

Ask participants to sit comfortably or lie on their backs on the floor and put on some soft music. Ask them to close their eyes and breath deeply. Once they are relaxed and comfortable, read out the visualization exercise below **very slowly**.

Imagine you have died. You are watching your own funeral or your own burial. How would you like your funeral to be? Where is it being held? Is there any music is playing? Who are the mourners?.....Is there anyone missing? Who is lowering the coffin? Are there flowers?

Do you have a sense of whether there is life after death? Any sense of heaven or something else? How does it feel to watch what is going on?

Allow some time and then ask participants to slowly come back to the room.

### **Discuss**

How was it? What role can you play in your funeral? Is there any preparation that you wish to do before you die?

### **MEMORY BOX**

This exercise, developed by Family Health International, helps us to think about how we would like to be remembered. It has been used in Uganda for many years.

“When I am sad, I take out the things left to me by my Mum and it makes me feel better. I know she loved me and I don't feel so alone”

*10 year old orphan, Uganda*

The Memory Box is a simple tool that can assist parents to produce simple ways of being remembered. Children are able to have things left by their parents that provide a sense of comfort, belonging and memories of love of their parents for the rest of their lives. Developing a Memory Box can help people come to terms with thinking about dying, writing wills and disclosing difficult feelings. This exercise has been adapted from the original one. This can be a powerful exercise that personalizes the process of developing a Memory Box and some of the emotions felt.

### Materials

Cards. Box with a large slot or lid, marked “Memory Box.”

### Steps

1. Introduce the idea of the Memory Box.
2. Sit in a circle and place the Memory Box in the middle.
3. Hand out the cards and ask participants to imagine that they are preparing to leave something behind for their children, family or friends in the event of their death. It could be memories, pieces of advice, photos, stories and so on
4. Ask participants to remain quiet and take time to reflect on the task.
5. Ask each person to write or draw each item on a separate card. Explain that they will not have to disclose what they write.
6. When they have finished, ask them to put cards in the box without speaking.
7. Allow enough time for everyone to finish.
8. Ask for any volunteers who would like to share with the group one or two items they put in the box and why they chose them.

### Debriefing

- Why did people choose the things they put into the box?
- What emotions and thoughts did people experience during the exercise?
- How can the Memory Box help both children and parents?
- If they were receiving a Memory Box would they want it before the person who made it died? Why? How would they feel opening it?



## OBJECTIVES

Participants will be able to:

- Understand how positive living can help us to combat stigma
- Identify some of the main features of positive living in order to support us



## TIME

4 hours



## MATERIALS

As many leaflets, brochures, resources on aspects of positive living as you can find (nutrition, hygiene, safe sex, etc.)

## ACTIVITIES

### *Card storm and presentations*

### **POSITIVE LIVING**

In pairs, ask the group to write all the different things they know are involved in positive living on cards—one per card. Cluster the cards according to categories

Assign each category to a group of participants to research. Ask groups to prepare a short (10 minute) presentation on their topic. (Give them enough time to prepare (2 hours or overnight homework?) Tell them to try to present new information that the group may not know about. Show them the resources you have brought.

### EXAMPLE OF POSSIBLE TOPICS ON POSITIVE LIVING



Food  
Hygiene  
Safe sex  
Emotional well-being  
Exercise  
Early Medical Care  
Treating OIs  
Alcohol intake  
ARVs

# “DON'TS” DON'T WORK!

## 10 EXERCISE



### OBJECTIVES

Participants will be able to:

- Analyze the “don’ts” prescribed by family members, friends, doctors, etc.
- Develop strategies for dealing with these “don’ts”—and turning them into opportunities to educate people about how it is to live with HIV



### TIME

1 hour

We have the right to make our own decisions.

Most people rebel against “don’ts”, being told what to do.

Sometimes people are trying to be kind, but they don't understand

So people should avoid telling us how to run our lives with a set of don'ts.

Instead they should provide information and let us make informed decision.

### ACTIVITIES

#### *Brainstorming*

#### **LISTING DON'TS**

Ask participants to make a list of “don’ts” in their lives—things they are told by other people that they should not do. After they have completed the list, review each “don’t” and discuss what you think about it.

#### **DON'TS**

Get married. Have sex. Have kids. Work too hard. Or work at all. Go out with friends. Stay out. Drink beer or smoke. Have a life!

#### *Paired discussion*

#### **SOLUTIONS**

Divide into pairs. Ask pairs to discuss, “What can we do to deal with the don'ts?”

#### **Paired Role-play**

Practice some of the ways you would like to respond to people who tell you don't.

#### **Summary**

- Society needs to learn that we are adults and can be fully functional and make decisions about how we want to run our lives.
- Giving us a set of conditions does not help. Telling us what to do will not lead to change.
- We welcome advice but please let us have a life!
- People who want to help should make the basic information available about the risks in different behaviors, and let us decide what to do. We want to lead a full life—one in which we control our own lives.

# MODULE



## Understanding Stigma Faced by Children

This module explores the impact that stigma has on children. Some of these exercises have been developed as a result of a small research study carried out in Zambia 2002-2003 on children's experiences of stigma.

The stigma is HIV-related and takes many forms. Some examples include:

- Children may be blamed for their parents' death (this is an especially strong belief in Ethiopia where orphans are seen as being born "unlucky");
- Children may be excluded from school, from families and from communities because of fear of infection if there is HIV in their family;
- Orphans are often treated differently from other children in families and accused of carrying on their parents "bad behavior";
- Street children are seen as dirty and "out of control" (though many are on the streets because their parents have died from AIDS).

The bulk of the exercises are for adults although some sample exercises for children are included to help them become more aware of stigma and to cope with stigma.



# HOW ADULTS AFFECT CHILDREN

## 1 EXERCISE



### OBJECTIVES

Participants will be able to:

- Have reflected on their own experiences of childhood
- Understand more about the way in which adults' behavior affects children's social, psychological and emotional development
- Understand a basic theory of the stages of child development



### TIME

1-2 hours



### MATERIALS

Statements Cards  
(True/false statements  
one written per card)

Erikson Handout  
(Annex 7)

### ACTIVITIES

#### *Word storm*

#### **THINKING ABOUT CHILDREN**

In small groups, on a flipchart, ask participants to draw an outline of a child (or prepare drawings in advance) and then word storm (on cards) "What do you think of when you think of children?"

Display all the cards and ask participants to read through them. Look at all the "positive," "negative" and neutral words. What do they tell us about adult's feelings and attitudes towards children?

#### **EXAMPLES OF WORDS**

**Positive:** Wonderful. Playful. Innocent. Joyful. Sweet.

**Negative:** Problem. Noisy. Hard work. Naughty.

**Neutral:** Hungry. The future. Sad.



#### **MEMORIES OF CHILDHOOD**

Give each participant two cards each. Ask each person to think about their childhood for a few minutes. Ask them to write on a card "The best thing about being a child" and "The worst thing about being a child."

Pair up and discuss what they have written.

Put up the cards under the 2 titles (Best thing/Worst thing). Divide participants into two groups.

**EXAMPLE**

If a best thing was “Not having any responsibilities” discuss how adults affect whether children have to worry about things or feel responsible.

**STATEMENTS ABOUT CHILDREN**

- Children do not really know what they need
- Children rely on adults for guidance and learning
- Children need to be punished severely if they make a mistake
- Once children can walk they do not need much physical contact with adults
- Children can take care of themselves
- Children should be encouraged to be as independent as possible
- A child's personality is developed by the time they are 2 years old
- Children often inherit bad behavior from their parents
- Children should always follow what adults tell them
- Children learn moral values from the adults around them
- Children have to learn to trust their parents
- Some children misbehave from the day they are born
- Children often beat each other for no reason
- Every new baby means an extra mouth to feed
- The most important things that children need are food, shelter and clothing

*Add more if needed or to include local beliefs*

**Discuss**

Which of the experiences depend on adults?

**TRUE OR FALSE**

Hand out one statement card to each participant. Ask them to decide if the statement is true or false. In the large group put up three sheets with True, False or Unsure. Ask participants to read out their statement and give reasons for where they place the card. Allow time for discussion.

Add more if needed or to include local beliefs

**Discuss (in large or small groups)**

- How much do children depend on adults?
- How do our beliefs about children affect the way we treat them?
- What are the most important influences in a child's development?

**Options**

Go through Erikson's Stages of Development. (Fact Sheet in Annex) In small groups discuss how this theory matches participants' own understanding of the children they have seen growing up or are caring for.

**Summary**

- Adults are not always aware of the huge impact that they have on the way a child grows up
- Children depend on adults for guidance and support, love and care
- If a child grows up feeling unloved or neglected, then this will influence how they behave as an adult

## MODULE F

### Understanding Stigma Faced by Children

# STIGMA FACED BY CHILDREN

## 2 EXERCISE



### OBJECTIVES

Participants will be able to:  
Describe and analyze the different forms of stigma faced by children



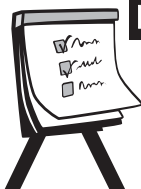
### TIME

2 hours



### MATERIALS

1 set of pictures illustrating Children's Stigma (B1-B10)



### PREPARATION

Set up 5 flipchart stations –flipchart paper on different walls of the room, with topic at the top of each sheet—Orphans, Street children, Children living with HIV, Teenage Girls, Teenage Boys

### ACTIVITIES

#### Warm-up

#### **CHILDREN'S REVOLUTION GAME** (version of “fruit salad”)

Set up chairs beforehand in a circle or square around room. Allocate a role to each person, in the circle alternately—Orphan, Street child, Child living with HIV/AIDS, Teenage Girl, Teenage Boy. Continue until everyone has been assigned a role. Then explain how the game works :

*I am the caller and I do not have a chair. When I call out two roles “Orphans” and “Street children,” all the “Orphans” and “Street children” have to stand up and run to find a new chair. I will try to grab a chair. The person left without a chair becomes the caller - and the game continues. The CALLER may also shout “CHILDRENS REVOLUTION” - and when this happens, everyone has to stand up and run to find a new chair.*

Then shout “Orphans and Street children” and get the “Orphans” and “Street children” to run to a new chair—and this starts the game. Carry on until everyone is wide-awake and energized!

#### Debriefing

Ask “How did it feel to be called an ‘Orphan’ or ‘Street child’ or ‘Child Living with HIV’?”

#### Rotational Brainstorm

#### **THINGS PEOPLE SAY ABOUT**

Divide into five groups based on the roles assigned for the first game: all the orphans together and all the street children in one group. Ask each group to go to its flipchart station. Hand out markers and ask each group to write on the flipchart all the

**EXAMPLE**

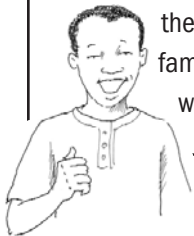
**Picture of family eating together and young girl eating all alone**

*What?*

Orphan girl is forced to sit all alone - excluded from eating with the family. She has less food than the others. She looks sad, scared, isolated.

*Why?*

She is being punished. The family doesn't want to share food with her because her parents died of AIDS. The orphan is poor and there to serve the family, not to eat with them.



things people say about those in the group. After two minutes, shout “CHANGE” or blow a whistle (or sing a song) and ask groups to rotate. Continue until groups have contributed to all five flipcharts and end up back at their original flipchart.

**Report back—Gallery Review**

Walk as a group around the room looking at each of the flipcharts.

**At each flipchart discuss**

Are any of these points true?

Why are attitudes so strongly against certain groups of children?

How do these attitudes affect children and youth?

How would you feel if you were called these names? (Ask those who were assigned this label to react to these names.)

**Picture Discussion**

**PICTURES OF CHILDREN’S STIGMA**

Display the pictures. Divide into pairs. Ask each pair to select a picture.

**Discuss**

What do you think is happening in the picture?

Why do you think this is happening?

**Report back**

Ask each group to report. Record points which show different types of stigma.

**ROLE PLAYING**

Divide into small groups. Give each group one of the children's pictures. Ask participants to develop a story and role-play from the picture, imagining the experiences of the child who has drawn the picture.

Share role-plays in large group. Use stop-start to explore what is happening/how child is feeling etc.

# ANALYZING STIGMA AGAINST CHILDREN

**3**  
EXERCISE



## OBJECTIVES

Participants will be able to:  
Identify the forms, causes and consequences of stigma against children



## TIME

2 hours



## MATERIAL

Picture B7

## ACTIVITIES

### Card storm

### FORMS, CAUSES, CONSEQUENCES

Divide into pairs and hand out cards. Ask participants to think about the different forms of stigma that children experience. Write down one on each card. Stick cards on wall.

In pairs, ask each pair to pick one “form” of stigma and stick it in the middle of a flipchart sheet. Ask them to write below all the causes they can think of, all the reasons why this type of stigma occurs (one point per card) and tape on the wall. (See example below) To explore the causes, keep asking why, why, why? Some may be root causes

Ask participants to change “stigmas” (and partners if they like). Ask participants to think about all the consequences of that form of stigma. Write them above the “form” of stigma. Try to look at both individual consequences of stigma and consequences for the community, society, economy etc.

## EXAMPLE

### Consequences

Low self-esteem

Many children with no education

Further poverty, lack of skills, failing economy

### Form

Orphans excluded from school

### Causes

Poverty

Orphans not valued

Orphans blamed for parents' death



Ask participants to read through the flip charts and clarify any questions with each other. Discuss “Are there any examples of “self-stigma? Are there any examples of secondary stigma?”

### Summary

- Sometimes the consequences of stigma become the cause of more stigma
- Stigma is often exacerbated by poverty which limits a family's capacity to cope. Orphans might be resented or blamed if there is not enough food, money, resources. Sometimes they bear the brunt of the stresses in the household and this leads to harsh punishments etc
- Sometimes children internalize stigma and believe that they are “no good,” useless, worthless.

### EXAMPLES FROM THE RESEARCH

#### Forms of Stigma (orphans, street children, children living with HIV)

Abuse/mistreatment—not given a bed, sleeping on the floor, not given enough food, overloaded with extra work.

Cursing and name calling—“Go to your mother’s grave. I didn’t kill your parents.”

Street girls are called “prostitutes.”

Being called dirty. Being ignored. Not having a place to rest/no fixed abode. Being chased from one place to another.

Stigma in different places: clinics, police station, shops—not given attention or being chased away.

#### Causes

Lives are not valued. Being blamed for parents behavior if they died from AIDS.

Being seen as “a waste of resources”. Poverty makes stigma worse.

Being seen as “unlucky”

#### Consequences

Not belonging anywhere, not accepted, taken away from siblings to a new family

Being chased from school by teachers if you are thought to be HIV positive. Being isolated by school friends. Gossip and blaming. Too sick to go to school, but not wanted at home.

Sent to poor schools or no school at all

Sexual abuse by some guardians

Emotional problems—sexual, physical, and emotional abuse.

#### Self-stigma

Taking on, or internalizing, stigma: feeling worthless, low self-esteem.

Feeling invisible—“you don’t matter, don’t exist.” No one talks about parents' death. Losing life-style you had before

#### Secondary stigma

Carrying the blame and guilt for their parent’s death.

Accused of misbehaving because of parents behavior.

**Self-reflection****STIGMA AND STREET CHILDREN**

Put up picture of street children begging (B7). Divide into small groups. Ask groups to discuss:

What do you do when you find a street child?

- Asking for money?
- Asking to carry your shopping?
- Asking to wash your car?

Report back to group.

**Summary**

- Sometimes street children are treated as invisible
- Adults can act as if street children do not exist.
- Sometimes we presume all street children are thieves.
- We need to look at why we are afraid of street children and how this fear links to stigma?

**STORY + DISCUSSION**

Ask a participant to read the story below. Then ask pairs to discuss how they feel about the story.

Chipo grew up with his father who was a small businessman. After the death of his father when he was 10 years old, he went to stay with an uncle who used to give him a shovel and pick and tell him that these were the “keys to his father’s grave” and he should go and ask his father for money.

After much abuse, Chipo ran away and joined other children on the street. He lost contact with his family. At one time he tried to commit suicide and was rushed to the hospital by his friends.

*From Fountain of Hope  
Children's Centre, Zambia*

**WHAT DO YOU DO?**

Turn away. Try not to stop. I don't talk to them. Sometimes I give money. I feel pity. I don't want them to touch my car. I wouldn't trust them with my shopping.



### ACTION IDEAS



Share in the big group—ask participants to make a commitment to at least one action point

### CHALLENGING STIGMA

Ask participants to write on a card: *“One thing we can do personally to lessen the stigma on street children.”*

Fold papers and put into a hat/pot. Pass it round, each person takes one and reads it out.

#### Stigma against children living with HIV or AIDS

Children who are known or suspected to be HIV positive often face stigma from teachers, children, neighbors, family members.

#### Cardstorm

### CHILDREN LIVING WITH HIV OR AIDS

In small groups, ask participants to write on cards

- All the types of stigma children living with HIV might face.
- Why you think this stigma exists?



### FROM THE RESEARCH

#### Street Children

Common stories from street children were of adults insulting them usually with reference to their appearance (“dirty smelling”) or how they “made the town dirty;” other stories were about being moved on by the police, or told to sell their goods in the market not on the streets.

In Choma most of the children do not live on the streets permanently, but work there, selling vegetables and fritters to bring money home for their families. In Lusaka, the children had often run away from abusive situations at home or literally had nowhere to stay, after the death or break up of their family.

““ When I go to town and there is no business that day, it means we won’t have something to eat at home. Thieves grab our food; the council and police chase us from the corridors (pavements). I have never been called names but I feel different to those who don’t sell on the street. ””

*14 year old girl, (apple-seller), Zambia*

““ The Police also chase us away. They say “go to school.” We are different from other boys who have everything because we are poor and are called street vendors, even at home they laugh at us when we go to sell. I don’t feel alright, anyway it hurts inside me. ””

*13-year-old boy, Zambia*



## Summary

- Children living with HIV/AIDS face particular stigma which is often linked to adults fear and lack of knowledge
- Some adults see children with HIV as “a waste of resources” thinking that they will die soon
- Many children with HIV lead “normal” lives, do well at school, play sports, take part in family life.

## QUOTES FROM CHILDREN LIVING WITH HIV AND AIDS IN ZAMBIA

“ There were times at school I was treated badly by friends who didn't want to play with me because I had TB. I felt I was different to them. They thought they might contract the disease from me ”  
*10-year-old boy, Zambia*

“ At home friends never used to like me. They said I had measles and TB. They used to run away from me. ”  
*13-year-old girl, Zambia*

“ My teacher chased me from school because I had sores on my body. I didn't have problems with my friends. ”  
*10-year-old girl, Zambia*



# SUPPORTING PARENTS AND GUARDIANS

## EXERCISE 4



### OBJECTIVES

Participants will be able to:

- Understand some of the feelings that orphans experience in families
- Understand stigma faced by orphans
- Share their own experiences of raising orphans
- Identify strategies for providing emotional support to orphans
- Identify strategies for coping in times of stress



### TIME

2-3 hours



### MATERIALS

Silhouette characters (F1-F9) or paper, crayons, paint, magazines and glues

Children's pictures (B1-B20)

Orphan True or False cards

### ACTIVITIES

#### *Pictures and discussion*

#### **FAMILIES**

Ask each participant to make a picture of his/her family—either using the silhouettes or drawing the members in the family.

Take turns to talk about the pictures in the group and allow participants to ask questions of each other. Focus especially on the children. If there are orphans—Who are they? How did they come to their home? How do they fit in with the other children? How do they feel about them?

Display pictures on the wall if possible.

#### *Card storm*

#### **JOYS AND CHALLENGES OF CARING FOR ORPHANS**

Ask participants to write down one “joy” or “challenge” on each card. Stick the cards up on 2 sheets. Get a participant to read them out and discuss as you go.

#### **EXAMPLES**

##### **Joys**

Pleasure. Laughter. Watching them learn. Friends to my children. Older brother to help in the garden. One big family.

##### **Challenges**

Disturbs our family. Does not get on with my daughter.  
An extra mouth to feed. No discipline. More worries.  
Always depressed. Misbehaves



**Picture-Discussion****CHILDREN'S EXPERIENCE OF STIGMA**

Hand out the pictures and quotes written by the children.  
 Ask participants to discuss in small groups:

**Discuss**

- What do you see in the pictures?
- Are there any experiences familiar to you?
- How do you feel about these children's experiences?

In large group, ask participants to share how they feel about the pictures and the children's experiences.

**Summary**

- Not all orphans experience abuse or mistreatment
- Many orphans are treated differently from other children in the family
- Many orphans get blamed when times are difficult, especially if poverty is there. Often adults treat orphans more harshly when they are struggling to make ends meet

**ORPHANS: TRUE OR FALSE****Preparation**

Write down the statements below on cards. At one end of the room put a sign saying "TRUE." At the other end a sign saying "FALSE." Ask participants to imagine a line between the two.

Give out the cards and ask a participant to read out their card. The others must move to the part of the "line" to show how true or false they think the statement is.

The person with the card can ask up to 3 people why they are standing where they are/what they think of the statement.

**Summary**

- The statements are all findings from research.
- They are all true for some children.
- Not all orphans are mistreated, but many are treated less favorably than other children.

**TRUE OR FALSE**

Orphans are given more work than other children in the family

Orphans often get harsher punishments if they make a mistake

Orphans are given less food to eat than the rest of the family

Many orphans do not go to school for economic reasons

Orphans are not allowed to eat with the rest of the family

Some people believe that orphans caused the death of their parents

Orphans have to draw more water than other children

Some people believe that orphans will misbehave and die from AIDS like their parents did

Some orphans run away to live on the street because things at home are so bad

Girl orphans are more vulnerable to sexual abuse than other children

# CARING FOR ORPHANS

## 5 EXERCISE

When their parents separate or die, many children are taken into a new family without any choice; they may be separated from other siblings, or moved to a new area (sometimes sent to the village from the town) where they no longer see friends or familiar faces.

### **Reflection**

#### **“A NEW FAMILY”**

Ask participants to find a comfortable place to sit and to spend a few moments alone thinking about a time when they have gone into a new situation. It might be moving to a new area, getting married, starting a new job, traveling to a new place. Ask them to think about how they were feeling- What were their worries? Hopes? Fears? How did they cope? What made things easier?

Find a partner and share your reflections.

Ask if anyone wants to share in the large group

### **Group role-play**

Ask for 6 volunteers to do a role-play based on the scenario below. (You need: the orphan; auntie; cousin 1; cousin 2; cousin 3; stepfather.) Give each character their role.

Act out the role-play and develop it using stop-start drama, to move towards showing how the family can help the orphan settle in.

Ask the rest of the group to observe which actions help the orphan to feel welcome.

### **Role-play scenario**

#### ***Orphan***

You have recently lost your Mother and it has been decided that you should come to stay with your Auntie, who you do not know very well. You are missing your sister who has gone to another Auntie.

#### ***Auntie***

Your cousin recently died and you have agreed to take in one of her children. You are worried about money and you don't know how you will pay for more school fees.

**Cousin 1**

You are 15 years old and you do not want this orphan to come and stay with your family, as you know there will be even less money to buy clothes and food.

**Cousin 2**

You are 10 years old and are looking forward to having a new friend to play with.

**Cousin 3**

You are an orphan and have been staying with the family for 2 years.

**Stepfather**

You are not very interested in the new child who is coming to stay.

Make 2 lists of the ways in which the family did and did not welcome the new child into the family.

**Summary**

- When an orphan comes into a new family, it will mean changes for everybody. The family dynamics will change. Careful preparation by the adults can ease this process: letting the other children in the family know what is happening, working out how to welcome the new child and so on.
- Remember when an orphan comes into your family, they have probably been through trauma—the death or separation of their parents and the upheaval of leaving their home behind. It may take a while for them to settle in. They may need to talk about what has happened. Guardians can make a big difference to how they experience the transition.

**ACTION IDEAS**

Ask participants if there are any actions on the list that they could carry out to help the children in their house. This is the homework!





**EXAMPLES**

We can't feed our own children, let alone the extra children. We can't afford more school fees

The extra burden is too much for us.

Caring for an extra child affects my own children.

There is not enough room in the house.

Stress and more work.

**Short drama**

**THE BURDEN OF CARE**

In pairs ask participants to write down some of the practical problems they have been facing them because of looking after orphans. Team up with another pair and make a short drama to show this problem to the rest of the group.

**In large group discuss**

Which of these problems is the most difficult?

What support do you need to cope with this extra responsibility?

What other strategies would help you to cope (e.g. Are there any agencies which support orphans and vulnerable children in your area, any orphan support programs?)

## MODULE F

### Understanding Stigma Faced by Children

# TALKING ABOUT STIGMA

## EXERCISE



### OBJECTIVES

Participants will be able to:

- Begin to understand what we mean by stigma
- See how stigma hurts
- Begin to think about what they can do about stigma



### TIME

1 hours



### MATERIALS

Children Stigma Pictures  
(B1-B20)

### ACTION IDEA/HOMEWORK

Look for stigma at home  
and in your community



### ACTIVITIES

#### Picture Discussion

### PICTURES OF CHILDREN'S STIGMA

Divide children into pairs. Ask each pair to select a picture

#### Discuss

- What do you think is happening in the picture?
- Why do you think this is happening?

#### Report back

Ask each pair to report. Record points which show different types of stigma. Ask the children: "Have you seen stigma happening in your school or community? What happened?"

### EXAMPLES FROM RESEARCH

#### Forms of Stigma (orphans, street children, children living with HIV)

Not belonging anywhere, not accepted, taken away from siblings to a new family.

Abuse/mistreatment—not given a bed, sleeping on the floor, not given enough food, overloaded with extra work.

Sexual abuse by some guardians.

Name-calling. Street girls are called "prostitutes."

Being called dirty. Being ignored. Being chased from one place to another.

Stigma in different places: clinics, police station, shops—not given attention or being chased away.

Being chased from school by the teacher because you are HIV+

Feeling invisible—"you don't matter, don't exist." No one talks about parents' death.



## OBJECTIVES

Participants will be able to:

- Have a better understanding of how name-calling can hurt
- Develop ways of dealing with being called names
- Explore what makes a good friend



## TIME

1 hours



## MATERIALS

Paper, crayons or paints

## ACTIVITIES

### *Reflection and drawing*

#### **THINK OF A TIME**

Ask the children to sit quietly, close their eyes and think of a time when they have felt lonely, or isolated or been called bad names by other children or adults.

Ask children to draw or paint a picture to show what happened. Share the pictures in the group listening to how the children were feeling- write up key feelings on the board.

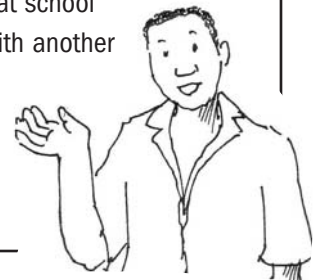
### *Story/drama*

#### **LONELINESS**

Read the story to the children

#### **STORY**

Gift is 9 years old and lives with his auntie and three cousins. Gift is small for his age and sometimes the other boys at school laugh at him. Two days ago Gift got into a fight with another boy who refused to let him join a game of football. The other boy shouted that Gift's Mother had died from AIDS. Gift ran home and felt very sad and lonely.



In small groups, ask the children to make a play about a similar story. Ask them to show how you can help someone who is feeling lonely. And what can you do if people call you names.

### **Discuss**

- Why do some children want to stop someone joining in a group or game?



- What is the effect of calling someone names?
- What can you do if something like this happens to you?
- How can you help someone who has been excluded?
- What can you do if you are feeling lonely?

**Brainstorm/Posters**

**“RULES FOR GOOD FRIENDS”**

In small groups, ask the children to think of all the things that make a good friend. They can write them or just discuss and feedback to the big group.

Write up a big list together called “Rules for Good Friends.” See if the group agrees to the list and if they will try to stick to the rules.

Ask the children to pick one of the rules and draw or paint posters showing “How to treat other people,” illustrating the “rule.”

**EXAMPLES OF “RULES”**

Share things with your friends. Play together nicely. Stand up for your friend in an argument. Stop your friend from fighting. Hug your friend if he is crying. Don't laugh at someone if they are feeling sad.

**Ideas for helping others at school or in the community**

Offer to help a friend who is having difficulty with his work. Be friendly and kind to all children. Cheer up someone who is sad with a smile and a kind word. Help those who are hurt. Make new children feel welcome. Help elderly neighbors with chores.



# STIGMA STOPS US FROM SPEAKING

## 8 EXERCISE



### OBJECTIVES

Participants will be able to:

- Raise the topic of AIDS in the family
- Understand how AIDS affects everyone in a family
- Begin to talk about coping with loss and grief
- Begin to identify ways of supporting each other and challenging stigma



### TIME

1 hour



### MATERIALS

Family story, lots of copied, cut-out silhouette figures (F1-F9)  
Glue, paper, cards.

### ACTIVITIES

#### *Story and discussion*

#### **FAMILY STORY**

Read the story to the children. Ask questions about the Chanda children's feelings (or discuss in small groups one or two questions each).

- How do you think the children are feeling after their Mothers death?
- What do you think about the reaction of the other children at school?
- How do you think the Chanda children feel at school?
- What can they do about it?
- Why have the neighbors stopped buying vegetables from them?
- Who can help them?

#### **FAMILY STORY: THE CHANDA FAMILY**

Mrs. Chanda had a thriving family business growing and selling vegetables. The Chandas have 4 children (aged 13, 11, 9 and 6), all of whom helped their mother with the vegetables after school. Sadly, 6 months ago Mrs. Chanda died of AIDS. Now children at school will not play with any of the children and they often call them names.

Mr. Chanda is a truck driver, but he has recently become sick and has been off work. The children are all upset and worried. They help the best they can by cleaning the house and picking the vegetables and cooking and trying to take care of their father. One of the neighbors helps sometimes by bringing food and buying vegetables but many of the neighbors have stopped buying from them.

Ask the children to think of ways the community could help families with these kind of problems.

- Do you know any families in a similar situation?
- How can you help families like this?
- How can we all help to stop stigma against families?

Record what the children say and display on the wall.

### ***Silhouettes***

#### **MY FAMILY**

Ask children to find silhouette shapes to represent the people in their household/family. If possible stick each “family” on to a piece of paper.

Ask children to take turns describing who is in their family  
 Brainstorm all 'the things you like about your family'.

(Check all children are feeling OK afterwards. Be aware of any things children say that need following up)

### ***Cardstorm/discussion***

#### **LOSING A LOVED ONE**

Introduce this exercise gently. Explain that some children may feel sad. They can talk to you at any time. Be ready to offer extra support to children who feel upset.

Card storm all the ways we can help a friend if their relative, gets sick or dies.

- How should we treat a friend who has lost a close relative?
- If it has happened to you, what do you think helped you, or would have helped you cope better?
- Who do you talk to about it?
- How are you feeling now?

Stick the cards on the wall, and ask children to read them out aloud.

### **RESEARCH FINDINGS**

One of the findings from the research about children and stigma was that many children who have lost parents or cared for sick relatives, have never discussed these experiences with anybody or talked about their sadness and grief. Sometimes this is because of stigma—perhaps an orphan lives in a family where no one really talks to them or they decide not to tell anyone out of fear. Many children bottle their feelings up; some believe that their parents died because of something that they themselves did and this may be reinforced by others who stigmatize them and scold them about their parents past behavior. Some children become depressed and even contemplate suicide.



“ So I used to feel bad by crying all the time and even wonder why my parents had to die. ”

“ I feel bad when I think of my parents and when I see friends who have both parents I cry to myself. ”

“ I know I am an orphan. My father and mother died. I feel like I'm just alone. ”

“ I don't know what killed my parents and people at home don't even want me to ask them about the death of my parents. ”



*Quotes from children  
from the research  
on children and stigma*

## **Summary**

- We all feel sad and lost when someone we love dies. If it happens to a friend we need to allow our friend to talk about their sadness, loss, fears
- Including the friend in games and activities so that they are not excluded
- Adults should accept how a child feels (they may be angry or not show any emotion)
- We need to be patient and gentle with each other
- Sometimes we want to talk about it, sometimes we don't
- We all need someone to listen to us
- We need to understand that it takes a long time to get over the death of a loved one

# MODULE

# G

## Moving to Action

When **action planning** is introduced as the final session in a workshop, it always feels like an empty ritual—something we are forced to do but without any commitment. It always comes too late in the workshop. By this time we have packed our bags (in our heads) and are ready to go and then the trainer says, “Okay, let’s make a list of the actions you are going to do when you get home.” We make the list, just to keep him happy, but we have no intention of carrying out what we have listed. These ideas die the minute we leave the workshop!

We don’t feel that **action planning** should be left as a last minute activity tacked on at the end of a workshop. It should come earlier and be an important part of the whole process. In fact we have built “action” into many of the earlier modules so people have already done the thinking about how to move against stigma and have started to practice the new knowledge and skills by carrying out mini-actions. Action is an important part of the learning process. As Paulo Freire has emphasized, learning which does not lead to action is itself an “empty ritual.”

The earlier modules include **action ideas**—suggestions on practical activities that participants can do at home. For example after exercises B5 and B6 participants map stigma in their own homes and talk about it with family members - and then report back on it at the next learning session. Mapping helps to show that stigma is everywhere. Talking with others helps to see what is involved in challenging stigma and build up the courage to do it. So look for opportunities to move to action after every module.

## G

## Moving to Action

This module will:

- Bring together all the things we have learned about stigma, including what can be done practically to change attitudes and behavior
- Focus on collective action and how to plan for effective action
- Support the development of skills needed to act against stigma.

By the end of this chapter, all participants should be expected to:

- Develop a specific plan of action for challenging stigma in their community.
- Make a public commitment to work individually and collectively to identify, understand and challenge stigma.

## **KEY MESSAGES**

We are all responsible for challenging stigma and discrimination, not just PLHAs. We can all play a role in educating others and advocating new attitudes and practice.

**Be a Role Model.** Apply what you have learned in your own lives. Think about the words you use and how you treat PLHAs and try to change how you think and act.

**Share what you have learned.** After the training tell others what you have learned and get others talking about stigma and how to change it.

**Challenge stigma when you see it in your homes, workplaces, and communities.** Speak out, name the problem and let people know that stigma hurts.

**Act against stigma as a group.** Each group can look at stigma in their own situation and agree on one or two practical things they can do to do to bring about change.

**Saying “stigma is wrong or bad” is not enough.** Help people move to action—agree on what needs to be done, develop a plan and then do it.

**Think big. Start small. Act now.**

## **Things You Can Do Yourself as Individuals**

- Watch your own language and avoid stigmatizing words
- Provide a caring ear and support to PLHA family members at home
- Visit and support PLHAs and their families in your neighborhood
- Encourage PLHAs to use the available services: counseling, testing, medical care, ARVs and refer them to others who can help.

### Things You Can Do to Involve Others

- Use informal conversations as opportunities to raise and talk about stigma
- Use real stories which put stigma into a practical context: stories of bad treatment of PLHAs resulting in depression; stories of good treatment
- Challenge stigmatizing words when you hear them—but do it in a way that doesn't turn people off—get people to think about how their words can hurt
- Encourage people to talk openly about their fears and concerns about HIV and AIDS
- Correct myths and misperceptions about AIDS and PLHAs
- Promote the idea of a friendly ear and support to PLHAs and their families

### Things to Get the Community Talking about and Acting against Stigma

Activities which get people to identify and analyze stigma in community examples:

- TESTIMONIES by PLHAs or their families about experience of living with HIV
- LANGUAGE WATCH—school children or youth group make a “listening survey” to identify stigmatizing words used in the community—in media or in popular songs
- COMMUNITY MAPPING of stigma—display map at community meeting place
- COMMUNITY WALK to identify points of stigma in community

- DRAMA by a youth group based on real examples—trigger for discussion
- PICTURES drawn by youth or children—focus or starting point for discussion

Community meetings to discuss what has been learned from the above methods and make decisions about what the community wants to do: agreeing on a code of conduct, specific support to families living with HIV and AIDS and orphans.

- Training workshops on stigma for community and peer group leaders
- Commitment. Make sure that people who want to make a difference are given an opportunity to state their commitment to challenge stigma publicly. Action starts with commitment and powerful commitment ensures that obstacles are challenged and overcome. The commitment of leaders serves as a role model and encouragement for others. Whenever possible, find examples of how one person's commitment led to action which made a difference in their community

# START WITH THE END IN MIND

## 1 EXERCISE



### OBJECTIVES

Participants will be able to:

- Identify some key obstacles to challenging stigma
- Identify specific actions which need to be taken to challenge stigma
- Begin to define what the result of successful interventions would look like



### TIME

1 hour

### ACTIVITIES

#### *Picture-storm*

#### **A WORLD WHERE THERE IS NO STIGMA**

Divide into pairs and hand out cards. Ask pairs to draw pictures and words for “a world where there is no stigma.” If there is time, have them draw a “before” and “after” illustrations—the world as it is—with stigma; and then as it might be - without stigma.

#### **Discussion**

Have participants explain their before and after pictures. What is the situation in the drawing? Why did they choose that particular subject/place?

- What has changed before and after? What needs to change?
- What are the obstacles to change?
- What would facilitate change?
- Who can help to facilitate change? Who is standing in the way?
- What's the first/next step in bringing about change?
- What, specifically, can we do to build this kind of world?

#### **Show**

Post these pictures around the room to serve as inspiration for remainder of the Action Planning Session.



# FINDING SOLUTIONS IN CONTEXT

## 2 EXERCISE



### OBJECTIVES

Participants will be able to:  
Develop practical strategies for  
overcoming stigma in their own  
context



### TIME

1 hour



### PREPARATION

Put up signs (in  
different parts of the  
room) for meeting  
spaces for different task  
groups. For instance:  
PLHAs, home based  
care, youth, counseling,  
health care, workplace,  
schools, faith groups,  
media

### ACTIVITIES

#### GROUP DIVISION

Ask participants to “vote with their feet”—to join the group of  
their own choice.

#### **Task Group Discussion**

Ask groups to develop concrete action plans:

- What forms of stigma do you see in your organization or  
community?
- What is the biggest stigma problem in your organization or  
community?
- What is the source of this problem?  
*Option:* Use problem tree or fishbone, if appropriate.
- What are some possible solutions to this problem?
- Identify 2-3 specific new things you would like to do to stamp  
out stigma in this context

Push groups to be concrete, “Think big. Start small. Act now!”

#### **Report back**

Ask each group to give a report then quick comments.

This exercise can be used in large workshops at the national or district or regional levels where there are participants from different NGOs or agencies. The exercise is built around task groups formed around different interests: PLHA support work, home based care, youth work, counseling, health work, workplace education, schools, media, depending on those present. This exercise can support the development of anti-stigma policies and practice.

### HEALTH CENTER

*Forms of Stigma:* Clinic creates gossip by isolating chronic patients. Limited physical contact with chronically ill patients because of fear of contracting disease—demoralizes patients—makes them feel unwanted and may destroy their will to live. Nurses make assumptions about patient’s sexual history— judge them for “having had many partners.” Some health workers give up on their patients, assuming they are going to die quickly, so “why waste their time.”

*Strategies to Combat Stigma:* Allow health workers to talk about their own attitudes, feelings, fears and behavior. Help them deal with fears about their status and burnout. Teach skills in sensitively handling patients. Develop codes of practice. Update health workers on HIV and stigma through in-service training. Get feedback from clients (community walk through clinic to identify stigma points)

### COMMUNITY

*Forms of Stigma:* PLHAs and families face isolation, insults and discrimination. In some cases they are kicked out of rental accommodation or their businesses suffer—people stop buying from them.

*Strategies to Combat Stigma:* 1) Involve community leaders and CBOs in promoting anti-stigma work. 2) Use PLHAs as role models and facilitators. 3) Organize community meetings, peer group meetings and home visits. 4) Organize drama performances. 5) Make links between clinic and community. 6) Inform community members what is involved in caring for PLHAs—physical care, counseling, etc

### HOME BASED CARE (HBC) WORKERS

*Forms of Stigma:* HBC workers face: 1) Stigma by association—rejected by the community who say they carry AIDS. 2) Rejected by patients when they make home visits. Wearing uniforms triggers stigma towards family (by neighbors). Visits are seen as a “death warrant.”

*Strategies to Combat Stigma:* 1) Stop wearing uniforms during home visits. 2) Raise awareness by providing correct information on HIV, TB, and stigma; and how to take care of PLHAs and TB patients.

### CHURCH/FAITH GROUPS

*Forms of Stigma:* HIV status associated with sin—promiscuity, adultery, immorality, many sexual partners. Gossip and condemnation. Silence and fear. Lack of adequate knowledge about HIV and AIDS among church leaders (pastors, deacons)—results in silence. No proper preparation for marriage.

*Strategies to Combat Stigma:* Use churches/mosques as place to discuss stigma. Get the faith group to recognize that they stigmatize: blame and judge people for getting HIV. Educate faith group leaders on stigma and help them play a lead role in anti-stigma action. Encourage them to become counselors in a non-stigmatizing way; and role models for treating PLHAs in non-stigmatizing ways

### WORKPLACE

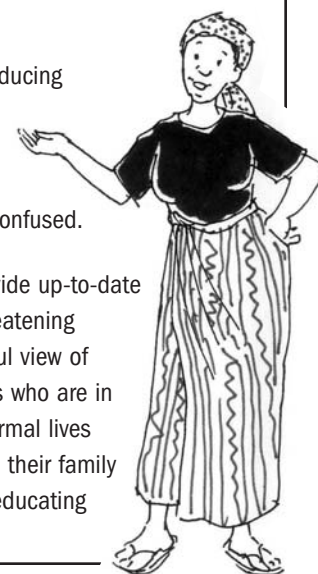
*Forms of Stigma:* Workers gossip about other workers who are assumed to have HIV. Loss of opportunities once one’s status is known, e.g. loss of job, promotion.

*Strategies to Combat Stigma:* Win support of the owners/managers—create trustful environment; workers won’t lose jobs if they disclose status. Work with managers to set policies: health benefits, continuity of employment. Incorporate stigma into benefits—offer VCT and ARVs - educate workers on rights. Encourage PLHA support groups within the workplace. Promote a code of conduct.

### MEDIA

*Forms of Stigma:* Incorrect, fear-inducing messages on AIDS and PLHAs. Disseminate message that AIDS = immediate death. Contradictory information so the community is confused.

*Strategies to Combat Stigma:* Provide up-to-date and correct information. Avoid threatening images. Give a positive and hopeful view of PLHAs: pictures which show PLHAs who are in good health and who are living normal lives and who can actively contribute to their family and the society. Involve PLHAs in educating media workers on these issues.



# TEN STEPS FOR MOVING TO ACTION

3  
EXERCISE



## OBJECTIVES

Participants will be able to:  
Work out a detailed strategy for  
taking action against stigma



## TIME

3 hours

## ACTIVITIES

### ACTION PLANNING

Divide into small groups (2-4 members) for this exercise. After each step get a quick report back and then move to the next step.

### SITUATION ANALYSIS

Ask “What is the current situation in the community regarding HIV stigma? What forms of stigma are common in the community? What are some of the background factors?”

- Lots of secrecy and silence around sex and AIDS - people find it difficult to talk
- Denial that AIDS is a problem
- AIDS affected households are the target for insults, exclusion and discrimination
- Lots of hidden conflicts between different households
- High levels of fear, fatalism and hopelessness
- Low knowledge and belief and fear of infection through casual contact
- Huge workload for women in AIDS affected households, including care of PLHAs
- High levels of poverty and unemployment - impact on AIDS and on stigma
- Young women at high risk - coercion, poverty and limited control over sexuality
- Poorly run and equipped health services and lack of trust in health services

## **VISION**

Ask “What will the situation in our community look like in two years time after our anti-stigma program?”

- More openness in talking about sex and AIDS
- Villagers helping each other in caring for PLHAs
- Less gossip and name-calling towards families affected by HIV/AIDS
- More knowledge about transmission and less fear about casual contact.
- More hope. Less feeling of fatalism and paralysis.
- More trust in and use of health services

## **ACTIVITIES**

Ask “What activities will you carry out to reach that goal?”

- Training workshops for community and peer group leaders and PLHAs
- Community and peer group meetings and awareness raising in schools
- Community participatory education on new facts about HIV/AIDS
- Development of community and peer group action plans
- Formation and operation of PLHA support/self-help groups
- PRA/PLA data gathering and analysis—community mapping, stigma walk
- Mini-campaigns on specific issues: stop stigma against orphans
- Home visits and support for AIDS affected households

## **PRIORITY ACTIVITIES**

Ask “Which activities are the most important?”

## **RESOURCES**

Ask “What resources do we need to do these activities?”

- Funds and materials for the training workshops.



### **OBSTACLES**

“What things might block our activities?”

- Resistance from faith group leaders
- Apathy and sense of fatalism—people feeling they cannot do anything
- Poverty—people too busy just trying to survive
- People resorting to faith healers and other solutions

### **INDICATORS**

Ask “What things will show that we have been successful?”

#### **TEN STEPS FOR MOVING TO ACTION**

<b>1</b> Where are you now? (Situational analysis)	This helps you to look at what is happening at the moment around stigma. You can ask “How have things been in the past?” and “How are they now?” “Where is the stigma in the community or workplace?”
<b>2</b> Where do you want to be? (Vision)	How would things look if you could really make a difference? Make a 'vision' of the future with reduced stigma.
<b>3</b> How will you get there? (Activities)	What kind of activities can you do to help reduce stigma? Brainstorm all your ideas - practical, new actions to solve the problem.
<b>4</b> Where will you start? (Prioritize)	What are the most feasible actions to start doing? What is the most important action?
<b>5</b> What do you need? (Resources)	Identify any resources, skills or training that will help with your action—and any partners who can help. Don't stop at this point—don't think you can't do anything because you have no funds.
<b>6</b> What might get in the way? (Obstacles)	Identify any obstacles that might prevent your action from being successful. Try to make plans or strategies on how to overcome these obstacles.
<b>7</b> How will you know that you are successful? (Indicators)	Decide how you will measure your success. Identify “indicators” or signs that will show you that stigma is reducing. (Are more people talking openly about testing HIV positive?)
<b>8</b> Action	Start the activities you have planned. Assign tasks to specific people
<b>9</b> Monitoring	Check how you are doing and whether anything is changing.
<b>10</b> Replan	Make changes to your plans based on what you learn from the monitoring.

# SUPPORTING AND RESISTING FACTORS

4  
EXERCISE



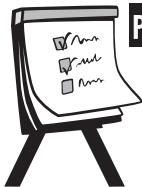
**OBJECTIVES**

- Participants will be able to:
- Identify the real issues which could prevent the group from realizing their vision
  - Identify what exists that will help the group achieve their vision



**TIME**

1 hour



**PREPARATION**

Put cards on wall—  
SUPPORTING FACTORS  
& RESISTING FACTORS

**ACTIVITIES**

**INTRODUCTION**

Explain that this session is to learn an approach to strategic planning called “**force field analysis**” and apply it to the planning of anti-stigma action. The aim is to identify the forces for and against a particular change in order to find ways of bringing about the desired change.

*Cardstorm*

**SUPPORTING AND RESISTING FACTORS**

Divide into pairs and ask pairs to write cards for “supporting factors” and “resisting factors” and tape them under the right heading.

**Report back**

Each person selects one card and explains why s/he has placed this factor under this heading.

Supporting Factors	Resisting Factors
<ul style="list-style-type: none"> <li>■ Schools—children advocating for caring</li> <li>■ Faith based groups—church members who are involved in home visits and caring</li> <li>■ Church’s own process to change moralizing messages and attitudes to PLHAs</li> <li>■ Peer groups, e.g., youth &amp; women’s groups</li> <li>■ Faith healers</li> <li>■ Family members</li> </ul>	<ul style="list-style-type: none"> <li>■ Leaders in denial themselves and moralizing about other people.</li> <li>■ People believe that stigma is a good thing</li> <li>■ Most people do not know they are HIV positive</li> <li>■ People have strong fears about being exposed and stigmatized</li> </ul>





### Force

- Faith based groups involved in caring
- Most people do not know their status

### Action Steps

- Work closely with faith based groups
- Promote counseling and testing

### Discuss

- What can you do to build on the supporting factors?
- What can you do to minimize the negative factors?
- Which blocks are within and which are outside the group's control?

### Select Realistic Action Steps and Plan

Decide which of the action steps are realistic and develop a plan for each action, including resources and possible timing.

# CHALLENGING STIGMATIZING STATEMENTS



## OBJECTIVES

Participants will be able to:

- Identify statements which are stigmatizing
- Develop arguments for challenging stigma when it occurs



## TIME

1 hour



## MATERIALS

Stigmatizing  
Statements written  
on flipchart or cards

## ACTIVITIES

### Hot Seat Exercise

### **CHALLENGING STIGMA**

Invite participants to take turns sitting in the "HOT SEAT". The person in the hot seat is expected to improvise challenges to statements which are presented one at a time. See list of statements below.

## EXAMPLES

People who sleep around deserve what they get  
Don't stand too close to someone with TB  
I feel sorry for the children who get HIV  
If I got AIDS I'd kill myself

You deserve to get sick if you behave badly

I don't want my children to go to school with a child who is HIV positive

She looked so thin, I said "Go and say goodbye to your mother."

If you have TB you must have slept with a woman who had an abortion

*Add any common statements relevant to the group/community/language*



## **STRATEGIES FOR CHANGING ATTITUDES**

Then discuss "What methods work best for challenging stigma? Be specific."

### **Summary**

The most powerful responses are those which make people stop and think, rather than attacking responses which make the stigmatizer defensive. Examples of strong responses:

- You only need to sleep with one person to get HIV.
- My sister had TB and she is fine now.
- You may be in the same boat in a year's time so you should be more compassionate to PLHAs now.



# HOW TO DEAL WITH DIFFICULT SITUATIONS



## OBJECTIVES

Participants will be able to:  
Be more confident in handling  
difficult situations



## TIME

1 hour



## MATERIALS

Critical Incidents

## ACTIVITIES

### DIFFICULT SITUATIONS

Ask participants to brainstorm difficult situations they have had to deal with. Write each situation on a card.

#### *Stop-Start Drama*

### PLAY AND ANALYZE

Ask participants to play out these situations and look for solutions. After each trial, invite others to try. Discuss what works and what doesn't work.

- A. PLHA gives testimony at community meeting.** Someone stands up and says—"He is lying. He doesn't have AIDS. He is only doing this for the money. People with AIDS don't look like him!"
- B. Community meeting.** Someone stands up and says—"You have been talking a lot about AIDS and telling us to get tested. Does that mean all of you have AIDS? Have YOU been tested for AIDS? Tell me now before you continue."
- C. Another person says in response to a presentation on HIV Stigma.** "You are only saying this because you work for an AIDS organization and you get paid to say these things. You don't really believe this. But if you don't say these things, you won't get paid."
- D. Villagers say they are bored with talks about HIV and AIDS.**

### Summary

- Practice presentations first in a comfortable situation. Try it out on a friend or colleague and ask them to give you feedback.
- Write down your points on a card if you are nervous.

# CHANGING ATTITUDES AND BEHAVIOR

## 7 EXERCISE



### OBJECTIVES

Participants will be able to:  
Develop a strategy for changing attitudes and behavior in a specific context



### TIME

2 hours

### ACTIVITIES

#### **SELECT SPECIFIC CONTEXT**

This can either be done as a single large group exercise, or participants can be split into groups to work on specific contexts.

#### **Strategy for changing attitudes**

Explain that this exercise will look at a strategy for changing attitudes in a specific context faith based organizations (FBO).

**Ask** “What are the attitudes of faith based organizations towards PLHAs?”

#### **Two types of attitudes which are contradictory**

- Caring and compassion towards PLHAs and their families
- Judging and condemnation—“You are promiscuous. You are a sinner.”

**Ask** “What strategies can we use to help the faith based organizations become less judgmental and more caring?”

#### **Suggestions for change**

- Build on their strengths—their capacity for care and support to PLHAs and families
- Help churches analyze their own approach to PLHAs and decide themselves they want to change their judging and stigmatizing habits
- Bring FBOs together to create a common message concerning stigma
- Participatory workshop in which they can talk about their concerns and fears

- Work with those FBOs who are already re-examining their views on HIV stigma. (Development and Peace section of Catholic Church)
- Modify the toolkit to suit the perspectives of each FBO: remove exercises on condoms to encourage its use by the Catholic Church
- Get well known theologians in each FBO to analyze holy texts (Bible and Koran) in order to identify positive sayings and stories to support non-stigmatizing behavior
- Develop appropriate tools (based on these texts) for clergy and lay leaders to use in preaching and Sunday school
- Provide training for FBO leaders on HIV/AIDS and stigma, including counseling skills, to change their attitudes and make them “AIDS-competent.”

### **Whose behavior needs to change?**

Who are the key individuals or groups in the organization whose behavior needs to change?

### **Behavioral analysis**

What is their current behavior? What is the ideal behavior? If the ideal is not feasible, what are some practical behaviors that can be encouraged?

### **Key factors**

What key factors influence their current behavior and make it easier or more difficult for them to change their behavior?

### **Activities**

What specific activities can we implement that will address these key factors and help them to change their behavior?

Summarize using a table similar to the **Behavior Change Model** illustrated next page.

**BEHAVIOR CHANGE MODEL**

Whose behavior needs to change?	What is the behavior (change) we want to encourage?	What are the key factors that influence this change?	What activities will we implement to bring about this change?
Church Leaders and Elders	Change from "stigmatizers" into "supporters" Specifically, to stop blaming and to practice and encourage compassion	They see their role as guiding people to moral behavior. Feel that showing people consequences of bad behavior will frighten them to behave morally; serve as "example to others." Position stigma as immoral. Provide examples of de-stigmatizing and compassionate behavior and the positive consequences of compassionate behavior	Interactive meetings, workshops and discussions focused on stigma and using the toolkit Identify and promote change agents and role models



# STIGMA RESEARCH FINDINGS

The International Center for Research on Women (ICRW), in partnership with organizations in Ethiopia, Tanzania, and Zambia, led a study of HIV and AIDS-related stigma and discrimination in these three countries. This project, conducted from April 2001 to September 2003, unraveled the complexities around stigma by investigating the causes, manifestations and consequences of HIV and AIDS-related stigma and discrimination in sub-Saharan Africa. It then uses this analysis to suggest program interventions.

Structured text analysis of more than 730 qualitative transcripts (650 interviews and 80 focus group discussions) and quantitative analysis of 400 survey respondents from rural and urban areas in these countries revealed the following main insights about the causes, context, experience and consequences of stigma:

- 1.** The main causes of stigma relate to incomplete knowledge, fears of death and disease, sexual norms and a lack of recognition of stigma. Insufficient and inaccurate knowledge combines with fears of death and disease to perpetuate beliefs in casual transmission and, thereby, avoidance of those with HIV. The knowledge that HIV can be transmitted sexually combines with an association of HIV with socially "improper" sex, such that people with HIV are stigmatized for their perceived immoral behavior. Finally, people often do not recognize that their words or actions are stigmatizing.
- 2.** Socio-economic status, age and gender all influence the experience of stigma. The poor are blamed less for their infection than the rich, yet they face greater stigma because they have fewer resources to hide an HIV-positive status. Youth are blamed in all three countries for spreading HIV through what is perceived as their highly risky sexual behavior. While both men and women are stigmatized for breaking sexual norms, gender-based power results in women being blamed more easily. At the same time, the consequences of HIV infection, disclosure, stigma and the burden of care are higher for women than for men.
- 3.** People living with HIV and AIDS face physical and social isolation from family, friends, and community; gossip, name-calling and voyeurism; and a loss of rights, decision-making power and access to resources and livelihoods. People with HIV internalize these experiences and consequently feel guilty, ashamed and inferior. They may, as a result, isolate themselves and lose hope. Those associated with people with HIV and AIDS, especially family members, friends and caregivers, face many of these same experiences in the form of secondary stigma.
- 4.** People living with HIV and AIDS and their families develop various strategies to cope with stigma. Decisions around disclosure depend on whether or not disclosing would help to cope (through care) or make the situation worse (through added stigma). Some cope by participating in networks of people with HIV and actively working in the field of HIV or by confronting stigma in their communities. Others look for alternative explanations for HIV besides sexual transmission and seek comfort, often turning to religion to do so.
- 5.** Stigma impedes various programmatic efforts. Testing, disclosure, prevention and care and support for people with HIV are advocated, but are impeded by stigma. Testing and disclosure are recognized as difficult because of stigma, and prevention is hampered because preventive

methods such as condom use or discussing safe sex are considered indications of HIV infection or immoral behaviors and thus stigmatized. Available care and support is accompanied by judgmental attitudes and isolating behavior, which can result in people with HIV delaying care until absolutely necessary.

6. There are also many positive aspects of the way people deal with HIV and stigma. People express good intentions to not stigmatize those with HIV. Many recognize that their limited knowledge has a role in perpetuating stigma and are keen to learn more. Families, religious organizations and communities provide care, empathy and support for people with HIV and AIDS. Finally, people with HIV themselves overcome the stigma they face to challenge stigmatizing social norms.

Our study points to five critical elements that programs aiming to tackle stigma need to address:

- Create greater recognition of stigma and discrimination
- Foster in-depth, applied knowledge about all aspects of HIV and AIDS through a participatory and interactive process
- Provide safe spaces to discuss the values and beliefs about sex, morality and death that underlie stigma
- Find common language to talk about stigma
- Ensure a central, contextually-appropriate and ethically-responsible role for people with HIV and AIDS

While all individuals and groups have a role in reducing stigma, policymakers and programmers can start with certain key groups that our study suggests are a priority:

- Families caring for people living with HIV and AIDS: programs can help families both to cope with the burden of care and also to recognize and modify their own stigmatizing behavior
- NGOs and other community-based organizations: NGOs can train their own staff to recognize and deal with stigma, incorporate ways to reduce stigma in all activities, and critically examine their communication methods and materials
- Religious and faith-based organizations: these can be supportive of people living with HIV and AIDS in their role as religious leaders and can incorporate ways to reduce stigma in their community service activities
- Health-care institutions: medical training can include issues of stigma for both new and experienced providers, while at the same time, risks faced by providers need to be acknowledged and minimized
- Media: media professionals can examine and modify their language to be non-stigmatizing, provide accurate, up-to-date information on HIV, and limit misperceptions and incorrect information about HIV and people living with HIV and AIDS

The complexity of stigma means that these and other approaches to reduce stigma and discrimination will face many challenges, but, at the same time, there exist many entry points and strong, positive foundations for change that interventions can immediately build on.

# SAMPLE WORKSHOP TIMETABLES AND EXERCISES

This Annex provides sample timetables for the following workshops:

- Half Day Workshop for Policy Makers
- One Day In-Service Training Workshop for Health Workers
- Three Day Community Workshop
- Stigma Education in the Workplace: 4 Weekly Sessions (2 hours each)
- Three Day Workshop for Home Based Care Workers

In addition PLHA Support Groups could plan a series of weekly sessions based on the exercises in Module E.

## **Half Day Workshop for Policy Makers**

- A1 – Naming Stigma through Pictures
- A2 – Our Own Experience as Stigmatizer and Stigmatized
- A6 – Forms, Effects and Causes (Problem Tree)

## **Action Planning**

- G1 – Start With the End In Mind
- G2 – Looking for Solutions In Different Contexts or
- G7 – Changing Attitudes Related to HIV Stigma

## **One Day In-Service Training for Health Workers**

### **Morning:**

- A1 – Naming Stigma through Pictures
- A2 – Our Own Experience as Stigmatizer and Stigmatized
- C2 – Things People Say about PLHAs and Others
- B3 – Fears about Non-Sexual Casual Contact

### **Afternoon:**

- C6 – Where Did You Get It?  
Analysis of their workplace and institution  
(institutional mapping of stigma)

### **Action Planning**

- G2 – Looking For Solutions In Different Contexts
- G3 – Ten Steps For Moving to Action or
- G7 – Changing Attitudes Related to HIV Stigma

## **Three Day Community Workshop**

### **Day One**

#### **Morning:**

- A1 – Naming Stigma through Pictures
- A2 – Our Own Experience as Stigmatizer and Stigmatized
- A5 – Effects of Stigma On Different Players

#### **Afternoon:**

- A3 – Naming Stigma in Different Contexts

### **Day Two**

#### **Morning:**

- A6 – Forms, Effects and Causes (Problem Tree)  
More Understanding and Less Fear (select exercise from this module)

#### **Afternoon:**

- C6 – Where Did You Get It?
- C4 – Judging Characters (Character Cards)
- C5 – Breaking the “Sex” Ice

### **Day Three**

#### **Morning:**

- D2 – Stigma in the Family
- D3 – Stigma Towards the Family
- F3 – Analyzing Children's Stigma

**Afternoon: Action Planning**

G1 – Start With the End In Mind

G2 – Looking For Solutions In Different Contexts

**Stigma Education in the Workplace**

Weekly Sessions (2 hours) over 4 weeks

**Session 1**

A1 – Naming Stigma through Pictures

A2 – Our Own Experience as Stigmatizer and Stigmatized

**Action Ideas (Homework):**

Conduct stigma mapping in the workplace  
Knowledge assessment—complete knowledge questionnaire on HIV/AIDS

**Session 2**

Debrief stigma mapping and Knowledge Assessment

B3 – Fears About Non-Sexual “Casual”

C4 – Judging Characters (Character Cards)

**Action Ideas:**

Brainstorm on information sharing about HIV/AIDS with other workers  
Plan events and activities, form a network, etc.

**Session 3**

D1 – How HIV Affects the Family

D2 – Stigma in the Family

D3 – Stigma Towards the Family

**Action Ideas:**

Get more information about the workplace policies related to HIV/AIDS and stigma (availability of ARVS, discrimination, coverage for sickness, etc.)

**Session 4**

Debrief data gathering on workplace policies

G2 – Looking For Solutions In Different Contexts

G3 – Ten Steps For Moving To Action

**Three Day Workshop for Home Based Care Workers****Day One****Morning:**

A1 – Naming Stigma through Pictures

A2 – Our Own Experience as Stigmatizer and Stigmatized

B3 – Fears About Non-Sexual Casual Contact

**Afternoon:**

D1 – How HIV Affects the Family

D2 – Stigma in the Family

D8 – PLHAs Can Live Long and Productive Lives

**Day Two****Morning:**

F3 – Analyzing Children’s Stigma

F6 – Talking About Stigma

**Afternoon:**

D4 – Neighbors Stigmatizing Neighbors

**Day Three****Morning:**

D3 – Relations between PLHA and Family

D7 – PLHAs Have Rights Too!

D12 – Burdens of Care

**Afternoon:**

C2 – Things People Say

G4 – Supporting and Resisting Factors

G5 – Challenging Stigmatizing Statements

G6 – How To Deal With Difficult Situations



# ANNEX 3 : Pictures For Exercises

## Introduction

This section includes different sets of pictures to be used as the stimulus for discussion in the educational sessions.

There are seven different categories of pictures –

- A. PROBLEM CODES** – These pictures show different forms of stigma or discrimination as a starting point for discussion. These pictures can be used as single pictures for a specific exercise; or a set from which participants select images for discussion.
- B. CHILDREN'S CODES** – This is a special set of 'problem codes' on children's issues. They include pictures drawn by the toolkit artist (Petra Rohr-Rouendaal) and children in Zambia.
- C. STORY PICTURES** – These pictures show different experiences of PLHAs over a period of time. Participants select a number of these pictures and use them to make up a story about how they see HIV/AIDS and stigma affecting the lives of PLHAs.
- D. PLHA'S RIGHTS** – These pictures show the different rights of PLHAs. The aim is to help demonstrate that people do not lose their rights once they are HIV positive. The pictures help participants look at which rights are not addressed by families.
- E. CHARACTERS** – These pictures show different categories or types of people – businessman, farmer, soldier, schoolgirl, housewife, orphan, sex worker, etc. These pictures can be sorted into piles, showing who is more stigmatized and less stigmatized – and why; or used as the basis for creating stories around how HIV affects different types of people.
- F. SILHOUETTES** – These pictures are used to create different types of families 'normal family' (father, mother, children), female headed family, grandparent headed family, child headed family, etc. After creating a family, participants then talk about how HIV and stigma affects the family.
- G. CONTEXT CARDS** – These pictures show the different contexts in which stigma takes place -family, community, clinic, school, workplace, church, market, bar, funeral, and media.

# A. PROBLEM CODES

A1:



A2:



A3:



A4:



A5:



A6:



A7:



A8:



A9:



A10:



A11:



A12:



A13:



A14:



A15:



A16:



A17:



A18:



A19:



A20:



A21:



A22:



A23:



A24:



A25:



A26:



A27:



A28:



A29:



A30:



A31:



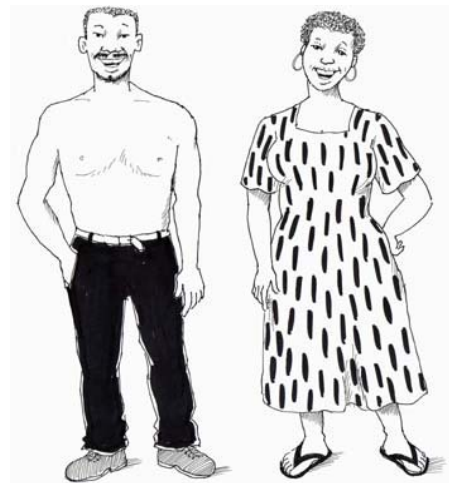
A32:



A33:



A34:



A35:



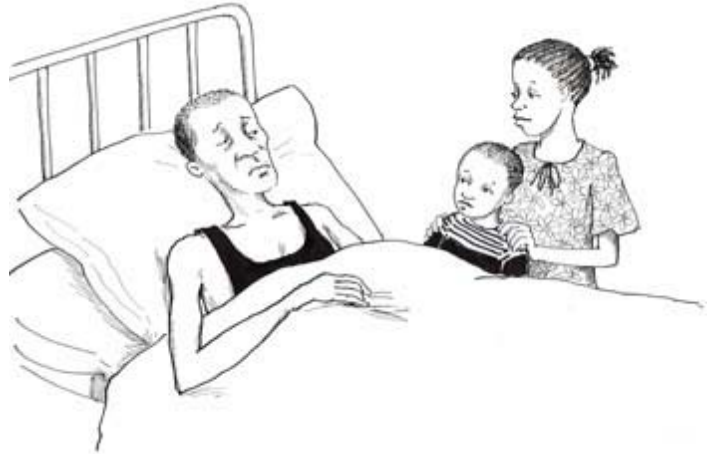
A36:



A37:



A38:



A39:



A40:



A41:





## B. CHILDREN'S CODES

B1:



B2:



B3:



B4:



B5:



B6:



B7:



B8:



B9:



B10:



## C. STORY PICTURES

### Description

The story pictures are 'open-ended' pictures which can be interpreted in different ways. Participants will select pictures from the set to make up their own stories about a woman who gets HIV and how she copes with life and stigma. The stories are then used to trigger discussion on aspects of stigma.

C1:



C2:



C3:



C4:



C5:



C6:



C7:



C8:



C9:



C10:



C11:



C12:



C13:



C14:



C15:



C16:



C17:



C18:



C19:



C20:



C21:



C22:



## D. PLHA'S RIGHTS

### Description

Each of these pictures represents one of the rights of a PLHA. The pictures will be used in PRA type exercises eg for ranking (putting into different piles). Participants would be asked, as an example: "*Which of these rights do families provide? Which do families try to remove?*" The pictures can also be used for discussion on a specific type of right eg right to say "No".

The pictures contrast with the problem codes. Instead of showing stigma or discrimination, they show how PLHAs should be treated - accepted, respected, loved, allowed to have safe sex and children, provided with food, medicine, clothing, shelter, hygiene, etc

A PLHA character appears in each picture – either a man or woman.

D1:



D2:



D3:



D4:



D5:



D6:



D7:



D8:



D9:



D10:





D11:



D12:



D13:



D14:



D15:



D16:



D17:



D18:



## E. CHARACTER CARDS

### Description

These cards are used to provide a set of character types which can be used for discussion or making stories. The cards allow us to talk about our assumptions about different types of people eg stigmatization towards sex workers and streetchildren.

### Use

There are four characters per page. Cut out each character and paste onto stiff board so that they can be displayed on the floor or wall or distributed to different participants.

### Source

The idea for producing this set of characters came from Dr. Gad Kilonzo, who suggested we adapt the character cards from the Fleet of Hope for use in anti-stigma education.

E1:



E2:



E3:



E4:



E5:



E6:



E7:



E8:



E9:



E10:



E11:



E12:



E13:



E14:



E15:



E16:



E17:



E18:



E19:



E20:



E21:



E22:



E23:



E24:



E25:



E26:



E27:



E28:



E29:



E30:



E31:



E32:



## F. SILHOUETTES

### Description

Each silhouette represents a different type of family member – grandfather, grandmother, father, mother, teenage boy, teenage girl, and baby. The cards are used to create different types of families eg 'normal family' (father, mother, children), female headed family, grandparent headed family, child headed family, etc. After creating a family, participants then talk about how HIV and stigma affects the family. The silhouettes make it possible for people to talk about their own experience of family issues but in an anonymous way.

### Use

Make several copies of the silhouettes so that different working groups can use them to make a silhouette family consisting of different generations of family members. Cut out each silhouette and paste onto stiff board so that they can be moved around easily.

### Source

The idea of using the silhouettes is adapted from: Mvula Trust (1998) **National Training Workshop Report and Reference Guide**. Mvula Trust, Johannesburg, March 1998

F1:



F2:



F3:



F4:



F5:



F6:



F7:



## G. CONTEXT CARDS

Each picture represents a different context in which stigma takes place eg family, community, clinic, school, workplace, church, market, bar, funeral, and media. Groups are formed around each context and the group analyses how stigma occurs in this context, and makes a play to show the stigma.

The cards could also be used for a ranking type exercise – identifying which are the contexts in which the most stigma occurs and why.

G1:



G2:



G3

G4:





G5:



G6:



G7:



G8:



G9:



G10:



# ANTI-RETROVIRAL THERAPY

## How HIV Makes the Body Sick

There are many different kinds of cells in our bodies. One is the **white cell**, also known as **CD4 cells**. White cells (CD4 cells) are found in our blood. Each person has many white blood cells. The cells are very small—one cell is much smaller than a grain of sand.

**White blood cells protect our bodies.** The white cells are like a fence around the body, protecting the body from diseases. They attack germs that get into the body so that we do not get sick. White blood cells keep our bodies healthy. They are part of our body's **immune system**—the system which protects us against sickness.

Once a person becomes infected with HIV, the virus begins to live and spread in the white blood cells. **HIV attacks and damages the white blood cells** so that the blood cells cannot do their work of keeping the body healthy. Germs then take advantage of the weakened immune system and attack the body.

**This weakening of the immune system takes place over a period of time.** People do not get HIV and die straight away. During part of this time a person often feels perfectly healthy and feels no sign of sickness. But over time the immune system gets weak. The body has to work harder to try to fight off other germs and diseases.

The body gets weaker and is attacked by different diseases, including TB, pneumonia, bowel infection, cancer, and meningitis. These diseases are known as “opportunistic infections” or AIDS related diseases. When the body is too weak to fight these diseases the person is said to have **AIDS**—a collection of diseases that attack a person after HIV has made the body weak. When the body becomes so weak the person can die.

## What is Anti Retroviral Therapy (ARV)?

ARV therapy is a combination of medicines—usually two or more medications—that are taken by an HIV positive person to **slow down the growth of HIV in the body**. ARV helps to improve the immune system and this helps the body protect itself against AIDS related diseases. If the medicine is properly taken, it can help a person live a healthier, more productive, and longer life.

**ARV is not a cure for HIV/AIDS.** The medicines will reduce the amount of virus in the body and make people feel healthier, but HIV is still in the blood. So once people start to use ARV therapy, they should continue with it for the rest of their lives. **ARV therapy is lifelong.** If people stop taking treatment, HIV will continue to grow and they will become sick again.

People taking ARV therapy need to **take their medicines at the right time and in the right way each day**. If they stop or forget to take their medicines, HIV will become stronger—and may become resistant to the medication—meaning that the medication will no longer work. ARV therapy is given to people who are HIV positive but do not yet have AIDS and to people who have AIDS. **But not every HIV positive person needs ARV therapy.** Only those people whose immune systems have been seriously weakened by HIV need ARV therapy.

Once a person discovers that he or she is HIV positive, he or she will get tests from health staff:

**Viral Load Test:** This measures the amount of HIV in the blood.

**CD4 Count Test:** This blood test measures the amount of white blood (CD4) cells.

The tests help to see if a person needs ARV therapy (when the CD4 count is low) and once a person starts ARV therapy to see how well the medicines are working—to see if the immune system is getting stronger.

When people start taking ARV therapy, their bodies may react to the medicine. These **side effects** may include: painful stomach, nausea and vomiting, diarrhoea, skin rash, excessive tiredness, headaches, tingling feeling in fingers and toes, and sleep disturbances. People should not stop taking the medicine when they have these side effects, but they should report them to the health staff.

**Is ARV therapy the only medication available for people with HIV/AIDS?** No. People living with HIV/AIDS often receive other medications for opportunistic infections such as TB.

People taking ARV therapy should try to live **healthy and positive lives**—in order to help the ARV therapy fight the HIV in their bodies. Things they can do include:

- 1. Eating good food and plenty of liquids** to strengthen their bodies and keep up body weight. (PLHAs lose weight as a result of opportunistic infections or lose nutrients because of diarrhoea or vomiting.)
- 2. Being physically active.** PLHAs will be healthier if they keep themselves busy.
- 3. Getting enough sleep and rest** to allow their bodies to recover.
- 4. Keeping their bodies and homes clean**—to help reduce the germs which can bring unwanted diseases.
- 5. Practising safe sex (using a condom).** PLHAs taking ARV therapy are still HIV positive and can pass HIV to others. By practising safe sex they can also protect themselves from getting re-infected (increasing the amount of virus in the body).
- 6. Living with hope and getting emotional support from family and friends.** This helps PLHAs feel loved, accepted and better about themselves and this strengthens them to live longer and more productively

# FREQUENTLY-ASKED QUESTIONS (FAQS) ABOUT HIV/AIDS

This fact sheet tries to address some of the common fears about HIV/AIDS.

### ***Can mosquitos transmit HIV from human to human?***

**No.** The HIV virus cannot live outside the human body. Mosquitoes do not inject blood into humans, they suck blood. (There is no “QQR.”)

### ***Can HIV be transmitted through razor blades or sharp instruments?***

There is a slight risk—where a razor is being used quickly to make incisions or cuts on many people one after the other without washing it. It is better and more hygienic anyway to sterilise sharp instruments by boiling them, or use new razors everytime. In terms of sharing razors to shave or cut hair—if a razor is covered in blood you would probably not use it anyway—or you would wash it thoroughly.

### ***Can I get HIV by touching someone who has open cuts and sores?***

**No.** Unless someone is covered in blood and you are injured badly yourself with open wounds, then there is **no** risk. Your skin protects you. If you are bleeding, your blood flows outwards, it does not suck things into your bloodstream!

Good hygiene would mean that if you are caring for someone (with HIV or not) and they are bleeding, you would use gloves or cover your hands, and wash well before and afterwards.

### ***What about cleaning up diarrhoea of an HIV patient?***

There is **no** risk. Diarrhoea does not contain the HIV virus, unless it has blood in. And it would still have to get inside your bloodstream. Use gloves or cover your hands for hygiene reasons anyway.

### ***How long can you live if you get HIV/AIDS?***

This depends on many things. If you are healthy and can eat well and have lots of love and support, you can live for many years. If you can access anti-retroviral drugs and take them consistently, you can live many years.

Remember that HIV and AIDS are different things. With HIV you have the virus but you are healthy. With AIDS, it means your immune system is low and you may have a number of infections (or “opportunistic infections”). It is important to treat these infections. Just remember finding out you are HIV positive is NOT a death sentence.

### ***Is it true that condoms are not really safe?***

If used properly, condoms offer 98% protection against HIV (and pregnancy). The virus cannot pass through a condom. Make sure your condoms are not out of date, and store them in a cool place. Don't use vaseline or oil on them as this can make them break. Never use more than one condom at a time! Some churches teach that condoms are not safe but this is not true.

### ***Is there any cure for AIDS?***

There is no “cure” but there are more and more treatments available which slow down the impact of the HIV virus. These are called Anti-retroviral drugs or ARVs. They are widely available in Western countries, and people there no longer think that HIV means you will die. ARVs are becoming more available, cheaper and easier to access in Africa. There are some big campaigns which are trying to force governments and drug companies to make the ARVs available to everyone. Ask your local clinic for information. (See ARVs Fact Sheet.)

# HIV TESTING

Most countries now have Voluntary Counselling and Testing—or VCT—services where people can go to get an HIV test.

## Thinking about testing

Most people with the HIV virus feel quite healthy. They do not know that they have been infected. The only way to know if you are HIV positive is to take an HIV test. Reasons for taking a test might be:

- That you had unsafe sex, or a condom broke
- You are thinking about getting married or having children
- Your partner tests positive
- You keep getting sick, and are worrying about HIV

It is YOUR decision to take a test. No one else can make you have the test

## Going for the Test

- First you will see a counsellor for 'pre-test counselling', to talk with you about why you have come for a test, and to think about possible results.
- A small amount of blood will be taken to be tested
- A counsellor will give you the result and talk through the what you will do next.

If you are **negative**, you may be asked to come back for another test. (There is a “window period” which means that the virus takes a 6-8 weeks before it shows up in your body.)

If you are **positive**, you will want to think about who you will tell. The counsellor should offer support and more counselling if you need it, plus advice about positive living and information about anti-retroviral drugs if they are available.

## Positive Living

If you find out you are positive, it does not mean you are going to DIE soon. Life goes on. There are some steps you can take to keep both your body and mind healthy- this is called 'positive living'. Ask the counsellor for more information, or join a support group if there is one in your area.

Here are some of the ideas behind positive living:

- Eat nutritious foods
- Drink less alcohol
- Talk about your fears and worries
- Spend time with friends and family
- If you work, carry on as normal
- Avoid stressful situations
- Practice safe sex so you don't get re-infected
- Practise good hygiene
- Get enough sleep
- Look after you spiritual and mental health
- Get treatments for infections as early as possible

For HIV transmission to take place, the quality of the virus must be strong, a large quantity must be present and there must be a route of transmission.

### Quality

For transmission to take place, the quality of the virus must be strong. HIV cannot survive outside the human body—it starts to die as soon as it is exposed to the air. If it is exposed to heat (for example if someone bleeds into a cooking pot) it will die. HIV does not live on the surface of the skin—it lives inside the body.

The only place the virus can survive outside the body is in a vacuum (like a syringe) where it is not exposed to air.

### Quantity

For transmission to take place, there must be enough quantity of the virus to pose any risk. HIV is found in large quantities in blood, semen and vaginal fluids and breastmilk. It is not found in sweat or tears. It is found in tiny amounts in saliva, vomit, faeces and urine but not enough for there to be any risk of transmission, unless blood is present.

### Route of Transmission

For HIV transmission to take place, the virus must get inside your bloodstream. Our body is a closed system. HIV cannot pass through unbroken skin or even broken skin very easily. If you cut yourself, the blood flows outwards, away from the bloodstream. If you touch someone else's cut, blood will not swim into your bloodstream!

Common sense and everyday hygiene mean that many concerns that people worry about would not really happen in everyday life. For example you wouldn't share a toothbrush if it was covered in blood; you would wash if you cut yourself; you would wear gloves or cover your hands if you are cleaning up someone's diarrhea.

Using "QQR" you can see why HIV CANNOT be transmitted by:

- Kissing
- Hugging
- Mosquitos
- Sharing cups and plates
- Shaking hands
- Giving blood
- Sharing toilets
- Using the same washing water
- Going to school together

## What is TB?

Tuberculosis is a fatal disease of the lungs and other parts of the body caused by germs that create 'holes' in the organs they affect.

Most people who have TB have TB of the lungs. TB can travel through the blood and can therefore attack any other part of the body, like the glands, brain, spine, hip, intestines.

## How is it transmitted?

TB germs are spread by TB patients who are not taking regular modern medical treatments to cure the TB. It is spread through sputum- by coughing up sputum in the air or spitting sputum with TB germs in it on the ground.

Not everybody who breathes in TB germs will get it. If people are healthy and strong they can fight the germs.

## How do you know if you have TB?

Some of the signs of TB include: feeling weak, coughing, loss of appetite, not being able to sleep, sometimes night sweats.

If you suspect that you have TB, you should go to your nearest clinic for some tests.

## TB is treatable and curable

The treatments for TB involves taking a tablet everyday for between 6 months-1 year. After the first 2-3 weeks of beginning the treatment, you are no longer infectious.

It is very important that you remember to take your treatment everyday, otherwise the TB germs can get stronger and medicine becomes less effective.

## Do TB patients need to be isolated?

NO! 2 weeks after you have started taking your treatments you are no longer infectious. This means you can eat, sleep, work together as normal. You do not need special utensils or separate bedding. Just remember to keep taking the treatments regularly.

## TB and HIV

If you are infected with TB it does not mean you have HIV or AIDS. However if you are living with HIV, you may be more vulnerable to catching TB because your immune (defence) system may be weak.

If you are HIV positive you can take a course of treatment that will prevent you from getting TB. In many places these treatments are freely available. If you are living with HIV and you do get TB, you can still cure the TB by taking the treatment.

# ANNEX 5

## QUIZ: WHAT DO I KNOW ABOUT HIV AND AIDS?

**HIV has been SHOWN to be transmitted through which of the following bodily fluids?**

- |        |                 |         |        |
|--------|-----------------|---------|--------|
| Blood? | Breast milk?    | Saliva? | Vomit? |
| Semen? | Vaginal fluids? | Faeces? | Urine? |
| Sweat? | Tears?          |         |        |

Answer: blood, breast milk, semen, vaginal fluids.

**What is the risk of catching HIV from:**

Contact with PLHAs	High risk	Some risk	No risk
Hugging			
Deep kissing			
Having sex without a condom			
Having dry sex			
Sleeping in the same room			
Sharing cups, plates, or utensils			
Sharing towels, blankets, or clothing			
Using the toilet after PLHA			
Dealing with bleeding wounds or cuts			
Cleaning PLHA who has diarrhoea			
Cleaning up spilled blood			
Eating food prepared by PLHA			
Eating from the same plate with PLHA			
Birth to HIV positive mother			
PLHA mother breastfeeding her child			
Playing football/netball with PLHA			
Being bitten by mosquitoes			
Carrying a dead PLHA to cemetery			
Using unsterilised needles or knives			
Using someone else's razor			
Blood transfusion			
Being spat on by PLHA			



# HIV/AIDS FACT SHEET

## HIV TRANSMISSION MODES

Unprotected sex, mother to child during pregnancy or birth, contact with infected blood. Body fluids.  
Degrees of risk - oral sex, MTCT, etc.

## HOW HIV IS NOT TRANSMITTED

Physical contact (shaking hands, kissing, etc) Sharing dishes, etc. Washing or carrying dead bodies.  
Mosquitoes. Condoms. Etc

## QQR (FORMULA FOR UNDERSTANDING HIV TRANSMISSION)

### Quality

HIV cannot survive outside the body. HIV can only survive for a few seconds outside the body—and exposure to air or water kills HIV.

### Quantity

There are different quantities of HIV in different fluids. There is very little HIV in saliva, sweat, tears, and urine so it is difficult to transmit HIV through these fluids. There are high proportions of HIV in semen, blood, vaginal and cervical fluids so it is easy to transmit HIV through these fluids. Breast milk has a smaller proportion of HIV.

### Route of Transmission

HIV has to get inside your body. Our body is a closed system. Even if the body gets punctured, blood flows out, not flowing in from the outside. Example: if you have a plastic bag of water and you hit it with a sharp knife, water flows out and not in.

## WHAT IT MEANS TO BE HIV POSITIVE

**Difference between HIV AND AIDS**—signs & symptoms, lab data:

**HIV**—infected with virus but have no signs and symptoms. Different HIV sub-types

**AIDS**—infected with virus + signs & symptoms—easy to get opportunistic infections

## TESTING

What test means—positive result, negative result, indeterminate result. Antibodies vs. virus. Window period. Different types of test. Counselling process. Discordant couples—if one is positive, sexual partner may be positive or negative.

## PROGRESSION OF HIV/AIDS

Different rates of progression. CD4, CD8, antibodies, viral load. Immune system.

## VIRAL LOAD

Amount of viral copies detected in body. Risk of HIV transmission goes up with increase in viral load. At start the viral load goes up then decreases with the increase of antibodies, then goes up again as the antibodies decrease.

## RISK OF MTCT COFACTORS

Reinfection (role of partner), weakens placenta

## ANTI- RETROVIRAL THERAPY

With food. When to start? Side effects. Costs. How they work in body (not a cure). Triple therapy. Drug resistance. Alternative therapies (e.g. herbs). Minerals and vitamins.

# ANNEX 7

# ERIKSON'S STAGES OF HUMAN DEVELOPMENT

The type of adults we become, how we act and react in different situations and how we interact with others are influenced by many things—our upbringing, environment, culture, traditions and families. One of the most important influences is what happens to us during childhood. Erikson was a psychologist and he described human development as happening in different stages (described below).

## **The First Stage: (Conception to 1 year old) "Trust and Mistrust"**

Normally during this time, the baby is held close to its mother most of the time. The baby learns to trust that at least one person will respond to its basic needs for food, contact (touch) and comfort. The Mother learns to recognize the baby's cry of hunger, discomfort or loneliness. If she does not respond, the baby will not learn to trust and may develop a strong sense of fear.

## **Second Stage (1-3 years) "Autonomy, Shame, Doubt"**

The child is learning to have some control over the body: walking, talking, dressing and controlling bowels. If the child is frustrated during this stage, or laughed at, or punished harshly, he/she will develop anger and rage against adults.

## **Third Stage (3-5 years) "Initiative/Guilt"**

A time of exploration and experimentation for the child. It is important the child is encouraged to take initiative and not punished or blamed when he or she makes mistakes. You can block the child's initiative if you shout or slap him/her. He/She will learn anxiety and feel "I am no good."

## **Fourth Stage (6-12 years) "Industry/Inferiority"**

Most children are learning to co-operate with others (at school or home) and to carry out tasks. The child

needs constant encouragement as she/he learns. If the child begins to feel like a failure, at this point they turn this feeling into blame and guilt.

## **Fifth Stage (13-18 years) "Identity/Role Diffusion"**

This is the time for discovery of one's identity as a young woman or man. Independence from parents begins. If a child has developed anxiety and guilt at earlier stages, they will find this time more difficult. They may feel shy, unloved, and uncertain. These feelings can last for many years.

## **Sixth Stage (19-25 years) "Intimacy/Isolation"**

The young person reaches a stage of self-assurance in relation to being a sexual person; she or he can develop relationships and intimacy. If they do not have the self-assurance, they may remain isolated and alone.

## **Seventh Stage (25-55 years) "Generativity/stagnation"**

Through the ability to know another person, there is the possibility of giving life to others, either through marriage and children, or through helping occupations, or informal relationships. Otherwise the person may feel unable to contribute to the growth of human society.

## **Eighth Stage (55 onwards) "Integrity/Despair"**

If a person has successfully completed the other stages in their life, this is the time they can look back and integrate all their experiences. They will be available to the younger generation as a 'wise person'. An 'unsuccessful' person will look to the future with despair, aware of not giving life to the world.

# ANNEX 8

## FEEDBACK FORM

To help improve this toolkit, please complete this form.

1. What exercises did you use?

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2. What kind of training did you use the exercises for and who was the target audience?

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3. Which exercises worked well? Why?

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4. Which exercises did not work well? Why?

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5. Please describe any changes or improvements you made to any exercises.

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6. What ADDITIONAL TOPICS need to be added to the toolkit?

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7. Have you developed any case studies or other materials on stigma? If yes, please describe and, if possible, send them to the CHANGE Project.

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8. Please provide your name and address so we can follow up.

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**Please send this form to:**

The CHANGE Project, Academy for Educational Development  
1825 Connecticut Ave. NW, Washington DC 20009-5721, USA  
[changeinfo@aed.org](mailto:changeinfo@aed.org)

# change

## **CHANGE Project**

Academy for Educational Development

1825 Connecticut Avenue NW

Washington DC 20009-5721

Tel: 202-884-8000

Fax: 202-884-8400

Website: [www.changeproject.org](http://www.changeproject.org)



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