

UNDERSTANDING AND CHALLENGING

# HIV STIGMA

Toolkit For Action



change

ICRW  
International Center for  
Research On Women

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## Trainers Guide

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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.

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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?”

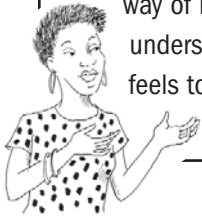
#### *Individual Reflection*

#### **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

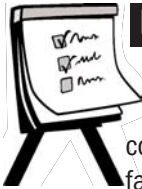
Participants will be able to:

- 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.”

# MODULE B

## More Understanding and Less Fear



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.