

Supporting community action on AIDS in developing countries

Understanding and challenging HIV stigma Toolkit for action

**MOVING TO
ACTION MODULE**

- Thinking about change
- Moving to action
- Developing skills for advocacy

About the organisations involved

Academy for Educational Development

Founded in 1961, the Academy for Educational Development (AED) is an independent, non-profit organisation committed to solving critical social problems and building the capacity of individuals, communities, and institutions to become more self-sufficient. AED works in all the major areas of human development, with a focus on improving education, health, and economic opportunities for the least advantaged in the United States and developing countries throughout the world.

www.aed.org

International Center for Research on Women

Since its founding in 1976, International Center for Research on Women (ICRW) has worked with partner organisations and governments throughout the world to promote gender equitable development, reduce poverty, and change the lives of millions of women and girls and their communities – undertaking focused, evidence-based, action-oriented research; providing technical assistance to partner organisations, donors and governments; and advocating for new or improved policies and programmes.

www.icrw.org

International HIV/AIDS Alliance

Established in 1993, the International HIV/AIDS Alliance (the Alliance) is a global partnership of nationally based organisations working to support community action on HIV and AIDS in developing countries. Our shared mission is to reduce the spread of HIV and meet the challenges of AIDS. To date, over \$140 million has been channelled to more than 40 developing countries in support of over 3,000 projects, reaching some of the poorest and most vulnerable communities with HIV prevention, care and support, and improved access to treatment.

Registered charity number 1038860

www.aidsalliance.org

For more information about Alliance publications, please go to www.aidsalliance.org/publications

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FROM THE AMERICAN PEOPLE



Understanding and challenging HIV stigma: Toolkit for action

About this toolkit

This toolkit was written for and by HIV trainers in Africa. It has been designed to help trainers plan and organise educational sessions with community leaders or organised groups to raise awareness and promote practical action to challenge HIV stigma and discrimination.

The toolkit evolved out of a research project on 'Understanding HIV-related stigma and resulting discrimination' that was conducted in Ethiopia, Tanzania and Zambia from 2001 to 2003. The research was implemented by the International Center for Research on Women (ICRW) in collaboration with research institutions in the three participating countries. The first edition of this toolkit was developed by the CHANGE Project AED (Academy for Educational Development) and ICRW in partnership with the research institutions and non-governmental organisations (NGOs) in these three countries who helped to design the original toolkit. It was developed and written by Ross Kidd and Sue Clay.

This edition was revised by the International HIV/AIDS Alliance country office in Zambia, building on the original toolkit, and includes experience of the Alliance's Regional Stigma Training Project, which has introduced the toolkit to many countries in Africa through a training of trainers (TOT) and networking process. The national TOT workshops and follow-up workshops conducted by members of the growing anti-stigma network have created a base of experience for revising and updating the toolkit. At a regional workshop in Zambia in August 2005, members of this network helped to review the toolkit and make changes and additions.

By the end of 2006, more than 300 anti-stigma trainers from many organisations have been trained by the Alliance using this toolkit. These include the following key partner organisations:

Burkina Faso: Initiative Privée et Communautaire Contre le VIH/SIDA au Burkina Faso (IPC)

Côte d'Ivoire: L'Alliance Nationale Contre le SIDA en Côte d'Ivoire (ANS-CI)

Ethiopia: ActionAid, Hiwot, Save Your Generation Association (SYGA)

Kenya: Regional AIDS Training Network (RATN), Network of people with HIV/AIDS in Kenya (Nephak)

Mozambique: International HIV/AIDS Alliance in Mozambique, Rede Nacional de Associações de Pessoas Vivendo Com HIV/SIDA (Rensida)

Nigeria: Network on Ethics, Human Rights, Law, HIV/AIDS Prevention, Support and Care (NELA)

Senegal: Alliance Nationale Contre le SIDA (ANCS)

Tanzania: Kimara, Muhimbili Medical College of Health Sciences (MUCHS)

Uganda: The AIDS Support Organization (TASO)

Zambia: International HIV/AIDS Alliance in Zambia, Network of Zambian People Living with HIV (NZP+)

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In memory of Martin Chisulu, Chama Musoka, Hamelmal Bekele (Happy), Andrew Mukelebai and Regina Mulope.

Contents

Moving to action module

Introduction	3
Key messages	4
Section 1 – Thinking about change	6
Exercises	
1 Start with a vision – a world without stigma	7
2 Thinking about change	8
3 Problem solving through stop-start drama	9
4 Problem solving in practitioner groups	10
5 Challenging stigma in our institutions	12
Section 2 – Planning for action	13
Exercises	
6 Community action against stigma	14
7 Specific campaigns against stigma	17
8 Ten steps for moving to action	19
Section 3 – Developing skills for advocacy	22
Exercises	
9 Advocacy skills	23
10 How to challenge stigmatising statements	25
11 How to deal with difficult situations	26
12 Stigmatising messages in the media	27

Other booklets in *Understanding and challenging HIV stigma: Toolkit for action* include:

Introduction

Using the toolkit

Module A

Naming the problem

Module B

More understanding, less fear

Module C

Sex, morality, shame and blame

Module D

The family and stigma

Module E

Home-based care and stigma

Module F

Coping with stigma

Module G

Treatment and stigma

Module H

MSM and stigma

Module I

Children and stigma

Module J

Young people and stigma

Picture booklet

General stigma pictures

Rights pictures

Additional booklets will be published as new modules are developed.

“ Our lives begin to end the day we become silent about things that matter. ”

Dr Martin Luther King Jr.

moving to action

Introduction

“ 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. 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 agree. 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 exercises so that people have already done the thinking about how to move against stigma and have started to practise the new knowledge and skills by carrying out mini-actions. Action is an important part of the learning process. As Paulo Freire has emphasised, learning that does not lead to action is itself an empty ritual.

The earlier exercises include action ideas – suggestions on practical activities that participants can do at home. For example, after the mapping exercise in module A, 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 builds up the courage to do it. So look for opportunities to move to action after every exercise.

This module is intended to:

- bring together all the things we have learned about stigma, including what can be done practically to change attitudes and behaviour
- build up our commitment to change things – to stop stigma
- focus on what we can do to change, as individuals, groups and communities
- agree on goals and how to achieve them.

By the end of this module, 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.

The module is divided into three sections:

1. Thinking about change
2. Planning for action
3. Developing skills for advocacy

Moving to action module

Key messages



- We are all responsible for challenging stigma, not just PLHIV. We can all play a role in educating others and advocating for new attitudes and practice.
- Be a role model. Apply what you have learned in your own lives. Think about the words you use about HIV and try to change how you think and act.
- Encourage community leaders to speak out – to talk to others about HIV and AIDS and condemn stigma.
- Encourage and support PLHIV to speak out in order to help people understand how it feels to be the object of stigma – and make sure that they are listened to.
- Share what you have learned. After the training, tell others what you have learned and get them talking about stigma and how to change it.
- Talk openly about HIV and AIDS. Show you are not afraid to talk about HIV. This will help people see that this is not a shameful thing that has to be hidden. Talking openly about HIV will also empower others and help relieve self-stigma.
- Facilitate discussion with family, friends and neighbours on stigma. What are the most common forms of stigma in your community? What perpetuates these abuses? What can be done to change things?
- Avoid using stigmatising words. Instead of saying ‘victims’, use positive words such as ‘people living with HIV and AIDS’, and use ‘us’, not ‘them’.
- Challenge stigma when you see it in your home, workplace and community. Speak out, name the problem and let people know that stigma hurts.
- Act against stigma as a community. Each community can look at stigma in their own situation and agree on one or two practical things they can do to bring about change.
- Saying ‘stigma is wrong’ 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! Have a big vision – but start with something small. And don’t wait – act now!



Things you can do yourselves as individuals

- Watch your own language and avoid stigmatising words.
- Provide a caring ear and support to family members living with HIV.
- Visit and support affected families in your neighbourhood.
- Encourage everyone to use the available services – e.g. counselling, testing, medical care, ARVs – and refer them to others who can help, e.g. counsellors.

Things you can do to involve others

- Use informal conversations as opportunities to raise and talk about stigma.
- Use the stigma pictures to get people talking about stigma.
- Use real stories that put stigma into a practical context, e.g. stories of bad treatment of PLHIV resulting in depression; stories of good treatment.
- Challenge stigmatising 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.
- Help normalise HIV and AIDS. Get people to regard PLHIV as 'people with an illness', not 'people with bad behaviour'.
- Encourage people to talk openly about their fears and concerns about HIV and AIDS.
- Correct myths and misperceptions about HIV.
- Promote the idea of a friendly ear and support to families living with HIV.

Things to get the community acting against stigma

- Examples of activities that can help people to identify and analyse stigma in the community:
 - **Testimonies** by PLHIV or their families about the experience of living with HIV.
 - **Language watch** – school children or youth groups can make a 'listening survey' to identify stigmatising words used in the community, media or in popular songs.
 - **Community mapping of stigma** – display the map at the community meeting place.
 - **Community walk** to identify points of stigma in the 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, e.g. agreeing on a code of conduct, specific support to families living with HIV and AIDS and/or 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 that made a difference in their community.

Section 1 Thinking about change

1 section 1

The exercises in this section get participants thinking about concrete strategies for action. The exercises assume that participants have already discussed stigma – its forms and causes – and are committed to doing something to change things.



Exercise 1 Start with a vision – a world without stigma

Facilitator's notes

This exercise helps us to think about the kind of world we should be aiming to build – as a starting point for action planning.

Objectives

By the end of this session, participants will be able to:

- identify some key obstacles to challenging stigma
- identify specific actions that need to be taken to challenge stigma
- begin to define what the result of successful interventions would look like.

Time

30 minutes

Preparation

Stick flipchart paper together to make one big sheet of paper – cover a wall or have it on the floor.

Step-by-step activity

A world without stigma

1. Hand out markers. Ask participants to draw pictures and write words to create a group vision of 'a world without stigma'. If there is time, have them draw a 'before' and 'after' picture: the world as it is – with stigma; and then as it might be – without stigma.
2. Then ask the group to talk about their drawings:
 - *What does it mean? What kinds of changes are envisaged?*
 - *What can we do to build this kind of world?*
 - *What are the first steps in bringing about change?*

Examples of a world without stigma

Future vision – results

- When we disclose to our immediate families we get support and love.
- We are no longer isolated and hiding our situation.
- We are leading active and productive lives and feeling good about ourselves.
- We are playing an active role in educating others.

What can we do to build this world?

- Increase understanding and reduce fears about HIV and AIDS.
- Educate the community to stop shaming and isolating us.
- Get community leaders to model and promote the new behaviours.
- Get the community to work together in addressing HIV and AIDS.

First steps in bringing about change?

- Change our own attitudes and language.
- Provide information on how HIV is spread in order to reduce fears about infection.
- Speak out against stigma towards PLHIV, women, MSM, widows, orphans, etc.



Exercise 2 Thinking about change



Facilitator's notes

This exercise provides an approach that uses our bodies to help us act against stigma.



Objective

By the end of this session, participants will have developed initial ideas and strategies for change.



Time

1 hour

Step-by-step activity

Back to back – ice-breaking game

1. Ask participants to pair off, then shout various instructions – e.g. “Front to front”, “Back to back”, “Foot to foot” – and after each command ask pairs to do the action. Then after a while, shout “Change!” and ask participants to find a new partner. You also grab a partner so that one person is left without a partner. He or she becomes the new caller and the game continues. Stop after five minutes.

Sculpturing

2. Explain that sculpturing is a method of using our bodies to show different images. Emphasise that it is a frozen, silent image, not a moving image with words, (i.e. it is not drama). It can be used to look at stigma. We show through our bodies, often unconsciously, how we feel about other people.
3. Ask participants to pair off and do a sculpture to learn the techniques, e.g. a husband comes home late at night and is challenged by his wife. Show the body language when the wife sees the husband. Remind people that it is a frozen image without dialogue.
4. **Before:** Ask pairs to make a sculpture showing how people stigmatise PLHIV. Then ask a few pairs to show their sculptures in the centre of the circle. After each demonstration ask:
 - Observers – *what do you see in the sculpture?*
 - Stigmatiser – *what are you thinking? Why are you stigmatising?*
 - Stigmatised – *how does this make you feel (hurt, rejected, isolated)?*
5. **After:** Ask pairs to make a new sculpture showing how people **should** treat PLHIV. Ask a few pairs to demonstrate in the centre – and after each sculpture ask, “*What do you see this time? How does it make you feel?*”

Discussion

6. Ask participants, “*What do you think caused the change in attitude from the ‘before’ sculpture to the ‘after’ sculpture? Why did people change their behaviour?*”

Examples of things that changed people's behaviour

- Hearing testimonies by PLHIV about their own experience and how stigma hurts.
- Finding out that our own siblings or family members are affected by HIV stigma.
- Religious teachings, e.g. love your neighbour as yourself.
- Self-interest – “Next year I might need the same care and support as him.”
- Not sure of one's HIV status so “I'd better be nice to those who know theirs.”
- Good role models, e.g. a leader who demonstrates compassion and a caring attitude.
- Peers challenge our language or attitudes, in a supportive way.
- More knowledge about HIV transmission so I am no longer scared about being affected.
- Mass ARV programme helps to make HIV and AIDS less fearful to the public.

Exercise 3 Problem solving through stop-start drama



Facilitator's notes

This exercise shows how to use stop-start drama as a way of testing the effectiveness and realism of different strategies for countering HIV stigma.



Objective

By the end of this session, participants will have developed initial ideas and strategies for change.



Time

1 hour

Step-by-step activity

Starter drama

1. Divide into threes and ask each group to select a context in which stigma takes place and prepare a 'starter drama' – a drama that shows the problem of stigma but leaves the problem unresolved.

Examples of contexts where stigma takes place

A PLHIV living at home wants to see his friend. The family, out of embarrassment, stops his friend from visiting, thinking this will lead to stigma by the whole community. (Tanzania)

Parents discover that one school child has an HIV positive parent. They force the head teacher to remove the child from the school. (Vietnam)

A doctor and nurse at a hospital discover that a patient is HIV positive. They use excuses to avoid seeing the patient and leave early so that the next shift has to deal with the patient. (Vietnam)

An orphan is adopted by her uncle. The uncle takes all of the things she has inherited from her father. She is poorly treated – forced to do all the work in the house and to eat alone. She is even abused by other children in the house. (Zambia)

Drama and discussion

2. Ask each group to present its drama. After each drama ask:
 - *What happened?*
 - *What is the root cause of the stigma?*
 - *How could this problem be solved if or when it occurs?*
3. Ask the group to select one drama to be used as the focus for stop-start drama. Try out different solutions through new, improvised dramas, with all participants taking part. After each new drama, discuss what happened and ask if the solution is realistic or working.

Examples of problem and solution

Problem of PLHIV not being allowed by his or her family to make any decisions about their life, e.g. who visits, what they do.

Solution sees PLHIV becoming assertive and demanding more say about his or her life; or a family member challenges the other family members when they stop someone taking part in a family discussion or decision-making.

Exercise 4 Problem solving in practitioner groups

Facilitator's notes

In this exercise participants work in practitioner groups – e.g. nursing staff, HBC workers, counsellors – to analyse problems in their own context and look for solutions. It can be used in large workshops where there are participants from different practitioner groupings.

Objective

By the end of this session, participants will have developed practical strategies for overcoming stigma in their own context.

Time

2 hours

Preparation

Put up signs on different walls of the room for meeting spaces for different task groups, e.g. support groups, HBC, youth work, counselling and testing, health care, workplace, schools, faith-based groups.

Step-by-step activity

Problems

1. Ask participants to vote with their feet – to join the group of their own choice.
2. Ask groups to develop concrete action plans by discussing these questions:
 - *What forms of stigma do you see in your organisation or community?*
 - *Prioritise – what is the biggest stigma problem in your organisation or community?*
 - *What is the source of this problem?*
 - *What are some possible solutions to this problem?*
 - *Can you identify two or three specific new things you would like to do to stamp out stigma in this context?*

Push groups to be make concrete suggestions, e.g. Think big! Start small! Act now!

Report back

3. Ask each group to give a report, followed by quick comments.

Examples from toolkit development workshop

Health centre

Forms of stigma: Isolation and neglect of chronically ill patients. Limited physical contact by nurses because of fear of getting HIV – lack of contact demoralises patients and makes them feel unwanted. Nurses gossip about patients' sexual history (saying 'promiscuous') and break their confidentiality. Some nurses give up on patients, assuming they are going to die quickly, so "why waste our time?" Nurses are too scared to get tested themselves, fearing stigma from colleagues.

Strategies to combat stigma: Update health workers on HIV, ARVs and stigma through in-service training. Help health workers talk about their own feelings and fears about HIV. Teach skills in how to handle patients sensitively. Develop codes of practice. Protect patients' right to confidentiality. Get feedback from clients (e.g. community walk through clinic to identify stigma points).

Community

Forms of stigma: PLHIV and families face isolation, insults and discrimination. In some cases they are kicked out of rented accommodation or their businesses suffer if people stop buying from them.

Strategies to combat stigma: Involve community leaders and community-based organisations in promoting anti-stigma work. Use PLHIV as role models and facilitators. Organise community meetings, peer group meetings and home visits. Organise drama performances. Make links between clinic and community. Inform community members what is involved in caring for patients – physical care, counselling, etc.

Exercise 4 Problem solving in practitioner groups



Examples from toolkit development workshop (cont.)

HBC workers

Forms of stigma: HBC workers face stigma by association – they are rejected by the community who say they ‘carry’ AIDS. They also face rejection by patients when they make home visits. Wearing uniforms triggers stigma towards the family by neighbours. Visits are seen as a death warrant.

Strategies to combat stigma: Stop wearing uniforms during home visits. Raise awareness by providing correct information on HIV, TB and stigma, and how to take care of PLHIV and patients with TB. Be a role model for family members to challenge stigma in the family.

Faith-based 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 (e.g. pastors, deacons) results in silence. No proper preparation for marriage.

Strategies to combat stigma: Use churches and mosques as places to discuss stigma. Get the faith group to recognise that they stigmatise, e.g. 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 counsellors in a non-stigmatising way, and role models for treating everyone in non-stigmatising 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 a trustful environment, e.g. where workers won’t lose jobs if they disclose status. Work with managers to set policies, e.g. health benefits, continuity of employment. Incorporate anti-stigma into benefits – offer voluntary counselling and testing, and ARVs. Educate workers on rights. Encourage support groups within the workplace. Promote a code of conduct.

Media

Forms of stigma: Incorrect, fear-inducing messages on AIDS and PLHIV. Disseminate messages that AIDS means 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 more positive and hopeful view of HIV, e.g. pictures which show PLHIV who are in good health and taking ARVs, who are living normal lives and who can still actively contribute to their family and the society.

Exercise 5 Challenging stigma in our institutions

Facilitator's notes

This exercise provides a simple approach for identifying stigma in our institutions and triggering discussion with staff and community members to do something about it. It could be used as part of stigma training in the workplace.

Objectives

By the end of this session, participants will be able to:

- identify points of stigma within their own institution
- develop concrete action plans to make specific changes in institutions to reduce HIV stigma and discrimination.

Time

3 hours

Step-by-step activity

Spot-the-stigma walk and talk

1. Identify the institution to be studied – e.g. health clinic, voluntary counselling and testing centre, NGO – in consultation with the staff of the institution.
2. Discuss with the staff what is to happen and how they will participate.
3. Set up a joint group – institution's staff and community members (including PLHIV and HIV-affected families) – to carry out the stigma walk and talk.
4. Orient the group beforehand. Discuss the objectives and what they will be looking for – i.e. places and activities **where stigma is a problem** – and how the activity will be debriefed and actions planned.

Conduct the stigma walk

5. Take notes during the walk and record the notes on flipcharts showing the different departments/sections and activities within the institution, and points of stigma.

Examples

Waiting area: Patients gossip about other patients while sitting on the bench. Stigma is directed towards people they suspect have HIV, e.g. patients who are thin or have skin rashes.

Nurse's room: One nurse shows fear of being infected – stays at a long distance from patients. One patient dropped his TB card and others saw it. This upset him and he left the waiting area. He was worried that people would stigmatise him since TB is associated with AIDS. Nurse's comments make people feel they are being judged (shamed and blamed).

Antenatal clinic: Women are tested for HIV as part of antenatal services. When women are told they have HIV, some react emotionally. Nurses provide very little support when giving this information.

Debrief

6. Hold a joint meeting with the institution's staff and community members to discuss:
 - *What major forms of stigma were identified?*
 - *What are their causes?*
 - *What can be done to avoid these problems?*

Develop an **action plan** with the following on the agenda:

- Identify specific change activities.
- Who will do each activity and by when?
- What indicators will show that the problem has been solved?

Note: Working out the detailed action plans could be done on a departmental basis (e.g. clinic, general nursing) so that each department feels some commitment to the plans they have to implement.

section 2

Exercises in this section are designed to get people thinking about concrete strategies for action. It assumes that they have already discussed stigma – its forms and causes – and are committed to doing something to change things.



Exercise 6 Community action against stigma

Facilitator's notes

Use this exercise as the agenda for a community meeting. Use one of the community's own stories or one of the stories on the following page.

Objective

By the end of this meeting, the community will have agreed on practical plans to stop stigma and discrimination towards PLHIV and to support HIV-affected households.

Time

2-3 hours



Step-by-step activity

1. Start with a warm-up song to build interest and a sense of community.

Community timeline

2. Ask the community to discuss:
- *What is the history of HIV in your community?*
 - *What happened when the community first learned about HIV and AIDS? Five years ago? Now?*
 - *What has been people's attitude towards PLHIV?*
 - *How have PLHIV been treated?*
 - *How has this treatment affected families living with HIV and AIDS?*

Action mapping

3. Ask, "What is the community already doing to support families affected by HIV?" For example; exemptions for school fees; people contributing donkeys to take patients to the clinic; increasing openness in talking about AIDS; support for HBC.
4. Ask, "What are other communities doing?" Tell local stories about how communities are organising themselves in response to HIV and AIDS.

Community action – Malawi¹

In one village in Malawi, the chief, a woman, was the chairperson of the village AIDS committee. The committee decided they wanted to mobilise support for orphans and other vulnerable children in the village.

Instead of calling all villagers to a meeting and ordering them to contribute money, the chief took a different approach. She started by donating her own land to grow crops to support the orphans. Every morning she woke up at dawn to plough these fields with her sons.

Later, she called a meeting and invited villagers to join her and her sons to farm the land and care for the orphans. Everyone agreed. They said, "If she can do it, we can also contribute. Our chief has shown us the way."

5. Discuss in small groups:
- *What happened in the story?*
 - *Why was the approach used in the story successful?*
 - *What can we do as a community to support AIDS-affected households?*

¹ The story is adapted from Foster, Geoff (2003) 'Understanding community responses to the situation of children affected by AIDS: Lessons for external agencies' in *One step further – Responses to HIV/AIDS, SIDA studies No. 7*, Stockholm.



Real stories to inspire action

Here are some examples of other people who have already acted against stigma.

1. A family takes action

The family did nothing at first. They were in denial. No one talked about their relatives who had HIV. They just wanted to keep everything quiet, to bury their heads in the sand, to keep the neighbours happy. Raising the issue would just bring shame on their heads.

But when three uncles died within a few months, the first-born brother was deeply affected. He called the family together and raised the issue of AIDS for the first time in a family meeting. *“My brothers and sisters, we can no longer continue like this in silence. If we do nothing, this thing will kill us all. Let’s do something.”*

So they started to plan and look at how they could support each other, especially those with HIV. They set up a family fund to provide money to deal with crises if someone got sick. They made plans about who would take care of the children and they worked out who would care for those who were sick. They also decided that the only way to protect the younger ones was to talk more openly about HIV and AIDS and how to stay safe.

2. Action in the workplace

“I work for a large NGO in the capital. We do a lot of work on HIV and AIDS. Last year we lost three members of staff. It was sad and nobody really talked about it much. Of course, we were all thinking about HIV but no one said anything. Then one of my colleagues came to me one day and asked if she could talk to me. She told me that a few weeks ago she had taken an HIV test and was positive. She was finding it difficult at work and had decided she really wanted people to know so that she could feel free to talk about it.

I helped her set up a special meeting that all the staff were invited to (even the guards and drivers). My colleague told her story, and the response was amazing! A lot of us cried and we all ended up hugging each other.

Since then we have all been more open with each other. Two more colleagues have ‘come out’ as HIV positive, and every month we all meet to talk about how HIV is affecting us. Some of us are caring for relatives or children with HIV, some have lost partners and family, others are living with the virus themselves. Now we can all support each other.”

Exercise 6 Community action against stigma



Real stories to inspire action (cont.)

3. Action for widows

In many countries there is a lot of stigma against widows. They are blamed for the death of their husbands (if they died from AIDS), they are suspected to be HIV positive themselves, and, as women living without men, they are seen as a threat to the community, especially by other women. Widows are often isolated and excluded. Some people refuse to do business with widows. Some husbands refuse to let their wives mix with them.

In a small community in Tanzania, a group of widows got together to talk about their problems and try to find ways of supporting each other. They set up a rotating credit fund that they all contributed to every month, and then took turns spending the money – helping each other to set up small food stalls. They also went to talk to the pastor about their problems and after that found that some of the other villagers became more sympathetic.

4. Individual action by a musician

Philly Lutaaya, a Ugandan singer, was one of the first well-known personalities in Uganda to come out publicly as living with HIV. Through his own courage in talking openly about HIV and AIDS, he captured the imagination and serious attention of millions of Ugandans, who learned about HIV from him. Before Philly's one-man campaign, Ugandans had heard about AIDS but they were still scared and in denial. After his campaign, they began to talk about it and deal with it seriously.

When Philly first revealed his status, there was lots of scepticism and criticism. Everyone kept asking him, "Where did you get it?" All of this criticism didn't stop Philly. He just kept going. He travelled all over Uganda talking to groups of people – at schools, churches, workplaces, bus stops, wherever he could meet people. He stood there and answered hundreds of questions. People were moved by his courage and affected by his willingness to talk openly about his situation – and they began to talk too, about how HIV and AIDS was affecting their own lives.

When he died in 1989, the national stadium was packed with people wanting to pay their last respects to this man who had touched their hearts and helped Ugandans start to talk.

Exercise 7 Specific campaigns against stigma

Facilitator's notes

This exercise provides a framework for specific action campaigns organised by communities or community groups, e.g. youth or women's groups.

Objective

By the end of this session, participants will have planned a campaign to stop specific forms of stigma and discrimination against PLHIV or other stigmatised groups.

 **Time**
2 hours



Step-by-step activity

Identify the target group

1. Ask the group to identify specific forms of stigma or discrimination in relation to a specific target group, e.g. PLHIV, orphans, widows.

Prioritise and analyse

2. Then ask the group to prioritise – select one form of stigma or discrimination to focus on.
3. Describe the stigma or discrimination and do a situation analysis:
 - *What is happening now?*
 - *How are people affected?*
 - *What are the obstacles to a solution?*

Action planning

4. Brainstorm practical actions that could solve the problem. Select the most feasible actions and develop an action plan. Ask participants to decide:
 - *What actions?*
 - *Who will do it?*
 - *When and where?*
 - *What action steps?*

Examples of possible actions

- Meet with community leaders to win their support for anti-stigma action.
- Organise training for community leaders and peer group leaders.
- Organise peer group meetings (facilitated by those who have been trained).
- Organise house-to-house visits to raise everyone's awareness.
- Organise a stigma walk or community mapping exercise.
- Organise awareness activities in the schools, e.g. an art or drama competition.
- Organise community meetings – ask peer group representatives to attend.
- Organise drama at the community meetings to raise the specific form of stigma that the group wants to change, e.g. stigma against widows.
- 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 and school fees.
- Organise a regular system of visits to HIV-affected households.
- Donate food, clothing and agricultural inputs to destitute households.
- Provide piecework for adolescent orphans working in others' fields.
- Organise income-generating activities to support vulnerable households.
- Get community members to share their 'HIV survival knowledge'.

Exercise 7 Specific campaigns against stigma

Examples of action campaigns against stigma		
Example	Situation analysis	Action steps
<p>Stigma against orphans (action ideas from Tanzania)</p>	<p>Children dumped with relatives. Property grabbing. Little support or comfort in their new home. Forced to do all the housework. Stopped from going to school. Orphans neglected and rejected. Community members say, <i>“If the parents died, the children will die too. Don’t play with them – they are getting ready to die.”</i></p>	<ul style="list-style-type: none"> • Identify the number of orphans in the community and work out how to support them. • Change the misperception that if the parents die, then the children will die too. • Educate families on HIV transmission so they stop stigmatising out of fear. • Stop the dumping of orphans with relatives who mistreat/abuse the children. • Get youth groups to raise this issue through drama or songs. • Organise competitions among the children to get them to express their ideas through pictures, poetry and stories – to give their views and talk about their feelings. • Get adults to look at how stigma affects children. • Get people to treat children seriously and allow children to talk about their feelings.
<p>Stigma against widows (action ideas from Tanzania)</p>	<p>Widows are stigmatised in three ways: as wives of men who have died (blamed for the death of their husbands); as women; and as people suspected of having HIV. Men stop their wives from being friends with the widows, who are viewed as dangerous and the source of evil and trouble. Widows are also stigmatised by other women who assume that widows will steal their husbands. The widows are isolated and forced to find new friends – they are expected to mix only with other widows. People boycott widows’ small businesses out of fear that they will get HIV from their commodities.</p>	<ul style="list-style-type: none"> • Build alliances between widows and other poor women in the village. • Bring widows together to share feelings and problems and discuss what can be done. • Initiate a rotating credit union and other income-generating activities. • Organise meetings with other women’s groups to win their support. • Organise community meetings to raise this problem and get the community to stop stigmatising widows.
<p>Property grabbing (example of real action in Tanzania)</p>	<p>Relatives were taking away the property of men who died and using shaming and blaming as a pretext to justify this action.</p>	<p>Youth groups identified property grabbing as a major problem in their community. They decided to stop this activity. When a man died, they decided to act quickly. Instead of confronting the dead man’s uncle directly, they talked to an elder in the village and told him they were angry about the threat of property grabbing. They asked him to talk to the uncle: <i>“Go and tell the uncle he is causing problems.”</i> This pressure from younger people stopped this case of potential property grabbing.</p>

Exercise 8 Ten steps for moving to action



Objective

By the end of this session, participants will have developed a detailed strategy for taking action against stigma.



Time

3 hours



Materials

Copies of the handout on page 20 – *Ten steps for moving to action* – one for each participant.

Step-by-step activity

Before starting the process, give out copies of the handout on page 20 and explain the steps. Divide the group into small groups of three or four. After each step get a quick report back and then move to the next step.

Situation analysis

1. Ask participants:

- *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?*

Examples

- Secrecy and silence around sex and HIV – people find it difficult to talk.
- Denial that HIV is a problem.
- HIV-affected households are the target for insults, exclusion and discrimination.
- Lots of hidden conflicts between different households.
- High levels of fear, fatalism and hopelessness.
- Lack of knowledge and fear of infection through casual contact.
- Huge workload for women in AIDS-affected households, including care of PLHIV.
- High levels of poverty and unemployment – impact on AIDS and 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

2. Ask, “*What will the situation in our community look like in two years’ time after our anti-stigma programme?*”

Examples

- More openness in talking about sex and HIV.
- Villagers helping each other in caring for PLHIV.
- Less gossip and name-calling towards families affected by HIV and AIDS.
- More knowledge about transmission and less fear about casual contact.
- More hope. Less feelings of fatalism and paralysis.
- More trust in and use of health services.

Exercise 8 Ten steps for moving to action

Handout: Ten steps for moving to action	
Step	Examples
1. Where are you now? Situation 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?”, “How are they now?” and “Where is the stigma in the community or workplace?”
2. Where do you want to be? Vision	How would things look if you could really make a difference? Create a vision of the future with reduced stigma.
3. How will you get there? Activities	What kind of activities can you do to help reduce stigma? Brainstorm all your ideas – practical and new actions to solve the problem.
4. Where will you start? Prioritise	What are the most feasible actions to start doing? What is the most important action?
5. What do you need? Resources	Identify any resources, skills or training that will help with your action – and any partners who can assist. Don’t stop at this point – don’t think you can’t do anything because you have no funds.
6. What might get in the way? Obstacles	Identify any obstacles that might prevent your action from being successful. Try to make plans or strategies to overcome these obstacles.
7. How will you know that you are successful? Indicators	Decide how you will measure success. Identify indicators or signs that will show you that stigma is reducing (e.g. are more people talking openly about testing HIV positive?).
8. Action	Start the activities you have planned. Assign tasks to specific people.
9. Monitoring	Check how you are doing and whether anything is changing.
10. Re-plan	Make changes to your plans based on what you learn from the monitoring.

Exercise 8 Ten steps for moving to action



Activities

3. Ask, “*What activities will you carry out to reach that goal? Which activities are the most important?*”

Examples

- Training workshops for community and peer group leaders and PLHIV.
- Community and peer group meetings and awareness-raising in schools.
- Community participatory education on new facts about HIV and AIDS.
- Development of community and peer group action plans.
- Formation and operation of PLHIV support/self-help groups.
- Participatory assessments, data gathering and analysis – community mapping, stigma walk.
- Mini campaigns on specific issues, e.g. stop stigma against orphans.
- Home visits and support for HIV-affected households.

Priority activities

4. Ask, “*Which activities are the most important?*”

Resources

5. Ask, “*What resources do we need to do these activities?*”

Obstacles

6. Ask, “*What things might block our activities?*”

Examples

- Resistance from faith group leaders.
- Apathy and a 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

7. Ask, “*What things will show that we have been successful?*”

Examples

- More people visiting each other and providing support and comfort.
- Increased prayer and care by faith groups for PLHIV.
- PLHIV have more say in family decision-making about their care.
- More openness in discussing issues around AIDS and sex.
- Increased use of health services.
- Increased knowledge that HIV cannot be transmitted through casual contact.
- Exemptions from water fees and other fees for HIV-affected households.
- Reduced resistance to and criticism of women using formula milk.
- PLHIV couples making plans for the future of their children.
- Reduced dropout from school by orphans.



Section 3 Developing skills for advocacy

3 section

Exercises in this section are designed to help participants develop practical skills to:

- explain stigma and discrimination simply and clearly
- facilitate discussion on stigma and what to do about it
- advocate for changes in attitudes when among one's peers
- motivate leaders and others to speak out against stigma
- challenge stigma and discrimination in a way that supports change.

These skill-building exercises can be introduced at appropriate points in any workshop as required. The trainers should first identify gaps in trainees' skills and introduce the exercises needed to fill these gaps.

Skills needed to support and facilitate action include:

- advocacy
- facilitation skills
- presentation skills – how to present ideas simply, clearly and persuasively
- being assertive in challenging stigma
- conflict resolution skills and methods to overcome opposition or resistance, e.g. hostile groups in the community.



Exercise 9 Advocacy skills

Objective

By the end of this session, participants will be able to demonstrate what is involved in advocacy on the issue of stigma.

Time

1 hour

Steps in advocacy

1. Select the issue or problem.

2. Analyse the issue.

3. Develop specific objectives. What do you want to achieve? Be clear.

4. Identify your audience. Who do you want to hear your message?

5. Identify your allies – people who support your cause and people who can influence change.

6. Create an action plan – the steps needed to achieve your goals and a realistic timeline.

7. Implement your action plan.

8. Monitor the action – and then make revisions.

Step-by-step activity

Meaning of advocacy

1. Ask participants, “What is the meaning of advocacy?”

Meaning of advocacy

Advocacy is a systematic and organised effort to change unhelpful laws, policies, practices or behaviour. It is about pleading for or supporting a cause. It is about social change – creating an environment where specific goals can be achieved. Advocacy can take many forms, including:

- quiet persuasion – to encourage other people to speak out on the issue
- confrontation – to publicise the issue and influence people.

Steps in advocacy

2. Explain to the group the steps in an advocacy campaign.

3. Divide into groups. Ask each group to select an issue they want to win support for (e.g. community support for HIV-affected families) and plan an advocacy process.

Strategising for advocacy – group work

4. Divide into groups. Ask groups to work on the matrix below.

- What *images* do people have about PLHIV?
- What are the *effects* of each image on PLHIV?
- What *changes* do we need to advocate for?

Image of PLHIV	Effects	How to change
Promiscuous. Sinners. Foolish. Careless/reckless.	Judged, blamed and condemned by society.	Work with the media to create positive images. 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.	Get involved in a campaign to support employment for PLHIV. Empower PLHIV to lead full, active lives. Create opportunities for PLHIV to use talents.
Dangerous – they can infect other people through touch.	Isolated and excluded – ‘quarantined’.	Educate people about HIV transmission so they stop fearing casual contact with PLHIV.

Exercise 9 Advocacy skills

Handout: Advocacy

Advocacy is a systematic and organised effort to change unhelpful practices or behaviour.

What skills are needed for advocacy work?

You will need the skills to be able to:

- Plan a campaign that will succeed in changing people's behaviour.
- Tell people what the issue is and make them support you.
- Find others who agree with you and are prepared to back you up.
- Negotiate – deal with the different actors involved in making change.

Choose an issue

Select a specific aspect of stigma that you want to focus on, e.g. stigma towards orphans, or discriminatory practices towards families living with HIV and AIDS. Ask yourself:

- Is the issue widely felt; i.e. by many people?
- Is it deeply felt – are people angry, frustrated, etc?
- Will it result in a real improvement in people's lives?
- Can you win on this issue?

Identify and brief key leaders

Look for key leaders who will support your campaign and influence others. Then consider what their interest is in the issue. Don't assume that they are opposed. They may already be convinced of the need to address the stigma issue. Find out their ideas about the issue and get them on board. Avoid making them look bad.

In many cases the leaders will not be adequately informed about the issue. Your job is to explain the issue and its importance clearly and persuasively. Use some of the 'naming the problem' exercises in Module A to help them understand how stigma hurts not only those of us living with HIV, but the whole community. Use words and arguments from their perspective. Put yourself in their shoes, learn as much as possible about their situation, and tailor what you are saying to their own interests and concerns.

Create some ownership of the need to change on the part of the leaders. Involve them in thinking through the issue themselves. Get them talking and help them see the issue from their own experience.

Ten steps in an advocacy campaign

1. Clearly state the problem or issue.
2. Develop a goal and a set of objectives.
3. Identify the target audience(s) to engage.
4. Identify groups who are affected by the campaign.
5. Formulate the advocacy message and identify the methods to get the message out to the target audience (e.g. meetings, drama).
6. Prepare a plan of action and schedule of activities.
7. Identify resource requirements (human, organisational, financial).
8. Get support from other key players, e.g. NGOs, government.
9. Identify monitoring and evaluation criteria and indicators.
10. Assess success or failure and determine next steps.

Exercise 10 How to challenge stigmatising statements

Facilitator's notes

This exercise helps participants practise how to challenge stigma. It could be used along with exercises in Module A as an action step.

Objectives

By the end of this exercise, participants will be able to:

- identify statements that are stigmatising
- develop arguments for challenging stigma when it occurs.

Time

30 minutes

Materials

Stigmatising statements written on flipcharts or cards.



Step-by-step activity

Challenging stigma – hot seat

1. Invite participants to take turns sitting in the 'hot seat'. The person in the hot seat is expected to improvise challenges to statements that are presented one at a time. Use the list of statements below and add any common statements relevant to the group/community/language.
Option: Ask pairs to practice responding to these stigmatising statements.

Sample statements

People who sleep around deserve what they get.
If I got AIDS I'd kill myself.
She deserves to get HIV for being so promiscuous.
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."
We should stop PLHIV from having children.
Women cause AIDS – they lure us into sex.

Strategies for changing attitudes

2. Then discuss, "What methods work best for challenging stigma? Be specific."

Summary

The most powerful responses are those that make people stop and think, rather than attacking responses that make the stigmatiser defensive.

Examples of strong responses:

- You are probably not aware that you are stigmatising.
- You only need to sleep with one person to get HIV.
- All of us are at risk of getting HIV so there is no point stigmatising others.
- You may be in the same boat in a year's time so you should be more compassionate to PLHIV now.
- Don't point fingers at anyone. As you point one finger towards others, four fingers are pointing back towards you – you are blaming yourself.

Exercise 11 How to deal with difficult situations

Facilitator's notes

This exercise is designed to help participants practise how they would deal with different situations using stop-start drama.

Objective

By the end of this session, participants will be more confident in handling difficult situations.

Time

1 hour

Materials

Copies of *critical incidents* (see right).

Step-by-step activity

Difficult situations – brainstorm

1. Ask participants to brainstorm difficult situations they have had to deal with. Write each situation on a card.

Trying out solutions – stop-start drama

2. Ask participants to play out the incidents below and look for solutions. After each performance, invite others to try. Discuss what works and what doesn't work.

Critical incidents

A. You are giving a testimony at a community meeting. Someone stands up and says, *"You are lying. You don't have AIDS. You are only doing this for the money. People with AIDS don't look like you!"*

B. In a 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 organisation 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

Practise presentations first in a comfortable situation. Try them out on a friend or colleague and ask him or her to give you feedback. Write down your points on a card if you are nervous.



Exercise 12 Stigmatising messages in the media

Facilitator's notes

This exercise is designed for media workers or NGOs who do radio programmes. It helps participants identify ways in which the media promotes stigma and come up with new messages to challenge stigma in innovative ways.

Objectives

By the end of this session, participants will have:

- identified how the media promotes stigma
- designed simple messages to challenge stigma.

Time

1-2 hours

Preparation

Collect articles in local newspapers dealing with HIV and AIDS issues. Photocopy them for use in the workshop and display them on tables.

Step-by-step activities

A. Fact, opinion or rumour – warm-up game

1. Read out one article from a local newspaper, pausing at the end of each statement. Ask participants to consider whether the statement was a fact, opinion or rumour.

Examples

The largest number of PLHIV in the world live in sub-Saharan Africa. (fact)
HIV is not the cause of AIDS. (opinion)
Many politicians are hiding their HIV status. (rumour)

2. Ask participants to use the following symbols to indicate what they think:

Fact – raise your hands in the air.

Opinion – put your hands on your head.

Rumour – fold your arms.

Summary

Explain that this exercise shows that we should not assume that everyone understands and thinks in the same way as we do. People have different views. The problem comes when people no longer respect each other's views. In order to solve a problem you need to understand and respect the views of others and make use of them in looking for solutions.

We should not simply accept whatever we hear; we have to assess and judge it. Stigma is often based on rumour or misinformation.

B. Spot the stigma – reading card storm

1. Divide into pairs and give each pair a newspaper article. Ask each pair to read their article and identify stigmatising language. Record each stigmatising phrase on cards and tape them on the wall. For example: 'AIDS kills', 'AIDS is a death sentence', 'People who get AIDS have nothing to live for', 'PLHIV are promiscuous', 'innocent victims'.



Exercise 12 Stigmatising messages in the media

! Action ideas

Plan some training or awareness sessions with key media people and institutions.

Debriefing

2. Ask each pair to read out the stigmatising phrases they found in their article. For each phrase ask, “*What are the attitudes behind the stigma?*”

Examples

‘AIDS kills’, ‘AIDS is a death sentence’, ‘nothing to live for’ – creates fear.
No positive images of PLHIV.
‘Innocent victims’ – implies that the others are guilty.
‘Promiscuous’ – shaming and blaming.
‘Victims’ – this is disempowering – PLHIV do not see themselves as victims.

Making anti-stigma messages – card storm in pairs

3. Ask the same pairs to write slogans on cards promoting a new anti-stigma message.

Examples of messages from anti-stigma campaigns in Uganda

- Give love and care to PLHIV and AIDS.
- Don’t point fingers. Anyone can get HIV and AIDS.
- People living with HIV and AIDS need your care and compassion.

Examples from a workshop

- PLHIV deserve hope. They can live long lives.
- If you care for PLHIV and give them the love they deserve, they will grow in strength. If you isolate them, they will die.
- We are all HIV-affected – AIDS is part of all of our lives.
- Who can cast the first stone? We have all sinned – so we have no right to throw stones at others!

Summary

The slogans should show that PLHIV’s lives are not over. They are not simply waiting to die – they can be just as productive as anyone else.

PLHIV who attended the stigma awareness workshop in Vietnam, in September 2002, told media workers: “*We deserve a more positive and hopeful image. We are not simply waiting to die. Many of us are living full and productive lives and we want others to know this. We are in good health and living normal lives, and we can still make a big contribution to our families and communities. This is the story that we want you to tell people.*”



Booklets in *Understanding and challenging HIV stigma: Toolkit for action* include:

Introduction

Using the toolkit

Module A

Naming the problem

Module B

More understanding, less fear

Module C

Sex, morality, shame and blame

Module D

The family and stigma

Module E

Home-based care and stigma

Module F

Coping with stigma

Module G

Treatment and stigma

Module H

MSM and stigma

Module I

Children and stigma

Module J

Young people and stigma

Moving to action module

Thinking about change

Moving to action

Developing skills for advocacy

Picture booklet

General stigma pictures

Rights pictures

Additional booklets will be published as new modules are developed.