

Understanding and Challenging HIV Stigma

Toolkit for Action





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- ➡ Selecting and making refinements to exercises from the original toolkit that were considered suitable for the Cambodian context, and removing those exercises that were considered inappropriate to Cambodia;
- ➡ Using stories, case studies, or role-playing scenarios drawn from the Cambodian or Vietnamese contexts; and
- ➡ Adding exercises that deal with the stigma towards drug users – a major problem in Southeast Asia.

The illustrations for this toolkit were produced by Am Reaksmei, a Cambodian graphic artist. The toolkit was designed by Novadesign in Cambodia.

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Understanding and taking action to reduce stigma towards people living with HIV is an ongoing process that can only improve as we build on practical experiences from the field. We would be most interested in any feedback and comments on this toolkit – please send your feedback to: info@pactworld.org or info@icrw.org.

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Welcome!



This toolkit is written for community leaders, AIDS educators, people living with HIV, health workers, teachers, media workers, and others involved in the AIDS field in Cambodia. Its aim is to build awareness and commitment to confront HIV stigma, and promote more care and support for people living with HIV.

We are all in the same boat! We are all at risk of getting HIV so there is no room for blaming and shaming people who already have HIV. We need to work together to change attitudes and promote a more accepting and supportive community.

The toolkit is designed to help you plan and organize educational sessions with community leaders, service providers, or organized groups to raise awareness and promote practical action to challenge HIV stigma and discrimination.

You also need to learn more about HIV stigma yourself. Before educating the community we need to look at our own attitudes, language, and relationships, and get a better understanding of stigma. Are we guilty of the same “shaming and blaming” practices that we are fighting against? We need to check our own behavior and attitudes first, before we start working with the community.

The toolkit is a resource kit of educational exercises. Use it selectively. Choose the exercises you need for your own purposes and your own target groups. You should feel free to select and adapt the materials to suit your own situation.

Since people living with HIV are expected to play a central role in challenging stigma, a chapter of the toolkit will focus on their needs – to strengthen their own understanding and confidence, help them overcome self-stigma, and equip them with the skills to take a lead role as educational facilitators.

Introduction to the Toolkit

SPECIAL NOTE

Us and Them

“At an AIDS planning meeting I attended some people referred to people living with HIV (PLHIV) as ‘those people,’ but we all knew people in the room who were HIV-positive. How did they feel when they heard these words? One HIV-positive woman leaned over to me and said, ‘What do they call us again—PLHA? PLWHA? PLHIV? Why all these names? Let’s do away with the naming.’

In our workshops we have moved away from talking about ‘them’ to talking about ‘us.’ It makes a big difference to the atmosphere and to participants, helping everyone recognize that any of us could be infected; that many of us are worrying about whether to test or not, about our partners or family; and so on.

We should never assume that just because some people are open about being positive, that everyone else is negative. ”

What Is the Toolkit?

The toolkit is a collection of participatory educational exercises for use in raising awareness and promoting action to challenge HIV stigma. Trainers will select from the exercises to plan their own courses for different target groups.

The exercises use a learner-centered, participatory approach to training, one that is built around discussion and small group activities. The aim is to facilitate open discussion on HIV-related stigma and what we can do to promote a change in attitude and practice.

Why Was the Toolkit Developed?

The toolkit was developed to provide people working in the HIV field with a set of flexible educational materials to raise their own understanding and help them promote 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, and what its root causes are – and develop strategies to challenge stigma and discrimination.

The idea behind the toolkit is to create a safe space where AIDS practitioners and community members can talk about their own fears and concerns about AIDS; look at the roots of stigma and how it affects people living with HIV, their families, children, and communities; examine their own attitudes and judgmental habits; and develop strategies and skills to confront stigma and discrimination in different settings.

How Was the Toolkit Developed?

The toolkit developed out of a research project on HIV stigma in Africa and Vietnam (2002-2004). As part of the research, a national workshop was organized for NGO staff in Vietnam. During the workshop, participants tried out participatory exercises on stigma. The exercises were a big hit and at the end of the workshop, participants asked for copies. This led to the idea of developing a “toolkit” of participatory educational exercises on stigma.



During the same period, ICRW was developing a stigma toolkit in Africa. The African toolkit was used as the starting point for developing the Vietnamese toolkit. The exercises in the African toolkit were adapted and new exercises were produced to address the situation in Vietnam. This process also included testing out the exercises with different target groups, including political leaders, media workers, health workers, teachers, and community leaders.

Purpose of the Toolkit

Goal

Break the silence on the issue of HIV stigma and discrimination and build a climate in which people living with HIV feel they are no longer condemned, isolated, and rejected.

Specific Objectives

1. Help everyone see that stigma exists and really hurts people living with HIV; we are all “part of the problem,” and by changing our attitudes and actions, we can help reduce stigma and remove this huge burden on people living with HIV and their families.
2. Improve the depth and quality of people’s knowledge about HIV and AIDS to address fears and misconceptions about: (a) HIV transmission through non-sexual casual contact; and (b) what it means to be HIV-positive (potential for long and productive lives if one takes proper care, rather than instant death).
3. Provide space in which individuals can discuss the values that underlie stigma, look critically at their attitudes and feelings towards people living with HIV (especially judging and blaming), and take ownership of a new set of principles, values, and norms.
4. Strengthen people living with HIV by helping them deal with the HIV diagnosis, overcome the self-stigma and associated shame, rebuild their self-esteem, and develop appropriate skills to contribute to anti-stigma action.
5. Provide information and skills on what is involved in caring for people living with HIV, and encourage people to care for others in a loving, non-stigmatizing way.
6. Provide opportunities for people to talk about how they can help reduce stigma and develop practical strategies for challenging stigma and discrimination.

Target Groups

The toolkit can be used with everyone. Some of the groups might include:

- ➡ AIDS educators and counselors: people who conduct educational sessions for community groups or provide individual or group counseling on AIDS issues.
- ➡ Community groups that AIDS educators work with: local clubs, women's groups, youth groups, and others.
- ➡ People, families, children, and youth living with or affected by HIV. Five of the modules (D, E, F, G, and H) deal with the needs of these groups.
- ➡ Community leaders and media workers who are in a position to educate others and advocate for action against stigma.
- ➡ Other groups. The materials can be adapted for use in training other groups, e.g., health workers and teachers.

Twelve Steps to Stop Stigma

1. Create a sense of community and build openness and safety to talk about HIV and AIDS, stigma, sex, injecting drug use, and death.
2. Name the problem: get people to describe how stigma occurs in different contexts.
3. Get people to own the stigmatizing disease: “We are all part of the problem.” Help people read and reflect on their own words, attitudes, and actions towards people living with HIV.
4. Help people see the effects of stigma on people living with HIV, their families, children, and communities – how it directly hurts those stigmatized and indirectly hurts those who are stigmatizing.
5. Analyze the root causes of stigma, e.g., fears and misperceptions about HIV and AIDS, and moralizing attitudes; and how stigma particularly affects women, children, and poor people.
6. Address fears and misconceptions about getting HIV through non-sexual casual contact, and what it means to live with HIV.
7. Challenge the judging and blaming built into stigma, and help people examine their own attitudes.
8. Build commitment to change attitudes and do something about stigma.
9. Help people living with HIV overcome self-stigma and build up self-esteem and skills to provide leadership on anti-stigma action.
10. Help family members learn the attitudes and skills to provide support and care for people living with HIV and children living with HIV.
11. Develop strategies and plans for taking action against stigma.
12. Take action to reduce stigma and discrimination, and monitor action.

How to Use the Toolkit

Use the Toolkit for Participatory Learning

The toolkit is designed for participatory learning. The idea is to get participants to learn through doing – sharing feelings, concerns, and experience; discussing and analyzing issues; solving problems; planning and taking action.

Don't use the toolkit as lectures. Changing attitudes around stigma requires more than giving people information. This form of change cannot be achieved by treating participants as a passive audience for your lectures. People learn best through figuring things out for themselves.

The process of helping people rethink their ideas needs to be participatory, and where they get a chance to reflect on and express their own ideas and feelings, share with and learn from their peers, and discuss and plan with others what can be done to challenge stigma. The idea is to create a safe space where they can express their fears and concerns; freely discuss sensitive and taboo issues, such as sex and death; and clear up misconceptions.

Help Participants Move from Awareness to Action

The toolkit is designed not only to build awareness but also to help participants move to action. Participants should be encouraged to put their new learning into action and start challenging stigma and violence in their own lives, families, and communities.

The learning and action are done collectively. Working with others makes it possible for participants to learn together about stigma, develop common ideas about what needs to be done, set group norms for new attitudes and behavior, and support each other in working for change.

Start with Yourself

Before you try to educate others, you should first use the toolkit to reflect on your own attitudes, values, language, and behavior towards people living with HIV.

How to Use the Toolkit

Pick and Choose Modules 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 those exercises that suit your own target group and needs and make up your own training program.

Mainstream Stigma Awareness in 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 by making it a regular part of all educational activities for AIDS educators and communities.

Exercises: How to Use Them

The toolkit consists of a number of training exercises, each with a detailed session plan. The session plans provide a step-by-step description of how to facilitate each session. The session plan will help you run each training exercise.

Each session plan is divided into the following parts:

Facilitator's Note: A brief note to the trainer on the importance of the training exercise or extra advice on how to conduct it.

Objective: What participants will know or be able to do by the end of the session

Time: Estimated amount of time needed for the exercise. This is a rough estimate – it will vary according to the size of the group. Larger groups will require more time (especially for "report backs").

Materials: Role-plays, stories, pictures, etc., that are used during the training session. We assume that basic training materials such as flipcharts, markers, and masking tape are already available.

Steps: The learning activities or training methods involved in the exercise, described step by step, and the training content

" STEPS " are the core of each session plan. This section includes information on:

Sub-Topics: The sub-topics covered within the session

Methods: Discussion, rotational brainstorming, cardstorming, role-playing, stop-start drama, case studies, picture discussion, etc.

Groups: Buzz groups or small groups – suggestions given on group size and tasks

Questions: Specific questions used to guide discussion

Responses: Examples of typical responses are presented in boxes. These are only examples, and are not meant to be the required output.

Report Back: Procedures for asking groups to give reports after discussion

Exercises: How to Use Them

Processing: These are additional questions and discussion, conducted after the report back, to help deepen the understanding and relating the new learning to a participant's own context.

Summary: Points to be emphasized in a summary at end of the session

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.

Small Groups

are used to maximize participation in discussions. Some participants feel shy in a large group, but in a small group they find it easier to talk. Small groups can also be used for task group work, with different groups exploring different topics.

Buzz Groups

are two people sitting beside each other – and 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, going around the circle and asking for one new point from each group. 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.

Toolkit Methods and Materials

Rotational Brainstorming

is another form of brainstorming done in small groups. Participants break into groups and each group is given a starting topic. Each group records points on its topic on a flipchart and, after two to three minutes, moves to a new topic and adds points. During the exercise, groups contribute ideas to all topics.

Pictures

The toolkit includes over 100 pictures that are to be used in different exercises. Some pictures show various aspects of stigma as a focus for discussion; others show different activities that may or may not involve HIV transmission; and still others show different members of a family. Participants make up their own stories around them.

Stories

are used in many of the modules as a method of describing what 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.

Drama or Role-Plays

are an alternative to stories. Participants act out the stories in the exercise 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.

Warmup 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.

Processing is one of the most important elements of anti-stigma training. If our aim is to raise awareness about how we can change HIV stigma, then we need to link the raising of awareness to action and behavior change.

Processing is one of the ways in which we can help to move participants from the realization of a problem to planning some action.

During a workshop there can be many different types of activities, e.g., role-playing, cardstorming, and small group discussion. If these activities are not processed, then there will be no acknowledgment of the learning that comes from them. Processing helps us to share the things we have learned to consolidate the new knowledge and make sense of what these new learnings mean for the future. It is through the processing that we can begin to see the need for behavior change at both individual and community levels.

Processing also links workshop activities to the real world outside the workshop.

As a trainer, there are key questions that you can ask a group to help them process information. These questions would usually follow an activity, e.g., a role-play or a cardstorm (after the cards have been clustered).

The processing may follow a series of steps:

1. Ask participants to reflect on what they have just done or seen.
What did you see? What was happening? What did you think about this?
2. Pull out the major themes or most important things.
What do you think are the most important things here? What are the key themes that have emerged?
3. Help identify the major lessons.
What did we learn from this? What does this tell us?
4. Link the lessons to the outside world.
How does this apply to your community/family/workplace? How does this link to the real situation out there?
5. Move participants to action.
What can we do to change this? What could be some of the solutions to the problem?

Working with Feelings

Many of the exercises in the toolkit involve working with feelings. Participants are asked to express the feelings that lie behind their attitudes. One example of this is the reflection exercise on stigma (A3). In this exercise, participants are asked to reflect on their own experience of being stigmatized. This brings out strong feelings. These feelings help participants see how hurtful stigma can be, but you need to be ready to deal with the emotions raised.

As trainers, it is important to create a safe, non-threatening space where feelings and fears can be discussed and explored openly.

The following tips may help:

- ➡ Set clear ground rules and expectations around confidentiality and listening.
- ➡ Be aware of your own feelings and fears about the topics you are going to cover. This will help you feel more confident during the exercise. Try out the exercises yourself beforehand.
- ➡ Participants are more likely to trust you if you can share your feelings openly. By doing this, you also lead by example.
- ➡ Leave enough time for participants to share their feelings and help the group create an atmosphere where participants know they will be heard.
- ➡ Offer participants a break in the session, if they need it.
- ➡ Remember that no feeling is wrong, but that some participants may find it difficult to accept certain feelings.
- ➡ Feelings are a powerful tool. Use them with the group to develop drama and role-plays, build on stories, and use as examples for the future.

Be aware that some participants may be HIV-positive or worried about their status. Many participants may not have undergone HIV testing, so some of the activities may raise emotional responses.

Remember – do not do any exercise that makes you uncomfortable.

Tips for Participatory Trainers

Be well prepared

- ➔ Plan each of the sessions before the training so you are well prepared.
- ➔ Bring all materials: toolkit, handouts, flipchart paper, markers, pens/pencils, cards, masking tape
- ➔ Arrive early so you are ready to welcome participants when they arrive.

Prepare the room

- ➔ Remove tables to make room for “doing” and to make training more informal.
- ➔ Set up the meeting space in a semi-circle. Check that all can see the flipchart.
- ➔ Some sessions where you are sharing can be done sitting in a full circle.
- ➔ Put flipchart sheets on the front wall.
- ➔ Set up a separate table for markers, masking tape, handouts, cards, and other materials.

Make participants feel comfortable

- ➔ Break the ice and put participants at ease at the start of the workshop.
- ➔ Learn participants’ names, be informal, and use games, songs, or buzz groups.

Find out what the learners really need to learn

- ➔ What do they really need to know or do?
- ➔ What are some of the problems they are facing in their work?
- ➔ What new attitudes or knowledge would really make a difference to their work?

Ask questions and lead discussion

- ➔ Ask clear, simple, open questions that allow people to give their opinions.
- ➔ Ask for contributions. Use your hands and body to encourage participants.
- ➔ Wait for responses. Give people time to think and come up with an answer.
- ➔ Encourage everyone to talk. Buzz groups get everyone talking.
- ➔ Keep asking, “Who would like to add to that?”

Tips for Participatory Trainers

- ➔ If there is no response, rephrase the questions.
- ➔ Show that you are listening and are interested.
- ➔ Praise responses to encourage participation.
- ➔ Rephrase responses to check that you and other participants understand.
- ➔ Redirect to involve others, as in: "He said.... What do others think?"
- ➔ Summarize and check agreement before moving to the next question or topic.

Use small groups to build participation

- ➔ Give a clear explanation of the group task, time, and reporting method.
- ➔ If the task is difficult, write it on flipchart so that everyone is clear.
- ➔ Vary the size of groups for different sessions: pairs, trios, fours and fives.
- ➔ Keep changing the groups so participants work with different people.
- ➔ When participants move into groups, go around to make sure they understand the task.
- ➔ Use "round robin" to make report backs more interesting and efficient.

Keep presentations short and simple!

- ➔ Give a presentation only when you are sure people do not know your topic.
- ➔ Write out your main points in key words on a flipchart, and then explain them.
- ➔ Speak slowly, clearly, and loudly.
- ➔ Look at people and use your hands and body to emphasize points.
- ➔ Keep it short and simple: no more than 10 minutes. Explain only the basics.

Keep changing your methods

- ➔ Use different methods for different topics to keep things interesting.
- ➔ Use your creativity. A story or case study can be turned into a role-play, and a report back can be turned into practice on how to present a convincing argument (advocacy skills).

- ➡ Use different sizes of groups. Don't "buzz" all the time; try trios or fours.
- ➡ Change the space. You can go outside and hold groups under the trees.

Check the energy level

- ➡ Observe body language. Do they look bored or sleepy?
- ➡ Ask, "How are you feeling? Is it time for a break?"
- ➡ Change the topic, take a break, or do a wake-up game.

Watch the timing and pacing

- ➡ Be time conscious. Decide how much time you need for each session.
- ➡ Remember that small group work takes more time than you expect. You will also need to allocate time for report backs.
- ➡ Do not go too fast. Let the group help you set an appropriate pace.
- ➡ Give groups enough time to do their work. Do not rush them.
- ➡ Do small group work in the afternoon when the energy level drops.
- ➡ Do not forget to take breaks to relax, get tea, and talk informally.
- ➡ End on time!

Evaluate throughout the workshop

- ➡ Evaluate as an ongoing activity, not just at the end of the workshop.
- ➡ Organize a short evaluation at the end of each day or get participants to review what was learned when you meet again.
- ➡ Assess what was learned and how the learning was done.

Team facilitation

- ➡ Plan and run the workshop with another facilitator and debrief afterwards.
- ➡ Take turns in the roles of lead facilitator and recorder (writes notes about the discussion on the flipchart, or other large sheet of paper).
- ➡ Support each other. If one runs into trouble, help him or her out.

A red-toned illustration of a man with short hair, wearing a polo shirt, pointing his right hand towards a list of items on a board. The list consists of several horizontal lines, some with small circles at the end, resembling a checklist or a set of instructions. The man has a focused expression.

Chapter A

Naming the Problem

Introduction

This module gets participants to name the problem, in order to see that:

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

This module also gets participants to own the problem, i.e., to recognize that we are all involved in stigmatizing people living with HIV. It is not someone else's problem. We are all part of the problem, even if at first we do not recognize it.

The module is designed for all groups – people living with HIV, health care workers, nongovernmental organization (NGO) and community-based organization (CBO) staff, and the community.



At the start of the session, review the basic definitions:

- HIV is a virus that destroys the immune system.
- AIDS is the condition of the body when its immune system has become weak.

The chapter introduces stigma through a number of optional exercises that bring out what stigma means and how it feels, using pictures, testimonies, stories, and drama. The aim is to get people to connect to the issue on a personal, emotional level, rather than a theoretical level (e.g., a definition). The definition comes later in the chapter, after participants have already developed an experience-based understanding of stigma.

The module looks at what stigma means for people:

- What are the forms of stigma? What does it look like in our attitudes, language, and behavior?
- What are the effects of stigma: on people living with HIV, their families, their communities, and their access to health services?
- What are the root causes of stigma?



Key Points

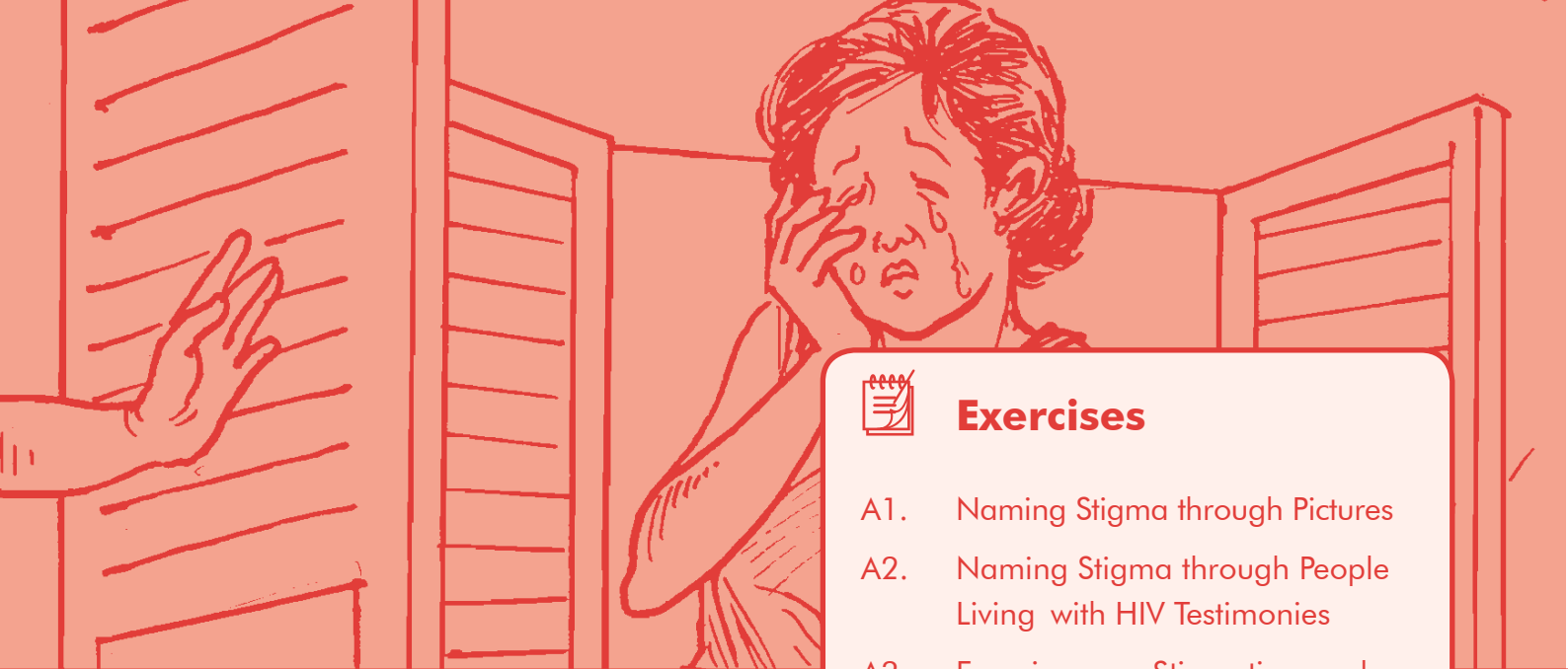
We all stigmatize.

We stigmatize when:

- ➡ we say things like, “she was promiscuous” and “he deserves it”
- ➡ we do things, such as isolating people when they get sick, excluding them from decisionmaking, and condemning them for their behavior

The main causes of stigma include:

- ➡ Fear and ignorance – People do not have a clear idea of how HIV can and cannot be transmitted. They fear they might get infected through contact with people living with HIV, so they isolate them.
- ➡ Moral judgments – People know that HIV can be transmitted by sex and by injecting drugs, and they make moral judgements about these behaviors. Rather than focusing on supporting people with HIV, some people focus on how people living with HIV were infected, and they judge or condemn people living with HIV.



The main forms of stigma include:

- ➔ Physical and social isolation from family, friends, and community
- ➔ Shaming and blaming people, i.e., condemning them for their behavior
- ➔ Depriving people of their rights and decision-making power

Other forms of stigma include:

- ➔ Self-stigma – when people blame and isolate themselves
- ➔ Secondary stigma – the family and friends of people living with HIV are also stigmatized
- ➔ Stigma by looks or appearance, or by type of occupation or lifestyle

The effects of stigma include:

- ➔ Feelings of shame, sadness, loneliness, rejection, hopelessness, and self-doubt
- ➔ Discrimination – people living with HIV kicked out of the family, the home, work, organizations, etc.
- ➔ Denial – it stops people from disclosing their status and getting help.



Exercises

- A1. Naming Stigma through Pictures
- A2. Naming Stigma through People Living with HIV Testimonies
- A3. Experience as Stigmatizer and Stigmatized
- A4. Naming Stigma in Different Places
- A5. What is the Meaning of Stigma? (Definition)
- A6. Forms, Effects, and Causes of Stigma (Problem Tree)
- A7. Effects of HIV Stigma on Different Players
- A8. Fear of Stigma Fuels the Epidemic (Story)
- A9. Challenging Stigma (Stop-Start Drama)
- A10. Comparing HIV and AIDS and Other Diseases

A1

Naming Stigma through Pictures



Objectives

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

- ➡ Identify different forms of stigma in different contexts
- ➡ Identify how stigma affects people living with HIV, their families, and their communities
- ➡ Begin to understand why stigma happens
- ➡ Discuss examples of stigma from their own communities



Target Groups:

All groups



Time:

1 hour



Materials:

Selection from stigma pictures (GS1 - GS19)



Steps:

1. **Picture Discussion:** Display the pictures on the wall. Divide into groups of two or three people. Ask each group to walk around and look at as many pictures as possible, and then select one of the pictures. Ask them to discuss:
 - ➡ What do you think is happening in the picture in relation to stigma?
 - ➡ Why do you think it is happening?
 - ➡ How does stigma affect people living with HIV? How does stigma affect other people?
 - ➡ Does this happen in your own community? If so, discuss some examples.

2. **Report back:** Each group presents the results of its discussion. Record points on flipchart sheets.

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Picture GS2 – The man is sitting alone on a chair holding an HIV test result.



The man looks very depressed and lonely. He is using alcohol to cope with this problem. No one is helping him talk about the problem.

Picture GS3 – The landlord is kicking the family out of the house.



The landlord is afraid of getting HIV from the man or woman. The whole family is affected, even though only one parent has HIV. The family feels rejected and does not know what to do.

Picture GS6 – The father is eating all alone.



The father looks thin, like an HIV patient. His wife looks sad. She fears HIV infection so she has to ask him to eat alone. He is upset but he has accepted the stigma (self-stigma).

Examples of Responses:

Picture GS7 – The family is hiding an HIV patient in the house.



The family does not want the visitor to know that they have someone sick with HIV. They fear they will be stigmatized by the community. They fear stigma by association.

Picture GS11 – The nurse is wearing mask and gloves and staying at a distance from the sick patient.



Fear-based stigma. Excessive use of gloves and mask. She is afraid the HIV patient will infect her.

Picture GS13 – The husband kicking his wife out of the house after he learns she has HIV.



The husband is blaming and shaming his wife for getting HIV (although he may have given it to her in the first place). A form of violence against people living with HIV.

3. Summary: Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

- ➡ Sometimes we treat people badly because of how they look or what we suspect they do. We isolate them, e.g., refusing to sit beside a person suspected to have HIV in the clinic, or we gossip about them and call them names because of the way they look. When we isolate or make fun of other people, this is called “stigma.”
- ➡ Stigma is a process in which we (society) create a “spoiled identity” for an individual or a group of individuals. We identify a difference in a person or group, such as a physical difference (e.g., physical disfigurement), or a behavioral difference (e.g., people having lots of sex), and then mark that difference as a sign of disgrace. This allows us to stigmatize the person or group. Stigmatized people lose status because of these assigned signs of shame that other people consider indications or evidence of sinful or immoral behavior.
- ➡ Stigma is the belief or attitude that leads to discrimination. The action resulting from stigma is discrimination or unfair treatment, such as people living with HIV being fired, kicked out of the house, or refused treatment at a clinic. When we stigmatize people living with HIV, we judge them, saying they have broken social norms and should be shamed or condemned, or we isolate them, saying they are a danger to us (because we think they might infect us with HIV).
- ➡ Stigma is not good. Stigma hurts people. When we stigmatize people, they feel lonely, ashamed, sad, and rejected. They feel unwanted and lose confidence. As a result, they might take less care in protecting their health (e.g., stop using clinics and condoms).
- ➡ People living with HIV are often stigmatized by their families and the community. They have to eat alone or they are forced to leave home and live somewhere else. This makes them feel very bad, and it affects their health. They are forced to lead a hidden, “underground” existence, and as a result they find it difficult to get work and housing, and to access health services that could save their lives.

➡ There are different forms of stigma:

- **Isolation and rejection** – based on ignorance and fear about HIV transmission. People living with HIV are forced to sit alone, eat alone, and live alone. Examples: GS3, GS6, GS11



- **Shaming and blaming** – Gossip, name-calling, judging, shaming. People living with HIV are shamed for “bad behavior.” Examples: GS7, GS13



- **Self-stigma** – People living with HIV stigmatize themselves in reaction to stigmatization from community. They accept the blame and rejection of society and isolate themselves. Examples: GS2, GS4, GS6



- **Secondary stigma** – The family of people living with HIV is also stigmatized. It is blamed for not raising the child properly. Examples: GS3, GS7, GS13



- ➔ Some effects of stigma are:
 - Feelings of sadness, loneliness, rejection, hopelessness, self-doubt
 - Shame and loss of confidence. Feel they are no longer accepted by others
 - Discrimination. People living with HIV are kicked out of family, job, organizations, etc.
 - Denial stops people disclosing status and getting help
- ➔ HIV stigma hurts people living with HIV and drives the HIV epidemic underground. Those stigmatized become silent and do not disclose their status to their partners, and as a result they may pass HIV to others.

A2

Naming Stigma through People Living with HIV Testimonies



Facilitator's Notes:

This exercise is designed for health care providers, NGO and CBO staff, and the community leaders. It builds on the power of testimonies given by people living with HIV. We have found that these stories have a powerful impact on participants. Often this is the first time they have heard people living with HIV talking about their lives and how HIV has affected them. It helps to give this issue a human face, to make stigma more personal.



Objectives:

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

- ➡ Name some of the forms of stigma experienced by people living with HIV
- ➡ Describe the feelings of being stigmatized, and how stigma hurts people living with HIV and affects their psychological health and their will to live



Target Group:

Health care providers, NGO and CBO staff, and the community



Resource Persons:

People living with HIV to be invited to give their personal stories



Time:

1 hour



Preparation:

Invite two or three people living with HIV who are open about their status to talk to participants. Approach the people living with HIV association in your area to identify people living with HIV who are willing to talk. Give them the following briefing on how to give their testimonies:

Talk about your own life and the life of your family before and after getting HIV. Talk about how you were treated by other people once they suspected you were HIV-positive – at home, in the community, in health institutions, and in your workplace. Talk about how it made you feel.



Steps:

1. **Testimonies:** Divide people into groups, each group with a person living with HIV as a resource person. Ask each person living with HIV to tell his/her story and invite participants to ask questions to clarify the story. Focus on the experience of the people living with HIV, but also encourage participants to respond to the person living with HIV's stories with their own examples of stigma in the family or community. Ask, "Have you seen or heard of things like this?"
2. **Report back:** If there is enough time, bring the groups back together and ask one of the participants in each group to give a brief summary of the story.

Then ask:

- ➡ What were the main forms of stigma identified in the stories?
- ➡ What were the features of non-stigmatizing behavior, e.g., when a person treated the person living with HIV with kindness.

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Stigma in the family

- Minimizing contact with people living with HIV, e.g., forced to sleep in corridor, forced to wash at river
- Forced to move out of the family house and move to a new area

Stigma in the community

- Gossiping and insults about people living with HIV behind their backs
- Neighbors refusing to lend things to the family
- Person living with HIV fired once it was discovered she/he had HIV
- Customers refusing to buy clothes from the person living with HIV's shop
- Blaming the woman, e.g., saying she had acquired HIV as a sex worker
- Refusing to admit the son of the person living with HIV into the nursery school

Stigma in the hospital

- No counseling before and after having HIV test
- Keeping the patient waiting a long time
- Breaking confidentiality, e.g., letting other staff and patients know the patient's status

3. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.
- ➔ This exercise helps us understand how it feels to be stigmatized. The feelings of being stigmatized are very painful. People get badly hurt.
 - ➔ Some community members fear infection from people living with HIV (as though HIV is a contagious disease) so they minimize contact,
 - ➔ Some community members judge or condemn people living with HIV, blaming them for getting HIV from “bad behavior” (immoral sex or drugs).
 - ➔ These two things, isolation and shaming, make people living with HIV feel like outcasts or as if they are no longer human. This has a serious effect on their health.
 - ➔ Stigma destroys people living with HIV’s self-esteem, and they begin to doubt themselves. They feel very alone, confused, and demoralized at a time when they really need the support and company of other people.

Examples of Testimonies: Ponleak



I am 37 years old. I got HIV through sharing syringes and needles. I am married and live with my wife, but we have no children of our own. We are raising three children of my brother who died. My wife goes to the market every day to earn money, and I stay at home and do the housework.

When I was demobilized from the army, I couldn’t get a job so I became very upset. I started to go out with friends and became addicted to drugs. I used drugs for three years. Once I found that I had HIV, I tried to give up drugs because I felt pity for my wife. The family tried to hide the fact that I had HIV. The neighbors suspected I might have HIV because they saw me go out with my gang who were selling drugs.

When some of my friends discovered I had HIV, they tried to avoid me out of fear. For example, when I come close to them, they move away. No one wants to hang out with someone who has HIV.

Community members are afraid of me. They don't dare say these things in front of me, only gossip behind my back. Even when I am inside my own house, I can hear neighbors gossiping about people living with HIV.

One of my HIV-positive friends told me how his family had mistreated him. His father died and his mother remarried, so he was forced to live with his grandmother and some relatives. Because of their fear, they didn't let him have meals with them. They even asked him to go to the river to bathe. They don't let him sleep inside the house, only in the corridor outside. As a result, he leaves the house for the whole day and sometimes stays out all night. He feels so hopeless, he doesn't want to live anymore.

Examples of Testimonies: Vireak



I am 36 years old. I come from a poor working class family. I work as a bicycle rickshaw driver. I got the funds to start this business from a support group for people living with HIV.

I used to be married, but ten years ago when my wife found out I was taking drugs, she ran away. I have tried lots of times to give up drugs, but I've never succeeded. Although my family is very poor, they give me small amounts of money to buy drugs and to stop me from stealing from others in the neighborhood.

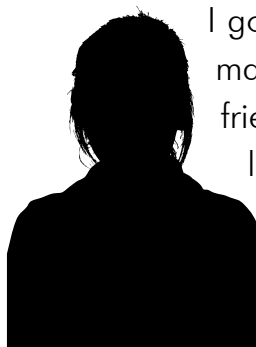
Six years ago I found out that I was HIV-positive. When I first heard this I was shocked and felt hopeless. I didn't want to work anymore and wanted to get revenge. I wanted to sleep with many entertainment workers and transmit HIV to all of them.

When my family first learned that I have HIV, they were afraid but gradually they have become more understanding. However, they still try to minimize contact with me. For example, they wash their clothes separately and get me to use a separate drinking cup.

My mother is the only one who genuinely cares for me. My older brother and sister-in-law keep their distance when they talk to me, and don't let me hold their child. My family is also stigmatized by neighbors, who refuse to lend us scissors or knives. My mother used to do lots of babysitting for children in the neighborhood, but now she has had to stop.

When community members see me face-to-face, they show no signs of stigmatizing me, but behind my back, they keep their distance. They are afraid to come close to me. They fear that if they antagonize me, I will look for revenge. But behind my back they look down on me as if I am a leper. They used to fear me because I am IDU [an injecting drug user], but now they fear me even more because I have HIV.

Composite Story Based on the Real Experiences of Several People Living with HIV



I got married when I was 18. I started a small sewing business, and got many customers. My husband was a cook in a restaurant. Through his friends he became addicted to drugs and got HIV. When the owner learned my husband was HIV-positive, he fired him. At the time, I didn't know he was fired because of his HIV. I thought it was because of his drug addiction.

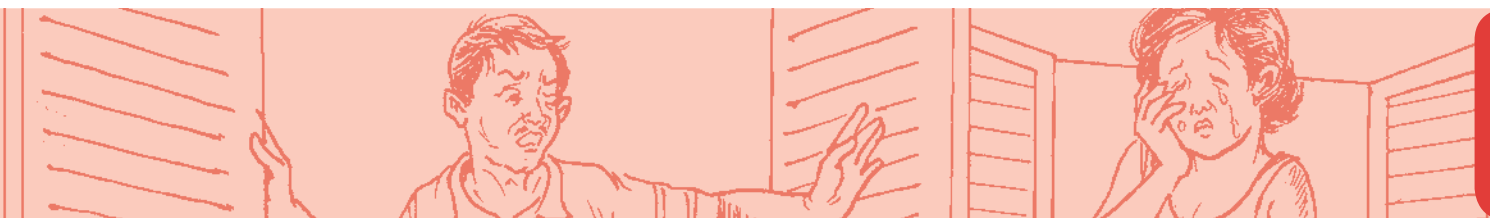
Soon after he lost his job, I got pregnant. I went to the government hospital to deliver my baby. They asked me to do a blood test, and then told me I was HIV-positive. They told me without any counseling or support. One nurse just walked up to me and said, "You have HIV." No one told me how to cope with this new situation. I was shocked and confused and angry. I didn't know what to do. This was when I first found out that my husband had infected me.

When the results came out, everyone in the hospital seemed to know my HIV status. Everyone in the hospital seemed to look at me in a funny way. Hospital staff kept me waiting a long time. Then they told me they could not deliver the baby, so I had to leave the hospital and go home. I went to a private hospital where they did not ask for a blood test. They delivered my baby.

I returned from the hospital to find another problem. Someone from the government hospital had told community leaders that I had HIV. The neighbors started to gossip about me, and my mother-in-law got worried. She refused to accept me back in her home. She said that we would put people at risk, so we had to move to another area in town and rent a room. This made me feel very depressed. I had to leave family and friends and start a new life in a new place.

I restarted my sewing business. Somehow people in the area found out about my HIV and most of my customers stopped coming to my shop. My business suffered badly. Some people even blamed me, saying I had got HIV as a sex worker and had infected my husband.

The one good thing about my life was my baby. He was a very healthy boy born without HIV, and he made my life worthwhile. When he was older, I tried to send him to the local nursery school, but the manager refused, saying that other parents would not allow it. So I had to send him to another school far from our place where people would not know my status. The child does not have HIV but he is suffering just like me – people say he is an AIDS child!



A3

Experience as Stigmatizer and Stigmatized



Facilitator's Notes:

This exercise is not for people living with HIV. It is designed for health care providers, NGO and CBO staff, and the community. It asks them to think about a time in their life when they felt stigmatized, and use this experience to help them understand how it feels to be stigmatized. This is a way of making them empathize with people living with HIV.

The exercise requires a lot of trust and openness within the group, so it should not be used as the first exercise. It works better if it is used after 2-3 exercises. By this point, participants are beginning to open up with each other and are now ready to share some of their own experiences.

You should also note that the exercise looks at stigma in general, and not HIV-related stigma in particular. This is why the instructions are: Think of a time in your life when you felt isolated or rejected for being seen as different from other people. Give participants a few examples (e.g., being made fun of because you came from a poor family, or being made fun of in school because you were smaller than others or poor at football). The examples will help participants understand what type of experiences they are expected to think about.

This exercise needs a good introduction to help participants break out of their initial discomfort about reflecting and sharing their own experiences with others. One way of getting started is by the facilitators sharing their own experience and feelings first. It is important to set ground rules for this exercise: Emphasize that the sharing is voluntary and no one is forced to share; and emphasize the importance of confidentiality, and that what is shared should stay in the room.

This exercise has two parts:

- a) Experience of being stigmatized
- b) Experience of stigmatizing others

Do not do these exercises back-to-back. Do them separately and with some time in between. This will give participants more time to become open about revealing their own attitudes and behavior.

This exercise can trigger painful memories or experiences for some participants. As the facilitator, you should be ready to deal with the emotions raised. Some suggestions on this are given in the notes on Individual Reflection provided in the introductory chapter, under: “Tips for Participatory Trainers.”



Objectives:

By the end of this session, 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



Target Group:

Health care providers, NGO and CBO staff, and the community



Time:

1-2 hours



Steps:

Part A: Experience of being Stigmatized

1. **Individual reflection:** Ask participants to sit on their own. 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 these do not need to be examples of HIV stigma but of any form of “isolation or rejection for being seen to be different”. Ask them to think about the following questions: What happened? How did it feel? What impact did it have on you?
2. **Sharing in pairs:** Say, “Share with someone with whom you feel comfortable.” Give the pairs a few minutes to share their stories with each other.

3. **Sharing in plenary:** Invite participants to share their stories in the large group. This is voluntary; no one should be forced to give his/her story. People will share if they feel comfortable. If it helps, give your own story to get things started. As the stories are presented, ask, "How did you feel? How did this affect your life?"

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Experiences of being stigmatized

Isolated by community for having an HIV-positive family member. Skin disease resulting in being shunned. Stigmatized to be born a girl.

How did you feel when you were stigmatized?

Angry. Ashamed. Misunderstood. Depressed. Rejected. Judged. Outcast. Invisible. Second- class citizen. Pushed down. Unaccepted. Useless. Failure. Hated. Discredited.

4. **Processing:** Ask, "What did you learn from the exercise about stigma? What feelings are associated with stigma?"
5. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

- ➡ This exercise helps us get an inside understanding of how it feels to be stigmatized—shamed, rejected, mocked despised.
- ➡ The feelings of being stigmatized are very painful and they last a long time.
- ➡ Stigma destroys people's self-esteem. People begin to doubt and hate them selves. They feel very alone at a time when they really need the support and company of other people.
- ➡ Everybody has felt ostracized or treated like a minority at different times in their lives. We have all experienced this sense of social exclusion.

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

I come from a poor family. We lived in a small house. The neighbors looked down on us and made fun of us for being poor. Sometimes they even threw rubbish at our house. These attitudes hurt us, but it made us work hard, and eventually our lives improved. But the neighbors could not accept our improved status and continued to make fun of us. I still feel the pain of being treated as a poor person. I felt despised. We were nothing, no matter what we did. This still makes me angry.



People have always stigmatized me as a woman. They underrate me, never listen to my ideas, and think my opinions are useless. When I was young I wanted to study, but my parents kept saying, "No, you are a girl. Your work is in the house, not in the classroom." They tried to block me from going further in my studies, but I never gave up and completed my university studies. Eventually they began to

Examples of Responses:

respect my ideas, and to see that girls can also do well. Now they listen to me and accept that I have something to contribute.



I was interviewed for a job with the police. The interviewer made fun of my height: “You are so short, even an AK47 is bigger than you.” I was not selected and felt stigmatized because of my height. I felt angry, embarrassed, frustrated, and disappointed, my future destroyed by regulations that I felt were discriminatory. I couldn’t do anything about changing my size, so I was told to go home.



I am a very good, obedient girl. I listen to the advice of my parents and I lead a strict life. I start work at 8 a.m. and come home at 5 p.m. to help my mother with the cooking. But in spite of leading a good life, our neighbors say I have a bad character – they have told everyone I have lots of boyfriends, and now people have stopped talking to me. This makes me very sad.



After having my first baby, I found it very painful to make love. My husband insisted on having sex and I agreed, even though it was very painful. My husband had no sympathy for me. Eventually he said, you are not giving me what I deserve, so I will go out and find another woman – and he did. Then he turned everyone against me. My relatives started to blame me for not sleeping with him. They said this was my duty as a woman. I began to accept this blame and blame myself, believing I was wrong.



Examples of Responses:

My uncle got HIV and died. To provide income, his wife began to sell food in front of the school, but the neighbors told schoolchildren not to buy food from her because her husband had died and the food was contaminated. As a result of these rumors her business collapsed. She was forced to move to another place.

Part B: Experience of Stigmatizing Others

This exercise should be done at a separate time, and not immediately after Part A.

1. **Individual reflection:** Ask participants to sit on their own. Then say, “Think about a time in your life when you isolated or rejected other people because they were different.” Ask them to think: 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 stigmatizing.
2. **Sharing in pairs:** Ask participants to share what they have written with someone with whom they feel comfortable.
3. **Sharing in plenary:** Invite participants to share their stories in the large group. This is voluntary, and no one should be forced to give his/her story. As the stories are presented, ask, “How did you feel? How did this affect your life?”

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Experiences of stigmatizing others

- Keeping at a distance from someone who has a skin disease
- Avoiding shaking hands with people who are suspected of having HIV
- Making fun of other people

How did you feel when you stigmatized others?

It made me feelSuperior. Powerful. It was a way to take revenge for being treated the same way by others. I felt guilty to hurt someone.

4. Processing: Ask, “What did you learn from this exercise?”**Our Experiences as Stigmatizers – Example**

As a young person I found it difficult to speak Khmer so I was mistreated in school. The teacher and other students made fun of my pronunciation. So when it was my chance to teach school, I made fun of the slow learners in the same way and encouraged other students to laugh at them. Later I reflected on this behavior and was ashamed. I saw that it was very painful to the students affected. I will never do this again.

5. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

- ➔ We often stigmatize unconsciously. We are only acting the way we have been socialized.
- ➔ Our culture and environment teach and condition us to stigmatize.
- ➔ We cannot blame people for stigmatizing if they have been conditioned to stigmatize.
- ➔ People will be more accepting if they have more exposure, experience, and knowledge.
- ➔ When we stigmatize others, we feel superior and more powerful. We stop dealing with the stigmatized person as a human being, and treat her/him as a threat to isolate or exclude.

A4

Naming Stigma in Different Places



Facilitator's Notes:

In this exercise, participants describe stigma and discrimination towards people living with HIV in a specific place, e.g., home, school, clinic, and workplace. This exercise can be done using different methods: as a rotational brainstorm, a drawing exercise, or as a form of role-playing. Select the method that suits your group.

This exercise is designed primarily for health care providers, NGO and CBO staff, and the community. They may not be aware of these examples of stigma, so you may want to invite a few people living with HIV to join the session and help the participants identify examples of stigma in each of the places.



Objectives:

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

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



Target Group:

All Groups



Time:

1-2 hours



Preparation:

Decide on the contexts suited to your group, e.g., home, community, clinic, workplace, market, tea house, pagoda, and bar. Put up sheets of flipchart paper on different walls of the room, with a different context written at the top of each sheet.

Method A: Rotational Brainstorm:

1. Divide into groups and assign each group a starting station (flipchart sheet).
2. Ask them to write a list of forms of stigma occurring at that context.
3. After two or three minutes, shout “Change” and ask groups to rotate – and add points to the next flipchart sheet.
4. When groups have completed all the flipcharts, review the outputs.

Method B: Drama or Drawing Method:

1. **Topic groups:** Ask people to “vote with their feet” and join the context group they want to join. Then ask groups to:
 - ➔ Identify forms of stigma that occur in that context, and write on flipchart
 - ➔ Make a role-play to show how the stigma occurs.
2. **Report back:** Ask each group to present their flipchart report and the role-play. For each role-play, discuss:
 - ➔ What happened? Why?
 - ➔ What are the attitudes here?
 - ➔ What are the contributing factors?
3. **Processing:** Then discuss some of the following questions:
 - ➔ What are some of the common features across the different contexts?
 - ➔ What are the attitudes and feelings in all contexts towards people living with HIV?
 - ➔ What are the effects on people who have been stigmatized?
 - ➔ What are the root causes of stigma and discrimination?
4. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

- ➔ Stigma is everywhere – homes, communities, clinics, workplaces, and markets
- ➔ Stigma takes two major forms:
 - isolation or rejection – based on fear of infection (or fear of other people knowing your status)
 - shame and blame – based on the assumed sexual behavior of the person who is living with HIV
- ➔ In addition, stigma takes the form of:
 - self-stigma – people living with HIV blaming and isolating themselves
 - secondary stigma – those associated with the people living with HIV, e.g., families and health workers are also stigmatized
 - layers of stigma – some individuals are already stigmatized, e.g., women, entertainment workers, and men who have sex with men (MSM). This adds another layer of stigma.
- ➔ Stopping stigma will take a huge effort by everyone. The starting point is to change ourselves: the way we think, talk, and act towards people living with HIV. We have to personalize the issue for ourselves, to see that we have to do something to change things. We first need to change our attitudes and the way we feel towards people living with HIV.
- ➔ After we have changed ourselves, we can start to educate and challenge others. It takes courage to stand up and challenge others when they are stigmatizing people living with HIV, but breaking the silence and getting people talking openly is the first big step.
- ➔ Talk with your family and friends, and get community leaders to speak out against stigma. Help everyone make these problems visible and these behaviors unacceptable.
- ➔ Reach out to people living with HIV and support them. Once they feel accepted, they will be more open to discussing their situation with others and accessing services.

Examples of Responses:

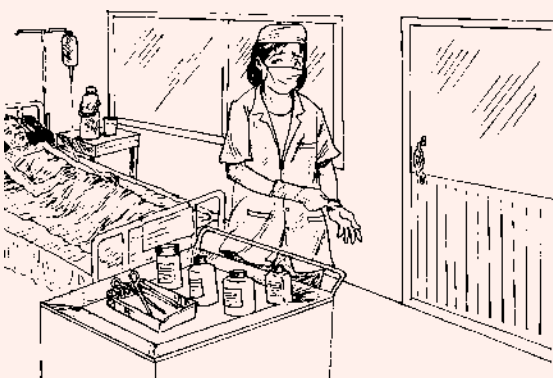
The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Experiences of stigmatizing others

- Isolation. Hide people living with HIV in back room with separate bed, blankets, clothes, plates, and food
- Some people living with HIV are kicked out of the house
- Family stops HIV-positive woman from having contact with her own children, e.g., send the children away
- Family members of people living with HIV are treated as useless and no longer able to contribute to the family
- Loss of place and recognition within the family, and excluded from family decision making
- Verbal abuse, e.g., being belittled and blamed for bringing shame on the family



Hospital/Clinic



- Staff are suspicious of anyone who looks as if he/she has AIDS symptoms out of fear of getting infected.
- Keep people living with HIV isolated from other people, and force HIV-positive persons to stay in separate room
- Neglect. Minimize touching of HIV-positive patients. Treat them last and provide "half treatment."

Examples of Responses:

- Unnecessary precautions, e.g., wear double gloves and masks to examine people living with HIV
- Breach of confidentiality, e.g., health workers tell other staff and patients about person's HIV status. Whispering. Gossip

Community

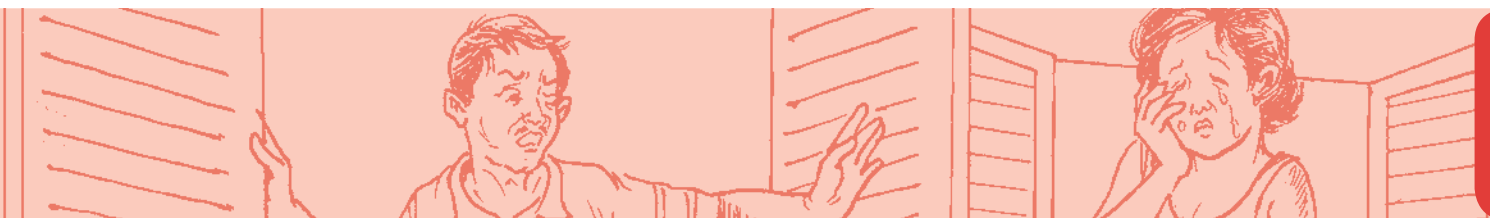
- Whispering. Gossip. Finger pointing. Pitying
- Neighbors isolate or shun people living with HIV, e.g., they stop visiting the family and sharing food
- Blame family for low morals, e.g., saying the parents did not raise their HIV-positive child properly
- Do not allow their children to play with children from the family of a person living with HIV



Workplace

- Gossip and isolation towards someone suspected to be HIV-positive
- Co-workers refuse to sit near or share drinking glasses, plates and cups with HIV-positive worker
- Manager looks out for mistakes or other excuses to justify firing the HIV-positive worker
- Person living with HIV is forced to take an HIV test and then is fired from her/his job





A5

What is the Meaning of Stigma? (Definition)



Facilitator's Notes:

Discussions on the definition of stigma should occur only after participants have developed a better understanding of stigma on an experiential basis through participating in some of the previous exercises.



Objectives:

By the end of this session, participants will be able to describe what stigma means and give examples.



Target Group:

All groups



Time

1-2 hours



Steps:

1. **Participants' ideas about stigma (brainstorm):** Ask, "What do you think is the meaning of 'stigma'?" Record participants' responses in a circle diagram. Below is an example of what this diagram might look like.



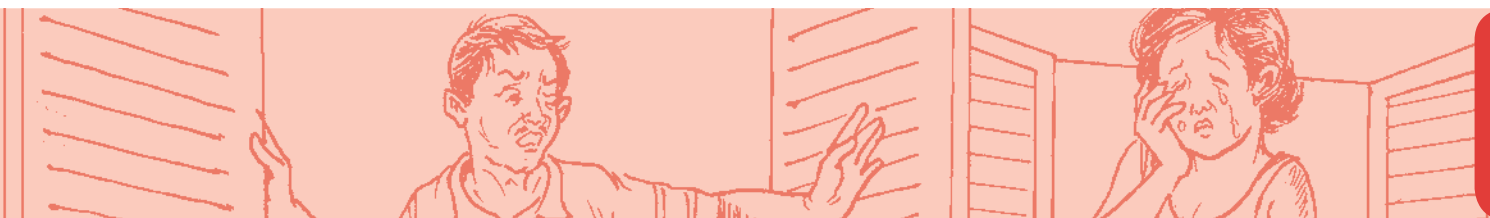
2. **Presentation:** Next, explain and discuss the following:

- ➔ Stigma is a process where we (society) create a “spoiled identity” for an individual or a group of individuals. We identify a difference in a person or group, such as a physical difference (e.g., physical disfiguration), or a behavioral difference (e.g., people having lots of sex) and then mark that difference as a sign of disgrace. This allows us to stigmatize the person or group. Stigmatized people lose status because of these assigned signs of shame that other people consider indications or evidence of sinful or immoral behavior.
- ➔ To stigmatize is to believe that people are different from us in a negative way, to assume that they have done something bad or wrong. When we stigmatize, we judge people, saying they have broken social norms and should be shamed or condemned; or we isolate people, saying they are dangerous or a threat to us.
- ➔ Stigmatizing beliefs lead to discrimination and unfair treatment. Stigma is the belief, and discrimination is a resulting action.

- ➔ Stigma and discrimination result in great suffering. People get hurt.
- ➔ Applying these terms to HIV:
 - HIV stigma takes two major forms: isolation or rejection, and shaming and blaming
 - HIV stigma has two major causes:

Fear and ignorance: People do not know how HIV is or is not transmitted, so, fearing they might get infected through contact with a person living with HIV, they isolate them.

Moral judgments: People know that HIV is transmitted mainly through sex or injecting drugs, so they assume that people living with HIV got HIV through these activities. Therefore, they condemn people living with HIV for immoral behavior.
- ➔ Stigmatization is a process:
 - We identify and name the differences in someone suspected to have HIV.
 - We make negative judgements about the person (e.g., promiscuity).
 - We isolate or judge/ridicule the person, thereby separating “her/him” from “us.”
 - The person who is stigmatized (isolated and judged) loses status.
- ➔ Stigma is viewed as something right. People think that it is acceptable to isolate and shame people. People are not aware of how stigma affects people living with HIV and how it affects the HIV epidemic.
- ➔ HIV stigma is wrong and unacceptable! HIV stigma hurts people living with HIV and drives the HIV epidemic underground. Those stigmatized become silent and do not disclose their status to others. In this way, HIV spreads.
- ➔ People living with HIV have the right to be protected from stigma and discrimination.
- ➔ We need to support people living with HIV, not blame them.



A6

Forms, Effects, and Causes of Stigma (Problem Tree)



Facilitator's Notes:

This is a good exercise to review all the things learned in the earlier exercises. It uses a Problem Tree method to make a list of forms, effects, and causes. Then the group can do further analysis on causes and start looking at solutions.

When doing this exercise, you cannot assume that all participants have “de-stigmatized” Attitudes regarding HIV. For example, some may believe that the cause of stigma is “the behavior of people living with HIV; they are bad people so they deserve to be stigmatized.” The trainer should flag these views and the stigmatizing language, and raise them for discussion.



Objectives:

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

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



Target Group:

All groups



Time:

1-2 hours



Preparation:

Using cards, set up the structure for the problem tree on the wall as follows:

Location	Feature	Question
Top	Effects	How does this affect the person stigmatized (e.g., isolation)
Middle	Forms	What do people do when they stigmatize? (e.g., name calling)
Bottom	Causes	Why do people stigmatize? (e.g., lack of knowledge)



Steps:

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.

1. **Card-storming (pairs):** Divide group into pairs. Hand out cards and markers. Ask pairs to write points on cards, one point per card, and tape at the appropriate level of the diagram. Ask participants to eliminate repetition and put similar points together. Give this task to pairs who have finished early.
2. **Debriefing (plenary):** Review one level at a time. To save time, ask participants to read the points individually and ask questions. Or, go around the circle and ask each participant to name one point that she/he feels needs to be emphasized.
3. **Analyzing causes and developing solutions (task groups):** This exercise produces a huge list of points, but it needs further analysis to get a comprehensive view.

- ➡ Reach agreement on the major causes. Then assign each cause to a task group.
- ➡ Ask each group to analyze its cause. Ask: "Why is this a root cause? How does this lead to stigma?" Ask the group to give examples.
- ➡ Then ask the group to develop solutions. Ask, "What can we do to deal with these causes?"

Problem tree analysis – Examples of responses from the pilot work shop

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Experiences of stigmatizing others

Shaming and blaming: Judging. Scolding. Insulting. Gossip

Isolation: Rejection. Exclusion. Neglect. Shunning.

Separate food, bedding and rooms

Self-Stigma: Blaming and isolating oneself.

Giving up on oneself

Secondary Stigma: Family, children, relatives, and friends of people living with HIV are also stigmatized.



Effects of Stigma

Personal (Effect on person living with HIV): Shame. Isolation. Withdrawal. Feeling excluded. Loss of self-esteem, rights, reputation, and hope. Feeling unproductive. Self-blame. Self-hatred. Take more risks. Stress. Anger. Violence. Alcoholism. Depression. Suicide

Family: Family quarrels, blame, and conflicts. Divorce or separation. Kicked out of home

Problem tree analysis – Examples of responses from the pilot work shop

Community: Fired from work. Forced to leave community. Drop out of school

HIV epidemic: Avoid getting tested and avoid disclosing status. Hide status and HIV spreads silently to partners, resulting in faster HIV transmission

Causes of Stigma



Fear and lack of knowledge: Fear about getting HIV through casual contact leads to isolating, rejecting people living with HIV. Beliefs about pollution, contagion, impurity. Fear of infection, death, the unknown

Moral judgments: View that people living with HIV are “morally corrupt” and have broken social norms

Gender and poverty: Women and poor people are more heavily stigmatized than men and rich people.

Appearance: Person living with HIV’s appearance, e.g., thinness and skin rashes, is used as a basis for stigmatizing

Media images: Images of horrible death make people afraid of people living with HIV.

Extra Analysis on Causes of Stigma

Fear and lack of knowledge

- Lack of in-depth knowledge about how HIV is actually transmitted leads to fear of getting infected through casual (non-sexual) contact, so people avoid any form of contact with people living with HIV, e.g., touch, sharing food, plates, and towels.
- Common misconceptions, e.g., HIV can be transmitted through the air or like a skin disease

Problem tree analysis – Examples of responses from the pilot work shop

- People fear that if they are HIV-positive, they will be locked away and shunned.
- Assume that people living with HIV get sick and die quickly, so their productive life is over and they are a burden on the family

Health workers fears and behavior

- Health workers often have limited knowledge about HIV transmission, so they fear any form of contact with patients, e.g., checking symptoms and taking blood samples.
- To “protect themselves” they try to find out who is HIV-positive (they say this is their right) and try to minimize contact with HIV-positive patients through compulsory testing, putting people living with HIV into separate wards or rooms, marking their files, and wearing "protective" clothing.
- By separating them from other patients, the health workers induce fear among everyone else, thereby creating and spreading stigma.

Morality and social norms

- Social norms require people to follow strict rules. The assumption is that a person getting HIV means she/he has broken these norms, has engaged in sex work or drug use, and is morally corrupt: “HIV and AIDS = SEX and DRUGS = SIN!”
- But not all people living with HIV are entertainment workers or drug users.
- Drug users are heavily stigmatized. It is assumed they will steal to get drugs. It is assumed they are HIV-positive
- We may judge people on the basis of assumptions or suspicion about their past behavior
- We judge people on the basis of how they got HIV. Those who got it “innocently” are labelled ‘innocent victims’.

Problem tree analysis – Examples of responses from the pilot work shop

Media images of people living with HIV

- Media workers have a strong influence on public opinion.
- Media workers often use stigmatizing words and negative images of people living with HIV.
- Negative, frightening, and sensationalist images, e.g., human skulls, bleeding syringes, and coffins are aimed at changing behavior through scaring people, but it only creates fear and stigma.
- There is no attempt to show AIDS with a human face, e.g., to tell stories of people living with HIV who are getting on with their lives and doing well.

Poverty and gender

- Poor people are already stigmatized because they are poor, and rich people may look down on the poor.
- Poor women are often forced by poverty to do sex work.
- Poor people, who are malnourished, are stigmatized by their looks. Cannot hide their HIV in the way a rich person can. Easily seen by neighbors. Forced to go to public clinic where status gets known. Rich people can hide their status, and benefit from seeing private doctors.
- The financial cost and workload involved in caring for people living with HIV can cripple poor households.
- Women are already stigmatized because they are women, and becoming HIV-positive adds to this stigma.
- Social norms are tougher for women. Women are expected to have only one sexual partner, whereas men can have many partners. Therefore, women who get HIV may be more stigmatized than men.
- Moral rules are often based on inequality of power. They are a way of punishing those who challenge men's control of women's sexuality. The men define what is acceptable and what is not acceptable in terms of sexual behavior. Stigma directed at women is rooted in women's inequality.

A7

Effects of HIV Stigma on Different Players



Facilitator's Notes:

This exercise can be used to assess the effects of HIV stigma on different players and on the epidemic itself. It can be used as an add-on activity after Exercise A6 (Problem Tree), which also deals with effects (but not in the same detail). The aim in focusing on effects is to help people see the importance of stopping stigma.



Objectives:

By the end of this session, participants will be able to identify the effects of HIV stigma on different players and the epidemic itself.



Target Group:

All groups



Time:

1 hour



Preparation:

Put up eight blank sheets of flipchart paper on different walls of the room, with a topic written at the top of each sheet as follows:

- 1) people living with HIV, 2) family, 3) community, 4) women, 5) men, 6) children, 7) health services, 8) effects on HIV epidemic



Steps:

1. **Rotational brainstorm:** Explain that the task is to make lists of the effects of HIV stigma on different target groups. Explain that effects include:

- ➔ immediate effects, e.g., shame and isolation
- ➔ spin-off effects, e.g., loss of jobs, and dropping out of school

Divide participants into groups, assign one group to each topic, and hand out markers. Ask groups to write points on their topic in response to the questions, “How does stigma affect your target group?” After three minutes, shout “Change!” and ask groups to move to the next topic and add points. Continue until all groups have contributed to all topics.

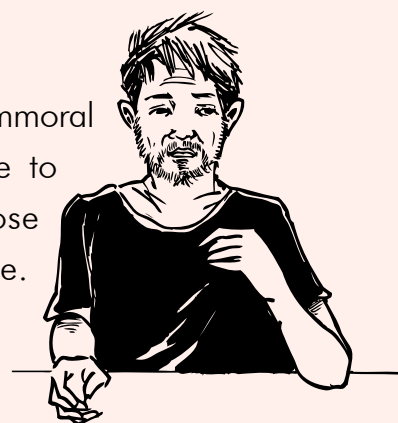
2. **Report back:** Review each flipchart and ask for clarifications. Then summarize:
 - ➔ Stigma has a range of different effects on different groups of people: people living with HIV, their families, communities, and health institutions
 - ➔ Stigma creates conflict and breakdown in communication.
 - ➔ Stigma results in economic losses and it makes families poorer.
 - ➔ The shame of stigma affects everyone: people living with HIV, their families, the community, and even health workers who care for them.
 - ➔ Stigma results in denial; people will refuse to admit that there is any problem.

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

People living with HIV:

Feel worried, isolated, excluded. Blamed and judged for immoral behavior. Kicked out of house. No longer contribute to family’s income so feel useless and unproductive. Lose privacy. Low self-esteem. Self-blame, guilt, and shame.



Examples of Responses:

Afraid to seek help and get services. Depression. Loss of hope. Take risks and become reckless

Family:

Shame and disgrace. Blame the people living with HIV for ruining family honor. Secrecy, e.g., hide people living with HIV from neighbors. Deny that there is a problem. Family conflicts, in which family members blame each other for loss of family status. Stigma reinforces existing power relations, e.g., wife is blamed for not raising child properly. Marriage collapses. Loss of income when breadwinner dies

Community:

Fear. Gossip. Shaming and isolating families perceived to have AIDS. Withdrawal of support

Women:

Isolation has strongest effect on women because community support is very important to them. Self-blame. Low self-esteem. Loss of income. Loss of support system of family and friends. Extra burden of caring for people living with HIV. Woman blamed for not raising her HIV-positive son/daughter properly. Separation or divorce. Avoid getting tested or seeking treatment

**Men:**

Loss of employment, status, self-esteem. Feel useless. Withdrawal from social contact. Self-stigma/self-blame. Suicide

Examples of Responses:



Children:

Shamed and excluded as children of HIV-positive parents. Made to feel guilty. Loss of support and care. Isolated by friends. Self-isolation. Loss of hope and loss of a sense of future. Depression. Some children carry the burden of becoming caregivers and breadwinners. Loss of childhood, and forced to accept adult responsibilities

Health services:

People living with HIV stop using services – testing, counseling, treatment, ARVs. Lack of resources and heavy workloads. Fear of contracting HIV makes health workers try to avoid AIDS work. Climate of silence around health care

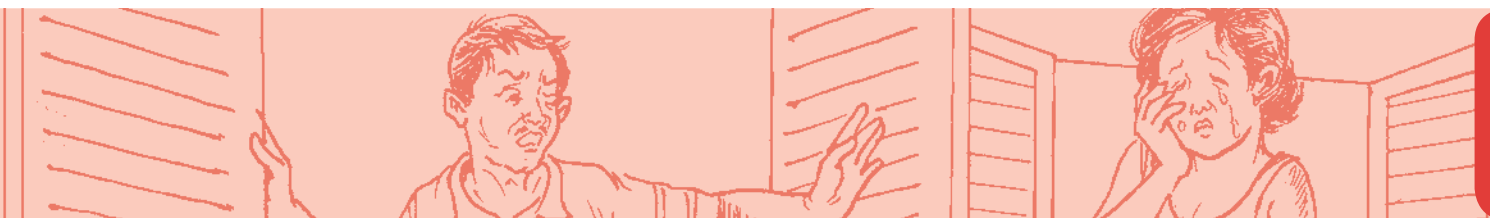
Effect on HIV epidemic:

Fear of stigma prevents people from getting tested, so they unknowingly pass HIV to their sexual partners. Fear of stigma keeps people who suspect they are positive from accessing treatment and counseling services

3. **Processing:** Review the points on how HIV affects the HIV epidemic and the use of HIV and AIDS services.
4. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

- ➡ Explain how stigma blocks both prevention and treatment of HIV and AIDS: Fear of stigma:
- Keeps people from learning their HIV status through testing and discourages them from telling their partners, and as a result the partners may contract HIV.
 - Keeps people who suspect they are positive from accessing treatment and counseling services.
 - Keeps HIV and AIDS underground. People are forced to trade off their own lives in order to remain invisible and not be stigmatized.

If, on the other hand, people living with HIV are treated with kindness, support, and care, they will be more likely to go for testing, disclose to their families, and take safety precautions in their sexual relationships.



Fear of Stigma Fuels the Epidemic (Story)



Facilitator's Notes:

This is an optional exercise to help participants understand how the fear of being stigmatized fuels the HIV epidemic. This fear stops people from getting tested and telling their partners who then may become infected with HIV.



Objectives:

Participants will be able to see how the fear of being stigmatized makes people who suspect they have HIV hide their status, and this puts their partners at risk.



Target Group:

All groups



Time:

1 hour



Steps:

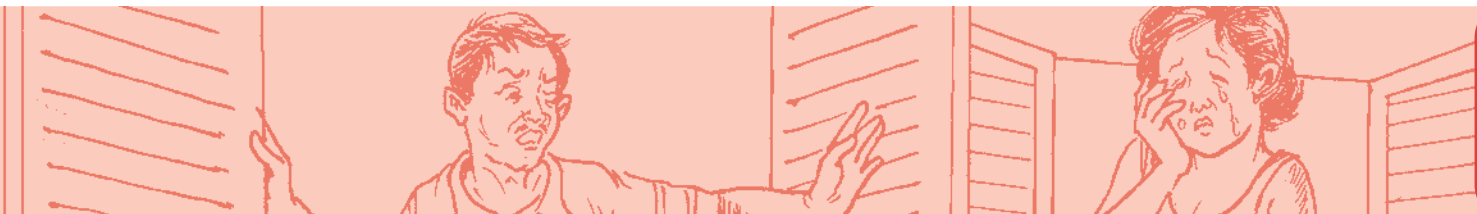
1. Story: Read the following story:

Sangha is a young man who is HIV-positive. After discovering that he is HIV-positive, he has kept this secret to himself. He falls in love with a girl called Chan, but does not know how to tell her that he has HIV. After a while Chan gets pregnant and Sangha becomes very worried that she will be HIV-positive. Chan goes for a prenatal check and after the blood test she is told she is HIV-negative. Sangha is very happy about this news and when the baby comes the baby is also negative. Sangha wants to marry Chan, but does not know how he can tell her the truth about his status.

2. Plenary discussion:



Why is Sangha worried about telling Chan his status?

- 
- ➡ How do you think Sangha can tell Chan that he is HIV-positive?
 - ➡ Once Chan knows the truth, what will she do? Will she marry him or leave him?
3. **Group discussion:** Divide into four groups. A and B discuss what Sangha should do, and C and D discuss what Chan should do. Then organize a report back.
4. **Plenary discussion:**
- ➡ How does HIV stigma affect disclosure and the use of HIV services?
 - ➡ How does HIV stigma result in the continuing spread of HIV?
5. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.
- ➡ Fear of being stigmatized stops people from taking appropriate action. Thus, they can pass on HIV to others. This fear stops people from finding out their own status and telling their partners.
 - ➡ Fear of stigma stops people who suspect they are HIV-positive from:
 - Testing to determine their status
 - Disclosing to partners. Sangha is afraid to tell Chan, fearing he would lose her if he tells her, so he remains silent. This puts Chan at risk of getting HIV.
 - Accessing treatment for opportunistic infections
 - Disclosing their HIV status if they are HIV-positive and getting counseling, care, and support. Because of stigma, people are afraid to tell others about their HIV status. As a result, they may be able to avoid HIV-related stigma, but may have more difficulty negotiating condom use, accessing services, support, and treatment for HIV, and therefore will be at risk for transmitting HIV to their partners.
 - ➡ Fear of stigma keeps HIV and AIDS underground.
 - ➡ If, on the other hand, people living with HIV are treated with kindness, support, and care, they will be more likely to go for testing, disclose to their families, and take precautions in their sexual relationships.

A9

Challenging Stigma (Start - Stop Drama)



Facilitator's Notes:

In this exercise, participants do short role-plays to show how stigma happens, and then more role-plays to show how to challenge the stigma. It uses two linked techniques:

- ➡ paired role-playing
- ➡ stop-start drama

This exercise is a continuous activity. Once participants have formed pairs, they should stay in those pairs throughout the exercise.



Objectives:

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

- ➡ Show how we stigmatize people living with HIV and AIDS, or their families
- ➡ Work out strategies to intervene effectively and challenge stigma



Target Group:

All groups



Time:

1 hour



Method:

The method involves two drama techniques:

- Paired Role-Playing: Participants, working in pairs, do role-plays to show specific forms of stigma. All pairs perform at the same time, which makes people less self-conscious about acting. After each paired role-play, ask a few pairs volunteer to show their role-plays at the center of the circle so that the whole group can watch.

Then the group suggests strategies to challenge the stigma, and a few participants play out each strategy through “stop-start drama” in the circle.

- b) Stop-start drama: Each strategy is played out by a few participants. The stigma scene is re-performed, and then one person intervenes to challenge the stigma. After each “challenging” scene, the group comments on its suitability or realism. If they decide the challenge does not work, other participants try out other strategies to challenge the stigma, until one works. Then the facilitator introduces the next form of stigma and the paired role-playing starts again, and so on.



Steps:

1. **Introduction:** Explain that the session is aimed at practicing how to challenge stigma when we see it in our lives. Participants will play out the following cases of stigma (or other scenarios suggested by them), and then look for interventions to challenge the stigma:

Scenario A: Parent tells HIV-positive son/daughter to sleep and eat separately.

Scenario B: Teahouse owner insults an HIV-positive client and asks him to leave.

Scenario C: Business owner fires employee when he discovers the employee has HIV.

Scenario D: Parent pressures the school to remove the son of a person living with HIV.

Scenario E: Person refuses to help a neighbor who is assumed to have HIV.

2. **Starter role-play: This is just a fun warm-up to demonstrate the technique**

Give the following instructions:

Everyone stand up and find a partner. Face your partner. A is the husband and B is the wife. Each pair should work out who is A and who is B. (Wait until they decide.) The situation is: The husband returns home after staying out all night. The wife reacts angrily. Say, “Play!”

After two minutes, ask a few pairs to show their role-plays in the center of the circle.

3. Scenario A:

Now let us try out the first scenario (the parent tells son/daughter to sleep in the corner and eat separately). Each pair should work out who is the parent (A) and who is the son/daughter (B). (Wait until all pairs have done this.) Parent should be told: Your role is to tell your son/daughter that you are worried about family members getting infected and so he/she should sleep and eat separately. Say, "Play!"

Let the role-plays run for three minutes. Then shout, "Stop!" and ask one pair to show their play at the center. At the end, ask, "What happened? Is it realistic?" If the group agrees that the scene is not realistic, invite another pair to give its role-play. Once the stigma is well presented, ask the group for strategies to challenge this stigma. Then re-play the scene and ask "challenger" (e.g., another family member) to intervene. At the end, discuss: "Did the intervention work?" If not, invite another person to challenge the stigma in a revised role-play. Continue until the group have agreed on a good strategy to challenge the stigma.

4. **New scenario:** Ask the group to select one of the other scenarios (B to E). Then repeat the process.

5. **Processing:** At the end, discuss the following:

- ➡ Those who played the person who was stigmatized: How did you feel?
- ➡ What have we learned about how to challenge stigma when we see it?

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

How did you feel as the person stigmatized?

- I felt treated like an outcast, like I was no longer part of the family.
- I felt very angry, very hurt, and wanted to run away and hide.

Strategies for challenging stigma

- Deal with the stigmatizer privately, not publicly, so he/she does not lose face.
- Do not get upset. Stay calm and remain polite.
- Do not criticize the stigmatizer.
- Help the stigmatizer get a sense of how it feels to be treated like this.
- Empower the person living HIV to speak for himself/herself.
- Get other family members to help challenge the stigma



Facilitator's Notes:

This exercise asks participants to make a comparison between the stigma towards people living with HIV and the stigma towards people affected by other diseases. The aim is to normalize HIV and AIDS as an illness and treat it as a manageable disease.



Objectives:

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

- ➡ Compare HIV and AIDS with other diseases that have been stigmatized
- ➡ Help participants view HIV and AIDS as any other manageable disease.



Target Group:

All groups



Time:

30 minutes



Preparation:

Write the matrix (see below) on sheets of flipchart paper. On each sheet, fill in only the headings across the top and the headings (diseases) down the left-hand column



Steps:

1. **Introduction:** Explain that the aim is to understand why HIV and AIDS are so heavily stigmatized by comparing HIV stigma with the stigma around other diseases.

2. **Matrix analysis:** Divide participants into groups of three or four people and give each group a copy of the largely blank matrix described above (written on flipchart paper). Ask the group to complete the matrix. Show them how to get started, and then leave them on their own.
3. **Report back:** Ask each group to tape its matrix on the wall, and then ask participants to compare the results.
4. **Processing:** Ask, “Why are some illnesses stigmatized more than others?” Use answers from matrices of groups. (Supplement, if necessary, with the answers on the sample matrix below.)

Are the reasons for the AIDS stigma misleading?

- ➡ AIDS is currently seen as a “death sentence,” without a cure. Once a person is diagnosed as having HIV, he/she is perceived as already dead. However, anti-retroviral drugs (ARVs) make it possible to rebuild the immune system and live a long life.
- ➡ HIV is considered contagious, like TB or leprosy, which are communicable diseases spread through air. However, HIV and AIDS are not contagious in this way.

5. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

AIDS has the highest level of stigma because:

AIDS combines all of the stigma factors of other diseases, and is feared as something that:

- (a) can be easily transmitted , (b) is incurable and leads to death , (c) is disfiguring
- (d) has a strong moral dimension associated with sex and drug use

Cancer: No transmission to others + no moral blame = no stigma
 Leprosy: Transmission to others but no moral blame = low stigma
 HIV and AIDS: Transmission assumed + strong moral blame = high stigma

Sample Matrix

Disease	Stigma level	What people say about the person	How the person feels	Reasons for stigma
HIV and AIDS	Highest	Deserves it. Person got it from bad behavior (drugs or sex). Stay away; she/he will infect us.	Shame and loss of self-esteem. Scared to die quickly.	Associated with sex and drugs (sex work is illegal in Cambodia; sex work and drug use seen to break social norms). Deadly disease. Fear of contagion.
TB	Highest	Unlucky; outside his person's control. Not her/his behavior. Feared because she/he is contagious.	Inferiority complex. Danger to others.	Associated with AIDS, so associated stigma.
Syphilis	Highest	Bad person; promiscuous. Stay away from the person.	Embarrassment. Shame.	Associated with sex,
Cancer	Low	Person is unlucky. Maybe it is because person did not worship his/her ancestors enough.	Loss of hope. Scared to die quickly.	Deadly disease but no association with sex. Not contagious.

Sample Matrix				
Disease	Stigma level	What people say about the person	How the person feels	Reasons for stigma
Diabetes	Low	No fear or stigma towards person. No risk to others.		Not curable. Need for continuous medication but no
Leprosy	Medium	Unlucky; it just happened to the person. Outside her/his control.	Rejected. Danger to others.	Not associated with sex.



Chapter B

More Understanding and Less Fear

Introduction

One day the mother learned that her son was taking drugs. Everyone in the family told her to kick him out of the house, but she refused. She cared for him and cooked for him and tried to get him to stop taking drugs. Six months later, however, he became sick and she found out he was HIV- positive. She took him to the hospital and left him there to die. His life was finished and her first duty was to protect the family.

This story is an example of fear-based stigma. The mother did not abandon her son when he was injecting drugs, but she gave up on him when he contracted HIV because of:

- ➡ the mistaken fear that the family would become infected, and
- ➡ the mistaken belief that getting HIV means instant death

This chapter will address this fear and this lack of understanding in relation to HIV and AIDS, particularly the fear of getting infected through casual contact with people who have HIV. The fear of contracting HIV through casual contact is the major focus of this chapter: the fear that people can get HIV through sharing the same space, meals, plates, towels, and toilets with people living with HIV.



This chapter will also address people's response to this fear, such as isolating and restricting social contact with people living with HIV. This is seen as a form of prevention, and a strategy to protect the family from getting HIV. Some families even buy extra plates, cups, utensils, towels and bed sheets for the person living with HIV. They force the person living with HIV to eat and sleep separately, and take their children away from them. But this response has no medical justification. It adds to the financial and workload pressures on the family, and represents a major form of stigma: it makes the person living with HIV feel like an outcast in his own home and a threat to those around him.

People have incomplete information about HIV and AIDS. They do not fully understand:

- how HIV is transmitted and not transmitted
- how HIV grows in the body over time and eventually leads to full-blown AIDS
- how a person with HIV can live for a long time, despite the mistaken assumption that he or she will die quickly

People may know a little about HIV, but not enough to help them deal in a rational way with their fears about AIDS. They do not understand how HIV is actually transmitted. Common misperceptions include the following:



- ➔ They know that HIV is transmitted through sex and injecting drug use, but they also think that HIV is transmitted through casual contact, such as touching, being in close physical contact with, or sharing food and blankets.
- ➔ Some assume that HIV is an airborne disease like tuberculosis (TB) or flu, or a skin disease.

Some assume that HIV can live on people's skin, food or clothing, or on toilet seats. They do not know that HIV dies quickly once it is outside the body.

- ➔ Some do not understand that HIV has to get inside your body to become infected – sex and injecting drug use makes this possible, but ordinary social contact cannot push HIV into your body.

This chapter will re-educate people on the basics on HIV transmission so that people have the right information and full understanding needed to overcome fears and mistaken beliefs about getting HIV through casual contact. At the same time, it will help them see that keeping people living with HIV at a distance and restricting social contact with them is not only unnecessary but also stigmatizing.

This chapter will also address the myth that an HIV-positive test result means immediate death. When people living with HIV are told this, they are quickly demoralized and give up on themselves. This chapter will provide information on HIV progression in the body, treatment for people living with HIV, and how people living with HIV can lead long and productive lives.



Re-education on basic AIDS knowledge will (1) create a safe space for people to raise all their fears, concerns, and questions about HIV and AIDS and receive accurate answers; and (2) provide correct information on how HIV is transmitted. We will use discussion-based methods that allow participants to internalize the new information, discuss it with their peers, connect it to their own ideas and experience, and apply it to their own lives.



Exercises

- B1. Assessing Knowledge about HIV and AIDS
- B2. Fears about HIV and AIDS
- B3. Fears about Casual Contact
- B4. Myths about HIV Transmission
- B5. Knowledge about living with HIV

Annex: Knowledge Test-30 True or False Questions

B1

Assessing Knowledge about HIV and AIDS



Facilitator's Notes:

The aim of these exercises is to help participants gain a sense of their knowledge levels and gaps in their understanding in relation to HIV and AIDS.



Objectives:

By the end of this session, participants will be able to identify what they know and what they do not know about HIV and AIDS



Target Group:

All groups



Time:

1 hour

Two Methods to Assess Knowledge (Use only one of these exercises)
Use the QQR – Quality, Quantity, Route of Transmission – Information Sheet found at the end of B3 as a resource for answering questions.

A. Brainstorming what we know about HIV and AIDS

Put up flipchart paper on different walls of the room and write a topic at the top of each sheet:

- ➡ What is HIV?
- ➡ What is AIDS?
- ➡ What is the difference between HIV and AIDS?
- ➡ How is HIV transmitted?
- ➡ What are the signs and symptoms of AIDS?
- ➡ HIV prevention methods



- ➡ How can one live positively with HIV?
- ➡ What do you know about ARVs?

Ask participants in pairs to walk around and write down:

- ➡ what they know about the topic
- ➡ questions, concerns, or fears

Then review each sheet and respond to questions, concerns, or misinformation.

B. Things we want to know about HIV and AIDS

Divide participants into pairs. Hand out five blank cards to each pair. Ask pairs to write on each card questions they want answered about HIV and AIDS, and tape the cards on the wall. Eliminate repetition of questions and cluster common points. Then discuss each question, with participants contributing their ideas. Help to sort out fact from misinformation.

Examples of Responses:

What is the difference between HIV and AIDS?
 What are the symptoms of HIV and AIDS?
 What is the life cycle of HIV?
 What body fluids have a high concentration of HIV?
 What precautions can people living with HIV and their families take?
 What is antiretroviral (ARV) treatment?
 Where can ARV drugs be found?
 What food and nutrition do people living with HIV need?
 What is the impact of HIV on a person living with HIV?

True-False Quiz – What do I know about HIV and AIDS?

Hand out the quiz which appears at the end of this chapter. Then, discuss the questions where most participants are confused about the responses.



Objectives:

By the end of this session, participants will be able to describe their fears about HIV and AIDS and how their fears affect their response to people living with HIV.



Target Group:

All groups



Time:

2 hours



Steps:

1. **Fears about HIV and AIDS (cardstorming):** Hand out cards and ask each person to write down his or her three greatest fears about HIV and AIDS, one fear per card. Tape the cards on the wall, eliminate repetition, and cluster common points.



Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Getting infected through casual contact

Getting HIV by caring for an HIV-positive family member

Dying slowly and painfully

Dying alone

Feeling helpless and hopeless

Being blamed and isolated

Family reputation destroyed

Losing friends

Losing job

Becoming a burden to my family

Our children getting addicted to drugs and becoming HIV-positive

Our children becoming orphaned with no one to care for them

2. **How do fears affect our behavior towards people with HIV? (buzz groups):** Divide participants into pairs. Ask pairs to discuss this question. Then organize a report back.

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

We minimize contact and stay at a distance.

We separate out his towels and bed sheets.

We asked him to sleep in the back room.

We asked her to stop preparing the meals.

When I visit, I avoid taking tea with that family.


I have stopped my child playing with his child.

I have stopped buying things from her shop.

I keep telling my son to stay away from drugs.

3. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

- ➡ It is natural to fear HIV and AIDS because there is no cure. This is a human reaction to a disease that can lead to people dying. Now that ARVs are available, however, HIV and AIDS should be treated as a manageable disease, like cancer or hepatitis.
- ➡ These fears are often promoted by the media and information, education and communication campaigns as a form of prevention. Instead of scaring people about AIDS, we should empower them to see that they are in control, and that they can do things to avoid HIV.

- 
- Some participants expressed fear of getting HIV through casual contact. This fear is rooted in lack of knowledge or myths about how HIV is transmitted.
 - As a result of this fear that we can get HIV through casual contact, we try to protect ourselves by minimizing social contact with people living with HIV.
 - These practices of limiting social contact with people living with HIV are not a form of protection, since HIV is not transmitted in this way.
 - These practices are stigmatizing. They make people living with HIV feel unwanted, despised, and rejected, and a danger or a threat to those living with them.



Facilitator's Note:

One reason people isolate and stigmatize people living with HIV is that they believe that people living with HIV might infect them through casual contact. This form of stigma is based on insufficient knowledge about how HIV is transmitted (and how it is not transmitted), and/or irrational fears about getting HIV.

This exercise explores participants' understanding of the risks of getting HIV in different forms of contact with people living with HIV. The aim is to address their knowledge gaps and irrational fears of getting HIV. If they know that they cannot get HIV through casual contact, they will be less fearful and stop isolating or rejecting people living with HIV.

This exercise elicits common misconceptions about how HIV is transmitted. These misconceptions are challenged with a simple, three-point explanation about how HIV is transmitted (or not transmitted) called QQR: quality, quantity, route of transmission.

For HIV transmission to take place, the quality of the virus must be strong, a large quantity must be present, and there must be a route of transmission into the bloodstream. All of these things must be present for someone to get infected with HIV.

Once the participants understand QQR, they will use the Margolis Wheel method (see number 4 below) to practice imparting this information and challenging misconceptions.



Objectives:

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

- ➡ Name common fears about getting HIV through non-sexual contact with people living with HIV
- ➡ Understand why people think these forms of contact might result in HIV infection
- ➡ Get a clearly defined tool (QQR) to explain how HIV is and is not transmitted



Target Group:

All groups



Time:

1 hour



Materials:

QQR information sheets to distribute; and myth information sheets (found at the end of B3 and B4, respectively) to distribute



Steps:

1. **Fears about casual contact (cardstorm):** Divide participants into pairs and say, “What are some forms of casual contact with people living with HIV through which community members fear they can contract HIV? These fears make them isolate or reject (stigmatize) others.” Ask pairs to write single points on cards and tape on the wall.

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Kissing. Sharing cups or utensils, food, clothing. Eating food cooked by a person living with HIV. Using the same bathroom or toilet. Mosquito bites. Washing clothes soiled by a person living with HIV. Carrying an injured person living with HIV. Needle prick or contact with blood during health care service delivery.

2. **Reasons and explanations for fears:** Ask each pair to select one point and have them explain why people might believe that they can get HIV through this form of contact.

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

- **Kissing** – believe that HIV is in saliva and there is exchange of saliva when kissing, so HIV is transmitted
- **Sharing cups or utensils** – Believe that HIV is in saliva and there is exchange of saliva when kissing, so HIV is transmitted
- **Eating food cooked by an HIV-positive person** – Person living with HIV cuts her finger, her blood gets into the food, and people who eat the food then get HIV
- **Sharing clothes or blankets** – Believe the virus in sweat gets into clothing and is transmitted
- **Toilet seat** – person living with HIV sits on toilet, his sweat gets onto the seat and transmits HIV to the next user
- **Carrying injured person living with HIV** – While carrying the person living with HIV, the carrier comes into contact with the HIV-positive person's blood from an open cut and gets HIV

3. **QQR:** Introduce QQR and say how it can be used to respond to each of the mistaken beliefs about HIV transmission that were listed in Step 2. Next, hand out the QQR Fact Sheet and Myth Fact Sheet.

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

There is no reason to fear ordinary contact with an HIV-positive patient. You cannot get HIV unless the virus from an infected person actually enters your bloodstream.

- **Touching the skin of an HIV-positive patient:** There is no HIV found in sweat, and there is no route of transmission into the bloodstream, so transmission is not possible.
- **Food cooked by person living with HIV:** HIV cannot survive outside the body, so even if the blood gets into the food, the virus would die as soon as it is exposed to air. In addition, the heat of cooking would kill the HIV.
- **Toilet:** There is no HIV in sweat so you cannot get HIV by coming into contact with sweat. There are only small quantities of HIV in urine or feces, and HIV does not survive once it is outside the body.
- **Carrying an injured person living with HIV:** While carrying the injured person living with HIV, the carrier might come into contact with his blood and get HIV. There is a slight chance of this, but this is unlikely because HIV does not survive very long outside the body. If your skin is intact (no visible cut), you would not get HIV even when you have HIV-positive blood on it. However, HIV can be transmitted if the HIV-positive blood comes in contact with an open cut.
- **Needle prick or contact with blood in health care settings:** These are possible ways in which HIV might be transmitted. A needle prick would allow HIV to go directly into one's body, which is one of the conditions for getting HIV. This would allow HIV to go directly into one's bloodstream. Contact with blood in a health care setting would be possible only if the health worker has an open cut, which would allow HIV to attach itself to the mucous membrane.

4. **Practicing QQR (Margolis Wheel):** When participants have learned QQR, allow them to practice using this information to convince people they should not fear certain forms of contact with someone with HIV. Set up the “Margolis Wheel,” i.e., chairs in two concentric circles so that each person has a partner. Ask the more confident participants to sit in the inner circle and be the “consultants.” Assign one question, e.g., “Tell me why there is no risk of getting HIV if a person living with HIV preparing my food cuts himself.” Ask the consultants to convince their partners. Then ring a bell, ask the outside row to rotate and ask a second question, and so on. After four questions, ask the two circles to change places and continue, so that all participants have a chance to practice using this information.

Examples of Questions–Margolis wheel

- Tell me why it is safe to use the same cup as someone who is living with HIV.
- Tell me why I cannot get HIV through mosquito bites.
- Tell me why there is no risk of getting HIV through sharing the same toilet.
- A woman is cleaning up after a small child living with HIV who has had diarrhea. She has cuts on her hand. What is the risk involved?

5. **How do fears affect our behavior toward people living with HIV? (Buzz Groups):** Divide participants into pairs. Ask pairs to discuss: “How do people’s fears affect the way they treat people living with HIV?” Then organize a report back.

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

They minimize contact and stay at a distance. Separate out towels and bed sheets. Ask a person living with HIV to sleep in the back room. Ask a person living with HIV to stop preparing the meals. When they visit, they no longer take tea with family. Stop their children from playing with the person living with HIV's child. Stop buying things from her shop.

6. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.
 - ➞ HIV is a fragile organism and does not survive for long outside the body. Exposure to air or water kills HIV.
 - ➞ HIV does not spread easily from person to person:
 - HIV is not transmitted through the air like TB or the flu: it is not transmitted through sneezing or coughing.
 - HIV is not transmitted through skin contact like a skin disease.
 - HIV is not transmitted through food or through plates, cups, sheets, etc., or through surfaces such as toilet seats.
 - ➞ HIV is only transmitted through infected blood, sexual fluid or mother's milk getting into the body.

- ➔ You can only get HIV through:
 - Sharing needles or syringes with an injection drug user who is HIV -positive
 - Having unprotected sex (no condom) with an HIV-positive person
 - HIV-positive mothers passing HIV to their babies before or during birth (through blood) or after birth through breast milk
 - Having HIV-positive blood enter your body through an open cut
- ➔ To become infected with HIV, the virus has to get inside your body. When we have sex, sexual fluid can get into the bloodstream through small cuts on the penis or in the vagina. When we inject drugs, the infected blood on needles or syringes can go directly into the bloodstream.
- ➔ Different infected fluids have different quantities of HIV. There are high amounts of HIV in blood, semen, vaginal fluids, and breast milk so it is easy to transmit HIV through these fluids. There is very little HIV in urine, feces, or saliva, so you cannot get HIV through these fluids. There is no HIV in sweat or tears.
- ➔ You cannot get HIV through ordinary casual contact, e.g., touching or sitting beside a person with HIV, or sharing a room, food, or towels.
- ➔ Some people think that in limiting such casual contact with a person living with HIV they are protecting themselves against HIV. This is not a form of protection because HIV is not transmitted by casual contact.
- ➔ These practices are stigmatizing: they make the person feel unloved, despised, and rejected, and a danger or threat to others.



Quality, Quantity, Route of Transmission (QQR) Tool for Understanding HIV Transmission

HIV transmission to take place, the quality of the virus must be strong, a large quantity of the virus must be present, and there must be a route of transmission into the bloodstream.

Quality: For transmission to take place, the quality of the virus must be strong.

- HIV cannot survive outside the human body. It starts to die the moment it is exposed to the air.
- HIV is not an airborne virus. This is why there is no risk of transmission in sitting close to or sharing the same room with someone living with HIV.
- HIV does not live on the surface of the skin; it lives inside the body. There is no risk from shaking hands or hugging someone. The only place the virus can survive outside the body is in a vacuum (like a syringe) where it is not exposed to air.
- HIV will die if it is exposed to heat (e.g., if someone bleeds into a cooking pot).

Quantity: For transmission to take place, there must be enough quantity of the virus to pose any risk.

- HIV is found in large quantities in blood, semen, vaginal fluids, and breast milk.
- HIV is not found in sweat or tears.
- HIV can be found in tiny amounts in urine, feces, and saliva, but there is not enough quantity to pose any risk of transmission.
- Cleaning or bathing a patient is quite safe, provided all wounds are covered.
- Kissing, even deep kissing, poses no risks.

Route of transmission: For HIV transmission to take place, the virus must get inside your bloodstream.

Our body is a closed system, and HIV cannot pass through skin.

- HIV can pass through the skin on the genitals (penis, vagina, or anus) during sex because the skin here is much thinner and has small openings where HIV can pass.

Common sense and everyday hygiene mean that many situations that people worry about would not really happen in everyday life. For example, you would not share a toothbrush if it were covered in blood; you would wash if you cut yourself; and you would wear gloves or cover your hands if you are cleaning up someone's diarrhea.

Using QQR, you can see why there is no risk of transmission by:

Kissing. Hugging. Sitting beside or sharing rooms with PLHIV. Mosquito bites. Sharing eating utensils, sheets, towels, or clothes. Giving blood. Sharing toilets. Using the same washing water. Sneezing or coughing.



B4

Myths about HIV Transmission



Facilitator's Notes:

This is an alternative exercise to B3. Participants generate a list of myths about HIV transmission and then work in pairs to challenge each myth.



Objectives:

By the end of this session, participants will be able to name and challenge myths about how people get HIV.



Target Group:

All groups



Time:

1 hour




Materials:

QQR information sheets (found at end of B3) to distribute; and myth information sheets to distribute



Steps:

1. **Brainstorming:** Ask participants to brainstorm things that people in their area have been saying about how HIV is transmitted. Write each statement on a separate card and tape on the wall. (See examples on Myth Fact Sheet – next page)
2. **Divide into pairs** and ask each pair to select one of the cards. Ask each pair to discuss if the statement is true or false – and why. Distribute QQR Fact Sheet, which participants will use in their discussions. Also distribute Myth Fact sheet below.

- 
3. **Report back:** Ask each pair to make their presentation. Their aim is to persuade the other participants that the statement is wrong.
4. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.
- ➡ Fear can stop us from being rational and finding out the correct information; or it can lead us to accept incorrect information.
 - ➡ Our fear that we can get HIV through casual contact makes us feel that HIV is beyond our control.
 - ➡ This fear stops us from focusing on our own responsibility for taking control of our lives and minimizing risks through sex.

Myths and Facts about HIV Transmission

Myth	Fact
HIV is transmitted easily from person to person.	False. HIV is a fragile organism that dies quickly once it is exposed to air. It does not survive outside the body.
HIV is transmitted through the air like TB or the flu.	False. HIV is not an airborne virus like TB or flu. Example: HIV is not transmitted through sneezing or coughing.
You can get HIV by sitting close to a person with HIV.	False. There is no risk of sitting close to a HIV-positive person in the home, on the bus, or in a tea shop.
You can get HIV by holding or shaking hands with a person living with HIV.	False. HIV does not live on the surface of the skin. It lives inside the body, so HIV does not spread through skin contact.
You can get HIV by kissing a person living with HIV.	False. There is no risk from closed-mouth (social) kissing. Very low risk from open-mouth kissing (no cases have been reported).
You can get HIV by cleaning or washing a person living with HIV, who has sores or cuts on his body.	False. if you use common sense. There is no risk of getting HIV through cleaning or washing a HIV-positive person, as long as the cleaner takes precautions, e.g., using gloves.
You can get HIV from sharing plates or spoons because there is HIV in saliva.	False. HIV is contained in saliva, but the quantities are very low, and not enough to transmit the virus. You would need to consume large amounts of saliva to get HIV.



Myth	Fact
You can get HIV from using a toilet already used by a person living with HIV.	False. HIV cannot survive outside the body so it does not live on environmental surfaces such as toilet seats.
You can get HIV through being bitten by a mosquito that has already bitten a person living with HIV.	False. Blood containing HIV goes into the mosquito's stomach where the virus is digested and killed. Mosquitoes only suck blood; they do not inject it into people. HIV is rare among children aged 5-15, even though this group is often bitten by mosquitoes.
All babies born to HIV-positive mothers will be infected with HIV. (Subsequent chapters will note the medicines HIV-positive mothers can take to lower the risk of transmission to their children.)	False. Roughly two-thirds of babies born to HIV-positive mothers will not be infected. The more HIV in the mother's blood, breast milk, and other fluids, the more chance of the baby getting HIV. Amount of HIV (viral load) depends on the stage of the illness. The viral load is high when a woman is first infected because there are no antibodies to fight the HIV. Later, the viral load rises if she gets opportunistic infections. When full-blown AIDS develops, it is very high and can easily be passed on. So, the chances of a baby being infected are greater if a woman (1) gets HIV while pregnant or breastfeeding or (2) gets pregnant or breastfeeds when she has full-blown AIDS.

Myth	Fact
People with sexually transmitted infections (STIs) have a lower risk of getting HIV than people without STIs.	False. Having an STI increases the risk of getting HIV. STIs produce sores in the genitals, which make it easier for HIV to pass into the bloodstream during sex. Prevention and early treatment of STIs will reduce the spread of HIV.
Women are at lower risk than men of getting HIV through unprotected sex.	False. Women get HIV during sex twice as easily as men. Semen has a higher amount of HIV than vaginal fluids. A woman's vagina has large areas of exposed and sensitive skin that can develop small tears during sex. This allows HIV to enter the woman's bloodstream. Semen stays longer in the vagina after sex, increasing the risk of transmission. In contrast the penis has a small surface area, which is in contact with vaginal fluids for a shorter time, and men can more easily wash off vaginal fluids after sex. Very young women are vulnerable to HIV infection through penetrative sex because their sexual organs are still not fully developed and are more vulnerable to wounding and tearing.





Objectives:

By the end of this session, participants will be able to describe what happens to a person who gets HIV (progression of illness, viral load, length of life, etc.).



Target Group:

All groups



Time:

1 hour



Steps:

1. **Quiz:** Ask participants to complete the quiz below.

Quiz questions:

If a person is HIV-positive:

1. Has the person got AIDS?
2. Is the person's life over?
3. Will the person be dead in two years?
4. Can the person pass HIV to other people?
5. Is there any medicine he/she can take?
6. Will others be able to tell if he/she has HIV?
7. Should he/she give up his/her job?
8. Should he/she stop doing physical work?
9. Is the person's sex life over?
10. Can he/she have children?

2. **Report back:** Review each of the questions and agree on the correct information.

3. **Cardstorm (optional):** Divide participants into pairs and hand out cards. Ask pairs to write on cards all the things they have heard that happen to a person once he/she tests positive. Eliminate repetition, cluster common points, and review the list. Explore the thinking behind any misconceptions and the effect they may have on persons living with HIV. Clarify any questions and uncertainties.

4. **Story:**

Tell the story about the mother who discovered that her son was injecting drugs (see Introduction). Instead of abandoning him, she cooked and cared for him. Later, when she learned he was HIV-positive, she assumed he would die immediately, so she took him to the hospital and left him there to die.

5. **Discuss:** Ask, “What did you learn from the story?”

6. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

- ➡ One reason families give up on people living with HIV is that an HIV-positive test result is perceived to mean imminent death.
- ➡ They treat that family member as someone who is already dead, no longer able to contribute. In addition they fear he is infectious.

Getting HIV does not mean instant death, because:

- ➡ HIV and AIDS are not the same. A person can have HIV and live for 10 years or more before the immune system is affected and the person develops AIDS.
- ➡ If the person with HIV lives positively and takes care, he/she can lead a long life.
- ➡ Most opportunistic infections, including TB, can be treated and cured.
- ➡ People living with HIV can continue to hold jobs and lead a productive life.
- ➡ ARVs slow down progression of the illness and increase immunity.



Questions

What is HIV? What is AIDS?

1. HIV is a virus that destroys the immune system.
2. AIDS is the condition of the body when its immune system has become weak.
3. HIV needs to penetrate the skin or mucous membranes to cause HIV infection.
4. HIV can live for a long time outside the body.

How is HIV Spread?

5. HIV can be transmitted when two people share needles during drug use.
6. All babies born to HIV-positive mothers are infected with HIV.

Who is at risk of getting HIV and AIDS?

7. Married people cannot become infected with HIV.
8. If you stick to only one partner, you cannot get HIV.
9. If you are fit and healthy, you will not become infected by HIV.

One can get HIV from:

10. Sharing food, drinks, or cutlery with an HIV-positive person.
11. Using the same toilet as an HIV-positive person.
12. Bites from mosquitoes.

One cannot get HIV from:

- 13. Breast milk from an HIV-positive mother.
- 14. Donating blood if sterilized instruments are used.
- 15. Sharing a toothbrush with an HIV-positive person.

Appearance of HIV:

- 16. You can tell that a person has HIV by just looking at him/her.
- 17. A person can have HIV for years before becoming sick with AIDS.
- 18. Some people have HIV but do not know they have it.

Signs and symptoms of AIDS:

- 19. Swollen glands, weight loss, diarrhea, and skin problems.
- 20. Burning pain when urinating and sores on the genitals.
- 21. Getting opportunistic infections such as TB, pneumonia, diarrhea, skin cancer.

HIV and AIDS can be cured by:

- 22. Having sex with a virgin.
- 23. There is no cure for AIDS.

You can prevent yourself from getting HIV by:

- 24. Not having sex (abstinence).
- 25. Choosing healthy-looking partners.
- 26. Using condoms during sex.

People with HIV can live normal lives for as long as possible if they:

- 27. Practice safe sex in order to minimize amount of HIV in the body.
- 28. Stop working immediately.
- 29. Eat well, avoid alcohol and tobacco, and avoid stress.

Answers

What is HIV and AIDS?



1. **HIV is a virus that destroys the immune system.**

☒ One type of white blood cell is the CD4 cell or T helper cell. These cells are a crucial part of the body's immune system, which is the system that protects us against sickness. The CD4 cells are like a fence around the body, protecting the body from diseases. They attack germs that get into the body so that we do not get sick. When HIV enters a person's bloodstream, it attacks, enters, and destroys the white blood cells so that the white blood cells cannot do their work of keeping the body healthy. Germs then take advantage of the weakened immune system and attack the body.

2. **AIDS is the condition of the body when its immune system has become weak.**

☒ AIDS is the advanced stage of HIV when HIV has weakened the body's immune system. With advanced HIV disease, opportunistic infections cause disease because the HIV-positive person's immune system has been weakened.

3. **HIV needs to penetrate the skin or mucous membranes to cause HIV infection.**

☒ In order for HIV to be transmitted, HIV in the blood, semen or vaginal fluid of an HIV-positive person has to get inside the body and into the bloodstream of the other person. The skin is normally a barrier to this type of penetration, but breaks in the skin such as cuts, sores, and ulcers, can allow the HIV virus to pass through and get into the bloodstream. HIV can pass through the skin on the genitals (penis, vagina, or anus) during sex because the skin here is much thinner and has small openings where HIV can enter. Infections in the genital area (e.g., sexually transmitted infections or STIs) provide an easy way for HIV to enter the blood-stream; this is why people with STIs are at higher risk of getting HIV than other people.

4. HIV can live for a long time outside the body.

- ✓ HIV is a fragile virus that cannot live outside the body for a long time. It starts to die the minute it is exposed to air. It does not live on the surface of skin; it lives inside the body.

How is HIV Spread?

5. HIV can be transmitted when two people share needles during drug use.

- ✓ Sharing needles during drug use carries a high risk of HIV transmission. Infected blood is easily passed from one person to another via an infected needle or other equipment used to inject drugs.

6. All babies born to HIV-positive mothers are infected with HIV.

- ✓ Roughly two-thirds of babies born to HIV-positive mothers will not be infected. The more HIV in the mother's blood, breast milk, and other fluids, the more chance of the baby getting HIV. Amount of HIV (viral load) depends on the stage of the illness. The viral load is high when a woman is first infected because there are no antibodies to fight the HIV. Later, the viral load rises if she gets opportunistic infections, and when she develops full-blown AIDS, it is very high and can easily be passed on. So the chances of a baby being infected are greater if a woman (1) gets HIV while pregnant or breastfeeding or (2) gets pregnant or breastfeeds when she has full-blown AIDS.



Who is at Risk of Getting HIV and AIDS?

7. Married people cannot become infected with HIV.

- ✓ Being married will not prevent HIV. Many women may be faithful, but men are more likely to have sex with other women. For many women, marriage is a risk factor for getting HIV, because they cannot refuse to have sex or ask their husbands to use condoms, even if they know their husbands have been unfaithful or already have HIV or STIs.

8. If you stick to only one partner, you cannot get HIV.

- ☒ Your partner may not be faithful to you, or he/she may have had sexual partners who were HIV- positive before meeting you.

9. If you are fit and healthy, you will not become infected by HIV.

- ☒ It does not matter how healthy you are; anyone can get HIV.

One can get HIV From:

10. Sharing food or drinks with an HIV-positive person.

- ☒ HIV is found in significant amounts only in blood, semen, and vaginal fluids and has to get inside the body and bloodstream of another person to spread. HIV cannot survive outside the body. These are the two reasons why HIV does not spread through sharing food or drinks (or shaking hands, sharing rooms or clothing, or using the same toilet).

11. Using the same toilet as an HIV-positive person.

- ☒ See Answer 10.

12. Bites from mosquitoes.

- ☒ The blood containing the virus goes into the mosquito's stomach where the virus is digested and killed. Mosquitoes only suck blood; they do not inject it into people. HIV is very rare among children aged 5-15, even though this age group is often bitten by mosquitoes.

One cannot get HIV From:

13. Breast milk from an HIV-positive mother.

- ☒ Babies may get infected with HIV when the mother is breastfeeding. The chances are higher if the mother has a high level of virus in her blood while she is

breastfeeding. If the mother has cracked nipples, painful swelling of breasts through mastitis, or if the baby has thrush or sores in the mouth, the risk of transmission becomes higher.

14. Donating blood if sterilized instruments are used.

- ☒ You cannot get HIV through donating blood using sterilized instruments.

15. Sharing toothbrush with an HIV-positive person.

- ☒ No one can get infected from sharing a toothbrush. But for reasons of hygiene, it is better not to share toothbrushes.

Appearance of HIV

16. You can tell that a person has HIV by just looking at him or her.

- ☒ There are no symptoms to show he/she has HIV. You can only know for sure from an HIV blood test. Most people who have HIV do not show any signs of illness for years. But the virus remains in their body and can be passed on to other people. People with HIV look ill only when they have full-blown AIDS.

17. A person can have HIV for years before becoming sick with AIDS.



18. Some people have HIV but do not know they have it.

- ☒ UNAIDS estimates that 90 percent of people with HIV are not aware of it. People can carry the virus for many years without knowing they have it, because there are no signs. They can look and feel entirely healthy before developing any symptoms of AIDS.

Signs and symptoms of AIDS

19. Swollen glands, weight loss, diarrhea, and skin problems.



20. Burning pain when urinating and sores on the genitals.



The above symptoms are the symptoms of some STIs, but not AIDS.

21. Getting opportunistic infections such as TB, pneumonia, diarrhea, skin cancer.



HIV and AIDS Can be cured by:

22. Having sex with a virgin.



Virgins do not have any power to heal HIV-infected individuals. This myth puts young girls at more risk of getting HIV.

23. There is no cure for AIDS.



There is no cure or vaccine for HIV infection. There are drugs (ARVs) to slow down the production of the virus in an infected person, but these do not cure AIDS. They can only postpone symptoms or death. After infection, HIV remains in the body for life.

You can protect yourself from getting HIV by:

24. Not having sex (abstinence).



25. Choosing healthy looking partners.

- ☒ There is no way to tell through looking whether a partner has HIV or not.

26. Using condoms during sex.

People with HIV can live normal lives for a long time if they:

27. Practice safe sex to minimize the amount of HIV in the body.

- ☒ This is important not only to stop HIV transfer to others but also to minimize reinfection (getting infected by others who also are HIV-positive). When the virus replicates in the body, it changes, so any HIV-positive person may have many variations of the virus. The body's immune system has to adapt to fight off each form of the virus, which puts further strain on the immune system. If two HIV-positive people have unprotected sex, they will re-infect each other with all the different forms of the virus that either may have.

28. Stop working immediately.

- ☒ People living with HIV should not be forced out of work. Many are still strong enough to hold down a job and through it earn some income; this is important for their morale and survival. People with HIV can live for many years before coming down with AIDS symptoms, so they should be allowed to continue to work.

29. Eat well, avoid alcohol and tobacco, and avoid stress.

- ☒ The body needs nutritious foods to build it up, give it energy, and make it stronger so that it can fight infections and sicknesses. Alcohol and cigarettes damage the body's ability to fight off diseases, so stopping or reducing their consumption can help to keep the body strong.

Chapter C



Sex, Drugs, and Morality

Introduction

In Cambodia, HIV is primarily transmitted through sex or injecting drugs so people assume that people get HIV through one of these two behaviors.

The link in people's minds between HIV and immoral behavior means that people living with HIV are judged or "shamed and blamed" by others for their "negative social behavior." This judging is perceived to be legitimate, and a way of shaming people into stopping sex work or drug use. But it represents a major form of stigma. It makes people living with HIV feel ashamed and helps to drive the epidemic underground.

This module aims to tackle the difficult subjects of sex and injecting drug use, and explores these issues in relation to HIV-related stigma.

This chapter is divided into a number of sub-sections. We encourage you in planning workshops to select exercises from each of the sections.



Exercises

- C1. We Are All in the Same Boat! (Bamboo Game – Warm-up)
- C2. The Blame Game, or Things the Community Says about

Judging and Stigma

- C3. Judging Characters (Character Cards)
- C4. Value Clarification Exercise

Gender and Stigma

- C5. Stigma and Gender: Introduction
- C6. Gender and Stigma: Life Cycle Exercise
- C7. Who Is Blamed for Bringing HIV Home?

Sex and Stigma

- C8. Breaking the "Sex" Taboo
- C9. Carrying Condoms Carries Stigma

Drugs and Stigma

- C10. First Thoughts about Drug Users
- C11. Naming Drug User Stigma in

Different Contexts

- C12. The Effects of Stigma on Drug Users
- C13. When Drugs and HIV Enter the Family

C1

We Are All in the Same Boat! (Bamboo Game – Warm-up)



Facilitator's Notes:

This is a game to introduce the idea that we are all affected by HIV, and yet we stigmatize those who have HIV. You can use any game that eliminates or excludes participants. These games trigger discussion on how it feels to be eliminated or excluded from the group. At the end of the game, ask those who were eliminated, "How did you feel when you were eliminated and left sitting watching the other players?"



Objectives:

By the end of this session, participants will be able to recognize that all people are at risk of getting HIV so there is no point stigmatizing those who have HIV.



Target Group:

All groups



Time:

15 minutes



Steps:

1. **Bamboo game:** Ask players to stand in a circle. Teach the two commands: "Bamboo" (crouching down) and "Bamboo shoot" (standing up). Then give these commands quickly, and ask participants to follow the commands. Tell those who make mistakes to drop out of the game. Then stop, and debrief while participants are still standing.

2. Debriefing: Ask:

- Those who were kicked out of the game: How did you feel?
- Those who remained in the game: How did you feel?
- What happened when someone made a mistake? How did that person feel?
- What can we learn from the game about stigma?

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Those kicked out of the game: How did you feel?

Why me? Anger. Confusion. Embarrassment. I felt I had made a little mistake, so I did not know why I was being kicked out. Why can't you give me another chance? I felt others were laughing at me. I felt all alone. I felt good when others were eliminated, because then I was not alone. I wanted others to fail, because then they would join me in the "loser" category.

Those who remained in the game: How did you feel?

I felt very nervous. I wanted to avoid being singled out so I was very careful. Yes, I did laugh at others, but it was a natural response. It was a very competitive situation and when someone makes a mistake, you laugh to relieve the tension.



Examples of Responses:

What happened when someone made a mistake?

People laughed, pointed fingers, mocked, insisted they leave the game.

What can we learn from the game about stigma?

- People laugh when others make a mistake – this is a form of exclusion – and make the person who was eliminated (stigmatized) feel bad.
- Laughing at others making mistakes can be interpreted as a form of blaming.
- Laughing at others' behavior happens naturally or unconsciously. It just comes out.
- Stigma is like this; we are often unaware that we are doing it. We are acting out in the way we have been socialized.
- It is easy to make a mistake in the game and in real life, e.g., not using a condom or taking risks in our sexual behavior.
- When you get HIV, it is final. You do not get "another chance."
- Those who were still in the game were watching and judging the behavior of others; this is similar to the way we stigmatize.

3. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

- ➡ This game shows us that "we are all in the same boat." There is no separation between "us" and "them." We are all facing and living with this epidemic together. We are all affected. We have all taken risks at one time in our lives and many of us still do. We all have friends or relatives who have died of AIDS.
- ➡ Lots of people like to laugh at and make fun of others, but one day they may also "fall into the river," and others will laugh at them. Remember: HIV affects everyone.

- ➔ Stigmatizing others makes us feel superior to others. It makes us feel that "we" are right and "they" are wrong. Yet we are all in the same boat.
- ➔ All of us are at risk of getting HIV so there is no point in stigmatizing or blaming those who are already affected. We could join them any day.



African Proverb:

**Whatever misfortune befalls me,
tomorrow it may be you!
Your friend's misfortune can become your
misfortune. Your funeral is my funeral.
When I have a funeral,
you will come to comfort me. We will
take care of each other's burdens.**



Facilitator's Notes:

This exercise is not designed for people living with HIV; it is designed for health care providers, NGO and CBO staff, and the community. It helps these groups look at stigmatizing words. The words can be very strong and insulting so participants need to understand why they are asked to make lists of stigmatizing words of marginalized groups.

The subtitle of this exercise is "Things the community says about..." This phrasing allows participants to express their own stigmatizing labels for other groups under the cover of attributing them to "the community." So while some of the words are those commonly used by the community, some are the words actually used by participants.

In doing this exercise, we should make it clear that we are using these words not to insult people, but to show how these stigmatizing words hurt.

In debriefing this exercise, it is important to focus on "how participants feel about these names," rather than the words themselves. This helps to avoid the embarrassed laughter. The whole point of this exercise is to help people recognize how these words can hurt.

Extra Tips for Facilitators:

- ➡ The number of flipchart stations/categories depends on the number of participants and the amount of time you have. With many participants you will need many stations/categories so that the individual groups are not too big.
- ➡ The rotational brainstorm is fun, but the real learning comes in the debriefing, so make sure you allow enough time and energy for this.
- ➡ You need to explore your own feelings about these issues before trying to facilitate this discussion with others
- ➡ Challenge the laughter. Often participants will laugh out of embarrassment. This is a good opportunity to ask, "How do you feel about the laughter?"



Objectives:

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

- ➡ Identify labels used by people to stigmatize people living with HIV and other stigmatized groups
- ➡ Understand that these words hurt



Target Group:

Health care providers, NGO and CBO staff, and the community



Time:

2 hours



Preparation:

Set up seven flipchart stations with blank sheets of flipchart paper on different walls of the room, with a topic on each sheet, e.g., people living with HIV, MSM (men who have sex with men), EW (entertainment worker), IDU (injecting drug user, orphan, widow, and street people. (Select the groups that are the most stigmatized in your area.) Other stigmatized categories might include an AIDS-affected family or entertainment worker's client.



Steps:

1. **Warm-Up with switching chairs game:** Set up the chairs beforehand in a circle. Allocate roles to each person, going around the circle: "person living with HIV, men who have sex with men, entertainment worker, drug user, orphan, widow." Continue until everyone has been assigned a role. Then explain how the game works, saying:

"I am the caller and I do not have a chair. When I call out two roles, e.g., 'person living with HIV' and 'MSM', all the 'persons living with HIV' and 'MSMs' have to stand up and run to find a new chair. I will try to grab a chair. The person left without a chair becomes the new caller, and the game continues. The caller may also shout 'Revolution', and when this happens, everyone has to stand up and run to find a new chair."

To start the game, shout: "Person living with HIV and MSM," and get the "Person living with HIV" and "MSM" to run to a new chair. Then ask the person left without a chair to call out more names, thereby getting participants to run again. Continue until all groups have had a chance to run a few times.

Debriefing: Ask, "How did it feel to be called a person living with HIV or MSM?"

2. **The Blame game, or things the community says about (Rotational Brain-storm):** Divide participants into seven groups based on the roles used in the game. Ask each group to go to its flipchart station. Hand out markers and ask each group to write on the flipchart all the things the community says about those in each group. After two minutes, shout "Change" and ask groups to rotate and add points to the next sheet. Continue until all groups have contributed to all seven flipcharts.

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.



Person living with HIV

Sex crazy. Many sex partners. Irresponsible. Stupid, because got infected. Useless. Unlucky. Got HIV because you betrayed your wife. Cursed. Immoral. Deserve to die. It is your own fault. Death sentence. Living but looks dead. When you die, no one will go to your funeral.



Men who have Sex with Men

Katooey. Sex crazy. Sex addicts. Abnormal. Cursed. Mentally sick. Painted boy. Third sex. Dirty. Disgusting. Rebellious. Half man-half woman. His penis died. Why can't you be a real man? HIV carriers. He looks like a girl, walks like a girl, and has a high voice – so he should have been a girl.



Entertainment Workers

Whores. Cheap golden flowers. Women without shame. Sex crazy. Irresponsible. Man trap. Husband stealers. Home breakers. Naughty. Disgusting. HIV carriers. Cheat money out of old men. Eating without having to work. Sell your bottom to feed your mouth. You are sex worker because your mother was sex worker. Lazy. Cares too much about money. When you die, no one will go to your funeral.

Examples of Responses:



Drug Users

Out of control. Dangerous. Criminals. Thieves. Bad people. Useless. Crazy about drugs. Rebellious. Did not listen to parents. Bottom of society. Outcasts. Flat ears. Deserve to die. Without morals. Society's burden. Money burner. Destroying family's assets. Black rice.




Orphans

Thieves. Criminals. Son of a whore. Children of parents with HIV. A bastard. Parents are bad people. Parents died of AIDS. Useless. Burden. No future. Diseased. Miserable. Misunderstood. Hopeless. Abused.



Widows/Widowers

Husband eaters. Husband stealers. Sex crazy. Kill to inherit wealth. HIV carriers. Dangerous. Threat to other women. Evil. Spreading disease. Useless.

- 
3. **Report back:** Bring everyone together into a large circle. Ask one person from each group to stand in the middle of the circle and read out the names on their flipchart, starting with “I am a person living with HIV (or other group) and this is what you say about me.....”
4. **Processing:** After all lists have been read out, ask the following questions:
- ➡ How would you feel if you (or your family members) were called these names?
 - ➡ Why do we use such hurtful language?
 - ➡ What are the assumptions behind some of these labels?
 - ➡ What does this show us about the link between language and stigma?

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

How would you feel if you were called these names?

Sad. Angry. Humiliated. Unfairly treated. Rejected. Embarrassed. Ashamed.

They are pointing fingers at me. It makes me sad and ashamed. I wish I could die.

I feel really bad. I feel rejected and criticized by others. They are pushing me away.

It makes me feel unfairly treated. It's no fault of mine I got HIV, but I am blamed.

I'm going to hide my illness from others so I won't be stigmatized.

I feel hopeless. All my confidence is gone. I don't know how I will survive.

I have teenage daughters and it makes me angry to hear these names.

5. Summary:

- ➔ Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.
- ➔ We are socialized or conditioned to judge other people. We judge people based on assumptions about their behavior.
- ➔ Sex is a taboo subject. It is regarded as something shameful that we should not talk about, so people who indulge in lots of sex are assumed to be shameful.
- ➔ Person living with HIV, MSM, EWs, and drug users were all labelled as sexually immoral. They were called promiscuous, sinners, irresponsible, and AIDS carriers.
- ➔ EWs are more stigmatized than their clients. While the EWs are morally condemned, the male clients are not blamed – the attitude is “boys will be boys” – and they are seen as indulging in play.
- ➔ Layers of stigma: People affected by HIV stigma are often those who are already stigmatized, e.g., women, EWs, MSM, IDUs. They do not have much power to challenge stigma.
- ➔ All of these labels show that when we stigmatize, we stop dealing with people as human beings. We forget their humanity by using mocking or belittling words, and this gives us a feeling of power and superiority over them.
- ➔ All of these labels are based on assumptions for which we have insufficient information. They are generalizations that have no validity; we simply assume that “the other people” are dirty, lazy, promiscuous, unlucky, and so on.
- ➔ We attribute characteristics to a group and to everyone who belongs to that group. We assume that all members of that group have the same characteristics, e.g., all people living with HIV are promiscuous or inject drugs.



- ➔ Stigmatizing words are very strong and insulting. They have tremendous power to hurt, humiliate, and destroy people's self-esteem.
- ➔ So how should we treat people living with HIV? We should give them: a) respect and affection; b) support and encouragement; and c) space, place, and recognition in society. If we do this, they will keep their self-esteem and this will help them to live a long life. But if we treat them badly, they will die quickly – not from the illness, but from the shame, the isolation and rejection they feel. Fear of stigma can make persons living with HIV remain quiet, and this will result in HIV being passed to others. Or they will react with anger and rage and actively try to spread HIV to others.
- ➔ Why do we condemn some groups and accept others? We are not saying that drug users or entertainment workers are right or wrong. Whether or not you agree with someone, you do not have the right to belittle them. You must look at a human being as a human being and empathize. Try to put yourself in the shoes of the other person: how would you feel if you were called these names? Even if you do not like a person, try to understand the person.

Judging Characters (Character Cards)



Facilitator's Notes:

This exercise is not designed for people living with HIV; it is designed for health care providers, NGO and CBO staff, and the community. If poorly facilitated, the exercise could reinforce stereotypes. Help the group focus on trying to understand the characters, rather than judging them.



Objectives:

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

- ➡ Understand more about the types of people we often judge
- ➡ Challenge the assumptions behind our judgments about other people



Target Group:

Health care providers, NGO and CBO staff, and the community



Time:

1-2 hours



Materials:

Selection from Character Cards (CC1-CC28)



Steps:

1. Divide participants into pairs and ask each pair to select one character. Ask each pair to make up a story about the character, e.g., what the person does for a living, his/her risk of being infected with HIV, and how the pair would judge the person ("innocent" or "guilty").

2. Ask each pair to place the character on the continuum, and then justify their choice in response to the question, “Why did you put the character at that point in the continuum?” Below are some examples of responses. They are not the required answers, and you are not expected to read them out loud.

Examples of Responses:

Character	Risk	Assumptions	Guilty/ Innocent
Policeman	High	Many partners. Force women and MSM to have sex	Guilty
EW	High	Has sex with many men	Guilty
Singer	High	Assumed to be promiscuous because of her profession	Guilty
Drug user	High	Careless habits/irresponsible, so exposes himself to HIV	Guilty
Businessman	High	Lots of travel away from home, many sex partners	Innocent
Market seller	High	Forced to sell sex to supplement income	Innocent
Housewife	High	Infected by husband. Cannot ask him to use a condom	Innocent
Crippled girl	High	Forced to have sex against her will	Innocent
Doctor	Low	Educated, i.e., knows how to avoid HIV	Innocent
Old man	Low	Not sexually active	Innocent

3. **Ask:** “How will stigma affect these characters? Will it make them more open to dealing with the problem (e.g., getting tested, disclosing status, using health services) or will it make them hide the problem?”

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

- Stigma will make people hide their HIV status or avoid getting tested.
- Even if they know they are positive, they may not tell their partners, and this will result in their partners’ getting infected.

4. **Processing:**

- ➡ What did we learn from this exercise?
- ➡ Why do people judge some people as “guilty” and others as “innocent”?
- ➡ What are the assumptions behind these judgments?
- ➡ If you were shamed like this, how would you feel and how would you behave?



Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Assumptions behind judgments

- People in certain occupations, e.g., EWs, policemen, and female singers are shamed and blamed for being promiscuous, breaking the moral code, bringing shame on their families, spreading HIV, etc.
- Businessmen are innocent because they are just doing what men are expected to do.
- Housewives are viewed as innocent because they have no control over their sexuality. They cannot ask their husbands to use condoms.
- A high-status person, e.g., the male doctor, is assumed to be HIV-negative because of his occupation; he is assumed to be sexually responsible and a role model.

How would this shaming and blaming make you feel and behave?

People who are shamed lose their self-esteem. Because of the fear of stigma, people are not willing to disclose their status to others.

5. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.
- ➡ We make assumptions about other people's behavior based on their occupation, appearance, or behavior. In making these assumptions we often generalize, assuming that each member of that group behaves in that way.
 - ➡ We stigmatize or condemn people without knowing their actual behavior. As human beings, we often believe or assume the worst about other people. But this assumption may be wrong.
 - ➡ We make moral judgments based on the fact that the behavior goes against core values; this is what gives the moral judgment power. We are not saying that the moral values are wrong; we are saying that the judging is wrong.
 - ➡ In Malaysia at the policy level, injecting drug use is being treated like alcoholism, i.e., as a disease. This is helpful because it removes the judging and the moral condemnation: people are regarded as simply having a "condition," rather than having failed morally.
 - ➡ Stigmatizing others through shame and blame is not acceptable. We are all sexual beings. We are all vulnerable, so we should stop judging other people with HIV.
 - ➡ Help to normalize HIV and AIDS. Get people to regard people living with HIV as "people with an illness," and not "people with bad behavior."
 - ➡ It does not matter how the person got HIV. The main thing is to help the person and his/her family manage the illness. Stop speculating on "how he/she got it" and instead focus on what can be done to deal with the condition.
 - ➡ HIV is not morally evil. HIV is an illness and it can be managed.





Facilitator's Notes:

This exercise is used at the start of a workshop to assess people's opinions. The difference of opinion can be used to drive the discussion/debate. The exercise also helps to show that people's views about persons living with HIV are often based on stereotypes or half knowledge, i.e., misconceptions.



Objectives:

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

- ➡ Analyze why different people are judged differently
- ➡ Analyze the assumptions behind our judgments about people living with HIV



Target Group:

Health care providers, NGO and CBO staff, and the community



Time:

1 hour



Materials:

Set of statements written on flipchart sheets and taped on the wall



Statements to write on flipcharts:

- A. Family members should be told when a member tests positive for HIV.
 - B. Health workers have the right to know which of their patients have HIV.
 - C. People living with HIV should eat and sleep separately from the rest of the family.
 - D. If one partner gets AIDS, the other partner should look after him/her.
 - E. HIV is a punishment for bad behavior. People living with HIV have been doing bad things.
 - F. HIV is a disease that only affects entertainment workers and drug users.
 - G. People living with HIV should not be allowed to get married.
 - H. Women who are living with HIV should not be allowed to have children.
 - I. The children of people living with HIV should not be allowed to go to school.
 - J. Drug users should be closely monitored by the community authority.
 - K. Prostitution should be legalized and entertainment workers provided with medical services.
 - L. Drug users should be removed from the general population and put on an island.
- (Add your own statements which are best suited to your context or target group.)



Steps:

1. **Rapid survey:** Ask participants to go to each flipchart and write down their opinion about each statement: "Agree (A)," "Disagree (D)," or "Not sure (NS)."
2. **Tabulate the results:** When participants are finished, record the results for each question, e.g., 15 agree, 10 disagree, 3 not sure.

3. **Plenary discussion:** Take one statement at a time. Ask one person to read the statement and the survey result. Then ask one person who agrees to explain why, and one who disagrees to explain why. Discuss. Then move to the next statement.
4. **Processing:** Ask, “What are the assumptions behind these statements?”


Example of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Statements A, B, C, and I are based on fear and lack of knowledge about HIV and AIDS: these statements assume that other people can get infected through casual contact with people living with HIV.

Statements E, F, and L involve social stigmatizing: people living with HIV or other stigmatized groups are blamed and shamed for certain behaviors.

5. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.
 - ➡ We are socialized or conditioned to judge other people based on assumptions about their behavior.
 - ➡ EWs, MSM, and drug users are regarded as breaking social norms, so they are viewed as morally evil and deserving of condemnation by society.
 - ➡ Many people assume that people living with HIV are former drug addicts or sex workers, so they also face the same social disapproval and shame. As humans we often believe or assume the worst about other people.

- 
- ➔ HIV is now affecting the general population, not just high risk groups. So we cannot continue to blame EWs and drug users as if they are the only people with HIV; they are only a small fraction of persons living with HIV.
 - ➔ Social stigma or “blaming and shaming” hurts! These words are very strong and insulting. They have tremendous power to hurt, humiliate, and destroy people’s self-esteem.
 - ➔ Stigmatizing others through “shame and blame” is not acceptable. We are all at risk of getting HIV, so we should stop judging other people. We are all sexual beings. We are all vulnerable.
 - ➔ We should stop blaming people living with HIV for “bad or shameful behavior.” We should look at people living with HIV as people with an illness, not people with bad behavior.
 - ➔ We are not saying that EWs, MSM, or drug users are right or wrong. We are saying that even if you disagree with someone’s behavior, you do not have the right to judge or belittle them. We should treat them as human beings, and allow them their humanity. To stigmatize is to wipe out their humanity and treat them as having no value. Try to put yourself in the shoes of the other person: how would you feel if you were called these stigmatizing names? Even if you do not like the person, understand and respect him or her.
 - ➔ So how should we treat people living with HIV? Give them respect and support. If we treat people living with HIV well, they will keep their self-esteem and this will help them to live a long life. But if we treat them badly, they will die quickly – not from the illness, but from the shame, the isolation and rejection they feel. And if we treat them badly, they will remain quiet, and this can result in HIV being passed to others.
 - ➔ We need to recognize that people living with HIV have rights, e.g., rights to have sex, get married, have children, have work, and have friends. Even if they have HIV their life has not come to a stop; they still have human rights and the capacity to make decisions.



Objectives:

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

- ➡ Analyze why there is so much concern about promiscuity
- ➡ Recognize how they sometimes judge others



Target Group:

All groups



Time:

1-2 hours



Steps:

1. **Definition:** Do a quick brainstorm and record points on flipchart. Ask, “What do you think of when you hear the word ‘promiscuous’?”.

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Why is it difficult to talk about sexual intercourse?

Irresponsible. Adulterous. Unfaithful. Disloyal. Prostitutes. Many partners. Sex is a game for them. Dangerous. Chasing AIDS. Sinner. No morals. Enjoy sex too much. Sex mad. Someone else – not me!



Based on their answers, summarize the discussion using some of the points from the summary below.

2. Gender difference (discussion): In gender groups, brainstorm about:

- ➡ What do you call a man who has many sexual partners?
- ➡ What do you call a woman who has many sexual partners?

Male Character	Female Character
A real man. Testing his manhood.	Prostitute. Sex crazy. Sinner. Chasing AIDS. Marriage-breaker.

3. Report back. Then discuss:

- ➡ Why are the judgments on women harsher than on men?
- ➡ Do women get blamed more than men if they are HIV-positive?
- ➡ Who decides whether someone is promiscuous?
- ➡ Who gets stigmatized because of their sexuality? Why?

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

More words in the women's list. The words about women are stronger and more insulting; whereas the men's words are less judgmental and even positive. The way in which sexually active women are judged leads to the blame and stigma if they get HIV.

4. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.
- ➡ Everyone's idea of promiscuous will be different, according to their beliefs.
 - ➡ Who judges who is promiscuous? How many past partners make you into a promiscuous person? Yet this word is heard a lot in terms of HIV, with many assumptions made about its meaning.
 - ➡ One definition of promiscuity could be: "Promiscuous just means that you have slept with one more person than me."
 - ➡ People living with HIV are often labelled promiscuous, although you can engage in sex just once with one HIV-positive person to become infected with HIV.





Objectives:

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

- Identify stigma at different stages in a man's and woman's life cycle
- Recognize how women face far more stigma than men, and how this increases their vulnerability to HIV and AIDS



Target Group:

All groups



Time:




1-2 hours




Steps:

1. **Life cycle:** Divide into four groups: two groups to look at stigma at different points in a man's life, and two groups to look at stigma at different points in a woman's life.



Stage	Woman	Man
Birth 	<p>If the baby is a girl, parents feel very unlucky. Their first choice is a boy.</p>	<p>Parents are happy and proud with a male child. Maintains family line.</p>
Childhood 	<p>Allowed to attend school, but after school given many family chores.</p>	<p>No housework. After school, plays with friends.</p>
Teenage/Puberty 	<p>Treated as a “time bomb” (treated as if it is only a matter of time before she brings trouble to the family or to herself). If she gets pregnant, or plays around with boys, she brings shame to the family. Seen as burden by parents; they want to get rid of her by getting her married.</p>	<p>Parents are worried that their boy may become addicted to drugs. If he does, his parents will beat him for ruining family honour and reputation.</p>

Stage	Woman	Man
Adulthood 	<p>When she gets married, pressure on family is reduced because parents are no longer responsible for her. If she does not get married, she is pitied: people say something is wrong with her, call her an "old girl."</p> <p>If she has no children, stigmatized as "barren;" if the baby is a girl, she will be blamed; if daughter has a poor marriage, she is blamed.</p> <p>If she gets divorced, she is blamed as person who killed the marriage.</p> <p>It is hard for a woman to find a job, because she is seen as less capable and not serious about full-time work. Assumed that she will have children and drop out of the work force.</p>	<p>If he gets work, earns money, and looks after his parents and family, his parents will respect him. It is acceptable for a man to go out with his friends, but he is stigmatized if he becomes a drug user.</p> <p>Acceptable for a husband to have sex with other women (e.g., when travelling); he is just "doing what men are expected to do." If he gets HIV, he is stigmatized by the community.</p>

2. **Report back:** Ask the groups to display their flipchart reports and compare the life cycles for women and men. Get agreement on the points made by all groups.

3. **Processing:**

- ➡ What are the differences between men's and women's life cycles? Why?
- ➡ Why do women face more stigma than men?
- ➡ How does this make women more vulnerable to getting HIV and AIDS?



Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Differences between men's and women's life cycles: A double standard

Women are stigmatized from the day they are born to the day they die.

- Girls are stigmatized for being born, being a burden, being a "time bomb" etc.
- Boys are regarded as a sign of good luck and are given special treatment.
- Girls are given housework, while boys are allowed to play with their friends.
- Girls are controlled through restrictions, while boys are given more freedom.
- Teenage boys and girls are treated as 'time bombs': e.g., the boy could become addicted to drugs; the girl could become pregnant or a sex worker.
- Girls are regarded as a burden and married off as quickly as possible.
- Women are stigmatized for everything: having no children, having female babies, not raising her children properly.
- It is acceptable for husbands to have sex with other women (if the men are away from home). The wife, however, is expected to have sex only with her husband.

Why do women face more stigma than men?

Male dominance. Cultural attitudes, especially lack of respect for women. Women are stigmatized as inferior, "bad luck," "a burden." Poverty. Unemployment.

How does this make women more vulnerable to getting HIV?

- Because of the fear of being stigmatized, women who suspect they may have HIV hide their symptoms and avoid getting tested. If they are not tested, they cannot access HIV services, so they cannot get treatment or counseling.

Examples of Responses:

- For the same reasons, women avoid disclosing their HIV-positive status to their husbands/partners. This increases the chances of HIV spreading.
- Because they fear violence, women who suspect their husbands are sexually promiscuous cannot ask them to practice safe sex (use a condom). This increases their vulnerability to getting HIV.

4. **Then add HIV to the discussion.** Ask, “What happens when HIV enters the picture? How does HIV stigma affect men and women?”

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Effects of HIV stigma on women and men

- If a married woman gets HIV, people assume she got it from her husband, so she is treated as a victim or “innocent” and receives some sympathy. But she is shunned and isolated out of fear that she will infect others (fear-based stigma, not “shame and blame” stigma).
- If a woman gets HIV as a sex worker, she will suffer both fear-based and “shame and blame” stigmas.
- If the woman is single and “playful,” it is assumed she got HIV from “bad behavior.”



Examples of Responses:

- If the husband is the first to show signs of HIV, the wife is expected to remain quiet, stay in the marriage and care for her husband. If the wife is the first to get diagnosed with HIV, the husband is likely to abandon her (often under pressure from the family).
- Men are assumed to get HIV from “bad behavior” (drug use or having sex with entertainment workers).
- Stigma has a huge impact on women, because of their close relationships with the neighbors. When a family member gets HIV, the whole family is stigmatized and isolated (out of fear) and this is like a death sentence for women. They want to keep their relationships with neighbors so they try to hide the HIV.

Who Is Blamed for Bringing HIV Home?



Facilitator's Notes:

This exercise is designed to show how women are more stigmatized than men. It should be used after the Life Cycle Exercise (C6), which identifies all the different forms of stigma faced by women.



Objectives:

By the end of the session, participants will be able to recognize that women are often more heavily stigmatized than men, and that the different layers of stigma they already face as women increase the impact of HIV on their lives.



Target Group:

All groups



Time:

1 hour



Steps:

1. **Layers of stigma (brainstorm):** Ask participants to brainstorm the layers of stigma faced by women. Record each layer on a card and tape on the wall.

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Layers of stigma experienced by women:

Being a woman is viewed as inferior. Being a “time bomb.” Being a burden on the family. Not getting married. Having no children (assumed it is woman’s fault).

Bad luck when she gets pregnant. Having girl children. Not raising children properly (e.g., blamed if son becomes a drug user). Not safeguarding family’s health (e.g., allowing HIV to infect family). Not treated as a serious or long-term worker.

Ask, “What is the effect of this stigma on women?”

2. **Who gets blamed for bringing HIV home? (story):** Ask participants to read and discuss the following story.



In the second year of their marriage Davi got pregnant. She went to the clinic for a check-up, was given a blood test, and found out she was HIV-positive. This was a shock. This was when she first discovered that her husband Thom was HIV-positive and a drug user before they got married. The clinic reported Davi’s status to her parents-in-law, who accused her of getting HIV through sexual relations before getting married and blamed her for infecting Thom. The father-in-law threatened to kick her out of the house, but the mother-in-law asked her to stay and look after Thom. Thom remained silent. He did nothing to defend her, but he did not chase her away. Thom got sicker and sicker and developed diarrhea and a serious cough. The

wife cared for him, even though she was sick herself. When he died, his parents kicked her out of the house.

- ➡ What happened in the story?
- ➡ Why was Davi blamed by her mother-in-law?
- ➡ What happens when AIDS enters the home? Who is more likely to get blamed, the wife or the husband? Why?

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

- **Stigma:** Families blame and reject members out of fear and moral views.
- **Women are the first to be blamed** and verbally abused for “bringing HIV home.”
- **Double standard:** If the wife gets HIV, she is kicked out. If the husband gets HIV, the marriage stands, and the wife is expected to care for him.
- **Women carry the heavy burden** of caring for HIV-positive family members.

3. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

- ➡ Women, who are already stigmatized as women, are more vulnerable to HIV stigma. They are more likely to be blamed for “bringing HIV into the household,” even if the husband has shown the first signs of illness.



- ➔ Women are often the first to get tested, since they use health services more than men and are tested when they are pregnant. As a result women often find that they are HIV- positive first and get blamed for “bringing the virus home.” However, in reality most women get the virus from their husbands or partners.
- ➔ When women find they are HIV-positive, they are often chased from the house, sent back to their own family, or abandoned when sick. They are also vulnerable to the violence that follows HIV and the poverty resulting from divorce.
- ➔ Blaming a partner for “bringing HIV home” does not promote the understanding needed to deal with HIV. As one person put it: “I got the virus from a woman, who got it from a man, who got it from a woman, who got it from a man, who got it from a woman.” The list is endless and shows it does not help to focus on “who brought it home.” The point is that HIV is here, and we must live with it positively.



Facilitator's Notes:

Sexuality is a taboo subject; particularly taboo is talking about sex that is considered "immoral" or "abnormal," and goes against traditionally sanctioned sexual practices. Our views about what is "appropriate" sex, or the views of the majority of society about what is proper sexual behavior, leads to a lack of social acceptance of people who do not conform to these views. The result is stigma against anyone who breaks these norms. This chapter will deal with sex, our beliefs about sex, and how these beliefs lead to stigma towards people living with HIV. Therefore, we need to help participants talk openly about sex. These exercises help to achieve this objective.

Use these activities on the second or third day of the workshop when participants are comfortable with each other and feel free to talk together.



Objectives

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

- ➡ talk more openly about sex and their feelings about "proper" and "improper or immoral" sex
- ➡ recognize that our unquestioned beliefs about what is "acceptable" or "proper" sex can be one of the root causes of stigma towards people living with HIV



Target Group:

All groups

Activities to talk about sex: In this exercise we are providing three different activities to get participants talking about sex:

Activity A: First thoughts about sex

Activity B: Anonymous participatory sex survey

Activity C: Why do men and women have sex?

Activity D: Breaking the sex taboo



Choose Activity A or B or C, or do them all, if you have enough time. Use the summary points which are given at the end of the exercise to help conclude each activity. After completing these activities, use Activity D to bring out what participants learned from Activity A, B, or C.

Activity A: First thoughts about sex

- ➡ Write the word “sexual intercourse” in the center of a blank flipchart sheet and ask, “What are your first thoughts when you hear the word ‘sexual intercourse’?”
- ➡ Record all responses on the flipchart.
- ➡ Then discuss three questions:
 - Why is it difficult to talk about sexual intercourse?
 - What are the social norms around sexual intercourse?
 - What does this tell us about stigma?

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

First thoughts when we hear the words “sexual intercourse”:

Fun. Exciting. Pleasure. Pain. Exercise. Love. Shame. Sin. Dirty. Embarrassing. Aroused. Feelings. Having babies. Fear of HIV. Condoms. Man and woman. Man and man. Rape. Violence.

Why is it difficult to talk about sexual intercourse?

Sex is a secret. Sex is a taboo subject. Sex is shameful. The word is insulting. Khmer cultural norms do not allow people to talk publicly about sex. If we do, others will stigmatize or blame us.

Examples of Responses:**Social norms around sexual intercourse:**

- Sex is acceptable only if it is between man and woman.
- Sex is only acceptable between people who are married and with the aim of producing babies.
- Good women do not say they enjoy sex; if they did, they would be stigmatized (shamed).
- Men/husbands decide when and how to have sex. Wife doesn't have a choice; she must have sex. If she says no, this will lead to violence. She does not initiate sex.

What does this tell us about stigma?

It is assumed that people living with HIV have been practicing immoral sex, so they are stigmatized.

Activity B: Anonymous participatory sex survey

- ➡ You need two people to run this exercise: one facilitator at the front of the room to read the questions, and the other facilitator at the back of the room to collect the answer slips and quickly record the results on a flipchart. The flipchart should be positioned so that the participants cannot see the answers during the survey.
- ➡ Explain that the survey is anonymous, i.e., no one will know who answered what
- ➡ Hand out nine slips of paper to each participant.
- ➡ Ask each question and tell participants to record their answer on a slip of paper and fold it up. Collect the slips after each question and record the results on a flipchart. Do not present these results until all the questions have been asked.
- ➡ Present and discuss the results. Then ask, "How did you feel answering the questions? What did you learn from the exercise?"



Examples & Question and Results	Yes	No	Total
Can you talk about sex openly with close friends?	16	8	24
Do you enjoy sex?	20	4	24
Have you ever used drugs or alcohol to make you feel sexy?	12	12	24
Have you ever participated in oral sex?	14	10	24
Have you ever participated in anal sex?	6	18	24
Do you have a friend who is an EW?	12	12	24
Have you ever taken an HIV test?	18	6	24
Did you use a condom the last time you had sex?	20	4	24
Have you ever paid for sex?	8	16	24

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

What did you learn from the exercise?

- The survey helped us reveal our own sexual experience without embarrassment.
- It was easier because it was anonymous. People were laughing, so it loosened people up.
- Most men can talk easily about sex, but most women feel uncomfortable talking about sex.

Activity C: Why do men and women have sex?

- ➡ Put up two flipcharts on the wall, entitled: (a) Why men have sex, and (b) Why women have sex.
- ➡ Divide into two groups: men in one group, women in the other. Ask groups to write on their flipchart their reasons for having sex.
- ➡ Once the groups have finished, ask one person from each group to read the points.
- ➡ Then compare and discuss the flipchart products:
 - What are the similarities? What are the differences?
 - What did we learn from this exercise?

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Why men have sex:

Fun/pleasure. Have orgasm. It is human nature. Have children. Prove he is a man. Love. Exercise. Make partner happy. Explore woman's body. Relieve stress. Relieve boredom.

Why women have sex:

Pleasure. Have orgasm. Human nature. Have children. Love. Find and keep partner. Relieve stress. Keep relationship. For sake of family. Give comfort to partner. Make money. Forced to have sex.





Examples of Responses:

Similarities: Fun/pleasure. Have orgasm. Human nature. Love. Relieve stress.

Differences: Women give comfort to partner. Find partner. Make money. Forced to have sex.

What did we learn from this exercise?

- There are differences, but there are many common reasons for having sex.
- Women often have sex to get something (e.g., money, partner); men to show they have power.
- Poverty and economic hardship forces entertainment workers to sell sex. Many sex workers do not want to do sex work, but they do it out of poverty or under force.

Activity D: Breaking the sex taboo

Note: This activity should be done as a follow-up to one or more of the previous ice-breakers.

Discuss as a large group: Ask, “Why is it difficult to talk about sex?” Record the participants’ responses on flipchart paper.

Why is it difficult to talk about sex?

- We never talk about sex publicly, unless we are making a joke about it.
- Parents (or teachers) find it hard to talk about sex with their children (or students).
- Service providers find it difficult to talk about sex with their clients.
- Sexual partners (including married couples) often do not talk about sex.
- Partners who have not disclosed their HIV status to each other may find it difficult to talk about safe sex.
- Sex is something positive, not negative, yet we use it to stigmatize others.
- We assume that others are having more sex than we are, or are "promiscuous."
- Information about others' sexuality – "promiscuity" – can be used to stigmatize.
- We judge others on the basis of how much sex we assume they are having.
- We stigmatize people living with HIV or sexual minorities. We assume they are engaged in immoral sex.
- Religion presents a big barrier. Churches often say that sex equals sin.

Summary: Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

- ➡ Discussing sex is a taboo. We have been socialized not to talk about sex, especially in our families, between generations, and even between husband and wife.
- ➡ HIV is about sex (as well as drug use), so if we are to control this epidemic, we have to become better at talking about sex, and learning to talk about sex in a non-judgmental way.
- ➡ Our views about the sexual practices of marginalized groups, such as EWs or MSM, are a major factor in stigma. We judge or stigmatize others because of their sexuality: for breaking the moral code by engaging in "immoral sex" (same sex, oral sex, anal sex, sex for money).





Objectives:

By the end of this session, participants will be able to analyze why condoms are stigmatized and to develop ways to challenge this stigma.



Target Group:

All groups



Time:

1 hour



Materials:

Package of condoms



Steps:

1. **Why are condoms stigmatized? (cardstorm):** Pass condoms around the group and then tape one condom on the wall. Divide into pairs and ask, “Why are condoms stigmatized?” Ask pairs to write their points on cards and tape on the wall.



Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Why are condoms stigmatized?

- Condoms are associated with entertainment workers or sex outside marriage.
- If anyone has a condom he/she is assumed to be doing something immoral/sinful.
- Condoms are, therefore, viewed as something bad or evil or shameful.

2. **Learning about condoms (demonstration):** Show participants how to use a condom correctly and get everyone involved. Then get participants to practice this skill. Then ask, "How did you feel about handling a condom?"

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

How did you feel about handling a condom?

I felt bad. Uncomfortable. Embarrassed. Ashamed. I've never done it before. At first we used the brand names ("Trust," "OK," "Yes"), not the word "condom."

3. **How to challenge the stigma (role-playing):** Divide participants into small groups and hand out the role-play scenarios below. Ask groups to prepare a role-play, i.e., to act out the situation and then show how the characters handled the situation.

Role-Play A: A mother asks her son to give her something that is in his pocket. As he reaches into his pocket, a packet of condoms falls out.

Role-Play B: A young man and young woman are talking about having sex for the first time. The young woman brings out a packet of condoms.

Role-Play C: A wife finds a condom in her husband's suitcase, just before he leaves on a business trip.

Role-Play C: Two male friends chat about HIV and AIDS in their country. One starts to discuss the importance of using condoms.

Role-Play D: A group of young women are chatting together at home. One girl is very religious. One brings out a packet of condoms to show the others.

Role-Play E: A husband and wife have recently tested HIV-positive. They discuss their future. The husband brings out a packet of condoms.

4. **Discuss:**

- ➡ How can we challenge the stigma around condoms?
- ➡ How can we promote the idea that using condoms is being responsible?

5. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

- ➡ Condoms are associated with “promiscuous sex” so they are seen as something evil. If someone has a condom, it is assumed that he or she is doing something bad.



- ➔ If a wife finds a condom in her husband's pocket or suitcase, she assumes he is having sex with another woman. If the wife asks her husband to use a condom, the husband would think that she does not trust him.
- ➔ If an unmarried girl is found with a condom, it is assumed she is an entertainment worker.
- ➔ The police use the number of condoms as an indicator of sex work and raid hotels where they find lots of condoms.
- ➔ We need to change our attitude to condoms and attach a positive message to them, i.e., if people use condoms, they are being responsible. EWs who use condoms should be seen as responsible and rewarded, not penalized.
- ➔ Using a condom is not a way of saying you do not trust your partner. It is a way to tell your partner that you respect and want to protect him or her. It is also a way for men and women to protect their own health. Everyone has a right to be healthy and a responsibility to protect their partner(s) from infection.

Optional activity: Organize a debate on the topic: "If a wife finds a condom in her husband's suitcase, is this acceptable or not?"



Facilitator's Notes:

This is a good introductory exercise. It is not designed for use with people living with HIV or drug users. The exercise is simple and starts the conversation about drug users. The idea is to encourage people to share their first thoughts about these issues, before we get into a detailed discussion.

The wording is: "What does the community think about drug users?" and not: "What do you think?" The aim at this point is not to personalize, but simply to get people talking about the views in the community. Later, we will draw out participants' own views. At this stage we do not want to put them on the spot, although they will be giving their own opinions.



Objectives:

By the end of this session, participants will be able to name their thoughts and feelings about drug users.



Target Group:

All Health care providers, police, NGO, and CBO staff, and the community



Time:

30-45 minutes



Steps:

1. **Buzz groups:** Divide participants into pairs and ask the following questions, one at a time. Get a quick report back at the end of each "buzz."
 - ➡ What do people think when they hear the term "drug user?"
 - ➡ What do people say about drug users?



- ➡ How do people treat drug users?
- ➡ What are people's biggest fears about drug users?

During the report back, ask follow-up questions about the reasons behind people's responses.

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

What do people think when they hear the term "drug user?"

Who are they? How did they become addicted? Why are they using drugs? What drugs do they use? What has the family done to prevent them getting into drugs? Fear. They are dangerous – keep them at a distance. Do not be seduced by them. Sympathy for their parents. Hope they can stop using drugs.

Follow-up questions:

Why fear? They may rob me to get money or seduce other youth into drugs.

Why keep a distance? Afraid they may have HIV and transmit HIV to me.

Why sympathy for parents? Because drug users waste family's money.

What do people say about drug users? (ask for words or terms)

AIDS guy. Junkies. Addicts. Sick guys. Dangerous. Criminals. Thieves. Scum. Useless. Immoral. Out of control. Lazy. Jobless. Deserve to die. Brown fairy (color of opium).

Follow-up questions:

How do people feel about drug users? Why do people look down on them?

Those who know it is bad and still do it are condemned. Bring hardship on family and community. Those who are addicted by accident are pitied, e.g., one man

Examples of Responses:

was injected by his brother while sleeping and became addicted. Pity for the fact that most drug users are young; the whole future generation ruined and their lives wasted, cut off from their families.

How do people treat drug users?

- Families use hard and soft methods to get them to stop drugs: they cry, beg, shout at them. Keep them prisoners to get them to quit drugs, e.g., locked in a room.
- Closely supervise them to prevent them from using drugs or stealing family property.
- Give up on them and kick them out of the house.
- Older people try to talk with them to get them to stop drug use.
- Prevent them from playing with or influencing children.
- At the workplace and in the street, people avoid them, or keep them at a distance.

Follow-up question: What is the effect on the family?

- Shame, anger, tension and conflict. Mother under lots of stress.
- Mother hides from the father the fact that her son is using drugs. She may even give money to her son (for drugs) without telling her husband.
- Some families want their sons who are drug users to die as soon as possible. They are tired of dealing with the problem, having property stolen, and having their life collapse.
- They feel their sons deserve to be punished. Everyone blames the family.
- They feel the only approach for dealing with drug addiction is a harsh one: punishment.



Examples of Responses:

What are people's biggest fears about drug users?

Violence and crime to feed their drug habit. Fear they will become aggressive and threaten people when they crave drugs. Fear that they will influence children to become drug users. Spread HIV. Family fears drug user will steal and will ruin family's reputation.

2. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.
 - ➡ People have many negative feelings and words about drug users.
 - ➡ These negative attitudes towards drug users constitute another form of stigma.
 - ➡ Stigma takes the form of judging and social isolation. Drug users are isolated out of social fear about their violence and criminal behavior (e.g., theft) and their potential influence on others (e.g., encouraging others to become addicted).
 - ➡ Addiction to drugs is viewed as morally evil because it is assumed this behavior destroys the stability and happiness of the family and has a negative influence on young people, who are the next generation.
 - ➡ People have lots of questions about drug use. This shows they want to understand why and how people use drugs.

C11

Naming Drug User Stigma in Different Contexts



Facilitator's Notes:

This exercise gets participants, working in groups, to identify the stigma of drug use in different places. Because there are six topic groups this exercise works well in a workshop with many participants. It also works well in the afternoons: The dramas prepared by the groups bring fresh energy to the group at a time when some participants may be dozing.

This exercise is designed primarily for health care providers, NGO and CBO staff, the police, and the community. They may not be aware of these examples of stigma so you may want to invite a few drug users to join the session and help the health care providers, police, and community identify examples of stigma in different places.



Objectives:

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

- ➡ Identify forms of drug use stigma in different places and how it affects drug users
- ➡ Begin to identify some of the root causes of stigma



Target Group:

Health care providers, police, NGO and CBO staff, and the community



Time:

1-2 hours



Preparation:

Tape place cards on walls of the room - family, community, health facility, workplace, market, and self-stigma. Next to each card, tape a sheet from the flipchart.



Steps:

1. **Topic groups:** Divide into six groups and assign each group to one of the place cards. Ask groups to:
 - ➡ Identify forms of drug use stigma that occur in that place, and write on flipchart
 - ➡ Create a role play to show how the stigma occurs

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Forms of drug use stigma

Family

- Suspicion. Close observation of the drug user. Checking to make sure he/she is not using drugs or stealing.
- Family want to protect their reputation so they try to hide the fact of drug use from neighbors
- Some drug users are kicked out of the house.
- Family at first tries to get the drug user to change, but after trying and failing they ignore the drug user. Give up on him/her.
- Drug user's family members are treated as useless and no longer able to contribute to the family.
- Verbal abuse, belittling and blame, e.g., "Why did you bring shame on the family?"
- Giving up on him/her. Telling the drug user he/she is no longer part of the family.

Examples of Responses:**Community and neighbors**

- Isolation. Name calling. Finger pointing. Whispering. Negative gossip. Angry or pitying looks.
- Neighbors try to avoid the drug user. When they meet him/her on the street, they turn away.
- Fear that the drug user may influence their children to take up drugs like him/her; do not allow their children to play with children from drug user's family.
- Avoid contact. Stop or reduce visits to the family. Stop sharing food and lending money.
- Condemn or blame the family for not raising the drug-using child properly.

Health facilities

- Health workers are suspicious of anyone who has AIDS symptoms for fear of getting infected.
- Complain about drug users' behavior of bringing drug-use equipment, like injection needles, into health facility and using drugs. Creates feelings of insecurity. See drug users as aggressive, so feel it is best to avoid them. See drug users as daring, reckless persons who may stab someone with needle.
- Some staff refuse to treat drug user patients. They try to pass on treatment to other staff.
- Breach of confidentiality, e.g., hospital staff reveal drug user's HIV status to other staff and patients. Whispering. Gossip.

Workplace

- Suspicion and gossip. Close observation of someone suspected to be a drug user.
- Some companies have compulsory blood test to determine who is taking drugs.
- If a manager discovers that a worker is an addict, he is fired.

2. **Report back:** Ask each group to present their flipchart report and the role-play. After each role-play, discuss: "What happened? Why? What are the attitudes?"

3. **Processing:** After the role-plays, discuss the following questions:

- ➡ What are the common features of stigma across the different places?
- ➡ What are the effects on drug users who have been stigmatized?

4. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

- ➡ Stigma is everywhere: in homes, communities, clinics, workplaces, markets
- ➡ Stigma takes two major forms: social isolation and judging:
 - social isolation: drug users are isolated out of fear of violence or of their influence on others (i.e., drawing other young people into drugs)
 - judging: drug users are condemned for their "immoral" behavior. Drug addiction is viewed as "immoral" because it destroys the stability and happiness of the family; and has a negative influence on young people
- ➡ In addition, stigma takes the form of:
 - self-stigma: drug users blaming and isolating themselves
 - secondary stigma: the wives and families of drug users being stigmatized
 - layers of stigma: someone who is both a drug user and HIV-positive experiences a double stigma, for being an drug user, and also for having HIV. Women drug users may face three layers of stigma: the first for being a woman, the second for taking drugs and potentially a third for living with HIV.
- ➡ Stigmatizing beliefs or attitudes lead to discrimination and unfair treatment of drug users, e.g., worker fired or a young man kicked out of the family's house.
- ➡ Drug users are often stigmatized by their own families and community. The resulting rejection affects how they manage their health, e.g., they become careless in their drug use, sharing needles rather than getting clean needles and thereby increasing their risk of contracting HIV.



Facilitator's Notes:

This exercise looks at how stigma affects drug users, and how drug user stigma fuels the HIV epidemic.



Objectives

By the end of this session, participants will understand that:

- ➡ It is okay to be angry that drug users do bad things, e.g., steal to get drugs.
- ➡ It is not okay to stigmatize drug users or to treat them as evil people.
- ➡ Stigmatizing drug users fuels the HIV epidemic by making drug users hide their drug use and take less care in using drugs (e.g., sharing needles rather than using clean needles), which exposes them to HIV. When they get HIV, stigma makes them even less careful and they may spread HIV to others with whom they share needles or have sex.



Target Group:

Health care providers, police, NGO and CBO staff, and the community



Time:

1-2 hours



Steps:

1. **Story - discussion:** Read the story below and then ask:
 - ➡ What happened? What are the attitudes of the family in the story?
 - ➡ What was the effect of the stigma on Tola's behavior?



In his fourth year of secondary school Tola started to have problems in school. He lost interest in studies and his marks were poor. He became more interested in music, girls, and motorbikes. His parents tried to get him to change, but he did not listen. He spent all his time with his friends, and eventually he got hooked on drugs. He failed his college entrance exams and dropped out of school.

When Tola's family discovered he was taking drugs, they begged him to stop. They watched him like a hawk and tried to stop him from buying drugs. He listened to them because he still loved and respected them, but the urge was too strong. He stole some things from the house to buy drugs and injecting equipment. When his parents discovered the missing things, they were very angry. They locked him in the house and told him he had to change. His parents felt they had to be tough with him. Every day his father came into the room to shout at him and tell him he was "dirty, useless, a stain on the family reputation." He was chained in his room for a month before his father let him out. Soon after he was released, he found a way to get money and started taking drugs again. When his father found out, he kicked Tola out of the house, saying: "You'll never change. You've already destroyed the family. Get out of our life and never come back!"

Tola left the home, not knowing what to do. His father's words felt like a knife! He felt angry, confused, hurt. He felt his family no longer loved him and had given up on him. He did not want to make his parents suffer. He knew he had to quit drugs, but did not know how. So he went to join his friends, who lived in the street, and they pulled him back into drugs. After a while he forgot about his parents. He did not have the money to buy drugs, so he started to share drugs and needles with his friends.

One year later, Tola became very sick and went to the hospital. They told him he had HIV.

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

What are the attitudes of the family?


- They view drugs and the drug user (Tola) as morally evil.
- They are worried that drugs will destroy the family's reputation and the family economy.
- They feel that a tough approach (punishment) is needed to deal with drug abuse.

What is the effect of these stigmatizing attitudes on Tola?

- Tola is confused and hurt, and his self-respect is destroyed.
- He wants to reform but does not know how.
- Without his family's support, he returns to drugs and a lifestyle on the street, where he resorts to sharing drugs and needles; this activity exposes him to HIV.

2. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

- ➡ Drug use and drug trafficking are bad and should be stopped. But we need to avoid "blaming and shaming" drug users for bad behavior because this stigma has negative effects.
- ➡ We have to stop the form of stigma that condemns drug users as bad people who do not deserve our support. This is what hurts, and this is what forces drug users to hide and isolate themselves, and not seek support. The hardest thing for drug users to accept is the loss of their family's respect and love.

- 
- ➡ We are not saying that the moral values or codes are right or wrong; we are saying that it is wrong for people to condemn others.
 - ➡ Stigma makes drug users feel despised and rejected, so they isolate themselves and stop acting in their own interest. They may start to share drugs and needles, and this puts them at greater risk of getting HIV. Once they get HIV, drug users are doubly stigmatized, and this further affects their ability to care for their own health and others' health. Drug users may hide their status from their partners and may have unprotected sex, and this allows HIV to continue to spread.
 - ➡ If we are to fight HIV, we need to stop calling drug users bad people. In Malaysia at the policy level, injecting drug use is beginning to be treated like alcoholism, as a disease. This is helpful because it removes the judging and the moral condemnation that drug users are simply regarded as having a medical condition, not as having failed morally.
 - ➡ Stigmatizing drug users does not help us to fight drug abuse nor to fight HIV. Instead of stigmatizing those who are already addicted, we should help young people to stay away from drugs and stop the drug traffickers who are making millions out of the drugs.
 - ➡ Instead of stigmatizing and rejecting injecting drug users we need to show care and compassion, so that drug users can lead a healthy life and act in their own and other people's interests (e.g., using clean needles, practicing safe sex). Cambodia has strong traditions of compassion, solidarity, and unity, which should be applied to supporting drug users.
 - ➡ It is justified to be angry and frustrated with drug users, because they do bad things (e.g., steal) as a result of their addiction. Fear and anger have a place, but should not lead to stigma towards drug users, especially from family members. For example, parents should think, "My son is sick, but he needs me, so we need to put our anger aside and take care of him. The past is the past and we cannot change it. We need to focus on the present and help him survive."

- ➔ Research shows that if you put people on the fringe of society, i.e., isolate or shun them, this is a poor strategy to help them to change their behavior. Stigmatizing drug users results in their feeling cut off from the family and the community. This lowers their self-esteem and undermines their ability to take positive action to change their lives.
- ➔ We need to use positive examples of families who have buried their anger and opened their hearts. Drug users who work the hardest to quit the drugs are those who have the love and support of their families.





Facilitator's Notes:

This exercise helps participants think about the impact on the family and the community of a family member becoming addicted to drugs and then getting HIV. Give each group a set of picture cards to make up a family story. This helps to get the group talking.



Objectives:

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

- ➔ Analyze the impact of drug use on the family
- ➔ Explore ways that the community can address these problems



Target Group:

Health care providers, police, NGO and CBO staff, and the community



Time:

2 hours



Materials:

- ➔ Character cards: pictures showing different family members (CC1-CC28)
- ➔ Case studies



Preparations:

- ➔ Make up different family sets with cards, and vary the family composition in each set.
- ➔ In each family, put a small colored dot at the back of one character (indicating drug use). Put dot on a different person in each group: father, mother, teenage boy, teenage girl, etc



Steps:

1. **Story-discussion: What happens when drug use and HIV enter the family (Story-telling):** Divide into groups of three people and give each group a “family” (envelope of cards). Then explain the exercise:

Step 1: Before drug use enters: Make up a story about your family along these lines:

- ➡ How is the family surviving? (e.g., form of income)
- ➡ What are the teenage children doing?
- ➡ How are family relationships? Any problems? (e.g., alcohol, violence, sexual affairs)
- ➡ What are the family’s hopes or plans for the future?

Step 2: Drug use enters family: Ask each group to turn over their cards and find which card has the dot on the back: This family member has become addicted to drugs. Discuss: “What are the major changes in the family resulting from this?”

2. **Report back:** Organize a round robin report back where each group provides one major change in the family.



Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

What are the major changes in the family after drug use has entered it?

- Shaming and blaming the drug user for destroying the family's reputation.
- Scolding, insults, threats, and begging to get drug user to stop taking the drugs.
- Lock up drug user in the house, so he/she does not go out to get drugs
- Give drug user money so he can buy drugs, rather than stealing from neighbors.
- Reduced contact with and hiding the problem from neighbors.
- Once the neighbors know, they isolate and condemn the family.
- Increased family conflicts. The family is no longer happy.
- The wife is blamed by her husband for not raising the boy properly and morally.
- Violence towards the wife by her drug-user husband.
- Children affected: forced to leave school, start to work, etc.

Step 3: HIV enters family: Ask each group to continue the story, adding that the drugusing family member gets HIV. Discuss: "What are the major changes in the family resulting from this?"

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.



Examples of Responses:

What are the major changes in the family resulting from drug user contracting HIV?

- More shaming and blaming towards the person living with HIV for “ruining their lives.”
- Family members fear infection, so they minimize contact with person living with HIV.
- Separate room, food, plates, towels, sheets, etc., provided for person living with HIV
- People living with HIV are prevented from contact with their children.
- Trying to hide the problem from neighbors
- Family disintegration: conflicts, separation, divorce
- If the wife gets HIV, the marriage collapses and she is kicked out. If the husband gets HIV, the marriage stands and the wife is expected to care for him.
- Children further affected: forced to leave school, start to work, etc.
- Women’s workload increases with the burden of caring for HIV-positive family members.

3. **Processing:** Ask, “What are the significant differences between Step 2 and Step 3?”

Examples of Responses:

- Drug use-related stigma includes both fear and social stigma, but the fear is not the fear of infection but the fear of the drug user’s behavior destroying the family.
- HIV stigma in this case adds an extra layer. It adds the fear of infection, and leads to people shunning the person living with HIV.

4. **What can be done? (Problem solving):** Discuss with the whole group:
- ➡ How can families cope better with this situation?
 - ➡ How can the community support families who have a drug user? Families who have a member with HIV and AIDS?

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Family's coping mechanisms

- Stop the "shaming and blaming" of drug use- and HIV-affected family members.
- Stop the isolation of HIV-positive family members.
- Promote a positive attitude: "It's not how he got it, but what we can do now."
- Focus on providing care and emotional support to the drug user and person living with HIV.
- Share the caring work among all family members.
- Help the family deal with the shame that they feel (loss of status).

Community support for families affected by drug use and HIV

- Get the community to name stigma as a problem and work to stop it, i.e., address the fear and lack of knowledge about HIV and its link with social evils.
- Get community leaders to speak out against stigma.
- Get the community to provide support for HIV-affected families.
- Share HIV and AIDS "survival knowledge" among community members.



A red-toned illustration of a family in a room. In the foreground, a young boy looks distressed. Behind him, a man and a woman are visible, with the woman holding a baby. The background shows a window with curtains.

Chapter D

Stigma in the Family and the Community

Introduction

Stigma and caring in the family are closely linked – some forms of stigma are triggered by family members not knowing what to do or how to care for someone who is sick with AIDS. This, coupled with poverty and economic stress, creates frustrations and feelings of being overwhelmed by the duty of care and support. Many family members have little idea how they can best look after family members living with HIV when they get sick.

This is an important area of practical knowledge that people need to learn. Many family members have the basic equipment – the love for their close relatives – but they need other knowledge and skills, e.g., how to provide emotional support effectively, respond to health crises, and share the burden of care. To manage HIV better in the household, people need skills, understanding, compassion, and external support, such as access to free treatment.

In this module, families can explore the challenges of caring for family members living with HIV. With their increased knowledge and sharing, stigma will be reduced. Please note that antiretroviral drugs (ARVs) are mentioned throughout this chapter. ARV treatment is a key treatment for HIV and will be discussed in detail in the final unit of this chapter.



Exercises

- D1. Stigma in the Family (A)
- D2. Stigma in the Family (B)
- D3. Stigma from Neighbors
- D4. Community Support
- D5. People Living with HIV Have Rights Too!
- D6. People Living with HIV Can Lead Long and Full Lives
- D7. Getting Treatment

D1

Stigma in the Family (A)



Objectives:

By the end of this session, participants will be able to identify various forms of stigma in the family.



Target Group:

All groups



Time:

1 hour



Materials:

Pictures GS3, GS4, GS6, GS7, GS8, GS13 taped on the wall



Steps:

1. **Picture-discussion (small groups):** Divide into small groups and ask:
 - ➡ What is happening in the pictures?
 - ➡ What other forms of stigma are practiced by families towards people living with HIV?
 - ➡ Why do families stigmatize their own family members?
 - ➡ How does this affect (i) the family? (ii) the family member living with HIV?



Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Pictures

- GS3: Landlord kicks HIV-affected family out of the house
- GS4: Man sitting all alone on a bed. No one is helping him. He looks very lonely.
- GS6: HIV-positive father is forced to eat apart from the rest of the family.
- GS7: Neighbor visits home. Family hides HIV-positive family member
- GS8: Father returns home to tell wife HIV test result. Worried about the impact
- GS13: Husband kicks wife (who is HIV-positive) out of the house.

Stigma within the family

- Physical isolation.
- Minimum physical contact. No hugging. Told not to touch/play with children
- HIV-positive person is hidden from neighbors so they cannot see him/her and stigmatize the family.
- Person living with HIV is treated as a burden, because extra money needed for additional nutrition needs and treatment
- Judging. Blaming. Condemning.
- Women face violence and/or divorce. In-laws blame wife for bringing HIV to the family.

Why do families stigmatize their own family members?

Fear of infection. Fear that any form of contact will give them HIV.

Shame and blame – assume that the person living with HIV got HIV by doing something bad.

Example of Responses:**Effects on the family**

Shock. Anger. Shame. Worry. Fear of caring for a person living with HIV; fear of infection. Fear of neighbors finding out and stigmatizing the family. Family denial; refuse to accept results. Inaction; do not know what to do. Blaming and shaming. Conflicts within the family. Divorce or separation. Heavy burden on the caregivers (women). Loss of income and money problems. Children dropping out of school.

Effects on person living with HIV

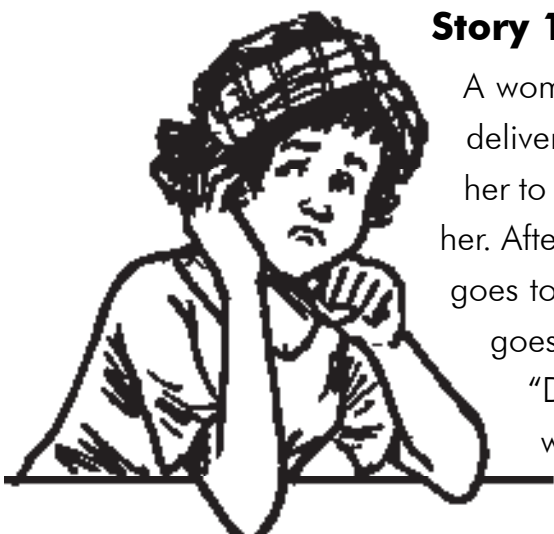
Loss of job, friends, and self-confidence. Become withdrawn and depressed. Worry, isolation, and self-isolation. Feels passive and helpless. No role in family. Treated as if invisible. No longer economically valuable to the family; made to feel useless.

2. How should families care for people living with HIV? (Stories):

Ask participants to read the two stories below:

Story 1:

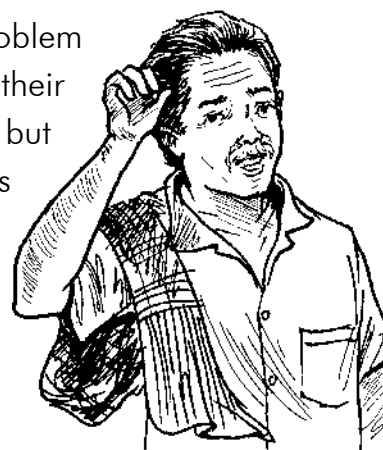
A woman finds out she has HIV when she is at the hospital delivering her baby. When her parents find out, they force her to leave the house. Her parents take her baby away from her. After two years, she misses her daughter so much that she goes to her parents' house to see her. When she arrives, she goes to hug the little girl, but her daughter refuses, saying, "Don't touch me. You are HIV. You will infect me." The woman starts to cry.





Story 2:

A young man finds out he has HIV. At first he hides his problem from his wife and his family, because he is worried about their reaction. One day he learns about ARVs (antiretroviral drugs) but is told they are very costly. He decides to tell his wife, his brother and sister about his status and ask for their help. They are very sad when he tells them, but they are very supportive. They listen to him without judging or blaming. They help him find information about ARVs and offer to help him pay for them. They even go with him to the hospital and ask questions to find out more about ARVs. He had been very skinny and desperate. With the support of his family as well as ARV treatment, he becomes very happy and positive about his life.



3. Discussion:

- What happened in each story? Why?
- What is the difference between the two stories and why?

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Story 1: The woman's family is afraid they will get HIV through contact with her, so they kick her out of the house and take her baby away. Losing her family's support and having them instil the same fear into her daughter hurts the woman terribly. This will have a negative effect on the woman's health.

Story 2: The wife and family have an attitude that is more accepting. They provide active support, e.g., helping to pay for ARVs and find out more about ARVs. Their supportive attitude makes the person living with HIV feel better about himself and his health improves.

4. **Processing:** What practical things can we do as families to support HIV-positive family members?

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

- Chat and spend time with them. Make them feel wanted.
- Encourage them to talk openly about their feelings and listen to them.
- Encourage them to disclose their status when the time is right.
- Encourage friends to visit and help them get to know other people living with HIV.
- Help obtain treatment for opportunistic infections and find out about ARVs.
- Provide good food and nutrition.
- Organize the sharing of “caring work” among all family members.

5. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

The first response of all Cambodian families is to provide care and support to family members who face difficulties. But for people living with HIV, this response is blocked because of stigma – fear of HIV infection and shame about a family member breaking the social norms. Stigma stops the family from providing the care and support they would normally provide.





Objectives:

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

- ➡ Identify how the family would deal with different types of family members
- ➡ Decide what they can do to support family members living with HIV



Target Group:

All groups



Time:

1 hour



Materials:

Individual Profiles – these are included at the end of this chapter.



Steps:

1. **Individual profiles:** Divide into small groups and give each group a number of profiles. Ask them to discuss:
 - ➡ Some of these individuals are already HIV-positive. For those who are not, what would happen if they became HIV-positive?
 - ➡ What can the family do to provide care and support?



Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Story 1:

Family with a son who is an injecting drug user. Parents try everything – threats, force, shaming and blaming, chaining inside house, etc. – to get the boy to stop taking drugs. When he becomes HIV-positive, they take him to hospital. They are afraid he will infect them and think he will die quickly.

Story 2:

Parents are worried their daughter might get pregnant or become an entertainment worker. They do their best to get her to “stop doing bad things” and get a job. When she gets HIV, they keep her at home, and out of sight of the neighbors. They are ashamed.

Strategies for caring and coping with HIV within the family

- Help family members deal with the anger and stigma towards drug use or sex work.
- Do not give up on the person living with HIV. An HIV-positive test result is not a death sentence.
- Help him/her live a longer, healthy life (including use of ARVs).
- Make him/her feel loved, wanted and welcome in the family. Spend time with him/her.
- Educate family members on HIV – help them see there is no reason to fear contact.
- Find out more about ARVs – where to get them, costs, food requirements, etc

Examples of Responses:

- Encourage the person living with HIV to get opportunistic infections treated quickly.
- Provide good food and nutrition.
- Organize the sharing of “caring work” among all family members.
- One mother said: “My son [who has HIV] already has a negative attitude towards life. If we are negative to him, we will have failed him.”

2. Summary: Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

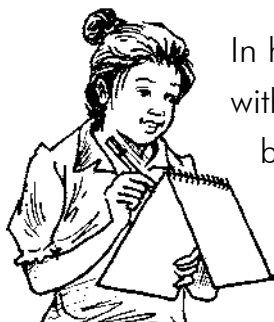
- ➡ Families should not give up on their children, even if they are angry with them. Blood is blood, and we need to focus on providing support for family members who are sick.
- ➡ An HIV-positive test result is not a death sentence. If a person living with HIV lives with a positive attitude (including using ARVs) he/she can live a long time. HIV is a condition that can be managed. It is important to learn caring and coping strategies. Families should focus on providing support. All people living with HIV need support from the family.

Individual Profiles, Story 1

Chakara is a young man who got pulled into drugs by his friends. Once they saw that his friends were having a bad influence on him, his parents tried to break those friendships. But they were unsuccessful and he refused to listen to them. Eventually, the drugs took over his life and he dropped out of school.



Individual Profiles, Story 2



In her fourth year of secondary school, Choum started to have problems with school. She lost interest in her studies and her marks were poor. She became more interested in music, boys and motorbikes. Her parents tried to get her to change, but she did not listen. Eventually, she dropped out of school.

Individual Profiles, Story 3

Sov's parents died of AIDS. The boy was sent to live with his uncle's family. The boy became very depressed and started to do poorly in school. Whenever he came home from school, he left the house and stayed out with his friends until late.



Individual Profiles, Story 4



Nimol comes from a poor working class family. He was in the army, but when he was demobilized he could not find a job. He started to go out with friends and became addicted to drugs. Eventually, he was sent to the drug rehabilitation center. While he was away, his wife left him so he moved back with his parents. He has just learned that he has HIV. He has been trying to give up drugs, but has been unsuccessful.

Individual Profiles, Story 5

Nary was married to Sambath, an injecting drug user. She married him in the hope that this would help him break his drug habit. Later she learned he had HIV. When he died, she returned home to live with her parents. She survives by selling vegetables in the market.

Individual Profiles, Story 6

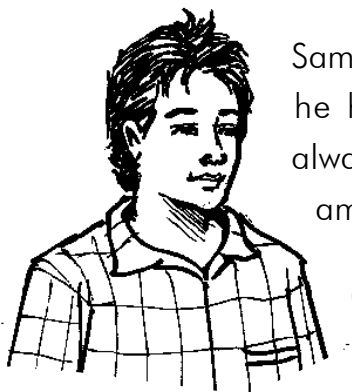
Phirun is a young factory worker. He is not yet married and lives with his parents. Whenever he can, he goes out with his friends to drink beer and gamble.

**Individual Profiles, Story 7**

Rachany worked as an entertainment worker in Phnom Penh. During this period, she had no connection with her parents. After five years, she got HIV and started to become sick. She returned home to her rural village to stay with her parents.



Individual Profiles, Story 8



Samphy is unemployed. He has tried to find work but for two years he has been unsuccessful. He stays with his parents, who are always bothering him about finding work. He tries to minimize the amount of time he stays at home.



Objectives:

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

- ➡ Describe how neighbors stigmatize families who are caring for a person living with HIV
- ➡ Develop strategies on how to address this form of stigma and discrimination



Target Group:

All groups



Time:

1 hour



Steps:

1. **Story:** Ask one participant to read the story below.

A woman babysits to earn some extra money for the family. She has an unmarried son who has HIV. She tries to hide the fact that he has HIV, but the neighbors become suspicious and begin to gossip about him and the family. They say he has been doing bad things and blame her for not raising the boy properly. They stop sending children to her for babysitting, and when she goes to their houses to borrow things, they always refuse. No one wants to lend her money. Women stop visiting and those who do visit refuse to drink her tea. The family becomes very isolated and struggles to survive on the husband's small pension. The mother feels totally isolated and alone.



Discuss:

- ➡ What happened in this story? Why?
- ➡ How do neighbors generally treat households they suspect have HIV? List forms of stigma mentioned in the story.
- ➡ Why do neighbors behave this way?
- ➡ What can we do to prevent stigma towards families living with HIV?

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Examples of forms of stigma towards families living with HIV

- Isolation and rejection. Name-calling. Finger pointing. Gossip. Rumor.
- Stop or reduce visits to family. Refuse to drink tea.
- Do not allow children to play with neighbor's children.
- Stop providing mutual help (e.g., exchanging food, loaning money, etc.).
- Stop hiring the family's services (e.g., babysitting).
- Condemn/blame family for not raising the children properly.

Why do neighbors behave this way?

- Misplaced fear of infection through casual contact
- Misplaced fear of children being infected through contact with family
- Lack of sympathy about family's burden in caring for the person living with HIV
- Feel they are stigmatized through association – the shame affects them



2. **Role-playing:** Divide into two groups of equal sizes – Group A is the family of a person living with HIV; Group B is the neighbors. Organize two short role-plays showing the two groups talking separately.

Family – What are you afraid that the neighbors will say about you?

Neighbors – What are your fears about the family? Why?

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Family

Fear of losing regular contact with our neighbors; fear they are judging us behind our backs. Fear of losing honor. If they ask us about him we say he is fine to stop them from judging us. We discourage people from visiting. If they visit, we keep him in the back room, or we tell them he is sleeping.

Neighbors

Fear our children will get infected so we have stopped our children from playing with theirs.

Family brings shame to the community. Judging – he was doing bad things with his IDU friends. He deserves it. We visit for a while, then at intervals, and finally we stop.

3. **Discuss:**

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



**Facilitator's Notes:**

This exercise is designed to get people talking about how the community can support families living with HIV, without creating more stigma; and why communities do not have a right to know the status of community members.

**Objectives:**

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

- ➡ Identify forms of stigma and discrimination practiced in the community
- ➡ Develop strategies for building community support for HIV-affected families – what organizations can do to help the family without creating more stigma

**Target Group:**

All groups

**Time:**

1 hour

**Steps:**

1. **Community support can trigger stigma (role-play):** Organize the following role-play:

Scene 1:

Family sitting alone. Suddenly, they are visited by a large group from a women's organization, who express their concern and give them lots of things.



Scene 2:

Members of the women's organization leave. Neighbors, who have just discovered that the family has a person living with HIV, begin to gossip about the family.

Discuss:

What happened? How did this visit make the family feel?

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

- The women's organization came with good intentions, but the visit resulted in stigma.
- The family felt invaded – they did not ask for support or help.
- The family felt they were being treated as poor people, as objects of charity. They felt ashamed to be seen as unable to stand on their own feet.
- The family had no say in what was provided.
- They felt angry that the women's organization had shamed them in front of neighbors.

Organize a report back. Discuss "How could the women's organization help without exposing the family to more stigma?"

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

- Meet with the family beforehand, in another place, to find out how to help them.
- Work with and through a local organization of people living with HIV in arranging the meeting.
- Send two or three people to meet with the family. Do not send a big delegation.
- Ask the family to determine areas where they need help, rather than imposing things.
- Advise the family on how they can get support from others.
- Treat them in the way you treat other families. Do not give special treatment.
- Help the family deal with their shame and fear. Promote a positive, non-stigmatizing attitude, as in: "It's not how he got it, but what we can do now."
- Be reassuring; say: "Don't worry – we can do something. People may tell you that your life is over, but ARVs and positive living can help you live a long life."

2. "We have the right to know who is HIV-positive."(Discussion):

Write the following text on the flipchart:

We have the right to know who in the community is HIV-positive. If we do not know who is HIV-positive, we cannot provide support and we cannot protect the community. We should be told.

Discuss: "What do you think of this view? Do you agree?"



3. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.
- ➡ Community organizations often want to be told who in the community has HIV. They feel they need this information to be able to “support the family and protect the community.”
 - ➡ Information about the results of an HIV test should only be given to the individual, his/her spouse, and the doctor and nurse who are treating the patient. No one else should be given this information. Only the person living with HIV can decide who else should be given this information.
 - ➡ If information on the HIV status of all community members were given to community organizations, this would be a denial of people’s human rights. It would make them a target for stigma.
 - ➡ Knowing who has HIV is not a form of protection, because HIV is not spread through the air like tuberculosis (TB), or through ordinary social contact.
 - ➡ Fears of getting HIV are partly based on inaccurate media coverage about people living with HIV. HIV, like cancer, is a chronic manageable disease. People with HIV can live a long life if they take ARVs properly and live positively.

D5

People Living with HIV Have Rights Too!



Facilitator's Notes:

This exercise raises the issue of a person living with HIV being denied their rights as a form of stigma. (For more on rights, see Chapter E, sections 4, 10, and 11.)



Objectives:

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

- ➡ Recognize that people living with HIV have rights and responsibilities just like other people
- ➡ Recognize that the rights of people living with HIV are often denied
- ➡ Decide on how the family and community can reaffirm those rights



Target Group:

All groups



Time:

1 hour



Steps:

1. **Cardstorm:** Divide into pairs and hand out blank cards. Ask pairs to brainstorm a list of rights and responsibilities of people living with HIV, writing one point per card and sticking the cards on the wall under the two categories.

Discuss:

- ➡ Which of these rights do families try to remove? Why?
- ➡ What are the effects on the person living with HIV if these rights are denied?
- ➡ What can be done to reaffirm and reinstate those rights?
- ➡ What are some of the responsibilities that go with these rights?



2. **Role play:** Divide into small groups. Ask each group to select one of the rights and perform a short role-play to demonstrate how this right might be broken.

Discuss:

How can we as families ensure these rights are met?

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Rights

To be respected. To have physical contact. To contribute to family decisions. To have friends. To have food. To have sex. To get pregnant. To have a child. To have medical care. To have clothing. To have shelter. To be clean. To participate in community events.

Responsibilities

Be open to advice. Help out in the house with family chores when you can. Listen to others. Help with earning income when you are well. Practice safe sex.

Rights being violated

People living with HIV expect family members to continue to love them, but out of fear, some families stop all physical contact and stay at a distance. This destroys an HIV-positive person's will to live.

3. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.
- ➡ We need to ensure that people living with HIV are involved in making decisions about their lives, even when they get sick.
 - ➡ People living with HIV need to understand the stresses on a family, which might mean that all their needs cannot be met.
 - ➡ As communities, we can look for ways to support families, which will enable rights and responsibilities to be respected.



People Living with HIV Can Lead Long and Full Lives



Objectives:

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

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



Target Group:

All groups



Time:

1 hour



Materials:

- ➔ Copies of case studies on people living with HIV not being allowed to do things
- ➔ Story: “Life goes on” (2 stories at the end of this chapter)



Steps:

1. **Ask:** What can people living with HIV do to lead long and productive lives?



Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

- Accept their status and accept themselves as they are
- Tell other family members and close friends, and ask for their support
- Maintain close, supportive, loving relationships
- Find out about getting ARVs
- Get treatment for opportunistic infections
- Avoid re-infection and other STIs
- Practice safe sex
- Get good food and nutrition
- Lead an active, healthy, social life
- Avoid depression and maintain a positive, cheerful attitude

2. **Person living with HIV not given chance to contribute:** Divide into groups and give each group one story. Ask groups to read them and answer the questions at the end.

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

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

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

D. Kiri loves football and plays for his local team every week. Recently, he has been sick, but since starting ARV treatment he is beginning to feel better. He turns up for football training one evening, and the coach tells him that he thinks it is better that he does not play since he has been so sick. His place on the team has been given to a younger man.

Discuss:

- ➡ What happened in each of the stories? Why?
- ➡ What does this say about an HIV-positive person's capacity to contribute?

3. "Life goes on" Ask participants to read the stories below.

Discuss:

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



Story 1

A truck driver got sick in 2000 and died in early 2002. When he first became sick, there was lots of gossip by neighbors. People said he acquired HIV on the road. They visited him when he first got sick and then the visiting stopped. The driver's wife, who worked as a tailor in a factory, cared for her husband. She often arrived late at work because of the heavy burden of caregiving, and was subsequently fired. After leaving her job, she set up her own small tailoring business in her house. She loved tailoring and many women came to her for dresses. She then discovered she was HIV-positive. She accepted her situation and did all she could to stay healthy, including ARVs. Although her husband died, her own health improved and she became stronger. She is alive today.

Story 2

Miss M was very unhappy when she learned that her boyfriend was an injecting drug user. She married him to strengthen his courage to give up drugs. Later she learned she had HIV, but she was able to have a child safely. With her family's support she overcame the criticism and went on to raise her children. Each day, she went to the market to sell vegetables and earn money. But her husband was still using drugs. He was arrested and sent to prison for three years. While he was in prison, he died. When she heard the news, she collapsed. Soon after, her own health got worse and she developed AIDS. In spite of all these difficulties, she was determined to live for her daughter. She continued her selling vegetables at the market, but many customers stopped coming. She recognized she needed to do something else. She joined the HIV education team in her area. She disclosed her HIV status and told her life story to other people. She gives speeches in different places and participates in information, education and communication programs to let people know that getting HIV does not mean life comes to an end. Life goes on!

4. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.
- ➡ People living with HIV can live long and productive lives if they are given a chance.
 - ➡ People living with HIV have many skills and can make a big contribution to their families, jobs, and communities.
 - ➡ People living with HIV can live long, productive lives by:
 - Accepting their status and accepting themselves as they are
 - Developing a loving and supportive relationship with family members
 - Telling their partners, family members, and friends about their status
 - Getting treatment for opportunistic infections as early as possible
 - Starting ARV treatment and adhering to the instructions
 - Practicing safe sex to avoid getting additional different strains of HIV into their bodies
 - Eating nutritious food, and avoiding too much alcohol and stress
 - Carrying on working and normal life





Facilitator's Notes:

This exercise introduces opportunistic infections and antiretroviral drugs (ARVs), since many families know little about these subjects. Knowing more makes it easier for families to provide support and care and it helps to break the stigma. Invite a medical expert (someone who knows about ARV treatment) to help you explain the issues and answer participants' questions.



Objectives

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

- ➡ Recognize that many opportunistic infections are curable
- ➡ Identify how to prevent and minimize opportunistic infections
- ➡ Explain some of the basic facts on ARVs



Target Group:

All groups



Time:

2 hours



Materials:

Handouts: Information Sheets (Appendix A) on ARVs, opportunistic infections, and TB



Steps: Presentation by medical expert

1. **Opportunistic infections (cardstorm):** Write the following topics on cards and tape on the front wall:
 - What are some common opportunistic infections faced by people living with HIV?
 - What are some of the symptoms of TB?
 - How can people living with HIV prevent opportunistic infections?
 - What kind of stigma do we face as result of opportunistic infections?

Divide participants into pairs and hand out cards and markers. Ask participants to write answers – one point per card – and tape on wall. Review and clarify points.

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

What are some common opportunistic infections faced by people living with HIV?

TB, diarrhea, pneumonia, bowel infection, fungal infection, skin cancer, Kaposi's sarcoma, candidiasis, herpes zoster, meningitis.

What are some of the symptoms of TB?

Weight loss. Persistent cough. Sharp chest pains. Night sweats. Poor appetite. Decline in immune status.

How can people living with HIV prevent opportunistic infections?

Regular medical check-up. Get treated as soon as symptoms appear. Get enough rest. Good food and nutrition. Good hygiene. TB prevention therapy. Avoid alcohol and smoking. Avoid milk to minimize diarrhea. Avoid sugar to stop fungal infection.

Examples of Responses:

What kind of stigma do people living with HIV face as a result of opportunistic infections?

Stigma increases because of the visible infections such as sores and rashes.

Family worries about what neighbors will say so they try to hide the person living with HIV.

No one wants to sit next to you or share food with you.

People think it is your fault; they say you are not looking after yourself.

People assume you are getting AIDS and will die soon.

2. **ARV treatment (cardstorm):** Hand out cards and markers. Ask participants to write points on the question: “What do you know about ARV treatment?” Ask participants to write one point on each card and tape on the wall.

Cluster common points and then review each point by asking:

- ➡ Do you agree with this point?
- ➡ Any corrections or additions?

Distribute ARV information sheet. Make sure the following issues are covered.

Issues to be covered:

Combination therapy. Different types of drugs. When to start treatment. CD4 and viral load tests. Adherence (right time of day, right number of pills every day). Adverse side effects. Toxicity. Where to get the pills. How much do they cost? Drug resistance (use people’s knowledge of resistance in relation to other illnesses, e.g., chloroquine malaria tablets). Length of treatment.



3. Treatment problems (critical incidents): Divide into small groups and give each group one of the problems listed below. Ask them to role-play the situation to try and find solutions.

- A. A man says to his HIV-positive son, "I'm sorry. We no longer have money to buy medicine." He privately tells his wife, "Why should we waste money on him? He is only going to die! And he caused this problem."
- B. A family goes into debt trying to find a cure for their HIV-positive son, moving back and forth between private doctors and traditional healers.
- C. A patient stops taking his ARV drugs and says he is better.
- D. The father goes to the clinic to get ARVs with his HIV-positive son and quarrels with the health staff because of the way they treat his son.

4. Summary: Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

- ➡ Many families do not have enough information about opportunistic infections, and this can lead to stigmatizing beliefs such as people living with HIV just get sick and die.
- ➡ If families know more about opportunistic infections and ARVs, they can provide better support and care.
- ➡ ARVs are more available these days and can provide HIV-positive people with hope for the future. But people living with HIV have to overcome the fear of being stigmatized to access ARV treatment.
- ➡ Even when ARVs are accessible, people living with HIV may still face problems linked to stigma.



Chapter E

Coping with Stigma

Introduction

In any community initiative that aims to combat stigma, it is important to include strategies for supporting people living with HIV to cope with the effects of stigma. People living with HIV can play a crucial role in identifying the many different types of stigma and raising community awareness about the damage and pain brought on by stigma and discrimination.

This module was written with a team of people living with HIV and is designed for use in HIV-positive support groups or training courses. The aim is to strengthen people living with HIV as individuals so that they can cope with stigma and develop leadership abilities to help and support others. The activities allow people living with HIV to share experiences and strategies, develop communication and assertiveness skills, and build self-esteem.



Exercises

- E1. Strategies for Coping with Stigma
- E2. Stigma and HIV Testing
- E3. Disclosure: Telling Your Family
- E4. HIV and Human Rights
- E5. Being Assertive to Demand Fair Treatment
- E6. Paranoia and Hypersensitivity
- E7. Coping with Depression
- E8. Building Self-Esteem
- E9. Coping with Stress
- E10. "Don'ts" Don't Work!
- E11. "Don't Have Children"

E1

Strategies for Coping with Stigma



Facilitator's Notes:

In this exercise, people living with HIV talk about their own experiences of HIV and stigma and their personal strategies for coping with stigma.



Objectives:

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

- ➔ Share experiences of being stigmatized and discriminated against
- ➔ Assess the effects of these experiences
- ➔ Begin to develop strategies for confronting stigma and discrimination



Target Group:

People living with HIV



Time:

1-2 hours



Steps:

1. Stigma Stories – Individual Reflection: Ask participants to sit on their own and think about “an occasion when you were treated badly by other people because you have HIV.” Allow five minutes of quiet, individual reflection.
2. Divide participants into pairs. Ask pairs to share their experiences of being stigmatized.
3. Bring the whole group back together and invite people to share their stories. This is voluntary.
4. Ask the group to choose one of the stories and role-play it.

5. After the role-play discuss: What happened? How did you feel? What are the root causes of this stigma?
6. Coping strategies (cardstorm): Divide participants into pairs and ask, "What are the personal strategies we use to cope with stigma and discrimination?" Write one strategy per card and tape on the wall. Ask participants to eliminate duplication and cluster cards into common categories.
7. Form small groups and ask groups to select three strategies they think work best and explain why.
8. Ask: "What are some of the ways that we cope with stigma with the help of others? How do we support each other as people living with HIV?" Record points on flipchart.

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Be quiet. Accept our own situation. Ignore people who are stigmatizing us – and do not let it affect us. Avoid situations of stigma. Challenge the stigmatizer. Disclose our status to friends and family so they can be supportive. Work on our own confidence. Talk to friends about experiences of being stigmatized. Join HIV-positive support group. Live positively and do useful work.

9. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise.



Facilitator's Notes:

Going for a test can be the first time that a person living with HIV experiences stigma, or the fear of stigma.



Objectives:

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

- ➡ Share their experience of going for an HIV test
- ➡ Explore ways in which fears of stigma could be tackled at an early stage



Target Group:

People living with HIV



Time:

1 hour



Steps:

1. **Experience of testing (discussion):** Ask participants to share in pairs:
 - ➡ What happened when you went for testing? What was good? What was bad?
 - ➡ What was your biggest fear when you learned you were HIV-positive?
 - ➡ If you could change anything about your experience, what would it be?

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Experience of being tested

- I arrived at the center very scared and they did little to help me deal with my fear.
- There was very little counseling – I didn't feel prepared for the result.
- There was no confidentiality – the information was shared within the staff.

Fears when learning HIV status

Death. All the pain ahead of me. All the uncertainty. What will people say about me? What will I tell my parents? The shaming and blaming. Losing my job, my friends. What will happen to my spouse and children?

2. Processing:

- ➡ How can we help people gain the courage to go for testing?
- ➡ How can we help counselors prepare people better to cope with stigma?

3. Summary:

Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

- ➡ Going for an HIV test may be the first time we encounter stigma (sometimes the stigma associated with even walking into a special clinic can prevent people from testing).
- ➡ As people who have gone through the process, we can advise the voluntary and confidential counselling and testing (VCCT) staff how to better support their clients and prepare them to cope with stigma.



Facilitator's Notes:

This exercise explores the issues of disclosure.



Objectives:

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

- ➡ Share experiences about disclosing their status to family members
- ➡ Develop skills and strategies for disclosing to family members



Target Group:

People living with HIV



Time:

1 hour



Steps:

1. **Fears about disclosure:** Ask participants to share in pairs: "What are your fears about telling your spouse/partner, family members, or friends?"

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Fears about disclosure

They may reject me. Fear of violence. Loss of financial and moral support. People may use this information against me. Gossip. Family members giving up on me, thinking that I will die immediately. Shaming me about my past behavior.

2. Experience of telling family members: In the same pairs share:

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

3. Practicing how to disclose (paired role-playing): This exercise is designed to give people living with HIV practice in disclosing to family members.

Discuss in pairs:

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

Ask each person to prioritize the people on his/her list according to:

- Important but difficult to tell – and why
- Less important but difficult to tell – and why
- Important but easy to tell
- Less important but easy to tell

Example List		
	Difficult to tell	Easy to tell
Important	father	mother
Less important	uncle	brother

Then explain that in the next exercise, participants should practice how to disclose to the “important but difficult to tell” person.

4. Role-play:

Divide into pairs. Each pair decides who is disclosing and who is being told in the pair. They practice disclosing their status to the other person. When pairs are finished, ask them to switch roles. After five minutes, ask one or two pairs to volunteer to come into the center and show their role-plays to the whole group.

5. Debriefing:

- ➡ How did you feel about disclosing your status?
- ➡ How did you feel about being told the other person's status?
- ➡ What techniques did you use to tell your story?
- ➡ What advice would you give to others about disclosing?
- ➡ What did we learn from this?

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Woman telling her husband

- Selected a suitable place and time, e.g., children asleep
- Broke the news slowly: started off by saying she had gone to the clinic for a checkup; then said her friend had been tested for HIV; then said she decided to get tested too
- At each point in the story, she stopped to check on the awareness and reaction of the partner before proceeding.

Brother telling his sister

- Best time? In the evening after the children were asleep



Examples of Responses:

- Started with the statement, “The reason I wanted to talk to you is because I know you can support and help me.”
- Why select sister? She already knows about HIV. She would be sympathetic.

Son talking to father

- Best time? Early Monday morning at home
- Why? Want to keep it short and let him think about it
- Second session: father blames son for his behavior
- Denial – father suggests that his son get another test
- This sheds light on the possibility of stigma towards the father – he feels he maybe blamed for not raising his son properly


Whom is it easier to disclose to?

- Someone of the same sex
- Brother or sister – why? Same status in the family

Strategies and approaches

- Start with relatives whom you are already close to.
- Find a time when it is easier for people to concentrate.
- Find a place where there will be no interruptions.
- Establish a good relationship and trust.
- Go slowly and at each stage see how the person is responding.
- Ask for their advice and support.
- Disclose gradually. If you get a supportive response from the first person, it gives you the courage to continue and you can approach a second person.
- If people respond well, you may want to tell others. If the response is hurtful, you may decide not to tell others.
- Use your own status to encourage others to be careful with their lives.
- If some relatives know your status and they are sick, they may seek advice from you. This will show how valuable you are (they can lean on you for help).

6. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.
- ➡ You do not have to tell everyone about your status. Choosing whom you want to tell is your decision. It is your choice and your right. You should never feel pressured into telling someone you do not want to.
 - ➡ Telling the wrong person may affect your life in ways you have not considered, so be selective about whom you tell. Do not tell people who might use the information against you.
 - ➡ Consider the five W's when thinking about disclosure:
 - Whom do you need to tell?
 - What do you want to tell this individual about your HIV infection, and what are you expecting from him/her?
 - When should you tell him/her?
 - Where is the best place to have this conversation?
 - Why are you telling him/her?
 - ➡ Do not rush the disclosure. Easy does it. Take your time to consider whom to tell and how. Do it when you feel comfortable.
 - ➡ Consider whether there is a real purpose for you to tell this person, or if you are simply feeling anxious and want to "dump" your feelings.
 - ➡ Practice telling someone. This can be a useful way to develop personal strategies.
 - ➡ Start off with people you are comfortable with, people you know will be supportive and not judge you.
 - ➡ Keep it short and simple. You do not have to tell the story of your life.

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- ➔ Ask for the person's advice and support. Establish trust.
 - ➔ You have a virus. That does not mean you have done anything wrong. You do not have anything to apologize for simply because you are HIV-positive.
 - ➔ There is no perfect approach for disclosure. Trust your instinct, not your fears.
 - ➔ Whatever the response you receive in a specific situation, and even if it does not go the way you had hoped, you are going to survive it and your life will go on. Millions of others have dealt with this experience and have found their way through it. You will get through it too.

E4

HIV and Human Rights



Facilitator's Notes:

This exercise is designed to help people living with HIV recognize that everyone has rights, regardless of their HIV status, and these rights should not be denied just because a person has HIV. Rights, which go hand-in-hand with responsibilities, should be recognized. Stigma and discrimination lead to the erosion of rights, whether in a family situation, the workplace, or in the community.

This exercise is linked to exercise E5 that explores the use of assertiveness skills as a tool for protecting rights. Exercises E4 and E5 focus on human rights.



Objectives:

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

- ➡ Identify some of the rights that get violated if we are living with HIV
- ➡ Identify situations in which people living with HIV may be denied their rights
- ➡ Understand the importance of being assertive to maintain their rights



Target Group:

People living with HIV



Time:

1 hour



Materials:

Flipchart; markers; stories



Steps:

1. **What are human rights? (buzz groups):** Divide into pairs and ask pairs to discuss two questions:
 - ➡ What are human rights?
 - ➡ What are examples of human rights?

Report back: Take each question, one at a time, and ask pairs to give one point each. Record their responses on flipchart.

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Please note: The examples below provide you with information about human rights that you can share with the group, if they have not already mentioned them.

What are human rights?

- Things which every person must have because they are human
- To be treated fairly by everyone regardless of who we are and what we do, i.e., regardless of our gender, age, occupation, ethnic group, sexual orientation, etc.
- Practices that protect human beings against ill-treatment or violence.
- As human beings we are entitled to have certain things or do certain things.

Examples of human rights

Right to: life, food, water, work, shelter, clothes, health, freedom, education, protection, dignity and respect, privacy (including confidentiality), legal representation, religion, sex, have a child, get married, make decisions, own land and property, choose (autonomy), vote, freedom of speech, freedom of movement, freedom from discrimination, freedom of association, freedom from fear.

2. **Buzz groups:** Divide into pairs and ask, “What are some of the rights that may be violated if we are living with HIV?”

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Please Note: Many of the examples below may be provided by the group. If they are not provided by the group, share the examples below with the group.

Right: Right to work. Right to marry. Right to have children. Right to health. Right to participate in family decisions. Right to express opinions. Right to have friends. Right to food, shelter and clothing. Right to education.

3. **Processing:** Take each right and discuss: “How does this right get violated?” Then ask:
 - ➡ What did we learn from this exercise?
 - ➡ What are some of the ways we can protect our rights?
 - ➡ Are there other rights that other groups in the community may lose because of being stigmatized? (e.g., drug users, entertainment workers)
4. **Optional exercise (stories):** Hand out the stories below. Ask participants to read them and discuss: “What rights are being violated?”

Stories on HIV and Human Rights – Story 1

Leap is a 28-year-old man living with HIV. He has been HIV-positive for two years and is in good health. He began training with a new company and was offered the opportunity to study overseas. As part of his application for overseas training, Leap is asked to take a medical exam that includes an HIV test. The next day he is told that he can no longer go on the training course and has been fired. Leap is devastated. To make matters worse, when he looks for other jobs, he finds that other companies have been told that he is HIV-positive and no one will hire him.



Stories on HIV and Human Rights – Story 2



Theary is a six-year-old girl. She is very bright and loves school. Although she is HIV-negative, her mother is HIV-positive. One day a nurse tells one of her friends, who teaches at Theary's school, that Theary's mother is HIV-positive. A week later Theary is told that there is no longer space for her at the school.

Stories on HIV and Human Rights – Story 3

Nakry is HIV-positive. When she went to the hospital to have an opportunistic infection treated, she stood in a queue to see the doctor. The nurse announced to all those waiting that those with HIV should stand on the left side of the corridor and those with other medical problems on the right. Nakry sees her neighbor in the corridor and is afraid to stand on the left. She decides to go home and come back another day.

**Stories on HIV and Human Rights – Story 4**

Sopheap and Ary have three children. When Ary was pregnant with her third child, she tested positive for HIV. Sopheap tested positive soon after. His condition worsened rapidly and he was soon too sick to work. Ary had to take a low-paying job in a shop and had a very hard time both working and caring for her family, but there was no choice.

To help relieve the burden, Ary asked a neighbor to look after her new baby during the day. Ary had taken the ARV drug, nevirapine, during the delivery and her baby was HIV-negative, but when the neighbor found out that Ary was sick, she refused

to help, saying she feared that her own children could become infected. Word soon traveled around the community. Neighbors shunned her, and many refused to shop where she worked. Her employer demanded to know if she was HIV-positive. When she refused to discuss her HIV status, she was fired.



5. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.
- ➔ People living with HIV experience human rights abuses because of HIV-related stigma, fear, and other misunderstandings. The unfair attitudes and actions of other people prevent HIV-positive people from enjoying their basic human rights.
 - ➔ Stigma and discrimination also weaken the fight against HIV. Because of their fears of stigma, people living with HIV do not get tested, and this makes the spread of the virus more likely.

E5

Being Assertive to Demand Fair Treatment



Facilitator's Notes:

Learning assertiveness skills can be one strategy to help challenge stigma and defend rights. This exercise is linked with the previous one, E4. Exercises E4 and E5 focus on human rights.



Objectives:

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

- ➡ Define and understand assertiveness
- ➡ Practice some assertiveness skills



Time:

1-2 hours



Materials:

Copies of scenarios



Steps:

1. What is assertiveness? Divide into small groups and ask groups to discuss:
 - ➡ What does it mean to be assertive?
 - ➡ How can being assertive help us?

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

What is assertiveness? (Brainstorm)

Standing up for your rights. Saying how you want things to be done. Claiming your space by standing up for your values. Deciding for yourself. Not being passive. Not being aggressive. Trying to get what you want. Being confident.

Definition of assertiveness

Saying what you think, feel, and want in a clear and honest way that is good for yourself and others. Being aggressive or showing anger is not assertiveness.

How can being assertive help us?

Increases our confidence. Allows us to stand up for our rights. We get more respect from others. Improves relationships. We gain more control over our lives.

2. **Practicing assertiveness (paired role-playing):** Divide into pairs and ask pairs to stand facing each other. Ask each pair to decide who is the person living with HIV and who is the other person. Then ask pairs to perform a role-play where the person living with HIV is not being assertive. For example, a mother tells the person living with HIV to eat alone and the HIV-positive person simply accepts this.

Then stop and ask the group:

- ➡ What happened in the play?
- ➡ How could the person living with HIV be more assertive?

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

How to be more assertive

Say, “No – I don’t think this is fair. You know that the virus isn’t spread by casual contact. How would you feel if you were asked to eat alone?” Maintain eye contact. Remain polite but firm.

Ask the same pairs to replay the scene, this time the HIV-positive person is being more assertive, refusing to eat alone.

3. **Scenarios:** Hand out the scenarios (below) and ask pairs to try out each scenario, one at a time. Before each round, ask partners to agree on who is the HIV-positive person in each pair. After each practice, invite a few pairs to show their role-play at the center of the circle.
4. **Debriefing:** After a few practice rounds, ask:
 - ➡ What happened? How did you feel? Were you assertive?
 - ➡ How can we assert our rights in day-to-day situations?
5. **Broken record:** This is one of the assertiveness techniques you can use to emphasize your point. It involves repeating your point gently in different ways. See example below.

HIV-positive person: I want to go see my friend.

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

HIV-positive person: I'll rest when I get home. I want to go see my friend.

Family: The neighbors will see you.

HIV-positive person: I'm not worried. What is there to see? I want to see my friend.

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

HIV-positive person: I'm stronger. This friendship is helping. I am going to see my friend.

6. **Summary:** Assertiveness techniques: Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

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

Handout Scenarios

1. You are staying with your mother. You have been sick but are now feeling better. When she is out of the house, you decide to help with the housework. Your mother returns and finds you sweeping. She says, "Go into your room. You shouldn't be doing that. Go!"
2. You are invited to your brother's house for lunch. While the other adults are talking together, you go outside to play football with your cousin. Your brother comes out and says to you, "You are too sick to be running around. You need to rest! Come inside."
3. You have been visiting some friends. One friend drives you home on his motorbike. When you arrive, your father says, "You should not be going out at night and mixing with those people. I forbid you to see them again!"
4. You bring your new girlfriend home to meet your parents. Later when your girlfriend has left, your father says to you, "You really shouldn't be moving with girls anymore. You need all your strength to get better."
5. You have been sick recently and are not getting better. The nurse comes to your house and discusses your health with your wife. When you join them, they stop talking.
6. After being sick, you return to work. Your boss says, "You really shouldn't be here. Why don't you look for a job that is less tiring?"
7. You have applied to go on a two-week training course. Your boss tells you, "I wish you could go, but I think you should stay close to home in case you get sick again."

Handout Scenarios

8. You decide you are feeling better and go outside to join your wife and brother in the field. Your wife says, "You should really be inside. It's not good to be in the sun when you are sick."
9. You have been out with your friends. It is the first time you have had a drink since you got sick. Your father tells you, "If you are going to start drinking alcohol again, I will not be looking after you."
10. Last year you were quite sick but since you have been taking ARVs, you have been feeling good. Today you have come to tell your sister that you are pregnant. Your sister is shocked and upset and says, "How can you be so irresponsible?"
11. You have been having some stomach pains and diarrhea. You go to your doctor's clinic. You want to see the doctor but the nurse tells you, "You should go home and rest. There is nothing more we can do for you."
12. You have just come back to your football team after being sick for a while. When you score a fantastic goal, you overhear a team mate saying, "Be careful about hugging him. You shouldn't get too close to him."
13. You go to the clinic for the third time to find out the results of your CD4 count. When you ask a nurse if the results are ready, she tells you, "I am so busy. We can't find your results. I think you will have to come back next week."
14. You are recovering after being sick. You have started taking ARVs and do not feel like eating big meals. When you ask for a little food, your mother says, "If you don't eat you will get sick again, and you will only have yourself to blame."

E6

Paranoia and Hypersensitivity



Facilitator's Notes:

This exercise explores how self-stigma can develop. It is important to explain that identifying self-stigma doesn't mean a person should be blamed for feeling self-conscious. Self-stigma happens in a climate of stigma. It is a reaction to or fear of being stigmatized.



Objectives:

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

- ➡ Identify symptoms and causes of paranoia and hypersensitivity rooted in stigma
- ➡ Gain insight into their own way of responding to people who stigmatize them



Target Group:

People living with HIV



Time:

1 hour



Materials:

Picture GS5 - Person living with HIV sitting alone on a bus



Steps:

1. **Paranoia and hypersensitivity (story-discussion):** Ask a participant to read the story below



Three weeks ago, Sorya took an HIV test and tested positive. At first he seemed to be okay and felt quite calm, but for the last few days he has been feeling that everyone is watching him and talking about him.

He takes the bus to work and overhears two women talking about someone who is sick and very thin. He looks at his own body and is sure that he is losing weight and beginning to look thin. He wonders if they are talking about him.

At work he notices a new poster, warning people of the dangers of AIDS. Sorya has not told anyone at work that he is HIV-positive, yet he thinks that someone has guessed and put the poster up as a way of telling others about him.

When his boss asks Sorya how he is feeling, he thinks he had learned about his status. He wonders if he is looking sick. He starts to sweat and feels the beginning of a headache. His boss tells him that he will be working on a new program from next week and although this is an opportunity he has looked forward to, now he thinks his boss is trying to get him out of the department.

The final straw comes when a woman brings him tea in a brand new cup. Now he is sure everyone is talking about the fact that he is HIV-positive.

2. Discuss:

- ➡ What happened in the story?
- ➡ Have you had similar experiences?
- ➡ What can we do to reduce these feelings of always being looked at or judged?

Examples of Responses:


The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Symptoms of paranoia and hypersensitivity:

- You think that everyone you meet on the street knows your condition.
- You misinterpret how people look at you or things they say to you.
- Example: If people ask, "How are you feeling?" you interpret it as if people are saying that you are sick and are going to die.

3. Summary: Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

- ➡ Learn to recognize that people living with HIV will face stigma in society, but if you are prepared you will not let it destroy you.
- ➡ Do not always assume that you are stigmatized in every situation.
- ➡ Discuss your experiences of being stigmatized with other people living with HIV, and try to distinguish between stigmatizing behaviors and those that are simply normal human reactions.

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- ➔ Encourage family members to stop “killing you with kindness,” help them see that too much sympathy also hurts.
 - ➔ Gain control over your feelings and emotions so they do not burden you.
 - ➔ Use humor as a way to cope with stigma, especially among other people living with HIV.



Facilitator's Notes:

Depression can be a response to stigma or self-stigma. Many people living with HIV become depressed because of stigma. If possible, ask a trained counselor to help run this session. This session should be done in conjunction with the next exercise, E8, which uses exercises to build self-esteem.



Objectives:

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

- ➡ Recognize emotional reactions to stigma, e.g., depression and self-pity
- ➡ Begin to look at some strategies for coping



Target Group:

People living with HIV



Time:

1 hour



Materials:

Pictures GS1, GS2, and GS4 – person living with HIV sitting alone



Steps:

1. **What is depression?** Put up the pictures and ask pairs to discuss:
 - ➡ What do you see in the picture?
 - ➡ What are the symptoms of depression?
 - ➡ Why do people get depressed?



Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Many of the examples below may be provided by the group. If they are not provided by the group, share the examples below with the group.

Symptoms of Depression

- Withdrawn. Overly quiet. Refusing to eat. Refusing to discuss issues
- Apathy. Loses interest in life, friends, family, work, and himself/herself
- Feels that he/she is no good at anything
- Has trouble sleeping, has no energy. Feels very irritable
- Gets angry and frustrated easily

2. **How to cope with depression:** Divide participants into pairs and ask them to discuss:

- ➡ What can we do if we start to feel depressed?
- ➡ How can we support friends who get depressed?

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Many of the examples below may be provided by the group. If they are not provided by the group, share the examples below with the group.

Strategies for coping with depression

Talk to a friend about what is happening to you. See a counselor. Do something physical, for example, exercise. Write your feelings down. Play with children – they can lift your spirits. Join a support group.

3. **Supporting depressed people living with HIV (Role-Playing):** Ask participants to role-play using the scenario below.

Daro and Pheary have been best friends for a long time. Daro has been HIV-positive for a while and is depressed. He does not visit his friends much any more. He no longer goes to the HIV-positive support group that he and Pheary used to attend. He denies that he is upset about anything, but he has been in a bad mood for a long time. Pheary is concerned. Daro is very withdrawn and is not talking to people. Pheary does not know what to do or how to approach him.

4. **Discuss**

- ➔ How did both of you feel in those roles?
- ➔ What skills or techniques did Pheary use that seemed to help?
- ➔ What methods did not work?

Tips for supporting someone who is depressed

What works	What to avoid
<ul style="list-style-type: none">• Acknowledge the problem but offer hope, e.g., “I know it must be really hard, but I also know you’re going to make it.”• Remind the person of happier times: “We have been friends for a long time, and you haven’t always been like this.” It allows the person living with HIV to reflect on his/her behavior and see that he/she can be a happier person. The depression will not last forever.	<ul style="list-style-type: none">• Don’t say things like, “Hey, we are all going through a hard time,” and then list your own sufferings.• Don’t condemn or label the person.• Don’t tell the person not to cry.• Don’t ignore what the person is saying.



What works	What to avoid
<ul style="list-style-type: none"> • Be frank: “What’s wrong, please tell me.” • Change the environment, e.g., take the HIV-positive person out for a drink or to visit friends. • Promise confidentiality. Do not assume it because you are a friend. • Listen more than talk, and show that you are listening. • Ask how you can help. • Resist the temptation to take over; let the person living with HIV stay in control. • Get support for yourself: Being around a depressed person can affect you. • If you are worried about the person or his/her depression becomes long-term, seek professional counseling. 	<ul style="list-style-type: none"> • Don’t get drawn into the HIV-positive person’s negativity. • Don’t give up on your friend. He/she needs to know you will be there no matter what. • Don’t gossip about the person.

5. Summary: Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

- ➡ Many people living with HIV go through times of depression.
- ➡ It is important that families stick by people living with HIV during these times and try to offer support and advice.
- ➡ It is important for family members to get counseling or other kinds of support for themselves to help cope with the depression.
- ➡ If a person living with HIV is depressed for a long time or family members are concerned, seek help from a trained counselor or specialist in mental health.



Facilitator's Notes:

This is a set of exercises on self-esteem. Choose one or two, or do them all over a period of time.



Objectives:

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

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



Target Group:

People living with HIV



Time:

Varies depending on the number of exercises



Materials:

Exercise A: Copies of word lists (or make your own word lists)

Optional Exercises

- A. **What kind of a person am I? (Word list):** Hand out the word lists and ask each participant to draw circles around the words that best describe her or him.

Examples for Word List

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

Discuss:

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

- B. Message to you (writing messages):** This exercise works best in a group whose members have known each other for a while.

Give each participant a piece of paper. Ask them to write their name at the top. Now stick or pin their paper onto their back.

Ask participants to write something that they really appreciate about each person on his/her piece of paper. Allow enough time for everyone to write on each other's paper.

Participants then read their messages out loud or to themselves.

- C. Building self-esteem (individual reflection):** Ask participants to sit on their own and answer the following questions:

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

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

- D. Body self-esteem (mime in circle):** Ask participants to think of three things that they like about themselves, e.g., appearance, mannerisms, thinking, relationships.

Go around the circle, asking each person to say, "One thing I like about myself is..." then make a gesture to show what it is he/she likes (e.g., if you like your hair, you might run your fingers through it; if it is your figure, you might wiggle your hips).

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

Summary: Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

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

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

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

(Some exercises were adapted from: Gordon, Gill. 1999. Choices: A Guide for Young People. London: Macmillan Education: 29.)





Objectives:

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

- ➡ Recognize some of the factors that cause stress, including stigma
- ➡ Develop skills and strategies for dealing with stress



Target Group:

People living with HIV



Time:

1 hour



Materials:

Story (see below)

Somalay's husband is away in the city. She has been having lots of diarrhea lately and thinks she may have AIDS. It is the farming season, and Somalay has to work alone in the fields because all of her children are young and in school. The weeds are growing fast and she cannot keep up with them. The rice stored from last year is almost finished, the price of food is going up, and the children are often hungry. Normally Somalay would discuss this with her neighbors, but recently they have not been speaking to her. The rains have brought malaria and her youngest daughter has a fever – Somalay worries she may get it too. She has not paid the school fees and the head teacher, whenever he sees her in the village, shouts at her. Her friend told her that he was spreading rumors about her illness. Somalay has problems sleeping. She wakes up each night and sits for hours thinking about her problems. Her heart beats fast and she shakes and she sometimes has nightmares. She finds herself shouting at the children and slapping them. They are shocked. Why is their mother behaving like this?



Steps:

1. **What is stress? (story-discussion):** Ask someone to read the story. Then discuss: What is happening to Somalay? Why is she behaving like this?
2. **How to deal with stress (group discussion):** Divide into small groups; distribute blank cards to each group.
 - Discuss what can cause you to feel stress. Write each point on a card. Then put the cards into two piles (i) what you can change and (ii) What you cannot change.
 - Select a few of the most important causes of stress and discuss what you might be able to do to reduce these causes.
 - Consider the stressful elements you cannot change. Ask, “What can you do to reduce stress caused by these things?”
3. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Ways to reduce stress:

- Do not carry all your problems on your shoulders. Try to see how others can help you in your home and outside. Maybe other family members can help.

Examples of Responses:

- Talk about your problems with someone you trust.
- Have a good cry – it can relieve stress and sadness.
- If your friends and neighbors have similar problems, meet together and share worries and feelings. Look for solutions that you can act on together.
- Put your problems in order of importance or seriousness, and set goals to solve one or two of the most important ones.
- Try a relaxation exercise to reduce stress. Example: Close your eyes and breathe slowly, focusing on the breath going in and out of your body. Now start from your left foot and relax all the muscles in it. Move up your calf muscle and so on until you have relaxed your whole body.
- Play some music that makes you feel relaxed.
- Do something that you enjoy – e.g., singing or reading – at least once a day.

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





Facilitator’s Notes:

When we tell family members and friends that we are living with HIV, they often give advice about what we should not do, e.g., don’t drink, don’t have sex, don’t have children, don’t stay out late, etc. This is a subtle form of stigma: people feel they have a right to tell us how to live our lives, just because we are living with HIV. As the title says, we have all found that “don’ts” don’t work.



Objectives:

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

- ➡ Analyze the “Don’t’s” prescribed by family members, friends, doctors, etc.
- ➡ Develop strategies for dealing with these “Don’ts” and turning them into opportunities to educate people about how it is to live with HIV



Target Group:

People living with HIV



Time:

1 hour



Steps:

1. **Listing Don’ts (Brainstorming):** Ask participants to make a list of “Don’ts” in their lives – things they are told by other people that they should not do. After they have completed the list, review each “Don’t” and discuss what you think about it.

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Don'ts

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

2. **Solutions (paired discussion):** Divide participants into pairs. Ask pairs to discuss: What can we do to deal with the don'ts?
3. **Paired role-play:** Practice some of the ways you would like to respond to people who tell you: "Don't."

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

- We have the right to make our own decisions.
- Most people rebel against "don'ts," or being told what to do.
- Sometimes people are trying to be kind, but they don't understand.
- Rather than telling us how to run our lives with a set of "don'ts," people who want to be helpful should provide information and let us make informed decisions.

4. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.
 - ➡ Society needs to learn that we are adults and can be fully functional and make decisions about how we want to run our lives.
 - ➡ Giving us a set of conditions does not help. Telling us what to do will not lead to change.
 - ➡ We welcome advice, but please let us have a life!
 - ➡ People who want to help should make the basic information available about the risks in different behaviors, and let us decide what to do. We want to lead a full life – one in which we control our own lives.





Facilitator’s Notes:

This exercise explores one of the most powerful “don’ts” – don’t have children.



Objectives:

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

- ➡ Discuss the stigma towards people living with HIV who choose to have children
- ➡ Explore the conflicting stigmas faced by women who are HIV-positive



Target Group:

All groups



Time:

1 hour



Steps:

1. **HIV-positive people having children (brainstorming):** Ask participants to brainstorm and identify things people say about HIV-positive women and men to stop them having children:

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Things people say:

- If a woman is HIV-positive, she cannot bear children.
- If she is HIV-positive, she will miscarry or the baby will be stillborn.
- If a woman is HIV-positive and gets pregnant, it will be a big strain on her immune system and she will die much sooner.
- HIV-positive people who have children are selfish; it is not fair to the children.
- Children will be orphans when their parents die.

In pairs discuss:

- ➡ How do these things make you feel?
- ➡ What can we do to cope with these attitudes?

2. **Having children vs. not having children (Cardstorm):** Women living with HIV are often caught between two stigmas: the stigma of being judged when choosing to have children and the stigma of being childless, which can be strong in many cultures. The choices are not easy.

Cardstorm: Hand out the cards and ask participants to make a list of the reasons for and against having children if you are HIV-positive.

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

For

- Joy of having children
- Child may be HIV-negative
- If the drug, Nevirapine, is available, risk is lowered
- Pride in having children
- Passing on one’s name
- Seals your marriage
- Proving that you are normal
- Satisfying cultural expectations
- Not being called barren by others

Against

- Child may be HIV-positive and die early
- Pain of seeing the child die
- Guilt of passing HIV to one’s child
- Drain on family resources
- Getting sick and not being able to look after the child
- Deciding what to do about breastfeeding

Examples of stigma of not having children

Society does not see me as a woman. There is no one to look after me when I am ill or old. People ask me, “Why I don’t have kids?” or they tell me I am useless because I have no children. If you do not have children, your partner leaves you. Pressure from relatives to have children. My name is not used to name a relative’s child for fear that my situation (childlessness) will be passed on. Fear of looking different and behaving differently from other women.

3. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

- ➡ Women, regardless of their HIV status, have the right to choose whether to have children. This is their decision.
- ➡ The right to have a family is protected by international law. The decision to have children rests with both parents but ultimately with the mother, as she is the one who will carry the child to term and give birth to it.
- ➡ A doctor does not have a right to sterilize a woman who is HIV-positive unless it is her own decision.
- ➡ Having children brings difficult decisions for HIV-positive women. Because of the social value attached to child bearing, women are often pressured to have children. At the same time, the family and community tell HIV-positive women to stop having children. This puts women in a dilemma.



Chapter F

Treatment and Stigma

Introduction

As antiretroviral drugs (ARVs) become more widely available, there is a lot of hope that treatment will reduce HIV stigma: People living with HIV will be able to live longer and healthier lives, the virus will be less associated with death, and treatment will ensure that many of the signs and symptoms of AIDS are less common.

However, it has been recognized that HIV stigma can be a barrier to accessing treatment, and fears around disclosure, exposure, and judgments all fuel this stigma. Many people still only get tested for HIV when they become very sick. Others are afraid to disclose their HIV status to their partners for fear of the consequences. Many professionals, particularly in the health field, fear stigma and judgments from colleagues and loss of social status. In these circumstances, if people are able to access treatment, it is often kept a secret. The treatment becomes a means of public disclosure and is hidden and taboo.

Adherence is a crucial part of ARV treatment: poor adherence causes drug resistance and less effective viral control. Stigma is also being cited as a barrier to good adherence. Studies have shown that where there is openness and acceptance, i.e., the opposite of stigma, both access and adherence to treatment are easier to achieve.



Community engagement and treatment literacy lead to populations who feel freer to discuss HIV, test for HIV, and seek treatment. They receive both family and community support to continue successfully with treatment.

This module contains exercises that try to disentangle and explore some of the ways in which stigma is a barrier to effective ARV treatment. For more information about ARVs, please see information sheet #6 in Appendix A.



Exercises

- F1. Treatment and Stigma: Problem Analysis
- F2. We Will Not Tell Anyone
- F3. Children, Treatment, and Stigma
- F4. Getting Treatment

Treatment and Stigma: Problem Analysis



Objectives:

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

- ➡ Understand how HIV stigma can affect access and adherence to antiretroviral (ARV) treatment
- ➡ Share ideas and experiences of stigma related to ARVs



Target Group:

All groups



Time:

30 minutes



Steps:

1. **Buzz groups:** Divide into pairs and ask pairs to discuss:
“How does stigma affect ARV treatment?”



Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

- Disclosure – You do not tell your family and keep your ARVs hidden.
- Secrecy – Your colleagues do not know you are taking ARVs.
- Health workers who are HIV-positive fear that their colleagues will find out about their status.
- Myths and rumors about side effects
- Your family does not want to spend money to support your treatment.

2. **Report back:** Discuss each of the problems listed. Share stories and experiences to try to understand the problems.
3. **Discuss:** What are some initial ideas of how we could change things?

**Facilitator's Notes:**

This exercise would work well with health workers to help them explore how discussing disclosure strategies with clients can support adherence to treatment.

**Objectives:**

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

- ➡ Explore how emphasizing confidentiality can hamper disclosure
- ➡ Look at how secrecy can create problems regarding treatment and adherence
- ➡ Look at ways we can support each other to find strategies for disclosing our status.

**Target Group:**

All groups

**Time:**

1 hour

**Steps:**

1. **Case studies:** Divide participants into small groups; have each group read through one case study together.
2. **Advantages:** Discuss the benefits of the person disclosing his or her status.
3. **Develop five tips** to give to the person in the case study on how to disclose HIV status. Write the tips on a flipchart.

4. **Report back:** Read through your case studies and present your tips.

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

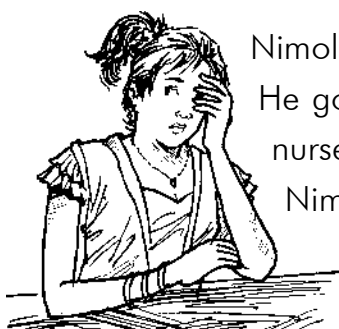
- Choose the right time and place.
- Practice what you will say with a friend or on your own.
- Ask a friend or other family member to be with you.
- Ask others who are in the same position as you for ideas.
- Ask your counselor to help you tell someone close to you.

Disclosure Case Studies – Case study 1

Ratana is 18 years old, single, and living with her parents in Phnom Penh. She is taking ARVs. Her parents know she is on treatment but they have agreed that it should be kept secret from the neighbors and extended family. Ratana would really like to tell her best friend at school.



Disclosure Case Studies – Case study 2



Nimol knows he is HIV-positive but has not yet disclosed to his family. He goes to the clinic for some advice about telling his mother. The nurse is impatient because she is overburdened with work, and tells Nimol that he should consider how much it will upset his mother.

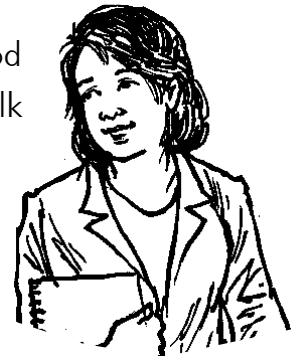
Disclosure Case Studies – Case study 3



Sokha is already on ARV treatment but he has not told his wife about the treatment or his HIV status. He takes the drugs while he is at work. Sokha's uncle sees him hiding the tablets in his briefcase. Sokha decides that it is time to tell his wife before someone else does.

Disclosure Case Studies – Case study 4


Phary is a school teacher at a primary school in town. She has a good friend at school, a fellow teacher with whom she would love to talk about her HIV status. She suspects her friend might also be living with HIV as she saw some ARV bottles in her bag.



Disclosure Case Studies – Case study 5



Raksmei found out that she was HIV-positive when she went to the clinic. The nurse has told her she should tell her husband, but she is scared of how he will react. She has started taking ARVs and keeps them at her sister's house nearby.

- 
5. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.
- ➔ When health workers focus on confidentiality, it can discourage us from thinking about telling people about our status.
 - ➔ We can feel that disclosing our HIV status is a difficult thing to do, but with support from friends and family, it becomes easier.
 - ➔ Sharing strategies with others in a similar position can help us to be more open.
 - ➔ Once we have disclosed, we are less vulnerable to stigma.
 - ➔ Being open helps us to talk about our health, take ARVs, and adhere to treatment.
 - ➔ Gender and power differences make disclosing to some people more difficult.



Facilitator's Notes:

This exercise is helpful to use with parents of children who are living with HIV.



Objectives:

By the end of the session, participants will have a clear idea about why and how to inform children about their HIV status and ARV treatment.



Time:

90 minutes



Steps:

1. **Brainstorm:** Ask participants to think about the questions that parents living with HIV might have about sharing their HIV-positive status with their children or telling a HIV-positive child about the child's status and why they are taking ARVs.



Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

- If a child is on ARV treatment, should you tell him/her what he/she is taking?
- Are you protecting your children by treating ARVs as normal medicine, rather than giving your children more information about ARVs and how they can manage it better?
- Is there a right age to be told you are HIV-positive?
- What about children's rights to know and understand their status and the medication?
- How can the child be supported when he or she is told?
- What happens to the family if the child tells everyone?
- Will the child be stigmatized at school?

2. **Reflection:** Remember being 12 years old

Ask participants to sit on their own and close their eyes. Ask them to:

Imagine you are a 12-year-old child. What is it like? What is important in your life? What do you like doing? Who are you close to, and who do you talk to about things? What do you worry about? (Wait a while to let people imagine.) Now imagine that you have been taking medicine for a while and you have asked your aunt what it is for. She tells you that you are living with HIV. How do you react? How do you feel? How will this affect you?

3. **Discuss in pairs:** How did the reflection go?

4. **Large group discussion:**

At what age and how do we tell a child about their HIV status and ARV treatment?

5. **Telling the child (paired role playing):**

Divide participants into pairs and find an empty space. Within each pair, participants should agree on who is the child and who is the parent.

Brief the “child” with the instruction: Your role is to ask your mother or father some of the following questions: What is this medicine? Why do I have to take it? Why are my brothers not taking it? When can I stop? You keep saying I will have to take it for my whole life. What do I have? Is it AIDS?


Let each pair work out how to role-play this situation. When they finish, invite one pair to perform their role-play. When they finish, ask: Do you agree or disagree with this approach? Why? If you disagree, how would you respond to your child? What other approach might be used?

If others have different ideas, ask them to volunteer to try it out. Use stop-start to show a range of approaches.

Debriefing: Ask: How did it feel being the child? Being the parent? How would you tell your child about her status? What kind of support do you need as a family?

6. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

- ➡ Children have a right to know about their HIV status, as long as this is done in a sensitive way. Talk to other parents who are in the same situation.

- 
- ➔ If a child starts asking questions, it is probably the right time for the answers.
 - ➔ You can also share your own HIV status with the child as a way of supporting him or her.
 - ➔ Discuss different coping strategies with your children on whom they should tell and how.
 - ➔ Ensure that your child understands the importance of adherence, and help him or her work out the best way to achieve it.
 - ➔ Find out if there are any leaflets or books that your child can read about children living with HIV.

**Facilitator's Notes:**

This exercise looks at opportunistic infections and ARVs. Invite a medical expert who knows about ARV treatment to help you explain the issues and answer participants' questions.

**Objectives:**

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

- Recognize that many opportunistic infections are curable
- Identify how to prevent/minimize opportunistic infections
- Explain some of the basic facts of ARVs

**Target Group:**

All groups

**Time:**

2 hours

**Preparation:**

Write questions on flipcharts and put them up in different parts of the room. Bring copies of information sheets 1 and 6 in Annex A (opportunistic infections and ARVs) to hand out.

**Steps:**

1. **Opportunistic infections (rotational brainstorm):** Divide participants into five groups, and assign each group to one of the flipcharts. After a few minutes, use a song to move groups to the next flipchart, moving clockwise. Continue until each group arrives back at their original flipchart.



Questions:

- ➡ What are some of the possible illnesses faced by people living with HIV?
- ➡ What are some of the symptoms of tuberculosis (TB)?
- ➡ How can a person living with HIV prevent opportunistic infections?
- ➡ How do infections affect the attitude of others?
- ➡ What kind of stigma do we face as a result of opportunistic infections?

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Many of the examples below may be provided by the group. If they are not provided by the group, share the examples below with the group.

What are some common opportunistic infections faced by people living with HIV?

Tuberculosis (TB), diarrhea, pneumonia, bowel infection, fungal infection, skin cancer, Kaposi's sarcoma, candidiasis, herpes zoster, meningitis.

What are some of the symptoms of TB?

Weight loss. Persistent cough. Sharp chest pains. Night sweats. Poor appetite. Decline in immune status.

How can people living with HIV prevent opportunistic infections?

Regular medical check-up. Get treated as soon as symptoms appear. Get enough rest. Good food and nutrition. Good hygiene. TB prevention therapy. Avoid alcohol and smoking. Avoid milk to minimize diarrhea. Avoid sugar to control fungal infection.

Examples of Responses:

What kind of stigma do people living with HIV face as result of opportunistic infections?

- Stigma increases because of the visible infections such as sores and rashes.
- Family members worry about what neighbors will say so they try to hide the person living with HIV.
- No one wants to sit next to you or share food with you.
- People think it is your fault, and say you are not looking after yourself.
- People assume you are getting AIDS and will die soon.

2. **ARV Treatment (Cardstorm):** Hand out cards and markers. Ask participants to write points in response to the question: “What do you know about ARV treatment?” Ask participants to write one point on each card and tape the card on the wall.

Cluster the common points and then review each point by asking:

- ➡ Do you agree with this point?
- ➡ Any corrections or additions?

Distribute ARV information sheet. Make sure the following issues are covered.

Issues to be covered:

Combination therapy. Different types of drugs. When to start treatment. CD4 and viral load tests. Adherence (right time of day, right number of pills, every day). Adverse side effects. Toxicity. Where to get the pills. How much do they cost? Drug resistance (use people’s knowledge of resistance in relation to other illnesses, e.g., chloroquine malaria tablets). Length of treatment.

3. **Treatment problems (critical incidents):** Divide participants into small groups and give each group one of the problems listed below. Ask them to role-play the situation and try and find solutions.



- A.** A man says to his HIV-positive son, "I'm sorry. We no longer have money to buy medicine." Privately he tells his wife, "Why should we waste money on him? He is only going to die! And anyway, he caused this problem."
- B.** A family goes into debt trying to find a cure for their HIV-positive son, moving back and forth between private doctors and traditional healers.
- C.** A patient stops taking his ARV drugs and says he is better.
- D.** The father goes, with his HIV-positive son, to the clinic to get ARVs and quarrels with the health staff because of the way they treat his son.

4. Processing:

What happened in the role-plays?

What did we learn?

How can we overcome some of the obstacles we might face on our treatment journey?

5. Summary: Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

- ➞ Many families do not have enough information about opportunistic infections, and this can lead to stigmatizing beliefs, such as: people living with HIV just get sick and die.
- ➞ If families know more about opportunistic infections and ARVs, they can provide better support and care.
- ➞ ARVs are more available these days and can provide HIV-positive people with hope for the future, but people living with HIV have to overcome the fear of being stigmatized in order to access ARV treatment.
- ➞ Even when ARVs are accessible, people living with HIV may still face problems linked to stigma.

An illustration at the top of the page shows two young boys playing soccer. One boy is on the left, seen from the back, wearing a light-colored shirt and dark shorts, with his arm outstretched. The other boy is on the right, wearing a light-colored shirt and dark shorts, with his hands on his knees, looking towards a soccer ball in the air. The background is a light blue sky with a few birds.

Chapter G

Children and Stigma

Introduction

This module explores the impact that stigma has on children affected by HIV. Stigma towards children takes many forms. Some examples include:

- ➔ Blame: children are blamed for their parents' death; for being a burden; or in some countries, orphans are seen as "unlucky children."
- ➔ Children affected by HIV may be excluded from school, families, and communities because of fear of stigma.
- ➔ Orphans are often treated differently from other children in families, including being given extra work, and they are often accused of carrying on their parents' "bad behavior."
- ➔ Street children are seen as dirty and out of control.

This module aims to help explore and understand the different ways in which children are stigmatized, and explore strategies to begin to change attitudes and experiences. The module is designed for children between 8 and 15 years of age. Facilitators will need to modify explanations and explain some terms depending on the ages of the children participating.



The module is divided into two sections:

➔ Exercises for children

These exercises aim to help children explore stigma and how it affects people living with HIV. Ideally, these exercises can be used by teachers to work with children and to challenge stigma.

➔ Exercises for adults – parents, caregivers, guardians

To help adults understand the stigma faced by children and explore ways of building effective skills and strategies to provide support and challenge the stigma.



Exercises

For Children

- G1. Naming Stigma through Pictures
- G2. Why Do We Isolate Others? Fear about HIV
- G3. What Happens When HIV Enters the Family? (Silhouettes and Story-making)
- G4. What Happens When HIV Enters the Family? (Stories and Discussion)
- G5. Drawing and Coping
- G6. What Makes a Good Friend?
- G7. Why Is Stigma Dangerous? (Love Story)
- G8. Value Clarification Exercise
- G9. How It Feels to be Stigmatized (Option)
- G10. Action against Stigma – What Can We Do?

For Adults

- G11. Memories of Childhood
- G12. What Do We Think of Children?
- G13. Analyzing Stigma against Children

Working with Children

Tips for working with children in workshop settings and other contexts

Age groups

It may be easier to work with groups of children of a similar age, e.g., 8-10 year olds; 11-15 year olds, etc.

Ensure children understand what is happening/why they are there

Always make sure that you explain the reason why you are having the workshop or doing some exercises with the children. Be clear and be ready to answer any questions.

Get consent

Always get consent from caregivers if you are working with their children. Ensure that they know where the children will be, the times and transport/pick-up arrangements, etc.

Extra Needs

Be prepared to accommodate different needs. Find out whether any children have special needs before the workshop, if possible. Have a plan ready if a child falls sick (a rest room, knowledge of the nearest clinic, etc.).

Meals or snacks

Think about providing a meal or snack before you start the workshop so that hunger does not prevent a child from participating (some of the children may not have regular meals).

Introductions

Think about simple non-threatening ways of getting children to introduce themselves to the group at the beginning of a workshop. Use songs, games and rhymes to help break the ice.

Guidance, not direction

Children may do things differently from the way adults might do them. Try to allow children to have as much control over a game or exercise as possible. Try to maintain a balance between gently guiding but not taking over and directing everything.

Work with grief

Many of the exercises will potentially lead to sad memories or thoughts of difficult times for the children – be prepared to provide support and comfort and do not

panic if a child starts to cry. This is likely to be the first time the child has had a chance to talk about some of the things he or she has been through. Crying is healing, and what is important is that the child be allowed to express himself or herself and be heard.

Think about your own experiences

Prepare yourself for the emotional part of working with children by thinking about your own experiences and try out some of the exercises yourself. This awareness will make working with children easier.

Photos

If you are going to take photos, always check with children and their caregivers, and inform them if there is a chance the photos will be used in any public way.

Let children speak

One of your primary aims should be to let children speak and to really listen to what they are saying. Affirm and encourage expression. Reassure them that there are no right or wrong answers when talking about their own experiences.

Language

Think about the way you explain things. Use simple words and not workshop jargon. Be sure that they understand what you have said.

Body language

Be aware of your body language. This may include sitting down or kneeling to be at the children's level.

Disclosure issues

Consider how you will respond if children disclose or raise issues of exploitation or abuse. Ensure that your organization has a plan or guidelines on what action should be taken in such cases.

Encourage less confident children

Think about ways and techniques for encouraging less confident children to participate. And remember that children have the right not to participate if they do not wish to.

Working with Children

Free time and play

Build free time and play into the workshop. It is important to give children different opportunities for mixing together and expressing themselves. Have some toys available (balls, dolls, crayons, etc.), when possible.

Songs

Songs, dance, games and drama work really well with children. Encourage children to lead the songs, share their favorites, demonstrate dances, etc.

Do not work alone

If possible, have a team of facilitators to help with the workshop. There may be times when different groups of children are doing different activities. Also ensure that there are both men and women in the team.

Physical safety

Before and during the workshop be aware of any physical safety issues, especially if you are using physical games. Make the space as child-friendly as possible.

Plan the program

Plan a mixture of exercises focusing on different things. If one exercise is difficult or brings out a lot of emotion, ensure that the next one is more light-hearted, with a focus on overcoming problems, resilience, support, etc.

Naming Stigma through Pictures



Facilitator's Notes:

This exercise is the same exercise as A1. It helps children begin to identify and talk about stigma. It helps to introduce the topic of stigma and discrimination and what they mean.



Objectives:

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

- ➡ Identify different forms of HIV stigma in different contexts
- ➡ Identify how stigma affects people living with HIV and their families, including children



Target Group:

Children between ages of 8 and 15 years



Materials:

Pictures: GS1, GS2, GS3, GS4, GS5, GS6, GS7, GS14, GS17, GS18 displayed on the wall



Steps:

1. **Naming stigma:** Divide participants into groups of three or four children. Ask each group to select one picture. Ask, "What do you see in the picture? What do you think is happening?"
2. **Report back:** Ask each group to hold up their picture so the whole group can see it and explain what is happening. For each picture, ask, "How do you think this makes the person (who is stigmatized) feel?"

Record the reasons why the children think that people are stigmatized.

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Picture GS1 – Woman sitting alone. Two other women are gossiping about her.

Two women gossip about the woman. They think she may have HIV. The woman looks very sad and lonely.



Picture GS4 – Man is sitting alone

The man has been left alone in a room. No one is visiting him. He looks very lonely and depressed.



Examples of Responses:**Picture GS6 – The father is eating alone.**

Father is eating alone. He looks thin – like an HIV patient. His wife looks sad. She fears HIV infection so she has to ask him to eat alone. He is upset but he has accepted the stigma (self-stigma).

**Picture GS7 – Family hiding HIV patient in the house**

Family is hiding an HIV patient in the house. They do not want the visitor to know that they have someone sick with HIV in their home. Fear they will be stigmatized by the community. Stigma by association.



3. Summary: Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

- ➞ Sometimes we treat people badly. We isolate or reject them, e.g., refusing to sit beside someone in class or on the bus; or we gossip about them or call them names. When we isolate or make fun of other people, this is called “stigma.”
- ➞ When we stigmatize we isolate people, saying they are a danger or a threat to us (because we think they might infect us with HIV), or we judge people, saying they have broken social norms (social rules about how people should behave) and should be shamed or condemned.
- ➞ Stigmatizing beliefs or attitudes lead to discrimination – unfair treatment of those who are believed to be inferior.
- ➞ Stigma is not good. Stigma hurts people. When we stigmatize, it makes people feel bad, lonely, worried, sad, and rejected.
- ➞ People living with HIV are often stigmatized by their own families and the community. They have to eat alone or they are forced to leave home and live somewhere else. This makes them feel very bad, which affects their health.
- ➞ There are different forms of stigma:
 - Isolation and rejection – physical separation from family and neighbors. People living with HIV are forced to be alone and use separate utensils. Based on ignorance and fear of HIV infection. Examples: GS3, GS4, GS5, GS6, GS7.
 - Shaming and Blaming – gossip, name calling, hurtful teasing. Shame people for their “bad behavior”. Examples: GS1, GS14.

- Self-Stigma – People living with HIV stigmatize themselves in reaction to stigmatization from society. They accept the blame and rejection of society and they isolate themselves. Examples: GS2, GS4, GS6.
- Stigma by Association – Some children are stigmatized because their parents have HIV or have died from HIV. Examples: GS17, GS18.



Some of the effects of stigma are:

- Shame and loss of confidence. Feel they are no longer accepted by others
- Feelings – sadness, loneliness, rejection, hopelessness, self-doubt
- Feelings of guilt, denial, self-hatred, and depression
- Staying quiet in order to avoid drawing attention to themselves
- Discrimination – people living with HIV kicked out of family, job, organizations, etc.
- People who think they have HIV worry about what others will do, so they do not get tested and do not tell others and get help, support, and treatment.



People living with HIV are often blamed for being infected with HIV. We need to support them, not blame them.





Objectives:

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

- ➡ Identify some of the reasons why people isolate people living with HIV
- ➡ Explain how HIV is transmitted and how HIV is not transmitted



Target Group:

Children between ages of 8 and 15 years



Materials:

Pictures: GS3, GS5, GS6, GS11, GS17



Steps:

1. Put up five of the pictures and ask, "Why are some people isolated or rejected by others?"

GS3: Why is the landlord kicking the HIV-affected family out of the house?

GS5: Why is the man sitting alone on the bus?

GS6: Why is the father in the family eating alone?

GS11: Why is the nurse wearing a mask and gloves?

GS17: Why is the boy sitting alone?



GS3: Why is the landlord kicking the HIV-affected family out of the house?



GS11: Why is the nurse wearing a mask and gloves?



GS5: Why is the man sitting alone on the bus?



GS17: Why is the boy sitting alone?



GS6: Why is the father in the family eating alone?

Record their answers.

Help the group understand that the main reason behind the isolation (stigma) in all pictures is fear – fear of getting HIV through physical contact with the person.

Explain that the fear about getting HIV through touch is wrong – you cannot get HIV through simply touching another person. You cannot get HIV by sitting together in class or on the bus, or eating together, or playing football.

If children ask how people get HIV, you may explain that people can get HIV in a few ways. A mother with HIV can pass the HIV to her baby before it is born, or in her breast milk. A person with HIV can pass the HIV in their blood on a needle or a razor to another person who uses the needle or razor without washing it first. A man or woman with HIV can pass the HIV into the body of another person when the man's penis is inside the other person. These are not usual activities in the life of a child. Usual activities like playing or studying or working or sleeping or eating or using the toilet cannot pass HIV from one person to another person. HIV does not pass through saliva, tears, vomit, feces, urine, or sweat, so it is okay to play or study or work or sleep or eat or share a toilet with a person who has HIV.

Homework: Ask children to take the five pictures home and discuss with their parents, brothers, and sisters. Have the children ask, "Can you get HIV through these activities?"



What Happens When HIV Enters the Family? (Silhouettes and Story-making)



Facilitator's Notes:

Exercises G3 and G4 cover the same issue – how HIV impacts on the family – but they use different techniques:

- ➡ Exercise G3 uses silhouettes and story-making (suggested for children grades 1-5)
- ➡ Exercise G4 uses stories and discussion (suggested for older children-high school)



Objectives:

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

- ➡ Identify some of the effects on the family when someone gets HIV
- ➡ Agree on ways to care for people living with HIV



Target Group:

Children grades 1 through 5



Materials:

Silhouettes (pictures of individual characters) showing father, mother, teenage boy, teenage girl, younger children (Annex D)



Steps:

Divide participants into four groups. Hand out a set of silhouette cards and ask groups to make up a story about their family. Tell each group how to start the story.

Group A – Positive story about HIV-positive person:

The father gets HIV. When the mother finds out, she takes him to the hospital and cares for and encourages him. She does not shout at him. Continue this story.

Group B – Negative story about HIV-positive person:

The father gets HIV. The mother becomes very angry and shouts at her husband. She blames him for ruining the family. She tells him to stay in his room. All the children feel miserable. Continue this story.

Group C – Positive story about drug users:

The teenage son becomes addicted to drugs. The mother takes her son to the counselor at the health center. She cares for him and encourages him to stop taking drugs. She encourages him to get involved in sport and other activities. Continue this story.

Group D – Negative story about drug users:

The teenage son becomes addicted to drugs. The father and mother shout at their son and slap him. They lock him in his room and refuse to let him out. They blame him for destroying the family's reputation. Continue this story.

Once the groups have finished, ask them to tell their stories. Then ask:

- ➡ What is the difference between the stories?
- ➡ What made the difference in the positive story?
- ➡ What would help the families become happy again?

Summary: Bring the session to a close by summarizing the main points which participants have made during the exercise.

What Happens When HIV Enters the Family? (Stories and Discussion)



Objectives:

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

- ➡ Identify some of the effects on the family when someone gets HIV
- ➡ Agree on ways to care for people living with HIV



Target Group:

Children in high school



Materials:

Stories below



Steps:

1. Hand out the two stories and ask groups to read and discuss. What do they think about the stories and the way people with HIV are treated by their families?

Story A:

A woman finds out that she has HIV. Once the family discovers this, her children are taken away from her and go to live with her parents. One day she misses her children so much that she goes to her parents' house to see her children. When she finds her four-year-old daughter she goes to hug the little girl, but her daughter refuses, saying, "Don't touch me. You have HIV. You will infect me." The woman starts to cry.

Story B:

A young man finds out he has HIV. At first he hides his problem from his wife and family. One day he learns about antiretroviral drugs (ARVs) but is told they are very costly. He decides to tell his wife, his brother and sister about his status. Instead of blaming and condemning him, they are very supportive. They offer to help him pay for ARVs and to look for more information about ARVs. They even go with him to the hospital and ask questions to find out more about ARVs. He had been very skinny and desperate. With the support of his family as well as ARV treatment, he becomes very happy and positive about his life.

2. Discussion:

- ➡ What happened in each story? Why?
- ➡ What is the difference between the two stories and why?

3. Summary:

Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

- ➡ In story A the parents of the woman have stigmatized her, and treated her as a threat to themselves and her daughter. They fear getting HIV through physical contact with the woman. They even warn the little girl not to touch her mother. This hurts the woman and will have a negative effect on the woman's health.
- ➡ In story B the wife and family take a different attitude. They are more accepting and provide active support (e.g., regarding ARVs). Their supportive attitude makes the person living with HIV feel better about himself and his health improves.

**Objectives:**

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

- ➡ Talk about difficult times
- ➡ Explore some of their experiences
- ➡ Talk about what helped them cope in these situations

**Target Group:**

Children between ages of 8 and 15 years

**Time:**

40 minutes

**Materials:**


Paper, crayons, markers, pencils

**Steps:**

1. **Picture drawing:** Ask the children to think about a difficult time in their life – something that happened, or a bad time when they were feeling sad. Ask each child to draw a picture to illustrate what happened.

As the children are drawing, ask them to explain their pictures.

When all the pictures are finished, stick them on the wall and ask the children to come and look at them. They can ask each other questions if something is not clear.

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- A red-toned illustration at the top of the page shows several children playing soccer. One child in the center is kicking a soccer ball, while others are running around. The style is simple and sketchy.
2. **Buzz and cardstorm:** Ask the children to think about what helped them get through that bad time. Who or what gave them hope and support? Ask pairs to discuss and write their points on cards. Tape the cards on the wall. Younger children should be asked to report their ideas verbally.
 3. **Role-playing:** Divide participants into small groups. Ask each group to take one of the ways they got through a bad time, and make a role-play to show how it can help children in difficult situations. Ask groups to perform their role-plays. After each performance, ask:
 - ➡ What was happening?
 - ➡ What helped the child?
 - ➡ How can we help children cope in situations like these?



Facilitator's Notes:

When children are asked what helps them cope with stigma, they often mention good friends who help them. This exercise builds on this theme.



Objectives:

By the end of this session children will have:

- ➡ Identified how friends can help them cope with difficult situations
- ➡ Identified how they can be good friends to others in trouble
- ➡ Understood the value and role that friends play



Target Group:

Children between ages of 8 and 15 years



Time:

45 minutes




Materials:

Drawing paper, pencils, pens, markers



Steps:

1. In small groups, ask the children to think of all the things that make a good friend.

- 
- A red-toned illustration at the top of the page shows several children playing soccer. One child in the center is kicking a soccer ball, while others are running around. The background is a solid red color.
2. Ask them to draw a picture to represent a good friend – an outline of a boy or girl on the flipchart. On the picture, ask them to write all the things that make a good friend.
 3. Share the pictures with the larger group.

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Helping each other in difficult situations. Solving small problems together. Helping each other with school studies/work. Playing different games together. Visiting one another. Helping during funerals and celebrations. Helping each other do different jobs. Forgiving each other's mistakes. Not gossiping about them or telling their secrets to others. Someone who visits you when you fall sick. If I am hungry and there is no food, I go to my friend's home to eat.



Objectives:

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

- ➡ See how stigma drives the epidemic underground by making people hide their status and put others at risk
- ➡ See why it is important to stop stigma



Target Group:

Children between ages of 8 and 15 years



Time:

1 hour



Steps:

1. Read the following story to the children:

Love Story – Chann and Jorani:

Chann is a young man who is HIV-positive. Chann falls in love with a girl, Jorani, but he does not know how to tell her that he has HIV. After a while, Jorani gets pregnant, and Chann becomes very worried that she will be HIV-positive. Jorani goes for a prenatal check and after the blood test she is told she is HIV-negative. Chann is very happy and he learns that the child is also negative. He wants to marry her, but does not know how he can tell her the truth about being HIV-positive.

2. Discuss:

- ➡ Why is Chann worried about telling Jorani his status?
- ➡ How do you think he can tell her that he is HIV-positive?

- ➡ Once Jorani knows the truth, what do you think she will do? Will she marry Chann or leave him?

Then divide into four groups. Groups A and B should discuss what Chann should do, Groups C and D should discuss what Jorani should do.

3. Organize a report back.

- ➡ How does HIV stigma affect people's willingness to tell others they have HIV?
- ➡ How does HIV stigma result in the continuing spread of HIV?

4. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

- ➡ Fear of stigma stops people who suspect they are HIV-positive from:
 - Testing
 - Disclosing to partners. Chann was afraid to tell Jorani because he thought he would lose her if she knew about his status, so he remains silent. This puts Jorani at risk of getting HIV.
 - Getting treatment for other infections. If a person's health is weakened by HIV, he or she is more open to getting other infections.
 - Disclosing and getting counseling, care and support. People are afraid to let others know about their situation because of stigma. They may avoid the stigma, but they remain sick, silent, and alone.
- ➡ Fear of stigma keeps HIV and AIDS underground.
- ➡ If people living with HIV are treated with kindness, support, and care, they will be more likely to go for testing, disclose to their families, and take precautions in their sexual relationships

**Facilitator's Notes:**

This exercise helps to reinforce what was learned in Exercise G2, which focuses on fear-related stigma and basic facts on HIV transmission. Many of the statements are based on fears about getting HIV through casual contact. The exercise is built around homework and then a review of what children have done at home.

**Objectives:**

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

- ➡ Analyze stigmatizing statements made about people living with HIV and see why they are wrong
- ➡ See how HIV-positive people's human rights are often denied because of stigma

**Target Group:**

Children between ages of 8 and 15 years

**Time:**

1 hour

**Materials:**

One-page handout of statements (below); same page with answers

**Steps:**

Homework: Give each student a sheet with the statements below. Ask them to decide which statements are "right" or "wrong" as homework. Ask the students to take the list of statements home with them and discuss with their parents and siblings.

Statements

1. Children with HIV should be allowed to go to school.
2. If a child has HIV, the whole class should be told who he/she is.
3. If a child has HIV, the teacher should move the child to a separate place in the class (away from other children).
4. Children with HIV should be put together into one class.
5. Children with HIV should be allowed to play with other children.
6. If you play with children who have HIV, you will not get infected.
7. If you sit next to a child with HIV, you should avoid touching him/her.
8. If parents get HIV, their children and relatives should care for them.
9. The community should care for children living with HIV and AIDS.
10. Children with HIV should eat, drink, and sleep separately from others.
11. People living with HIV and AIDS should be treated the same as people who have other diseases such as flu or diarrhea.
12. Children with HIV parents should be removed from their home and taken to live with their relatives.

Next Day: Hand out a sheet giving the correct answers and ask students to review their own answers. Then discuss.

Right – Statements 1, 5, 6, 8, 9, 11

Wrong – Statements 2, 3, 4, 7, 10, 12

Summary: Many of the “wrong” statements are based on fear and lack of knowledge about HIV. These statements assume that people can get infected through casual contact with people living with HIV. This is wrong and should be clearly pointed out. A person cannot get HIV from casual contact with HIV-positive people or their children.

To help the children understand why these statements are wrong, get them to discuss the consequences of the statements. For example, statement 12 says that children of HIV parents should be removed. Ask, “Would you like to be separated from your parents?”

Children should not be separated from their parents because the children are not at risk. They cannot get HIV from parents through physical contact.





Facilitator's Notes:

The exercise requires a lot of trust and openness within the group so it should not be used as the first exercise. It works better if it is used after 2-3 exercises. By this point participants are beginning to open up with each other and are now ready to share some of their own experiences.

You should also note that the exercise looks at stigma in general, not HIV-related stigma. This is why the instructions are, "Think of a time in your life when you felt isolated or rejected for being seen as different from other people." Give a few examples (e.g., being made fun of because you came from a poor family, or being made fun of in school because you were smaller than others or poor at football). The examples will help participants understand what type of experiences they are expected to think about.

This exercise needs a good introduction to help participants break out of their initial discomfort about reflecting and sharing their own experiences with others. One way of getting started is by the facilitators sharing their own experience and feelings first. It is important to set ground rules for this exercise: Emphasize that the sharing is voluntary – no one is forced to share; and emphasize the importance of confidentiality – that what is shared should stay in the room.

This exercise can trigger painful memories or experiences for some participants. As the facilitator you should be ready to deal with the emotions raised.



Objectives:

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

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



Target Group:

Children between ages of 8 and 15 years



Time:

1 hour



Step:

1. **Our own experience of being stigmatized (individual reflection):**
Ask the children to close their eyes, and then say, “Think about a time in your life when you were treated badly by others, rejected, or called names.” Explain that this does not need to be examples of HIV stigma and could be any form of isolation or rejection for being seen to be different. Ask them to think about their experience, and ask, “What happened? How did it feel? What impact did it have on you?”
2. **Sharing in pairs:** After a few minutes, ask the children to share what happened in pairs. “Talk to one other child you feel comfortable with.”
3. **Report back:** Then call the whole group together and debrief with the following questions:
 - ➡ How did you feel when you were stigmatized?
 - ➡ What were your feelings?

Examples: Shame. Embarrassment. Felt bad. Left out. Rejected. Upset.

Ask, “What did you learn from the exercise?”

4. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.
- ➡ This exercise helps us get an "inside understanding" of how it feels to be stigmatized – shamed, rejected, etc.
 - ➡ The feelings are very painful. People get badly hurt.
 - ➡ The feelings last a long time.
 - ➡ Stigma destroys people's self-confidence. People begin to doubt and hate themselves. They feel very alone at a time when they really need the support and company of other people.
 - ➡ Being stigmatized makes people feel bad. So they want to hide their status and not talk to others.

Homework:

What can we do as children to counteract this type of discrimination?

1. Talk to your parents about what you can do and then come back tomorrow and tell us what you can do.
2. Talk with friends or family members about what you have learned about stigma. Get them to talk about their own experience of being rejected or made fun of as a way of helping them understand how it feels to be stigmatized.





Objectives:

By the end of this session, children will be able to work out how to stop stigma and promote care and support for people living with HIV and their children.



Target Group:

Children between ages of 8 and 15 years



Time:

1 hour




Steps:

1. **Introduction:** Review discussion on stigma and how it hurts people living with HIV and their children. In this session we will discuss what we can do to stop stigma.

Examples of Responses:

- Stop using negative or insulting words when we talk about people living with HIV or their children.
- Ensure that the children of people living with HIV are treated equally in school.
- Play with the children of people living with HIV and tell other children that it is okay to play with them.
- Visit them at home and invite them to our homes.
- Teach others about how HIV is spread (and how it is not spread). Help them see there is no reason to fear contact with people living with HIV or their children.
- Stop family members when they isolate people living with HIV within the home or school.
- Treat people living with HIV like you would do other people – no difference!
- Offer kindness, support, and comfort to people living with HIV.

- 
- A red-toned illustration at the top of the page shows several children playing soccer. One child in the center is kicking a soccer ball, while others are running around. The style is simple and sketchy.
2. Ask, “What can we do to stop stigma?”
 3. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.
 - ➡ Stopping stigma requires effort by everyone. The starting point is to change the way we think, talk, and act towards people living with HIV and their children. We first need to change our own attitudes – the way we think and feel about people living with HIV and their children. Treat them like you would treat anyone else.
 - ➡ After we have changed ourselves, we can educate others. It takes courage to stand up and challenge others when they are stigmatizing people living with HIV, but this is one way to stop stigma. Getting people to talk openly is the first big step.
 - ➡ Reach out to people living with HIV and do not stigmatize them. They deserve our respect and support. Once they feel accepted, they will be more open to discussing their situation with others and getting the support they need and deserve from the community.

Action Ideas:

Talk with other students about what you can do to de-stigmatize the school. How can you make the school stigma-free?

Extra Story – The Little School Girl

It was raining heavily and I drove my motorbike to the primary school to collect my son. When I arrived I noticed a little girl around seven years old. She was wet and using a leaf to cover her head from the rain. She was carrying broken slippers in her hand. Seeing her look so miserable made me feel very sad – like a knife sticking into my heart. My son arrived and introduced me to the girl, whose name was Hong. He asked me to give her a ride home.

I became aware that Hong lived in my neighborhood, only 700 meters from my house. Just before I put her on my motorbike I heard an angry shout from an older woman, who said, “Leave her alone. She won’t die from standing in the rain and if she dies, I will have less of a burden.” It was Hong’s grandmother, the mother of her father. After I greeted the grandmother, my son found a way of solving the situation – he told her that it was his birthday and he wanted to invite Hong to his birthday party. I felt so relieved because of my son’s idea, and I asked her grandmother to let Hong come with us.

The grandmother, however, continued her warnings. She said, “Don’t get close to the girl since her father died of AIDS. She is our biggest burden. We want her to die but as long as she lives she is our burden.”

I told her not to worry because she would not infect us. Then I put the girl on my motorbike and drove her home.

At my place, I took off her clothes and gave her a shower. I noticed that she had many sores and pimples all over her body. I recalled what the grandmother had said and I felt scared. What would happen to me? Would I get HIV?

At that time I knew nothing about HIV. In spite of my fears I washed her thoroughly and dried her with a towel, because I didn’t want her to get cold after the shower. After the meal I asked her why she had so many pimples on her body. She told me that her grandmother didn’t let her sleep in the room – she was forced to sleep in the kitchen.

Extra Story – The Little School Girl

Her father, a drug addict, had been caught and sent to prison. Her mother was jobless. Hong's only income was a small teashop in front of her house. Hong slept at my house and I cooked her two meals. I thought that the girl's family would pick her up and take her home. When no one came to collect her, I drove her home.

Three months later, I attended a meeting on AIDS organized by the women's union. Each member came up to the stage and told her story. One woman was Hong's mother, and I learned she had HIV and was a member of a Bright Future Group (HIV support group).

I assumed that this was the reason why the grandmother mistreated Hong, even though she might not know if the girl had HIV or not. By this time the father had died and her mother was really sick. Fortunately the women's union was willing to support the girl. Her grandmother has become more understanding and gives more care to Hong.

This story shows that stigma is very damaging. It can destroy relationships and the love among a family. Some people can push their own son or grandchild to their death without pity, and they can consider their own loved one as a life burden.

Exercises for adults about children and stigma

These exercises can be used to train caregivers, teachers, or others who are working with children. The children may be children living with HIV, or any children in the appropriate age range (8-15 years of age). They can also be incorporated into general stigma workshops to help adults begin to understand and appreciate stigma towards children.



Facilitator's Notes:

These introductory exercises help participants explore their own attitudes towards children and childhood. This is important in terms of understanding how children can be affected by different factors and how stigma affects children.

This exercise can bring up some difficult memories for some people. Be prepared, allow people to express emotions, and encourage the group members to support each other.



Objectives:

By the end of this session participants will have:

- ➡ Reflected on their own experiences of childhood
- ➡ Understood more about how experiences during childhood have an effect on us as adults



Target Group:

Health care providers, NGO and CBO staff, and the community



Time:

45 minutes



Steps:

1. **Memories of Childhood:** Give each participant two cards each. Ask participants to think about their childhood for a few minutes. Ask them to think about two topics: "The best thing about being a child " and "The worst thing about being a child." Ask them to write these on the cards.

2. Ask participants to pair up with someone they feel comfortable with and discuss what they have written.
3. Bring the whole group together and stick the cards on the wall.

Discuss:

- ➡ How was it to do this exercise?
 - ➡ What did we learn from it?
 - ➡ Would anyone like to share their memories? (Allow enough time for people to share)
4. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.
 - ➡ What happens to us when we are children can have a lasting impact on our lives.
 - ➡ As children, we are more likely to remember something bad that happens to us than something good. We should help children to talk about their past and encourage them to remember good things as well as bad.



Facilitator's Notes:

This exercise is like a group survey on attitudes towards children. This exercise works best if you have a team of three facilitators: one to read out the statements, and two to collect the statements and tabulate the results. Try to ensure that you collate and record the answers quickly on to the flipchart answer sheets.



Objectives:

By the end of this session participants will have:

- ➡ Reflected on their beliefs about children
- ➡ Clarified their attitudes towards children



Target Group:

Health care providers, NGO and CBO staff, and the community



Materials:

One-page handout of statements (below); same page with answers



Time:

1 hour



Steps:

1. **Preparation:** Arrange the room so that participants are sitting apart from each other and will not be able to see each other's answers. Prepare answer flipcharts: write each statement (below) at the top of a separate flipchart sheet and draw table to show yes/no/men/women answers. Give each participant a

set of 10 slips of paper. (Use one color for men, another for women.) Ensure everyone has a pen.

Example of answer table for flipcharts

	Yes	No
Women		
Men		

2. **Explain as follows:** "I am going to read out some statements about children and I want you to record your answer for each statement. Use a different slip for each statement. If you agree with the statement put a tick on your paper, if you disagree put a cross. Then fold your slip of paper. After each statement a facilitator will come and collect your slip of paper. It will be anonymous, so no one will know what you have written."
3. **Read the first statement.** Give participants time to answer. Ask them to fold their papers. Collect papers in a hat/box/basket. Try to get the answers recorded before the next statement has finished, but do not make the process too long. Do not present the answers yet.
4. **Discussion:** When you have read all the statements and collected all the answers, present the answer flipcharts one by one and ask participants how they feel about the results.
 - ➡ Were there any surprises?
 - ➡ How do our beliefs about children affect the way we treat them?

Statements

1. Children do not really know what they need.
2. Children need to be punished harshly if they make a mistake.
3. Children learn moral values from the adults around them.
4. Children should be encouraged to be as independent as possible,
5. A child's personality is developed by the time he or she is two years old.
6. Children often inherit bad behavior from their parents.
7. Once children can walk, they do not need much physical contact with adults.
8. Children should always follow what adults tell them.
9. Some children misbehave from the day they are born.
10. Children should be seen and not heard.

Add more if needed or change to include local beliefs

Optional:

Go through Eriksson's Stages of Development. (See attached handout.) In small groups, discuss how this theory matches the participants' own understanding of their own children or those they have seen growing up or are caring for.

5. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

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

If a child...

If a child grows up in an environment of criticism, the child will learn to criticize.

If a child grows up in an environment of hate, the child will learn to fight.

If a child grows up in an environment of shame, the child will learn to feel guilty.

If a child grows up in a praising environment, the child will learn to appreciate.

If a child grows up in an encouraging environment, the child will learn to be confident.

If a child grows up in an environment of understanding, the child will learn to be patient.

If a child grows up in a just environment, the child will learn to be fair.

If a child grows up in a secure environment, the child will learn to trust.

If a child grows up in an approving environment, the child will develop self-esteem.

If a child grows up in an environment of acceptance and friendship, the child will learn to find love in people.

Eriksson's Stages of Human Development

The type of adults we become, how we act and react in different situations, and how we interact with others are influenced by many things: our upbringing, environment, culture, traditions, and families. One of the most important influences is what happens to us during childhood.

Erik Eriksson was a psychologist and he described human development happening in different stages (described below):

The First Stage: (Conception to 1 year old) "Trust and Mistrust"

Normally during this time, the baby is held close to its mother most of the time. The baby learns to trust that at least one person will respond to its basic needs for food, contact (touch) and comfort. The mother learns to recognize the baby's cry of hunger, discomfort, or loneliness. If she does not respond, the baby will not learn to trust and may develop a strong sense of fear.

Second Stage (1-3 years) "Autonomy, Shame, Doubt"

The child is learning to have some control over the body: walking, talking, dressing and controlling bowels. If the child is frustrated during this stage, or laughed at, or punished harshly, he/she will develop anger and rage against adults.

Third Stage (3-5 years) "Initiative/Guilt"

This is a time of exploration and experimentation for the child. It is important that the child is encouraged to take initiative and not be punished or blamed when he or she makes mistakes. You can block the child's initiative if you shout or slap him/her. He/she will learn anxiety and feel, "I am no good."

Fourth Stage (6-12 years) "Industry/Inferiority"

Most children are learning to cooperate with others (at school or home) and to carry out tasks. The child needs constant encouragement as she/he learns. If the child begins to feel like a failure, at this point she/he turns this feeling into blame and guilt.

Fifth Stage (13-18 years) "Identity/Role Diffusion"

This is the time for discovery of one's identity as a young woman or man. Independence from parents begins. If a child has developed anxiety and guilt at earlier stages, they will find this time more difficult. They may feel shy, unloved, uncertain. These feelings can last for many years.

Sixth Stage (19-25 years) "Intimacy/Isolation"

The young person reaches a stage of self-assurance in relation to being a sexual person; she or he can develop relationships and intimacy. If they do not have the self-assurance, they may remain isolated and alone.

Seventh Stage (25-55 years) "Generativity /Stagnation"

Through the ability to know another person, there is the possibility of giving life to others, either through marriage and children, or through helping occupations, or informal relationships. Otherwise the person may feel unable to contribute to the growth of human society.

Eighth Stage (55 onwards) "Integrity /Despair"

If a person has successfully completed the other stages in their life, this is the time they can look back and integrate all their experiences. They will be available to the younger generation as a "wise person." An "unsuccessful" person will look to the future with despair, aware of not giving life to the world.



Objectives:

By the end of this session participants will be able to identify the forms, causes, and consequences of stigma against children



Target Group:

Health care providers, NGO and CBO staff, and the community



Time:

1 hour



Materials:

Different colored cards



Steps:

Forms, Causes, Consequences (Cardstorm):

1. Divide into pairs and hand out cards. Ask participants to think about the different forms of stigma that children experience. Write down one on each card. Stick cards on wall.
2. Give each pair one flipchart sheet. Ask each pair to pick one form of stigma and stick it in the middle of their sheet. On their cards, ask them to write all the causes they can think of for this type of stigma (one point per card) and tape these onto the sheet, below the stigma-naming card. (See example below.) To explore the causes, keep asking: why, why, why? Some may be root causes.

3. Ask pairs to think about all the consequences of that form of stigma. Write one point per card and stick these above the stigma-naming card. Try to look at both individual consequences of stigma and consequences for the community, society, economy, etc.
4. Now ask pairs to pick one of the causes on their flipchart and discuss some of the solutions. Ask, "What could help to change things?" Write ideas on a separate flipchart.
5. Display all the flipcharts for a gallery report-back.
6. Ask participants to read through the flip charts and clarify any questions with each other.

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Forms of Stigma towards Orphans and Vulnerable Children

Abuse and mistreatment, e.g., not given a bed, sleeping on the floor, not given enough food, overloaded with extra work

Cursing and name calling

Being called "dirty." Being ignored. Not having a place to rest/no fixed abode.

Stigma in different places: clinics, police stations, shops – not given attention or being chased away

Examples of Responses:**Causes**

Lives are not valued. Blamed for parent's behavior if they died from AIDS
Seen as a waste of resources. Poverty makes stigma worse
Seen as "unlucky"
Thought to be HIV-positive

Consequences

Separated from sibling to a new family
Health suffers. Too sick to go to school, but not wanted at home
Sent to poor schools or no school at all
Emotional problems
Sexual, physical and emotional abuse

7. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.
- ➡ Sometimes the consequences of stigma become the cause of more stigma.
 - ➡ Stigma is often worsened by poverty, which limits a family's capacity to cope. Orphans might be resented or blamed if there is not enough food, money, other resources. Sometimes they bear the brunt of the stresses in the household and this leads to harsh punishments.
 - ➡ Sometimes children internalize stigma and believe that they are "no good," useless, or worthless.





Chapter H

Youth and Stigma

Introduction

Stigma towards young people is similar to that faced by adults, but it is often exacerbated because of vulnerability and judgements about age, morality, education, and experience.

Young people are stigmatized for a variety of reasons: having relationships, being sexually active, using drugs, questioning their parents and authorities. If young people are living with HIV, they face even greater stigma and harsher judgments.

The impact of stigma on young people has many consequences, including exclusion, isolation, dropping out of school, and delaying the start of antiretroviral (ARV) treatment.

This chapter is designed to be used with young people. The exercises help them identify the particular stigma issues they face; analyze the causes and consequences of stigma; address the link between stigma, gender, and sexuality; and empower them with skills to cope with stigma and build strategies for change.

The exercises can also be used with adults to help create greater awareness and understanding of stigma faced by young people and to initiate change.



Exercises

- H1. Things the Community Says about Young People
- H2. Analyzing Stigma and Young People
- H3. Relationships and Stigma
- H4. Sexual Rights and Responsibilities
- H5. Sex and Stigma
- H6. Talking about Gender Issues
- H7. Young People Living with HIV

H1

Things the Community Says about Young People



Facilitator's Notes:

This is a version of Exercise C2. It has been adapted to look at the language used against young people. This exercise can be used with adults as well as young people. The processing step (getting people to look at how it feels to be called these names) at the end is very important. Try to build an atmosphere of seriousness and purpose.

The title of this exercise is, "Things the community says about..." This phrasing allows participants to express their own stigmatizing labels for other groups under the cover of attributing them to "the community." So while some of the words are those commonly used by the community, some are the words actually used by participants.

In doing this exercise, we should make it clear that we are using these words not to insult people, but to show how these stigmatizing words hurt.

In debriefing this exercise it is important to focus on "how participants feel about these names," rather than the words themselves. This helps to avoid the embarrassed laughter. The whole point of this exercise is to help people recognize how these words can hurt.

Extra Tips for Facilitators:

- ➡ The number of flipchart stations/categories depends on the number of participants and the amount of time you have. With many participants you will need many stations/ categories so that the individual groups are not too big.
- ➡ The rotational brainstorm is fun, but the real learning comes in the debriefing – so make sure you allow enough time/energy for this.
- ➡ You need to explore your own feelings about these issues before trying to facilitate this discussion with others.
- ➡ Challenge the laughter. Often participants will laugh out of embarrassment. This is a good opportunity to ask, "How do you feel about the laughter?"



Objectives:

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



- ➡ Explore the relationship between language and stigma
- ➡ Explore how different groups of young people are stigmatized for different behaviors
- ➡ Look at how judgements about young people link to HIV-related stigma



Target Group:

Health care providers, NGO and CBO staff, police, and the community



Time:

1 hour



Materials:

Put up six flipcharts on the walls, each with a different heading.

Headings: “Things people say about young people who...”

- ➡ Use drugs
- ➡ Get pregnant
- ➡ Have HIV
- ➡ Live on the street
- ➡ Become entertainment workers
- ➡ Are in a relationship



Steps:

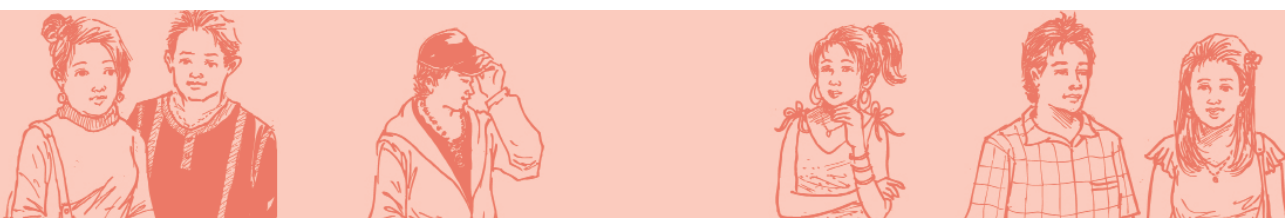
1. **Warm-up:** Switching chairs game: Set up the chairs beforehand in a circle. Allocate roles to each person going round the circle, e.g., “You are someone who uses drugs; you are pregnant; you are living with HIV; you live on the street; you work as an entertainment worker; you are in a relationship. Continue until everyone has been assigned one of these 6 roles. Then explain how the game works, saying:

"I am the caller and I do not have a chair. When I call out two roles, e.g., "drug user" and "pregnant," all the "drug users" and "pregnant" have to stand up and run to find a new chair. I will try to grab a chair. The person left without a chair becomes the new caller – and the game continues. The caller may also shout "revolution" – and when this happens, everyone has to stand up and run to find a new chair."

Then shout, "drug user and pregnant," and have the "drug users" and "pregnant" to run to a new chair and this starts the game. Then ask the person left without a chair to call out more names, and get participants to run. Continue until all groups have had a chance to run a few times.

Debriefing: Ask, "How did it feel to be called a drug user or pregnant?"

2. **The Blame game:** Things the Community Says about... (Rotational Brainstorm): Divide into six groups based on the roles used in the game. Ask each group to go to its flipchart station. Hand out markers and ask each group to write on the flipchart all the things people say about those in the said group. After two minutes, shout "change," and ask groups to rotate and add points to the next sheet. Continue until groups have contributed to all six flipcharts. Then ask them to come back to the circle with the flipchart sheets.
3. **Processing:** Sit in a circle. Ask a member of each group to stand in the center of the circle and say, "I am a young person who... (e.g., uses drugs) and this is what you say about me." and then ask them to read all the names out. When they have finished, leave the flipchart sheets lying in the circle, and then someone from the next group can read their own in a similar way. Continue without comments until all the flipcharts have been read.
4. **Ask:**
 - ➡ What do you think about these names?
 - ➡ How do you feel about this exercise?
 - ➡ What do we learn?
 - ➡ What kind of impact do these names have on young people?
 - ➡ Is the stigma different for young men and young women?



5. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.
- ➔ There is a strong link between language and stigma. The way that groups of young people get labeled means that they are separated from the rest of society and become excluded. If they are facing problems because of their behavior, they will be reluctant or unable to access help.
 - ➔ Young people get stigmatized for just being young people. Certain behaviors or situations can bring double stigma or multiple stigmas. For example, if you are a young person living with HIV and in a relationship, you will be judged on many levels.
 - ➔ We can all do something to change the way we talk about young people by changing our own language and challenging others who use stigmatizing language.

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Things people say about young people using drugs

Foolish. No sense of direction. Junkies/Addicts. Sick. Dangerous. Criminals. Thieves. Bad. Scum. Useless. No morals. Out of control. Lazy. Jobless. Deserve to die.

Things people say about street youth

Homeless. Streetdogs. Scavengers. Children with problems. Drug abusers. Orphans. Hopelessness. Don't wash – bad smell. Sorry for them – they do not get parental care.

H2

Analyzing Stigma and Young People



Facilitator's Notes:

This is a good opening exercise for a workshop focused on young people. It helps young people identify stigma from their own experiences. It uses an exploratory technique: a step-by-step analysis that uses different colored cards. This produces a massive card storm, so you will need lots of wall space.

You could spend half a day, if you cover all the steps, to analyze the different types of stigma faced by young people. You can also select two or three of the steps for a shorter exercise.



Objectives:

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

- ➡ Identify the forms, causes, and effects of stigma faced by young people
- ➡ Identify the different contexts where stigma faced by young people occurs



Materials:

Different colored cards



Time:

2 - 3 hours



Steps:

1. **Stigma toward young people (cardstorm):** Divide participants into pairs and hand out cards and markers to each pair. Ask, "What are some of the things we get stigmatized for as young people?" Ask pairs to write one point per card and stick the cards on the wall. Generate as many ideas on cards as possible.



Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Being young and therefore seen as reckless. We are vulnerable. Not allowed to make decisions. Have no rights. Society does not care about young people. Having too much sex. Not respecting adults or parents.

2. Ask volunteers to cluster the cards into similar points and give a brief summary of the main points.
3. **How are we stigmatized?** Give new colored cards to each pair. Now ask, "How are we stigmatized?" Ask pairs to write one point per card and tape on the wall, cluster and summarize as before.

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Name calling. Isolation. Kicked out of the house. Isolated from community meetings. Basic rights are denied, e.g., freedom to associate, freedom to have sex.

4. **Where are we stigmatized?** Ask, “Where does stigma towards young people take place?” As people give suggestions, hand them a card and ask them to draw a simple picture of that context, e.g., home, school, street, pagoda, workplace, community center. Stick the cards on different walls of the room, away from the earlier card storm.
5. **Task groups:** Divide participants into groups, asking people to go over the picture of the context they want to work on. Form a group to analyze stigma in that context. Group task: Think about what type of stigma happens in that setting, and write points on cards. You can use some of the cards from the first card storm, and add your own.
6. **Why are we stigmatized?** Now ask the groups to think about why the stigma happens in their context. Give groups cards of a different color to add to their context analysis.
7. **Report back – gallery walk:** Walk around the different group products together and ask any questions for clarification and take comments.
8. **Processing:** In the large group, ask, “What are the effects of this stigma on us as young people?”





Facilitator's Notes:

Young people do not usually have an opportunity to discuss relationships. Generally, all relationships are prone to some level of judgment from the community, families and peers. This exercise is not primarily about stigma, but it helps young people explore what makes a healthy or unhealthy relationship and how different situations and pressures may link to stigma.



Objectives:

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

- ➡ Identify how stigma can exist within and towards a relationship
- ➡ Discuss and explore healthy and unhealthy relationships



Time:

40 minutes



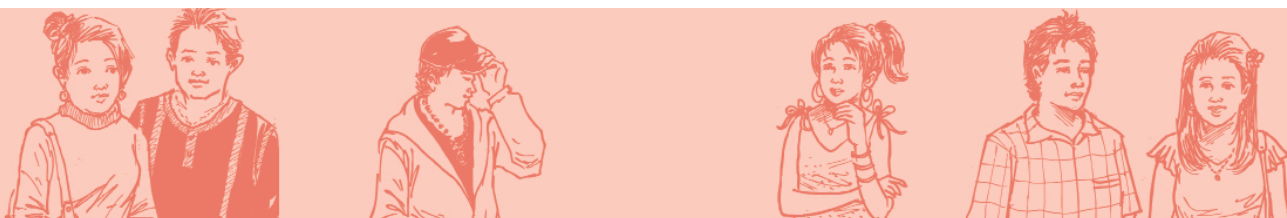
Materials:

Cards with situations written on them. Three big cards written in large letters Healthy, Unhealthy, and Depends. Place these signs on the wall.



Steps:

1. **Brainstorm:** Ask the participants to describe some of the qualities that make a healthy relationship. Write on flipchart.
2. **Buzz groups:** Divide into pairs. Hand out the situation cards (examples below) to each pair and ask them to discuss the situation and its impact on a relationship, and determine if it falls under the category of "Healthy," "Unhealthy," or "Depends."
3. Ask pairs to move to the front of the room and place their situation cards under the category they think is most appropriate and explain their reason to the group. If



there is a lot of disagreement, refer to the qualities of a healthy relationship that the group identified earlier.

4. Ask the group, "Are there any situations where stigma might play a role?" Discuss in the large group and decide which ones and why.
5. Ask participants to select one situation and make a role-play in small groups to show how a couple can cope with or challenge stigma towards their relationship.
6. **Processing:** Ask and discuss:
 - ➔ Why do you think people stay in unhealthy relationships?
 - ➔ How can friends and family help couples cope with stigma?
 - ➔ What do we learn from this?

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

- The most important thing in the relationship is sex.
- You never disagree with your partner.
- You spend some time by yourself without your partner.
- You have close friends outside your relationship.
- You feel closer and closer to your partner as time goes on.
- You will do anything for your partner.
- Sex is not discussed.
- One person usually makes every decision for the couple.
- You stay in the relationship because it is better than being alone.
- One person hits the other in order to have this person obey him or her.
- You argue and fight often.
- One partner is much older than the other.
- One partner wants to start having sex; the other is not ready.

H4

Sexual Rights and Responsibilities



Facilitator's Notes:

This is a good exercise to make participants begin to think about rights and how they can relate them to responsibilities. One of the biggest things that young people get judged for is their sexuality. Introducing the idea of sexual rights and responsibilities can form part of a strategy to empower young people and challenge stigma.

You may want to prepare a definition of "a right" and "a responsibility" when introducing the exercise.



Objectives:

By the end of this session participants will:

- ➡ Be aware of and able to articulate sexual rights
- ➡ Be able to view sexual rights and responsibilities as part of a larger concept of individual autonomy



Time:

60 minutes



Preparation:

Write on two flipcharts: "My Sexual Rights and My Sexual Responsibilities"



Materials:

Cards, markers, crayons, and paper



Steps:

1. **Brainstorm:** Ask, “What are some examples of basic rights that we have as individuals?” Examples: the right to free speech, to practice your own religion. Then ask, “What are some examples of basic responsibilities we have as individuals?” Examples: the responsibility to respect the property of others by not stealing, provide for your family, obey laws.
2. Divide participants into pairs and hand out cards and markers. Display two cards with the titles, “My Sexual Rights” and “My Sexual Responsibilities.” Ask the pairs to discuss some of their sexual rights and responsibilities and write one per card. Stick them under the appropriate cards.
3. Make sure that the following sexual rights are included (add them if they do not appear):
 - ➡ Right to sexual enjoyment
 - ➡ Right to protect yourself from disease
 - ➡ Right to prevent unintended pregnancy
 - ➡ Right to not have sex if you do not want to
 - ➡ Right to express your sexual orientation
 - ➡ Right to obtain information on sexuality and sexual health

Make sure that the following sexual responsibilities are included:

 - ➡ To respect a person’s right to say no
 - ➡ To inform a partner if you are infected with a sexually transmitted infection or STI (including HIV)
 - ➡ To respect your partner’s decision about protection in sexual matters
4. Ask each participant to select the item on the “My Sexual Rights” list that is most important to him or her and read it aloud. Ask for a few volunteers to share their reasons for selecting the item.



Objectives:

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

- ➡ Examine situations in which it is difficult for a person to abstain from sex, ensure that their partner is faithful, or negotiate condom use.
- ➡ Discuss the options that a young person has when they are having difficulty protecting themselves from HIV and other STIs.
- ➡ Practice communicating healthy decisions through role-plays.



Time:

90 minutes



Steps:

1. **Divide into five groups.** Give each group a case study and ask them to read it and answer the questions. After doing this, they should make a role-play in which the main character communicates a healthy decision.
2. **Report back:** Ask each group to present the case study and their answers, and perform the role-play.
3. **Processing:** Ask and discuss:
 - ➡ What can we learn from these case studies?
 - ➡ Does this happen in real life?
 - ➡ Can you share similar situations to this that you have witnessed?
 - ➡ What decisions did other people make in those situations?
 - ➡ How did those decisions affect their lives?

4. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

In each of these situations, one person was acting in ways that made it difficult for the main character to protect himself/herself. However, the main character still had the right to make his/her own decision.

Case study 1: Tola



Tola lives with her mother and her three younger sisters. Her mother has been ill and, therefore, Tola has struggled to provide for her family. An older man named Phirun talked with her about her struggles.

He made her a proposition. He suggested that she become his girlfriend. In exchange, Phirun will provide her with some cash every week and will help her find a better job. Tola is interested in these benefits, but she is afraid of becoming Phirun's girlfriend. She knows that being Phirun's girlfriend would require having sex with him. Tola is not ready to be sexually active. She is willing to be his friend, but does not want a sexual relationship with him.

Questions:

- ➡ What options does Tola have in this situation?
- ➡ What negative things could happen to Tola as a result of her deciding to have a sexual relationship with Phirun?
- ➡ How could Tola communicate with Phirun that she is not interested in being his girlfriend?

Case study 2: Pich



Pich is 18 years old. Among his friends, Pich is the only one who is a virgin. At night, Pich's friends like to hang out, play pool, and drink alcohol. One night, after drinking, Pich's friends ask him why he has never had sex before. They tease him and tell him that he is not a real man. They also suggest that he is a virgin because he does not like girls. He denies this. They inform him that the only way he can prove he likes girls is to have sex. They tell Pich that they are going to visit an entertainment worker later that night and he should join them. Pich does not want to do this. He does not want to lose his virginity and he does not want to have sex with an entertainment worker. He feels pressured by his friends and is afraid that they think he is not cool.

Questions:

- ➔ What options does Pich have in this situation?
- ➔ What negative things could happen to Pich as a result of him deciding to have sex with the entertainment worker?
- ➔ How could alcohol influence Pich's decision?
- ➔ How could peer pressure influence Pich's decision?
- ➔ How could Pich communicate with his friends that he does not want to have sex with an entertainment worker?



Case study 3: Sothy



Sothy and Ary have been dating for a year. Sothy cares for Ary, but he also likes to have sex with other girls. He would never tell Ary about this, because he knows that Ary would leave him if she ever found out. For the past month, Sothy has been asking his friend, Heng, to tell Ary lies about where he has been in order to keep her from learning about his cheating. Heng is getting tired of lying for his friend. He is also concerned about all of the sexual partners that Sothy is having, and the risk it is posing to Ary.

Questions:

- ➔ What options does Heng have in this situation?
- ➔ What negative things could happen to Ary as a result of Sothy's cheating?
- ➔ What negative things could happen to Sothy as a result of his cheating?
- ➔ How could Heng communicate his concerns to Sothy about his cheating?

Case study 4: Maly

Maly has been seeing Phala for more than a year. They are sexually active and because Maly is on the contraceptive pill, the couple never considered using condoms in the past. A few months ago, Phala moved to another town. He still sees Maly one or two times per month when he travels home. Maly is concerned that Phala may be having sex with other women and wants to begin using condoms to protect herself. She is concerned that Phala will not understand her desire to use condoms.



Questions:

- ➔ What options does Maly have in this situation?
- ➔ What negative things could happen to Maly as a result of continuing to have unprotected sex with Phala?
- ➔ How could Maly communicate with Phala that she wants to start using condoms? What might Phala say if Maly asks him?



Case study 5: Kiri

Kiri has been seeing Mean for some time. The last time they were together they almost had sex for the first time. However, Kiri did not have a condom and he did not want to have unprotected sex. Mean didn't care about using a condom. In fact, she was offended that Kiri wanted to use one. Mean said "condoms are only for entertainment workers" and that "condoms don't feel good." Kiri feels that he needs to talk with Mean about condoms again before they have another romantic encounter. He is committed to using condoms or not having sex at all.



Questions:

- ➡ What options does Kiri have in this situation?
- ➡ What negative things could happen to Kiri as a result of having unprotected sex?
- ➡ How could Kiri communicate with Mean that he wants to use condoms?
- ➡ What might make Mean willing to use condoms?



Facilitator's Notes:

This exercise begins to explore gender and how stigma can be different for young men and young women.



Objectives:

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

- ➡ Explore how boys and girls face different types of stigma
- ➡ Discuss how stigma can impact on boys and girls differently



Time:

45 minutes



Steps:

1. Divide participants into gender groups of girls and boys. Give each group a flipchart.
2. Tell participants you are going to take them through some steps. Each time you stop, they should discuss and write down some ideas. The girls' group should picture a girl in the scenario; the boys' group should picture a boy.
3. Read the following scenario. Stop for a few minutes after each question to let participants write their notes. Be mindful of the time; do not wait too long.
4. **Report back:** Stick up all the flipcharts, read through the story again, and give participants a chance to read through both sets of answers after each step.



Story steps:

1. You are 15 years old and have been living with your aunt for the last two years since your mother died. There are three other smaller children in the house. What are some of the tasks that you are expected to do in the house?
2. Your aunt remarries and your new uncle moves into the house. He is very harsh and beats you sometimes. One day he sees you near a bar waiting for your friend. He shouts at you. What are some of the things he says about you?
3. You decide that you can no longer stay with your uncle and you want to run away. What are some of your options for ways of surviving?
4. After about a year, you begin to feel sick and decide to return to your aunt's house. What kind of welcome do you get when you arrive?

5. Processing: Ask and discuss:

- ➡ What are the differences between the girls' and boys' answers?
- ➡ What is the impact of stigma on a) girls b) boys?
- ➡ How do gender issues link to stigma?
- ➡ How can we change things?

H7

Young People Living with HIV



Facilitator's Notes:

This exercise uses case studies based on real-life experiences to explore the stigma faced by young people living with HIV.



Objectives:

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

- ➡ Understand the stigma faced by young people living with HIV
- ➡ Develop strategies for changing the impact of stigma on young people



Time:

1 hour



Steps:

1. **Case study:** Divide participants into small groups. Give each group the full set of case studies and assign each group one of the case studies. Ask each group to read its case study and to record their points on flipcharts.
2. **Report back to the large group:** Each group shares their case study and the issues discussed.
3. **Processing:** Ask and discuss: "What did we learn?"
4. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.



Case study: Jorani



You are 22 years old and have been with your boyfriend for the last two years. You have recently tested HIV-positive and have decided not to tell him yet. You have been given information about reinfection and you also want to protect your boyfriend, so you need to find a way to start using condoms. You don't know how to bring up the subject.

Question: What advice could you give Jorani?

Case study: Sov

You are 14 years old and are living with HIV. You are in secondary school. You have a bad skin rash that comes and goes sometimes and you notice that your friends do not mix with you freely. Whenever the teacher mentions HIV, he looks directly at you and you feel uncomfortable. You no longer enjoy school.

Question: What should be done to help Sov?



Case study: Kosal



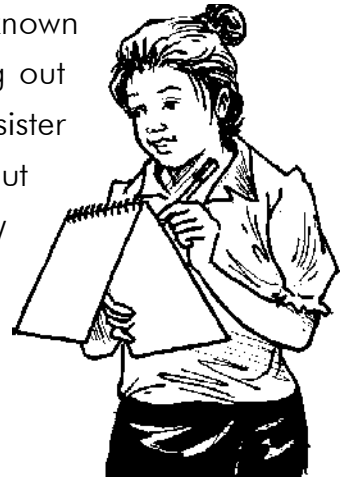
You are 19 years old and you are the youngest member of a HIV-positive network. You think that young people should be more included in the programs but you feel that you are not taken seriously and find it hard to contribute to meetings when everyone else talks loudly.

Question: What needs to happen to change things?

Case study: Bouphe

You are 17 years old and are living with HIV. You run a well-known support group for young people living with HIV. You love going out with your friends and dressing in the latest fashions. Your older sister tells you one day that the neighbours are starting to talk about the miniskirts you like wearing. She suggests you change the way you dress.

Question: What would you advise Bouphe to do?





Case study: Chhay



You are 12 years old and stay with your grandmother and young brother. People at the pagoda know that your parents died of an AIDS-related illness and often whisper about how you look. You overhear someone saying, "I hope he won't start misbehaving like his mother." You tell your grandmother that you no longer want to go to the pagoda.

Question: What could help the situation?

Case study: Sophon

You are 16 years old and living with HIV. Last year you were very sick and were even hospitalized. You have now recovered and are taking ARVs and feeling very healthy. Now you find that every time you want to meet up with your friends or go out with your sisters, your mother stops you and says it is better that you stay at home and rest.

Question: What can Sophon do to change the situation?





Chapter I

Moving to Action

Introduction

This toolkit builds “action” into many of the exercises so that people have already done the thinking about how to act against stigma and have started to practice the new knowledge and skills. Action is an important part of the learning process.

The earlier exercises include “action ideas,” which are suggestions on practical activities that participants can do at home. Talking with others helps everyone see what is involved in challenging stigma and developing the courage to do it. Facilitators should look for opportunities to move to action after every exercise.

This module is intended to:

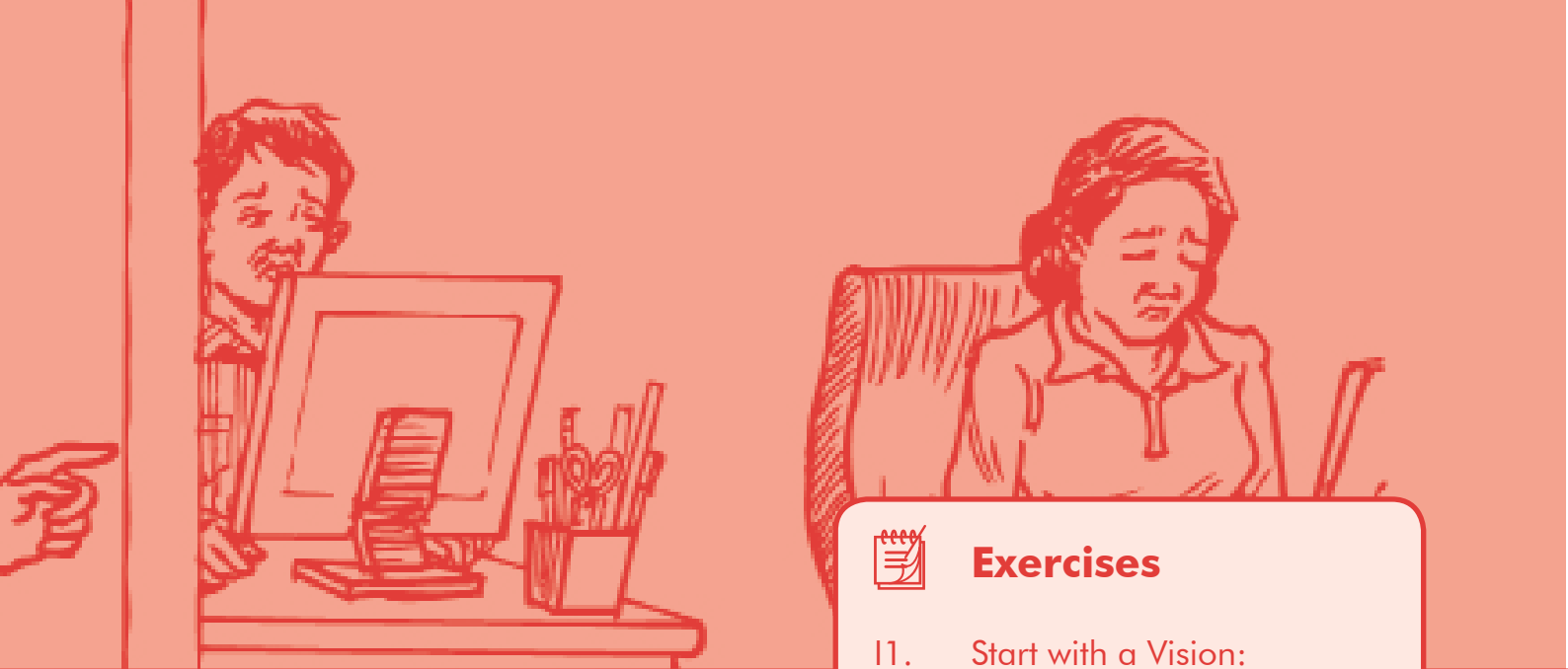
- ➞ Bring together everything we have learned about stigma, including what can be done to change attitudes and behavior
- ➞ Commit to change things to stop stigma
- ➞ Focus on what we can do to change as individuals, groups, and communities
- ➞ Agree on goals and how to achieve them

By the end of this module, all participants should be expected to:

- ➞ Develop a specific plan of action for challenging stigma in their community, and
- ➞ Make a public commitment to work individually and collectively to identify, understand, and challenge stigma.

Key Messages

- ➞ Each of us has a responsibility to challenge stigma. 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 to talk about people living with HIV and try to change how you think and act.
- ➔ Encourage community leaders to speak out about HIV and AIDS and condemn stigma.
- ➔ Encourage people living with HIV to speak out to help people understand how it feels to be the object of stigma.
- ➔ Share what you have learned. After the training, tell others what you have learned and get others talking about how to reduce stigma.
- ➔ Talk openly about HIV and AIDS. This will help people see that the topic is not shameful or taboo. Talking openly about HIV will also empower people living with HIV and help relieve some of their self-stigma.
- ➔ Facilitate discussion with family, friends, and neighbors 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 stigmatizing words. Instead of saying “victims,” use positive terms such as “people living with HIV,” 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.



Exercises

11. Start with a Vision: “A World without Stigma”
12. Problem Solving in Practitioner Groups
13. AIDS Law or Policy
14. Challenging Stigma in our institutions
15. Community Action against Stigma
16. Specific Campaigns against Stigma
17. Ten Steps for Moving to Action
18. Advocacy Skills
19. How to Challenge Stigmatizing Statements
110. Challenging Stigma in the Media



- ➡ Act against stigma as a community. Each community can look at stigma in their own context 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 do it.
- ➡ Think big! Start small! Act now! Have a big vision but start with something small. And don’t wait – act now!

Things you can do as individuals

- ➡ Watch your own language and avoid stigmatizing words.
- ➡ Support family members who are living with HIV.
- ➡ Visit and support people living with HIV and their families in your neighborhood.
- ➡ Encourage people living with HIV to use the available services, e.g., counseling, testing, medical care, and antiretroviral drugs (ARVs), and refer them to others who can help, e.g., counselors.

Things you can do to involve others

- ➡ Use informal conversations as opportunities to 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 people living with HIV; stories of good treatment
- ➡ Challenge stigmatizing words when you hear them, but do it in a way that does not offend people. Get people to think about how their words can hurt.
- ➡ Help normalize HIV and AIDS. People living with HIV should be seen as people with an illness, and not people with bad behavior.
- ➡ Encourage people to talk openly about their fears and concerns about HIV and AIDS.



- ➔ Correct myths and misperceptions about HIV and HIV-positive people.
- ➔ Promote the idea of a friendly ear and support to HIV-positive people and their families

Things to Do to Get the Community Acting against Stigma

- ➔ Examples of activities that get people to identify and analyze stigma in community:
 - Testimonies by people living with HIV or their families about their experiences of living with HIV
 - Language watch: school children or youth groups can make a “listening survey” to identify stigmatizing words used in the community, media, or popular songs
 - Community mapping of stigma: get the community to make a map of places stigma occurs and display the map at a community meeting place
 - Community walk to identify points of stigma in community
 - Drama by a youth group based on real examples, which can be the 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, and specific support to families living with HIV 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 his or her community.

11

Start with a Vision: “A World without Stigma”



Facilitator's Notes:

This exercise helps us develop a vision of the kind of world we want to build – a world without stigma – and then use this vision to decide on the steps to reach this vision.

If you are running a workshop that includes many different groups, divide participants into different target group to conduct this exercise (e.g. health care workers, police officers, NGO and CBO staff, and community leaders). The aim is to have stakeholders working in the same field (e.g., health workers) do this exercise as a group and agree on the changes needed within their working context (e.g., health facility).



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
- ➡ Define what the result of successful interventions would look like



Target Group:

All groups



Time:

1 hour



Steps:

1. **A world without stigma:** Hand out cards and markers. Ask participants to write pictures and words for “a world without stigma” and tape the cards on the wall as a group drawing. 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.



Then ask the group to talk about their drawing. Ask:

- ➡ 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 Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Future vision

- When people living with HIV disclose to their immediate families, they receive support and love.
- People living with HIV and families affected by HIV are no longer isolated, or hiding their situation.
- People living with HIV lead active and productive lives and feeling good about themselves.
- People living with HIV play 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 people living with HIV and accept them.
- Get community leaders to model and promote the new behaviors.
- 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 to reduce fears about infection
- Speak out against stigma towards people living with HIV, drug users, entertainment workers, women, orphans, etc.
- Encourage people living with HIV to get involved in educating the community on HIV and AIDS.



Facilitator's Notes:

In this exercise, participants work in their professional groupings, e.g., nurses, counselors, home-based care workers, teachers, etc., to analyze problems in their own context and look for solutions. This exercise can be used in large workshops where there are participants from different practitioner groups.



Objectives:

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



Target Group:

Health care providers, NGO and CBO staff, community leaders and professionals.



Time:

2 hours



Preparation:

Put up signs on different walls of the room for meeting spaces for different task groups. For instance: a) HIV-positive support groups; b) home-based care; c) counseling and testing; d) health workers (e.g., nurses); e) workplace; f) schools.



Steps:

1. **Divide into groups:** Ask participants to join their own professional groupings.



2. **Task groups:** Ask groups to discuss the following issues and develop concrete action plans:

- ➡ What forms of stigma do you see in your organization or community?
- ➡ Prioritize: what is the biggest stigma problem in your organization or community?
- ➡ What is the source of this problem?
- ➡ What are some possible solutions to this problem?
- ➡ Identify two or three specific things you would like to do to stamp out stigma in this context.

Push groups to be concrete. Say, “Think big. Start small. Act now!”

3. **Report back:** Ask each group to give a report then solicit comments from others.

4. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

Encourage groups to focus on what they can do within their own type of work, and find “small and doable” actions that they can start to do immediately, without depending on lots of outside resources.

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Health Center

Forms of stigma: Isolation and neglect of chronically ill patients. Limited physical contact by nurses because of fear of getting HIV. Nurses gossip about patient’s

Examples of Responses:

sexual history and reveal their status to other patients. Some nurses give up on patients, saying, “They will die quickly, so why waste our time.”

Strategies to combat stigma: Update health staff on HIV, ARVs, and stigma through in-service training. Help health workers talk about their own feelings and fears about HIV and treating patients. Teach how to handle patients sensitively. Teach about universal precautions. Develop codes of practice. Protect patients’ right to confidentiality. Organize “community walk” through clinic to identify stigma points (see I4 below for details of this type of activity).

Community

Forms of stigma: People living with HIV and families face isolation, gossip, and discrimination. Neighbors stop visiting, sharing food, buying from their shops or using their services, e.g., babysitting.

Strategies to combat stigma: Raise awareness and overcome fear and stigma by providing correct information on HIV and how to take care of people living with HIV. Involve people living with HIV as facilitators. Organize community meetings, peer groups, and home visits. Involve health workers in community meetings.

Home-based care (HBC) Workers

Forms of stigma: HBC workers face stigma by association; they are rejected by the community who say they carry AIDS. Patients reject them when they make home visits. Wearing uniforms triggers stigma towards the family (by neighbors).

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



Examples of Responses:

Workplace

Forms of stigma: Workers shun and gossip about other workers who are assumed to have HIV. Loss of opportunities (job, promotion) once status is known.

Strategies to combat stigma: Win support of the managers to create trustful environment and have them assure all workers that they will not lose jobs if they disclose status. Work with managers to set policies, e.g., health benefits, continuity of employment. Offer voluntary counseling and testing, and ARVs. Educate workers on rights. Encourage HIV-positive support groups in workplace. Promote a code of conduct.

Media

Forms of stigma: Sensationalized, incorrect, fear-based messages on AIDS and people living with HIV, e.g., “AIDS kills,” and “AIDS is a death sentence.” Messages that AIDS means immediate death. Contradictory information so people are confused.

Strategies to combat stigma: Provide up-to-date and correct information. Avoid threatening images. Provide positive and hopeful view of people living with HIV, e.g., pictures showing HIV-positive people in good health, living normal lives and actively contributing to their family and society.

**Facilitator's Notes:**

This exercise is designed to familiarize participants with the new AIDS law in Cambodia.

**Objectives:**

By the end of this session, participants will be able to describe the legal provisions related to HIV and AIDS in hospital settings.

**Target Group:**

All groups

**Time:**

30 minutes

**Materials:**

New AIDS Law – presentation and handouts

**Steps:**

1. **Starter quiz:** Write single questions on different sheets of paper and give one question to each participant at random. Ask each participant to read out his/her question and answer it.



- ➔ Can a health facility refuse to treat a patient because he/she is HIV-positive?
- ➔ Is a health care worker allowed to work if he/she has HIV?
- ➔ Does the hospital director have the right to know the HIV test result of a patient?
- ➔ Are pregnant women provided ARV treatment free of charge to reduce the risk of mother-to-child HIV transmission?
- ➔ Is it legal if an HIV test is conducted without a patient's knowledge?
- ➔ Under what circumstances can a person ask for an HIV test for a family member?
- ➔ The health facility that conducts the HIV test should provide the patient with pre- and post-test counseling. True or false?

2. **New AIDS Law (presentation):** Give a presentation on the new AIDS Law, using the issues raised above as a trigger for discussion. Then hand out copies of the law or a handout on the main points in the law.



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. Aimed at health and community center workers, this unit can be used as part of stigma training in the workplace.

This exercise ("Stigma Walk and Talk") could also be used as the starting point for developing a new code of practice aimed at creating a stigma-free clinic or hospital.



Objectives:

By the end of the 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



Target Group:

Health care providers, NGO and CBO staff, police, the community



Time:

3 hours



Steps:

"Spot the stigma" walk-and-talk:

The aim of this activity is to identify points of stigma in institutions that provide services to the community and then facilitate discussion to make appropriate changes. The steps in this process include:



1. **Identify the institution to be studied**, e.g., clinic or hospital, voluntary counseling and testing center, AIDS-related nongovernmental organization, etc., in consultation with the staff of the institution.
2. **Discuss with the staff** what will happen and how they will participate.
3. **Set up a joint group** comprising institution's staff and community members (including people living with HIV and HIV-affected families) to carry out the stigma walk.
4. **Orient the group beforehand.** Discuss the objectives and what the group will be looking for, i.e., places and activities where stigma is a problem, and how the activity will be debriefed and actions planned.
5. **Conduct the stigma walk.** 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 of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Waiting area: Patients shun other patients who have noticeable symptoms. Stigma is directed to people whom they merely suspect have HIV, e.g., they look very thin or have skin rashes.

Examples of Responses:

Nurse's room: One nurse showed her fear of being infected when stayed at a distance from patients. One patient dropped his tuberculosis (TB) card and others saw what happened and noticed the card. This upset him and he left the waiting area. He was worried that people would stigmatize him because TB is associated with AIDS.

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 informing women of their HIV status.

6. **Debrief:** Hold a joint meeting with the institution's staff and community members to discuss:

- ➡ What were the major forms of stigma identified?
- ➡ What are their causes?
- ➡ What can be done to avoid these problems?

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

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



Note: The detailed action plans should be developed by each department (e.g., general nursing, and antenatal) so that each department feels some commitment to the plans they have to implement.

Code of Practice: This exercise could also be used to develop a code of practice, which is a set of guidelines for health workers aimed at creating a stigma-free clinic or hospital. These guidelines would be written by the health workers and used on the job. Writing the guidelines would help to build a strong sense of ownership among staff, who would be more likely to implement the new procedures.

Applying the new code of practice on a daily basis will help to reinforce and deepen what was learned during the training. Staff will begin to internalize the new, non-discriminatory ways of working, which will become standard practice. In this way, the staff will create a stigma-free, “safe and friendly” clinic or hospital.

A number of hospitals have already developed their own codes of practice. Each code includes guidelines on the following areas of practice:

- ➡ Access to HIV Services
- ➡ Counseling and Testing
- ➡ Confidentiality
- ➡ Universal Precautions
- ➡ Training on HIV/AIDS
- ➡ Policy Implementation



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 pages below.



Objectives:

By the end of the meeting the community will have agreed on practical plans to stop stigma and discrimination towards people living with HIV and to support HIV-affected families.



Target Group:

All groups



Time:

2 - 3 hours



Steps:

1. **Warm-up:** Start with a warm-up activity to build interest and a sense of community.
2. **Community timeline:** Ask the community to discuss these questions:

What is the history of HIV in your community? What happened when the community first learned about HIV and AIDS? What is happening now?

What have been people's attitudes towards people living with HIV? How have people living with HIV been treated? How has this treatment affected families living with HIV and AIDS?

What is the community doing already to support people living with HIV?



Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

HIV and AIDS education in schools. Support for home-based care.

3. **What are communities doing?** Tell local stories about how communities are organizing themselves in response to HIV and AIDS. One example is given below.

4. **Discuss in small groups:**

- ➡ What happened in the story?
- ➡ Why was the approach successful?
- ➡ What can we do as a community to support HIV-affected households?

Examples of Responses:

In one village in Malawi the chief, a woman, was the chairperson of the village AIDS committee. The committee decided they wanted to mobilize 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."

Real Stories to inspire action

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

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 neighbors quiet. Raising the issue would bring shame.

But when three uncles died within a few months, the first-born brother was deeply affected. He called a family meeting and raised the issue of AIDS for the first time. "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 consider how they could support each other, especially those with HIV. They set up a family fund 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 to talk more openly about HIV and AIDS to protect the younger ones.



Action in the Workplace



I work for a large nongovernmental organization 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. We were all thinking about HIV and AIDS but no one said anything. Then one of my colleagues came to me and told me that a few weeks ago she had taken an HIV test and tested 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 for all staff. 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 shared their HIV-positive status 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.

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 of being 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 to try and find ways of supporting each other. They set up a rotating credit fund, to which they all contributed each month. They 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 eventually found that some of the other villagers became more sympathetic.



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 having 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 and AIDS from Philly. 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 skepticism and criticism. Everyone kept asking him, "Where did you get it?" All of this criticism did not stop Philly. He traveled 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 eventually they began to talk too, about how HIV/AIDS was affecting their own lives.

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



Facilitator's Notes:

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



Objectives:

By the end of the session, participants will have planned a campaign to stop specific forms of stigma and discrimination against people living with HIV or other stigmatized groups



Target Group:

Community, community groups



Time:

2 hours



Steps:

1. **Identify the Target:** Ask the group to identify specific forms of stigma or discrimination in relation to a specific target group, e.g., people living with HIV, and orphans.

Then ask the group to go through the following process:

- ➡ Prioritize: select one form of stigma/discrimination to focus on.
- ➡ Describe the stigma/discrimination and do situation analysis and ask: What is happening now? How are people affected? What are the obstacles to a solution?



- ➔ Make an action plan to bring about change. Brainstorm practical actions that could solve the problem. Select the most feasible actions and develop action plans by asking: What actions? Who will do it? When and where? What specific steps?

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

- Meet with community leaders to win their support for anti-stigma action.
- Organize training for community leaders and peer group leaders.
- Organize peer group meetings (facilitated by those who have been trained).
- Organize house-to-house visits to raise everyone's awareness.
- Organize a stigma walk or community mapping exercise.
- Organize awareness activities in the schools, e.g., art and drama competitions.
- Organize community meetings, and ask peer group representatives to attend.
- Organize 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 and provide support
- Organize a regular system of visits to HIV-affected households.
- Organize income-generating activities to support vulnerable households.
- Get community members to share their "AIDS survival knowledge."

Examples of Action Campaigns Against Stigma

Situational Analysis

Stigma against Orphans

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, and community members say:
 “If the parents died, the children will die too. Don’t play with them – they are getting ready to die.”

Action Steps

(Ideas from Tanzania)

- Identify the number of orphans in the community and work out how to support them.
- Change the misperception that if the parents die, the children will die too.
- Educate families on HIV transmission so they stop stigmatizing out of fear.
- Stop the “dumping” of orphans with relatives who mistreat and abuse the children.
- Get youth groups to raise this issue through drama or songs.
- Organize competitions among the children to get them to express their ideas, views and feelings through pictures, poetry, and stories.
- Get adults to look at how stigma affects children. (See exercises in Chapter G: Children and Stigma)
- Get people to treat children seriously and allow children to talk about their feelings.



Examples of Action Campaigns Against Stigma

Situational Analysis	Action Steps
<p>Stigma against Widows</p> <p>Widows stigmatized in three ways: (a) as wives of men who have died (blamed for the death of their husbands); (b) as women; and (c) 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 stigmatized by other women, who assume that widows will steal their husbands. Widows are isolated, 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 the commodities sold.</p> <p>Property Grabbing</p> <p>Relatives were taking away the property of men who had died, and using shaming and blaming as a pretext to justify this action.</p>	<p>(Ideas from Tanzania)</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 rotating credit union and other income-generating activities. • Organize meetings with other women's groups to win their support. • Organize community meetings to raise this problem and get the community to stop stigmatizing widows. <p>(Example of real action from Tanzania):</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. They told the elder they were angry about the threat of a property grabbing, and they asked him to talk to the uncle. This pressure from younger people stopped this case of potential property grabbing.</p>



Objectives:

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



Target Group:

All groups



Time:

3 hours



Steps:

Moving to Action (Small Groups): Divide into small groups (three or four members) for this exercise. After each step get a quick report back, and then move to the next step.

1. **Situational Analysis:** Ask:

- ➡ What is the current situation in the community regarding HIV stigma?
- ➡ What forms of stigma are common in the community?
- ➡ What are some of the background factors?



Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

- Lots of fear, secrecy and silence concerning HIV, and people find it difficult to talk
- HIV-affected households are the target for exclusion and discrimination.
- Fear of HIV transmission through casual contact
- Huge workload for women in HIV-affected households, including care of people living with HIV
- High levels of poverty and unemployment resulting from HIV and stigma

2. **Vision:** Ask, "What will the situation in our community look like in two years' time after our anti-stigma program?"

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

- More openness in talking about sex and HIV
- More knowledge about transmission and less fear about casual contact
- Community members helping neighbors support and care for people living with HIV
- Less gossip and name-calling towards families affected by HIV

3. **Activities:** Ask, "What activities will you carry out to reach that goal?" See list of specific actions, in the Handout at the end of this Section. Then prioritize. Ask, "Which activities are the most important?"
4. **Resources:** Ask, "What resources do we need to do these activities?"

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Funds and materials for the training workshops.

5. Obstacles: Ask, “What things might block our activities?”**Examples of Responses:**

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

- Apathy and sense of fatalism: people feeling they cannot do anything
- Poverty: people too busy just trying to survive

6. Indicators: Ask, “What things will show that we have been successful?”**Examples of Responses:**

- More people visiting each other and providing support and comfort
- People living with HIV have more say in family decision-making about their care
- More openness in discussing issues around HIV, drug use, and sex
- Increased use of health services
- Increased knowledge that HIV cannot be transmitted through casual contact
- Lower school dropout rates by orphans



Handout: Ten Steps for Moving to Action

Step	Examples
1. Where are you now? (situational analysis)	This helps you to look at what is happening at the moment regarding the stigma. You can ask, "How have things been in the past? How are they now? Where is the stigma in the community or workplace?" and other similar questions.
2. Where do you want to be? (vision)	How would things look if you could really make a difference?
3. How will you get there? (activities)	What kind of activities can you do to help reduce stigma? Brainstorm all your ideas: practical, new actions to solve the problem.
4. Where will you start? (prioritize)	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 help. Do not stop at this point; do not think you cannot 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 on how to overcome these obstacles.
7. How will you know that you are successful?	Decide how you will measure your success. Identify "indicators" or signs that will show you that stigma is decreasing (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. Replan	Make changes to your plans based on what you learn from the monitoring.

**Objectives:**

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

**Target Group:**

All groups

**Time:**

1 hour

**Steps:**

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

Advocacy is a systematic and organized effort to change and implement laws, policies, practices, or behavior. It is about social change, which involves 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 publicize the issue and influence people

2. **Steps in advocacy:**

- ➡ Select the issue or problem.
- ➡ Analyze the issue.
- ➡ Develop specific objectives. What do you want to achieve? Be clear.



- ➔ Identify your audience: Whom do you want to hear your message?
- ➔ Identify your allies: people who support your cause and people who can influence change
- ➔ Create an action plan: Describe the steps to achieve your goals and create a realistic timeline.
- ➔ Implement your action plan.
- ➔ Monitor the action, and then make revisions.

Divide participants 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.

3. Strategizing for advocacy (group work): Divide participants into groups. Ask groups to work on the matrix given below.

- ➔ What images do people have about people living with HIV?
- ➔ What are the effects of each image on people living with HIV?
- ➔ What can we do to change things? What can we advocate for?

Examples of Responses:

Images of People Living with HIV	Effects	What We Can Do
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,” i.e., we all put ourselves at risk at times in our lives.

Examples of Responses:

Images of People Living with HIV	Effects	What We Can Do
Useless. No longer productive. Waiting to die.	Treated as no longer able to contribute	Educate the community that people living with HIV can live long and productive lives. Organize a campaign against victimization of HIV-positive employees.
Dangerous: they infect other people through touch	Isolated and excluded: "quarantined"	Educate people about HIV transmission so they stop fearing casual contact with people living with HIV.

Advocacy – Handout

Advocacy is a systematic and organized effort to change or implement practices or behavior for positive social change.

Skills needed for advocacy

You will need the skills to be able to:

- Plan a campaign that will succeed in changing people's behavior
- Tell people about an issue and ask them for their support
- Find others who agree with you and are prepared to support you
- Negotiate 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, and discriminatory practices towards families living with HIV. Ask yourself:



- Is the issue widely felt, i.e., by many people?
- Is it deeply felt? Are people angry and/or frustrated?
- 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 might support your campaign and influence others. Learn about their position on the issue. Don't assume that they are opposed. They may already be convinced of the need to address stigma. Work towards garnering their support. 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 people living with HIV but the whole community. Use words and arguments from their perspective and understand their situation. Tailor what you are saying to their own interests and concerns.

Give the leaders a sense of ownership of the problem and of the need to change. Involve them in thinking through the issue themselves. Get them talking, and help them see the issue in light of their own experience.

10 Steps in an advocacy campaign

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

How to Challenge Stigmatizing Statements



Facilitator's Notes:

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



Objectives:

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

- ➔ Identify statements that are stigmatizing
- ➔ Develop arguments for challenging stigma when it occurs



Target Group:

All groups



Time:

1 hour



Materials:

Stigmatizing statements written on flipchart or cards



Steps:

1. **Challenging stigma (hot seat):** 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 or community.

Option: Ask pairs to practice responding to these stigmatizing statements.



Sample Statements:

All people living with HIV are drug users or entertainment workers.

People living with HIV deserve what they got because they have been doing bad things.

I do not want my children to go to school with a child who has HIV parents.

People living with HIV should not have children or marry.

Entertainment workers cause AIDS because they lure us into having sex.

Health workers have the right to know which of their patients have HIV.

Drug users should be closely monitored by the community authority.

Drug users should be removed from the general population and put on an island.

2. **Discuss:** “What methods work best for challenging stigma? Be specific.”

3. **Summary:** Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

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

➡ Examples of strong responses:

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



Facilitator's Notes:

This exercise is designed for all groups. It helps participants identify ways in which the media promotes stigma, e.g., fearful images, and come up with new messages to challenge stigma in innovative ways.



Objectives:

By the end of the session participants will have:

- ➡ Identified how the media promotes stigma
- ➡ Designed simple messages to challenge stigma



Target Group:

All groups



Time:

1 - 2 hours



Preparation:

Collect materials showing images of AIDS in the media, e.g., articles in local newspapers, AIDS posters, and short video clips. Photocopy them for use in the workshop, and display on tables.



Steps:

1. **Fact, opinion, or rumor (warm-up game):** Read aloud one article, pausing at the end of each statement. Ask participants to consider whether the statement was a fact, opinion, or rumor.



Ask participants to make the following responses to indicate what they think:

Fact	Raise hands in the air
Opinion	Put hands on your head
Rumor	Fold your arms

Examples of Responses:

The most common route for HIV transmission in Cambodia is sex. (Fact)
 People who get AIDS have nothing to live for. (Opinion)
 Many people living with HIV are deliberately infecting other people. (Rumor)

Summary: Bring the session to a close by summarizing the main points which participants have made during the exercise. In giving your summary you may use some of the following points, if they have not already been mentioned by participants.

The media have tremendous power to influence public opinion. What is communicated through the media, however, is often based on misinformation or rumor. We should not accept whatever we hear; we have to assess and judge it. Stigma is often based on rumor or misinformation.

2. **Spot the stigma (reading):** Divide into pairs and give each pair a newspaper article. Ask each pair to read its article and identify stigmatizing language. Record each stigmatizing phrase on cards and tape on the wall.

Debriefing: Ask each pair to read out the stigmatizing phrases they found in their article. For each phrase, ask:

- ➡ What are the attitudes behind the stigma?
- ➡ How would this make an HIV-positive person feel?

Examples of Stigmatizing Phrases

"AIDS kills."

"AIDS is a death sentence."

"People who get AIDS have nothing to live for."

"People living with HIV are all drug addicts."

"Innocent victims."

"A person living with HIV took revenge on a neighbor by injecting his son with contaminated blood."

Summary: Explain that fear-based messages do not change people's behavior but help to drive the epidemic underground.

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

- Creating fear: "AIDS kills," "AIDS is a death sentence," "nothing to live for"
- No positive images of people living with HIV and AIDS
- "Innocent:" implies that the others are guilty
- "Promiscuous:" shaming and blaming
- "Victims:" this is disempowering; people living with HIV do not see themselves as victims

How would this make an HIV-positive person feel?

Shunned. Misunderstood. Wanting to die immediately. Scared.



3. **Making anti-stigma messages (cardstorm in pairs):** Ask the same pairs to write slogans on cards promoting a new, more caring message, e.g., “The whole leaf covers the torn leaf.”

Summary: The slogans should show that HIV-positive people’s lives are not over. They are not simply waiting to die. They can be just as productive as anyone else.

Examples of Responses:

The examples below are not the required answers, and you are not expected to read them out loud. They are included to illustrate the type of responses expected and can help you identify issues you may want to raise, if they are not raised by participants. However, you should let each group come up with their own ideas. Remember: There are no right or wrong answers.

Examples of messages from anti-stigma campaigns in Africa

- A friend with HIV is still a friend.
- Do not point fingers. Anyone can get HIV and AIDS.
- People living with HIV need your care and compassion.

Messages from a workshop

- The community has a duty to look after each other.
- People living with HIV deserve hope. They can live long lives.
- We are all HIV-affected: AIDS is a part of all of our lives.

Optional Exercise on Stigma and Media:

People living with HIV who attended the stigma awareness workshop in Vietnam (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.”

1. Provide different types of media, e.g., AIDS posters, newspaper stories and short video clips, which show positive and negative images of people living with HIV.
2. Divide into groups to analyze these materials:
 - ➡ What do you think about these images? What feelings do they trigger? (e.g., fear)
 - ➡ What is the rationale behind these images? (e.g., fear is used to persuade people to avoid social evils like drug use and commercial sex.)
 - ➡ What are the problems with this fear-based approach? What are the unintended consequences of this approach? (e.g., it creates stigma towards people living with HIV and makes them want to conceal their illness and avoid getting treatment)
 - ➡ What alternative approaches can be used in the media? Example: cultural images or proverbs promoting a more caring approach. Example: “The whole leaf covers the torn leaf” means the community has a duty to look after each other. What are the core values in Cambodian culture that support a more caring approach?

Annex A – Information Sheets

Information sheet 1	HIV and AIDS: The Basics
Information sheet 2	HIV Transmission
Information sheet 3	HIV and AIDS – Frequently Asked Questions
Information sheet 4	Mother to Child Transmission (MTCT)
Information sheet 5	Tuberculosis (TB)
Information sheet 6	Antiretroviral (ARV) Therapy
Information sheet 7	HIV Testing – Voluntary and Confidential Counseling and Testing (VCCT)

Annex A

Information Sheet 1

HIV and AIDS: The Basics

What is HIV?

HIV stands for **H**uman **I**mmunodeficiency **V**irus:

Human: HIV affects only human beings, and its mode of transmission is person-to-person.

Immunodeficiency: HIV creates a deficiency within the body's immune system and weakens it, thereby making the body more vulnerable to disease and infection.

Virus: HIV is a virus, classified within a family of viruses known as "retroviruses."

How does HIV work inside the human body?

HIV attacks the body's immune system. The immune system is the body's defense against sickness and disease, and includes CD4 cells that fight against germs entering the body. When a person contracts HIV, the virus invades the CD4 cells and damages them to the extent that these cells can no longer perform their function of protecting the body and keeping it healthy. Germs then take advantage of the weakened immune system and attack the body.

How does HIV harm the body?

When HIV invades a host CD4 cell, it uses the machinery of the cell to make copies of itself. These copies (new viruses) leave the host cell to infect more cells. Each infected cell becomes damaged and eventually dies, thereby weakening the immune system. HIV can exist and flourish alongside antibodies produced to fight against it by the host cell, so the body continues to weaken.

This weakening of the immune system occurs over a period of time. People do not acquire HIV and die immediately. Most people who have been recently infected with HIV do not display or notice any symptoms. Some people may suffer flu-like symptoms for a few weeks shortly after being infected, but there are no other signs of early HIV infection. The infected person feels healthy for a while, but over time the immune system becomes weak and unable to resist germs and disease. (However, the virus remains in the body and can be passed to other people.) At this stage the person is "HIV-positive" but has not developed Acquired Immunodeficiency Syndrome or AIDS.

Eventually, the weakened body becomes so vulnerable to infection that it is attacked by diseases such as tuberculosis (TB), pneumonia, cancer and meningitis – what are called "opportunistic infections" or OIs. When the body is too weak to fight these diseases, the person is said to have AIDS: a collection of diseases that attack a person after HIV has made the body weak. When the body is severely weakened, the person can die from one or more of these opportunistic infections.

HIV invades the body like termites invading a house. To begin with, there is no warning and no visible damage. The virus hides inside white blood cells (CD4 cells) and multiplies – just like termites hide inside and eat the timber which holds the house together. Nobody realizes that the structure of the house is being slowly and invisibly weakened. One day a strong wind comes along and knocks the house down.

What is AIDS?

AIDS stands for Acquired Immunodeficiency Syndrome:

Acquired: not born with; something that a person gets from another person

Immuno-: relating to the body's immune system, which is the part of the body which fights off germs

Deficiency: the immune system is not working properly to fight off disease/infection

Syndrome: a set of illnesses that attack the body when its immune system is weak

AIDS is the advanced stage of HIV infection at which the body's immune system has become extremely weak. HIV slowly destroys the power of the body to fight infection and disease. The person becomes seriously sick and vulnerable to a group of diseases or "opportunistic infections," and falls ill frequently from one or more of these infections. This is called the "syndrome," and can eventually lead to death. The symptoms of AIDS include swollen glands, weight loss, frequent fever, diarrhea, cough and skin problems.

Information Sheet 1 – HIV and AIDS: The Basics

What is the difference between HIV and AIDS?

- HIV is the virus that causes AIDS. It develops slowly in the body over a period of time and, as it develops, destroys the body's capacity to fight infection and disease.
- AIDS is the advanced stage of HIV infection when HIV has destroyed the CD4 cells which protect the body's immune system. The body is then susceptible to infections, including TB, pneumonia, cancer, meningitis and other illnesses.

A person infected with HIV can remain healthy for many years with no physical signs or symptoms of infection. A person with the virus but no symptoms is HIV positive. Most people living with HIV do not even know that they have the virus.

Once a person living with HIV begins to get sick and develop opportunistic infections, she/he is said to have AIDS. "AIDS" is a clinical definition given to people living with HIV who have a CD4 count of below 200, or have contracted one of a number of infections including TB, rare cancers, and eye, skin and nervous system conditions. (A CD4 count is a test to count the number of CD4 cells, the infection-fighting blood cells which are attacked and killed by the HIV virus. As these cells are destroyed, the body's immunity is lowered and it becomes susceptible to a variety of opportunistic infections.)

Where does HIV come from?

Nobody knows where HIV came from, exactly how it works, or how to eliminate it from a person. When AIDS first appeared in a country, people mistakenly blamed the causation and spread of the disease on groups such as poor people, sex workers, men who have sex with men, migrant workers, and similarly-marginalized social groups who were more vulnerable to HIV infection because of poverty and lack of access to services or information. People who did not belong to the accused groups erroneously thought that only those groups were vulnerable to HIV infection and that "it can't happen to me." Misinformation and confusion about where AIDS comes from, how it works and whom it affects make many people deny that it even exists.

How is HIV transmitted?

There are three ways that HIV is passed from human to human. The most common way is through sex.

1. **Sex:** If a person is HIV positive, HIV can be passed from his/her infected blood, semen or vaginal fluids directly into another person's bloodstream through the lining (mucous membrane) of the vagina, penis or rectum. During sex it is normal that friction will cause tiny scratches (or micro-abrasions) in these linings, which permit HIV to enter the bloodstream.
2. **Mother-to-child transmission (MTCT):** HIV can be passed from an HIV-positive mother to a baby during pregnancy, delivery, and breastfeeding. However, not all babies born from HIV-positive mothers will have HIV. About one-third become infected with HIV if the mother has not been treated with antiretroviral (ARV) drugs. (See MTCT Information Sheet).
3. **Blood transfusions and unsterilized equipment:** HIV can be transmitted by HIV-infected blood transfusions, contaminated injecting equipment (syringes/needles), and razors. People who inject drugs are at risk of contracting and spreading HIV through sharing needles. Care should be taken with needles used for injections and with razors: every needle or razor should be sterilized. In the case of repeated use, the needle or razor should be re-sterilized before it is used by another person. Open wounds should be kept covered at all times, on every person, whether the person is living with HIV or a caregiver.

For HIV to spread, HIV found in an infected person's blood, semen or vaginal fluids has to get inside the other person's blood supply through openings in the skin, like needle punctures, cuts and wounds.

Information Sheet 1 – HIV and AIDS: The Basics

How is HIV not transmitted?

HIV can live only inside a human body. It cannot survive outside the human body – it starts to die as soon as it is exposed to the air. If HIV is exposed to heat (for example, if an HIV-positive person bleeds into a cooking pot) it will die.

HIV cannot pass through the skin on the outside of your body unless there is an open cut. It is easier, however, for HIV to pass through the skin on genitalia during sex because the skin in this area is thin and permeable, allowing HIV to pass through. Infections in the genital area (e.g., sexually transmitted infections or STIs) provide an easy way for HIV to enter the bloodstream, so people with STIs are at higher risk of becoming infected with HIV than other people.

HIV cannot be transmitted through saliva, tears, vomit, feces or urine, although tiny amounts of HIV have been found in these fluids. HIV is not found in sweat.

HIV cannot be transmitted through unbroken skin (skin not broken by cuts, wounds, sores, lesions, etc.).

HIV cannot be transmitted through casual contact, including: touching someone with HIV; touching or using something an HIV-positive person has used (e.g., clothing); sharing eating or drinking utensils; using the same toilet seats.

Caring for people living with HIV is not risky if the person follows sensible precautions such as disposing of sharp needles safely and keeping cuts covered.

HIV is not transmitted by mosquitoes or other blood-sucking insects. Most insects do not pass blood from one person to another when they bite humans. For example, the malaria parasite enters the bloodstream in mosquito saliva, not blood.

How can you prevent HIV infection and spread?

- If you have sex with many partners or you are unsure of your partner's sexual relations, always use or insist on a condom during sex.
- Protect yourself from contaminated bodily fluids.
- Use disposable syringes obtained from a reliable source. Never reuse syringes.
- Women who are pregnant or intending to get pregnant should access MTCT prevention services to prevent HIV transmission. (See MTCT Information Sheet).
- Blood transfusion: insist on having blood that has been tested for HIV from a licensed blood bank. It is safer when a known person donates blood for you but not foolproof, so all transfused blood should be pre-tested for HIV.

The HIV Transmission Equation

Human host with HIV: a human being has to carry the virus in order to infect another person

- + **Body fluid that carries large amount of HIV:** blood, semen, vaginal fluid or breast milk
- + **Opening into the bloodstream:** such as needle holes or cuts/tears in the anus, vagina, or penis
- + **Activity that can move these fluids between people:** unprotected sex (anal, oral or vaginal), sharing infected needles, breastfeeding, or blood transfusion with infected blood

= **Possibility of infection**

QQR Quality, Quantity, Route of Transmission

For HIV transmission to take place, the quality of the virus must be strong, a large quantity must be present, and there must be a route of transmission into the bloodstream. All of these things must be present for someone to get infected with HIV.

Quality: For transmission to take place, the quality of the virus must be strong.

- ➡ HIV cannot survive outside the body. It starts to die the moment it is exposed to the air.
- ➡ HIV is not an airborne virus. This is why there is no risk of transmission in sitting close to or sharing the same room with someone living with HIV.
- ➡ HIV does not live on the surface of the skin; it lives inside the body. There is no risk from shaking hands or hugging someone. The only place the virus can survive outside the body is in a vacuum (like inside a syringe) where it is not exposed to air.
- ➡ HIV will die if it is exposed to heat, e.g., if someone bleeds into a cooking pot.

Quantity: For transmission to take place, there must be enough quantity of the virus.

- ➔ HIV is found in large quantities in blood, semen, vaginal fluids, and breast milk.
- ➔ HIV is not found in sweat or tears.
- ➔ HIV can be found in very small amounts in saliva, vomit, feces, and urine, but the quantity of HIV is not enough for there to be any risk of transmission.
- ➔ Cleaning or bathing a patient is quite safe, provided that if the caregiver has any wounds, these are covered.
- ➔ Kissing, even deep kissing, poses no risks.

Route of Transmission: For HIV transmission to take place, the virus must get inside your bloodstream.

- ➔ Our body is a closed system, and HIV cannot pass through unbroken skin.
- ➔ HIV can pass through the skin on the genitals – penis, vagina, or anus – during sex because the skin there is much thinner and has small openings through which HIV can pass.
- ➔ The vagina has a large surface area of mucous membranes which can get cut during sex, allowing HIV to get into the body and bloodstream of the woman.
- ➔ The rectum has a large surface area and the skin in the rectum is very susceptible to tears during anal sex, especially if the inserting partner is not using lubricant. This is why it is very important to use water-based lubricant during anal sex.
- ➔ The skin on the penis is stronger than the skin in the vagina; it is less prone to cuts so it is less vulnerable to penetration by HIV. However, HIV contained in blood and rectal fluids can pass through the urethra of the penis or under the foreskin of someone who is uncircumcised. Men who are uncircumcised are more likely to become infected with HIV if exposed during unprotected anal sex than men who are circumcised.
- ➔ When we inject drugs, the infected blood can go directly into the bloodstream.

Information Sheet 2 – HIV Transmission

Following common sense and observing good everyday hygiene means that many occurrences people worry about would not really happen in everyday life. We would not put ourselves in these positions because of standard concern about hygiene. For example, you would not share a toothbrush if it were covered in blood; you would wash if you cut yourself; and you would wear gloves or cover your hands when cleaning up someone's diarrhea.

Using QQR you can see why there is no risk of HIV transmission by:

Kissing. Hugging. Sitting beside or sharing rooms with people living with HIV. Mosquito bites. Sharing cups, glasses, plates, bowls, and chopsticks. Sharing sheets, towels, or clothes. Giving blood. Sharing toilets. Using the same washing water. Sneezing or coughing.

These three conditions quantity, quality and route of transmission (QQR) explain why HIV cannot be transmitted by activities such as:

- ➡ Touching the skin or sweat of a person living with HIV
- ➡ Changing the clothes of or serving food to a person living with HIV
- ➡ Taking the blood pressure of a person living with HIV
- ➡ Shaking hands with someone living with HIV
- ➡ Hugging someone with HIV
- ➡ Kissing someone with HIV when your mouths are clean and clear of cuts or sores

Factors which increase the risk of HIV transmission through sex:

- ➔ Viral load of the HIV-positive person: Higher viral load increases the risk of HIV transmission. The highest viral loads occur at the initial stage of HIV infection (before an individual even tests positive for HIV) and in the final stages (full-blown AIDS).
- ➔ Having multiple partners: If you have sex with multiple people regularly and do not use condoms with all partners, HIV can pass quickly to other members of your sexual network. Remember, a viral load (quantity) is highest immediately after infection. So, if you got infected last week and have unprotected sex with someone else today, you are more likely to pass on the virus.
- ➔ Presence of cuts or wounds: Wounds or cuts on either sexual partner's body increase the risk of HIV entering the bloodstream during sexual activity.
- ➔ Presence of other sexually transmitted infections (STIs): STIs cause sores or broken skin, making it easier for infected blood to get through the skin into the bloodstream.
- ➔ Having sex during a woman's menstrual period: The presence of blood increases the vulnerability to and risk of HIV transmission.
- ➔ Using Vaseline, lotion or oil as a lubricant for condoms: Not using a water-based or silicone-based lubricant can cause condoms to break.

Annex A

Information Sheet 3

Frequently Asked Questions (FAQs) about HIV and AIDS

Can you tell if someone has HIV by looking at them?

No. The only way to know if someone is infected with HIV is from the results of a blood test. Most people living with HIV look healthy, and do not have symptoms for many years. It is only at the end stages of HIV infection that people tend to become visibly ill, showing the signs and symptoms of AIDS.

Can mosquitoes transmit HIV from one human being to another?

No. The HIV virus cannot live outside the human body or a closed vacuum like in syringes. HIV (H = Human) is a virus that cannot survive in mosquitoes.

Can HIV be transmitted through razor blades or sharp instruments?

There is a slight risk. For example, if a razor is used quickly to make incisions or cuts on many people one after the other without washing it, there is a risk of transmitting HIV. The same holds for sharing razors to shave, or to cut hair. It is safer – and more hygienic – to sterilize sharp instruments by boiling them or washing thoroughly with rubbing alcohol, or to use new razors every time. If a shared razor is covered in blood, you should wash it thoroughly before using it.

Can I get HIV by touching someone who has open cuts and sores?

No. Unless a person is covered in her/his blood and you are injured badly yourself with open wounds, then there is no risk. Your skin protects you. If you are bleeding, your blood flows outwards and away from your bloodstream. For the sake of good hygiene, if you are caring for someone (regardless of her/his HIV status) and she/he is bleeding, you should use gloves or cover your hands, and wash well before and afterwards.

What about cleaning up diarrhea of an HIV patient – can I get infected?

There is no risk. Diarrhea does not contain the HIV virus, unless there is blood in the feces. Even then, the bloody feces would still have to get inside your bloodstream. For hygienic reasons, you should use gloves or cover your hands at all such times.

How long can you live if you get HIV?

This depends on many factors. If you are healthy, can eat well, maintain a positive attitude, and surround yourself with other people's love and support, you can live for many years. If you

can access antiretroviral drugs (ARVs) and take them correctly and consistently, you can lead a healthy, productive and long life. Remember: HIV and AIDS are different things, because they are different stages of disease. With HIV, you are infected with the virus but you are healthy. With AIDS, your immune system has become significantly weakened and you may have a number of opportunistic infections. It is important to treat these infections. Always remember: discovering that you are HIV-positive is NOT a death sentence.

Is it true that condoms are not really safe?

If used properly, condoms offer 98% protection against HIV and other sexually transmitted infections or STIs (and pregnancy). The virus cannot pass through a condom. Make sure your condoms are not out-of-date, and store them in a cool and dry place. Do not use Vaseline, lotion or oil on a condom, as this can make them break. Never use more than one condom at a time, because the friction between condoms can cause tears and breakage.

Is there any cure for HIV?

There is no cure yet, but an increasing number of treatments are available which slow down the impact of the HIV virus. The combination of treatments is called antiretroviral therapy, or ARV therapy. ARVs are becoming more available, cheaper and easier to access in Cambodia. (See ARV Information Sheet).

Can a man cure HIV or STIs by having sex with a virgin?

No. The man will still have the virus or STI in his body after sex, and he may infect the virgin as well.

Can oral sex spread HIV and other STIs?

If there are no cuts, sores or STIs present, oral sex is very low risk for getting HIV. Saliva contains a natural enzyme that kills HIV. However, oral sex is high risk for spreading other STIs, such as chlamydia and gonorrhea.

Is it true that I can get HIV from someone even if they tested negative?

Yes. Many people choose to have unprotected sex because they think their partner is negative. Too often, people forget about or do not know about the “window period.” When a person contracts HIV, it takes up to three months for that person to test positive. This “window period” is when the viral loads are highest, and a time when a person is most infectious.

Annex A

Information Sheet 4

Mother-to-child Transmission (MTCT)

What is mother-to-child transmission (MTCT)?

When HIV passes from an HIV positive mother to her baby, it is called “mother-to-child transmission” or MTCT.

How does the baby become infected with HIV?

- ➡ Babies may contract HIV while they are in the mother’s womb. The blood circulatory system of the fetus is separate from the mother’s system. The fetus floats in a bag of liquid, and is attached to the mother’s uterus by the placenta, which acts as a barrier between the mother's blood and the fetus's blood. The mother’s blood carries nutrients to feed the fetus after passing through the placenta. The placenta is meant to filter out entities that can harm the fetus, like infections, but sometimes fails. At such times, HIV can pass from an HIV-positive mother into the fetus.
- ➡ Babies may contract HIV through direct contact with blood and fluids during birth. Most HIV transmission occurs during labor and delivery. When the baby travels through the mother’s birth canal, the baby’s skin can get damaged and HIV can be transmitted when the baby comes into contact with the HIV-positive mother’s blood. If the mother experiences bleeding during delivery due to cuts, or from medical and other instruments used to facilitate the delivery, the baby's chances of contracting HIV increase.
- ➡ Babies may become infected with HIV when the mother is breastfeeding. The chances of the baby contracting HIV are high when the HIV-positive mother has a high level of the virus ("high viral load") in her blood at the time of breastfeeding. If the mother has cracked nipples, painful swelling of the breasts through mastitis (an infection of the breast tissue that causes pain, swelling and redness), or if the baby has thrush (fungal disease) or sores in the mouth, the risk of transmission increases.

Why do some babies born to HIV-positive women get infected and others do not?

Roughly one-third of HIV-positive mothers pass the virus to their babies. The more HIV is present in the mother's blood, breast milk and other fluids, the higher the chance of transmitting HIV to the baby. The amount of HIV present varies, depending on the stage of the illness. Soon after a person is infected with HIV, a high viral load is present in the blood and bodily fluids because fewer antibodies are present to fight the virus. Later, if the person gets sick with illnesses caused by HIV, the viral load increases. When the person becomes very ill (has AIDS), the virus is very high and can be passed on easily. Therefore, if a woman becomes infected with HIV while she is pregnant or breastfeeding, then the chances of that baby contracting the virus increase. If a woman gets pregnant or breastfeeds when she is showing signs of AIDS, then the chances of the baby contracting HIV are high.

What can be done to reduce mother-to-child transmission?

Antiretroviral (ARV) treatment is available for expectant mothers during pregnancy and delivery and may be prescribed to the newborn infant as a precaution. With treatment, the chance of MTCT is reduced from 30 percent to 10 percent.

Treatment regimens and feeding guidelines to reduce MTCT vary across different countries and regions. Single-dose nevirapine (NVP) is commonly prescribed to mothers in addition to a prophylactic treatment regimen for the newborn. All expectant mothers should be tested for HIV, so that if they are living with HIV, they can receive a treatment regimen that is right for them during pregnancy, delivery and post-delivery. It is just as important to prevent HIV infection in the expectant mother during pregnancy and later, when she is breastfeeding.

How can HIV transmission during breastfeeding be minimized?

Exclusive substitute feeding – that means never giving the baby breast milk – significantly reduces HIV transmission. However, for many women, exclusive substitute feeding may

Information Sheet 4 – Mother-to-child Transmission (MTCT)

not be feasible or sustainable in their community due to unclean drinking water and/or unaffordable alternative feeding options. If formula is prepared without clean drinking water, the newborn may become infected by other significant diseases. Therefore, if clean drinking water is not available or if exclusive substitute feeding is not sustainable, exclusive breastfeeding is advised.

To minimize HIV transmission, women who cannot exclusively substitute feed their babies are advised to engage in exclusive breastfeeding. Breast milk provides the baby with the best nutrition and protection from infection. Mothers who choose to breastfeed should engage in exclusive breastfeeding for the first four to six months – this means giving the baby breast milk only, with no other food or drink, not even water. If the baby takes anything else besides breast milk, e.g., cow's milk or other foods, these foods can damage the lining of the baby's alimentary canal (e.g., stomach and intestines). If the mother is HIV-positive, the virus can infect the baby through the damaged lining. Babies who receive mixed feeds (e.g., mixing formula and breast milk, or feeding with breast milk and also with other fluids or solids) are more likely to become HIV-infected than those who receive exclusive breastfeeding or exclusive substitute feeds. It is therefore advisable to wean the infant abruptly after six months of exclusive breastfeeding. Mothers should change to exclusive substitute feeding without mixing feeds.

In addition to exclusive breastfeeding for the first four to six months, newborn infants may receive extended ARV prophylaxis to prevent HIV transmission.

What is the role of men in preventing MTCT?

The most important step to reduce MTCT is to prevent HIV infection to begin with. Men can help prevent MTCT by being tested themselves for HIV, and if HIV positive, by taking steps to prevent HIV transmission to their partners (e.g., by using condoms), and by supporting their partners to be tested for HIV. It is important to prevent infection in the expectant mother during pregnancy and later, when she is breastfeeding. For the health safety of everyone in the family, and particularly the expectant mother, men should minimize risks that will lead to infection with STIs, including HIV. They can avoid infections

by staying faithful to their partners and not having sex with other partners. If they are not able to abstain from sex with other partners, they should use condoms with all sexual partners, i.e., their counterparts in casual sex and their long-term partners/wives.

Men should support their partners to be tested for HIV before planning a pregnancy. Men with expectant partners living with HIV can help prevent MTCT by encouraging their partners to seek and adhere to treatment for preventing MTCT during pregnancy, childbirth and breastfeeding.

Answers to Some Questions on MTCT Prevention

Why are all babies born to positive mothers not infected with HIV?

Many people do not realize that the baby's blood system is separate from the mother's. The placenta acts as a barrier between them. Sometimes HIV can move across the placenta to the baby due to failure of the placenta to block harmful entities, but this is uncommon. During delivery, when the baby travels through the mother's birth canal, damage can occur to the baby's skin and HIV can be transmitted when it comes into contact with the mother's blood. Medical and other instruments used to facilitate delivery also can cause similar damage to mother and baby. This is why MTCT of HIV occurs mostly during labor and delivery.

How can ARV drugs be used to prevent mother-to-child transmission of HIV?

There are different national guidelines for using ARV drugs to prevent MTCT. An ARV drug (such as AZT or zidovudine) may be given to the mother starting as early as the 28th week of pregnancy and may continue post-delivery. Single-dose nevirapine may be used in combination with lamivudine during labor, and a prophylactic ARV regimen may be administered to the newborn after delivery and during breastfeeding. The use of ARVs during pregnancy and delivery significantly reduces the risk of HIV transmission from mother to child.

**Information Sheet 4 –
Mother-to-child Transmission (MTCT)****What is the effect of ARV drugs on the mother?
Is there any harm to the child?**

The ARV drug slows viral replication and lowers the amount of virus in the body. This reduces MTCT and does no harm to the pregnant woman. The sole purpose of using this drug is to reduce the risk of passing HIV to the child. The drugs have no negative effect on the child.

If a woman takes this ARV drug to prevent MTCT and then stops, won't her viral load shoot up and her immunity become much worse?

When a mother takes ARVs for MTCT prevention, her viral load will fall. This is how HIV transmission is prevented. When she stops taking it, her viral load will return to the level she had before she started taking the ARVs. Therefore, although stopping ARVs will not deal with the mother's HIV condition, it will not make it worse. It will not increase her viral load or weaken her immune system.

Is there a risk of drug-resistant HIV developing if a pregnant woman takes ARVs?

This risk is considered to be minimal when taking a short course of ARVs.

Can a mother keep taking ARVs after the baby is born, for her own health?

Taking a single ARV is not effective in treating HIV. It is usually recommended that a combination of two, usually three ARVs is needed to treat HIV. Therefore, taking one ARV drug alone on a long-term basis may not be of any benefit to the mother. This can also lead to drug resistance. It is best to consult a health professional to determine the right treatment regimen for the mother before, during, and after pregnancy.

We are told that women should not take medicine during pregnancy because the medicines can damage the baby. Can AZT harm the unborn baby?

AZT use for MTCT prevention is recommended by the World Health Organization (WHO) and is safe for the baby.

Shouldn't HIV-positive women be discouraged from having children?

It is every woman's right to decide for herself whether or not to have children. The responsibility of health workers is to provide HIV-positive women and their partners with comprehensive information about the risks associated with childbearing, the risks of MTCT and the additional burden on the family if the child is HIV-positive. But the final decision is the woman's, and she should not be pressured into not having children. The health workers should support whatever decision she makes.

If a pregnant woman is HIV positive, shouldn't she be forced to tell her husband?

Ideally, all people living with HIV and AIDS should disclose their status to their partners, in order to prevent HIV transmission to an uninfected partner and to gain the partner's support. The couple should be encouraged to come together for counseling and the partner encouraged to seek Voluntary Counseling and Testing (VCT) to learn his/her status.

However, some HIV-positive pregnant women will feel unable to discuss this with their husbands/partners. They may be concerned that they will be blamed, beaten and abandoned. If an HIV-positive pregnant woman decides to disclose her status then discussion with her partner would be valuable, but the initial decision to disclose status or not should be hers.

Annex A

Information Sheet 5 **Tuberculosis(TB)**

What is Tuberculosis (TB)?

Tuberculosis, which is commonly called TB, is an often fatal disease of the lungs and other parts of the body caused by germs. Most people with TB have TB of the lungs (pulmonary TB). TB can travel through the blood, and therefore can attack other parts of the body, including bones, brain, glands, kidneys, nervous system and spine.

How is TB transmitted?

TB germs are spread by TB patients who are not undergoing medical treatment for TB. TB is spread through sputum (droplet nuclei) through actions including coughing, spitting and sneezing. People nearby may breathe in this bacteria-containing sputum and become infected. However, not everyone who breathes in TB germs will get the disease. If a person is healthy and strong, the body may successfully fight the germs.

How does a person know if she/he has TB?

Some of the signs of TB include: coughing (productive and bringing up sputum or blood, rather than a dry cough), weakness and fatigue, loss of appetite, unexplained weight loss, pain in the chest, chills, fever, sleeplessness and, sometimes, night sweats. A person who suspects that she/he has TB should go to the nearest clinic and undergo testing.

TB is treatable and curable.

The treatment for TB requires a person to take a tablet every day for a period between six months and one year. After the first 2-3 weeks of starting the treatment, the person is no longer infectious. It is very important that the patient remember to take the treatment every day without missing a dose, otherwise the TB germs may get stronger and the medicine will become less effective.

Do TB patients need to be isolated?

No. Two to three weeks after treatment is started, the patient is no longer infectious. However, during these initial 2-3 weeks, the patient's house must be well-ventilated, and the patient should cover the mouth when coughing. After 2-3 weeks, the patient can eat, sleep, and work with others as usual, as long as the medicine is taken regularly. There is no need for special utensils or separate bedding.

TB and HIV

If a person is infected with TB, it does not mean she/he has HIV or AIDS. However, if a person is living with HIV, vulnerability to contracting TB is increased because the body's immune (defense) system is weakened by HIV. An HIV-positive person can take a course of treatment that will prevent becoming infected by TB. In many places, this preventive treatment is freely available. If a person is living with HIV and becomes infected with TB, the TB can be cured with treatment.

Annex A

Information Sheet 6

Antiretroviral (ARV) Therapy

How HIV makes the body sick. There are many different kinds of cells in the human body. For example, blood contains numerous microscopic white blood cells, also known as CD4 cells.

White blood cells protect the body. The white blood cells are part of the body's immune system. They attack germs that get into the body, thus preventing illness and maintaining health.

Once a person becomes infected with the Human Immunodeficiency Virus or HIV, the virus takes up residence and multiplies in the white blood cells. HIV attacks and damages the white blood cells. As a result, the white blood cells cannot do their work of preventing infection and thereby keeping the body healthy. Germs then take advantage of the weakened immune system and attack the body.

This weakening of the immune system occurs over a period of time. People do not contract HIV and die immediately. Most people who have been recently infected with HIV do not display or notice any symptoms. The infected person feels healthy for a while, but over time the immune system becomes weak and unable to easily resist germs and disease. (However, the virus remains in the body and can be passed to other people.) At this stage the person is "HIV-positive" but has not developed Acquired Immunodeficiency Syndrome or AIDS.

Eventually, the weakened body becomes so vulnerable to infection that it is attacked by diseases such as tuberculosis (TB), pneumonia, cancer, and meningitis – what are called "Opportunistic Infections" or OIs. When the body is too weak to fight these diseases, the person is said to have AIDS: a collection of diseases that attack a person after HIV has made the body weak. When the body is severely weakened, the person can die from one or more of these OIs.

What is antiretroviral therapy (ARV therapy)? Antiretroviral (ARV) therapy is a combination of medication – usually two or more medicines – that is taken by an HIV-positive person to slow down the spread of HIV in the body. ARV drugs help improve the immune system, and this helps the body protect itself against AIDS-related diseases. ARV drugs reduce the level of the virus in the body or the "viral load," and prevent the destruction of CD4 cells (thereby increasing the CD4 count). If ARV drugs are taken properly, they can help a person lead a healthy, productive and long life.

ARV therapy is not a cure for HIV or AIDS. The medicines will reduce the amount of virus in the body and make people feel healthier, but HIV is still in the blood. Therefore, once people start to use ARV therapy, they should continue with it for the rest of their lives. ARV therapy is a lifelong commitment: If people stop taking treatment, HIV will continue to grow in their bodies and they will become sick again.

People taking ARV therapy need to take their medicine at the right time and in the right way every day. If they stop, or forget to take their medicines, HIV will become stronger and may become resistant to the medication which, consequently, will no longer work.

ARV therapy is given to people who are HIV-positive but do not yet have AIDS, and to people who have AIDS. However, not every HIV-positive person needs ARV therapy. Only those people whose immune systems have been seriously weakened by HIV need ARV therapy.

Once a person discovers that she/he is HIV-positive, the following tests will be provided by health staff:

CD4 Count Test: This blood test measures the amount of white blood (CD4) cells. The CD4 Count Test establishes a person's need for ARV therapy (when the CD4 count is low).

Viral Load Test: This blood test measures the amount (viral load) of HIV in the blood. The Viral Load Test evaluates the efficacy of the medicine and determines the extent to which the immune system is becoming stronger.

Information Sheet 6 – Antiretroviral (ARV) Therapy

ARV therapy is usually started during the final phase of HIV infection when the CD4 count is less than 250. Treatment is begun before the patient becomes too sick from OIs. If treatment is started too late, the patient will be too sick for the immune system to be helped to fight off OIs.

When people start ARV therapy, their bodies may react to the medicine. These side effects may include: stomach pain, nausea and vomiting, diarrhea, skin rash, excessive tiredness, headaches, tingling feeling in fingers and toes, and sleep disturbance. People should not stop taking the medicine when they have these side effects, but they should report them to the health staff.

Advantages of ARV therapy:

- ➡ People living with HIV remain healthy longer, and are able to lead a normal life and contribute to family income.
- ➡ Being productive and healthy reduces the occurrence of depression.
- ➡ ARV reduces the viral load and, consequently, the risk of infecting others.

Possible disadvantages of ARV therapy:

- ➡ Cost: The cost is high, but some government hospitals are providing ARV drugs free of charge with support from the Government and donors.
- ➡ Side effects: These can occur, but most side effects disappear after a few months.
- ➡ Adherence: ARV drugs need to be taken in a timely manner for the rest of the HIV-positive person's life.
- ➡ Drug resistance: ARV drugs must be taken correctly or the virus can mutate and become resistant to a particular drug, thereby rendering ARV therapy useless.

Non-adherence and drug resistance

- ➡ The correct doses of ARV drugs should be taken on a regular and ongoing basis for the rest of the HIV-positive person's life.
- ➡ Some patients want to stop taking ARVs after six to twelve months, which is when they may start to feel better. This is dangerous to the patient's continued well-being and should be discouraged.

If patients stop treatment, even for a short period, this could result in:

- ➡ Rapid decline in health, increase in OIs, and faster progression of HIV infection
- ➡ Drug resistance: ARV drugs initially prescribed will no longer be effective. This reduces the number of treatment options from this point on.
- ➡ When HIV becomes resistant to one drug, it may become resistant to other drugs in the same group.
- ➡ Anyone infected by the person who has drug-resistant HIV will not be able to use those ARVs to which the virus is resistant, because drug resistance is passed on with the virus.

Is ARV therapy the only medication available for people with HIV? No. People living with HIV often receive other medications for opportunistic infections such as TB.

People taking ARV therapy should try to live healthy and positive lives to help the ARV therapy fight the HIV in their bodies. Things they can do include:

1. Eating good food and drinking plenty of liquids to strengthen their bodies and keep up body weight. People living with HIV lose weight as a result of OIs or lose nutrients because of diarrhea or vomiting.
2. Being physically active: People living with HIV will be healthier if they keep themselves busy.
3. Getting enough sleep and rest to allow their bodies to recover.
4. Keeping their bodies and homes clean will help reduce the number and prevalence of germs causing disease.
5. Practicing safe sex (using a condom): People living with HIV and on ARV drugs are still HIV-positive and can pass HIV to others. By practicing safe sex they can also protect themselves from getting re-infected and increasing the amount of virus in the body.
6. Living with hope and getting emotional support from family and friends: This helps people living with HIV feel loved, accepted and better about themselves, thus giving them the strength and confidence to live healthy, productive and long lives.

Information Sheet 6 – Antiretroviral (ARV) Therapy

Answers to Some Questions on ARV Therapy

What is ARV therapy?

ARV therapy is the main medication for HIV. It uses a combination of medication: usually two or more medicines. It slows down the growth of HIV and improves the immune system.

Is ARV therapy a cure for HIV and AIDS?

No. There is no cure for HIV and AIDS. However, if a person takes ARV drugs properly, she/he will feel better and the viral load will be reduced to the point where it can no longer be detected in the body. However, ARV therapy can never take the virus out of a person's body completely, so it is essential to continue the medication for the rest of the person's life.

How many extra years of life can ARV drugs give a person living with HIV?

ARV therapy is known to extend many people's lives up to 10 years or even longer, depending on how advanced the HIV infection had been when the person started ARV therapy. Ongoing research suggests that new medications are likely to increase this period. An HIV-positive person's general lifestyle, diet and adherence to ARV therapy will determine how well ARVs will work for him/her.

How is ARV therapy different from other medicine?

Like many other medications, ARV drugs have side effects. However, unlike many other medical regimens, ARV therapy requires 100% adherence in order to prevent HIV from becoming resistant to medication.

What is the danger of drug resistance?

The danger of drug resistance is very high, because no other drugs are available yet to treat HIV and prolong life. The newly-resistant HIV could subsequently spread to other areas and countries. This is why the use of ARV therapy requires the highest level of responsibility and commitment from everyone affected by HIV.

What are possible side effects of ARV therapy?

Some patients will experience some of the following side effects: nausea, vomiting, diarrhea, muscle pains, headaches, tiredness, changes in menstrual patterns, skin rashes, numbness in hands and feet, and changes in body shape.

Why should people living with HIV stop smoking and using alcohol?

Smoking and drinking are bad for a person's health and weaken a person's immune system.

Annex A

Information Sheet 7

HIV Testing–Voluntary and Confidential Counseling and Testing (VCCT)

What is an HIV Test?

An HIV test determines if a person is infected with HIV. The test involves taking a sample of blood from a person and analyzing the sample in a laboratory. HIV tests look for the presence of HIV antibodies in the person's bloodstream, rather than the virus itself. Antibodies are produced by the immune system to fight off HIV infection. If the test shows that HIV antibodies are present, the person is infected with HIV, which is called being "HIV-positive." If there are no antibodies, the person is not infected with HIV, which is called being "HIV-negative."

What is the window period?

When a person is infected with HIV, it takes three months for the body to show detectable levels of antibodies in a test. This length of time is called the "window period." During this period, the test will not show the antibodies and the results will show the person to be HIV-negative – even though she/he may have HIV. This is why a second test is needed three months after the first test.

Why should people take an HIV test?

If people are worried that they have HIV, the test can put their minds at rest. Knowing their status will help them plan for their future and future of their family. People who test positive can take steps (e.g., good diet) to look after their health, get early medical attention for any health problems, and delay the onset of AIDS. They can inform and protect their partners from getting HIV. People who test negative can change their sexual lifestyle so that they can avoid contracting HIV in the future.

What is voluntary counseling and testing (VCT)?

Voluntary Counseling and Testing (VCT) is a system of testing people for HIV and providing counseling about the full implications of being tested. VCT includes pre-test counseling, HIV testing, and post-test counseling.

VCT is more than testing blood and giving people counseling. It is a point of entry to other HIV and AIDS services, including anti-retroviral treatment, prevention of mother-to-child transmission (MTCT), prevention and treatment of opportunistic infections, and psycho-social support.

VCT provides information and benefits for those who test positive as well as those who test negative. VCT helps people deal with worries about their status, increases their perception of their vulnerability to HIV, promotes behavior change, facilitates early referral for care and support, and helps to reduce stigma in the community.

What are the conditions for VCT?

- ➔ **Voluntary:** the individual decides to take the test and no one can force him/her to get tested
- ➔ **Right to counseling:** the individual who decides to take the test has the right to be counseled by a trained counselor
- ➔ **Informed consent:** the individual knows what is involved before making the decision to be tested, and cannot be tested without his/her knowledge
- ➔ **Confidential:** personal information disclosed to the trained counselor must remain confidential

What are the advantages of VCT?

- ➔ VCT is the first step in a continuum of care. It is the entry point for prevention, treatment, support and care.
- ➔ If the HIV test result is positive, a person can:
 - Start to practice a healthy lifestyle to live a long and productive life, and delay the onset of AIDS
 - Get early access to opportunistic infection or OI treatment, antiretroviral (ARV) therapy and prevention of mother-to-child transmission (MTCT) of HIV

Information Sheet 7 – HIV Testing – Voluntary and Confidential Counselling and Testing (VCCT)

- Get access to counseling, support groups, and social support services
- Adopt safe sex practices and protect sexual partners from contracting HIV
- If the HIV test result is negative, a person can change his/her practices to avoid contracting HIV and thereafter infecting sexual partners.
- If people are worried that they have HIV, they can put their minds at rest.
- If a number of people in the community get tested, it can help to de-stigmatize HIV and AIDS.

What are the disadvantages of VCT?

- ➡ Some people who test HIV-positive may not be able to cope with these results. Before a person takes the test, it is important to think about how she/he will react to the possible result: positive or negative.
- ➡ Being classified as HIV-positive can lead to stigma, violence, and discrimination

What are the steps in VCT?

VCT involves a number of steps, including thinking carefully, in advance, about pre-test counseling, the actual test, and post-test counseling.

1. Thinking about testing

Most people with the HIV virus feel quite healthy. The only way to know if they are HIV-positive is to take an HIV test.

Reasons for thinking about taking an HIV test include:

- ➡ Had unsafe sex or a condom broke
- ➡ Is thinking about getting married or having children
- ➡ Has a spouse/partner who has tested positive
- ➡ Keeps getting sick, and is worried that she/he may have HIV It is the individual's decision to take a test. No one else can make him/her have the test.

2. Pre-test counseling

Pre-test counseling helps the client prepare for the HIV test. She/he talks with a counselor about:

- ➡ the HIV test procedure: how it is done, the meaning and implication of a positive result and a negative result
- ➡ the reasons for being tested: this may influence the client's decision to take/not take the test
- ➡ the client's potential HIV risks and ways to reduce HIV risk
- ➡ the client's to-do plan after getting the test results (including the client's own reaction to a positive or negative result, how the partner(s) would be informed, how to reach out for love and support)

3. Test

If the client has decided to go through with the test, she/he provides a blood sample, which is then tested for HIV anti-bodies.

4. Post-test counseling

Post-test counseling helps the client deal with the result. The client talks with the same trained counselor about the result and what she/he will do next.

If the result is negative, the client will be asked to come back for another test three months later, at the end of the "window period." She/he will also be encouraged to stay negative by reviewing all relevant risks and how to minimize them.

If the result is positive, the result will be explained to the client. A positive result does not mean the client has AIDS or will die soon – only that she/he has HIV. Many people who test positive stay healthy for several years, even without treatment. The counseling session will also discuss what to do next, including:

Information Sheet 7 – HIV Testing – Voluntary and Confidential Counselling and Testing (VCCT)

- ➔ who to tell about the results and how to do this
- ➔ how to live a healthy life and thereby delay the onset of AIDS
- ➔ how to prevent infecting sexual partners with HIV
- ➔ how to deal with opportunistic infections
- ➔ how to access ARV drugs and treatment

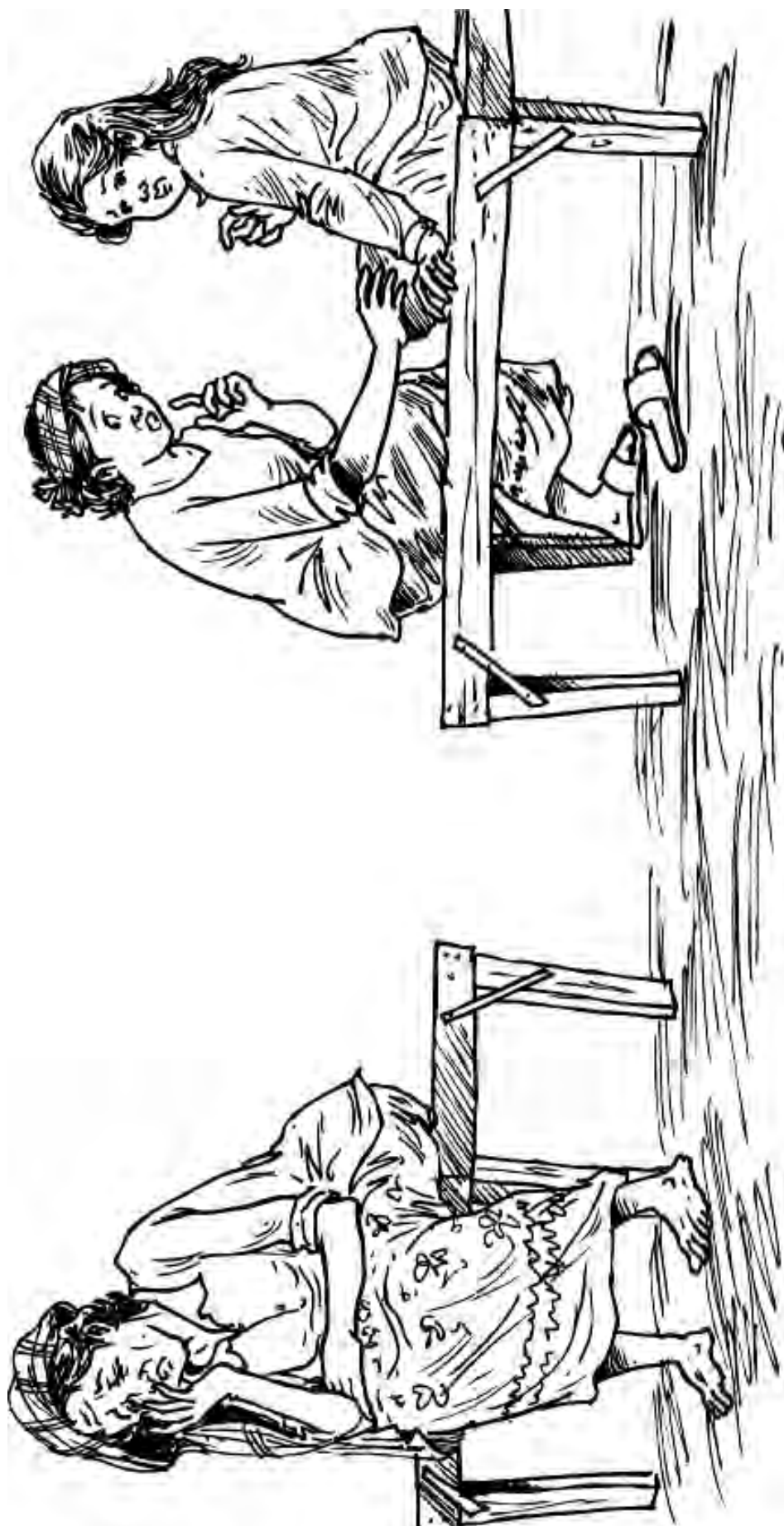
Women who test positive will be counseled on options available to prevent mother-to-child transmission (MTCT) of HIV.

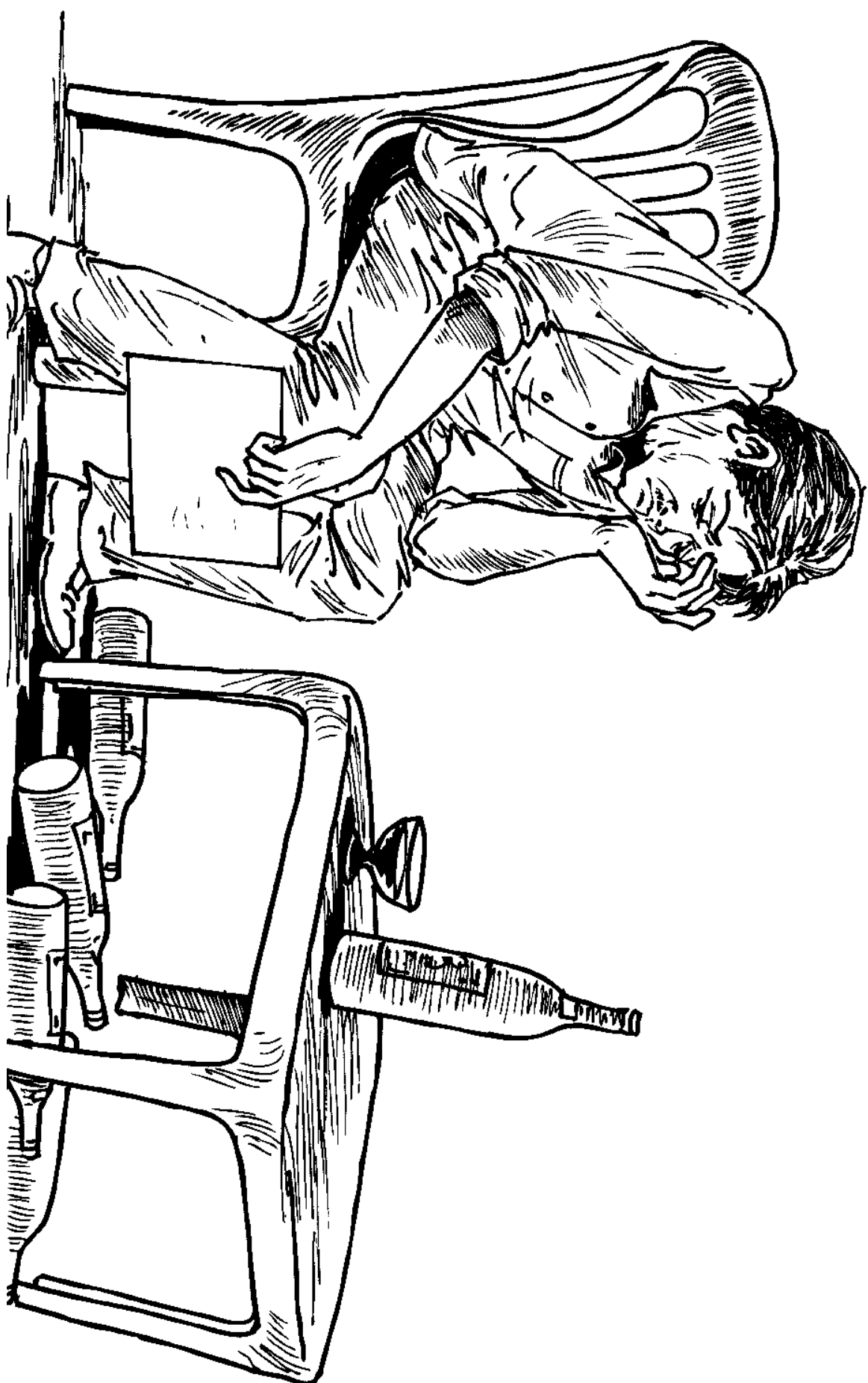
Can a person be tested for HIV without permission?

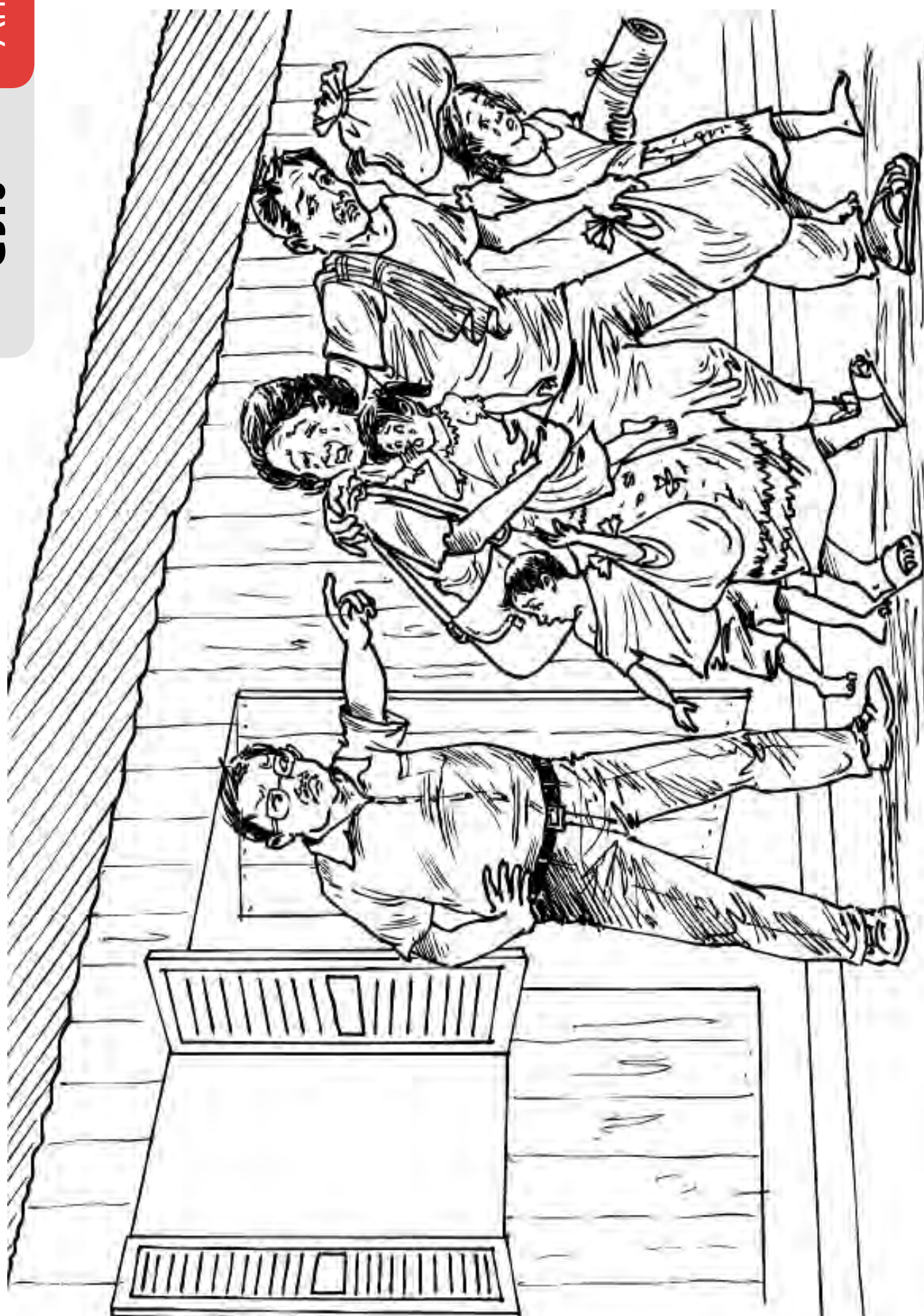
No. This is against the law. If an individual goes to the hospital or clinic for treatment, she/he must consent to all tests and treatment. It is a client's right to be asked to give, or to refuse to give, consent for every medical test.

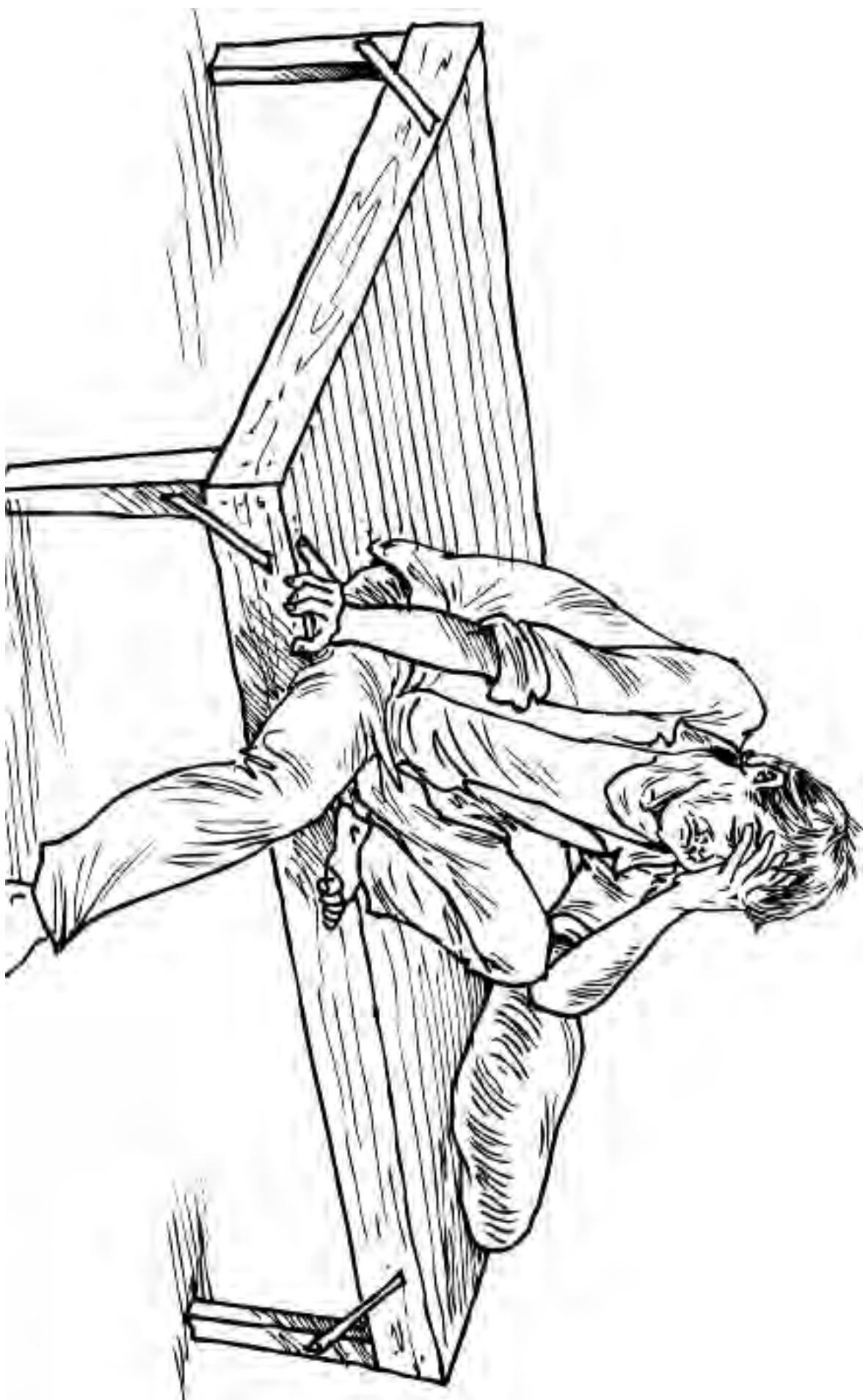
Annex B –

Stigma Pictures





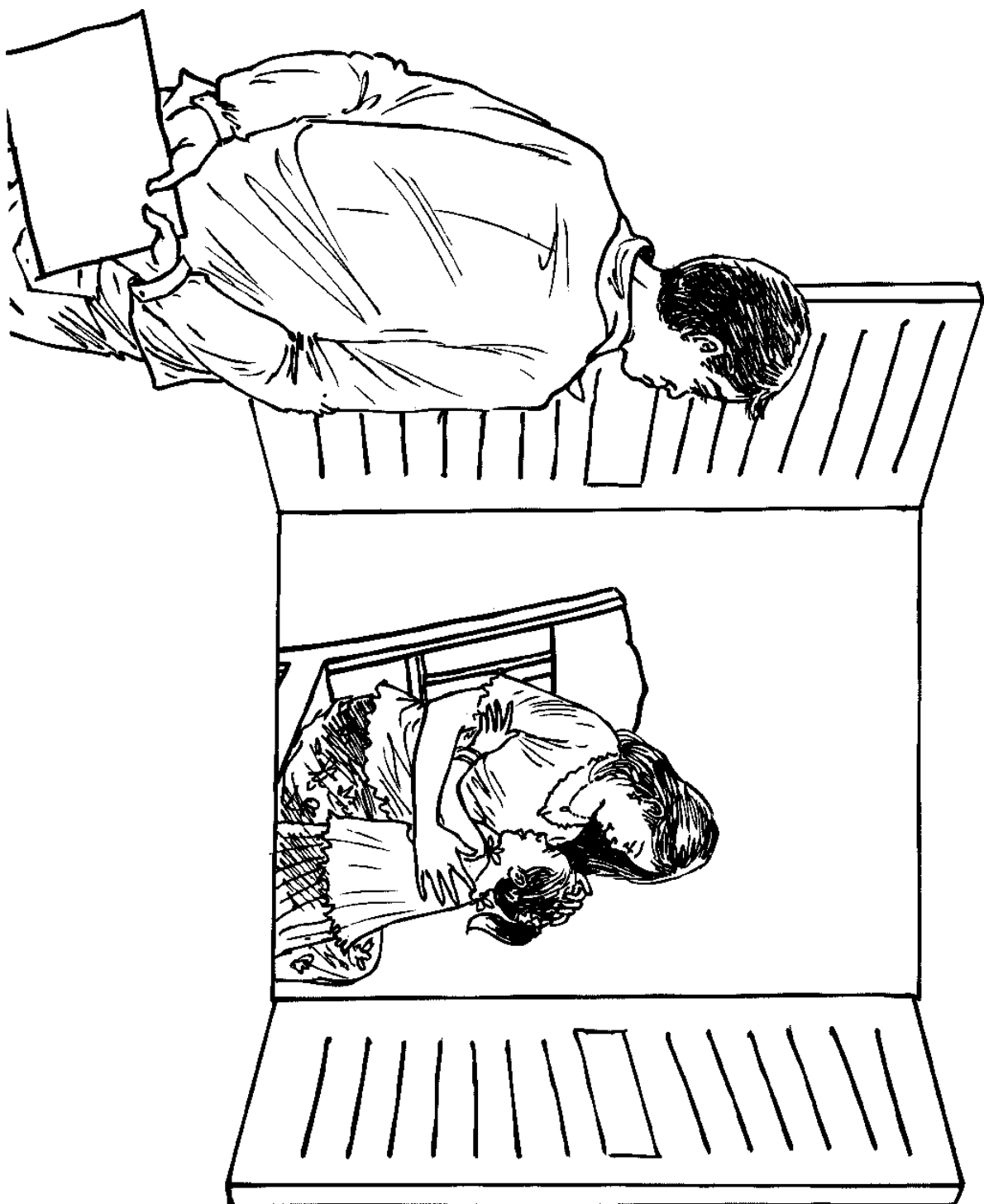




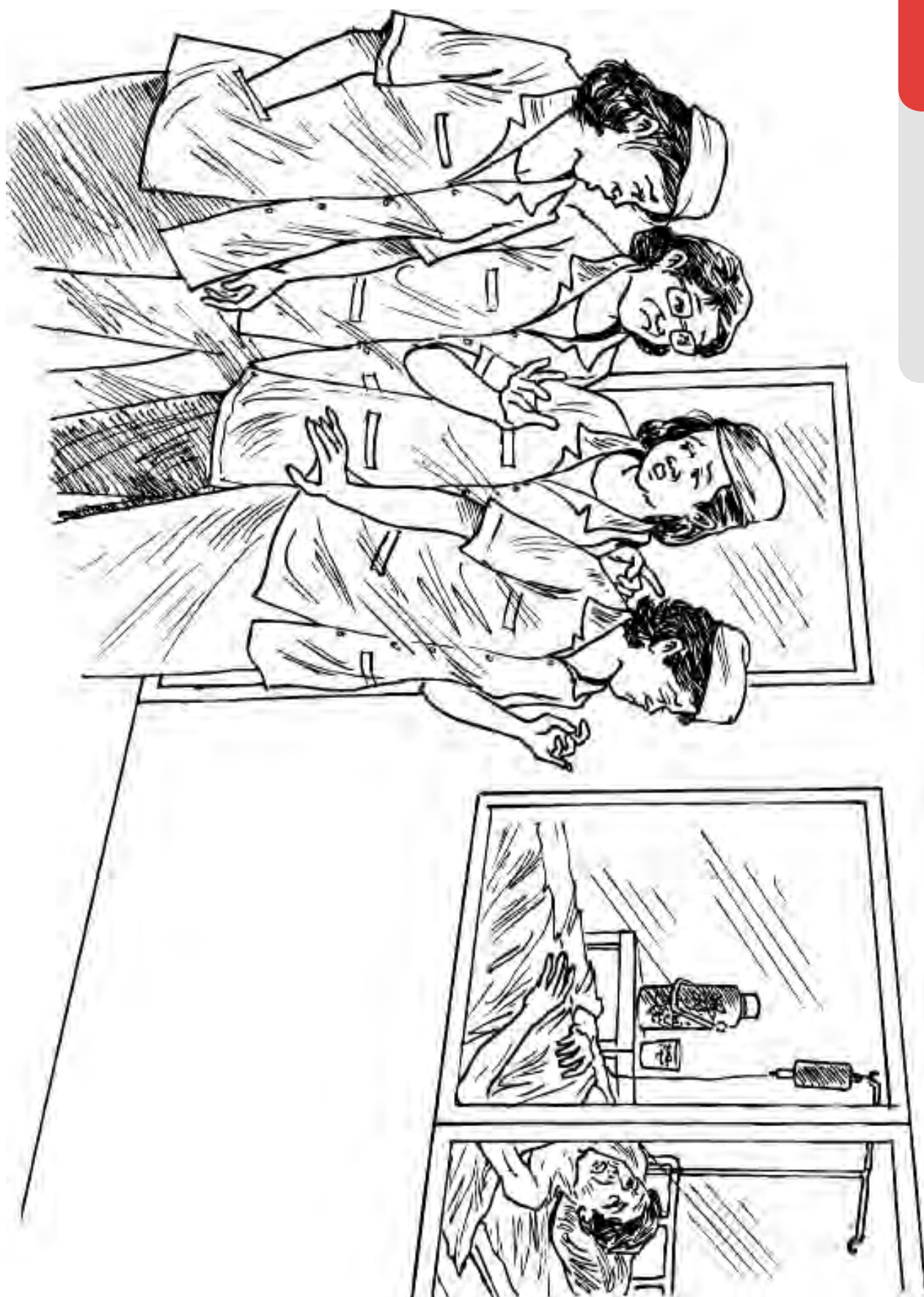


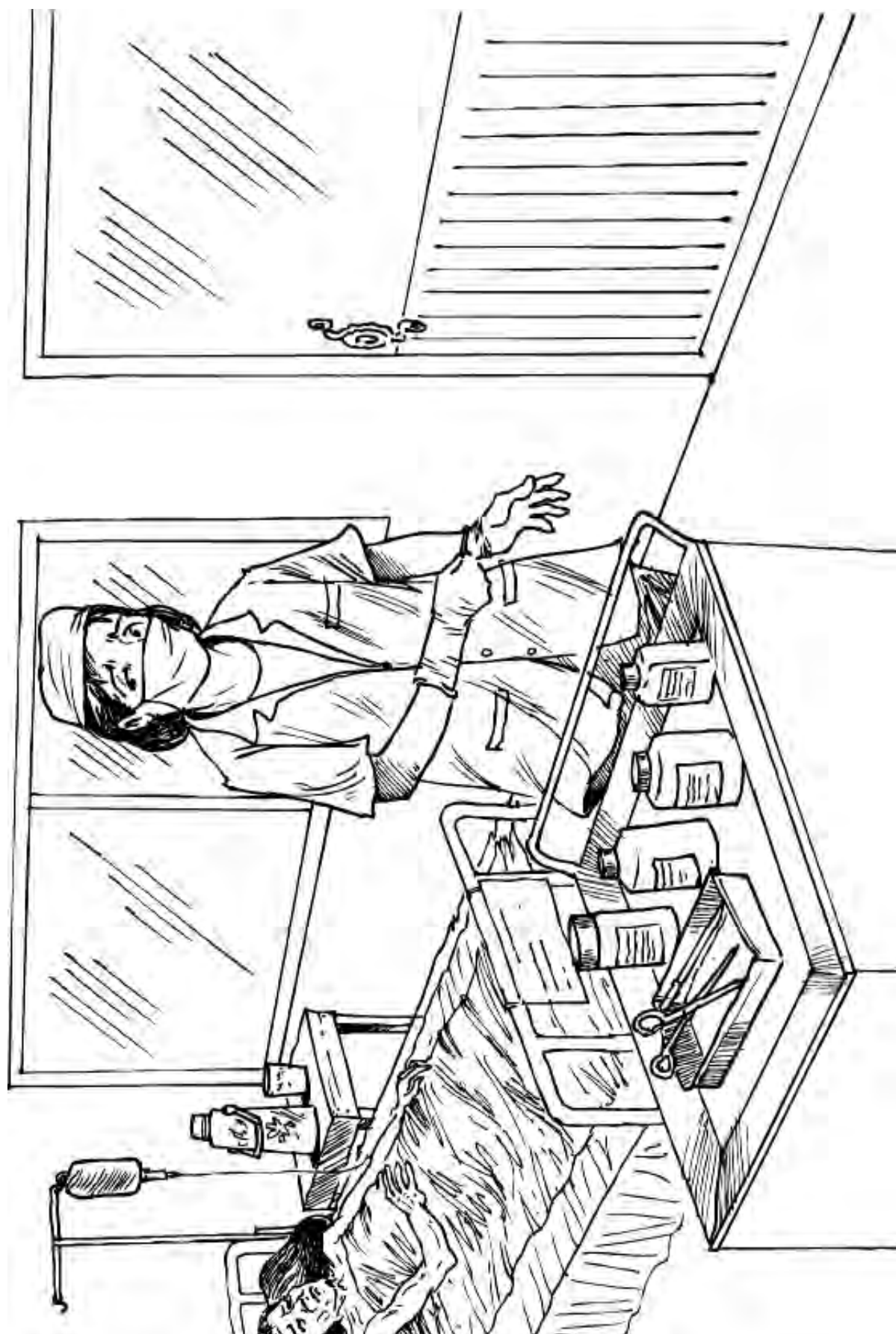


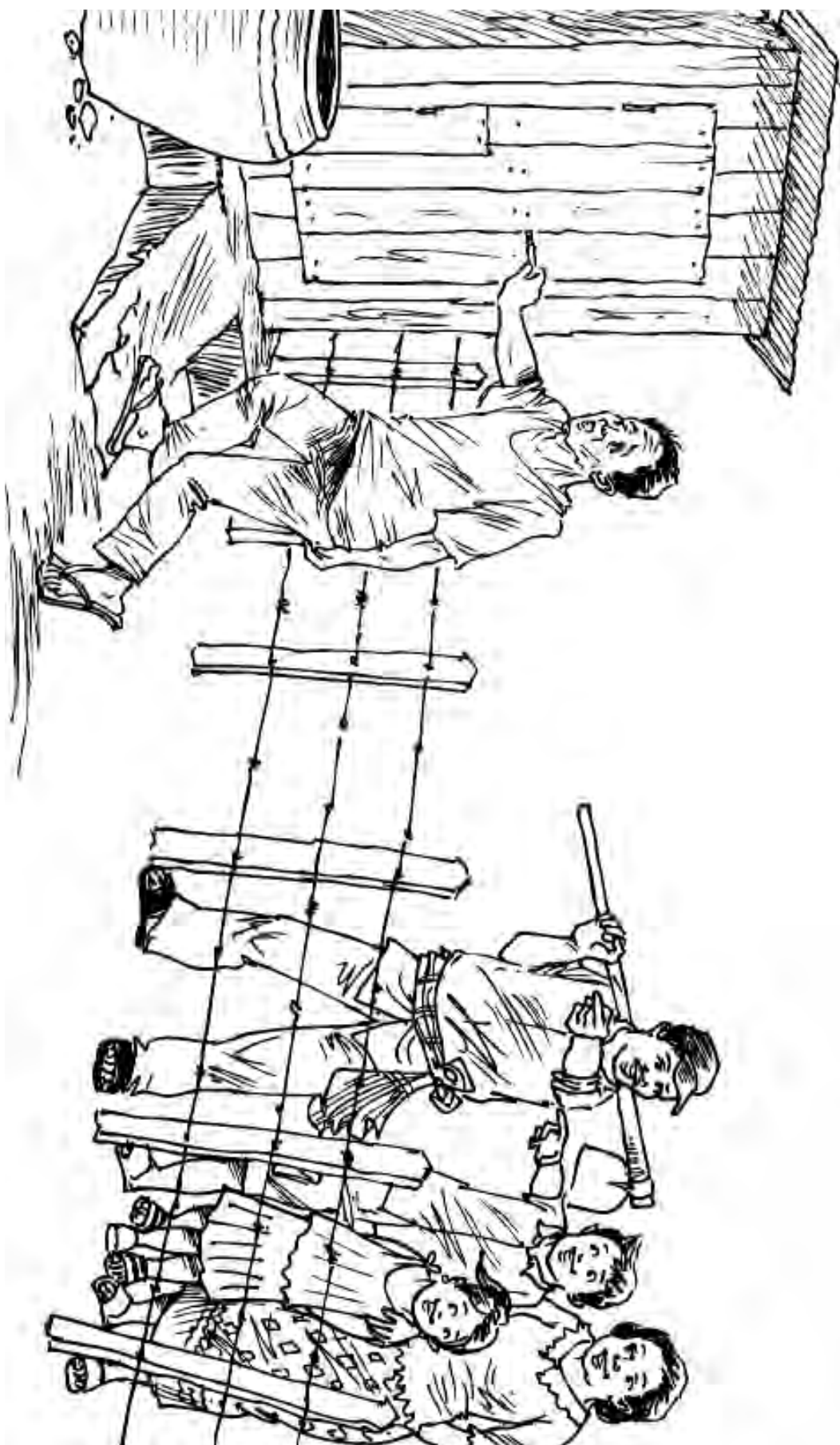


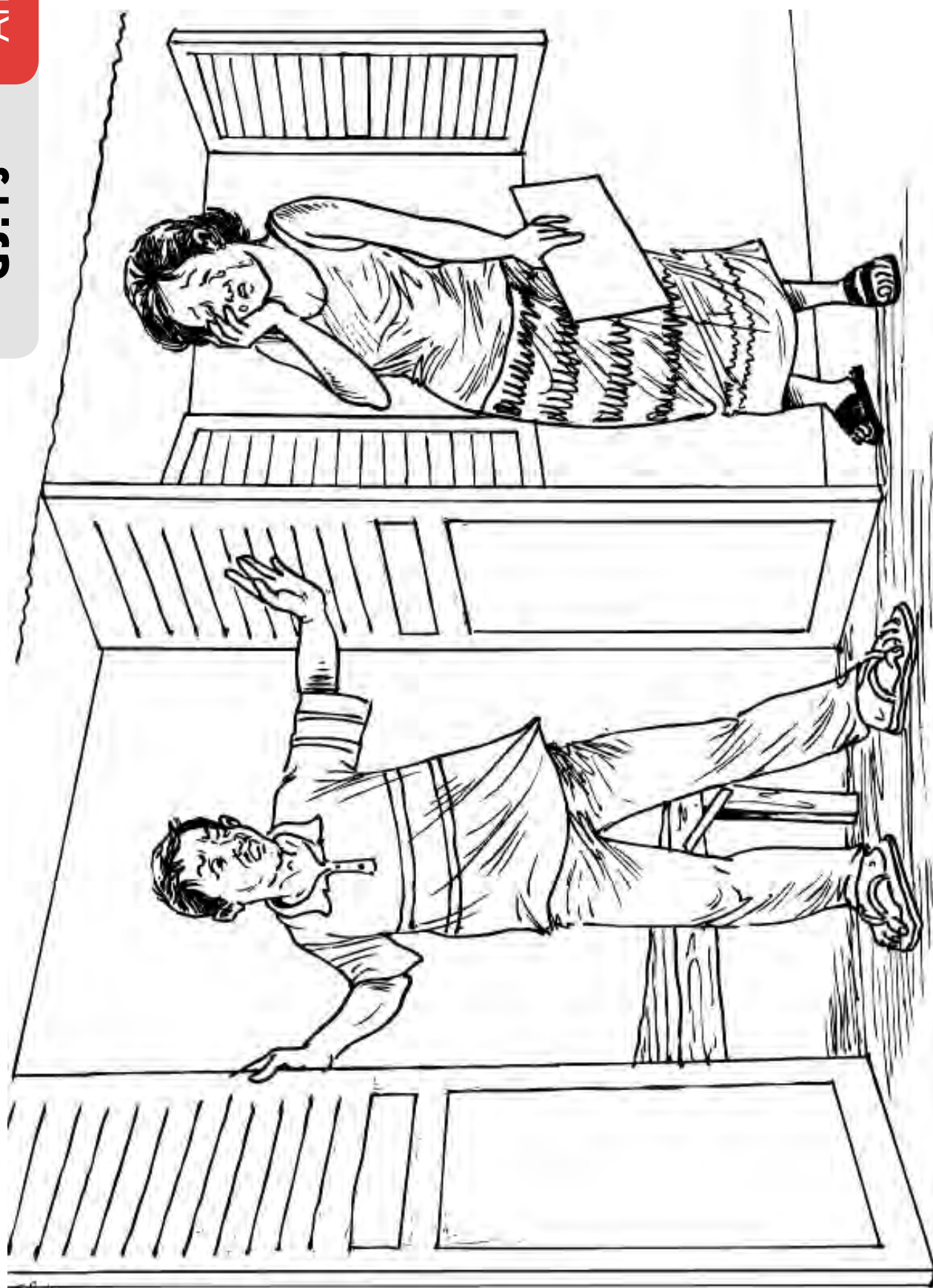


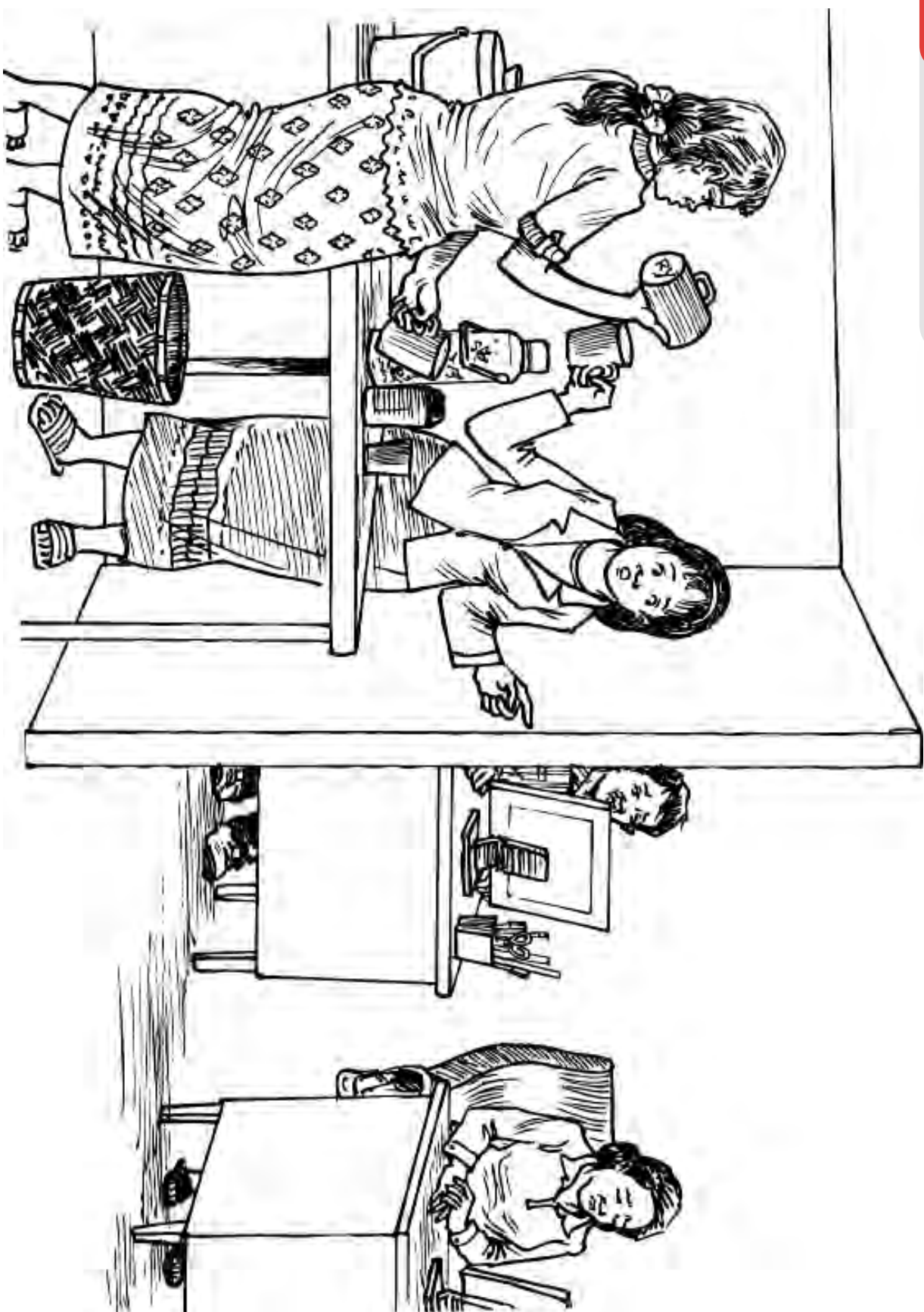




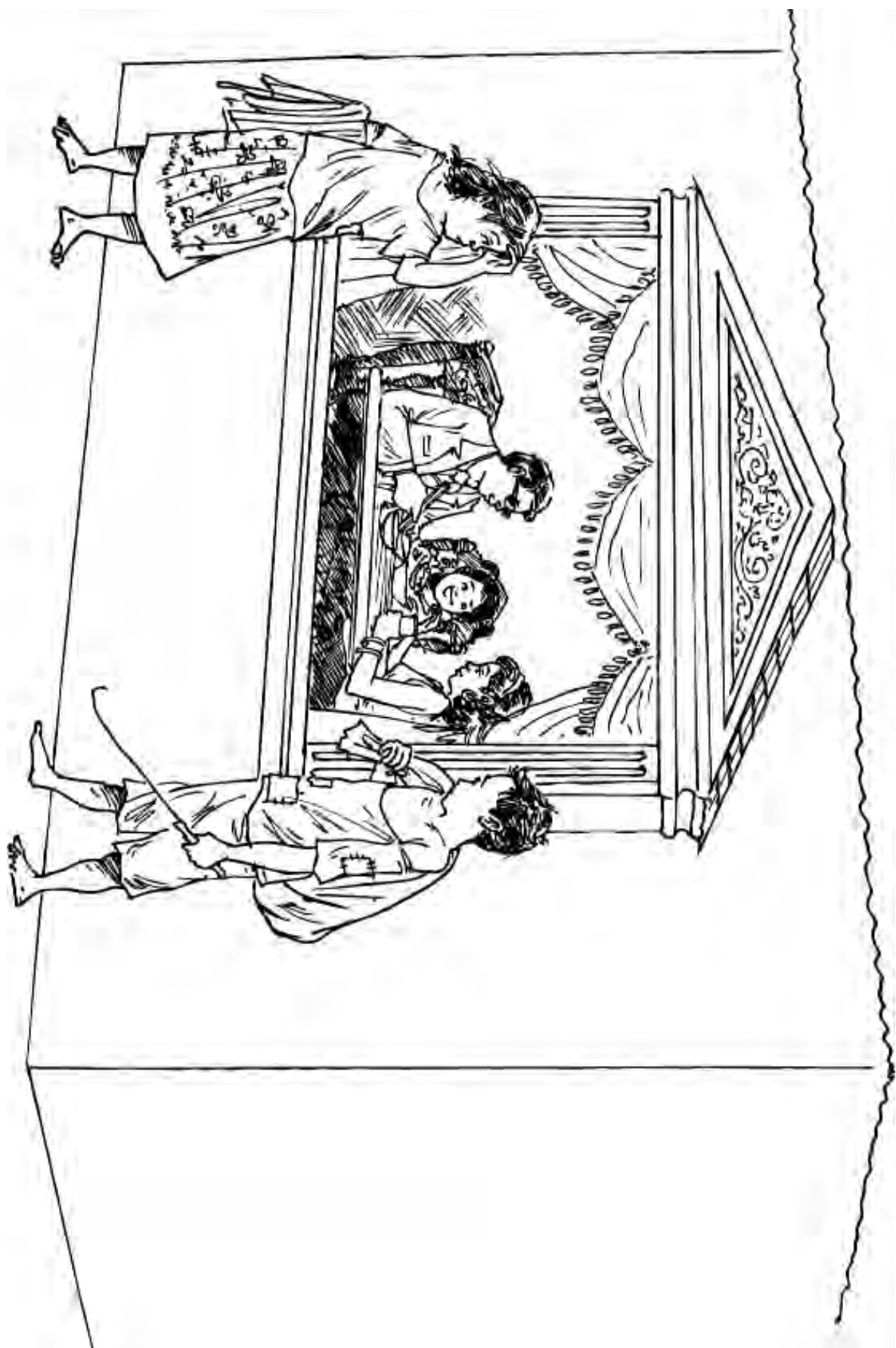


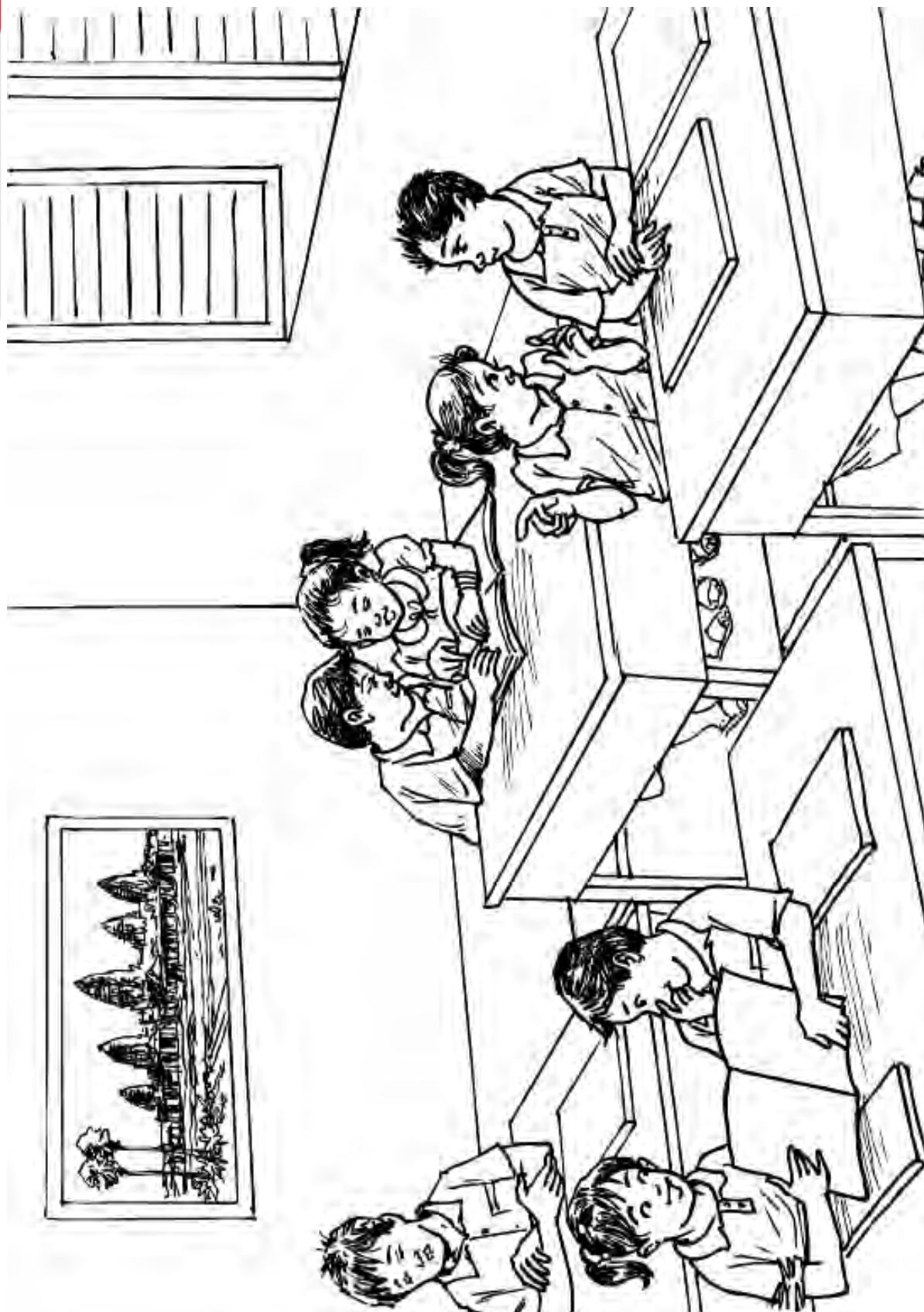
















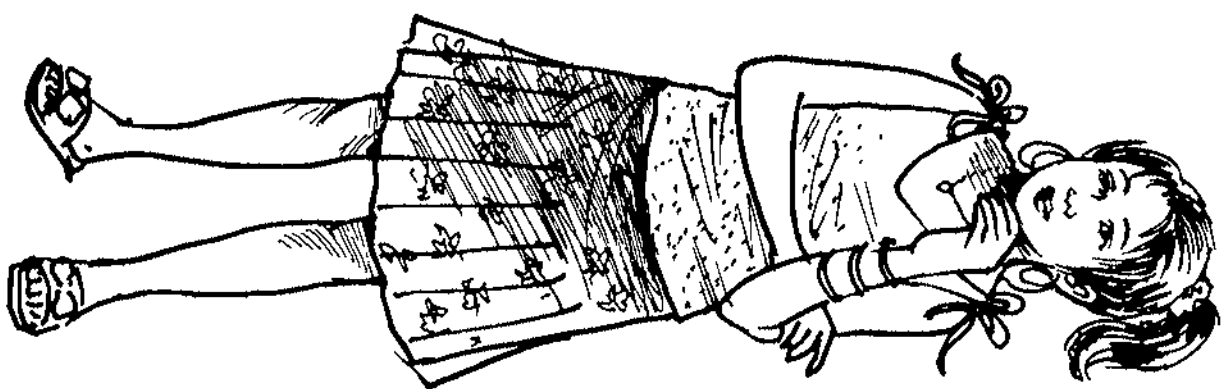
Annex C –

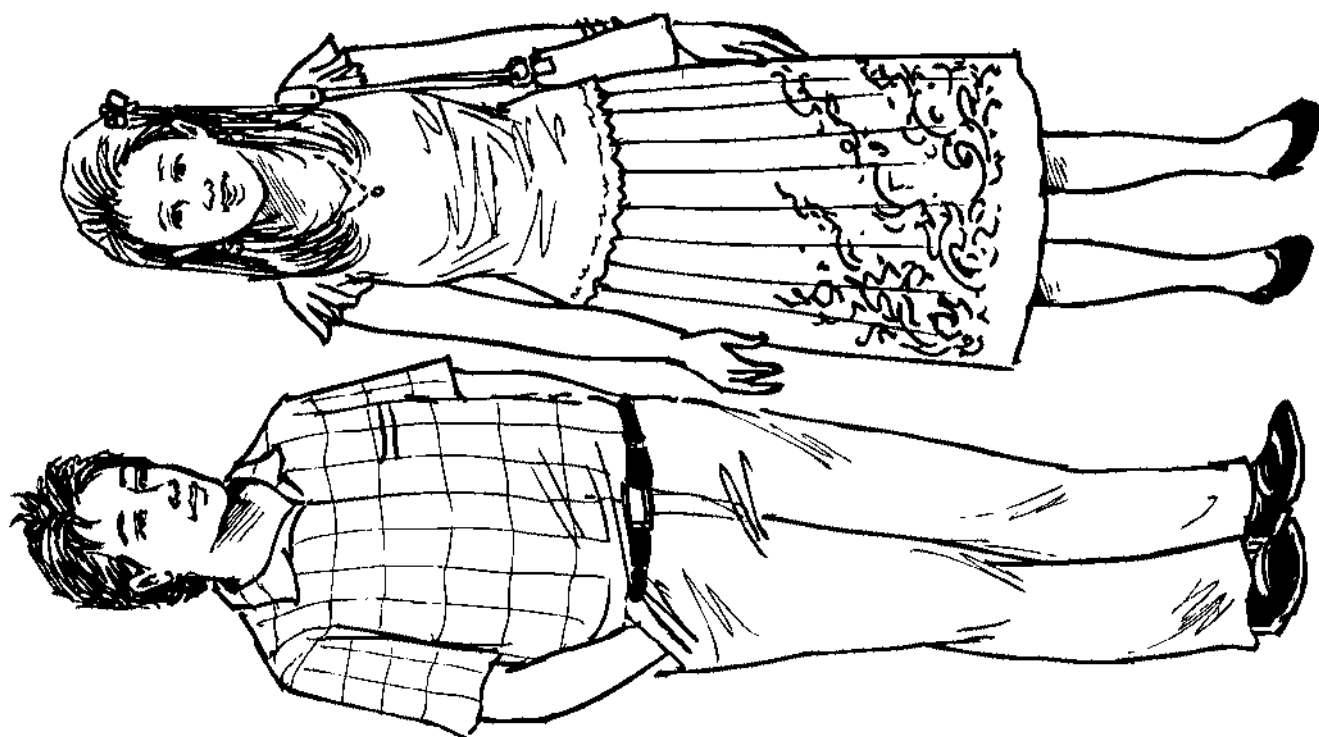
Character Cards

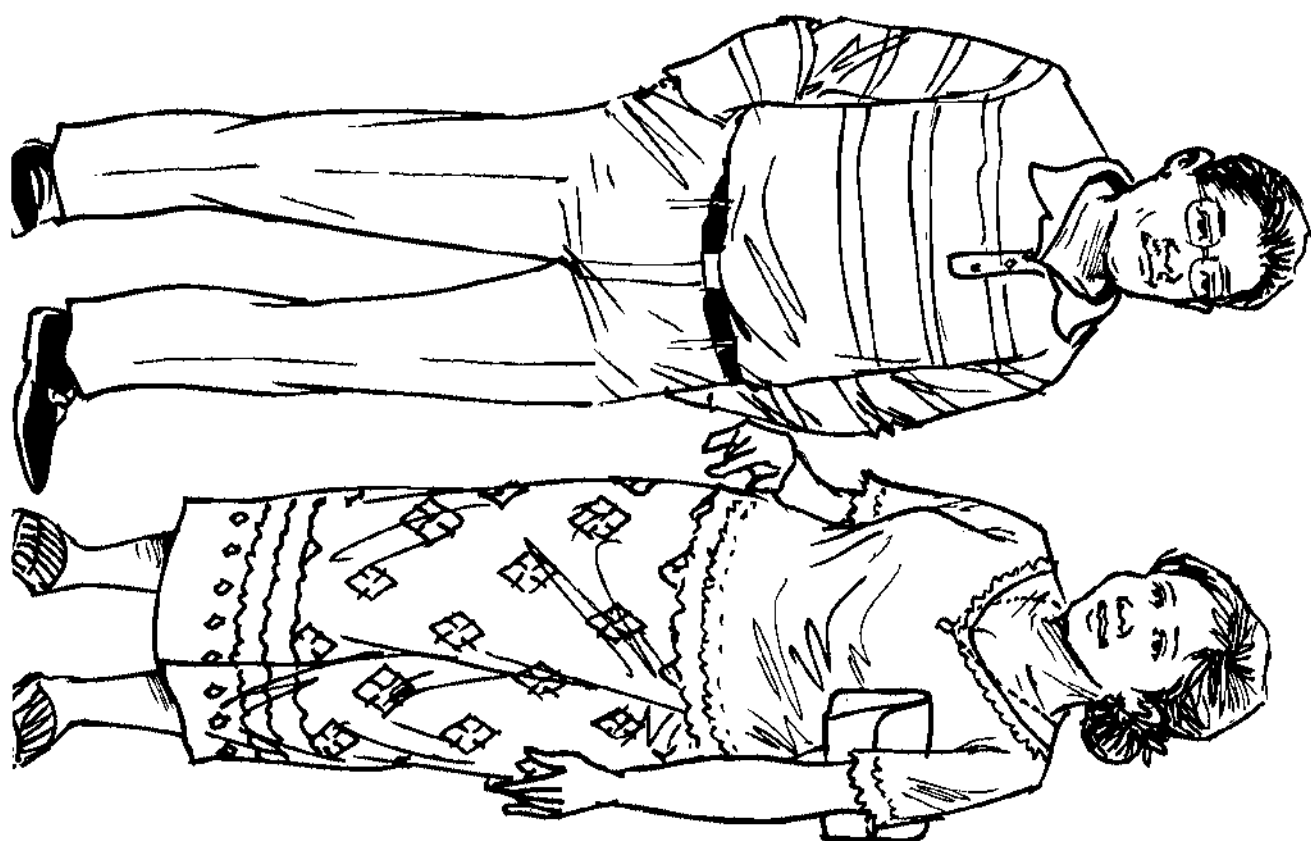


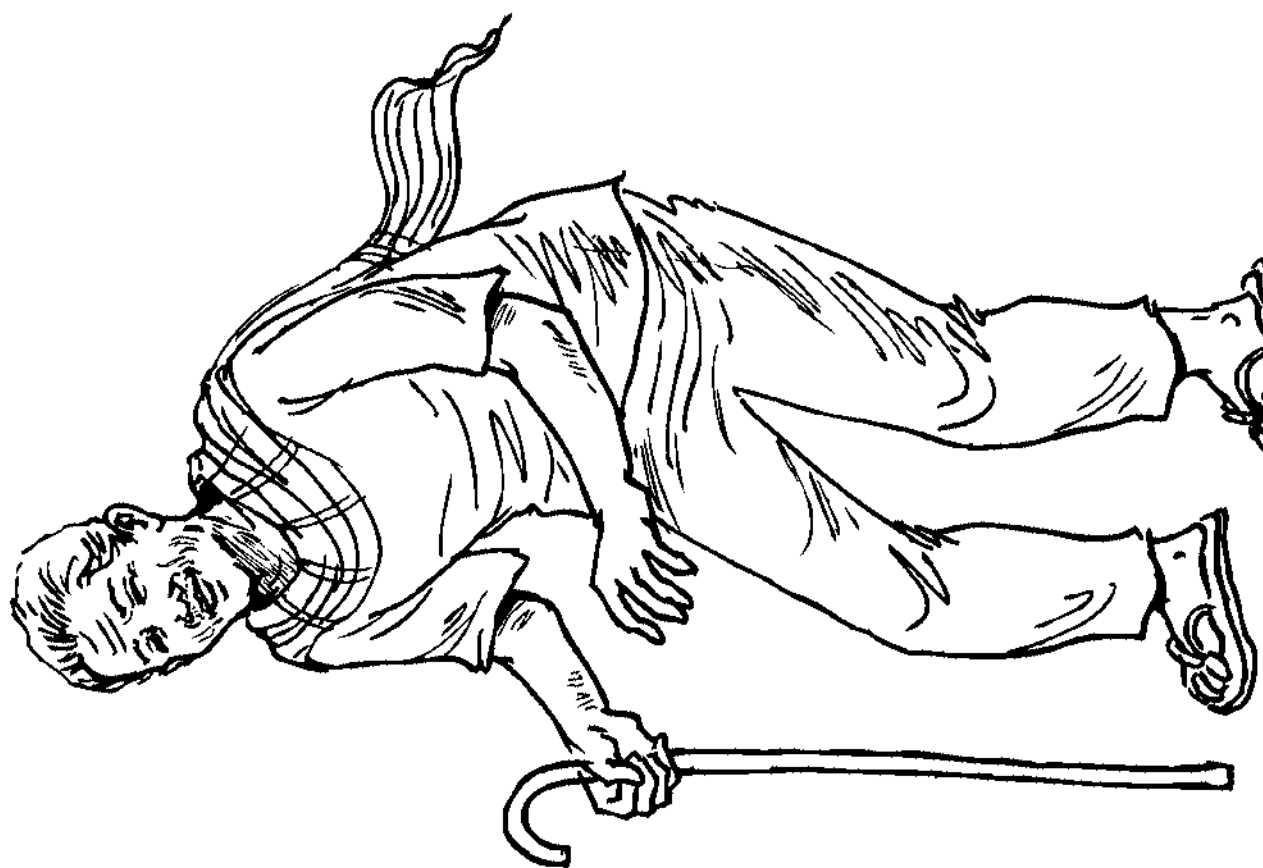








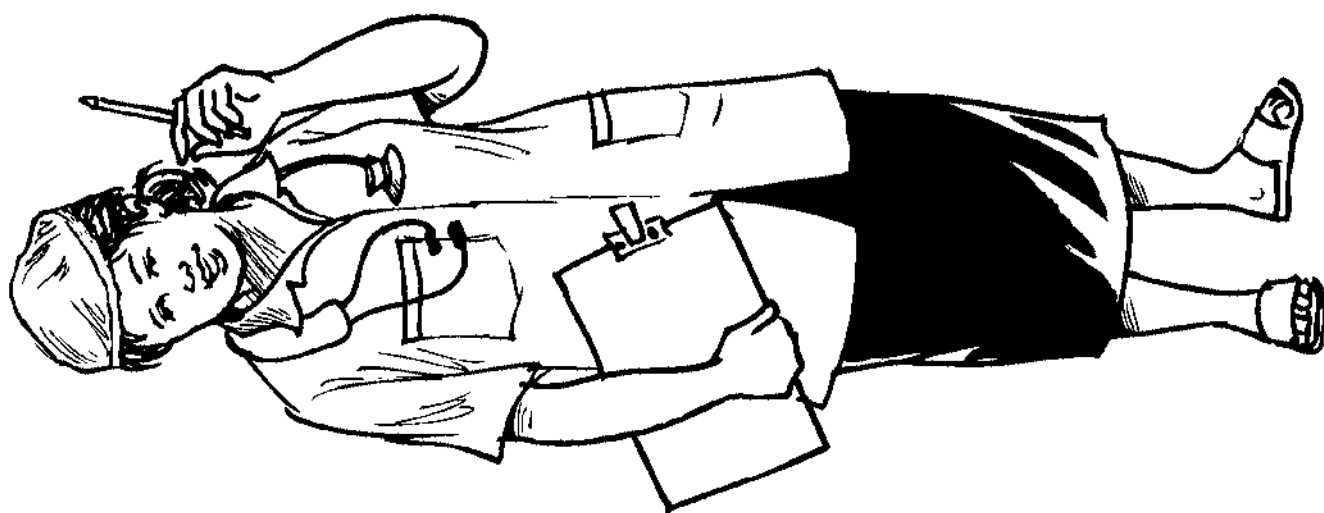


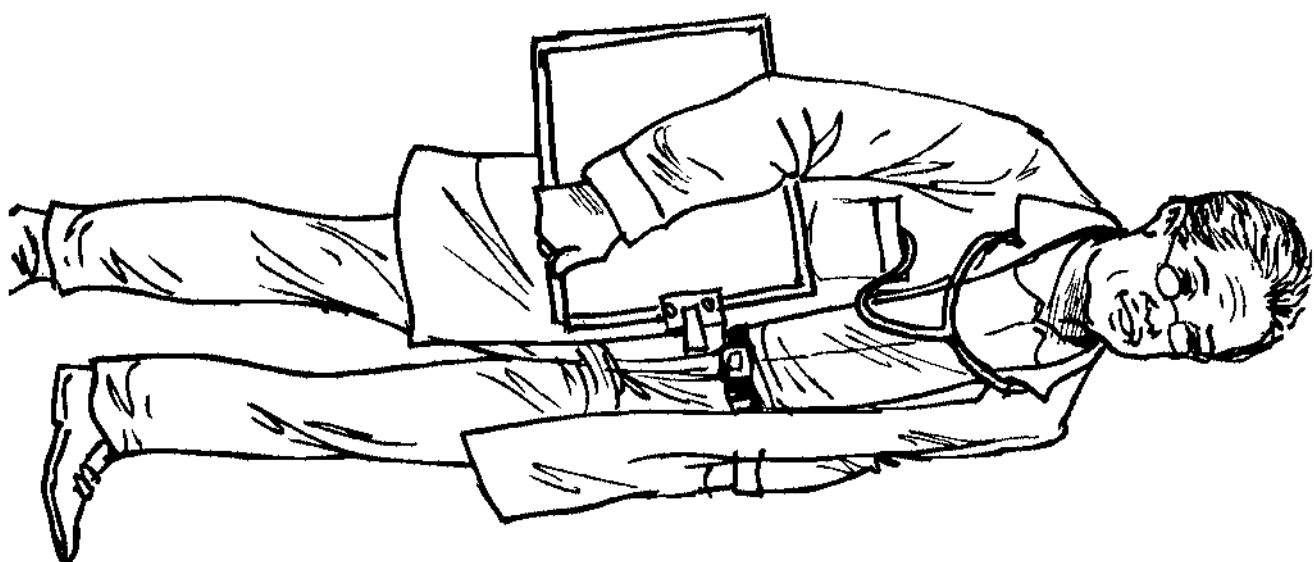


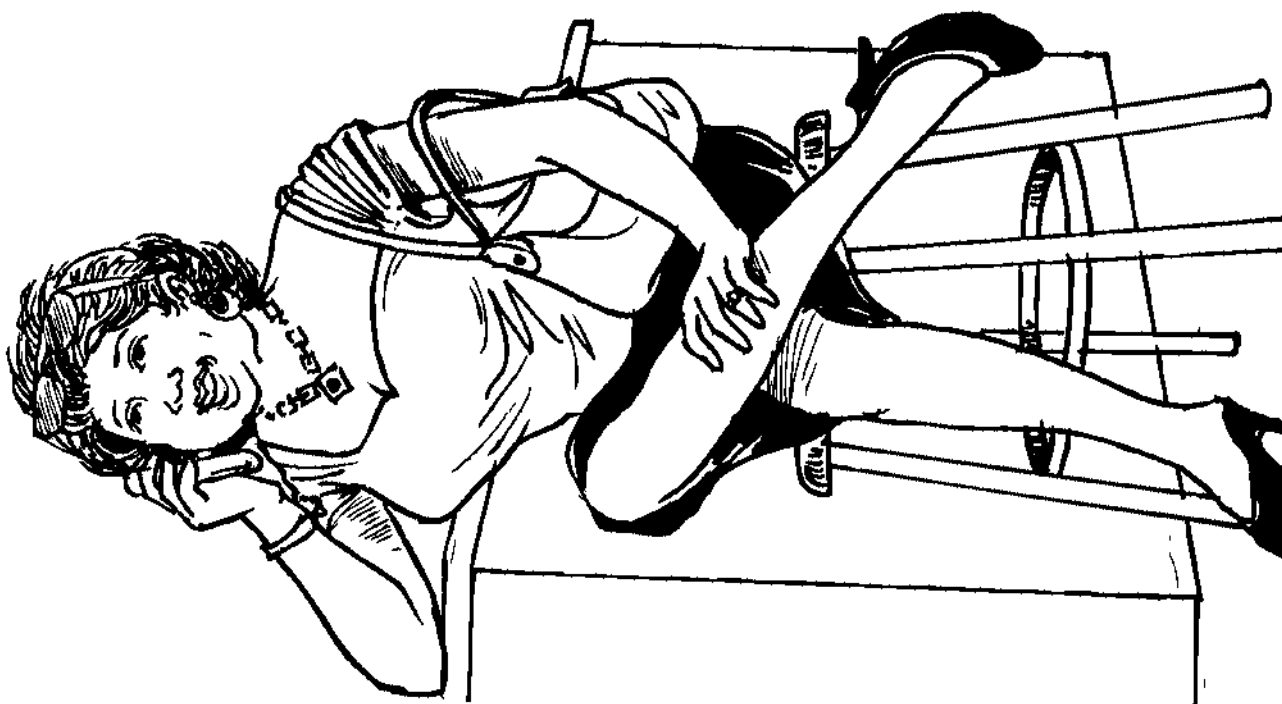


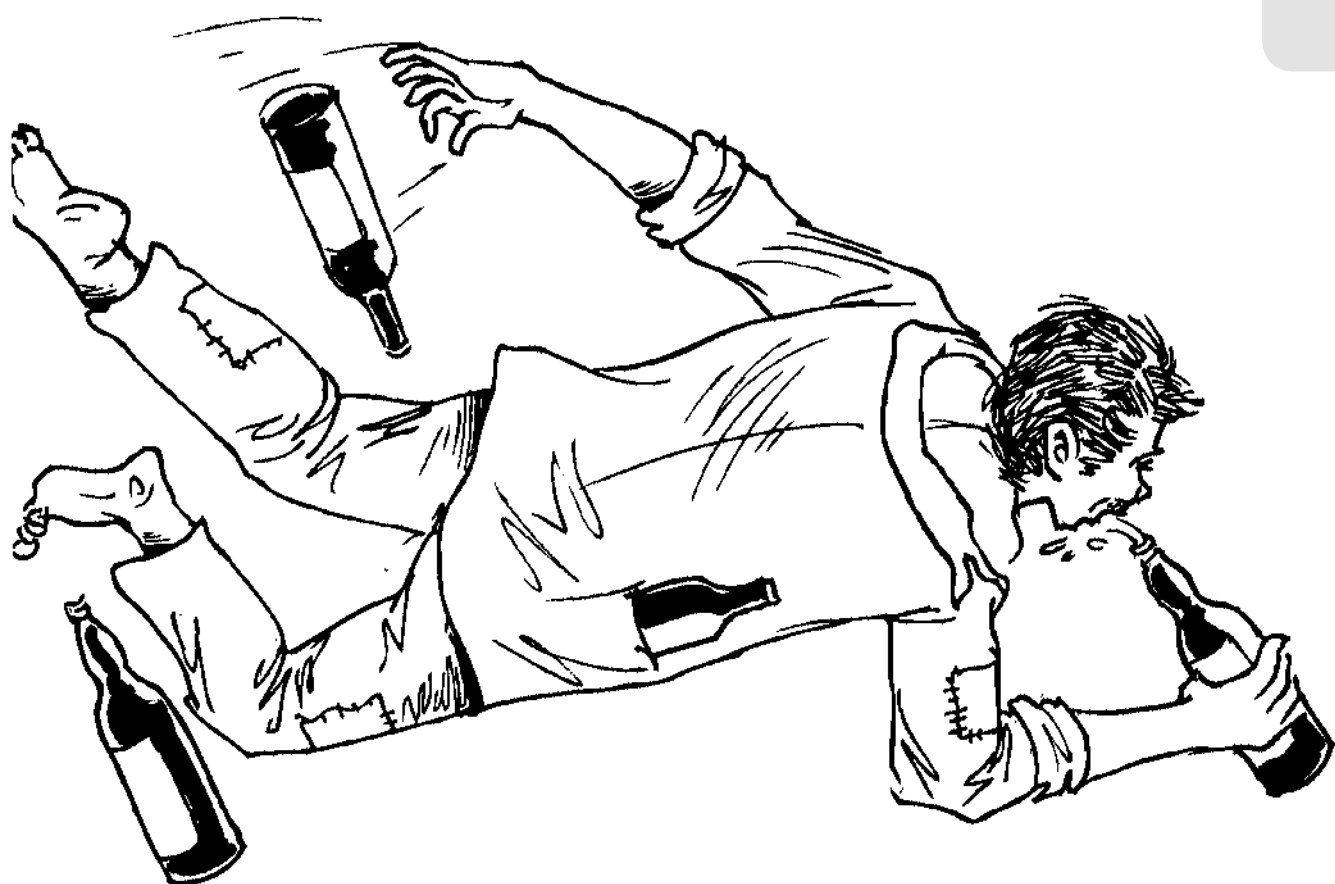


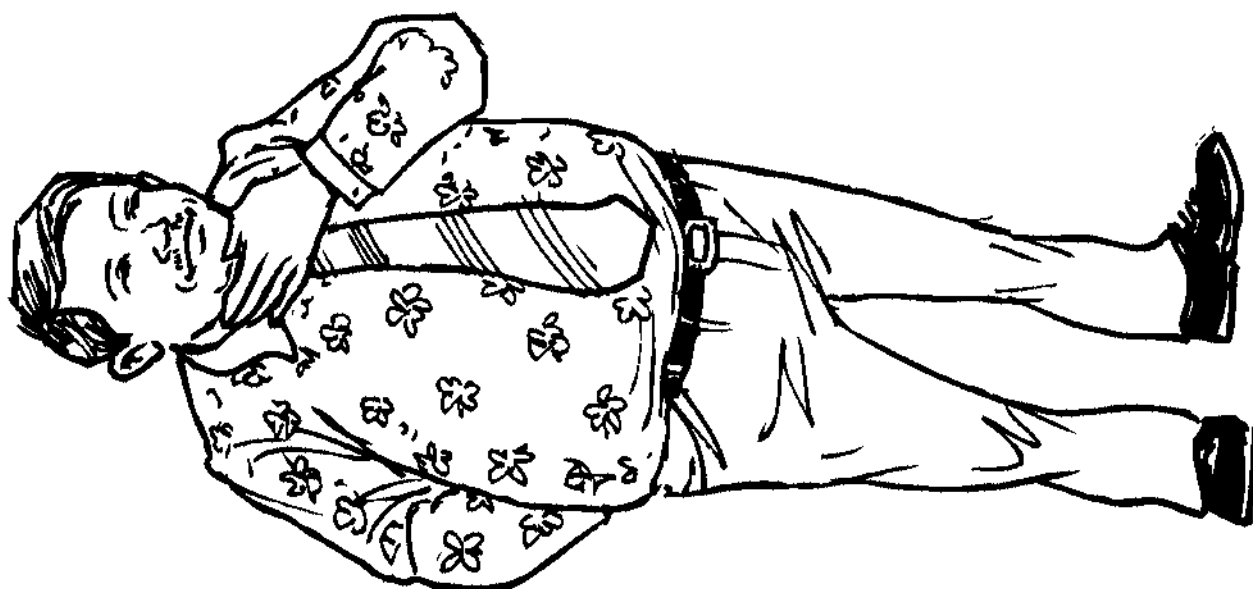


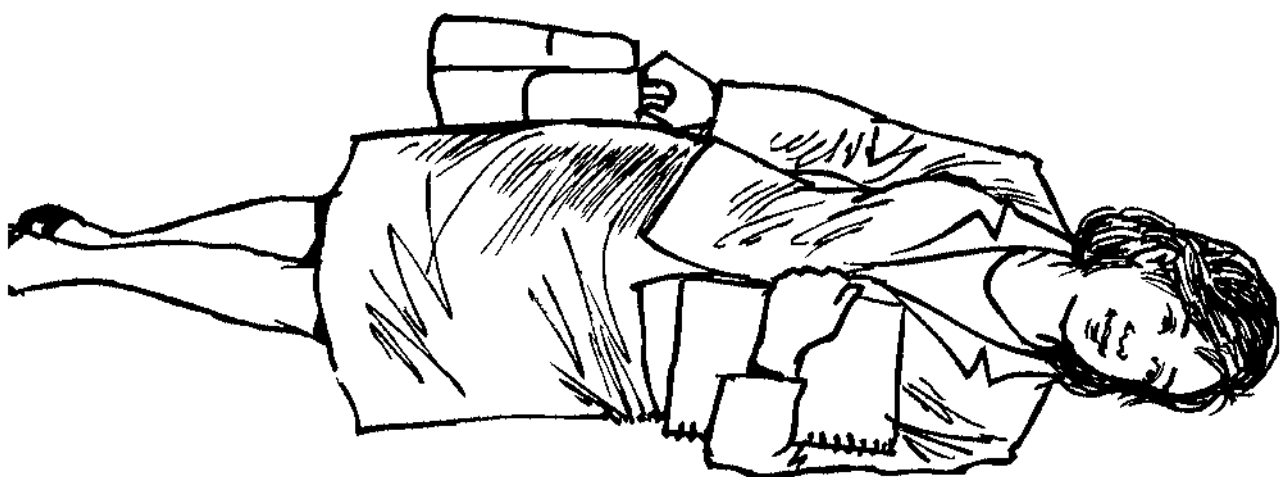




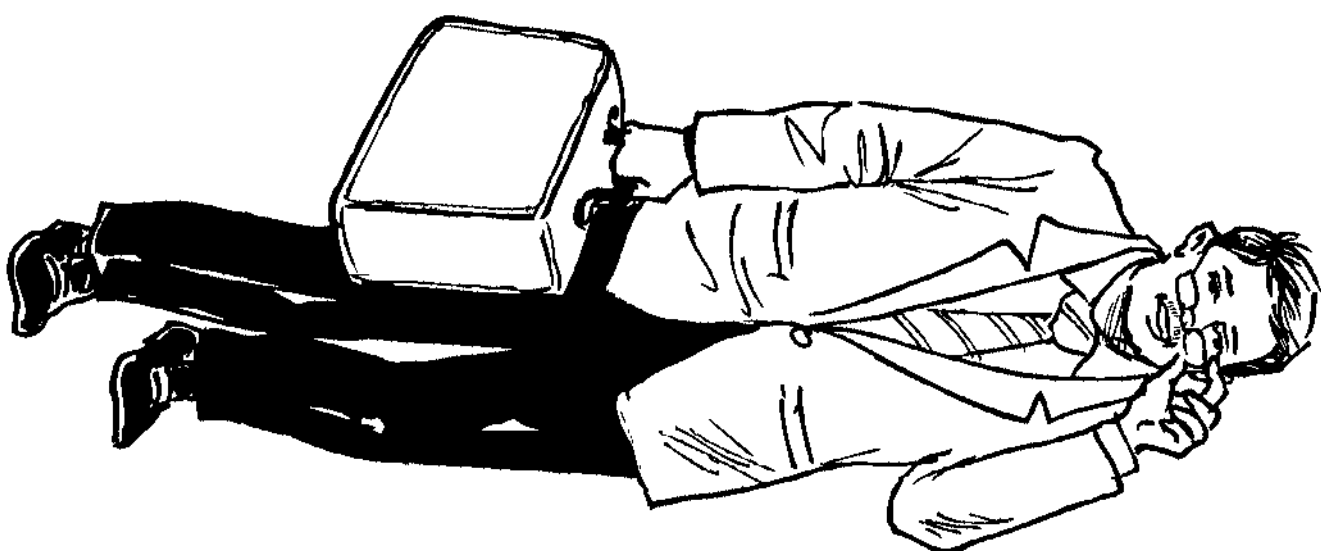


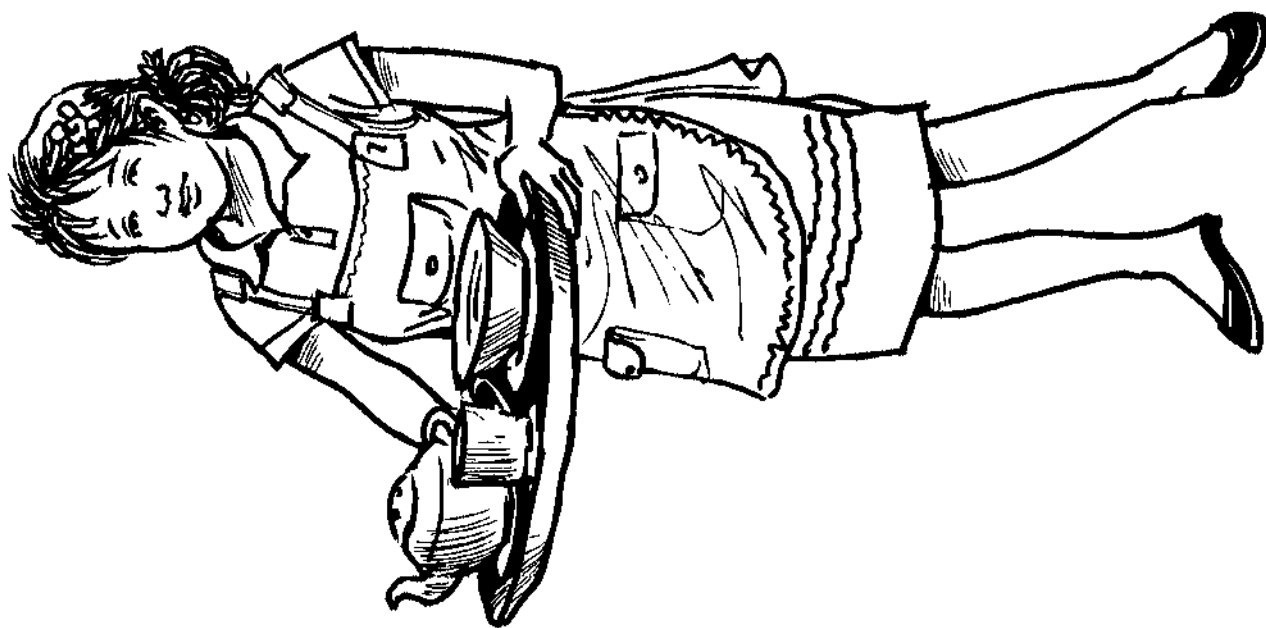


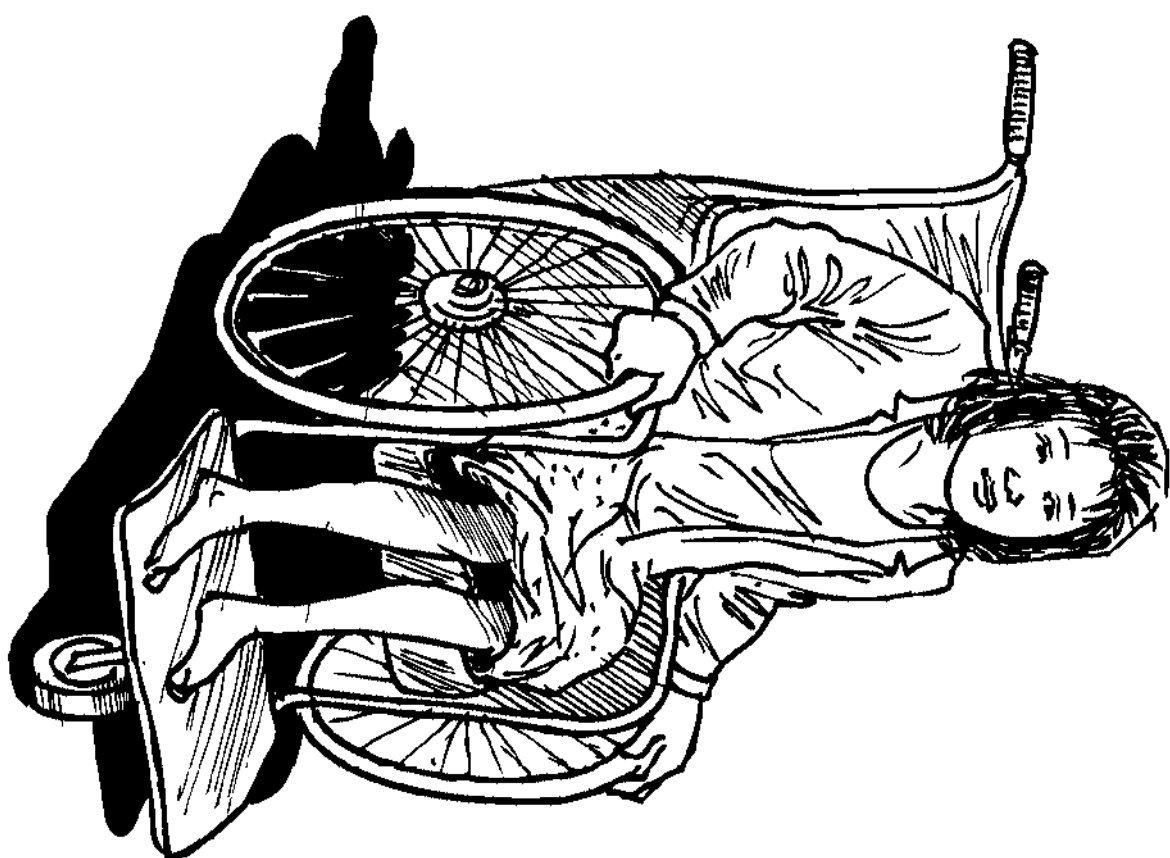




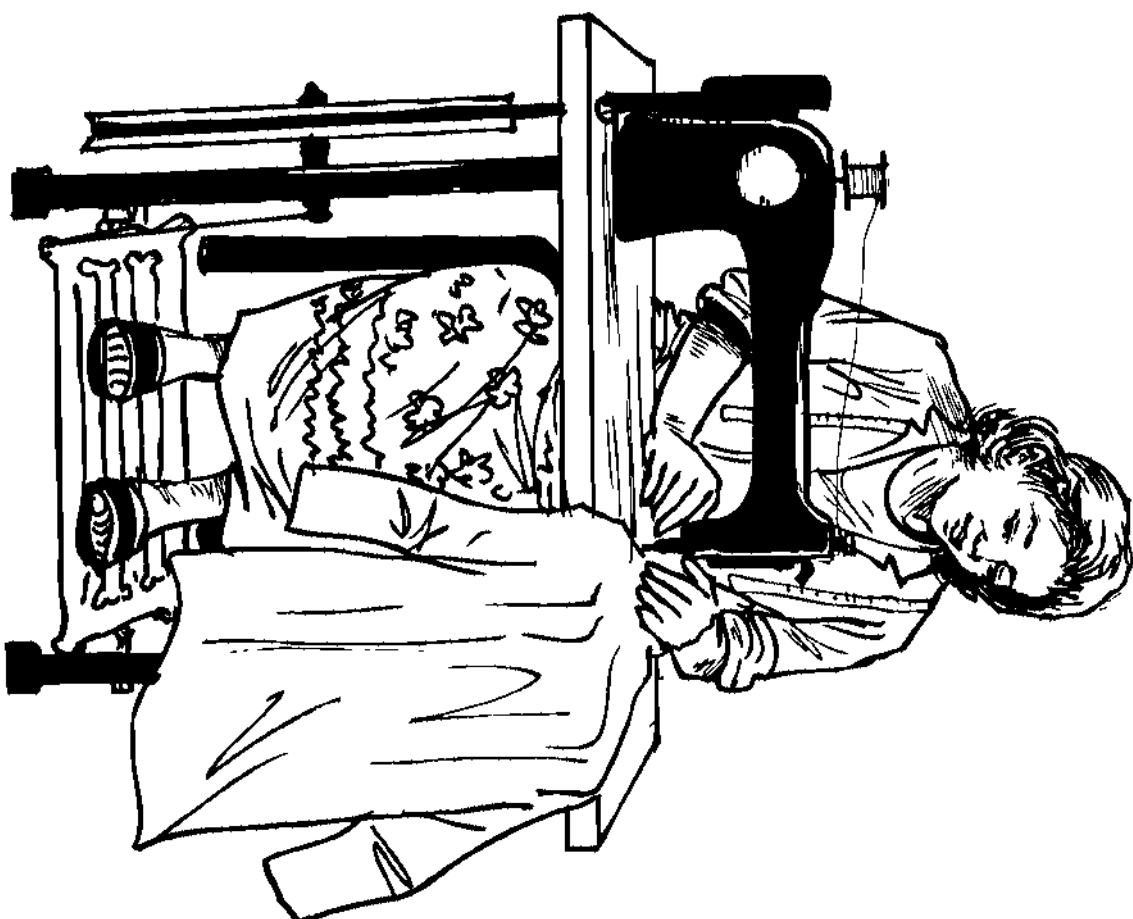


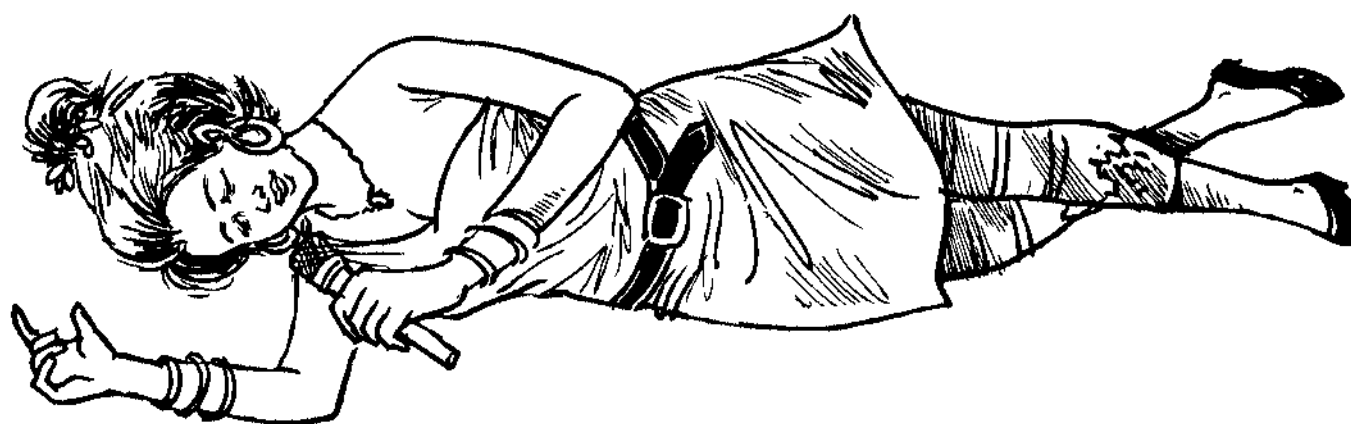


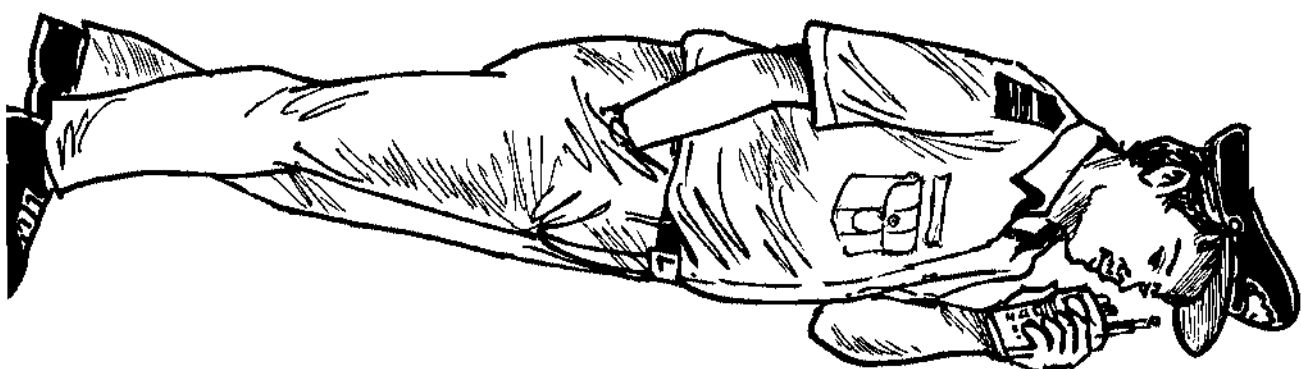


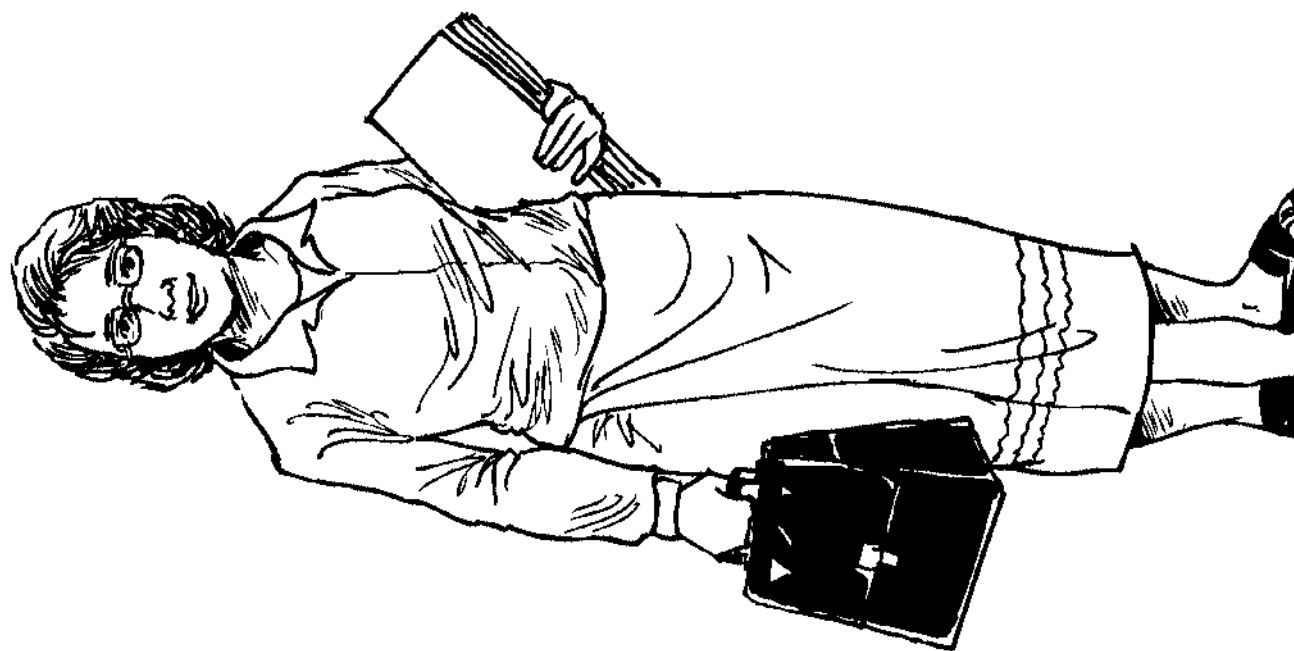




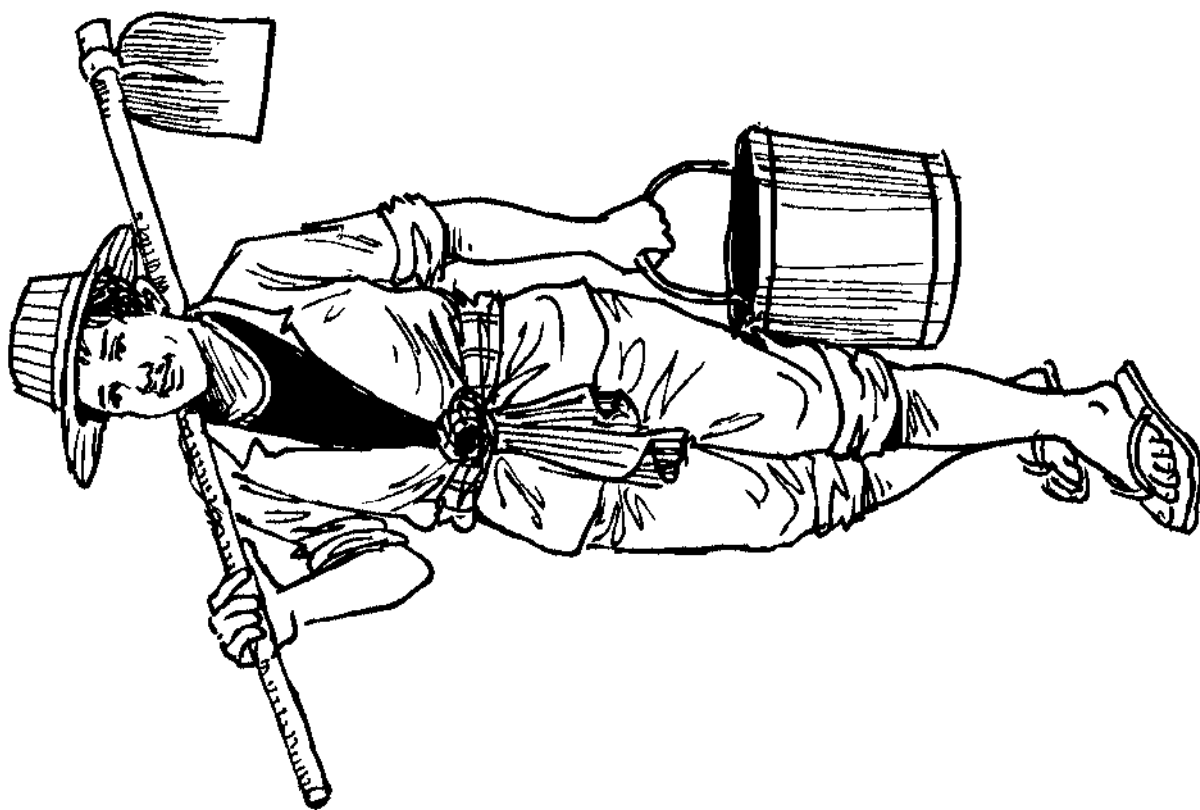














Annex D –

Silhouette Pictures





