Chapter A: HIV Stigma – Naming and Owning the Problem

“HIV is definitely going to weaken and kill people infected with HIV, without a doubt, but one should not kill them by stigmatizing.” (Traditional birth attendant’s [TBA] comments from the Reducing Stigma and Violence Toolkit for Health [SVTH] pilot workshop)

Introduction
This chapter gets participants to NAME AND OWN THE PROBLEM, to see that:

- Stigma exists and takes two major forms – isolating and blaming/shaming;
- HIV stigma has two major causes – fear and lack of understanding of how HIV is transmitted, and moral judgment of others;
- We are all involved in stigmatizing, even if we are not aware that we do it;
- Stigma hurts – people living with HIV feel ashamed and isolated, and their self-esteem is damaged;
- Stigma results in people living with HIV avoiding getting tested or seeking services or comfort;
- Stigma puts the partners of people living with HIV at risk of infection;
- Stigma helps the virus to spread and exacerbates its impact;
- Stigma is harmful to ourselves, our families, our practice and our communities; and
- We can make a difference by changing our own thinking and actions.
This chapter also gets participants to **name the problem in their own work context** – to recognize how they, as health care providers, stigmatize people living with HIV. The aim is for them to declare their own behavior as stigmatizing and decide how they want to change.

Most of the modules focus solely on HIV stigma, but a few (A5, A10, A12, A13) deal with both stigma and **gender violence**.

### Modules

- **A1. Introduction to Stigma – Animal Cards**
- **A2. Naming HIV Stigma Through Pictures**
- **A3. How It Feels to be Stigmatized (Reflection Exercise)**
- **A4 How It Feels to be Stigmatized (Testimonials)**
- **A5. Stigma and Violence in Different Contexts**
- **A6. Naming Stigma in Our Own Workplace**
- **A7. Stigma Walk – Mapping Stigma in a Health Facility**
- **A8. How Health Providers Are Stigmatized**
- **A9. Forms, Effects and Causes of Stigma – Problem Tree**
- **A10. Effects of Stigma and Gender Violence**
- **A11. Effects of Stigma on the HIV Epidemic**
- **A12. When HIV Enters the Home – Stigma and Violence**
- **A13. Women’s and Men’s Life Cycles – Stigma and Violence**
- **A14. Comparing AIDS, Cancer, Leprosy, TB, etc.**
- **A15. Review – Ten Questions on HIV Stigma**
A1. Introduction to Stigma – Animal Cards

Facilitator’s Note: This is a good starter activity to get participants talking about stigma and help them understand its meaning. It helps participants see that stigma is an everyday part of life and that we often stigmatize unconsciously.

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

a) Understand the meaning of the word “stigma”; and
b) Recognize that we are socialized to stigmatize others.

Time: 1 hour


Steps:

1. CHOOSING AND REJECTING (Individual Activity): Hand out a pair of cards to each participant and ask them to do the following:

   Look at your two cards and decide which bird, animal or person you would select and which you would reject. Why are you attracted to one and not the other?

2. REPORT BACK (Circle): Ask each person around the circle to explain his or her choices – which picture was chosen, and which was rejected. Record the reasons why people prefer certain animals/people and reject others.

Sample Responses:

<table>
<thead>
<tr>
<th>Positive characters – and why?</th>
<th>Negative characters – and why?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sparrow – helps people</td>
<td>Vulture – victimizes other animals</td>
</tr>
<tr>
<td>Dove – bird of peace – good luck</td>
<td>Owl – bad omen – brings bad luck</td>
</tr>
<tr>
<td>Swan – beautiful and graceful</td>
<td>Crow – chases away other birds</td>
</tr>
<tr>
<td>Cow – provides milk and income</td>
<td>Ox – big and threatening</td>
</tr>
<tr>
<td>Horse – means of transport</td>
<td>Bear – dangerous – it bites</td>
</tr>
<tr>
<td>Deer – beautiful</td>
<td>Lion – dangerous</td>
</tr>
<tr>
<td>Squirrel – small and friendly</td>
<td>Elephant – big and threatening</td>
</tr>
<tr>
<td>Rabbit – harmless</td>
<td>Monkey – creates nuisance</td>
</tr>
<tr>
<td>Goat – source of income</td>
<td>Pig – dirty and ugly</td>
</tr>
<tr>
<td>Fisherman – honest living</td>
<td>Old man – can’t do anything</td>
</tr>
<tr>
<td>Tailor – provides services to people</td>
<td>Injecting drug user – harmful activities</td>
</tr>
<tr>
<td>Young man – able to do anything</td>
<td>Washer – dirty job</td>
</tr>
<tr>
<td>Teacher – educates young people</td>
<td>Trucker – drinks alcohol, spreads HIV</td>
</tr>
<tr>
<td>Weaver – useful skill/craft</td>
<td>Migrant laborer – despised as dirty</td>
</tr>
<tr>
<td>Carpenter – provides useful services</td>
<td>Prisoner – danger to society</td>
</tr>
<tr>
<td>Rickshaw puller – hard worker</td>
<td>Beggar – dirty and bad habits</td>
</tr>
<tr>
<td>Businessman – high status</td>
<td>Dancing girl – promiscuous</td>
</tr>
<tr>
<td>Doctor – respected</td>
<td>Sweeper – low caste</td>
</tr>
</tbody>
</table>
3. PROCESSING: Ask–

a) Why do we like some animals/people and dislike (stigmatize) others? How do we form opinions of prejudice toward different animals or people?

b) Why is stigma a problem?

c) Why is it important to learn more about and take action against HIV stigma?

Sample Responses:

<table>
<thead>
<tr>
<th>Why do we stigmatize others? How do we form opinions of prejudice?</th>
</tr>
</thead>
<tbody>
<tr>
<td>■ All of us are taught to like certain animals or people, and to dislike others.</td>
</tr>
<tr>
<td>■ Stigma is to look down on other people, attributing bad things to them.</td>
</tr>
<tr>
<td>■ We stigmatize, often without realizing it, e.g. we all stigmatize crows.</td>
</tr>
<tr>
<td>■ We are socialized to stigmatize, to think negatively about other people, occupations and even animals. We say they are “bad,” “dangerous” or “dirty.”</td>
</tr>
<tr>
<td>■ These negative attitudes are not based on personal experience, but on what we have been told over the years by other people.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Why is stigmatizing others a problem?</th>
</tr>
</thead>
<tbody>
<tr>
<td>■ Animals and birds that look beautiful are valued more than those that are ugly, but some animals and birds that are rejected are also useful to society.</td>
</tr>
<tr>
<td>■ Stigmatized people may be viewed as bad by society, but they all make a contribution in building a better world, so they should be accepted.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Why is it important to learn more about and take action against HIV stigma?</th>
</tr>
</thead>
<tbody>
<tr>
<td>■ Stigma is a major factor in the HIV epidemic. Fear of stigma means people don’t get tested and disclose their status, which leads to further transmission of HIV.</td>
</tr>
<tr>
<td>■ Stigma results in people living with HIV being discriminated against and not getting access to health and other services.</td>
</tr>
<tr>
<td>■ People blame people with HIV as immoral or bad, rather than focusing on how to help them stay healthy and prevent HIV from being transmitted to others.</td>
</tr>
<tr>
<td>■ Caring for and supporting people living with HIV (the opposite of stigma) helps to stop HIV spreading, because it encourages them to practice safer sex.</td>
</tr>
</tbody>
</table>
4. MEANING OF STIGMA: Ask – What do you think is the meaning of stigma? As participants give their ideas, record them in a circle diagram like the one below. Then present and discuss the summary on the following page.

![Meaning of Stigma Diagram]

5. SUMMARY

- We have been socialized to stigmatize others – to judge or devalue them. We are often not aware that we are stigmatizing.

- **Stigma** is when we look down on another person as being bad in some way; we assign negative labels to the person (e.g., “promiscuous”) and don’t value him/her.

- **Discrimination** is the action resulting from stigma when a person is treated differently (e.g., fired from work, kicked out of accommodation or school, stopped from attending meetings, not allowed to use the village well).

- **Stigmatization** is a process:
  
  a) We identify and name the differences in someone;
  
  b) We make negative judgments about a person – “he has been promiscuous;”
  
  c) We isolate or judge/ridicule the person – separating “him” from “us”; and
  
  d) The person who is stigmatized (isolated and judged) loses status.

- Stigma and discrimination result in great suffering. People get hurt!

- **Stigma is viewed at present as something normal – as something not to be taken seriously.** People are not aware of how it affects people living with HIV and how it affects the HIV epidemic.

- **HIV stigma is WRONG – it is NOT ACCEPTABLE!** HIV stigma hurts people living with HIV and drives the epidemic underground. Those stigmatized become silent and don’t disclose their status to others – and as a result spread HIV.
A2. Naming HIV Stigma Through Pictures

Facilitator’s Note: This exercise helps participants to “name” HIV stigma impersonally – saying that stigma happens, but not yet saying “we are the stigmatizers.”

The pictures for this exercise can be used in different ways. In the process described below, pictures are handed out to pairs of participants to analyze. Another option, for a literate group, is to tape the pictures, along with flipchart paper, on the walls of the training room and ask participants to move around the room writing their comments regarding each picture.

We also have found that the pictures can be used by participants as a stimulus for discussing stigma with their families, neighbors and friends – a good form of follow-up. So we recommend that you make photocopies and hand them out to your participants.

“Everyone in the village liked this man. He was always so cheerful and good to people. But when he got sick, they stopped visiting him. A few came, but this was just to see this new disease called ‘AIDS.’ He was kept in a back room and people forgot about him. There were lots of rumors flying around the village about his ‘immoral behavior’ when he had worked in Kolkata. And when he died, no one went to the cremation. People were scared they would breathe in the fumes from the cremation fire and get HIV.”

(Rural medical practitioner’s [RMP] story that emerged out of this session during the SVTH project.)

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

a) Identify different forms of stigma in different contexts; and
b) Identify how stigma affects people living with HIV and their families.

Time: 1 hour


Steps:

1. NAMING STIGMA (Picture-Discussion): Divide into pairs. Ask each pair to select two pictures. Ask them to discuss, What do you see in the picture? How does this picture show stigma?

2. REPORT BACK (Circle): Ask each participant to hold up one picture for everyone to see and explain its contents. Record points on flipchart. For each picture, ask, How do you think this makes the person who is stigmatized feel?
Sample Responses:

**Picture A3 – Two men gossiping about another man**
One man is sitting alone while two other men are gossiping about him. He looks sad. They know that he has HIV so they are making fun of him, rather than supporting him.

**Picture A4 – Father, mother, and children being thrown out of house**
The owner is kicking an HIV-affected family out of his house. The family looks lost and miserable – they don’t know where they will go.

**Picture A6 – Man sitting all alone on a bed**
This man has been isolated – put into a room on his own and forced to stay there all alone. He has no visitors. No one is there to comfort or help him. He looks abandoned.

**Picture A7 – Health worker meeting with the family – positive woman is sitting alone**
The health worker is consulting the family about an HIV-positive family member but she is left out of the meeting. When you get HIV, you are seen as useless and left out of family decision-making.

**Picture A8 – Man outside counseling room, saying, “What am I going to do now?”**
He is worried about his situation. He is worried that he may be rejected by others once they find out that he is HIV-positive. What will people say or do? He looks desperate and confused.

**Picture A12 – Man is fired for being HIV-positive**
The man has been fired from work in the factory. He is not sure what he is going to do. He looks depressed – this may lead him to commit suicide.

**Picture A13 – Doctor talking to nurse beside patient’s bed**
The doctor and nurse are keeping a distance from the patient and gossiping about him. Excessive use of gloves and mask makes the patient feel rejected.

**Picture A20 – Children playing, one girl left out of the game**
The children exclude one girl from the game. Secondary stigma – she is stigmatized because her parents have HIV. Other parents may have told them not to play with her.

3. **PROCESSING:** Ask–

a) What are the major forms of stigma?

b) Why are people stigmatizing people suspected to have HIV?

c) How did it make the people who are stigmatized feel?

d) Have we seen examples of stigma in our own communities?

4. **SUMMARIZE:** Refer back to the pictures to make some of the following points:

- We have been socialized to stigmatize others – to judge or devalue them. We are often not aware that we are stigmatizing.

- **Stigma** is when we look down on another person as being bad in some way; we assign negative labels to the person (e.g., “promiscuous”) and don’t value him or her.

- **Discrimination** is the action resulting from stigma, when a person is treated differently (e.g., fired from work, kicked out of accommodation or school, stopped from attending meetings, not allowed to use the village well).
The main **FORMS** of stigma include:

- **ISOLATION & REJECTION** – Physical separation from family, friends and neighbors. Person living with HIV may be forced to stay alone in a separate room and use separate utensils. Based on ignorance and fear of HIV infection. Example: neighbors not attending the cremation of a person suspected to have died of AIDS out of fear that the smoke would carry HIV.

- **SHAMING AND BLAMING** – Gossip, name calling, insulting, belittling. Based on moral views. Shame people for assumed bad behavior.

- **TREATING PEOPLE AS USELESS** – People living with HIV may be excluded from decision-making, assumed to no longer be able to make a contribution to family.

- **SELF-STIGMA** – People living with HIV stigmatize themselves in reaction to stigmatization from society. They accept the blame and rejection of society, and end up isolating themselves.

- **STIGMA BY ASSOCIATION** – The family of a person living with HIV is stigmatized by the community – their family reputation is affected. RMPs and other health workers are stigmatized as “AIDS doctors.”

- **SECONDARY STIGMA** – Some individuals (e.g., women, dalits, widows) are already stigmatized and discriminated against. Having HIV adds another layer of stigma.

Some of the **EFFECTS** of stigma are:

- Shame, humiliation and loss of self-esteem;
- Feelings of sadness, loneliness, rejection, hopelessness, worry and self-doubt;
- Feelings of uselessness and inability to contribute;
- Stress, depression, suicide and alcoholism;
- Shame (loss of status) to family;
- Violence and other conflict;
- Discrimination – person living with HIV is kicked out of family, job, organizations, etc.;
- Denial, which stops people from getting tested or seeking services and support; and
- Silence – people living with HIV do not disclose their status and may pass HIV to others.

**Action Ideas:**

a) **Take the pictures home and discuss** them with family members and friends. Help others see what HIV stigma means in our lives – how it happens and how it hurts people.

b) **Discuss** – What can you do to stop HIV stigma?

**Examples:** Treat people living with HIV with the same respect as anyone else. Avoid using words that hurt people.
A3. How It Feels to be Stigmatized (Reflection Exercise)

**Facilitator’s Note:** This exercise is one of the most important because it draws on personal experiences to bring out the feelings of being stigmatized. The exercise requires a lot of trust and openness within the group, so it should not be done at the start of the training. Wait until participants are comfortable with each other, so that everyone can talk openly about their experience and how it made them feel. The facilitators can help participants get started by sharing their own stories and feelings first.

Set a quiet, serious tone for the exercise. Try to minimize outside interference. Keep the door closed so that no one can come in and disturb the group’s concentration.

Sharing one’s story is voluntary. No one should be forced to give their story.

Encourage group members to listen carefully to each other’s stories.

The exercise can be very emotional and painful for some participants. Participants are being asked to think and talk about strong feelings. You should be ready to deal with the emotions raised. (See the Introductory chapter for suggestions on how to do this.)

“The exercise helped me understand how it feels to be stigmatized. I reflected back on my own experience of being stigmatized as a widow when I was very young. How I cried! I remembered the emotion of being rejected and blamed as a widow – something which was very painful to me at the time.” (TBA participating in the SVTH project)

Some trainers have combined this exercise with the reflection on violence (module B3) – thinking of experiences of being abused or beaten. The choice of combining these exercises or treating them separately is up to you. The advantage of combining the two issues is that they are often closely linked. The disadvantage is that most of the stories end up focusing on violence and not enough attention is given to stigma.

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

a) Describe some of their own personal experiences concerning stigma; and
b) Identify some of the feelings associated with being stigmatized.

**Time:** 1–2 hours

**Steps:**

1. **OUR OWN EXPERIENCE OF BEING STIGMATIZED** (Individual Reflection): Ask participants to sit on their own at a distance from other participants. Then say – *Think about a time in your life when you felt isolated or rejected for being seen as different from others – or when you saw other people treated this way. Explain that this does not need to be examples of HIV stigma – it could be any form of isolation or rejection for being seen as different. Ask them to consider, What happened? How did it feel? What impact did it have on you?*

2. **SHARING IN PAIRS:** Share with someone with whom you feel comfortable. *If you prefer to remain silent, this is okay too. There is no pressure on anyone to share.* Help participants pair off if they are having difficulties.
3. REPORT BACK: Invite participants to share their stories in the large group. This is not compulsory – people will share if they feel comfortable. You may choose to use your own story first to break the ice. As the stories are presented, ask – How did you feel? How did this affect your life?

Sample Responses:

**Experiences of being stigmatized**
Caste discrimination. Experience of being widowed. Women being rejected by their husbands. Having a different dialect. Dressing differently. Skin disease resulting in being shunned.

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

4. PROCESSING: Ask – What did you learn about stigma from this exercise? What feelings are associated with stigma?

5. SUMMARIZE:
- This exercise helps us get an inside understanding of how it feels to be stigmatized – shamed or rejected.
- The feelings of being stigmatized are very painful. People get badly hurt.
- The feelings of being stigmatized last a long time.
- Stigma destroys people’s self-esteem. 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.
- This exercise helps put us into the shoes of people living with HIV. It helps us understand how painful it is to be stigmatized. People living with HIV go through this experience every day of their lives, and it is very demoralizing.
**Action Ideas:**

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

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**Stories and Experience of Being Stigmatized**

1. I was widowed at 25. I am now 56. When I was widowed, I already had four children – the oldest age 10. Everyone told me, “How can you raise four children on your own?” This made me feel very bad. I told myself, “Why do people tell me I’m helpless? Why can’t I educate my own children?” So instead of allowing this stigma to demoralize me, it challenged me to do something. I worked very hard at dress-making to earn extra money to put my children through school. And later I became a TBA, but the stigma did not stop. On my first delivery, the owner of the house said, “Oh, look at you, a widow coming to my house to deliver – this is a bad omen!”

2. When I was small, my brother and I used to play with two children in our area, both of them from dalit families. One day my father came home and found us playing with them. He shouted at them and kicked them out of our house. This made me cry. I felt very bitter, I was so ashamed. This girl was my best friend. My brother and I did not accept this treatment. When my father was not around we would still go and play with them.

3. I have long hair and used to tie it in a ponytail, wrapped in a dhoti. One day on the bus schoolchildren sat behind me and pulled my hair. This made me feel very bad. They made me feel different because of my hair.

4. I married a man from another area, where the accent is quite different. When I first moved in with his family, I found it hard to understand their accent and they used to tease me about my accent, always imitating some of my words. So I felt very isolated in this household – they made me feel different from the others because of my language.

5. When I was 18, I decided to leave home, find work and survive on my own. I went to a bigger city and tried to find work. People said, “You look well fed, too spoiled to be able to do manual labor.” So no one hired me. I then tried to get work as a security guard, but no one hired me – they said I had no experience. So again I failed to find work. Demoralized I returned home, feeling I was a failure.

6. As women we are stigmatized from the day we are born to the day we die. As a child I was always treated as if I was nothing – my brothers always got more love and better treatment. When I became a teenager, my life stopped – I was pulled out of school and sent to work in the fields . . .

7. As dalits we are branded as outcasts. We are treated as being inferior and as a danger to other people. People don’t mix with us, don’t eat with us, don’t marry us, don’t accept us – we have to live separately in our own colonies.
Facilitator's Note: We consider this exercise to be very important. In it, two or three people from the Network of People Living with HIV address the health workers and answer their questions. Hearing first-hand about the lives of people living with HIV and how they are treated by their families, workmates, communities and health workers helps to make stigma real for health workers.

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

a) Name some of the forms of stigma experienced by people living with HIV; and

b) Describe the feelings of being stigmatized.

Time: 1 hour

Materials and preparation: Invite guest speakers (people living with HIV) and brief them beforehand on how to give their testimonies. Ask them to:

- Talk about your own life and the life of your family before and after getting HIV. Talk about how you were treated in the family, in the community and in health facilities once people discovered you were HIV-positive – and how it made you feel.

- If possible use your own stories to get health workers talking about their own experience with stigma – examples they have they seen or heard about stigma.

Steps:

1. TESTIMONIES: Ask each speaker to tell his or her story and invite participants to ask questions to clarify the story. Focus on the experience of the speakers, but also encourage participants to respond to the stories with their own examples of stigma in the community or health settings. Have you seen or heard of things like this?

See example of a testimony on the next page.

2. PROCESSING: Ask–

a) What were the main forms of stigma identified in the stories?

b) What should/would be your responsibility and response, as health care providers, in similar situations?

Sample Responses: Stigma and discrimination in the story (on the following page)

**Stigma in the family**
- Person living with HIV is verbally abused by other family members – mother-in-law blames her for her husband’s infection.

**Stigma in the community**
- Neighbors gossip once they discovered she had HIV.
- People stopped buying goods from the family shop.
- Neighbors stopped their children playing with her son.

**Stigma in the health facility**
- No confidentiality – letting other staff and patients know her status.
- No proper counseling – no comfort, encouragement or reassurance.
3. SUMMARIZE:

- This exercise helps us understand **how it feels** to be stigmatized. The feelings of being stigmatized are very painful. People get badly hurt.

- Some people living with HIV say that health workers are afraid that treating them will lead to HIV infection. As a result, health workers minimize contact with patients who they suspect have HIV.

- Some HIV-positive patients think that health workers judge them – blame them for getting HIV through “bad behavior.”

- These two things – isolation and blame – make people living with HIV feel like outcasts. This has a serious effect on their psychological health.

- **Stigma destroys the self-esteem of people living with HIV.** 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.

- While taking the necessary precautions to protect their own safety, health workers **need to focus on the well-being of their patients and take the feelings of people living with HIV into account.**

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**Example – a composite story based on the real experience of people living with HIV**

I got married when I was 16. Soon after we were married, my husband left to work in Kolkata. He stayed there for eight years, returning once or twice a year to see the family, and make me pregnant. During the last part of his stay he began to get sick. Eventually he was kicked out of his job and he returned home. At first he didn’t tell me what was wrong with him, but I suspected he might have this new disease called “AIDS.” He got sicker and sicker and eventually he died.

I was pregnant at the time and went to the health center for a check-up. They asked me to do a blood test – and then told me I was HIV-positive. They told me with very little counseling and support. And after telling me the results, no one told me what to do, how to cope with this new situation. I was shocked and confused and angry – I didn’t know what to do. This was the first time for me to find out that my husband had infected me.

Everyone at the health center seemed to know my HIV status. They looked at me in a funny way and kept their distance. Sometimes I had to wait for a long time. But they helped me deliver the baby.

I returned home to find other problems. My neighbors started to gossip about me and my mother-in-law began to tell stories about me. She blamed me for infecting her son. This made me feel very depressed.

I started a sewing business to bring in extra income. At first I got customers but when people found out about my situation they stopped coming. 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 sent him to school, but other children refused to play with him and he had to sit separately in class. He does not have HIV but he is suffering just like me – people say he is an AIDS child!
A5. Stigma and Violence in Different Contexts

Facilitator’s Note: This activity, which uses rotational brainstorming, is especially good for workshops that bring together different types of health workers.

Rotational brainstorming requires literacy skills, so to complete this activity with groups including TBAs you may need extra recorders (one recorder per group). At each flipchart the recorder reads out the points already written by other groups and asks the group to add new points.

The choice of combining stigma and gender violence within a single exercise or treating them separately is up to you. In our experience it is better to deal with them separately when training TBAs; otherwise it is too overwhelming. On the other hand, combining the two issues in a single exercise helps bring out the close links between stigma and gender violence.

During the group reports, debrief on the health facility and workplace contexts last. This provides a link to the next module on “Stigma in the Workplace.”

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

a) Identify different forms of stigma and violence that take place in different contexts; and

b) Work out solutions to stop stigma and gender violence.

Time: 1–2 hours

Materials and preparation: Put up flipchart paper on different walls of the room, with a context written on each sheet: Home, Community, Market, School, Health Facility and Workplace.

Steps:

1. ROTATIONAL BRAINSTORMING (Small Groups): Divide into six groups and assign each group to a topic. Ask each group to write down on the flipchart forms of HIV stigma and gender violence that occur in their context. (Ask them to start writing their first thoughts immediately, not stand talking for a long time without writing.) After three to four minutes shout “CHANGE” and ask groups to move to the next topic and add points. Continue until each group has contributed ideas to every context.

2. REPORT BACK (Rotational): The whole group moves around the room, looking at one topic at a time. Ask one participant to read out the points quickly.

Option: Another way to report back is to ask each group to return to the flipchart where they started and prepare a presentation. This would include presenting the main points and doing a drama.
Sample Responses: Identifying forms of stigma and gender violence

Home
- No respect or love. Family members stop touching or comforting HIV-positive family members.
- Isolation – hide people living with HIV in back room – separate bed, blankets, clothes, plates, food.
- Some people living with HIV are kicked out of the house and forced to move to another place.
- Hide people living with HIV from neighbors. Stop them going outside so neighbors won’t see them.
- HIV-positive women are prevented from having contact with their own children.
- Loss of place and recognition within family. Excluded from family decision-making.
- Verbal abuse – insults, belittling and blame, e.g. “Why did you bring shame on the family?”
- Viewed as burden on family. Treated as useless – no longer able to contribute to the family.
- Women are the first blamed for bringing HIV into the home and abused verbally and physically.
- Property grabbing by relatives – women lose out. Resulting poverty.
- Family shame – family honor/reputation ruined – self-stigma by family.
- Wife blamed for not raising (HIV-positive) child properly. Often leads to violence.
- Stigma at home is very painful. This is the place of last resort. If your own family stigmatizes you, you have nowhere else to go.

Community
- Verbally abuse people living with HIV – call them “promiscuous.” Whispering and finger-pointing.
- Neighbors isolate or shun people living with HIV – they stop visiting the family and sharing food.
- Neighbors only visit as voyeurs to see how thin the people living with HIV are or how the skin looks.
- They stigmatize the family. Blame family for low morals – not raising their child properly.
- Don’t allow their children to play with children from the HIV-affected family.
- Refuse to provide services, e.g. washerman will not wash the family’s clothes, barber will not cut the hair of a person living with HIV.
- People living with HIV are prevented by community members from attending functions.
- When a person dies from AIDS, community members refuse to take the body for the cremation and to attend the cremation.
- Sexual harassment and abuse of women and teenage girls.

School
- Children who have HIV-positive parents are stigmatized by other children – prevented from playing with them or taunted and teased.
- These children are given separate places in the classroom.

Market
- People stop buying products from someone suspected to be HIV-positive – say goods are contagious.
- Teasing and gossip, e.g. “Her husband died recently from AIDS.”
- Isolation – stay away from the seller.
- Loss of respect, erosion of morale and business collapses.

Workplace
- Gossip and isolation toward someone suspected to be HIV-positive.
- Forced to take HIV test and then fired from job.
- Loss of status/reputation – viewed by everyone as unreliable.
- Sexual harassment and abuse of women and teenage girls.

Health facility
- Staff are suspicious of anyone who seems to have AIDS symptoms – fear of getting infected.
- Isolate people living with HIV – forced to stay in separate room. Keep food and utensils separate.
- Insults – blame him for getting HIV through promiscuous behavior, i.e. sleeping with sex workers.
- Neglect. Minimize touching of HIV-positive patients. Treat them last and provide “half treatment.”
- Overprotection – wear gloves to examine HIV-positive patients. Maintain distance in giving injections.
- RMPs and other health workers are stigmatized – called “AIDS doctors.”
- Cases of battered women are treated as “accidents,” not cases of violence.
3. PROCESSING – SOLUTIONS: Ask, What can we do to stop HIV stigma and gender violence?

Sample Responses:

- Change our own attitudes and language toward people living with HIV and women – stop “blaming and shaming” and using words such as “promiscuous.”
- Stop using negative words when we talk about people living with HIV or women.
- Educate others on how stigma and gender violence feel and why they are wrong.
- Speak out against stigma and violence toward women.
- Get the community to name HIV stigma and gender violence as problems.
- Provide up-to-date information about HIV and AIDS so that people no longer isolate people living with HIV out of fear of casual contact.
- Stop family members from isolating family members with HIV within the home.
- Stop family members from abusing women (physical, emotional, sexual or economic).
- Treat positive people like you would treat other people – no difference!
- Offer kindness, support, comfort and good listening to people living with HIV and battered women.
- Encourage people living with HIV to use available services, such as antiretroviral treatment, preventing parent-to-child transmission treatment and medical care.
- Encourage women to report violence to police and get police to treat cases seriously.
- Empower women and people living with HIV with assertiveness skills.
- Provide legal services for women and people living with HIV.
- Encourage people living with HIV to be involved in family and community gatherings.
- Introduce new practices in health facilities, e.g., no separate rooms or seating for people living with HIV.
- Treat cases of battered women differently – as cases of violence, not “accidents.”

4. SUMMARY:

- Stigma and gender violence are everywhere – homes, communities, health facilities, workplaces, markets, etc.
- Stigma takes two major forms:
  a) Rejection and isolation – people are rejected because others fear getting infected (or they self-impose isolation from fear of other people knowing).
  b) Shame and blame – people are judged, condemned, belittled, mocked – often based on the assumed sexual behavior of a person who has HIV.
- Other forms of stigma include:
  c) Self-stigma – people living with HIV blaming and isolating themselves.
  d) Stigma by association – families and health workers associated with people living with HIV are stigmatized.
  e) Secondary stigma – some individuals are already discriminated against (e.g., women, dalits and widows). HIV adds another layer of stigma.
- Violence takes four major forms – physical, emotional, sexual and economic.
- Emotional violence is similar to stigma – women are blamed and shamed (verbally abused) for being a burden on the family, not having children, etc.
■ **STOPPING STIGMA AND VIOLENCE** will take a huge effort by everyone. The starting point is to change ourselves – change the way we think, talk and act toward people living with HIV and women. We have to personalize the issue to see that we have to do something to change things.

■ Open your mind. Lose your prejudices. Respect differences.

■ 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 or abusing women – but this is one of the most important ways to stop stigma and violence. Breaking the silence and getting people talking openly is the first big step.

■ **Action Ideas:**

■ Talk with your family, friends and clients about HIV stigma and gender violence, and how they both hurt people and cause the virus to spread.

■ Get community leaders to speak out against stigma and violence. Help everyone make these problems visible and unacceptable.

■ Reach out to, accept and support people living with HIV and abused women. Once they feel accepted, they will be more open to discussing their situation with others and accessing services.
A6. Naming Stigma in Our Own Workplace

Facilitator’s Note: In this module participants look at how they, as health workers, stigmatize people living with HIV, and what they can do to change these practices.

The health workers explained during the pilot project that people living with HIV rarely come to them for medical help. TBAs, for example, said that they had not yet delivered babies for a positive mother. This module helped participants understand that people living with HIV will not come to them for help unless they show that they will provide treatment fairly and without stigma.

Because every health setting produces different forms of stigma, you should adapt this module to suit each of the target groups – rural medical practitioners, traditional birth attendants and community health workers (auxiliary nurse midwives and multi-purpose health workers).

“If an HIV-positive woman asks us to deliver her baby, we should never refuse. After all we are all mothers – we cannot leave her for her own destiny.”

“One should be near a person at the time of birth and death, so we are going to help deliver babies for any woman who comes to us.”

“From now on we are going to touch our HIV-positive patients. If we touch them, then only others will believe and behave.”

(TBA comments from SVTH project)

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

a) Describe how they stigmatize people living with HIV or people suspected to have HIV in their own working context – and how it affects their HIV-positive clients; and

b) Take responsibility for changing the way they relate to people living with HIV.

Time: 2 hours

Materials and preparation: Pictures A13 to A15 (Annex 5), taped to the wall.

Steps:

1. NAMING STIGMA IN OUR WORKPLACE (Picture Discussion & Brainstorm):

Ask–

a) What forms of stigma do you see in the pictures?

b) What other forms of stigma take place in health care settings? How does this affect people living with HIV?

c) How are YOU treating clients whom you suspect have HIV? Do you treat them in a different way than other patients?

d) What fears do you have about providing services to people living with HIV?
Sample Responses:

Forms of stigma toward people living with or suspected to have HIV

- Avoid touching patients and minimize contact when checking symptoms.
- Force HIV-positive patients to sit in a separate area or on a separate bench.
- Judgmental – “You guys play these dirty games – you deserve to get AIDS!”
- No proper counseling – no comfort, encouragement or reassurance.
- Break confidentiality – gossip about people living with HIV to patients or community.
- Refer them to private testing centers – and get a commission. (Extra financial burden on patient, who could get free testing at an Integrated Counseling and Testing Center.)
- Reject clients suspected to have HIV, giving as an excuse that they don’t know how to treat this disease.
- Charge extra fees for treating people living with HIV – “risk allowance.”

How stigma affects people living with HIV

- Makes them feel unwanted and demoralized – lose their self-esteem.
- May avoid going to health workers for help, fearing that they will be treated badly.

How are you treating HIV-positive clients?

- We have treated them in an aggressive or impersonal way, showing very little concern.
- We do not have many patients who are HIV-positive.
- We refer them to other health workers.
- We have very little experience working with HIV-positive patients.

Fears about treating HIV-positive patients

- We are afraid we may get infected while we are checking their symptoms.
- We fear our businesses will suffer if our other patients see us treating the HIV-positive patients.

2. NAMING STIGMA IN OUR WORKPLACE (Story):

As an alternative or additional activity, read or act out the following story:

In one village, a father gets HIV and eventually dies. His wife becomes very sick, but her son makes no attempt to get her treatment. Dayamani, a TBA, hears about the situation and comes to visit, even though neighbors tell her this is dangerous. After talking with the woman, she tells the family that she is going to take the woman for treatment. But the family and neighbors try to stop her. She refuses to listen and takes the woman to the hospital. At the hospital, the doctor scolds her for bringing the woman and sends her to the outpatient unit for first aid. Dayamani then takes the woman home. When she returns to her own home, household members stop her from entering her house until she has had a bath and washed herself completely.

Then ask–

a) What forms of stigma took place in this story? How do you think the woman with HIV felt?

b) Have you had similar experiences in trying to treat people living with HIV? If so, what happened?
3. CHANGING OUR TREATMENT OF PEOPLE LIVING WITH HIV (Paired Role Play): The exercise below is designed for RMPs. You should adapt it for the other health workers.

Tell participants, “We are now going to practice how to change the way we relate to people living with HIV and AIDS.”

**Step 1 (Clinic Situation):** We are first going to imagine that a man who suspects he has HIV comes to get help at your clinic. Everyone stand up and find a partner. A is the RMP, B is the client. In each pair agree on who is A and who is B. (Wait until they decide.) The situation you will play is: B arrives at A’s clinic and asks A to help him – B has been having lots of diarrhea. PLAY!

Let the plays run for three minutes. Then shout “Stop!” and invite one pair to show their play to the group. At the end lead the following discussion:

a) Ask the group, What happened? How did the RMP deal with the client?

b) Ask the client, How did this approach make you feel?

c) Ask the group, What other approach might be used to make him feel better?

**Sample Responses:**

<table>
<thead>
<tr>
<th>a) What happened? How did the RMP deal with the client?</th>
</tr>
</thead>
<tbody>
<tr>
<td>■ He kept at a distance, showing his fear of the patient.</td>
</tr>
<tr>
<td>■ He was very cold and refused to touch the patient.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>b) Client – How did this approach make you feel?</th>
</tr>
</thead>
<tbody>
<tr>
<td>■ I felt he was shunning me. I felt very bad and demoralized and wanted to leave.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>c) What other approach might be used to make the client feel better?</th>
</tr>
</thead>
<tbody>
<tr>
<td>■ Welcome the client with a warm smile and kind words.</td>
</tr>
<tr>
<td>■ Sit closer to the client and ask him questions about his health.</td>
</tr>
<tr>
<td>■ Ask questions to get him talking.</td>
</tr>
</tbody>
</table>

Use the suggested approaches (Question C) as the basis for a new role play, building on the first one. Ask the person who suggests the improved approach to take over the role of RMP, while the original person continues to play the role of the client. Then play the scene again, and afterwards debrief how it went – Did the new approach work? How did it make the client feel? What made the difference?

Continue this process until the group has agreed on a good strategy to respond positively to the client.

**Step 2 (Family Situation):** If there is enough time, try out the following situation, using the same pairs as in Step 1: We are now going to look at a new situation, where a woman comes to ask the RMP to visit her sick husband, who is thin and has a high fever. Change the roles. The person who was the RMP now becomes the woman. The other partner plays the RMP. NOW play out the new situation. PLAY!

After three minutes shout “Stop!” and ask one pair to show their play to the group. Debrief and continue to use role play and discussion to work out approaches to deal with this new situation.
4. CHANGING OUR TREATMENT OF PEOPLE LIVING WITH HIV (Group Role Play):

As an alternative to #3, divide participants into two groups. Ask one group to develop a role play showing a negative, stigmatizing approach used by a health worker interacting with an HIV-positive client, and ask the other group to develop a role play showing a positive, supportive approach. Then ask both groups to perform their plays and discuss.

a) What happened in each role play?

b) RMP: Why did you treat the patient like that? (e.g., fear)

c) Patient: How did it make you feel?

d) What approaches should be used to deal with an HIV-positive client?

5. PROCESSING: Ask–

a) What approaches can we use to build good relations with an HIV patient?

b) What approaches can we use to help a family accept the new situation and take responsibility for caring for the family member with HIV?

c) How can we support people living with HIV to cope with stigma?

Sample Responses:

<table>
<thead>
<tr>
<th>Approaches for building good relations with an HIV patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>■ Treat patients with HIV the same way you treat other patients.</td>
</tr>
<tr>
<td>■ Empower/encourage the patient to talk – to explain how she or he is feeling.</td>
</tr>
<tr>
<td>■ Touching patients with HIV (to check their symptoms) is okay. Touching is important because people living with HIV rarely get touched (because of the fear within family/community).</td>
</tr>
<tr>
<td>■ Be reassuring. Say things like “Don’t worry – we can do something. People may tell you your life is over, but there is a new medication called antiretroviral therapy that can help you. If you look after yourself, you can live a long life.”</td>
</tr>
<tr>
<td>■ Tell the patient how to get tested and how it will help.</td>
</tr>
<tr>
<td>■ Advise on how to get support from others. Encourage disclosure to a trusted family member or friend.</td>
</tr>
<tr>
<td>■ Provide basic information on antiretroviral treatment and how it can be obtained.</td>
</tr>
<tr>
<td>■ Help him focus on the positives, e.g. It is important to stay alive for your children.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Approaches for dealing with the family</th>
</tr>
</thead>
<tbody>
<tr>
<td>■ Help the family focus on the health situation and avoid “shaming and blaming.”</td>
</tr>
<tr>
<td>■ Provide basic information on HIV and AIDS and clear up misconceptions.</td>
</tr>
<tr>
<td>■ Help the family accept responsibility for caring for the person with HIV.</td>
</tr>
</tbody>
</table>
6. SUMMARY:

We should STOP:

- Sending clients with HIV away and refusing to help them (because we fear getting HIV from them or fear that we will lose our other clients);
- Breaching confidentiality – telling other clients about our patients with HIV;
- Separating patients – putting people living with HIV in a separate room/space; and
- Charging people living with HIV extra for services.

We should START telling our patients with HIV about:

- When and how to disclose to family and/or friends to get support;
- Why, where and how to get Integrated Counseling and Testing;
- How to avoid transmitting HIV during childbirth through Preventing Parent-to-Child Transmission (PPTCT) programs;
- The meaning of a CD4 test; and
- When and how to obtain antiretroviral treatment.

We should develop a CODE OF PRACTICE to treat people living with HIV in a stigma-free, accepting way. They deserve our respect and support.

Action Ideas:

Talk with other health workers and clients about what you can do to de-stigmatize your practice. How can you change the setup in your clinic to make it stigma-free? How can you educate your clients who do not have HIV so they are more supportive toward clients with HIV?

Meet with the RMP Association or other groups of health professionals to develop a CODE OF PRACTICE on how to treat people living with HIV in a stigma-free, accepting way. Encourage all health workers to sign it.

Example of what the “CODE OF PRACTICE” might look like:

This is the code of practice drawn up by the RMP Welfare Association of Ichhapuram

We will follow this code of practice and live by it on a daily basis:

We will treat people living with HIV with love and give them courage.

We will touch people living with HIV and make them feel comfortable.

We will use disposable syringes for every patient.

We will not show any discrimination to people living with HIV. We will treat all patients equally.

We will give people living with HIV good suggestions, courage and ideas to help them live a healthy life.

We will not disclose the status of HIV patients to others.

We will not organize separate rooms at clinics for HIV patients.

We will not charge HIV patients more than other patients.

We will raise the awareness of our communities on stigma, discrimination and gender-based violence.
A7. Stigma Walk – Mapping Stigma in a Health Facility

Facilitator’s Note: This module is an option to use along with A6 and is used to identify different forms of stigma in a health center. Staff walk through different rooms or spaces in their facility to observe how health workers interact with patients. This provides a non-threatening way for health staff to learn how patients (including those with HIV) perceive practices at the facility, and which practices are potentially stigmatizing.

Objective: By the end of this session, participants will be able to identify potential forms of stigma in each area of the health facility.

Time: 1 hour

Materials and preparation: Meet with the head of the facility beforehand to get permission to use the space. Explain the purpose of the “walk” and offer to debrief him or her afterwards on the forms of stigma found in the center. Try to minimize defensiveness and allay fears about criticism by clarifying that the aim is to find ways to improve relations with clients.

Steps:

1. INTRODUCTION: Explain the purpose of the walk and discuss with participants which issues should be explored during the walk (e.g., body language or words used by health staff to patients, separate spaces for patients with HIV, special codes used to identify HIV patients, use of Universal Precautions, etc). Decide on the locations to be visited. For a community health center, for example, you might visit the operating room, consulting room, wards, labor room, dispensary, injection room, dressing room, Integrated Counseling and Testing Center (ICTC), medical lab, X-ray room and incinerator. You might invite community leaders or some patients to join you for the walk.

2. STIGMA WALK: Divide into two groups for the walk and assign one facilitator to accompany each team. Ask each group to visit each room, make notes on what they observe, and hold short discussions with the staff or patients who are there.

3. REPORT BACK: At the end of the walk, reconvene and ask groups to report on their findings. Taking one room at a time, ask one group to report, and then ask the other group to add missing points. The second group can report first on the next room, and so on.
Sample Responses:

**Integrated Counseling and Testing Center:** Avoid touching patients. Excessive use of gloves. Treat them from a distance. Inform other staff of their status. Call them “AIDS people.” Give reports to them in anger. ICTC staff are stigmatized by other staff – one staff member writes HIV to identify staff who belong to this unit.

**Outpatient Room:** Patients gossip about other patients while sitting on the bench. Stigma here is directed to people they suspect have HIV, e.g. with symptoms of thinness or skin rashes.

**Patients’ Ward:** Separate wards, or separate beds within the ward. Some patients have asked to be moved or discharged once they learn they are sharing a room with an HIV patient.

**Operating Room:** Show difference in surgery process for patients with HIV. Excessive use of gloves (double gloves for every operation). Charge HIV patients more.

**Labor Room:** Minimize contact. Talk in codes. Doctors don’t do delivery for HIV-positive mothers, they ask nurses to do it for them; senior nurses pass responsibility to junior nurses; and junior nurses delegate this work to class 4 employees.

**Dressing Room:** Staff in this room give material to HIV patients and ask them to do the dressing themselves.

**Dispensary:** Make HIV patients wait a long time. Minimize contact.

**Lab:** Disclose their status to others. Scold and insult them. Serve them last.

4. PROCESSING:

Make a diagram of the health center and record the stigma in each area.

Break into small groups and discuss what can be done to create a stigma-free facility.

**Sample Responses: How to create a stigma-free facility**

- Stop separating HIV patients within the wards.
- Avoid stigmatizing or coded language for people with HIV.
- Do not violate confidentiality; do not gossip.
- Provide counseling and encouragement.
- Treat patients living with HIV like other patients.
- Tell them about how they can live a positive life, e.g. early treatment of opportunistic infections, a healthy diet, etc.
- Tell them about antiretroviral therapy and how to access antiretroviral drugs.
- Use disposable syringes consistently.

**Action Ideas:**

Decide how the group will address each recommendation generated, including:

a) Who will do each activity;

b) By when; and

c) What indicators will show that the problem has been solved.
**A8. How Health Providers Are Stigmatized**

**Facilitator’s Note:** This exercise looks at how health workers are stigmatized for treating people suspected to have HIV. This is a real issue facing health workers; some RMPs have lost clients as a result.

In the pilot project, doing this module encouraged RMPs to start talking about the need for educating the larger community about stigma. They said that “unless we change the environment that we work in – the thinking of our communities toward people living with HIV – we will continue to lose our clients, and people living with HIV will continue to live in fear and isolation. To break the stigma in the villages we need to work together with other health workers to change the community’s attitudes.”

“I am a bachelor. It is difficult for me to find a wife because I am viewed as a health worker dealing with HIV.” (Lab technician)

“It’s true – I did lose clients in that village when I started to treat people living with HIV. But I began to talk to people and help them understand HIV and little by little they began to come back to me and use my services. The workshops taught me to stop fearing contact with people living with HIV and that I must serve them, no matter how it affects my business. If all RMPs stand together and make a commitment to serve people living with HIV, then we can bring a change. Even RMPs who have not gone through [this training] process are willing to learn from us and start treating people living with HIV.” (RMP)

**Objectives:** By the end of this session, participants will be able to:
- Describe how they are stigmatized for treating people living with HIV and how it affects them;
- and
- Work out a strategy for coping with this situation and countering stigma.

**Time:** 1 hour

**Steps:**

1. NAMING THE STIGMA WE FACE AS HEALTH WORKERS (Story Discussion):
   Read the following story:
   One RMP has a good practice and a good name in the village and is always available to help people. One day a man who was HIV-positive came to him for treatment. The man told the RMP that his wife had died of AIDS and that he was weak and suffering from fever. The RMP gave him some medication and followed up with visits to the man’s house to check on his progress. But the other villagers started to gossip about this patient – accusing him of killing his wife. They also began to talk about the RMP. They suspected the RMP was using the same medical instruments to treat the man and other people, and they worried that they would also become infected. So they stopped going to him for treatment.
   
   **Ask—**
   - What happened in the story?
   - What stigma do you face as a health worker who treats clients with HIV?
   - How do you feel about this? How does this affect you?
   - What can you do?
Sample Responses:

**Stigma faced by RMPs for treating clients with HIV**
- RMPs who treat people living with HIV are teased as “AIDS doctors.”
- Relatives of RMPs tell them not to treat patients with HIV.
- Some clients who hear that a RMP is treating patients with HIV ask him to stop.

**How does stigma affect RMPs?**
- If many people with HIV come to them for treatment, they may lose other clients.

**What can RMPs do about this situation?**
- We should educate the community so they stop stigmatizing people living with HIV and RMPs who treat HIV patients.
- We need to change the public mindset – help people understand that:
  a) People living with HIV are not dangerous; and
  b) RMPs will not become infected by providing services to HIV-positive patients.
- We can’t do it alone. If we all work stand together against stigma, we can help to break it.
- If we all adopt a common approach, and all agree to provide services to people living with HIV, then public attitudes will change and we will build acceptance.

2. **SUMMARY:**
- **Health workers themselves face stigma** for treating clients with HIV.
- To counter stigma, we need to **educate the community:**
  a) **Clear up misconceptions** about HIV; and
  b) Help people understand how **stigma can be hurtful** to people living with HIV, to health workers and to the community.
- **Working together** with other health workers and adopting a common approach will help us change public attitudes and build public acceptance.

**Action Ideas:**
- **Talk with your family, friends, and clients** about HIV stigma and how it both hurts people and causes the virus to spread.
- **Get community leaders** to speak out against stigma. Help everyone make the problem visible and unacceptable.
- **Reach out to, accept and support people living with HIV.** Once they feel accepted, they will be more open to discussing their situation with others and accessing services.
A9. Forms, Effects and Causes of Stigma – Problem Tree

Facilitator’s Note: In the earlier modules participants have analyzed the forms and effects of stigma. This exercise reviews forms and effects and looks at the causes of stigma.

This activity uses the “problem tree”—a method that describes the forms, effects, and causes of stigma by comparing them to the trunk (the forms of stigma), branches (effects), and the roots (causes) of a tree. Participants write each form, effect, or cause on a card and tape the card at the appropriate level of a tree diagram.

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

a) Describe different forms of stigma and how stigma affects people; and
b) Identify some of the root causes of stigma.

Time: 1–2 hours

Materials and preparation: Draw a large tree diagram on flipchart paper, with the “Effects,” “Forms” and “Causes” labeled at appropriate levels (see below). Write one example of the type of response expected at each level on a card and tape the cards at their respective levels.

<table>
<thead>
<tr>
<th>Location</th>
<th>Part of Tree</th>
<th>Feature</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Top</td>
<td>Branches</td>
<td>EFFECTS</td>
<td>loneliness</td>
</tr>
<tr>
<td>Middle</td>
<td>Trunk</td>
<td>FORMS</td>
<td>name calling</td>
</tr>
<tr>
<td>Bottom</td>
<td>Roots</td>
<td>CAUSES</td>
<td>lack of knowledge</td>
</tr>
</tbody>
</table>

Steps:

1. CARD-STORMING: Divide into pairs. Hand out cards and markers. Ask pairs to write points on forms, effects and causes – one point per card – and then tape them at the appropriate level of the tree. Remind them to consider HIV stigma as it affects various groups: people living with HIV, their families and health care providers.

Cluster common points and eliminate repetition.

2. EFFECTS: Divide into small groups and ask each group to analyze the effects of stigma on a specific group, e.g., men, women, children, etc.

   Group A: If the person stigmatized is a woman – what are the effects on her?
   Group B: If the person stigmatized is a man – what are the effects on him?
   Group C: If the people stigmatized are children – what are the effects on them?
   Group D: If the entire family is stigmatized – what are the effects on them?
   Group E: If health providers are stigmatized – what are the effects on them?
   Group F: What is the effect of HIV stigma on the epidemic?

3. CAUSES: Continue the same process in the same groups. Ask groups to analyze the causes of stigma for their group (women, men, children, etc.) and identify possible solutions.
Problem tree drawn by participants in pilot workshop.
### Sample Responses:

#### Effects of stigma


**FAMILY** – Family quarrels, mutual blame and conflicts. Family members leave/get kicked out of home. Divorce or separation.

**COMMUNITY** – Loss of productivity as people living with HIV are fired from work or forced to leave the community.

**EPIDEMIC** – Spread of infection. Fear makes people refuse to have HIV test – they prefer not to know.

#### Forms of stigma


**SELF-STIGMA** – Blaming and isolating oneself. Giving up on oneself. Withdrawal from activities.

**STIGMA BY ASSOCIATION** – Family and friends of people living with HIV and health staff are also stigmatized.

#### Causes of stigma

**MORAL JUDGMENTS** – View that people living with HIV are sinners, promiscuous. Breaking social norms. People’s beliefs about pollution, contagion, impurity.

**FEAR AND IGNORANCE** – Lack of knowledge and misconceptions about HIV transmission leads to fear about getting HIV through casual contact – people isolate and reject others. Fear of infection, fear of the unknown, fear of death.

**GENDER AND POVERTY** – Women and poor people are more stigmatized than men and rich people.

**SECONDARY STIGMA** – Women, mobile workers (e.g. sex workers, truckers, migrant laborers), backward castes are already stigmatized – so they get easily blamed.

**APPEARANCE** – The physical appearance of people living with HIV, e.g. thinness, skin rashes, is used as a basis for stigmatizing.

**MEDIA IMAGES** – Images of horrible death in the media make people scared of people living with HIV.
A10. Effects of Stigma and Gender Violence

**Introduction:** This exercise can be used after doing the problem tree (A9), which also deals with effects (but not in the same detail). The overall aim in focusing on effects is to help people see the importance of stopping stigma and gender violence.

**Objective:** By the end of this session, participants will be able to identify the effects of stigma and gender violence on different groups and institutions.

**Time:** 1 hour

**Materials and preparation:** Put up blank sheets of flipchart paper on different walls of the room, with a target group written at the top of each sheet – People Living With HIV, Family, Community, Women, Men, Children and Health Services.

**Steps:**

1. **HOW STIGMA AFFECTS DIFFERENT GROUPS (Rotational Brainstorming):** Divide into groups and assign one target group to each. Ask groups to brainstorm—How does stigma affect your target group? – and record. Ask participants to look for both immediate effects – shame, isolation, depression, hiding one’s status; and larger effects – loss of jobs, dropping out of school, suicide, etc. After three minutes shout “Change!” and ask groups to move to the next topic and repeat the process. Continue until each group has contributed to all seven topics.

2. **HOW GENDER VIOLENCE AFFECTS DIFFERENT GROUPS (Rotational Brainstorming):** The same exercise can be done on gender violence. Use the following target groups: Women, Family, Community, Children and Health Services.
### Sample Responses: Effects of HIV stigma and gender violence

<table>
<thead>
<tr>
<th>HIV STIGMA</th>
<th>GENDER VIOLENCE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>People living with HIV</strong></td>
<td></td>
</tr>
<tr>
<td>Rejection – chased away by family and friends. Dumped at back of house. No</td>
<td></td>
</tr>
<tr>
<td>longer contribute to family’s income so feel useless. Resort to secrecy –</td>
<td></td>
</tr>
<tr>
<td>hide status. Low self-esteem. Loss of hope. Loss of social status and self-</td>
<td></td>
</tr>
<tr>
<td>Take risks and become reckless. Scared to tell others, get tested, and get</td>
<td></td>
</tr>
<tr>
<td>help/services/support.</td>
<td></td>
</tr>
<tr>
<td><strong>Family</strong></td>
<td></td>
</tr>
<tr>
<td>Shame, disgrace, loss of reputation/honor. Rejected by community. Secrecy</td>
<td></td>
</tr>
<tr>
<td>– hide person living with HIV so neighbors can’t see. Concerned about how</td>
<td></td>
</tr>
<tr>
<td>other people will see/judge them. Deny that there is a problem. Family</td>
<td></td>
</tr>
<tr>
<td>conflicts – blame each other for loss of family reputation. Stigma reinforces</td>
<td></td>
</tr>
<tr>
<td>power relations – wife blamed for not raising child properly. Family</td>
<td></td>
</tr>
<tr>
<td>disintegration. Divorce or separation. Children dumped with relatives. Loss</td>
<td></td>
</tr>
<tr>
<td>of income when breadwinner dies. Property grabbing.</td>
<td></td>
</tr>
<tr>
<td><strong>Community</strong></td>
<td></td>
</tr>
<tr>
<td>Finger-pointing and discrimination among community members. Destroys</td>
<td></td>
</tr>
<tr>
<td>relationships. Rumors about AIDS used as a weapon to shame other families.</td>
<td></td>
</tr>
<tr>
<td>Isolate/shun families perceived to have AIDS. Conflict and disunity.</td>
<td></td>
</tr>
<tr>
<td>Community organization weakens. Loss of breadwinners.</td>
<td></td>
</tr>
<tr>
<td><strong>Women</strong></td>
<td></td>
</tr>
<tr>
<td>Breakup of marriage – separation or divorce. Kicked out of house. Kept</td>
<td></td>
</tr>
<tr>
<td>away from children. Husband finds another wife. Property grabbing. Loss of</td>
<td></td>
</tr>
<tr>
<td>income/support. Extra burden of caring for HIV-positive husband. Avoid</td>
<td></td>
</tr>
<tr>
<td>getting tested or seeking treatment.</td>
<td></td>
</tr>
<tr>
<td><strong>Men</strong></td>
<td></td>
</tr>
<tr>
<td>Loss of employment. Loss of face. Feel useless. Rejection by women. Loss</td>
<td></td>
</tr>
<tr>
<td>of manhood. Associated with promiscuity. Withdrawal from social contact.</td>
<td></td>
</tr>
<tr>
<td>Avoid getting tested or seeking treatment.</td>
<td></td>
</tr>
<tr>
<td><strong>Children</strong></td>
<td></td>
</tr>
<tr>
<td>Isolated. Lose their friends. Forced to sit separately from other students</td>
<td></td>
</tr>
<tr>
<td>in school. Kicked out of school. Kept at home. Not allowed to play with</td>
<td></td>
</tr>
<tr>
<td>other children.</td>
<td></td>
</tr>
<tr>
<td><strong>Health Services</strong></td>
<td></td>
</tr>
<tr>
<td>AIDS services and programs are stigmatized. People living with HIV don’t</td>
<td></td>
</tr>
<tr>
<td>use AIDS services (testing, counseling, treatment, PPTCT, opportunistic</td>
<td></td>
</tr>
<tr>
<td>infection treatment). Discrimination against health staff. Heavy workloads,</td>
<td></td>
</tr>
<tr>
<td>burnout and fears cause health workers to desert AIDS work.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Family disintegration and breakdown in communication. Climate of fear. Children</td>
</tr>
<tr>
<td></td>
<td>become depressed and silent. Less productivity and income.</td>
</tr>
<tr>
<td></td>
<td>Neighbors talk about the family, and this hurts their social status. No</td>
</tr>
<tr>
<td></td>
<td>understanding between husband and wife – more scope for HIV to enter the</td>
</tr>
<tr>
<td></td>
<td>marriage.</td>
</tr>
<tr>
<td></td>
<td>Injuries, disfigurement, miscarriages, trauma. Stress. Poor physical and</td>
</tr>
<tr>
<td></td>
<td>emotional health. Feel belittled and worthless. Chronic fear and self-</td>
</tr>
<tr>
<td></td>
<td>isolation. Loss of sense of control over life. Anxiousness, depression, feeling</td>
</tr>
<tr>
<td></td>
<td>suicidal. Weakened ability to negotiate safe sex. May get HIV from husband</td>
</tr>
<tr>
<td></td>
<td>through forced sex. Reduced ability to work and generate income.</td>
</tr>
<tr>
<td></td>
<td>Psychological problems and effects on school performance. Girls grow up</td>
</tr>
<tr>
<td></td>
<td>believing violence is a norm and with low self-esteem. Boys see violence as</td>
</tr>
<tr>
<td></td>
<td>a way to deal with conflict – may be violent to future partners.</td>
</tr>
<tr>
<td></td>
<td>Gender violence is treated as a norm – no effort by health care workers to</td>
</tr>
<tr>
<td></td>
<td>solve this problem.</td>
</tr>
</tbody>
</table>
3. REPORT BACK: Ask the groups to present the main points from each topic and then ask for clarifications and additions. Note common or unusual points.

4. PROCESSING: Discuss–
   a) What are the differences in the effects on different groups?
   b) What are the common effects across all players?

If there is enough time, ask groups to discuss how to stop or reduce stigma in relation to different categories of stigmatized groups (i.e., women, men, children, etc). Assign each group to focus on one category.

5. SUMMARY: Stigma has a range of different effects – on people living with HIV, their families, communities and health institutions.
   - Stigma and gender violence divide families and communities – they create conflict and breakdown in communication.
   - Stigma and gender violence can result in economic losses, making families and communities poorer.
   - The shame of stigma affects everyone – the person living with HIV, his family, the community, and even health workers who care for him.
   - Gender violence harms women, families, children and communities, and puts women and men at greater risk of HIV infection.
   - Stigma results in denial – people refusing to admit that there is any problem. Gender violence is also often denied or viewed as a norm, rather than a problem that must be dealt with.
A11. Effects of Stigma on the HIV Epidemic

**Facilitators’ Note:** This can be used as a stand-alone exercise, or it can be added onto the problem tree exercise (A9) to take the effects discussion further.

**Objective:** By the end of this session, participants will be able to identify the effects of stigma on the HIV epidemic.

**Time:** 1 hour

**Steps:**

1. **STIGMA AND THE HIV EPIDEMIC (story):** Read the following story.

   Raju was a carpenter from Andhra Pradesh. He worked for 10 years in Kolkata, returning three times a year to see his family – his wife Lakshmi and two sons. While he was in Kolkata his wife gave birth to a girl and another boy. After awhile Raju started to suffer from a constant fever and extreme tiredness. He went to the hospital where he was given a blood test. They told him in a brutal way that he had HIV – no other advice, he was just told to go home. When his employer discovered he was HIV-positive, he was fired. He found it difficult to get other work, so eventually he returned to his village. When he arrived home, he told no one. He didn’t want to face any more shame. Lakshmi asked him what was wrong, but he kept silent. He survived for one more year before dying. During this year one of his sons started to get chronically sick, too. After he died, Lakshmi went for an HIV test and learned that she was HIV-positive.

   Discuss–
   a) What happened when Raju’s status was disclosed in the hospital and his workplace?
   b) Why did he not tell his wife?
   c) What are the consequences of Raju not disclosing his HIV status?

2. Ask the group to construct a positive story – which shows how HIV can be stopped. In the new story, Raju gets HIV but from that point on people deal with the situation in a positive, more supportive way.

3. **SUMMARY:**

   - Fear of stigma stops people who are living with HIV from:
     a) Disclosing to their partners;
     b) **Accessing treatment** (antiretroviral therapy or treatment of opportunistic infections);
     c) **Using other services** – for example a pregnant woman living with HIV is discouraged from making use of the PPTCT program; and
     d) **Disclosing and getting counseling, care and support.** They refuse to acknowledge that they or anyone in their family has HIV. As a result they avoid the stigma, but they remain sick, silent and alone.

   - 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 disclose to their families and take precautions in their sexual relationships.
A12. When HIV Enters the Home – Stigma and Violence

**Facilitator’s Note:** This exercise helps participants understand the impact of HIV entering the home. It works well as a combined module, since both stigma and gender violence can occur when the family discovers that one member has HIV.

**Objectives:** By the end of the session participants will be able to:

a) Analyze the impact of HIV and AIDS on the family; and
b) Explore ways that the community can provide families with better support.

**Time:** 1–2 hours

**Materials and preparation:** Using the Family Cards (Picture Set C in Annex 5), make up family sets, varying the family structure and number of children in each set. In each family, draw a colored dot at the back of one character. This dot will indicate that the character is living with HIV or AIDS. Put the dot on a different family member in each group.

**Steps:**

1. **STIGMA AND VIOLENCE IN THE FAMILY (Trios):** Divide into groups of three and give each group a “family” (envelope of cards). Then explain the exercise:

   **Step 1: Before HIV Enters:** Make up a story about your family–
   a) What are the family members doing in terms of work and/or study?
   b) How are family relations – any problems? (e.g. alcohol, violence, sexual affairs)
   c) What are the family’s hopes or plans for the future?

   **Step 2: HIV Enters the Family:** Ask each group to turn over their cards to see which card has the dot on the back. This family member has HIV. Discuss–
   a) What happens when the family finds that one member has HIV?
   b) What forms of stigma and violence might happen?
   c) How would this affect the family?
2. REPORT BACK: Ask each trio to give a brief report.

Sample Responses:

- Women are at huge risk if they disclose their status to husbands.
- Emotional violence – wife accused of bringing HIV home (i.e. other partners) or blamed for not raising their (HIV-positive) child properly/morally.
- Physical violence – women get beaten by their husbands or parents-in-law.
- If wife gets HIV, she loses her right to property and her right to her children.
- Double standard – if the wife gets HIV, the marriage collapses and she is kicked out. If the husband gets HIV, the marriage stands and his wife is expected to care for him.
- Person with HIV becomes isolated within home – separate room, bed, food, utensils.
- Family disintegration – conflicts, communication breakdown, separation, divorce.
- Family shame and loss of honor. Denial – try to hide the problem from neighbors.
- Children affected – forced to leave school, start to work, etc.
- Women’s burden caring for positive family members – increasing costs and workload.

3. PROCESSING: Ask–

a) Why was there such a big change in the family once one member became HIV-positive?

b) How are women treated compared to men?

4. SUMMARY:

Women face severe violence (physical, emotional, economic) and stigma when HIV enters the home. They are blamed and verbally abused for bringing HIV home. They are chased from the household and sent back to their relatives. Their property is grabbed. Their children are taken away from them. When they become sick, they are abandoned and left on their own.

5. PROBLEM SOLVING: Discuss with the whole group–

a) How can families cope better with this situation?

b) What can we do to minimize the impact on women?

c) How can the community support families with HIV? What local institutions can support these families?
Sample Responses:

**Family coping mechanisms**
- Stop the shaming/blaming and verbal abuse toward HIV-affected family members.
- Treat HIV-affected members in the same loving way other family members are treated.
- Help the family deal with the sense of shame and stigma they feel.
- Teach family members about HIV transmission to help overcome their fears of infection.
- Treat HIV like other diseases, such as cancer or high blood pressure, which are often fatal but for which we have coping mechanisms.
- Create a supportive environment for the person living with HIV.
- Give the person living with HIV responsibilities and encourage him or her to continue working.
- Stop the isolation of positive family members (e.g. putting them in a back room, making them use separate plates, etc.).
- Stop violence (physical and emotional) against women.
- Promote a positive attitude, e.g., *It’s not how he got it, but what we can do now.*
- Allow normal life to continue, e.g. children should not be stopped from studying.
- Share the caring work among all family members.

**How to minimize the impact on women**
- Help everyone understand that HIV and AIDS is *not* a “woman’s disease.” Many women are faithful, but their husbands bring HIV home.
- Teach women about their sexual rights.
- Make men aware of gender violence.
- Empower women with assertiveness skills.
- Form women’s groups and encourage women to support each other.
- Let people know about the Domestic Violence Act (see Annex 4) and push the government to enforce it.
- Encourage women to report violence cases to the police and get the police to treat these cases seriously.
- Provide legal services for women.
- Provide counseling for couples.
- Address problems of excessive drinking.

**Community support for battered women and families affected by HIV and AIDS**
- Get the community to name stigma and gender violence as problems, and to take action that addresses the root of the problems.
- Get community leaders to speak out against stigma and violence.
- Get the community to support HIV-affected families.
- Give exemptions to HIV-affected families for water fees, school fees, etc.
- Stop property grabbing.
- Provide a neutral person to help mediate conflicts.
Action Ideas:

Discuss with friends or your peer group how to reduce stigma and violence within and against families living with HIV. How can community members support each other and in this way reduce stigma and violence?

Example of story (exercise 1)

There are nine members in the family: grandfather (65), grandmother (60), father (45), mother (35), three boys (17, 5 and 1) and two girls (13 and 9).

The father is a mechanic who works in Kolkata. His wife takes care of her parents-in-law and her own children, and does all the housework. She also works as a daily paid agricultural laborer. The oldest boy studies at intermediate level and tutors other children to earn money. The eldest girl studies in 8th class and takes tailoring classes. Her younger sister also studies.

Family’s hopes: to educate their children so the boys can get good jobs and the girls can marry good boys; to construct a nice house for themselves; and to earn more money to live comfortably.

The family is close and loving. There is no alcoholism and no violence. Even though the husband is away from the family, he is not a promiscuous man.

The older girl frequently gets sick so the family takes her to a doctor who says she has HIV. The father puts her in a room and asks her if she has had sexual relations with a boy. He assumes she did, so he beats her up. (Some time ago, she had received a blood transfusion with contaminated blood – that is how she got infected.)

Her brother finds out and beats her up too out of shame. Her father and grandparents scold her mother, saying that the mother failed to raise the girl properly. The husband goes out and gets drunk and then beats his wife. He stops working out of depression.

The father stops the older girl from going to school. He assumes she contracted HIV through “bad behavior,” so he also stops the younger girl from going to school.

Their biggest worry is that their family honor will be destroyed once people find out they have a person living with HIV in their family, so they keep it a secret and get her married.

Violence increases in the family, especially toward the mother and daughter. The husband becomes alcoholic and the feeling of love and affection disappears.

Suspecting that there is something wrong with the family, the neighbors and relatives begin to behave differently. They keep their distance.

Effects: The family feels depressed. The girl feels like ending her life, with the thought that she is suffering even though she had not done anything wrong.
A13. Women’s and Men’s Life Cycles – Stigma and Violence

Facilitator’s Note: This session analyzes life cycles as the basis for comparing the impact of stigma and violence on women and men.

Quotes from TBAs in SVTH Project

“A women endures stigma and violence from the day she is born until the day she dies.”

“As a girl is growing, stigma and violence towards her is also growing.”

“Being born a girl is a big mistake – they are needed when they are young, and they are rejected when they are old.”

“Husbands have sex with other women, but this is not taken seriously; his sins are washed off like he has taken a bath. But with women it’s a serious matter!”

“Men are stigmatized and sometimes beaten if they make a mistake, but women are stigmatized and beaten, even if they make no mistake.”

“Men do wrong, but society says that women are responsible for their wrong.”

Objectives: By the end of the session participants will be able to:

a) Identify stigma and violence at different stages in a man’s and a woman’s life cycle; and

b) Recognize how women face far more stigma and violence than men – and how this increases their vulnerability to contracting HIV.

Time: 1–2 hours

Materials and preparation: Life Cycle cards (Picture Set D)

Steps:

1. CARDSTORM: Divide into groups. Give half the groups women’s life cycle cards and the other half men’s life cycle cards. Then ask each group to write forms of stigma or violence that occur at each stage of the life cycle on blank cards.
## Sample Responses:

<table>
<thead>
<tr>
<th>Stage</th>
<th>Woman</th>
<th>Man</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-birth</td>
<td>If parents find out from an ultrasound that the baby will be a girl, they may abort.</td>
<td>Parents happy/proud with male child—maintains family line. Big celebration. Looked after with lots of affection. If mother dies during childbirth, he will be cursed/blamed for “killing mother.”</td>
</tr>
<tr>
<td>Birth</td>
<td>Parents feel unhappy, unlucky, guilty if baby is girl. Have small celebration. If she is pretty, everyone will love her, but if not, she will get no attention or affection. Don’t like to spend money on female baby after 21 days.</td>
<td></td>
</tr>
<tr>
<td>Childhood</td>
<td>Little appreciation from family. Allowed to attend school, but after school given big workload, caring for younger siblings. Eats leftover food along with mother. If a girl gets lots of food and matures quickly, her parents will then have to arrange for her marriage, so they deprive her of good food.</td>
<td>Male child – good luck. Treated with respect as if he is a prince. No housework – after school plays with friends. Given good clothing and best food.</td>
</tr>
<tr>
<td>Teenage</td>
<td>Rules/restrictions – “Don’t talk to boys,” “Don’t talk too loud,” “Don’t make demands.” If she breaks the rules, she gets beaten. Menstruation starts: not allowed to cook, pray or go to temple. Forced to leave school and find wage labor. Sexually harassed at work, harassed by parents at home. Seen as burden by parents: want to get rid of her by getting her married. If she does not marry a good boy with a low dowry, her parents will curse her.</td>
<td>If he studies well, he is respected. If he does poorly in his studies, he is beaten and forced to leave school and find wage labor. If he talks to girls, he will be scolded – “remember – you are a man, not a woman.” If he does not get work, he will be blamed for being lazy. If he acquires bad habits such as drinking or chasing women, parents will curse and beat him for giving bad name to the family.</td>
</tr>
<tr>
<td>Middle Age</td>
<td>Has to earn wages and care for her family. Big workload, low consumption – eats last. If she does not obey husband or run the house properly, beaten by husband. Sexual harassment at work. If she has no children, she is stigmatized as “barren;” if she has a baby girl, she will be blamed. If her daughter has a poor marriage, she will be blamed. If her son gets HIV, she will be blamed. If her husband dies, she loses community respect.</td>
<td>If he gets work and looks after his parents and family, he will be respected. If not, his parents will criticize him. If he drinks, curses and beats his wife, or has affairs and gets sexually transmitted infections (STIs), he will be stigmatized by the community. If there are no children, he is not stigmatized as barren. He is only blamed for his own behavior, not for that of his family.</td>
</tr>
<tr>
<td>Old Age</td>
<td>No respect – viewed as a burden, waste of food. Family members wait for her to die. No one gives her attention or listens to her. Kept hidden and isolated. Daughter-in-law curses her. Beaten by her children.</td>
<td>Some grandfathers are respected by their families. In other cases they are neglected and cursed by the children. Some grandfathers are beaten for revealing their family secrets.</td>
</tr>
</tbody>
</table>

2. REPORT BACK: Review and quickly check that people agree with the points made by each group.

3. PROCESSING: Discuss—
   a) What are the differences between men’s and women’s life cycles? Why?
   b) Why do women face more stigma and violence than men?
   c) How does this make women more vulnerable to getting HIV and AIDS and worsen the epidemic?
   d) How are stigma and gender violence connected?
Sample Responses:

**Differences between men’s and women’s life cycles: Double standard**
- Women are stigmatized and subjected to violence from their birth to the day they die.
- They are even cursed and violated (aborted) in the womb if fetus is found to be female.
- Girls and women are cursed for being born, being a burden, having no children, etc.
- Boys are regarded as good luck and given special treatment – good clothes and food.
- Girls are given housework, while boys are allowed to play with their friends.
- Parents make a big fuss if their son is sick, but don’t worry if their daughter is sick.
- Girls are kicked out of school in their teens, while boys are allowed to continue schooling.
- Girls are controlled through rules/restrictions, while boys are given more freedom.
- Girls are regarded as a burden to the family and married off as quickly as possible.
- Women are blamed/stigmatized for everything – having no child, having girl babies, “not raising her children properly” (if son gets HIV or daughter gets poor marriage).
- If the husband gets AIDS, the wife is expected to remain quiet, stay in the marriage and care for her husband. If the wife gets AIDS, the husband “has the right” to divorce her and grab all the property, leaving her with nothing.
- It is accepted that married men will have sex with other women (especially if they are away from home). The wife, however, is expected to sleep only with her husband.
- Violence occurs at all stages in a woman’s life – pre-birth (aborted), childhood (from parents), marriage (husband), workplace and old age (beaten by children).
- Men face much less violence. They get beaten for misbehaving (e.g. drinking or chasing girls) and ruining the reputation of the family.
- Men are stigmatized for making a mistake, women even if they make no mistake.

**Why do women face more stigma and violence?**
- Male dominance.
- Cultural attitudes – lack of respect for women. Women are stigmatized as inferior, “bad luck,” “a burden.”
- Violence against women is regarded as acceptable – a normal thing. Men think they have the right to beat their wives.
- Poverty and unemployment make stigma and violence against women worse.

**How does this make women and men more vulnerable to getting HIV?**
- Because of the fear of being stigmatized and beaten, women who suspect they have HIV hide their symptoms and avoid getting tested. Without being tested, they cannot access HIV services such as treatment or counseling.
- Because of the same fear, women avoid disclosing to their husbands/partners. This increases the chances of HIV spreading.
- Because of the fear of violence, women who suspect their husbands are sexually promiscuous cannot ask them to practice safe sex. This increases their vulnerability to getting HIV.
- Women are vulnerable to getting HIV because of their vulnerability to other forms of violence such as rape in the workplace or from survival (commercial) sex.

**How are stigma and violence connected?**
- Women are stigmatized (not respected) and these negative attitudes are expressed in the form of violence – both verbal abuse and physical abuse.
4. **SUMMARIZE** drawing on the points in the box and then say: *Given the high levels of stigma and violence faced by women, we need to change our behavior – to give women more respect, support and encourage them, and stop all forms of gender violence.*

**OPTION:** Extra session with female health workers on specific forms of stigma faced by women.

If you have time, you could add an extra step when conducting this module with the TBAs and other female health workers to address their own experience as:

a) Widows;

b) Women who don’t have children, or don’t have boy-children; or

c) Women who are unmarried or divorced.

If you can help female health workers think through these experiences, it can help them get a better sense of how it feels to be stigmatized as a person living with HIV.

Encourage them to reflect on their own experiences and then share with one another.

**Sample Responses:**

<table>
<thead>
<tr>
<th><strong>Stigma toward widows</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Viewed as a source of bad luck, especially if people see a widow by accident.</td>
<td></td>
</tr>
<tr>
<td>If a widow touches water, she spoils it – no one will drink the water.</td>
<td></td>
</tr>
<tr>
<td>Widows cannot enter the house.</td>
<td></td>
</tr>
<tr>
<td>Widows are excluded from marriages and functions.</td>
<td></td>
</tr>
<tr>
<td>Sometimes her children want her to die quickly.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Stigma toward women without children</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Lots of pressure to do prayers to make sure she gets pregnant and has a child.</td>
<td></td>
</tr>
<tr>
<td>People stop her coming into contact with children – bad omen.</td>
<td></td>
</tr>
<tr>
<td>If she is childless, the husband might get another wife.</td>
<td></td>
</tr>
<tr>
<td>Inauspicious to see her face in the morning.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Stigma toward divorcees</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Viewed as breaking culture, disrespecting customs, being anti-man.</td>
<td></td>
</tr>
<tr>
<td>She doesn’t know her role in society, doesn’t respect her parents.</td>
<td></td>
</tr>
<tr>
<td>Viewed as bad woman who is only interested in extra-marital relations.</td>
<td></td>
</tr>
<tr>
<td>Viewed as a threat to other women – she will steal their husbands.</td>
<td></td>
</tr>
<tr>
<td>Threats – you will face lots of problems, anybody can rape you.</td>
<td></td>
</tr>
<tr>
<td>“You need to stay under a husband’s protection.”</td>
<td></td>
</tr>
</tbody>
</table>
A14. Comparing AIDS, Cancer, Leprosy, TB, etc.

Facilitator’s Note: This exercise is good to use with health workers because it builds on their knowledge of different diseases.

“No patients are blamed for getting high blood pressure, diabetes, or cancer, so why are we blaming AIDS patients?” (TBA participating in SVTH project)

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

a) Compare HIV and AIDS with other diseases that have been connected with stigma; and
b) Help participants view HIV and AIDS as they do any other manageable disease.

Time: 1 hour

Materials and preparation: Draw the matrix (below) on sheets of flipchart paper.

Steps:

1. INTRODUCTION: Explain that the aim of this exercise is to compare HIV stigma with the stigma around other diseases.

2. MATRIX ANALYSIS: Divide into groups of three to four people and give each group a copy of a blank matrix 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.

Sample Responses:

<table>
<thead>
<tr>
<th>DISEASE</th>
<th>STIGMA STATUS – 30 YRS AGO</th>
<th>REASONS</th>
<th>STIGMA STATUS – PRESENT</th>
<th>REASONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leprosy</td>
<td>High stigma – forced to live in separate colonies.</td>
<td>Fear contagion. Not curable, no medicine.</td>
<td>Less stigma – no longer stay in separate colonies.</td>
<td>Medicine is now available and more awareness, yet still a contagious disease.</td>
</tr>
<tr>
<td>TB</td>
<td>High stigma, patients abandoned.</td>
<td>Fear of contagion. TB patients seen as half dead – so isolated.</td>
<td>Some stigma because of fear of contagion.</td>
<td>Associated with AIDS – associated stigma. Medicines available – can be cured.</td>
</tr>
<tr>
<td>DISEASE</td>
<td>STIGMA STATUS – 30 YRS AGO</td>
<td>REASONS</td>
<td>STIGMA STATUS – PRESENT</td>
<td>REASONS</td>
</tr>
<tr>
<td>--------------</td>
<td>----------------------------</td>
<td>----------------------------------------</td>
<td>--------------------------</td>
<td>----------------------------------------</td>
</tr>
<tr>
<td>Diabetes</td>
<td>Not curable – need for continuous medication.</td>
<td>No stigma.</td>
<td>Not curable, but medicines are available and no association with sex. Not contagious.</td>
<td></td>
</tr>
<tr>
<td>STIs</td>
<td>Some stigma.</td>
<td>Association with sex.</td>
<td>Not much stigma.</td>
<td>Medicines available and can be cured.</td>
</tr>
<tr>
<td>HIV and AIDS</td>
<td>High stigma.</td>
<td></td>
<td></td>
<td>Associated with sex</td>
</tr>
<tr>
<td>Mental Illness</td>
<td>High stigma.</td>
<td>Not curable.</td>
<td>High stigma because of shame.</td>
<td>Deadly disease Fear of contagion</td>
</tr>
</tbody>
</table>

4. PROCESSING: Ask – Why are some illnesses stigmatized more than others?

5. SUMMARY:

- HIV and AIDS has the highest level of stigma because:
  a) It is associated with SEX (main source of HIV transmission) – and sex, along with death, is a major taboo. People living with HIV are shamed because it is assumed they got HIV through immoral (sexual) behavior. (TB patients are not shamed – they are seen as unlucky, as getting TB through chance).
  b) At present there is NO CURE – it is perceived as a deadly disease. (Antiretroviral therapy, however, makes it possible to rebuild the immune system and live a long life).
  c) AIDS is seen as CONTAGIOUS (like TB or leprosy, which are communicable diseases spread through the air) – even though it is not contagious through casual non-sexual contact.

- In comparison, cancer is an incurable disease (like AIDS) but it is not contagious and it is not associated with sex – so it has no stigma associated with it.

- TB is curable (even for AIDS patients) but is somewhat stigmatized because it is contagious and is associated with AIDS (many AIDS patients also have TB). TB is more contagious than HIV but it is less stigmatized, because it is curable and not associated with sex.

- Leprosy is stigmatized because it is a disfiguring disease. Lepers are stigmatized because of their appearance. Similarly, patients in advanced stages of AIDS are stigmatized because of unsightly sores or rashes.

  “Before when lepers died, they buried them, rather than cremating them, saying they are the devotees of Shiva.” (RMP participating in SVTH project)

- Mental illness is stigmatized because the symptoms are viewed as abnormal.

- One indicator that AIDS is heavily stigmatized is that people refer to it indirectly – instead of saying “AIDS,” they say “this thing,” “that disease,” “that four-letter word.”
A15. Review – Ten Questions on HIV Stigma

Facilitator’s note: This exercise can be used at any time in the training program. It is simply a series of questions to help participants review the main issues covered in this chapter.

Objective: By the end of this session, participants will have reviewed what they have learned about HIV stigma.

Time: 1–2 hours

Steps:
1. QUESTIONNAIRE: Hand out the following questionnaire or write the questions on a flipchart. Ask participants to complete the questionnaire. Then review the responses as a group.

QUESTIONNAIRE

1. What is the meaning of STIGMA?
2. HOW do people stigmatize people living with HIV? What are the FORMS of stigma?
3. WHY do people stigmatize people living with HIV?
4. How does it FEEL to be stigmatized?
5. What are the EFFECTS of stigma on people living with HIV and their families?
6. What are the EFFECTS of stigma on the HIV EPIDEMIC – and WHY?
7. How have HEALTH WORKERS been stigmatizing people with or suspected of having HIV and AIDS?
8. How can we STOP stigma in our HEALTH PRACTICE?
9. How can we STOP stigma in our FAMILIES AND COMMUNITY?
10. Why does AIDS have a much stronger stigma than cancer or TB?