



Supporting community action on AIDS in developing countries

# Understanding and challenging HIV stigma

## Toolkit for action

**MODULES D & E**

- The family and stigma
- Home-based care and stigma

## About the organisations involved

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

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

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# Understanding and challenging HIV stigma: Toolkit for action

## About this toolkit

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

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

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

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

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

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

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

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

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

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

**Senegal:** Alliance Nationale Contre le SIDA (ANCS)

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

**Uganda:** The AIDS Support Organization (TASO)

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

## This edition, developed and written by

Ross Kidd, Sue Clay and Chipso Chiiya

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

# Contents

## Module D – The family and stigma

Introduction	3
<b>Exercises</b>	
D1 Stigma in the family	4
D2 How HIV has affected my family	6
D3 Stigma towards the family	7
D4 Neighbours stigmatising neighbours	8
D5 Community support	10
D6 Money and resources (A)	11
D7 Money and resources (B)	12
D8 Keeping rights in the family	14
D9 We can lead long and productive lives	15
D10 Disclosing to the family	17
D11 Burdens of care	19

## Module E – Home-based care and stigma

Introduction	20
<b>Exercises</b>	
E1 Making home visits as an HBC volunteer	21
E2 Involving the family in caring roles	24
E3 Contact with bodily fluids	27
E4 Challenging stigma in the home	29
E5 Fears about status, disclosure and being stigmatised	30
E6 Relations between PLHIV and the family	31

## Pictures

Silhouettes	33
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Other booklets in *Understanding and challenging HIV stigma: Toolkit for action* include:

### Introduction

Using the toolkit

### Module A

Naming the problem

### Module B

More understanding, less fear

### Module C

Sex, morality, shame and blame

### Module F

Coping with stigma

### Module G

Treatment and stigma

### Module H

MSM and stigma

### Module I

Children and stigma

### Module J

Young people and stigma

### Moving to action module

Thinking about change

Moving to action

Developing skills for advocacy

### Picture booklet

General stigma pictures

Rights pictures

Additional booklets will be published as new modules are developed.

# Module D

### Introduction

Stigma and caring in the family are closely linked – some forms of stigma are triggered by family members not knowing what to do or how to care for someone who is sick with AIDS. This, coupled with poverty and economic stress, creates conditions where frustrations can easily lead to stigma, with PLHIV being blamed for ‘being a burden’, or neglected because families feel overwhelmed by the duty of care and support. Many family members have little idea how they can best look after PLHIV when they get sick.

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

We hope that through this module, families will be able to explore the challenges of caring for family members living with HIV, and that through more knowledge and sharing, stigma will be reduced.

“ They built him a small hut where he lay day and night, waiting to die. No one visited him to socialise, only to put food on the floor and leave. I went to visit him but no one allowed me to enter his room. I insisted. When I opened the door to get in the stench was unreal! I went outside, fetched some water and warmed it. I bathed him with the help of two young men in the family. We sat him in the sun – something he hadn’t done for months. We cleaned his room and washed his clothes, which were caked with filth. As we were cleaning the room, porridge was cooking on the fire. After the cleaning, I sat there, feeding him porridge and talking to him. Daily I came to see him, bath and feed him. The relatives started doing the same. He died three weeks later, not an outcast, but one loved and created in God’s image. When I told him God loved him and that Jesus died for him, he held my hand tight. ”

Report of church volunteer, in HIV/AIDS study pack for community development workers, *Tearfund case study series*, April 1999.



## Exercise D1 Stigma in the family



### Facilitator's notes

This exercise is designed to introduce the overall topic of stigma in the family, and do some agenda setting.



### Objectives

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

- discuss more openly how HIV and stigma affects the family
- identify some of the critical issues related to living with, caring for, and not stigmatising PLHIV in the family/home
- agree on the specific issues they would like to discuss in more detail.



### Time

1 hour



### Materials

Selection of *general stigma pictures* from the Picture booklet, showing families.

### Step-by-step activity

#### Picture discussion

1. Divide participants into small groups and give each group a *general stigma picture* showing a family.
2. Discuss in small groups:
  - *What is happening in this picture?*
  - *What happens when the family finds that one family member has HIV?*
 Write answers on a flipchart
3. Feed back from small groups.

#### Processing

4. Ask the whole group:
  - *What are families doing already to provide care and support for family members with HIV?*
  - *What is preventing families from helping family members with HIV?*
  - *What practical things can we do as families to support family members with HIV?*

**Option:** As a starting exercise, get the small groups to organise a role play based on one of the themes in the picture.

### Summary

Explain how stigma in the family takes many forms.

#### Examples

##### Effects on the family

Shock. Anger. Disappointment. Worry. Grief. Sorrow. Fear of caring for PLHIV – burden and fear of infection. Put him or her in an isolated bedroom. Fear of neighbours finding out and being stigmatised. Family denial – refuse to accept results. Family inaction – don't know what to do. Hatred within family. Blaming and shaming – “I told you not to go out at night”. Conflicts within the family. Divorce or separation. Heavy burden on the caregivers (usually women) leading to burnout. Loss of income and money problems. Children drop out of school and may become orphans. Widows. Sexual cleansing. Property grabbing.

##### Effects on family member living with HIV

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



## Exercise D1 Stigma in the family

### ! Action ideas

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



### Examples (cont.)

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

Taking PLHIV family members for medical treatment to hospitals, faith groups or faith healers (traditional doctors). Raising funds for medical treatment. Getting help from faith groups. Trying to provide good food and nutrition. Informal counselling. Supporting members on ARVs. Giving support on adherence.

#### What is preventing families from helping PLHIV?

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

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

Encourage PLHIV to talk openly about their feelings and listen. Don't decrease interaction – treat them as you treat other family members. Find out about ARVs. Encourage getting treatment for opportunistic infections. Create a fund for family emergencies related to HIV and AIDS. Connect members with other PLHIV for sharing experience and feelings. Encourage friends to visit. Encourage family members to practise safe sex to avoid further infection. Get help from and participate in a home-based care (HBC) programme. Get help from a hospice, support from a church. Arrange schooling and support for orphans. Organise the sharing of 'caring work' among all family members. Resolve conflicts between partners.



## Exercise D2 How HIV has affected my family



### Facilitator's notes

The aim of this exercise is to build trust and openness in the group and to encourage participants to share stories from their families. Often as HIV workers we see HIV as something 'out there', yet particularly in Southern Africa, nearly everyone's family has been affected.

This can be a moving and emotional exercise and it is important to take care of people's feelings. Be sure to use an activity to bring people back together into the large group at the end.



### Objectives

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

- identify how their own family has been affected by HIV
- discuss openly their fears, worries and hopes for the future.



### Time

1 hour



### Materials

Make several sets of the *silhouettes* (see pages 33-40) of different family members.

### Step-by-step activity

#### Silhouettes

1. Split into small groups and arrange chairs so that each group sits apart from the others. Give each group a set of *silhouettes*.
2. Ask each group member in turn to describe how their own family has been affected by HIV, using the *silhouettes* to represent their family members.

#### Processing

3. Arrange chairs in a close circle. Come back together in the large group.

Ask the participants:

- *How was the exercise?*
- *What does this show us?*

Give participants time to respond and ask if anyone wants to share their experiences.

#### Bring the group back together

4. Use a healing song or other gentle group activity to bring comfort and togetherness to the group.

### Summary

It doesn't make sense to stigmatise. This exercise shows us how we are affected by HIV. Sometimes we don't talk enough about what is happening in our own homes. If we learn to share more about ourselves we can support each other and ask for help when we need it.



## Exercise D3 Stigma towards the family



### Facilitator's notes

This exercise looks at stigmatisation towards the family by neighbours.

It can also be used as a workplace exercise. You may want to photocopy the story to use in small groups.



### Objectives

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

- describe how a community stigmatises families where someone is living with HIV
- develop strategies on how to address this form of stigma and discrimination.



### Time

1 hour



### Action ideas

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



### Step-by-step activity

#### Story discussion

1. Either ask one participant to read the story below to the large group, or split into small groups and give each group a copy of the story.

#### Mr Lima's story

Mr Lima, a farm worker married with two children, fell sick. He was admitted to hospital. During the stay in hospital he took an HIV test and tested positive. During the counselling session Mr Lima agreed to have the HBC team visit his home for continued care and support.

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

The farm owner, under pressure, fired Mr Lima and told him and his family to leave the farm.

From Zambia toolkit workshop

#### Discussion and processing

2. Ask participants to discuss:

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

#### Examples

##### Forms of stigma towards families living with HIV

Isolation and rejection towards families suspected to have HIV and AIDS. Name-calling. Finger-pointing. Gossip. Rumour. Backbiting. Jealousy. Rumours about HIV and AIDS used as a weapon to denounce families. Suspicion – speculate about other people based on observed symptoms. Stigma triggered by visits/food relief provided by HBC workers. Shame – loss of family honour – “You have discredited/shamed our family”. Snooping – people visit to see the condition of the PLHIV – “Is she finished”? Not allowing children to play with neighbour's children. Refusing to share things with the family (pots, stools, containers, etc.).

## Exercise D4 Neighbours stigmatising neighbours

### Objectives

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

- describe how neighbours react to a family with a member suspected or known to be living with HIV
- develop strategies to deal with the problem of neighbours stigmatising neighbours.

### Time

1 hour



### Step-by-step activity

#### Buzz groups

1. Ask the group to divide into pairs and ask each other:
  - *How do neighbours treat households where they suspect someone is living with HIV? Why?*

#### What will the neighbours say? – role play

2. Divide into two groups of equal sizes. Group A is the family where someone is living with HIV; group B is the neighbouring family. Ask the groups to take it in turns to perform a short sketch showing what they are talking about.
  - HIV family – *What are you afraid that the neighbours will say about you?*
  - Neighbours – *What are your fears about the family? Why?*
 See if the two groups want to talk together in the role play.

#### Discussion

3. Ask participants to come together and discuss:
  - *What kind of stigma is going on here?*
  - *What can we do to change things?* (Use stop-start drama to try out some action ideas.)

### Examples from Ethiopia toolkit workshop

#### How do neighbours treat households they think have HIV?

Tell the landlord to kick the family out of rented accommodation. Stop the family or family member living with HIV using the communal toilet. Stop visiting the family but worry about being blamed for not visiting. Stop exchanging foodstuffs with the family. Gossip about anyone who uses the communal toilet frequently. Openly talk and joke about the patient dying – “He won’t live until Christmas!”

#### Why do neighbours behave this way?

Misplaced fear of infection through sharing the same toilet. Misplaced fear of children being infected through contact with the HIV-affected family. Lack of sympathy about the heavy burden for the family caring for the PLHIV. Feel they are stigmatised through association – shame affects them.



## Exercise D4 Neighbours stigmatising neighbours

### ! Action ideas

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



### Examples from Tanzania workshop

#### Neighbours

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

#### Family

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



## Exercise D5 Community support



### Facilitator's notes

This exercise is designed to get the community talking about how they can support families living with HIV and AIDS.



### Objectives

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

- identify forms of stigma and discrimination practised in the community
- develop strategies for building community support for HIV-affected households.



### Time

1 hour



### Materials

Three *general stigma pictures* from the Picture booklet:

*Picture 1* – group of people turning their backs to a woman

*Picture 2* – community pointing fingers

*Picture 3* – group of people pointing at a man.



### Action ideas

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

### Step-by-step activity

#### Stigma in the community – picture and group discussion

1. Divide into three groups and give each group a picture. Ask participants to discuss:
  - *What do you see in the picture? How does this make us feel, especially if we are living with HIV?*
  - *What other forms of stigma and discrimination are practised by the community?*
2. Divide into threes and ask, “*What practical things can we do to build and mobilise more support for HIV-affected households in our community?*”

#### Report back

3. Organise a report back using a ‘round robin’ technique. Then review the list of proposed actions and select one or two that the group wants to work on.

### Summary

It is important to get the whole community, and not just those families who are immediately affected, to mobilise around HIV and AIDS. Addressing the problem of AIDS is the responsibility of the whole community. Emphasise that we are all at risk of getting HIV, so we should all work to support those who are already affected by HIV. Community mobilisation will help to normalise HIV and this will begin to reduce stigma.

#### Possible actions

- Organise a community meeting to discuss what to do about HIV in the community.
- Form associations of families, neighbours and church groups to deal with HIV.
- Find out about ARVs and share the information.
- Talk about adherence strategies and how to support each other to stick to adherence.
- Identify the most vulnerable households (e.g. child/orphan-headed households, grandparent-headed households) and provide support.
- Provide exemptions for HIV-affected families from water fees, school fees, etc.
- Provide neutral people to help mediate disclosure or conflicts in families.
- Facilitate the sharing of ‘HIV survival knowledge’ among community members.
- Organise a regular system of visits to HIV-affected households.
- Donate food, clothing and agricultural inputs to destitute households.
- Carry out repairs to houses or help cultivate the fields of vulnerable households.
- Provide piecework for adolescent orphans working in others’ fields.
- Organise income-generating activities to support vulnerable households.
- Provide communal fields for vegetable gardening.
- Form burial associations and rotating credit and loan clubs.

## Exercise D6 Money and resources (A)



### Facilitator's notes

This is the first of two exercises on the same topic. Just choose one! It could be helpful to use in HBC training and community mobilisation.



### Objectives

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

- analyse some of the financial problems facing HIV-affected households
- develop practical strategies for mobilising and managing money effectively
- develop strategies to combat stigma that is fuelled by money problems.



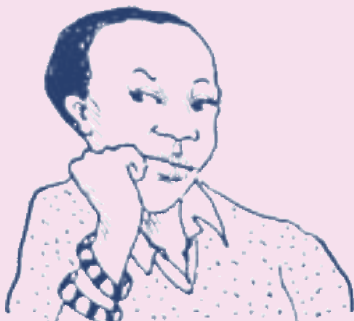
### Time

2 hours



### Materials

Green and orange cards for the *income and expenditure tree*.



### Step-by-step activity

#### Financing care for sick family members – the income and expenditure tree

1. Divide into threes and hand out cards. Ask each group of three to make an *income and expenditure tree* for a family on the wall, using orange cards for roots and green cards for leaves.

**Roots** – the different ways the family earns money, e.g. selling crops, piecework, selling things, income from wage workers, etc.

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

2. Then ask participants to discuss:

- *What are the changes when a family has to care for a PLHIV?*
- *Which items of expenditure go up significantly?*

#### Money problems – role play

3. Ask participants to perform a role play using the following scenario:

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

4. Ask participants to discuss:

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



### Action ideas

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

# Exercise D7 Money and resources (B)

## Facilitator's notes

This exercise<sup>1</sup> is an alternative to the previous one.

## Objectives

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

- analyse financial problems facing families living with HIV
- develop strategies for mobilising and managing money
- develop strategies to combat stigma fuelled by money problems.

**Time**  
2 hours

## Step-by-step activity

### Problem tree – causes and effects analysis

1. Explain that the problem tree is a method to analyse the causes (roots) and effects (branches) of a problem. We will start with the main problem – no money – at the centre of the diagram. Then we will add root causes at the bottom of the diagram and later on add effects at the top.

### Causes

2. Hand out cards and ask participants to write down the causes of 'no money' on cards – one point per card. After a few cards have been written, ask for root causes – the underlying reasons – to be added. This can be done by asking people, "But why? But why? But why?" until they have reached the bottom card, e.g. lack of knowledge about HIV.

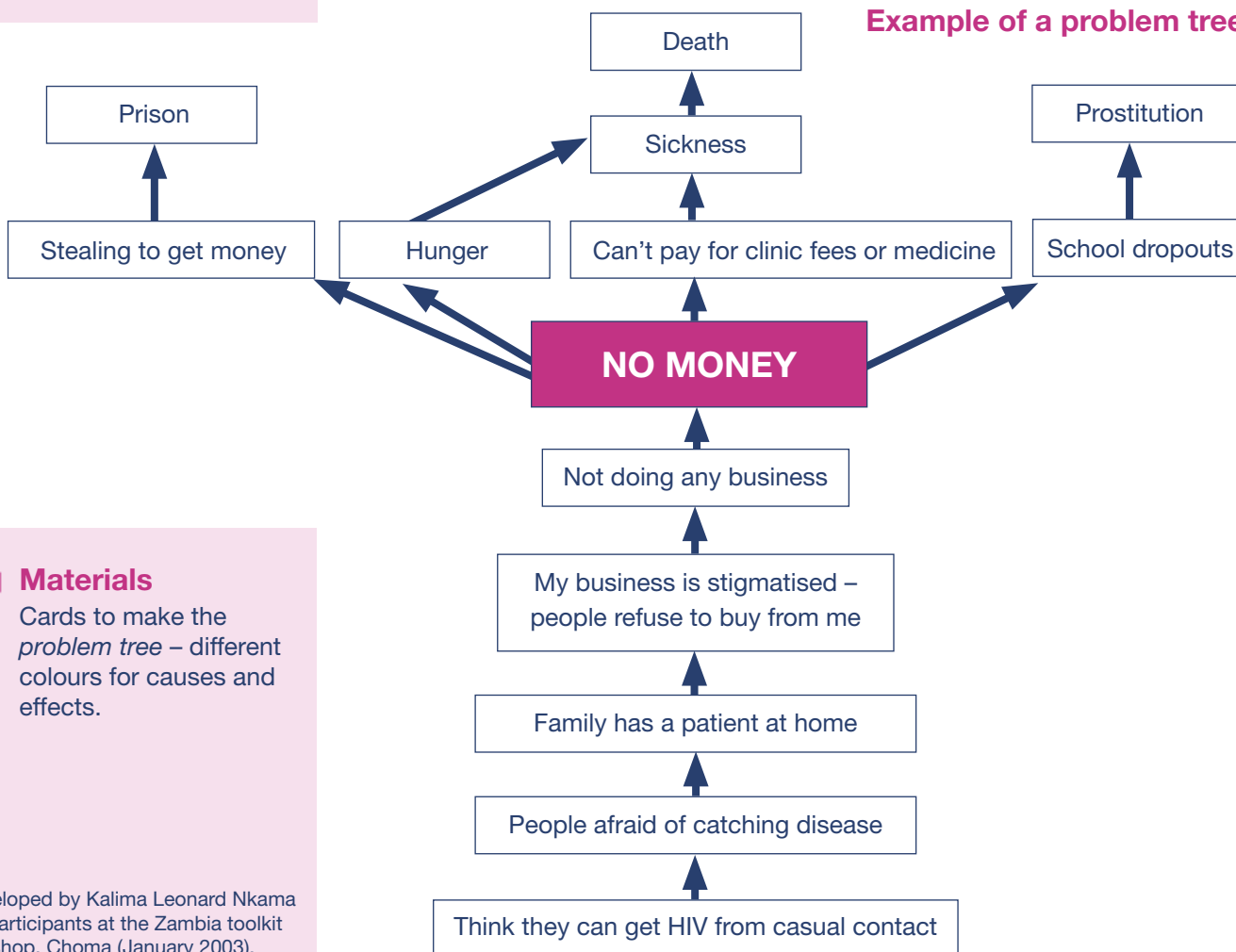
### Effects

3. Ask participants to add cards at the top of the diagram, showing effects in a ladder form, each effect causing the effect above it.

### Solutions

4. Then ask, "What can we do?" Focus on root causes – "Which root cause can we remove to solve the problem? What can we do to address this cause?"

### Example of a problem tree



## Materials

Cards to make the *problem tree* – different colours for causes and effects.

<sup>1</sup> Developed by Kalima Leonard Nkama and participants at the Zambia toolkit workshop, Choma (January 2003).

## Exercise D7 Money and resources (B)



### ! Action ideas

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

### Problem story from Zambia workshop

My dad fell sick in 1995 when I was away at boarding school. When I came home at the end of the year, I found that my dad's relatives, including his own mother, had given up on him. They were just waiting for the day when he would die so they could bury and forget about him. They had been told at the hospital that he had TB, so they concluded that he had AIDS. Because of this assumption that he had AIDS, they made no effort to see or comfort him. My dad's mother, who used to stay with us, ran away from our home the day she learned that my dad had TB.

In May 1996 my mother sent me to my dad's relatives to inform them that his condition had become critical. He couldn't work and we had no money to take him to the hospital. To my surprise they refused to help and told me that my dad was already a walking corpse and so there was no need to take him to the hospital.

We took my father on our own to the hospital and he was admitted. From that day until he died, one month later, none of his relatives visited him at the hospital or sent food for him. The only people caring for him were my mother, my brother and me.

Two days after my father was buried, his brothers called a family meeting. At the meeting one brother said he would take over my dad's house, the children and the property. He said that my mum should be sent to the village because they didn't have money for her coffin. He said she was going to die soon because my father had died of AIDS. This really upset me. We managed to keep control of our house and to have my mum stay with us. But the relatives were furious and called her names.

In 1997 I heard that my mother was in the hospital. The rumours started to flow again. When I returned home, I was told *"to be a man and look after your brothers and sisters, since your mum is going to die. Your dad died of AIDS and she will die of AIDS."* All they really wanted was the property. All the rumours and gossip and insults were a means to grab the property.

However, my mother recovered and they have not succeeded yet in stealing our property.

### Action planning

5. Develop a plan to implement the solutions discussed in Step 4.

## Exercise D8 Keeping rights in the family



### Facilitator's notes

This exercise raises the issue of PLHIV being denied their rights as a form of stigma.



### Objectives

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

- recognise that PLHIV have rights and responsibilities just like other people
- recognise that the rights of PLHIV are often denied
- agree on how the family and community can reaffirm those rights.



### Time

1 hour



### Materials

Selection of *rights pictures* from the Picture booklet.



### Action ideas

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

### Step-by-step activity

#### Rights – card storm

1. Divide into pairs and hand out blank cards. Ask pairs to brainstorm a list of rights that may get violated if we are living with HIV. Write one point per card and stick them on the wall.

Then discuss:

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

#### Picture role play

2. Divide into small groups. Ask each group to select a *rights picture* and perform a short role play to demonstrate this right and how it gets violated.

Discuss:

- How can we as families ensure these rights are met?

### Examples of rights and responsibilities

#### Rights

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

#### Responsibilities

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

### Summary

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



## Exercise D9 We can lead long and productive lives

### Facilitator's notes

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

### Objectives

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

- recognise that PLHIV can lead long and productive lives
- identify the main features of living positively with HIV (treatment, emotional health, successful disclosure, food and nutrition and safe sex).

### Time

2 hours

### Materials

Copies of *case studies A, B, C, D* or *Life goes on* (see pages 15 and 16).

### Step-by-step activity

#### PLHIV can lead long and productive lives – collective story

1. Ask the group to sit in a circle. Start a story about a PLHIV, who is committed to living positively. Tell the first part of the story to 'set the scene' and then pass the story to the person beside you. That person takes over, makes up a few sentences to develop the story – and then passes the story to the next person.
2. Ask participants to discuss:
  - *What happened in the story?*
  - *What did we learn about the way we think PLHIV live?*
  - *What can we do to lead long and productive lives?*

### Examples

#### What we can do to lead long and productive lives

- Find out about accessing ARVs.
- Follow adherence strategies, get support from family and friends.
- Get care and emotional support in a helpful atmosphere.
- Aim for successful disclosure with family members and others who are close.
- Get treatment for infections.
- Use alternative therapies.
- Avoid re-infection and other sexually transmitted infections.
- Practise safe sex.
- Get good food and nutrition.

#### Option 1: We are not given a chance to contribute – discussion

1. Divide into small groups. Hand each group a copy of a case study. Ask participants to read them and discuss:
  - *What happened in each of the stories? Why?*
  - *What does this say about the capacity of PLHIV to contribute?*

### Case studies

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

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



## Exercise D9 We can lead long and productive lives

### ! Action ideas

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



Things we can do to lead long and productive lives include:

- ✓ getting love and care from those around us
- ✓ accessing ARVs and sticking to the regime
- ✓ successful disclosure to partners, family members and friends
- ✓ getting treatment for infections as early as possible
- ✓ practising safe sex
- ✓ getting good food, avoiding too much alcohol and stress
- ✓ carrying on working and leading a normal life.

### Case studies

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

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

### Option 2: Life goes on! – discussion

1. Ask participants to read the case study 'Life goes on'. Then discuss:
  - *What happened to the husband and the wife?*
  - *Why did the wife live a long life?*

### Case study – Life goes on!

Kabila, a long-distance truck driver, got sick in 2001 and died in early 2002. When he first became sick, there was lots of gossip by family and neighbours. People said he acquired HIV on the road. People at first visited him and then the visiting stopped. His sister came to stay for a while to look after him. When she saw that he wasn't getting better and was not dying, she left.

When the sister left, Kabila's wife, Barbara, who worked as a tailor in a factory, took over the caring for her husband. Because of the heavy burden, she often arrived late at work and was fired.

After leaving her job she set up her own small tailoring business on the veranda of her house. Barbara loved tailoring and many women came to her for *chitenge* outfits. She then discovered she was HIV positive. She accepted her situation and did all she could to stay healthy, including starting on ARVs. Although her husband had died, her own health improved and she became fatter. The neighbours, who originally had avoided her, saying she had killed her husband, started to forget the earlier situation. They said her husband had been bewitched. She is still alive today.

Based on a case study from the Tanzania toolkit workshop

### Summary

Emphasise to participants that:

- we can lead long and productive lives (see checklist on the left)
- we can make a big contribution to our families, jobs and communities. Our ability to contribute should be recognised and valued.

## Exercise D10 Disclosing to the family

### Facilitator's notes

This exercise looks at the issue of disclosure and how the family can support this process.

### Objectives

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

- describe some of the issues involved in supporting PLHIV to disclose their status to other family members
- understand some of the difficulties involved in disclosure.

### Time

1 hour

### Materials

Select *general stigma pictures* from the Picture booklet, showing disclosure scenarios (e.g. pictures 15 and 31).



### Step-by-step activity

#### Introduction – brainstorm

1. Ask participants to brainstorm, “*Why is it important for us to disclose our status to our partners and other family members?*”

#### How to disclose – rotating buzz

2. Arrange chairs in two rows opposite each other. Change partners for each question. Ask:
  - *What are the difficulties in disclosing to other family members?*
  - *If one of your family has told you they have HIV, how did you react?*
  - *Have you told anyone else in your family?*

#### Examples of difficulties in telling others

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

#### Practise disclosure – paired role playing

3. The aim is to help participants practise how to disclose the status of a loved one to other family members or friends. Divide the group into pairs and read out the following scenario:

#### Kamangala's story

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

4. One participant plays Kamangala telling the family member; the other plays the family member. After a few minutes swap roles. Ask two or three pairs to perform the role play to the group.

#### Report back

5. Ask the participants:
  - *Kamangala – How did you feel about telling the other person?*
  - *Family member – How did you feel?*
  - *What techniques worked to tell the story?*

## Exercise D10 Disclosing to the family

### Extract from E's story, Zambia – My burden was lifted

After hearing about the sudden death of one of her brothers, E decided to disclose to her two other brothers. She was worried about their behaviour (one is divorced and one has many short relationships with women he meets in bars). She felt that if they knew what had happened to her, they might take less risks in their own sexual lives. She was the eldest so she felt they would accept her story and not challenge her.

So she arranged to meet them at their workplace and she explained to them, *“You are seeing me get sick a lot of the time and can appreciate why I decided to go for an HIV test. I am HIV positive”*. She explained that she was now feeling better and had started taking ARVs.

Her brothers were completely quiet and said nothing. They changed the topic but have continued to support her. E says, *“Since then my burden has been lifted”*. The last time she got sick, her brothers cared for her – their children running errands – doing housework, visiting her and giving her advice.



### Summary

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



# Exercise D11 Burdens of care

## Facilitator's notes

This exercise looks at the burdens on families who are caring for patients in the family and how this links to stigma. It also looks at the pressures on the primary caregivers.

This exercise would be particularly suited to caregivers. It gives them a chance to share their own experience of caring for PLHIV.

## Objectives

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

- identify the root causes of the workload or burnout problem affecting caregivers
- identify inequalities in who the burden of care falls upon
- develop strategies to reduce the workload/burden.

## Time

2 hours

## Materials

A selection of drawings showing men, women and children.

## Step-by-step activities

### Burdens of care – card storm

1. Brainstorm a list of the tasks involved in caring for a patient in the home. Write one task on each card and stick them on the wall.
2. Ask participants to arrange the cards according to who carries out the tasks (use drawings of men, women and children).
3. Discuss in pairs:
  - *How is caring organised in your household?*
  - *Who does what? When? How?*In the large group, ask anyone if they want to share.

### Who does the work? – buzz groups

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

### Report back

5. Ask participants in a ‘round robin’:
  - *If one person is doing all of the work, is this a problem? Why?*
  - *If so, what can be done to share the burden?*

### Changing the workload – stop-start drama

6. Perform a drama to show the person in the house who is doing the most work. Ask her to share how she is feeling. Ask participants:
  - *What happens if a person comes in and helps her?*
  - *What happens at a family meeting where the family discusses caring for the patient? Can they help the over-burdened carer?*Add extra scenes to show these possibilities.

## Summary

Women are viewed as homemakers, so any caring activity usually falls on them. Caregivers are often older women who are expected to do the caring with very limited resources. This creates a huge strain on them. Burnout is a common problem for many caregivers. The workload becomes too much, they begin to resent the job and this can lead to a poorer quality of care and stigmatising the patient. It is important that carers are able to talk about their workload and look for support if they are over-burdened. Families and governments need to care for the carers.

## Action ideas

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

## Module E – Home-based care and stigma

# E module

### Introduction

This module is for people involved in HBC – both professionals and volunteers. The aim of the training is to help HBC workers understand and take preventive action to minimise HIV stigma within their working situation.

The training programme should start off with selected exercises from modules A, B and C to help participants become aware of their own stigmatising attitudes and then look at how they can challenge stigma when they see it in the household and community. So include selected exercises from other modules plus the exercises in this one.



# Exercise E1 Making home visits as an HBC volunteer

## Objectives

By the end of this session, volunteers will have skills and strategies for:

- entering HIV-affected households with confidence
- building family and PLHIV trust
- intervening effectively to deal with challenges raised by the family.

## Time

2 hours



## Facilitator's notes

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

The main method used in this exercise is a rotating cycle of:

- **Paired role playing** – trainees, working in pairs, do role plays on how to deal with specific challenges raised by the family. All pairs perform at the same time (this ensures that everyone gets practice), then one of the role plays is replayed in the centre of the circle so that the whole group can watch, analyse how it was done and work together on developing solutions/strategies.
- **Stop-start drama** – the replayed role plays are used for stop-start drama. After each role play trainees are asked to comment on the strategy used (to deal with the family's challenge) and to suggest other approaches. These other approaches are played out by the trainees who suggested them – they come into the circle and take over the volunteer's role and try out their strategy. The facilitator summarises and records all strategies used. Once an appropriate strategy has been developed by the group through the stop-start process, the facilitator introduces a new challenge and asks all of the pairs to try it out. Then one of the pairs are invited to show their role play and this is used as the starter for stop-start drama, and so on. During the role plays at the centre, other trainees play the other family members.

## Step-by-step activity

### Introduction

1. Explain that the session is aimed at helping participants learn through practice how they would:
  - enter an HIV-affected household
  - build the family's and PLHIV's trust
  - start their counselling work
  - intervene effectively to deal with different responses/challenges raised by the family.

### Identifying challenges – card storm in buzz groups

2. Divide into pairs, hand out cards and markers, and ask, "*When you visit a household for the first time, what problems or challenges will you expect to face from the family?*"
3. Stick the cards on the wall. Then ask participants to sort out the cards – eliminate repetition and put similar cards together. Then ask them to put the cards into two categories: high and low priority. High priority should include problems/challenges that they are the most worried about and would like to practise dealing with.

## Exercise E1 Making home visits as an HBC volunteer



### Examples of possible problems/challenges faced by volunteers

- Suspicion and anger about visit by volunteer – *“Who told you to come to our house?”*
- Not trusting volunteer – *“You are a stranger. We’ve never seen you before.”*
- Doubts about the skills/capacity of HBC volunteer – *“What can you do?”*
- Neighbours curious about what is going on – *“What is the volunteer doing?”*
- Denial – family refuses to accept they have a problem. It’s the first time the family names their problem as HIV. *“You have wrong information. No AIDS here!”*
- Not accepting HIV diagnosis – saying this is not HIV, it is witchcraft.
- Believing that traditional medicine will cure the PLHIV family member.
- Feeling of shame that family member has HIV – worries about neighbours’ stigma.
- Not accepting responsibility for caring for PLHIV.
- Worries about where to get money to pay for testing, hospital care, drugs, etc.
- Concerns about the huge workload/burnout in caring for the PLHIV.
- Fears about getting infected through contact with PLHIV during caring.
- Stigma (and discrimination) in the home towards the PLHIV.
- Excluding the PLHIV from decision-making about his or her life.
- Family has other priority concerns – *“Why should the PLHIV be given priority?”*

### Developing strategies – paired role playing and stop-start drama

4. Facilitate the following process, using these instructions from Step 1. to 4.

**Step 1. (role play – this is just a fun warm-up to demonstrate the technique):** Everyone stand up and find a partner. Face your partner. A is the husband and B is the wife. In each pair agree on who is A and who is B. (Wait until they decide.) The situation is: the husband returns home after staying out all night. The wife reacts angrily. Shout “Play!” After one minute ask one pair to show their role play in the centre.

**Step 2. (starter role play):** Now, let’s try out how an HBC volunteer enters a household. Agree in each pair who is the volunteer and who is the householder. (Wait until all pairs have done this.) Volunteer, your role is to knock on the door, introduce yourself and your purpose. Householder, you are worried about this stranger who wants to see the person who is sick. Shout “Play!”

Let the role plays run for three minutes. Then shout “Stop!” and ask one pair to show their play in the centre. At the end ask, *“What happened? How did the volunteer deal with the problem? What other approach might be used?”* Invite the person who suggests a new approach to take over the volunteer’s role, then debrief at the end. Continue this process until participants have agreed on a good strategy to overcome some of the initial fears/suspicion/challenges by the family.

## Exercise E1 Making home visits as an HBC volunteer



**Step 3. (new challenge):** Select one of the other priority challenges. Ask pairs to stand up and face each other. Pairs, switch roles: A is now the householder and B is the volunteer. Now play out the new situation. At the end shout “Stop!” and ask one pair to show their play in the centre. Debrief and continue to use role play and discussion to work out approaches to deal with this type of challenge.

**Step 4. (challenging stigma):** One of the role plays should focus on a situation where the volunteer observes the family stigmatising the PLHIV and tries to intervene.

5. At the end discuss the following questions:

- *How did you feel as the HBC volunteer?*
- *What did you learn about the situation in the household?*
- *What approaches did you learn that you can apply in your work?*

Then summarise the approaches used to build rapport and acceptance, overcome fears, and get the family to accept their responsibility for caring for the PLHIV.

**Option:** After finding a solution that everyone feels comfortable with, ask the pairs to try it out and get their reaction.



### Examples from Zambia regional trainers workshop

#### How did you feel as the HBC volunteer?

- At first I felt intimidated by the strong reaction from the family.
- Through the practice sessions I gained more confidence. I saw that I could win their trust and acceptance.

#### What did you learn about the family situation?

- Stigma within the family towards PLHIV is a more serious problem than the stigma towards the HBC volunteer.

#### Approaches for overcoming resistance and challenges

- Agree on a time for the visit that suits the family.
- Explain the purpose simply and clearly.
- Use informal chatting to build rapport/relationship/acceptance.
- Explain your own background – who you are.
- Avoid getting upset – stay calm.
- Remain committed to the idea of visiting the person who is sick.
- Empower the patient to speak for himself or herself.
- Get another family member to challenge or assert their rights.

## Exercise E2 Involving the family in caring roles

### Facilitator's notes

In the HBC approach, families are expected to take responsibility for the care of HIV positive family members. Some families have not yet accepted this responsibility, some lack the skills, and some have fears about caring for PLHIV, thinking they will get infected. The aim of this exercise is to show HBC workers how they can help families accept their responsibility and learn the skills to take on this caring role.

### Objectives

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

- overcome their dependency on the HBC volunteer
- accept responsibility and ownership for caring for their family member
- overcome fears of doing caring tasks (fear of getting infected)
- develop skills and confidence to do caring tasks, e.g. handling patients and simple counselling.

### Time

2 hours

### Materials

Paper and markers for drawing.

### Step-by-step activity

#### Put the family in the driver's seat

1. Explain that the session is aimed at helping participants think through how they can:
  - build a strong sense of responsibility/ownership by the family for caring
  - overcome dependency on the HBC volunteer; i.e. family takes the driver's seat.

#### 'Before' and 'after' – picture drawing and discussion

2. Ask participants to draw pictures and add words to show:
  - A. the family situation **before** the HBC volunteer arrives (and before the family has accepted responsibility for caring)
  - B. the family situation **after** the family has accepted responsibility for caring.
3. Ask half of the group to draw pictures of A and the other half pictures of B. Get them to work in pairs or threes. Tape pictures on the wall.

#### Report back

4. Ask each group to explain their pictures and record the main features on the flipchart.

#### Examples of what we might see in the pictures

**Before:** Stigma/isolation – PLHIV left alone in separate room and not visited. Eating alone. PLHIV chased from home. PLHIV laughed at. PLHIV forced to fend for themselves. Fear of infection. Very limited caring. Lack of skills/confidence to do caring tasks. Family confused. Arguments/disunity in home. PLHIV left out of decision-making.

**After:** Unity in family. Acceptance. Emotional support and encouragement for PLHIV. Being together – sharing together, eating together, going to church together, playing together. PLHIV involved in decision-making. PLHIV contributing to house or farm work. Neighbours visiting. Family mobilising local resources, e.g. sugar and salt to make oral rehydration solution.

#### Roadblocks – buzz groups

5. Divide into pairs and ask the pairs to discuss, "What roadblocks prevent the family from taking full responsibility for caring?"

#### Report back

6. Gather the group in a 'round robin' and record possible roadblocks on A4 sheets – one point per sheet.



## Exercise E2 Involving the family in caring roles



### Examples of possible roadblocks

- Stigma towards PLHIV – judgemental attitudes.
- Denial – refuse to accept that their family member has HIV.
- Shame and fear about being stigmatised by neighbours or extended family.
- Fears about getting infected through handling PLHIV or cleaning up blood and fluids.
- Skill gaps – family lacks the communication and other skills to do effective caring.
- Relations between the PLHIV and the home carer, if sour, affects level of support/caring.
- Poverty – where to get the money for treatment, gloves, extra food, transport, etc.
- Heavy workload or burnout – more physical work.
- Gender imbalance – women expected to do the caring and they end up with an extra workload.
- Cultural aspects – difficult for women (or men) to bathe and clean the opposite sex.
- Some families view caring as a professional task – feel they need a nurse.
- Psychological effect – PLHIV may not like the food, may want to remain alone, etc.
- If the carer has a job, they are unable to provide support during the day while away at work.



### Strategies to overcome roadblocks

7. Ask the participants to prioritise the list of roadblocks. Then divide into groups of three and ask each group to select one of the prioritised roadblocks. Ask the groups to discuss, “*What strategies can be used by you, the HBC volunteer, to help the family overcome this roadblock?*”

### Report back

8. Ask each group to give a short report, focusing on the main strategies they have identified.

### Processing

9. Each time a strategy/solution is proposed, ask, “*Will it work? Is it realistic? Will it put the family into the driving seat?*”

At the end of all the reports ask, “*As HBC volunteers, which roadblocks can we realistically help the family to overcome?*” For example, poverty is a big issue and you should not be expected to solve it, but you can help the community think of ways of helping each other.

### Overcoming dependency – drama and buzz groups

10. Organise a short drama showing the volunteer doing everything and not allowing the family to take responsibility.

## Exercise E2 Involving the family in caring roles



11. Then divide into pairs and ask:

- *What happened?*
- *What can we do as volunteers to break the dependency of the family on our help?*

### Summary

- Explain your tasks and limits as a volunteer – the number of families you assist, what you can do, what you can't do.
- Do things with the family – demonstrate how to perform caring tasks and then encourage them to do it.
- Avoid telling the family what to do – instead ask questions and encourage them to find their own solutions.
- Help the family develop the skills and confidence to do the caring.
- Facilitate the family to identify what they can do.
- Facilitate the family to identify locally available resources.
- Facilitate the family to identify other support systems, e.g. church, extended family.
- Offer problem-solving counselling to get the family working together, especially if relations are sour.
- Facilitate action planning, e.g. *"I'm going away for three days – what should we expect to see when I get back?"*



Poverty is a big issue and you should not be expected to solve it, but you can help the community think of ways of helping each other.

# Exercise E3 Contact with bodily fluids

## Objectives

By the end of this session, participants will have:

- reduced their fears about getting infected through contact with bodily fluids
- improved their understanding of HIV transmission
- looked at how stigma is triggered by fears around HIV infection and the ways in which protective clothing (e.g. gloves) is used.

## Time

2 hours

## Step-by-step activity

### Introduction

1. Many of us have fears about getting HIV through contact with blood and other bodily fluids when we are caring for PLHIV. This exercise will help us get a better understanding of HIV transmission, deal with our fears about getting infected and look at the stigma associated with how we handle patients.

### Activities that bother us – card storm

2. Divide into pairs and ask each pair to write down on cards, “What things do you not like doing when you are caring for a patient?”

#### Examples

Cleaning spilt blood, vomit or diarrhoea. Washing dirty bedding. Washing clothes. Feeding someone who is coughing a lot. Carrying someone who is dirty.

### Beliefs, fears or hygiene? – rotational brainstorm

3. Place the cards from Step 2 at each of the flipchart stations – Fear, Belief of HIV risk, Unhygienic, Physical response – and ask groups to write down their responses to, “Why do we not like doing these things?”

Check with the group if they want to explore the fears or beliefs about transmission. Use the QQR fact sheet from the Modules B & C booklet if needed.

Fear	Belief of HIV risk	Unhygienic	Physical response
Feeding someone who coughs a lot	Cleaning up blood	Washing clothes	Cleaning vomit, cleaning diarrhoea

### Processing

4. Ask participants to discuss, “How can we ensure that our responses to certain tasks don’t lead to our patients feeling stigmatised?”

## Summary

It is natural for us to respond with disgust to cleaning spilt blood, vomit, diarrhoea or faeces. We have been taught from a young age to react with disgust when we have to deal with these fluids. We are not afraid to touch faeces (for example), but we have been taught to react with disgust. Our reaction to these bodily fluids is a mixture of culture and natural reaction (disgust).

Some of us refuse to touch bodily fluids because of our fears about getting infected with HIV, (i.e. belief that HIV is transmitted like this). Others refuse because this is a natural reaction of disgust – “I’m going to vomit if I see or smell those bodily fluids”.

## Exercise E3 Contact with bodily fluids



Research has shown that some people don't want to share food because of a natural disgust of saliva. People refuse to eat together because they are worried about eating someone else's saliva.

So you should not feel bad about not wanting to touch bodily fluids. You should be able to express your frustration and disgust. Working in a house without water where you have to do all the washing and there is lots of vomit to clean up is a thankless task.

People think that touching blood with or without gloves puts us at risk. We need to educate PLHIV and family members that using gloves is a protection not only for the user but also for the PLHIV. If he or she has low immunity and is vulnerable to infections then the gloves help protect him or her.

## Exercise E4 Challenging stigma in the home



### Objective

By the end of this session, participants will have developed strategies for challenging stigma when they discover it during an HBC visit.



### Time

2 hours

### Ways of challenging stigma without creating conflict

- ✓ Talk to the PLHIV or another family member to challenge the stigma.
- ✓ Ask another trusted person (e.g. elder, pastor) to raise the issue.
- ✓ Raise the issue yourself in a way that helps the stigmatiser see what he or she is doing and how it hurts.

### Step-by-step activity

#### Forms of stigma in the home – card storm

1. Divide into pairs and hand out cards. Ask participants to write points on the cards about different forms of stigma in the home.
2. Ask, “What are the forms of stigma you may discover as an HBC volunteer?”

#### Examples from Zambia regional workshop

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

#### How to challenge stigma – story discussion

3. In small groups read the following story.

Martinho, an HBC volunteer, has been visiting a house for three weeks and helping the patient. He is trusted by the family but there is a lot of talking behind his back. He observes the patient being poorly treated by his brother.
4. Ask the whole group, “How would you finish this story? How can an HBC volunteer raise the issue of stigma in a way that does not create conflict and block his or her access to the patient?”

#### Processing

5. After each proposed approach to the above question, ask the group:
  - How would you feel about speaking out about stigma in this way?
  - How would the stigmatiser feel to be challenged in this way?

**Option:** Divide into small groups. Ask each group to select one form of stigma and make a short role play to show how a volunteer would challenge this stigma. During the report back (role play presentations), use stop-start drama to try out different approaches to challenging stigma.

## Exercise E5 Fears about status, disclosure and being stigmatised

### Objective

By the end of this session, participants will have discussed some of their own fears about being HIV positive, disclosing to others and being stigmatised.

### Time

2 hours



### Step-by-step activity

#### Feelings about our status and being stigmatised – individual reflection

1. Ask participants to sit on their own. Then say, “*Think about your work as an HBC volunteer, how has it affected your feelings about your own status, or about getting tested or about disclosing to others?*”

Share in pairs.

#### Processing

2. Ask everyone to come back to the group and ask:

- *How did it feel to do this exercise?*
- *What did we learn from this?*
- *What support do we need as volunteers to disclose and to go for treatment?*

### Summary

If we are nursing someone, we may not want to know our status. We sometimes feel it would be easier not to know. Others may want to know so they are no longer living in doubt and worry, and can then access treatment.

#### Option: group reflection

1. Form groups of three. Explain that people should sit with those they feel the most comfortable with because the sharing is very personal.

2. Read out the questions below – one by one. After each question, ask participants to reflect on their own for a few minutes, and then share their feelings within their groups. Emphasise that no one has to share his or her thoughts unless he or she feels comfortable.

- *How has HIV affected your life?*
- *If you were told you were HIV positive, in what ways would it change your life?*
- *Who would you share the information with (or who do you share with?) and who would you keep it secret from?*
- *How would you want to be treated by your family and by other community members?*

#### Processing

3. In plenary, ask participants:

- *How did you feel answering these questions?*
- *How can our attitudes about HIV and AIDS affect our work?*
- *How can thinking about these topics help us become better at our jobs?*

### Summary

As HBC workers we need to be aware of our feelings and attitudes about HIV and AIDS. If we do not address our personal reactions and attitudes, we may, without thinking, stigmatise or discriminate against PLHIV.

# Exercise E6 Relations between PLHIV and the family

## Objectives

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

- analyse relations between the family and PLHIV
- develop practical strategies for improving relations.

## Time

1 hour

## Materials

Copies of *role play arguments* (below right).



## Step-by-step activity

### Pressures on the family and PLHIV – card storm

1. Divide into pairs and ask each pair to write on cards points on:
  - pressures and difficulties families face when caring for a PLHIV
  - pressures and difficulties PLHIV face in their families.

### Examples

#### Pressures faced by families

Financial pressure – extra money for food and treatment. Extra workload caring for PLHIV. Stigma from neighbours. Loss of income. Emotional pressure. Not knowing how to counsel.

#### Pressures faced by PLHIV

Feeling isolated. Feeling treated as a burden. Feeling left out of family decision-making. Worrying about financial issues. Stigma. Violence.

### Playing out the relationship – back-to-back role plays

2. Divide into pairs. Each pair agree on roles of family caregiver and PLHIV. Read out the points from Step 1. and the role play arguments below. (Two facilitators show how to do it.) Then sit in chairs, back-to-back, and take turns speaking about the difficulties you face. After five minutes swap roles.

### Role play arguments

#### Family caregiver

You are short-tempered.

I can never satisfy you.

You are so demanding.

I don't have time to talk to you – I only have time to cook and clean for you.

You keep demanding food and other things we can't afford.

I have to go to the market to sell things for our survival.

I don't have time to look after you.

#### PLHIV

You're not giving me enough attention.

You don't understand my needs.

You never listen to me. You are always rushing away to do something.

You treat me as if I am invisible.

You don't spend enough time with me.

You are always shouting at me.

You do things for me rather than with me.

You always assume things that I want rather than asking me what I need.

You are neglecting me.

## Exercise E6 Relations between PLHIV and the family

### ! Action ideas

Discuss with other participants ways you can give each other support, e.g. set up a support group or arrange to meet once a week or month with a friend to talk about your difficulties.

3. Ask a few pairs to show their role play in front of the large group.

4. Ask participants to discuss:

- *What were the concerns expressed by family carers? By PLHIV?*
- *What were the concerns common to both groups?*
- *What can we do to improve relations within the family?*

### Summary

Families under serious economic pressure can become discouraged by the demands of PLHIV. PLHIV may ask for things that the family cannot afford (e.g. one man asked for mangos outside the mango season). Some caregivers get fed up with these demands and want to run away – to go somewhere else where they don't need to face this pressure. Others feel angry and frustrated, and sometimes take this out on the PLHIV. Sometimes poverty really fuels stigma.



# pictures

## Silhouettes<sup>2</sup>

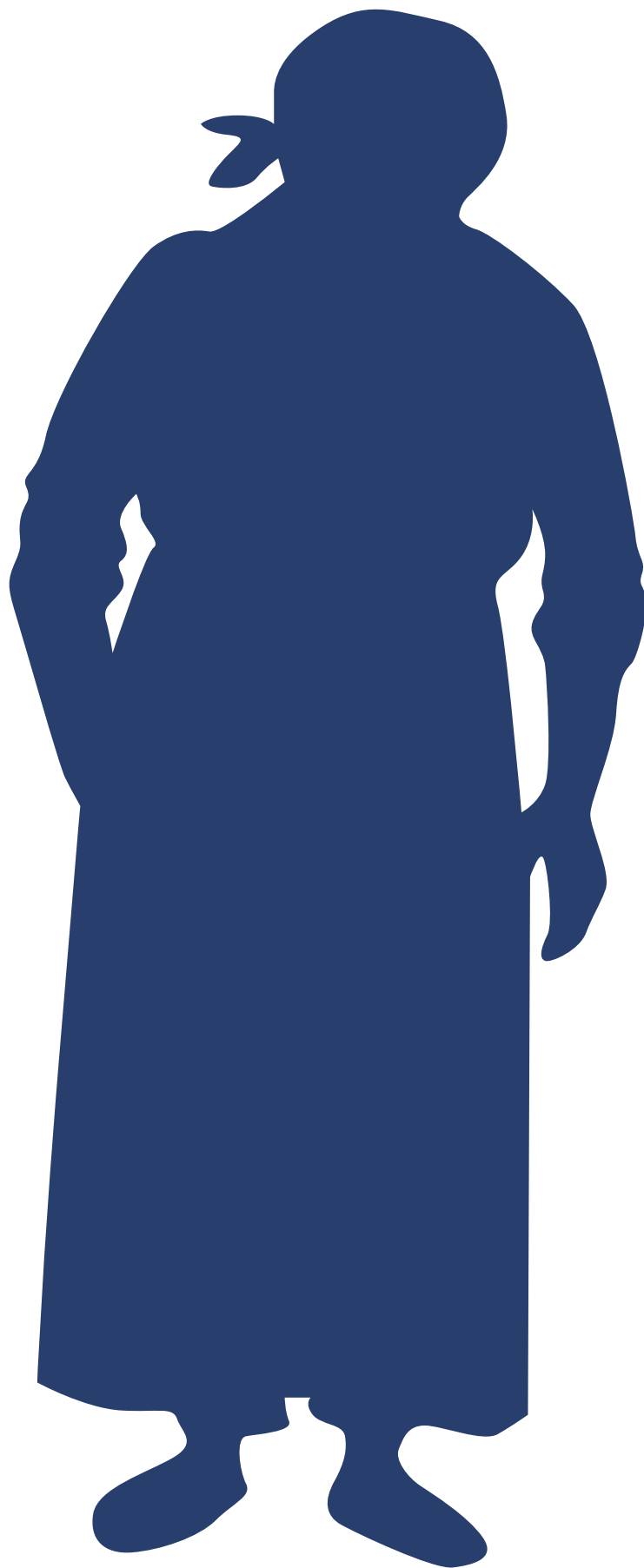
Each silhouette represents a different family member – grandfather, grandmother, father, mother, teenage girl, teenage boy and baby. The cards are used to create different types of families, e.g. nuclear family (father, mother and children), female-headed families, grandparent-headed families and child-headed families. After creating a family, participants then talk about how HIV and stigma affects their families. The silhouettes make it possible for people to talk about their own experiences of family issues in an anonymous way.

<sup>2</sup>These silhouettes are adapted from: *National training report and reference guide*, Mvula Trust, Johannesburg, March 1998.

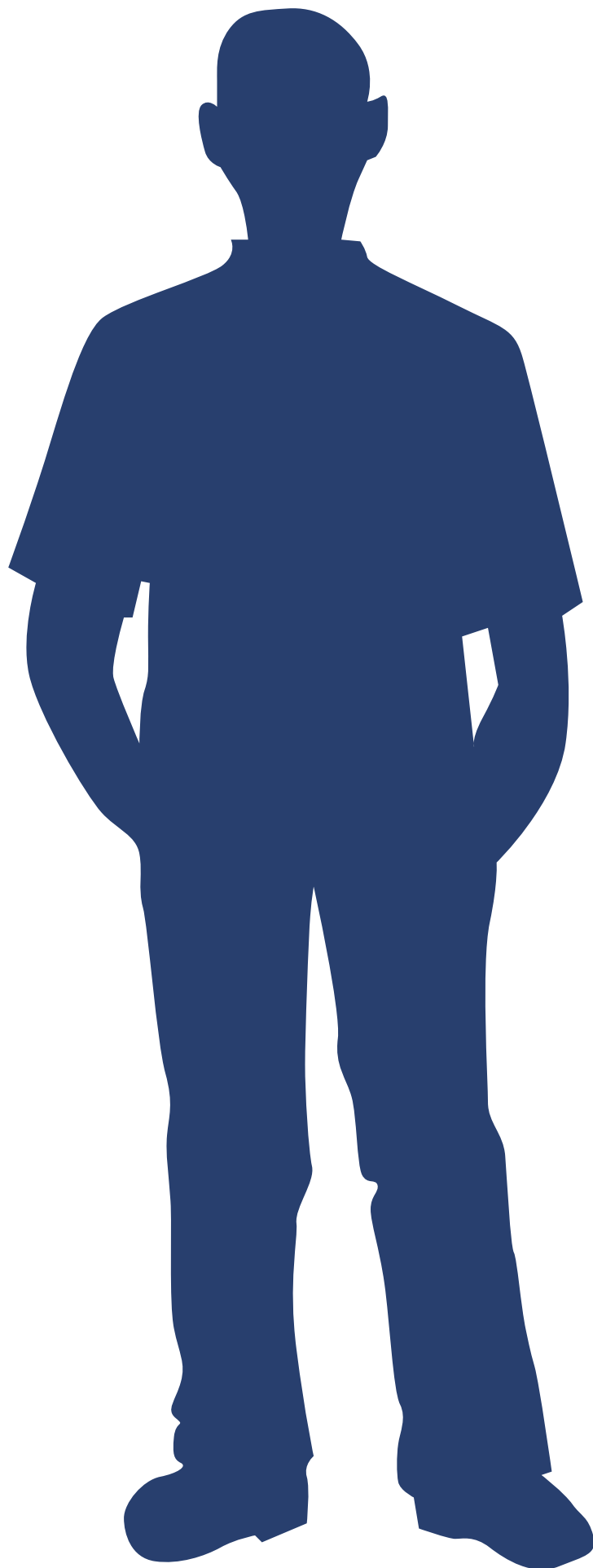
Silhouette 1



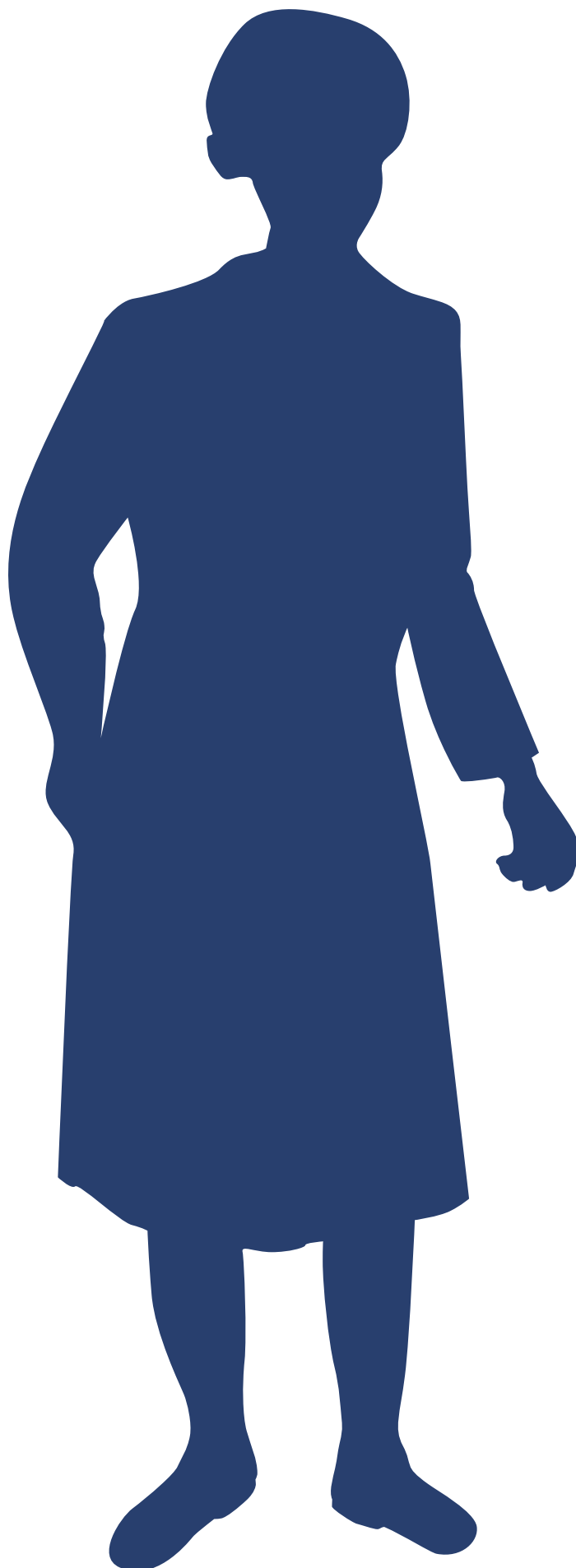
## Silhouette 2



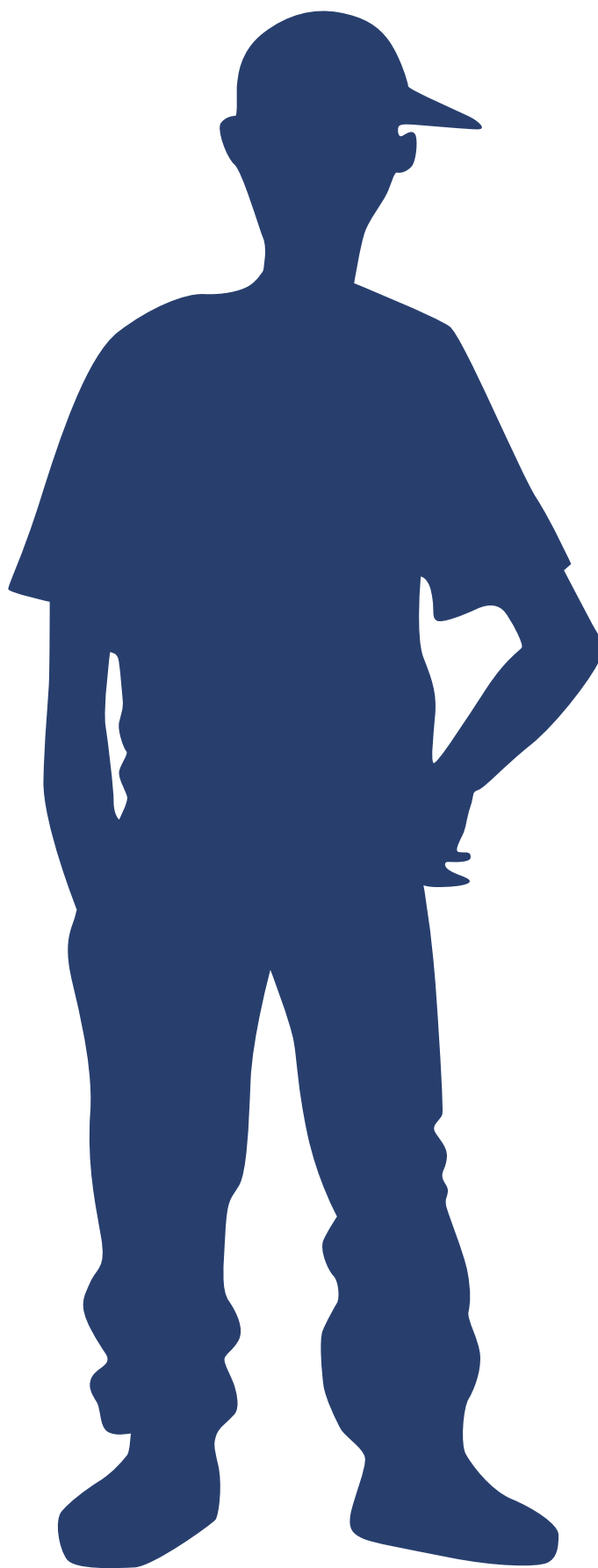
Silhouette 3



## Silhouette 4



Silhouette 5



## Silhouette 6



Silhouette 7





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

**Introduction**

Using the toolkit

**Module A**

Naming the problem

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**Module B**

More understanding, less fear

**Module C**

Sex, morality, shame and blame

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**Module D**

The family and stigma

**Module E**

Home-based care and stigma

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**Module F**

Coping with stigma

**Module G**

Treatment and stigma

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**Module H**

MSM and stigma

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**Module I**

Children and stigma

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**Module J**

Young people and stigma

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**Moving to action module**

Thinking about change

Moving to action

Developing skills for advocacy

---

**Picture booklet**

General stigma pictures

Rights pictures

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Additional booklets will be published as new modules are developed.