Understanding and challenging HIV stigma
Toolkit for action

INTRODUCTION & MODULE A

- **Using the toolkit**
- **Naming the problem**

About the organisations involved

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

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

International HIV/AIDS Alliance
Established in 1993, the International HIV/AIDS Alliance (the Alliance) is a global partnership of nationally based organisations working to support community action on HIV and AIDS in developing countries. Our shared mission is to reduce the spread of HIV and meet the challenges of AIDS. To date, over $140 million has been channelled to more than 40 developing countries in support of over 3,000 projects, reaching some of the poorest and most vulnerable communities with HIV prevention, care and support, and improved access to treatment.
Registered charity number 1038860
www.aidsalliance.org

Wood pulp sourced from sustainable forests

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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 Chipo Chiiya

Contents

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

Module B
More understanding, less fear
Module C
Sex, morality, shame and blame

Module D
The family and stigma
Module E
Home-based care and stigma

Module F
Coping with stigma
Module G
Treatment and stigma

Module H
MSM and stigma

Module I
Children and stigma

Module J
Young people and stigma

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

Picture booklet
General stigma pictures
Rights pictures

Additional booklets will be published as new modules are developed.

Welcome

This toolkit is written for and by HIV trainers in Africa. The aim of the toolkit is to support HIV trainers to work together to confront HIV stigma, promote more care and support for people living with HIV (PLHIV) and to defend our rights. We are all in the same boat! We are all at risk of getting HIV so there is no room for blaming and shaming people who already have HIV. We need to work together to change attitudes and promote a more accepting and supportive community.

The toolkit is designed to help you plan and organise educational sessions with community leaders or organised groups to raise awareness and promote practical action to challenge HIV stigma and discrimination.

It is also designed to help you understand HIV stigma yourself. Before educating the community we need to look at our own attitudes, language and relationships, and get a better understanding of stigma. Are we guilty of the same 'shaming and blaming' practices that we are fighting against? We need to check our own behaviour and attitudes first before we start working with the community.

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

We encourage you to start using the toolkit and to tell us what does and doesn't work so we can make revisions. You can do this by sending an email to **publications@aidsalliance.org**. Make the toolkit your own!

Introduction to the toolkit

Special note on the acronym 'PLHIV'

We have used the acronym PLHIV (people living with HIV) in order to shorten the text and make reading easier. However, we would discourage the use of this acronym in workshops and instead promote use of the full phrase.

About the toolkit

What is the toolkit?

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

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

Why was the toolkit developed?

The toolkit was developed to provide people working in the HIV field with a set of flexible educational materials to raise their own understanding and help them facilitate awareness-raising with community groups. The aim is to help people at all levels understand stigma – what it means, why it is an important issue, what its root causes are – and develop strategies to challenge stigma and discrimination.

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

How was the toolkit developed?

The toolkit developed out of a research project on HIV stigma in Ethiopia, Tanzania and Zambia. During the project, NGOs who were given awareness training on stigma asked for copies of the workshop exercises. Out of this grew the idea of creating a toolkit of participatory exercises on stigma. There are few training materials available on HIV stigma, so the toolkit was proposed to fill this gap. NGOs took part in a series of workshops to help develop the first toolkit, which was printed in 2003.

Over the last three years, the toolkit has been disseminated to different countries in Africa through the Regional Stigma Training Project. The toolkit has been tested through TOT workshops and follow-up workshops organised by network members in each country. Then a regional workshop was organised to review this experience and produce a revised and updated version of the toolkit. The toolkit has also been translated into several languages, including Amharic, French, Portuguese and Swahili. Adapted versions have also been developed in Vietnamese and Telugu (South India).

The toolkit will continue to evolve – **your input into this process is important**.

Us and them

" At an HIV meeting I attended some people referred to PLHIV as 'those people', but we all knew people in the room who were living with HIV. How did they feel when they heard these words? One woman leaned over to me and said, 'What do they call us again – PLHA? PLA? Why all these names? Let's do away with the naming.'

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

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

Target groups

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

- **HIV trainers and counsellors** – people who conduct educational sessions for community groups, or provide individual or group counselling on AIDS issues. This includes full-time professionals (NGO staff) and part-time peer educators.
- **Community or peer groups** that AIDS educators work with – women's groups, youth groups, church groups, family support groups, etc. Many of the same exercises developed for HIV trainers can be used with community groups.
- **People, families and children (and guardians) living with HIV and AIDS.**
- **Other groups** – the materials can be adapted for use in training other groups, e.g. health workers, home-based care workers, media workers, teachers, etc.

Introduction to the toolkit

Twelve steps to stop stigma

1. Create a **sense of community** and build **openness and safety** to talk about HIV and AIDS, stigma and sex.

2. **Name the problem** – get people to describe how stigma occurs in different contexts.

3. Get people to **own the stigmatising disease** – *"We are all part of the problem."* Help people read and reflect on their own words, attitudes and actions towards PLHIV.

4. Help people see the **effects** of stigma on PLHIV, families, children and communities – how it hurts those stigmatised and indirectly hurts those who are stigmatising.

5. Analyse the **root causes** of stigma – e.g. fears and misperceptions about HIV and AIDS, moralising attitudes, power and poverty – and how it particularly affects women, children and poor people.

6. Address **fears and misconceptions** about getting HIV through non-sexual casual contact, and what it means to live with HIV and AIDS.

7. Challenge the **judging and blaming** built into stigma and help people explore their own attitudes.

8. Build **commitment** to changing attitudes and doing something about stigma.

9. Help PLHIV overcome **self-stigma** and build up **self-esteem** and **skills** to provide leadership on anti-stigma action.

10. Help family members learn the attitudes and skills needed to provide care and support for PLHIV and children living with HIV and AIDS.

11. Develop **strategies and plans** for taking action against stigma.

12. **Action** and the **monitoring** of action.

Start with yourself
You should first use the toolkit yourself to reflect on your own attitudes, values, language and behaviour towards PLHIV before you try to educate others.

How to use the toolkit

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

So don't use it as a series of lectures. Changing attitudes around stigma requires more than giving people information. This form of change cannot be achieved through spoon-feeding – treating participants as a passive audience for your lectures. People learn best through figuring things out for themselves.

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

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

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

Many of the modules have suggestions on immediate mini-actions that participants can try out at home, at work, or with their friends, and there is *Moving to action module,* that helps participants start planning actions which they can take as a group.

Pick and choose modules to make your own training programme
The toolkit is **not** a standardised package for a single training course or programme. You are not expected to work your way through all of the modules. Use it selectively. Pick out those exercises that suit your own target group and needs, and make up your own training programme.

Mainstream stigma awareness into existing programme activities
The toolkit focuses solely on stigma, and workshops can be organised on this theme alone. But we would also encourage you to integrate these sessions into other AIDS education activities. The aim should be to mainstream stigma – to make it a regular part of all educational activities for AIDS educators and communities.

Introduction to the toolkit

The session plans – how to use them

The toolkit consists of a number of training exercises, each with a detailed session plan. The session plans provide a step-by-step description of how to facilitate a learning activity. The session plan will help you run each training exercise. Each exercise is divided into the following parts:

Facilitator's notes
A brief note to the trainer on the importance of the exercise or extra advice on how to facilitate it.

Objectives
What trainees will know or be able to do by the end of the session.

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

Materials
Role plays, stories, pictures, etc. that are used during the training session. We assume that basic training materials – flipcharts, markers and masking tape – are freely available.

Preparation
Any specific preparation the facilitator needs to do before starting the exercise.

Steps
The learning activities or training methods involved in the exercise, described 'step-by-step', and the training content. Steps are the core of each session plan and include information on:

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

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

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

Questions: Specific questions used to guide discussion, presented in *italics*.

Responses: Examples of typical responses are presented in boxes. Please note – these are only examples – they are not meant to be the required output or the basis for a lecture.

Report back
Procedures for asking groups to give reports after discussion.

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

Summary
Points to be emphasised in a summary at the end of the session.

Action ideas
Suggestions on how participants can start trying out what they have learned when they return home or to their job context.

Making your own training programme – sample timetables for different workshops

Remember

You don't need to go through the whole toolkit exercise by exercise. Select those activities that suit your objectives, target groups or context. Once you have selected an exercise, read through the entire session plan and get an idea of what is required. Ensure that you are clear about the purpose and methods of the exercise. This will help you to prepare.

Try out the exercise as it is presented at least once, especially if you do not have much experience of using the methods described. Once you are comfortable using the exercise, you can adapt and change it to suit your purpose and target group.

Planning your own workshop

The exercises can be used to design different types of workshops for different groups.

You may want to introduce stigma as one of a number of topics in a course for health workers, or you may want to run a short workshop on stigma as a topic on its own. Feel free to select and adapt the materials to suit your own purposes.

We would expect you to use exercises from modules A, B, C, and selected exercises from other modules, depending on your target group. If there is limited time, we have some key exercises that we recommend you use. We have provided lots of options (in modules A, B and C) to keep trainers and participants interested. Different trainers like different types of activities.

Sample: Workplace programme (2 hours a week)

Session 1
Naming stigma through pictures
Our experience of being stigmatised

Session 2
Assessing knowledge levels
Fears about casual contact

Session 3
Stigma in the family
Disclosing to the family

Session 4
Breaking the sex ice
Carrying condoms carries stigma

Sample: Half-day workshop for policy-makers/managers

Time	Exercise
1 hour	Naming stigma through pictures
45 minutes	Our experience of being stigmatised
1 hour	Forms, effects and causes of stigma

Sample: Three-day community workshop on stigma

Day 1	Day 2	Day 3
Naming stigma through pictures	Things people say...	Stigma in the family
Our experience of being stigmatised	Breaking the sex ice	Understanding assertiveness
Fears about casual contact	Judging characters	Treatment and stigma in different contexts
Fears about HIV at home	Promiscuity, prostitution and preaching	Thinking about change

Introduction to the toolkit

Toolkit methods and materials

The toolkit uses a wide variety of participatory training methods and materials:

Discussion is the core method; the activity through which participants reflect on their own experience, share with others, analyse issues and plan for action together. All of the sessions are built around discussion.

Presentations are kept to a minimum and only used in summarising sessions or explaining some of the HIV and AIDS facts where participants are confused.

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

Buzz groups – two people sitting beside each other – are a trainer's secret weapon. They help get instant participation. It is hard to remain silent in a group of two people!

Report backs are used to bring ideas together after small or buzz groups. Often round robin reporting will be used – one new point from each group going around the circle. This ensures that all groups get a chance to contribute equally.

Card storming is a quick way of getting ideas and everyone involved. Participants, working individually or in pairs, write single points on cards and tape them on the wall, creating a quick brainstorm of ideas. Once everyone is finished, the cards are organised into categories and discussed.

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

Pictures: the toolkit includes more than 100 pictures that can be used in different exercises. Some pictures show various aspects of stigma as a focus for discussion; others show different activities that may or may not involve HIV transmission; and others show different members of a family and participants can make up their own stories around them.

Stories are provided in many of the exercises as a way of describing what stigma looks like in a real situation and as a focus for discussion. In other exercises participants are asked to write their own stories about stigma.

Drama or role plays are an alternative to stories. Participants act out either the stories in the exercise or their own stories, or they act out their analysis of an issue as a way of reporting back what they have discussed. Drama helps to make things real.

Warm-up games and songs: trainers are encouraged to use their own games and songs to break the ice, build group spirit and create energy for sessions.

Processing

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

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

During a workshop there can be many different types of activities, e.g. role plays, card storms, reflections. If these activities are not processed, then there will be no acknowledgement of the learning that comes from them. Processing helps us to share the things we have learnt, to consolidate the new knowledge and to make sense of what these new learnings mean for the future. It is through processing that we can begin to see the need for behaviour change at both individual and community levels.

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

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

Processing may follow a series of steps:
1. **Help people to reflect on what they have just done or seen.**
   e.g. *"What did we see?"*
       "What was happening?"
       "What do you think about this?"

2. **Pull out the major themes or most important things.**
   e.g. *"What do you think are the most important things here?"*
       "What would you say were the key themes that have emerged?"

3. **Help identify the major learnings.**
   e.g. *"What do we learn from this?"*
       "What does this tell us?"

4. **Link the lessons to the outside world.**
   e.g. *"Does this apply to your community/family/workplace, etc?"*
       "How does this link to the real situation out there?"

5. **Move participants to action.**
   e.g. *"What can we do to change this?"*
       "What could be some of the solutions to this problem?"

Now that we have finished the activity, let's talk about what we have learnt.

Introduction to the toolkit

Remember
Working in participatory ways on stigma and the feelings around HIV and AIDS is potentially risky.

If there are any exercises you do not feel comfortable leading, find a co-trainer who can help out. If you have counselling skills, you are more likely to be confident in working with feelings. Otherwise you might find a trained counsellor to support you in the training.

Working with feelings

Many of the exercises in the toolkit involve working with feelings. Participants are asked to express the feelings that lie behind their attitudes. Examples of this are the reflection exercises on stigma and violence. In these exercises participants are asked to reflect on their own experiences of being stigmatised or of being abused. This brings out strong feelings. These feelings help participants see how hurtful stigma and violence can be, but you need to be ready to deal with the emotions raised.

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

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

Be aware that some participants may be HIV positive or worried about their status. Many participants will be untested, so some of the activities may raise emotional responses.

Remember!
Don't do any exercise that you feel uncomfortable with.

Tips for participatory trainers

Be well prepared
- Plan each of the sessions before the training so you are well prepared.
- Bring all materials – toolkit, handouts, flipchart paper, markers, cards, etc.
- Arrive early so you are ready to welcome participants when they arrive.

Prepare the room
- Remove tables to make room for 'doing' and make training more informal.
- Set up the meeting space in a semi-circle – check that everyone can see the flipchart.
- Some sessions where you are sharing can be done sitting in a full circle.
- Put flipchart sheets on the front wall.
- Set up a separate table for markers, tape, handouts, cards, etc.

Make trainees feel comfortable
- Break the ice and put participants at ease at the start of the workshop.
- Learn participants' names, be informal, use games, songs or buzz groups.

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

Ask questions and lead discussion
- Ask clear, simple, open questions that allow people to give their opinions.
- Fish for contributions – use your hands and body to encourage participants.
- Wait for responses – give people time to think and come up with an answer.
- Encourage everyone to talk – buzz groups get everyone talking.
- Keep asking, *"Who would like to add to that?"*
- If there is no response, rephrase the questions.
- Show that you are listening and are interested.
- Praise responses to encourage participation.
- Rephrase responses to check that you and other participants understand.
- Redirect to involve others – *"He said… What do others think?"*
- Summarise and check agreement before moving to the next question or topic.

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

Introduction to the toolkit

Keep presentations short and simple!
- Give a presentation only when you are sure people don't know the topic.
- Write out your main points in key words on a flipchart and then explain them.
- Speak slowly, clearly and loud enough.
- Look at people and use your hands and body to emphasise points.
- Keep it short and simple – no more than ten minutes. Only explain the basics.

Keep changing your methods
- Use different methods for different topics to keep things interesting.
- Use your creativity – a story or case study can be turned into a role play, or a report back used to practise presenting a convincing argument (advocacy skills).
- Use different sizes of groups – don't buzz all the time; try threes or fours.
- Change the space – you can go outside and hold groups under the trees.

Check the energy level
- Observe body language – do participants look bored or sleepy?
- Ask, *"How are you feeling? Is it time for a break?"*
- Change the topic, take a break or do a wake-up game.

Watch the timing and pacing
- Be time conscious – decide how much time you need for each session.
- Remember, small group work takes more time than you expect. You will also need to allocate time for report backs.
- Don't go too fast – let the group help you set an appropriate pace.
- Give groups enough time to do their work – don't rush them.
- Do small group work in the afternoon when the energy levels drop.
- Don't forget to take breaks to relax, get tea and talk informally.
- Finish on time! Don't drag things on forever at the end of the day.

Evaluate throughout the workshop
- Evaluate as an ongoing activity, not just at the end of the workshop.
- Organise a short evaluation at the end of each day or on the following morning to encourage participants to review what was learned.
- Assess what was learned and how the learning was done.

Team facilitation
- Plan and run the workshop with another facilitator and debrief afterwards.
- Take turns in the lead facilitation role and as the flipchart recorder.
- Support each other – if one runs into trouble, help him or her out.

module A

Introduction

This module gets participants to **name the problem**, in order to see that:
- stigma exists and takes many forms – rejecting, isolating, blaming and shaming
- we are all involved in stigmatising, even if we don't realise it
- stigma is harmful to ourselves, our families and communities
- we can make a difference by changing our own thinking and actions.

This module also gets participants to **own the problem** – to recognise that we are all involved in stigmatising people living with HIV and AIDS. It is not someone else's problem. We are all part of the problem, even if at first we don't recognise it.

The module starts with people's own experience of and feelings about being stigmatised and stigmatising others. The aim is to get people to connect to the issue on a personal, emotional level rather than a theoretical level (through a definition). People can see how stigma affects everyone through their own experience of being isolated or excluded – and how it hurts.

Then the rest of this module looks at what stigma means for people:
- What are the forms of stigma? What does it look like – in our attitudes, language and behaviour?
- What are the effects of stigma on individuals, families, communities, people's access to health services, etc?
- What are the root causes of stigma?

> " A man who is isolated and alone can be regarded as a sort of discarded person. He is a man cast out of society, and that type of man, in the old days would have been killed. Let me say this – and I say it very seriously: there is nothing worse than being isolated. "
>
> **Dinizulu, King of the Zulus, 1910,** quoted in Malan, Rian (1970) *My Traitor's Heart,* London, Vintage Books

Module A – Naming the problem

> In our African idiom we say, 'A person is a person through other persons.' None of us comes into the world fully formed. We would not know how to think, or walk, or speak, or behave as human beings unless we learned it from other human beings. We need other humans in order to be human. The solitary, isolated human being is really a contradiction in terms.

Archbishop Desmond Tutu, 2000

We all stigmatise

We stigmatise when we say things like "she was promiscuous" and "he deserves it", and we do things such as isolating people when they get sick, excluding them from decision-making, etc.

The main **causes** of stigma include:
- insufficient knowledge, misbeliefs and fears about HIV transmission
- moral judgements about people
- fears about death and disease
- lack of recognition of stigma.

The main **forms** of stigma include:
- physical and social isolation from family, friends and community
- gossiping, name-calling, violence and condemnation
- loss of rights and decision-making power.

Other forms of stigma include:
- self-stigma – when people blame and isolate themselves
- stigma by association – the whole family is affected by stigma
- stigma by looks/appearance/type of occupation/lifestyle.

The **effects** of stigma include:
- being chased from the family, house, work, rented accommodation, organisation, etc
- dropping out of school (resulting from peer pressure – insults)
- depression, suicide, alcoholism.

Facilitator's notes

This is a good starter activity to get participants talking about stigma through discussion and doing a simple task in pairs. At this point trainees are analysing stigma externally – through commenting on pictures, rather than examining their own behaviour – so it is easier and a good lead into self-reflection.

During the report back, you can use different hand claps to 'appreciate' each group.

Objectives

By the end of this session, participants will be able to:
- identify different forms of stigma in different contexts
- identify how stigma affects individuals, families and communities
- begin to understand why stigma happens
- discuss examples of stigma from their own communities.

Time

1 hour

Materials

Selection of *general stigma pictures* from the Picture booklet.

Step-by-step activity

Picture discussion

1. Display the selection of *general stigma pictures* on the wall, floor, washing line, etc.
2. Divide into groups of two or three people. Ask each group to walk around and look at as many pictures as possible.
3. Ask each group to select one of the pictures. Ask them to discuss:
   - *What do you think is happening in the picture in relation to stigma?*
   - *Why do you think it is happening?*
   - *Does this happen in your own community? If so, discuss some examples.*

Report back

4. Ask each group to present their analysis.
5. Record key points on flipchart sheets.

Processing

6. Read through the points from the flipchart.
7. Ask the whole group, *"What do we learn from this exercise?"*

Examples from Ethiopia NGO workshop

Man seated all alone on a bed
No one is caring for him. Utensils under bed show that people are not sharing utensils with him. Looks lonely and worried – seems to have lost all hope.

Parents pushing pregnant daughter out of house
Unwanted pregnancy. Is she HIV positive? Maybe she will get an abortion, drop out of school or become a sex worker to survive.

Woman sitting all alone crying
Maybe she has just learnt that she is HIV positive and people are rejecting her. Depressed, hopeless, anxious. No one to share her problems with.

Child eating alone in the corner
Looks sad and worried. Maybe she is an orphan. Has less food than others. Maybe living with HIV. She is isolated because her parents died from AIDS.

Exercise A1 Naming stigma through pictures

! Action ideas

Take the pictures home and discuss them with family members and friends. Help others see what HIV stigma means in our lives.

Summary

Forms of stigma

- **Moral judgements** – people blamed for their 'behaviour'. HIV is a sexually transmitted disease so people assume that the person has had many partners.
- **Physical isolation** – being forced to eat alone. No visitors, no physical contact. Separation – 'us' versus 'them'. Based on ignorance and fear of HIV and AIDS.
- **People treated as useless** – no longer able to make a contribution. This undermines self-esteem and self-confidence.
- **Self-stigma** – people blame and isolate themselves as a reaction to stigmatisation from society – internalise the shame and blame of society.
- **Stigma by association** – family members or orphans stigmatised; family status affected.

Objectives

By the end of this session, participants will be able to:
- describe some of their own personal experiences of stigma
- identify some of the feelings involved in being stigmatised.

Time

1 hour

> " This exercise changed the whole workshop. Getting people to think about their own experience of 'being isolated or rejected for being seen to be different' helped them see how it really feels to be stigmatised. People could see how HIV stigma hurts people. This was when the workshop took off! "
>
> **Trainer, Ethiopia toolkit workshop**

☑ Facilitator's notes

- This is one of the most important exercises in the toolkit because it makes the discussion of stigma more personal. It asks participants to reflect on their own experience of being stigmatised and how it felt. These feelings help participants get an insider's view of stigma – how it hurts and how powerful those feelings are.
- The exercise looks at stigmatisation in general, not HIV-related stigma. This is why the instructions are, *"Think of a time in your life when you felt isolated or rejected for being seen as different from others."*
- If you can, use outside space for the reflection.
- You might have to push people a little to sit alone for Step 1. Participants may automatically sit together.
- The sharing should be voluntary – no one should be forced to give his or her story.
- Drama is an option for situations if it feels appropriate – it helps to make things real. Where there are strong feelings, don't use this drama technique.

Step-by-step activity

Individual reflection

1. Ask participants to find some space alone, at a distance from other participants. If possible use outside space.
2. Then say, *"Spend a few minutes alone thinking about a time in your life when you felt isolated or rejected for being seen to be different from others."* Explain that this does not need to be about HIV. It could be any form of isolation or rejection for being seen to be different.
3. Ask them to think about, *"What happened? How did it feel? What impact did it have on you?"* Tell participants to spend a few minutes reflecting alone, and then when they feel ready they can share their experience with someone with whom they feel comfortable.

Report back

4. Arrange chairs in a close circle. Begin by asking, *"How was the exercise? What kind of feelings came up?"*
5. Invite participants to share their stories in the large group. Give people time. There is no compulsion – people will share if they feel comfortable.

   #### Option: Stop-start drama

   Invite some of the storytellers to act out their stories in short role plays (with other participants playing the other roles). This activity helps to make the stories come alive so participants can see the feelings involved – the pain in being rejected, isolated, or condemned. At the end of each scene ask the role players, *"How did it feel to be stigmatised?"*

6. Find a way to bring participants gently back to the group, e.g. ask participants to stand and hold hands or arms around shoulders and use a gentle song to come together.

Exercise A2 Our experience of being stigmatised

Summary

Everybody has felt ostracised or treated like a minority at different times in their lives. And it is okay to feel like that because you are not alone. We have all experienced this sense of social exclusion.

Story from Zambia workshop

Mary

A couple had four girls and two boys. When they died, they left their children four houses. The houses were not distributed equally. One sister got two houses, one sister one house, and one brother one house. The other brother – the oldest in the family – and two sisters got nothing. Those who took over the houses began renting out rooms to make money.

The older brother was forced to stay in a shanty compound. He was given money by his siblings for food and rental payments. After a while he became sick and his wife abandoned him. He was taken to the hospital, where he was told he had tuberculosis (TB) and placed in the TB ward. This news disturbed his siblings, who quarrelled over who should look after him. His brother agreed to buy food for him and his sister (the youngest) agreed to take the food to the hospital.

Eventually he was discharged and sent to stay with his brother. This brought confusion again – the siblings wanted to send him back to the shanty compound. However, the older brother refused. He said, *"Who will look after me, since my wife has run away? I want to stay with you."*

They all refused to help apart from one sister who offered to look after him. After two days she kicked him out, saying that she could not care for him since *"He is a man and needs to be looked after by another man."* So he moved into his brother's house and was given one of the rental rooms. His brother told him, *"Since you are using the room which I would have rented to make money to buy you food, you will have to find your own money for food."* And he told his wife not to cook for his older brother.

The older brother is now struggling to find money to buy food, working as a tailor. He has very little contact with his brother, who tries to avoid him. The three siblings continue to earn money from rental, but the income is not shared with their siblings.

Examples from workshops in Ethiopia, Zambia and Kenya

Experiences of being stigmatised
- Being fired from a job without any clear reason for being dismissed and then laughed at or shunned by fellow workers.
- Going to another region of the country and not being able to speak the local language – as a result feeling isolated and lonely and thinking that people are making fun of me.
- Being left handed – *"As a child my left hand was tied up in a cloth to stop me using this hand. This made me feel different from other people, like an outcast – children laughed at me."*
- When I finally told my wife that I had tested HIV positive, she said she would never forgive me. She packed her bags and left with the children. I have not seen her again.

Story from Ethiopia toolkit workshop

Evil eye people
In Ethiopia the most heavily stigmatised group are craftsmen – pot-makers, blacksmiths and weavers – who have been stigmatised for centuries as 'evil eyes'. People believe that contact with the 'evil eye' can lead to harm, so they avoid eye contact with them and warn their children against them. As a result, 'evil eye' people are forced to live apart in separate colonies. People don't mix with them, eat with them or marry them.

There have been various attempts historically to defend these groups against stigma and discrimination. In the Bible and Koran there are passages appealing for the protection of stigmatised people and setting punishments against those who discriminate. In 1908 Emperor Menelik II made a proclamation to stop the persecution of the craft-makers. He said, *"Don't discriminate against the pot-makers and blacksmiths. You brand these people as outcasts out of ignorance. These people produce useful things which we all have in our homes – cups, baskets, ploughs, leather goods, etc. We use these things to make our lives better. These people are very productive so they should be accepted and respected. Those who discriminate will be punished."*

The stigma against 'evil eye' people has even been accepted by 'evil eye' people themselves as a form of self-stigma. Some 'evil eye' people deliberately cover (or hide) themselves to make it easier for other people to avoid eye contact. They have accepted the view that they are 'evil eye' or a danger to other people. Hiding their eyes or turning their backs stops eye contact with other people. This act removes the fear and the sense of threat.

Exercise A3 Our experience of stigmatising others

☑ Facilitator's notes

This is a similar exercise to A2 but should be used later in the workshop. Do not use the two exercises back to back as the feelings involved are very different. The exercise helps us to see how and why we have all stigmatised others at different times in our lives.

➡ Objective

By the end of this session, participants will be able to describe some of their own personal experiences of stigmatising others.

🕐 Time

1 hour

Step-by-step activity

Individual reflection

1. Ask participants to sit on their own. Then say, *"Think about a time in your life when you isolated or rejected other people because they were different."* Ask them to think about, *"What happened? How did you feel? What was your attitude? How did you behave?"*

2. Ask participants to write down any thoughts, feelings or words that they associate with stigmatising.

Sharing in pairs

3. Ask each participant to share their experience with someone in the group with whom they feel comfortable.

Processing

4. Ask, *"How was the exercise? What happened?"*

5. Ask participants to share any points from their list. Ask them, *"What do we learn from this?"*

Experiences of stigmatising others from Zambia workshop

- Using abusive language to street children or orphans.
- Avoiding shaking hands with people who are suspected to have HIV.
- Refusing to speak up for an HIV positive friend at the hospital.

Facilitator's notes

This exercise works well in a workshop with many participants or in a community setting. It works well as an afternoon exercise for a low-energy time of day. It also works well in an outside space.

Objectives

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

- identify different forms of stigma in different contexts
- identify how stigma affects people with HIV
- begin to identify some of the root causes of stigma.

Time

1-2 hours

Materials

Context cards on pages 34-42.

Preparation

Tape up *context cards* (family, community, clinic, school, workplace, church, market, bar, media) on different walls of the room or on different trees.

Step-by-step activity

Walk around

1. Ask participants to walk around the 'community' in twos or threes and as they reach the different places discuss the kind of stigma that happens in that place. After a few minutes, shout "Stop!"
2. Ask participants to form groups at their nearest context (e.g. market, church).
3. Then ask groups to:
   - identify and write down on flipchart paper the forms of stigma that occur in that context
   - make a role play to show how the stigma occurs.

Report back

4. Ask each group to present their flipchart report and the role play.
5. For each role play, discuss:
   - *What happened? Why?*
   - *What are the attitudes here?*
   - *What are the contributing factors?*

Processing

6. Finish the session by discussing some of the following questions:
   - *What are some of the common features across the different contexts?*
   - *What are the attitudes/feelings in all contexts towards PLHIV?*
   - *What are the effects on people who have been stigmatised?*
   - *What are some of the root causes of stigma and discrimination?*

Examples from Ethiopia NGO workshop

Home: Family tries to hide sick son at back of house so that neighbours don't know. Shame – honour/reputation of family destroyed – lose face. Stigma reinforces existing power relations: husband concerned about protecting family honour; wife more concerned about practical issues (e.g. care). Wife blamed for not raising child properly. More tolerance/sympathy for men getting HIV; no tolerance for women. Associated stigma – family stigmatised for having PLHIV in their house; often assumed that they are all HIV positive. Family breakdown – children dumped with relatives, abandoned and become street children.

Community: Gossip. Neighbours visit as voyeurs to see how thin the patient is. Stop PLHIV from using communal bucket at the well. Stop patients holding children. Show disgust when they shake hands.

Market: People stop buying from a market seller suspected to have HIV. Isolation and gossip about their health status. The market is a very public space – problems are raised in public, lots of shame.
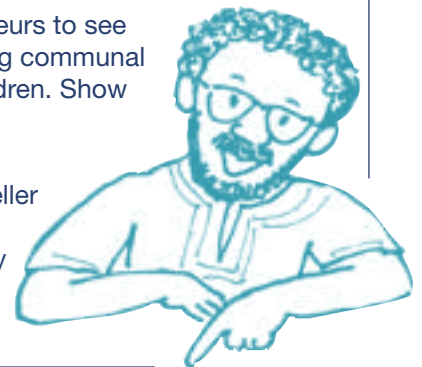
Exercise A4 Naming stigma in different contexts

Examples from Ethiopia NGO workshop (cont.)

Workplace: Workers shun and make comments about person suspected to have HIV. PLHIV viewed as unreliable. Boss blocks promotion or further studies and tries to get rid of worker.

School: Children whose parents are living with HIV are treated badly. Rejection and name-calling – not sharing seats and books. Teasing – *"Your father died because of immoral behaviour."* Result – feel isolated/depressed, concentration declines, leads to dropout. Some communities force school to fire teacher with HIV.

Clinic: Nurses minimise contact with HIV patients. Some nurses insist on the use of gloves. Some people are denied drugs because this is viewed as waste of resources – *"This person will die soon."* Blaming and judging – *"You have had too many partners – you deserve to die."*

Media: Negative messages ("AIDS kills") promote fear and panic. Image of PLHIV as people who are about to die – nothing to live for. Constant repeating of negative messages.

Faith groups: PLHIV have sinned – promiscuity, adultery, breaking moral laws. Curse – *"You are punished for not following God's laws."*

Bar: Source of initial infection but no stigma. No sanctions against casual sex – *"spicing up our life"*. Sometimes people talk more freely in bars and stigmatise more.

Example of a role play

A teenage girl learns she is HIV positive. She tells her sister but they are scared to tell the father. They tell their mother, who tells their father. The father gets angry, shouts at the girl and raves about bringing shame to the family. The family hide her and prevent people from seeing her.

Discussion

- Family has judged their daughter to be bad – father assumes the worst.
- Father fears the loss of their family's reputation – disgrace and shame.
- He wants to protect the family's reputation by kicking his daughter out of the house.
- He wants the daughter to die quickly to get rid of the problem.
- Mother is worried about what the community will say about them.
- Mother wants to hide the daughter in the back room out of sight to prevent people from seeing her.
- Men (father and son) are angry and focus on the shame and morality.
- Women are more concerned about practical issues of survival.
- Daughter feels self-stigma, self-hatred and blame – feels her life is over.

☑ Facilitator's notes

This is a good exercise to encourage communities to map stigma in different places – in homes, at the market, in the school and clinic, etc. It provides a starting point to get communities to recognise stigma and begin to move against stigma.

➡ Objectives

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

- identify different contexts in which HIV stigma occurs in the community
- identify some of the common features of stigma.

🕐 Time

1 hour

✂ Preparation

If possible, select an open area near the training room or do it in the room.

Step-by-step activity

Community mapping

1. Divide into small groups and ask each group to make a quick map of their community, showing roads and major institutions using natural objects (e.g. stones, sticks).
2. While the group makes the map on the ground, one member draws it on flipchart paper.
3. Ask the group to indicate places where stigma occurs in the community.

Report back

4. Put the maps up on the front wall and make a list of places where stigma occurs.

Processing

5. Ask the group to discuss:
   - *Who are stigmatised? Who are the stigmatisers?*
   - *What forms of stigma take place in each context?*
   - *How do you think people who are stigmatised would be affected?*

Summary

- Stigma occurs in many different contexts – home, neighbourhood, school, clinic, workplace, marketplace, bars, buses and other public places.
- In all of these contexts it takes similar forms – isolation and rejection, name-calling and insults, shaming and blaming.

❗ Action ideas

Try out this activity in your own group or community. The community mapping of stigma could be a good start for getting the community to name the problem publicly and start thinking about what they want to do to change it. Put up the stigma community map in the community hall or other public place where others can see it.

Exercise A6 What is the meaning of stigma?

Facilitator's notes

This exercise can be used to explain the definitions and theories on stigma. It should be used after participants have developed their own ideas about stigma through some of the experience-based exercises.

Objective

Participants will be able to define the meaning of stigma and give examples.

Time

30 minutes

Step-by-step activity

Card storm

1. Hand out cards and ask participants to buzz with the person next to them about, *"What do you think is the meaning of stigma?"* Write one idea per card. Encourage people to give examples of stigma or define it, or to find local words that describe stigma.
2. Explain the definition below or give it out as a handout.

Textbook definition

Stigma is a spoilt identity. To stigmatise is to label someone; to see them as inferior because of an attribute they have.

Types of stigma
- Self-stigma – self-hatred, shame, blame; people feel they are being judged by others so they isolate themselves. PLHIV practise self-stigma – isolate themselves from their families and communities.
- Felt stigma – perceptions or feelings towards PLHIV.
- Discrimination – enacted stigma; attitudes or thoughts put into action.

Stigma is a process that:
- points out or labels differences – *"He is different from us – he coughs a lot"*
- attributes differences to negative behaviour – *"His sickness is caused by his sinful and promiscuous behaviour"*
- separates 'us' and 'them', e.g. shunning, isolation, rejection
- creates loss of status and discrimination (loss of respect, isolation).

Other important dimensions
- Often people do not understand the word stigma in English.
- Difficult to find a word in other languages that is equivalent – use a phrase.
- Differs in intensity – sometimes blatant, sometimes subtle.
- Targeted mostly at people who are assumed to be HIV positive.
- Targeted at stereotyped and scapegoated groups, e.g. women, sex workers.
- Other diseases, such as TB, are stigmatised because of HIV.
- AIDS disfigures so stigma changes according to the stage of the disease. Stigma increases as the symptoms of the disease become more visible.
- HIV, sex and death are value laden.
- Motives for stigma change according to the setting.
- Disrupts social relations.
- People fear that HIV is very contagious.
- People hide their stigmatising attitudes.
- Discrimination and human rights.

Facilitator's notes

This exercise gets people to look at how body language communicates HIV stigma. It uses a technique called sculpturing, in which groups of people show an issue in the form of a frozen image using their bodies. The images are then used as a focus for discussion.

Objectives

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

- show how we stigmatise through body language
- analyse the attitudes behind this form of stigmatisation.

Time

1 hour

Materials

General stigma picture 1 from the Picture booklet.

Step-by-step activities

"Oh Josephina!" – warm-up game

1. Ask participants to stand in a circle. Explain that this game will show how we communicate through our voices and bodies. Demonstrate how to play the game. Show how you can say "Oh Josephina" in different ways – with anger, fear or humour. Then ask each participant (going around the circle) to say "Oh Josephina" in a different way, expressing a different feeling. When everyone has had a turn, ask, *"What did you learn about the way we express emotions or feelings?"* (e.g. loud or soft voices, confident or unconfident tones, facial expression).

Picture introduction

2. Display *general stigma picture 1* and ask, *"What do you see in the picture?"* Use this to explain body language – communicating feelings through bodies. Explain that this session will look at how we communicate stigma through our bodies. We show through our face, hand movements, and the way we hold our bodies – often unconsciously – how we feel about other people.

Sculpturing – practice 1

3. Explain or demonstrate that sculpturing is using our bodies in a frozen image. Emphasise that this is not moving drama; it is a stationary image, like a picture. Ask participants to pair off and do a simple sculpture to learn the technique, e.g. a husband returns home late at night. In each pair decide who is the husband, who is the wife. After each practice session, ask a few pairs to demonstrate. After each demonstration, ask:

- *What do you see in the sculpture?*
- *What is being communicated?*

Sculpturing – practice 2

4. Ask the pairs to make a new sculpture showing how people treat sex workers. Ask them to decide on roles. One of the pair is the stigmatiser, the other the stigmatised. Then ask a few pairs to show their sculptures in the centre of the circle. After each demonstration, ask:

- *What is being communicated?*
- *What do you think are the attitudes or judgements behind this body language?*
- *What are you thinking? Why are you stigmatising?* – ask the stigmatiser
- *How are you feeling?* – ask the stigmatised

Sculpturing – practice 3

5. Ask the pairs to make a new sculpture showing how people treat PLHIV. This time the pairs should swap roles. One plays the stigmatised, the other the stigmatiser. Ask them to make the new sculpture. Then ask a few pairs to demonstrate in the centre.

After each demonstration, ask:

- *What do you see in the sculpture?*
- *What is the meaning of the body language?*

Exercise A7 Stigmatising through body language

- *What are the judgements behind those feelings?*
- *How do we communicate when we isolate people?*

Sculpturing in facing lines

6. Divide participants into two groups and ask them to face each other in two lines. Assign roles – one group are stigmatisers and the other are the stigmatised. Now show with your bodies how you feel about the others. Start the sculpturing by shouting "Play!" Debrief this activity and record it on a flipchart. Then reverse the roles.

Summary

We have learned that we can also stigmatise through body language – facial expressions, judging eyes, finger-pointing and keeping a distance.

Examples from Zambia workshop

Body language

Finger-pointing. Open mouth – shock! Showing our backs – shows rejection. Eyes looking down – shows sympathy. Want to hug him. Avoidance – scared he will infect me.

Feelings of the stigmatisers

Laughing – *"How did you get this?" "Why were you doing this?" "You deserve it!" "I don't want to have anything to do with him." "Unbelievable." "She deserves it."*

How do the stigmatised feel?

Low. Depressed. Everybody is looking at me. Centre of attention. I feel judged and rejected. Some are making me feel okay. Sympathy from some lightens the situation.

Facilitator's notes

This is a high priority activity and we encourage all groups to use this exercise. It helps to analyse and understand the forms, causes and effects of stigma using the problem tree method for analysis. It works best later on in the workshop.

You can expand the session by following the stigma problem tree exercise with the optional activities.

Objectives

By the end of this session, participants will be able to:
- identify different forms of stigma and how stigma affects people
- identify some of the root causes of stigma.

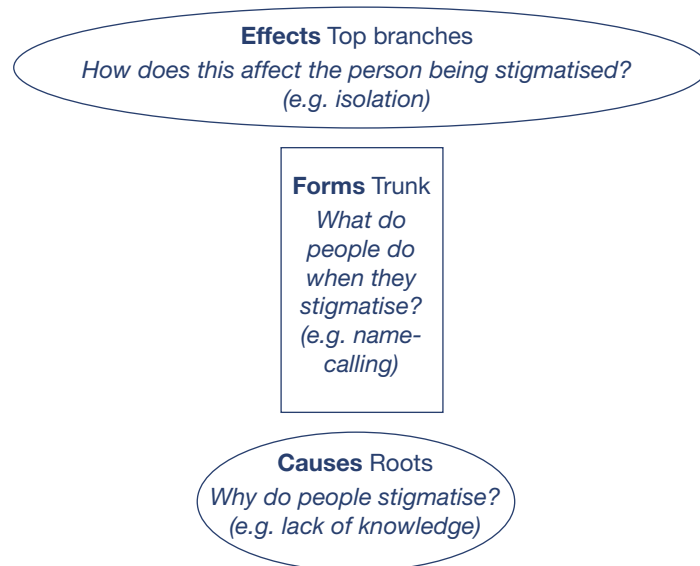## Time

1-2 hours

Preparation

Using flipcharts and cards, set up the structure for the problem tree on the wall or use a picture of a tree (see right).

Put up a few example cards especially for the forms of stigma, e.g. gossip, segregation.

Step-by-step activity

Stigma problem tree

1. Ask participants to work in pairs. Think about the **forms** of stigma. Write one point per card and tape them on the wall diagram to make a problem tree showing forms of stigma (main trunk).
2. Then move on to the **effects** (branches) and **causes** (roots).

Effects Top branches
How does this affect the person being stigmatised?
(e.g. isolation)

Forms Trunk
What do people do when they stigmatise? (e.g. name-calling)

Causes Roots
Why do people stigmatise? (e.g. lack of knowledge)

3. Ask participants to cluster similar points together for each category and then to give a summary of each part. Help participants see different levels; for example, **immediate effects,** impact on people living with HIV (e.g. isolation), **spin-off effects** (e.g. loss of jobs) and **wider effects** on the economy (e.g. loss of employment, lack of productivity, no development).

Option 1: Further analyse the cards

In small groups, participants can further analyse the cards.
One group looks at effects:
- *What are the effects on the family, the community, the nation?*
- *How can we as programmers minimise the effects of stigma?*
And the other group looks at causes:
- *Why is this a root cause? Can you explain, using examples?*
- *What can you do to change or challenge this cause of stigma?*

Option 2: Planning action

Organise a topic group for different cards and ask groups to do a detailed analysis.
- *As people who are concerned about HIV stigma, what can we do to change these root causes?*
- *How can we design our HIV programmes to avoid these effects or lessen their impact or support people to deal with these effects?*

Exercise A8 Forms, effects and causes – stigma problem tree

Examples from stigma workshop

Effects or consequences

Shame. Denial. Self-isolation. Loneliness. Neglect. Loss of hope. Depression. Death. Alcoholism. Isolation. Self-rejection – give up on yourself. Self-blame. Self-pity. Self-hatred. Anger. Violence. Withdraw from public activities, e.g. church membership. Become very quiet. Commit suicide or start thinking about suicide. Die alone, without love. Feel unproductive/useless/not contributing. Forced to leave community. Family disruption. Divorce or separation. Kicked out of family. Fired from work. Loss of promotion, scholarship opportunities, rented accommodation. Decline in school performance or dropout from school. AIDS orphans and street kids. Abuse or poor treatment by relatives. Deprived of medical care – health staff argue that this is a "waste of resources". Sent back to the village and property grabbing. Quarrels within the family – argue over who is responsible for this situation and who will take care of the sick PLHIV. Stop making use of clinics, voluntary counselling and testing programme, and home-based care programme. Reluctance to take medication. No treatment. Spread of infection.

Forms of stigma

Name-calling. Scapegoating. Finger-pointing. Teasing. Ridicule. Labelling. Blaming. Shaming. Judging. Backbiting. Rumour. Gossiping. Making assumptions. Suspecting. Neglecting. Rejecting. Isolating. Separating. Not sharing utensils. Hiding. Staying at a distance. Harassment. Physical violence. Abuse. Self-stigma – blaming and isolating oneself. Stigma by association – whole family or friends also affected by stigma. Stigma by looks/appearance. Associated stigma – family and friends also affected by stigma.

Causes

Morality – view that PLHIV are sinners, promiscuous, unfaithful, sleeping around. People's beliefs about pollution, contagion, impurity. Fear of infection, of the unknown, of death. Ignorance – lack of knowledge and misconceptions makes people fear physical contact with PLHIV. Misconceptions. Inferiority and superiority complex. Gender and poverty – women and poor people more stigmatised than men/rich people. Prejudice. Tendency to judge others.

Extra analysis on causes

Poverty
- Poverty can lead people to stigmatise.
- Poor women are forced into transactional or commercial sex.
- Poor people who are malnourished are stigmatised by looks. Cannot hide their HIV condition in the way that a rich person can – no walls – easily seen by neighbours. Already stigmatised as poor people.

Ignorance
- Lack of knowledge on how HIV is transmitted.
- Believe that casual contact with PLHIV can result in infection.
- Some have the knowledge but don't believe it – think that they can still get HIV through casual contact.

Facilitator's notes

This exercise can be used on its own or as a sub-activity within the processing of the *Stigma problem tree* on page 29.

Objective

Participants will be able to identify the effects of stigma on different people in different places/institutions.

Time

1 hour

Step-by-step activity

Different people, different places

1. Divide participants into different groups, e.g. youth, women, men, health care workers, children. If appropriate, get participants to work in the same group as their real target groups.
2. Put up blank sheets of flipchart paper on different walls of the room showing different places, e.g. clinic, workplace, school, church, family.

Rotational brainstorm

3. Ask groups to brainstorm – *"How does stigma affect your group at this place?"* – and record on the flipchart paper. Ask participants to look for both immediate effects – shame, isolation, depression, hiding one's status – and long-term effects – loss of jobs, dropping out of school, suicide, etc.
4. After a few minutes shout "Change!" (or beat a drum/sing a song). Ask groups to move to the next flipchart and add points. Continue until groups have contributed to all of the places.

Report back

5. Ask the original group to present the main points of each place and then ask for clarifications and additions. Note common or unusual points.

   Option: Each group can take one flipchart and discuss what they can do as HIV workers to help tackle stigma in that place.

Processing and summary

6. Explain how stigma blocks both prevention and treatment of HIV and AIDS:
   - Stigma keeps people from learning their HIV status through testing and discourages them from telling their partners and family.
   - Stigma keeps people who suspect they are positive from accessing treatment and counselling services.
   - Stigma discourages people from using other services, e.g. prevention of mother-to-child transmission.
   - Stigma prevents people from caring for PLHIV.

Action ideas

Try out this activity in your faith group, women's group, youth group or workplace. Get the group to discuss the effect of stigma on group members or their families.

Annex 1 Stigma research findings

ICRW, in partnership with organisations in Ethiopia, Tanzania and Zambia, led a study of HIV and AIDS-related stigma and discrimination in these three countries.[1] This project, conducted from April 2001 to September 2003, unravelled the complexities around stigma by investigating the causes, manifestations and consequences of HIV and AIDS-related stigma and discrimination in sub-Saharan Africa. It then used this analysis to suggest programme interventions.

Structured text analysis of more than 730 qualitative transcripts (650 interviews and 80 focus group discussions) and quantitative analysis of 400 survey respondents from rural and urban areas in these countries revealed the following main insights about the causes, context, experience and consequences of stigma:

1. The main causes of stigma relate to incomplete knowledge, fears of death and disease, sexual norms and a lack of recognition of stigma. Insufficient and inaccurate knowledge combines with fears of death and disease to perpetuate beliefs in casual transmission and, therefore, avoidance of those with HIV. The knowledge that HIV can be transmitted sexually combines with an association of HIV with socially improper sex, such that people with HIV are stigmatised for their perceived immoral behaviour. Finally, people often do not recognise that their words or actions are stigmatising.

2. Socioeconomic status, age and gender all influence the experience of stigma. The poor are blamed less for their infection than the rich, yet they face greater stigma because they have fewer resources to hide an HIV positive status. Youth are blamed in all three countries for spreading HIV through what is perceived as their highly risky sexual behaviour. While both men and women are stigmatised for breaking sexual norms, gender-based power results in women being blamed more easily. At the same time, the consequences of HIV infection, disclosure, stigma and the burden of care are higher for women than for men.

3. PLHIV face physical and social isolation from family, friends and community; gossip, name-calling and voyeurism; and a loss of rights, decision-making power and access to resources and livelihoods. PLHIV internalise these experiences and consequently feel guilty, ashamed and inferior. They may, as a result, isolate themselves and lose hope. Those associated with PLHIV, especially family members, friends and carers, face many of these same experiences in the form of secondary stigma.

4. PLHIV and their families develop various strategies to cope with stigma. Decisions around disclosure depend on whether or not disclosing would help to cope (through care) or make the situation worse (through added stigma). Some cope by participating in networks of PLHIV and actively working in the field of HIV, or by confronting stigma in their communities. Others look for alternative explanations for HIV besides sexual transmission, and seek the comfort of religion.

[1] Nyblade, L. and Pande, R. et al (2003) *Disentangling HIV and AIDS Stigma in Ethiopia, Tanzania and Zambia*, Washington D.C., ICRW

5. Stigma impedes various programmatic efforts. Testing, disclosure, prevention and care and support for PLHIV are advocated, but are impeded by stigma. Testing and disclosure are recognised as difficult because of stigma, and prevention is hampered because preventive methods such as condom use or discussing safe sex are considered indications of HIV infection or immoral behaviour, and thus stigmatised. Care and support are accompanied by judgemental attitudes and isolating behaviour, which can result in PLHIV delaying care until absolutely necessary.

6. There are also many positive aspects of the way people deal with HIV and stigma. People express good intentions not to stigmatise those with HIV. Many recognise that their limited knowledge has a role in perpetuating stigma and are keen to learn more. Families, religious organisations and communities provide care, empathy and support for PLHIV. Finally, PLHIV themselves overcome the stigma they face to challenge stigmatising social norms.

Our study points to five critical elements that programmes aiming to tackle stigma need to address:
- create greater recognition of stigma and discrimination
- foster in-depth, applied knowledge about all aspects of HIV and AIDS through a participatory and interactive process
- provide safe spaces to discuss the values and beliefs about sex, morality and death that underlie stigma
- find a common language to talk about stigma
- ensure a central, contextually appropriate and ethically responsible role for PLHIV.

While all individuals and groups have a role in reducing stigma, policy-makers and programmers can start with certain key groups that our study suggests are a priority:
- **Families caring for PLHIV** – programmes can help families both to cope with the burden of care and also to recognise and modify their own stigmatising behaviour.
- **NGOs and other community-based organisations** – NGOs can train their own staff to recognise and deal with stigma, incorporate ways to reduce stigma in all activities, and critically examine their communication methods and materials.
- **Religious and faith-based organisations** – these can be supportive of PLHIV in their role as religious leaders and can incorporate ways to reduce stigma in their community service activities.
- **Healthcare institutions** – medical training can include issues of stigma for both new and experienced providers, while at the same time, risks faced by providers need to be acknowledged and minimised.
- **Media** – media professionals can examine and modify their language to be non-stigmatising, provide accurate, up-to-date information on HIV, and limit misperceptions and incorrect information about HIV and PLHIV.

The complexity of stigma means that these and other approaches to reduce stigma and discrimination will face many challenges, but at the same time, there exist many entry points and strong, positive foundations for change that interventions can immediately build on.
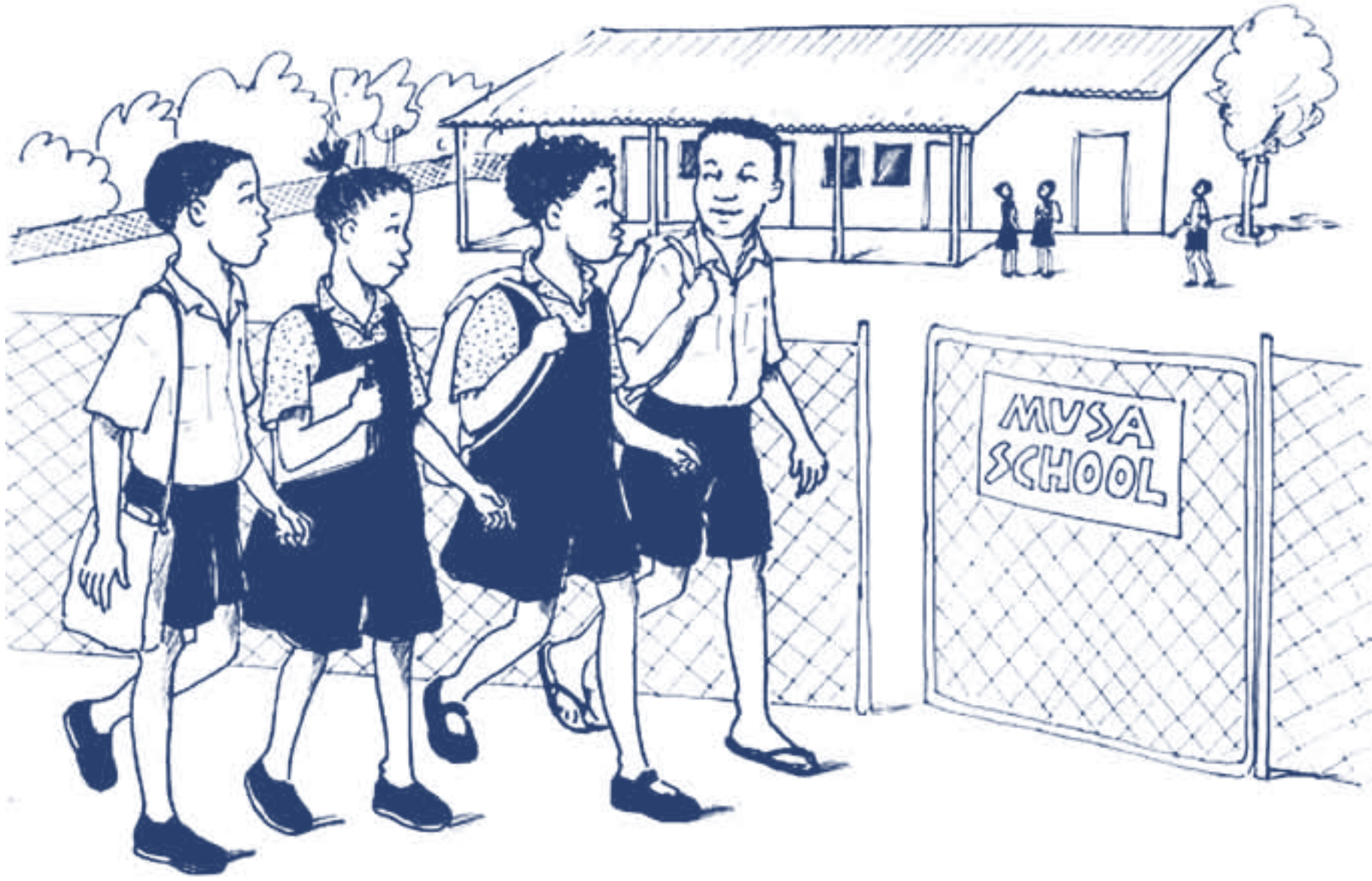
Context card 1

These pictures show different contexts in which stigma takes place – family, community, clinic, school, workplace, church, market, bar and in the media. Use them in exercises that talk about different contexts or settings.
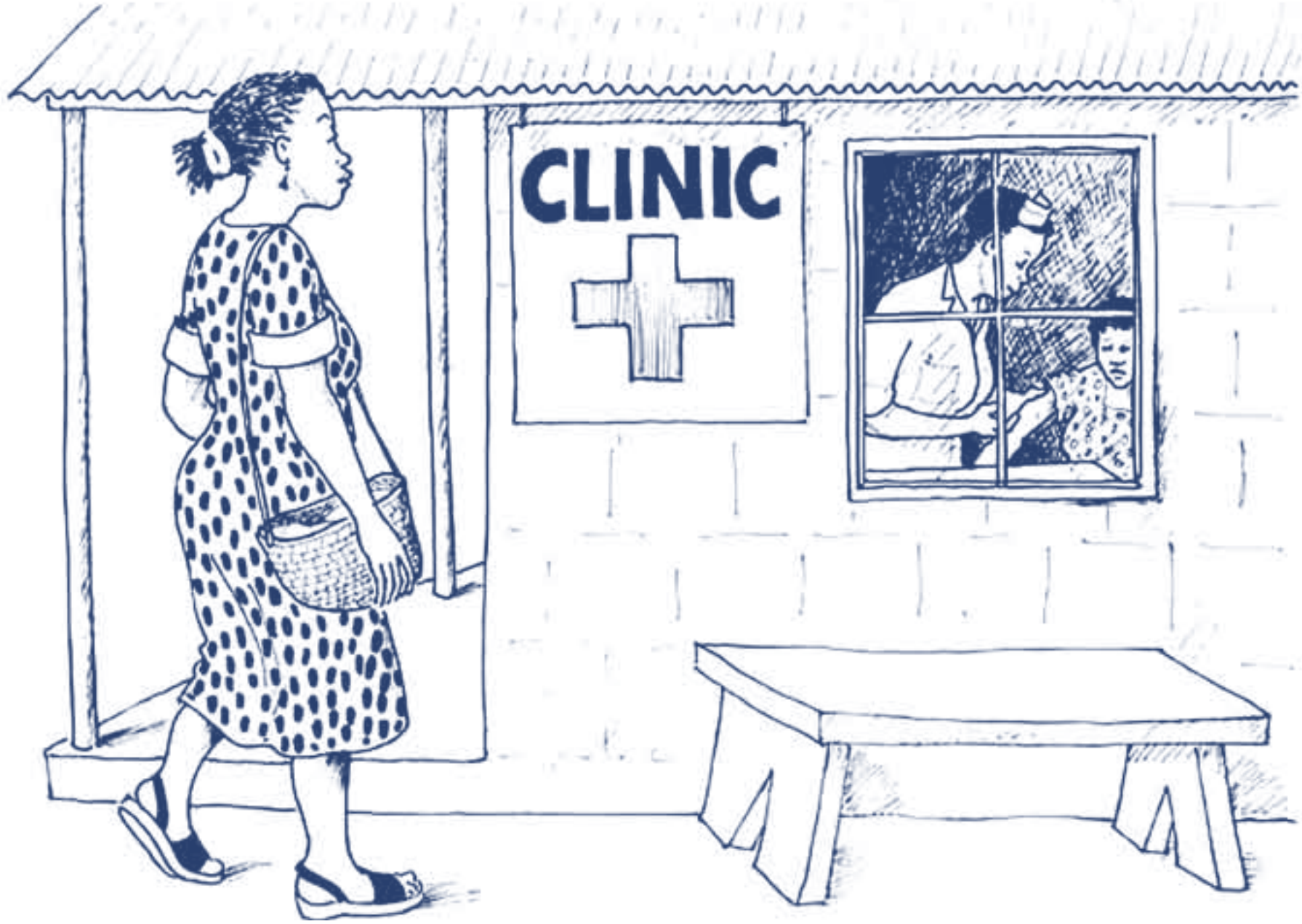
Context card 5

Context card 7

Context card 9

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

Introduction
Using the toolkit
Module A
Naming the problem

Module B
More understanding, less fear
Module C
Sex, morality, shame and blame

Module D
The family and stigma
Module E
Home-based care and stigma

Module F
Coping with stigma
Module G
Treatment and stigma

Module H
MSM and stigma

Module I
Children and stigma

Module J
Young people and stigma

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

Picture booklet
General stigma pictures
Rights pictures

Additional booklets will be published as new modules are developed.

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