International HIV/AIDS Alliance

Supporting community action on AIDS in developing countries

INTEGRATING STIGMA REDUCTION INTO HIV PROGRAMMING

Lessons from the Africa Regional Stigma Training Programme

ABOUT THE TOOLKIT

This document illustrates lessons learned from implementing the toolkit *Understanding and Challenging HIV Stigma* across Africa. *Understanding and Challenging HIV Stigma* was written for and by HIV trainers in Africa. The toolkit has been designed to help trainers plan and organise educational sessions with community leaders, or organised groups 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 nongovernmental organisations in the three countries who helped to design the original toolkit. It was developed and written by Ross Kidd and Sue Clay.

The second 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.

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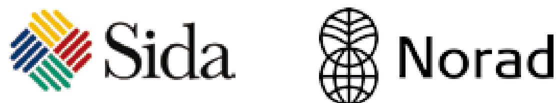

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ACRONYMS AND ABBREVIATIONS

AIDS	Acquired immune deficiency syndrome
GNP+	Global Network of People living with HIV
HIV	Human immunodeficiency virus
ICRW	International Center for Research on Women
NGO	Nongovernmental organisation
PEPFAR	President's Emergency Plan for AIDS Relief
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS

INTRODUCTION

THE IMPACT OF STIGMA

Through its Africa Regional Programme, the International HIV/AIDS Alliance (the Alliance) has been working to reduce stigma across Africa for the last six years. This resource sets out ways of integrating stigma reduction strategies and activities into HIV programmes and policy work, using examples from organisations across the programme. It is a call for the integration of HIV stigma reduction activities into all HIV programmes.

Research, personal experiences and statistics bear witness to the fact that stigma and discrimination continue to be some of the greatest barriers to effective HIV prevention, care, support and treatment in many parts of sub-Saharan Africa. This is not a new problem, but the question that still remains for many programmers is 'What can we do about it?' This resource aims to provide some answers.

Stigma affects people in many ways:

- the health worker who travels to a faraway clinic to get her monthly supply of antiretrovirals, fearing that her colleagues will find out that she is HIV positive
- the doctor who self-tests and self-medicates, and never discusses his HIV status to anyone for fear of losing professional credibility
- the woman who is threatened with violence and disinherited by her family when she discloses her status
- the school that asks orphans to line up separately from other children, not thinking of the impact in the playground
- the national AIDS council which excludes strategies to support vulnerable groups like men who have sex with men, because they consider it 'against our culture'
- the marketeer whose stall is boycotted by a fearful community when rumours are spread about her HIV status
- the religious leader who uses his weekly sermon to teach that HIV is God's punishment
- the military institution with no clear policy about HIV, but officers know that if they 'get sick' then they can no longer serve
- the newspaper, protected by an out-of-date law that criminalises same sex relationships, which prints names and addresses of suspected gay men, not caring that those men may be attacked or killed.

Stories like these continue to emerge from all across the African continent (and elsewhere). When people are given a chance to reflect on and share their experiences of stigma, the examples are endless.

The impact of stigma has been well documented but should never be underestimated. For an individual, stigma can mean the loss of family and support, being shamed and blamed, and losing self-esteem. It can even result in the loss of someone's livelihood when their job is affected. Families too are affected by stigma. Children living with HIV and orphans may be segregated, neglected or punished more harshly than others in the family, or they may miss out on education and other opportunities. HIV is passed from husband to wife (or vice versa) because of the fear of what disclosure could bring. Even suggesting condom use in a relationship can bring judgments and assumptions.

The impact of stigma can be felt from the community all the way up to the national level. Clinics and schools become understaffed because health workers and teachers are sick; stigma or fear of stigma prevents people from going for HIV testing and treatment; and education standards fall, healthcare is less available, and productivity levels drop because of sickness or discrimination. Stigma has had a huge impact on many countries' development.

Ideas for challenging stigma are easily shared. But how can we translate individual experiences and ideas into collective action, at the different levels that are needed to ensure meaningful impact, in order to reduce stigma and discrimination? Reducing stigma is one of the crucial steps to removing barriers to universal access to HIV prevention, care and treatment. As well as breaking the cycle of infection, reducing stigma also restores dignity and respect to individuals and families, and brings about greater equality and appreciation of differences in a community.

It is not easy to measure changes in stigma levels, or to attribute reduced stigma to any one intervention. If stigma reduces, more people in a community may decide to test for HIV, some may disclose their positive status to family and friends, and others may decide to send to school a child they had previously considered a waste of money. On a wider scale, governments may support new legislation against discrimination or remove old legislation that condones it.

Stigmatising attitudes and behaviour are influenced by many factors. A lot of research has been carried out to develop an array of tools and indicators to support programmers in monitoring and evaluating interventions that aim to reduce stigma, but measuring change is still one of the biggest challenges.

We hope that this resource will provide inspiration to partners, programmers, donors and other stakeholders, and help them integrate stigma reduction into the HIV programmes they run, manage and fund. In this way we can move towards an expanded response.

ABOUT THIS TOOL

The aim of this tool is to present different examples of stigma reduction activities that have been integrated into HIV programmes for long-term impact and sustainability. These examples have been taken from organisations and programmes around Africa.[1]

Stigma reduction activities have been integrated with wider programmes in a number of ways as a result of initial training by the Regional Stigma Training Programme. The most common approach has been through the incorporation of stigma exercises into training courses or workplace and community activities. However, there are also examples of how stigma reduction has been integrated into policies, throughout programmes, and how it has led to national government interventions to understand structural issues around stigma. The overall results show that creating opportunities for greater awareness and understanding of stigma is the first step to changing it; strategies to then scale up the change, through integration at different levels, can have real impact.

We hope that the range of examples shared here will illustrate how stigma interventions can be tailored to fit many contexts. The main part of this tool is divided into eight thematic sections. Each of these sections follows the following format:

- **an outline of the principles and rationale for integrating stigma reduction into that thematic area**
- **examples showing how different organisations achieved integration**
- **significant change stories and case studies that provide more detail.**

1. Although the programme has been focused in Africa, studies show that stigma does not change significantly across contexts. The Alliance's stigma toolkit has been used around the world and many lessons in this resource have global relevance (see page 8).

BACKGROUND

PROGRAMME BACKGROUND

The Regional Stigma Training Programme is one of the components in the Alliance's Africa Regional Programme. The stigma team is based in Alliance Zambia and works across Southern, East, West and more recently North Africa.

The stigma programme provides training, action-planning and ongoing technical support for stigma reduction at all levels. The toolkit *Understanding and Challenging HIV Stigma: Toolkit for Action* (see page 8) is the core resource used by the programme in the training.

Participants are chosen for training on stigma reduction based on an analysis of the situation and priority needs in a given country. For example, trainees may come from nongovernmental organisations (NGOs), government ministries, national AIDS councils, faith-based organisations, health institutions, groups of people living with HIV, or the private sector. Participants attend with the commitment and support of their organisations to roll out and integrate stigma reduction throughout their programmes and policies.

After initial training, the programme provides follow-up support and monitoring; technical assistance for expansion or integration of stigma reduction programmes; and mentoring of trainers through regional lesson-sharing, coaching and supervised training practice.

To date, participants have been trained from the following countries: Algeria, Botswana, Burkina Faso, Cap Verde, Comoros, Côte d'Ivoire, Ethiopia, Ghana, Guinea, Guinea-Bissau, Kenya, Lebanon, Lesotho, Liberia, Madagascar, Malawi, Mali, Mauritania, Mauritius, Mayotte, Morocco, Mozambique, Namibia, Nigeria, Reunion, Senegal, Seychelles, Sierra Leone, South Africa, South Sudan, Swaziland, Tanzania, Togo, Tunisia, Uganda, Zambia and Zimbabwe.

COMPONENTS OF THE REGIONAL STIGMA TRAINING PROGRAMME

There are seven parts to the stigma training programme, which can be used or adapted to initiate and implement stigma reduction programmes in most contexts. Parts 1 to 5 focus on building the capacity of stigma trainers or 'agents', giving them the knowledge and skills to implement and support a wider programme. Parts 6 and 7 are about rolling out the programme and scaling it up.

1. **5-day training workshop**

   The aim of the initial training is fourfold:

   - to deepen participants' own understanding and awareness of stigma
   - to familiarise participants with the stigma toolkit
   - to build participants' facilitation skills and training capacity
   - to help participants plan how to integrate stigma exercises into their HIV programmes by adapting what they learn to fit their context.

2. **Follow-up meetings**

   These meetings serve two main purposes: to bring trainers together to review skills, experiences and challenges as stigma reduction trainers, and to monitor the progress of roll-out activities and integration. Meetings can also be tailored to suit a specific issue or organisation's needs.

3. **Technical exchange and distance support through the stigma e-forum**

   Technical assistance can be provided by lead trainers or trainers from other programmes, organisations and countries. This works well in terms of sharing experiences about integrating stigma reduction activities. An e-forum for stigma trainers was set up and the global Stigma Action Network (SAN) website www.stigmaactionnetwork.org will be an important forum.

4. **Mentoring of selected participants to become master trainers**

   Extra coaching and training can be provided for trainers who will have a lead role in stigma strategies so that they can become expert trainers. Co-facilitating alongside other trainers during training courses, involvement in different programmes, and specific training on participatory facilitation techniques are all components of mentoring trainers.

5. **Regional meetings**

   These bring together trainers from different organisations, or different countries, to share knowledge, technical expertise and tool development.

6. **Roll-out activities and policy work**

   Organisations integrate stigma reduction activities into their programmes and, in some cases, small grants can be provided to targeted organisations to support initial roll-out activities or specific pieces of work. Grants can also support policy work; for example, meetings to bring together key policymakers or research to provide evidence for policy change.

7. **In-country proposal development and fundraising**

   In order to develop sustainable interventions, and to integrate stigma reduction across all programmes, stigma activities can be integrated into new HIV programme proposals.

STIGMA REDUCTION METHODOLOGY

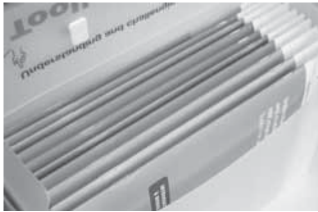
Nearly six in ten survey respondents agree with the statement "We have strong training materials and tools for reducing stigma." One important resource is the toolkit Understanding and Challenging HIV Stigma*. With a customizable menu of options and its availability in several languages, the toolkit is being used with a wide range of groups.*

International Center for Research on Women, ICRW, 2010[2]

Although knowledge is increasing about stigma tools, there is still a need for guidance on how to integrate the use of these tools into HIV programmes. Research conducted across varied settings has identified three key drivers of stigma:

- lack of awareness and knowledge of stigma and discrimination
- fear of acquiring HIV through everyday contact with infected people
- values that link people with HIV with behaviour considered 'improper and immoral', thus justifying discrimination.

The stigma toolkit *Understanding and Challenging HIV Stigma: Toolkit for Action* (www.aidsalliance.org/publicationsdetails.aspx?id=255) contains exercises to address these drivers, using creative approaches and methodologies.



The toolkit is a key resource that has been developed, used and revised by the Regional Stigma Training Programme. It originated from a three-country research study on stigma led by ICRW[3,4] and was developed with communities, NGOs and networks of people living with HIV.

2. Carr D, Eckhaus T, Brady L and Nyblade L (2010), *Roadmap Toward an Expanded Response to HIV Stigma and Discrimination*, ICRW.

3. Kidd R, Clay S, Chiiya C (2007), *Understanding and Challenging HIV Stigma: Toolkit for Action*, 2nd edition, Brighton, UK: International HIV/AIDS Alliance, CHANGE Project, Academy for Education Development, International Center for Research on Women, and PACT Tanzania.

4. Nyblade L, Pande RP, Mathur S, et al. (2003), *Disentangling HIV and AIDS Stigma in Ethiopia, Tanzania and Zambia*, Washington, DC: International Center for Research on Women.

The toolkit is primarily a trainer's manual containing hundreds of participatory exercises that can be used to help identify, understand and change the many manifestations of stigma. Modules include:

- Naming the problem
- More understanding, less fear
- Sex, morality, shame and blame
- The family and stigma
- Home-based care and stigma
- Coping with stigma
- Treatment and stigma
- Men who have sex with men and stigma
- Children and stigma
- Young people and stigma
- Moving to action
- Picture booklet
- TB stigma

Workshops and training sometimes have negative connotations in development circles; they can be synonymous with luxury hotels, large per diem allowances and limited outputs. So although the term 'stigma training' has been used in the regional programme, it is important to explain how the training is part of the stigma reduction strategy. What happens in the training is the first step in the process of changing stigma, initially on an individual level, which then leads to wider action and change. Changing stigma is about changing behaviour and often begins with personal transformation. This can then be used to instigate change on other broader levels.

The content of the training, and the way it is delivered, is carefully designed to create an environment conducive to stigma reduction. Each activity is planned so that participants are taken through a journey, from greater awareness and understanding of stigma to becoming an agent of change.

The process is both simple and complex. The tools are easily understood and can be used in a number of different ways, but the way they are facilitated is particularly important to create change. Participants practise how to adapt exercises in the toolkit to fit various settings and contexts, and then plan how to integrate activities into their programmes and roll out the change.

MEASURING STIGMA REDUCTION

One of the challenges of integrating stigma reduction activities into programmes has been finding effective ways to monitor and measure the impact of interventions. Some of the organisations that have successfully integrated activities have reported that stigma has reduced, but it has been difficult to measure that change and attribute it to the stigma reduction activities.

Effective monitoring and evaluation of activities helps to identify best practice models that can then be scaled up; it also provides evidence of which types of integration activities work best in different contexts and with different populations. Evaluating stigma reduction programmes can also show whether a programme is having unintended results. For example, a recent evaluation of the stigma training

programme found that as stigma reduced, some things did not improve for people living with HIV; for one thing, time spent waiting in queues at the clinic increased as more people accessed antiretrovirals. Evaluation will enable the positive and unexpected results of stigma reduction to be better planned for.

There has been a lot of research into how to measure stigma reduction and some very comprehensive reports and indicators are available. This section aims to give a brief overview of different methodologies and tools for evaluation, and some reference points for further information.

Stigma indicators

ICRW (www.icrw.org) have carried out several studies about measuring stigma reduction, including *Can We Measure HIV/AIDS-Related Stigma and Discrimination?*[5] In this study, indicators were developed around four stigma 'domains': fear (of casual transmission of HIV); values (and morality-related attitudes); discrimination; and disclosure.

The first two domains are often targeted by stigma reduction interventions; the third covers the actual experience and observation of enacted stigma; and the fourth covers disclosure of HIV status. The last domain is often viewed as a proxy measure for stigma: where disclosure is widespread, it is generally assumed that stigma is less prevalent. Examples of indicators under each domain are contained in Table 1.

TABLE 1: INDICATORS FOR THE FOUR STIGMA DOMAINS

Domain	Example of indicators
Fear	% of people expressing fear of contracting HIV from non-invasive contact with people living with HIV % of people working in institutions/facilities (such as managers and health care workers) who are uncomfortable working with or treating people living with HIV
Values	% of people who would feel shame if they associated with someone who was living with HIV % of people working in institutions/facilities (such as managers and health care workers) who report blame
Discrimination	% of people who know someone personally who has experienced stigma in the past year because they were known or suspected to have HIV % of people living with HIV who experienced stigma in the past year
Disclosure	% of people in a relationship tested for HIV who have disclosed their status to their primary sexual partner and who disclosed within six months of learning their status

5. Nyblade L and MacQuarrie K (2006), *Can We Measure HIV-Related Stigma and Discrimination?* Washington, DC: International Center for Research on Women.

One approach to indicators is to develop them in the community or institution where a stigma reduction activity is planned. This was done with stigma trainers in Uganda and Kenya by the regional programme, to see whether the indicators would correspond with commonly accepted ones. The process started with a wide question, such as 'How would you know that stigma has reduced in this community?' Answers were then clustered into the four domains. New indicators that emerged focused particularly on children living with HIV and those whose parents had died from AIDS-related illnesses. An increase in the number of these children attending school, or being better cared for in families, was proposed as an indicator. Since antiretroviral treatment has become widely available, increases in the number of people accessing HIV testing and treatment are also commonly used as stigma reduction indicators.

Once defined, indicators can be used to design questionnaires for baseline and endline surveys (surveys carried out before and after an intervention) and to monitor successful referrals to clinics, for example.

People Living with HIV Stigma Index

The *People Living with HIV Stigma Index* (www.stigmaindex.org) was developed by the International Planned Parenthood Foundation (IPPF) and the Global Network of People living with HIV (GNP+). It is both a monitoring tool and an advocacy tool that measures and detects changing trends in the stigma and discrimination experienced by people living with HIV. The process of collecting the data, which is carried out by people living with HIV, is just as important as the product. The index aims to address HIV-related stigma but also delivers advocacy messages about the key barriers and issues that are perpetuating stigma, which itself is a key obstacle to HIV prevention, care, support and treatment.

The index is an important tool and can be incorporated into plans for stigma reduction interventions, ideally in partnership with the local or national network of people living with HIV, which should provide leadership in its administration.

Qualitative measures

Stigma is a complex issue and because stigma reduction is about changing behaviour, it lends itself to more qualitative evaluation. Tools like *The 'Most Significant Change' (MSC) Technique*, developed by Rick Davies and Jess Dart (www.mande.co.uk/docs/MSCGuide.pdf), have been used successfully to record accounts of stigma change at individual and community level, and the technique can be taught easily to community groups so changes are recorded over time.

Follow-up meetings with community partners, trainers and other stakeholders can play a valuable role in monitoring the progress and impact of stigma reduction activities, and can give programmers an opportunity to share stories of challenges and successes. Case studies can also be documented. For example, regional meetings held as part of the stigma training programme have provided a valuable forum for stigma trainers from different African countries to come together, share lessons and develop good practice around stigma reduction.

INTEGRATING STIGMA REDUCTION INTO PROGRAMMES

1. TREATMENT ACCESS

It is widely recognised that stigma acts as a major barrier to HIV testing and prevents people living with HIV from accessing antiretroviral treatment programmes. Stigma effectively reduces survival rates as delayed testing leads to delayed diagnosis and delayed access to treatment.

Stigma also impedes adherence to medication. Antiretroviral treatment needs strict adherence to be effective, and adherence is the strongest determinant of patient survival. If people are afraid to disclose their HIV status to their family and friends because of stigma, they may resort to hiding their treatment and be more likely to miss doses.

Since 2006, antiretrovirals have become widely available in many sub-Saharan African countries and numerous treatment programmes have been set up to roll out services. Lessons and exercises from stigma training have been integrated into several treatment programmes by stigma trainers who have been trained through the regional programme.

MODULE G

Exercise G1 Treatment and stigma problem analysis

Facilitator's notes
This is a good starter exercise if you are focusing on treatment and stigma. You may wish to share your own experiences of accessing ARV treatment if it seems appropriate.

Objectives
By the end of this session, participants will be able to:
- begin to understand how HIV stigma can affect access and adherence to ARV treatment
- share ideas and experiences of stigma related to ARVs.

Time
30 minutes

Materials
Selection of *general stigma pictures* from the Picture booklet and *treatment story pictures* (see page 49).

Step-by-step activity
Buzz and card storm
1. Distribute cards and markers. Ask participants to buzz with the person next to them some of the ways in which stigma affects effective ARV treatment. Write one point per card.
2. Stick cards up and ask some participants to help cluster similar points.
3. Divide into small groups and give each group one of the clusters to analyse further. Share stories and experiences to try to understand the problems more.

Report back
4. Groups present summaries of their discussions in any way they choose, e.g. flipchart, story, role play.

Processing
5. Ask participants:
- *What do we learn from this?*
- *What are some inital ideas about how we could change things?*

Examples of treatment and stigma from ACER partners
- Disclosure – you don't tell your family and keep your ARVs hidden.
- Secrecy – your colleagues don't know you are taking ARVs.
- The church teaches that you need to pray instead of taking medicine.
- Health workers don't take time to tell you about adherence, especially if you look dirty or poor.
- Health workers fear colleagues finding out their HIV status.
- There are myths and rumours about side effects.
- The family doesn't want to spend money to support your treatment.

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MODULE G

Exercise G5 'We will not tell anyone'

Facilitator's notes
This exercise could be a good one to use with counsellors and other health care workers to help them explore how discussing disclosure strategies with clients can support adherence.

Objectives
By the end of this session, participants will be able to:
- explore how emphasising confidentiality can hamper disclosure
- look at how secrecy can create problems around treatment and adherence
- look at ways we can support each other to find strategies for disclosing our status.

Time
1 hour

Materials
Copies of case studies on page 31.

Step-by-step activity
Case studies
1. Divide into small groups and read through a case study together (see page 31).
2. Discuss what would be the benefits/advantages of the person disclosing their status.
3. Develop five top tips that you would give to the person in the case study, on how to disclose. Write them on a flipchart.

Report back
4. Groups come back into plenary, read the case studies and present their top tips.

Option: Role play the disclosure based on trying out your top tips.

Examples of top tips
- Choose the right time and place.
- Practise what you will say with a friend, or on your own.
- Ask a friend or other family member to be with you.
- Ask others who are in the same positon as you for ideas.
- Ask your counselor to help you to tell someone close to you.

Summary
- When counsellors or other health workers focus so much on confidentiality, it can discourage us from thinking about telling people about our status.
- We can feel that disclosing is a difficult thing to do, but with support from friends and family it becomes easier.
- Sharing strategies with others in a similar position can help us to be more open.
- Once we have disclosed we are less vulnerable to stigma.
- Being open helps us to talk about our health, taking ARVs and sticking to adherence.
- Gender and power differences make disclosing to some people more difficult.

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Sample exercises and picture cards from Module G: Treatment and stigma

PRINCIPLES OF INTEGRATING STIGMA REDUCTION INTO TREATMENT PROGRAMMES

Principles	Rationale
Include stigma reduction at programme planning/proposal development stage	Plan activities to reduce stigma from the outset and plan for the impact of positive results (such as an increase in the number of people accessing testing and treatment) Examples of possible activities: ■ incorporate stigma exercises from the toolkit into other training programmes for programme partners ■ train a pool of stigma reduction agents on how use the stigma toolkit. They can then work with community partners to implement stigma reduction activities ■ link with national stigma trainers to roll out a stigma training programme for all programme partners ■ conduct a series of awareness-raising workshops/meetings about stigma for all health workers
Work alongside networks and support groups of people living with HIV	People living with HIV (who are on antiretrovirals) are the most effective advocates for accessing antiretrovirals. They are also effective anti-stigma agents because they can share personal experiences and strategies for coping with stigma
Ensure stigma interventions receive support from high-level management	Once managers have a clear understanding of stigma tools and processes, support for integrating stigma reduction strategies can be sustained
Encourage a variety of stigma activities/ innovation/creativity	Stigma reduction activities can take many forms and community partners should be encouraged to be innovative and creative, and use community structures whenever opportunities arise If partners have had some training on stigma reduction, activities can include the important elements of reflection, experience-sharing and action-planning for maximum impact
Aim for long-term sustainability	If stigma reduction is recognised as a valuable and effective programme component, it can be incorporated into longer-term strategies. For example, stigma exercises can be written into training curricula, which may last longer than the programme funding
Include activities to monitor and evaluate stigma reduction	Programmes should build in a range of monitoring and evaluation methods to measure stigma reduction. This could include baseline and end-line surveys (such as knowledge, attitude and practice, or KAP surveys); indicators linked to increased service access and adherence; significant change stories and case studies (see page 9 for more on measuring stigma reduction)

> *People in our community here have the tendency of going to different areas where no one knows them, like Monze or Mazabuka District Hospital. But now many files are being transferred back to this clinic.*
>
> Magoye Clinic, Mazabuka

USING EVERY OPPORTUNITY

Antiretroviral community education and referral (ACER) project, Zambia

The ACER project, based at Alliance Zambia, was one of the earliest and most pioneering treatment programmes, starting in 2005 as an operational research project.

The key focus of the project was to provide information and foster community involvement in antiretroviral treatment, to provide treatment support, and to carry out activities to reduce stigma and discrimination. The first stage of the programme was based in two districts Zambia – N'gombe in Lusaka and Nkwazi in Ndola – and then scaled up to 13 new districts. The stigma training component was integrated into the programme so that treatment support workers were also trained as 'stigma reduction agents'.

Opportunity knocks…
An unplanned result of the stigma integration was that the reach of the trainers was much wider than the funded activities; trainers also became very innovative and committed to using a variety of different structures to tackle community stigma.

- In **Choma**, anti-stigma support groups were formed in two of the clinics and some health workers contributed funds to help start a garden. Now that members are planting and growing vegetables, they are seen as productive members of the community, helping to break down stigma. During one of the stigma workshops, several nurses encouraged other nurses living with HIV to form a support group for positive nurses.
- In **Kaoma**, trainers took the anti-stigma messages and exercises to churches in their district while they waited for funds to come through. They worked with the Evangelical and United Churches of Zambia, Seventh Day Adventists and New Apostolic church, getting pledges from them to change their attitudes.
- In **Kalomo**, agricultural meetings with farmers were used to get messages about stigma out to villagers and headmen. Other opportunities, such as talks at the water pump, were also used to share ideas about stigma.
- In **Mongu**, one of the trainers has been elevated to become an *induna* (chief's headman) and he has used this opportunity to sensitise other *induna* and headmen. On one occasion he travelled to Lealui across the flood plain and at first met resistance from *induna* who said, "This does not involve us." However, when he asked "Is there anybody here whose family has not lost a member to this disease?" there was silence. They now realise that they are all part of the struggle against stigma and HIV, and are taking anti-stigma messages back to their villages.
- In **Mumbwa**, one of the trainers' organisations, Christian Children Fund, has decided that at every meeting there will be a short talk about stigma. Staff and stakeholders were told that if any of them were living with HIV and wanted to come and talk to them, they would be welcome. Twenty people have come so far and they have formed a support group.

> *People are disclosing their status to their families, which helps with reducing transmission. There is a general improvement in relationships between the couples as there is no longer a need of hiding the drugs in the chicken's house as some couples used to. This results in an improvement in adherence as families can remind one another what time to take medication.*
>
> Health worker, Mazabuka Clinic, Zambia

SUPPORT GROUPS LEAD THE WAY

Networks project, Alliance Uganda

Based on the experience of the original ACER project in Zambia, the Alliance Networks project was started in Uganda in 2006, funded by $7.6m from USAID over three years. The main aim of the project was to use networks of people living with HIV to increase access to HIV services. This was done by building the strength and skills of support groups for people living with HIV so that they could link communities with local health services. The project started in seven districts and was rapidly scaled up to 40 districts in the second year.

One example of how the stigma training was rolled out through the project was reported by a trainer from Mityana, west of Kampala. Mityana Forum of People Living with HIV and AIDS (MIFOPLA) has integrated stigma activities into HIV programmes by working with 32 groups of people living with HIV. The groups have run a wide range of stigma activities.

- Exercises from the toolkit were used in community meetings to raise awareness about stigma in the community.
- Church leaders and catechists requested HIV training. This was provided by members of the forum who were all open about being HIV positive; they incorporated stigma exercises throughout a five-day workshop.
- Trainers used health talks in clinics to address stigma issues with clients who were getting ready to start on antiretroviral treatment.
- Stigma activities were also integrated into public celebrations like Philly Lutayas Day, Candlelight Day, World AIDS Day, Independence Day, and other health days that are officially recognised at local level.
- Stigma has also been included as a key topic in a special radio programme about prevention of mother-to-child transmission. Clients are invited to talk about HIV stigma in relation to mother-to-child transmission of HIV.

Members of Nabitende Emberi Ekuba Mwino PLHIV group, Uganda © Alliance Uganda

AIMING FOR LONG-TERM INTEGRATION

Zingatia Maisha (Hold onto Life) treatment programme, Kenya

Zingatia Maisha is a consortium of three partners: African Medical and Research Foundation (AMREF), Elizabeth Glaser Pediatric AIDS Foundation, and the Network of people living with HIV and AIDS in Kenya (NEPHAK).

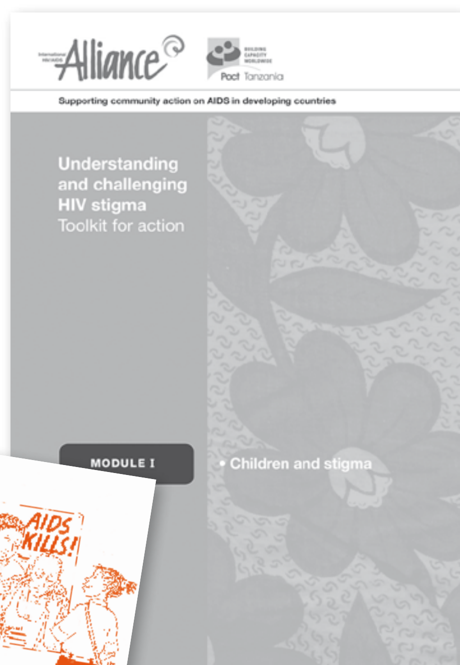
Two national stigma trainers were employed by Zingatia, and they spearheaded a stigma training programme that was rolled out across five provinces. Traditional leaders, health workers, support groups and other community stakeholders were trained so they could help reduce stigma and increase access and adherence to antiretroviral treatment.

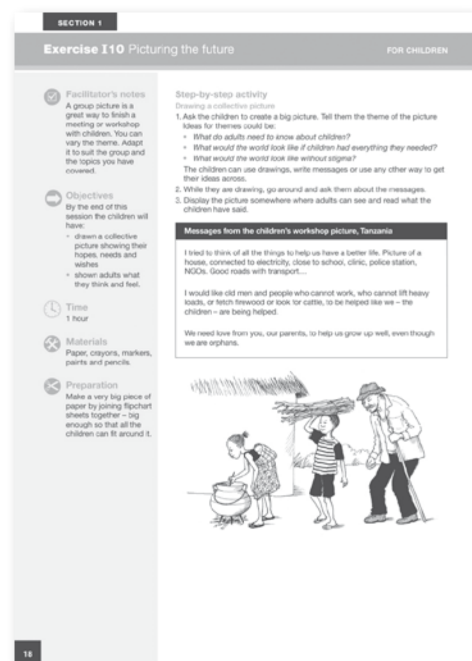
The stigma training has been so successful that it has now been integrated into the established curriculum on the adherence support course run by AMREF.

2. CHILDREN'S PROGRAMMES

The stigma toolkit contains a module on children and stigma that was developed from a small research project looking at children's experiences of stigma in Zambia,[6] and in conjunction with Pact in Tanzania to support their programme for orphans and vulnerable children. Groups of children from schools, the street, care centres, and rural and urban areas shared their experiences of how HIV has affected them and the impact stigma has had on their lives. These stories were used to develop the exercises and pictures that make up the module.

Many HIV and health-related programmes in sub-Saharan Africa are focusing on orphans and vulnerable children, and they increasingly recognise the need to improve psychosocial support to children and provide for their practical and material needs. Strategies to address the stigma faced by children have been integrated into several programmes.




SECTION 1

Exercise I10 Picturing the future — FOR CHILDREN

Facilitator's notes
A group picture is a great way to finish a meeting or workshop with children. You can vary the theme. Adapt it to suit the group and the topics you have covered.

Objectives
By the end of this session the children will have:
- drawn a collective picture showing their hopes, needs and wishes
- shown adults what they think and feel.

Time
1 hour

Materials
Paper, crayons, markers, paints and pencils.

Preparation
Make a very big piece of paper by joining flipchart sheets together – big enough so that all the children can fit around it.

Step-by-step activity
Drawing a collective picture
1. Ask the children to create a big picture. Tell them the theme of the picture. Ideas for themes could be:
   - *What do adults need to know about children?*
   - *What would the world look like if children had everything they needed?*
   - *What would the world look like without stigma?*

   The children can use drawings, write messages or use any other way to get their ideas across.
2. While they are drawing, go around and ask them about the messages.
3. Display the picture somewhere where adults can see and read what the children have said.

Messages from the children's workshop picture, Tanzania

I tried to think of all the things to help us have a better life. Picture of a house, connected to electricity, close to school, clinic, police station, NGOs. Good roads with transport....

I would like old men and people who cannot work, who cannot lift heavy loads, or fetch firewood or look for cattle, to be helped like we – the children – are being helped.

We need love from you, our parents, to help us grow up well, even though we are orphans.

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Sample exercises and picture cards from Module I: Children and stigma and Module J: Young people and stigma

Using creative tools to talk about stigma experiences

6. Clay S, Bond V and Nyblade L (2003), *We Can Tell Them AIDS Doesn't Come Through Being Together: Children's Experience of HIV and AIDS Related Stigma in Zambia*, Lusaka, Zambia: ZAMBART Project, School of Medicine, University Teaching Hospital.

PRINCIPLES OF INTEGRATING STIGMA REDUCTION INTO CHILDREN'S PROGRAMMES

Principles	Rationale
Include stigma reduction at programme planning stage	Include stigma reduction in programme proposals that focus on children's well-being, access to health care, education and poverty reduction Examples of possible activities: ■ incorporate stigma exercises from the toolkit into programme training with partners/caregivers. For example, psychosocial counselling support for children, caregivers training, and paediatric treatment for health workers ■ include volunteers in the training ■ support home-based carers to address stigma during home visits to families with children living with HIV ■ hold focus group discussions with children to share their experiences of stigma and explore strategies for coping ■ conduct a series of awareness-raising workshops/meetings on stigma for teachers, community leaders and guardians ■ work with leaders, musicians and artists to spread anti-stigma messages in creative ways
Work alongside policymakers and government ministries	Longer-term changes in attitudes towards children take time. Professionals who work with children can be role models and lead the way Stigma reduction programmes can be integrated into teachers' training and professional training for social workers and caregivers. This can institutionalise the training and lead to long-term sustainability Examples of activities: ■ working with the Ministry of Education to run programmes in schools is a good way of ensuring that stigma activities and training are sustained. If all teachers are trained to understand stigma and how to address it, they can work with pupils and encourage them to create 'stigma-free schools' ■ organise a national forum to showcase and discuss tools and processes that support stigma reduction strategies with decision-makers
Include programmes for both adults and children	Stigma reduction in children's programmes should have components to address stigma among children. This will support children to understand stigma, reduce stigma perpetuated or copied by children, and enable children to identify ways of coping with and challenging stigma
Include activities to monitor and evaluate stigma reduction	Develop a range of monitoring and evaluation methods to measure stigma reduction at community level. This could include a baseline survey to build evidence of the need to tackle the problem Present the baseline results to key stakeholders and outline plans for an anti-stigma programme

TRAINING CAREGIVERS TO ADDRESS STIGMA

Pact, Tanzania

In 2006, Pact won a large multi-year project to address stigma associated with HIV and to provide services to Tanzania's most vulnerable children (vulnerability due to HIV, poverty, neglect, and malaria or other health reasons). The programme, funded under the President's Emergency Fund for AIDS Relief (PEPFAR), is called Jali Watoto (Care for children).

Pact implements the programme in collaboration with the Department of Social Welfare and through sub-grants to NGOs and faith-based organisations. As well as managing the grants, Pact provides capacity building and technical training in care-taking skills, children's rights and stigma reduction.

Tool development

In order to address the stigma faced by children and young people, Pact partnered with the Alliance's Regional Stigma Training Programme and Kimara Peer Educators (Tanzania) to develop two new tools that could be used in the community. These tools, *Children and Stigma* and *Young People and Stigma*, were added as new modules to the stigma toolkit. The tools were developed through participatory workshops with children, and the exercises to address stigma were based on their stories and experiences.

The new tools were used to train all 40 of Pact's partner organisations and over 3,000 community leaders, teachers, health care workers, volunteers from NGOs and faith-based organisations, and members of Most Vulnerable Children's Committees to address stigma faced by children and young people. Organisations were also given grants to roll out stigma activities in the community.

High-profile anti-stigma work

As well as working at community level, Pact also used high-profile events to get across the message about stigma. For example, they worked with popular Bongo flava musicians to spread anti-stigma messages through songs. These songs were an effective way to reach guardians and caregivers, to highlight the trauma that stigmatised children face, and to popularise stigma reduction messages.

Pact also got the support of the Tanzanian First Lady for the Jali Watoto programme, and used the launch of the Tanzanian National Plan of Action for Orphans and Most Vulnerable Children (which was attended by the then US First Lady, Laura Bush) to present her with a copy of the stigma toolkit.

ADDRESSING STIGMA IN FAMILIES

Centre for Positive Care, Limpopo, South Africa

The Centre for Positive Care (CPC) is an NGO working in four districts in Limpopo, South Africa. CPC focuses on three programmatic areas: HIV prevention through peer education and counselling; community home-based care services; and care and support for orphans and vulnerable children.

A provincial training course for stigma trainers was held in 2009 for CPC and their partners, with the result that the orphans and vulnerable children team committed to integrate the tools into their community activities. The aim was for the community to understand stigma and its effects on the well-being of orphans and vulnerable children.

Some of the methods used to address stigma in families were door-to-door outreach work in villages, visiting children and their caregivers at home and at traditional ceremonies, where anti-stigma messages were incorporated in drama and dance.

ADDRESSING STIGMA IN THE COMMUNITY

Copperbelt programme for orphans and vulnerable children, Alliance Zambia

The Copperbelt programme for orphans and vulnerable children supports government structures, such as the Ministry of Community Development and Social Welfare, and community organisations to co-ordinate services to meet the needs of vulnerable children. It is funded by Irish Aid.

Before the stigma programme started, many local community-based organisations were providing practical support to children in the form of school uniforms, fees and books, but there was less focus on psychosocial needs. The regional stigma team developed a straightforward training course for caregivers and social workers to give them a greater understanding of the stigma faced by children, and to build training skills for use in community settings.

At the end of the course, participants were able to run short community workshops for both adults and children, to help address stigma.

After the training

The Vulnerable Orphans and Widows Association (VOWAS), based in Ndola, is one of the partners on the programme. VOWAS provides psychosocial, educational and nutritional support and protection to orphans and their caregivers in eight districts. After the stigma training VOWAS integrated the stigma techniques into their community activities.

A support group takes action

A team of home-based carers who had been trained as anti-stigma agents were carrying out home visits and came across an elderly lady whose daughter had died from AIDS-related illnesses. She had left a two-year-old baby boy who was HIV positive.

The lady told them she was finding life difficult because the entire community was whispering about her late daughter and pointing fingers at her grandson. She said that even her own children had stopped going to school because the stigma was too much. At the clinic health workers had even started counselling her about the possibility of losing her grandson. She started hiding her grandson from neighbours to avoid their pointing fingers.

The home-based care team introduced her to a support group for carers. In one of the meetings, they were talking about stigma and she told her story. The rest of the support group members decided to take action, carrying out several stigma awareness sessions and inviting key members of the community. Afterwards people seemed to be more accepting of the lady and there was less gossiping.

Her children have now gone back to school, and her grandson has started antiretroviral drugs and has been registered on the list of children receiving support from VOWAS.

IN-SERVICE TRAINING FOR TEACHERS

IPC, Burkina Faso

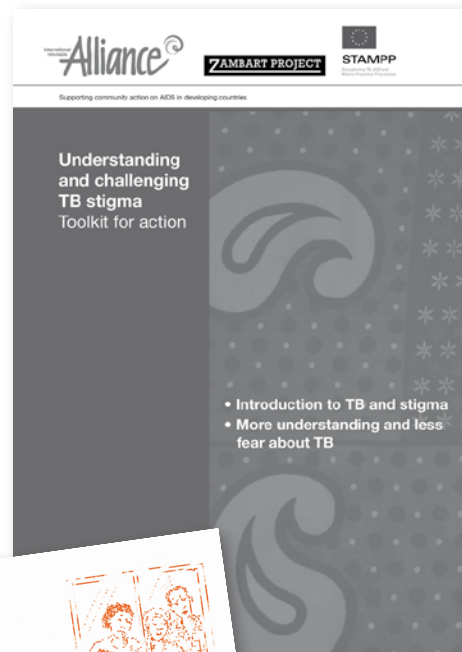
The Alliance's linking organisation in Burkina Faso, Initiative Privé et Communautaire de lutte Contre le VIH/SIDA au Burkina Faso (IPC), works to improve access to HIV prevention, care and support services for people living with HIV, community support for orphans and vulnerable children, and HIV treatment services.

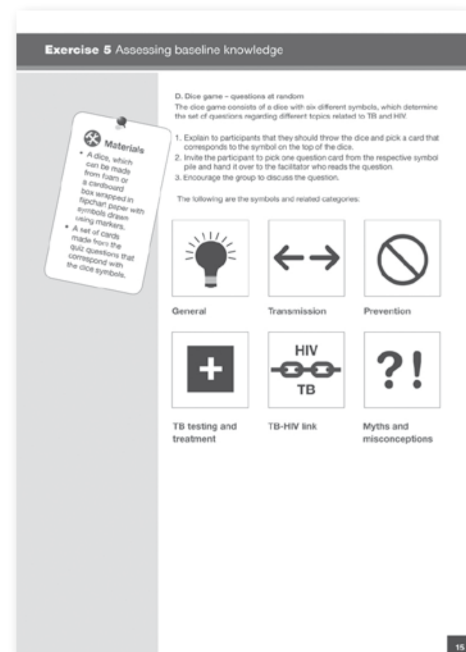
A national stigma training workshop was held with IPC and partners in 2008, and since then the stigma toolkit has been used in many programmes. IPC has also worked with the Ministry of Education to develop an in-service training course for teachers on HIV, with stigma exercises integrated into this course as a major component.

3. TUBERCULOSIS PROGRAMMES

In many parts of sub-Saharan Africa there is a dual epidemic of HIV and tuberculosis (TB). People living with HIV are much more vulnerable to developing TB due to their compromised immunity, and the stigma faced by TB patients has increased because a TB diagnosis is often assumed to signal underlying HIV infection. Any TB programme should include a component to address stigma, because there is still so much fear – and lack of knowledge – about TB. This affects the way people feel about TB, and hampers access to testing and treatment.

In 2009, the Regional Stigma Training Programme worked with the Zambia AIDS-related TB (Zambart) project to develop a new module for the stigma toolkit, *Understanding and Challenging TB Stigma* (www.aidsalliance.org/publicationsdetails.aspx?id=343). The exercises contained in the module are based on the real experiences of TB patients and health workers from TB services, and are designed to be used in many different contexts.





Exercise 5 Assessing baseline knowledge

Materials
- A dice, which can be made from foam or a cardboard box wrapped in flipchart paper with symbols drawn using markers.
- A set of cards made from the quiz questions that correspond with the dice symbols.

D. Dice game – questions at random
The dice game consists of a dice with six different symbols, which determine the set of questions regarding different topics related to TB and HIV.

1. Explain to participants that they should throw the dice and pick a card that corresponds to the symbol on the top of the dice.
2. Invite the participant to pick one question card from the respective symbol pile and hand it over to the facilitator who reads the question.
3. Encourage the group to discuss the question.

The following are the symbols and related categories:

General
Transmission
Prevention
TB testing and treatment
TB-HIV link
Myths and misconceptions

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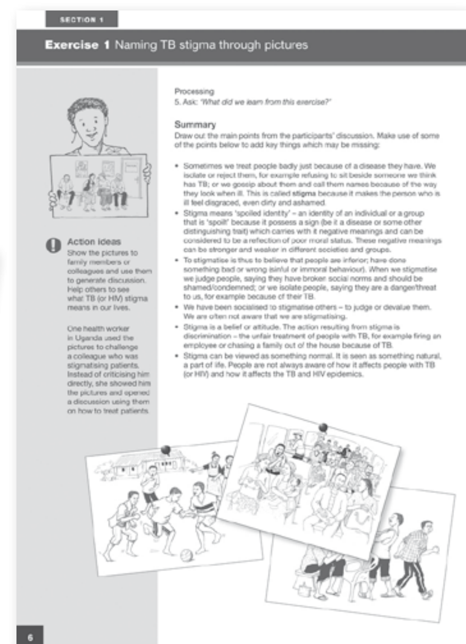
Sample exercises and picture cards from the TB stigma module



SECTION 1

Exercise 1 Naming TB stigma through pictures

Processing
5. Ask: *"What did we learn from this exercise?"*

Summary
Draw out the main points from the participants' discussion. Make use of some of the points below to add key things which may be missing:

- Sometimes we treat people badly just because of a disease they have. We isolate or reject them, for example refusing to sit beside someone we think has TB; or we gossip about them and call them names because of the way they look when ill. This is called **stigma** because it makes the person who is ill feel disgraced, even dirty and ashamed.
- Stigma means 'spoiled identity' – an identity of an individual or a group that is 'spoilt' because it possess a sign (be it a disease or some other distinguishing trait) which carries with it negative meanings and can be considered to be a reflection of poor moral status. These negative meanings can be stronger and weaker in different societies and groups.
- To stigmatise is thus to believe that people are inferior; have done something bad or wrong (sinful or immoral behaviour). When we stigmatise we judge people, saying they have broken social norms and should be shamed/condemned; or we isolate people, saying they are a danger/threat to us, for example because of their TB.
- We have been socialised to stigmatise others – to judge or devalue them. We are often not aware that we are stigmatising.
- Stigma is a belief or attitude. The action resulting from stigma is discrimination – the unfair treatment of people with TB, for example firing an employee or chasing a family out of the house because of TB.
- Stigma can be viewed as something normal. It is seen as something natural, a part of life. People are not always aware of how it affects people with TB (or HIV) and how it affects the TB and HIV epidemics.

Action ideas
Show the pictures to family members or colleagues and use them to generate discussion. Help others to see what TB (or HIV) stigma means in our lives.

One health worker in Uganda used the pictures to challenge a colleague who was stigmatising patients. Instead of criticising him directly, she showed him the pictures and opened a discussion using them on how to treat patients.

6

PRINCIPLES OF INTEGRATING STIGMA REDUCTION INTO TB PROGRAMMES

Principles	Rationale
Include stigma reduction at programme planning/proposal development stage	Assume TB stigma will impact on the programme and take steps to address it from the outset Examples of possible activities: ■ train a pool of community facilitators on how to use the TB stigma toolkit so they can then monitor activities at community level ■ carry out TB stigma awareness training for all programme staff, including volunteers, health committee representatives, counsellors and nurses ■ work with health workers to include anti-stigma activities in their health centres ■ carry out awareness-raising workshops/meetings on stigma with community leaders, religious leaders and support groups
Work with government stakeholders, such as ministries of health	Obtain high-level support for integrating stigma reduction into health centres that provide TB services to ensure effective implementation TB stigma reduction programmes can be integrated into other training for health workers
Include activities to monitor and evaluate stigma reduction activities	Ensure that a range of monitoring and evaluation methods are in place to measure stigma reduction at community level Present the baseline results to key stakeholders and outline plans for an anti-stigma programme

TRAINING COMMUNITY STIGMA FACILITATORS

STAMPP and Zambart, Zambia

The Zambia AIDS-related TB (Zambart) project has been working on TB in Zambia for more than 20 years. Since 2008 Zambart has been carrying out a community-based randomised trial (ZAMSTAR) and a collaborative malaria, TB and HIV prevention project (STAMPP). Anti-stigma education has been rolled out to all 19 programme sites across six provinces.

Trainers from each province trained community facilitators who formed community facilitation teams. These teams initiated and monitored community-based anti-stigma activities with the help of small grants. Examples of these activities have included using stigma exercises in church groups and schools, stigma action days and dramas.

A pastor's success story

The following story was narrated by a trained anti-stigma facilitator who is a pastor and former instructor at a youth training centre. It is an example of how integrating anti-stigma activities in all structures can help address stigma.

"I was once a lecturer at Lumuno Training Centre for youth in cutting and designing. One of the boys in my class was always silent and would on many occasions sit isolated from other students.

I decided to talk to the sister-in-charge of the training centre about the boy's behaviour. She told me that the boy was a TB patient. This is when I realised why the other pupils did not want to interact with the boy and the reason that he seemed to be isolating himself.

I asked for permission to talk to the pupils about TB and stigma. I came to class putting on my caregivers T-shirt. The minute I entered the class the pupils became silent because they had never seen me dress like that. I told the class that I had come that day not to teach cutting and designing but to talk to them about stigma. I talked about stigma and its effects, and gave the example of what had transpired at the school. I also talked to them about love. I could see that during my presentation some of them broke down. I asked them to ask themselves if they had contributed to the isolation of the boy, who by then had stopped going to school. During the discussion I discovered that the boy had confided in the coordinator, who later on announced to the class his condition. This caused the boy to shun school; he even told his guardians that he had stopped school.

After the session we went to see the boy at his home and persuaded him to come back to school. He came the next day. As he came late he found the other pupils in class. Most of the pupils rushed out of class to meet him, some even hugging him. The whole scenario was very touching.

4. WORKPLACE PROGRAMMES

The rapid spread of HIV is having a big and increasing impact on the operations of many workplaces. In countries and communities where HIV is most concentrated, workplaces have experienced increased production costs, reduced profits and greater difficulty delivering products and services because of the loss of skilled workers.

Discrimination against and stigmatisation of employees living with HIV undermines efforts to promote HIV prevention and often leads to people delaying testing and treatment, and even the death of employees in the workplace.

Many workplaces now have HIV programmes for employees to build awareness and provide information about services. These are often run as peer education programmes, where focal point employees are trained and become resource people for the workforce. Stigma reduction can easily be integrated into these programmes.

Sample exercises from the Moving to action module

PRINCIPLES OF INTEGRATING STIGMA REDUCTION INTO WORKPLACE PROGRAMMES	
Principles	**Rationale**
Include stigma reduction at programme planning/proposal development stage for HIV workplace programmes	Integrate stigma training into workplace programmes from the outset, to ensure that it is not a barrier to employees accessing information and services Examples of activities: ■ brief or train trainers to orient technical staff about the stigma tools and techniques ■ train focal point employees in companies ■ develop workplace policies that address stigma and discrimination, and provide job protection for employees who are HIV positive
Involve management in plans to integrate stigma reduction into the workplace	If management understands that tackling stigma can improve productivity through improved health of employees, it will support the programme and ensure its continuity Example of activities: ■ design a short demonstration or presentation for managers to show how the stigma tools can work ■ demonstrate how tackling stigma can save money and increase profits ■ promote the idea of senior managers as role models to tackle stigma
Adapt the tools to suit the workplace situation	The stigma toolkit is extensive and workplace programme are, by their nature, often time limited. Choose the most relevant exercises or develop a mini-toolkit suitable for the workplace
Incorporate stigma principles into the organisation's HIV workplace policies as a starting point for integration	When supporting organisations to develop HIV policies, ensure that stigma and discrimination are covered in the policy and the rights of staff who are HIV-positive are protected Good practice guidelines and codes of conduct can help to address stigmatising behaviour, as well as policies and disciplinary codes to protect employment rights
Include anti-stigma activities in the workplace where relevant	Help to create a stigma-aware workforce and an environment that is open and accepting Examples of activities: ■ promote the idea of a 'stigma-free zone' to employees and clients (using posters and T-shirts, for example) ■ encourage employees living with HIV to set up a support group ■ provide incentives to come up with creative ways to tackle stigma
Include activities to monitor and evaluate stigma reduction	Build indicators into programme proposals to show how stigma reduction will be measured Encourage employees and peer educators to document stories of change

PUTTING STIGMA INTO POLICIES

Afya Mzuri, Zambia

Afya Mzuri ('Good Health') is a Zambian NGO established in 2003, specialising in the implementation of HIV prevention and wellness interventions for workplaces and their host communities. The organisation works with the private sector, mainly on commercial farms and in the mining sector.

After attending the national stigma training, the organisation decided to incorporate a stigma reduction programme as part of its core technical assistance offered to clients in the workplace and host communities. This was done by intensifying awareness and sensitisation programmes that promote positive behaviour change towards people living with HIV.

Stigma was also seen to be an important policy issue, and Ayfa Mzuri ensured that an anti-discrimination clause was developed in all workplace-related policies and manuals. HIV programmes in the workplaces included technical assistance and training to implement the policies.

INTEGRATING STIGMA INTO WORKPLACE TRAINING PROGRAMMES

Kindilimuka, Mozambique

Kindilimuka is a community-based organisation and support group for people living with HIV, based in Maputo, Mozambique. Several members of the organisation were participants in an extensive stigma training programme run in conjunction with the Alliance's regional programme.

Kindilimuka is a partner of the Joint United Nations Programme on HIV/AIDS (UNAIDS), which has provided funding for some of its community programmes. UNAIDS invited the organisation to develop an HIV workplace programme to be used as part of its orientation programme for new United Nations staff.

The programme covers HIV prevention and treatment, and Kindilimuka has incorporated stigma reduction exercises into each of its components to ensure success.

5. HEALTH CARE SETTINGS

> *They even moved my uniform and placed it where the patients' clothing was hung – to mean that I belonged there.*

Nurse living with HIV, Tanzania

In recent years there has been greater recognition of the level of stigma that exists in health facilities, from health workers towards clients and, sometimes, among health workers towards colleagues who are suspected or known to be living with HIV. Addressing stigma in health facilities is one of the cornerstones of increasing access to HIV services.

In recognition of the problem, a consortium of international agencies, including the Alliance (represented by the regional stigma team), Engenderhealth, World Health Organization, UNAIDS, United Nations Development Programme, International Labour Organization, GNP+ and ICRW, has been involved in the development of a stigma reduction module specifically targeting health workers. Several of the stigma trainers trained by the Alliance's regional programme have been involved in developing and testing out this new tool. The tool will be finalised and disseminated in 2011.

Picture cards from the new health workers and stigma toolkit

PRINCIPLES OF INTEGRATING STIGMA REDUCTION INTO HEALTH CARE SETTINGS

Principles	Rationale
Train all new health care workers in medical schools and nursing colleges about stigma	This is the most effective and sustainable way to address stigma in health care settings in the long term. Partnerships with ministries of health, nursing unions and other medical bodies to integrate stigma reduction exercises into the curricula of training schools could mean all newly trained health workers understand stigma before they graduate into the clinics and hospitals
Use other training programmes as opportunities to raise awareness among existing health care staff	Stigma awareness sessions should be integrated into other training programmes for personnel wherever possible. All staff can be involved in plans to understand and address stigma – that includes management, ancillary staff and those on casual contracts
Train health workers to train others on stigma reduction	*"Health workers are difficult people who may not accept being trained by just anybody,"* (nurse, Kenya). From extensive experience in Tanzania, programmers found that health workers respond best to training from fellow health workers
Work with health structures at all levels, including district, provincial and national	This ensures that stigma reduction tools and methodologies are widely shared and can be adopted into programmes for long-term sustainability
Ensure policies are in place to support stigma reduction	Where stigma reduction programmes are being carried out, it is important to ensure that policies are in place to support clients and staff living with HIV. If there is less stigma, more staff will access HIV testing and treatment, so it is important to ensure that their employment rights are protected and that measures are in place to address any stigma they do face in the workplace. It is equally important to ensure that clients' rights are protected; simple codes of conduct or patients charters can help maintain standards of good practice
Be ready to meet increased demand	Successful stigma reduction programmes in health care settings will result in increased demand for services, so factor in plans and resources to address this demand
Involve health workers living with HIV as trainers	This can help to build the confidence of other health staff to go for testing and treatment, and reinforce a positive environment where disclosure of HIV status does not lead to discrimination

INTEGRATING STIGMA REDUCTION INTO EXISTING IN-SERVICE TRAINING

Muhimbili national hospital, Tanzania

Muhimbili University College of Health Sciences is the national referral hospital in Tanzania and provides HIV testing, treatment and biomedical care services to members of the public. Integrating stigma reduction training here was done by training health workers as stigma trainers (some of whom were open about being HIV positive). They then conducted stigma awareness training for fellow health workers in the hospital. The strategy also involved senior staff from across departments and wards in training sessions, which helped gain their support.

PITC training

One of the most effective strategies at the hospital was to integrate stigma reduction programmes into existing in-service training courses. For example, the Centre for Disease Control funded a big programme of provider-initiated testing and counselling (PITC) training courses, and the trainers negotiated for the integration of stigma exercises into the training. Over 650 health workers, including 60 health workers living with HIV, were trained in stigma reduction through this programme.

When the PITC programme was evaluated, it was found that health workers who were trained in both PITC and stigma reduction were better service providers than those trained in PITC alone. Those services with health workers who had been through the training recorded increased uptake of antiretroviral treatment among clients, as well as higher disclosure rates.

WORKING WITH LOCAL HEALTH AUTHORITIES

Tunajali programme, Tanzania

Tunajali (‘We care’) is an HIV care and treatment project funded by PEPFAR in Tanzania. Its aims are to rapidly increase and sustain the number of Tanzanians receiving HIV clinical care and antiretroviral treatment, and increase the number of civil society organisations contributing to the national HIV response. Self-stigma, family stigma and community stigma had been identified as some of the main reasons for patients dropping out of antiretroviral treatment programmes.

Translating tools

Trainers identified the treatment module in the stigma toolkit as the most relevant tool for the programme and obtained funds to translate it into Swahili. Health workers from five provinces were trained and they then rolled out training across treatment centres.

The programme resulted in a dramatic increase in the number of people enrolling for treatment (because of lower levels of stigma in the health facilities), and better adherence was reported alongside a lower incidence of opportunistic infections. The local health authority took over funding the programme and is providing resources to ensure stigma reduction activities continue.

6. THE MILITARY

Members of the military and uniformed services are highly vulnerable to HIV because their work environment, mobility, age and other factors expose them to higher risk of infection. For this reason, extensive HIV testing and treatment services are often set up for the armed forces, but uptake is hampered by high levels of fear and stigma. However, uniformed services offer a unique opportunity for HIV awareness and stigma reduction training as there is a large 'captive audience' in a disciplined and highly organised setting.

PRINCIPLES OF INTEGRATING STIGMA REDUCTION TRAINING INTO HIV PROGRAMMES FOR THE MILITARY

Principles	Rationale
Integrate stigma reduction activities into all Department of Defence (or equivalent) HIV programmes	To ensure that Department of Defence HIV programmes are effective, stigma reduction can be built into new HIV programmes, or integrated into existing programmes and service provision within the military forces. Programme staff can be trained in the use of stigma tools and techniques that can then be rolled out to service providers in a planned, strategic way
Gain the support of the high command for the programme	Ensure that the high command are aware of strategies to reduce stigma in the forces. Start with them, if possible, by demonstrating tools and techniques, sharing stories and garnering support for a wide programme Include action to review policies that perpetuate discrimination against members living with HIV and make a commitment to reform them
Address policies that can lead to discrimination	As well as stigma reduction training, it is important to work with the high command to make sure that any policies seen to discriminate against people living with HIV are reviewed
Use existing military training structures	Work with Department of Defence training schools to integrate stigma reduction into all their courses. Run short orientation courses for teaching staff to practise the skills and techniques used to address stigma; these can be passed on easily to new recruits and new officers, for example, through the training courses

WORKING TOWARDS LONG-TERM INTEGRATION

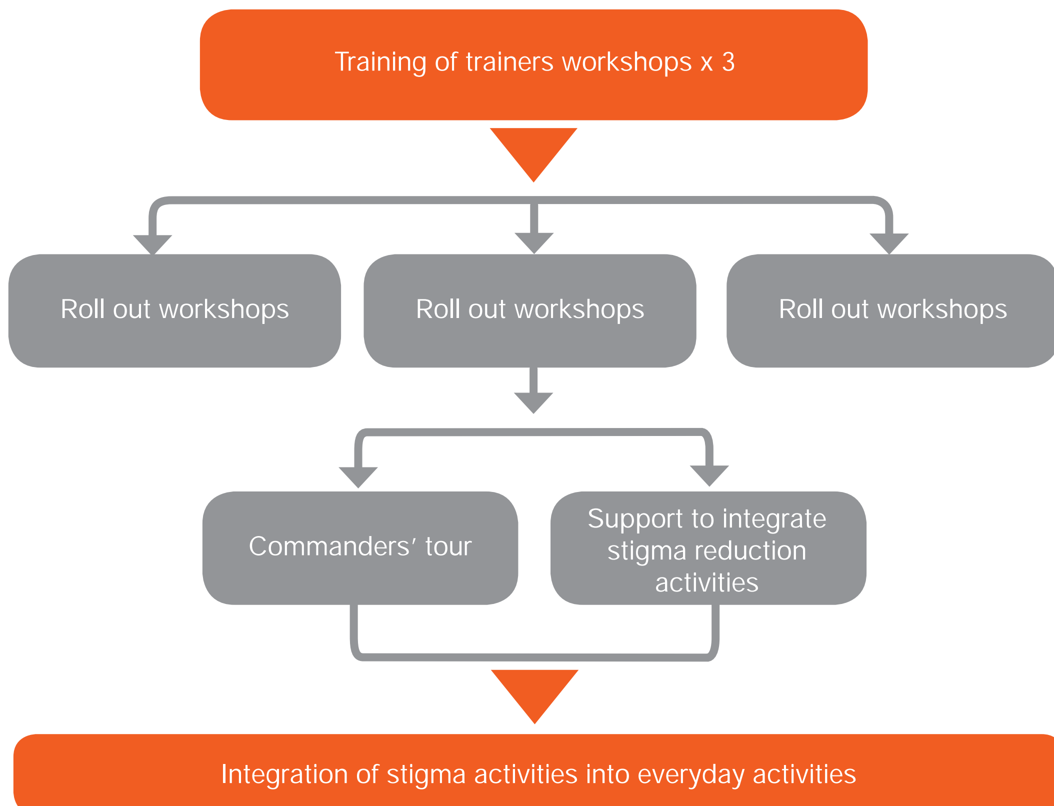
Department of Defence, Kenya

From 2009–2010, the Alliance's regional stigma team worked alongside national trainers in Kenya to integrate stigma reduction training into the Kenyan Department of Defence.

A programme was designed to train teams of trainers who would then be able to use the stigma toolkit to train others to lead stigma reduction initiatives and advise on ways of integrating the initiatives into everyday activities. Three training-of-trainers workshops took place in different regions, co-facilitated by trainers from the regional programme and Kenyan national trainers.

After the training workshops, small grants were made available to the trainers to carry out short stigma awareness activities with targeted groups. Kenyan national trainers co-facilitated these with the newly trained Department of Defence trainers.

A 'commanders' tour' was carried out, reaching over 100 commanders. These meetings were received with enthusiasm by the commanders; many testified that they had witnessed colleagues and junior officers dying because of fear of stigma. Commitments were made by commanders during the tour to raise policy issues in the relevant fora. PEPFAR also agreed to continue the stigma programme in the department's work plan for the following year.



Components of the Kenyan Department of Defence training model

EXAMPLES OF DEPARTMENT OF DEFENCE STIGMA TRAINERS' IDEAS FOR INTEGRATING STIGMA REDUCTION INTO DAILY ACTIVITIES

Structure used	How
Department of Defence training courses	Officers from the national training centre to include stigma exercises into training programmes for new recruits, junior and senior leadership courses, and the junior command course
Barakas and muster parade	*Barakas* are open meetings or social gatherings held in a unit where an officer will often make a speech to raise morale or introduce a topic for discussion. Commanders agreed that *barakas* would provide a good opportunity to show leadership in the fight against stigma. Muster parade and padre hour were also identified as events where HIV and stigma could be discussed
Using sermons and preaching	The chaplaincy can play an important role promoting stigma reduction messages in sermons and Friday messages. They are often given opportunities to hold group talks and discussions (even with commanders) so can use these to show leadership against stigma
Comprehensive Care Centre for HIV services	Integrate stigma exercises into in-service training courses for Department of Defence health workers. These courses include prevention of mother-to-child HIV transmission, voluntary counselling and testing, and care for orphans and vulnerable children Develop a policy for the Comprehensive Care Centre to protect the rights of health workers living with HIV
Working with families of military personnel	Many trainers recognised the importance of including anti-stigma work with officers' spouses, children and other family members if stigma is to be reduced on all fronts. Several identified groups of wives, widows and children to be targeted for training

7. TRAINING INSTITUTIONS

Training personnel to run services that respond to the HIV epidemic has been an ongoing task for governments, public and private sectors. Health workers, counsellors, carers and community volunteers all need training to make sure there is an informed and skilled response. Training is provided by many different types of agencies and institutions, and one of the most frequent ways that the stigma training has been used is by integrating specific stigma exercises into existing HIV training curricula.

PRINCIPLES OF INTEGRATING STIGMA REDUCTION INTO TRAINING INSTITUTIONS

Principles	Rationale
Identify key stakeholders in an institution who can take responsibility for integrating stigma exercises	It is important to work directly with members of the institution who will commit to spearheading the integration of stigma exercises. If an institution has a training department or co-ordinator these would be the most obvious candidates Once candidates have been identified: ■ review existing curriculum to assess the most appropriate way to integrate stigma exercises ■ work with trainers to identify the most appropriate stigma exercises to integrate ■ incorporate exercises into the courses, reviewing these at regular intervals to ensure relevance
Conduct a training workshop to demonstrate the value of integration to other trainers, key partners and management, using selected stigma exercises that are relevant to the institution	It is important that the exercises selected are in line with the organisation's objectives. This makes it easier for institutions to integrate stigma activities in ongoing activities even if there is no funding Gain support from managers and partners who can promote the added value of tackling stigma as part of existing courses. This can ensure long-term sustainability
Adapt the tools and exercises to fit the institution's training and context if appropriate	Exercises may need to be translated or adapted for the local context. This can be done with clients, trainers and other stakeholders
Involve people living with HIV within the institution	Include people living with HIV as role models from within the institution to support and lead the stigma sessions
Provide refresher training-of-trainers workshops every so often to maintain the quality of the stigma training and accommodate staff turnover or project expansion	It is important for quality assurance that there are regular refresher courses. These can keep trainers up to date on the latest thinking on stigma, and new tools and approaches
Recognise the added value that stigma reduction techniques bring to training courses	Integrating stigma into core courses adds value to an institution's courses and can be a unique selling point to organisations or individuals who are looking for training. Most organisations recognise the importance of addressing stigma, but do not have the necessary materials to deal with it

EXAMPLES FROM THE FIELD

TRAINING COUNSELLORS TO REDUCE STIGMA

TASO, Uganda

The AIDS Support Organisation (TASO) is one of the longest-running, most established HIV organisations in Uganda. It provides HIV services, including training on HIV counselling and other related topics.

After the national stigma trainers' workshop in Uganda in 2005, which was conducted by the regional stigma team in partnership with TASO, stigma was incorporated into TASO's core course curricula. This was done so that all trainees passing through TASO receive training on stigma awareness and how to integrate stigma reduction into their HIV programmes.

TASO works closely with Strengthening Counsellor Training (SCOT) and the Infectious Disease Institute (IDI), who also run training courses, and both these organisations have followed TASO's lead with the integration of stigma exercises into their curricula. This will ensure long-term sustainability and the integration of stigma exercises into counsellor training in Uganda.

A GOOD FIT FOR STIGMA TRAINING

Mildmay, Uganda

Mildmay is an HIV service organisation in Uganda that provides care, treatment and training. One of its training officers attended a national training-of-trainers workshop in 2006 and since then has worked with Mildmay to integrate stigma modules into its training course curriculum for counsellors. (Course participants include health workers, religious leaders, school teachers and school nurses.)

The particular focus of the counselling training at Mildmay is to help participants examine how they can change and what change HIV counselling can be expected to bring. So the stigma toolkit's model of self-awareness fits well and has helped to change attitudes and approaches to dealing with stigma.

“*My personal experience is that the more one understands issues regarding stigma, the more one is empowered and equipped to manage it. It is especially important for those who are HIV negative or those who would like to think they are, caregivers, activists and all those involved in the battle against HIV to understand the stigma implications in prevention, care, support and treatment.*

HIV ignorance and the related stigma thrive on fear and secrecy. The best weapon against these is information. If I was not open about my HIV status to my family, workplace and church, and if I had not worked on my self-esteem, I would not have lived for 20 years plus with HIV, and I am still living and still able to work and teach people.

Trainer, Mildmay

ADAPTING STIGMA TOOLS FOR THE COMMUNITY

NACWOLA, Uganda

The National Community of Women Living with HIV/ AIDS (NACWOLA) in Uganda was founded in 1992. It promotes positive living for women and children living with HIV by providing psychosocial support, economic empowerment and advocacy. NACWOLA has been integrating stigma into its daily HIV and TB work since two national training-of-trainers workshops took place in 2006 and 2007.

After trying out the tools in counselling sessions, staff began to integrate exercises into their training in the community, primarily the 'memory book' work that NACWOLA is known for.[7] This proved to be so effective that NACWOLA decided to adapt the tools and make their own manual for community workers. This used several exercises from the stigma toolkit and some new ones that were developed with their community groups.

7. NACWOLA's memory books work is a framework and guide to help parents or guardians to write down important information for children who are at risk of losing contact with their birth family and community.

EXTENDING COURSES TO INCLUDE STIGMA EXERCISES

Positive Vibes, Namibia

Positive Vibes is an innovative HIV communication initiative based in Namibia. The organisation adapts courses and implements participatory approaches to HIV communication led by people living with HIV. It aims to address the epidemic at an individual, family and community level.

Positive Vibes is particularly known for its 'AIDS and me' course, which helps participants to develop personal and collective action plans for dealing better with HIV and the problems associated with it. Trainers from the national stigma training workshop worked with the training team to integrate stigma exercises into 'AIDS and me' and other courses run by Positive Vibes. As a result the course was extended from three to five days in recognition of the importance of including stigma in the curriculum. The integrated course was tried out in the Karas, Khomas and Oshana regions of Namibia. The integrated course is now one of Positive Vibes' core courses that it provides to a wide range of organisations.

The most effective workshop was with the Namibian police. The chief of the police was very negative in the beginning, he even suggested we had a separate town for people living with HIV and gays and lesbians. However, at the end of the workshop, which included the three days on stigma, he said, 'Madam facilitator, I am a changed person. I am not the same person you met on day one. Today I am speaking like someone who is HIV positive, who might have a son or a brother who is gay.'

Trainer, Positive Vibes

7. DEVELOPING POLICIES TO ADDRESS STIGMA REDUCTION

Strategies to integrate stigma reduction into wider HIV programming can be implemented more effectively if policies are in place to support the integration.

EXAMPLES FROM THE FIELD

LINKING NATIONAL TRAINERS AND POLICYMAKERS

KANCO, Kenya

Kenya AIDS NGOs Consortium (KANCO) is a national network and membership organisation for NGOS and community- and faith-based organisations working on HIV and TB in Kenya. In 2010 KANCO worked on a series of strategies to address stigma and discrimination at policy level.

After meeting with the team of national stigma trainers (who attended the Kenyan national training workshop in 2006) to plan the strategy, KANCO organised seven regional meetings with policymakers and civil society organisations at provincial level. During these regional meetings, participants identified some of the key forms and causes of stigma in their province, and discussed policy changes that would help to address the issues.

A national meeting was then held in Nairobi that brought together stakeholders and policymakers to map out the way forward. At the meeting, the National AIDS Control Commission (NACC) outlined how stigma and discrimination were included in the Kenya National HIV/AIDS Strategic Plan (iii) and how they were also promoting a new drive to integrate the principle of the greater involvement of people living with HIV in HIV programmes at all levels.

As a result of the policy meetings, NACC agreed to work with the national stigma trainers to raise awareness about how to address stigma and discrimination across the country. NACC is also exploring the possibility of adopting the stigma toolkit as the national stigma reduction tool.

INTEGRATING STIGMA TOOLS INTO THE NATIONAL PLAN

ANS-CI, Côte d'Ivoire

Since its establishment in 2005, Alliance National contre le Sida en Côte d'Ivoire (ANS-CI) has been supporting community groups to take action on HIV, working towards its vision of preventing new HIV infections and AIDS-related deaths, and tackling stigma and discrimination towards people living with HIV.

Following a regional stigma training in West Africa, which involved staff from ANS-CI and the Ministry for the Fight against AIDS, ANS-CI worked with the ministry to adapt and develop the stigma toolkit to fit the national context. Because of the involvement and support of the ministry, the revised toolkit has been adopted as the national stigma reduction tool. This will mean that all HIV programmes have a standardised approach to stigma reduction, resulting in interventions that will be easier to monitor and measure.

SUPPORTING ONGOING POLICY WORK

IPC, Burkina Faso

The Initiative Privé et Communautaire de lutte Contre le VIH/SIDA au Burkina Faso (IPC) is an NGO that works to improve access to HIV prevention and care services. In 2007 the Alliance's regional stigma project and IPC worked together to carry out national stigma training for partner organisations and government ministries.

Creating a national committee on stigma and discrimination

IPC were already working with the government on anti-discrimination practice and policies, and had commissioned a research study to explore how stigma and discrimination directed towards key populations creates barriers to prevention and treatment services.

IPC and its partners started a national process to create a strategic framework on stigma and discrimination that would guarantee the rights of positive people and marginalised groups. The resulting National Committee on Stigma and Discrimination adopted a consensus-building approach that was led by IPC and a technical advisor from the Ministry for the Promotion of Human Rights. This initiative, which saw civil society and government working together as equal partners with different and complementary skills, has been hailed as both new and very important to the national response to HIV.

The Ministry for Promotion of Human Rights is responsible for all questions and activities on the subject of stigma and discrimination. The Ministry of Health is responsible for questions regarding barriers to treatment of marginalised groups, while the Ministry of Social Affairs supports interventions for orphans and vulnerable children and other marginalised groups.

With such broad involvement, IPC has helped address stigma and discrimination as well as the difficulties faced by key populations in Burkina Faso.

An earlier attempt to work on research about men who have sex with men failed when it was blocked by the government, so it was clear to all involved that a step-by-step approach was needed.

National stigma training

As an Alliance linking organisation, IPC selected participants for the regional stigma programme's national training workshop from the organisations and agencies involved in the national stigma committee. The workshop provided a platform for exploring and discussing sensitive issues in more depth, as well as training on how to use stigma tools to create greater understanding and action.

The evaluation of the training showed that many of those working to address stigma in government ministries felt 'empowered and equipped' after the training and ready to proceed with policy change and action.

IPC continues to implement stigma reduction work at programme and policy level. It recently commissioned a study on service accessibility for sex workers to support further development of strategies for key populations. The findings of the study were launched at a national advocacy workshop to garner support for policy change.

Linking policy to practice

"*After attending the training-of-trainers stigma workshop plus the work that we are doing with IPC on policy, it made me reflect about how we needed to proceed as the Ministry of Human Rights. So after the workshop we began discussing with colleagues within the ministry about having a strategic plan on how stigma should be tackled. Those who have been exposed to the stigma training and information were enough to advocate for policy.*

Participant on stigma training-of-trainers workshop

Going a step further after personal transformation

“I coordinate HIV activities in the Ministry of Social Affairs and I also belong to a committee consisting of members from various government ministries tasked to fight stigma.

After the training-of-trainers workshop I realised that it was about time that stigma and discrimination were tackled directly. So I initiated a meeting with provincial directors of the ministry so that I could introduce stigma as a topic. Pictures from the picture code exercise from the toolkit were photocopied and distributed for purposes of the provincial directors initiating discussions in various provinces.

On a personal level I must admit that I have gone through some sort of transformation. During the workshop when we tackled the issue of men who have sex with men I was challenged when one of the participants said, ‘What if the person being persecuted was your son, how would you feel?’ This was a challenge to me especially as I have children and I really did put myself in the position.

On returning to the ministry I introduced the issue of men who have sex with men and at first it was a very sensitive issue. Many appeared not to be interested in what I was talking about, but then after some time people approached me and wanted to talk more about it. Later a colleague approached me and he disclosed to me that he had sex with men and faced many challenges in accessing healthcare.

Participant on stigma training-of-trainers workshop

DEVELOPING NATIONAL GUIDELINES FOR INTEGRATING STIGMA REDUCTION INTO HIV PROGRAMMES

MUCHS, Tanzania

The Tanzania National Policy on HIV/AIDS (2001) and the Health Sector HIV/AIDS Strategic Plan (2008–2012) identified the role of stigma in increasing the spread of HIV, and recognised stigma reduction as a key guiding principle for all sectors at all levels.

Muhimbili University College of Health Sciences (MUCHS) had a history of research and programming on stigma, and was keen to support a sector-wide approach based on research evidence and examples of stigma reduction best practice.

Recognising that specific funding for stigma reduction activities was limited, MUCHS developed a set of national guidelines on how to integrate stigma reduction into wider HIV programming. These guidelines were shared with the Tanzanian AIDS Control Commission, who adopted the document as a national guide. The guide was launched jointly with the Ministry of Health and Social Welfare in 2009.

The guidelines contain:

- an introduction to addressing stigma and integrating stigma reduction into HIV programmes
- key concepts about stigma
- approaches to scaling up and examples of how stigma reduction has been integrated into programmes by some organisations
- recommendations for the way forward
- references to resources, examples of information and education materials, recommended exercises, and a contact list of all the master trainers.[8]

8. Individuals trained by the Alliance regional stigma programme.

ANNEXES

The following sample exercises from the stigma toolkit are those most commonly cited by organisations who have integrated them into programmes.

NAMING STIGMA THROUGH PICTURES

STEP-BY-STEP ACTIVITY

Picture discussion

1. Display the selection of general stigma pictures on the wall, floor or washing line.
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?"*

OUR OWN EXPERIENCES OF BEING STIGMATISED

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

THINGS PEOPLE SAY…

STEP-BY-STEP ACTIVITY

Fruit salad – warm-up game

1. Set up the chairs beforehand in a circle. Allocate roles to each person, going around the circle: person living with HIV, sex worker, teenage girl, a man who has sex with men, orphan, widow. Continue until everyone has been assigned a role. Then explain how the game works: *"I am the caller and I do not have a chair. When I call out two groups – for example, people living with HIV and sex workers – all the people living with HIV and sex workers have to stand up and run to find a new chair. I will also try to grab a chair. The person left without a chair becomes the new caller and the game continues. The caller may also shout 'Revolution!' and when this happens, everyone has to stand up and run to find a new chair."*

   Start the game by shouting, *"People living with HIV and sex workers!"* and get the people living with HIV and sex workers to run to a new chair.

2. Divide into six groups based on the roles used in the game; for example, all the sex workers, all the orphans and so on. Ask each group to go to their flipchart station. Ask each group to write on the flipchart all the things people say about those in that group. After two minutes, shout *"Change!"* and ask groups to rotate and add points to the next sheet. Continue until the groups have contributed to all six flipcharts and end up back at their original list.

Report back

3. Bring everyone together into a large circle. Ask one person from each group to take turns standing in the middle of the circle and reading out the names on their flipchart, starting with *"I am a street child (or other group) and this is what you say about me…"*

Processing

4. After all lists have been read out, ask the following questions:
   - *How do we feel about these names?*
   - *Why do we use such hurtful language?*
   - *What are the assumptions behind some of these labels?*
   - *What does this show us about the link between language and stigma?*

A global partnership:
International HIV/AIDS Alliance
Supporting community action on AIDS in developing countries

What is the International HIV/AIDS Alliance?

Established in 1993, the International HIV/AIDS Alliance (the Alliance) is a global alliance of nationally based organisations working to support community action on AIDS in developing countries. To date we have provided support to organisations from more than 40 developing countries for over 3,000 projects, reaching some of the poorest and most vulnerable communities with HIV prevention, care and support, and improved access to HIV treatment.

The Alliance's national members help local community groups and other nongovernmental organisations to take action on HIV, and are supported by technical expertise, policy work, knowledge sharing and fundraising carried out across the Alliance. In addition, the Alliance has extensive regional programmes, representative offices in the USA and Brussels, and works on a range of international activities such as support for South–South cooperation, operations research, training and good practice programme development, as well as policy analysis and advocacy.

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