

Module

R. Smart

1.4

HIV/AIDS-related stigma and discrimination







About the author

Rose Smart is an independent consultant and the former Director of the South African National AIDS Programme, specializing in workplace issues, policy development and implementation, mainstreaming HIV and AIDS, community-based responses and affected children. She is also a member of the EduSector AIDS Response Trust network and was a member of the Mobile Task Team (MTT) on the impact of HIV/AIDS on education.

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..... HIV/AIDS-RELATED STIGMA AND DISCRIMINATION

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Aims

The aim of this module is to enable you to recognize AIDS-related stigma and discrimination and to equip you with strategies to challenge and reduce these within the education sector. In the first part we define stigma and discrimination; we discuss its causes and state how it affects populations. In the second part we look at stigma and discrimination within the education sector, and how the problem should be seen as a human rights issue. Then we examine AIDS-related stigma and discrimination in the workplace or at the ministry level and then within schools. In the final section we discuss how prevention programmes can be developed to effectively diminish stigma and discrimination.



Objectives

At the end of the module you should be able to:

- define stigma and discrimination;
- explain the causes, effects and consequences of stigma and discrimination;
- describe different forms of stigma and discrimination;
- apply a rights-based approach for confronting and reducing discrimination;
- understand how stigma poses obstacles to education and prevention programmes;
- explain strategies and practical actions to challenge and reduce AIDS-related stigma and discrimination in education systems.

Before you begin...



Questions for reflection

Take a few minutes to think about the questions below. You may find it helpful to make a note of your ideas in the spaces provided. As you work through the module, see how your ideas and observations compare with those of the author.

How would you define stigma and discrimination?

What is the difference between stigma and discrimination?

What are some of the causes of social stigma and discrimination?

What do you think are the effects of stigma and discrimination on a person living with HIV?

How can AIDS-related stigma and discrimination manifest themselves in the education sector?

How do stigma and discrimination hinder effective responses to HIV and AIDS?

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..... HIV/AIDS-RELATED STIGMA AND
DISCRIMINATION



Introductory remarks

At the end of 2004, 39.4 million people were living with HIV, and during that year 3.1 million died from AIDS-related illnesses. Since the onset of the disease in the early 1980s, HIV and AIDS have triggered responses of fear, denial, stigma and discrimination, often targeted at those groups seen as the most affected (injecting drug users, sex workers, etc.). In some cases, people living with HIV have been rejected by their loved ones and their communities, unfairly treated in the workplace, and denied access to education and health services – this holds true for the industrialized as well as the developing nations. AIDS-related stigma can take many forms – rejecting, isolating, blaming and shaming, and we are all involved in stigmatizing even if we don't realize it.

Box 1 Quote from UNFPA Executive Director on World AIDS Day 2003

"After two decades ... the global AIDS epidemic shows no signs of abating ... Among the main reasons ... is the persistence of stigma and discrimination against those infected. This outrageous violation of basic human rights drives the disease underground, crippling efforts for prevention and care."

Fear of discrimination often discourages people from seeking treatment or from disclosing their HIV status, which makes prevention and management of the disease very difficult. The stigma attached to HIV and AIDS extends into the next generation, placing a heavy emotional burden on those left behind. It is especially hard for children who may already be grieving a parent or family member.

AIDS-related stigma and discrimination remains one of the biggest barriers to effectively managing the AIDS epidemic. Within the education sector, children are refused access to school because they come from an AIDS-affected household. Teachers can be dismissed because of their HIV status.

Box 2 Quote from Archbishop Njongonkulu Ndungane

"Stigma is the unfair, uneducated and unholy disgrace we have allowed to develop around the disease. Stigma destroys self-esteem, destroys families, disrupts communities and takes away all hope for future generations."

Stopping the stigma and discrimination against people and marginalized groups who are affected by HIV and AIDS is as important as developing a vaccine itself. Education plays a key role in diminishing stigma and discrimination. Strategies to address stigma are critical for HIV prevention and education programmes and must extend into communities to be effective. As we have seen with gender issues, stigma reduction should also be mainstreamed into every aspect of education policies, programmes and practices.

1. Definitions of stigma and discrimination

Box 3 Quote from Regional Consultation on Stigma and HIV/AIDS in East and Southern Africa (2001)

"HIV/AIDS-related stigma is a real or perceived negative response to a person or persons by individuals, communities or society. It is characterized by rejection, denial, discrediting, disregarding, underrating, and social distance. It frequently leads to discrimination, and violation of human rights."

There are a number of definitions of stigma and discrimination which can help us to understand these complex issues.

Stigma: The holding of derogatory social attitudes or cognitive beliefs, a powerful and discrediting social label that radically changes the way individuals view themselves or the way they are viewed by others.

Discrimination: An action based on a pre-existing stigma; a display of hostile or discriminatory behaviour towards members of a group, on account of their membership to that group.

Disclosure: Refers to a process that results in a person living with HIV deciding to give others information about their status (and perhaps then also talking openly about living with HIV or AIDS). Disclosure is a positive response that has many benefits but it is made very difficult, or indeed impossible, in situations where stigma and discrimination are present. The benefits of disclosure could include:

- improved emotional and physical health through increased acceptance of status;
- better access to healthcare services and support;
- more opportunities to learn about HIV and AIDS;
- being able to enter into important discussions, e.g. about safer sex;
- becoming equipped to influence others to avoid infection;
- removing the mystery and silence surrounding HIV and AIDS;
- enabling others to show love and care.

These benefits in turn contribute to reducing stigma and discrimination. This cause and effect cycle where disclosure is compromised because of stigma needs to be broken before any real progress in terms of HIV prevention, treatment, care and support, and impact mitigation can take place.

2. Causes and types of stigma and the language used

The causes of AIDS-related stigma are multiple and include the following:

- Ignorance or insufficient knowledge, as well as misbeliefs and fears about HIV and AIDS.
- Moral judgements about people and assumptions about their sexual behaviour.
- Associations with 'illicit' sex and/or drugs.
- Fear of death and disease.
- Links with religion and the belief that AIDS is a punishment from God.

Self-stigma is, for example, self-hatred, shame, blame etc. Self-stigma refers to the process whereby people living with HIV impose feelings of difference, inferiority and unworthiness on themselves.

Box 5 Quote from stigma-aids e-forum

"The way I saw myself fundamentally changed within a matter of minutes. I thought that I was marked, different from everyone else. I felt dirty, ashamed, guilty (although I wasn't sure why I felt guilty; it just felt like an appropriate response)."

Felt stigma are perceptions or feelings towards a group, such as people living with HIV, who are different in some respect.

Enacted stigmas are actions fuelled by stigma and which are commonly referred to as **discrimination**.

Self-stigma

Manifestations of self-stigma include:

- feelings of shame, dejection, self-doubt, guilt, self-blame and inferiority;
- feeling that the person deserves to be in that particular situation;
- loss of self-esteem and confidence;
- social withdrawal and isolation;
- no longer dining with or expressing physical affection towards partners and family members;
- self-exclusion from services and opportunities, and refusing help that is offered;

- stopping work in the belief that one is no longer capable or worthy of employment;
- high levels of stress and anxiety;fear of disclosure;
- denial;

Self-stigma is worse when an individual:

- is first diagnosed (especially with no or limited emotional support at the time of diagnosis);
- has a limited support system;
- already feels minimal self worth (this includes when dual or multiple stigmas are present);
- has preconceived irrational or mythical beliefs about HIV and AIDS.

Overcoming self-stigma is assisted through:

- early referral to peer support;
- good quality pre-, post-test and on-going counselling;
- disclosure of HIV status to loved ones;
- encouragement to remain a productive member of the community;
- information about HIV and AIDS;
- access to antiretroviral treatment for those in need of medication;
- respect for the rights of all people diagnosed as being HIV positive;
- training and employment of positive persons.

Box 6 Extract from Siyam’kela: Measuring HIV/AIDS-related stigma – preliminary indicators

“Fear and moral judgement are considered to be the root sources of HIV/AIDS stigma. HIV/AIDS is associated with many different fears. People may fear the casual transmission of the virus, the loss of productivity of people living with HIV, that resources may be wasted on people living with HIV, living with the disease, or imminent death.

Similarly, moral judgement may cause stigma. people living with HIV are often seen as self-blaming and convinced that they deserve it because the transmission of the virus is linked to stigmatised behaviour, which allows people to understand HIV/AIDS in terms of the concept of blame. It is important to note that HIV/AIDS stigma can be experienced not only by people living with HIV/AIDS but also by people who are suspected to be living with HIV/AIDS ...” (POLICY Project, 2003b: 4).

Felt stigma

Stigma can be blatant or subtle, but it is always value-laden and compromises the human rights of those affected. Stigma is characterized by denial, ignorance and fear. Other features of stigma include:

- pointing out or labelling differences – "they are different from us";
- separating 'us' and 'them' – leading to avoidance, shunning, isolation and rejection;
- stereotyping;
- attributing differences to negative behaviour – "his sickness is caused by sinful or promiscuous behaviour";
- loss of status;
- overt abuse (may occur).

Enacted stigma

The effects of stigma are wide-ranging and may include actions taken by the person concerned in response to the stigma, and actions taken against the person concerned, which are discriminatory. Felt and enacted stigma can take many forms such as:

- physical and social isolation from family, friends and community;
- being kicked out of one's family, house, rented accommodation, school, and community groups;
- gossip, name-calling and insults;
- judging, blaming and condemnation;
- loss of rights and decision-making power;
- stigma by association – e.g. the whole family is affected by the stigma;
- stigma by looks/appearance/type of occupation;
- loss of employment;
- impaired access to treatment and care;
- dropping out of school;
- depression, suicide, alcoholism;
- avoiding getting tested for HIV;
- break-up of relationships;
- violence;
- loss of perceived 'manhood' or 'womanhood'.

Box 7 Extract from Love - and death - in the time of AIDS

“Love in the time of AIDS meant embracing death together for a married couple in West Bengal as the duo preferred to end their miseries instead of dying a little of humiliation everyday. (...) Probir and Basanti Sarkar were a happy couple since their love marriage four years ago. But in an infection apparently caused by blood transfusion, Basanti was recently found to be HIV positive. The ordeal began with friends, neighbours and even family members socially boycotting them after she was diagnosed as HIV positive. (...)It was alleged that Basanti was even prevented from boarding a cycle rickshaw by some neighbours because of her infection and no one wanted to provide the couple with a vehicle for taking her to hospital for admission. Probir, who was not infected, could not bear to see his wife living as a social outcast and after Basanti's discharge from hospital they took the drastic step. Thursday night after dinner, Probir gave his wife half a glass of poison and after he was sure that she had died, he hanged himself” (Indo-Asian News Service Kolkata, September 10th, 2005).

Box 8 Extract from stigma aids e-forum

"In 2001, the Tanzanian media published a story of a primary school girl who was HIV-positive and as a result was forced by the school authorities to wear a red ribbon to show her sero-status as a warning to other pupils. The story became the best seller but it was soon forgotten and there was no serious media follow up on measures taken against the headmaster or on the feelings of the girl after she was stigmatised in this most inhuman manner. The media only concentrated on the sensational part of this gross violation of human rights and did not even mention that it was stigmatisation – a discrepancy in reporting that reflects a serious problem in Tanzanian media involvement on AIDS issues" (HDN Key Correspondent Report, June 7th 2001).

Powerful metaphors related to HIV and AIDS reinforce stigma and re-affirm social inequalities, thus rendering already stigmatized groups even more stigmatized. Words like 'promiscuous' and 'risky' assign shame and blame and underline a moral tone that reinforces the notion of 'them' and 'us'. Words such as 'victim', 'AIDS carrier' and 'sufferer' stigmatize people living with HIV and create images of powerlessness. Prejudices are perpetuated by media portrayals of HIV-infected persons as helpless and hopeless. This media reporting compounds irrational fears and prejudices associated with HIV and AIDS by using the language of guilt versus innocence, and the metaphors of war and plague.

The impact of stigma is mediated by gender and its impact is experienced more by women than men. This is rooted in the current social constructions of sexuality and sexual relations. In many cultures, where women are frequently perceived as vectors of illness, AIDS is seen as a woman's disease. And, women may be blamed by their partners, families or community for not raising their HIV-positive son or daughter 'properly'. Similarly, children may experience stigma related to their own HIV status or because they live in an AIDS-affected household. The latter is very common and is known as 'secondary stigmatization' or 'stigma by association'. These children may:

- be perceived as 'innocent victims';
- be neglected/abused by their new 'parents';
- grow up without trust and love;
- become street kids;
- become introverted, or experience difficulty handling grief;
- experience depression, or loss of hope and a 'sense of future';
- be isolated by friends;
- effectively lose their childhood, as they are forced to accept adult responsibilities;
- not have access to school or any form of education.

3. Consequences of stigma and discrimination for programmes

Stigma and discrimination impede both willingness and ability to adopt HIV preventive behaviour, to access treatment and to provide care and support for people living with HIV.

- Fear of stigma impedes prevention efforts, including discussions of safer sex and preventing mother-to-child transmission. Because of the separation between 'us' and 'them', people avoid confronting their own risk and adopting preventive behaviours.
- Utilization of voluntary counselling and HIV testing (VCT) services and disclosure of HIV status are constrained because of the anticipated stigma and the actual experiences of people living with HIV.
- Resources like medicine, transport to health services, food and other amenities may be withheld because of a perception that people living with HIV are hopeless cases and will die anyway.

These represent just some of the barriers created by stigma. On the positive side, the process of disentangling stigma reveals many opportunities for interventions.

Box 9 Extract from Disentangling HIV and AIDS stigma in Ethiopia, Tanzania and Zambia

There are five critical elements that programmes need to address:

- creating greater recognition of stigma and discrimination;
- fostering in-depth, applied knowledge about all aspects of HIV and AIDS through a participatory and interactive process;
- providing safe spaces to discuss the values of and beliefs about sex, morality and death that underlie stigma;
- finding common language to talk about stigma; and
- ensuring a central, contextually-appropriate and ethically-responsible role for people with HIV and AIDS.

Source: Nyblade et al., 2003.

Box 10 Example of a workplace programme – from Positive Action at Work (Nairobi)

Positive Action at Work was launched on 29 November 2004 by the Kenya HIV/AIDS Business Council and the UK's National AIDS Trust. Positive Action at work seeks to address stigma as a barrier to successful implementation of comprehensive workplace HIV/AIDS programmes by using positive images in HIV awareness and education and by encouraging the discussion of prejudice and social exclusion.

Materials, developed with peer educators, are available on www.gsk.com/positiveaction/at-work.htm.

4. Policies and laws: human rights and education

At sectoral, national and international levels, policies, laws, and conventions can either enable access to services and to exercising rights, or they can inadvertently perpetuate discrimination and stigmatization.

Enabling and protective policies and laws

Most countries have now enacted policies and laws to protect the rights and freedom of people living with HIV and to safeguard them from discrimination. Much of this legislation has sought to ensure their rights to education, employment, privacy and confidentiality, as well as rights to access information, treatment and support.

In relation to education, the Convention on the Rights of the Child (CRC) commits signatory nations to strive to:

- make primary education compulsory and available free to all;
- encourage the development of different forms of secondary education; and
- take measures to encourage regular attendance at school.

Similarly, the **Millennium Development Goals** (MDGs) aim at:

- Universal primary education (UPE) by 2015: that all children, boys and girls alike, be able to complete a full course of primary education; and
- achieving gender equality: that girls and boys have equal access to all levels of education.

The AIDS epidemic represents a major challenge to the realization of these goals, not least because stigma creates enormous barriers to access to education and to gender equality, but also because this stigma and discrimination can create obstacles to prevention programmes in schools and in the workplace. As rights-based institutions, schools should play a major role in protecting pupils and teachers against discrimination.

Discriminatory and stigmatizing laws and policies

In many countries, stigmatization is expressed through laws and policies directed at those living with HIV that claim to protect 'the general population'. Examples of such discriminatory legislation include limitations on international travel and migration, compulsory screening and testing for HIV, compulsory notification of AIDS cases, prohibition of people living with HIV from certain occupations, and even isolation of people living with HIV from the general population.

Box 11 Comment from stigma-aids e-forum

"While nearly a million HIV-positive American citizens enjoy the freedom to leave and travel outside their country, the United States government prohibits HIV-positive individuals from other countries entry to the United States! Without a doubt, this ban is the most blatant display of discrimination against HIV-positive people to date! This ban continues to fuel discrimination, while a worldwide community strives to stop the stigma and discrimination surrounding HIV and AIDS!" (Bradford McIntyre, Canada).

In most cases discriminatory practises, such as the compulsory screening of 'risk groups', both further the stigmatization of these groups and create a false sense of security among individuals who are not considered members of such groups or who are at high-risk of contracting HIV. Conversely, enabling programmes and laws can have an *unintended* discriminatory effect on the beneficiaries rather than an enabling one. For example, healthcare workers may perpetuate stigma during treatment, counselling and care of people living with HIV. In an education-related example, in spite of the many national and international subsidies and support programmes to support orphans' education, children in Uganda were unhappy being singled out as orphans and said they felt ridiculed at school because of their subsidized uniforms or other forms of monetary assistance that made their status easily recognized (Munaaba, Owor et al., 2004).

Box 12 Inadvertently perpetuating stigma

"Socially excluded groups are often at great risk for discrimination. During interviews in Botswana, Uganda and Malawi, children orphaned by HIV/AIDS reported several cases of discrimination. Some children claimed they were sent home from school due to unpaid school fees, or untidy uniforms and some said they did not go for fear of being teased or unaccepted" (Bennell, Hyde and Swainson, 2002).

5. Confronting stigma and discrimination in the education sector

There are many forms of AIDS-related stigma and discrimination occurring in schools and ministries of education across the world, with perhaps the most prominent discrimination being termination of employment or refusal to offer employment based on an employee's actual or assumed HIV status. Other discriminatory practices involve:

- unequal training and/or promotion opportunities based on HIV status;
- inconsistent or absent practices to deal with instances of AIDS-related discrimination;
- breaches of confidentiality regarding an employee's HIV status.

Box 13 Examples from stigma-aids e-forum

My colleague told me he hated HIV, and people with HIV, because when they came to his desk he had to disinfect everything.

Someone suggested we should not recruit new staff from Africa because they'd all have HIV and die.

A staff member asked why someone was having their contract renewed since he was dying (in fact, although this person had HIV he was extremely healthy).

People in my team made jokes about AIDS assuming that nobody in the room had HIV.

Some people suggested we test everyone and put them into separate vehicles when we travel so that if there is an accident the 'innocent negative' staff won't be put at risk.

Team members suggested that people who are living with HIV were only hired because we felt sorry for them - implying they were not competent.

Box 14: 'Debbie' speaking to the National AIDS Trust, UK, 2002.

"My foster son, Michael, aged 8, was born HIV-positive and diagnosed with AIDS at the age of eight months. I took him into our family home, in a small village in the southwest of England. At first relations with the local school were wonderful and Michael thrived there. Only the head teacher and Michael's personal class assistant knew of his illness. Then someone broke the confidentiality and told a parent that Michael had AIDS. That parent, of course, told all the others. This caused such panic and hostility that we were forced to move out of the area. The risk is to Michael and us, his family. Mob rule is dangerous. Ignorance about HIV means that people are frightened. And frightened people do not behave rationally. We could well be driven out of our home yet again."



Activity 2

Stigma and discrimination in the education sector

- A. Consider how stigma and discrimination impact on HIV prevention, treatment, care and support, and impact mitigation programmes in your country for:
1. pupils.

 2. teachers and other education sector employees.
- B. Now select one impact on HIV prevention, one on treatment, care and support and one on impact mitigation and discuss possible interventions to prevent or reduce the impact.
- C. Can you think of other barriers that stigma produces within the education sector, such as how stigma can affect the following:
1. the implementation of a policy of universal primary education; or
 2. the morale and productivity of an infected teacher; or
 3. the learning environment of children from an affected community?
-

Effects of stigma and discrimination in the education sector

The effects of stigma and discrimination in the education sector can be very disruptive. For example:

- they can negatively affect teacher morale;
- they can result in reduced productivity (e.g. teacher absence);
- they can compromise employee health, in instances where stigma constitutes a barrier to access to treatment and care;
- they can result in the loss of human resources if infected employees leave;
- they will undermine HIV prevention programmes.

Local-level discrimination in the education sector

At the school level and in communities, children living in AIDS-affected households can be sent away from school, refused access to services and robbed of their property. We will discuss stigma and discrimination within the classroom further in this module.

Strategies

Education sector strategies to address stigma and discrimination in the workplace should include the following:

- Conducting an HIV and AIDS policy analysis to assess the extent to which policies address (or perhaps reinforce) AIDS-related stigma and discrimination.
- Informing all teachers, staff and employees of AIDS-related stigma mitigation policies and practices, so that there is widespread understanding of the consequences of discriminatory behaviour.
- Targeting prevention programmes specifically at school employees and staff in addition to programmes for students.
- Mainstreaming AIDS-related stigma mitigation policies into other functions, such as communication strategies and strategic plans.
- Protecting the rights of all employees who are infected or assumed to be infected with HIV and acting decisively when cases of stigma and discrimination do occur.
- Encouraging sensitivity and understanding among co-workers regarding AIDS issues.
- Encouraging HIV-infected teachers to disclose their status within a safe, accepting and supportive environment.
- Providing managers at all levels with clear guidance on which they can base managerial decisions when confronted with issues relating to HIV and AIDS.
- Ensuring that mechanisms are in place to protect the confidentiality of information related to teacher and staff health, including their HIV status.
- Involving people living with HIV in all workplace HIV and AIDS activities, as well as inviting them to share their experiences with parents and students.
- Encouraging school staff to form networks and associations with people living with HIV to promote acceptance and understanding.
- Monitoring the implementation of AIDS policies, including the stigma mitigation aspects of these policies, and monitor interventions for their sensitivity in relation to stigma.

Leadership within the education sector

HIV and AIDS leadership and visible and vocal commitment have enormous potential to address stigma and discrimination. These should be evident in three areas:

1. **Internally** – leadership on AIDS issues within the sector, the organization, and the school.
2. **Externally** – leadership with other stakeholders.
3. **Personally** – acting as a role model, for example by demonstrating solidarity with people living with HIV or getting tested for HIV.

Activity 3

Provision for AIDS-related stigma reduction in annual operational plans

Develop an objective that could be one of the objectives in the annual operational plan of your ministry and that clearly states the desired outcome in terms of a stigma-free working and learning environment.

Select some of the stigma reduction workplace strategies that would be appropriate in your ministry or at school.

Then, using a simple work-plan template that consists of the headings in the example table below, develop a work plan for one year that includes the step-by-step activities that relate to the selected strategies. For example, what are the steps necessary to undertake analysis of a stigma reduction policy?

ACTIVITY	TIME FRAME	RESPONSIBLE UNIT OR PERSON	OUTPUT/ OUTCOME

6. Education as a tool to counter stigma and discrimination in the classroom

Education has a key role in lessening stigma and discrimination. It can affect change where the law cannot, such as in families and among friends. Furthermore, people working in education are ideally placed to pass on information that challenges the stigma related to HIV and AIDS.

UNAIDS differentiates three types of education to promote HIV prevention and awareness:

- **Public education:** Information provided to the general public to increase knowledge of the disease. Can be done through media campaigns, newsletters.
- **Professional education:** By changing the attitudes of respected professionals, this can have positive effects on the behaviours and attitudes of others around them. An example would be workplace interventions within your ministry.
- **Targeted or focused education:** This refers to education programmes tailored to specific communities and groups, such as teen groups, workplace groups, religious groups or women's groups.

Box 15 Extract from the Conference on HIV/AIDS and the Education Sector

“My name is Mpho from the North West Province (South Africa), and I’m seventeen years old. I believe that teachers can have a huge impact on the lives of learners who are affected and infected by AIDS. I lost my mother and a sister in 1999 and in 2000 I was raped by my father. A year later I discovered that I’m HIV positive. The first person who knew about this was a teacher and the attitude that she had is the cause of my positive living in life” (South Africa Department of Education, 2002: 10).

Prevention programmes must take into account the messages students are receiving from the community and at home. If not, the fears and misunderstandings that create stigma and cause discrimination will be perpetuated. If education is the best means of stopping the spread of HIV, these prevention programmes must successfully break this cycle.

Box 16 Addressing stigma and discrimination through education

An effective way to address stigma and discrimination is through training and educating people and children about HIV and AIDS and about the causes and effects of stigmatization and discrimination. Below are some examples of education programmes that were effective in diminishing stigmatization.

Prevention in schools through peer education

HIV/AIDS life skills day camps (Tanzania)

Designed by Global Service Corps and based in Arusha, these camps provide a framework for secondary school students to learn about HIV/AIDS, prevention, relationships and sexuality in a fun, creative, and ultimately sustainable manner. A primary goal of the camp is for the participants to form health clubs in their respective schools to share their knowledge of HIV/AIDS with the rest of the school. This way the discussion of HIV/AIDS can be continued throughout the year.

Peer education and theatre

Tabor Wegagen Anti-AIDS Association (Ethiopia)

A programme established in conjunction with UNICEF over six years ago by a group of young people who came together to inform their peers about HIV and AIDS. Using the principles of peer education, the groups share information on HIV prevention and also engage in sensitization activities, such as theatre, to diminish stigma and discrimination.

Activity 4

Stigma and discrimination at school

A) First read the three questions from a Save the Children UK study. Concentrate on how stigma impacts on the education and well-being of these children. Focus on who is stigmatized and by whom; where within the learning environment; and why – the context and causes.

1. "They are laughing outside of the class. They laughing at the fact that her mother has AIDS. She is angry and going away. She feels angry and she also feels like beating them but she knows they will report her at the office."

2. "You are afraid the teachers will tell all the other children at assembly. Then other children will start playing cruelly with you and tease you that your mother has got AIDS. Just like the one that I share a seat with. She shifted and sat somewhere else in the class after I told her. Then she went to tell the class teacher."

3. "Sometimes they'll chase us back home if we don't have exercises (books). They say they will chase us away, it is not their problem."

B) Now consider what a school could do to (a) prevent situations of stigma and discrimination from occurring and (b) to respond if they do occur. Make a note of your ideas below.



Summary remarks

Stigma and discrimination are pervasive and destructive, and need to be recognized as significant obstacles to any effective education sector response to HIV and AIDS. Stigma is a systematic process that reinforces existing divisions in society. Discrimination can take away a person's rights. They are, however, difficult to tackle due to their dynamic nature; changing both when an individual progresses from HIV to AIDS and as the epidemic evolves in a learning community. Understanding the causes and consequences of stigma, as well as the different forms of stigma, can offer opportunities to challenge and reduce stigma and discrimination. There are a number of practical actions that an education sector or institution can take to create a caring, enabling, supportive and stigma-free environment, the benefits of which will rapidly become apparent.



Lessons learned

Lesson One

Stigma and discrimination are different but interrelated phenomena involving negative attitudes about a person or group of persons, and the actions resulting from the holding of these negative attitudes.

Lesson Two

Stigmatization and discriminatory behaviour are hampering Education for All and Millennium Development Goals.

Lesson Three

Failure to understand the types, features and effects of stigma will jeopardize HIV prevention programmes.

Lesson Four

Education has a key role in diminishing discrimination and supporting the rights of all children.

Lesson Five

Stigma is an obstacle to successful prevention programmes and policies. These programmes and policies can unintentionally reinforce stigma and discrimination.

Lesson Six

Education sectors should define the strategies to challenge and reduce stigma – in learning situations and throughout the sector – and should ensure that these become an integral part of their overall AIDS response.



Answers to activities

Activity 1

There is no one answer to this activity and you may want to discuss your answers with a colleague or mentor. Alternatively, referring to the section 'Causes and types of stigma and the language used' might be useful. You may also want to try to analyze the language in one or two media articles about AIDS and decide if it is 'enabling' or 'discriminatory'. The two essays now published as a book, *Illness as metaphor and AIDS and its metaphors* (Sontag, 2001), also give some interesting insights into the language we use when talking about illness and more especially AIDS. See also *Presentation of self in everyday life* (Goffman, 1990)

Activity 2

- Teachers, other staff and pupils may not take personal protective action, despite receiving consistent correct prevention messages, as a result of perceiving AIDS to be a 'problem of those other people'.
- Infected staff may resist accessing treatment for fear of being identified as infected and being stigmatized as a result. Affected families may not apply for fee exemptions for their children for fear of being labelled.


Activity 3

- Supervisors and managers could attend sessions that focus on managing situations of stigma and discrimination against staff who are infected (or perceived to be infected).
- Policies, practices, protocols, etc. could be reviewed to ensure that they do not, even inadvertently, reinforce stigma.
- A person living with HIV, who is open about his/her status, could be given opportunities to interact with groups to open the debate and challenge some of the myths and misconceptions that feed stigma.

Activity 4

- Invite schools, teachers and other staff to provide pupils from affected families with uniforms, lunches, books, etc. so that they are the same as all other pupils (as being different often feeds stigma).
- Help address stigma by ensuring access to education for all members of society, including orphans, girls and youth.
- Affirm and show visible support for pupils and teachers who are infected or affected (i.e. becoming a positive role model) will challenge stigma.
- Make schools 'safe places' where discrimination is not tolerated and where information is given to continue awareness.
- Have established referral procedures in place for teachers as well as clearly defined roles with respect to social and health workers to access the services needed to support vulnerable children.

- Be sure to consider human rights as the basis for education and prevention campaigns against HIV and AIDS.
- Participate in wider community-based activities that challenge stigma and discrimination. Children and communities need to be involved in the decision-making process when developing support programmes for poor and vulnerable children.
- Involve people living with HIV in school and community activities to promote a greater understanding of their situation and to diminish stigma and misconceptions about how HIV is spread.
- Consider your schools' activities within the context of the community and/or related NGO activities within your country.
- Institute forms of participatory training for pupils, teachers and education sector staff. Use peer groups which have been proven effective.
- Take early and decisive action to address instances of discrimination.



Bibliographical references and additional resource materials

Documents

- ACORD. 2004. *Unravelling the dynamics of HIV/AIDS-related stigma and discrimination: the role of community-based research*. Case studies of northern Uganda and Burundi. www.acord.org.uk/b-resources.htm
- Bennell, P.; Hyde, K.; Swainson, N. 2002. *The impact of the HIV/AIDS epidemic on the education sector in sub-Saharan Africa: A synthesis of the findings and recommendations of three country studies*. Brighton: Centre for International Education, University of Sussex.
- Goffman, E. 1990. *Presentation of self in everyday life*. New York: Anchor.
- Kidd, R.; Clay, S. 2003. *Understanding and challenging HIV stigma: Toolkit for action*. Washington, DC: The Academy for Educational Development/The CHANGE Project. www.changeproject.org/technical/hivaids/stigma.html
- Munaaba, Owor et al., 2004. *Comparative studies of orphans and non-orphans in Uganda*. Boston: Center for International Health and Development, Boston University School of Public Health.
- Nyblade, L.; Pande, R.; Mathur, S.; MacQuarrie, K.; Kidd, R.; Banteyerga, H.; Kidanu, A. 2003. *Disentangling HIV and AIDS stigma in Ethiopia, Tanzania and Zambia*. Washington, DC: The Academy for Educational Development/CHANGE Project. www.icrw.org/docs/stigmareport093003.pdf
- Parker, R.; Aggleton, P. 2002. *HIV/AIDS-related stigma and discrimination: A Conceptual Framework and an Agenda for Action*. Horizons Program. www.popcouncil.org/pdfs/horizons/sdcncptlfrmwrk.pdf
- POLICY Project. 2003a. *Siyam'kela. HIV/AIDS-related stigma: A literature review*. Cape Town, South Africa: USAID; POLICY Project/South Africa; Centre for the Study of AIDS at the University of Pretoria; Chief Directorate: HIV, AIDS & TB, Department of Health. www.policyproject.com
- POLICY Project. 2003b. *Siyam'kela: HIV/AIDS Stigma Indicators: A Tool for Measuring the Progress of HIV/AIDS Stigma Mitigation*. Cape Town, South Africa: USAID; POLICY Project/South Africa; Centre for the Study of AIDS at the University of Pretoria; Chief Directorate: HIV, AIDS & TB, Department of Health. www.policyproject.com
- POLICY Project. 2003. *Siyam'kela. Measuring HIV/AIDS-related stigma – tackling HIV/AIDS stigma – guidelines for the workplace*. Cape Town, South Africa: USAID; POLICY Project/South Africa; Centre for the Study of AIDS at the University of Pretoria; Chief Directorate: HIV, AIDS & TB, Department of Health. www.policyproject.com
- POLICY Project. 2003. *Siyam'kela. Measuring HIV/AIDS-related stigma – preliminary indicators – workshop report*. Cape Town, South Africa: USAID; POLICY Project/South Africa; Centre for the Study of AIDS at the University of

Pretoria; Chief Directorate: HIV, AIDS & TB, Department of Health.
www.policyproject.com

Save the Children (UK). 2001. *The role of stigma and discrimination in increasing the vulnerability of children and youth infected with and affected by HIV/AIDS*. UK: Arcadia.

Sontag, S. 2001. *Illness as metaphor and AIDS and its metaphors*. USA: Picador.

South Africa Department of Education. 2002. *Report and Plan of Action*. Government of South Africa- Department of Education, Plan of Action: *Improving access to free and quality basic education for all*, June 14, 2003.

UNAIDS. 2003. *HIV/AIDS-related stigma and discrimination and education fact sheet*. Geneva: UNAIDS.

UNAIDS; HDN; SIDA. 2001. *Advocacy for action on stigma and HIV/AIDS in Africa*. Regional Consultation Meeting on Stigma and HIV/AIDS in Africa, 4 - 6 June 2001, Dar-es-Salaam. www.hdnet.org/Stigma/Advocacy%20Statement%20-%20final.htm

USAID. 2004. *Big issues in brief: Scaling up responses to HIV/AIDS: Stigma and HIV/AIDS – a pervasive issue*. Washington, DC: Synergy Project.
www.synergyaids.com/documents/BigIssues_StigmaRevDec04.pdf