

change learn empower

ACT now!

human rights

speak up

respect

equality

a
resource guide
for young
women on HIV/AIDS



United Nations
Development
Fund for Women



The Association for Women's
Rights in Development

UNIFEM is the women's fund at the United Nations. It provides financial and technical assistance to innovative programmes and strategies that promote women's human rights, political participation and economic security. UNIFEM works in partnership with UN organizations, governments and non-governmental organizations (NGOs) and networks to promote gender equality. It links women's issues and concerns to national, regional and global agendas, by fostering collaboration and providing technical expertise on gender mainstreaming and women's empowerment strategies.

The Association for Women's Rights in Development (AWID) is an international membership organization connecting, informing and mobilizing people and organizations committed to achieving gender equality, sustainable development and women's human rights. AWID's goal is to cause policy, institutional and individual change that will improve the lives of women and girls everywhere.

The views expressed in this publication are those of the authors, and do not necessarily represent the views of UNIFEM, the United Nations or any of its affiliated organizations.

Act Now: A Resource Guide for Young Women on HIV/AIDS

ISBN: 0-912917-64-4

© 2002 United Nations Development Fund for Women
United Nations Development Fund for Women (UNIFEM)
304 East 45th Street, 15th Floor
New York, NY 10017
USA
Tel: (212) 906-6400
Fax: (212) 906-6705
E-mail: unifem@undp.org
Website: www.unifem.undp.org

Text and Moderation of Discussion List: Sisonke Msimang and Shamillah Wilson

Editorial Assistance: Jennifer Cooper

UNIFEM and AWID would like to thank the hundreds of members of AWID's Young Women's Leadership Email List for their valuable contributions to the discussion.

Cover and Book Design: Linda Helfet, NewsDesigns



Table of Contents

Introduction	2
Why is HIV/AIDS a Gender Issue?	3
Behaviour Change and Gender Norms	5
Education and Sexual and Reproductive Health Services	6
Summary	8
Just the Facts	9
Getting the facts	10
Myths and Rumours	10
Summary	12
The Global Picture	13
Treatment	15
Stigma and Discrimination	15
Summary	17
Collective Responses to HIV/AIDS	18
Women's Organizations	19
Resources for Youth	20
Summary	21
Putting it All Together:	
Recommendations for AIDS programmes	22
Best Practices	23
Appendix	25
Planning an HIV/AIDS Workshop for Young Women	29
Facilitators Guidelines	30
Running the Workshop	32
Focus on the Facts	33
Handout 1A	34
Handout 1B	35
The Problem Tree	37
Choosing a Project	38
Developing a Plan of Action	39
Handout 2	40
Endnotes	42

Introduction

In February 2002 UNIFEM and AWID launched an on-line discussion aimed at young women.



EMAIL DISCUSSION: “Young Women and HIV/AIDS”

February 18, 2002 – March 8, 2002

The Association for Women’s Rights in Development (AWID) and the United Nations Development Fund for Women (UNIFEM) co-hosted a three-week email discussion on YOUNG WOMEN AND HIV/AIDS. Moderated on AWID’s Young Women and Leadership (YWL) list-serve, the discussion explored the following:

- (i) Intersections between youth, gender and HIV/AIDS
- (ii) Emerging challenges and successes in HIV/AIDS for young people (particularly young women)
- (iii) Ways in which youth can participate in addressing gender and youth issues in HIV/AIDS programs

The YWL list serve is a vibrant on-line forum for young women interested in human rights and development issues and individuals identifying with the concerns of young women’s rights. The primary aim of the list is to share ideas and important information and initiate debates on issues that affect young women in their different contexts. The forum also exists to provide a space for young women to articulate their visions and perspectives for the advancement of the women’s rights and social justice agenda internationally. Though the discussion on young women and HIV/AIDS has concluded, you are welcome and encouraged to participate in upcoming discussions on topics that are of concern to you. If you have access to the Internet, you can subscribe to the YWL list-serve by email: ywl@awid.org

For more information on AWID’s work, go to: <http://www.awid.org>

During the three weeks of the discussion, the list received an avalanche of messages from women all over the world. In total there were 500 participants. They told us their thoughts and opinions, shared stories and gave concrete examples of the work they are all doing to bring an end to gender inequality and HIV/AIDS.

Mindful of the fact that only a fraction of the world has access to the Internet, and committed to linking cyberspace to the “real world,” we decided to put together a booklet based on the on-line discussion. The result is *Act Now: A Resource Guide for Young Women on HIV/AIDS*.

This booklet is targeted at young women who are leaders in their communities. It provides an overview of the on-line discussions, highlights and profiles young women’s leadership in HIV/AIDS, and provides useful activities for those who want to start campaigns to raise awareness and decrease stigma in their communities.

We hope you enjoy reading the guide and doing the exercises as much as we have enjoyed gathering the information and resources that are in it.

Shamillah Wilson, AWID, Shamillah@awid.org

Sisonke Msimang, UNIFEM, sisonke.msimang@undp.org

Why is HIV/AIDS a Gender Issue?

We open our discussion with the issue of gender because it is central to an understanding of how HIV/AIDS functions. The epidemic is growing among women, with infection rates on the rise. There are very specific reasons for this fact, which we shall see below. In order to reverse this trend an understanding of gender is crucial.



ISSUES FOR YOUNG WOMEN

HIV is a gender issue because the underlying causes and consequences of HIV infection are shaped by whether you are a man or a woman. There are five broad challenges young women face regarding HIV/AIDS, and each is intrinsically linked to gender.

1. The Gender Double Standard

Gender norms often reinforce young people's unsafe sexual attitudes and behaviors. Young women often fear that seeking information will make them look like "bad girls." Young women in Thailand reported that being knowledgeable about sex would compromise others' views of them. Also boys are affected by gender norms. Young men are expected to be knowledgeable, so they don't ask questions either. In Kenya, a quarter of boys surveyed did not know where they could obtain a condom. And a study undertaken in Guatemala revealed a widely held perception that having numerous sexual partners was a necessary feature of a young man's physical and mental development.

2. Policies and Laws Preventing Access to Reproductive Health Information and Services

In many countries young people aren't allowed to buy or use contraceptives until the age of 18. Girls and young women are often considered too young to be having sex unless they are married - and thus are often barred from life saving information and services about their sexual and reproductive health and rights. In the past 10 years there has been a huge debate about whether young people should be allowed to receive reproductive health information, contraceptives and services. The 1990 Convention on the Rights of the Child declares that every child has the right to health care. Activists have extended this to include reproductive health.

3. A Question of Biology?

Much has been made of women's biological vulnerability to HIV transmission. Studies in some African communities indicate that rates of infection among young women between 15 and 19 years of age may be as much as six times the rates among young men. But is biology really the culprit? Yes and no. Girls' less mature genital tracts are more likely to tear during sexual intercourse than older women's. Also, many women and girls have sexually transmitted infections (STIs) without knowing it due to failure to recognize the symptoms. For men, the symptoms of most STIs are easier to recognize. Because the presence of STIs facilitates the





HIV transmission, women often unknowingly stand at higher risk than men. However, social factors compound biological ones. Many young women and girls are coerced into sexual relationships before they are ready. Gender norms make it difficult for girls to negotiate the terms of sexual activity. They are far more likely than boys to be involved in sexual relationships in which there is a significant age gap, and older men are much more likely to be infected than younger men, thus increasing young women's chances of infection.

4. Caring/Working for Families

Girls and young women feel the impact of HIV/AIDS at a family level. Many adolescent girls are responsible for increased housework, as well as for the care of sick family members. As a result, they are withdrawn from schools at a higher rate than boys. Surveys indicate that compared with women who have some post-primary schooling, women with no education are five times more likely to lack basic information about HIV/AIDS, and illiterate women are three times more likely to think that a healthy-looking person cannot be HIV-positive. The long-term effects of this lack of information have the potential to destabilize societies and reverse the gains made in educational enrolment and gender equality in many parts of the world over the last few decades.

5. Child-headed Households

A generation of orphans is now raising children. The gender implications of growing up in a child-headed household have yet to be measured, but it is clear that children who are orphaned are less likely than others to stay in school. Girl children and young women who are orphaned often resort to survival sex to fend for themselves and their younger siblings. At the same time, traditional gender roles are destabilized, and there are opportunities to develop new ways of constructing gender roles.

Questions

1. Behaviour change is said to be the most difficult part of HIV/AIDS efforts. Why do you think this is?
2. How do gender norms contribute to increased risk for HIV infection?
3. What do you think young women and young men have a right to know regarding HIV/AIDS?



Behaviour Change and Gender Norms

Behaviour change and harmful gender norms pose tough but essential challenges in the fight against HIV/AIDS. Participants in the on-line discussion agreed.

While individual behaviour change should be a focus of HIV/AIDS prevention programmes, discussants were very aware that long-term behaviour change must take into account the gender dynamics of our societies.

As Maria De Bruyn from the United States of America put it, not only girls, but boys are negatively affected by gender norms:

My experience is that even young teens can recognize and begin to analyze the impact of gender-biased norms on their lives, and potential risks.... As one young man who participated in a workshop that I facilitated said, "Sure, I would like to be sensitive to girls, but my friends would all laugh at me." Working to create enabling environments is SO important.

Thieva Lingam from Malaysia suggested that much of the responsibility for behaviour change should be shouldered by schools:

I was reading the comment by Maria De Bruyn, and I agree that behaviour change is the most difficult part of HIV/AIDS effort....[I]t is... a taboo to include sex education as part of the school syllabus because authorities are worried about what kids these days would do with the information. They fail to realize that only proper education will stop the rot right from the beginning. I have facilitated youth workshops on HIV/AIDS, and I found that many young girls engaged in unprotected sex and did not know the dangers. Most of them even shy away from identifying male and female anatomy. Basic issues such as these must be tackled early to avoid misconceptions and mistakes. We must train people from a young age and make them understand gender-sensitive issues. Only when they realize and appreciate these issues, will we be able to see some changes.

Writing from West Africa, Jennifer Scharff gave valuable insights on the effects of gender norms on girls in terms of the burden of domestic labour. She stressed the need for education and empowerment. But she also suggested that families need to get boys involved.

Boys can make it very hard for girls to go to school. They often tease girls in class. Or they run off to study and yell at their sisters when they come back and the meal is not yet prepared. Boys put a lot of pressure on girls. And it is these boys who they will be having sex with, now or in the future. Boys need to know that if a girl knows how to use a condom, she is not dirty, she is smart.

It is not through girls alone, or their families, that we can reach our goal. The whole community should be implicated. Little by little, as more and more educated women come from smaller and smaller villages, people will begin to see that their girls, too, have amazing potential.



Banu Khan wrote from Kenya about the consequences for the future when young people are forced to drop out of school.

I think that programmes need to be broader in outlook such that there is more to them than just providing information on issues. In Kenya, we have a population of over 30 million people, half of whom live below the poverty line. Many young people drop out of school because they can't pay the fees and to care for their families I feel that there is an urgent need to empower young people economically by providing them with life options that will not constrict their economic well-being.

Vanessa Von Struensee let us know how much more complicated behaviour change is in societies that are in transition. Based on her experiences in the Ukraine, she wrote:

In general, these are communities which have suffered the most from economic decline. In some regions of Ukraine, the levels of unemployment and de-industrialization are much higher than the country's average. The heavily industrialized Dnepropetrovsk, Donetsk, Zaporozhje, Lugansk and Kharkov oblasts will perhaps suffer most of all In Ukraine, this transition has been traumatic on so many levels. People are not clear as to what it is reasonable to expect of each other, what are "correct" or "acceptable" values, and how and where to organize to achieve the goals they desire.

Rounding up the discussion, Lia De Pauw made her point succinctly and powerfully.

It rapidly becomes apparent that the amount of control an individual has over their health is very limited. And in order to encourage people to change risky behaviours, environments that support health must be created. This means focussing on things like poverty, harmful gender norms and cultural beliefs/practices, etc.

Because gender inequality makes young women and girls more vulnerable to exploitation, poverty and ill health, young women activists have a critical role to play in actively advocating for governments and communities to make real the rights agreed to on a global level. For a more in-depth look at the international agreements that promote and protect human rights, see Appendix A.

Education and Sexual and Reproductive Health Services

While behaviour change was considered important to discussants, access to information and sexual and reproductive health services for youth were hotly debated. Lia gave a comprehensive response about what she feels young women have a right to know about HIV/AIDS.

I think that young women and men have the right to factual information about HIV/AIDS: what it is, how it is transmitted, and how the level of harm associated with risk activities - sex and substance use - can be reduced. This means removing the culturally based value and belief systems (e.g., abstinence as the only option) from education. It means valuing the lives of people over their adherence to cultural and societal ideals. And it means trusting



...that people are capable of making the best choices possible for their life and situation.

Across the world in South Africa, Naume Ziyambi weighed in. She argued that the availability of protection and the choice of method were directly related to use. Increasing the availability of protection requires adequate support from governments and communities. According to Naume:

The decision to engage in less risky sexual behaviour needs to be supported by availability of protection. A survey of the pharmacies in my area found that most of them do not stock the female condom, the reason being that not many women ask for them. It then becomes a cycle: People who might have tried them become discouraged, and the demand for them may never grow.

However, not everyone agreed with Naume. Claudia Shilumani suggested that

Making condoms available does not necessarily mean that they will be used, otherwise we would see a decline in the number of new cases of HIV infection. But the opposite happens. I think the ABC principle should be strengthened until we can come up with the best solution, more especially the AB.

A = Abstain

B = Be Faithful

C = Correct, Constant Use of Good Quality Condoms

But this comment by Claudia also proved to be contentious. Abbey Hatcher wrote:

I would like to comment on the effects of following ideologies like strengthening the ABC principle. As an advocate for social change and improved health, I find it detrimental to filter the AIDS crisis through a lens of puritanism or heightened chastity. While ideals of abstinence, utmost faithfulness, and regular condom use are desirable and would certainly impact transference of STIs, it seems conservative and reactionary to hope that preaching moral changes will lessen the catastrophe of the AIDS epidemic.

Wanjiru Mukoma suggested adding a "D" to the ABCs and stressed the need to fit education into a community context.

We have shifted focus from categorizing risk as high, medium or low risk.... Rather, we focus on the fact that there is a risk in any act during which there's exchange of fluids that can transmit HIV. And to the ABC, the students that run our peer education programme have added a "D" that stands for DIY - Do It Yourself (There are) ways of having a healthy and fun relationship without penetrative intercourse.

I think it's time we stopped counting on some curriculum recipe written in some other place and worked with the resources and assets available in our communities, taking into consideration that most of what works depends mostly not on whether we followed the curriculum and applied the correct recipe, but rather on how well it responds to the context and is therefore acceptable to the community concerned.



While the debate over education and access to sexual and reproductive health services continues, it is important for young people to contribute to the dialogue. By voicing your opinions, as in the on-line forum, you can have a say in the creation of programmes that will address your needs.

Summary

Participants agreed that while it is important to examine individual attitudes, behaviours and ideas, it is critical that successful behaviour change programmes take into account all of the environmental factors that limit or facilitate healthy decisions. Self-esteem, assertiveness and the ability to make decisions based on what works best for the individual are profoundly connected to the individual's environment. Young women who are poor, illiterate or uneducated, who are married or in abusive relationships or who are injecting drug users all face different situations that stem from larger cultural circumstances.

Discussions of gender norms and HIV/AIDS also consider the environment of the household and the impact that caring for the sick has on girls and young women. Despite our attempts to focus the discussion on this issue, there were few direct comments in the on-line forum, demonstrating the highly invisible nature of this work. As children are stretched beyond the breaking point, heading families orphaned by poverty and AIDS, we cannot lose sight of the intersection between the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) and the Convention on the Rights of the Child (see Appendix). Every child has a right to education, health and a happy family life. Pulling boys in to alleviate the burdens of girls is a short-term and less than ideal solution. Parents, community leaders, teachers, all of us can carry forth the message: Adults need to care for children. It is both unfair and against international law for girls or boys to lose out on opportunities because they are caring for sick family members.

Programmes based on the solid foundation of international human rights agreements that seek to alter the environment in which young people learn and grow work best when they take an approach that is holistic. They offer support and services for a range of issues like substance abuse, violence and unwanted pregnancies. Human rights agreements and international plans of action such as those listed in Appendix A provide a basis from which to address the larger issues facing young people. They ask governments to agree to ideals and then commit them to putting in place the laws, services and programmes to achieve these ideals. While changing gender norms and risky behaviours can be tackled one mind at a time, programmes that ask young people to delay sex and/or only have protected sex, can only succeed where there is a human rights environment that recognizes young people's confidentiality, their need for services related to their sexual and reproductive health and the reality that sometimes they cannot make the choices they would like to make. Obviously the larger goal of all of us who work on AIDS is to make sure that young women and men have options and choices, not just about whether to have sex, but about health, education and all of those other issues that influence their decisions about sex.

Now we turn to a focus on the facts (see Resource Guide Handout 1 for a comprehensive list of facts about HIV/AIDS). According to the Joint United Nations Programme on HIV/AIDS (UNAIDS), too many young people still don't know some of the most basic facts about HIV/AIDS. Almost two thirds of sexually active girls aged 15–19 in Haiti do not believe they can get HIV, and more than 50 per cent of girls in the same age group in Zimbabwe agree with this. In Mozambique, 74 per cent of young women and 62 per cent of young men aged 15–19 are unaware of one single thing they can do to protect themselves against AIDS.

So, to kick things off, we posted a short description of what HIV/AIDS is and how it works, followed by a few questions.



LET'S TALK ABOUT SEX AND HIV/AIDS:

HIV (Human Immunodeficiency Virus) is a virus that weakens the body's defense (immune) system until it can no longer fight off illnesses. HIV infects and kills the cells (CD4- or t-cells) in your body that direct your immune system to defend against infection. When your CD4 count is less than 200 (an average CD4 cell count in a healthy immune system is 1,150), you are considered to have AIDS.

The virus is transmitted through semen, pre-ejaculate fluid, blood, vaginal secretions and breast milk. It is overwhelmingly a sexually transmitted disease, but can also be transmitted by sharing needles, including those used for injecting drugs.

To avoid HIV infection you can take any or all of the following steps:

- Abstain from sex
- Only have sex using a male or female condom
- Only have sex with an HIV-negative partner (but you must be **100% CERTAIN**, and the only way to confirm your HIV status is to get tested)
- Stay away from used or dirty needles

If you are even slightly unsure about the risk of infection, use a latex barrier. **There is no cure or vaccine for either HIV or AIDS.** But there are drug treatments that can help people with HIV stay healthy longer and delay the onset of AIDS. These are called anti-retrovirals (ARVs) and are widely available only in developed countries.¹

Questions

Do you have any questions about the facts of AIDS?

Do you trust that condoms are effective?

Do you think that young people in your community know the basic facts?

Do you think that they take steps to protect themselves?

What are some of the myths and rumours about AIDS?



Getting the Facts

Writing from Uganda, Agnes Yawe sent the following message:

There are so many young people especially in developing countries like Uganda, my homeland, who do not know the basic facts about HIV. The situation in our countries is a lack of information communication channels like the opportunity I have now to read about the international experience using such discussions. So many of my brothers and sisters do not have access to these opportunities. Also, there is social, cultural hindrance in families when parents do not discuss sexuality. The feeling that these are still young people who should not be involved in such discussions has done more harm than good, yet peer pressure is increasingly exposing the young people to HIV/AIDS dangers.

Mia Roman, from the United States, voiced a similar concern about lesbian, gay and bisexual youth:

I'm concerned that these ...groups are not completely aware of or feel indifferent about the issues surrounding HIV/AIDS and other STIs including the rate at which they are increasing, the groups vulnerable, access to contraceptives/forms of protection and more. Many queer women I've met, have a general attitude that they are not vulnerable to contracting HIV, which outrages and concerns the heck out of me.

Adding her voice, Jennifer Scharff, a volunteer at a school in West Africa, argued that young people don't know the facts about AIDS because the truth is hard for the community as a whole to face. She wrote:

The local hospital will never say someone died of AIDS. They don't have to. They die of malaria, tuberculosis, fatigue. Never AIDS. Populations are shocked to learn that AIDS has surpassed malaria as a killer in developing nations. There are so many widespread myths and rumours regarding AIDS and condom use that the only feasible way to battle is to get out there and talk to people.

Many factors inhibit the spread of correct information about HIV/AIDS. Many of them stem from a denial of the problem and a desire to exclude young people from the debate. However, as participants realized, lack of awareness about the facts of HIV/AIDS puts lives at risk.

Myths and Rumours

Participants agreed that they had all heard myths about AIDS that are detrimental to efforts to fight the epidemic. For example, Clara Anyangwe from Cameroon commented:

Some ethnic mbororos believe that once a leader string (called a laya) is tied around the waist of a man, he can never become HIV positive. [Another



myths that] the virus came out of American laboratories. Still other people imagine you get the disease if bewitched or poisoned!

While these myths may sound silly or strange to some people, it is important not to dismiss them. Myths are an important part of how societies understand themselves. AIDS is a relatively recent phenomenon, and as people struggle to understand why so many are getting sick and dying, they turn to familiar traditions and ideas about bad luck or to spirituality. If you live in a community where people believe that AIDS can be cured or prevented in a way that does not involve condoms or abstinence, try to think about creative ways of getting the right information across to them to work within their belief system.

The most important reason not to ignore myths is the fact that they affect the way people behave. According to Lia De Pauw in Canada,

The myth in Canada about HIV/AIDS as a disease of gay men and injecting drug users has contributed to a situation where women and heterosexual men do not consider themselves at risk for HIV infection. This has an impact on prevention and testing. Heterosexuals generally do not consider themselves at risk (or at least not as at-risk as gay men) and are not as careful with prevention as they should be.

Lia's statement was reinforced by Jennifer Fanuel from Tanzania, who wrote:

There is a big debate whether using condoms is really a way of protecting oneself from contracting AIDS. Since condom campaigns began, HIV cases have increased terribly. The community still wonders whether condoms provide protection.

Jennifer's allusion to a belief among some people that there might be a relationship between using condoms and getting HIV/AIDS is very useful. A number of people associate condoms with HIV/AIDS and think that it is the condoms themselves that carry the virus. Therefore, condoms are seen as dangerous, and in order to avoid infection, people will often avoid them. Others think that using a condom is like admitting that you have HIV/AIDS. In order to avoid the stigma, young people might refuse to engage in safer sex.

In order to combat myths, it is important that you understand where they come from. The idea that condoms carry AIDS can be easily associated with a deep distrust some people have for foreigners from Europe and America, especially wherever colonialism, racism and exploitation are part of local history. As Clara explained in Cameroon, "AIDS = American Idea to Discourage Sex." This acronym can be found in other parts of Africa, where it is used as both a joke, and an indication of people's ignorance and fear.

Strategies that attempt to provide good information have to take such issues of distrust into account by addressing the root problems at the same time that they give out the facts. For example, if you know that in your community there is a very low level of knowledge about HIV/AIDS and how it is transmitted, you need to figure out why people don't know. Sometimes, even when the facts are



available, people don't believe them because the facts contradict their way of thinking. If people believe that headaches are caused by wicked women who bewitch villagers, why would they believe that AIDS is caused by a virus? It wouldn't make sense. You need to work with friends and teachers to explain that many ailments have other causes.

A good way to think through these issues is to develop a problem tree. Exercise 3, in the attached guidelines provides instructions for running a session that helps to identify problems, their root causes and their consequences.

Summary

The comments above highlight the need to develop approaches to packaging facts so that they take into account the differences between young people. In addition, many participants pointed out the need to focus in particular on information for young women. We know that literacy levels in many parts of the world are lower for girls than for boys. We know too that many more taboos surround girls' and young women's sexuality than young men's and boys'. Therefore, as we think about the facts, it is important to think about how to convey them in a manner that is girl-friendly.

This means, depending on where you are in the world, that it may not be a good idea to simply hand out flyers with written information telling people what HIV/AIDS is and how it is transmitted. Girls may not be able to read them; they could even get in trouble with their parents for having flyers in their possession. **Exercise 1** gives you some practice in talking about sexuality and AIDS, and provides a full list of all the facts that young people are entitled to know to prevent HIV.

activism...



The Global Picture

Having considered the ways in which gender norms and misinformation fuel the epidemic, the discussion moves on to take a global view. AIDS dominates the headlines in many of our countries, and the issues are not just about information and individual or community change. The discussion examined some of the broader aspects of AIDS activism, in particular treatment access and stigma and discrimination against persons living with AIDS.



YOUNG WOMEN AND HIV/AIDS DISCUSSION THE GLOBAL PICTURE

1. Access to Treatment

There is no cure for AIDS. However, there are treatments that can prolong and improve the lives of people who are HIV positive. Ironically, most of the drugs used to treat HIV/AIDS are available in North America and Western Europe, while most of the people living with HIV/AIDS are in Africa, Asia, Latin America and Eastern Europe. According to the Global AIDS Alliance, 95 per cent of people living with HIV/AIDS around the world do not have access to anti-retrovirals (the most effective drugs in treating HIV/AIDS). The issue of treatment access is complex. On the one hand, many non-governmental organizations argue that every person living with HIV/AIDS should be provided with free or very cheap drugs. They advocate for good public policies and good management of national budgets to support the purchase of AIDS drugs by the governments of poor AIDS-affected countries. But the ability of governments in developing countries to buy drugs is influenced by costs. Some governments say that although HIV/AIDS represents a grave threat to their citizens, it is only one of many illnesses, such as malaria and tuberculosis, that require massive health spending.

One solution pursued by governments and NGOs representing people living with HIV/AIDS is the easing of restrictions on the production of generic drugs. Generic drugs are those that are not name-brand but contain the same properties as those made by large corporations. Generics can be produced at a fraction of the cost of name-brand drugs currently on the market. The production of generics is seen by drug companies as an infringement of their patents.²

Drug companies argue that once their patent rights are violated, their primary method of earning money is destroyed. They also say that their drugs cost a lot because of the research and development necessary to produce them. AIDS activists suggest that this is not true and that drug companies are exploiting poor nations in order to profit from a disease that can be managed with the right combination of drugs.³





2. Stigma and Discrimination

On World AIDS Day, 1998, a South African woman named Gugu Dhlamini announced to her community that she was HIV positive. A few days later, she was killed by a group of young men who were angry that by disclosing her status she was “shaming” her community. This event showed why stigma and discrimination keep many people silent about their HIV status. Despite this tragic event, it is generally accepted that if you are in a safe environment, telling family members and loved ones that you are HIV positive, and being accepted and cared for, helps you to live a healthier and fuller life.

In many people’s minds, HIV/AIDS is associated with behaviours that are considered “deviant,” such as having multiple sexual partners, being gay, or using drugs. So people with HIV/AIDS are often thought to be “responsible” for contracting the disease. Therefore, they are seen to deserve some form of punishment. This punishment can take the form of either social ostracism or violence. Some people lose their jobs or are not hired on the basis of HIV/AIDS screening, which in many parts of the world is illegal.⁴ This is called discrimination.

Of course, at the heart of it all is misinformation about the disease, which fuels an irrational fear of contracting HIV from casual contact. For women, stigma takes on particularly harsh forms. Many women are seen as the “carriers” of HIV/AIDS and are assumed to have brought AIDS into the family. The reason is that they are often first to be diagnosed (through prenatal screening or the birth of a sick child). Stigma results in discrimination in a wide range of areas including housing, employment, access to health care, education and access to public services. Within households and communities, women are often subject to emotional harassment, thrown out of their homes or physically abused for their HIV-positive status.⁵

Questions

What are your opinions on the treatment access debate?

Have you witnessed, been the subject of, or participated in discrimination against people living with HIV/AIDS (PLWHAs)?

Does stigma against PLWHAs who are young people or women, or both, have a different dimension from general stigma against all PLWHAs? How and why?



There was broad agreement that ant-retrovirals (ARVs) should be provided to people living with HIV/AIDS. Maricion Martires, a medical student in the Philippines, made a statement that was echoed by others:

ARVs having been manufactured by bigwig pharmaceutical companies, are too expensive for PLWHAs living in developing countries.... Isn't it immoral for these multinational manufacturers to deprive these people of the only hope they have to extend their lives with their families and friends? Can't we do anything to regulate the prices?

Dr. Asraf Mizra from Pakistan suggested that:

An HIV-positive woman begins an emotional journey that takes her through anger, shame, fear, guilt and the pain of being faced with her own mortality. Living with HIV may mean living with the stress of keeping her HIV status secret. She may live with the fear of discrimination and of harassment of herself or her children. If she seeks medical help, she will find that there is little research into the nature of the disease in women. She may not know any other HIV-positive women. She may not know about or feel comfortable using specialist AIDS services. She cannot come out and discuss her status freely. She may not find any woman counsellor, which is important in our society.

Poverty and gender discrimination often combine to deny access to drugs and services that can effectively treat HIV/AIDS. Debate over the distribution of ARVs continues to take place among drug manufacturers and international agencies, as does work to reduce the biases that discourage women from seeking male and female condoms and HIV/AIDS medications. If you are interested in finding out more or assisting PLWHAs in your community, you may contact organizations like HOPE Worldwide, UNICEF and Global Treatment Access for more information.

Stigma and Discrimination

A posting by Anasuya Sengupta in India gave participants a chance to think about the way in which the stigma against certain types of women combines with stigma against AIDS. Writing about the attitudes of police to sex workers, Anasuya wrote:

I've just returned from a "gender sensitization" workshop with police personnel in a rural district of India. In the wrap-up session, a senior officer asked me what to do about the sex workers they had rounded up in raids who had HIV/AIDS. "How do we keep them isolated from society?" Every bit of this question was disturbing to me, except for the fact that he knew about HIV/AIDS. Under the prevention of immoral trafficking act in India, sex workers are not criminals, the pimps and brothel owners are. How did the police officer know that these women had AIDS? A doctor who carried out tests on them had told the police. Was any attempt made to inform the



women and give them details of counselling centres? I'm certain that most of those sex workers were adolescent girls and young women.

Abbey Hatcher told us of an eye-opening experience in Kenya that demonstrated how deep stigma can be:

I was recently blessed by the opportunity to volunteer in a hospital in eastern Kenya, where an AIDS clinic had just been founded. I excitedly asked the head physician if the town was overjoyed by the new clinic. He informed me that the one patient who agreed to medical treatment insisted on absolute confidentiality, and that no other patients had accepted their diagnosis of the disease when he opened the clinic. With adequate funding and increased access to drugs that combat AIDS, the clinic could drastically influence the lives of people in the town. Yet, before people are treated, they must first agree to medical care and accept their diagnosis. It is imperative that, somehow, societal understandings of AIDS are improved, and stigmas associated with it are lessened. Education will serve far better to improve our chances against AIDS than any amount of campaigning for abstinence.

Supporting Abbey's observation, in Malaysia, Thieva provided a few examples:

Stigma and discrimination have a lot to do with behaviour, education and perception. A doctor who touches an HIV patient with the end of a pen, parents who refuse to accept a child who is HIV positive, an employee dismissed after being found HIV-positive, families who do not attend funerals of loved ones who have died of AIDS-related diseases: All these are actual stories narrated by volunteers who have undertaken the task of basically being a friend to people who have HIV/AIDS and their families. This programme is conducted by the organization I volunteer for - the Community AIDS Service Penang in Malaysia.

I can see the frustration and sadness on their faces whenever they narrate these stories. No matter how hard we try to educate people, they do not waver from preconceived notions. Because HIV/AIDS has been perceived to be a sexually transmitted disease, many have set notions that he/she must be promiscuous to contract the virus. Thus, he/she is bad and deserves what he/she got. In the minds of people, they picture that anyone who has HIV/AIDS is bad and does not deserve any respect. I guess there has been a little change in people's minds if you look at five years ago and now....People are more sympathetic, slightly less judgemental and more open to these issues. Perhaps in the future, this will not be an issue any longer.





Anuska pointed out the problem of discriminatory laws that prevent open discussion of vital topics:

I think the emphasis needs to shift from target groups like truckers and sex workers to all sexual relationships, whether homosexual (this can't be publicly done because through an archaic law that the British left behind, homosexuality is still illegal in India) or heterosexual. In heterosexual relationships ... more and more groups will have to focus on male partner awareness because that's where the power of decision-making lies.

Many PLWHAs do not even know that they have the virus in their blood because they refuse to seek diagnosis for fear of the discrimination attached to HIV status. This stigmatization of the disease leads to discrimination in many arenas. Social stigmas also silence dialogue and prevent people from gaining the education they need to protect themselves. Sometimes HIV/AIDS education requires the challenging of harmful stigmas for the sake of saving lives.

Summary

Services and treatments are limited in low resource areas. Respondents were nearly unanimous in their agreement over the injustice of this situation. Maricion called for price regulation of ARVs to provide hope for persons living with AIDS.

The discussion on stigma and discrimination provided excellent ideas about how young women are dealing with discrimination in their communities. Abbey Hatcher looked at how her community responds to AIDS with denial, and demonstrated that denial leads people to forgo critically needed services even when a clinic and doctors are present in the community. The lesson is that having information or services available is not equivalent to ensuring access if people are unwilling to deal with an HIV-positive diagnosis. Thieva's message, however, provided a ray of hope. Even though social ostracism is still commonplace, we need to recognize that change takes time. As she said, "people are more sympathetic, slightly less judgemental and more open to these issues. Perhaps in the future, this will not be an issue any longer."

4 Collective Responses to HIV/AIDS

The discussion moved to a look at civil society, in particular how the women's movement and the youth movement have responded to the crisis of HIV/AIDS.



COLLECTIVE RESPONSES TO HIV/AIDS

In the early 1980s when AIDS was first discovered in North America, it was known as a gay-related immune disease. Almost all known cases back then were amongst men who had sex with men and amongst injecting drug users. Gay men in North America mobilized and succeeded in bringing down HIV rates in their communities. At the same time they forced medical professionals and policy makers to take the disease seriously.

Early AIDS activists established support groups, political action committees and AIDS service organizations, and lobbied municipal, state and national governments to ensure that people living with HIV/AIDS had hospital care, housing, meals, and government benefits. Twenty years later, the face of the epidemic has changed. It is now largely transmitted through heterosexual contact.

In 1985, women represented just 12 per cent of AIDS cases reported in France. A decade later, this figure had risen to approximately 20 per cent. An even more frightening increase was recorded amongst Brazilian women. Only one woman was infected for every 99 men in 1984. A decade later, women accounted for a quarter of all those with HIV. In sub-Saharan Africa there are now six women with HIV for every five men.

Because women are disproportionately affected by the epidemic, women's organizations at grass-roots level have actively mobilized against AIDS in many parts of the world. In Africa and Asia, women's organizations have dealt largely with the impact by setting up homes, providing food and basic care for people living with HIV/AIDS and supporting the growing number of orphans. Increasingly, African women's groups such as the Society for Women and AIDS in Africa (SWAA) have called for greater attention to the fact that poverty and lack of education put women at risk of HIV infection.

Young people have responded to HIV/AIDS largely through peer education projects, theatre, awareness-raising in schools, music and sports. Yet, anecdotal evidence suggests that youth responses to HIV/AIDS often do not take into account the needs of young women. Often youth-led initiatives involve youth centers and venues in which girls cannot or do not feel comfortable. In terms of reproductive health, both young women and young men are often excluded because youth-friendly health services are not widely available.





At the same time negative attitudes by health providers and laws and policies preventing young people from accessing services are a problem. Central to the response of young people's organizations has been an appeal for youth participation in all aspects of the global response to HIV/AIDS. Many have argued that not only are young people valuable partners in prevention, they are also critical partners in thinking up campaigns, advocating for policy measures that include young people's interests, and monitoring and evaluating programmes. After all, no one knows young women better than young women do.⁶

Questions

Does the women's movement in your country have the capacity to address the interests of young women?

How have youth groups mobilized to fight AIDS? Have they made their programmes accessible to girls' and young women's concerns, voices and perspectives?

Women's Organizations

Although HIV/AIDS is an epidemic that directly affects older women and young women and girls, statistics indicate that young women aged 15 – 19 are the fastest growing group in terms of new infections. In the last few decades, women's groups have developed strategies for dealing with a range of development challenges, including reproductive and sexual health. Knowing this, we wanted to see how women's groups are responding to the needs of young women, a distinct subgroup with specific concerns.

From the Democratic Republic of Congo, we heard of efforts that women's groups are making to support the needs of young women. Mvioki Nkadi, an activist for a humanrights NGO, wrote:

Because of rapes, forced marriages and population displacement, the already threatened health of women and young girls as they face STIs and AIDS has worsened.... The feminist movement has made significant efforts to sensitize and disseminate information to women and young girls in their struggle against HIV/AIDS in the large urban centers.

It is, however, hard to have access to these campaigns, which would help...young girls who are not informed and well trained to fight the pandemic. This is caused by a lack of funds to hold HIV/AIDS awareness initiatives. The low level of formal education of women also is an obstacle to their training. It restricts their access to the information available in books and on videotape and the Internet.



Nkadi's example illustrates the difficulty of working in settings that have few resources and lack political stability. The fact that her project deals consciously with adolescent girls as well as with adult women demonstrates that commitment is a critical first step, especially where there is little else to work with.

Resources for Youth

Shantal Munro from Barbados made the point that without proper coordination between women's groups and the youth sector, it is difficult for young women to become meaningfully involved in HIV/AIDS work, even where there are a lot of AIDS resources. According to Shantal:

In Barbados there is no young women's movement per se, and there has been no coordinated response to tackle issues affecting young women in particular. Our efforts have been reduced to peer counselling and other such methodologies. I say "reduced" because, while there is quite a lot of money for AIDS programmes in Barbados, and the youth sector is seen as the problem, programmes are created for them. Money isn't given directly, so they cannot come up with their own programmes and implement them.

Shantal's message made it clear that young people are often seen as the root of the problem, rather than as part of the solution to AIDS. As one participant noted,

Young girls themselves, through no fault of their own in most cases, and society as a whole, erect barriers to adequately addressing their needs. Young women are often resistant or unable to make their needs known for various socio-economic reasons. Therefore more work needs to be done to break down social norms and barriers that prevent their participation.

As Shantal wrote, "programmes are created for (young people), and money isn't given directly, so they can not come up with their own programmes and implement them." The lesson participants were sharing is that even when a programme is well-conceptualized, if it does not recognize that young women need to be involved in determining the shape and direction of activities, in the long-term it will fail. As one participant so eloquently stated:

Attention needs to be put into... empowering young women to take what is already there and make sure it addresses all their issues and that they have the voice to make it work for them in terms of support, prevention and education.

Maria from the United States drew connections between risk factors and suggested that young people need services that cater to the full range of their particular needs:

Programmes that focus on HIV/STIs or violence are necessary so that youths learn the facts, but it is the same risk situations and risk factors that make them vulnerable to violence, substance abuse, unwanted pregnancy, unsafe



connections and HIV/STIs. We need to do more to show how there can be links between the problems and to develop youth-oriented prevention and care facilities that offer a full range of services. Such services need not be separate clinics from those that focus on adults; they should, however, have personnel and/or hours that focus on the needs of young people.

You as young people have a direct stake in creating programmes that will effectively address your needs. Adults sincerely want to help, but they need input from you to make sure that the programmes they create really reach the people they are meant to serve. You can help by creating links between your organizations, women's groups, and care facilities to keep everyone informed and aware.

Summary

The discussion made it clear that there is an inter-generational gap that needs to be bridged. Women's organizations cannot simply treat young women as smaller versions of themselves. Working with young women requires different outreach strategies, a refocussing of objectives, and a re-evaluation of indicators of success. At the same time, youth organizations need to make more efforts to reach out to young women's groups. Young women, though, should also take responsibility for starting discussion groups, clubs or associations that allow them to express themselves. Given all the work young women have to do – homework, caring for siblings, helping to provide an income for the family, household chores - that is often very difficult. Nevertheless, it is important.

In addition, the youth sector needs to be pushed to develop mechanisms for guaranteeing young women's participation in programmes and projects. Find out whether your National Youth Development Council has a young women's caucus, and then ask whether a committee or coalition of young women exists in your country to advocate for the interests of girls and young women in sexual and reproductive health. If there is a group or coalition, you might want to join it. If there isn't, then here's your chance to think about whether one is needed and to start planning for that first meeting.

Putting It All Together: Recommendations for AIDS Programmes

The discussion exposed the complexity of the issues confronting young women as they participate in global efforts to slow the spread of HIV/AIDS. Young women are grappling with the same issues that all activists, programme planners, teachers and community leaders are dealing with: how to plan effective programmes, how to ensure that they are sustainable and how to work with others in meaningful partnerships where everyone speaks and is listened to.

But for young women, these issues are underpinned by the knowledge that, in most societies, gender norms and expectations make it difficult to learn how to speak up and even harder for them to be heard in the halls of power. The daily experience of being both young and a woman has implications for how young women formulate solutions. Participants' comments and responses to our questions highlighted the fact that programmes need to include the following:

- All the facts related to sex, sexuality and HIV transmission
- Strategies to empower girls and promote gender equity (not just recognize difference)
- Involvement with all generations - including parents, teachers and community leaders of all ages - throughout the planning and implementation of all activities
- Participation and decision-making: safe spaces for young women to voice their concerns, aspirations and ideas.

While the on-line discussion touched on many of these challenges and provided insight into the types of programmes and activities young women are planning, managing and participating in, it is clear that there is a need for greater focus on preparing young women to be advocates for their own concerns. In doing so, it is critical that gender inequality be explicitly challenged.

Many of the messages we received made reference to gender and the need to take into account the role that it plays in young women's lives. Yet few explicitly talked about challenging gender injustice. Over the last 20 years, gender and development practitioners have introduced the language of gender as a tool for understanding the relationships between women and men.

These ideas had their origin in feminism. However, the ways in which programmes are planned and implemented by development agencies have sometimes resulted in the simple recognition that women and men have neither equal power nor the means to acquire it.

Many programmes try to make sure that they don't reinforce or worsen gender inequality, but they don't go as far as promoting true change between women and men. Young women involved in activism against HIV/AIDS need the tools to



make the arguments about the necessity of gender equality. They also need to organize and mobilize in a coordinated fashion, using the experience and support of women's groups. We have culled a few examples of effective programmes and partnerships from among many that exist internationally. These programmes have proved to be effective ways of reaching and involving youth in spreading the word about HIV/AIDS.

Best Practices

Nepal: National Adolescent Girls' Congress

A two-day National Adolescent Girls' Congress, the first of its kind, was organised on March, 14-15 2002, in Pokhara, Nepal, with the main objective of advocating the needs of adolescent girls. The Congress was facilitated by Aamaa Milan Kendra (AMK) and supported by government officials of various departments and the Center for Development and Population Activities. It was entirely run by the adolescent girls themselves. They strongly raised their voices and issued a declaration, "Voices of Adolescent Girls for Positive Change." The successful Congress shows that given opportunities and encouragement, adolescent girls can advocate for their rights and can be active agents for change.

For more info: http://www.unescobkk.org/ips/arhweb/arhnews/newsfiles/declaration_nepal.htm

South Africa: *Soul City*

Health and media organizations joined forces to produce a highly successful multimedia soap opera called *Soul City*. The soap opera is set in a South African township and is broadcast on prime-time television and on radio. Additional information and storylines are emphasized through newspaper booklets and publicity and advertising campaigns. Each week the programme deals with issues such as domestic violence, HIV/AIDS, mental health, gender equity in male and female relationships, and immunization. Programmes have used dramatic storylines to get listeners and viewers engaged in the lives of their characters. They have reached up to 11 million people.

For more info: <http://www.soulcity.org.za>

Uganda: *Straight Talk*

Straight Talk is a newspaper targeted at young people. With a circulation of around 100,000 per month, it has broken new boundaries in its explicit discussion of sex and has won a large and involved audience. The paper is targeted at 14 -19 year-olds and is sent to all Ugandan high schools. It is also distributed in *New Vision*, one of the main Ugandan newspapers. *Straight Talk* is filled with comments and questions from readers and the advice given is forthright. *Straight Talk* has contributed to an openness about sexuality and HIV/AIDS prevention in Ugandan society.

For more info: <http://excellent.com.utk.edu/greenlee.html>



If you have access to the Internet you may learn more information about your programmes by connecting to the websites that are listed. We have attached a set of Exercises. They and the tips and handouts that accompany them were inspired by the on-line discussion. We have also included in the appendix to this book a list of international conventions and agreements that can be used as a basis for action. You may refer to them to familiarize yourself with the ways in which international organizations approach certain aspects of human rights. They offer strong tools for advocating for your rights and for taking action to assert them. We all know that real power lies in the hands of young women, and we hope this helps you to use your power wisely.



Appendix: International Agreements and Conventions

If your government has signed and/or ratified conventions such as the Convention on the Rights of the Child and the Convention on the Elimination of All Forms of Discrimination Against Women, it has promised the world that it will promote and protect your rights in particular ways. Conventions are pieces of international law and are often referred to as “binding agreements.” This means that the international community can enforce them by calling upon your country to report on its progress towards achieving each of the goals that are part of the conventions it has signed.

In addition to conventions, there are international declarations and agreements. These are not binding and are usually made at the end of large gatherings and international events such as the Fourth World Conference on Women (Beijing, 1994). Not being binding does not mean that they aren’t important. They demonstrate your government’s agreement with certain positions.

If young women are unable to get the information or services they require in relation to HIV/AIDS or do not have the opportunity to attend school or inherit land as their brothers do, they have a right to speak up. Sometimes it can be as easy as asking your government to write new policies or start campaigns. If your country has not signed on – and you need to work with officials to convince them of the importance of the issues you are raising – you can use the exercises attached to help you to make a plan.

If your government has not signed any of the conventions and is not a signatory to the international plans, then your goal is clear: get to work reading up on each and finding out which ones are a priority for you and your peers. Working as part of a coalition advocating for young women’s rights, you can develop a campaign aimed at claiming the same rights that young people and women have in other parts of the world.

International Convention	Year	How It Can Protect You
Universal Declaration of Human Rights (1949)	1948	<p>Article 1: All human beings are born free and equal in dignity and rights.</p> <p>Article 16: Men and women have the right to marry and to found a family, and that marriage should only be entered into with the full consent of both intended spouses.</p> <p>Article 3: All human beings have the right to life, liberty and the security of person.</p>
Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)	1981	<p>Article 16 states parties shall take all appropriate measures to eliminate discrimination against women in all matters relating to marriage and family relations.</p> <p>Articles 12 and 14 affirm women’s rights to equal access to family planning services and information and counselling in this respect.</p> <p>CEDAW Committee General Recommendation Number 12: Considering that articles 2, 5, 11, 12 and 16 of the Convention require the States parties to act to protect women against violence of any kind occurring within the family, at the workplace or in any other area of social life, they should include in their periodic reports to the Committee information about:</p> <ol style="list-style-type: none"> 1. The legislation in force to protect women against the incidence of all kinds of violence in everyday life (including sexual violence, abuses in the family, sexual harassment at the workplace etc.). 2. Other measures adopted to eradicate this violence. 3. The existence of support services for women who are the victims of aggression or abuses. 4. Statistical data on the incidence of violence of all kinds against women and on women who are the victims of violence.
Convention on the Rights of the Child (CRC)	1990	<p>Article 1: A child is anyone under the age of 18.</p> <p>Article 24: Every child has a right to health care services.</p> <p>Article 28: Every child has a right to education.</p>
International Plans of Action and Declarations		
International Conference on Population and Development (ICPD) Program of Action	1994	<p>The objectives of the POA include:</p> <ol style="list-style-type: none"> (a) Eliminating all forms of discrimination against the girl child and the root causes of son preference, which results in harmful and unethical practices regarding female infanticide and prenatal sex selection. (b) Increasing public awareness of the value of the girl child, and concurrently, strengthening the girl child’s self-image, self-esteem and status. (c) Improving the welfare of the girl child, especially in regard to health, nutrition and education. 

<p>Fourth World Conference on Women in Beijing Platform for Action</p>	<p>1995</p>	<p>Paragraph 96: The human rights of women include their right to have control over and decide freely and responsibly on matters related to their sexuality, including sexual and reproductive health, free of coercion, discrimination and violence. Equal relationships between women and men in matters of sexual relations and reproduction, including full respect for the integrity of the person, require mutual respect, consent and shared responsibility for sexual behavior and its consequences.</p>
<p>Millennium Development Goals (Millennium Summit)</p>		<p>Goal 2: Achieve universal primary education. Ensure that, by 2015, children everywhere, boys and girls alike, will be able to complete a full course of primary schooling.</p> <p>Goal 3: Promote gender equality and empower women. Eliminate gender disparity in primary and secondary education preferably by 2005 and in all levels of education no later than 2015.</p> <p>Goal 6: Combat HIV/AIDS, malaria, and other diseases. Have halted by 2015 and begun to reverse the spread of HIV/AIDS.</p>
<p>United Nations General Assembly Special Session (UNGASS) Declaration of Commitment on HIV/AIDS</p>	<p>2001</p>	<p>Paragraph 4: By 2005, reduce HIV prevalence among young men and women aged 15 – 24 in the most affected countries by 25 per cent and amongst all youth by 25 per cent globally by 2010, and challenge gender stereotypes and attitudes and gender inequalities in relation to HIV/AIDS, encouraging the involvement of men and boys.</p> <p>Paragraph 53: By 2005, ensure that at least 90 per cent and by 2010 95 per cent of young men and women aged 15 – 24 have access to the information, education and services necessary to reduce their vulnerability to HIV/AIDS.</p> <p>Paragraph 59: By 2005, bearing in mind the context and character of the epidemic and that globally women and girls are disproportionately affected by HIV/AIDS, develop and accelerate the implementation of national strategies that: promote the advancement of women and women’s full enjoyment of all human rights; promote shared responsibility of men and women to ensure safe sex; empower women to have control over and decide freely and responsibly on matters related to their sexuality to increase their ability to protect themselves from HIV infection.</p>

Notes:



Planning an HIV/AIDS Workshop for Young Women



Facilitator Guidelines

Facilitator Guidelines

The attached Exercises and the Handouts that accompany them have been designed and/or adapted so that they can be used by:

- ⊙ Established young women's organizations that are working on development issues but want to get involved in HIV/AIDS
- ⊙ New or informal young women's groups that may not have a mission yet but want to plan HIV/AIDS activities

Each Exercise Card is designed to help you to analyze the challenges related to sexuality, gender and HIV/AIDS, and plan ways to address these issues in your context. The Cards can be used separately or followed consecutively to form a workshop. We advise that if you run each activity on different days, you do so in order, because each Exercise Card builds on the one that preceded it.

How to Use the Exercises

Each exercise requires some level of literacy. When necessary, adapt the Exercise Cards so that they are less reliant on reading and writing. Keep in mind that they have been designed so that they can be used by young people who are somewhat familiar with gender, know the basics about HIV/AIDS and human rights, and have the interest and the time to do a bit more background reading.

Also, if you've never been a facilitator before, don't worry! You'll learn through the process. It's a good idea to team up with someone who has some experience, so you can observe how they work. If you can't find someone with experience, we recommend that you still get together with another person. Training can be physically and emotionally draining, and even the experts usually train in twos.

Preparation

- ❑ Plan, plan, and plan some more. Read all the Exercises thoroughly before you decide to run a workshop. Make sure that you understand the objectives and Facilitator Guidelines, have understood all the concepts and terms used and have access to all the materials. You don't need to be an expert (acting like one will probably put off the participants in your workshop), but you do need to have done a lot of preparation. This includes writing out flip charts ahead of time, preparing copies of handouts and setting up the room if necessary.
- ❑ Listen, listen and then do some more listening. The process of training is not about teaching in the usual sense of the word. It is about learning in a group. Even though you have read ahead, you have as much to learn from the experiences of others as they have to learn from you.
- ❑ Understand group dynamics and encourage respect. You should be thinking about both the content – what people are saying and learning– and the process – how they are saying it and how they feel about the subject and the other people in the room. Ideally, you want to create an environment in which everyone's words are valued and respected. Gender and sex are sensitive topics, so at times the conversations may be difficult. A mature attitude and belief in what you're doing is essential.



Logistics

It's easy to get so involved in the content of the sessions that you forget about the logistical issues. As you plan, ask yourself the following questions:

- ☐ When and where will workshops take place? Make sure you plan them during a time and at a place convenient for everyone and get their agreement ahead of time. Check with your school, church or community centre – all of which should not cost anything to book. Ask them in advance if they can provide you with a quiet place for the amount of uninterrupted time that you need.
- ☐ What will your sessions cover? Before you start planning, make sure that your group has met and wants to participate in these sessions. Go over the general topics with them to make sure everyone is comfortable with the idea. Otherwise you will not get full attendance, or people might come with negative attitudes.
- ☐ How will everyone get to the session venue and back home afterwards? You may have to arrange transport or get people to walk in groups so that they will feel safe.

The Role of a Facilitator

Once the workshop starts, your role will be to:

- ☐ Set the tone for the exercises
- ☐ Set clear objectives
- ☐ Provide clear instructions
- ☐ Provide easy-to-read materials
- ☐ Keep to the time schedule
- ☐ Sum up and conclude discussions and initiate new sessions

You will also play the important role of maintaining the group dynamic. Listen carefully to everything that is said, watch the interactions of participants, point out differences of opinion and manage conflict and tension – but also point to agreement and shared concerns. Be aware that personal disagreements may enter into the training room. Do not ignore these tensions. If necessary you might have to speak to the individuals involved privately, or if appropriate, talk to the whole group about the problem. Be prepared to handle these situations, but also be prepared to have fun and to laugh.⁷

Running the Workshop

Introductions, Expectations & Ground Rules

To start things off, make sure that everyone in the group introduces themselves – and don't forget to include yourself. You can do this in a fun and interesting way. For example, ask each participant to use an adjective that describes themselves and starts with the same letter as their name. For example, "Merry Meena," or "Strong Sara." Another idea is to pair everyone up. Yell "Start" and ask each person to tell their partner about themselves for 30 seconds without being interrupted. Yell "Stop," and then ask the participants who had been listening to begin talking when you shout "Start" again. Then ask each person to introduce their partner – not themselves – based on what they heard. It's a good exercise to encourage listening.

As soon as you have finished the introductions, spend some time going over ground rules. The best way to do this is to ask everyone what rules they would like to live by during each session. You can announce that for the purpose of the workshop the training room is a new country. After this, ask each "citizen" to develop a Constitution. You can make up a country name and write down everyone's ideas about what is acceptable and not acceptable in that country. Each item on this list should be agreed to and then put up prominently on a wall where everyone can see it. If anyone in the group forgets the rules, you or anyone else in the room can politely remind them of the promise they made to observe the laws of the land. Examples of laws or rules are: no interrupting while others are talking, speaking only in "I" statements to avoid generalizing – e.g., "I think the world is flat."

Objectives

Go over the objectives and state your expectations for the end of the workshop:

- ☐ To explore and clarify the facts about HIV/AIDS and gender
- ☐ To introduce participants to the difficulty of talking about sex, HIV/AIDS and gender
- ☐ To examine how access to human rights can contribute to HIV/AIDS prevention in young women
- ☐ To plan a specific project or activity
- ☐ To provide tools for further planning and implementation

Materials

For each session you will need the following items:

- ☐ Paper
- ☐ Pens or pencils
- ☐ Markers
- ☐ Flip chart paper
- ☐ Relevant fact sheets or Handouts as indicated on each Activity Sheet.

Focus on the Facts

Time: 2hrs 45 mins

Objective

To explore and clarify the facts about HIV/AIDS and young women's human rights.

Facilitator Instructions

1. Give each participant a copy of the questionnaire (Hand out 1A) and ask them to answer each question to the best of their ability. Explain that the first half of the questionnaire is factual and the second half is based on opinions. Tell them not to worry about getting everything right – this is not a test and they should not write their names on the questionnaires. (15 mins)
2. Once everyone has completed the questionnaires, read aloud the correct answers for Section A and ask each person to mark their own papers. Take any questions. (20 mins)
3. Read through each statement in Section B and ask participants how they responded. Discuss these responses as a group. (40 mins)
4. Split the participants into small groups and ask them to develop a three-minute role-play in which one of the statements made in Section B of the questionnaire is used. Each role-play should include both men and women and focus on the consequences of believing the statement being acted out. For example, the statement "It's okay to turn down sex" could be used to develop a role-play about an empowered young woman who says no to sex. (45 mins)
5. Bring the participants together to watch each other's role-plays. (45 mins)

Facilitator Notes

- ◎ The role-plays do not need to involve everyone in acting. Some participants may prefer to help write, while others may want to direct or think of ideas about how to set up the room. Walk around to each group to make sure that no participants are excluded.
- ◎ Once the role-plays are over, have a thorough discussion of what each scene meant in terms of society's roles and expectations of boys and girls when it comes to sex and sexuality.

Questionnaire on HIV/AIDS Facts and Social Behaviour

Section A: HIV Facts ⁸

- 1. You can get HIV drinking from the same glass that a person with HIV/AIDS has just used.....
- 2. AIDS can be cured if you are given medicines early enough.....
- 3. It is safe to have sex without a condom, once you know the person really well.....
- 4. Once you have HIV/AIDS, you cannot do anything to rid your system of the virus.
- 5. People living with HIV/AIDS are always skinny and look very sick.
- 6. You can test negative for HIV and still be HIV positive
- 7. It is easier for a girl to get infected with HIV than a boy.....
- 8. Mosquitoes carry HIV/AIDS and can pass it on to people.
- 9. If you test HIV positive it means you will soon die.....
- 10. A person who already has an STI is at greater risk of getting HIV/AIDS than someone who does not.
- 11. There is no difference between HIV and AIDS
- 12. Babies can get HIV/AIDS from their mothers through breast-feeding
- 13. Condoms do not protect against HIV/AIDS
- 14. AIDS weakens your body so that it cannot fight off other diseases such as tuberculosis and meningitis.

T*	F*

Section B: Social Behaviour

- 1. I would be too embarrassed to ask my boyfriend to use a condom
- 2. If my boyfriend suggested that we use a condom, I would become very suspicious
- 3. If I heard someone in my class had a family member with AIDS, I would stay away from them.....
- 4. A girl should not feel bad about enjoying sex.....
- 5. If a man beats his girlfriend, it means that he loves her so much that he cannot control himself.
- 6. For girls, education is a luxury, not a right.
- 7. If I thought I had an STI, I would go to the clinic.....
- 8. Girls should be allowed to play as much as boys.....
- 9. Nurses are allowed to turn teenagers away because they are too young to have sex.....
- 10. I think it's okay to delay or refuse sex if I'm not ready.
- 11. Pregnant girls should not be allowed to attend school
- 12. Teaching young people about sex makes them want to have sex
- 13. Once you have made a boy excited, he needs to have sex, otherwise he will be in a lot of physical pain.....
- 14. If I had a choice between the male and female condom, I would use the female condom.....
- 15. I think boys are naturally more aggressive than girls.

A*	D*

T* = true, F* = false A* = agree, D* = disagree

NOTE: These pages can be photocopied for participants.

Answer Key


Section A: Answers

1 = F, 2 = F, 3 = F, 4 = T, 5 = F, 6 = T,
7 = T, 8 = F, 9 = F, 10 = T, 11 = F, 12 = T,
13 = F, 14 = T

Section B: Points for Discussion

There are no right or wrong answers here. Each statement is open for discussion. Here is some extra information that should assist the discussion. Once everyone has made their point about a particular statement on the questionnaire, you can raise the issues below if they have not been adequately addressed. However, give participants time to discuss and draw out their ideas. Some of these points will be covered later in more detail in Exercises 2, 3 and 4.

1. The alternative to discussing condom use is silence. What are the consequences of young women's silence? (The consequences will be discussed in Exercise 3: The Problem Tree.)
2. Think about the facts. Any boyfriend who wants to use condoms is responsible and mature; one who doesn't cares more about his ego than your health. Or maybe he just doesn't know the facts about HIV/AIDS, and you can teach him. Condoms protect against pregnancy.
3. Think about why you would shun this person. This is a form of stigma. It's important to confront irrational fears.
4. If you are having sex because you are comfortable, happy and not pressured, and you are protecting yourself against HIV/STIs, then you should be able to enjoy sex. It's normal.
5. Article 3 of the Universal Declaration of Human Rights states that everyone has the right to life, liberty and security of person. That means anyone who beats you up is violating your human rights, jeopardizing your health and may scare you into having sex when you don't want to under conditions that you can't control. This could result in unwanted pregnancy and/or infection.
6. Article 28 of the Convention on the Rights of the Child (CRC) states that every child has a right to education. Girls who are pulled out of school to help their families are being denied their rights. This is a difficult issue because poverty is often the reason. Education has a direct relationship with HIV/AIDS awareness. (See on-line discussion.)
7. Four fifths of all women with STIs go undiagnosed simply because they don't see or recognize the symptoms.⁹ If you know the signs and are worried, go to the clinic. You have a right to health care. (CRC Article 24)
8. The CRC recognizes that all children have a right to rest, leisure and play. Article 2 of the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) condemns discrimination against women in all its forms. Denying girls the right to play contravenes CEDAW.

- 
9. Check the policies and laws in your country. Young people have a right to health care (CRC Article 24), but in some countries, this is not enforced.
 10. At the Beijing Conference on Women in Beijing, nations agreed that women's human rights include the right to have control over and decide freely and responsibly on matters relating to sexuality including sexual and reproductive health, free of coercion, discrimination and violence.
 11. Preventing pregnant girls from going to school forces them to drop out. Boys rarely are punished in the same way for getting someone pregnant. Is this fair?
 12. Teaching young people about sex does not encourage sex. It informs and encourages responsible behaviour. Many studies have been done that prove this.
 13. No one needs sex to live, and nothing bad happens to boys if they are aroused and then don't have sex. Petting and caressing can be fun, but if you don't want to have sex, the boy will not get sick as a result.
 14. The female condom is not widely available. Ask if anybody has seen one and discuss how it might be better or worse than the male condom. If possible, bring in an example.
 15. The only "natural" differences between boys and girls and men and women are biological. All other behaviours are based on what we are taught. Boys can learn how to be less aggressive just as girls can learn how to be more aggressive. And remember not to generalize. Not all boys are aggressive, and many girls are assertive. Think about the role culture plays.

The Problem Tree¹⁰

Objective

To analyze the causes and consequences of HIV/STI infection on the lives of girls and young women

Facilitator Instructions

1. Ask the participants to stand for a physical exercise.
2. Give the following instructions while acting them out yourself:
 - ☐ Use your body as an acting tool. Imagine yourself as a small seed; get down on your knees and curl up
 - ☐ While I count to 10, start growing to become a full blooming tree with your arms as branches and your fingers as fruits.
 - ☐ Feel a gentle breeze blowing the branches back and forth, then a storm and then a wind dying down. (Move your arms around gently and then roughly and then gently again.)
 - ☐ Let the tree feel itself. Let the roots move a little (move your toes), then the branches (hands) and the fruits (fingers).
 - ☐ Now imagine the tree is being poisoned. The poison enters the tree through the roots and moves up to the fruits. Your fingers are dying; now the branches (your hands) are dying. Now the poison has moved to the trunk. Finally the whole tree dies (end by falling down to the floor). (5 mins)
3. Ask the group to sit down now that they have had a bit of exercise. There may be laughter and excitement. Once everyone has settled down a bit, explain that a healthy tree gets its nutrients from its roots. But if the “fruits” begin turning bad, it indicates that something is wrong. The tree either has too few nutrients or has been poisoned. What we can see first are the visible signs above the ground – the fruit, leaves, branches and trunk getting sick. This lets us know that something is probably wrong at the root level. It is the same for life problems, such as unsafe abortions. They are the visible result of other problems (unwanted pregnancy caused by not using contraceptives) that existed before we ever saw the signs. (7 mins)
4. Next, split into two (or four, depending on the number of participants) groups. Give each group a big sheet of paper on which you have drawn a tree with several large roots and numerous branches bearing fruit. The trunk of one tree should have “Unwanted Pregnancy” on it, and the other should have “HIV/AIDS/STI infection” on it (see illustration). Ask the groups to write the causes of the problem on each of the roots of the tree and the consequences (results) of the problem on the branches and the fruit. When they are finished, tell the groups to write, beside the trunk, some possible solutions for the causes and the consequences of HIV/AIDS and/or STIs.

Report back to the main group (60 mins)

Facilitator Notes

- ⊙ Point out the gender-based differences in the consequences of problems. For example, young women who have unprotected sex face more potential repercussions than young men. Ask the group to think about the causes and consequences from the perspective of a boy and compare them to those of a girl.
- ⊙ Explain that problems can have both direct and indirect causes. Direct causes are easier to identify; indirect causes are less obvious and therefore harder to point out. For example, not using a condom can be a direct cause of HIV infection. But indirectly, gender norms that say women and girls shouldn't be assertive about sex and boys should be knowledgeable can contribute greatly to a young women engaging in unprotected sex. (See on-line Discussion Booklet.)

Choosing a Project

Time: 75 mins

Objectives

To find out what different organizations in your community are doing about AIDS.

To find out if and how you can participate in the activities of AIDS organizations in your community

Facilitator Instructions

1. Split the participants into four groups. Ask each group to draw two maps: one identifying specific places where they feel they are safe, and the other identifying places where participants feel unsafe. The safe list can include schools, community centres, clinics, shops owned by kind people, playgrounds, etc. The danger list should identify places like local bars where a lot of drunk people hang out, clinics with rude health workers, or bridges where girls have been raped. (20 mins)
2. Ask each group to report on its lists. Each group should have an explanation of why participants feel safe or scared of a particular place. (20 mins)
3. Go through each "safety list" and identify organizations or community groups that are affiliated with each safe place. (10 mins)
4. Then, as a group take out the list of potential solutions to HIV/AIDS that you developed during Exercise 3 and decide whether any of these solutions are being addressed by the organizations you have just identified. (15 mins)
5. Agree on three or four organizations or "places of safety" for participants to visit and assign small groups to visit each to ask them about what they do. Each organization or agency visited should be asked the following questions:
 - ☐ What do you do to help young people?
 - ☐ What do you do to help young women in particular?
 - ☐ Do you need any help in planning or running your activities?
 - ☐ What other organizations do you work with in the community or city?
 - ☐ Do you work with any formal groups of young women? If so, do you have their contact details?
6. Explain to everyone that the above will be "homework" (5 mins) and wrap up the day's activities.
7. When you meet again, get feedback from each of the teams about what each organization is doing and how your group might be able to collaborate.

Facilitator Notes

- ⊙ Make sure you tell participants the etiquette of making appointments. They need to contact each of the organizations ahead of time to set up an appointment. They should be on time and prepared with questions and writing material.
- ⊙ You might want to assist by calling local organizations before you run this exercise to make sure that they are available to meet with the participants. Then schedule the appointments during the afternoon, so that if you start this session in the morning, it can be completed in the afternoon, and you can report back the following morning.
- ⊙ Ask each group to collect as much material as possible from the organizations they visit. Brochures, pamphlets and other materials will be useful in letting everyone know what services are available in the community. They will also be helpful if your organization wants to develop materials of its own or to provide referrals to community services.

Developing a Plan of Action

Time: 2hrs 5 mins

Objective

To draft a Plan of Action for your campaign or activity.

Facilitator Instructions

1. Each group should report on its community visits. Ask whether it was a difficult exercise, how participants were treated at each organization, and whether they felt that being young and a woman influenced the way they were spoken to and treated during each interview. (30 mins)
2. Split the group into new small groups of four or five people. Make sure that these groups are not based on the same ones that went on organizational visits.
Keeping in mind that you have gone through a series of exercises focussing on the facts, analyzing problems, and community mapping, answer the following:
 - ☐ What is your goal? (See flip chart paper developed in Exercise 3.)
 - ☐ What are you trying to achieve? (See solutions listed in Exercise 3.)
 - ☐ How will you achieve your goals?
 - ☐ What individuals and groups would you like to work with? (Decide based on the organizations listed as a result of Exercise 4.)
 - ☐ Who do you want to be involved in planning your activity?
 - ☐ Where will your activities take place?
 - ☐ What times will your activities take place?
 - ☐ What is your time-frame – how many months, weeks or years will it continue? (45 mins)
4. Choose (via a fair process that everyone agrees to), which of the projects presented will be implemented by your youth group. Remind everyone that this is just the first activity and they will get a chance to do other things later. (30 mins)
5. Distribute Handout 2 to all participants, and explain that it is a resource for those who will need to write an action plan/proposal. The “Needs Assessment” and some of the “Planning” components of its grid will have been completed by those who went through each session. Go over the action plan grid and clarify any questions. (20 mins)

Facilitator Notes

- ◎ Once the group has agreed on a first project or activity, your organization should be ready to get moving with a new set of ideas and planning skills.
- ◎ As a final closing session, it will be important to ask everyone how they felt about the process of thinking about gender, HIV/AIDS and human rights. Also, ensure that everyone is comfortable with the outcomes of all the sessions accomplished together. To make certain, ask everyone to write down their thoughts and feelings about the areas covered. Make sure to plan a full 30-minute to 1- hour session for participants to share their thoughts and feelings about the exercises.

Designing an Action Plan

NEEDS ASSESSMENT	What to do	How to do it
	Find out what young women are concerned about	Form a focus group, do a survey or run an exercise like Exercise 3 or 4.
	Find out what information exists on the topic you are interested in	What are the HIV/AIDS statistics in your region or country? What studies have been done on teenage pregnancy? What government policies exist in relation to HIV/AIDS and young people – particularly young women? Are there laws preventing young women from getting birth control pills, condoms and other types of contraception?
	Decide on what you want to do about it	See Exercise Card 3.
	Find out who is doing what in your community.	See Exercise Card 4.
PLANNING	List your objectives	What do you want to achieve? (For example, we want to increase young women's ability to avoid HIV and STI infection.)
	Develop a strategy for achieving your objectives?	How are you planning to implement your program? Education (i.e. IEC campaigns, sexuality education for youth, peer education groups). Access to reproductive health information and services. Advocacy/Policy. Community mobilization (treatment/stigma/care and support).



Facilitator Notes

The group will already have covered the Needs Assessment if you conducted each of the activities in order. If you did not cover them in order, simply ignore this handout. It will, however, be very important to do a Needs Assessment if you want to proceed with your activities. So go back and cover the other exercises.

Designing an Action Plan

	What to do	How to do it
IMPLEMENTATION	<p>Get down to the details</p> <p>Note: A comprehensive programme might have more than one of the elements described in the next column</p>	<p>Questions for implementation:</p> <ul style="list-style-type: none"> • How often will you meet? • Where will you meet? <p>Find a space that is easily accessible to all and a time when most people can be there. Remember, some girls and young women have children, and/or younger brothers and sisters to take care of, as well as household chores and homework.</p> <ul style="list-style-type: none"> • Who will be responsible for carrying out each activity? Assign each action and write down who will do it so that things don't fall through the cracks. • How will you know you have achieved your objectives? <p>You can develop indicators – markers – to measure your progress. For example, if you quiz young women before you start your programme, you can quiz them afterwards to learn whether their knowledge has increased. Their level of knowledge is an indicator of your success or failure.</p> • Have you decided on how decisions will be made and how conflicts will be resolved? Is there a need for a leadership structure, or does everyone have the same right to make decisions? <p>Note: <i>There is very little documentation about young women's activism, so it is important to keep track of what you do, how you do it and how you get around obstacles. This will help others who are planning their own programmes and will help you</i></p>
RESOURCES	<p>Work out your resource requirements</p>	<ul style="list-style-type: none"> • How much – if any - money do you need? • How many people do you need to help, and what special skills should they have? • Do you need space? • Will you need technology? E.g., a computer, radio, microphone, TV and video • How can you obtain some of this support? Perhaps you can get space from a community group. Training might be available for some of the young people to do the work so that you won't have to make use of trained staff. Find creative ways to get support and choose activities that will be the least costly and/or most effective. You can also ask someone from an NGO to assist you in identifying possible funding sources and supporting you in developing the necessary proposals.

Endnotes

- ¹ Source: American Association for World Health
website: <http://www.aaw hworldhealth.org/WAD99/basicfacts.html>
- ² A patent is a legal document that protects inventors from having people steal their ideas. If something has a patent, you need to get permission to use it. It is like a copyright for products.
- ³ Source: <http://www.globaltreatmentaccess.org/>
- ⁴ Source: ILO Code of Good Practice on HIV/AIDS
- ⁵ Source: <http://www.aidslaw.ca/maincontent/issues/discrimination>
- ⁶ Sources: Fact Sheet on gender and HIV/AIDS website:
http://www.un.org/ga/aids/ungassfactsheets/html/fsgender_en/htm
Women and HIV/AIDS Facts and Figures <http://www.avert.org/womenaid.htm>
- ⁷ Adapted from: *Oxfam Gender Training Manual*, Oxfam University Press, 1985.
Additional material was adapted from: HDN/IPAS, *Sex and Gender: Who Cares: A Skills-Building Resource Pack on Gender and Reproductive Health for Adolescents and Youth Workers*, Chang Mai, Chapel Hill, 2001.
- ⁸ Parts of the questionnaire were adapted from <http://www.vso.org.uk>
- ⁹ Source: <http://www.avert.org/women.htm>
- ¹⁰ Adapted from: HDN/IPAS, *Sex and Gender: Who Cares: A Skills-Building Resource Pack on Gender and Reproductive Health for Adolescents and Youth Workers*. Chang Mai, Chapel Hill, 2001.

Notes:

Notes:



United Nations
Development
Fund for Women

UNIFEM Headquarters
304 East 45th Street, 15th floor
New York, NY 10017, USA

Tel: (212) 906-6400
Fax: (212) 906-6705

E-mail: unifem@undp.org
Website: www.unifem.undp.org



The Association for Women's
Rights in Development (AWID)

96 Spadina Ave., Suite 401
Toronto, ON
Canada, M5V 2J6

Tel: (416) 594-3773
Fax: (416) 594-0330

Email: awid@awid.org
Website: www.awid.org