Gender, Sex and HIV: how to address issues that no-one wants to hear about

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Abstract: This paper discusses the limitations of conventional Information, Education and Communication (IEC) approaches to HIV prevention and describes Stepping Stones, one approach which 1) is more holistic in recognising the location of HIV in a broader sexual and reproductive health (SRH) context; 2) emphasises the importance of a gendered perspective throughout; and 3) works on the basis that, with good facilitation, ordinary community members are those most able to develop the best solutions for their own sexual health needs.

Introduction

We are all members of the human race and, one way or another, have relationships through family, through community and/or through professional ties with one another. For all of us there are issues and choices which, during some stage in our lives we are likely to need to face, relating to sex. Without our parents having had sexual intercourse, (almost) none of us would be here. So sex is in fact a basic ingredient to all our lives. We all of us are aware of our sexual identity. Whether we view ourselves as male or as female - or as something else - is critical to all of us. It influences how we are viewed by others and how we ourselves view the world. Yet most of us find sex and issues related to sex extremely difficult to talk about.

Death too is an issue around which there is perhaps even more taboo than sex. Although we are surrounded by both these subjects in the news and in the popular press, and although we will all one day die, most of us find it a huge challenge to talk either about our own sex lives or our own deaths(see Table 1).

Thirdly, gender issues raise the tempers of many people. Whilst gender inequalities around the world are huge[1], there are many who consider that it is the natural place of women to have inferior status to men and inferior access to and control of goods and produce, as well as inferior access to their children. Those who attempt to challenge these views are often accused of imposing Western views in an inappropriate way, and of interfering with traditional values. The recent Supreme Court vote in Zimbabwe, which found 5-0 in favour of withdrawing women's rights to equal inheritance with men (a right which was gained 19 years ago at Independence) is just one example of how entrenched such views still are.

Yet unfortunately, with the growing rates of global HIV infection, all three of these are subjects which are increasingly in need of discussion and attention[2]. Because of our difficulties in addressing them, the HIV epidemic has been able to grow and flourish. Latest UNAIDS figures indicate that 33[3] million people worldwide are infected with the HIV virus. A quarter of all adults in Botswana and Zimbabwe are HIV positive. 4 million people in India alone are now HIV positive. Most of those infected are in the 15-49 years age group, which is the group which is most economically productive in society. Whilst only 43% of women are infected, compared to 57% of men, the vast majority of the burden of caring for the sick and dying falls on women, thereby forcing them to give up many other activities to support their loved ones. There are also now increasingly large numbers of orphans who are either being

Table 1 - Who we are - and how we relate

sisters fathers peers

babies children boyfriends

priests youth aunties

uncles

community workers

girlfriends teachers

mothers grandparents...

sex HIV pregnancy STIs

excitement rape abuse

love marriage violence

pleasure AIDS inheritance

dowry growing-up money

sex work status power

and death.....

looked after by ageing grandmothers, or who are having to fend for themselves. HIV is not a problem which will go away by itself.

The two personal case studies below, from West and East Africa respectively, give some idea of the range of challenges facing individuals with HIV.

Albert, C∗te d'Ivoire[4]:

"I haven't told any members of my family that I'm HIV-positive," says 32 year-old Albert, "but I've done a will, explaining everything about my situation. I can't tell them I've got HIV because I'm the eldest and the best educated in the family, and it would be like admitting that I can't do anything for them. They would feel betrayed.

"I used to be a school teacher in Mauritania, but I lost all my money and possessions when I was expelled in 1989, because of the war with Senegal. I was living with a Senegalese woman, and we had a baby girl, but I had to leave them behind in Dakar. I'm worried about them of course. How are they managing without me? And they might have HIV too.

"I went for a blood test because I'd heard about CIPS (Centre pour Information et Prevention du SIDA) on the radio. The counselling they gave me before the test was really good. In fact if it hadn't been for that, I'd never have had the courage to go back for the result. I suspected I could have HIV because my penis was swollen and covered in lumps at the time, and also because I'd had shingles in Mauritania.

"But when CIPS sent me to a hospital for treatment, things were not so good. The first doctor I saw was very nice, but she sent me to another department for treatment. I had to expose

Consolata, Kenya[5]:

"I'm 30 years old and I was born and brought up in Kisumu. I had my first sexual encounter when I was only 14. This was quite normal in my neighbourhood. I was in the final year of primary school, and it was the 'in thing' for girls to engage in sex. No-one knew the dangers of sex then. We just did it.

"I then went on to high school. I had a steady boyfriend and sex was part of our relationship. I remember how once I missed my period and got into a big panic. I took twelve malaria tablets because I'd heard they induce abortions. Nothing happened but my periods came later anyway.

"Four years later I got married. I was 18 years old. My husband worked as a mechanic in Nairobi, and I lived in Siaya in Western Kenya. After five years of marriage we still had no children and we had a big disagreement because my husband said I was barren, so I left him and went back to my mother's house. Three months later I discovered I was pregnant but I didn't tell my husband. In November 1990 I delivered two beautiful twin girls.

"After the delivery I began getting sick, and this went on for more than a year. I got better but one of the twins began getting diarrhoea, vomiting and having oral thrush. She was tested for HIV and found to be positive. Four months later she

myself to some trainee doctors, and afterwards I overheard them talking about me. One was saying 'Hey, did you see that guy with AIDS, with all the lumps on his penis?' It was really humiliating for me, and I complained to the doctor about it.

"Because I couldn't pay for the medicines they prescribed, they sent me to CASM (Centre pour Assistance Socio-Medicale), where I was received very warmly. They gave me coffee and bread, the doctor examined me, and I was given the medicines I needed. When the Friends' Club started I got involved, and now I'm in charge of the small projects to help our members earn some money.

"I also started going to church, and that's helped me a lot. I used to feel very bitter and wanted to revenge myself on society, but that's all gone now.

"But I still have quite a few problems. I stay with a cousin and his family, but they don't know my HIV status. I'm afraid they'd reject me if they knew. My cousin is already suspicious. He says if I've got AIDS I should tell him.

"I'm desperate for a job too. When you don't work, you think of suicide all the time. But I'm afraid of my HIV status becoming known because employers sometimes test their staff for HIV without telling them."

became very sick and died. I felt very guilty. I kept blaming myself for her illness. I took a test myself and it was positive, but my health was very good.

"In 1994 I got news that my husband had died. I buried him but refused to be inherited (by my husband's brother, which is the tradition here). I told my family I was HIV-positive but they said I was just looking for an excuse not to be inherited. I went to Nairobi, and I met with TAPWAK (The Association for People with AIDS in Kenya), where I met a lot of people who helped me to live positively with HIV. I did some courses and started counselling people. Then I came back to Kisumu, where I work for TAPWAK as a counsellor. We have young people here in their teens and early twenties living with HIV. We all know we have limited time so we try to make the best possible use of it.

"I feel very strongly about the abuse of married women by their husbands. They are afraid of speaking out even when they know their husbands are unfaithful. They stay in marriages because of the children and the need for security. I knew my husband was having women left, right and centre but I was afraid to leave him. When I finally did leave him, it was too late. He had already infected me.

"From my own experience I would say that the youth should receive sex education from as early as ten years of age. When I started having sex I knew nothing about the real dangers. I only knew it was forbidden. Ignorance is still a problem today. Just recently I learned that my 11 year-old niece was being treated for an STD. What is our society coming to?"

This presentation charts the responses to this epidemic, explains briefly their drawbacks and describes a training package, called Stepping Stones which is designed to help people to address and overcome their fears, and to face these important issues for themselves.

Whom shall we blame?

Initial responses to the epidemic focused the blame on others (see Table 2). For instance, in different parts of the world, foreigners, sex workers, gay men, and women have all been blamed. In Africa, AIDS is often known as "**A**merican **I**nitiative to **D**iscourage **S**ex", an allusion to Western ideas about family planning and population levels. Injecting drug users, uneducated people, rich men, sinners.... all in turn have been blamed.

Measures have been introduced in various countries to exclude foreigners with HIV, to test sex workers and, for instance most recently in South Africa, to make HIV a notifiable disease (so that anyone who tests HIV positive is named to public health officials, in order to try to trace their sexual contacts). In most countries, however it soon became clear that such measures were both unethical and unworkable. (In South Africa again, UNAIDS recently

reported the death of Gugu Dlamini, a 36-year-old mother of a son. She died last December as a result of the beating she received by neighbours in her own home. They had accused her of having

Table 2 - whom shall we blame?

!men!
!foreigners!
!sex workers!
!women!
!youth!
!rich people!
!uneducated people!
!gay people!
!Americans!
!drug users!
!sinners!
!you!
?me??

brought shame to their community, Kwamashu, in the outskirts of Durban, after she openly revealed on December 1 --World AIDS Day - that she was HIV positive[6]. HIV rates in this neighbourhood stand at about 30% of the adult population. Yet few people in South Africa are now likely to dare to be tested, for fear of a similar fate.) HIV has no preference for gender, nationality, sexual orientation, occupation, skin colour, religion or age. HIV *is* to do with the risks that each of us take as individuals, and our personal abilities to make choices about those risks. And some of us have far more choice than others. A recent study of married monogamous women in India[7], for instance, found that HIV infection amongst them is increasing and that the most likely means of infection is through unprotected sex with their husbands.

It has thankfully become increasingly clear, therefore, in most countries of the world, that blaming others only serves to increase fears, to reduce openness amongst one another and therefore to increase the chances of HIV gaining ground.

The IEC Approach

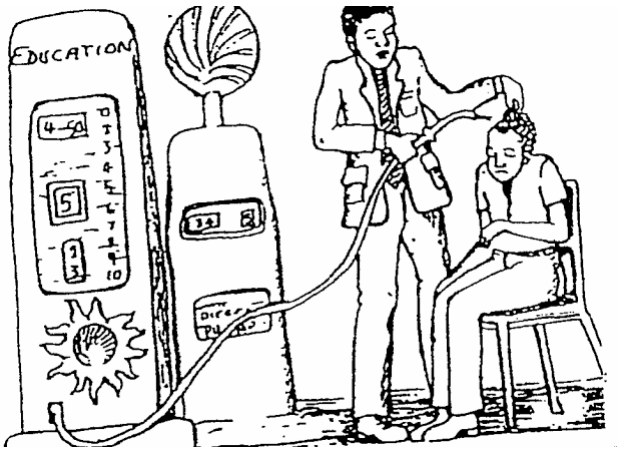
Those who were able to look beyond blame to a less biased and more measured approach began to develop public awareness campaigns, based on a public health "Information, Education and Communication" (IEC) model. These campaigns were based on the principle that if the public were given enough information about the issues, then they would surely halt their risk-taking activities, thereby stopping the chances of HIV spreading. Unfortunately, however well-intentioned, a lot of the campaigns (such as the one in UK in the mid-1980s, which presented HIV as an iceberg floating towards the TV viewer) were too negative, sombre and frightening for most viewers, who responded by laughing at the threat, or ignoring it, turning their heads away from the adverts.

Anti-HIV campaigns, like anti-smoking or health food campaigns, can rarely succeed through information alone. Recipients of the messages (see Table 3) are not empty vessels and already have many of their own ideas and experiences which influence their views. For instance many AIDS campaigns have ignored the facts that sex can also be enjoyable and creative. So by

only focusing on the negative issues, and by only linking sex with death and not with life too, the messages have often been over-simplified and have just switched people off from wanting to hear any more.

Table 3 - pouring information into an empty head?

***A**bstain! **B**e faithful! Or use **C**ondoms!*



As well as basing such campaigns on our great fears around sex and death, the campaigns presented the idea of a simple solution to our fears: namely the "ABC" approach to safer sex. This stands for "**A**bstain, **B**e faithful, or use **C**ondoms". Unfortunately, the presentation of simple solutions in public health campaigns often implies that if we find them difficult to follow, we must be stupid or failures. This has also been the case of such anti-HIV campaigns, especially because the "ABC" approach is extraordinarily difficult for most people to follow.

Although in an ideal world there might be nothing wrong with the "ABC" approach, it is a highly gender-insensitive message, which just does not meet the needs of most of its intended audience, men or women. For the vast majority of women in the world. who are economically dependent on their husbands, and who are in danger of losing their children if they leave the marital home, the idea of telling their husbands that they want to abstain from sex, or use a condom for sex is impossible. Without her husband's permission, such a woman has no choice over her sex life and these messages, which imply that she does, have only served to undermine her self-esteem. Even women who are without husbands, especially poor women, often need to sell sex for money or goods. If their only choice is between receiving some support to feed their children, or insisting on sex with a condom, they rarely have any option but to choose unsafe sex.

Next, the "ABC" message has not adequately reflected the role that parenthood has in many countries of the world. Motherhood and fatherhood are central to adulthood in so many societies that, once more, abstaining from sex or using condoms is not an option which people are prepared to consider, since they do not meet people's more immediately felt needs.

Thirdly, being faithful also presents a conundrum. No matter how much an individual is faithful to their partner, if the latter is having unprotected sex with others, that individual is at risk. For many women - as in the case of the Indian wives cited earlier - this has proved to be a huge challenge, since in many societies it is culturally acceptable for men to have sex with multiple partners without their wives' knowledge or consent; and culturally *un*acceptable for women to discuss such matters with their husbands. Once more, therefore, this message is beyond the choice of women, who have no power to determine their husbands' actions.

This is not meant to be an anti-men treatise. There are huge problems for many men too, as Albert's story from C*te d'Ivoire shows us. He had to hide his status from his family. Others dare not tell their wives. For instance, if a man has had unsafe sex in the past and fears that he may be infected, he may wish to use condoms in future with his wife. But if she wants to have children and also associates condoms with the sex trade, how can he start using them to protect her? There are huge dilemmas here both for women and for men and their relationships with one another (see Table 4). The simple "ABC" message fails to address any of them and provides very few members of the public with acceptable solutions.

Table 4 - The "ABC" message is too simplistic[8]

"Yes, we can stop sex for money, but what are we going to do to have our needs fulfilled, such as clothes? The problem is lack of employment"
(Young women, Malawi)

"Girls are running away from us because they do not trust us..."

"Avoiding relations with young men has reduced the number of teenage pregnancies"

"How do we reconcile the two groups and share on their dreams? A challenge for us all!"
(Tanzanian project workers)

In conclusion, although the IEC approach to behaviour change in general may bring greater *public* attention to an issue, such as HIV, it has had very little effect on people's actions in their *private* lives. There has been raised awareness, therefore, but with no acknowledgement of the complexity of the gender dimension to the issue, virtually no behaviour change has taken place. People have felt that the issues are too complicated for them to solve by themselves, they have then felt helpless and have decided that the best thing to do is nothing and to try to stop worrying about it, in the hope that the problem won't affect them and will go away by itself. Of course, it does affect them and it won't go away. So what next?

Three lessons learnt for more recent responses

More recent responses have been based on three growing realisations. Firstly, we have learnt that people learn to find strategies to change their behaviour far more easily through discussions with their peers of *their own* needs and situations, than they do through being fed messages from others. Secondly, we have seen that HIV can often be more readily addressed by people as yet another branch of those sexual and reproductive health problems which have faced people for many years, such as unwanted pregnancy, sexually transmitted infections (STIs), infertility and so on, rather than as a totally new problem. Thirdly, we have learnt that HIV and these related issues are greatly influenced by gender inequalities, which need to be recognised and addressed if the challenges are to be overcome. These three significant realisations have shaped current thinking on HIV community work.

Lesson number one: *local* group discussions and analysis for action. The general development world has changed much over the past ten years. Moving away from externally generated, large-scale, technological interventions, with scarcely any local consultation, the PLA movement[9] has recognised the importance of involving community members as central players in needs assessment, planning, implementation and on-going monitoring of development work. Projects have often become more small-scale, more tailored to local contexts, more socially and environmental aware with more emphasis on local capacity building, on locally generated resources and on training. The concept of "handing over the stick" to local people, thereby

Table 5 - Exploring the causes and effects of STIs experienced by community members in Cambodia[10]

Causal flow chart exploring causes and effects of a major sexual health problemm or need in a local community. Hum Touch and Sok Mayong, BFD, Banteay Meanchey, Cambodia. November 1996.

recognising their own skills, experience and expertise in living their own lives and understanding their own context, has grown into a central tenet of this approach to development. Methods have been developed which need no formal educational background for community members to take part. With a range of participatory techniques, including drawing of maps, charts (see table 5), seasonal diagrams; role-playing and "rehearsing for reality"; and so on, local community members have been able to articulate *their own* felt needs, concerns and aspirations and then to develop *their own* ideas for achieving change, rather than just having a project dumped on them from outside. Although there is still much room for improvement, this has greatly changed the face of general development work and has also, more recently, influenced the way in which HIV workers approach their challenges.

Lesson number two: beginning where people's *own* concerns lie. This second lesson has also built on the experience of the PLA movement which has learnt, for instance, that it is unwise to go rushing in with an EPI (childhood vaccination) programme, when people's main concerns are about diarrhoeal disease and malaria control. The point is that although EPI may also be important and valuable to a community, they will not view it as such unless and until their more directly felt needs are addressed first. In the same way, therefore, it makes little sense for us

to rush into a community in W. Africa or in UK waving our banners about HIV, when people there have little or no direct knowledge of or concern about the matter. However, if we were to address people's *more immediate concerns* in these places, such as unwanted teenage pregnancies[11], or infertility (often caused by STIs) or impotence, we would be gaining the trust of a community far more effectively. Moreover, in helping to address these problems, we would often be going a long way to reduce HIV transmission risks in any case.

Lesson number three: the role of gender. We have also learnt how the most effective way of working with groups on these issues is by asking community members to divide themselves into smaller groups based on gender - and also often on age. Thus most community groups divide themselves easily into groups of older women, older men, younger men and younger women. (Sometimes even younger groups are formed of, say 9-13 year olds, depending on the community wishes.) Some communities use marriage as a dividing line between younger and older groups; others use parenthood - the important thing is for them to choose the criteria for themselves - so that they feel most at ease with others in their own group, with whom they can identify and address commonly experienced issues. In this way, there is far more chance of more community members being involved, through membership of separate groups more relevant to their own needs. The groups of less powerful, more marginalised people in a community begin to find a voice, instead of the discussions only taking place amongst the male leaders. Each group has a chance to have safe private time and space to explore concerns particular to its members. Every so often, these groups are then brought together to present their hopes and fears to the other groups in the community. This "fission and fusion" approach then allows the separate groups to exchange and share these ideas and build on them to create new plans for the future[12].

The Stepping Stones project - one response based on these lessons

The Stepping Stones training package is one such recent response, which is based on the three lessons described above. Originally published in 1995 for use in sub-Saharan Africa[13], it has now been distributed to over 1500 organisations in 103 countries worldwide. Local groups have translated and adapted it for their own use in many different countries, including Sri Lanka (singhala), Cambodia (khmer), Russia, urban South Africa, Tanzania (ki-swahili), Argentina (spanish) and Mozambique (portuguese). These translations and local adaptations are exciting because they keep the package alive and useful to new communities, rather than letting it gather dust on a shelf or being used to keep a cupboard door open. For instance, the South African version has added new sessions on fertility, on STIs, on gender violence and on grief and bereavement[14]. The package is supported by the Stepping Stones Training and Adaptation Project (SSTAP), which is currently setting up local regional advisers around Africa, Asia and L. America, who will be able to provide advice, support and training to organisations wanting to develop participatory approaches to sexual and reproductive health issues in general, including HIV.

Table 6 - the Principles and Approach of Stepping Stones

Principles:

- *that the best prevention strategies are those* ***developed by community members*** *themselves*
- *that peer groups need* ***their own time and space*** *to identify and explore their own needs*

- *that behaviour change will be more effective and sustained when* ***all members*** *of the community are involved*

Approach:

- *working with groups, usually based on gender and age, for example:*

  older women ***older men*** ***younger women*** ***younger men***

- *all the work is based on* ***people's own experiences***

- ***role-play, drawing, song and dance*** *mean that* ***everyone*** *can take part, without formal education*

The workshop sessions

The original Stepping Stones package suggested that a total of 18 separate workshop sessions be held over a period of 9-12 weeks in a community. Spreading the sessions over several weeks like this enables community members who want to join the workshop to put what they have learnt into practice between sessions, turning rehearsal into reality. All the sessions are based on exercises using creative skills such as drawing, acting, song and dance, none of which need any formal education background for participants to take part. The role-play work, all of which is based on participants' own experience, is based on the ideas of Augusto Boal[15]. The drawing work is based on the PRA ideas of general development workers (see above.)

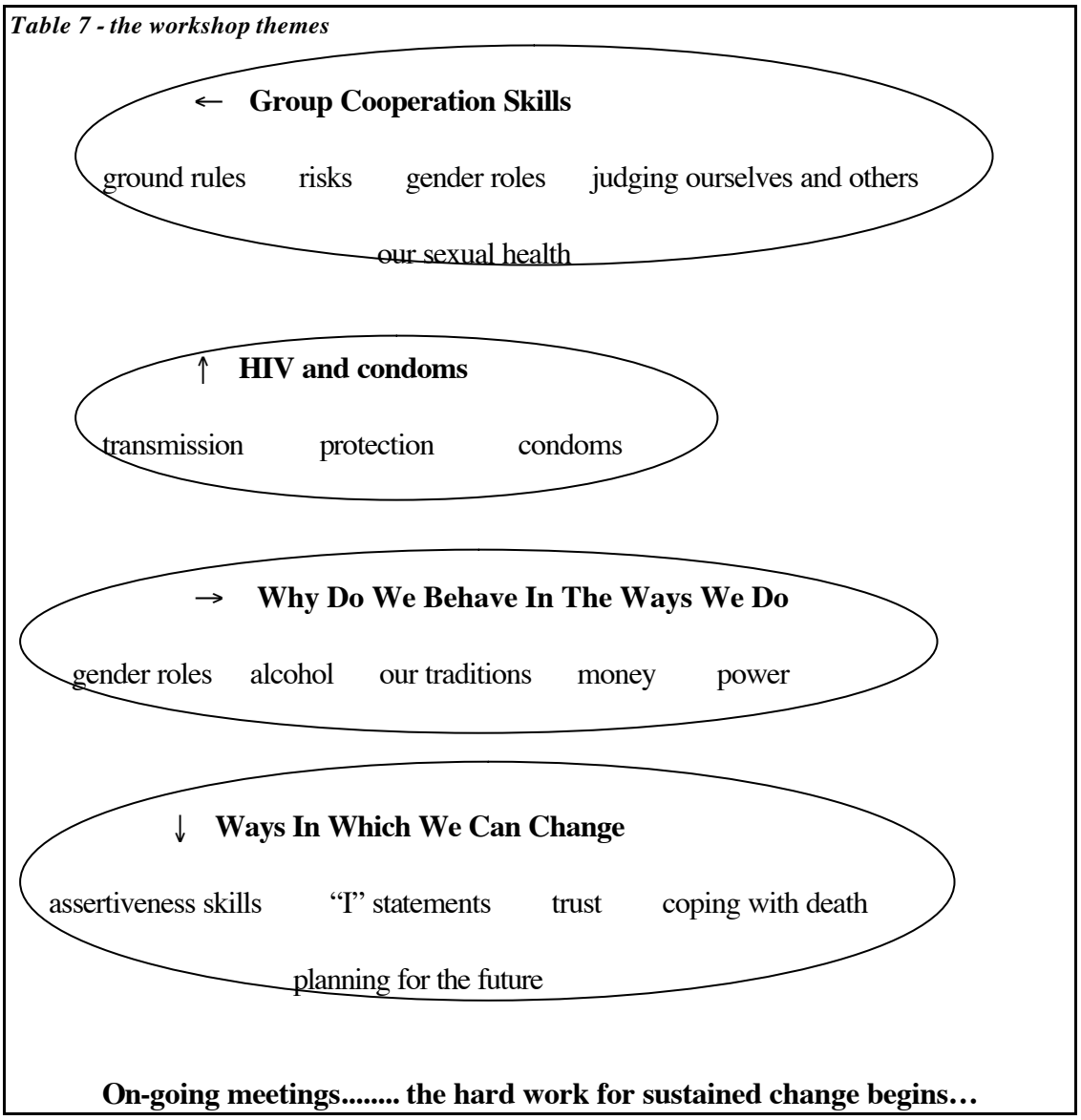
There are four themes for the whole training process (see Table 7). The first theme, covering the first few sessions, establishes the identity of each group which has been formed and enables them to develop group cooperation skills. It helps participants to explore the risks that we take in our lives, helps them to think about how we judge ourselves and others, starts to look at the gender roles which we have in our lives and addresses the good feelings and concerns that we have about our sexual health.

The second theme covers HIV: its transmission, protection and condoms. Workshop participants are given information about different possible options presently available for them to practise safer sex. Each and every workshop participant has the individual opportunity, if they want to, to touch and feel a condom and learn how to use one effectively. (This is in sharp contrast to more conventional campaigns, where one "educator" has stood up in front of a large group of onlookers, whilst placing a condom on a dildo.) However, no workshop member is told that they must do one thing or another. Instead they are having the opportunity to ask questions of their workshop facilitator (who is of similar gender and age to themselves), to share their thoughts and experiences, and to work out for themselves what is best for them.

The rest of the workshop sessions deal with theme three: "why we behave in the ways we do" and theme four: "ways in which we can change". This is where there is the big departure from more conventional health education approaches and where workshop participants really begin to start exploring for themselves the complexities of our lives. One session looks, for

instance, at the role of alcohol in our lives - its pleasures, it dangers and how we might learn to control it rather than it control us (unsafe sex often takes place under the influence of alcohol or other drugs). Other sessions address household expenditure - who takes responsibility for paying what, and who takes decisions for expenditure within the household. (Often, men spend their earnings on themselves and women have to find money for their children's health care or clothing by other means, such as sex with other men.) The sessions explore the fairness of

Table 7 - the workshop themes



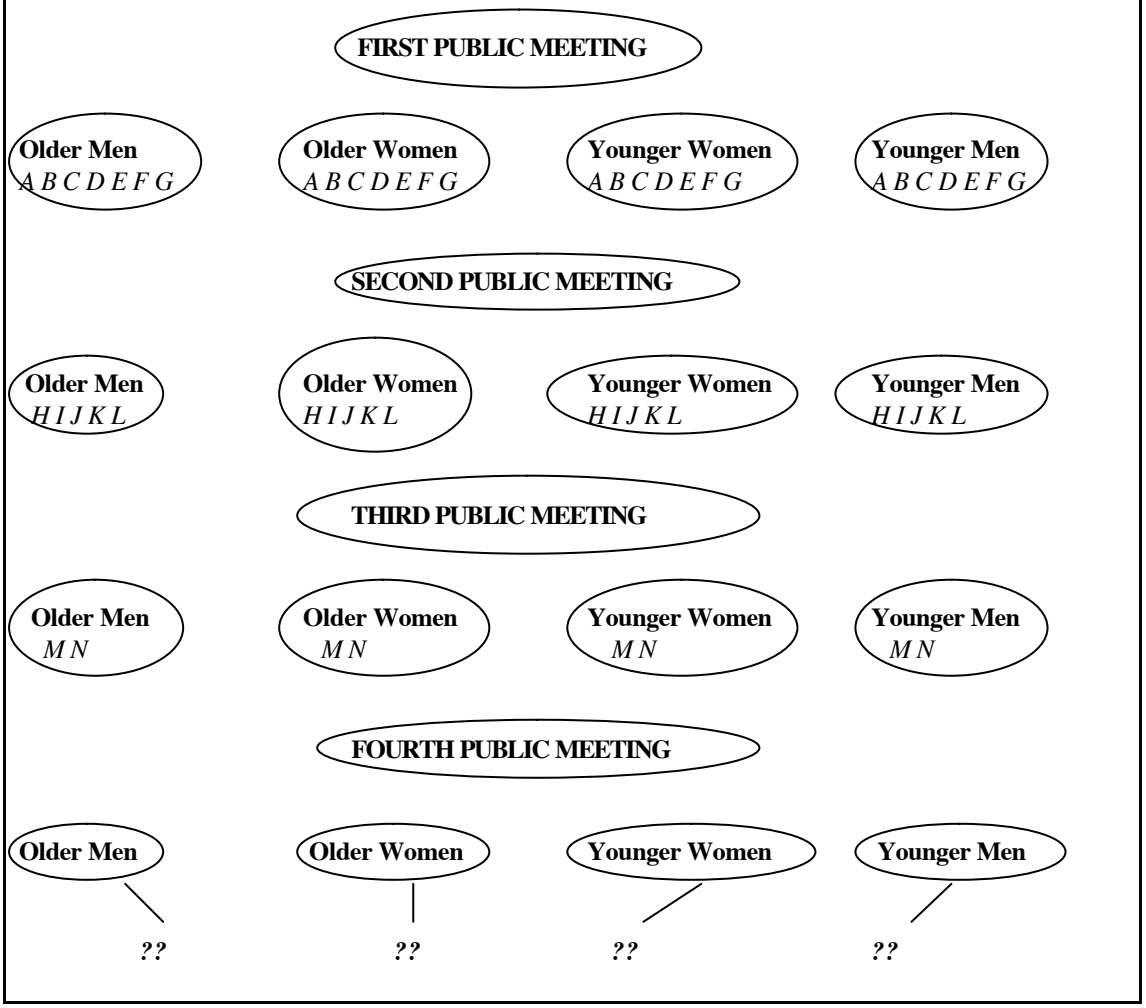
existing systems. Another session looks at traditional practices. All societies have time-honoured practices, some of which may be good, others of which may have problems now attached to them. For instance, in much of southern Africa, a widow would be re-married to her dead husband's brother. This might traditionally have ensured that she and her children were cared for by the husband's extended family. But nowadays, if her husband or she were infected with HIV, this may not be a wise option. Moreover, she may prefer anyway to remain single and establish her own household without a man, as we saw in the case of Consolata from Kenya, earlier on. Such traditions are aired and new, alternative options are explored.

The final sessions of the training workshop address "ways in which we can change" and explore assertiveness skills, "I" statements, trust, coping with death and planning for the future. These are difficult and challenging sessions and it is especially important that these sessions are only covered once the groundwork of the preceding sessions has been firmly laid.

Of course, people cannot be expected to change their approach to life on the basis of nine weeks' work. This workshop can only be seen as the starting point for changes within a community. So workshop participants are encouraged to continue meeting by themselves after

"Fission and fusion" of workshop groups

Table 8 - workshop fission and fusion structure



the last session is completed. We consider that these continued meetings enable participants to sustain the changes that they have decided to make in their lives and act as a support group, enabling people to compare and share their successes and failures and to renew their determination to do things differently in future - a tall order, but one made easier by sharing the experience with a group of similarly committed people.

It was explained earlier how groups are encouraged to meet alone and then to come together for large group exchanges (see Table 8). This principle of "fission and fusion" allows two important things. It creates the private time and space for discussion of personal issues, which many individuals might find far too embarrassing or painful for wider group discussion. It also creates the public space where the less powerful groups in a community have an equal platform with the more powerful groups[16]. Each group in turn presents a role-play or tableau (a frozen scene) to the other groups and the issues raised can then be discussed by everyone present. The intimate details of the small group discussions can get ironed out of this public presentation, but it enables the young women, for instance, to present the dilemmas which they face with "sugar daddies" who pursue them for sexual favours in return for school fees; or for older men to present the loss of self-esteem that turns them to drinking when they are made redundant. These sharings between groups enable everyone in the community to develop more awareness of the needs and difficulties of others around them, as well as increasing their own self-esteem and self-respect through having their own needs appreciated more clearly. This reciprocal experience of growth in self-knowledge and growth in awareness of others has a powerful and positive effect on community cohesion. Such meetings produce many comments such as "I never realised that...." and "now I understand why..." As the community members begin to understand themselves and one another more, simultaneously at the individual level, with peer level support and also with wider community understanding, so the foundation stones for change are laid.

What Changes can Happen after using Stepping Stones?

As an integral part of the SSTAP we are supporting organisations to develop their own participatory approaches to monitoring and evaluation with communities with whom they work. We believe that people's own involvement in charting the progress of the work forms an integral part of its sustainability. Inevitably there are both good and bad changes to report!

To start with the **positive** changes first, table 9 illustrates changes reported by a community in Uganda, 16 months after a Stepping Stones workshop had been conducted there.

Each of the four separate groups involved in this workshop were interviewed separately about their perceived changes in the community. It was a useful cross-reference to see that each reported change was mentioned by at least two separate groups. It was particularly encouraging to see that young men and young women felt that they now had a better sense of trust between them. Previously, each had been blaming the other group for spreading AIDS - now however members of both these groups were describing how they had realised that they had to work together to overcome the challenge.

It was also exciting to see how community members were beginning to write wills and that these wills were being respected by community leaders - this had not previously been the case and reflected a huge shift in people' courage and capacity to prepare for and cope with death.

Table 9 - Changes in Buwenda, Uganda recorded 16 months after Stepping Stones workshop, December 1995

(OM: older men; OW: older women; YM: younger men; YW: younger women)

Changes: mentioned by	**OM**	**OW**	**YW**	**YM**
less quarrelling between couples and more sharing of household costs	3	3	3	--
less wife-beating	3	3	--	--

a respect for the wills of those who have died, regarding the rights of their spouses and children	3	3	--	--
a greater sense of well-being and respect for others	3	3	3	3
greater mutual respect between young men and young women	--	--	3	3
greater ability of women to discuss sexual matters with their children	--	3	3	--
greater self-esteem among young women	3	--	3	--
a reduction in alcohol consumption, by older men especially	3	3	--	--
a sustained increase in condom use by participants from all peer groups and others	3	3	3	3
continued peer group meetings	--	3	3	3
wish to become economically self-sufficient	--	--	3	3
improved relations amongst others in the community who had learnt about the workshop from participants	3	3	3	3
development of care and support for HIV positive people and their carers within the community	--	3	--	3
enquiries from other communities about the workshop process	--	3	--	3

Thirdly it was very encouraging to see the young men reporting that they were now starting to visit and help people with HIV and their carers in the community. Whilst older women had been doing this anyway, the young men had said that they had previously just ignored or even ridiculed such people. Now, however, they reported that they had decided to do something to help them. This particular reported change was particularly heartening, since it had not been something which had been addressed explicitly in the workshop sessions. So this unexpected response was especially welcome. This change will be considered further later.

Finally, it was encouraging to see that most of the groups (which had not existed prior to the workshop) had continued to meet regularly over the ensuing months. This would appear to be another key ingredient to sustained change. The one group which did not continue to meet was the older men's group. This leads us on to the reported problems which have resulted.

A number of **negative** changes were reported during a participatory review of the use of Stepping Stones, which took place in two other communities in Uganda in 1998. There has also been information from Tanzania, where a less detailed review also took place in 1998, and from informal feedback from trainers and facilitators in Zimbabwe.

Key issues which were mentioned included: condoms, exclusion of non-attendants, insufficient husbands in attendance, facilitators' problems with running later sessions, organisations' own discomfort with the radical approach which Stepping Stones takes, and lack of training support and/or follow-up.

Condoms. Some feared that use of condoms led to an increase in sexual activity and multiple partners. Others reported problems with condom disposal. Clearly, more work is needed here. Condoms are a huge challenge to use and, whilst they can be successfully adopted by those who are determined to use them, there are still many fears and moral judgements made about their use.

Exclusion of non-attendants. It was reported that those who were attending the SS workshops became rather cliquey and excluded those who had not. (The difficulty here is partly that after the first session or two, newcomers are discouraged to join in, because the existing participants have learnt so much already that they feel held back by those who haven't been there previously. Yet later on, more want to join up, because they have seen and

heard the participants' interest in the sessions.) In Tanzania, people who hadn't attended the SS workshops accused those who had of being "saved". This has religious connotations which is sad because Stepping Stones has no formal religious stance. However, in Uganda it was suggested that one way round this exclusivity would be for each workshop participant between each session to share something about what they had learnt with a friend who was not attending, so that the workshops could be seen to be helpful to a wider group of people. It would be important elsewhere also to develop this basis of sharing and openness with others about what participants had been discussing and learning in the sessions, so as not to turn it into an exclusive club.

Absent husbands. It was reported that where both husbands and wives attended Stepping Stones workshops together, there was far greater chance of mutual progress in the relationship than if the wives alone attended (which was the usual case). This too is an expected drawback. It has always been difficult to get men involved in such workshops. Moreover, many men are absent from their communities in any case, because of migrant labour. This highlights the importance of increasing the numbers of good male facilitators who have the right kind of approach to encourage men to come forward and join in. It also highlights the need to explore the possibilities of running training workshops during periods of male workers' home leave from work.

Facilitators' problems. This became clear in Zimbabwe, when facilitators seemed to have few problems with running the sessions covered by the first two themes. But they seemed to stop their activities at page 100, which is where the first session of the third theme begins. This theme, "why do we behave in the way we do" and the fourth theme, "ways in which we can change", cover radically different issues from those with which facilitators have been familiar in the past. Whilst the first two themes are only going over issues with which facilitators on the whole are comfortable, page 100 onwards moves into hugely challenging issues to do with gender relations, with assertiveness skills and with death - issues which very few facilitators have previously addressed in their own lives - let alone have helped others to address for themselves. So we were expecting too much of facilitators to assume that they could just run these sessions with community members. This realisation has led the organisations involved in facilitator training in Zimbabwe to restructure their training. Facilitators are now given the time and space to experience Stepping Stones first for themselves as participants, before they go on to learn about how to facilitate the sessions for others. Sessions on gender issues are included in the facilitator training also. In this way facilitators have felt more confident in moving further through the manual and to help others to face these issues for themselves.

Organisations' discomfort with Stepping Stones. We have also realised that the approach taken by Stepping Stones - and other radical approaches to development work, such as the Reflect Freirian literacy project[17] - are quite daunting for many development agencies, whose style of working has been much more agency - led than the Stepping Stones approach advocates. The gender issues, the frank talk about sex and facing up to death are also all hugely different from the work content of most NGO (Non-Governmental Organisations) and CBOs (Community-Based Organisations). Furthermore, the facilitation process, where the facilitator sits as one with a group, instead of standing up in front of them like the teacher or the health professional, is still hugely challenging to many agencies' views on appropriate learning methods, especially where the agencies' main work is in health service delivery and health education. So when people take on Stepping Stones, it is possible that they have taken on not just another training package, but another way of thinking about development - and one with which they may feel distinctly uncomfortable.

Lack of training support and/or follow-up. The final problem to be discussed here addresses the importance of local support and advice on how this - and indeed any -training package may best be adapted to suit the needs of local organisations in an area. While in Uganda and many other countries there have been local training workshops held for facilitators from different organisations, in Tanzania there has been virtually no such activity. This absence of training has been reflected in the mainly poor up-take of the package compared to that seen in other countries. Organisations in Tanzania have reported that they already have their own training worked out and that Stepping Stones looks too long and cumbersome for them to make use of. They could not see how the package could be adapted for use in their own areas of concern. Yet the author of the report felt that there was a distinct use for the material in Tanzania provided that appropriate training and follow-up support could be given to agencies, so that they could adapt it and incorporate its approach into their existing work. These findings from the Tanzania review have been incorporated into our plans to develop local regional SSTAP advisers, who will be able to provide precisely this kind of back-up on a local basis.

There are clearly some challenges for us to address here. **Overall,** however, there has been an overwhelmingly positive response to the package which, we believe, is reflected partly in the time and effort invested independently by others in translating and adapting the package for local use. In 1997 a postal questionnaire of Stepping Stones recipients was conducted. In the words of one respondent:

> *"When I started on the programme I used to feel ashamed of some issues, but after I started to use the manual I became more confident...it has guided me on a daily basis. I have also maybe changed my attitudes and approach to the community and my family. I love it.* (Steve Paradzai Mushambi, Dananai Home Based Care Programme, Zimbabwe)

The questionnaire findings concluded that:

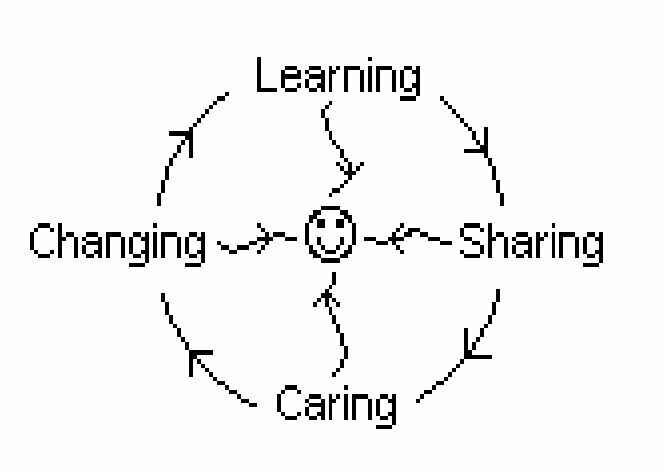
> *"It is clear that Stepping Stones materials have been enthusiastically received and put to good use....Feedback has been overwhelmingly positive. Real change has been reported, particularly in the kinds of areas in which conventional HIV/AIDS prevention strategies have been notoriously weak... The changes noted by respondents indicate that SS serves a more profound function in promoting behaviour change: addressing the less tangible and deeper aspects of interpersonal communication."* (Dr Andrea Cornwall, Stepping Stones users' questionnaire report[18])

But What Does "Behaviour Change" *Mean*?

The questionnaire described above gave us some insight into what various users of Stepping Stones on HIV prevention and support projects actually meant when they said that "behaviour change" had taken place in the communities where they work. What was clear was that the phrase "behaviour change" means different things to different people. We realised that their comments could be sorted into four different types or stages of behaviour change, namely "learning, sharing, caring and changing". By "learning", we mean knowing the basic facts about SRH and HIV. By "sharing", we mean beginning to talk about issues of concern to us with our friends, our parents, our children, our partners. By "caring" we mean that we begin to care for others in our community who are infected with or affected directly by HIV, instead of ignoring or shunning them. By "changing" we mean that we are empowered through our own individual will, combined with the mutual support of our peers and wider communities, to change our actions. We decided to draw a diagram which we called the "wheel of change"

which would include these different forms of "behaviour change" which we had received and which might help us to understand "behaviour change" more clearly as an on-going process.

Table 10 - The Wheel of Change

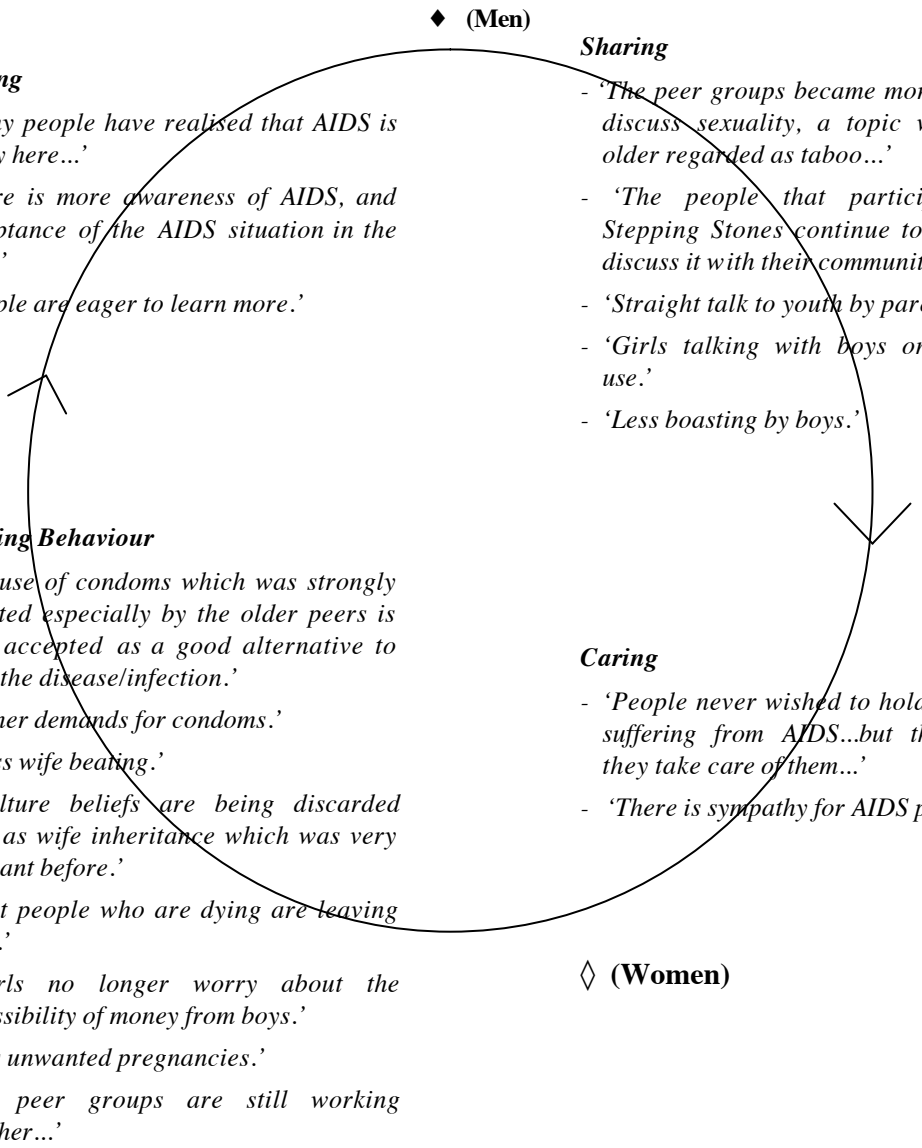


KEY: The smiling face in the centre of the wheel stands for "sustained behaviour change"

We can think of this wheel as one on a bicycle moving along a long and bumpy road, where each of the forms of change is a spoke of the wheel. As the wheel turns, so we can move along. If we can make the wheel move forward, we can create the force and momentum of "sustained behaviour change", represented in the diagram by the smiling face at the hub of this wheel.

In Table 11 a number of the responses to the questionnaire survey are shown according to the categories into which we then sorted them for our model of behaviour change.

Table 11 - Some examples of different stages of reported behaviour change



However, since we first developed this model of the "wheel of change", we have since realised that this too is an ungendered model, in the sense that it assumes that everyone has an equal opportunity to move from one stage to the next. In reality, as this paper has already explained, this is clearly not the case. The truth of the matter is that in most conventional IEC approaches to this work, many women are stuck on the wheel, between "caring" and "changing" (see table 11). Many of them are already involved in the care of others who are infected with HIV. Many women also *want* to reduce their vulnerability to HIV and other infections. But few women have the power by themselves to change their own behaviour. Meanwhile, men are also stuck on this wheel and they too need to be helped to move along it. But the position for most men is between "learning" and "sharing" (see table 11 again). Although many men may have *heard* about HIV, most men find it very difficult to begin to *talk* about it seriously amongst their peers and particularly with their sexual partners. And yet,

from what we have seen, those men who have begun to *share* their thoughts with others, and especially those who have actually started to *care* for others, have really then been able to *change* their own behaviour and thereby support and enable the women around them to change theirs also. It has been especially exciting for us, therefore, after Stepping Stones workshops, when we have heard young men reporting that they have begun to visit the sick and their carers in their own communities, instead of shunning them or laughing at them as they had done previously. At that point we know - and they know too - that a critical breakthrough is beginning, not just for a few individuals, but across their community. From this point, *real* behaviour change, both for men and for the women who depend on them, can begin to flow.

Conclusions

Through working on all these issues we have learnt how conventional IEC approaches may help people to *learn* about issues, in some external, impersonal form. But learning about something alone, especially something as frightening as HIV, rarely influences people sufficiently to change their actions in a sustainable manner. If we are all really to find this holy grail of *sustained* behaviour change, we really need to adopt a far more radical approach to our working practices, so that we *dare* to address the unmentionable and so that "sharing, caring and changing" can then begin to take place also, both for men and for women. In so doing, there are now possibilities of enabling women and men of all ages and backgrounds - ourselves included - to feel safe about exploring - and learn to take more control of - the most personal details of our lives.

What is so encouraging about these approaches is that people *do* feel able to begin to address these issues, about which they have immediately felt concerns, for themselves. In so doing, they are also helping to challenge conventional attitudes about women's rights, about traditional gender roles and about their own behaviour, as well as starting to meet their own sexual and reproductive health needs. Through such routes as these, we believe, sex, death and gender *can* begin to become subjects surrounded with less taboo and therefore less fear. By such means, there *is* a way ahead in the fight against the causes and consequences of gender conflict.

Work in such areas will also alleviate vulnerability to HIV transmission of course, and enables it then to be addressed as an *extension* of these other issues, rather than as an isolated and insurmountable problem, which bears no relation to the rest of our lives.

One final thing which is also clear is that problems related to sex and gender are global issues and not just problems of poorer countries. In UK too, for instance, there are huge challenges. UK currently has the highest rate of teenage pregnancies in Europe. Chlamydia - which has few noticeable symptoms and can cause infertility in both men and women - is also on the increase in Britain at a disturbing rate. We have a great deal to learn about "behaviour change" in the North from the pioneering work of individuals and communities in the South, who are daring to address these challenges. An extra challenge for us then is to get better at listening.

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[1] See for instance PANOS briefing 1998

[2] This article deals primarily with heterosexual transmission of HIV. Other transmission routes, such as mother-to-child transmission, injecting drug use, same-sex transmission and transmission through unsterile implements are also important issues, but are not addressed here. One good source of information about same-sex transmission in Asia is the Naz Project.

[3] For the latest update on figures worldwide, see www.unaids.org

[4] From Williams et al 1995

[5] From Williams et al 1997

[6] See www.unaids.org press release of 5th January 1999

[7] Gangakhedkar et al 1997. The study group consisted of 916 women, including 525 female sex workers (FSWs). The rate of infection in FSWs was nearly 50%, versus about 14% among those who were not sex workers. The researchers note that the infection rate among non-sex workers was "disturbingly high", considering their relatively low-risk behavioural profile. However, they say the rate may be explained by the discovery that non-sex workers had a higher incidence of STIs than FSWs and that some women were referred to STI clinics by husbands recently diagnosed with an STI. Source: Gender-AIDS: Gender-related articles, December 1997. E-mail: gender-aids@bizet.inet.co.th

[8] Quotes and illustrations taken from CAFOD 1998

[9] See for instance RRA Notes, subsequently renamed PLA Notes, 1989-present, Chambers 1992, Pretty et al 1995

[10] From International HIV/AIDS Alliance report 1996

[11] See for example Kambou et al 1998, Mbowa R 1997

[12] See Guijt et al 1999 for further discussion of this

[13] See www.stratshope.org

[14] Information, advice and guidelines about these and other adaptations and about training are available from www.steppingstonesfeedback.org

[15] Boal 1979

[16] Adaptations of the original SS package have called for more public meetings of workshop participants than the original manual suggested

[17] David Archer, pers. comm

[18] Cornwall 1997

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For more information about the use of the Stepping Stones package, see www.steppingstonesfeedback.org