



GENDER and HIV/AIDS

Overview Report

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The author would especially like to thank Dawn Cavanagh, Project Empower, for her support throughout the conceptualisation and writing process and Laura Washington from Project Empower for her comments on the first draft. Credit is also due to BRIDGE team members Hazel Reeves, Charlotte Sever, and Ra'ida Al-Zu'bi, for their substantive input and feedback into this report.

BRIDGE is grateful for the financial support of the following agencies: The Canadian International Development Agency (CIDA), The Commonwealth Secretariat, The Danish Ministry of Foreign Affairs, The Department for International Development, UK (DFID), The New Zealand Ministry of Foreign Affairs and Trade, The Norwegian Agency for Development Cooperation (NORAD), The Norwegian Ministry of Foreign Affairs, The Swedish International Development Cooperation Agency (Sida), The Swiss Agency for Development and Cooperation (SDC).

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Acronyms

ACORD	Agency for Co-operation and Research in Development
ADAPT	Agisanang Domestic Abuse Prevention and Training
AIDS	Acquired Immune Deficiency Syndrome
AWID	Association for Women's Rights in Development
CAFOD	Catholic Agency for Overseas Development
CEDAW Women	Convention on the Elimination of All Forms of Discrimination against Women
CIDA	Canadian International Development Agency
DAW	United Nations Division for the Advancement of Women
DAWN	Development Alternatives with Women for a New Era
DFID	Department for International Development, UK
ECHA	East, Central and Horn of Africa
EU	European Union
FIDA	Association of Uganda Women Lawyers
GIPA	Greater Involvement of People Living with or Affected by HIV/AIDS
HDN	Health & Development Networks
HIV	Human Immunodeficiency Virus
ICASO	International Council of AIDS Services Organizations
ICRW	International Centre for Research on Women
ICW	International Community of Women living with HIV/AIDS
IGAD	Intergovernmental Authority on Development
ILO	International Labour Organization
JOHAP	Joint Oxfam HIV/AIDS Programme
MAP	Men as Partners
MTCT	Mother To Child Transmission
NGO	Non-Governmental Organisation
NORAD	Norwegian Agency for Development Cooperation
OCAA	Oxfam Community Aid Abroad
PLHA	People living with HIV/AIDS
PTCT	Parent To Child Transmission
SAfAIDS	Southern Africa AIDS Information Dissemination Service
SDC	Swiss Agency for Development and Cooperation
SHIP	STD/HIV Intervention Project
Sida	Swedish International Development Cooperation Agency
SRRW	Sexual and Reproductive Rights and Wellbeing
STD	Sexually Transmitted Diseases
STI	Sexually Transmitted Infections
TB	Tuberculosis
UNAIDS	Joint UN Programme on HIV/AIDS
UNGASS	United Nations General Assembly Special Session
UNIFEM	United Nations Development Fund for Women
UNRISD	United Nations Research Institute for Social Development
W@B/HDN	Women at Barcelona/Health & Development Networks
WASN	Women and AIDS Support Network
WHO	World Health Organisation

Executive Summary

Critical gender challenges:

- Using a gendered human rights framework.
- Ensuring policy and programmes on HIV/AIDS are informed by the complex and diverse realities of women, men and children's lives.
- Changing or transforming unequal power between men and women to create a context where women have equal power and both women and men are less vulnerable.
- Developing a co-ordinated response to HIV/AIDS that is multi-levelled, multi-faceted and multi-sectoral as well as institutionalised.

HIV/AIDS is not only driven by gender inequality – it entrenches gender inequality, putting women, men and children further at risk. Defining and stigmatising those 'at risk' as men who have sex with men, sex workers and drug users has until recently obscured the increasing infection rate among people generally thought to be 'safe', including married and older women. The dominant risk factor is now heterosexual sex. It is estimated that almost 50 per cent of those living with HIV and AIDS are now women. As individuals and in their social roles as mothers and carers, women are now disproportionately affected by HIV/AIDS.

Causes and impacts

Traditional health-based approaches have been, and continue to be inadequate, ignoring the social, cultural, economic and human rights dimensions. A focus on sexual and reproductive rights for women and men is an important corrective measure. Yet a broader human rights framework is needed to address the range of inequalities that drive HIV/AIDS – including poverty and that recognises the rights of those that contracted HIV through ways other than sex. The Convention on the Elimination on All Forms of Discrimination Against Women (CEDAW) is one such framework. Another useful tool is 'Women and HIV/AIDS: The Barcelona Bill of Rights' (July 2002) which includes, among others, the right to equality, economic independence, and education.

The denial, blame and stigma surrounding HIV has silenced open discussions, delayed effective responses, and added to the burden of those living with HIV and AIDS. Women's sexuality is particularly subject to stigma and control. Indeed, the social construction of sexuality – who should or should not express one – including men who have sex with men, young people, people with disabilities, and those beyond reproductive age, means they are often denied appropriate sexual health information and services.

When it comes to decision making in relationships, men are expected to dominate and women to be passive. Unequal parties are not in a position to negotiate when they have sex, how often and how they can protect themselves from sexually transmitted infections (STIs) and HIV. The double standard of condoning multiple sexual partners for men, and the expectation that men should know more about sex, puts them and their partners at risk as well as preventing them seeking sexual health advice.

The relationship between HIV, gender and poverty is complex. Pressing concerns for short-term survival may lead poor women to engage in survival sex which paradoxically can expose them to the long-term risk of illness and death through HIV infection. Poverty also limits people's access to sexual health information, prevention technologies and treatment. Whilst this is true for women and men, gender inequality shapes different experiences of poverty and impacts on women and men's ability to move out of poverty. Social spending cuts often lead to increased pressure on women and girls to take on the role of social safety net, caring for sick relatives and securing a livelihood as earning family members become sick and die. This is one of the invisible impacts of HIV/AIDS.

Approaches

Unfortunately, many approaches to combat the spread and impact of HIV/AIDS have failed to take gender differences and inequality into account. Some have reaffirmed ideas of female passivity and male dominance in decisions on sex and reproduction. Others have responded to the different needs and constraints of women and men, but failed to challenge the gender *status quo*. Interventions should both seek to empower women and transform gender relations.

Starting from the everyday realities of people's lives and with their priorities is a must. The International Community of Women Living with HIV/AIDS (ICW) addresses the question 'What do HIV-positive women want?' and the Sonagachi project in India supports the self-defined priorities of sex workers including negotiating safer sex with their clients. Both programmes are led by the women themselves. Genuine participation in defining both problems and solutions is fundamental to achieving empowerment.

Women and men living with HIV can lead lives of dignity and enrichment when they are supported by the societies and communities they live in, rather than stigmatised. As one HIV-positive woman in Mexico said 'I know I am a woman of worth'. Such positive reinforcements are the result of concerted efforts by individuals, communities, and organisations, such as ICW.

However, 'empowerment' is in danger of remaining just rhetoric if the unequal power in gender relations at a personal, collective, institutional and broader societal level is neglected.

Transformation of the unequal power in gender relations is at the heart of the Stepping Stones participatory approach to HIV, which works with both women and men in developing their communications and relationship skills. Impacts have included a decline in domestic violence and better communication between women and men on sexual matters.

The power imbalance between development institutions and those they seek to support have to be contested if approaches are to be empowering and transforming. Development practitioners need to question their prejudices around HIV and their vulnerability to HIV. So breaking down the artificial division between the 'experts' and those 'at risk'. Likewise, recent trends towards working solely with men need to be challenged if they are at the expense of programmes for women, or target men but do not address gender inequality. Instituto PROMUNDO successfully works with young male peer-promoters in Brazil to challenge the acceptance of gender-based violence.

The complex nature and magnitude of the HIV/AIDS epidemics requires a co-ordinated response that occurs at all levels, encompasses different approaches, such as service delivery, capacity building, research and advocacy, and is incorporated into all sectors. In South Africa the Joint Oxfam HIV/AIDS Programme (JOHAP) has, through dialogue and funding, supported partner organisations in mainstreaming an approach to gender and HIV/AIDS in all their work.

The effectiveness of responses to HIV/AIDS depends on our ability to deal with the inequalities that both drive and are entrenched by the epidemic. We must open up debates around issues of sexuality and address gender equality in sexual relationships, and challenge the stigmatisation and discrimination faced by those living with HIV and AIDS. Those most affected should both define the problem and identify the solutions. Through collective action at all levels, from local to international, we can harness the energy to translate this challenge into a co-ordinated action.

Executive summary written by Emma Bell.

This summary has been adapted from the lead article for *In Brief* no. 11

1. Introduction

HIV/AIDS acts as a spotlight, exposing inequalities, including gender inequality, globally. The HIV/AIDS epidemics are at their worst in regions where poverty and economic inequality is extensive and deep, gender inequality is pervasive and access to public services is weak and uneven (Collins and Rau 2000). The vast majority of the total number of people living with HIV live in the 'developing' world, with 71 per cent of the men, women and children infected living in Sub-Saharan Africa (UNAIDS 2002).

Bennett (1990) refers to three successive global epidemics:

- the *HIV epidemic* or the *silent epidemic* — is largely hidden and spreading rapidly throughout the world.
- the *AIDS epidemic* – represents the visible consequences of HIV.
- the *third epidemic* – moves beyond the medical to the social and refers to the denial, blame, stigmatisation, prejudice and discrimination which is present in every country dealing with HIV/AIDS.

The third epidemic of social, cultural, economic and political reaction to AIDS [...] is as central to the global challenge as AIDS itself (Mann in Bennett 1990: 2).

In order to effectively address the three epidemics, it is vital to both understand the factors that drive men and women's increasing susceptibility to infection, as well as to analyse the impact that HIV/AIDS is having on individuals, households, communities and society. This report takes the position that effective responses fall along the prevention-care continuum, within a human rights framework. The prevention-care continuum addresses the impact of HIV/AIDS for all people *affected*. This encompasses those not infected with the virus, people that have to cope after the death or deaths of family members, people living with HIV as well as those men, women and children who are sick from AIDS-related symptoms. Using such a framework requires comprehensive goals of integrated prevention, and care and support for individuals and families affected by HIV/AIDS. Gender inequality is evident at all stages of the prevention-care continuum, and affects among other things, the possibilities of prevention, access to appropriate materials, information and resources, the quality of care received, and chances of survival. Hence the need for the prevention-care continuum to be placed within a human rights framework that directly challenges inequality.

HIV/AIDS has opened up debates around issues of sexuality and has served to highlight the importance of gender equality in sexual relationships as well as the importance of equality and respect in all social relationships. In a statement for the United Nations General Assembly

Special Session (UNGASS) on HIV/AIDS in 2001, Stephanie Urdang, United Nations Development Fund for Women (UNIFEM) advisor on gender and AIDS, noted a growing global understanding that the epidemic is less about epidemiology and more about social factors. What is needed is a clearer definition of what the social as well as economic and political factors are, in terms of both cause and impact. Gender and gender relations, based on power, are central:

Unless gender inequality, which rests on power relations is specifically addressed in every strategy, policy and programme that is undertaken from the global and governmental level to the community and family level – our efforts to reverse the epidemic will be stalled. Gender equality is not simply a matter of justice or fairness. Gender inequality is fatal (p4 ibid).

In an article in the *New York Times*, Mr Mocumbi, Mozambique's former Minister of Health, a physician and a Board member of the International Women's Health Coalition, made the point that AIDS is spreading rapidly among heterosexuals because of gender inequality:

In Mozambique the overall rate of HIV infection among girls and young women, 15 percent, is twice that of boys their age, not because the girls are promiscuous, but because nearly three out of five are married by age 18, 40 percent of them to much older, sexually experienced men who may expose their wives to HIV and sexually transmitted diseases [...]. Abstinence is not an option for these child brides. Those who try to negotiate condom use commonly face violence or rejection. [...] As a father, I fear for the lives of my own children and their teenage friends. Though they have secure families, education, and information and support the need to avoid risky sex, too few of their peers do. As prime minister, I am horrified that we stand to lose most of a generation, maybe two. The United Nations estimates that 37 percent of 16-year-olds in my country will die of AIDS before they are 30. [...] We must summon the courage to talk frankly and constructively about sexuality. We must recognize the pressures on our children to have sex that is neither safe nor loving. We must provide them with information, communications skills, and, yes, condoms. To change fundamentally how girls and boys learn to relate to each other and how men treat girls and women is slow, painstaking work. But surely our children's lives are worth the effort' (Mocumbi 2001).

Despite the acknowledgement of the importance of gender inequality in driving and determining the impact of the HIV/AIDS epidemics, there is little done to address this. For example, gender advocates attending the 14th International AIDS Conference in Barcelona, 2002, felt that the information presented was 'gender-blind'. 'We are still missing key information on how HIV/AIDS does, or may, impact differently on women and men' (W@B/HDN Moderator 2002).

The complexity and inter-connectedness of the three epidemics demand an in-depth analysis that deepens understanding about how the HIV/AIDS epidemics have been 'allowed' to spread globally at such a rapid rate. Why, 20 years after the first diagnosis, are discrimination and stigma still prevalent and impacting on both the spread and consequence of HIV/AIDS?

This report will outline:

A rights-based approach:

- The importance of locating HIV/AIDS within a *gendered* human rights framework.

Evolving epidemics:

- The history of the epidemics and the role of discrimination and stigma.
- An analysis of how gender inequality shapes the economic, political, and social factors driving the HIV epidemics.
- How HIV/AIDS exacerbates inequality, including gender inequality.

Critical challenges towards transformation:

- The critical challenges for a gendered agenda.
- A framework to assess the extent to which HIV/AIDS responses address gender, with the ultimate goal being the empowerment of women and the transformation of gender relations.
- An institutionalised gender response to HIV/AIDS through a multi-level, multi-faceted and multi-sectoral approach.

2. A rights-based approach

A rights-based approach, which includes women's rights, should be the basis of the response to HIV/AIDS

The initial response to HIV/AIDS in many countries was to view and address HIV as a health issue, ignoring the social, economic and human rights dimensions that impact on both prevention and care. As noted by Wiseberg, Hecht and Reekie (1998) the response was 'often reactionary, invoked in the name of public health and frequently at the expense of human rights' (p1). The health model views health as something over which the individual has personal control. Thus, the health framework is to give information and encourage 'healthy' choices. The responsibility for health is placed on the individual, in a social vacuum. This fails to acknowledge that choices and decisions will be shaped by not only what is known, but also by fears and prejudices, as well as by limitations on the means of the individual to act (Richardson 1996). Such an approach can undermine the health and well being of women and men.

A human rights approach emphasises the claims or entitlements that all people have to a full and satisfying life, in which each person is able to develop to his or her full human potential. Human rights set global standards for human well being and development (DAW, WHO, UNAIDS 2000).

HIV/AIDS is a human rights issue because:

- A lack of access to prevention methods, appropriate information and materials, treatment and care, leading to vulnerability¹ to HIV is linked to human rights violations such as poverty, inequality, racism and sexism.
- People living with HIV/AIDS and those affected by these epidemics are often unable to live a life of equality, dignity and freedom as their rights are often violated on the basis of their HIV status. This includes the right to privacy, confidentiality, access to acceptable healthcare, reproductive and sexual health services, employment, education, freedom of movement and the right to travel.

¹ The term vulnerability is contested, which some warn promotes an image of powerlessness and a victim mentality, arguing that within a vulnerability framework the focus is on the individual's ability to protect him or herself from HIV infection (Cohen and Reid 1999; Collins and Rau 2000). However, Mann and Tarantola (1996) view vulnerability as the opposite of empowered. It is possible for men, women and children to be vulnerable in certain aspects of their lives, and empowered in others. For the purpose of this report and analysis, vulnerability includes the context in which people live their lives and links this to their susceptibility to HIV.

A focus on the concept of human rights alone is, however, not sufficient as often articulations of human rights do not take women into account. Evidence of this can be seen on a daily basis where gender-based abuse and discrimination is sanctioned or tolerated by society. Furthermore, as Charlesworth notes, traditional human rights formulations are based on a typical male model and applied to women as an afterthought, if at all (Peters and Wolpe 1995). There is also a tension between acknowledgement of and implementation of human rights. For example, men may care about reproductive freedom, but their lives are not threatened by the lack of it, and they do not face the same consequences of failure to enjoy and access reproductive freedoms (Cook 1995).

The Joint UN Programme on HIV/AIDS (UNAIDS), in partnership with the Office of the High Commissioner for Human Rights, developed a series of guidelines for member states. The 12 guidelines are meant to assist in designing policies and programmes which are sensitive to the context of the HIV/AIDS epidemics and which protect and promote human rights. Whilst the guidelines are comprehensive and provide a broad framework in which to develop progressive responses to HIV/AIDS, they are largely gender neutral. More recent thinking and analysis on gender within UNAIDS has not been incorporated.

Given the often sexual dimension of infection, HIV/AIDS is linked to reproductive and sexual rights. The social and cultural dimensions of sexual and reproductive activity promote and entrench gender inequality and increase both women and men's vulnerability to HIV infection. Reproductive rights refer to rights that focus on and relate to the potential and ability to procreate. This includes issues such as fertility, family planning and termination of pregnancy.

Reproductive rights take on another dimension in relation to HIV/AIDS, as hard-fought battles of the feminist movement are being eroded. Examples include the control often exerted by healthcare workers over the reproductive choices of women living with HIV/AIDS. Incidents of women living with HIV requesting termination of pregnancy and being 'forced' into sterilisation have been noted (Mthembu 1998). Often, women living with HIV/AIDS are not given accurate information regarding pregnancy and breast-feeding (Seidel and Tallis 1999). Women often face difficult decisions regarding breast-feeding as a culturally preferred option. A decision to not breast feed can lead to a forced disclosure of women's HIV status (Paxton 2001). Women have also reported judgmental and hostile attitudes from service providers, including testing without consent and refusal of services (Manchester and Mthembu 2002).

'When I was pregnant and went for antenatal care, I was told to have a blood test. They did not tell me what the test was for. Every woman who came to the clinic had to have her blood tested. They did not explain at all what kind of test they were doing. I realised it was the AIDS test when I received the result'

Thai woman aged 29 (*ibid*)

Whilst reproductive rights are vitally important, they are by definition narrow, in that they address the rights of heterosexual men and women of child-bearing age. It is important in the context of HIV/AIDS that we also talk about sexual rights, a more inclusive term which focuses on the ability of men and women to make choices about the expression of their sexuality and their sexual lives, including who they have sex with, how, and why (Hlatshwayo and Klugman 2001).

Hlatshwayo and Klugman (2001) suggest a sexual rights framework for men and women which embodies the right to:

- Have control over one's own body.
- Have sex when, with whom and how one wants and not be forced to have sex.
- Make decisions about their own sexuality.
- Have sexual enjoyment.
- Protect themselves from the risk of the consequences of sex, such as pregnancy, sexually transmitted infections and HIV.
- Have access to non-judgemental, responsive services which help deal with sexual health concerns.

Sexual and reproductive rights are seen as rights and freedoms for women, men and couples. Sexual and reproductive rights are vital if women are to access quality of life and well being, have increased options and if HIV/AIDS prevention and care efforts are to be successful. 'Sexual and reproductive well-being is the wellspring for all dimensions of our lives – physical, material and psychological' (Cornwall and Welbourn, in press).

However, it is also critical that women enjoy other basic human rights if the broader inequalities that drive the epidemic are to be addressed. Moreover, whilst HIV/AIDS is predominately transmitted sexually, it is important to note other modes of infection, such as intra-venous drug use and blood transfusions, and to ensure that the rights of such marginalised groups are upheld.

There are different conventions, that is, pieces of international law which are signed by countries and are referred to as binding (UNIFEM / AWID 2002). These declarations have clauses that can be used in activism and advocacy to reduce vulnerability to and the impact of HIV/AIDS. For example, the Convention on the Elimination on All Forms of Discrimination against Women (CEDAW) is a critical tool to both understand and act against gender inequality and discrimination.

Aspects of CEDAW which relate to HIV/AIDS include:

- Sexual stereotypes and the knowledge gap
- Physical exposure
- Gender-based violence and sexual exploitation
- Gender inequality and safer sex
- Access to health services
- Pregnancy and perinatal transmission
- Care and care-giving
- Women's leadership and participation

(UNIFEM 2002)

Specific declarations developed by gender and AIDS activists which strongly emphasise sexual and reproductive rights along with broader social, economic and political rights include:

- The International Community of Women Living with HIV/AIDS (ICW) developed 12 statements asserting the needs of women living with HIV/AIDS globally.
- The Women and HIV/AIDS: The Barcelona Bill of Rights² (July 2002). One of the central tenets of which is the right to live with dignity and equality.

(See Supporting Resources Collection for a complete list of recommendations from ICW and the Barcelona Bill of Rights).

² The Women and HIV/AIDS: Barcelona Bill of Rights was initiated by Women at Barcelona and Mujeres Adelante with lead involvement by the International Women's AIDS Caucus of the International AIDS Society and the International Community of Women Living with HIV/AIDS during the Barcelona 14th International AIDS Conference, July, 2002.

3. Evolving epidemics

3.1 The HIV and AIDS epidemics

HIV and AIDS have been with us for approximately 20 years and still continue to challenge us globally. Since the onset of the HIV epidemic, more than 60 million people have been infected with HIV. Initially HIV was thought to only affect men who have sex with men. However, the first woman diagnosed with AIDS was recorded as early as 1982. The main modes of transmission remain heterosexual sex, sex between men, sharing needles for intravenous drug use and the infection of infants during pregnancy, during birth or through breast-feeding.

Whilst men still constitute a larger percentage than women living with HIV/AIDS, the UNAIDS global estimates of the number of people living with HIV/AIDS show that women make up an increasing share of all people living with HIV/AIDS. In 1997 41 per cent of adults living with HIV and AIDS were women (UNAIDS 1998a), in 2001 the figure has risen to almost 50 per cent (UNAIDS 2002)³. A rise is apparent even in countries which initially reported epidemics amongst men who have sex with men and intravenous drug users. There are certain groups of women who are particularly vulnerable, for example, young women and women who have sex in exchange for goods, services or money. An analysis of data from epidemics around the world shows a similar pattern of HIV in women – the prevalence of HIV infection is highest in women aged 15 – 25 and peaks in men between five to ten years later. An emerging epidemic is being seen in some countries amongst older people (over 50 years), especially women, with the numbers increasing 40 per cent in the last 5 years (UNAIDS, 2002). The dominant risk factor is heterosexual sex. Older women are specifically vulnerable due to the sexual behaviour of their partners, as well as physiological changes which occur during menopause, including thinning of the vaginal walls and reduced lubrication.

The global history of HIV/AIDS is complex and includes both individual histories and peculiarities of HIV/AIDS epidemics at community, national and regional levels, as well as some significant common features among these histories. Some countries, mainly in Africa, have well-established HIV epidemics and have begun to deal with the impact of AIDS. Others are beginning to see HIV prevalence and incidence rates steadily increasing, and it is only a matter of time before the rates escalate. Many countries have low national prevalence rates, but this often hides serious epidemics which are initially concentrated in and limited to certain localities or among specific groups within the broader population. An example is that of

³ Adults living with HIV/AIDS in 2001, 37.1 million. Women living with HIV/AIDS, 18.5 million (UNAIDS 2002).

Myanmar (Burma), South East Asia, which has a national prevalence of less than 2 per cent but among intravenous drug users infection is known to be as high as 60 per cent, with a 40 per cent prevalence rate amongst sex workers. Throughout the world there are examples of countries which did not respond appropriately when the prevalence was low and are now having to deal with serious epidemics. In 1990, the first antenatal survey conducted in South Africa showed that 1 per cent of pregnant women were living with HIV. Twelve years on and the prevalence is 24 per cent, with one province recording a prevalence rate of over 36 per cent (UNAIDS 2000).

3.1.1 The third epidemic – stigma and taboo

Men, women and children living with HIV/AIDS often experience high levels of stigma and discrimination on the basis of their HIV status. HIV/AIDS related stigma, the third epidemic, is highly complex, dynamic, and deeply ingrained in society. It is linked to broader, existing inequalities evident in society, and in societies' often negative view of expressions of sexuality. Analyses of stigma seldom focus on the differences in how men and women are stigmatised and how they experience such stigma. The stigma surrounding HIV has silenced open discussion around both the causes of HIV infection as well as appropriate responses to deal with those consequences (Aggleton and Parker 2002). Stigma also invokes powerful psychological feelings in people living with HIV/AIDS including how people view themselves. The fear of being stigmatised results in women, men and young people being unable to look after their sexual and reproductive health, for example, accessing sexual health information, treatment, and methods for HIV and STI prevention, such as the female condom. Thus stigma is evident in and impacts all levels of the prevention-care continuum. The story of Thembi, an AIDS activist from South Africa clearly illustrates this.

Thembi – an AIDS activist from South Africa.

Thembi⁴ was a bright young woman who had left school early due to financial difficulties at home. She found a job as a domestic worker and was able to contribute financially to the family, which included her parents and her two children. When she was pregnant with her third child she was told at the clinic that she was HIV positive. She lost her job when her employers were informed about her HIV status.

Thembi joined a support group, which consisted of five women. Thembi had good leadership and organising skills and soon took over as the group leader. As most of the women were unemployed, they started an income generation project after they were trained in sewing. A successful funding proposal resulted in the group acquiring three sewing machines and materials.

When Thembi had told her parents about her HIV status, she was banished from the house and in desperation turned to the Church to which she belonged. The minister and his wife took her in. Thembi began to be more and more open about living with HIV and spoke to church groups and youth groups. She was offered a job as an AIDS educator – it was her first formal job and things were looking up for her.

After a year in the job, her last born child, Nana, who was three years old, began to get sick. After a couple of weeks in a hospital Nana died of AIDS related symptoms. After a period of mourning, Thembi returned to work with even more resolve to educate others. She approached churches, businesses, women's groups, clinics and schools and told her story.

When Thembi became ill her colleagues attempted to get her admitted to a semi-private hospital – when they eventually succeeded she lay in a bed for almost two weeks without any treatment, due to her own lack of funds and the hospital's lack of commitment to treat people with AIDS. She was then transferred to a larger, public hospital but it was too late – Thembi died two days later.

(Adapted from Tallis 1998)

Link and Phelan (ICRW 2002) highlight four components of stigma which are shaped by social, economic, and political power:

- distinguishing and labelling difference;
- association of human difference with negative attitudes;
- the separation of 'us' from 'them';
- status loss and discrimination.

The causes and consequences of stigma are clearly illustrated in the left-hand square in the figure below, reinforcing high-risk behaviour and inadequate responses to the epidemics. However, across the world HIV/AIDS has sometimes triggered responses of compassion, solidarity and support. Such responses are capable of creating and reinforcing a positive cycle of attitudes and behaviours. Unless we make a concerted effort to eradicate HIV/AIDS-related stigma then the positive cycle illustrated on the right-hand side cannot be achieved.

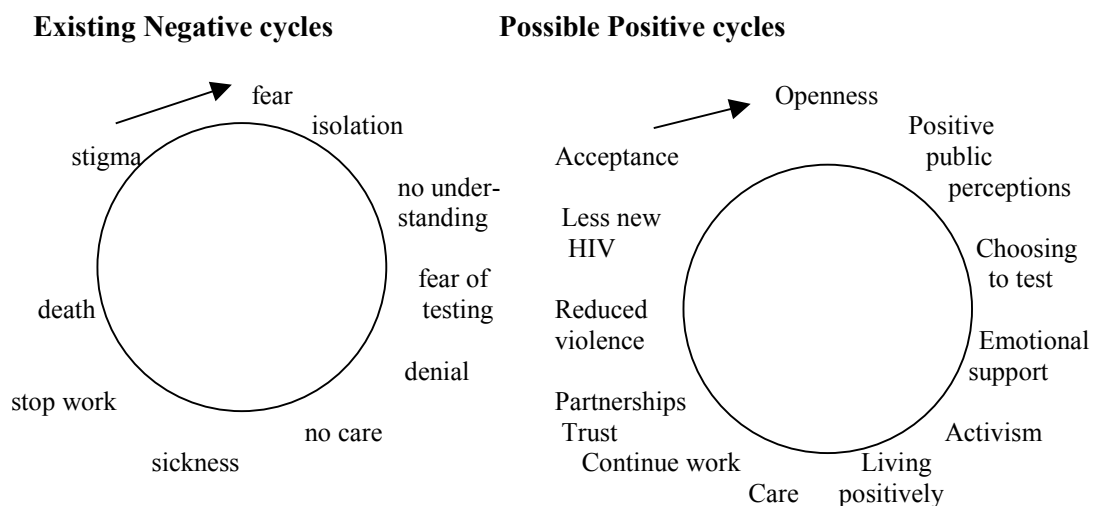
Nath (2001) notes, based on her work with women living with HIV in Mexico, high levels of self-esteem amongst the HIV-positive women who are supported by their communities rather than stigmatised. Women were able to lead lives of 'dignity, positivity and enrichment' (p51). As

⁴ Names have been changed.

one of the women said 'I know I am a woman of worth. I exercise more and try not to become depressed. I take care of my health and my son's health. He is not infected' (p52).

Tarisa's, a woman living with HIV/AIDS told Sunanda Ray of the Southern Africa AIDS Information Dissemination Service (SAfAIDS), 'Openness about my HIV status has changed many people's perception that HIV is a result of prostitution, promiscuity, and punishment from God. It has helped other HIV-positive people come to terms with their status. Now they now look at me as a whole person. They now accept that I can have sex as an HIV-positive person, the same as eating, drinking, going to work. Some people don't get tested because then they think they will have to stop having sex if they test positive' (The Communications Initiative 2002).

Negative and positive cycles of behaviours and attitudes



(Manchester and Welbourn 2001)

3.2 What drives the HIV/AIDS epidemics?

There are complex sets of micro- and macro factors that are fuelling the HIV epidemics at a country, regional, continental and global level. Whilst the epidemics follow diverse courses in different countries, there are common threads with regard to main mode of transmission and patterns of distribution, which help us account for the rapid spread of the virus globally over the last 20 years. Baylies (2000) notes that factors driving the epidemic are 'deep-seated and intransigent, embedded in the very power relations which define male and female roles and positions, both in intimate relations or the wider society' (p1).

Mann and Tarantola (1996) outline three separate but interconnected sources of vulnerability of the individual to HIV and AIDS, namely, personal, programmatic and societal. In its entirety the

model can provide a useful framework to perform a detailed analysis of women and men's susceptibility to HIV infection, contextualise the lives of men and women, and to define solutions based on this context. It is especially useful in highlighting the role that institutions, policy and programmes play in enhancing or reducing vulnerability, which is often overlooked when analysing the factors driving the epidemic. Institutions at different levels, be they state or part of civil society, by not taking into account the realities of peoples' lives, fail to act effectively and increase vulnerability and susceptibility of women, men and children to HIV/AIDS (Welbourn, pers. comm. 2002).

Factors which increase the vulnerability of women and men to HIV include certain cultural practices, inadequate access to and control of wealth and resources, especially healthcare, education and welfare, religious practices and beliefs, poor governance, migration, conflict, violence, urbanisation, and stigma and discrimination of marginalised groups (for example, men who have sex with men, injecting drug-users, people in prisons). All of these factors have gender dimensions.

For the purpose of this discussion, factors addressed are social, economic, and political. However they often overlap and reinforce each other, for example all three factors shape migration processes that often lead to greater vulnerability of men and women to infection. However, in this report migration is featured under social factors.

3.2.1 Social factors

There are many social factors which impact on the spread of HIV. This section will focus on sexuality and power, gender-based violence, religion and culture.

Sexuality and power

Patriarchal relationships involve, to varying degrees and within different sites, inequalities of power, and without power women are likely to experience little control over sexual relations with men. It is within the context of unequal power relations that women are required to take preventative and protective actions aimed at minimizing their risk of contracting HIV (Travers and Bennett 1996: 67).

Masculinity and femininity are socially constructed ideals of what men and women should be like. Masculinity is associated with dominance, femininity with passivity. Sexuality too is socially constructed and for men the range of expressions of sexuality, including heterosexuality and homosexuality, are an important means of proving masculinity. Social constructions of femininity generally stipulate that women's sexuality should be invisible and that it needs to be controlled. Its association with masculinity and femininity is complex and differs in different historical and cultural contexts. Yet despite such differences both the social perception and the practices associated with heterosexuality have certain common elements.

Different sexual roles are defined for men and women, however they are not just different, but also unequal. Almost everywhere, primacy is accorded to male desire and women are perceived to be the passive recipients of male passion (Doyal 1994). Women are often socialised into believing that sex happens to them whilst men believe that sex is something that they do.

Unequal power in sexual relations leads to the sexual double standard which has alarming implications for both men and women's ability to prevent the sexual transmission of HIV (Wilton 1997). Unequal parties are not in a position to negotiate when they have sex, how often and how they can protect themselves from STIs and HIV. Baylies and Bujra (2000) note the difficulties for women to challenge male power 'in the lonely moment of private relations and to negotiate for safer sex' (p xii). Sex is often the currency by which girls and women are often expected to pay for shelter, food, and goods (UNAIDS in Baylies 2000). Globally, the condoning of multiple partner relationships for men is a social norm that increases women's vulnerability. In many cultures, both women and men believe that a variety of sexual partners is acceptable and essential for men but not appropriate for women.

In a study of women from over ten countries undertaken by the International Centre for Research on Women (ICRW) the following was noted: 'Though many women expressed concern about the infidelities of their partners, they were resigned to their lack of control over the situation. Women from India, Jamaica, Papua New Guinea, Zimbabwe and Brazil report that raising the issue of their partners' infidelity can jeopardise their physical safety and family stability' (Gupta and Weiss 1993: 405).

It is also important to stress that the sexual double standard also puts men at increased risk. When men do not take care of their sexual health or do not believe it necessary to seek advice on such matters they put themselves and their partners at risk. The social construction of who has and who does not have a sexuality or what is a legitimate sexuality puts everybody at risk from HIV/STI infection, for example, societies often fail to recognise that young people, people with disabilities and those people beyond reproductive age have sex. As a consequence they are often denied appropriate sexual health information. This is also true when societies fail to recognise homosexuality.

Gender-based violence

One of the most serious implications of gendered relations of power is male violence against women and girls of all ages, which is pervasive in all societies and has serious implications for women's ability to protect themselves from HIV infection. Violence against women and girl children, physical, emotional and/or sexual, is a product of the social construction of masculinity, which often condones male dominance over women. The nature and extent of violence reflects pre-existing social, cultural and economic disparities between men and

women. Such acts of violence happen in many contexts – home, marriage, workplace, and in public spaces. All women and girls may live in fear of violence and this fear may be heightened in particular environments and at certain times.

Gender-based violence is both a cause and consequence of HIV infection:

- Girls and women who are raped may be infected with HIV as a result of the rape.
- Most women who are raped have no access to post-exposure prophylaxis⁵ and live with the fear of possible sero-conversion⁶.
- The fear of violence may prevent women insisting on the use of condoms or other safer sex methods.
- Myths such as having sex with a virgin will cure you of HIV result in rape and sexual abuse.

Many women and girls who disclose their HIV status to partners, family members, and communities are physically and emotionally abused. In December 1998, a young South African woman, Gugu Dlamini, was beaten to death by members of her community after disclosing her HIV status as she was seen to be a disgrace to the community (Vetten and Bhana 2001).

In war and conflict situations the risk and incidents of gender-based violence escalate. This is due to a combination of factors, including the breakdown of law and order, and large-scale population movements, specifically of women and children. Conflict situations increase vulnerability of women and girls due to:

- Rape of women and girls by opposing forces coupled with the fact that HIV rates are often higher in military personnel. Rape is also common in refugee camps – often by emergency personnel.
- Increased survival sex, as women deal with the loss of income, a home, and supportive family members.

(Gordan and Crehan 1999).

Culture and religion

Culture and religion have a profound effect in maintaining the gender status quo and up-holding social norms and expectations of men and women, and can create some of the most significant barriers to effective HIV prevention. A key example is the stance of the Catholic Church on the use of condoms. For the most part the position taken by organised religion on sexuality and HIV/AIDS is extremely conservative and seldom challenged, yet many people trust their church

⁵ Post-exposure prophylaxis (PEP) refers to the administration of antiretroviral medication as a method which may reduce the likelihood of HIV infection after a high-risk exposure. Theoretically, PEP may either prevent establishment of infection or prevent new infection while allowing clearance of already infected cells (Anderson 2000).

⁶Sero-conversion refers to the initial development of antibodies after contact with HIV.

and turn to its leaders in times of crisis. Culture and religion will continue to increase men and women's vulnerability to infection as long as they continue to represent sex and sexuality as a taboo subject.

However, there are increasing examples globally of how religious organisations can address HIV/AIDS in a progressive way to reduce vulnerability. For example, different religions have had to deal with, and re-frame their position on the issue of condoms. Within some organisations in the Catholic Church, there is a move to give individuals full information about all means of HIV prevention which is based on scientific proof, including condoms (CAFOD 2001). In Indonesia, a project training Islamic preachers focused on compromising on principles in the interest of social welfare, arguing that whilst sex outside of marriage is a sin it is a greater sin if done without a condom (KangGURU Radio English 2000).

Migration

O'Brien (1995) notes that it is vital to understand patterns of mobility behaviour in order to prevent the spread of HIV and care for those affected. Globally, two billion people migrate on a temporary and permanent basis, including between and in-country mobility. Increased poverty, women's unequal rights, lack of access to formal labour, and economic and political changes have led to an increase in the last few decades in the number of women seeking work overseas or in other areas of their countries. However women are often invisible both in terms of statistics and as major actors in the migration process (Zlotnik in Sweetman 1998). Being a migrant is not in and of itself a risk factor for HIV infection. However, changed circumstances may lead to personal risks, for example, separation from family, sexual partners and the stresses and vulnerabilities associated with the migration process.

Social factors as well as economic realities play an essential role in who migrates. Household decisions about who should migrate are determined by the availability of labour markets and the roles of family members at home, both of which are gendered. Migration, especially under forced conditions, for example, in conflict situations, or 'illegal' population movement, may lead to low status, low paid and/or isolated work and living conditions which increases dependence on others, who are often more powerful, for key aspects of survival and this increases vulnerability to HIV/AIDS. This is particularly the case for women whose options are often limited to low status, low paid and/or isolated work (including marriage, domestic, factory and sex work). Their low status and isolation from family and social support networks make them vulnerable to abuse and STI/HIV infection. In regions where there is a high male migration for work vulnerability to HIV/AIDS can be a problem. In Cambodia, for example, there is an expectation that men will have multiple sexual partners while travelling, which also compounds the risk of HIV infection for him, his partner(s) at home and other sexual partners (Sellers, Panhavichetr, Chansopha and Maclean, in press).

Despite the risks associated with the migration process it is important to recognise the right to 'freedom of movement and travel irrespective of HIV status' (ICW 12 Statement and the Barcelona Bill of Rights 2002). This was a focal point during the Barcelona HIV/AIDS conference in 2002, because the Spanish authorities denied visas to numerous people from the South – many who were open about their HIV status. Some countries do have discriminatory policies re travel of people living with HIV/AIDS (PLHA) and others are instituting stricter controls. For example Canada have recently introduced the need for an HIV test for people emigrating to Canada. Whilst they say it will not affect the final decision it is not clear why they need the information.

3.2.2 Economic factors

Critical economic factors include macro-economic frameworks and policies, and poverty and inequality.

Macro-economic frameworks and policies

The macro-political and economic factors that impact on development in general, located at a country, regional and global level, are increasingly impacting on access to socio-economic rights, and this, in turn, heightens vulnerability to HIV and AIDS. To an increasing extent, pressures that arise out of the global economy influence national government decision making. National debt, capital speculation, the imposition of macro-economic adjustment programmes and jobless growth are some key processes in the global economy that influence negatively the health and well-being of poorer countries. Cutbacks in social spending have been accompanied by the 'silent adjustment' – the undue hardship and pressure that women experience as a result of structural adjustment (Kaihuizi 1999; Singh and Zammit 2000; Rowbotham and Linkogle 2001; Riley 2001). This is especially true in the absence of alternative forms of livelihoods and social services to meet the basic needs of poor people.

At a country level, the fiscal policies of governments mean that political choices are made which are often not in favour of the poor and marginalised, particularly poor women, rural women and groups such as intravenous drug users. One of the first areas to be impacted upon is that of health and development. The links to HIV infection are clear.

Poverty and inequality

Women and men experience poverty differently because of gender inequality:

The causes and outcomes of poverty are heavily engendered and yet traditional conceptualisations consistently fail to delineate poverty's gender dimensions resulting in policies and programmes which fail to improve the lives of poor women and their families (Beneria and Bisnath in Cagatay 1998:2).

Even when women have access to income and assets (such as land, equipment, employment, knowledge and skills) these are often controlled by men, and women are less able to move out of living in poverty (May 2000; Nkiru Igbelina-Igbokwe 2002).

The relationship between HIV and poverty is complex – while most people living with HIV/AIDS are poor, many non-poor people are also affected and infected. However, people living in poverty are more likely to become sick and generally die more quickly due to malnutrition and lack of access to appropriate health care. Thus the HIV epidemic is bi-modal with peaks among the richer and better educated as well as amongst the poorest in society (Collins and Rau 2000). The HIV epidemic among richer people is due to access to disposable income and position in society, including the ability to travel, which provides them with the opportunity to engage in sex that puts them at risk. According to Baylies (2000) it is mainly men that fall into this category and their behaviour is seen as an ‘expression of their power’ (p12). This contrasts with the situation of the poor, especially poor women, whose poverty may lead to risky actions for survival as well as preventing them from taking protective action.

Some examples of the link between gender, poverty and HIV include:

Bio-medical – Factors predisposing girls and women to increased risk of infection, including chronic anaemia and early first coitus, are exacerbated by poverty (Farmer in Collins and Rau 2000). A lack of control by poor women over the circumstances in which intercourse occurs may increase the frequency of intercourse and lower the age at which sexual activity begins.

Survival sex – Evidence from all regions of the world suggests that the overwhelming motive behind the exchange of sexual services for the provider is economic opportunity (Tawil *et al.* in Collins and Rau, 2000). The context of most sex work in Africa is survival sex, and sex work is about making money for women and their families to remain alive. In this way, survival sex is a form of small-scale informal money making. Some women in the informal sector are simply extending their existing capabilities and livelihoods and doing work that is typified as women’s work. They are seldom, as is usually the case with women’s work, well paid for their efforts. Sex work that is poverty driven is more likely to foster behaviours that are risk taking.

The paradox of what we refer to as survival sex, be it strictly commercial or not, is that relatively short term (but none the less, pressing) social survival is achieved only at the expense of exposure to the long term risk of illness and death through HIV infection (Preston Whyte 2000: 3).

*Mother to child transmission (MTCT)*⁷ -- Access to relatively inexpensive drugs that can reduce mother to child transmission substantially is denied to all those women who cannot afford them in most 'developing countries'. Furthermore, infections through breast-feeding can be eliminated through exclusive bottle-feeding, but poor women have neither the money to buy formula feed, nor the access to basic facilities and infrastructure, such as clean water with which to prepare bottle feed and so reduce the risk of other infections (Seidel and Tallis 1999). Poor women have less privacy due to living in overcrowded and over populated conditions, and the decision not to breast feed may be noticed by neighbours and lead to disclosure of HIV status.

Access to technologies – Poverty can also limit women's ability to access antiretrovirals, the female condom and microbicides. There have been discussions at the national and international level about funding or subsidising access to such technologies. However, does it make sense that antiretroviral treatment access programmes are now starting up in clinics where running water is not yet available? This was discussed at the 14th International AIDS Conference in Barcelona, 2002. However, the Women and HIV/AIDS: Barcelona Bill of Rights includes the right to access acceptable, affordable and quality comprehensive healthcare including antiretroviral therapies.

3.2.3 Political factors

An effective response to the epidemics calls for political will and commitment at the highest possible level. Countries that have made some headway in reducing the spread of HIV and dealing with the impact of HIV/AIDS have in common a fairly high level of political commitment coupled with sustained public leadership (for example Uganda, Thailand, Brazil). Whilst some countries have demonstrated leadership and commitment, it does not necessarily mean that the response falls within a gendered human-rights framework. An example is the homophobia of the President of Uganda who, over a period of years, has systematically denied gay and lesbian people access to their rights. This has been achieved through persecution and denying the existence of gay men and lesbian women in Uganda, and so increasing their marginalisation and vulnerability to HIV/AIDS.

Lack of political will hampers effective prevention and care programmes by not providing a conducive or enabling environment. The most stark example of this is in South Africa with the lack of political will demonstrated by President Mbeki and his denial of the link between HIV

⁷ There are currently debates around the term mother to child transmission (MTCT) versus parent to child transmission (PTCT). In an effort to remove the blame from women some prefer to focus on parent rather than mother. This term is commonly used in Zimbabwe for example with a focus on involving men in reproductive and sexual health issues faced by women. Other activists believe that using the term 'parent' masks the reality that men are seldom involved in pregnancy, may reject a woman once she finds out her HIV status and are often not committed to providing care once the child is born (personal communications with women living with HIV/AIDS).

and AIDS. However, the leaders of most countries have been slow to act or have denied the extent of HIV/AIDS. An initiative to involve world leaders was launched at the 14th International AIDS Conference (2002) is being spearheaded by ex-President Bill Clinton. Gender advocates need to ensure that political commitment includes a commitment to gender equality.

3.3 Impact of the epidemics

AIDS is now the leading cause of death in Sub-Saharan Africa and the fourth cause of death globally (UNAIDS 2002). The impacts of HIV and AIDS are social, economic, political and demographic as well as personal. Growing numbers of women and men are living with HIV/AIDS and have to deal with a multitude of complex mental, emotional, social and financial issues. HIV/AIDS affects all women and men regardless of class, race, sexual orientation and HIV status – however these factors will influence how HIV/AIDS impacts on their lives.

Much has been written about the impact of HIV/AIDS but there has not been much success in measuring the human impact of HIV, especially in relation to gender (Whelan 1999). Despite this, there is ample evidence that women are affected disproportionately. A key impact of HIV/AIDS is the entrenching of gender inequalities and other factors that drive the epidemics.

3.3.1 Social impacts

The impact of HIV/AIDS on women has been referred to as 'triple jeopardy' (Bennett 1990). This addresses the key gender roles that women are generally expected to fill: productive, reproductive, and community. HIV/AIDS affects women as individuals, mothers and caregivers in these socially defined roles. The socially defined roles of men and boys will also condition the impact of the epidemics on them.

Women as individuals are affected by HIV/AIDS but in programmes focusing on HIV/AIDS they are often represented as mothers and carers only. A study in Durban, South Africa, focusing on the experiences of women living with HIV who were pregnant highlighted the extent to which women's empowerment has been neglected. Women interviewed had limited understanding of and information about AIDS and other STIs. Many of the women acknowledged that their partners were not monogamous, but had not had the opportunity and space to think through, analyse and personalise what this could mean for them. Women stayed in these relationships mainly through fear of violence, and because of financial dependence on men. This was exacerbated by the fact that many of the women were unemployed, and few had skills that would make them employable. Sexist customs and practises such as the payment of *lobola*

(bride wealth) and *inhlawulo* (payment of 'damages' to the women's family for pregnancy⁸) were dominant themes in the study (Tallis 1997).

Women as mothers with HIV/AIDS are affected in three ways. Firstly, many mothers of young adults are fearful of their children becoming infected with HIV but often lack the skills to discuss sexuality openly with them. Secondly, more and more mothers have to care for their young and adult children as well as the partners of their children when they become sick. Finally, for a mother who is HIV-positive there is the risk of transmitting HIV to her child, during pregnancy, during birth or after birth through breast-feeding. The latter may occur if a mother is unaware of the risk or is not in an economic position to afford formula feed (Tallis 1998).

Women are bearing the burden of AIDS care. This is true both in the formal or informal sectors. The majority of nurses and social workers (the formal care sector) are women. In a developing country, the bulk of AIDS care happens in the community, informally, with women caring for their partners and children. Grandmothers often have to take care of their grandchildren whose parents are unable to care for them or have died (Tallis 1998). May (2000) refers to the 'time poverty' experienced by women which is the result of the long hours women spend on their reproductive roles – collecting fire-wood, water, child care, cooking and cleaning – to the detriment of their own well being. Many women living with HIV also have the added pressure of being ill themselves and having to provide care for their partner and / or sick child. For a woman living with HIV, such an increase in workload often means that she does not have time to adequately care for herself and attend to her own needs (Bennett 1990). As noted by Mary Crewe home-based care is a middle-class concept as it assumes that the resources (including human) are available in the home but it is usually not the case (2002). The contribution of women in prevention and care is seldom recognised and quantified.

Research has also shown that health-seeking behaviour differs between men and women. Women's health-seeking behaviour is more often than not determined by reproductive roles, either as a pregnant woman or as a mother with a sick child. Factors which impact on health-seeking behaviour include money, time, attitude of healthcare workers and mobility. Research also shows that men often receive better care than women. Men are more likely to have access to better healthcare through the private sector, for example access to workplace clinics or access to medical benefits which increase the quality of care available (Tallis 2001).

The social impacts do not just affect adults but children as well. A growing trend is to take children, especially girls, out of school to care for the sick and help with other household duties.

⁸ The family of unmarried pregnant women seek 'damages', that is money or goods, from the man responsible for the pregnancy. For women the importance goes beyond material value but has an important impact on her self-worth and self-esteem and how she feels about the pregnancy. Women whose partner acknowledges his responsibilities are more likely to have positive feelings about the pregnancy.

For example in Swaziland school enrolment has fallen by 36 per cent due to HIV/AIDS with girls most affected. This impacts on their education and future prospects (Desmond *et al.* 2000). Although withdrawal from school is often associated with girls, studies show that in certain cases boys are also withdrawn from schools when relatives become ill or die. However, it is more likely that they will be expected to supplement family labour on farms or in income generating activities (Bennell, Hyde, and Swainson 2002).

3.3.2 Economic impacts

All the social impacts mentioned above also have economic impacts, for example, when women fall ill or have to look after relatives they have less time to work on productive activities which benefit them, their families, communities and whole nations. There is also the critical economic impact on women and the household when they lose the primary wage earner. Women and their children will then be expected to fulfil a greater economic role in supporting the family. Although the economic impacts of HIV/AIDS are well documented at both the macro and micro level (Whiteside and Sunter 2000; Desmond, Michael and Gow 2000), the full economic impact on women has not been quantified. This is because their work in the home, the community and in productive work outside the formal sector is still not considered seriously by economists.

3.3.3 Political impacts

There is now a realisation that the impact of HIV/AIDS on political processes must be anticipated and planned for. This is evident in the growing number of research initiatives in Southern Africa where the impact of HIV/AIDS on political stability and the ability of officials to govern is being examined. This area of investigation is still relatively new but poses a major challenge to development and human well-being especially in the regions where incidence and prevalence rates are high and development indicators already low and falling. Much of the focus to date has been on developing political will and political commitment to address HIV/AIDS and not on analysing the political factors driving the epidemic and addressing the impact of HIV/AIDS on political processes and stability (Altman 2002).

3.3.4 Demographic impacts

HIV/AIDS are impacting on the major demographic processes, that is, mortality and fertility, which could lead to changes in population growth and size. AIDS is killing men, women and children who typically have the lowest mortality rates and this impacts on life expectancy. Development gains are being eroded. There has been little research to quantify the gender imbalance that will occur.

The impact on fertility is less well understood, however the impact is being felt in three ways:

- There will be fewer births if women die before reaching the end of their child-bearing years.
- Women living with HIV/AIDS are less fertile.
- The use of prevention methods such as male and female condoms will also reduce fertility.

(Whiteside and Sunter 2000).

4. Critical challenges: towards transformation

The analysis of the HIV/AIDS pandemics including the driving forces and huge impact on individuals (women, men and children), households and communities, clearly shows that gender inequality is at the centre of the epidemics and that a human-rights approach is an important lens through which to view HIV/AIDS. The main focus of approaches should incorporate a careful analysis of gender power relations and the particular context in which men and women live, and a deeper understanding of women's position in the HIV/AIDS crisis. Furthermore, it must address power and sexuality as a central concern.

For many, working in a gendered way is defined by who one is working with as well as what. Initially a 'gendered' approach meant working with only women, for example on educating them in condom use. However, with a stronger recognition of the factors constraining women's ability to negotiate safer sex, sometimes a focus on gender has allowed a shift in focus from women to working with women and men, or with a focus solely on men. This is certainly true in HIV/AIDS where the focus of many programmes and campaigns is now on involving men. This is not a problem in itself, but when programmes targeting men are at the expense of programmes for women, or target men but do not challenge gender inequality, such approaches should be challenged.

A gendered approach should therefore not be at the expense of a feminist agenda which gives a high priority to help women change or transform power dynamics. Baden and Goetz (1999) caution that in some policy applications gender has lost its feminist political content. Thus gender becomes descriptive, focusing on the different roles and responsibilities of women and men, but does not challenge the power imbalance.

The critical challenges for a gendered rights-based approach to HIV/AIDS are:

- dealing with the lived realities of women, men and children
- ensuring participation
- gender transformation as a goal
- defining a gendered response
- a co-ordinated response that is multi-levelled, multi-faceted and multi-sectoral
- institutionalising both gender and HIV/AIDS

However to-date programmes have generally not successfully addressed these challenges although there are an increasing number of approaches that are transforming gender relations

and seek to empower. Gupta's (2000) framework to assess the extent to which HIV/AIDS responses address gender identifies five levels:

- a focus on stereotypes
- gender neutral
- gender sensitive
- transformatory
- empowerment

This paper will explore each one, but for the purpose of this report empowerment approaches will be discussed as processes that occur before transformatory approaches. It is understood that, although empowerment is an integral part of the transformation process, transformation of gender relations, rather than empowerment is the end goal. The Gupta model is important as it provides a framework within which to locate responses to HIV/AIDS and programmes and has been specifically designed to address the gender/HIV interface. This paper will also address how the goal of empowerment and transformation should be incorporated into the work of institutions.

4.1 Current approaches

4.1.1 Focus on stereotypes

Many approaches use gender stereotypes to get their message across, which result in entrenching HIV/AIDS related stigma. Gupta describes this approach as programmes and or materials which promote a 'predatory, violent, irresponsible image of male sexuality' (p8) whilst women are portrayed as powerless victims. It also includes materials that focus on other stereotypes of women, like materials that portray sex workers as a source of infection. Some examples include a prevention poster in which a sex worker is depicted as a skeleton, with the caption 'What you see is not what you get: AIDS Kills' and a prevention postcard which depicts the following: **Joystick** (on male body covering a penis) – **Play-station** (on woman's body covering vagina) **Game over** (on picture of virus).



(You only have one life, use a condom)

Such images reaffirm the idea that men are active in sexual relationships and women are passive. Or that people who fall outside the remit of acceptable feminine or masculine behaviour (for example sex workers, gay men or men who have sex with men) are 'to blame' for the spread of the virus. These images also portray a diagnosis of HIV as an instant death sentence that only serves to further stigmatise people living with HIV/AIDS.

4.1.2 Gender-neutral programme

Gupta defines gender-neutral programmes as programmes or materials that do not distinguish between the needs of women and men, but that do no harm. Examples given are messages such as 'be faithful', 'stick to one partner' or 'use a condom'. It can be argued however, that gender-neutral programmes or messages do, in fact, cause harm. If we analyse the example used by Gupta, messages such as 'be faithful' or 'stick to one partner', could, in fact, lead to increased vulnerability of women to HIV infection. This is because many women who are faithful to their partner believe that because they are faithful, they are safe from HIV infection, when it is not necessarily the case (Abdool Karim 1998).

Many HIV/AIDS programmes are gender neutral, for example, many National AIDS Control Programmes.

Most countries have a National AIDS Control Programme, which may or may not integrate tuberculosis (TB) and STIs, and are typically health focused and based in health departments. These departments or units are generally based on frameworks set by the World Health Organisation (WHO) in the earlier days of the epidemic and more recently, by UNAIDS.

National AIDS Programmes are important sites for integrating gender because:

- They set national policy for prevention and care.

- They hold responsibility for the co-ordination of the process of implementation of the National AIDS Plan and Programme.
- They have budgets that are large enough to support a range of interventions and programmes that deepen understanding of and capacity to integrate gender into HIV/AIDS work.
- In many countries, they have influence over and attempt to exert control over the response to HIV / AIDS by non-governmental organisations (NGOs) and civil society in general. (Tallis 2000).

The main goal of any National AIDS Control Programme is to reduce both the spread and impact of the HIV epidemic within the country. To succeed at this goal, a gendered approach to HIV/AIDS is necessary. However, in a study of the role of National AIDS Programmes in integrating gender, a sample of 15 countries in Asia Pacific, Europe, Americas and Africa showed there was a lack of understanding about gender and the relationship to HIV/AIDS, little commitment to integrate gender at all levels, and a lack of capacity and tools to do gender analyses, planning, and monitoring and evaluation (Tallis 2000).

Gender-neutral programmes: Improving the response in Senegal

There has been much progress in Senegal in dealing with HIV and AIDS and the country's response is described by UNAIDS as best practice for the following reasons:

- Immediate response to HIV when the first people living with HIV were identified and a National AIDS Programme was established.
- Support from politicians to the HIV/AIDS response.
- Political leadership extended to civil society leadership.
- Stable leadership of the National AIDS Programme which enjoyed political support.
- Leadership open and honest about the epidemic.
- Identified and dealt with obstacles to programme success, for example, dropping excise tax on condoms.
- Key role players mobilised and involved such as religious leaders and the scientific community.
- Maximised use of existing political structure.
- Resources mobilised nationally and internationally.

(UNAIDS 1999a; Sidebe 2000)

Sidebe (2000) notes that this response could be improved if the existence of attitudes and practices that increase men and women's vulnerability and dis-empower women are dealt with both at an individual and societal level. Within Senegal 'civil inequality is widespread and is often linked to social practices that alter relations between the sexes' (p8).

Factors that increase women's vulnerability to HIV include the following:

- Early marriage is common among women from Senegal despite laws that forbid marriage of girls under 16 years of age. These young women are vulnerable due to early sexual activity, financial dependence on the husband due to limited schooling and limited access to viable alternatives. The husband is usually an older man who has had other partners.
- Although a 'family code' exists which promotes marital fidelity from both men and women, the reality is that women are expected to be faithful while men are not.
- Traditional practices exist which increase women's vulnerability. These include levirate or widow inheritance and female genital mutilation. Although female genital mutilation was outlawed in 1999 it is still practiced illicitly in many areas.

(Sidebe 2000)

Sidebe states that the 'NACP is not doing enough to improve women's knowledge of both HIV/AIDS and their legal rights on such issues as early marriage and the levirate' (p 9). The response is overwhelmingly gender neutral which in some instances is increasing women's vulnerability. The fact that human rights codes and laws, such as the laws which prohibit female genital mutilation, exist but are not being implemented or upheld increases vulnerability.

Where are women on the research agenda

Despite women being diagnosed with HIV/AIDS from the early 1980s, little research has been done to investigate the implications of the knowledge that there are differences between men and women in disease progression, opportunistic infections and management. The research has been gender neutral. Researching HIV/AIDS in women is at an early stage and there are many more questions that need to be answered. At the end of 1999, women only accounted for 12 per cent of total trial participants. Some research has shown that there are differences in length of survival, levels of viral load and drug toxicity between men and women and therefore antiretroviral treatment and opportunistic infection management needs to be tailored for women and men differently. Ignoring the differences in disease progression for men and women leads to gender-neutral conclusions and solutions.

4.1.3 Gender-sensitive approaches

Gender-sensitive approaches respond to the different needs and constraints of individuals based on their gender and sexuality. Many current AIDS programmes operate at this level,

where women's practical needs are identified and attempts are made to meet those needs through service delivery. This includes programmes which focus on the provision of the female condom, income generation or increasing women's access to health services. Approaches to working with men may also fall into this category, providing education to men that is based on their roles as decision makers in their relationships with women and help them look at how they can make better, safer decisions that can protect themselves, their female partners and their present and future offspring. These approaches often play into the concern of the man about his lineage being sustained, by encouraging him to keep HIV negative and therefore have a healthy baby to carry on the family line.

Gupta gives the example of microbicides as a prevention method which will meet the needs of women and men who have sex with men. Gender-sensitive programmes will thus impact on the immediate lives of women, but will not necessarily challenge the gender status quo. The advent of an effective microbicide⁹, however, has the potential to increase women's control over both their reproductive and sexual health.

Gender advocacy: the call for a microbicide.

The Global Campaign for Prevention Options for Women is a broad-based, international effort designed to encourage investment into microbicide products that women and men could use vaginally or rectally to protect themselves and their partners from HIV and other sexually transmitted infections. The Campaign presently has over 70 partner organisations worldwide that mobilise political will and ensure that as science proceeds, the public interest is protected and women's needs and perspectives are integrated into all phases of microbicide research, development and introduction. A microbicide has the potential to expand women's options so that they are exercising both their reproductive and their sexual rights. (www.global-campaign.org)

Gender-sensitive approaches fall short of challenging the status quo whereby men hold decision-making power and use this power to control the sexuality and sexual rights of their partners.

4.1.4 Approaches that empower

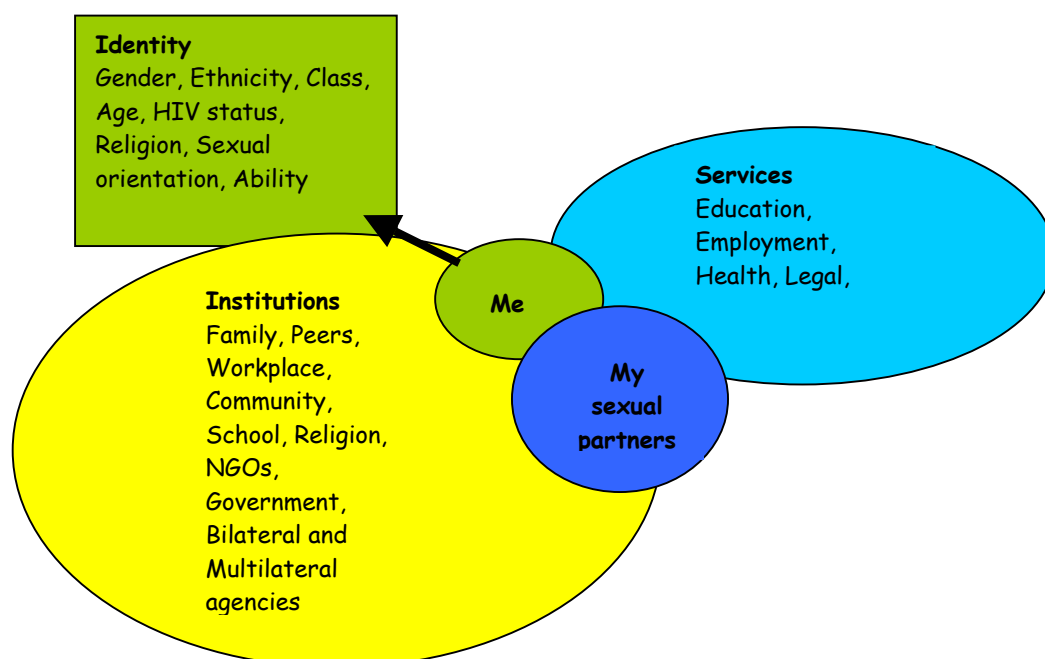
Programmes that empower women focus on improving access to information, skills, services and technologies, but also go further to ensure participation in decision making at all levels.

⁹ According to Dr Peter Piot of UNAIDS, developing a microbicide that is safe and effective will take 'some years' (HDN Key Correspondent 2002). It is estimated that the product will be available in 2007 at the earliest.

Empowerment, in its most literal sense refers to people taking control over their own lives, gaining the ability to do things, to change and define their own agendas (Young 1997). This view of empowerment implies collective, and personal empowerment. Steps include:

- building a positive self image and self confidence
- developing the ability to think critically
- building up group cohesion
- fostering decision making and action

Approaches that empower start with people's lived realities which are complex and diverse (Welbourn pers. comm. 2002). A number of projects including the Working Women's Project in Bradford, in the UK, have looked at the importance of addressing the concerns of the beneficiaries of development work and those most affected by any development issue. Such concerns are determined by the contexts within which people live. Only by addressing and recognising the issues fundamental to women's lives, such as avoiding violence from clients, police and pimps¹⁰, were the project workers in Bradford able to go on to work with them on the issues of HIV prevention and improved sexual health (Butcher and Welbourn 2001). Lived realities are experienced differently by each individual through three critical and inter-linking levels: identity, services and institutions as shown in the diagram below. These levels will be more or less important in different contexts and at different times in a person's life.



(Adapted from Welbourn pers. comm. 2002)

¹⁰ A pimp is a person, usually a man, who solicits customers for a sex worker or a brothel, usually in return for a share of the earnings.

ICW: The Voices and Choices Project (Zimbabwe)

'From the beginning of this project positive women were involved in deciding the issues which will be researched and that was very encouraging. During the process I realised I was being empowered. I have really changed, gained confidence and I have also gained status in the community. I am now invited to workshops and meetings whenever there are women's issues being discussed' Otilia Tasikani (ICW 2002: 17)

The ICW Voices and Choices project is an example of an international organisation working at a national level which has as a key aim the empowerment of women living with HIV/AIDS.

ICW, in partnership with a national organisation in Zimbabwe, Women and AIDS Support Network (WASN), facilitated a two-year action research process from 1998 – 2000 to determine the needs of women living with HIV/AIDS in Zimbabwe. The research included a skills building process in a group of women living with HIV/AIDS who were responsible for most of the data collection, and given support in collation, analysis and planning (Butcher and Welbourn 2001).

A workshop was held to develop an advocacy strategy to address the issues facing women living with HIV/AIDS in Zimbabwe. The next phase of the project is to implement the plans developed at the workshop (Cavanagh and Tallis 2001).

(See *In Brief* for more information on this project)

Cornwall and Welbourn speak of projects that 'offer powerful possibilities for realising rights both in enabling people to become aware of and be able to articulate their rights and in making real entitlements to reproductive and sexual well-being' (in press). The ICW project has achieved this, both by empowering women individually and collectively, as well as providing opportunities for women living with HIV/AIDS to lead the process of addressing their own defined issues with the support of other organisations.

Empowerment requires genuine participation. This refers to the 'intent to hand over power to interpret, analyse and come up with solutions' (Akerkar 2001: 2). Participation can be seen as a means to an end, that is, lead to more efficient development. However, participation that is empowering is an end in itself. Cornwall and Welbourn (in press) speak of participation as a human right, which ensures that people have a voice as well as choice. The people most affected by any development issue must be part of the process of defining the problem and finding solutions. In responding to HIV/AIDS, this will include the poor and the marginalised, for example, women, men who have sex with men and injecting drug users.

Sonagachi Project

The Sonagachi Project, working with sex workers in India, illustrates the importance of the women initiating change themselves rather than 'outsiders' bringing change or acting as catalysts for change. Sex workers in Sonagachi are successfully negotiating safer sex relationships with clients as well as better treatment from society including from the police. In 1992 the STD/HIV Intervention Project (SHIP) set-up a Sexually Transmitted Diseases (STD) clinic for sex workers to promote disease control and condom distribution, however their focus soon broadened to address structural issues of gender, class and sexuality. The sex workers themselves decide the programme's strategies. 25 per cent of managerial positions are reserved for sex workers and they hold many key positions. The sex workers are peer educators, clinic assistants and clinic attendants in the project STD clinics. SHIP aims to build sex workers' capacity to question the cultural stereotypes of their society, and build awareness of power and who possesses it (see Supporting Resources Collection).

Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)

GIPA was launched at the Paris AIDS Summit 1994 and endorsed by heads of 42 States. It aims to recognise the important contribution that people living with HIV/AIDS (PLHA) can and do make, and to create a space for their involvement in all spheres from policy to practice (UNAIDS, 1999). In South Africa, the GIPA programme has been in existence since 1998. Initially, positions were created for people living with HIV/AIDS in various organisations and businesses. The second phase of the programme concentrated on specific government departments at a national level, such as health, social development, land and agriculture, the aim being to involve people living with HIV/AIDS in the development of work-place policies and programmes. In an evaluation of the programme (UNAIDS 2002b) the value of GIPA was twofold: enhancing effectiveness of the placement institution by personalising HIV, and creating a supportive environment for people living with HIV/AIDS. Whilst these are important gains, the true point of the GIPA principle has not yet been met – that is the involvement of men and women living with HIV at all levels of policy, planning and programmes.

Empowerment can be seen as an end in itself, as well as a means to an end, that is, the transformation of gendered power relations. When women and men are empowered, they are able to take the necessary actions at a personal, group/collective 'community' level and at an institutional and broader societal level to confront, address and shift the inequality within gender power relations. ICW, Sonagachi Project and GIPA, have to varying degrees of success recognised and acted on this need to transform unequal social relations at different levels.

Hence the women involved in the ICW project are working on a national advocacy strategy, the women in Sonagachi are working to ensure better treatment from male clients, pimps and the police, and GIPA question the right of people not living with HIV/AIDS to set the agenda for HIV/AIDS programmes.

Women together...

At the 13th International AIDS Conference, held in Durban South Africa, a group of women, including the International Women's AIDS Caucus decided to hold events off the conference site to involve more local women, who would not have access to the conference due to the exorbitant registration fees. These events were also to ensure that women and men from the North did not dominate the agenda. A series of workshops were planned throughout the duration of the conference.

Given the success of this programme, a similar process occurred in Barcelona for the 14th International AIDS Conference. Initiatives included capacity building workshops, the drafting of the Bill of Rights and a march by women, both attending the conference and those involved in Mujeres Adelante. Those involved called for treatment for HIV positive women, an end to violence and human rights for all.

Lessons should be learnt from Durban and Barcelona to ensure that all women are involved in the planning and implementation of international policy on HIV/AIDS.

Baylies and Bujra (1995) note that claims of empowerment are often just rhetoric. Given that HIV in Africa is transmitted largely through heterosexual sex in the context of gender inequality, impacting on the spread requires a transformation in gender relations. In this context, the focus has been on the 'empowerment of women' but in practice, transformations in gender relations are 'hard-won against the embedded structures of male power, even where, as in the case of AIDS, sexual relations put men at risk too. If the reality of power is neglected, the call for empowerment may remain little more than a slogan' (p195).

4.1.5 Transformation

Why is transformation so crucial for HIV/AIDS? The HIV/AIDS epidemics clearly flourish in the context of power dynamics that oppress women and add to their vulnerability. The challenge is to change or transform unequal power between men and women to create a context where women have equal power and both women and men are less vulnerable. Gupta (2000) focuses on relationships as the critical point at which transformation occurs. For the purpose of this report transformation will be defined more broadly to include radical change at personal, relationship (including the redefinition of heterosexual relations), community and societal levels,

addressing the systems, mechanisms, policies and practices that are needed to support such genuine change. Calls for the transformation of society have spanned generations, and whilst gains have been made, progress has been slow. The imperatives of the HIV/AIDS epidemic may provide the catalyst that is needed to recognise, confront and address the inequality of women.

Stepping Stones – a participatory training method

Stepping Stones focuses on gender, HIV, communication and relationship skills, for use with whole communities to challenge gender inequalities and inter-generational inequalities, between men and women and between older and younger people. A Stepping Stones workshop was first conducted in the village of Buwenda in Uganda. An impact assessment showed that condom usage increased, but also that interpersonal communications in relationships improved and domestic violence and alcohol abuse declined. Young women reported rising levels of self-esteem and assertiveness, along with a determination to be economically independent and more involved in political life. Sexual matters were more easily discussed and there was more care and support given to those suffering from HIV/AIDS. (Reeves 1998)

In a gendered approach, the transformation of gender relations leading to gender equality is the key objective, and must happen at a personal, organisational, programmatic and societal level. Whilst the initial point of entry may vary between these levels, it is vital that the progressive realisation of the transformation goal occurs at all four levels. This does not mean that each organisation has to engage at each level. Working towards a common goal, that of gender equality, can be tackled from different angles.

Puntos de Encuentro's – a Nicaragua feminist NGO

Born into a post-revolutionary country under a right wing government, Puntos de Encuentro's mandate is to foster equal and positive relations. Their main goal is to influence public opinion to ensure cultural change, especially around gender and sexuality norms, stigma, and social support systems. They also seek to strengthen women's movements and youth movements. This organisation recognised the importance of starting from the specific interests of young people, and was also concerned about getting more people involved in the feminist movement, and wanted to build alliances to confront domination and create equal relationships between people. This led the organisation to bring young people and also men into the institution and to get involved with work with both groups. Puntos de Encuentro use a multi-media strategy, including radio and television shows to achieve their aims. Specific work on HIV/AIDS is about to be given a huge push in all their multi-media and community work over the next few years (see Supporting Resources Collection for more information).

Is working with men transformatory?

Focusing on women alone may add to women's burden of HIV and often leads to the view that women are to blame. However, the involvement of men does not in itself improve the lives and health of women, and may in fact entrench the gender inequalities that exist in society. There has been a recent tendency in HIV/AIDS work of shifting resources previously used for women towards projects targeting or involving men. As stated by Bujra (1999), targeting men in ways that men will respond to may run the risk of reinforcing the dominance of men over women in intimate relationships.

The potential problems of focusing on men at the expense of women are highlighted in the debates¹¹ around potential microbicides – focusing on women using a microbicide without their partner knowing. Covert use of microbicides is often seen as bad and the involvement of men as paramount. However, it is important to focus on why a microbicide is necessary and to look at the realities of women's lives – that many women are vulnerable to HIV and STIs for many reasons including the fact that they have little power in their relationships. Not all microbicide usage will be 'covert' – some women will be in a position to communicate with their partners. Many other women will not be able to, or choose not to negotiate use of a microbicide with their sexual partners.

Despite the above reservations, men hold the power in society, including in relationships, therefore working with men is crucial and must involve challenging the position they hold in society, and in their relationships. Men's dominance in deciding how and when sex takes place, their use of violence against women, their reluctance to pay attention to their health needs and some men's resistance to using condoms are among the biggest challenges to reducing HIV risk worldwide (Barker 2002). Women's self empowerment is unlikely to lead to greater equality in relationships with men unless men themselves change. Corresponding work aimed at women and men in the community should not be neglected because the wider community plays a crucial role in reaffirming negative constructions of masculinity.

Working with young men in Brazil

Instituto PROMUNDO, Rio de Janeiro Brazil initiated a project engaging young men in gender violence prevention. The project was started due to high levels of condoned gender-based violence in Brazil, with domestic and sexual violence very much part of the social script. PROMUNDO worked with young men because evidence suggests that attitudes and behaviours towards women are formed during adolescence. The project started with an extensive research phase which identified young men who were opposed to

¹¹ This paragraph is a summary of a discussion on GENDER-AIDS Listserve 2002.

gender-based violence and worked with them to identify what made them have a different belief system to the majority of young men in the community. The next step in the process was to recruit

facilitators, men who had demonstrated their belief in gender equality through activism. The facilitators were responsible for training young male peer promoters who took part in the research phase.

The peer promoters then developed and performed an interactive play based on their own lives, highlighting issues around gender-based violence and the impact on men and women. Printed material in the form of a photo-novella was used to back up messages promoted in the play. Successes of the project include providing a supported voice and expression for gender-sensitive men and boys which led to further empowerment, developing insight into both positive and negative masculine constructs of gender-based violence and providing an alternative way of behaving. Using young male group facilitators that demonstrate gender equitable attitudes and behaviour strengthened the impact of PROMUNDO's work, as did the creation of this potentially alternative peer group for the young men. (See *In Brief* for more information and Barker, forthcoming)

Men as Partners (MAP) Programme in South Africa

Instead of focusing solely on domestic violence or HIV or reproductive health, MAP educators create opportunities for men to explore and challenge each others' attitudes about gender, violence, sexual and reproductive health, HIV, care giving and community action. MAP staff have developed collaborative relationships with many groups in society: traditional healers, chiefs and village elders, priests and government officials, truck drivers and commercial sex workers, in-school and out-of-school young people and their parents, men in taverns and at sporting events and with men in trade unions and the workplace. (Interview by Dean Peacock with MAP staff Steven Ngobeni, Malibongwe Puzi, Boitshepo Lesetedi, Gertie Mbhalata and Patrick Godana in November 2001)

Programmes with women, including married women, must continue to be supported. Whilst women may be vulnerable this does not mean that they are powerless – programmes empowering women do work and provide an important arena for more focused work on their needs. The example of ICW discussed earlier bears reference to this.

Programmes that work with *both* men and women are important, however, women and girls often feel uncomfortable talking about sexual health issues in front of men (Shah, Kambou, and Monahan 1999).

Stepping Stones Gambia has initiated a programme with both men and women in the community but split them into separate groups so villagers can develop their own sensitive solutions to the problems of HIV prevention. This is the only forum in which sexual matters can be discussed relatively freely. It was important for the participants to do the same exercise in each group so that the men were not suspicious that they were conducting a population control exercise with the women once separated into their group. The discussions culminate in the final community workshop where each peer group makes a 'special request' to the whole-assembled village, participants and non-participants alike (see Supporting Resources Collection).

Although gender-sensitive approaches are a good start, the empowerment of women is an important goal and a means to truly address the spread of HIV/AIDS. However in most societies empowered women are often mistrusted and marginalised within their own communities. Only with the transformation of gender relations at all levels of society will women and men be able to have healthy (and happy) relationships.

4.2 Institutionalising gender and HIV/AIDS

Although recognised, the inequalities in power between institutions (including development institutions) and those they 'target' often go unchallenged. To ensure that approaches to HIV/AIDS and gender are truly empowering and transformatory, development institutions need to re-consider their own practices and programmes they support.

The integration of gender and/or approaches to HIV/AIDS into institutions and programmes is commonly known as mainstreaming. Mechanisms are needed at different levels, situated both internally and externally to ensure change. Whilst many individuals and organisations are committed to mainstreaming gender and/or HIV/AIDS at a policy, programme and project level they may lack the necessary planning skills and tools. The use of mainstreaming tools such as gender analysis and gender planning must be based on a political and personal commitment to a principle of social justice, which includes gender equity.

Internal gender and HIV/AIDS mainstreaming ensures relevant policies and programmes are put in place within the organisation. Policy addresses the extent to which gender equity and a

commitment to addressing HIV/AIDS is enshrined in the principles, philosophy and institutional arrangements of the organisation. External mainstreaming focuses on the integration of gender and HIV/AIDS into the core purpose of the organisation. This is done through the identification of key issues that impact on gender and HIV/AIDS. These issues are then addressed through advocacy, service delivery, research, capacity building and raising awareness.

UNAIDS (Whelan 1999) commissioned research into responses of organisations in addressing gender and HIV. It was noted that a broader understanding of the complexities and challenges of gender is needed within institutions. Such a lack of understanding limits the extent to which programmes have been able to address gender within interventions to reduce vulnerability. A commitment to gender, a participatory approach to developing mechanisms for addressing gender and the incorporation of gender across programmes was not evident. There was a gap in the availability of tools to undertake gender analysis, which could be used by staff involved in implementation as well as specific indicators enabling interventions to measure reduction in gender inequalities as they relate to vulnerability to HIV (Whelan 1999). Tools have now been developed by a range of organisations specifically focusing on gender, sexual and reproductive rights and HIV/AIDS (see Supporting Resources Collection).

Although there should be greater emphasis on gender mainstreaming in approaches to HIV/AIDS, it is important that HIV/AIDS not be relegated to the health sector or tackled as a separate development issue altogether. Development programmes need to not only mainstream gender but a gendered approach to HIV/AIDS as well.

The United Nations – from gender blind to gender action

As a leading player in the global response to the epidemics, the United Nations has acknowledged the link between gender inequality and HIV/AIDS. Established in 1996, one of the key roles of UNAIDS is to advise international, national and local role-players on what constitutes an appropriate response to the HIV/AIDS epidemic. The question is whether UNAIDS are able to advise on gendering the response? To what extent is the work of UNAIDS itself gendered? They have produced various resources dealing with HIV/AIDS and gender – these include technical and best practice papers. Best practice focuses on learning, reflection and analysis of what works or does not work, and why. A set of five criteria is used to identify strengths and weaknesses, describe the lessons learned and is key to the success of a policy, project or programme. The criteria detailed are gender blind – and thus the assessment of what works and what does not, is not analysed in terms of gender. Whilst specific projects are put forward as best practice in terms of gender, other projects and programmes seen as good practice could, in theory, at best do no harm, but could unintentionally, increase gender inequality.

The first UNAIDS paper on gender and AIDS, produced in 1998, outlined seven key steps in promoting a gender-sensitive approach to HIV/AIDS:

- Promoting gender awareness.
- Promoting prevention technologies.
- Developing new technologies.
- Expanding HIV/STI services.
- Reducing women and men's vulnerabilities.
- Reducing the gender impact on living with HIV.
- Ensuring equity in care giving responsibilities.

(UNAIDS, 1998b)

Whilst a useful start, this approach did not address the core of the problem, women's oppression and inequality, and did little to move beyond the gender status quo. Furthermore, the steps focused very much on what to do but not how to do it.

The latest technical paper, produced in 2001, goes further than the gender-sensitive approach apparent in 1998, and outlines suggestions for dealing with gender and HIV/AIDS including:

- Emphasising the role of women and women's organisations in HIV/AIDS policy development, programming and implementation at all levels of government.
- Empowering both men and women within the context of the Beijing Platform for Action.
- Advocating for women's rights as basic human rights and demanding structural changes, including the transformation of social norms and practices that do not uphold these rights.

Despite improvements on the initial gender and AIDS paper, these suggestions, although touching on the need to empower women and men, and the transformation of social norms, fall short by not articulating how organisations should action their recommendations. It is evident that whilst UNAIDS has taken gender on board as policy, the issue is not mainstreamed throughout the organisation itself and into all programmes and projects.

UNIFEM has recently established a co-operation framework with UNAIDS, which has provided the opportunity for enhanced inter-agency co-operation. For example, in the East, Central and Horn of Africa (ECHA) Region, UNIFEM/UNAIDS and the Intergovernmental Authority on Development (IGAD) jointly hosted a regional conference on Gender and HIV and AIDS for ten countries in the region. The outcome document, 'Kampala Declaration on Gender and HIV and AIDS', provides a framework for addressing women's empowerment and gender equality in the context of HIV/AIDS, as well as a strategy paper to guide the region for the next two years (UNIFEM forthcoming).

Although the UN and bilateral agencies are important actors, leadership by civil society in defining a gendered agenda, mobilising and advocating for action, and building capacity to act is vital. At present a social movement dealing with HIV/AIDS and related issues does not exist. Whilst international networks exist, (for example, ICW representing women living with HIV/AIDS, International Council of AIDS Services Organizations (ICASO) representing AIDS Service Organisations), and are doing good work, there is greater potential to realise the goal of transformation if other key sectors and movements are brought on board. Globally, groups of individuals and organisations are dealing with critical issues, for example Development Alternatives with Women for a New Era (DAWN) and the World Social Forum, that impact on and are affected by the HIV/AIDS epidemics. The challenge is to make linkages between sectors, increase exchange and work towards stronger networks and solidarity.

OXFAM: Joint Oxfam HIV/AIDS Programme (JOHAP)

JOHAP was set up in 1998 as one of the first South Africa based joint projects between Novib (Oxfam Netherlands), Oxfam Canada and Oxfam Community Aid Abroad (Australia). Oxfam globally has a strong tradition of working on gender. The programme is built around gendered human rights principles. A key challenge is the integration of gender at all levels of the aid chain. Whilst Oxfam as a donor may be committed to gender mainstreaming, partners may not have the skills to mainstream gender within the organisation.

The JOHAP programme has, through dialogue and funding, supported partner organisations in incorporating an approach to gender and HIV/AIDS in all their work. Increasing the gender sensitivity of partner organisations is seen as the first step towards empowering and transformatory programmes. Successes of JOHAP include:

- Thinking about, discussing, debating and analysing the interface between gender and AIDS. This was at a time when there was much rhetoric about the interface but few examples of organisations that were actually getting to grips with how to work on it.
- Supporting the establishment of the Gender AIDS Forum, which is involved in bringing AIDS and gender organisations together to debate the issues and design appropriate responses.
- Capacity building for partner organisations interested in working more effectively on gender and HIV/AIDS. For example, providing checklists to integrate gender into organisational and programmatic processes, and help putting together funding proposals and implementing monitoring systems.

(Pers. comm. with Dawn Cavanagh (ex-JOHAP), Denise Parmentier (NOVIB), Kate Simpson (OCAAA), Tallis, research in progress, Lee and Kroon 2001)

Development practitioners need to question their prejudices around HIV and their vulnerability to HIV. So breaking down the artificial division between the 'experts' and those 'at risk'. During a satellite panel at the Barcelona 14th International AIDS Conference (2002) that brought together UNIFEM and International Labour Organization (ILO) representatives and one community person to discuss the issues of HIV/AIDS in the world of work, a participant stated that 'HIV is now the leading cause of death among UN workers, worldwide'. Development agencies have to think about what they are doing for their own staff in terms the HIV/AIDS epidemics.

Kate Butcher (consultant) found during an HIV/AIDS mainstreaming workshop in Nepal that UK-based development workers are more likely to keep HIV at an impersonal level than their national counterparts. Their attitudinal response is extremely well disguised by politically correct and development terminology which obscures any real response and avoids addressing HIV/AIDS as a personal issue (see Supporting Resources Collection). However the workshop also showed that development workers feel that some people are more 'worthy' of treatment than others. Therefore, they may find it easier to listen to the voices of mothers living with HIV/AIDS infected by their partners than sex workers or intravenous drug users. The workshop offered participants the opportunity to explore the broader implications of HIV, both personally and professionally. Such work helps break down the barrier between 'us' and 'them' (Butcher and Welbourn 2001).

4.2.1 Multi-pronged approaches

The complex nature and magnitude of the HIV/AIDS epidemics requires a co-ordinated response that is multi-levelled, multi-faceted, and multi-sectoral. A co-ordinated response involves actors from a variety of backgrounds, for example, local and international NGOs, government agencies, and academic institutions. However these approaches need to ensure that they include goals of empowerment and transformation.

The analysis presented in this report of the evolving epidemics and the global response, exposes a range of issues to be addressed by different stakeholders at different levels. The responsibility for these actions needs to be addressed by various agencies depending on:

- The level at which a particular institution is operating i.e. global, national, or local.
- The core function of the organisation (capacity building, service delivery, advocacy or research).
- The sector or thematic area the organisation is focusing on, for example, development, labour, rural, urban.
- Funding priorities.

Few NGOs have the resources to ensure a multi-pronged approach, however it is important to be aware of work being conducted in their region of focus. This will ensure that there is not an overlap in efforts or a clash in methods and goals.

The response to HIV/AIDS must be **multi-levelled**, that is simultaneously occurs at an international, national and local level. Each level has a unique contribution to the global response. It is important that the levels link and engage with one another but that the agenda is not set top-down.

The United Nations Development Fund for Women (UNIFEM) has recently launched a three-year multi-level programme to build national capacity to review existing laws and policies related to HIV/AIDS prevention, care and treatment in order to identify provisions that need to be revised to ensure gender equality. UNIFEM will work with National AIDS Councils and key policymakers to increase their understanding of the impact of HIV/AIDS on women. Work at the community level will focus on equality between men and women. The ten countries covered by the programme include Kenya, Nigeria, Senegal, Zimbabwe, Rwanda, India, Cambodia, Thailand, Barbados and Brazil (www.unifem.undp.org/hiv_aids/).

The strategies to deal with HIV/AIDS at a programme level are **multi-faceted** and include service delivery, capacity building, advocacy and research. Each of these four strategies must address the basic needs of men, women and children, as well as women's practical needs and strategic interests. It is important to address the context in which the epidemics flourish, that is inequality, as well as HIV specific issues, for example, treatment. The different facets include:

Service delivery: Whilst many are engaged in providing services to prevent, care for and treat HIV/AIDS, some service providers are devising strategies to make their work more gender sensitive, or at the very least, addressing women's practical needs. A focus on service delivery should not be confined to health services but true mainstreaming would require other sectors to incorporate approaches to addressing gender inequality and HIV/AIDS into service provision, for example, in the education sector and for entrepreneurs.

Capacity building: Although many equate capacity building with training, it is used in this report in a broader way and refers to capacity building for institutions and individuals. Capacity building thus refers to a process of empowerment based on experiential learning principles that may involve skills building, mentoring and support, as shown in the work of ICW. Studies mentioned in this overview also show that there is a general lack of understanding of how gender conditions people's well being and how to incorporate gender into programmes, demonstrating the need for gender training, tools and guides.

Building skills for better communication in personal relationships is vital. Although improving access to information about sexual health is important, it does not take into account the barriers that women and girls face in using this knowledge to achieve healthy relationships. Group work has been used to initiate discussions and reflection on gender roles and relationships, often challenging general beliefs and behaviour as well as building skills to improve partner communication. The peer education work conducted by PROMUNDO is a good example as is the work conducted by Kate Butcher for DFID, UK.

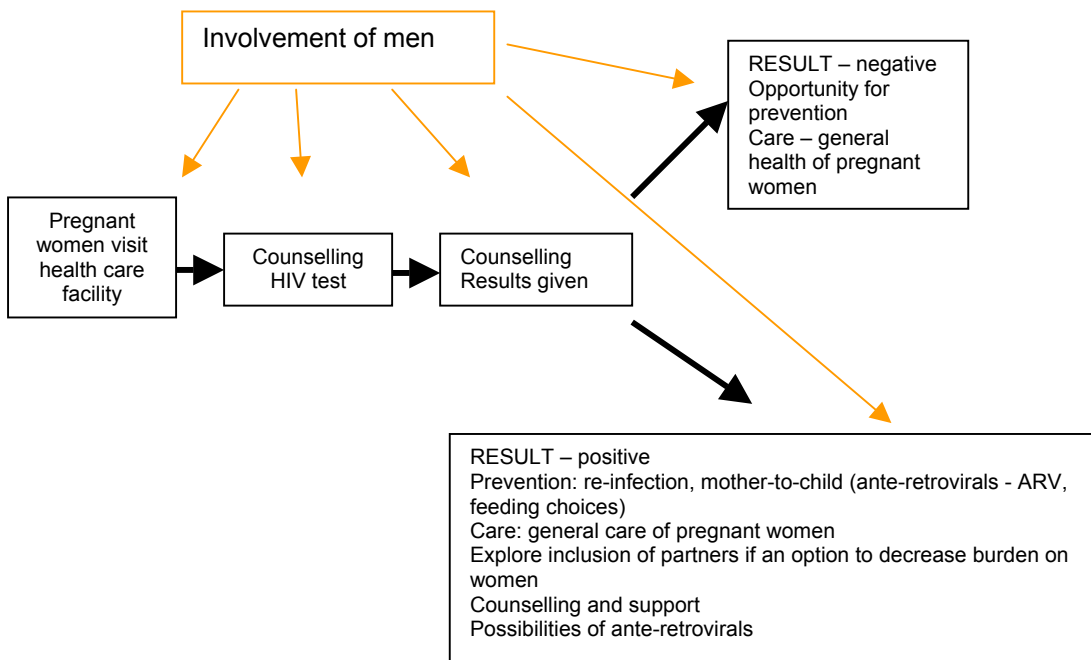
Advocacy: Advocacy for policy formulation, setting research agendas and the allocation of resources that take account of the differing needs and interests of women and men is critical. Ensuring that people are aware of differences based on gender and age, ethnicity, class, ability and sexuality help ensure that people are not marginalised.

Research: There is an enormous amount of HIV/AIDS related research – focusing on people's needs, factors that facilitate spread, impact studies, evaluations of the impacts of programmes. Due to male bias women have often been invisible in research, particularly HIV-positive women.

Multi-faceted approaches- Mother to child transmission (MTCT) Plus

This programme, initiated by Columbia University in 2002, is an attempt to move beyond the focus of preventing infection in children. The programme, introduced due to **advocacy** efforts on the part of women and AIDS organisations puts the ‘mother’ back into MTCT and provides holistic services for pregnant women who are both HIV negative and positive. It also encourages the participation of male partners at all stages. It will be important in the programme to build the **capacity** of healthcare workers to address the different elements of the programme in order to ensure better **service delivery**.

The following diagram highlights critical intervention points to shift the focus of MTCT programmes.



(Adapted from Quarraisha Abdool Karim 2002: personal communication)

It is now widely accepted that HIV/AIDS is both a development and human rights issue. Health-based responses have proven to be ineffective in addressing the HIV/AIDS epidemics. A **multi-sectoral** or expanded response is needed. This will involve planning for HIV/AIDS in all development work, at an institutional and programme level. A critical component of the multi-sectoral approach is that of communication and co-ordination, often a weakness in the response at country, local and other levels. There are few examples of a co-ordinated multi-sectoral response that incorporates a gendered approach to HIV/AIDS, however, there are some good examples of how sectors, beyond the health sector, have addressed gender and HIV/AIDS.

Key aspects of a multi-sectoral response to HIV/AIDS:

- Considering HIV/AIDS and its implications in all areas of policy making.
- Involving all sectors in developing a framework to respond to the epidemic, at international, regional, national, district and community levels.
- Identifying the comparative advantages and roles of each sector in implementing the response, and where sectors need to take action together and individually.
- Encouraging each sector to consider how it is affected by and affects the epidemic, and developing sectoral plans of action.
- Developing partnerships within government between ministries responsible for different sectors, and between the public sector and private sector and civil society.

(Commonwealth Secretariat 2002: 55)

Mainstreaming gender into a multi-sectoral response

- Building capacity for training in gender sensitisation and analysis for all key professionals and workers at national and local levels (including developing locally relevant training materials, training of trainers, and allocating time and resources).
- Establishing system wide processes in each sector to oversee programme development, implementation, monitoring and evaluation, taking into account women's and men's needs, interests and contributions.
- Enhancing capacities for the collection, analysis and use of sex-disaggregated data.

(Commonwealth Secretariat 2002: 59)

As mentioned before many NGOs will not have the resources and influence to operate across many sectors. However they can ensure that their work on different sectors and issues incorporates a gendered approach to HIV/AIDS.

Linking microenterprise initiatives to HIV prevention in South Africa

The goal of this initiative is to develop and evaluate an approach to the prevention of HIV/AIDS, which explicitly addresses key structural factors driving the epidemic, such as poverty, gender-based violence and broader gender inequalities. This programme will integrate and mainstream gender awareness and HIV education into an existing microenterprise initiative. This programme is a collaborative effort between the NGO sector (Small Enterprise Foundation and Agisanang Domestic Abuse Prevention and Training - ADAPT), Northern and Southern academic institutions (the London School of Hygiene and Tropical Medicine and the University of the Witwatersrand) and the national government (South African National Department of Health). (Kim, Dr. J., email: Jkim@soft.co.za)

The legal sector in Uganda

Agency for Co-operation and Research in Development (ACORD) has developed a strategy both as a means of empowering women to challenge patriarchal structures and traditions in their society and also, in so doing, to protect themselves against the risk of contracting HIV/AIDS. They have teamed up with The Association of Uganda Women Lawyers (FIDA) to develop a legal awareness-raising project. A parallel process of challenging traditional power relations within the household, including the negotiation of safer sex, has also been implemented. (Hadjipateras, Angela , email: angelah@acord.org.uk)

5. Conclusions and recommendations

The HIV and AIDS epidemics are becoming increasingly complex over time. The 1990s were characterised by an expanding and dangerous gap between the pace of the HIV/AIDS pandemic, and national and international efforts against it. This trend has continued into the 2000s. Whilst the epidemics in some countries have slowed down, which is in part as a result of successful prevention programmes, larger analyses suggest that the epidemics are not going away: they are merely shifting to new and vulnerable populations. Attention has now also been given to people with perceived lower levels of risk behaviour, for example married women.

There is increasing recognition that gender equality is part of the common global goal. There is also increasing commitment, experience and resources that can be applied to forward this transformatory goal and there is sufficient knowledge to shape a common agenda to support this goal. This knowledge, together with the tools and skills development, must be increasingly accessible to all stakeholders, at all levels across sectors. As the supporting resources collection of this pack attest to there are now numerous excellent guides and tools.

The last decade has seen a mushrooming of responses to HIV/AIDS at an international, national and local level. Whilst there are growing expressions of commitment to addressing the gender dimensions of HIV/AIDS, action at a policy and practice level still needs development. The effectiveness of the response depends on the ability to deal with the many inequalities that are driving the epidemics.

Critical gender challenges:

Use a gendered human rights framework:

Various conventions and declaration provide useful frameworks for action which strongly emphasise sexual and reproductive rights along with broader social, economic and political rights. The Convention on the Elimination on All Forms of Discrimination Against Women, UNIFEM have produced a useful booklet: 'Turning the tide: CEDAW and the gender dimensions of the HIV/AIDS Pandemic' which outlines specific aspects of CEDAW that relate to HIV/AIDS (see section two for a short list).

Specific recommendations in the Barcelona Bill of Rights include but are not limited to the right to:

- Sexual and reproductive health services, including access to safe abortion without coercion.

- Access user-friendly and affordable prevention technologies, such as female condoms and microbicides, with skills-building training on negotiation and use.
- Choose to disclose their status in circumstances of safety and security without the threat of violence, discrimination or stigma.
- Live their sexuality in safety and with pleasure irrespective of age, HIV status or sexual orientation.
- Choose to be mothers and have children irrespective of their HIV status or sexual orientation.
- Gender equity in education and lifetime education for all.
- Economic independence such as to own and inherit property, and to access financial resources.
- Freedom of movement and travel irrespective of HIV status.

(See Supporting Resource Collection for a complete list of recommendations).

HIV/AIDS policy and programmes must be informed by the complex and diverse lived realities of women, men and children:

- The people most affected by any development issue must be an integral part of the process of defining the problem and finding solutions. Development initiatives should therefore start with their priorities.
- Involve women and men living with HIV and those most vulnerable at all levels of policy, planning and programmes. This will probably involve building their capacity, including skills training, to do so (see the Supporting Resources Collection for a list of 12 statements from ICW on improving the situation of women living with HIV and AIDS throughout the world).
- Acknowledge and do not stigmatise the sexuality of young people, women, men who have sex with men, lesbian, bisexual and trans-gendered people, older people, and people with disabilities.
- Listen to the concerns and experiences of women and men living with HIV/AIDS and those most vulnerable and helping to ensure that they have access to forums in which they can express themselves. This will help to challenge the stigma, taboo, blame and denial associated with HIV/AIDS.
- Research, both social and scientific, should ensure that participants include both women and men and researchers need to know how to recognise and analyse the influence of gender inequality and differences.

Change or transform unequal power between men and women to create a context where women have equal power and both women and men are less vulnerable:

- Recognise that although the empowerment of women is an important goal of HIV/AIDS interventions, the transformation of gender relations is needed before empowerment is fully realised.
- Involve men in HIV/AIDS interventions that challenge the gender status quo because their involvement is crucial in transforming gender relations and because gender roles and expectations also put them at risk.
- Ensure that interventions with men do not compromise women's rights, reaffirm stereotypes, or replace working with women.
- Work with only women is good but may not transform the gender relations that constrain their rights.
- If HIV/AIDS programmes work with both men and women we should not forget factors that constrain women's ability to participate in discussions and decisions on an equal level.
- Women and girls also have to address their role in perpetuating negative constructions of masculinity.
- Treatment and preventative technologies need to be accompanied by strategies that address the gendered barriers to such methods. On their own they will not alter the imbalance in power that leads to the abuse of women's sexual and reproductive rights.

Develop a co-ordinated response to HIV/AIDS that is multi-levelled, multi-faceted and multi-sectoral and institutionalised:

- Recognise that all sectors and development programmes need to take gender and HIV/AIDS into account and that there is no sector to which it is irrelevant
- Although programmes may not have the resources to be multi-pronged, programmes need to support a co-ordinated response that is both empowering and transformatory.
- Development programmes need to not only mainstream gender but a gendered approach to HIV/AIDS as well.
- Although governments around the world and UN agencies play an important part in addressing the gender inequality that drives HIV/AIDS, civil society actors should define the gender agenda.
- Networks of organisations and people working on HIV/AIDS and gender need to be supported and strengthened.
- Private, civil society and government alliances will help to bring about a co-ordinated approach that is multi-sectoral (see section 4.2.1 for more specific recommendations from the Commonwealth Secretariat), multi-levelled and multi-faceted.
- Development professionals are also affected by HIV/AIDS and have their own vulnerabilities and prejudices. This involves breaking down the barrier between 'us' and

'them' in terms of who is affected by HIV/AIDS and who is involved in perpetuating the epidemics.

Through collective action at all levels from local to international, we can harness the energy to translate these challenges to co-ordinated action.

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