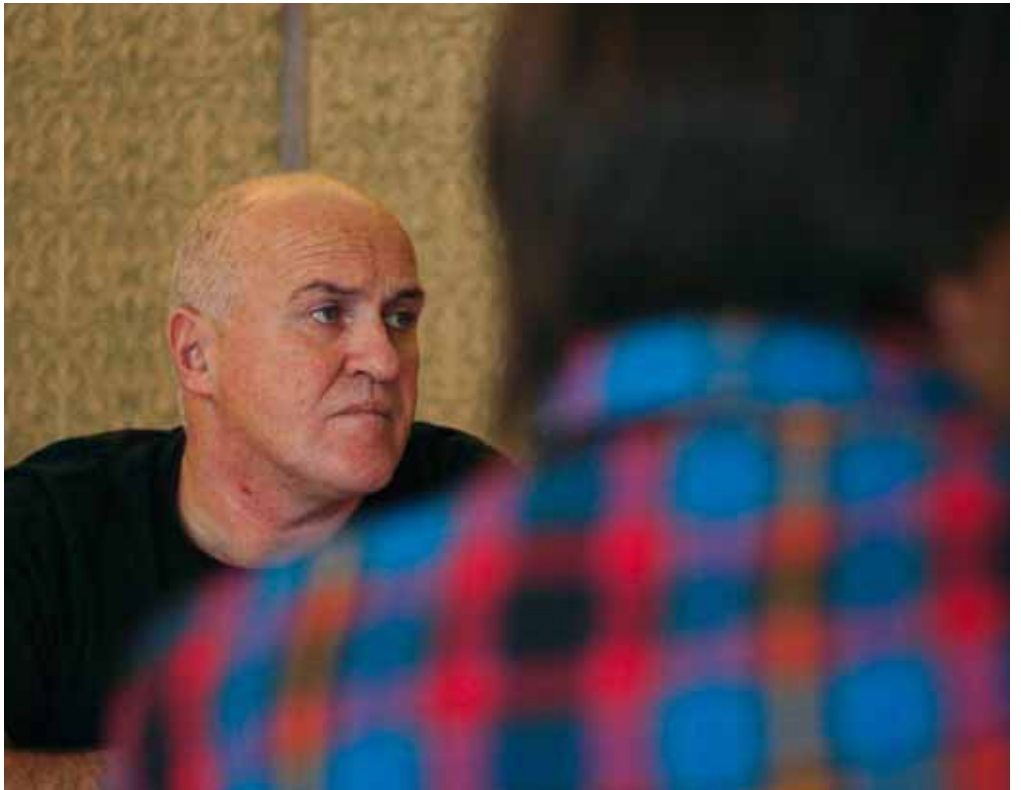
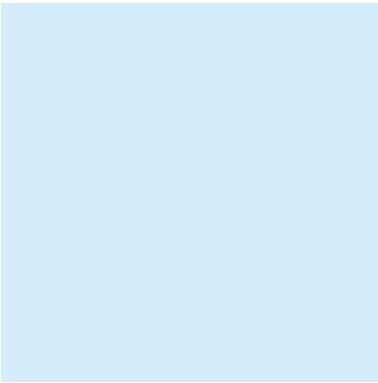
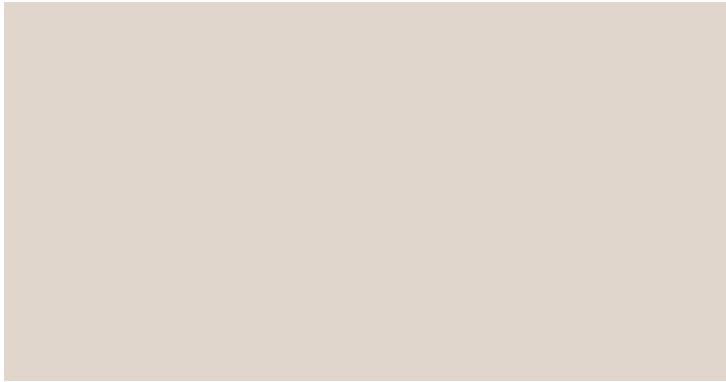


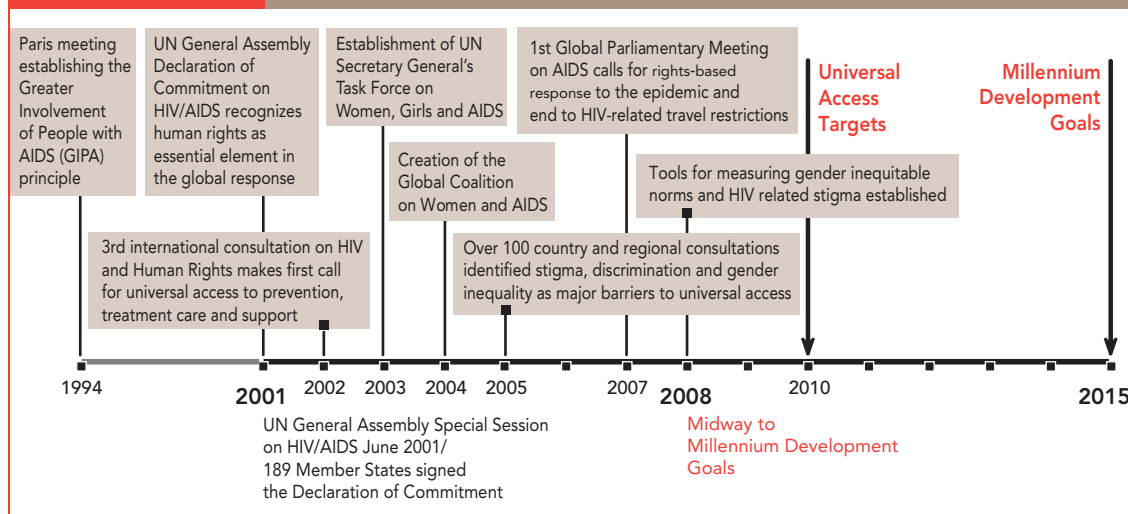
Addressing societal causes of HIV risk and vulnerability



Chapter 3



FIGURE 3.1 Selected events related to social determinants of the HIV epidemic



Key findings

- Long-term success in responding to the HIV epidemic will require sustained progress in addressing human rights violations, gender inequality, stigma, and discrimination.
- Significant investment in girls' education, supported by policies mandating universal primary and secondary education, would substantially reduce HIV risk and vulnerability for women and girls.
- Evidence-informed programmes to forge norms of gender equity should be brought to scale, with particular attention to initiatives focused on men and boys.
- National governments and international donors should prioritize strategies to increase women's economic independence and legal reforms to recognize women's property and inheritance rights.
- All countries should ensure rigorous enforcement of antidiscrimination measures to protect people living with HIV. The one third of countries that lack legal protections against HIV-based discrimination should immediately enact such laws. Countries should also protect populations most at risk from discrimination and ensure their equal enjoyment of human rights.
- Countries should include anti-stigma strategies as integral components of their national AIDS plans, investing in a broad range of activities, including public awareness and "know your rights" campaigns, legal services for people living with HIV, expansion of access to antiretroviral drugs, and expressions of national solidarity in the HIV response.
- Much stronger financial and technical support is needed for capacity-building for organizations and networks of people living with HIV, and groups most at risk of HIV infection.

HIV is a biological entity that is responsive to medical interventions, but the epidemic has continued to expand, largely due to the failure to tackle societal conditions that increase HIV risk and vulnerability. This chapter examines two sets of societal factors that affect HIV risk and vulnerability but have not been effectively addressed in most countries:

- gender inequality and the lack of empowerment of women and girls; and
- discrimination, stigma, and social marginalization.

This chapter also includes a brief discussion of the role of economic inequality in the HIV epidemic. The social factors differ in their manifestation, intensity, and impact between and within regions, but they are present to some degree worldwide, and in all cases impede an effective, evidence-informed and rights-based response to the epidemic (Mann & Tarantola, 1996).

Relatively few studies have rigorously examined strategies to minimize these and other

societal sources of HIV risk and vulnerability. Nevertheless, sufficient evidence exists to guide national initiatives that aim to minimize the societal sources of HIV risk and vulnerability and to create more enabling environments for the human rights, health, and well-being of all people, including those most at risk of exposure to HIV. In particular, tools have been developed in recent years to measure gender inequality and HIV-related discrimination and stigma, facilitating improved social science research and programme evaluation. Efforts to change the contextual influences that increase HIV risk and vulnerability using a variety of initiatives—including a new generation of social change communication strategies—should constitute an integral part of any comprehensive national HIV strategy. This chapter is complementary to Chapter 4, which discusses the components of effective, comprehensive programmes to prevent new HIV infections.

Attempting to change the societal determinants of HIV risk and vulnerability could be

Defining HIV risk and vulnerability

Risk is defined as the probability or likelihood that a person may become infected with HIV. Certain behaviours create, increase, and perpetuate risk. Examples include unprotected sex with a partner whose HIV status is unknown, multiple sexual partnerships involving unprotected sex, and injecting drug use with contaminated needles and syringes.

Vulnerability results from a range of factors outside the control of the individual that reduce the ability of individuals and communities to avoid HIV risk. These factors may include: (1) lack of knowledge and skills required to protect oneself and others; (2) factors pertaining to the quality and coverage of services (e.g. inaccessibility of service due to distance, cost or other factors); and (3) societal factors such as human rights violations, or social and cultural norms. These norms can include practices, beliefs and laws that stigmatize and disempower certain populations, limiting their ability to access or use HIV prevention, treatment, care, and support services and commodities. These factors, alone or in combination, may create or exacerbate individual and collective vulnerability to HIV.

Based on: UNAIDS (2007a).

considered beyond the resources, time frame or mandate of public health programmes. Yet the HIV epidemic has already led to major alterations in international development and global public health practice, dramatic changes in attitudes, and monumental shifts in social norms. The history of the epidemic demonstrates the pitfalls of a response that is too narrow and focused only on the short term. Far-reaching changes in social norms and practices are possible if there is sufficient political leadership, community engagement, programme direction, and international solidarity. In recent years, the attitudes, behavioural patterns, and laws that cause, reflect, and reinforce the societal determinants of HIV

risk and vulnerability have been exhaustively mapped in diverse settings. A growing body of scientific evidence is available to guide policy responses and programmes.

Moreover, now is the time to address the root causes of HIV risk and vulnerability. Important, if uneven, progress has been made in expanding access to many HIV prevention strategies (see Chapter 4), but efforts to curb the spread of HIV are being undercut by gender inequality, stigma, and discrimination. Especially in hyper-endemic settings—where modest changes in risk behaviour that might keep low-level epidemics in check would be unlikely to have sufficient impact—broader social changes are required to bring the epidemic under control (SADC, 2006).

Rights-based approaches to HIV

A human rights-based approach to HIV ensures that matters often considered discretionary are recognized as legitimate entitlements of all individuals. This approach also ensures that governments, the UN system, donors, and the private sector are obligated and empowered to assist in the realization of the rights necessary to respond to HIV. It brings human rights standards and principles into the heart of all HIV programming processes, and empowers people to know and claim their rights. It helps stakeholders to address power imbalances that exist at household, community, and national levels. In particular, a human rights-based approach to HIV ensures:

- a focus on the vulnerable and marginalized in the HIV epidemic (e.g. women, young people, people living with HIV, orphans, men who have sex with men, drug users, sex workers, mobile populations, ethnic and indigenous groups, and refugees);
- equality and non-discrimination in expenditure on HIV programmes and applications;
- programmes to empower those vulnerable to, or living with, HIV, including law reform, legal aid, human rights education, social mobilization, social change communication, and support for civil society;
- programmes designed to achieve human rights standards relevant to HIV (e.g. protection from sexual violence, gender equality, education, information, health, employment, access to scientific progress);
- informed, active, free, and meaningful participation by those affected by HIV in HIV-related programme design, implementation, monitoring, and evaluation; and
- accountability mechanisms for governments, intergovernmental organizations, donors, and the private sector (e.g. UNGASS and the “Three Ones” principles).

Gender inequality and harmful gender norms

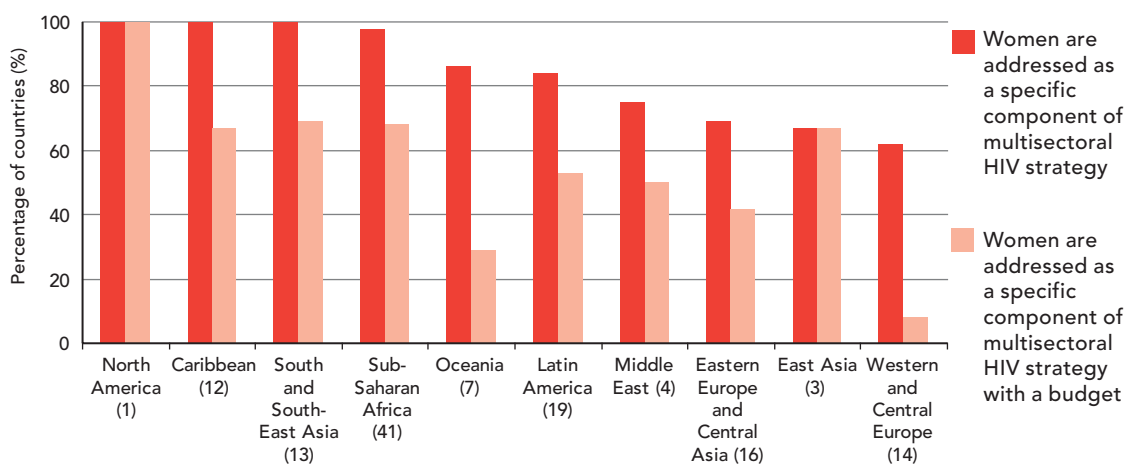
The many and varied links between gender inequality and increased vulnerability to HIV infection among women and adolescent girls have been well documented.¹ Cultural or social norms often restrict women’s access to basic information about sexual and reproductive health. Even if women have access to information and commodities (e.g. condoms), gender norms that prescribe an unequal and more passive role for women in sexual decision-making undermine women’s autonomy, expose many to sexual coercion, and prevent them from insisting on abstinence or condom use by their male partners.

Gender inequality has a clear, demonstrable impact on the epidemic. In Botswana, individuals who held three or more discriminatory gender beliefs (e.g. extramarital sex is less permissible for women than for men, a husband is justified in beating his wife if she has sex

outside the marriage) were nearly three times more likely to have had unprotected sex with a non-marital partner in the previous year than those without such beliefs. A related study in Swaziland found that people who had six or more discriminatory gender attitudes were more than twice as likely to have multiple sex partners than those without such attitudes (Physicians for Human Rights, 2007).

Traditional expectations related to masculinity and male sexual behaviour also increase the risk of infection among men and boys. Typical male roles that call for men and boys to be tough, aggressive, sexually dominant, and risk-taking are often associated with behaviours that increase men’s risk of HIV infection. Such behaviours include a high number of sexual partners, use of drugs or alcohol, and refusal to seek medical care for sexually transmitted infections (ICRW, 2007; WHO, 2007). The mutually harmful nature of some gender norms underscores the importance of involving men and boys in any effort towards change.

FIGURE 3.2 Percentage of countries in regions reporting that women are addressed as a specific component of their multisectoral HIV strategy with a specific HIV budget for their activities



Source: UNGASS Country Progress Reports 2008.

(number of countries reporting)

¹ For a summary of what is known about how gender inequality increases HIV risk and vulnerability, see Global Coalition on Women and AIDS (2006a).

National policy responses to gender inequality

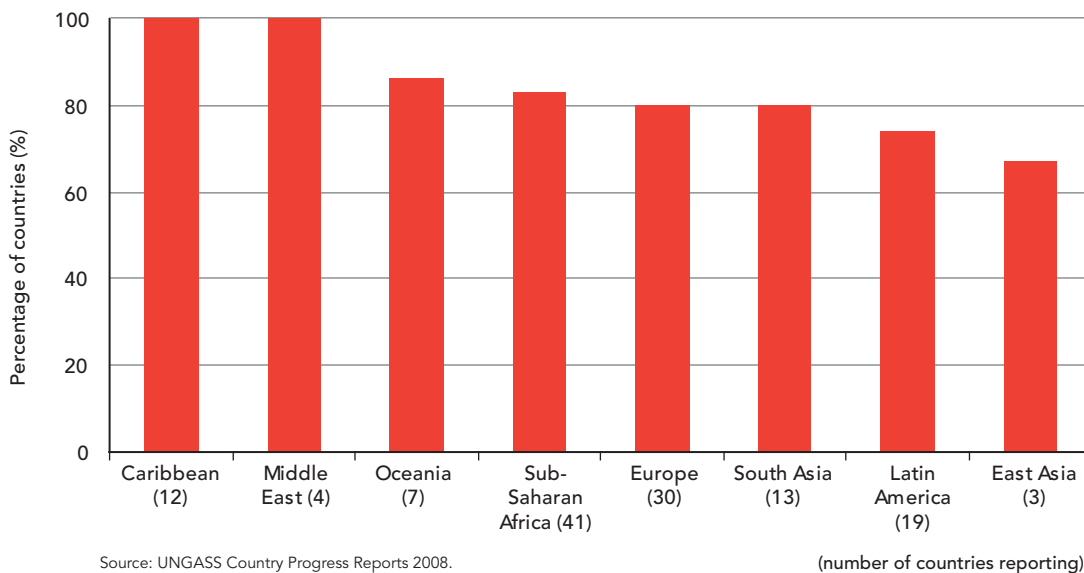
Although a large majority of countries have begun to recognize gender issues in their HIV planning processes, a substantial number lack budget and policy support for such issues. More than 80% of national governments report a focus on women as part of their multisectoral strategy for HIV, but only 52% report having a dedicated budget allocation for programmes addressing women’s issues (UNGASS Country Progress Reports, 2008). The largest proportions of countries with reported budgets for such efforts are in Asia (69%) and sub-Saharan Africa (68%) (Figure 3.2).

In 2007, nongovernmental respondents in 82% of countries reported having policies in place to ensure equal access to HIV prevention, treatment, care, and support for women and men, with

important regional variations, as shown in Figure 3.3 (UNGASS Country Progress Reports, 2008). This is an increase from 2003, when 69% of national governments reported that such policies were in place. Despite the large number of countries with such policies in place, nongovernmental informants in 12% of these countries report the existence of other laws and policies that present obstacles to the delivery of services to women (UNGASS Country Progress Reports, 2008).

Based on countries’ responses to 14 questions about policies related to women, UNAIDS rated each country on a policy index ranging from 0 (for those with none of the equitable policies in place) to 14 (for those with all of them). As Figure 3.4 illustrates, the lowest scores on policies ensuring equal access to women were in Eastern Europe and Centralo Asia, and the highest were in sub-Saharan Africa.²

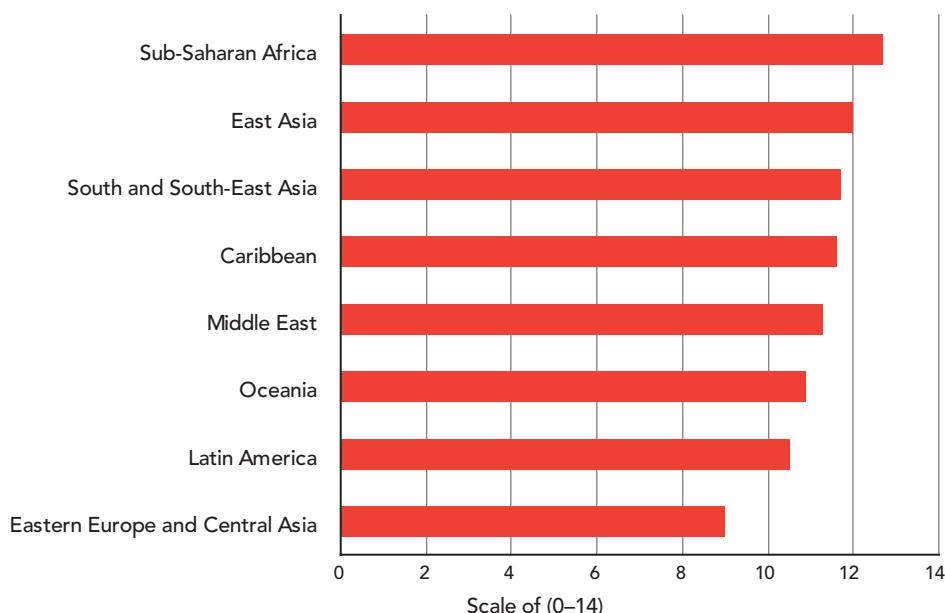
FIGURE 3.3 Percentage of countries (by region) reporting policies in place to ensure equal access to HIV prevention, treatment, care, and support for women and men



² The 130 responding countries were rated according to their replies to 14 policy questions in NCPI. Each country was given a score of 1 for each policy in place. Questions related to inclusion of specific women’s issues in national strategic plans and in development plans, in HIV prevention (government response) and in human rights (nongovernmental response). A value of -1 was given if a country responded positively to the question on whether there are laws, regulations or policies that present obstacles to HIV programmes for women.

FIGURE 3.4

Index of policies related to women's vulnerability to HIV



Source: UNGASS Country Progress Reports 2008.

Despite important progress in developing national policy frameworks related to women's vulnerability and HIV, key gaps remain in many countries. For example, nongovernmental informants reported that nearly one third of countries (31%) do not have non-discrimination laws or regulations in place that explicitly mention women (with a range across regions of 12%–50%) (UNGASS Country Progress Reports, 2008). According to government reports, 32% of countries lack information, education, and communication policies or strategies to encourage the involvement of men in reproductive health programmes (UNGASS Country Progress Reports, 2008).

Effective strategies to reduce gender inequality and change harmful gender norms

A growing number of strategies, discussed below, can reduce gender inequality and change harmful gender norms. These strategies are:

- education;
- multicomponent efforts to change harmful gender norms;
- reduction in gender-based violence;
- income-generating strategies; and
- advocacy and support.

Promoting universal education

Earlier in the epidemic, evidence about the relationship between educational attainment and risk of HIV infection was ambiguous, but more recent data from 11 African countries clearly link higher educational levels with lower HIV prevalence (Hargreaves, 2008). A recent study in rural South Africa found that each additional year of educational attainment reduced the risk of HIV infection by 7% (Bärnighausen et al., 2007). In particular, schooling offers an excellent means of reducing girls' HIV risk and vulnerability.

Measuring changes in normative beliefs relating to gender between men and women

The global history of women's empowerment demonstrates that it is feasible to radically alter gender norms. Until recently, however, it has been difficult to establish whether particular initiatives to promote equity between men and women have led to changes in gender norms and practices. This shortcoming has stemmed primarily from the absence of reliable measures in this area.

Fortunately, this barrier has been overcome, creating the potential for easier and more rigorous programme evaluation studies. Developed and tested by the Horizons project in Brazil, and subsequently tested in Asia and Africa, the Gender Equitable Men scale provides HIV programmes with a practical and reliable way to measure key beliefs and norms that contribute to gender inequality.

Horizons researchers found they could characterize prevalent gender norms by asking respondents if they agreed with a small set (15–25) of questions, such as “There are times when a woman deserves to be beaten” and “A man should have the final word about decisions in his home.” The resulting scale enables programmes in widely varying contexts to demonstrate their impact on equitable gender norms. In Brazil and India, for example, the scale was used to evaluate a six-month programme of peer-led, interactive sessions with young men that included role play, dialogue, and other techniques to prompt critical reflection on gender norms and their consequences. The study also evaluated an intensive arm of the programme that supplemented the standard activity with a “lifestyle social marketing campaign” to promote sexually responsible, non-violent male behaviour. In both Brazil and India, both the standard and the intensive activities significantly reduced support for inequitable gender norms at 6 and 12 months, in comparison with a control group that had not participated in these activities. In Brazil, the young men who abandoned inequitable gender norms after taking part in the programme were less likely to report a sexually transmitted infection and more likely to use condoms with their regular partners. In Mumbai, India, men who took part in the programme were twice as likely to have used a condom with their most recent sexual partner, and were significantly less likely to engage in violence with their intimate partners. Verma et al., 2006; Pulerwitz et al., 2006).

Girls who complete primary education are more than twice as likely to use condoms, while girls who finish secondary education are between four and seven times more likely to use condoms, and are less likely to be infected with HIV (Hargreaves & Boler, 2006).

Unfortunately, in many low- and middle-income countries, girls are systematically denied equal educational opportunities. In the least developed countries, girls are 11% less likely to attend primary schools than boys (UNDP, 2007). By the time girls reach

secondary school age, their educational opportunities are even further diminished. In least developed countries, girls are 19% less likely than boys to be in school. In Benin, Côte d'Ivoire, and Guinea, girls are only slightly more than half as likely as boys to attend secondary school (UNDP, 2007).

Since 1999, the global disparity in school attendance between the sexes declined, from a 9% deficit among girls to a 6% deficit in 2005 (UNESCO, 2007). However, 113 countries lacked gender parity in primary and secondary school attendance in 2005, and UNESCO projections suggest that only 18 of these countries are likely to achieve equal access to education by 2015 (UNESCO, 2007). Gender disparities in schooling are much larger in secondary and tertiary education than in primary education. Of 144 reporting countries, only Botswana, China, Mexico, and Peru had achieved parity in tertiary education (UNESCO, 2007).

Strategic national efforts can close gender gaps in education. For example, in Burkina Faso, Ethiopia, and a number of other countries, strong national commitment to push towards global Education for All³ goals has been associated with a significant narrowing of educational gaps between girls and boys (UNESCO, 2007). In parts of Africa, the elimination of school fees has led to dramatic increases in girls' primary school enrolment (Burns, Mingat & Rakotomalala, 2003; Deininger, 2003; UNICEF, 2005). In India, young women (both in and out of school) who participated in skills building and vocational training, and received referrals to comprehensive age-appropriate reproductive health services, were more likely to delay marriage until age 18, to report more consistent condom use, and to exhibit stronger health-seeking behaviour (CEDPA, 2001).

Multicomponent efforts to change harmful gender norms

National leadership and intervention programmes can help accelerate the process of forging more equitable gender norms. All such efforts should aim to promote dialogue at national and community levels, to examine the costs of inequitable gender norms to both women and men, and to explore new ways of thinking about gender.

A wide array of promising programmes have arisen to help communities develop equitable gender norms. Stepping Stones workshops⁴, used in more than 40 countries, have helped to reduce the acceptability and prevalence of violence against women and promoted HIV awareness and condom use by fostering community dialogue (Jewkes et al., 2007). Participants in the Men as Partners programme in South Africa, implemented through Engender Health, were more likely to believe men and women should have equal rights, and that wife-beating was wrong (Kruger, 2003; Peacock & Levack, 2004; Bott, Morrison & Ellsberg, 2005). In Brazil, Instituto Promundo's Program H has demonstrated improvements in young men's attitudes toward gender equality and reductions in risk of HIV and sexually transmitted infections. Program H used small group sessions, reinforced by a social marketing campaign, to replace community norms of male dominance with attitudes of respect and trust (Pulerwitz, 2006).

Confronting learned, shared attitudes is an important element of success in promoting gender equality. A meta-analysis of programmes to promote gender equality found that 29% were effective in producing changes in relevant attitudes or behaviour (Barker, Ricardo & Nascimento, 2007). Programmes that expressly aimed to transform gender roles through critical reflection, role play, and other interactions were

³ The 'Education for All' movement began in 1990 at the World Conference on Education for All. At the World Education Forum in Dakar, Senegal, in 2000, governments pledged to achieve quality basic education by 2015, with particular attention to girls' education.

⁴ Stepping Stones is a workshop that aims to alter behaviours and norms pertaining to HIV, gender and relationships. (See Wellbourn, 1995)

most likely to be effective in producing changes in the targeted attitudes and behaviours.

Reducing gender-based violence

Widespread violence against women not only represents a global human rights crisis but also contributes to women's vulnerability to HIV. Between 40% and 60% of women surveyed in Bangladesh, Ethiopia, Peru, Samoa, Thailand, and the United Republic of Tanzania said they had been physically and/or sexually abused by their intimate partners (Garcia-Moreno et al., 2005). In conflict situations, rape and other forms of sexual coercion are often used as weapons of war (Raise Initiative, 2007). In parts of the Democratic Republic of the Congo affected by conflict, the prevalence of rape is believed to be the highest in the world (McCrummen, 2007).

In several African countries, the risk of HIV among women who have experienced gender-based violence may be up to three times higher than among those who have not (Global Coalition on Women and AIDS, 2004). Fear of

violence can be a barrier to HIV disclosure (Medley et al., 2004); for example, in Cambodia, fear of violence contributes to the low numbers of women accessing counselling and testing services in antenatal clinics (Duvurry & Knoess, 2005).

International experience has shown that rates of violence can be lowered. However, 29% of national governments report that they lack laws or policies to prevent violence against women. To be successful, efforts to reduce gender violence must reverse social norms that hold violence to be natural and acceptable. Norm-changing programmes should be supported by legal reform, enhanced law enforcement to hold perpetrators of violence to account, and activities to address the attitudes and conditions that may contribute to gender-based violence.

In February 2007, Zimbabwe enacted legislation that expands protections for survivors of domestic violence and imposes penalties of up to 10 years in prison for offenders. Police stations are required by law to have personnel on duty

Addressing cultural practices that increase risk and vulnerability of women and girls

Globally, between 100 million and 140 million girls and women have undergone partial or total removal of the external female genitalia, or other injury to the female genital organs for non-medical reasons. An additional 3 million girls are affected each year by such practices (UNAIDS et al., 2008). In addition to reflecting and reinforcing women's subordinate status, female genital mutilation also exposes women to considerable health risks. In 2008, UNAIDS joined with nine other UN agencies to urge rapid implementation of laws and policies to eliminate the many forms of female genital mutilation (UNAIDS et al., 2008).

National laws and community awareness initiatives are increasingly addressing female genital mutilation and other cultural practices that can increase women's risk and vulnerability. Legislation passed in Zimbabwe in 2007 prohibits forced marriages or servitude, and in 2005 the Zambian Government amended the penal code to prohibit "widow cleansing", a practice whereby women whose husbands have died submit to sex with a village leader in order to be re-accepted into the community (UN Office for the Coordination of Humanitarian Affairs, 2005; Gable, 2007).

Women's ability to negotiate for safer sex is severely limited in many countries



with expertise in domestic violence. The law also grants law enforcement personnel the authority to arrest alleged perpetrators without a warrant if harm appears reasonably imminent. In support of this initiative, UNICEF has partnered with the national government and the Zimbabwe Women Lawyers Association to train more than 300 chiefs and traditional healers on how to apply the act to support survivors of violence and prevent abuse in their communities.

Countries are advised to approach violence prevention in the same way as other public health problems. Steps include developing a national action strategy, improving data collection and analysis, evaluating programmes to assess their results, reporting strategies and results through mass media, and investing in care and support services for survivors (Mercy, 2007). In general, research on the prevention of violence in low- and middle-income countries has attracted meagre financial support (Institute of Medicine, 2008).

In addition to programmes to encourage men to regard gender-based violence as unacceptable

(whether directed at men or women), national and local laws can also help to reduce women's vulnerability to violence. However, laws against gender-based violence are meaningful only if they are effectively enforced. For example, Zambia established specialized police units to respond to reports of gender-based abuses (Human Rights Watch, 2007).

Income-generating strategies

In many regions, gender inequality may result in women's economic dependence on men, which may in turn heighten their vulnerability to HIV. In places where laws or social customs deprive women of an independent means to generate income, and permit husbands to abandon their wives if they are disobedient, women often have little, if any, means to insist on abstinence or condom use by their husbands.⁵ According to a recent study in Botswana and Swaziland, women who lack sufficient food are 70% less likely to perceive personal control in sexual relationships, 50% more likely to engage in intergenerational sex, 80% more likely to engage in survival sex,

⁵ For a discussion of the contribution of economic inequities to the disproportionate HIV infection rates among adolescent females in sub-Saharan Africa, see Chapter 4.

and 70% more likely to have unprotected sex (Weiser et al., 2007).

Women who own property or control other economic assets have higher incomes, a secure place to live, and greater bargaining power within their households. With a heightened sense of self-efficacy, women are better able to remove themselves from domestic violence, or to leave a relationship that threatens them with HIV infection. With greater ownership and control over economic assets, women are more empowered to negotiate abstinence, fidelity, and safer sex, and can avoid exchanging sex for money, food, or shelter (Strickland, 2004; Gupta, 2005; Global Coalition on Women and AIDS, 2006b). Young women with higher socioeconomic status also are more likely to delay sexual debut, have fewer sexual partners, and to use condoms (Hallman, 2004; Hallman, 2005).

In many countries heavily affected by HIV, however, laws do not recognize women's right to own or inherit property. Such institutionalized discrimination is often compounded by cultural norms, such as the practice in some communities that requires widows to marry a male relative of the deceased (Carpano, Izumi & Mathieson, 2007). The Canadian HIV/AIDS Legal Network is collecting "best practices" in the area of legislative reform to empower women, with the goal of drawing up model legislation and a legal toolkit to aid country-level advocacy (Carpano, Izumi & Mathieson, 2007).

In settings where women's economic rights are recognized, efforts are often required to acquaint women with their rights and to assist them in protecting those rights. In several African countries, grass-roots organizations help women to navigate the legal process, and train paralegals and others in the enforcement of women's property, inheritance, and legal rights (ICRW, 2006b). For example, Women's Land Link Africa links grass-roots organizations in 10 African countries to improve women's access to land and property ownership, and to advocate greater inclusion of women in policy-making processes (Carpano,

Izumi & Mathieson, 2007). In India, the Lawyers Collective integrates training in HIV prevention and care into its legal services for women (Global Coalition on Women and AIDS, 2006b). Women who participated in a World Vision programme combining HIV education and microfinance showed greater economic resilience, higher levels of HIV awareness and prevention behaviours, and improved educational attainment and nutrition among their families (World Vision, 2008). A multiyear project in Mozambique aims to increase the gender sensitivity of judicial officers (Carpano, Izumi & Mathieson, 2007). However—according to a survey of nongovernmental organizations in Bangladesh, India, Nepal, and Sri Lanka—efforts to link women's property rights to HIV initiatives have largely been fragmented and ad hoc (ICRW, 2007).

In addition to legal reform to increase property ownership by women, substantially greater international support is needed for women-focused microfinance initiatives that provide direct financial support for women's economic independence. A study of the IMAGE project in South Africa, which combines microfinance with gender and HIV training, demonstrated a 55% reduction in intimate partner violence against women (Pronyk et al., 2006).⁶

Advocacy and support

Globally, many organizations and networks are actively working to build solidarity among women living with HIV, and to undertake joint advocacy to address the epidemic's disproportionate impact on women and girls. National governments and international donors should increase their capacity-building support for women's organizations that are working to advance women's rights and reduce women's vulnerability.

In Kenya, for example, GROOTS (Grassroots Organizations Together in Sisterhood) is a network of women's self-help groups that works to build the capacity of women to protect their

Finding support in an HIV microcredit programme

*Imane, a 27-year-old woman in Algeria, believes her story “might seem to be the story of millions [of] HIV-positive women in the Arab world” **

When she was married five years ago, her husband did not disclose that he was HIV-positive. When Imane showed the medicines he took to one of her sisters, the sister urged Imane to take an HIV test. Although her 4-year-old daughter tested negative, tests showed that Imane had become infected with HIV. “When my doctor asked me if I knew about my disease I couldn’t believe him,” Imane says. “HIV! The disease of the prostitutes. This was my thinking then. This is the thinking in my culture!”

Today, Imane knows better. “The majority of HIV-positive women I know are women who never get out of their houses... more than 60% of the HIV-positive women I know are infected by their husbands.”

Imane’s physician explained that HIV had become a chronic disease and that she could live a normal life with antiretroviral drugs. Still, she had difficulty accepting the diagnosis and became depressed. Her husband displayed little empathy for her situation, and her best friend cut off contact after learning that Imane was living with HIV. Caring for her daughter became Imane’s sole concern.

Eventually, a woman at her local hospital, who had been living with HIV for 10 years, invited Imane to visit El Hayet, a network of people living with HIV. El Hayet helps HIV-positive people to generate income by enabling them to obtain a diploma in one of a number of vocational fields, such as traditional pastry making, sewing, or painting. The organization links its members with microcredit opportunities generated through El Hayet’s partnership with the Ministry of Solidarity and Social Affairs.

Through participation in El Hayet’s income generation programme, Imane found a group of people who understood her and who gave her support. “I went several times until I felt totally relaxed when being there, and less and less lonely as days went through... There is a very positive atmosphere and so great relationship between the trainers and the trainees. What I found great here is that you may learn or teach... and speak freely about your disease with no fear.”

“Today, with El Hayet, my wounds have healed.”

* Imane requested that her photograph not be used.

legal and economic rights. In Nigeria, 150 women's groups joined together in August 2007 to launch the National Coalition on Women and AIDS. The aim was to address the root causes of women's vulnerability to infection, under the leadership of the country's First Lady.

Globally, the Huairou Commission links grass-roots women's organizations to share resources, information, and political and community organizing strategies (Carpano, Izumi & Mathieson, 2007).

Stigma, discrimination, and vulnerability to HIV

Stigma, discrimination, and social marginalization are causes of HIV risk and vulnerability, and consequences of being HIV-positive. Human beings are inherently social animals, and their physical and psychological health is damaged when they are isolated and cut off from their social group (Jenkins & Sarkar, 2007).

Stigmatizing attitudes to HIV and those most at risk of HIV infection derive from two principal sources. The first is fear of contagion, which has been a source of disease-related stigma through the ages. The second is negative, values-based assumptions about people living with HIV, which fuels prejudice and discrimination (ICRW, 2006a). In some cases, discrimination against people living with HIV is enshrined in national and local laws. According to the European AIDS Treatment Group, 74 countries restrict the entry or stay of people based on their HIV status, including 12 countries that ban people living with HIV from entering for any reason or for any length of time.

HIV-related stigma and discrimination undermine HIV prevention efforts by making people reluctant to be tested (Ford et al., 2004; Wolfe et al., 2006; Ma et al., 2007; Pulerwitz & Barker, 2008); to seek out information about how to protect themselves from infection; and,

Stigma and discrimination

HIV-related stigma is defined as: "...a 'process of devaluation' of people either living with or associated with HIV and AIDS" (UNAIDS, 2003).

Discrimination refers to action based on stigma. HIV-related discrimination follows stigma, and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status (UNAIDS, 2003).

Discrimination against people living with HIV and those perceived to be living with HIV occurs within families and other social networks, and is often institutionalized. Examples of institutionalized discrimination include government laws, policies, and procedures that negatively target people living with HIV or groups perceived to be living with HIV, and discrimination in workplace settings or health-care settings. Omission can also be a form of discrimination where, for example, the needs and interests of people living with HIV or stigmatized populations are ignored or minimized.

Discrimination is a human rights violation and is prohibited by international human rights law. The Commission on Human Rights, now the Human Rights Council, has stated that discrimination on the basis of "other status" includes health status, including HIV.

⁶ For a discussion of the role of microfinance in mitigating the epidemic's impact on women, see Chapter 6.

in some cases, reluctant to use condoms for fear of being identified with the disease or with marginalized populations that are most heavily affected (Nyblade et al., 2003). Fear of stigma and discrimination also makes people living with HIV less likely to seek care and treatment, adhere to treatment, and disclose their HIV status to their sexual partners (White & Carr, 2005; Liu et al., 2006; Mills, 2006). In some cases, family members, caregivers, and the children of people living with HIV are also subject to discrimination and shame. Far too often, the health-care system itself—including doctors, nurses, and staff responsible for the care and treatment of people living with HIV—are prime agents of HIV-related stigma and discrimination (Reis et al., 2005; Mahendra et al., 2007; USAID, 2007a). In 2006, UNAIDS-facilitated consultations with civil society and government stakeholders in 122 countries consistently identified HIV-related stigma and discrimination as one of the top five barriers to achieving universal access to HIV prevention, treatment, care, and support.

Law can be a force to change or to legitimizing distinctions made about groups. Laws can protect people living with HIV from discrimination or can increase discrimination against them. For example, broadly applying the criminal law to HIV transmission sends the message that people living with HIV are potential criminals. The law can also protect other groups (e.g. men who have sex with men, drug users, or sex workers) from human rights violations, particularly violence, vilification, discrimination, and lack of due process. However, where the activities of some groups are criminalized (e.g. men who have sex with men, drug users, or sex workers) the law and its enforcement can become a major barrier to access and uptake of HIV prevention, treatment, care, and support. Institutionalized discrimination is also reflected in acts of omission, such as when the level of HIV resources directed towards the needs of men who have sex with men, injecting drug users, or sex workers is not commensurate with

local epidemiology, or when HIV surveillance systems fail to track such groups.

Reducing stigma, discrimination and social marginalization

Over the past few years, the harmful effects of stigma and discrimination have become even more clearly understood, and a growing number of institutions and organizations have focused greater attention on these effects. A number of successful approaches and strategies have emerged and are discussed below. Successful approaches include:

- preventing HIV-based discrimination;
- promoting HIV knowledge and awareness, tolerance, and compassion;
- increasing involvement and visibility of people living with HIV;
- scaling up treatment;
- prohibiting discrimination against populations most at risk;
- empowering the community among populations most at risk.

Preventing HIV-based discrimination

Legal protections against HIV discrimination are an essential prerequisite for a sound national HIV response. A large majority of countries (67%) report that laws and regulations are in place to protect people living with HIV from discrimination. Namibia's 2008 report to UNAIDS indicates that, following advocacy by the AIDS Law Unit, the Namibian parliament included HIV as a prohibited basis for discrimination in the country's Labour Bill passed in 2007. Laws in the Bahamas, Malawi, South Africa, and Zimbabwe prohibit mandatory HIV testing as a condition of private employment (Gable et al., 2007). Cambodia, Guyana, and other countries have laws specifying the right of people living with HIV to equal access to high-quality health care (Gable et al., 2007). However, the degree to which these laws are enforced or

Measuring stigma

As with gender inequality, a challenge to effective action to reduce stigma historically has been the absence of agreed methods for measuring stigma.

In more than 10 studies conducted over eight years, the Horizons project demonstrated that stigma and discrimination can be recognized and measured in widely diverse settings in Latin America, Asia and Africa. Focusing both on people who experienced stigma and also on “the stigmatizers”, Horizons developed a practical conceptual framework that applies in different cultural settings. This framework recognizes that people living with HIV struggle with internalized stigma (self-stigma), perceived stigma, and enacted stigma (discrimination).

In-depth qualitative research revealed that the problem becomes manageable, measurable, and changeable when it is broken down and addressed in four parts. The first part is to undertake formative research, which involves defining specific attitudes, beliefs and behaviours, and documenting the problem locally. This is essential for part two, which involves helping people to recognize the issue. Horizons’ baseline studies showed that people who discriminate and shame people they believe are associated with HIV often do not realize they are doing anything harmful. The third part is to provide accurate information on HIV and create a supportive environment, to counter the fear-based drivers of stigma (e.g. fear of infection through casual contact). The fourth part is to facilitate reflection on the social judgements that are entailed in HIV stigma (“blame and shame”), and to confront people with the fact that those judgements are often inaccurate and unfair to the realities of people affected (e.g. assumptions about reckless pleasure-seeking or sexual excess). An essential part of the strategy is to partner with people living with HIV as educators and facilitators. To guide and document these efforts, Horizons’ partners developed stable measures of stigmatizing attitudes (recognition, fear, and “blame and shame” components) events (isolation, verbal stigma, loss of identity and status, and loss of access to resources), and tools for measuring improvements in the environment that can be adapted and applied worldwide.

Building on a common knowledge base, other promising tools to track HIV-related stigma have been developed. People Living with HIV Stigma Index, developed by the Global Network of People Living with HIV/AIDS and the International Community of Women Living with HIV/AIDS, is being implemented in the Dominican Republic, and in Asia and the Pacific, with studies in additional areas planned for 2008 (IPPF et al., 2008a; IPPF et al., 2008b). Other indices have been used to measure stigma and discrimination among medical providers and within HIV facilities in Kenya (USAID, 2007b), India (Mahendra et al., 2006), and Ukraine (USAID, 2007a).

In 2007, Tajikistan undertook its first national effort to identify the level and types of HIV-related stigma and discrimination. Tracking HIV-related stigma is consistent with UNAIDS’ *Practical guidelines for intensifying HIV prevention*, which encourage policy-makers and programmers to “know your epidemic” and “match your response to the epidemic” (UNAIDS, 2007a).

to which people have access to them has not been documented.

Moreover, in the third decade of the epidemic, one third (33%) of countries still do not report having such laws. Though governments report a significant improvement in the availability of legal services for people living with HIV since 2003, nongovernmental informants indicate that less than half (47%) of countries reported the availability of such services in 2007 (UNGASS Country Progress Reports, 2008) for the nearly 9.6 million in need of treatment. Nongovernmental informants in three quarters of all countries (75%) report the existence of programmes designed to educate and raise awareness among people living with HIV of their human rights (UNGASS Country Progress Reports, 2008). The quality, scale, and coverage of such programmes have not been measured or evaluated.

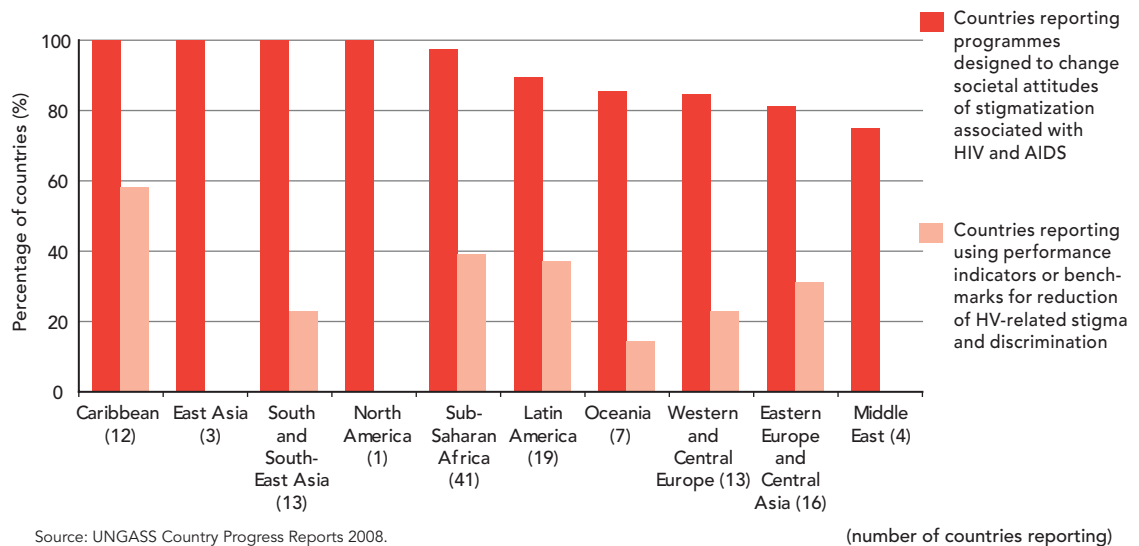
Prioritizing the reduction of HIV-related stigma and discrimination within a national HIV plan is important, but without a specific effort to track

stigma and discrimination over time, progress will be difficult, if not impossible, to measure. However, according to nongovernmental reports, only 33% of countries use performance indicators or benchmarks for the reduction of HIV-related stigma and discrimination (UNGASS Country Progress Reports, 2008;) (Figure 3.5). In early 2007, the Brazilian Government created a mechanism for confidential reporting to authorities of violations of the country’s law prohibiting HIV-based discrimination.

Similarly, nongovernmental informants indicate that countries have not systematically implemented mechanisms to report, document, and address cases of discrimination against people living with HIV or populations most at risk (UNGASS Country Progress Reports, 2008) (Figure 3.6).

Civil society can play an important role in enforcing antidiscrimination laws. In Belize, for example, the Alliance Against AIDS celebrated its 10th anniversary of work to reduce HIV-related stigma and discrimination in 2007. Over the last

FIGURE 3.5 Percentage of countries (by region) reporting programmes designed to change societal attitudes of stigmatization associated with HIV and/or using indicators for reduction of HIV-related stigma and discrimination



Source: UNGASS Country Progress Reports 2008.

(number of countries reporting)

two years, this nongovernmental organization has successfully united a broad civil society coalition to undertake intensified anti-stigma efforts, including a public awareness campaign highlighting continuing discrimination against people living with HIV in health-care settings.

Promoting HIV knowledge and awareness, tolerance, and compassion

Three root causes of stigma and discrimination that can be successfully addressed through programming include:

- lack of awareness and knowledge of stigma and discrimination and their harmful effects;
- fear of acquiring HIV through everyday contact with infected people because of lack of detailed knowledge and information;
- linking people living with HIV with behaviour that is considered improper and immoral (UNAIDS, 2008).

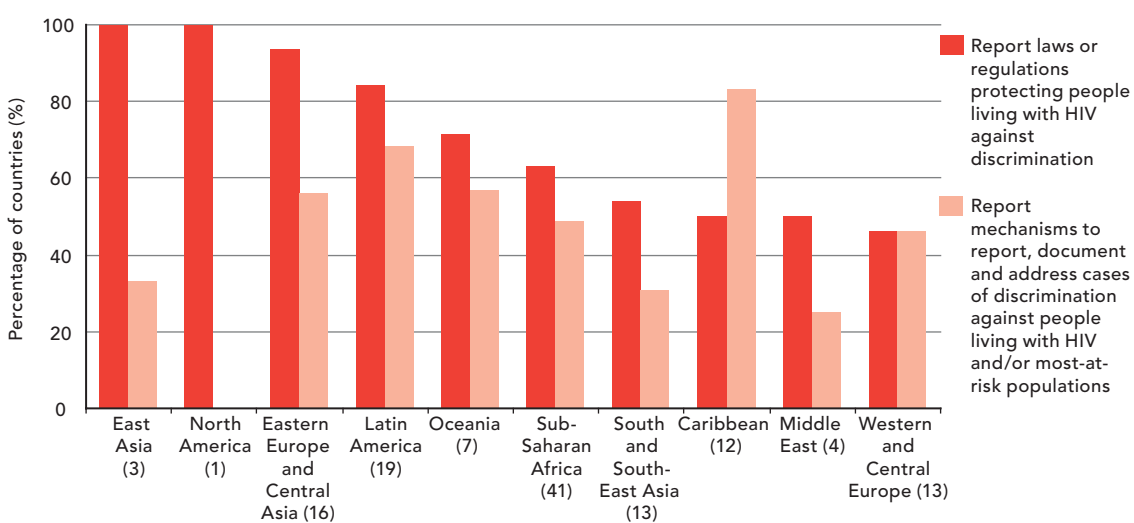
Programmes that address such issues should be an integral part of national strategic plans, and should be supported by other nongovernmental

stakeholders. Interactive programmes that foster greater understanding of the harm caused by stigma and discrimination are particularly effective. Active involvement of people living with HIV and of representatives from other affected populations in planning and implementation will help ensure that their needs are addressed.

Because stigma and discrimination are multifaceted, programmes to address these issues need to operate at various levels (individual, family, community, organizational, institutional, government, and legal) and use a range of approaches to engage many different groups. Successful programmes often include the following components: empowerment of people living with HIV, education about HIV, and activities that foster interaction between people living with HIV and key audiences, including policy-makers and high-profile celebrities (UNAIDS, 2008).

In India, researchers worked in partnership with national HIV authorities to implement an anti-stigma programme in three major hospitals where people living with HIV reported having been badly treated. After educating hospital staff

FIGURE 3.6 Percentage of countries (by region) reporting legal protections against discrimination and relevant mechanisms



Source: UNGASS Country Progress Reports 2008.

(number of countries reporting)

about the presence of stigmatizing attitudes, the programme implemented a series of policies that improved safety for providers (e.g. gloves, ready availability of post-exposure prophylaxis in case of blood exposure) and prohibited discriminatory practices, such as segregation or delay of treatment for patients with HIV. Selected staff members of all levels participated in interactive training workshops for two hours, every other day, for two weeks. All levels of hospital workers (from ward staff to department heads) were provided with information and the opportunity to participate in small-group discussions within the hospital. This multifaceted programme led to significant decreases in stigmatizing attitudes and practices by all levels of health-care workers, and to significant improvements in adherence to guidelines on confidentiality and informed consent for HIV testing and counselling (Population Council, 2006). Comparable improvements in quality of care were achieved in Viet Nam following implementation of an anti-stigma programme in four hospitals (Oanh et al., 2008).

National governments in nearly all countries (98%) report addressing stigma and discrimination as part of their national HIV strategy, including all countries with a generalized HIV epidemic reporting this data (UNGASS Country Progress Reports, 2008). Nongovernmental informants in the vast majority of countries (92%) say programmes are in place to change societal norms to reduce stigma and discrimination. Most of these efforts involve the use of various strategies including the media, school-based education, and personalities speaking out about AIDS (UNGASS Country Progress Reports, 2008). However, the UNGASS indicators do not measure the scale or effectiveness of such programmes.

The media can play a critical role in reducing HIV stigma and discrimination. In 2007, the Zambia National AIDS Network trained more than 300 journalists to report on HIV issues. Ghana's National Campaign Against HIV-Related Stigma, launched in January 2007,

Criminalization of HIV transmission

The recent increase in the use of criminal law in cases of HIV transmission where other, less punitive public health programmes would be more appropriate, is a dangerous trend that fuels the perception that people living with HIV are criminals, and undermines the goal of universal access (UNAIDS, 2002). Laws criminalizing HIV transmission exist at the national or subnational level in at least 36 countries (GNP+ & TGT, 2005; Chan, 2006; Burris, 2007; Klein, 2007; Pearhouse, 2007).

Though such laws may stem from frustration at the continuing high rates of new infections, they are short-sighted strategies that fail to give people any meaningful ways, legal or otherwise, to reduce their vulnerability to HIV. Investment in evidence-informed HIV prevention programmes for both HIV-positive and HIV-negative individuals is a more rational and effective way to reduce infection than implementation of laws criminalizing HIV transmission, which fan the flames of HIV stigma. Where countries retain criminal penalties for transmission, UNAIDS recommends that the criminal law only be applied to cases involving the *intentional* transmission of HIV, that is, where someone intended to transmit HIV, acted with such intent, and did transmit HIV.



Women and girls become sex workers for many different reasons.

included advertisements on national television and radio that asked, “Who are you to judge? People living with HIV are just like you”.

Greater involvement and visibility of people living with HIV

Silence, fear, and shame are some of the factors that enable HIV stigma and discrimination to flourish. To reverse these conditions, it is necessary to:

- promote the visibility of people living with HIV;
- ensure their integral involvement in the planning and implementation of strategies and programmes;
- invest in strategies that empower people living with HIV to work to change the social conditions that facilitate HIV stigma and discrimination.

Networks of people living with HIV can help to foster leadership; also, social mobilization coupled with legal advocacy, can enable social change. In South Africa, for example, the Treatment Action Campaign has used a supporting legal framework and strategic litigation to promote access to HIV treatment

(Heywood, 2002; Jones, 2005). In Malawi, the Malawi Network for People Living with AIDS and its many partners in the human rights field create awareness of people’s rights and of where to go for redress. In Belize, the Alliance Against AIDS has forged a broad-based alliance to advocate against stigma and discrimination in health-care settings, and to promote education on sexual and reproductive health.

Between 1996 and 2007, the Network of Zambian People Living with AIDS (NZP+) grew from 28 members to more than 50 000. NZP+ operates on an empowerment model, expressly rejecting the notion that its members are vulnerable “patients” who must depend exclusively on charity. Through more than 3000 self-help groups, NZP+ mobilizes its members to combat HIV stigma and to demand better access to high-quality services.

Unfortunately, in only 20% of countries do nongovernmental respondents indicate that civil society organizations have meaningful access to financial support (UNGASS Country Progress Reports, 2008). National governments and international donors should prioritize capacity-building to support networks of people living with

Increasing the visibility and involvement of people living with HIV in the UN system

UN Plus, the advocacy group of UN staff living with HIV, has significantly increased the visibility of people living with HIV in the UN system. Formed in 2005 to provide support and an effective voice for UN staff living with HIV, UN Plus developed an e-workspace to facilitate online discussions on relevant topics. UN Plus meets with decision-makers in the UN system to address key concerns of staff living with HIV. The group has also partnered with UN Cares, the system's HIV workplace programme, to ensure that all staff know the facts about HIV prevention, treatment, care and support, including the UN codes of conduct that require equal treatment and respect for all staff, regardless of their health status.

Hosted by UNAIDS, UN Plus helps other international organizations to establish and strengthen advocacy groups for HIV-positive staff. UN Plus is an example of "UN reform in action", in that it brings together staff from 37 countries in 27 different UN agencies and associated programmes.

HIV. In particular, donors should examine their decision-making processes to assess the degree to which they are helping to empower people living with HIV to lead the response to HIV. An instructive example is the Collaborative Fund for HIV Treatment Preparedness, a joint project of the Tides Foundation and the International Treatment Preparedness Coalition. Funding and policy decisions for the Collaborative Fund are made exclusively by people living with HIV, who work in regional groupings to identify funding priorities and project recipients for treatment preparedness work.

Scaling up treatment

In addition to saving lives and reducing suffering, public investment in antiretroviral treatment helps to mitigate HIV stigma by underscoring the value attached to the lives and well-being of people living with HIV, and reflecting the inclusion of HIV-positive people in the body politic. Scale-up of treatment increases incentives for people to be tested for HIV, which can in turn promote more open public discussion of HIV issues. A longitudinal study in Mombasa, Kenya, found that individuals on antiretroviral drugs had

lower levels of internalized stigma 12 months after starting therapy and were more likely to disclose their HIV infection to family members (Kaai et al., 2007).

However, introduction of treatment on its own is unlikely to eradicate negative attitudes towards people living with HIV. In the United States, for example, where HIV treatments have been widely available for more than a decade, 68% of Americans say they would be uncomfortable having an HIV-positive dentist, and 27% would prefer not to work closely with a woman living with HIV (Blumenthal, 2008).

Prohibiting discrimination against populations most at risk

Few countries report having non-discrimination laws or regulations that specify protections for populations most at risk of HIV. Nongovernmental informants in 26% of countries report the existence of laws that protect men who have sex with men; also, anti-discrimination laws for sex workers and injecting drug users are reported in 21% and 16% of countries, respectively (UNGASS Country Progress Reports, 2008). Figure 3.7

illustrates the legal and regulatory environment regarding non-discrimination in countries that reported good-quality coverage data for HIV prevention programmes serving different populations most at risk. Among countries submitting coverage data, the reach of HIV prevention programmes for populations most at risk is generally better in countries with non-discrimination laws in place than countries without such laws.

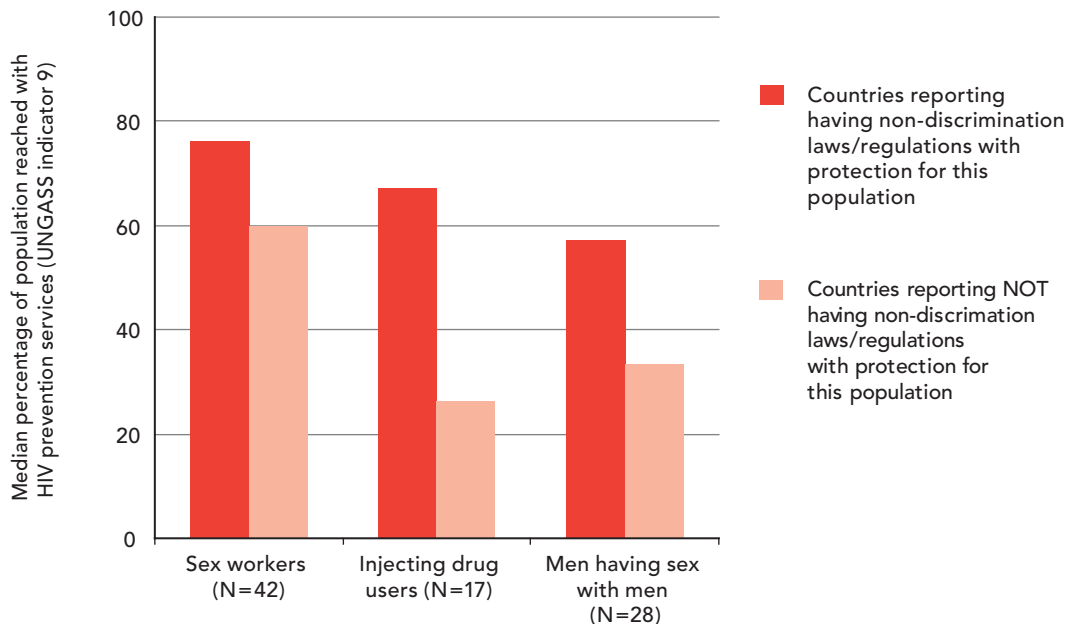
In addition, an international nongovernmental organization reports that, in 2007, 91 countries (mostly low- and middle-income) had laws prohibiting sexual activity between consenting adults of the same sex (Ottosson, 2007). Seven countries impose the death penalty for men who have sex with another man. However, in recent years, several countries have repealed

laws criminalizing same-sex sexual relations, sometimes in response to judicial rulings. In 2003, the Supreme Court of the United States struck down all state anti-sodomy laws on the grounds that they were a human rights violation under the country’s constitution. South Africa’s post-apartheid constitution specifically prohibits discrimination on the basis of sexual orientation (Gable et al., 2007).

Overall, nongovernmental sources report that a significant minority of countries have laws that interfere with their ability to provide services to injecting drug users (40%), men who have sex with men (32%), and sex workers (45%) (UNGASS Country Progress Reports, 2008).

Most jurisdictions worldwide prohibit the sale and purchase of sex, making protection of the human rights of sex workers (including

FIGURE 3.7 Median percentage of population reached with HIV prevention services within the specified legal environment



Source: UNGASS Country Progress Reports 2008.*

* Between one third and a half of the countries did not provide information on non-discrimination laws/regulations for most-at-risk populations. Information from NCPI: a different data set (from different countries) from that reflected in Figure 4.10.

Brazil without homophobia

In 2004, the Brazilian Government launched the “Brazil Without Homophobia” programme to reduce stigma and discrimination against people who engage in same-sex sexual activity. Building on the national commitment to address homophobia, the government launched a national initiative in 2008 to address HIV and sexually transmitted infections among men who have sex with men and transgender individuals. The 2008 initiative was prompted by the government’s concern over continued high infection rates among men who have sex with men, who accounted for 40% of all reported AIDS diagnoses among males between 2000 and 2005.

The initiative aims to involve civil society—as well as federal, state, and local governments—to address the role of stigma and discrimination in increasing HIV risk and vulnerability of Brazilian men who have sex with men. In mid-2008, the Brazilian President is convening the first National Gay, Lesbian, Bisexual, Transvestite and Transsexual Conference, to promote a national dialogue on homophobia and HIV. The 2008 initiative, which sets forth concrete targets to be achieved by 2011, will also be discussed.

their rights to HIV prevention, treatment, care, and support) a daunting challenge (Gable et al., 2007). Even where sex work is not prohibited, sex workers are often the target of police harassment. Since decriminalizing sex work in 2003, New Zealand has taken steps to promote condom use during sex work (Gable et al., 2007). A key aim of progressive legal reform for sex work is to reduce the stigmatization and harassment of sex workers, and to prevent workers from being placed in situations that threaten their health and safety. Some advocates for legal reform have favourably cited the “Swedish model”, which penalizes the purchaser of sex but not the sex worker. However, critics of this approach say that criminal surveillance and official harassment of sex workers continue under such laws (Open Society Institute, 2006a). Involvement and sensitization of police is a critical component of an effective long-term response that aims to increase sex workers’ access to HIV prevention, treatment, care, and support.

Hostility towards populations most at risk, often abetted by laws that do not expressly pertain to HIV, may undermine otherwise sound and progressive policy reforms. For example, Ukraine began implementing buprenorphine-based substitution therapy programmes for injecting drug users in 2005, but the continuing high prevalence of stigmatizing and discriminatory attitudes and practices stops many people from using these programmes. Stigmatizing and discriminatory practices include criminalization of drug use and requirements that users be registered in law enforcement agencies and health-care facilities. According to surveys of drug users and sex workers in Ukraine, police officers frequently harass outreach workers from harm-reduction projects, and health-care providers often actively discriminate against drug users. Many Ukrainian drug users avoid seeking treatment for their addiction or their HIV infection due to legal requirements that their names be reported to the police (Human



Building community among men who have sex with men in Burundi

Georges Kanuma is the president and founder of the Association for the Respect of Homosexuals' Rights in Burundi

Georges Kanuma was 18 years of age by the time he realised that he must be gay.

But most people in his home town of Bujumbura do not believe that there are African homosexuals. As a result, many gays and lesbians in Burundi suffer secret shame and isolation, and those who are open about their sexual orientation are discriminated against at every level of society.

These problems led Kanuma to start an organization called the Association for the Respect of Homosexuals' Rights (ARDHO), which now has 25 members. "We are here to demonstrate that homosexuality is an evident reality in Burundi," says Kanuma. "We founded ARDHO in order to fight for our social integration, to claim understanding from the society, and to fight against our marginalization, and [against] HIV/AIDS within our community."

In a hostile world, the association provides a supportive community. It also defies taboos by conducting HIV education and safer sex workshops, in which the risks of unprotected anal sex are openly discussed. The association has found that few men who have sex with men are aware of their physical vulnerability to the virus, wrongly believing that they can only be infected by penile–vaginal sex. "We try to organize information sessions on the ways of HIV infection and modes of prevention," says Kanuma. "We meet twice a month and we mobilize our homosexual fellows and our partners on the use of gel and of condoms."

The climate of homophobia seems to extend to other organizations involved in the response to HIV. Apart from UNAIDS, only two nongovernmental organizations support the association. This means that ARDHO remains unregistered, and experiences a continuing shortage of educational materials, condoms, and other resources. Targeted HIV services for men who have sex with men—particularly those who have suffered gender-based violence—are also much in need, but remain a distant dream.

All the members of the association have their own tales to tell about the stigma and discrimination that they have experienced. "Our parents refuse to pay for our school fees for example, and they refuse to take care of us when we are ill," says Flaviana, an association member. "Our brothers and sisters insult us and mock at us... and we suffer from this discrimination even at the work place. The religious people incite the population against us, saying we are a precursory sign of the end of the world."

One member of the group was beaten by his father and thrown out of the family home; another was forced to drop out of school because his teachers believed that he was cursed by God. Kanuma says that this kind of treatment leads to alcohol and drug abuse, which in turn increases the risk of HIV.

Despite all of these challenges, Kanuma and his friends are happy with their lives. "Finally I've got a boyfriend," he says, "I accept my life and I'm proud of it."

Rights Watch, 2006). However, experience in Asia demonstrates that anti-drug laws need not permanently prevent the introduction of harm-reduction programmes. Various countries including China, the Islamic Republic of Iran, and Viet Nam have recently introduced or expanded evidence-informed initiatives to prevent HIV transmission among injecting drug users (see Chapter 4).

As with HIV-based discrimination, enactment of laws prohibiting discrimination against the groups most at risk of HIV exposure should be supported by energetic efforts to enforce these laws. In Peru, for example, the national government has attempted to improve reporting and redress of violations under the country's human rights laws by mapping the determinants of stigma and discrimination against men who have sex with men, sex workers and prisoners, and capacity-building initiatives for subnational ombudsperson offices. However, nongovernmental informants indicate that a majority of countries in most regions lack mechanisms to record, document, and address cases of discrimination experienced by people living with HIV and populations most at risk of HIV. Countries in the Caribbean and Latin American regions are most likely to have such mechanisms in place (UNGASS Country Progress Reports, 2008).

Community empowerment among populations most at risk

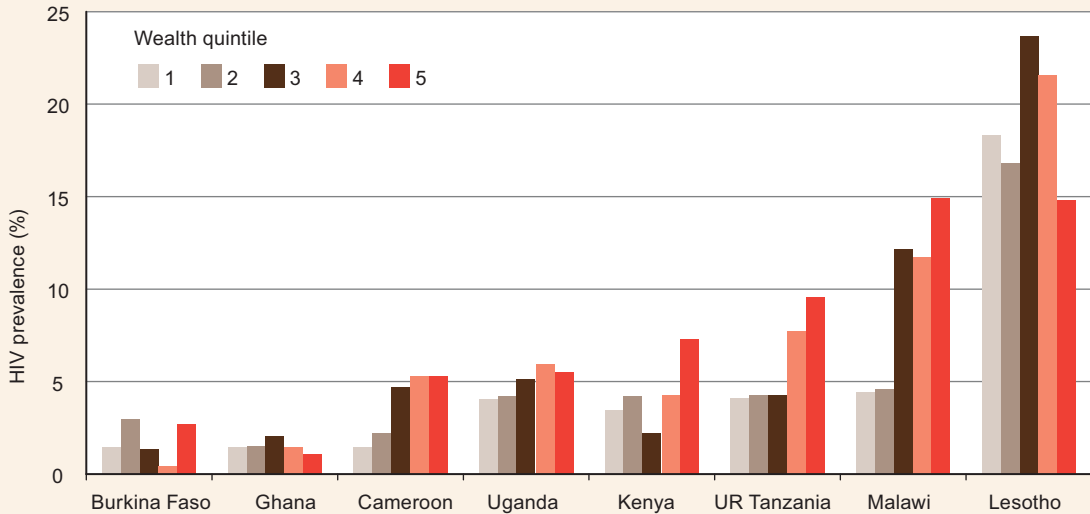
Access to social support—sometimes referred to as “social capital”—is vital to reducing vulnerability of marginalized or disempowered groups. In nearly all countries where the HIV epidemic has been reversed, grass-roots community mobilization was at the heart of the national HIV response (Merson, 2008). However, not all countries have a tradition of community engagement and empowerment. In populations whose risk behaviours may be criminalized, there is little capacity to mobilize in response to the epidemic. Despite these obstacles, communities across the globe have organized to address

the HIV challenge, often with few resources and at considerable risk to the individuals involved. International donors have been slow to support these efforts, highlighting a serious gap in the global HIV response that should be rectified.

The situation with sex workers exemplifies the need for social support. Hundreds, perhaps thousands, of grass-roots groups and nongovernmental organizations either represent or serve sex workers throughout the world. In general, however, financial support for these groups is scarce, although certain funders have prioritized assistance for community-building, mutual support, and advocacy activities among sex workers (Open Society Institute, 2006b). HIV prevention funding has supported programmes to reach sex workers in all regions, but often such programmes are not run by and for sex workers (Open Society Institute, 2006a). Some HIV-prevention initiatives that focus on sex workers have primarily regarded workers as “vectors of transmission”, but the most successful initiatives have empowered sex workers. For example, the Sonagachi project in Calcutta, India, which used an empowerment approach to strengthen health services for sex workers, was associated with significant increases in condom use and declines in incidence of HIV and sexually transmitted infections (Pardasani, 2005; Jenkins & Sarkar, 2007). Unfortunately, the laws of national governments and rules of multilateral organizations often make it difficult to register nongovernmental organizations representing sex workers (Open Society Institute, 2006a).

In high-income countries in the epidemic's early years, gay men were able to build strong community-based responses to HIV based on community infrastructures that existed before the HIV epidemic (Shilts, 1987). Group consciousness and community organization among men who have sex with men are increasing in many countries, but community infrastructures remain weak in most low- and middle-income countries, especially in

FIGURE 3.8 HIV Prevalence by wealth status: men



Source: Mishra V, Bignami-Van Assche S, Greener R, Vaessen M, Hong R, Ghys P, Boerma T, Van Assche A, Khan S, Rutstein S, "HIV infection does not disproportionately affect the poorer in sub-Saharan Africa", 2007, AIDS, Vol 21 Supplement 7, November 2007

Poverty, income inequality and vulnerability to HIV

The relationship between socioeconomic status and health is well documented, with higher income individuals generally enjoying better health status than those with lower socioeconomic status. This has been shown to be the case for most measures of health, including nutrition, morbidity and mortality, and for health-care use. Variations in health status often run along a gradient, with individuals in each successive income level having better health than those directly below them (Marmot, 2006; Commission on the Social Determinants of Health, 2007).

HIV has no socioeconomic boundaries; however, the vast majority of people living with HIV in the world are in low- and middle-income countries, and poorer regions of the world bear a substantially greater burden of HIV disease. For example, sub-Saharan Africa—which has one of the highest rates of extreme poverty in the world—is home to just over 10% of the world’s population but accounts for more than two thirds (68%) of all people living with HIV (Population Reference Bureau, 2007; UNAIDS, 2007d). More than 40% of the region’s population live on less than one US dollar per day (Chen & Revillon, 2004).



The disproportionate burden of HIV in low-income countries, and the more severe impact of the disease on poor households, often lead to the assumption that HIV is a “disease of poverty”, and that poor people are at greater risk for infection. In fact, the relationship between absolute poverty and risk of infection is more nuanced, being also highly dependent on context.

In sub-Saharan Africa, for example, HIV prevalence is highest not in the poorest countries, but in two of the wealthiest—South Africa and Botswana—where prevalence is 18.8% and 24.1%, respectively (UNAIDS, 2007b). In this same region, a recent analysis of eight national surveys found greater HIV prevalence among adults with higher levels of wealth than among those with the lowest levels of wealth (Mishra et al., 2007) (Figure 3.8). This finding is tied to the fact that wealthier and better educated individuals tend to have greater sexual autonomy and higher rates of partner change (due to their greater mobility) and greater likelihood of living in cities (where HIV prevalence is generally higher) (Gillespie, Kadiyala & Greener, 2007). These findings highlight the importance of prevention strategies that target all socioeconomic strata.

Some researchers speculate that this dynamic may be shifting in later stages of the epidemic, because wealthier individuals are more likely to have access to HIV prevention information and condoms, and to adopt behaviour changes (Lopman et al., 2007). A recent review of the relationship between educational attainment and risk of HIV documents a shift over time towards higher HIV prevalence among the least educated in sub-Saharan Africa (Hargreaves et al., 2008).

Although poorer individuals, as a group, are not necessarily at greater risk of infection, there are situations where the combination of gender and poverty confers risk. For example, food insecurity is associated with increased chances of risky sexual practices among women, including increased likelihood of selling sex for money or resources, and of engaging in unprotected or intergenerational sex (Weiser et al., 2007). Women who are poor or economically dependent on their male partners may also be less likely to avoid or leave a relationship that threatens them with infection.

Other studies point to a potential relationship between income inequality and HIV risk, with greater risk (as measured at the population level by HIV prevalence) in countries with more income inequality (Gillespie, Kadiyala & Greener, 2007; Piot, Greener & Russell, 2007). The exact pathways through which income inequality contributes to HIV risk and vulnerability—and, indeed, whether such a causal relationship exists—are still not fully understood. However, some researchers suggest that income inequality may reflect the level of social cohesion in a society, with greater income disparities reflecting greater social stratification between socioeconomic groups. Additional subnational and community-level research is required before sound policy formulation in this regard would be possible.

settings where homosexuality remains highly stigmatized. In 2005, funding for lesbian, gay, bisexual, transgender, and intersex organizations in low- and middle-income countries totalled less than US\$ 10.5 million (Funders for Lesbian and Gay Issues, 2007). In 2005, the average annual budget for such organizations in low- and middle-income countries was US\$ 7600. In a global mapping exercise, Latin America accounted for more than half (54%) of lesbian, gay, bisexual, transgender, and intersex organizations identified in low- and middle-income countries (Funders for Lesbian and Gay Issues, 2007).

Among drug users facing the world of HIV initiatives, the slogan has become “Nothing About Us without Us” (Canadian HIV/AIDS Legal Network 2008). Community empowerment initiatives can help drug users, and their advocates and service providers, to overcome institutional barriers to service access. In the Philippines, for example, early support for a peer-based initiative of drug users from the International HIV/AIDS Alliance and the Philippine NGO Support Programme was leveraged to obtain longer-term support from the Global Fund. The project trains injecting drug users as harm reduction advocates, and promotes alliances with local government officials. In addition to providing sterile needles, and condoms, the project has formed a peer educator group that has helped bring drug users out of the shadows, and has increased public awareness and acceptance of harm reduction services. Although quantitative data on the project are still limited, the number of local 'shooting galleries' has dramatically declined since the project began, and the visibility of current and former drug users has significantly increased.

Leadership for change

It has long been recognized that the response to HIV must be both evidence-informed and rights-based. In this regard, the HIV epidemic has shown time and again that effective responses are those that also empower individuals and groups through the realization of their human rights—the rights to education, expression, privacy, health, and gender equality, and the rights to freedom from discrimination and gender-based violence. But changing harmful gender norms to reduce vulnerability to HIV, and eliminating stigma and discrimination, will require bold leadership on the part of many stakeholders. Issues that are often considered private or secretive must be brought out into the open and discussed, and laws, government policies, and programme priorities may need to change. In particular, women, young people, people living with HIV, and key populations at risk—particularly men who have sex with men, sex workers, and injecting drug users—need to have a more meaningful role in collaborative decision-making, planning, and continued monitoring of progress towards the goal of universal access.

There is an urgent need to develop greater technical capacity on issues of gender and human rights, to move from conceptual support for a rights-based approach to practical implementation of such an approach. The adoption of policies to address these societal level causes of HIV vulnerability is an important first step. However, it is ultimately the allocation of sufficient resources and the use of proven programmes (including social change communication strategies to change social norms) that will determine success.

Implementation will require a long-term view of the epidemic, recognizing that the impact of some programmes will only be measurable over time. Existing efforts to integrate HIV programming into broader poverty alleviation and development frameworks must also be accelerated. There is also important synergy to be gained from stronger partnerships between those working in the field of HIV and others working on human rights, including the rights of women and children.

At the national level, the prioritization of vulnerable populations may lead to calls for shifts in funding between programme areas or populations, and for the implementation of strategies that not only have an impact on HIV but also on society as a whole, and may therefore be considered politically controversial.

However, the use of HIV funding on strategies that do not go to the core of HIV vulnerability and risk among women, young people, people living with HIV, and key populations at risk is inefficient, and it is this approach that should be considered most controversial.

Emerging evidence from the field has helped to identify effective strategies for reducing gender inequality and HIV-related stigma and discrimination. These factors are outside the direct control of the individual, but have a profound effect on HIV risk and vulnerability. In the past few years, understanding of the complex association between HIV, income inequality, and poverty has also evolved. More research and additional models of successful programmes are needed, but the time for action is now.

Social change communication

Social change communication involves the strategic use of advocacy, communication, and social mobilization strategies to facilitate or accelerate social change. In the context of HIV, Social change communication strategies can help to change underlying social attitudes and behaviours that contribute to HIV risk and vulnerability.

Successful communication programmes blend mass media approaches, community engagement strategies, and empowerment strategies with other forms of informational and motivational communication and advocacy. The goal of Social change communication is to act as a catalyst for action at the individual, community, and policy levels.

Social change communication programmes work. They have been rigorously evaluated and have been shown to make significant and durable change in deeply rooted practices. In August 2007, UNAIDS held a Technical Consultation on Social Change Communication to develop a better understanding of the role of Social change communication in the global response to HIV (UNAIDS, 2007e). In 2008, UNAIDS will develop practical guidance and technical support on Social change communication for national AIDS programmes.

Source: Based on a UNAIDS definition of social change communication developed with a group of international stakeholder during a Technical Consultation in August 2007. The meeting report and a background discussion paper are available online at <http://www.unaids.org>.

Evidence for action

Are the right actions being taken?

- A total of 80% of countries specifically address women as a component of their national HIV strategy, and 83% of countries report having a policy to ensure equal access for women and men to HIV services.
- About two thirds (67%) of countries report have laws protecting people with HIV from discrimination.
- A majority (67%) of countries report having laws, regulations, or policies that provide protection against anti-discrimination to people living with HIV.

Are the right actions being undertaken in the right manner?

- Only about half (53%) of countries report budget allocations specifically devoted to HIV-related programmes for women and girls.
- Less than half (47%) of countries report supporting the provision of legal services to assist people living with HIV in enforcing their rights under anti-discrimination protections.
- Nearly two thirds (63%) of countries report having laws, regulations, or policies in place that impede access to HIV prevention, treatment, care, and support among populations most at risk.

Have these actions been sufficiently scaled up to make a difference?

- Civil society organizations have meaningful access to financial assistance in one in five countries.
- Few countries have legal protections for the populations most at risk of HIV infection. A total of 26% of countries report having laws that protect men who have sex with men, 21% have anti-discrimination laws for sex workers, and fewer than one fifth (16%) protect injecting drug users from discrimination.
- There is still insufficient data on the scale, quality, coverage, or impact of the programmes reported by countries above.

Source: UNGASS Country Progress Reports, 2008.

Camp Goodtime



"I'm not like other schoolgirls", says Stephanie, an Australian teenager living with HIV. "Well, I am... but I also have to deal with secrecy, discrimination, uneducated attitudes at school, what to tell my negative friends, and the constant fear of being found out..."

Stephanie was born with HIV when Australia was in the grip of terror about the condition. Although a first-rate medical system has kept her healthy and strong, she has suffered at the hands of an otherwise caring community.

"For any teenager, high school is hard, but the cloud of secrecy looms over my head every day", she says. "A fairly normal activity for an Aussie teenager—sleeping over at a friends' house—demands more consideration than simply packing pyjamas and a toothbrush. It becomes a major issue, with having to hide medications from friends and their family."

At school, Stephanie has experienced the full extent of people's fear and ignorance about HIV—from cruel jokes to active discrimination. At her previous high school she disclosed her HIV status to the Vice Principal and was told that unless she informed the whole school, she would have to leave. So she left—but not before the staff was informed of her HIV status.

"There are many heart-breaking stories of little kids being humiliated because of a disease they inherited. But the HIV teenagers of Australia are not going down without a fight", she says. "The very fact that people like me are still here shows that people with HIV are some of the strongest people in the world..."

There is only one brief period in the year when Stephanie does not have to fear discrimination: that is when she goes to Camp Goodtime, the annual national camp for HIV-positive children and their families. "There is nothing like the bond between positive teenagers. When we get together there is no stopping the laughter, tears, support, and stories of past camps and members who have died", she says.

The camp means more to positive teenagers than their medicine. "Camp Goodtime means acceptance, love... and the power of being able to speak freely, without fear", she says.

Stephanie feels that she owes her survival to the camp, and to the support and strength she has received from her mother and HIV-positive friends. An inspired mentor who introduced her to a support group for HIV-positive women also helped her define her role as an advocate for teenagers living with HIV. "She opened my eyes to making the change for yourself instead of waiting for someone else to."

When she was 15 years old Stephanie addressed a group of HIV-positive women at the International Women's Summit. She challenged them with the words "My name is Stephanie. I have lived through the war of HIV and I have something to say to the world. Do you?"

