



Commonwealth Secretariat Health Updates

HIV/AIDS and stigma and discrimination: the need for leadership An update for World AIDS Day 1st December 2008

Overview

It is increasingly acknowledged that confronting the stigma and discrimination surrounding HIV/AIDS is an essential step in both achieving Universal Access of people living with AIDS to drug therapy, and increasing the scope and effectiveness of prevention campaigns. The social barriers of stigma and the legal barriers of discrimination can often result in people living with HIV/AIDS being unable to access anti-retroviral (ARV) drug therapy, even if expansions in health care facilities and improvements in drug distribution mean that drugs are available for them. Confronting these social barriers demands a different approach to the more traditional dimensions of the fight against HIV/AIDS, such as developing new and effective drugs, improving health facility coverage and tackling international pharmaceutical regulation to make ARVs more affordable. Above all, addressing these social challenges demands leadership; leaders who take a stand against stigma, decrying the social inequalities from which it often originates, and leaders who are prepared to challenge policies and legislation which often represent the enactment of this stigma. The Commonwealth Secretariat is therefore glad that with the theme for this year's World AIDS Day being 'Leadership' the spotlight will be on this critical issue in the fight against HIV/AIDS.

1. What is HIV/AIDS stigma and discrimination and what are the impacts?

Stigma refers to negative beliefs and attitudes while discrimination refers to

actions or omissions, for instance in policy or legislation, and can be described as the enactment of stigma. Stigma and discrimination are related and are the consequence of widespread social inequality which gives credence to the idea that inequalities are reasonable and therefore acceptable. Stigma associated with HIV/AIDS often both creates and strengthens existing social inequalities (1,2,3,4,5). This is especially true for inequalities based on gender, sexuality and race and ethnicity (6). HIV/AIDS related stigma and discrimination build upon and reinforce existing prejudices against men who have sex with



men (MSM), sex workers (SW), and injection drug users (IDUs).

HIV/AIDS related stigma and discrimination continues to present an enormous barrier to effectively fight the HIV/AIDS epidemic. Fear of discrimination often prevents people from seeking treatment for AIDS or from admitting their HIV status publicly (7). People with or suspected of having HIV may be turned away from healthcare services, employment or even refused entry into a foreign country (9). In some cases they may be evicted by their families and rejected by their friends and colleagues, which in some instances extends to the next generation. This impact is especially strong in small states

Key Points:

Stigma and discrimination act as barriers to treatment and testing

Coherent cross-sectional planning is required to challenge negative attitudes and reduce stigma

Legislative action can be an important approach for challenging discriminatory laws, however enforcement of any new laws or policies is essential

Strong leadership at all levels is required to achieve a reduction in stigma and discrimination.



and jurisdictions where people live in tight-knit communities.

2. Approaches for overcoming HIV/AIDS stigma and discrimination

2.1 Challenging attitudes and overcoming stigma

As highlighted above, stigma surrounding HIV/AIDS can have a number of negative impacts, from jeopardising the health and treatment outcomes of those living with AIDS (knowingly and unknowingly), to the social isolation and strain encountered by those living with AIDS and their families who are stigmatised in their community. Such negative attitudes therefore impact on interpersonal relations and individual decisions (for instance in a person's decision to seek HIV testing or to access treatment), but they can also influence legal and policy decisions which influence the experience of people living with HIV/AIDS. Conversely, existing laws and policies can also influence the attitudes people adopt towards the disease and those living with the disease, with punitive laws such as the criminalisation of HIV transmission and the criminalisation of some sexual relations likely to be viewed as legitimising the stigma.

Reducing stigma surrounding HIV/AIDS therefore demands changing attitudes. Possible approaches for stigma reduction include:

- The creation of awareness-raising programmes;
- Addressing inequality through interactive and inclusive education;
- Empowering marginalised groups and enabling them to take the lead in support and advocacy;
- Mobilising religious and community leaders to foster openness and respect;
- The provision of integrated care for people living with HIV/AIDS, such as national AIDS programmes.

Furthermore, with the connection between stigma and discriminatory laws and policies, stigma reduction also requires enforcement of existing positive anti-discrimination and public health laws and challenging existing discriminatory laws.

Box 1: Successful stigma reduction campaigns

In 2004 Lesotho became one of the first countries to launch a nationwide effort to test its entire population, an initiative dubbed the 'Know Your Status Campaign' (KYS). This campaign sought to reduce the stigma surrounding HIV/AIDS and the resulting reluctance of the population to undergo HIV testing. The KYS review indicated that the campaign had been successful in reducing stigma and in encouraging individuals to seek HIV testing, with over 240,000 individuals in 2007 being identified as HIV+ following increased number seeking testing, compared with only 50,000 people in Lesotho being aware of their HIV status in 2004.

2.2 Challenging discrimination

Efforts to address discrimination are more challenging. Such efforts aim to de-institutionalise discrimination through the implementation of non-discriminatory policies, professional codes of conducts, training and education of employers and employees and of those in similar positions. Other approaches to address HIV/AIDS discrimination include the use of legal action to challenge discrimination and human rights violations in various arenas or ensuring there is some form of redress, the establishment of rights awareness programmes, and raising the awareness of people living with HIV/AIDS to their rights.

Some improvements in policies, laws and regulations promoting and protecting the rights of people living with HIV/AIDS have occurred in Commonwealth countries; however, still half of all countries submitting reports for the 2006 Report on the Global AIDS epidemic acknowledged the existence of policies that interfere with the rights of certain people to HIV prevention and care measures. These include amongst others: laws criminalising consensual sex between adult males, prohibiting condom and needle access for prisoners, or using residency status to restrict access to prevention and treatment services (7).

There is a growing recognition that legal measures should be utilised to promote and protect the human rights of people living with AIDS, in particular those who are members of vulnerable groups (including women and



children, men who have sex with men (MSM), injection drug users (IDU) and sex workers (SW).

Identifying which legal measures are appropriate will vary between countries, depending on what legal barriers or anti-discrimination legislation currently exists and what the status of enforcement is. An assessment of the legal challenges surrounding HIV/AIDS that exist nationally is needed to recognise specific areas for action. Depending on the challenges it might be appropriate to enact new legislation to protect the vulnerable groups, or to review and amend existing legislation, or to review and amend the enforcement of existing legislation. It is worth noting that according to UNAIDS, in many cases existing national laws and regulations to protect people living with HIV from discrimination have not been fully implemented or enforced, due to lack of budgetary allocations (7).

Traditionally, interventions in the area of reforming policies and laws often have focused on one particular issue such as the right to treatment, the decriminalisation of sex work, homosexuality, drug use, birth registration, the inheritance rights of orphans and widows, or property rights of women.

Box 2: Successful legal challenges to HIV/AIDS discrimination

In South Africa several non-governmental organisations used the judicial system to successfully challenge the government to make treatment available to those who need it.

In Namibia the AIDS Law Unit successfully challenged the Namibian Defence Force's policy of pre-employment testing and excluding HIV-positive people from employment (5,6).

3. The need for leadership

The theme for the 2008 World AIDS Day is 'Leadership'. The World AIDS Campaign in selecting this topic have stated that "Leadership must be demonstrated at every level to get ahead of the epidemic – in families, in communities, in countries and internationally" (8). Leadership at all levels is of crucial importance for addressing the stigma and discrimination surrounding HIV/AIDS. In the case of addressing HIV/AIDS stigma and discrimination there are four categories of leader-

ship that have particular potential for impact: political leaders, community/religious leaders, lawyers and civil society.

Through their social standing, political leaders, community leaders and religious leaders have the potential to influence social attitudes towards HIV/AIDS. These leaders should therefore use their position to challenge stigma and discrimination towards people living with HIV/AIDS, and to advocate for change.

In recognition of the pivotal role that legislation plays in creating or overcoming stigma and discrimination, lawyers also have a responsibility to act. Lawyers and their professional organisations are important actors for ensuring the enforcement of laws and the redress of discrimination. Interventions should therefore focus on training and supporting lawyers and lawyers' collectives in developing their approach to human rights and HIV/AIDS or creating collectives specialising in HIV/AIDS related concerns. The Lawyers Collective in India, for example, successfully defended the rights of people living with HIV/AIDS and marginalised groups before court on numerous occasions (5).

Finally, it has been evidenced in several examples of successful legislative interventions that civil society organisations, in particular organisations composed of individuals living with the disease, are powerful actors for challenging discriminatory laws and legislation. There have been examples in which groups working for the rights of HIV/AIDS patients have effectively used domestically ratified international conventions to challenge discriminatory legislation or where groups have collected and conveyed evidence on the impacts of human rights violations against those living with HIV/AIDS to policy makers. In addition to their advocacy role, some civil society organisations offer community based legal services and paralegal counselling which both provide legal advice but also encourage a greater understanding among people living with HIV/AIDS of their legal rights.



4. Conclusion

The various approaches to addressing HIV/AIDS stigma and discrimination are mutually reinforcing. Broad based strategies, which promote an enabling environment, de-institutionalise discrimination, reduce stigma and empower people living with HIV/AIDS and marginalised groups, are central to reducing stigma and discrimination. Leadership at all levels to advocate for and operationalise these strategies is also pivotal. On this World AIDS Day 2008 we therefore call for leaders at all levels to recognise the impact of stigma and discrimination on the health and well-being of people living with HIV/AIDS and their friends and families, and to take up their active role in addressing these barriers.

References:

1. Brown, e.a., *Interventions to Reduce HIV/AIDS Stigma: What have we learned?* 2001 Population Council Inc;

2. Hackett, e.a., *Champions for Change; Reducing HIV/AIDS Stigma and Discrimination in the Caribbean, Caribbean Community*. 2005, Georgetown, Guyana: Secretariat/Pan Caribbean Partnership Against HIV/AIDS

3. Nyblade, L., *Disentangling stigma to find entry points for intervention*, in *Sexual Health Exchange*. 2004;

4 Parker, R. and P. Aggleton, *HIV/AIDS-related Stigma and Discrimination: A conceptual Framework and an Agenda for Action*. 2002, Population Council Inc;

5. UNAIDS, *HIV-related Stigma, Discrimination and Human Rights Violations; Case studies of successful programmes*, in *UNAIDS Best Practice Collection*. 2005, UNAIDS: Geneva, Switzerland;

6. UNAIDS and WHO, *Fighting HIV-related Intolerance: Exposing the links between Racism, Stigma and Discrimination*. 2002.

7. UNAIDS, *2006 Report on the Global AIDS epidemic*. 2006, UNAIDS: Geneva

8. http://www.unaids.org/en/KnowledgeCentre/Resources/FeatureStories/archive/2007/20070316_WAD_Theme_2007.asp

9. <http://www.worldaidscampaign.org/en/Thematic-Campaigns>

Authors: Dr Joseph Amuzu & Victoria Hall

Health Section, Social Transformation Programmes Division
Commonwealth Secretariat
Marlborough House
Pall Mall, London, SW1Y 5HX

For more information please contact:

Hamida Gulamabbas
Programme Assistant
Phone: 020 7477 6286
Fax: 020 7747 6287
Email: h.gulamabbas@commonwealth.int