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HIV and AIDS REPORTER: focus on stigma 20 March 2007

produced by the [IDS Health and Development Information](#) team in collaboration with [Eldis](#) and the [DFID Health Resource Centre](#)

This is our monthly email bulletin, bringing together research to inform policy debates on health in developing countries.

The HIV and AIDS Reporter aims to provide readers with a more in-depth look at a particular area of health policy. This month's theme is **stigma**. The bulletin also features summaries of new documents and other additions to the [HIV and AIDS Resource Guide](#).

[HIV and AIDS Reporter archive](#) - an archive is now available on the HIV and AIDS Resource Guide. See previous issues of the HIV and AIDS Reporter at <http://www.eldis.org/health/archive.htm>

All documents listed below are available free on the web. If you are unable to access any of these materials online and would like to receive a copy of a document as an email attachment, please contact i.young@ids.ac.uk.

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Feature: stigma

There is increasing recognition that prevention, treatment, care and impact mitigation must be planned and delivered with the full inclusion of people living with and affected by HIV. However, as a result of HIV-related stigma, many people still feel unable to disclose their HIV status and to participate in HIV programmes or use HIV services. Case studies and testimonies collected by the [International HIV/AIDS Alliance](#) shows that many people living with HIV and AIDS (PLHA) experience violence and aggression within families, violence and extortion by the police and discriminatory treatment in accessing health services as a direct result of their HIV status.

HIV-related stigma is highly complex and deeply ingrained in social values and inequalities. It is based on fear and ignorance about HIV and AIDS and is also linked to fear, ignorance or prejudice towards the groups most affected by HIV, such as men who have sex with men, sex workers and injecting drug users. HIV-related stigma is also exacerbated by existing inequalities and prejudices surrounding issues such as gender, age and poverty. While HIV-related stigma can result in discrimination towards PLHA, [the Policy Project](#) describes how PLHA can also internalise HIV-related stigma. Internal stigma -also described as felt, imagined, or self stigma - is the product of the internalisation of shame, blame, hopelessness, guilt, and fear of discrimination associated with being HIV-positive. This internalisation can result in people not accessing treatment and other services, or not adhering to treatment regimes if they begin them. It can also lead to PLHA becoming isolated, avoiding emotional or sexual relationships or even feeling disempowered and unable to negotiate safe sex.

Stigma can also act as a barrier to people's ability to network, organise and participate the responses to HIV and AIDS. Already under-represented in decision-making processes, further marginalisation acts as a viscous cycle, making the experiences of PLHA invisible to policy and decision makers. However, experience has shown that when PLHA and other relevant communities are involved in responses to the epidemic, they are often the most effective actors in the response with expertise of lived experience and the ability to reach people who are hard to reach.

Combating stigma is an ongoing process and much more needs to be done to understand how it is experienced, how this impacts on the epidemic and how to fight it. [ICRW](#) suggests that, in order to address stigma and to overcome the social fears that perpetuate it, it is critically important to involve PLHA, who have the unique experience and knowledge necessary to design appropriate stigma-reduction responses. They also argue that work needs to be done with communities, health care providers and the media to develop, test and evaluate stigma-reduction efforts.

For more information see:

- International HIV/AIDS Alliance focus on Stigma www.aidsalliance.org/sw45398.asp
- Stigma related studies and resources from the Policy Project

www.policyproject.com/stigma/

- ICRW resources on stigma and HIV
www.icrw.org/html/specialevents/stigmaevent-toronto.htm/
- Eldis Gender & HIV Dossier: Stigma
www.eldis.org/gender/dossiers/stigma.htm
- HIV and AIDS Resource Guide: Stigma and discrimination
www.eldis.org/hivaids/citizenship/stigma.htm

Recommended readings on stigma

1. Stigma, scale-up, and treatment governance: stumbling block or window of opportunity?

Authors: Stephens, D.

Policy Project, Futures Group, Washington, 2006

This paper from the POLICY Project examines the problems and opportunities associated with the current expansion of access to anti-retroviral therapy (ART) for people living with HIV. The paper outlines a treatment governance approach to the development of ART services and draws on research from Vietnam to illustrate the importance of encouraging the participation of those living with HIV in the development of treatment policies. Treatment governance stresses the importance of monitoring and managing the impact of ART. This means strengthening comprehensive treatment monitoring, encouraging multisectoral collaboration and using an interdisciplinary approach to the management of treatment services.

The expansion of access to ART services creates particular challenges and opportunities concerning anti-HIV stigma and discrimination. There is no evidence that the wider availability of ARV automatically lessens anti-HIV stigma, and there is in fact an increased potential for people to be stigmatised and discriminated against since accessing treatment involves disclosing one's status. However, the shift from HIV being a fatal to a chronic illness, and the ability of people with HIV to continue working and maintain other social activities, should decrease the levels of stigma. But the potential for increased access to treatment to effect these changes in stigma depends on the effectiveness of the treatment governance, and in particular such factors as the quality of the service and the integration of HIV positive people into the process of developing and managing the service.

Available online at: <http://www.eldis.org/cf/rdr/rdr.cfm?doc=DOC23939>

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2. HIV/AIDS stigma: finding solutions to strengthen HIV/AIDS programs

Produced by: ICRW / International Center for Research on Women (ICRW), USA, 2006

AIDS related stigma has pernicious effect on the epidemic's prevention. Fear of stigmatisation dissuades people from seeking help from treatment, care and support services. What factors perpetuate and contribute to stigma against those infected with HIV/AIDS? Contrary to common assumption, this report finds that causal factors of AIDS stigma were similar across all four countries studied - Ethiopia, Tanzania, Vietnam and Zambia - and that woman bore the brunt of it.

Recommendations to address stigma and overcome social fears that perpetuate it include:

- build knowledge about HIV and AIDS and provide information on how HIV is not transmitted
- create stigma-free messages and safe discussion spaces to delink HIV from social taboos involve infected persons, as they have unique experience and
- knowledge necessary to design appropriate stigma-reduction responses
- measure stigma quantitatively
- work with communities, healthcare providers and the media to develop, test and evaluate stigma-reduction efforts ICRW and its partners have also developed an HIV stigma-reduction toolkit based on this report

Available online at: <http://www.eldis.org/cf/rdr/rdr.cfm?doc=DOC23134>

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3. A closer look: the internalization of stigma related to HIV

Authors: Brouard, P; Wills, C

Produced by: Policy Project, Futures Group, Washington, 2006

This report from the USAID-funded POLICY project examines the internalised stigma experienced by people living with HIV (PLHA). It presents findings from the Siyam'kela project in South Africa and the Mo Kexteya project in Mexico. These initiatives were established to study stigma and discrimination experienced by PLHA, and those affected by HIV, and to develop guidelines for mitigating its effect. A key objective was to develop indicators that can be used by programme managers to measure stigma and discrimination and to measure the effectiveness of efforts to mitigate these.

People affected by HIV internalise HIV-related stigma through a complex process involving social, contextual and individual factors. Social factors include gender norms and homophobia and contextual factors include living conditions and whether the person has a supportive family and community. Individual factors include educational status, health status and belief system. Internalised stigma can lead to people with HIV not accessing treatment and other services, or not adhering to treatment regimes if they begin them. It also leads to people with HIV becoming isolated, avoiding emotional and sexual relationships or feeling disempowered and unable to negotiate safe sex. The report recommends that action must be taken on each of the three levels to mitigate the effect of internalised stigma. These actions include working with cultural institutions and health systems, developing support groups for people with HIV, and supporting people with HIV in building their self esteem and becoming positive role models for others.

Available online at: <http://www.eldis.org/cf/rdr/rdr.cfm?doc=DOC23725>

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4. Addressing stigma in implementing HIV/AIDS workplace policy: the ACORD experience in Uganda

Author(s): Hadjipateras, A.; With Abwola, S; and Akullu, H. I

Produced by: International NGO Training and Research Centre (Intrac), 2006

This Intrac Praxis Note describes the experience of ACORD Uganda in their efforts to implement an effective HIV and AIDS workplace policy. It focuses on the importance of addressing stigma

within the organisation - both as an objective of the policy itself and as a prerequisite of its effective implementation. The paper sets out the reasons for developing the policy and examines the key challenges that arose during the process, as well as the strategies developed to address these challenges.

The note outlines a number of lessons learned from the experience. It highlights the importance of involving all staff in the policy process, which ensures that views are represented as well as creating a sense of policy ownership. It is also essential to gain management commitment and support for effective policy implementation. Other key lessons include that: promoting a stigma-free workplace environment should make up the main aims of the policy; tackling stigma involves both informal discussions and more formal awareness-raising and education sessions; cost and funding considerations are critical to policy implementation but should not be held up by budgetary constraints; and developing partnerships and co-operating with other actors, such as health service providers and counselling institutions is critical. [adapted from author]

Available online at: <http://www.eldis.org/cf/rdr/rdr.cfm?doc=DOC22100>

5. Stigma and HIV infection in Russia

Author(s): Drobniowski, F.

Produced by: id21, 2007

HIV is sweeping across Russia. Just as in the early days of HIV in Western Europe, sufferers are stigmatised for becoming infected. This stigma must be removed if the epidemic is to be brought under control. Bart's and The London School of Hygiene and Tropical Medicine (UK) conducted a study of attitudes towards HIV sufferers in Russia. By May 2005, 0.7 percent of the population of the Samara region in south-eastern Russia had been infected with the virus. Three quarters of registered patients became HIV-positive through using an infected needle.

Non-judgmental health services are necessary if the disease is to be brought under control. More people will come forward for tests if less stigma is attached to the virus. A number of group discussions with HIV-positive people and other members of the public were held in Samara in May and June 2004. The groups were divided by age, sex, level of education and HIV status. Each of the 15 group had 14 members. During the discussions many HIV patients, particularly women, talked of depression and suicide attempts after they had been diagnosed with the virus. Men said they continued to share needles even though they knew about the risks involved. When they tried to buy syringes at chemists or use a needle exchange they found the police waiting outside to arrest them.

Available online at: www.id21.org/health/h5fd1g1.html

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Other recommended readings

1. Responding to HIV and AIDS in the fishery sector in Africa: proceedings of the International Workshop, February 20-21 2006, Lusaka, Zambia

Published by: The WorldFish Center, 2006

This paper from the WorldFish Centre examines how fishing communities in Africa have responded to the impact of HIV. It presents the findings of a workshop held in Zambia in 2006 and attended by representatives of thirteen African countries and international organisations. A wide range of community-led programmes have been developed by fishing communities to respond to the issues of health, livelihoods and resource-use affected by the high prevalence of HIV in these communities. Community participation in and ownership of programmes are essential for their success, but they also need technical expertise from the health and economic sectors urgently. Programmes also need to focus on the whole community and sector rather than specific groups who are believed to be at higher risk.

The paper recommends that successful interventions need to be scaled up and studied more fully so this knowledge can be used elsewhere. It also recommends increased levels of communication, co-operation and co-ordination between government and non-governmental agencies and between regional, local and national government. Service providers need to engage more with fishing communities and the fishing sector, and resources are needed by HIV services in fishing communities and by the fishing sector more generally.

Available online at: <http://www.eldis.org/cf/rdr/rdr.cfm?doc=DOC23931>

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2. Making the links: addressing HIV/AIDS and gender equality in food security and rural livelihoods programming

Author(s): Hill, C

Published by: Canadian International Development Agency (CIDA / ACDI), 2005

This toolkit from the Canadian International Development Agency (CIDA) provides guidelines for integrating HIV and gender equality into the development and implementation of agricultural and food security programmes. The guidelines highlight the ways in which food security, gender, poverty and HIV intersect. It presents questions and tips to guide policy formation and action in implementing a multisectoral approach to this issue.

In rural areas improving the food and livelihood security of a household can reduce people's risk of HIV infection. Women and girls are more vulnerable to HIV because of their unequal social status and they are also disproportionately responsible for the burden of caring for those who become ill. Women's unequal status also makes them vulnerable to having their land stolen from them when a husband or male partner dies. The toolkit outlines some key interventions to promote gender equality and address the impact of HIV when developing food security programmes. These include promoting property and inheritance rights for women, providing flexible farm finance services which are sensitive to HIV and gender equality concerns and providing labour saving technologies. The toolkit recommends a range of education and training interventions to raise awareness of HIV and gender, to promote knowledge of nutrition and to empower women. It also recommends working with boys and girls to preserve agricultural knowledge and also to assist them in developing life skills.

Available online at: <http://www.eldis.org/cf/rdr/rdr.cfm?doc=DOC23927>

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3. HIV/AIDS among the Azande

Authors: Allen, T.

Published by: World Vision, 2006

This report from World Vision examines the perception of HIV among the population of a rural area of Sudan. Ezo county is on the Sudanese border with Democratic Republic of Congo and the Central African Republic, and is close to Uganda. Migration into the region is expected to grow as the security situation stabilises and development programmes expand. Some of this migration is expected to be from areas with relatively high HIV prevalence. Over 90 per cent of adults and over 80 per cent of primary school students were aware of HIV, and over 70 per cent of both groups identified it as the most serious health problem in the county.

The authors comment that these findings are surprising given the small number of people in the region who have been diagnosed. The report identifies the awareness raising activities of a small number of individuals who have publicly identified as HIV positive as one reason for this. The report also shows a high level of awareness of how HIV is transmitted. However, while most respondents identified controlling sexual behaviour as the most important element of HIV prevention, they also expressed doubt about the feasibility of this: while awareness about condoms was high their reported use was low. The majority of respondents were enthusiastic about the development of HIV testing services in their area. The report recommends the introduction of a testing service and the development of prevention and treatment services in the region.

Available online at: <http://www.eldis.org/cf/rdr/rdr.cfm?doc=DOC23930>

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4. HIV and AIDS treatment education: a critical component of efforts to ensure universal access to prevention, treatment and care

Authors: Sass, J

Published by: United Nations Educational, Scientific and Cultural Organization (UNESCO), 2006

This report from UNESCO and WHO presents the key points and recommendations of a two-day technical consultation on HIV and AIDS treatment education held in 2005. The consultation focused specifically on two aspects of treatment education: treatment literacy and community preparedness. The contributors emphasised the importance of using person-centred approaches when developing and implementing treatment education programmes: it is important to include HIV positive people in the development, review and evaluation of education material and in the implementation of treatment education interventions. It is also important to ensure that the information used in developing materials is accurate, gender-sensitive, culturally relevant and available in the user's language.

An important consensus emerged during the consultation that treatment education must be integrated into general approaches to HIV education rather than being developed as a separate component. The contributors also emphasised the importance of using a wide range of approaches for different settings and audiences. Interventions must be informed by an awareness of the social and political context, and a particular effort needs to be made to reach vulnerable population groups that may not have been addressed by conventional treatment education programmes. Finally, treatment education programmes should also be collaborative, and bring together a range of national and local organisations: the people for whom a treatment education intervention is being implemented, and the community as a whole, should have a sense of ownership over it.

Available online at: <http://www.eldis.org/cf/rdr/rdr.cfm?doc=DOC23940>

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<http://www.eldis.org/hivaids/index.htm>

See the complete list of new additions, announcements, job adverts at: www.eldis.org/hivaids

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- HIV and AIDS Resource Guide - <http://www.eldis.org/hivaids/index.htm>

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