

ANNOTATED BIBLIOGRAPHY

Stigma and discrimination against people living with HIV and AIDS

Title: How can we tackle stigma and discrimination through effective communication?

Author(s): Panos/Healthlink Worldwide

Publication year: 2007

Publisher: SPARK

Annotation:

Regarding stigma: Not mentioned

Regarding gender: PWLHA might suffer violence, particularly gender-based violence related to their HIV status and includes society's attitudes around gender as one of the reasons why stigma and discrimination have long been neglected in HIV and AIDS responses.

Regarding rights: Mentions legal and national policy frameworks that uphold human rights and do not perpetuate discrimination as one of the recognised approaches to fight stigma.

Regarding communication: Authors highlight importance of interpersonal communication and sustained dialogue with communities as well as radio listeners clubs in HIV and Aids communication.

URL: Spark-stigmabackground.pdf

Acquisition cost: Free material

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Title: Assessing HIV/AIDS Stigma and Discrimination in Developing Countries

Author(s):

Publication year: 2007

Publisher: AIDS Behaviour 2008: Springer Science+Business Media, LLC 2007

Annotation: Most published stigma scales are not comprehensive and have been primarily tested in developed countries. We sought to draw on existing literature to develop a scale with strong psychometric properties that could easily be used in developing countries.

Regarding stigma:

Regarding gender: I

Regarding rights:

Regarding communication:

URL:

Acquisition cost:

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Stigma and discrimination against people living with HIV and AIDS

Title: HIV/AIDS Stigma: Finding Solutions to Strengthen HIV/AIDS Programs

Author(s): International Centre for Research on Women (ICRW)

Publication year: 2006

Publisher: ICRW

Annotation: Research in Ethiopia, Tanzania, Vietnam, Zambia and Tanzania from 2001 to 2005 found that: stigma shares several core causes and consequences; women bear a disproportionate share of blame for HIV and are more harshly condemned. Stigma stems from misinformation, bias. Fear of stigma can lead to failure in prevention, treatment and care.

Regarding stigma: Stigma can be tackled by: Building knowledge about HIV and AIDS; Creating stigma-free messages by delinking HIV and AIDS from sensitive and/or taboo social issues associated with its transmission such as sex; involve PLWHA in stigma reduction and programme development

Regarding gender: Very strong gender analysis. 'Women Held to a Double Standard. In the Tanzania study in 2004-5, nearly two-thirds of women with HIV reported experiencing stigma in the past year, as opposed to slightly less than half of men. Why? Women are expected to uphold the moral traditions of their societies. And communities view HIV status as evidence that these women are failing to uphold that moral imperative.

Regarding rights:

Regarding communication:

URL: http://www.icrw.org/docs/2006_stigmasynthesis.pdf

Acquisition cost: Free

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Stigma and discrimination against people living with HIV and AIDS

Title: Accelerating Action against AIDS in Africa

Author(s): UNAIDS

Publication year: 2003

Publisher: UNAIDS

Annotation: Report highlights successful initiatives to conclude that 'AIDS is a problem with a solution: human intervention works, even under the most difficult circumstances... accelerating action against AIDS on the continent is the overall challenge facing Africans'

Regarding stigma: Stigma is a result of many factors: ignorance, traditional beliefs, prejudice, absence of widespread treatment or a cure, irresponsible portrayal of the epidemic in the media, fears about death, and deep-rooted taboos about sexuality, illness and drug use. Positive legislation, education and dialogue are the main weapons that can be used against it. People living with HIV are often their own best ambassadors, but politicians, religious leaders, teachers and employers must be their allies too.'

Regarding gender: 'The gender gap: 'The vulnerability of African women and girls to HIV infection is integrally linked to underlying gender inequalities, societal norms and discrimination. Sustained changes in this vulnerability will require fundamental shifts in the relationships between men and women, and in the way societies view women and value their work and contributions. In the last two decades, much has been learned about the reduction of the HIV/AIDS gender divide. Now the problem is implementing these strategies on a scale that can make a real difference to African women and their families. As girls and young women are at particular risk, strategies to prevent HIV infection among them and reduce the impact of the epidemic on their everyday lives should include: national legislation that affirms equal rights for women; income-generating opportunities for women; prevention education for girls and young women to foster risk-avoidance life skills; education programmes for young people that address gender-related cultural and social norms and develop more equitable behaviour; provision of condoms and other barrier methods, especially those that can be controlled by women (e.g., microbicides); voluntary counselling and testing centres and other HIV-related health services that are friendly to women and girls; programmes to improve the socioeconomic conditions of girls and young women; zero tolerance of rape and abuse of women and girls; gender-sensitive HIV prevention, care and support; and support to women who provide care to family members.'

Regarding rights: 'Discrimination against people living with HIV or those believed to be infected is a clear violation of their human rights. The principle of non-discrimination is

central to human rights frameworks and practices. All international human rights instruments and the African Charter prohibit discrimination based on race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, fortune, birth or other status. Recent resolutions of the UN Commission on Human Rights have clearly stated that the term “or other status” should be interpreted to cover health status in general and HIV/AIDS in particular. They have confirmed that “discrimination on the basis of HIV/AIDS status, actual or presumed, is prohibited by existing human rights standards”.’ Litigation is an essential strategy in reducing stigma and discrimination and in fostering the implementation of human rights at national level. The Universal Declaration on Human Rights (Article 8) states, “Everyone has the right to an effective remedy by the competent national tribunals for acts violating the fundamental rights granted him by the constitution or law”. Litigation holds governments accountable for action or inaction. When private actors are sued or prosecuted, litigation provides the necessary testing and enforcement of law and public policy. Litigation can also empower the socially disadvantaged, including those groups most vulnerable to infection, and can also influence legal and policy reform.

‘Litigation has been used extensively to test and advance HIV/AIDS law and policy in many countries and in many different contexts. Common law areas include discrimination, treatment access, HIV transmission, civil responsibility and liability, inheritance, workplace injury compensation and family matters.

The recent growth of HIV/AIDS litigation in Africa can be attributed to at least two factors: an increase in the number of violations, as well as an increase in protection.

The law is increasingly being used to enforce positive action.’

Regarding communication: That advocacy and campaigning work esp against stigma and discrimination is done largely by PLWHA undermines such work as it is cut short by illness and death; Legislators can improve AIDS advocacy by speaking out against stigma; A national plan that is well-costed and budgeted is a powerful advocacy and resource mobilization tool

URL: http://data.unaids.org/UNA-docs/icasa_report_2003_en.pdf

Acquisition cost: Free

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Title: AFRICAN WOMEN'S UNIQUE VULNERABILITIES TO HIV/AIDS: Communication Perspectives and Promises

Author(s): Linda K. Fuller

Publication year: 2008

Publisher: Palgrave

Annotation: Examines the biomedical, socio-cultural, economic, legal/political, and educational aspects faced by real women in Africa, at the same time offering areas of hope in terms of communication for development case studies and role models [...] [based on] experience working in West Africa with a number of HIV/AIDS and media organizations. (from Palgrave website description)

Regarding stigma:

Regarding gender:

Regarding rights:

Regarding communication:

URL: <http://www.palgrave-usa.com/catalog/product.aspx?isbn=1403984050>

Acquisition cost: USD 89.95

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Stigma and discrimination against people living with HIV and AIDS

Title: Taking Action - The UK's strategy for tackling HIV

and AIDS in the developing world

Author(s): UK Department for International Development

Publication year: 2004

Publisher: DFID

Annotation: Outlines the overall framework for the DFID strategy towards HIV and AIDS.

Regarding stigma: UK prioritises actions that combat stigma and discrimination

Regarding gender: Stigma and discrimination are mentioned 18 times. With respect to women and girls, DFID intends to "Support efforts to promote girls' education and work to support programmes tackling

gender violence and stigma and discrimination." See Chapter 5 on considerations regarding women in national AIDS programmes for more info.

Regarding rights: Rights are mentioned 47 times. UK committed to "Address social, cultural and economic barriers, using a rights-based approach"

Regarding communication: UK recognises the importance of civil society advocacy, in particular advocacy by faith based organisations. They learned in South Africa work that "civil society and faith-based organisations ... carry

significant leadership and influence. They have an important role to play in advocating for

greater attention to be paid to AIDS. They are also important voices in social change processes and in reducing stigma and discrimination."

URL: www.dfid.gov.uk/pubs/files/hivaidstakingaction.pdf

Acquisition cost: None

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Stigma and discrimination against people living with HIV and AIDS

Title: Taking Action Against HIV Stigma and Discrimination: Guidance Document and Supporting Resources

Author(s): UK Department for International Development

Publication year: 2007

Publisher: DFID

Annotation: Very useful overview of the current thinking with 7 case studies and a listing of useful tool kits for different sectors and evidence based talking points.

Regarding stigma: Outlines 5 features of effective programmes: 1. Addresses underlying causes. 2. Addresses multiple layers of stigma Vulnerable groups typically experience stigma from multiple sources (e.g., drug use, sexuality, gender, sex work, HIV). 3. Operates at multiple levels: Individual; family; community; organisational/ institutional; and government/ legal. 4. Engages multiple target groups, potential change agents, marginalised and vulnerable populations. These groups might include: opinion leaders (e.g., politicians, faithbased leaders), frontline HIV responders (e.g., health care workers, NGO and community workers), people living with HIV and other stigmatised groups, communities, the media, private sector, schools, police, and the judiciary. 5. Employs a range of approaches: 1. Prevent and reduce stigma 2. Challenge discrimination, particularly in institutional settings 3. Promote and protect human rights

Regarding gender: Gender is mentioned 17 times. "Stigma and underlying norms around gender, sexuality and other factors are often enforced at the family, community, institutional, and legal and policy levels. Thus, a comprehensive response to stigma and discrimination, aimed at creating an enabling environment for individuals to practice prevention and access services, will have the greatest and broadest impact."

Regarding rights: Rights are mentioned 49 times. "Lack of respect for human rights intensifies vulnerability to HIV and hampers effective health for people with HIV and AIDS." "The DFID-supported Code of Good Practice provides a set of principles and practices for an effective, rights-based response to HIV."

Regarding communication: Highlights importance of evidence based approaches, and mentions importance of involvement of people living with HIV: notable successful example: the Treatment Action Campaign. The active involvement of people with HIV and AIDS is crucial for developing and implementing effective anti-stigma and discrimination efforts. A participatory approach is at the core of several promising stigma-reduction interventions.

URL: [www.aidsportal.org/repos/stigma guidance doc.pdf](http://www.aidsportal.org/repos/stigma%20guidance%20doc.pdf)

Acquisition cost: None

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Title: Guidelines for Inclusion of Individuals with Disability in HIV/AIDS Outreach Efforts

Author(s): NE Groce, R Trasi, AK Yousafzai

Publication year: 2004

Publisher: Yale University

Annotation: Provides guidelines for the inclusion of individuals with pre-existing disabilities in HIV/AIDS outreach efforts and a three part typology which constitutes a continuum of inclusion in and access to HIV/AIDS services that range from: I) inclusion of individuals with disability in general HIV/AIDS outreach efforts at little or no additional expense to currently existing programs, II) programs where minor to moderate modifications can be made to existing programs to ensure greater participation of individuals with disability at relatively little expense, to III) outreach efforts that are targeted to disabled audience that entail specific allocation of resources.

Regarding stigma: Not focusses on stigma reduction, but the interaction between stigma and disability and HIV is mentioned. • The lives of individuals with disability are no less valuable than the lives of all other citizens and there can be no substantive argument that justifies assigning individuals with disability to the bottom of an HIV/AIDS priority list.

Regarding gender: Despite the fact that the risk factors associated with disability – extreme poverty, social stigma and marginalization, strikingly high rates of unemployment and lack of access to education and health care - are similar to those for HIV/AIDS, there has been almost no attention to the impact of the AIDS epidemic on this large and largely overlooked population. Stigma and marginalization, poverty, illiteracy, unemployment and the lower probability that individuals with disability will be considered eligible marriage partners, significantly diminish the ability of many individuals with disability worldwide to be able to negotiate safer sex.

Regarding rights: It is strongly argued that inclusion of individuals with disability in HIV/AIDS outreach efforts simply cannot wait until all other groups in the population are addressed. The issue is one of both basic human rights AND basic public health.

Regarding communication: Formal and informational disability advocacy groups can be most helpful if they are included as partners in HIV/AIDS initiatives at the outset of a program and not just contacted for their approval at the very end of the process. Importantly such groups are often run on shoestring budgets. If they are asked to participate in HIV/AIDS outreach efforts, funding to help support such outlay of time and energy would be most helpful.

URL: http://cira.med.yale.edu/globalsurvey/inclusion_guidelines_hiv aids.pdf

Acquisition cost: None

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Title: Educate Girls, Fight AIDS

Author(s): Global Coalition on Women and AIDS

Publication year: 2005

Publisher: UN AIDS

Annotation: The education of girls is a key strategy in overcoming the spread of AIDS. 4 page overview on the subject.

Regarding stigma: Very little

Regarding gender: Advocates teaching gender sensitive HIV prevention in schools. Does not provide further info on that subject.

Regarding rights: No mention

Regarding communication:

URL: http://data.unaids.org/GCWA/GCWA_FS_GirlsEducation_Sep05_en.pdf

Acquisition cost: none

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Title: PARTNERING TO ADDRESS LINKS BETWEEN VIOLENCE AGAINST WOMEN AND HIV/AIDS

Author(s): UNIFEM

Publication year: 2007

Publisher: UNIFEM

Annotation: 2 page doc describes UNIFEM funded projects in 2007 focussing on Gender Based Violence and HIV and AIDS. Refers to 5 projects, incl 2 in Africa.

Regarding stigma:

Regarding gender: Violence against women is both a significant cause and a consequence of this devastating HIV/AIDS trend. Women facing violence within intimate relationships often cannot negotiate safer sex practices, such as condom use. Rape and harmful practices such as female genital mutilation also spread the virus.

Regarding rights: In addition to untenable levels of stigma and discrimination from the community, women who test positive for HIV are often subjected to physical abuse from partners and can face eviction from their homes. Further, as a result of such stigma associated with HIV/AIDS, they are prevented from obtaining life-saving medical care and treatment.

Regarding communication: The UNIFEM partnership supports initiatives aimed at reducing gender-based violence to lower rates of HIV/AIDS among women and strengthens efforts to reduce violence that prevents HIV-positive women and girls from seeking justice and obtaining treatment and care.

URL: www.unifem.org/news_events/story_detail.php?StoryID=561

Acquisition cost: None

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Stigma and discrimination against people living with HIV and AIDS

Title: Tackling HIV and AIDS with faith-based communities: learning from attitudes on gender relations and sexual rights within local evangelical churches in Burkina Faso, Zimbabwe, and South Africa

Author(s): Mandy Marshall and Nigel Taylor

Publication year: 2006

Publisher: Gender and Development: Oxfam UK

Annotation: Recognising that unequal gender relations are a driving force behind the AIDS pandemic, this article explores the position of local evangelical churches in Africa with respect to gender relations and sex, and the implications for HIV and AIDS. Based on desk and field research carried out by the UK-based NGO Tearfund, the findings indicate that these churches were largely silent on the issue of gender and sex, or were reinforcing traditional values which contribute to HIV infection. Tearfund is funding a small pilot initiative to try new ways of working with the church to change behaviours, and to balance biblical theology and work to address the gender inequity in the relationships between men and women in the church. Working with and funding the two partners, Vigilance and CAT, the pilot programmes seeks to gain a better understanding of the gender issues in the evangelical church context and facilitate a change in attitudes in the areas where the partners work. Vigilance and CAT will work with a number of churches exploring issues of gender, sexual rights and HIV and AIDS with the intention of enabling them to find appropriate responses to the issues.

Regarding stigma:

Regarding gender: Cultural issues seem to reinforce, and are in some cases reinforced by evangelical attitudes. The interrelationship is such that it demands that we address not only African cultural traditions and their impact on HIV and AIDS, sex and gender relations, but also challenge the church on its position on the issues. Evangelical beliefs can compound the situation when an incomplete knowledge or biased selection of biblical texts leads to an unbalanced view. For example, many Christians are familiar with only selected biblical texts that refer to the submission of women, and neglect to balance this with other texts that speak of the necessity of equal submission to one another in love, and of men and women being created equally in the image of God.

Regarding rights:

Regarding communication: Tearfund is funding a small pilot initiative to try new ways of working with the church to change behaviours, and to balance biblical theology and work to address the gender inequity in the relationships between men and women in the church. Working with and funding the two partners, Vigilance and CAT, the pilot

programmes seeks to gain a better understanding of the gender issues in the evangelical church context and facilitate a change in attitudes in the areas where the partners work. Vigilance and CAT will work with a number of churches exploring issues of gender, sexual rights and HIV and AIDS with the intention of enabling them to find appropriate responses to the issues.

URL: publications.oxfam.org.uk/oxfam/display.asp?TAG=&CID=&K=002J1186

Acquisition cost: None

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Title: Action on Gender Based Violence and HIV/AIDS: Bringing Together Research, Policy, Programming and Advocacy

Author(s): Centre for Women's Global Leadership

Publication year: 2007

Publisher: Centre for Women's Global Leadership/Harvard School of Public Health

Annotation: Report of a meeting at 2006 International AIDS Conference. Primarily concerned about the links between gender based violence and HIV and AIDS.

Regarding stigma:

Regarding gender:

Regarding rights: In certain circumstances, human rights sensitive language and approaches used in public health interventions and some of the terms used in relation to gender or HIV have created confusion and triggered discriminatory or stigmatizing responses by community members.

Regarding communication: Participants agreed on the need to be able to clearly present the linkages between GBV and HIV/AIDS to donors, activists, policymakers, researchers, government and UN officials, and even public health authorities, many of whom remain unaware or unconvinced of these connections. In fact, even allies sometimes have a lack of clarity about the connections.

URL: www.cwgl.rutgers.edu/globalcenter/policy/HIVAIDS/toronto.pdf

Acquisition cost: None

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Stigma and discrimination against people living with HIV and AIDS

Title: Girls and HIV

Author(s): Global Health Council

Publication year: 2007

Publisher: AIDSLink

Annotation: Magazine style publication focused on youth especially girls and HIV. Broad range of concerns with emphasis on prevention. Contains interviews with girls with HIV about their experiences. Includes case studies from about 8 countries, including some in Africa.

Regarding stigma: From a story of a girl with HIV: I am glad that I have managed to fight both self-stigma and discrimination. I have realized that I can do anything and everything that any girl my age does. I am open about my status because I realized that it is good therapy. At the empowerment village I was taught that it can help one overcome the stress and anxiety associated with HIV. People no longer whisper when I am around or gossip about me because they know that I am fine with talking about my status. Also, I was taught that sometimes people die of the virus, but more often they die of loneliness.

Regarding gender: Some mention of gender based violence and HIV

Regarding rights: AIDSLink-Girls and HIV-2007.pdf

Regarding communication: In favour of youth advocacy, primarily focused on prevention.

URL: www.ungei.org/resources/1612_1275.html

Acquisition cost: None

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Title: HIV/AIDS, Stigma and Faith-based Organisations A review

Author(s): Centre for AIDS Development, Research and Evaluation; Warren Parker and Karen Birdsall

Publication year: 0

Publisher: DFID-funded Christian Aid HIV and AIDS programme of the Anglican Church of Southern Africa:

Annotation: Whilst there is much reference to the FBOs as settings where stigma and discrimination prevail, there are few research findings that document specific instances and manifestations of the problem. Examples given in the broader literature are largely anecdotal. There do not appear to be any systematic investigations of stigma and its forms within FBOs. Rather, it is assumptions about the moral underpinnings of faith, in conjunction with conservatism about sexuality, that forms the basis for such attribution. We have found a predominance of literature that has identified a growing trend in positive and proactive responses within FBOs, and these contradict accounts of FBOs as contexts where stigma is widespread. This is not to say that stigma and discrimination are not problems in FBO settings, but rather that they may coexist alongside proactive positive responses to HIV/AIDS. It is this interaction that is important to understand.

Regarding stigma: Responses to HIV/AIDS stigma involve a range of strategies including knowledge oriented activities (such as providing factual information about HIV transmission as well as stigma), legal and rights-oriented strategies, leadership approaches, and community-level initiatives. These strategies are not mutually exclusive, and are more likely to succeed if there is some level of integration.

Regarding gender: Gender was found to be a cross-cutting issue whereby women were 'expected to be sexually faithful, chaste and morally upstanding' and thus, when infected with HIV, there was a greater attribution of blame.

Regarding rights: suggests that responses to stigma and discrimination should be framed by broader concepts of equality and rights and principles of non-discrimination.

Regarding communication: A number of authors note that HIV advocacy and rights are under-emphasised areas among FBOs

URL: www.cadre.org.za/files/CADRE-Stigma-FBO.pdf

Acquisition cost: None

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Stigma and discrimination against people living with HIV and AIDS

Title: HIV/AIDS and Gender: Fact Sheet

Author(s): UNAIDS Inter-Agency Task Team on Gender and HIV/AIDS

Publication year: 0

Publisher: UNAIDS Inter-Agency Task Team on Gender and HIV/AIDS

Annotation: This is a key document providing an extensive outline of rights based gender sensitive approaches to HIV and AIDS with significant reference to stigma and discrimination.

Regarding stigma: Laws, policies, strategies and practice should address all forms of discrimination that increase the impact of HIV/AIDS. This includes the promotion of education and training programmes designed to counter discrimination and stigma associated with gender and with HIV/AIDS.

Regarding gender: Stigma and discrimination associated with HIV/AIDS reinforces prejudices, discrimination and inequalities related to gender, poverty, sexuality, disability and ethnicity. This contributes to the vulnerability to infection of minority or otherwise weaker groups, as those members at risk or affected by HIV and AIDS may be reluctant to contact health and social services. The result is that those most in need of information, education and counselling will not benefit even where these services are available.

Regarding rights: A poor respect for human rights increases the prevalence and worsens the impact of HIV/AIDS. International treaties provide the overarching legal framework for a rights-based approach in relation to HIV/AIDS. Equality and non-discrimination are not only cornerstone principles of international human rights law; they are also vital to HIV/AIDS prevention and to ensuring equitable access to care, treatment and support for those infected and affected by HIV/ AIDS

Regarding communication: HIV/AIDS responses should include strategies for ensuring equal access of men and women to their full rights as citizens. They must address equality and non-discrimination in areas such as education, political rights, marriage and family, property, employment, health and protection from violence.

URL: www.genderandaids.org/downloads/events/Fact%20Sheets.pdf

Acquisition cost: None

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Stigma and discrimination against people living with HIV and AIDS

Title: HIV AND AIDS STIGMA VIOLATES HUMAN RIGHTS IN FIVE AFRICAN COUNTRIES

Author(s): Thecla W Kohi and 9 others

Publication year: 2006

Publisher: Hursing Ethics

Annotation: The human rights of people living with HIV and AIDS were violated in a variety of ways, including denial of access to adequate or no health care/services, and denial of home care, termination or refusal of employment, and denial of the right to earn an income, produce food or obtain loans. The informants living with HIV and AIDS were also abused verbally and physically. Based on focus groups with 251 people living with HIV in Lesotho, Malawi, South Africa, Swaziland and Tanzania

Regarding stigma: Country governments and health professionals need to address these issues to ensure the human rights of all people.

Regarding gender: Not mentioned

Regarding rights: Human rights are mentioned over 70 times in this 12 page document. See key arguments/main points.

Regarding communication: Recommends that the issues around the human rights of PLWHA be used to teach the process of advocacy to health professionals in African countries. They need to be extremely well informed about the relevant legislation in their own countries, in order to advocate on behalf of vulnerable PLWHA.

URL: nej.sagepub.com/cgi/reprint/13/4/404

Acquisition cost: US20 for one day access or subscription to Nursing Ethics on line journal

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Stigma and discrimination against people living with HIV and AIDS

Title: Working Report: Measuring HIV Stigma: Results of a Field Test in Tanzania

Author(s): Laura Nyblade and several others

Publication year: 2005

Publisher: International Center for Research on Women

Annotation: At 224 pages, this publication provides extensive field test results of numerous ways of measuring stigma including self-stigma. Valuable reference on ways to measure stigma.

Regarding stigma: Not directly addressed

Regarding gender: There are marked differences in the experience of stigma by gender. Women experienced each form of stigma more often than men, in some cases much more. Women were threatened with violence, abandoned by a spouse or family, and had property taken away far more often than did men. They also experienced noticeably more verbal stigma. In only two situations did men experience more stigma than women: men more often were denied a promotion or training opportunities and were given poorer quality health services

Regarding rights: Data indicate that people living with HIV are not aware of the specific rights and protections afforded them in laws and policies. Research methodology included measuring whether health care workers, for example, were aware of rights of PLWHA.

Regarding communication: Not mentioned

URL: www.icrw.org/html/specialevents/stigmaevent-toronto.htm

Acquisition cost: None. Several other useful documents are available at this website.

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Stigma and discrimination against people living with HIV and AIDS

Title: CAN WE MEASURE HIV/AIDS-RELATED STIGMA AND DISCRIMINATION? CURRENT KNOWLEDGE ABOUT QUANTIFYING STIGMA IN DEVELOPING COUNTRIES

Author(s): Laura Nyblade and

Publication year: 2006

Publisher: International Center for Research on Women

Annotation: Provides Recommended Indicators for Questions for Fear of Casual Contact with People Living with HIV/AIDS, for Values (Shame, Blame and Judgment), Enacted Stigma (Discrimination) and for Questions of Disclosure

Regarding stigma: Provides clear approaches to measuring level of stigma

Regarding gender: Contains a few attitude measurement questions specific to women, but not many.

Regarding rights: Brief reference, not the major focus of the indicators which centre more on beliefs and attitudes.

Regarding communication: Not mentioned.

URL: [www.policyproject.com/pubs/generalreport/Measure HIV Stigma.pdf](http://www.policyproject.com/pubs/generalreport/Measure%20HIV%20Stigma.pdf)

Acquisition cost: None

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Title:

Author(s): Margaret Sandelowski and 2 others

Publication year: 2004

Publisher: Journal of Nursing Scholarship

Annotation: Both perceived and enacted stigma were pervasive in the lives of HIV-positive women. HIV-related stigma was intensified in women because they were women. Stigma management largely involved efforts to control information in the service of preserving social relations and maintaining moral identity

Regarding stigma: HIV-related stigma is as much a reflection of others as it is central to the experience of HIV-positive people themselves. Even those not infected with HIV are still affected by it and are thus appropriate targets for interventions to reduce its negative effects.

Regarding gender: Entire study concerns women.

Regarding rights: Not mentioned

Regarding communication:

URL: www.ncbi.nlm.nih.gov/pubmed/15227758

Acquisition cost: requires subscription to journal or access to a medical library that has a subscription.

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Title: A Faith-Based Response to HIV in Southern Africa: the Choose to Care Initiative

Author(s): UN AIDS Robert Vitillo

Publication year: 2006

Publisher: UNAIDS

Annotation: Detailed case study of the Catholic Church in South Africa response to HIV and AIDS.
Part of UNAIDS Best Practice Collection

Regarding stigma: 'The stigma of HIV and AIDS is often a great burden to families and caregivers, sometimes a greater burden than the person who is ill...Our service of the suffering humanity demands that we confront head on misconceptions around HIV/AIDS and destructive attitudes such as judgement and social stigma, fear of being labelled and ostracised...There is an increased need to focus on being Communities of Care. People infected and affected by HIV need to find comfort, support, information and care in our church communities.'

Regarding gender: Very little mention of gender

Regarding rights: Very little concern with rights.

Regarding communication:

URL: http://data.unaids.org/pub/Report/2006/JC1281_Choose_To_Care_en.pdf

Acquisition cost: none

ANNOTATED BIBLIOGRAPHY

Stigma and discrimination against people living with HIV and AIDS

Title: Keeping the Promise: An Agenda for Action on Women and AIDS

Author(s): Global Coalition on Women and AIDS

Publication year: 2006

Publisher: N/A

Annotation: To be more effective, AIDS responses must address the factors that continue to put women at risk. The world's governments have repeatedly declared their commitment to improve the status of women and acknowledged the linkage with HIV. In some areas, progress has been made. By and large, though, efforts have been small-scale, half-hearted and haphazard. Major opportunities to stem the global AIDS epidemic have been missed. It is time the world's leaders lived up to their promises. That's why the UNAIDS-led Global Coalition on Women and AIDS is calling for a massive scaling up of AIDS responses for women and girls. 42 page doc details how this can be done.

Regarding stigma: Mentions stigma, but is not focused on it. It recommends: Defuse the stigma, fear and violence that deter women from taking advantage of HIV services.

Regarding gender: All people living with HIV are confronted with HIV stigma and discrimination. But studies suggest that women experience it more frequently, are more likely to experience the harshest and most damaging forms, and find it more difficult to deal with.³² Studies among people living with HIV in India, Indonesia, Philippines and Thailand have found that women were significantly more likely than men to suffer discrimination, harassment, physical assault, and being forced to change their place of residence.³³ The upshot is a pernicious—and potentially deadly—combination of gender discrimination and stigma. Stigma makes it much more difficult for women to practice safer sex, for example. When women carry or insist on using condoms, they are often targeted with accusations of immoral behaviour or infidelity.³⁴ Fear of stigma and its consequences also hinder access to routine reproductive health services and information, as well as HIV services—putting women, and their infants, at greater risk of HIV infection.³⁵ Rolling back stigma and discrimination is every bit as essential as rolling out more, better HIV prevention and treatment services. One without the other will not do.

Regarding rights: Laws and policies that affirm and protect the rights of women are vital for winning the struggle against AIDS. But laws are not enough to secure women's rights. It is equally important to challenge social norms which undermine women's rights, and expand legal services for women.

Regarding communication: Laws and policies that affirm and protect the rights of women are vital for winning the struggle against AIDS...Women's rights need to become

women's realities. Actions: • Ensure that laws – whether statutory, de jure or customary – protect women against violence, and uphold their right to own and inherit property. • Invest in strategies to educate the police, the judiciary, social service providers, civil servants and community leaders about laws and their legal responsibilities. • Develop and fund programmes to improve legal aid services and other forms of support so that women can claim their rights.

URL: http://data.unaids.org/pub/Booklet/2006/20060530_FS_Keeping_Promise_en.pdf

Acquisition cost: None

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Stigma and discrimination against people living with HIV and AIDS

Title: Integrating Gender into HIV/AIDS Programs: A Review Paper

Author(s): World Health Organisation, Dr Geeta Rao Gupta, Mr Daniel Whelan and Ms Keera Allendorf of the International Center for Research on Women (ICRW) in Washington, D.C

Publication year: 2003

Publisher: World Health Organisation

Annotation: By curtailing women's sexual rights and autonomy, encouraging irresponsible and risky sexual behaviour among men, restricting women's access to and use of economic resources and fostering homophobia, gender norms have contributed to creating a culture of silence and shame that surrounds sexuality and an unequal balance of power between women and men. Together these pose a significant challenge for policies and programmes that seek to contain the spread of the HIV/AIDS epidemic.

Regarding stigma: Not specifically mentioned

Regarding gender: Particularly strong norms that reify virginity and a culture of silence about sex makes accessing treatment services for sexually transmitted diseases highly stigmatizing for adolescent and adult women. AND The economic vulnerability of women also exposes them to graver consequences when faced with the stigma and discrimination typically associated with being infected or affected by HIV/AIDS. When faced with the social ostracism and abandonment that often result, women frequently face tragic consequences because they lack the necessary economic resources to cope.

Regarding rights: Not mentioned

Regarding communication: Not mentioned

URL: [www.who.int/gender/hiv_aids/en/Integrating\[258KB\].pdf](http://www.who.int/gender/hiv_aids/en/Integrating[258KB].pdf)

Acquisition cost: None

ANNOTATED BIBLIOGRAPHY

Stigma and discrimination against people living with HIV and AIDS

Title: Stop Violence Against Women Fight AIDS

Author(s): UNAIDS Global Coalition on Women and AIDS

Publication year: 0

Publisher: UNAIDS Global Coalition on Women and AIDS

Annotation: Does not focus on stigma. "Addressing violence against women is essential to achieve key international targets articulated in the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) Declaration of Commitment and the Millennium Development Goals, such as reducing new HIV infections, increasing access to AIDS services, and promoting women's human rights and gender equality. This will require far greater acceptance of the links between violence against women and HIV, and enhanced political leadership, resource investments, and sustained commitment at national and international levels."

Regarding stigma: 4 page document briefly refers to an initiative: By fostering greater community dialogue, Stepping Stones workshops in 29 countries – mostly in Africa but increasingly in Asia and Europe – have helped to reduce the acceptability and prevalence of violence and to promote discussion and awareness about HIV. By changing attitudes and behavior related to violence against women, and reducing stigma and discrimination in the community, these programs work to lower HIV vulnerability for women.

Regarding gender: Only reference to stigma is at left.

Regarding rights: No mention of rights as they relate to stigma.

Regarding communication: Suggests national governments should support community-based training and information campaigns to change harmful norms and behaviors that perpetuate violence against women and reinforce its social acceptability. This includes working with men and communities to address violence, as well as engaging women's, faith-based, and other groups in preventing and coping with violence and its links to HIV.

URL: <http://womenandaids.unaids.org/themes/docs/UNAIDS%20VAW%20Brief.pdf>

Acquisition cost: None

ANNOTATED BIBLIOGRAPHY

Stigma and discrimination against people living with HIV and AIDS

Title: Asleep at the wheel? 5 years of G8 promises on global health

Author(s): World Aids Campaign

Publication year: 2006

Publisher: World Aids Campaign

Annotation: In preparation for 2006 G8 Summit: calls for G8 accountability and leadership on Aids.- Promises on health made by G8 are reviewed.

Regarding stigma: A promise made by G8 in 2002 in helping Africa to combat the effects of HIV & Aids was to: support high level political engagement to increase awareness and reduce stigma associated with HIV and AIDS.

Regarding gender: 1 mention of gender: Supporting the development, adoption and implementation of gender-sensitive, multi-sectoral HIV/AIDS programs for prevention, care, and treatment 2 mentions of discrimination: Strong national health systems will continue to play a key role in the delivery of effective prevention, treatment and care and in improving access to essential health services and commodities without discrimination.

Regarding rights: No mention of rights, stigma and discrimination against PLWHA

Regarding communication: 1 mention on communication: support where appropriate for the use of information and communication technologies for medical treatment. No mention of advocacy.

URL:

Acquisition cost: None

ANNOTATED BIBLIOGRAPHY

Stigma and discrimination against people living with HIV and AIDS

Title: WOMEN, HIV/AIDS AND HUMAN RIGHTS:

An Annotated Syllabus

Author(s): the International Reproductive and Sexual Health Law

Programme, Faculty of Law, University of Toronto

Publication year: 2008

Publisher:

Annotation: Sex, gender and social context in the HIV & AIDS pandemic and challenges in access to prevention, treatment and care

Regarding stigma: HIV/AIDS related stigma drives the epidemic underground and is one of the main reasons that people do not wish to know their HIV status. Unless efforts to reduce stigma are, as one peer educator put it, “written in large letters in any HIV/AIDS campaign rather than small”, stigma will remain a major barrier to curbing the HIV/AIDS pandemic.

Regarding gender: This report describes the effects of gender inequality, stigma and discrimination on the HIV/AIDS pandemic in Botswana and Swaziland, the two countries with the highest HIV prevalence in the world.

Regarding rights: The goal was to create a comprehensive law that protects the rights of persons living with HIV/AIDS. Substantive provisions of the legislation address issues of discrimination, disclosure of HIV status, safe working environments, social security payments, informed consent, access to treatment, risk reduction, information education and communication, and state obligations. The draft legislation is currently under consideration by the Government of India.

Regarding communication: It mentions advocacy. "During the past decades, legal advocacy has played a critical role in changing the realities of women's reproductive lives in countries worldwide." "Advocacy and educational organizations are encouraged to adopt and adapt these materials for their teaching and skills-building purposes."

URL:

Acquisition cost: None

ANNOTATED BIBLIOGRAPHY

Stigma and discrimination against people living with HIV and AIDS

Title: Women, Girls, HIV & AIDS and the World of Work

Author(s): International Labour Organisation (ILO)

Publication year: 2004

Publisher: ILOAIDS Brief

Annotation: Economies feel the impact but women bear the brunt Risk of transmission is greatest fro girl and young women Low status of wmen linked directly to their risk of HIV Keeping girls in schools Empowering women tto workwill reduce transmission of HIV.

Regarding stigma: The document doesn't mention stigma reduction but covers stigma and discrimination. "HIV/AIDS-related stigma and discrimination alter individual behaviour, damage employment and career prospects, and blight the quality of health and other social services. It is recognized that women are more likely than men to be stigmatized or repudiated. In the workplace, discrimination can mean mandatory testing, quarantine, exclusion, and outright job loss."

Regarding gender: "The greater the gender discrimination in societies and the lower the position of women, the more negatively they are affected by HIV."

Regarding rights: Some mention of rights and discrimination. For expl: "To promote women's empowerment, protect their rights, target actions to raise their status, and provide them with training, life skills and access to work will enable them to gain better control of their lives, their bodies and their sexual relations".

Regarding communication: No mention of communications or advocacy.

URL:

Acquisition cost: None

ANNOTATED BIBLIOGRAPHY

Stigma and discrimination against people living with HIV and AIDS

Title: Show us the money: Is violence against women on the HIV/AIDS funding agenda?

Author(s): Women Won't Wait Campaign, Action Aid

Publication year: 2007

Publisher: Action Aid

Annotation: This report, "Show Us the Money: is violence against women on the HIV&AIDS donor agenda?" analyses the policies, programming and funding patterns of the four largest public donors to HIV&AIDS: the Global Fund to Fight AIDS, Tuberculosis and Malaria, the President's Emergency Fund for AIDS Relief (PEPFAR/US), the UK Department for International Development (DFID), and the World Bank, and UNAIDS (the Joint UN Programme on HIV/AIDS). The report is the first step in an effort by this coalition to monitor the policies, programmes, and funding streams of international agencies and national governments, and to hold these agencies accountable to basic health and human rights objectives.

Regarding stigma: According to the five-year PEPFAR plan, the US government pledges to work with "communities, donors and other stakeholders to reduce stigma, protect women from sexual violence related to HIV, promote gender equality, and build family skills in conflict resolution."

Regarding gender: Poverty, discrimination, gender inequality and stigma also drive high rates of HIV infection among men and women in marginalised groups who have sexual and reproductive health needs.

Regarding rights: Several mentions on Rights but none on Rights and stigma and discrimination. This unit also works with UN treaty bodies and Special Procedures to advocate that they address issues of gender and HIV, where relevant, in an effort to expand the dialogue about human rights, gender and HIV.

Regarding communication: No mention of communications but several mentions of advocacy such as: "Its reports and briefing documents are useful advocacy tools, and by providing catalytic funding, the coalition seeks to build an evidence base that affirms the linkage between violence against women and girls and HIV, as well as identifying promising practices that can be brought to scale."

URL:

Acquisition cost: None

ANNOTATED BIBLIOGRAPHY

Stigma and discrimination against people living with HIV and AIDS

Title: Developing Indicators for Measuring Stigma and Discrimination and the Impact of programmes to reduce it: Summary of Projects and Research to Date

Author(s): UNAIDS, GNP+, IFRC

Publication year: 0

Publisher: UNAIDS, GNP+, IFRC

Annotation: 1. HIV/AIDS-related stigma can be described as a 'process of devaluation' of people either living with or associated with HIV/AIDS. This stigma often stems from the underlying stigmatization of sex and intravenous drug use – two of the primary routes of HIV infection. HIV/AIDS-related stigma builds upon, and reinforces, existing prejudices. It also plays into, and strengthens, existing social inequalities – especially those of gender, sexuality and race. When stigma exists people often prefer to ignore their real or possible HIV status. This can lead to the risk of faster disease progression for themselves and also to the risk of them spreading HIV to others. 2. Discrimination follows stigma and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status. This treatment can be either an act or a failure to act. Combating discrimination requires providing a supportive legal environment. 3. HIV/AIDS-related stigma and discrimination play a key role in producing and reproducing relations of power and control. They cause some groups to be devalued and others to feel that they are superior. Ultimately, stigma creates and is reinforced by social inequality. Stigma and discrimination breach fundamental human rights and can occur at a number of different levels including: political, economic, social, psychological and institutional. 4. Stigma and discrimination are social processes used to create and maintain social control, producing, legitimizing and perpetuating social inequality. They must therefore be resisted and challenged by addressing social and community changes through community mobilization and social transformation.

Regarding stigma: In relation to external and internal stigma, the paper focuses on the indicators which have been developed by various projects to measure changes in levels of stigma. Many of these indicators can be used or adapted to other settings and by measuring the level of stigma and discrimination at the commencement of an intervention (baseline survey) and then at various time intervals; it is possible to measure a reduction in stigma and discrimination, and depending on the study design and variables in the setting, it may be possible to impute a reduction in stigma and discrimination to the intervention itself. Note that it is possible to develop other indicators. In relation to measuring discrimination, the paper outlines the tools developed to date and relates these to advocacy opportunities which exist in relation to protecting human rights and holding states accountable to their international obligations.

Regarding gender: The document is curiously ambivalent about gender. The word is used, but with little in-depth exploration of the implications. For example: "It has been suggested that this indicator be used to measure differences in discrimination or stigma by gender. Although some research suggests that female PLWHA are more likely to be treated and viewed more harshly than male PLWHA; other recent surveys have shown little difference in response to gender specific questions about stigma and discrimination."

Regarding rights: A rights-based approach is the subject of one case study: "Discriminatory acts vary from inappropriate comments to breaches of patient confidentiality, from treatment delayed to treatment and basic care and hygiene refused. Some of these acts are not only a violation of basic human rights but they can also have a considerable negative impact on the health of both the individual and the broader community." AND "Below are several resources which are aimed at identifying discrimination. However, once again they are not designed to measure the impact of interventions to prevent discrimination or mitigate its effects; rather they are designed to measure the prevalence of discrimination or monitor the construction of a legal framework to protect the human rights of PLWHA and those people perceived to be infected."

Regarding communication: No.

URL:

http://www.gnpplus.net/component/option,com_docman/task,cat_view/Itemid,53/gid,48/orderby,dmdatecounter/ascdesc,DESC/

Acquisition cost:

ANNOTATED BIBLIOGRAPHY

Stigma and discrimination against people living with HIV and AIDS

Title: Development and Psychometric Assessment of a Multidimensional Measure of Internalized HIV Stigma in a Sample of HIV-positive Adults

Author(s): Jennifer N. Sayles, Ron D. Hays, Catherine A. Sarkisian, Anish P. Mahajan, Karen L. Spritzer, William E. Cunningham

Publication year: 2008

Publisher: AIDS Behav (2008) 12:748–758 DOI 10.1007/s10461-008-9375-3

Annotation: There is a need for a psychometrically sound measure of the stigma experienced by diverse persons living with HIV/AIDS (PLHA). The goal of this study was to develop and evaluate a multidimensional measure of internalized HIV stigma that captures stigma related to treatment and other aspects of the disease among sociodemographically diverse PLHA. We developed a 28-item measure of internalized HIV stigma composed of four scales based on previous qualitative work. Internal consistency reliability estimates in a sample of 202 PLHA was 0.93 for the overall measure, and exceeded 0.85 for three of the four stigma scales. Items discriminated well across scales, and correlations of the scales with shame, social support, and mental health supported construct validity. This measure should prove useful to investigators examining in the role of stigma in HIV treatment and health outcomes, and evaluating interventions designed to mitigate the impacts of stigma on PLHA.

Regarding stigma: To effectively study, measure, and ultimately reduce the stigma for PLHA, it is critical to capture the full range of perceptions and experiences of the process of stigma in a given cultural context and community.

Regarding gender: Little.

Regarding rights: No.

Regarding communication: No.

URL: <https://commerce.metapress.com/content/j73t710555685j65/resource-secured/?target=fulltext.pdf&sid=gk1en1m14pqqt45svkzpoqn&sh=www.springerlink.com>

Acquisition cost: 34

ANNOTATED BIBLIOGRAPHY

Stigma and discrimination against people living with HIV and AIDS

Title: HIV/AIDS Stigma: Finding Solutions to Strengthen HIV/AIDS Programs

Author(s): ICRW

Publication year: 2006

Publisher: ICRW

Annotation: HIV/AIDS-related stigma has long been recognized as a crucial barrier to the prevention, care and treatment of HIV and AIDS. Yet not enough is being done to combat it. One reason has been a lack of information: How do we define stigma? Can stigma be measured? Another reason has been the assumption by development practitioners that stigma is too tied to culture, too context-specific and too linked to taboo subjects like sex to be effectively addressed. Action also has been impeded by a lack of tools and tested interventions. Seminal research by ICRW and in-country partners on HIV/AIDS stigma coupled with the development of tools to combat stigma and indicators to evaluate the effectiveness of stigma-reduction efforts represents significant progress in both filling information gaps on stigma and dispelling myths that stigma cannot be addressed or measured.

Regarding stigma: Programs can help to eliminate stigma by delinking HIV from the sensitive and often taboo social issues that are associated with its transmission, in particular sex and intravenous drug use. This delinking can be done without sacrificing effective communication of information about prevention. For example, messages, programs and policies should discuss the behaviors that can lead to HIV transmission without direct reference to particular individuals or groups to avoid the temptation to single out these groups as “vectors” of transmission. Also because people may be uncomfortable discussing some of the norms and values typically associated with HIV and AIDS, it is important to create safe spaces with a trusted facilitator for people to openly discuss their fears and opinions that can lead to stigmatizing behavior.

Regarding gender: Only in context of gender-based violence and, then, only minimally.

Regarding rights: No.

Regarding communication: Also in Vietnam, ICRW and a local partner are working with the Central Commission for Ideology and Culture—the government body responsible for vetting all media and serving as the conduit of government social policy—to create national guidelines for reporting on and discussing HIV and AIDS in a non-stigmatizing way. The guidelines will be designed for use by media and others who communicate and educate on HIV and AIDS, covering topics such as language use; delivery of accurate and precise information on transmission, risks, prevention, treatment and care (rather than vague and sensationalized stories); and how people with HIV and AIDS should be

represented in the media. Though compliance to the guidelines will not be formally monitored, the government practice of reviewing and censoring all media content before release means that items not conforming to the guidelines likely will be rejected for publication or dissemination.

URL: HIV/AIDS Stigma: Finding Solutions to Strengthen HIV/AIDS Programs

Acquisition cost:

ANNOTATED BIBLIOGRAPHY

Stigma and discrimination against people living with HIV and AIDS

Title: Responding to HIV/AIDS – A Practitioner’s Guide to Mainstreaming in Rural Development Projects

Author(s): Iris D. Onipede, Sabine Dorlöchter-Sulser

Publication year: 2005

Publisher: Bischöfliches Hilfswerk Misereor e.V., Mozartstr. 9, 52064 Aachen, Germany.
www.misereor.orgne Dorlöchter-Sulser

Annotation: The Practitioner's Guide provides comprehensive information on HIV/AIDS mainstreaming and shows how to translate the mainstreaming approach into practice. It is structured as follows: Chapter 1: background on the mainstreaming concept. Chapter 2: overview of the root causes of HIV/AIDS in Sub-Saharan Africa and the impact of HIV/AIDS on rural societies. Chapter 3: step-by-step approach to identifying suitable areas for HIV/AIDS mainstreaming Chapter 4: good practice examples of HIV/AIDS mainstreaming. Chapter 5: institutional arrangements for enhancing HIV/AIDS competence in rural development projects, lobbying and advocacy approaches in the broader policy dialogue.

Regarding stigma: It is generally recognised thinking that HIV/AIDS is a fundamental development issue and must therefore become everybody's business in the field of development. The mobilisation of all actors in every sector of society according to their specific professional expertise and comparative advantage commonly described as “mainstreaming” has therefore become an important strategic weapon in the fight against HIV/AIDS.

Regarding gender:

Regarding rights:

Regarding communication:

URL: http://www.misereor.org/fileadmin/user_upload/pflege_thema/Mainstreaming_3-13_content.pdf

Acquisition cost:

ANNOTATED BIBLIOGRAPHY

Stigma and discrimination against people living with HIV and AIDS

Title: Writing for Our Lives: How the Maisha Yetu Project Changed Health Coverage in Africa

Author(s): WRITER: Mercedes Sayagues EDITOR: Kathleen Currie

Publication year: 2006

Publisher: International Women's Media Foundation

Annotation: This publication, *Writing for Our Lives*, documents best practices from Maisha Yetu, whose defining feature has been continuous in-house mentoring and training on health care reporting in six African media houses over a two-year period. The uninterrupted presence of journalist-trainers (as opposed to the more widespread model of one-time workshops on health care reporting) has allowed for the integration of theory and practice, resulting in dramatic changes in the quantity and quality of reporting on HIV/AIDS, TB and malaria. It has created champions of health care journalism in mid- and upper-level management where there was little or none before. It has helped journalists to recognize the centrality of women's stories in the HIV/AIDS crisis.

Regarding stigma: As in other African countries, silence, denial and stigma drive the HIV epidemic. Few people are willing to state publicly that they are HIV-positive, although free ARV treatment is changing this as people see that an HIV diagnosis is no longer a death sentence... The assessment found a need for: • Reducing stigma and negative stereotypes that are still prominent in news reporting.

Regarding gender: Some importance given to the need to explain gender issues and to ensure that they are adequately understood and covered by development workers and journalists.

Regarding rights: Not really.

Regarding communication: The continent of Africa bears the largest human burden of the HIV/AIDS pandemic. In the absence of a cure for AIDS, accurate and relevant messages on prevention, care and support are necessary to reduce prevailing stigma and bring about behaviour change. Information about malaria drug policies and TB treatment strategies can save lives – if people know about them. The African media, therefore, have an important role to play in helping to prevent, cure and better understand these public health issues. This role goes beyond simply reporting the latest statistics. It requires holding governments accountable for their actions and reporting on the human face of disease. It goes beyond merely reporting facts to questioning actions, recording the lives of those living with major illness, and helping save those lives.

URL: http://www.iwfm.org/docs/9464_WFOLforweb2.pdf

Acquisition cost:

ANNOTATED BIBLIOGRAPHY

Stigma and discrimination against people living with HIV and AIDS

Title: Putting It Together: AIDS and the Millennium Development Goals

Author(s): International AIDS Vaccine Initiative (IAVI)

Publication year: 2006

Publisher: IAVI

Annotation: This document is a summary of the IAVI report Putting it Together: AIDS and the Millennium Development Goals, a literature review of primary sources published between 2000 and 2005. The full report can be accessed at www.iavi.org/AIDSandMDGs_report

Regarding stigma: Nothing.

Regarding gender: No.

Regarding rights: No.

Regarding communication: No.

URL: <http://www.iavi.org/viewfile.cfm?fid=33080>

Acquisition cost:

ANNOTATED BIBLIOGRAPHY

Stigma and discrimination against people living with HIV and AIDS

Title: Development of a Brief Scale to Measure AIDS-Related Stigma in South Africa

Author(s): Seth C. Kalichman, Leickness C. Simbayi, Sean Jooste, Yoesrie Toefy, Demetria Cain, Chauncey Cherry, and Ashraf Kagee

Publication year: 2005

Publisher: AIDS and Behavior, Vol. 9, No. 2, June 2005 DOI: 10.1007/s10461-005-3895-x

Annotation: Although there has been progress in AIDS stigma research, there are no multi-item AIDS stigma scales that have been shown reliable and valid in Africa. The current research reports the development of the nine-item AIDS-Related Stigma Scale. Research conducted in five South African communities (N = 2306) found the scale internally consistent, $\alpha = 0.75$ and time stable over 3 months, $r = 0.67$. The scale was also reliable in three different languages (English, Xhosa, and Afrikaans). Correlations showed that the AIDS-Related Stigma Scale was moderately inversely correlated with years of education and AIDS knowledge. In addition, individuals who stated that HIV positive persons should conceal their HIV status had higher AIDS-Related Stigma Scale scores. Also supporting the scale's construct validity, individuals who refused to report whether they had been tested for HIV scored higher on the AIDS-Related Stigma Scale.

Regarding stigma: Nothing.

Regarding gender: No.

Regarding rights: No.

Regarding communication: No.

URL: <http://www.ncbi.nlm.nih.gov/pubmed/15933833>

Acquisition cost:

ANNOTATED BIBLIOGRAPHY

Stigma and discrimination against people living with HIV and AIDS

Title: Measurement of the Role of Families in Prevention and Adaptation to HIV/AIDS

Author(s): Willo Pequegnat, Laurie J. Bauman, James H. Bray, Ralph DiClemente, Colleen Dilorio, Sue Keir Hoppe, Loretta Sweet Jemmott, Beatrice Krauss, Margaret Miles, Roberta Paikoff, Bruce Rapkin, Mary Jane Rotheram-Borus, and Jos ́e Szapocznik

Publication year: 2001

Publisher: AIDS and Behavior, Vol. 5, No. 1, 2001

Annotation: HIV is a family disease. Family research in HIV is challenging because of complexities of family measurement, the range of family constellations across cultures, and the issues specific to HIV-affected families. A Consortium of NIMH-funded investigators is conducting HIV research on families—defined as networks of mutual commitments. A procedure for identifying the “family” is proposed. This article reviews assessment strategies from two research traditions, both of which have been greatly concerned with social context: family assessment tradition—family membership, parenting, and interactional dynamics; HIV/AIDS research tradition—HIV-relevant constructs generalized to minority families. Initially, a systematic procedure for defining family membership is provided. Constructs and measures derived from the family assessment tradition are described, including self-report and observational procedures. Constructs and measures of relevance to family research that originated in the HIV/AIDS research tradition are described: HIV knowledge, stigma, disclosure, and social support. Constructs presented derive from the Consortium’s research on the role of families in prevention and adaptation to HIV/AIDS. Most of the research conducted by the Consortium has taken place with inner-city, minority, heterosexual families. By informing the selection of constructs and measures relevant to investigating the role of families in HIV prevention, and adaptation to living with HIV/AIDS, it is the Consortium’s intention to enhance the quality and quantity of research at the intersection of families and HIV/AIDS.

Regarding stigma: Stigma and disclosure are closely linked interpersonal processes, in which as stigma increases, the likelihood of disclosure decreases. However, research is needed on family level process that are supportive of family members who (at the individual-level of measurement) suffer stigmatizing illnesses such as HIV, and of the kind of problem solving and conflict management skills that may encourage or discourage constructive disclosure in families, and in particular disclosure of stigmatizing illnesses and conditions.

Regarding gender: No.

Regarding rights: No.

Regarding communication: Only in the context of the family.

URL:

<http://www.ingentaconnect.com/content/klu/aibe/2001/00000005/00000001/00292918?crawler=true>

Acquisition cost: 44

ANNOTATED BIBLIOGRAPHY

Stigma and discrimination against people living with HIV and AIDS

Title: Can We Measure HIV/AIDS-Related Stigma and Discrimination? Current Knowledge About Quantifying Stigma in Developing Countries

Author(s): USAID

Publication year: 2006

Publisher: USAID

Annotation: This report lays out current knowledge and recommendations for quantitatively measuring S&D in a developing country context. Although recent work in the development of indicators has brought the international community closer to measuring stigma quantitatively, more work is needed to reach the goal of using quantitative measures to describe the state of S&D in any given setting with confidence and clarity or to draw comparisons across settings. In particular, the following next steps are needed: (1) capture stigma's multiple domains; (2) test the viability of a standard set of quantitative measures; (3) standardize and refine wording of data collection items; (4) design appropriate questions for surveys; and (5) develop indicators for understudied aspects of stigma.

Regarding stigma: To measure the impact of stigma-reduction programs, a comprehensive, standardized and streamlined set of indicators is needed that can feasibly be collected in the context of limited resources.

Regarding gender: No.

Regarding rights: PLWHA Rights Index is referred to.

Regarding communication: No.

URL: <http://www.policyproject.com/pubs/generalreport/Measure%20HIV%20Stigma.pdf>

Acquisition cost:

ANNOTATED BIBLIOGRAPHY

Stigma and discrimination against people living with HIV and AIDS

Title: Narrative in Times of Crisis: AIDS Stories in Ghana

Author(s): Kwesi Yankah

Publication year: 2004

Publisher: Journal of Folklore Research, Vol. 41, No. 2/3, 2004 Copyright © 2004 Department of Folklore and Ethnomusicology, Indiana University

Annotation: Within the African context, verbal taboos, or the notion of the unspeakable, constitute one important kind of response to tragedies and calamities that befall a locality or state. The society proscribes direct verbal references to such catastrophic events in the belief that the power of the spoken word can cause a recurrence or unduly evoke memories of past tragedies. In some contexts, references to those calamities have been made the sole preserve of the king, who may allow citizens to make sparing use of similar references when they are contesting or claiming ownership of important property. The global AIDS crisis and the numbers and distribution of those infected worldwide constitute one important issue that should engage the attention of the folklorist. Relevant issues include what types of lore or discourse the epidemic has generated in localities of high concentration. What are the folk constructions of the disease and its spread? What are lay perceptions of risk and vulnerability? What are folk notions of prevention and safe sex?

Regarding stigma: Even in the general perception of disease, deadly diseases are distanced and depicted as exotic, and so are carriers of such diseases. Folk constructions often characterize imaginary victims as having exotic profiles, or features that diverge from the speaker. In this case, the emphasis is on the endangered Other, and the secured Self. Invariably, the protagonist, for the sake of self-preservation or the protection of vital social interests even in the face of realities, disclaims exposure to risk. This way, the self and the familiar are lent greater legitimacy, while the exotic Other is depicted as an aberration. The AIDS pandemic should attract the attention of the folklorist and generate intense discussion over the scope and complexity of what may be called AIDSlore: namely all folk practices and interactions that are generated by the AIDS pandemic. It is only through appreciation of folk constructions of the disease and the interactions engendered that a final cure may be considered feasible.

Regarding gender: No.

Regarding rights: No.

Regarding communication: No.

URL: http://muse.jhu.edu/login?uri=/journals/journal_of_folklore_research/v041/41.2yankah.html

Acquisition cost:

ANNOTATED BIBLIOGRAPHY

Stigma and discrimination against people living with HIV and AIDS

Title: HIV/AIDS Stigma: Reliability and Validity of a New Measurement Instrument in Chennai, India

Author(s): Carla E. Zelaya, Sudha Sivaram Sethulakshmi, C. Johnson, A. K. Srikrishnan, Suniti Solomon, David D. Celentano

Publication year: 2007

Publisher: AIDS Behav (2008) 12:781–788 DOI 10.1007/s10461-007-9331-7

Annotation: HIV/AIDS stigma is a frequently cited barrier to HIV prevention, including voluntary counseling and testing. A reliable and valid measurement instrument is critical to empirically assess the extent and effects of HIV/AIDS stigma. The paper reports the development and psychometric testing of an HIV/AIDS stigma scale among 200 men in India. The resulting 24-item scale and the four subscales had good internal consistency (Cronbach's alpha overall was 0.81; subscales were 0.86, 0.73, 0.72 and 0.76, respectively). The scale and distinct subscales suggest a valid and reliable measure for HIV/AIDS stigma in a setting with highly prevalent HIV risk behaviors.

Regarding stigma: By measuring the current level, distribution and predictors of HIV/AIDS stigma, future reduction efforts can be appropriately designed and targeted, and the effectiveness of stigma interventions can be assessed through monitoring and evaluation. Measuring perceived community stigma (i.e., perceptions of how people in one's community behave, act or feel toward those living with HIV/AIDS) among individuals who do not know their HIV status may reveal an important predictor for participation in HIV VCT.

Regarding gender: Nothing.

Regarding rights: No.

Regarding communication: No.

URL: <http://www.springerlink.com/content/h078g464280v02h4/>

Acquisition cost:

ANNOTATED BIBLIOGRAPHY

Stigma and discrimination against people living with HIV and AIDS

Title: Asleep at the Wheel? Five Years of G8 Promises on Global Health

Author(s): World Aids Campaign

Publication year: 2006

Publisher: The World AIDS Campaign Warmoesstraat 149-151 1012 JC Amsterdam The Netherlands

Annotation: The 2005 G8 Gleneagles communiqué appeared promising on AIDS, given its call to the Joint United Nations Programme on AIDS (UNAIDS), the World Health Organization (WHO) and other international bodies to "... develop and implement a package for HIV prevention, treatment and care, with the aim of coming as close as possible to universal access to treatment for all those who need it by 2010." But does that promise offer any more hope of fulfilment than previous G8 commitments on health? The annals of recent G8 statements on health (see section 2) provide a gloomy set of insights.

Regarding stigma: Supporting high level political engagement to increase awareness and reduce the stigma associated with HIV/AIDS.

Regarding gender: Supporting the development, adoption and implementation of gender-sensitive, multi-sectoral HIV/AIDS programs for prevention, care, and treatment.

Regarding rights: No.

Regarding communication: We will encourage and support where appropriate the use of information and communication technologies for medical treatment.

URL: <http://www.worldaidscampaign.org/en/Key-events/G8/Asleep-at-the-Wheel-Five-Years-of-G8-Promises-on-Global-Health>

Acquisition cost:

ANNOTATED BIBLIOGRAPHY

Stigma and discrimination against people living with HIV and AIDS

Title: Partnerships between Churches and People Living with HIV/AIDS Organizations

Author(s): World Council of Churches

Publication year: 2005

Publisher: WCC

Annotation: HIV-related stigma is seen to be at the heart of many failed efforts over the years – both church and secular – to respond to HIV, particularly to break the silence and denial surrounding the existence of HIV in communities.¹ Many interventions, whether for HIV prevention, care, support or treatment, have also been less than effective due to HIV-related stigma. These guidelines are intended to assist churches in a transformation process that in some cases has already begun and in others is yet to begin, and to steer that process. They are targeted at all levels of the church, whether church leaders, parish priest or ministers, people working in faith based organizations etc. – anyone within a church working on HIV should be able to benefit from partnering with PLWHA.

Regarding stigma: In the past twenty-three years, any organization working on any aspect of HIV and AIDS has encountered the frustration caused by HIV-related stigma, which can limit the effectiveness of prevention, care, support and treatment interventions. Any effective intervention, therefore, requires mainstreaming stigma eradication strategies into all interventions – something that cannot be achieved without forming partnerships with PLWHA organizations. As stressed above, “building partnerships is about working with others to achieve what we cannot achieve on our own,” and the pervasiveness of HIV-related stigma underlines the fact that all organizations responding to the epidemic need to be in partnership with PLWHA organizations.

Regarding gender: The AIDS epidemic is closely related to social relationships; it has not responded to interventions that have failed to make gender considerations central to their activities. Since most prevention activities have focused (and continue to focus) on some version of ABC, the failure to mainstream gender has rendered most of these projects less than effective. Churches and faith-based organizations need to listen to PLWHA tell their stories in order to grasp the centrality of gender and the importance of mainstreaming it in projects and programmes. All interventions need to systematically mainstream gender into all stages i.e., planning, implementation, monitoring and evaluation of all projects and programmes.

Regarding rights: We ask the churches to help safeguard the rights of persons affected by HIV/AIDS and to study, develop and promote the human rights of people living with HIV/AIDS through mechanisms at national and international levels... Breaking the silence around HIV and AIDS also involves respecting the rights of marginalized groups.

For example, members of the World Alliance of Reformed Churches (WARC) have different views on homosexuality but Christians can agree that it is wrong to violate human rights because of sexual orientation... Find ways to help people renew their duty to alleviate suffering, to affirm personal faith and to lead a life that fully respects the dignity and rights of others.

Regarding communication: Churches must also face the challenge of entering new arenas of activity - arenas that they have previously generally ignored or felt lay outside their responsibility, including the political arena. Access to treatment must be high on churches' agenda. Churches have a legitimate, even essential role in advocating for policies, laws and programmes that prevent HIV infection and provide care for PLWHA. This means using a full range of advocacy efforts for being involved in policy discussions right through to direct action on the street.

URL: <http://www.oikoumene.org/en/resources/documents/wcc-programmes/justice-diakonia-and-responsibility-for-creation/health-and-healing/hivaids/wcc-statements-and-studies/2005-partnerships-between-churches-and-people-living-with-hivaids-organizations.html>

Acquisition cost:

ANNOTATED BIBLIOGRAPHY

Stigma and discrimination against people living with HIV and AIDS

Title: WOMEN, HIV/AIDS AND HUMAN RIGHTS: An Annotated Syllabus

Author(s): Prepared by the International Reproductive and Sexual Health Law Programme, Faculty of Law, University of Toronto

Publication year: 2008

Publisher: University of Toronto

Annotation: In 2006, the International Reproductive and Sexual Health Law Programme, along with several partner organizations, hosted a Women, HIV/AIDS and Human Rights Skills Building Workshop Series at the University of Toronto Faculty of Law. The Skills Building Workshop Series, which took place during the XVI International AIDS Conference, was designed to enable participants to frame the neglect and marginalization of women's needs and circumstances in the context of HIV/AIDS as not simply poor health and social policy, but as violations of women's human rights. The Series further addressed collaborative legal and political approaches to hold state and non-state actors accountable for the violation of women's rights in the clinical, health systems and underlying socio-economic contexts. The Women, HIV/AIDS and Human Rights Syllabus was originally distributed to participants of the Skills Building Workshop Series. It was re-structured and updated in December 2007, and again in April 2008 to reflect developments in reports, articles, and case law. Advocacy and educational organizations are encouraged to adopt and adapt these materials for their teaching and skills-building purposes.

Regarding stigma:

Regarding gender:

Regarding rights:

Regarding communication:

URL: http://www.law-lib.utoronto.ca/diana/women_hiv_aids/contents.htm

Acquisition cost:

ANNOTATED BIBLIOGRAPHY

Stigma and discrimination against people living with HIV and AIDS

Title: Women, girls, HIV/AIDS, and the world of work

Author(s): International Labour Organization

Publication year: 2004

Publisher: ILO

Annotation: There is growing recognition of the damage HIV does to national economies, and clear evidence now that women are bearing the largest share of the costs.

Regarding stigma: HIV/AIDS-related stigma and discrimination alter individual behaviour, damage employment and career prospects, and blight the quality of health and other social services. It is recognized that women are more likely than men to be stigmatized or repudiated. In the workplace, discrimination can mean mandatory testing, quarantine, exclusion, and outright job loss.

Regarding gender: Gender inequality has magnified the HIV epidemic into an economic and social crisis, especially in Africa. The challenge is to pursue two parallel lines of action simultaneously. There is an urgent need to address the problem of AIDS now, and women must have their fair share of treatment. At the same time, it is essential to address the root causes of HIV transmission. To address the low status of women is the means to intervene and avert the violence against women and girls that places them directly in harm's way. To promote women's empowerment, protect their rights, target actions to raise their status, and provide them with training, life skills and access to work will enable them to gain better control of their lives, their bodies and their sexual relations.

Regarding rights: The ILO Code of Practice provides guidelines to both employers and workers as well as governments with respect to workplace actions. It includes the principles of gender equality, stressing that successful prevention and impact mitigation will depend on more equal gender relations and the empowerment of women.

Regarding communication: No.

URL: <http://www.ilo.org/public/english/protection/trav/aids/publ/women-iloaids-brief.pdf>

Acquisition cost:

ANNOTATED BIBLIOGRAPHY

Stigma and discrimination against people living with HIV and AIDS

Title: Show Us the Money: Is Violence Against Women on the HIV&AIDS Funding Agenda?

Author(s): Women Won't Wait

Publication year: 2007

Publisher: Women Won't Wait Campaign

Annotation: In response to the growing body of evidence on violence and HIV&AIDS, and in response to calls by human rights advocates for effective action on these issues, international institutions and national governments have articulated a concern to address gender-based violence, including within the context of HIV&AIDS. Little is known, however, about what is actually being done to address these issues in policies, programming and funding, and whether the efforts that are underway are truly based on the human rights and health agenda advocated for so long by women's movements throughout the world. In order to better understand the level of resources – in policy, programming and funding -- committed to this deadly intersection, a report was commissioned by an international coalition of organizations working on women's human rights, development, health and HIV& AIDS. This report analyses the policies, programming and funding patterns of the four largest public donors to HIV&AIDS: the Global Fund to Fight AIDS, Tuberculosis and Malaria, the President's Emergency Fund for AIDS Relief (PEPFAR/US), the UK Department for International Development (DFID), and the World Bank, and UNAIDS (the Joint UN Programme on HIV/AIDS). The report is the first step in an effort by this coalition to monitor the policies, programmes, and funding streams of international agencies and national governments, and to hold these agencies accountable to basic health and human rights objectives.

Regarding stigma: Necessary steps to address the intersection between HIV&AIDS and violence against women and girls include political will, financial and human resources and a wide range of creative and strategic interventions, such as: • efforts and strategies to respect, protect and fulfil women and girls' human rights to HIV& AIDS prevention, treatment and care and support and to anti-violence programming work to change social norms in order to establish women's and girls' rights to bodily integrity and choices • women's legal rights in general and, in particular, rights-protection for survivors of violence and women and girls living with and affected by HIV&AIDS.

Regarding gender: More attention – through policy dialogue, policy priorities, programming and funding – is crucial. Ultimately, however, without a clear understanding and analysis of its impact, donor support will only mitigate, but not arrest, either HIV&AIDS or violence against women, and will not achieve gender equality. Because the current framework for HIV&AIDS funding is not built on an understanding of gender inequality, many programmes fail to reduce HIV infections among women or mitigate the more general impact of the disease on women and girls.

Here, PMTCT (prevention of mother-to-child transmission) programmes, for example, treat women only in the context of childbearing, while ABC (abstain, be faithful, use condoms) initiatives generally ignore the fact that many women and girls are not in a position to negotiate the conditions of a sexual encounter. The current axiom of universal access to prevention, treatment, support and care will not reach its goals nor halt the feminization of the pandemic without a gender-sensitive realignment fully anchored in human rights norms and standards. Nor will a results-based focus that emphasises quantity over quality necessarily protect the rights of women, unless it includes gender equality among the results it measures.

Regarding rights: A gender- and human-rights-sensitive approach to HIV&AIDS and violence against women and girls is essential to finding innovative and effective solutions. Addressing the human rights implications of HIV&AIDS and violence against women requires grappling with gender inequality and other forms of discrimination at all levels – from reforming policies, to reformulating services, to educating and mobilizing communities. Moreover, the links between human rights, HIV&AIDS and violence against women must be made in practical ways that have immediate impact on women’s lives. Women benefit most when ‘rights-based approaches’ emphasising principles of non-discrimination, accountability, transparency and participation are used in provision of services, as well as in advocacy efforts.

Regarding communication: Cultural patterns that negate the value and rights of women, dehumanizing practices such as domestic violence and sexual abuse persist, and laws are in effect that impede women from making their own reproductive decisions. Customs, beliefs, the media and marketing, even humor, reveal social attitudes that threaten women’s dignity and generate discrimination against women and vulnerable populations, thereby increasing their susceptibility to the virus.. As a result of this new aid architecture, it is clear that the emphasis must shift to engaging governments proactively at the level of policy dialogue on a variety of issues, including the question of the intersection of violence against women and girls and HIV&AIDS. In addition, donors must make specific commitments to design monitoring and evaluation methods that allow for a clear understanding about the extent and impact of programming that works at the intersection of the epidemics. Yet, they must also be careful to support the capacity of civil society actors to engage in more effective advocacy with their own governments.

URL:

http://www.womenwontwait.org/index.php?option=com_content&task=view&id=27&Itemid=1

Acquisition cost:

ANNOTATED BIBLIOGRAPHY

Stigma and discrimination against people living with HIV and AIDS

Title: If I Kept It To Myself: Young Women Intervene in a World with AIDS

Author(s): World WYCA/The Global Coalition on Women and AIDS

Publication year: 2006

Publisher: World WYCA

Annotation: Statistics clearly show that young women and girls are highly affected by the AIDS pandemic. While the situation is serious, young women are by no means idly hoping for better days. At the YWCA, we are seeing another type of response. This response is unique and challenging, and gives the word courage a new, humbling meaning as we see young women treading upon grounds that many only dream or dare talk about. Young women are the drivers and implementers of policies and programmes, which are reaching out and touching lives and communities. The World YWCA has documented these inspiring stories to highlight how young women are working to alleviate the suffering caused by HIV and AIDS. However, this is not just story telling but a tool for empowerment. We want other young people, and the not so young, to benefit from lessons learnt by these courageous young activists. Whatever your background, age and social environment, you will be inspired to take action. In the pages that follow, you will meet young women from all over the world, who have shaken their communities as peer counsellors and educators, as care givers, and as people living openly with HIV and AIDS; giving hope to many and promoting a humanistic response to the pandemic. Other young women are simply using their professional skills to create tools and platforms for dialogue and empowerment.

Regarding stigma: Stigma is often mentioned as one factor.

Regarding gender: Gender inequality and gender issues are cited as part of the context.

Regarding rights: Human rights context is mentioned with emphasis on women needing to know their rights.

Regarding communication: Section of stories on media and communications.

URL:

http://www.worldywca.info/index.php/ywca/world_ywca/communications/resources/if_i_kept_it_to_myself

Acquisition cost: