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SHAME, STIGMA, DISCRIMINATION & HIV&AIDS

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“Long-term success in responding to the HIV epidemic will require sustained progress in addressing human rights violations, gender inequality, stigma, and discrimination” according to the 2008 UNAIDS Report on the global AIDS epidemic. How are shame, stigma and discrimination being addressed in your context? Share your successes and lessons learned with our AIDSLink community by sending your contributions to international.aids-consultant@sim.org

*Those who look to the Lord are radiant;
their faces are never covered with
shame.
Taste and see that the Lord is good;
blessed are those who take refuge in
him.*

Psalm 35:5,8

Diane

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1. BIBLICAL FOUNDATIONS: SHAME & STIGMA

Consider the connections between leprosy in biblical times and HIV&AIDS today. Both are associated with fear, shame, stigma and social exclusion. Those infected are considered impure, unclean and defiled, sometimes even under God’s judgment. Both shock. There is no apparent cure.

1. Read Mark 1:40 “You can make me _____” (Leviticus 13:45-46). Think about his life.
2. Jesus was indignant. Read 1:41 Why?

Jesus reaches out, touches and speaks. Note the important connection between the plea for compassion and Jesus’ actions. Jesus habitually breaks social taboos and boundaries that alienate people from others. What does this teach us?

3. Read 1:42-45. What were the results?

By identifying with the afflicted man, Jesus the pure and holy One becomes ritually unclean. There is no place for shame because Jesus has dealt with his problem.

4. How many times does the word “clean” appear? Much more than healed physically, the man is now clean or pure - he is acceptable to God and to the religious leaders and to everyone.

5. Many secular HIV&AIDS interventions promote the community’s acceptance of infected and affected people. What makes a Christian response to stigma and discrimination distinct?

6. To what extent has accessibility to antiretrovirals (ARV) changed the level of expression of stigma and discrimination in your community?

2. STIGMA & DISCRIMINATION – Nigeria

The following article was contributed by Nehemiah Ghata of The Evangelical Church of West Africa (ECWA) AIDS Ministry Team. For further information and networking, e-mail: TEAM@hisen.org or tnghata@gmail.com

Stigma is a powerful and discrediting social label that radically and negatively affects the way individuals view themselves and the way they are viewed by others. Stigma reduces a person from wholeness to a tainted, discounted being. Discrimination occurs when a distinction is made against people that results in them being treated unfairly and unjustly on the basis of belonging, or perceived belonging, to a particular group. This may include exclusion or restrictions as a result of their status.

“Quarter to go, quarter to go, quarter to go,” the children shout as he puts his head down and tries to pretend he is not hearing their taunts. As he gets close to his house, he dashes in as fast as his legs can carry him. Inside the house he hangs onto his mother’s legs crying, “Mother, can’t we leave this area? Can’t we get a house somewhere far away from this neighbourhood?” Alex is just a boy somewhere about 8 years old who is HIV positive.

Causes:

1. Ignorance and fear: Many people discriminate because of their lack of knowledge. They think that sitting next to, eating with or doing things with people living with HIV&AIDS will give you the virus. Consequently they consciously or unconsciously, avoid those infected.

2. Pride and self-righteousness: Some stigmatize because they think they are better or more holy than people living with HIV. This is like the Pharisees.

3. Lack of self-esteem: Many people living with HIV look down on themselves because of their sero-status, seeing themselves as worthless, finished and a disgrace to themselves and their families. Sadly, their poor self-esteem only encourages stigma against them.

Effects:

Stigma and discrimination, for whatever reason and at whatever level, bring negative consequences, and are a 'no win' situation. Both those stigmatizing and the ones being stigmatized lose.

Apart from health and wellbeing, those being stigmatized often lose the love of friends, family and neighbours. They have difficulties accessing community and palliative care or even services such as ARVs. They miss out on real Christian love and opportunities to hear the gospel. This is very serious as everyone should be able to hear about God's offer of eternal life.

As well as the infected, those affected by HIV are also impacted by stigma. I have met parents who find it difficult to associate with peers because a son or a daughter is living with HIV or has died of AIDS. They live their old age in shame and disgrace.

The church has both lost and gained credibility by its treatment of people with HIV and AIDS. It can lose its right to share the gospel. Jesus Christ said, "By this shall all men know that you are my disciples, if you have love one for another." We cannot be witnesses to people we are running away from. This becomes more important in cases where the church perceive that the person has it as a result of sin. Instead of distancing ourselves from those infected and affected, we need to help them get right with God. This is what Jesus would do. Do we run the risk of losing the commendation by Jesus found in Matthew 25:35,36,40 ". . . you did for me"?

3. RURAL AREAS, STIGMA & VCT – SOUTH AFRICA

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In rural areas many still believe that there is no AIDS. Many are bound by witchcraft. If a person is sick they believe that a spell has been cast upon them. HIV&AIDS is a complex problem with devastating effects on communities and families worldwide. Each country requires many tools in order to turn the tide of this epidemic. Voluntary Counselling and Testing (VCT) is a tool for primary prevention intervention. It can serve as an entry to care and support services for infected persons.

We are working with the caregivers in rural areas visiting terminal ill patients in their homes. They share their difficulties in accessing VCT programs. In these areas people living with HIV&AIDS (PLWHA) find it difficult to disclose their status to family members because of stigma. It is difficult to visit VCT sites for post-test counseling for fear of being seen and stigmatized by community members who lack information and education on HIV&AIDS. Even in social gatherings like wedding parties and funerals, PLWHA they may be prevented from participating in home chores like preparing food. It may be difficult to set up support groups. PLWHA need help with disclosure and adherence in medication.

Community outreach in our setting includes educating families about HIV&AIDS, providing information for PLWHA on steps to disclosure, and journeying with them in this process. It includes visiting the terminal ill which may include counselling, bathing, discussing the future of the patients and their children, sorting out the burial clubs or schemes, and supplying most needed resources like disposal nappies, mouth-wash medicine, and linen-savers. Community outreach is at the heart of our activities.

Lessons Learned: Successful community-based programs addressing stigma and discrimination:

- Begin small and grow slowly as the needs and resources of the community grow and change
- Involve people from the community in each stage of the work from planning to implementation to evaluation
- Engage leaders whose main interest is serving the community, not advancing their careers or making money

- Are facilitated by people who are open to new ideas and adapt to the changing needs of those served by the project
- Are holistic, not thinking about health just in terms of prevention and treatment of the disease but of each person's social emotional and physical situation

Community outreach and community mobilization work is strengthened by using advocacy and lobbying, using policy and legal frameworks, promoting human rights literacy, running workshops to raise awareness, and partnering with influential institutions."

4. CONDEMNED, INVISIBLE & ISOLATED – SUDAN

In Sudan there is an urgent need for an action plan to address issues of stigma and discrimination affecting more than 300,000 people living with HIV, most of whom do not yet know they are infected. A Christian Aid report June 2008 *Condemned, invisible and isolated: Stigma and support for people living with HIV in Khartoum*, examines the stigma and prejudice faced by people living with HIV in the Sudanese capital, Khartoum, and explores the social, economic and medical repercussions of HIV.

The report (p2) notes: "Stigma is the most significant single barrier to effective work against HIV. The effects of being stigmatized as a result of HIV infection or association can be devastating. They include social rejection by friends, family and colleagues, and the psychological damage that comes with it, particularly at a vulnerable time after diagnosis, when empathy and respect are sorely needed. PLWHA face job loss or restriction of professional opportunities, a reluctance to seek health services (usually for fear of discovery) endangering health still further, a reluctance to be tested for HIV, and the sheer, grinding exhaustion of having to put up with the ignorance and discrimination of others. In Sudan, and particularly in Khartoum, there is an urgent need for an action plan to address issues of stigma and discrimination.

A number of simple interventions would help start this process: the widespread promotion of workplace HIV policies, public anti-stigma campaigns and the dissemination of accurate and comprehensive information, and scaling up non-stigmatizing home-based care for people with HIV and their families. For the complete report and recommendations (926kb) see:

www.christianaid.org.uk/issues/hiv/resources/stigmatisation.aspx

5. PEOPLE LIVING WITH HIV STIGMA INDEX

The *People Living with HIV Stigma Index* (2008) is a comprehensive tool to measure changing trends in relation to stigma and discrimination experienced by PLWHA. In the activity, the process is as important as the product. It aims to address stigma relating to HIV while also advocating on the key barriers and issues perpetuating stigma - a key obstacle to HIV treatment, prevention, care and support.

The Stigma Index has been designed by and for people living with HIV, using a questionnaire that focuses on different aspects of stigma and discrimination experienced by positive people including: social exclusion, access to work and health services, internal stigma, having children, knowledge and use of legal protection, effecting change, and HIV testing and disclosure. It is designed to detect the prevalence of and changes in stigma over time and can be a useful policy, advocacy and capacity-building tool for organizations working at the community and national levels.

Visit the Stigma Index website: www.stigmaindex.org

6. STEPPING STONES RE-VISITED

Stepping Stones Revisited: Stories from the Village of Buwenda, Uganda (2008) by Glen Williams. The original and popular 'Stepping Stones' training package, published in 1995 by Strategies for Hope and ActionAid, is now used in over 100 countries worldwide. The package, containing a 240-page manual and a 70-minute workshop video, is designed to help women and men explore their social, sexual and psychological needs; to analyse the communication blocks they face; and to practise different ways of addressing their relationships.

This new DVD takes us on a journey back to a village in southwest Uganda, where the original 'Stepping Stones' workshop was conducted and the video filmed in 1994. Participants in the original workshop tell us about the changes that have since occurred in their lives: less domestic violence,

reduced alcohol consumption, greater self-esteem among women and young people, greater teamwork between spouses, greater understanding and support for HIV-positive people, a sustained increase in condom use, and greater abstinence from sex especially amongst widows who realize that this is their right, if they want it.

To order copies of 'Stepping Stones Revisited', contact info@talcuk.org Website: www.talcuk.org
To view a 7 min clip of 'Stepping Stones Revisited', see: www.stratshope.org/t-video-revisited.htm
For more information about Stepping Stones, visit: www.steppingstonesfeedback.org

Organisations based in sub-Saharan Africa that are unable to purchase this or other Strategies for Hope materials may request free copies from: Series Editor, Strategies for Hope Trust
Email: sfh@stratshope.org Website: www.stratshope.org Fax: +44 1865 436069.

7. MAKING IT KNOWN – PACANet

The Pan African Christian AIDS Network (PACANet) is holding a Pre-ICASA conference: *The Church and HIV and AIDS: Challenged or Changed?* 29 Nov - 2 Dec 2008, Dakar, Senegal.

The planning activities will be divided into theme and worship/theological reflection sessions. The HIV theme sessions consist of four focus areas: OVC, prevention, treatment and care, and M&E skills building. There will be five cross-cutting themes incorporated into each of the four focus areas: gender, advocacy, participation by people infected with HIV, leadership, and stigma. For further information contact the conference organizer at dakar@pacanet.net



8. TIP of the MONTH – MAPPING STIGMA

Mapping stigma is useful to identify the contexts in which stigma occurs, to explore reasons for stigma and its effect on different people and for identifying strategies for reducing stigma. It can be used as a tool to plan and evaluate interventions addressing stigma.

1. In large group, discuss what stigma is - an attribute that singles out an individual or a specific group of individuals as different. They are regarded in a negative and judgmental way because they possess that attribute, in this case HIV
2. In pairs or threes, walk through the community or location identifying places where stigma occurs. Draw this on a map
3. Each group explains their map to the larger group
4. Create a 'cause, effect and strategies' diagram participants from input by the participants on (1) reasons for stigma in different places, (2) the effects of it, and (3) strategies for reducing it

Tips for facilitators:

Stigma mapping is best done in small groups. Participants may not physically be able to walk around the community or location for example if the distances are too great. Participants can also map stigma by looking at a map of the community or location and discussing where stigma occurs. Alternatively, identify locations in the community (such as the market, bus station and so on) and put up signs representing these locations around the place being used for the session. Participants can then walk around the venue in pairs or threes to discuss where stigma occurs.

This tool has been adapted from *Tools Together Now*, 2006, p17 by AIDS Alliance and is available for downloading (2.9MB, 250 pages) at: www.aidsalliance.org/sw36326.asp



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