

# **Operational Research Agenda for Stigma and HIV/AIDS in Africa October 2001**

## **Introduction**

In 2001, Health & Development Networks (HDN) and the UNAIDS Inter-country Team for East and Southern Africa, worked together to facilitate the development of an operational research agenda on stigma and HIV/AIDS in the African region. Project activities included:

- Structured discussion on the Stigma-AIDS e-mail discussion forum
- Literature review
- Focus group discussions and key informant interviews
- Regional Consultation Meeting, 4-6 June 2001 in Dar-es-Salaam, Tanzania

Out of these activities and process, the operational research agenda below was developed in the form of research questions and ideas for research and action. It has been extracted in its current form for easy reference, from the report of the regional consultation meeting.

The agenda has been divided into six main categories to help focus on the various operational research gaps that need to be highlighted:

- Definition and context
- Health care sector
- People living with HIV/AIDS
- Religious sector
- Communication
- Indicators to measure stigma

### **Stigma: definition and context**

- What factors work best in reducing HIV/AIDS-related stigma as it affects children?
- What culturally acceptable approaches can be used successfully to reduce stigma?
- What factors have enabled some communities to overcome and move beyond stigmatising responses to HIV/AIDS?
- How do individuals move beyond stigma to face the possibility of having HIV within the current environment? What personal factors enable these people to seek testing, and what enables those who test positive to deal openly with their status?
- What forms does HIV/AIDS-related stigma take across different East and Southern African cultural groups, communities and countries?
- What are the common characteristics of HIV/AIDS-related stigma in East and Southern Africa?
- What are the determinants of HIV/AIDS-related stigma in different contexts?
- What 'best practice' models of stigma reduction are there that can influence interventions and programs.
- How do we understand better the relationship between stigma, discrimination and human rights in specific settings?
- What are the power relations that surround stigma? In particular, we must address the question of who defines stigma – is it the stigmatized individual, or is it those observing the stigmatization process and participating in it?
- What have been the most effective educational campaigns to reduce stigma on a societal level?
- How have countries actually modified the political culture to produce the supportive environment and to actualize pro-HIV policies that help reduce stigma?
- What is the damage done to those experiencing stigma?

### **Stigma and the health care sector**

- To what extent is stigma present amongst health care providers (HCP)?
- What are the determinants of stigma among HCP?
- Does access to specialized provision of care and support reduce stigma?
- Does development of links between clinical and community-based facilities reduce stigma?
- What is the impact of stigma on voluntary counselling and testing (VCT): uptake, quality of counselling and outcomes?
- What is the impact of VCT on stigma? Does it increase stigma or help to reduce it?
- Assess longitudinally people who access VCT over period of time. Start before pre-test to see whether people are self stigmatizing and/or experience stigma from outside.
- Assess to what extent the surrounding environment perpetuates stigmatisation within VCT settings and how we can intervene.

#### *Ideas for Intervention*

- In the intermediate and long term, design a practical guide for in-service orientation and sensitization tool and build motivation and awareness among health care providers to recognize and avoid stigmatizing behaviors.
- Conduct intervention linked research to better understand the potential impact of antiretrovirals on reducing stigma.
- At the client, care provider and hospital management levels, promote disclosure of results to significant others while protecting confidentiality.
- Assess the PLHA-friendliness of services.

### **Stigma and people living with HIV/AIDS**

- Do all HIV-positive people experience self-stigmatisation? If not, how do people avoid this vicious cycle?
- What can be done to help people move more quickly through the stages of realization and toward full and productive lives as positive people?
- What are the effects of HIV-related stigma, including self-stigma, on the productivity of an HIV-positive individual?
- Is perceived stigma worse than actual stigma and do both require different approaches in terms of understanding, research and interventions?
- To what degree is disclosure an effective tool in HIV prevention? Do public testimonials of HIV-positive individuals influence sustained reductions in risk behaviours among the uninfected?
- What are the reasons that HIV-positive people go public with their positive status?
- Do people experience different levels of stigma when they are healthy and living with HIV and when they are sick with AIDS?
- What is the relationship between stigma and secrecy vs. shared confidentiality?
- What is the relationship between the greater involvement of people living with HIV/AIDS (GIPA) strategy, support groups, PLHA associations and stigma?
- What is the relationship between stigma and risk perception?
- What is the link between provision of effective care/treatment/nutrition and stigma or stigma reduction?
- What impact does stigma have on the quality of life for children and youth (Adapt the WHOQOL standard psychometric tool)?
- What is the impact of stigma on behaviour change.

#### *Ideas for Intervention*

- A checklist to assess the level of stigma. This should be a diagnostic tool that can assess the level of stigma within a family/community which will be useful in counselling, disclosure,

community organisation, advocacy, etc. Checklist could be used to read the situation at national, community, or family levels.

- A strategic approach to disclosure that prepares people for how, when and where they should disclose.
- National policies for essential package of care, where each player has clearly defined roles, government, NGOs, PLHA organizations etc. Governments should provide the policy framework and coordination.
- Longitudinal programme impact research on psychosocial support initiatives for children
- Youth and child participation in programming.
- Effectiveness and impact of life skills education to cope with stigma.

### **Stigma and the religious sector**

- What are indicators for stigma within a religious group, and what makes these indicators unique to the religious group?
- What are the differences in stigmatization between religions?
- Do we have examples of religious groups where stigma is minimal or has substantially decreased over the past two years?
- What is the relationship between strict moral teaching and stigma?
- Within the local community experience, how can personal faith be explored, respected, and affirmed as a fundamental strength for community response and destigmatization?
- What are the characteristics of an integrated care and prevention approach that allows for conflict resolution and results in stigma reduction?
- Regarding partnerships of the religious sector with other non-sectarian agencies, how can theological principles and identity be expressed respectfully, and linked to practices that are encouraged by the partners (such as counselling, behaviour change interventions, harm reduction, family protection, etc.)?
- What evidence exists that organizational response can be accelerated by community participation approaches that involve people, including leaders, from the religious sector?
- Can we compare levels of stigma in different communities by having one community where religious leaders talk openly, for example, about condoms and another where they do not?
- What is the impact of accumulating loss in families and communities? How does faith and future hope interrelate with the accumulating loss?
- How can capacity for shared confidentiality within groups be linked to scaling up both care and prevention action and impact?
- What is the level of knowledge, attitude and practices of religious leaders about HIV/AIDS?
- In what ways do religious leaders stigmatise and discriminate as perceived by communities?
- In what ways do members of the congregation (community) stigmatise and discriminate against individuals and families affected by HIV/AIDS?
- How are shame, guilt and isolation fueled by religious teachings and values?
- To what extent do religious values and teaching help to reduce stigma?
- How can religious leaders and groups be influenced to give accurate information to members of their communities?
- What is the relationship between stigma and gender inequalities within religious groups

### **Stigma and communication**

- How does the media perpetuate stigma?
- What types of media messages and images perpetuate stigma?
- What types of media messages and images reduce stigma?
- What role do mass media have to play in the AIDS information, communication and education challenge, with special focus on stigma?
- Is the media considered a credible source of HIV/AIDS information in African countries? How can the role of the media be strengthened to improve the credibility?
- What type of communication is the most appropriate?
- What media is effective in reducing stigma?

- How can the infected and affected people be involved in the information and communication process to influence the desired change?
- What is the effectiveness of sensitisation programmes for media people aimed at better HIV news coverage?
- What are the issues of stigma and denial within media ranks?
- How much influence does the commercial element have in constraining the mass media from fulfilling their social obligation to inform and challenge AIDS stigma?
- How do HIV/AIDS project planners value the mass media as an integral part of the overall communication process, and what strategic links have been established?  
Who is appropriately positioned to communicate about stigma in various settings?
- When is it appropriate to deliver the message?
- How does personal communication contribute to/decrease stigma?
- Which language is appropriate and not appropriate for use? How do we use stigma?
- To deliver effective messages we must first work out who are the prime target audiences, by sex, age, gender, educational background, values, perceptions, beliefs, lifestyles, sexual behaviour.

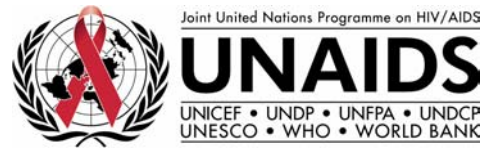
### **Indicators to measure stigma**

- Identify indicators for global dimensions of stigma and methods for illiciting local dimensions of stigma.
- Methods to understand underlying causes of stigma in Africa need to be explored and disseminated.
- Methods that look at issues around disclosure and stigma in a family setting need to be explored (including checking longitudinal data).
- Example of specific indicators:
  - ▶ How many men and women go for testing as an indicator?
  - ▶ How many men and women are open about their status?
  - ▶ Percentage of AIDS funerals attended by at least 75% of the village population divided by the percentage of AIDS funerals (Care International)
  - ▶ Percentage of people in a community going for VCT
  - ▶ Percentage of people testing positive and disclosing status to various categories of people
  - ▶ Percentage of people using AIDS hotline services
  - ▶ Percentage of positive people joining support groups (by sex)
  - ▶ Percentage of people with HIV who report they delay seeking care
  - ▶ Percentage of people who seek care located far away
  - ▶ Percentage of people who report self segregation of personal items

### *Gaps in existing tools for measuring stigma:*

- Questions on different dimensions of stigma and denial, such as willingness to disclose, social isolation, or enacted stigma.
- Guidelines for qualitative explorations of stigma, denial and discrimination that could facilitate the development of locally relevant indicators, within globally relevant dimensions.
- Validation and adaptation of existing tools in new settings.
- Tools for assessing stigma, denial, and discrimination in new settings that include not only different cultures, but different institutions (e.g. workplaces, hospitals).
- Questionnaire items on actual, as opposed to hypothetical, incidents. For instance, questions that can be posed to family care givers, health care workers.
- Questionnaire items that address stigma directed towards people who are not necessarily HIV positive, but who are associated with HIV/AIDS or with PLWA, such as health care workers, sex workers, injecting drug users, providers of home-based care, and family members.
- Tools to capture stigmatizing representations of PLHA in media, public health communications, and in government policy.

For more information about project activities or for more documentation please visit the HDN website below.



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