A meeting entitled “Stigma and HIV/AIDS in Africa: Setting the Operational Research Agenda” was convened in Dar-es-Salaam, Tanzania from 4-6 June 2001. It was attended by 80 participants representing organisations of people living with HIV/AIDS, physicians, nurses, researchers, communications specialists, community workers, faith-based organisations and UN agencies from 15 countries, primarily from Eastern and Southern Africa.
**Context for Action**

The participants of this regional consultation on stigma and HIV/AIDS in Africa recognise that, in one way or another, we are all living with or affected by the epidemic. We also recognise that stigma - characterised by silence, fear, discrimination and denial - fuels the spread of HIV/AIDS. It undermines prevention, care and support; it also increases the impact of the epidemic on individuals, families, communities and nations.

For these reasons, stigma must urgently be confronted. This paper describes the context in which stigma against persons with HIV/AIDS occurs, and makes recommendations for tackling it.

**Stigma and discrimination**

In the AIDS context, stigma is most simply defined as negative thoughts about a person or group based on a prejudiced position. The “undesirable differences” and “spoiled identities” that HIV/AIDS-related stigma causes do not naturally exist, they are created by individuals and by communities. HIV/AIDS-related stigma builds upon and reinforces earlier prejudices. It plays into, and reinforces, existing social inequalities - especially those of gender, sexuality and race. HIV/AIDS related stigma also derives from HIV/AIDS’ association with some of the most elemental parts of the human experience: sex, blood, disease and death. It is also associated with behaviours that may be illegal or forbidden by religious or traditional teachings, such as pre- and extra-marital sex, sex work, men having sex with men, and injecting drug use.

HIV related discrimination is action that results from stigma. It occurs when a distinction is made against a person that results in their being treated unfairly and unjustly on the basis of their actual or presumed HIV status or their belonging, or being perceived to belong, to a particular group. HIV-related stigma and discrimination is widespread. In Africa as in other parts of the world, such stigma results in rejection, denial, and discrediting, and consequently leads to discrimination which inevitably frequently leads to the violation of human rights - particularly those of women and children.

**Leadership**

Leaders at all levels - not just those in government but also religious and traditional leaders - have a clear responsibility to create a more open society that is free from stigma, silence or denial about the epidemic.

Modelling honest and open discussion about HIV/AIDS is a way leaders can strongly encourage supportive attitudes and responses to all those living with and affected by the epidemic. In particular, they should acknowledge that they personally, as well as professionally, are living with and affected by the epidemic as anyone else in society. Experience from around the world shows that by discussing HIV/AIDS openly and sensitively and then taking action, leaders can make a difference.
People living with HIV/AIDS
The active involvement of persons living with or affected by HIV/AIDS is central to the fight against stigma. This is a crucial lesson learned in all countries that have succeeded in countering the epidemic. However, the responsibility is not theirs alone: all individuals and all sectors of society must accept the moral obligation to fight stigma and to promote openness, acceptance, and solidarity.

Human rights
Existing human rights instruments (notably international conventions, Treaties, Covenants and national legislation) confirm that discrimination against people living with HIV/AIDS, or those thought to be infected, is a violation of their human rights.

These instruments also provide an array of formal mechanisms to monitor and enforce HIV/AIDS related rights and rights of people living with HIV/AIDS, and to redress discrimination. However, in order to comprehensively address HIV/AIDS related stigma and discrimination, complementary strategies are required within homes and communities, health care settings, religious organisations and various communications media, both to prevent prejudicial thoughts being formed and to address or redress the situation when stigma leads to discriminatory action, negative consequences or denial of entitlements or services.

The following recommendations stem from recognition that such complementary strategies are needed, and propose practical means for implementing them.

Recommendations for action

Stigma and the family
Stigma within the family, or directed toward an affected family, is the most subtle and debilitating form of stigma and the hardest to address. By inhibiting open, honest communication, stigma makes disclosure within the family difficult; without disclosure, prevention and care is almost impossible. Families and communities - the two are deeply intertwined in the African context - should therefore be supported in preventing stigma, which will further enable their natural caring role. This will also promote self-esteem for people living with HIV/AIDS and their carers, and avoid vicious cycles of self-stigma.

The meeting prioritised the following key responses to stigma within families and communities:
• Conduct research on disclosure and stigma in the family setting, and use the findings to design actions to promote openness and acceptance.
• Promote life-skills education and counselling to help HIV-infected and affected children cope with stigma.
• Ensure that an essential “package” of services including voluntary counselling and
testing (VCT) and follow-up care are available: This will enable individuals to learn their
serostatus and provide support for deciding whether to disclose their status to other
family members.

- Raise awareness so that families and communities can access interventions (e.g.,
  prevention of mother-to-child transmission, care and support services, etc.) as they
  become available, or hold authorities accountable if not available.

**Stigma in health care settings**

People working on the “frontlines” of HIV/AIDS care and prevention have both a
responsibility and a unique opportunity to overcome stigma within their professions and
workplaces. Their professional codes of ethics and conduct, social and professional
authority, and their ability to act as educators and role models for their communities, all
place them under an ethical obligation to be “change agents” for reducing stigma.
Unfortunately experience shows that health care institutions and individuals sometimes
perpetuate stigma by stigmatising and discriminating people, despite their professional
codes. Further, health care workers who are (or are presumed to be) HIV-positive may
suffer discrimination from colleagues and from their communities.

The meeting prioritised the following key responses in health care settings:

- Scale up provision of health services that are “friendly” to people living with HIV/AIDS,
  including VCT and care and support services.
- Develop discharge and referral systems that specifically avoid stigmatising patients.
- Ensure codes of ethics and professional conduct for health care services are in place
  and are enforced, offer sufficient forms of redress should violations of professional
  ethics occur, and that their application to HIV/AIDS is taught within professional
  training curricula.
- Encourage practical and attitudinal HIV-related training for all health care workers.
- Promote VCT and care and support for health care workers.
- Establish and provide adequate funding for comprehensive HIV/AIDS care within the
  existing health systems.

**Stigma and the religious sector**

The religious sector (churches, mosques, religious schools, lay groups, religious NGOs,
ecumenical groups, etc.) have far-reaching influence throughout Africa and the rest of the
world. They therefore have a responsibility to promote prevention, and to provide care,
comfort, and spiritual support to individuals and communities who are HIV-infected or
affected. In particular, religious leaders must play an active role in disseminating non-
stigmatising and discriminating preventive messages, and in leading the fight against
stigma wherever it occurs.

The meeting prioritised the following key responses for the religious sector:

- Ensure religious leaders are “AIDS-competent” by including HIV/AIDS-related subjects,
  including counselling skills, in their pre- and in-service training.
• Integrate holistic care and support programmes in service and education activities, including life-skills for youth, home-based family care, support groups for infected and affected persons, and support for orphans.
• Identify religious language and doctrines that are stigmatising, and promote alternative language that is caring and non-judgmental.
• Promote humanitarian and spiritual values of compassion for marginalised and stigmatised groups.

**Stigma and communications**

While mass media - such as radio, TV, print, and the Internet – can unintentionally promote stigma, they can also serve as powerful tools to help reduce it. Given their potential to shape the attitudes, values and perceptions of large numbers of people, communicators have a responsibility to create clear messages about HIV/AIDS, to report accurately, and to do so in a sensitive, non-stigmatising manner.

The meeting prioritised the following key responses for mass media:
• Build skills and capacity for journalists, editors, producers, AIDS activists, communicators and people working in the field of HIV/AIDS.
• Provide resources for sustained communication about HIV/AIDS that effectively reduces stigma.
• Develop media standards for reporting on HIV/AIDS in a non-judgemental and non-stigmatising manner.
• Hold communicators (both individuals and their organizations) accountable for upholding the above standards through broad-based monitoring mechanisms developed on a country/regional basis.

**Conclusion**

Promoting hope and acceptance is a key response to stigma at all levels of society. In contrast, doing nothing about stigma can only contribute to the growing death toll, as well as to distress and reduced quality of life for millions of people.

All those with influence and authority within society have a responsibility, individually and collectively, to act in order to reduce stigma about HIV/AIDS within their spheres of influence. Accountability - based on transparency, honesty and openness - is a key component in improving HIV/AIDS prevention, care and support efforts, and to bring them to more people on an ongoing, sustainable basis. Clearly, it is essential that stigma and discrimination be monitored and redress be provided when discrimination occurs in all of the areas discussed in this paper.

While we may never fully eliminate stigma and discrimination, the recommendations contained in this paper will go a long way to reducing them, and to building the responsibility and accountability that is so desperately needed.