



UNAIDS-AFRICASO HUMAN RIGHTS AND HIV/AIDS PROJECT IN TANZANIA

Report of Tanzania Needs Assessment on HIV/AIDS and Human Rights¹

¹ The assessment was undertaken July 2002 – June 2003

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BACKGROUND

The UNAIDS-AFRICASO Human Rights and HIV/AIDS Project in Tanzania is hosted by EANNASO - Eastern African National Networks of AIDS Service Organizations (formerly ANNEA) on behalf of UNAIDS and AFRICASO as partners. UNAIDS is the sole financier of the Project. Technical and financial support for the project was provided for by UNAIDS, Law and Human Rights office, Geneva, Switzerland

EANNASO has been mandated to conduct and coordinate this countrywide Project.

The Project is part of a greater program for advancing the promotion and protection of Human Rights in relation to HIV/AIDS as they relate to prevention, care and support for people infected with or affected by HIV/AIDS in Africa.

The first phase of this project is being undertaken in two countries in Africa namely Tanzania and Burkina Faso. The two were selected for implementation of the project, as they were both considered priority countries within the International Partnership Against AIDS in Africa (IPAA) framework and to create a balance between French-speaking Africa and English-speaking Africa.

The general goal of the Project is to increase the capacity of NGOs and CBOs including People Living With HIV/ AIDS (PLHAs) to understand the importance of advancing the promotion of Human Rights as part of creating a supportive environment to respond to HIV/ AIDS and promote the adoption of policies and programs at national level that respond to HIV/ AIDS, whilst protecting human rights and reducing discrimination.

Specific objectives of the Program include, among others:

- To strengthen the link between national NGOs, CBOs, PLHA groups and Human Rights Organizations.
- To disseminate the existing guidelines on Human Rights and HIV/ AIDS;
- To strengthen the link between national AIDS NGOs, CBOs, PLHA groups and Human Rights organizations;
- To sensitize and train NGOs, CBOs and PLHAs on identification, analysis and advocacy for Human Rights issues;
- To document the Best Practices identified and dissemination of information.

It is expected that at the end of the project, following benefits will be realized:

1. Established mechanisms at the national level to monitor HIV/AIDS related human rights violations and for redressing the same;
2. Sensitized/trained national NGOs, CBOs and PLHA groups in Human Rights issues, including:
 - Identifying and analyzing HIV/AIDS related Human Rights issues in prevention, care and support activities and programme;

- Lobbying and advocating for effective policies and programme, which promote and protect Human Rights principles in the context of HIV/AIDS.

3. Human Rights and HIV/AIDS documents disseminated, including the *International Guidelines on HIV/AIDS and Human Rights*.

4. Enhanced established links between National AIDS NGOs and National Human Rights Organizations.

FOCUS OF THE PROJECT

The Project focuses on NGOs, CBOs, and PLWHA groups looking at their knowledge, focus and undertakings in the area of Human Rights and HIV/AIDS. The intention is to build their capacity in the area.

Primary project beneficiaries will be people infected and those affected by HIV/AIDS. The capacity building through this project will empower them to seek redress when violations of their rights (in relation to HIV/AIDS) occur. The secondary project beneficiaries will be the NGOs, CBOs and PLWHA groups whose capacity in the area will have been enhanced.

The project was scheduled for an initial duration of two years and scaling up would depend on achievements in the first phase.

Components in the project package for the first phase include: -

- Needs Assessment Study
- Situation analysis
- A Country Human Rights Workshop
- A joint UNAIDS, EANNASO and AfriCASO publication of 'Lessons Learnt' and 'Best Practices' in Tanzania in the area of Human Rights and HIV/AIDS.

Achievements of the project so far: -

- Recruitment of Human Rights Officer to be based in EANNASO to receive complaints of violation of human rights from PLAWs
- Successful Needs Assessment conducted on HIV/AIDS and Human Rights
- Training Workshop on HIV/AIDS and Human Rights scheduled for May 2004

METHODOLOGY OF THE NEEDS ASSESMENT STUDY

The methodology used for the Needs Assessment exercise included the following: -

- Qualitative questionnaires administered to respondents.
- Qualitative guides for consultations for structured interviews were used.
- Other tools developed: including Consultation List, Consultation Plan and Travel Plan.

The above instruments were submitted to UNAIDS, AfriCASO, and to the National Focal Point (EANNASO) for appraisal/comments. A meeting with UNAIDS was held, to discuss the methodology. Comments and corrections were used to modify the drafted tools.

The Needs Assessment exercise was done in two phases namely administration of questionnaires, and face-to-face consultations.

Questionnaires

The questionnaires covered active NGO and CBO working on HIV/AIDS and those working on Human Rights (there are about 300 AIDS Service Organizations in the country). The questionnaires, which were in both English and Kiswahili, were administered to a total of 220 NGOs, CBOs and other institutions.

Consultations

Consultations were made with the selected NGOs, CBOs institutions and individuals. The final list of organizations, institutions and individuals to be consulted was prepared using the following selection criteria:

NGOs and CBOs

- Non Governmental Organisations working on HIV/AIDS
- Community Based Organisations working on HIV/AIDS
- Human Rights Organisations
- PLHA Organisations

Government Departments and Public Institutions

Relevant government ministries were earmarked; their relevance arising from the role they have played/are playing in the area of Human Rights and or HIV/AIDS at the level of policy making, legislation or regulation or in the various aspects of practical implementation.

Other criteria included whether the organization is national in character and the scope of operations and whether the organization has, any programme dealing with any aspect of Human Rights and HIV/AIDS.

Individuals

Individuals comprised of key interested persons and persons who are experts in the field of HIV/AIDS, Human Rights or/and HIV/AIDS and Human Rights.

Results

- A total of 78 Questionnaires were received from respondents
- A total of 70 consultations were done throughout the country

GENERAL FINDINGS

Overview

An overview of general findings includes:

1. Lack of Networking:

There is hardly any networking among AIDS Service Organizations (ASOs) in Tanzania and there is very little among Human Rights organizations and least between ASOs and Human Rights/legal aid organizations. Whatever networking exists is in very rudimentary stage and almost ineffective.

2. Duplication of programs and activities:

As a result of lack networking among the Organizations, there is duplication of programme and activities among them. In some cases the same kind of activities are implemented over the same geographic area whereas other areas in need of such services do not get them.

3. **Most NGOs work on education and raising awareness for prevention:** For some reason, this appears to be the easiest thing to do, or so it would appear to them.
4. **The mushrooming and ‘deaths’ of NGOs on a regular basis.**
5. **There are very few CBOs:** of the few existing most have very little capacity in terms of management, administration and resources.
6. **Concentration of NGOs in urban areas:**
Most of the NGOs prefer to work in urban areas and most of their programs and activities do not reach the rural areas and the rural areas are left behind in efforts against HIV/AIDS.
7. **‘Briefcase’ NGOs:**
Of the more than 300 NGOs working on HIV/AIDS in the country most are what are generally referred to as ‘Briefcase’ NGOs. These are normally established to target Donor funds and are characterized by: -
 - Absence of offices
 - Absence of permanent addresses of their own
 - Lack of a well defined administrative machinery and organizational structure
 - Lack of reliable contacts like telephone, e- mail, postal address. At best, they can only be reached through mobile telephone numbers of one of the officials or a friend
 - They are sometime hosted by other organizations or share offices with other organizations of their type but the individual officials are in most cases not available in office
 - They are not yet registered; have no certificates of registration or ‘are still pursuing registration
 - They are very good at searching for and pursuing conferences, training and other meetings to ‘justify’ their existence, earn per diem and collect certificates.

Specific

1) Gaps in terms of activities

There is duplication of activities among NGOs in the same areas. The most common of activities is education and awareness rising. As a result, there is lack of activities in many other aspects of the response to the HIV pandemic, activities in the area of human rights being no exception

Very few NGO/CBOs have programme and activities that can properly be said to fit exactly within the subject of HIV/AIDS and Human Rights. All the projects, be they by Human Rights organizations or by HIV/AIDS organizations tend to touch either of the two areas just by chance and not as part of a deliberate, integrated strategy. Examples are- ‘Will Writing’ training sessions by AIDS NGOs or legal aid by a Human Rights Organization to a widow who is HIV+ who seeks to administer her deceased husband’s estate for her own benefit and for her orphaned children.

In both cases, these are neither considered as among priorities nor are they built as specific programme.

2) Gaps in knowledge

Most organizations, depending on their field of expertise/inclination (AIDS Service or Human Rights) lack the basic knowledge and have had no training in the area of human rights or human rights in the context of HIV/AIDS. Human Rights as they relate to HIV/AIDS have never been a priority among NGOs and are very rarely found in programme of organizations working on HIV/AIDS. This is regardless the fact that after brief discussions on the link between human rights and HIV/AIDS they all agree that the subject is indeed important and that HIV/AIDS is by and large, a human rights issue.

There is so far no local literature on HIV/AIDS and Human Rights. Very few Organizations are aware of the existing International guidelines on HIV/AIDS/Human Rights. A very insignificant number have actually seen the NGOs summary and most have never been trained in advocacy for Human Rights and HIV/AIDS work.

3) Focus on the subject

Only a few organizations/individuals have a focus on the subject. Very few have programme or activities related to the subject and most are not in any way focused on the subject. In a nutshell, all organizations and individual surveyed need orientation in the subject.

The scenario situation is made more cumbersome by absence of a national policy/legal/regulatory framework on human rights as they relate to HIV/AIDS from which they could draw insights.

ISSUE FINDINGS: HUMAN RIGHTS VIOLATIONS

The following were violations of HIV/AIDS related Human Rights that the needs assessment revealed. These are not in order of priority:

1) Appropriation of Estate of Deceased Spouse

It is very common, a general rule so to speak, for relatives of a deceased husband to throw out a widow after the death of the husband. This scenario has now been worsened by HIV/AIDS. When it is suspected or known that the deceased has died of AIDS the practice is to take the widow back to her parents and the estate is taken over by the in-laws. If she is lucky, the widow is left to live in the matrimonial house while the rest of the property is taken.

2) Stigmatization and Discrimination of PLHAs and the Affected

- There is widespread stigmatization and discrimination of PLHAs who decide to go public. A PLHA testified that she was dismissed from her job after announcing to the public that she was HIV positive.
- There is rampant stigma among the health and medical personnel over People Living with HIV/AIDS at the time of delivery of services. Denial of service is not uncommon.

3) Abuse of 'GIPA'

- Some NGOs have been fighting over PLHAs; seeking to control PLHAs and PLHA groups. Each NGO claims to 'own' the PLHAs over whom they quarrel. This has gone to the point where the PLHAs in question or PLHA groups are restricted in their relationship with other organisations or groups by the controlling NGO. Many rights of the PLHAs have been infringed upon in the process.

- Further, it has been observed that many NGOs use PLHAs and PLHA groups as bait for to donor support for the benefit not of the PLHAs but of the NGOs themselves.

In other cases, PLHAs are prevented from getting assistance from sources other than their sister NGOs and are even threaten so that they don't cooperate with NGOs considered as competition.

4) Harmful Traditional Practices

These practices are common in many parts of the country. Whereas they are more or less likely to have a bearing in the transmission of HIV, they also play a big role in violation of human rights the infected and the affected and more particularly women and children:

- **Widow inheritance** is a common traditional custom in most tribes. Widows whose husbands have died are as a matter of custom, supposed to be 'inherited' by their late husband's brothers. The person inheriting may already have more than one wife. The widow being inherited has no real choice since on refusal, she is normally sent back to her parents leaving all the matrimonial property behind. Customarily, the family of the deceased husband will divide the property among themselves. Conversely, a man whose wife has died can be given a sister of the late wife to be his new wife and to take care of the children left behind by her sister.

When the estate of the affected family is grabbed, little or no consideration is given to the future of the children and they normally end up dropping out of school and have no proper care.

All this is done without sufficient knowledge of what was the source of the death of the deceased, increasing the likelihood of further infection.

- There is a **wife-sharing practice** among the Maasai of the same age group. The practice is commonly known as 'Spear Sex'.
- **Female Genital Mutilation (FGM)** is a common traditional practice in most of Tanzania despite government and civil society efforts to have it stopped. In addition to the dangers of the possibility to transmit HIV from victim to victim, consent of the victim of FGM subjects is usually irrelevant.
- There are **food taboos** whereby women especially pregnant women are not allowed to eat some foods like eggs, meat, milk which would otherwise help in their health and the well being of the foetus.
- There are no tight government controls over **traditional medical practitioners** who use on patients medicine which has never been tested and scientifically and approved by the Government.

5) Voluntary Counselling and Testing

- It has been observed that women do not necessarily have the decision to test for HIV. It has been reported that in many cases, unless a married woman goes testing secretly, men have a decision over whether or not their wives should go testing. Men are not usually cooperative in that respect.
- The duty of confidentiality at times compromises rights and lives of third persons at risk. Counselors have a duty not to disclose a person's sero status to a third person and are at a loss as to what to do when a sero-positive person they know/counseled engages in dangerous sexual practice that may result into others being infected.

- Currently, there is a wave of school children visiting Voluntary Counselling and Testing Centers (VCTs) seeking to undergo tests, questions have arisen concerning their age as some have not attained the age of majority (which is 18 in Tanzania), their right to do so and what are the ethical implications thereof remain unclear and undefined. Most VCTs have proceeded to test them.

6) Care and Support for AIDS orphans

There is neither country policy nor any coordinated mechanism for assistance to AIDS orphans whose numbers have been multiplying rapidly and who suffer multiple prejudices emanating from the stigma in society in addition to other problems suffered by orphans generally. Efforts by NGOs are made in isolation and even overall statistics of the magnitude and dynamics of the problem countrywide are not available. There is also a scenario in which the elderly who are old and need care themselves are left to care for their grandchildren - orphans whose parents have died of AIDS.

In other cases the orphans are the ones to take care of the grandparents as well as their younger sisters and brothers since the grandparents are old and sometimes sick. Either way, a range of rights of each of these groups of people is compromised in the process.

7) HIV/AIDS in Prisons

Generally, there is no access to HIV/AIDS information or care and treatment for prison inmates.

CONCLUSIONS

The findings above are not peculiar to the specific zones or region only. They were observed and/or cited repeatedly in all the respective zones. They are general to the whole country save for a few specific situations such as traditional practices, which will be specifically attributed to a particular area or community in the Country Needs Assessment Report.

Conclusions arising from the findings above can be summarized as follows:

- That knowledge/awareness among NGO, CBOs, Human Rights and PLHA Associations in Tanzania on the links between human rights as they relate to HIV/AIDS is insufficiency and generally lacking. As a result, no specific programs or activities focusing on the subject are actually initiated and undertaken.
- As such, the situation calls for initiatives and concerted efforts to address the gaps and issues identified.
- The Assessment confirms the need for HIV/AIDS-related human rights programs and activities to ensure a multi-disciplinary approach to redressing HIV/AIDS

RECOMMENDATIONS

Activities or themes to be undertaken to address the gaps include the following:

1. Human Rights Education

Under the current socio-economic circumstances, human rights education for Tanzanians is indispensable. Education at all levels on both human rights in general and human rights as they relate to HIV/AIDS in particular need special attention.

There is need for extensive and intensive education and training of stakeholders in the subject of human rights as they relate to HIV/AIDS and raising awareness in all its aspects;

Given the background in which human rights awareness is very low, there is need to build on human rights education as the backbone of any efforts to reverse the state of human rights *vis-a vis* HIV/AIDS in the country.

Human rights education will be made effective through empowerment of civil society stakeholders namely AIDS Service Organizations, Human Rights Organizations and PLHA Associations. These can be trained with a view to build their capacity to train others (e.g. paralegals, village and Ward leaders, etc.) so that they in turn can raise awareness in the community as well as help deal with human rights issues that may arise in the communities.

2. Collaboration between Civil Society Stakeholders

Creation of linkages between AIDS service organizations (NGOs and CBOs) on the one hand, human rights organizations (including those for advocacy and those for legal aid) on the other hand and PLWHAS groups in redressing the existing situation: There are only a few linkages between some NGOs and some legal aid organizations but and in most cases no linkages exist between these institutions.

The collaboration will help in identification of instances and cases of abuse of human rights and their redress through legal aid and litigation.

It is at the grassroots level that most violations of human rights occur and it is also at that level that most are reported (mostly to NGOs and CBOs). **Any efforts towards redress mechanisms should as a matter of principle focus on building strong mechanisms at the community and grassroots level though the above-mentioned strategy, among other things.**

3. Evolution of Paralegals

There is need for empowering the above 'civil society stakeholders' to be able to evolve paralegals at the grassroots level who can act as 'reference of first instance' for complaints of human rights violations relating to HIV/AIDS.

4. Facilitation of establishment and further strengthening of PLHA Associations

To ensure more autonomy, independent thinking and capacity to discharge their programme and activities, it is imperative that PLHA associations be deliberately empowered. It is important that to avoid misuse and abuse of GIPA, which leads to abuse and violation of rights of, PLHAs there be developed guidelines on engaging PLHAs or PLHA groups in programs and activities.

5. A Toolkit for PLHAs and the Affected

A Toolkit primarily for the infected and the affected who are the ones suffering violation of their rights will be a very useful instrument under the Tanzanian conditions. The toolkit can be published in a simple, user-friendly language and ought to contain instructions on the following, among other equally important things, such as a sample will; List of organizations (ASOs or Legal aid organizations) that may offer assistance in case of a human rights problem; Brief information on rights of a person in relation to HIV/AIDS;

6. The Judiciary and the HIV/AIDS Question

Judges and Magistrates need to be empowered on the subject. The Civil society stakeholders, once empowered, can be used to assist empower the Judiciary on this subject.

The civil society stakeholders can also be used to assist the victims of human rights violation to institute and litigate cases in courts so as to enable the courts to develop jurisprudence on the subject through the cases.

7. Coalition for Advocacy

The Civil Society Stakeholders need to form a coalition to effect several things including all what is proposed above. In addition to the 'tripartite' collaboration for legal aid mentioned, a coalition/network can be forged to deal with issues of common concern arising out of the subject. The said stakeholders can spearhead the coalition, which may include all the interested parties and engage in information exchange, sharing of best practices and most importantly, LOBBY AND ADVOCACY. A network on Law, Ethics, Human Rights and HIV/AIDS (of which not one exists in Tanzania) is one example such a coalition/network. Among others, issues that such a coalition may take on can include: -

- A Policy/legal and regulatory framework on Human Rights and HIV/AIDS in the country;
- The critical issue of Inheritance, its gender inclinations and further complications brought about by the HIV/AIDS scourge;
- The critical issue of access to treatment for PLHAs as well as the availability of medication, including ARVs;
- Creation of a policy and regulatory framework to address the ever-growing problem of AIDS orphans;
- The issue of autonomy and independence of PLHA associations and the right of freedom of association for individual PLHA's;
- Regulation by the government of traditional medical practitioners who allege to have the cure of HIV and AIDS. These do advertise widely and practice their medicine to PLHAs, some charging very huge fees and without necessarily following acceptable and ethical processes and procedures commonly used by medics;
- Inclusion of not only HIV/AIDS but also human rights in the context of HIV/AIDS in the curricula of learning institutions for more effective results.

8. GIPA – Greater Involvement of Persons Living with Affected by HIV/AIDS

GIPA is one principle that has proven effective in stigma reduction and in greater realization of rights of PLHAs. The civil society stakeholder should, in addition to meaningful involvement of PLHAs and the affected in all aspects of the efforts against the pandemic, also advocate for implementation of GIPA at all levels of the community.

9. IEC Materials

Production of IEC materials on Human Rights as they relate to HIV/AIDS should be given a special focus in addition to activities in advocacy and human rights education for it is very crucial. The IEC material can be very effective in stigma reduction as well as in raising the awareness of the communities.

10. Capacity Building and Curriculum Development

Capacity building for the civil society stakeholders is crucial in reversing the existing situation: capacity building in terms of how to initially handle and process complaints of human rights violations is crucial since most of the infected and affected persons whose rights have been violated normally approach such NGOs and CBOs for help. A specialized Institution to train others and help in curriculum development would be beneficial under the Tanzanian circumstances.