

Survey of the Impact of HIV/AIDS Among Rural and Urban NGOs in Uganda

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INTRODUCTION

This study was conducted on various HIV-AIDS related NGOs in Kampala, Uganda. After the identification of AIDS in 1983, many organizations, individuals and government bodies came up to check the spread of this disease in addition to providing support and care to patients affected by it.

Among the local Non-Governmental Organisations that came up to this effect were: The AIDS Information Center (AIC) which started operation in 1989, The AIDS Support Organization (TASO) founded in 1987, Uganda Business Coalition on HIV/AIDS among others.

Of note is the fact that religious or faith based Organisations have also been active participants in the fight against this pandemic. For instance those of the Islamic faith have been among others been organized under their overarching body the Uganda Moslem Supreme Council (UMSC) and the more specialized Uganda Moslem Medical Bureau (UMMB). While those of the Anglican faith were, amongst others organized under the Uganda Protestants Medical Bureau (UPMB).

THE AIDS INFORMATION CENTER

This is a NGO established in 1990, to provide the public with voluntary and anonymous counseling and testing for HIV. Doctor Mueller Olaf was the first coordinator of the AIC.

The center expanded from one site to six in the major towns of the country and has collaborated with 31 districts and by December 2003 had established 111 indirect sites(sub-centers). Cost sharing was introduced in 1994 and rapid testing started in 1997.

Objectives.

The objectives of the project were based on the situation on the ground. For by 1983 the spread of HIV-AIDS had become evident at Kasensero and Lukunyu fish landing sites in Rakai district, and was beginning to spreading like a wild bush fire through out the major economic and social centres of the country. For by 1988 October, 5998 cases had been reported to the Ministry of Health. At this moment in time, this was the highest number of HIV-AIDS cases to have been reported in the world. Most alarming, however, was the fact that it was only a fraction of the existing cases of those infected with HIV-AIDS that was being reported to the health officials!

Hence their was a dire need to check the spread of this disease's spread. And it was this need that motivated to the formation of the AIC. And the AIC's three main objectives were:

- To establish a testing laboratory for the general public.
- To offer a valuable impact on cutting down transmission chains, especially in a country with already a high HIV seroprevalence.
- To free the blood transfusion services from potentially dangerous donors. That is, those who do not donate to save life, but to know their HIV status.

Challenges met in the beginning

- There was lack of confidential information possibilities for the individuals. This can be interpreted to mean, that many feared the disease, but the subject was still a taboo to be discussed.
- Hospitals had HIV testing facilities but lacked the kits and qualified personnel to manage them.

Solutions to the challenges.

- The lack of confidential information was overcome by the idea and subsequent agreement to setting the project in a hospital environment. This would enable anyone to walk in and out freely.
- The lack of test kits and qualified personnel was overcome by the help rendered by the implementing organization in Uganda. This assisted the project through its existing infrastructure in the country and took responsibility in financing the house.

Focus areas of the project.

The main focus areas included:

- Provision of information or education to the public about the HIV/AIDS pandemic.
- Provision of safe blood for transfusion to the patients in need and the establishment of a functioning surveillance system in the country.

Other comments

Despite the numerous successes registered, there's need to:

- Urge the government to incorporate Voluntary Counseling and Testing in the national budget and facilitate supportive services.
- Encourage formation of Post Test Clubs at community level to enhance behavioral change.
- Encourage the community to engage in self help projects.
- Intensify community sensitization and ensure male involvement in Voluntary Counseling and Testing.
- Advocate for VCT and support services among the donor communities.

UGANDA MOSLEM SUPREME COUNCIL HIV/AIDS PROGRAMME

Background

The program was started in 2003 by the Moslem leadership after realizing the lagging behind of the Moslem people. Various aspects inspired the inception of the program among which are:

The Moslem's belief, that HIV/AIDS was for other religious groups. Many believed that the disease could not be acquired by Moslems because of their faith.

The polygamous practices associated with Moslems, was an avenue of exposure. With many wives comes many children and this had led to increase in numbers of orphans which needed re-addressing.

The government policy of condom use was inefficient to the Moslems. This was mainly because of the Moslem faith which advocates for faithfulness and abstinence.

The formation of the inter-religious council of Uganda to deal with HIV/AIDS at a religious level inspired the program. This assured funding and a wider space for outreach.

Objectives

- The major objective of the program was to integrate the Islamic teachings in the fight against AIDS. According to Mr. Salim, the Quran quotes a disease that would come in the later years of the world times. This was believed to be the time for that philosophy to pass.
- Empowerment and capacity building of Moslem community based organization was another objective. This was mainly because many were left lagging behind and lacked support.
- Sourcing for funds for the needy and vulnerable. This was to be achieved through applying for donor support through presenting project proposals to potential supporters. The sourcing was to cut across all religious groups since beneficiaries were not only Moslems.
- Provision of care and support to the infected and affected vulnerable children and their guardians. This was to be availed through home based care.

Focus areas

- Care and support to persons living with AIDS, orphans and vulnerable children. This is achieved through home based care, counseling and referral to other resource options: for example Nsambya home care. Orphans are provided with scholastics but not fees, for those out of school vocational training is provided.
- The program also focuses on prevention. This is done through the use of Islamic teachings especially the Quran, seminars and meditation during festivals and prayers. Encouragement of abstinence is a key in prevention. To this training in life skills and psycho-social counseling to the orphans and vulnerable children is added.
- Voluntary counseling and testing is another focus area. However to note is that most of the activities are not directly implemented by the program, but they sub

grant other organizations to carry out the work. UMSC only tracks the progress apart from counseling.

Challenges

- Assuring someone to be faithfully is quite a challenge. This is mainly because of the contradicting teachings among the different religious.
- Belief in prayer to totally heal a patient is another challenge. Most are deceived that prayer alone can heal, this is because in most cases the infected are brought to the cadres at very late stages. According to Mr. Salim,

“HIV/AIDS in its terminal stages has a different approach. This is because the virus has already destroyed the victim’s anti-bodies, so there is no need to be there. In most cases when this person has already been prayed for and decides to prove by testing: the results may turn out negative”

This is misleading and it’s hard to convince this person to seek better ways of combating the disease.

- Being a religious institution, the staff of the programme have been branded a particular category. Most believers take it that HIV/AIDS is a punishment from God. This makes them negative towards the different activities organized by the agitators of the program.
- Over expectation from the community. The program according to Mr. Salim has only five staff who are not all paid by the sponsors (USAID). Most district co-ordinators are not salaried and this delays work plans.
- The numerous unending wrangles among the different Moslems sects; for example the tabliqs and other believers. This has majorly affected the funding, for example the Arabs do meet fund because they believe this is promoting promiscuity.

Solutions

- Sensitization on how HIV/AIDS is acquired, for example through transfusion, mother to child, has helped in overcoming the belief of the disease as a punishment from God.
- Misleading information by the leaders is overcome by providing information about the stages of infection. This makes the community equipped with all the facts about the disease.
- Over expectations has been overcome by taking opportunities of funding at first hand. For example proposals are presented to support organizations such as USAID which when approved provide funds for the extra program staff. Recently the program, proposal was approved by the ministry of gender and labour.
- The organization and branding of the program workers has been overcome by the appearance to the community as individuals. This has also helped to curb on the wrangles among the various Moslem sects towards the fight against HIV/AIDS.

LESSONS LEARNT

- It has been learnt as having been a good idea for it provided Moslems an avenue for outreach. Moslems would easily be approached through their own gatherings with people they believe in.

- It has also been learnt that religious are not as enemies as earlier perceived. This is proved by the inter-religious council; this brought together leaders from all religions to fight a common enemy.
- It has also been learnt that amalgamating the HIV/AIDS approach with religion is fair game. This provides faithfulness to self and God.

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THETA

The abbreviation stands for Traditional and modern Health practitioners Together against AIDS and other diseases. This was founded in 1992 as a clinical study by a number of doctors who considered themselves as doctors without borders. It was basically born out of the initiative of 3 individuals – Dr. Kalibala, Rachel King and Dr. Jaco Hensy. These saw the importance of involving traditional healers in the fight against HIV/AIDS.

The inspiration according to MS Nakafeero was driven by the constant carrying of jerry cans of herbal medicine by the victims who sought conventional treatment to the AIDS clinic present today TASO. This paved the way to research into the effectiveness and subsequent improvement of the herbs towards the AIDS fight.

Objectives

- Improving and strengthening traditional medicine as a complementary health care practice.
- Research, document and disseminate information about traditional medicine.

Challenges

- Most healers were illiterate. This affected mainly the interpretation of policies provided by the organization.
- The traditional medicine bill which is not yet passed in parliament. This hinders many programs of the organization.
- Stigma to the THETA staff and those associated with it. Thus there is need for advocacy. A topic on traditional healers should be tabled and also address the negative practices.
- Funding is a big problem. This is so because most organization associated traditional healers with witch craft and human sacrifices. Thus prefer not to fund them.
- Contradicting interests among the modern and traditional practitioners.

Solutions

- Stigma has been overcome by cooperation with the community in which one operates.
- Sensitization of the community about the facts of the traditional healers and their practices.
- Alternation funding from other income generating activities. For example Mr. Kisatira carries out a nursery bed from which seedlings are sold. He is also a drama copy write.
- Language barrier and illiteracy has been overcome by changing the prospectus into local languages. There has also been on job learning by the traditional healers.

Lessons learnt

- Cooperation is vital across society organization. This should cut across society including the church, medical workers and opinion traders.
- Record keeping helps in community sensitization. This is basically through victim identification, medical prescription to the patients.

- Most NGOs have not ventured into educating the healers in other areas but provided on shot solutions. According to Mr. Kasatira:
“... These people should teach me how to fish for myself but not provide a none time meal”

Focus areas

Mainly the organization basically deals with traditional healers and their practices.

It also focuses on training but no treatment. The traditional healers are trained into counselors, educators and peer providers.

Research and demonstration of herbs as they are developed.

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MENGO PARISH HIV/AIDS PROJECT

This was founded in 2000 as an expansion of Pascal Lutaaya (Chairperson) visions with around 10 other people. It started as a youth project with the aim for community support. The project was established with the help of CHAI among others such as the Canadian delegation, and the Government under the National Youth Council.

The inspiration according to Pascal was derived from the various society misfortunes, such as drug and other substance abuse, idleness of the use and the increasing number of orphans in the area.

Objectives

- The major objective was to help the vulnerable community. This was to be achieved through mobilization of the youth into productive groups.
- Sensitization to the community about the HIV/AIDS pandemic, and other social injustices that may lead to the same. This was to be achieved through drama and other activities. For example the 'my del troupes' drama group was formed to this effect.

Focus areas

- The main target group was the youth. These according to Mr. Lutaaya are categorized into two. First are those between 2 years to 13 years age bracket and those between 14 years to 30 years.
- The project also targeted particular youths with social problem, such as orphanage, unemployment (idleness) and addicts of all aspects. In this "prostitutes have been counseled and brought to term with social behaviour."

Challenges

- The project has faced a challenge of increased orphans. This has been evidenced by the extreme numbers of those being registered. Today the project caters for 470 orphans as opposed to the aspect 20 or 50 by the start.
- The project also faces a challenge of most youth being unemployed. This has oppressed the finances in terms of food supply. Most youths look to the organization for their welfare.
- Vulnerability is another challenge especially in the age group of 2-13 years. These are normally taken advantage off by the grown ups which leads to misguidance and at times drug abuse.

Solutions

- Proposals are presented to donor agencies. This has helped especially in rescuing education for the vulnerable. For example 24 orphans are on scholarship from vision Africa.
- Alternatives have been devised to supplement on the funding of the project. For example "my Del troupe" has staged shows both locally and internationally and what is earned supplements other project activities.

- Stigma, though at a minimal level has been overcome by counseling and sensitization. For the social injustices seminars on awareness are carried out to equip the youths with the necessary life skills.

Major lessons learnt

- Paperwork and record keeping is important. This helps in monitoring and evaluation of the project's progress. In addition it avails the opportunity of knowing where one is so as to decide on one's destiny and strategy.
- People or the communities are important in problem resolution. There is need to cooperate with society at all levels, "service above self is the key, be below so as to come up a winner at the end."
- Exposure to the world helps a lot in outreach. There is need to venture into different organizations or countries so as to gain and give knowledge. For example 18 members of the project were delegated to Tanzania in February.

THE AIDS SUPPORT ORGANISATION

This was founded in 1987 by Doctor Noelin Kaleeba and other 15 colleagues, but many of these have passed away.

The founding of the organization was based on people that were united by common experiences faced when encountering HIV/AIDS at a time of high stigma, ignorance and discrimination. The inspiration was that these people were either directly infected with HIV or implicitly affected because their very close families were infected.

Today, a total of 83,000 people with HIV/AIDS have been registered and 22,000 directly received care and support.

Objectives

- The major objective was to contribute to a process of restoring hope and improve the quality of life of persons and communities affected by HIV infection.
- The foundation also had an objective to reduce a crisis that was spreading like wildfire that is the boat was built while sailing. There was no major planning.

Challenges

- Funding was a problem as these were individuals that had to save from their earnings.
- The wave of event at the time was one with stigma and ignorance about the disease. This was evidenced by the lack of hope in case one was found to be infected by the virus.

Solutions to the challenges

- The challenge of funding was overcome by the support offered to the organization by the donor community. For example in 1987, it received its first funding from Action aid and in 1991, received a grant of US Dollars 94550 from USAID to enable the provision of counseling services and training programs.
- The challenge of stigmatisation was overcome through training of counselors who provided help to create a relationship between the counselor and the affected or infected person.

Focus areas

This can be viewed from the activities of the organization as noted below:

- Training of counselors, community AIDS workers and trainers and counselor supervisors.
- The beneficiaries were to cut across communities that are individuals, families, those seeking HIV tests at local and national levels.

Lessons learnt

Various lessons have been learnt since the start of the organization and these include:

- It is a fact that political good will and support is important to success in HIV/AIDS services. This is mostly to improve at district levels.

- The quality of people living with HIV/AIDS can be greatly improved even without ARVs. That is time timely management and treatment of opportunistic infections.⁷
- People living with HIV/AIDS should be taken as senior partners in the fight against HIV/AIDS. This is because they are knowledgeable of their condition.
- It has also been learnt that the biggest worries among people living with HIV/AIDS relates to their children. That is if there is support assurance for the children, the heavy load is lifted off the former minds.
- Communities are willing to be active in the fight. They only need to be equipped with the basic skills and motivation.
- Cooperation of organizations should be enhanced. This is so, because non of them can solve all the problems single handedly.
- That behavioral change evolves overtime, thus the need for sustained efforts in order to bring about lasting behavioral change.
- HIV/AIDS and poverty are closely intertwined, thus the need to develop strategies that tackle both to achieve success.
- HIV/AIDS work is very stressing especially for the frontier staff. Thus the need for organizations to arrange for care of careers programs in order to avoid burnout and maintain staff moral.

MULAGO II COMMUNITY BASED HIV/AIDS PROJECT

This came into existence in 2000 with the help of community HIV/AIDS initiative (CHAI). The founder member is Mrs. Beatrice Ntege who carried out the initial mobilization of other six members. These formed a management committee which participated in problem identification. The members were chosen from each zone of the parish.

The inspiration was derived from the increasing number of orphans due to HIV/AIDS, the number of infected persons yet preferred to stay in hide because of fear for the stigma. These problems were identified through hearsay and physical witnessing of those who were severely suffering from the disease.

Objectives

- To enhance advocacy for HIV/AIDS in the area. This was to help restore hope to those who were infected by HIV/AIDS and those indirectly affected by the same.
- To mobilize resources to support members and their families. Access to care and support by the organizations that cater for victims was based on groups and not individuals.

Challenges

- Stigma was the biggest challenge faced in the start. This was mainly because most people were not willing to come up and disclose their status. Thus many lost out on the care and support that would have sustained their lives a little longer.
- Fake entrants were a challenge. Many of there were non-positive subscribers who joined to take advantage o the freebies that were provided by the support of CHAI.
- Large numbers of orphans in the area. This was mainly a challenge in terms of funds to avail basics to the children.

Solutions

- The problem of stigma was overcome through counseling to the victims. This was supplement by the openness about the matter especially among the executive members of the organization. The respondent pointed out the commendable work by Ms. Zalwango who is a member of the executive.
- The challenge of fake victims was overcome through sensitization that was provided by CHAI to the members of the organization. This equipped them with basic skills of victim identification of those that are positive living.
- The challenge of funding was overcome by fundraising from members and other willing organizations. In this Hope for African Child Initiative was identified as a key player. CHAI is the basic funds provider, though was associated with delays, which affects work plans of the organization.

Lessons learnt

- It is important to meet and outlay problems. This provides avenues for collective solutions and lessens on the burden carried by one victim.
- Sensitization has been accepted to provide means of problem identification and thus avail immediate attention.

- Acceptance by victims eases their minds and provided a possibility of living longer. The people living with HIV/AIDS if not disposed to petty and themselves, isolating from others, creates an enabling environment for them.

RESPONDENT: MRS. BEATRICE NTEGE

CHILD RIGHTS ADVOCACY & COMMUNITY HIV/AIDS INITIATIVE

This project was started by the community under the CHAI project. It started with seven committee members, two representatives from each zone of the parish to bring the number to 19. On these opinion leaders and their vices were included.

The first project funding was received in October 2002 and this was the commencing year. The project began as one advocating for child rights, but with time it has expanded to include HIV/AIDS issues.

Objectives

- To provide food stuffs and other basic requirements to the vulnerable children in the area. This was in response to the increasing number of orphans in the area due to HIV/AIDS.
- Advocate for child rights which were continually being abused. This abuse was mainly in child labour due to the slummy situation in the area.

Focus areas

- The organization mainly tackles issues with orphans due to HIV/AIDS.
- The organization also focuses on street kids. This is mainly a problem emanating from increased domestic violence that forces the children out of their homes on the streets.
- The organization further focuses on school dropouts. This is so because many are exposed to social injustices such as prostitution and drug abuse which tend to expose them to the risk of being infected by HIV/AIDS.
- The organization also focuses on adults. These mainly involve widows who indirectly benefit from the services of the project. Mainly they are provided with free counseling and testing or referrals for support and care.

Challenges

- Community ideology: This was mainly the expectation from the community; many were of how do I gain?
- Ideology. Others had the thought that all their burdens were to be handled by the organization.
- Power conflict with regard to the organization leadership. Many of those who joined were eager to be in management with expectations of gaining personally.
- Making people appreciate the organization without direct gain. Most believed in after seeing. Thus many ignored the initiative in the start.
- Fake donor organization with prior organizations had instigated negatively among the community. These had promised but never delivered, so the community had a bias on the initiative.

Solutions

- Sensitization and workshops were carried out to avail information to the community about the objectives and management of the organization.
- Counseling and testing was to be provided free of charge so as to help in curbing opportunistic infectious.

- Stigma was overcome by encouraging positive living. For example Mrs. Kiggundu was identified as one of the people living with HIV/AIDS.

Lessons learnt

- Leaders need to cooperate with the community for their success in the fight.
- Attention to every individual problem is necessary.
- All problems cannot be solved by one organization thus there is need for networking among them.
- Women talents are enormous but lack their promotion. For example tailors lack machines thus tenders are missed which could improve on their status.
- Work place programs are important because most people may fall out of the focus groups but can be approached at their places of work

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