COMMUNITY EMPOWERMENT IN HIV/AIDS PREVENTION

A Case Study of the Integrated Community Care and Support Project in Kenya
(By Daudi N. Nturibi – Family Programmes Promotion Services)

HIV/AIDS Situation in Kenya

Kenya is among the countries in sub Saharan Africa where the devastation of AIDS has had a profound effect. Although the level of awareness and knowledge has continued to be widespread and high, at 98% (NASCOP) there are still a number of misconceptions about modes of infection and considerably low rates of behaviour change, especially in respect to adoption of safe sex practices, persistence of unsafe cultural practices such as the dominance of men and violence over women in sex matters, Female Genital Mutilation, early debut of sexual intercourse and marriage especially of young girls with older men.

Infection prevalence rates have shown a rising trend as reported through antenatal and STD clinic surveillance sites. In 1990 the rate was 5.1%, 9.5% in 1995, and it rose to 13.4% in 2000 and declined to 9.4% in 2003 (NASCOP). A more dramatic drop to 7.6% was recorded by the 2003 Demographic and Health Survey (DHS). The prevalence rates also show a marked difference between urban (15-17%) and rural areas (5-10%); Men and women in age groups 15 – 49, infections being roughly in the ratio of 1:2, with girls more severely affected in the 10 – 15, 20 – 29 ages; men’s rates begin to overtake women in the 30 – 49 ages. This trend has been attributed to inequality in gender power and decision making in sexual matters.

The estimated numbers of those infected and dead are 2.5 million and 2.2 million with over one million orphans, who end up being cared for by economically impoverished and ailing grandparents or overstressed relatives and siblings.

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1 Further information on this case study can be obtained from the Family Programmes Promotion Services (FPPS) Box 46042 – 00100. Tel: 254-2715002/2710705 Fax: 254-2715115 Email: fpps_k@net2000ke.com

2 NASCOP – National AIDS and STD Coordination Programme
The burden of the AIDS pandemic has been overwhelming on women and girls who have had to take on the roles of care for the sick as an addition to food production, house chores, search for water, fuel wood and feeding livestock. Many young girls drop out of school, migrate to cities in search of menial jobs or resort to prostitution, ending up with unwanted pregnancies, STD and HIV infections.

At the national level the effects of the pandemic include:

i. Rising rates of poverty due to under employment, loss of jobs and agricultural labour

ii. Strain on health services, workers and volunteers; around 50% of hospital beds are occupied by HIV patients.

iii. Declining national average age at death (from 65 – 48 years) especially made worse by infections and under five mortality rates and a resurgence of T.B.

iv. Arising level of dependence due to deaths of economically productive young men and women.

v. Depleted and depressed economic situations of families and employers due to the cost of care for the terminally ill, burial expenses and replacement costs in training of new employees

vi. Overwhelming stigma and discrimination of the infected and their family members due to fears of being infected through association or contact.

vii. A burgeoning population of impoverished street families in urban areas and increased slum population living below the poverty line.

In order to address the effects of the AIDS pandemic and stem the rate of infection the Government of Kenya, however belatedly, has declared HIV/AIDS a national disaster and come up with an AIDS policy and also set up a National AIDS Coordinating Council (NACC), which has formulated a strategic plan with aims to work with government ministries, faith led, Non-governmental and community organizations as well as the private sector.
These organizations are involved in planning and implementing awareness raising, prevention education, care and support of those infected. The activities involve employers, workers, women, men and youth volunteers using public meetings, seminars, drama, music, dance, printed materials and mass media messages through radio, TV, film and videos shown at community viewing centers. The Ministry of Health, on its part is responsible for programme planning, surveillance and monitoring research and epidemicology, sourcing for local and international funds supply of condoms and anti-retroviral drugs.

**A PARTICIPATORY PREVENTION EDUCATION APPROACH**

In 2001 the Family Programmes, Promotion Services (FPPS), a Kenyan NGO involved in community education, with funding from the Ford Foundation conducted an HIV/AIDS situation analysis in eight communities (4 urban and 4 rural) through individual interviews of PLWAs, grandparents caring for orphans and families of the infected. The study sought to find out;

i. How HIV infection had affected the respondent and their families
ii. The problems and challenges faced by the infected and their families
iii. How the infected had changed their behaviour and how their families were behaving to protect themselves from infections
iv. Prevention activities being undertaken by various agencies in their communities.

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2 PLWAs – People Living With AIDS
3 Published under four titles:
- Dr. Catherine Ndungo: *Situation Analysis Report for “Integrated Community Care and Support PLWAs, AIDS Orphans and Elderly Caregivers/Orphan Guardians Project”* Family Programmes Promotion Services Nairobi 2002
- *Kenyan Families Coping with HIV/AIDS*
- *Breaking The Silence*, - 2002
- *The Burden Of Care And Support On Grandparents For HIV/ AIDS Orphans In Selected Areas Of Kenya* - Nairobi, 2001
- *Progress report*: January 2004
The survey revealed:

i. Very high emotion drain and hopelessness among the infected, their families and caregivers.

ii. Low levels of revelation of test results among couples, friends, and community members.

iii. Tests are done and results given without proper counseling, complicating reception and planning of positive living.

iv. Changes in behavior after knowledge of infection are claimed by 74% of respondents with 62% abstaining from risky sex and 22% using condoms for protection.

v. Some women had learnt to say ‘No’ to unprotected sex, albeit with difficulties faced by those in marital unions, where men insist on their conjugal rights.

vi. Spiritual and social support of the infected by churches and family members is needed, appreciated, and reported as crucial in adjusting to their status and in coping with the widespread stigma in their communities.

vii. Women and children are the most affected by the pandemic in terms of psychological and economic needs.

viii. Impoverishment, desperation, and dependence of the infected, abandoned by their families, especially orphans.

ix. Widespread use of traditional medicine for management of opportunistic infections due to inadequate conventional health care.

**Project Design**

Based on the findings of the situation analysis, a three-year (2002 – 2004) project was developed and funded by the Ford Foundation to work with five communities. It specifically set out to encourage involvement and participation of community groups, agencies, and individuals and support them to use community resources to increase HIV/AIDS prevention and meet the needs of PLWAs, families and grandparents taking care of orphans. Apart from AIDS prevention, education, and information strategies, the project also aimed to support those infected and affected to seek in resources for Home Based Care and financial support for PLWAs, orphans.
and elderly guardians through skills training and management of projects. The integrated approach was advocated by communities involved as a holistic strategy which would involve both the uninfected, infected and affected. Project designers have often been accused of being unfeeling because they give information without assisting with spiritual and physical needs of those infected. Specific strategies for empowerment in HIV/AIDS prevention also include efforts to stem mother to child infections, address harmful cultural rites, drug and substance abuse.

Project activities were planned to:

i. Increase awareness and knowledge of infection routes
ii. Promote safe sex through increasing the (ABC) of sexes abstinence, reduction of sexual contacts and being faithful to one uninfected partner and consistent use of condoms
iii. Reduce STD infections, increase in treatment rates and partner tracing
iv. Promote voluntary counseling and testing (VCT) and encourage public testimony by those found to be positive.
v. Advantage public advocacy for programme support, protection of the rights of PLWAs and orphans, stigma reduction, policy formulation and legal actions to enforce legal compliance.
vi. Strengthen community responses and capacity through training in planning and skill development of volunteers to engage in information, awareness raising, counseling and home based care.

The intervention models adopted in implementation of projects aims at culturally appropriate and age group based peer to peer sharing of information because of the sensitive nature of the sexual content of prevention behaviour which is embarrassing when shared in mixed age groups. Group influences in shaping individual behaviour are also culturally recognized and emphasized. The informal modes of information dissemination on one to one basis are reinforced by use of print materials: pamphlets, posters, murals and mass meetings such as seminars, film and video shows. Health workers and community volunteers also visit or meet clients for counseling in homes, clinics, churches, and mosques. Youth groups have been
active in the use of entertainment to pass messages and appeal for behaviour change through drama, song and dance and puppetry shows.

The project communities sites involved are:

i. The Kenya Network of Women with AIDS (KENWA). An urban project organized by infected women in four Nairobi Slum areas. Their main objective is to support each other and generate resources to care for the children living in impoverished situations, provide home based care, clinic care, and food supplements.

ii. WEM Integrated Health Services in Thika (prevalence – 6.7% 2003). A pre-urban project mainly coordinated by women. They organize farming on leased land, keep pigs and engage in petty trading, selling paraffin, poultry keeping, VCT, home-based care and run a day care centre for orphans.

iii. Kitui Catholic Diocese AIDS Programme in the semi-arid district of Kitui (prevalence – 5.1%, 2003). Heavily supported by the Catholic Church for resources, drugs and community workers, VCT, health education, support for AIDS orphans primary and secondary school education.


v. South Nyanza Sugar Company Home Care Project. A private sector initiative for employees, dependents and the local community. It is in a province where poverty is acute and HIV prevalence is highest in the country. (41% - NACOP, 2003). It provides VCT, home based care and orphan support.
**Project Activities**
The operations of the project emphasize partnership between the communities and government, NGOs and FPPS. Main tasks in this have consisted of modalities of interagency harmonization, definition of roles, organization of project administration, motivation of community volunteers and community leaders. The role of FPPS has been to support projects with finances to enable them to initiate activities; skill development by organizing workshops and seminars; monitoring and evaluation and facilitation of group processes for planning, financial sourcing, management and quality control of income generating projects.

Capacity building has consisted of formation of project implementation committees to include formal and informal community leaders, government and NGO, CBO officials. Coordinators are then appointed and oriented in administrative processes, financial accounting and report keeping. The committees select volunteers to be trained as community health workers and puppeteers. They also plan project activities, fundraising, mobilization, monitoring and evaluation processes. Government leaders, CBOs and faith led organization backstop committees with resources and skills.

Skill training and empowerment approaches take the form of active, hands-on orientation where the learners are taken through practical exercises in need assessment, problem solving and planning exercises. For information, education and communication techniques they have to do issue identification and definition, message development and pretests, materials development by constructing and producing communication aids, planning of dissemination through entertainment, and dialoging with viewers, participatory education theatre questioning and action planning. Thus they engage and stimulate reflection of community members on their situation and existential reality.

Members of communities who are identified as fast learners and have experience in participatory adult learning methodologies have been given extra training as trainers (ToTs), so that they can facilitate learning and planning processes when FPPS
facilitators are not on site. Thus sustainability and ownership are propagated. Some of the community volunteers are also trained as counselors, Home Based Care workers and participants in specifying topics to be painted on murals on walls donated at shopping centers or public buildings.

Occasional intra-project and inter-project meetings have been held to share experiences, reflect on lesson learned and to demonstrate processes of accomplishing planned activities. In this way the participants inspire, encourage and learn from each other.

**Accomplishments And Outcomes**
The combination of prevention activities with care and support of PLWAs, orphans and their care givers seems to meet the felt needs of the communities involved and to have symbiotic effects in building their capacities for organization, planning and management of their activities. Sizeable number of volunteers have been realized in the five project sites, although efforts still need to be made to meet all their expectations as will be discussed under challenges facing projects. Though overworked and strained by emotionally draining over work and the demands for counseling, care and support of the infected and their families, community health workers are enthusiastic to learn more skills and have managed to engender some openness in communities where no one was willing to disclose the sero status infection of self or relatives. The determination to fight infections, care for those afflicted and not to stigmatize those who disclose their status is growing. PLWAs are themselves at the forefront of this campaign. On the one hand more PLWAs are seeking and receiving care in their communities while medical workers are also teaming up with community members to spread their services from otherwise congested facilities.

The demand for condoms, a previously unmentionable word, has increased and the adamant opposition by religious faiths is softening, due to the numbers of faithfuls who have succumbed to the pandemic and all others who are in great need of spiritual support one project reported continued drop on STI, HIV cases in their
monthly reports. Although the effects of income generating projects have to be fully assessed, having come into the project late, the enthusiasm with which communities have started them is encouraging. Already projects have stated IGAs: retail kerosene, bake and sell bread, lease out entertainment equipment and utensils to organizers of parties and ceremonies, soap making, small retail shops, pig keeping, and poultry keeping have been initiated after skills in planning, forecasting and production were instilled.

Groups have also been trained to produce and disseminate locally appropriate messages through entertainment and participatory education theatre. These are backed by print and electronic media sources distributed and organized by CHWs, puppeteers and other volunteers. Sizeable crowds attend performances, although the majority are children and youth with more males than females due to their various involvement’s. Over 9204 people have been reached with HIV/AIDS messages, 3000, posters and 5000 brochures produced and distributed so far.

Problems and Challenges
The greatest challenge in ameliorating AIDS problems in Kenya is that of coping with numbers. The resources available just never seem to satisfy demand and to reach everyone in need. Whether it is for one to one counseling, palliative care or treatment of PLWAs with ARVs or supply of home care kits, the problems are compound by the level of poverty. This is more evident in efforts to provide adequate nutrition, a problems that compromises the immunity levels of the infected.

On their part the project leaders and volunteers expect rewards for their contributions. When this has not been realized some have engaged in unorthodox ways by paying themselves allowances from the meagre funds meant to meet the needs of the afflicted. In this respect the most difficult issue has been to sustain volunteers motivation and retain their services. After some time many drop out or are pre-occupied with personal, family or social engagements as they seek their livelihood in small-scale businesses or employment. The youth on their part are a highly mobile population due to the fact that they relocate or migrate from their
communities in search of spouses, jobs or training. Thus projects have often suffered from lack of quorums and lateness at meetings and unfulfilled responsibilities for non-remunerated assignments. This complication also affects PLWAs who have volunteered to enhance information giving through their testimonies in an effort to motivate communities to care for those infected and reduce stigma and discrimination. Expectations for payments has also affected respondents to interviews by researchers, compounding specification of sampling methods and building of case studies.

Prevention efforts have been constrained by the level of stigma discrimination and fear to reveal ones sero status. Efforts to help the infected to live positively by adopting safe sex practices cannot succeed if the infected keep secrecy and live in denial. The attitudes of community members and faith led organizations, who condemn the behaviour of those infected as sinful and promiscuous has not encouraged those who would have wished to come out and reveal their situation. So they conceal this knowledge from spouses, friends, relatives and all others, sometimes with disastrous consequences, as they continue to infect others or reinfect themselves. Utilization of VCT services and condoms is also constrained by this behaviour.

The level of sustainability of income generating activities often depends on perceived and actual returns to the beneficiaries – orphans, grandparents giving care, PLWAs and project implementers – CHWs and committee members. Although the proceeds are primarily meant to assist the first group, all the others also expect to benefit. Unfortunately the magnitude of the projects initiated so far does not allow for this, due to the fact that the products are sold in fairly poor neighbourhoods. We however need more time to see how the projects will develop as demand for the products increases. So far the committees have been encouraged to devote their proceeds to the needs of PLWAs, orphans and incidental expenses of volunteer CHWs. It also took a long time to change the desire of members of committees from
thinking about projects that would benefit them and PLWAs as individuals rather than jointly owned and implemented projects.

**Lessons Learned**
The approach of grounding the project in communities adopted by using existing structures such as churches, women, youth groups, schools and the local leadership and administration has ensured acceptability and ownership. It has ensured autonomy from facilitators and financier’s and encouraged internal mobilization of resources and accounting to the beneficiaries. It has also fostered broad-based involvement and participation.

The strategy to use community-based educators has enabled participants to focus on well-understood and felt problems in their message development, using local languages and idioms. The volunteers are available after performance for consultation and dialoging. They have proved good and skilled in awareness raising and have shown interest, energy, creativity and appeal. They have been trained to use a problem-posing approach to conscientize the viewers on issues they have to address in their lives. Thus avoiding imposition of pre-digested agendas.

The level of awareness and knowledge of HIV/AIDS and it’s consequences is high although a few myths about infections still persist in some age groups and communities. The real challenge is to translate the widespread knowledge, fear and will to avoid infection into behaviour change and to sustain the change.

Capacity building in the community is determined by building of reinforcing partnerships with the various players and stakeholders in development. These include community groups, NGOs, government agencies and private sector operators. All these can be relied upon to support and legitimize the operations of projects. A number of the project sites have realized substantial inputs from these players. The involvement of churches has been critical in provision of spiritual welfare, material and organizational support, while it is practically impossible to run community projects without recourse to and the blessing of the local administration.
**Possibilities For Replication**
Community based approaches in HIV/AIDS prevention education are a viable strategy in empowering groups through involvement and participation. This approach will break the culture of dependence on outside resources, as communities are encouraged to look inward and build self-reliance for their organization, planning and management of activities to solve felt problems. They will be encouraged to look for affordable solutions, which might require low inputs rather than thinking of grand projects based on false expectations. As they develop home-grown solutions they will animate those among them with culturally relevant skills, which are plentiful in our communities. Entertainment groups are a resource that can be tapped through their orientation and skill building.

The strategy of Primary Health Care has been tested in a number of countries where community based health workers have been trained to backstop the work of formal health workers to extend services to otherwise poorly served and unreached poor communities. When properly trained and supported volunteers make useful animators, role models and health consultants in their communities.
Bibliography


- Dr. Catherine Ndungo: *Situation Analysis Report for “Integrated Community Care and Support PLWAs, AIDS Orphans and Elderly Caregivers/Orphan Guardians Project”* Family Programmes Promotion Services Nairobi, 2002

- Family Programmes Promotion Services,
  - *Kenyan Families Coping with HIV/AIDS*
  - *Breaking The Silence*, - 2002
  - *The Burden Of Care And Support On Grandparents For HIV/AIDS Orphans In Selected Areas Of Kenya* - Nairobi, 2001
  - *Progress report* - January 2004

