USAID/KENYA
CARE AND SUPPORT PORTFOLIO

FINAL EVALUATION REPORT

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ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral (Drugs)
BCC	Behavior Change Communication
BUCOSS	Butula Community Based Services
CBO	Community Based Organization
CHV	Community Health Volunteers
CHW	Community Health Workers
COGRI	The Children of God Relief Institute
COPHIA	Community Based HIV/AIDS Prevention, Care and Support Program
DHMT	District Health Management Team
FBO	Faith Based Organization
FHI	Family Health International
FP	Family Planning
FPAK	Family Planning Association of Kenya
GoK	Government of Kenya
HBC	Home-Based Care
HIV	Human Immunodeficiency Virus
IAP	Integrated AIDS Program
ICROSS	International Community for Relief of Starvation and Suffering
IEC	Information, Education and Communication
IGA	Income Generating Activity
IMPACT	Implementing AIDS Prevention and Care Project
KARI	Kenya Agricultural Research Institute
KENWA	Kenya Network of Women with AIDS
K-Rep	Kenya Rural Enterprise Program
LIP	Local Implementation Partner
MOH	Ministry of Health/Medical Officer of Health
NASCOP	National AIDS and STI Control Program
NGO	Non-Government Organization
OI	Opportunistic Infection
OVC	Orphans and Vulnerable Children
PEPFAR	Presidential Emergency Plan for AIDS Relief
PEP	Post-Exposure Prophylaxis
PSI	Population Services International
PLWHA	People Living with HIV/AIDS
PMTCT	Prevention of Mother-to-Child-Transmission of HIV
PTC	Post Test Club
REEP	Rural Education and Economic Enhancement Program
SFTC	Speak for the Child
STI	Sexually Transmitted Infection
TASO	The AIDS Support Organization (Uganda)
TBA	Traditional Birth Attendants
TOT	Training of Trainers
USAID	United States Agency for International Development
VCT	Voluntary Counseling and Testing

EXECUTIVE SUMMARY

This evaluation of the USAID/Kenya's HIV/AIDS care and support portfolio was to review the status of home-based care (HBC) for persons living with HIV/AIDS (PLWHA), orphans and vulnerable children (OVC), and related activities and make recommendations regarding the contributions of these activities towards the revised and expanded HIV/AIDS strategy.

During the evaluation, the evaluation team (hereinafter referred to as the "team") found that family members are the predominant caregivers for PLWHA in the home. These family members require supplies, education and support in order to provide this care. Health facilities, whether public, private or faith-based, play a key role in the delivery of HBC. Clinicians provide diagnosis, clinical management and treatment to ill clients as well as supervision and training to community health workers (CHW). The CHW are generally members of the community with little or no medical background who are offering their services either voluntarily or in return for minimal incentives. Many of the CHW are on the same socioeconomic level as the patients and often have income generation activities and cannot devote all their time to HBC. Many CHW abandon the care activities due to their own illness, or because they have obtained full time employment elsewhere. Although their clients are asking for food, medication, supplies, and/or transport assistance, CHW can only offer some very basic services and good will.

Stigma and poverty complicate the community's ability to provide care. Some families have rejected PLWHA who in turn often change residence in order to escape from stigma. Others are fearful that visits from CHW will indicate to their neighbors their HIV status. Many PLWHA informed the team that they had never been to a voluntary counseling and testing (VCT) center.

The team found that caregivers of PLWHA and CHW lack the necessary skills, supplies and/or support to care for the PLWHA. Availability of medications and food supplementation vary and depend on the HBC program's ability to secure outside funding for these needed resources. Support groups for emotional counseling and income- generating activities for caregivers or bedridden clients are lacking. Provision of training and supervision for the CHW is not uniform. Families do not have the training and the needed resources to care for the clients adequately. None had a home-based care kit for the provision of care in the home. Linkages between implementing partners providing HBC and health care facilities vary considerably. Some facilities have staff that actively participates in HBC as supervisors to provide training and guidance to CHW and that make home visits for care and treatment to bedridden clients. In other cases, health care facilities had contributed only minimally to HBC activities, yet these linkages are crucial to HBC. Individuals with advanced HIV/AIDS require close monitoring of symptoms if they are to begin ARV therapy or medications for opportunistic infections (OI). Throughout the evaluation, the team noted that CHW, who do not have medical training, are conducting home visits without an initial plan of care developed in conjunction with a medical provider. None of the HBC programs that the team visited had implemented a plan based on physical, nutritional, psychosocial assessment of the client. Regular and frequent supervision and on the job training are therefore needed.

This evaluation established that the basic daily needs of PLWHA and their families such as food, soap, linen, clothing and drugs are generally lacking. Primary care needs such as palliative medications, and opportunistic infection prophylaxis are also lacking. Almost none

of the PLWHA visited were on antiretroviral therapy (ART). The evaluation also established that in order for antiretroviral drugs (ARV) to reach those in most need, increased awareness, stigma reduction, transport and nutrition needs, and methods of distribution must be addressed.

From a care and support perspective, HBC in Kenya is in its infancy and is largely donor-driven. The Government of Kenya (GoK) specifically, National AIDS and STI Control Program (NASCOP) has developed HBC guidelines, but it lacks financial and human resources to monitor implementation of the guidelines. HBC services are fragmented due to the numerous donors who have not made coordinated efforts in the provision of HBC services. The GoK and its partners should facilitate NASCOP to refine and more vigorously support the HBC models through monitoring and evaluation of HBC, dissemination of information, and through a more active participation in HBC. Without active involvement of NASCOP, and a coordinated response by donors, faith-based organizations (FBO) and non-governmental organizations (NGO), home-based care will be unable to address the HIV/AIDS epidemic adequately and consistently.

Future strategies in planning and implementation of HBC should include upgrading the quality of service delivery for care and support through the strengthening of linkages with health care facilities as well as ensuring that the necessary supplies and treatments are available to the PLWHA. Additional health care facility staff will require training and sensitization in order to provide more supervision to CHW and to effectively refer clients to HBC. Comprehensive Care Centers can play a pivotal role in the provision of HBC to PLWHA through their staff participation as referrers and supervisors as well as in the provision of comprehensive care to the PLWHA. Replicating the Port Reitz Palliative Care Center, which initiates care and education of the PLWHA and the family during the hospital stay through a successful linkage with the CHW, and provides a holistic approach to care, is advised. Future strategies should also consider addressing the high rates of stigma with a more inclusive approach whereby clients with other terminal illnesses can receive services. Sustainable HBC programs were noted to be those that were either strongly linked with the health infrastructure and included capacity building of the community through linkages with food security and income generation activities and mission hospital home-based care programs which provided clinical supervision and a focus on psychosocial support of recipients and providers of HBC.

The future of USAID funded HBC programs should be in the direction of ensuring that its programs are strongly linked to existing health facilities and that all programs include the necessary components or linkages for prevention, outreach, income generation, capacity building, psychosocial support and food security activities. Because of the diverse and numerous needs of OVC, services provided to them should be specific to this population and will need to address, the many issues facing the growing number of OVC in Kenya.

The team considers that the gains and shortcomings or constraints experienced so far in the implementation of programmatic activities can be looked upon as opportunities and lessons learned that should improve performance and enhance benefits. The evaluation team has made many recommendations in this report that may require selective implementation, depending on the priorities of USAID and the needs on the ground.

BACKGROUND

In 1998, USAID/Kenya designed a strategy to address the areas of HIV prevention, and care and support for PLWHA and the families that care for them. Under this plan, specific activities have emphasized a community-based approach to providing physical and psychosocial support to adults and children affected by AIDS. Such activities have made progress on a number of objectives, including:

- Improving the ability of local communities to identify their needs in home-based care by engaging in extensive community mobilization and participation of local leaders and community members;
- Increasing the capacity of local NGOs engaged in prevention and treatment programs by partnering with institutions with resident technical expertise;
- Strengthening existing systems of home-based care, support, and referral for HIV+ adults and children by linking doctors, nurses, social workers, and community health workers; and
- Helping communities identify the specific needs of HIV positive orphans and vulnerable children and specific needs of their caregivers, and facilitating support for these individuals.

According to the 2003 Kenya Demographic and Health Survey (KDHS), adult seroprevalence is 6.7%. Over 100,000 people died from AIDS in 2003 *(AIDS in Kenya, NASCOP).* Currently, 1,100,000 adults (age 15-49) and 62,000 adults over the age of 50 are living with HIV. Approximately 100,000 children are currently infected with HIV. One of the worst impacts of AIDS deaths to young adults is an increase in the number of orphans. There are currently 1,700,000 OVC under the age of 18 from all causes and over 900,000 children under the age of 15 have lost one or both parents to HIV/AIDS *(KDHS Preliminary Report, 2003)*.

Given the nature of the epidemic in Kenya, and Kenya's strong partnership with the Government of the United States of America in efforts to mitigate the impact of HIV/AIDS, Kenya was among twelve African nations chosen to benefit from significant resources from the Presidential Emergency Plan for AIDS Response (PEPFAR). These additional resources carry a requirement to reach aggressive targets for prevention, care and support, and treatment with ART. Most relevant to this report is an expectation of reaching 1.25 million HIV positive Kenyans (including OVC, home-based care, and other non-ART clients) and treating 250,000 PLWA with ARV by the year 2008 *(PEPFAR Targets).*

The objective of the evaluation of the USAID/Kenya's care and support portfolio was to review the status of home-based care, OVC, and related activities, and make recommendations regarding the contributions they can make to this revised and expanded HIV/AIDS strategy. Specific attention of the evaluation was to focus on the extent to which presently funded programs can scale up and/or offer some of the complex care and treatment services under proposed PEPFAR, as well as scale up of prevention of mother-to-child transmission (PMTCT) initiatives.

USAID's HBC IMPLEMENTATION PROCESSES

HIV/AIDS care and support programs have focused on how to achieve greater community participation, both in minimizing congestion on the formal health sector and in meeting the extensive needs of people infected and affected by HIV. Donors, local FBO, NGO, and community outreach groups look upon community mobilization as key to the sustainability and success of care and support strategies. There is an enormous potential for home care teams to contribute to HIV prevention and care and support at the family and community levels. However, the team noted that community involvement, particularly in the provision of services, can be difficult to initiate or sustain and is especially hard to establish on a wide scale. The reality is that families and communities are not always able or ready to help relatives or friends who have AIDS. This is partly due to the great stigma associated with HIV and AIDS, as well as the fact that most of these families tend to lack the skills and resources to care for such ill persons. Many of the community health workers are on the same socio economic level as the patients and simply cannot afford to do much except share good will. Community health workers tend to suffer from burn out, or simply do not have the time or commitment to sustain their volunteerism.

USAID funds IMPACT, COPHIA, COGRI, and AED to work with local NGOs to provide services that address prevention of HIV and care and support of PLWHA at the community level. In order to improve the quality of life of families affected by HIV, the home based care programs have focused on; prevention and behavior change activities, training of CHW, developing working relationships with health facility staff, forming community committees, and creating linkages with food security, medical provisions, nutritional support and microfinance activities.

Currently, USAID funded HBC programs are being implemented in one of two ways: 1) Community-based (either by NGO, CBO or FBO) or, 2) Health facility-based (mission or government hospitals). A third approach is emerging whereby a CBO or NGO is incorporated within a health care facility that offers comprehensive services such as ICROSS in Nakuru and to an extent COPHIA in Thika and in Port Reitz. (Table 1) Where the HBC services are health facility based (mission hospitals and /or government hospitals), the team saw a stronger linkage with health care personnel. The team noted that mission hospitals and FBO had stronger psychosocial support for CHW and PLWHA but economic barriers prevent many from obtaining the needed medical services. Community based organizations such as some that COPHIA is working with, varied in their access to food, medications and the provision of support services, as well as their focus and hub of activities (pharmacy, versus outpatient clinic versus community outreach). Community based organizations, for the most part had weaker linkages with health facilities, and weaker support to the caregiver. It is outside of the scope of this evaluation to appraise and comment in detail on each.

Table 1: Home-based care models

HOME-BASED CARE MODELS	**Linkages with HC facilities**	**Psycho-social support**	**Community mobilization and outreach**	**Access to medications, supplies, nutrition support**	**Drawbacks**	**Linkages with ancillary facilities** (VCT, PMTCT, STI, TB CLINICS)
Health Facility Based Mukumu Hospital St. Mary's Hospital Bungoma Hospital	strong	stronger in mission hospitals	variable	dependent on institution	cost stigma (for FBO) limited geographical coverage	variable
Community-Based COPHIA AED COGRI	weak	stronger with PLWHA networks or FBO	usually strong	donor dependent and variable	lack of technical supervision isolated (stand alone)	weak
Emerging integrated model COPHIA (Thika and Port Reitz) ICROSS (Nakuru)	strong	available as part of services offered	variable	donor &/or institution dependent	need for collaboration possible high cost	strong

USAID's HOME-BASED CARE PROGRAMS: A BRIEF OVERVIEW

1. COPHIA

The Community-Based Program on HIV/AIDS Care, Support and Prevention (COPHIA) is the largest home-based care program funded by USAID in Kenya. Initially, it was to run for three years, from June 1999 and implemented through Pathfinder International (PI). Following a Mid-term evaluation conducted in June-July 2001, USAID granted a cost extension until June 2003, followed by a second extension from July 2003 to June 2005. COPHIA's approach is to build the capacity of communities, local implementing partners (LIP), community volunteers, PLWHA, members of vulnerable households such as orphans and caregivers to enable them to develop appropriate skills. Provision of home-based care (HBC) to PLWHA is the primary focus for the COPHIA project.

One of COPHIA's approaches to HBC is to use existing cadres of community-based workers who are active and in touch with local residents to provide support and to bridge the gap between hospital professionals and caregivers at home. The project also provides training for LIP as a way of building their capacity. At Mukumu Mission Hospital, the evaluation team was able to get more insight into the workings of the COPHIA approach to HBC that uses a cross referral model (community to health facility and health facility to community with outreach follow up) through CHW backed up by clinical supervisors from the hospital. This model works effectively and efficiently for those who can afford it. It also provides the essential clinical links that add value to HBC. The format of providing services is comprehensive and includes, among other things:

- Hospital admissions based on assessment of patient condition
- Provision of home-based care and outreach services
- Provision of VCT services
- Diagnostic testing including CD4 count
- Links with a micro-finance scheme
- Presence of a post test club (PTC) within the health facility that links with other support groups

The other approach that COPHIA uses is the community-based model in which the responsibilities for providing HBC and support services are community-based, and volunteer or community-driven. In implementing this model, local implementing partners in the form of youth groups, women's groups, FBO, CBO, and community pharmacies (Bamako Initiative Centers) receive funding specifically to promote community mobilization and provide HBC and support. COPHIA also trains health facility staff and more experienced CHW or community members to provide supervision to the CHW. Some of these partners (KENWA, REEP, Redeemed Gospel) also provide primary medical care in the form of health clinics staffed by a nurse. Community based organizations are usually accessible and play an important role in prevention activities. These organizations are often able to mobilize additional resources.

2. FHI/IMPACT

At St. Mary's Hospital in Mumias, the team found that FHI/IMPACT uses a health facility-based model with a component of community outreach. Community health workers are the link between the hospital and the community-based caregivers. Several levels of support are at work in this model. At the hospital, there is a multi-disciplinary team consisting of doctors, nurses, auxiliaries and social workers contributing to home-based care related services. Nurses and CHW make regular home visits to provide needed services, deliver supplies or monitor the progress of clients. A social worker can provide services directly, supervise service provision by the HBC caregiver, or refer the client to the nearest appropriate referral center. The Bungoma program, now under the MOH but previously run by FHI/IMPACT and ICROSS, also uses this model based at Webuye Sub-District Hospital.

FHI/IMPACT has recently begun introducing a new model for care that involves the establishment of comprehensive care centers at selected sites within the Kenyan government's general hospitals in Western, Rift Valley, Nairobi and Coast Provinces. Six of these centers are already operational with 16 more proposed in the near future. An FHI/IMPACT comprehensive care center offers a wide range of services, including VCT, OI prophylaxis and management, ART, nutritional advice, PLWHA support, STI treatment and management, treatment of TB, adolescent counseling and services, and reproductive health services. Great opportunities thus exist for the expansion of HBC outreach services that can easily operate out of these comprehensive care centers that would seal the gaps for clinical supervision and other needed HBC services.

3. ICROSS

ICROSS, which is a partner of IMPACT in Bungoma and a REACH partner in Nakuru, is unique in that it includes aspects of sanitation and nutrition. The sanitation component involves digging of VIP pit latrines while the community food bank involves maintaining a

food (largely beans and dry maize) surplus over the course of the year. Teachers, religious leaders and other community members have been able to secure donations in the form of food from large farms or well to do benefactors. This surplus is stored and PLWHA who are in greatest need are able to access the food supplies. The ICROSS model also includes working with both Government health facilities and private health providers to back up community outreach HBC. The policy of ICROSS is not to stay on sites beyond introducing this model and establishing its operational linkages with those of the government, community and private providers with the goal of future ownership and sustainability.

4. THE LEA TOTO PROJECT

The Children of God Relief Institute, (COGRI) manages the Lea Toto Project in order to provide homecare services to HIV infected children up to age of 18 years. Activities include community mobilization, outreach activities and home visits. Social workers provide supervision to the CHW. The Lea Toto Project has two nurses who provide basic medical care including drugs for opportunistic infections (OI) to clients and their families in their clinics. There is also a food distribution program through CRS for malnourished children. Sick children are referred to nearby health facilities. There are support groups for CHW and there is regular supervision of the staff by outside facilitators. There is a plan to offer microfinance loans to CHW and caregivers.

5. READY-TO-LEARN/SPEAK FOR THE CHILD

The Ready-to-Learn/Speak for the Child (SFTC) project, implemented by the Academy for Education and Development (AED) addresses the physical, cognitive and psychosocial needs of under five OVC by providing support and education to caregivers regarding the emotional development and health of children. Another aspect is to build capacity of other organizations in Kabras Location in Western Province, to deliver OVC support and services in their communities. SFTC has obtained funds for food distribution that is solely for their OVC target group under the age of five years. SFTC assists preschool age children to enroll in pre-schools. The project has developed linkages with health facilities to ensure that OVC and caregivers seek out health services for vaccinations, and other medical care.

PREVENTION

Current USAID funded HBC programs all have a component of prevention. Partners have made significant strides in mobilizing communities through the formation of community implementing committees as well as sensitizing various religious groups and other organizations. CHW refer clients and community members for VCT, PMTCT and STI clinics, distribute condoms, and mobilize and educate their communities. Youth groups have been trained as peer educators to conduct behavior change activities in order to reduce stigma associated with HIV/AIDS in their communities and improve self-risk perception among youth. CHW have been trained to address issues of stigma and prevention as well as provide care and support to PLWHA. The question remains whether CHW, as volunteers with no clinical background can adequately address all the issues of HIV prevention as well as provide care and support to the PLWHA. In the future, consideration should be made as to whether some of the prevention activities could be shared with the existing group of Kenyan public health technicians.

VOLUNTARY COUNSELING AND TESTING ACTIVITIES

As part of the questionnaire administered during the evaluation, sixty nine PLWHA were asked the following question, *"Have you or anyone in your household ever been to a VCT center?"* In Mombasa, 42%, Western, 24% and Central 19% reported never having been to a VCT center. VCT and knowledge of serostatus may encourage people to reduce risky behavior. It can also be an entry point for the provision of other services such as PMTCT, TB detection and treatment, ARV, and psychosocial support. These clients are recipients of HBC services in the form of health education, medications, nutrition support etc, but are unwilling to discuss their illness or HIV status with the person providing them care.

In some of the areas that the team visited, people lamented of a lack of VCT centers (Kongowea in Coast Province, Bungoma and Kabras in Western Province). In the larger hospitals such as Thika, and Coast General, there is a two-week waiting period for VCT services due to high demand. CHW and program staff informed the evaluation team that there might not be enough VCT centers to cater to all who need these services. However, there may in fact be underutilization of VCT centers in some areas and over utilization in other areas due to issues of stigma. People may prefer VCT centers located in large hospitals where they may be able to maintain their anonymity.

Recommendation:

1. **Prior to consideration of adding or expanding current VCT centers, USAID should collaborate with NASCOP and implementing partners to conduct a needs and service utilization assessment that would establish the level of usage of existing VCT centers.**

PEP ACTIVITIES

While transmission of HIV in health care settings is not a major mode of transmission, prevention of such a transmission should be part of health care service delivery. In resource

poor health facilities with a high patient population HIV prevalence rate, the risk of occupational transmission may be higher.

PEP activities were for the most part nonexistent in health facilities visited. The team asked health care facility managers if PEP activities were in place. Out of seven health facilities visited, only two had posted the PEP guidelines (FPAK in Nakuru, and Tawfiq Hospital in Malindi). Neither of these facilities actually stocked ARV. The five government facilities visited had not yet posted guidelines nor had they begun to educate hospital personnel. This policy needs to be fully implemented not only as a response to work related injuries but also to address rape victims who in some areas of Western province are being referred to Nairobi for PEP. Addressing the problem of occupational risk and exposure may also boost staff morale and thus improve patient care.

Recommendation:

2. **Those identified to be responsible for the distribution of PEP guidelines should ensure incorporation of training so that health care staff is aware and knowledgeable of those guidelines, as well as have the necessary medications and supplies needed to implement them.**

BCC AND IEC ACTIVITIES

CHW indicated that they actively participated in the distribution of Information, Education and Communication materials (IEC). However, upon inspection of homecare bags, there were no educational materials in the form of pamphlets, brochures, stickers or leaflets for distribution to their clients or other members of the community. The team noted that a number of CHW did not read or speak in English. All area managers stated that the behavior change communication (BCC) and IEC materials were inadequate. Some LIPS had file cabinets with some IEC and reference material stored away that seemed difficult to access.

Recently, NASCOP produced a number of home-based care documents for use at various levels of implementation. They include a policy guide, a service program guideline, a training curriculum, a reference manual, an orientation pack for health workers, a flip chart for training CHW and a pamphlet. Dissemination/distribution of the guidelines seems haphazard and non-existent at the care providing level.

The team saw BCC in the form of PSI trained youth groups in Western and Central Provinces. However, in the Mombasa area the team did not meet any representatives of youth groups and it was not clear as to whether these groups are currently active.

Recommendations:

3. **If IEC items are made available to implementing partners, the distribution of these items should include instructions and training on methods of use. Some reference materials for CHW who are illiterate or read/speak only Kiswahili is needed.**

4. **COPHIA should work more closely with PSI to ensure that PSI funded youth groups are more visible in the Coast Province and promoting the COPHIA care and support activities.**

CONDOM USE/DISTRIBUTION

A large number of clients interviewed stated they did not use condoms for various reasons: In Mombasa, 24 out of 31 (77%) PLWHA interviewed stated they did not use condoms, whereas in Central province the rate was 81% (17 out of 21) and it was 71% (12 out of 17) in Western province. The most common reason for not using condoms was that the client was practicing abstinence. However, as ART becomes more accessible to these clients they are likely to regain health and become sexually active. In this regard, CHW will need to be equipped to engage their clients in discussions about condom use.

CHW carried and distributed condoms, but only two carried a penile model for demonstration of condom use. All health facilities and collaborating agencies visited by the evaluation team distributed condoms with the exception of St Mary's and Tawfiq Hospital for religious reasons. Several CHW also stated that for religious reasons they could not discuss or distribute condoms. Each health facility distributed from 250 to 1000 pieces weekly.

PREVENTION OF MOTHER TO CHILD TRANSMISSION (PMTCT)

In order to assess women's awareness of PMTCT 28 women were asked the following, *"Do you know how HIV can be transmitted to babies?"* and *"Do you know how transmission of HIV can be prevented in babies?"* Thirty nine percent of the women in Western Province (7 out of 18) and 63% (5 out of 8) in Mombasa did not know how HIV could be transmitted to babies. Regarding prevention of transmission, 67% (12 out of 18) of women in Mombasa did not know how HIV transmission could be prevented from mother to child, whereas 50% (4 out of 8) of the women in Western province stated they did not know. In Central Province, there were only 2 respondents both of who knew at least one method of transmission and prevention.

As per the COPHIA 2003 Cost Extension Proposal, future refresher trainings would include community-based interventions for PMTCT. While the team did not directly assess the CHW knowledge of, or training in PMTCT, none of the CHW mentioned any involvement with PMTCT education to the community or to their clients as one of the services/activities they provided.

Five of the health facilities visited by the team offer PMTCT services (Tawfiq Hospital-Malindi, Nakuru Hospital, Port Reitz Hospital-Mombasa, Khunyangu Sub District Hospital-Butula, and Redeemed Gospel-Nairobi). The number of PMTCT clients per week was; Redeemed-10, Tawfiq-5, Nakuru: n/a, Port Ruiz-33, Khunyangu-30, and Port Reitz-33.

The need for CHW participation in the mobilization of communities regarding PMTCT activities was reported in the 2003 Evaluation of UN supported pilot projects of PMTCT activities in Kenya. More CHW should be trained in counseling of ANC clients for VCT testing, and to educate women on the importance of exclusive breast feeding for the first six months after birth. According to the 2003 Kenya Demographic and Health Survey, supplementation of breast milk starts early. Only 29% of children under the age of 2 months are exclusively breast-fed. This figure drops to 9% in children under 4 months of age who are

exclusively breast-fed. CHW can also catalyze leaders of communities to endorse men's involvement in PMTCT. Lack of male support hinders women from receiving PMTCT services especially HIV testing, completing ARV treatment, and using breast milk substitutes.

Recommendations:

5. **There should be greater collaboration between CHW and TBA and PMTCT health care staff to educate women and their partners in the community about PMTCT services. Ministry of Health and its collaborating implementers should include TBA in CHW trainings on infection prevention and PMTCT.**

6. **In order to increase the effectiveness of PMTCT services, CHW should take a more active role in counseling ANC clients for VCT testing, educating women on PMTCT, exclusive breast feeding and the importance of family planning.**

STIGMA REDUCTION

Stigma was raised as an issue by CHW in almost sites visited. Butula in Western Province was an exception. Here, many PLWHA had come out openly with their HIV status. CHW stated they no longer mobilize for VCT as clients themselves are bringing in friends and relatives for testing. When asked why stigma had declined in this area, it was partially attributed the decline to a "Butula AIDS Day" where 60 people declared their status. They also mentioned their close proximity with Uganda as an explanation and responded that HIV had been particularly widespread and devastating in the Butula area, therefore accepted by the community as a problem that needed to be tackled openly. They also mentioned the fact that past political leadership in the area (the immediate former MP) had confronted the matter openly.

Methods and amount of time devoted to addressing stigma varied. Most HBC programs were addressing stigma through youth group activities such as theater groups presented to churches, community gatherings and schools. CHW were involved in mobilizing their communities and discussing condom use, transmission of HIV and the importance of VCT.

Members of PSI funded youth groups were well spoken and active in their work, most were living positively, and many requested CHW training. They discussed the difficulty in raising HIV/AIDS awareness in schools. As part of COPHIA's two-year project extension one of the three community activities was to focus on increasing self-protective behaviors among in-school and out-of-school youths ages 15-24. Youth groups cited the teachers' attitudes as major blocks to sensitizing children particularly those under age 15. They described many teachers as lacking adequate knowledge of HIV/AIDS in terms of the transmission and precautions.

Recommendation:

7. In the future, the prevention activities of care and support programs should address HIV education in schools at a younger age and in particular, target teachers.

TRAINING AND SUPPORT

INCENTIVES

All COPHIA supported CHW receive a minimal financial incentive of Shs. 2,000/=. The incentive provided, cannot be considered a salary yet for some CHW this is their only source of income. In the event that CHW are to be paid for their work, careful consideration would have to be given to the criteria and selection of community members being chosen as CHW. This would mean that they are recruited through a competitive process.

Many of the CHW have been given bicycles and uniforms. CHW verbalized their appreciation for the bicycles, as they must often travel long distances to visit clients as well to attend supervisory meetings. COPHIA has agreed to provide uniforms and bicycles to all CHW. Yet, in all the sites visited a portion of the CHW did not yet have uniforms or bicycles.

In Mombasa, and Malindi, CHW receive Shs. 2,000/= transport allowance per month. In Malindi, the CHW allocate Shs. 500/= out of this monthly allowance directly to Tawfiq Hospital on behalf of each new client they refer to the hospital for basic supplies, care etc. Some CHW complained that the hospital would not accept a second referral in the same month as the hospital would not get an additional Shs. 500/=. In Mombasa, CHW allocated Shs.50/= -100/= to each client. While it is commendable that the entire group of CHW in Coast province had agreed to allocate 1/4 of their allowance to needy clients, giving a few coins to each client is an ineffective and unsustainable method for assisting these clients.

ICROSS Community Health Volunteers (CHVs) and clinical supervisors, and IMPACT CHW, appeared to do their work on a voluntary basis. They are involved in microfinance schemes, receiving loans to start small businesses. There was no difference in caseload noted between CHW who received an incentive and those that did not.

Recommendations:

8. **USAID and other donors should consider providing special funding to Tawfiq Hospital in defined areas in order for the hospital to have a stronger waiver system instead of accepting donations from CHW for newly referred clients.**

9. **If CHW in the Coast Province are to continue donating 1/4 of their incentive to needy clients, a more sustainable method should be developed whereby the Shs. 500/= is invested for or on behalf of the clients to enable them and their dependants to benefit in the form of loans, medications, or food.**

10. **Every effort should be made for future CHW training and support activities to be comparable throughout all HBC programs and with a more timely distribution of necessary supplies and equipment.**

SUPPORT OF THE CHW

Out of the 69 PLWHA visited, the team observed provision of care only once. Most of the time, CHW did not have a homecare kit while accompanying evaluators on home visits. When possible, home care kits were inspected, and depending on who was supplying the contents,

they varied from adequately filled to severely lacking anything to provide care. In order to assess adequacy of materials, the team asked CHW what was in their homecare bag that day. Thirteen percent of CHW in Western province and 16% of CHW in Central stated they did not have any materials whatsoever. In Central and Western Provinces, almost 50% of CHW did not have disinfectants. Thirteen percent of CHW in Central and 26% of the CHW in Western did not have any gloves in their bags. (Table 2)

In homes visited, there were no available HBC kits. This meant that bedridden clients did not have Jik, gloves, soap, dressings or basic medications.

Table 2: Items carried by CHW (as percentage)

TABLE 2 CONTENTS OF HC BAG	CENTRAL (N=30)	WESTERN (N=31)	MOMBASA (N=30)
Gloves	87%	74%	97%
Soap	60%	58%	87%
Dressings	43%	65%	73%
Drugs	13%	29%	7%
Disinfectants	53%	55%	90%
Nutritional supply (porridge or vitamins)	20%	10%	3%
IEC materials	17%	16%	27%
Other(nail file, tongue depressor,etc)	53%	23%	30%
None	13%	16%	0%

Stocking homecare bags only once in a month is inadequate to meet the needs on the ground. CHW had an average of 4-6 mobile clients and 1-2 bedridden clients. They make an average of 8-12 home visits per week. One bottle of Jik, and a few bars of soap, one box of latex gloves, and one roll of toilet paper might be adequate for home visits but is not enough if they are expected to assist clients and caregivers. CHW sometimes borrow from one another but their bags are restocked by COPHIA only once per month.

Regarding support groups, 18 of the 31 CHW (60%) interviewed in Mombasa, reported that they did not belong to a support group as compared to 29% (9 out of 31) in Western and 27% (8 out of 30) in Central. Those that did, most often cited the benefit of the support group as financial (getting K-Rep loans). The community health workers are in a difficult situation of being friends, neighbors or acquaintances of the clients, usually in similar economic situations, as well as often being of positive status themselves. They report exhaustion, feeling overwhelmed, and emotional burnout and describe feeling compelled to reach into their pockets to buy their clients food, drugs, or pay their transport to the hospital.

Clinical supervision of CHW is for the most part, weak. The team noted that it was strongest in the Thika area as well as within ICROSS and mission based hospitals. In Thika and Nakuru, the team found that both area managers and clinical supervisors were well aware of the health status and issues of their clients. In Mombasa, COPHIA field supervisors were unaware of several critical field issues that required their attention and intervention. COPHIA has identified supervisors as TOTs who are either senior experienced CHW or clinical officers working in health care facilities. Some of these TOTs are assigned to health facilities and are overwhelmed with other duties. The discrepancy between available TOTs with little to no formal clinical background, and those with extensive clinical background has several effects. Meetings with supervisors vary from daily, to weekly to monthly. (Table 3) Sick or bedridden clients may not get the best medical consultation from a non-clinical TOT. Their client will have to travel to a health facility for medications and treatment while when a clinically trained TOT makes home visits and carries drugs, they may be able to provide care and treatment in the home and thus relieve the burden on the health facility.

Table 3: Percentage of CHW reporting on frequency of meetings with supervisor

Meetings with Supervisor	CENTRAL (N=30)	WESTERN (N=31)	MOMBASA (N=30)
Weekly	37%	45%	43%
Monthly	33%	16%	23%
2xmonth	17%	16%	20%
>2x week	7%	10%	7%
Never	7%	0%	7%

It was noted during the evaluation that CHW were not using initial assessments or care plans. CHW should use an assessment or "care plan" regularly to assess the needs and issues of each client. A clinical supervisor would do this within the first month then reviewed and adjusted as Without a basic evaluation of each client's status, needs, issues and goals, there is no guiding standard to give direction to the CHW in how to proceed with his or her work. Both CHW and supervisors should be assessing whether CHW have reached the goals set, or whether the goals need to be revised.

As per NASCOP homecare guidelines, each CHW should have an average caseload of 6 to 7. The motivation of CHW should be considered in relation to caseloads. Some have made volunteerism a career. Others look at it as a stepping-stone to paid work. Others tend to concentrate on other money earning ventures. Some CHW are ill or are caring for ill family members. Western province seems closest to this targeted number having an average of 6.1 clients. In Central Province, CHW had an average of 4.8 clients and in Mombasa 4.3. Caseloads varied anywhere from 20 to 1. For reporting purposes, some CHW are counting all clients who have been referred to them including those who have resumed daily activities and no longer require homecare. Clients who no longer require services should be discharged from the active register list.

Recommendations:

11. **Care and support programs should assist in the formation and functioning of support groups for CHW on how to deal with burnout.**

12. **It should be a priority for care and support programs to reach out to MOH staff to raise the awareness of the need for successful collaboration with health facility personnel to provide homecare services. All CHW should have equal access to and supervision from clinicians in the field. This will benefit the clients as well as the CHW.**

13. **All homecare kits should have adequate stocks of basic materials for providing care to the client as well as enough to assist in creating a homecare kit for the home. Stocks of supplies should take cognizance of the number of bedridden clients each month.**

14. **Care and support programs and NASCOP should be sure to undertake the implementation of initial plans of care in all HBC programs. The plans should be prepared within the first month of the registration of a new client by a clinical supervisor together with the CHW on the case. This care plan, of which a copy would be left in the home with the caregiver, would include general status of the client, care to be provided by caregiver, goals, and issues that need to be addressed by the CHW.**

TRAINING OF CHW

The CHW were asked to list all refresher and in-services (on other topics) that they had attended. A significant number stated they had not attended either a refresher and/or an in-service since beginning with the project. (See Table 4) Some CHW raised the issue that refreshers and in-services were presented as theory rather than by demonstration or practicums.

Table 4: Attendance and types of training sessions for CHW

PAST TRAINING	CENTRAL (N=30)	WESTERN (N=31)	MOMBASA (N=30)
Initial Training	100%	100%	100%
In-service training	67%	68%	57%
Refresher training	27%	26%	37%

Community health workers were asked, *"What kind of services do you provide in the home?"* (Table 5) The CHW were free to think about their work, and offer the evaluator examples of what they did, or list in general terms what they do. Less than 65% of all CHW mentioned infection prevention specifically.

Table 5: Services provided in the home by CHW

SERVICES PROVIDED IN THE HOME	CENTRAL (N=30)	WESTERN (N=31)	MOMBASA (N=30)
Other	33%	3%	13%
Nursing Care	67%	58%	63%
Administration of Medicines	27%	16%	43%
Health Education	80%	94%	87%
Counseling	73%	87%	53%
Nutrition Support	50%	71%	73%
Infection Prevention	57%	65%	50%

Recommendations:

15. **All CHW should have the homecare manual in their bags, and other information should be provided to those who cannot read English.**

16. **Since the CHW are adult learners with varying educational backgrounds, refresher and in-service trainings should be offered on a quarterly basis, with a concentration on actual demonstrations and practicums rather than theory. Clinical supervisors should use the opportunity presented by their weekly meetings to discuss either new issues, or review previously taught topics.**

BARRIERS TO EFFECTIVE HBC CARE

STIGMA

Stigma remains a barrier to accessing services. As stated previously, some clients of HBC have not been to a VCT center and are unwilling to discuss their status. CHW are providing care and support to some people who are unwilling to discuss their HIV status openly.

CHW in Mombasa region, reported fewer referrals: three out thirty (10%) to VCT than Western 7 out of 31 (23%) and Central 10 out of 30 (33%) in the week prior to the evaluation. This is consistent with reports of high rate of stigma and denial in the Mombasa region. The team noted that the community health workers in all areas visited verbalized the difficulty they had with stigma and the attitudes the community had towards them.

The CHW also expressed to the team that, due to the nature of their work, their communities often stigmatize them. In all the sites visited community health workers told evaluators that they were referred to as *"those who work with HIV*". It seems that for some CHW this in itself was a problem. Since CHW are themselves members of the communities they are serving, stigma may be a barrier for them as service providers as well. On the other hand, there were scattered complaints of CHW not maintaining confidentiality, or lacking the skills to approach the discussion of the client's need for VCT.

In Thika, the Integrated AIDS Project (IAP) PLWHA support group refused to meet with evaluators in the same location as the CHW. The clients did not feel comfortable revealing themselves to other CHW. In several locations, there were stories of HIV concordant couples that refused to discuss or disclose their positive status with their spouses.

Recommendations:

17. **All CHW and other social and community workers should be trained in counseling to most effectively refer members of their community for VCT.**

18. **Further consideration should be taken as to whether a more inclusive HBC program that provides services to all those that need them could decrease the stigma associated HIV/AIDS and with the CHW.**

WEAK REFERRALS AND LINKAGES

Referrals and linkages between HBC and health facilities are crucial to the health care continuum. CHW that have no formal clinical training require clear communication from healthcare providers regarding the care and needs of their clients.

Effective referral systems between HBC and adjacent health facilities vary considerably from site to site. Most CHW had a referral form to send with clients to a VCT center, clinics, or hospitals. In some instances, the evaluators were informed that CHW personally accompany

their clients to the health care facility. This ensures communication but may not be the best use of their time.

Clinical supervisors for the most part have been able to access waiver systems from their institutions for their HBC clients. Of seven health facilities visited, five (Khunyangu, Tawfiq, Nakuru, FPAK-Nakuru, Port Reitz) stated that a waiver system was in place.

The government facilities do not formally refer their clients to HBC. The exception to this was the Palliative Care Center of Port Reitz in Mombasa that calls the CHW in to meet the client before discharge and initiates home based care training of caregivers prior to the discharge of the client.

In Nakuru, ICROSS has developed strong linkages, and the clinical supervisors who work in health facilities do meet regularly with their community health volunteers (CHV) for supervision and joint home visits.

In Thika, Speak and Act has developed strong linkages with hospital staff. It was started by 30 CHW who were working independently and then registered as a CBO. The hospital has provided them with a weekly meeting venue, as well as clinical supervisors were are able to make weekly home visits with the CHW they supervise.

Recommendations:

19. **Care and support programs should strongly encourage health facilities, particularly where clinical supervisors work, to formally refer clients using referral forms to HBC. This would facilitate an initial assessment and provide CHW and family caregivers adequate information regarding the care and needs of the client.**

20. **Since the Port Reitz palliative care center model seems to be working very well, replicating it in other health facilities where possible would enhance linkages between hospital and home through the initial training of caregivers. Involving CHW closely with these palliative care centers could improve the care of the PLWHA through more accessible and ongoing communication between clinical staff and the families or caregivers of the PLWHA.**

LACK OF SUPPORT TO CAREGIVERS

While HBC can decrease the burden of care on hospitals, the caregivers at home take on an additional burden. Many of the caregivers visited are caring for several orphaned children and were the sole breadwinners of the family. In addition, they must provide palliative care, food, medicine, and personal care to one or more sick or dying relative. Caregivers require enough training and instruction as well as psychosocial counseling and support to deal with this increased burden. During the evaluation, caregivers were found to be predominantly family members with the exception of Central Province where out of 14 caregivers four were either friends or neighbors. It is presumed that in urban slum areas, family members have less of a role in caring for PLWHA and the issue of institutional care in the form of hospice, or respite care may be needed.

Fifty-six caregivers were asked, *"Do you belong to a support group*?" In Western Province 41% (9 out of 22) of caregivers belong to a support group. In Mombasa 10% (2 out of 20) and in Central Province 21% (3 out of 14) stated they belong to a support group.

The team was informed by caregivers that they lacked necessary skills and knowledge to adequately care for the PLWHA. Caregivers were asked *"In what areas did you receive training from the community health worker?"* (Table 6) Many caregivers stated that they lack the skills and training to provide palliative care, to administer medications correctly, to identify signs and symptoms of TB or other illnesses that require medical attention as well as to implement infection control measures in the home. In Western Province, 77% reported that they had not received additional training from the CHW in the past year. In Mombasa, 65% and in Central 43% caregivers stated they had not received additional training.

Table 6: Skills transfer from CHW to caregiver in home

AREAS OF TRAINING FROM CHW	WESTERN (N=22)	MOMBASA (N=20)	CENTRAL (N=14)
Personal/palliative care	41%	50%	57%
Administration of medications	23%	40%	29%
Nutrition care support	50%	55%	64%
Signs/symptoms of TB	9%	40%	21%
Signs/symptoms requiring medical follow up	27%	40%	36%
Infection control	41%	50%	64%
Have you received additional training in past year? YES	18%	35%	57%
NO	77%	65%	36%

Recommendations:

21. **Caregivers require additional training and support in order to care for PLWHA.**

22. **Care and support programs should assist in the formation and functioning of support groups for caregivers, train and provide counseling to support group members.**

LACK of FOOD/ADEQUATE NUTRITION

When caregivers were asked, *"What is the most difficult condition for you when caring for the client?"* providing palatable meals was one of the most frequently mentioned issues particularly for Western and Central. They cited lack of food, and/or lack of appropriate food for an ill client (Table 7).

Table 7: Percentage of caregivers reporting on the most difficult conditions encountered when providing care to PLWHA

DIFFICULT CONDITIONS	WESTERN (N=31)	MOMBASA (N=17)	CENTRAL (N=21)
Diarrhea	14%	10%	14%
Pain	5%	5%	7%
Providing palatable meals	32%	5%	36%
Bedridden	18%	25%	0%
Skin	5%	5%	0%
Nausea/vomiting	5%	25%	0%
No difficulty encountered	5%	25%	29%
No appetite	0%	10%	7%
No response	0%	5%	14%

When asked, "W*hat makes it difficult for you to provide care in the home?* They mentioned lack of food and lack of money most often. (Table 8)

Table 8: Percentage of caregivers reporting on why it is difficult to provide care to PLWHA

DIFFICULTY IN PROVIDING CARE	WESTERN (N=31)	MOMBASA (N=17)	CENTRAL (N=21)
No supplies	27%	5%	29%
No money	68%	60%	36%
No time	5%	5%	14%
No food	50%	25%	57%
No drugs		15%	7%
Distance	9%	5%	0%
Bedridden	9%	0%	0%
Other		30%	14%

HIV/AIDS patients frequently suffer from lack of appetite and difficulty swallowing food due to thrush and diarrhea due to opportunistic infection or malabsorption. They are weak, often malnourished, and depleted of essential nutrients. These conditions, combined with the need to take numerous medications, require a balanced, supplemented nutritional intake. HIV infected patients require more calories than non-infected individuals do. The need for additional food was voiced throughout the sites visited, and a variety of ways to provide clients with an increased nutritional intake are being implemented.

In Rongai, Nakuru District, ICROSS has assisted the community members in starting a community food bank that has maintained a surplus over the course of the year. Teachers, religious leaders and other community members have been able to secure donations in the form of food from either large farms or well to do benefactors. This surplus is stored and, PLWHA who are in greatest need are able to access the food supplies. BUCOSS in Busia has started a demonstration kitchen garden project with indigenous plants of nutritional and medicinal value. CHW sell some of these greens as part of IGA as well as give some to their clients in need. Ready-to-Learn in Kabras and Speak and Act in Nakuru plan to collaborate

with agricultural organizations to provide seeds and education to clients and caregivers regarding gunnysack gardens, and small kitchen gardens.

The Provincial AIDS Control Officer for Coast Province made the team aware of the fact that in this region only 4% of arable land is under cultivation and out of a total of six districts, four are on relief food. The population here has relied on donor funded food relief for a long time. A portion of the population consumes raw cassava, a food of poor nutritional value.

Recommendations:

23. **The health care and agricultural sectors should collaborate and work closely together in order to increase food supplies to PLWHA and their families. GoK agricultural extension officers and CHW should join forces in the promotion of kitchen gardens and/or subsistence farming methods.**

24. **Ministry of Health, together with its development and implementing partners, should design a strategy for modifying care and support programs to include components of food supplements for clients in greatest need. More community groups should be encouraged to start food banks and kitchen garden projects such as those in Rongai and Busia.**

25. **When implementing community based organizations and groups are able to secure outside funding for necessities such as food, or medications, they should negotiate or seek assistance for secure storage for these items as a matter of priority. For example, Integrated Aids Program (IAP) in Thika has been able to secure food from an outside funding source, but does not have a space to store it.**

MITIGATION OF THE CLINICAL EFFECTS OF HIV/AIDS

ANTIRETROVIRAL DRUGS (ARV)

At the time of initiation of HBC in Kenya, the objectives were predominantly to provide palliative care in the home, as a way to lessen the burden on overwhelmed hospitals. With ART becoming more accessible in Kenya, other issues have developed. HBC programs will have to consider these emerging issues if they are to participate in or support a successful large-scale distribution of ARV. For many of the PLWHA visited by the team, ARV seemed like the only answer. Yet, the questions that came up repeatedly were how ARV would be taken on empty stomachs and how the clients would get these medications regularly. Throughout the sites visited, lack of food and money was the biggest issue

Until now, ARV have been offered at charges between Shs. 1,500/= and 4,500/= per month. Diagnostics required such as CD4 count, blood work and x-rays also are billed to the client. Even where ARV are available free of charge, access has been limited by transport and stigma. The number of children on ARV is negligible.

During the evaluation, some clients and caregivers had never heard of ARV, or misunderstood them to be "cures" for HIV. Some clients had been referred to hospitals by CHW for ARV, only to learn that beginning ARV required several visits, diagnostics and commitment in terms of money and time. Clients who are eligible for ARV will need food supplements in order to take these medications. It is unclear what role CHW would have regarding the provision and administration of ARV. Lack of knowledge of clinical manifestations of HIV/AIDS among the CHW is widespread. (Table 9) It is doubtful they could play any role in identifying potential candidates for ARV or OI drugs without intensive training.

Table 9: Percentage of CHW identifying possible sign/symptoms of AIDS

SIGN/SYMPTOMS OF AIDS	CENTRAL (N=30)	WESTERN(N=31)	MOMBASA (N=30)
Prolonged fever	27%	61%	27%
Prolonged diarrhea	47%	84%	73%
Rashes	63%	48%	67%
Lymph node swelling	17%	19%	13%
Unintended weight loss	50%	68%	80%
Prolonged cough	53%	68%	57%
Thrush	57%	45%	43%
Herpes zoster	63%	42%	50%
Night sweats	7%	3%	3%

A major concern regarding ARV therapy is compliance, which could be hindered by lack of food and lack of funds for transport needed to obtain the medications regularly. There also has to be an uninterrupted supply of these drugs at the distribution centers. The team noted that over 39% of PLWHA in Mombasa (12 out of 31) and 33% of PLWHA in Central Province (7 out of 21) were taking TB medications. All the clients who were taking TB drugs stated that these drugs *never* run out. Health care facilities confirmed that stocks of TB drugs are maintained throughout the year. If processes that have ensured availability of TB drugs could be put in place for ARV, some of these problems could be circumvented.

Recommendations:

26. **Care and support programs should enhance the capacities of CHW through further training and sensitization on ARV provision, particularly in the areas related to benefits, compliance and need to notify the physician in the case of possible side effects of the drugs.**

27. **USAID, NASCOP and implementing partners should further explore the possibility of linking the TB and HIV/AIDS programs to make it possible to distribute ARV drugs in a similar manner as TB drugs.**

28. **Care and support programs should sensitize communities on what ARV are, as well as provide clear information on what the procedure for assessing eligibility actually entails.**

MITIGATION OF THE SOCIAL EFFECTS OF HIV/AIDS

INCOME GENERATION ACTIVITIES

Poverty is exacerbated by HIV/AIDS. The majority of PLWHA in Kenya are those between the ages of 18-45 who are usually the family breadwinners. As their disease becomes more advanced, they are unable to work and the family income is compromised. Caregivers are severely stretched with the burden of providing medical care and supportive care to debilitated members of the family. In addition, the CHW who is working voluntarily also has a family to care for. Thus, economic opportunities for the PLWHA, CHW and caregivers are greatly needed. With an income, families can afford to buy medications and or food both of which when lacking, can be barriers to effective home-based care. During the evaluation, CHW informed evaluators of small-scale business ventures begun through their participation in support groups offered by HBC programs that have raised the levels of their household incomes. Representatives from K-Rep informed the team that repayment of loans was generally over 90%. As part of the evaluation, PLWHA were asked if they were receiving assistance in the form of IGA and found that only a few of the clients interviewed were receiving microfinance loans (Mombasa 3% N=31, Western 12% N=17, Central 14% N=21). There were more CHW reporting access to microfinance loans than caregivers or PLWHA. This is attributed to the greater number of support groups being offered to CHW than to PLWHA and caregivers. K-Rep loans are distributed through these support groups. In order for a PLWHA to obtain a loan, there must be a support group as a mechanism to guarantee the loan.

Recommendation:

29. **All HBC programs should include a component of microfinance schemes and ensure that they are made available to PLWHA and/or their caregivers through an accessible and available number of support groups for PLWHA and their caregivers.**

ORPHANS AND VULNERABLE CHILDREN (OVC)

The increasing and alarming number of orphans in Kenya presents an enormous challenge to government, communities and families as well as to the agencies and organizations assisting them. Institutional care is not a preferred method for the care of children in African nations. Decentralized family and community-based initiatives must be strengthened. The burden of orphans in society affects other structures such as health, education, and social services. Access to these services decrease as wage earners fall sick and are unable to work. Vaccination coverage in Kenya has decreased from 65.4% in 1998 to 59.2% in 2003*(KDHS 2003).* "One fifth of Kenyan children are underweight, with 4% classified as severely underweight"*(KDHS 2003).* There has been an increase of 30% in both infant and under five mortality rates from 1989 to 2003. Infant mortality was 60 deaths per 1,000 live births in 1989 and in 2003 increased to 78 per 1,000. Under-five mortality increased from 89 per 1,000 live births to 114 per 1,000 *(KDHS 2003).*

The evaluation team noted that care and support programs are addressing the OVC crisis in several ways as well as through the identification and registration of OVC. The CHW in all

COPHIA sites are identifying OVC as part of their work in the community. Unfortunately, this has simply become a new burden for the CHW as the numbers are on the incline and available resources are limited. The needs of these children include medical care, vaccinations, food, clothing, psychosocial counseling, school uniforms, preschool fees, and at times legal assistance. In older children, they include secondary school fees, or vocational training. As part of the evaluation, caregivers of OVC were asked, *"What services do you receive for the OVC?"* Central and Western regions indicated a higher response rate than Mombasa for counseling, food/seeds, clothes, and school fees. This higher response rate can be attributed to some respondents being recipients of services from either Lea Toto or SFTC. For the most part, due to lack of resources, willing and able caregivers and the legal requirements, the needs of OVC are not being adequately addressed. Individual CBO are attempting to provide needed services but unfortunately, the problem is overwhelming and these CBO cannot address all the multifaceted issues pertaining to OVC.

The two USAID funded OVC programs that the team visited have important components serving a great need, but each were found to be lacking necessary requirements and in the future, should combine their components to form a more inclusive/integrative approach which would address more OVC issues. Care and support programs specifically for OVC must include HIV prevention in order to prevent further cases of orphans. Education and outreach activities on family planning and PMTCT and VCT must be incorporated into any OVC program. Home care provided by either mentors, social workers or CHW must address HIV testing particularly so that early treatment of OI and AIDS can be initiated. The government is needed to stimulate collaboration among donors and agencies to design and implement strategic plans, monitor that children's rights are being protected through monitoring of service provision and assist on legal issues and resource procurement. Community volunteer groups who are caring for children should be given needed training and small incentives such as microfinance opportunities.

Speak for the Child and Lea Toto project are two USAID funded projects providing services specifically directed to OVC. The entry point for services varies considerably from one program to the other. Speak for the Child has identified orphans or vulnerable children (having lost one parent) from birth to age five. Lea Toto provides services only to children who are verified as HIV positive and their families.

The criteria used for eligibility for services were seen as limitations by the team. In the case of The Lea Toto Project, a parent or caregiver may have a sick child who would benefit from services offered but for reasons of stigma, is unwilling to have the child tested for HIV. Often a caregiver will wait until illness is very advanced before seeking out assistance and agreeing to have the child tested. On the other hand, SFTC, which provides HBC to OVC, has not incorporated counseling for HIV testing in the children to whom they provide services. Proper education on infection prevention, PMTCT and treatment with ARV or OI drugs cannot take place without first addressing the issue of HIV status in these children.

The Lea Toto Project

The Lea Toto Project is a community-based project that seeks to provide education care and resources to HIV infected children and their families. Lea Toto conducts mobilization activities and has formed implementing management committees. Forty-five peer educators have been trained in BCC, in order to target peers in schools. There are six social workers (SW) and two volunteer SW who provide supervision to the CHW. Two Lea Toto nurses provide basic medical care to clients and their families from clinics in Kawangware and Kangemi where they have OI drugs, and a VCT center. Nurses may make home visits when

necessary. Sick children are referred to neighboring health care facilities. The accomplishments include caregiver support groups and monthly counseling sessions to address burnout, an quarterly award to the hardest working CHW, training of caregivers in solar skills and micro enterprise development and provision of CRS food donations to neediest children.

Out of six caregivers interviewed receiving services from Lea Toto, four claimed that the last time the CHW visited the home was over one month ago. Linkages with neighboring health facilities do not seem to have been fully developed. There is no communication back to Lea Toto regarding medical needs upon discharge from neighboring hospitals. CHW have no homecare kits. They have been given bags, umbrellas and shoes. There is no waiver system in place with Nyumbani so that neither comprehensive care (such as ARV) nor diagnostics can be obtained from Nyumbani.

The Lea Toto Project has addressed psychological, legal, and resource issues but has not strengthened linkages with health facilities to the extent it should. Given that for reasons of stigma, caregivers are only consenting for HIV testing once a child shows signs of advanced AIDS, these children can be presumed to be quite ill and would benefit from increased medical care. This medical care should come in the form of trained medical personnel who supervise CHW and also make home visits when possible. CHW, if provided with necessary supplies and training in HIV/AIDS, could in turn transfer skills to caregivers and provide palliative care to sick children.

Ready-to-Learn/Speak for the Child

Speak for the Child (SFTC), has addressed the physical, cognitive and psychosocial needs of OVC under the age of 5 by providing support and education to caregivers regarding the emotional development and health of children. Community volunteers, coach and problem solve with caregivers around issues in nutrition, health and psychosocial care. Another of its objectives is to build capacity of other organizations in Western Kenya to deliver OVC support/services in their communities.

In homes where SFTC provides care, evaluators noted that children had dolls, or other play material, and caregivers stated they were educated in emotional care of children as well as in nutrition. SFTC has received funding for food distribution that is solely for this target group of children. SFTC has purchased and distributed seed and fertilizer for caregivers. All pre-school age children visited were in preschools. SFTC has developed linkages with health facilities to ensure that OVC and caregivers seek out health services for vaccinations. Almost all children seen by the team were up to date with their vaccinations.

Unfortunately, the serostatus of the clients were not known because mentors do not advise on HIV testing of children whose parents either have died of AIDS related illnesses or who show signs of advanced AIDS disease. SFTC will refer ill parents or caregivers to COPHIA program working in the area but the children must be referred directly to health care facilities. The children may remain in the program until age five and then begin to be phased out slowly from the project since the mandate is for up to age five only.

Cognitive and developmental growth are critical issues which when a caregiver is sensitized, may affect the child's care in a positive manner. This program provides important components

to vulnerable children living in poverty by ensuring that they are cognitively and emotionally cared for in addition to be being adequately nourished and vaccinated. Since many of these children are at risk for HIV, and the fact that ART may soon be available to them, a more direct health education approach must be taken whereby mentors are trained in HBC of HIV/AIDS children as well as in counseling for HIV testing. The fact that children at age five are slowly phased out of the program, returns the burden on communities and families again as they must find other sources of support.

Recommendations:

30. **All OVC programs should include care and support activities for HIV infected children through the establishment of strong linkages with health care facilities as well the enhancement of skills in counseling and care.**

31. **OVC programs should allocate funds for secondary school education as a priority for children who qualify to continue their education. Vocational training should be limited to children who did not qualify for secondary school.**

SUSTAINABILITY

The evaluation team did not find any comprehensive sustainability plan in any of the projects. The strongest sustainability indicators for care and support were seen in:

- The experiment with community food banks by ICROSS in Rongai,
- The nascent kitchen garden experiments in Western Province, and
- Access to micro-finance for small-scale business ventures that can address the livelihoods of the families affected by HIV/AIDS.
- Strong working linkages between health care facilities and home-based care as seen in ICROSS Nakuru, Speak and Act in Thika, and the Mission Hospitals.
- The focus on the spiritual aspects of volunteerism by faith based organizations.

Proceeds from successful small businesses make it possible for clients to meet the costs of producing or purchasing food, buying drugs, paying school fees and meeting daily household expenses. Several partners raised the issue of the sustainability of ARV therapy. Using donor funds for compensating CHW and volunteers for their time and services is also not sustainable.

Recommendations:

32. **USAID and the implementing agencies will need to address sustainability more specifically in the subsequent phases by providing functional sustainability indicators and benchmarks.**

33. **The cross referral model that includes clinical supervision (COPHIA's Mukumu Hospital and IMPACT's St. Mary's Hospital) appears to be sustainable. This model should be strengthened.**

34. **USAID should make deliberate efforts to broaden the scopes of both IMPACT and COPHIA projects to link HBC to wherever comprehensive care centers are already established, or due to be established.**

35. **Both COPHIA and IMPACT can benefit from the ICROSS model that also includes sanitation and community food bank components, and working with private providers. This model should be replicated by both COPHIA and IMPACT in Coast and Western Provinces.**

36. **The kitchen garden concept for ensuring food supplies, food security, and income to the sick is sustainable and should be promoted and implemented as part of care and support.**

37. **USAID should increase its investment portfolio in the micro-finance assistance through K-Rep loans to enable larger numbers of PLWHA to access the micro-financing facility and benefits. This scheme holds promise for sustainability as it establishes economic independence for households and thereby creating base for socio-economic survival of the sick and their families.**

CONCLUSION

With the AIDS epidemic still in full force, there is a need to expand, replicate and/or scale up existing programs that have shown promise in curbing the effects of the scourge. In addition to preventive measures currently underway, care and support must continue to be provided to those already infected and affected by HIV/AIDS. HBC programs must be comprehensive, incorporating services that address the physical, emotional, psychosocial and economic needs of those infected and affected. During this evaluation, the need for successful integration of the healthcare infrastructure with community-based services was recognized as key to ensuring that medical services and supplies reach the PLWHA. The team found that sustainable HBC programs are those that are strongly linked with the health infrastructure and include capacity building of the community through linkages with food security and income generation activities.

The provision of medical care, (which in the future will include ART), and psychosocial care to PLWHA and their families will be more effective where stronger linkages exist. Caregivers in the home will need more training and support in the future to ensure that PLWHA receive proper palliative care. Stigma remains a challenge in most areas and continues to hinder services. A more inclusive approach to HBC may need to be considered in the future whereby homecare services are provided to all those that require them. This would make a more rational use of resources and would assist in the capacity building of a larger group of recipients. A HBC program that mainstreams HIV/AIDS rather than isolating it as a qualitatively different medical condition could have a strong impact on stigma and denial.

Many CHW are respected members of, and selected by their communities to be trained to provide HBC services on a voluntary basis. Currently, due to lack of education, training, supplies, and linkages with and supervision by medical providers, the CHW were found to have a minimal effect as providers of HBC to PLWHA. Half of all CHW have only a primary level of education. In order to enhance the effectiveness of delivery of HBC by CHW, either selection criteria will have to specify higher levels of education and previous training and include a salary or more frequent trainings and refresher courses with closer supervision and monitoring by clinicians will need to be integrated into the programs. For reasons of cost as well as sustainability, it seems likely that they will require the latter. They will also need adequate materials and supplies to perform their work. Their role should not be as the initial trainers of caregivers but rather to reinforce training and education that was initiated by a referring health facility. To extend the lifespan of the many young people affected, HIV/AIDS care requires close monitoring of symptoms in order to effectively treat opportunistic infections and to monitor ART. The CHW have weakly linked health care providers and families mainly through referrals to health care facilities and minimal skills transfer and education to families. CHW can play a role in communicating information between PLWHA and their caregivers and health care providers, they can reinforce training initiated by health care providers, they can make observations and relay those observations. CHW cannot be expected to carry the brunt of care and support in the communities particularly without the education, training, skills, and supplies that are required.

Thus, the future role of the CHW should be linked closely with healthcare facilities that become the center of the CHW activities. This working relationship can be attained through a more active role on the part of the health care provider. It is the HC provider who should guide the care and the CHW who will facilitate it. The health care provider is needed to

actively supervise the CHW, initiate training of the caregivers, provide counseling, initiate a plan of care, as well as provide the necessary medical care. These clinicians are needed to monitor the status of bedridden clients and reevaluate treatments. Health care facilities need to be strengthened, with more personnel trained and aware of the need for appropriate care and support of the HIV/AIDS client.

THE WAY FORWARD

The ICROSS programs have focused on developing linkages with health care providers in the public and private sector with a goal of sustainability of these linkages. This approach seems to have demanded more accountability on the part of the government for outpatient care of PLWHA. In a short-term period ICROSS has established linkages between HBC and MOH staff. The CHV, working voluntarily together with medical personnel in health facilities, are providing care, education and support to PLWHA and their families. CHV include malaria prevention (through distribution of mosquito nets) and sanitation (through building of VIP latrines) as part of their care and support activities. The inclusion of these additional activities that are not necessarily associated with HIV/AIDS clients may help reduce stigma of current HBC programs. The CHV have also identified and assisted in the mobilization of community groups to meet some of the nutritional and financial needs of their communities. The ICROSS model is a sustainable model that has involved government health facilities in HBC more thoroughly than other models. The team recommends that the current staff of projects in Bungoma and Nakuru receive a funding extension to ensure a smooth handing over to the government.

An approach similar to that of ICROSS should be implemented whereby the health facility is established as the hub of home-based care and community activities. Some of the currently funded HBC programs of COPHIA should be incorporated into either the existing or planned FHI/IMPACT Comprehensive Care Centers or other health care facilities. Health facility personnel should provide clinical supervision to all CHW. An example of where this is already happening is in Thika where the CHW of Speak and Act are supported by Thika district hospital through provision of meeting venues and some clinical supervisors who are available to make joint home visits with CHW. Health care personnel should formally refer clients that require home-based care to a representative of home-based care who is on the premises. When possible, an office and/or meeting area should be available for support groups, conferences and trainings. All field managers should be clinically trained and involved in supervision, monitoring and evaluation, with the goal of handing over to the health facility. Healthcare providers should receive training in care and support and HBC and in the role of the CHW. Discussions at the provincial level should take place to ensure that added HBC responsibilities of HC staff are authorized and sanctioned. The CHW should continue to play a role in community mobilization and prevention activities in close collaboration with other cadres of health workers.

While the TASO model in Uganda cannot be a panacea, Kenyan care and support managers should have opportunity to review this and other notable HBC programs in Africa to adopt what may work in their own circumstances. In the TASO model, a team of one physician, nurse and counselor, located on the grounds of provincial health centers with a catchment area encompassing a thirty-five kilometer radius (each center has its own vehicle), provide homecare and other supportive services. A clinic is held twice weekly and home visits are conducted for bedridden clients. A users' fee of approximately .30$ is charged per visit. Counselors and staff within TASO are very active in AIDS awareness and advocacy issues. PLWHA or "members" are encouraged to join support groups and live openly and positively. TASO center has different donors and different community initiatives depending on the community's needs. TASO also strengthens the health facility in which they are located by providing the center with basic drugs.

KENWA in Nairobi is a COPHIA partner that is demonstrating the capacity to grow and expand. It has an infrastructure that could handle ARV and other clinical services. The fact that there is strong leadership that understands the issues surrounding PLWHA, and the fact that all CHW are PLWHA, goes very far in addressing stigma, which is one of the biggest blocks to provision of HBC services. The team recommends that USAID consider additional allocation of funding to KENWA with the purpose of expanding its services to a greater number of PLWHA and OVC.

As USAID's largest recipient of funds for home-based care in Kenya, COPHIA has played an important role in training and mobilizing over 700 CHW in their communities.
The policy of CHW incentives is not sustainable, and should be reassessed. The contents and method for restocking homecare kits must also be reviewed. In regards to some of COPHIA's implementing partners, of which there are many and most are relatively newly formed CBO, it is supposed that a great deal of time and effort is expended on upgrading and monitoring and maintaining program performance and response mechanisms throughout the regions. A more cost effective and less time-consuming method for COPHIA would be to work with fewer organizations that can be scaled up to provide services to larger areas and to more people. Some of COPHIA's implementing partners have the potential for replication or expansion, but not without further upgrading and closer monitoring and evaluation of current activities. There is need for a systematic and comprehensive capacity assessment of current COPHIA partners and their capabilities for expansion.

The mission hospital HBC programs currently being funded by COPHIA and FHI/IMPACT have the necessary linkages with health care staff, as well as a sustainable infrastructure and a focus on psychosocial support. HBC in other similar hospitals could be replicated. Distribution of ARV at no charge would have the necessary network in place to ensure that the medications are available to those found to be eligible. These organizations would need additional funding so that their services could be made available to a greater number of PLWHA and OVC at affordable costs.

Current HBC programs do not have the capacity, resources or training to address the growing number of OVC. Children require several other facets of care not included in caring for adults. Home-based care services for children will remain nonexistent unless these services are set up explicitly for children. Programs for OVC will need to be comprehensive. They must address medical, nutritional, developmental issues as well testing/disclosure, psychosocial and legal matters. Existing OVC programs are few and address some but not all the aforementioned issues. SFTC must address HIV testing in vulnerable children enrolled in its program. Lea Toto must develop stronger working relationships with medical facility staff trained to supervise the CHW in the field.

The evaluation has not mentioned urban slum areas in particular, but the team found that PLWHA are receiving less care in these areas because they often do not have relatives as primary caregivers. In urban areas, it was noted that more caregivers were friends or neighbors who could not provide round the clock care. Food security was also a bigger problem as land for farming or even planting a kitchen garden is unavailable. In urban areas, there might be a need for communities to come together to provide care in the form of hospice, institutional, or respite care.

Infrastructure for care can improve the access to and utilization of ART, and it is a basic requirement. Palliative care services in Kenya are needed on a much larger scale than is currently available. Services should be available for adults and children living with HIV disease and their families, from diagnosis through death and bereavement. The model of palliative care as seen in Port Reitz should be replicated in other regions. Port Reitz is a short-term, 14 bed in-patient facility located on the grounds of the district hospital of Mombasa that provides holistic care, linkages to ancillary services and discharge planning. Training and education of the caregiver is initiated prior to discharge as well as linking the CHW with the family. This facility provides care to anyone with a terminal illness. While the client is in the hospital, issues of nutritional needs, financial needs, medical needs (ARV) and psychosocial needs are addressed. The approach of training the caregivers prior to discharge ensures that families are more knowledgeable and skilled to deal with care of the PLWHA as well as more prepared to face issues of stigma and denial. Caregivers are expected to remain with the clients throughout the duration of the hospital stay. The newly established relationship with health care providers continues after discharge through follow up clinic visits and support groups. The health care provider links the CHW with the family, through a formal referral and introduction that may give greater credibility to the CHW. Ideally, a palliative care center should be set up in each district health center where a number of beds are reserved for HIV/AIDS and terminal illness patients. Staff in each district hospital would be identified as palliative care staff trained in counseling as well as in HIV/AIDS care. These staff members would share the work of palliative care, education and training of clients and families and would supervise the community health workers. Health facility staff should be able to arrange their work schedules in order to spend two days per week in the field seeing bedridden clients. These district health centers could also become satellite centers for ARV distribution once clients have been enrolled.

It should be mentioned that in most government facilities where the stronger linkages with homecare had been established, the team found more motivated health care personnel, who were committed to helping the HIV/AIDS population (Port Reitz Hospital, Coast General Hospital, Bungoma Sub District Hospital, Provincial General Hospital in Nakuru, Thika District Hospital). It was also noted that these facilities had undergone some structural renovations and improvements, and the general atmosphere of staff and clients was more amenable. USAID should continue to fund renovations and structural improvements particularly in health facilities which could or are currently participating in home-based care activities.

The GoK should be continually encouraged to invest funds and participate more comprehensively in HBC activities, particularly as a source of support and supervision to CHW as well as proper treatment for PLWHA. It should assume full responsibility for the training of the relevant district level staff in care and support of PLWHA at the health facility and community levels where appropriate. The GoK, through NASCOP, should be actively involved in monitoring and evaluating all HBC activities. In addition, NASCOP should be a full participant in any future coordination efforts of all donors involved in HBC. Further, the GoK should consider the inclusion of medicines and food/nutritional supplementation in the HBC kits as a way of augmenting its HBC services. Where possible, there should be linkages with private sector providers to ensure that private facilities participate in HBC services. Wherever possible, USAID should be involved in NASCOP strategic planning activities as well as considering the sustainability of care and support programs by encouraging active government participation and planning activities.

ANNEX 1

Team Members

Sandra Haim Team Leader, Consultant

Deryck Omuodo, Consultant

Pauline Mwololo, NASCOP

Janet Paz-Castillo, USAID Kenya/OPH

Dr. John Wasonga, USAID Kenya/OPH

ANNEX 2

Methodology

Quantitative information was obtained through questionnaires to:

- Seven health care facility staff members
- 56 family/friend caregivers,
- 91 CHW
- 100 beneficiaries (PLWHA and OVC).
- 28 women of childbearing age

Qualitative information was obtained through:

- Observations of 74 homes
- Unstructured interviews with area managers of IMPACT, COPHIA, COGRI and AED, stakeholders and provincial and/or district health officers

The following is a list of collaborating agencies and locations that were visited during the evaluation:

WESTERN PROVINCE

Busia	REEP
Butula	BUCOSS
Shingalu	Mukumu Hospital
Kabras East	Jua Kali
Kabras West	Speak for the Child
Bungoma	ICROSS
Webuye	ICROSS
Mumias	St. Mary's
Kakamega	Prison
Kakamega	Provincial District Officer

NAIROBI

Mathare	KENWA
Soweto	KENWA
Korogocho	Redeemed Gospel Church
Riruta	RICOAN
Karangware	LEA TOTO
Kangemi	LEA TOTO

THIKA

Thika town/	District Hospital
Kiandutu	Speak and Act
Mangu	IAP

NAKURU

Nakuru	District hospital
	FPAK
Kaptembwa	ICROSS
Rongai	ICROSS

MOMBASA
Coast Province General Hospital
Port Reitz District Hospital

Changamwe	Jomvu BI
	Bangladesh BI
Kisauni	Freretown BI
	Mtopanga BI
Malindi	Tafiq Hospital and HBC
Likoni	Mtongwe BI
	Shika Adabu BI

Meetings were held with the following stakeholders:
FHI/IMPACT
PATHFINDER
NASCOP
NACC
ICROSS
PACC in Mombasa
Provincial medical officers in Kakamega and Thika

ANNEX 3

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ANNEX 4

Scope of Work

1.0 Introduction/Rationale

USAID/Kenya continues to make progress towards its Intermediate Result 2, "Increased use of proven, effective interventions to decrease risk of transmission and mitigate the impact of HIV/AIDS" under the Mission's Strategic Objective 3, "Reduced fertility and risk of HIV/AIDS transmission through sustainable integrated family planning health services".

Based on stakeholder consensus, in 1998 USAID/Kenya designed an HIV/AIDS strategy designed to address areas of prevention of HIV transmission in conjunction with care and support for persons living with HIV/AIDS (PLWHA) and the families that care for them. Under this comprehensive HIV strategic approach, specific activities have emphasized a community-based approach to providing physical and psychosocial support to adults and children affected by AIDS. Such activities have made progress on a number of objectives, including:

- Improving the ability of local communities to identify their needs in home-based care by engaging in extensive community mobilization and participation of local leaders and community members;
- Increasing the capacity of local NGOs engaged in prevention and treatment programs by partnering with institutions with resident technical expertise;
- Strengthening existing systems of home-based care, support, and referral for HIV+ adults and children by linking doctors, nurses, social workers, and community health workers; and
- Helping communities identify the specific needs of HIV+ orphans and vulnerable children and specific needs of their caregivers, and facilitating support for these individuals.

This evaluation will review the current status of home-based care, OVC, and related activites make recommendations regarding the contributions they may make to the revised and expanded HIV/AIDS strategy currently under review by USAID/Washington. The following programs will be examined:

- The Community-Based Program on HIV/AIDS Care, Support, and Prevention (COPHIA)
- FHI/IMPACT – St. Mary's Hospital
- FHI/IMPACT – ICROSS, Bungoma
- Community REACH – ICROSS, Nakuru
- CRS/COGRI – Lea Toto orphans support project
- Academy for Educational Development (AED)'s Ready to Learn/Speak for the Child Project

The results of this evaluation will guide USAID/Kenya's future endeavors in comprehensive community-based HIV/AIDS care and support activities. Specific attention will focus on the extent to which presently-funded programs can scale up and/or more offer some of the complex care and treatment services that will be expected under the Presidential Emergency

Plan for AIDS Response (PEPAR) and Prevention of Mother-to-Child Transmission (PMCT) initiatives.

2.0 Background

The 2002 UNAIDS report on the global HIV/AIDS situation ranks Kenya as fourth worldwide in terms of number of people infected with HIV. Kenya's national seroprevalence has remained at 10-13% for several years, indicating that although levels may have peaked, the nature of any possible decline remains uncertain. There is significant regional variation in prevalence and incidence of HIV in Kenya.

Given the nature of the epidemic in Kenya and Kenya's strong partnership with the USG to date in efforts to mitigate the impact of HIV/AIDS, Kenya was designated a Rapid Scale-Up country under USAID's Expanded Response to HIV/AIDS Strategy and is among twelve African nations to benefit from significant resources from PEPAR. To achieve the global targets set forth under PEPAR, as well as targets described by the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) and proposal objectives of the Global Fund for AIDS, TB, and Malaria (GFATM), by 2008 USAID/Kenya's strategy plans, in concert with partners, to:

- Reduce HIV seroprevalence by 20-30% among 15-24 year olds;
- Provide access to prevention of mother to child transmission (PMCT) counseling and services for 25% of pregnant women who are HIV positive; and
- Ensure care for 25% of the people infected with HIV and 25% of the children affected by AIDS.

USAID/Kenya is committed to partnering with the Government of Kenya to help achieve these goals, and expects to add goals related to treatment as PEPAR and PMCT requirements are made clear.

3.0 Scope of Work

3.1 Objectives

The evaluation team will examine activities in USAID/Kenya's Care and Support Portfolio to assess the following:

- the progress of individual projects and the portfolio as a whole towards the achievement of specific project objectives and USAID/Kenya's Intermediate Result 2;
- the overall performance of projects and areas in which they should place more emphasis in order to improve results;
- the pace of project implementation given project extensions and expansions of scope, and any general changes in area of emphasis *and* changes in specific activities necessary to successfully carry out project objectives;
- the viability of the current diverse, comprehensive mandates (i.e., are there "mission creep" issues in terms of expecting HBC providers to be all things to all people);
- the current and potential role of this portfolio of activities to developing sustainable community-based care and support of HIV+ individuals and the families that care for them;

- the current and potential relevance of this portfolio of activities to the needs of children affected by HIV/AIDS;
- overall challenges and lessons learned; and
- key areas of future focus for the portfolio, the value and potential for expansion into longer-term, more comprehensive activities and the actions necessary to realize this.

3.2 Participants, critical skills, and audience for the evaluation

Team Members:
- Team leader (likely a US-based expert)
- Local expert consultant
- UNICEF staff member
- MOH staff member

Audience:
- Mission management
- OPH portfolio managers
- Project implementers

Key Informants
- Project representatives
- Home based care workers and recipients
- MOH/NASCOP personnel
- USAID staff
- Other donors, as appropriate

3.3 Issues to be addressed by the team

3.3.1 Topical Issues

The evaluation will include, but not be limited to, an exploration of the scope and effectiveness of current efforts and potential capacity in the following program areas:

<u>Prevention</u>
- behavior change communication and IEC materials;
- distribution of condoms;
- voluntary counseling and testing (including post-test clubs, synergies between activities engaging in VCT, and community mobilization for VCT);
- treatment of sexually transmitted diseases; and
- reduction of stigma surrounding HIV+ individuals and adults/children with AIDS.

<u>Care and support</u>
- appropriate training in both community awareness raising/mobilization and in home care;
- strategies and incentives for sustained participation of community health workers;
- effectiveness of referrals for clinical/tertiary care and referrals from clinical/tertiary to community (including referrals for TB, other OIs, family planning, and STIs);

- physical and psychosocial support specifically designed for children with or affected by HIV/AIDS and their families;
- effectiveness of current home-based care, focusing on –
  - psychosocial benefit/s to clients and family members
  - palliation or "comfort care"
  - identification and appropriate referral for treatment of opportunistic infections (especially TB);
- potential for contribution to future care/treatment objectives, including –
  - prevention and/or treatment of common opportunistic infections, including community-based DOTS for TB treatment
  - distributing and/or monitoring effective adherence to more complex treatment regimens, including ART; and
- care for pregnant HIV+ women, including knowledge of and referrals for prevention of mother-to-child transmission.

3.3.2 Process Issues

The team will assess issues related to the process of implementation of prevention, care and support activities, including, but not limited to the following.

Achievement of goals and objectives

The evaluation team will assess and comment on the extent to which projects have:

- met stated goals and objectives;
- developed and implemented appropriate monitoring and evaluation tools to track progress towards stated goals and objectives;
- developed capacity of partner organizations;
- acted upon/implemented recommendations from previous assessments; and
- responded to changed environment for HIV/AIDS treatment and care by revising goals and objectives, where appropriate.

Reporting:

While the primary objective is to assess programmatic effectiveness, the team will also assess the degree to which projects have complied with USAID reporting requirements.

3.4 Specific activities

Activities to be conducted by the team will include, but not be limited to:

- Entry conference with USAID/Kenya staff during which the team will present a proposed schedule for undertaking the evaluation;
- Review of relevant documentation (including project studies, status reports, evaluations, USAID HIV/AIDS strategy documents, and other reports related to community-based home care programs in Kenya).
- Meetings with project staff of individual projects;
- Site visits and meetings with MOH officials and other stakeholders including project staff, community health workers, and families;

- Structured interviews conducted with a representative sample of home-based care providers and their clients/family members of clients to assess their satisfaction with the project in question and to secure recommendations for future program direction/project improvement; and
- Exit conference during which the team will present the first draft of the evaluation report, highlighting key findings and recommendations.

3.5 Report and recommendations for future program direction

The team leader will submit a draft report to USAID prior to the post-evaluation debriefing. The final report will be submitted no later than 14 days from the date of the final debrief to USAID. The document will be organized as follows:

I. Executive Summary
II. Background
III. Summary of key findings and conclusions
IV. Recommendations for future directions
V. Annexes
   a. Scope of Work
   b. Evaluation Team Members
   c. List of Interviewees
   d. Methodology
   e. Questionnaire tools

3.6 Level of effort

3.6.1 Proposed schedule

The evaluation will take place during the first four weeks beginning February 9, and will include:

- A desk review of materials
- Team briefing and orientation
- Site visits and interviews
- Completion of written report
- Presentation to USAID on March 3, 2004

Total number of working days for Team Leader: 25 (18 on-site, 7 for final report preparation)

Total number of working days for Team Members: 20

3.7 Logistics and Support

Office space and equipment, travel/transportation support, per diems, hiring of consultants

USAID will provide travel, transportation, per diem expenses, and consultant fees. The Team Leader will be in charge of the travel budget for the team e.g. taxi fare. The Team Leader and the local consultants will be expected to provide their own laptop

computers. Arrangements for field transportation and office space will be negotiated by USAID/Kenya with appropriate project representatives.

3.8 Relationships

The team leader will report directly to the Senior HIV Advisor for Care and Treatment Activities, Office of Population and Health. The team leader will work closely with OPH's Senior Technical Advisor in AIDS and Child Survival, and other OPH staff as necessary.

3.9 Completion of deliverables

The contract will be considered successfully completed when the Team Leader submits to USAID/Kenya the final report document.

Before the debriefing on March 4, 2004, the Team will submit its first draft report to USAID. USAID OPH will provide comments not later than March 11, 2004. The team leader will submit a final document free of typographical and grammatical errors, in both paper and electronic versions, not later than March 25, 2004.

Payment Options: 20% upon submission of the first Draft to OPH and 80% upon submission of an acceptable final report.

ANNEX 5

Evaluation Tool

Project:
Area Manager:
Date:

Please provide the following information:

1. Objectives of project

2. Size and population of project area

3. Estimated number of target population

4. Current number of clients being served

5. Prevention strategies

   a. BCC and IEC information and materials adequate _____Yes_____No

   b. Quality of information and materials _____Adequate_____Inadequate

   c. Number of condom promotion activities in past month_____

   d. Number of community mobilization activities in past month_____

   e. Number of condoms distributed in past month_____

   f. Number of abstinence promotion activities in the past month

6. Number of currently active CHWs_____

EVALUATION OF USAID CARE AND SUPPORT PROGRAMS

Area Manager

7. Number of CHWs who ceased working in past year _____

8. Level of formal education of CHWs (indicate number in each category)

None _____ primary to standard 4 _____completed primary _____

completed secondary school _____ Tertiary _____other _____

9. List all types of in-service training and number of participants at each in past year

10. How many clients have been referred to other facilities in the last one week

Number of clients	Reasons for referrals
…….	……
…….	……
…….	……
…….	……

11. List of other organizations that are supporting care and support programs in your project areas and what they do?

12. In the past year, how often have supplies for CHW kits run out?

Only once_____often_____supplies not stocked_____

EVALUATION OF USAID CARE AND SUPPORT PROGRAMS

The following will be by discussion with Area Manager

13. What has the project implemented from the home based care policies and guidelines?

14. What has the project implemented from the orphans care policies and guidelines?

15. Accomplishments of the project

16. Lessons that have been learned from the implementation of the project

17. What you see as the future direction of the project

18. Constraints experienced in implementing the project

19.Request Area Manager to provide verification/confirmation on current number of clients being served

EVALUATION OF USAID CARE AND SUPPORT PROGRAMS

Project:

Health Facility (identify HIV/AIDS service provider):

Date:

Please provide the following information:

1. What structures does your health facility have in place to offer HIV/AIDS care and support services to client/patients in relation to:

   Out patient services
   ……

   In patient services
   ……

   Follow-up services
   ……

2. Are the service provider adequately prepared to offer HIV/AIDS care and support services……..

   Explain…….

   ……

3. How is your institution involved in capacity building for enhancing provision of HIV/AIDS care and support services for the following:

   Health workers
   ……..

   Community members
   …….

   Family/care givers
   …….

   Clients/patients
   ……

EVALUATION OF USAID CARE AND SUPPORT PROGRAMS

Health Facility

4. What referral system do you have in place;

Formal with referral letters
……

Informal by word of mouth
……

5. How many clients do you refer for community home based care per week and for what reasons do you refer?

……

6. How many clients are referred to this facility from community home based care per week and for what reasons?

……

7. Who are your collaborators in the implementation of care and support services and which are the areas of collaboration;

……

How often do you meet…….

9. Accessibility of services to clients;

Free services?

Chargeable? How much?

Waver system in place?

EVALUATION OF USAID CARE AND SUPPORT PROGRAMS

Health Facility

10. In the past year, how often have you run out of any of the following?

	Only once	often	don't stock
ARVs			
OI drugs			
TB medications			
Viral load test			
CD4 test			
Eliza test			

11. What post exposure prophylaxis (PEP) activities do you have in place?

    a. Counseling and testing ……..

    b. ARV……..

    c. Educating health workers and community on PEP …….....

       If yes, how often…….

12. What are your current programs and the total number of clients seen in the past one week?

    PMCT……

    VCT…….

    ARV……..

    HBC……

    STI Management……...

    Condom promotion and distribution…….

    Others……

EVALUATION OF USAID CARE AND SUPPORT PROGRAMS

Health Facility

13. What do you know about COPHIA/IMPACT/ICROSS activities

……

……

14. Are you satisfied with the way services are provided at the community level? Explain

……

Project:

Community Health Worker [ ]:

Community Social Worker [ ]:

Date:

1. What do you know about activities related to the following
   COPHIA……..
   IMPACT…….
   ICROSS……..

2. What type of services do you provide as a community worker

Other……
Nursing care …….
Giving medication…….
Health education ……..
Counseling ..…….
Nutrition care support……
Infection prevention……..

3. When did you begin working as a community worker?
   ……

4. What type of training have you received including in-service while on this project

Type of training	Duration of training
……..	……..…….
……..	……..…….
……..	……..…….
……..	……..…….

List the number of clients that you are caring for this week and their condition.

Mobile	bedridden
……..	……..…….

5. What is the highest number of clients have you cared for in a given week?.....

EVALUATION OF USAID CARE AND SUPPORT PROGRAMS

Community Health/Social Worker

6. How many home visits do you make in a week? ……..

7. How often are you involved in community mobilization and other prevention activities

Weekly	[ ]	Twice a month	[ ]
Monthly	[ ]	Others……..	

8. What supplies and drugs do you have for the provision of care?

Gloves	[ ]	Disinfectants	[ ]
Soap	[ ]	Nutritional supplements	[ ]
Dressing materials	[ ]	IEC materials	[ ]
Drugs (specify)……		other	[ ]

9. How many clients have you referred to the health facility in the last one week

Number of clients	Reasons for referral
……..	……..…….
……..	……..…….

10. What records do you keep and how do you use them?

Type of records	Use
……..	……..…….
……..	……..…….

11. How often do you meet with your supervisor?

Daily	[ ]	Twice a week	[ ]
Weekly	[ ]	Twice a month	[ ]
Monthly	[ ]	Others ……..	

What are the advantages and disadvantages of these meetings?

Benefits

……
……..…….

Drawbacks

……
……..…….

EVALUATION OF USAID CARE AND SUPPORT PROGRAMS

Community Health/Social Worker

12. Do you know the signs and symptoms of AIDS?(tick as per responses)

Fever > 1 month	…….	cough > 1 month	…….
Enlarged lymph nodes	…….	thrush of the mouth	…….
General pruritic dermatitis	…….	recurrent Herpes Zoster	……
Weight loss <1 month	…….	persistent diarrhea	……..
Disseminated progressive Herpes simplex	……		

13. Are you currently a member of a caregivers' support group?

Yes …… No …….

If yes, have you found it beneficial? In what ways?

If no, why not?

14. What are the factors that would make provision of services better?

……
……..……..
……

15. What are your constraints in providing care?

……
……..…….
……

EVALUATION OF USAID CARE AND SUPPORT PROGRAMS

Project:
Observation checklist (Home)
Date:

1. How is the care provider received in the home?
   Positively received [ ]
   Negatively received [ ]
   Neutral [ ]

2. What does the community worker discus during visit
   ……
   How does the home environment look like?
   Well maintained [ ]
   Needs some improvement [ ]
   Neglected [ ]

3. Is there a home care kit available?
   Yes [ ]
   No [ ]
   If yes, what is the condition? ……..

4. Is there clean water available for use?
   Yes [ ]
   No [ ]
   Comments……

5. Is there food available for the client? Comments
   Yes [ ]
   No [ ]
6. Any care being provided during the visit?
   Yes [ ]
   No [ ]
   If yes, observe the process of care giving

7. What is the general condition of the client?
   Good (up and about) [ ]
   Fair (sickly but not bedridden) [ ]
   Bedridden [ ]

8. Who are the other members of the family

EVALUATION OF USAID CARE AND SUPPORT PROGRAMS

Project:

Care Giver:

Date:

1. Is your client your relative, friend, or neighbor?

2. Do you know the nature of the clients' illness?……yes……no

3. What types of care/support do you provide

Nursing care	…….
Counseling	…….
Medications	……..
Nutrition care support	……..
Infection prevention	……..
Health education	……..
Other	……..

4. In what areas did you receive training?

Personal/palliative care	……
Administration of medications	……
Nutrition	……
Signs and symptoms of Tb	……
Signs and symptoms requiring medical followup	……
Infection control	……

5. Have you received any additional training or information in the past year?

Explain……

6.How many clients are you currently caring for

Adults	……
Orphans	……

EVALUATION OF USAID CARE AND SUPPORT PROGRAMS

Care Giver

5. How often does the HCW visit you in the home?

   Less than once per week …….
   More than once per week …….
   Irregularly …….

6. Which signs and symptoms in a client would you refer to a medical

   Facility……

7. What is the most difficult condition for you to manage in your patient?
   Explain

8. What supplies and drugs do you have for the provision of care?

   Gloves Disinfectants
   Washing Nutritional supplements
   Dressing materials Drugs (specify)…….

9. What makes it easy for you to care for your patient?
   Explain

19. What makes it more difficult for you to provide care in the home?
    Explain

20. Are you currently a member of a caregivers' support group?

    Yes…….. No ……

    If yes, Have you found it to be beneficial?…….yes…..……..no

    If no, Why not…….

EVALUATION OF USAID CARE AND SUPPORT PROGRAMS

Project:

Clients/Beneficiaries PLWAs)

Date:

1. What are your major health problems?

2. What do you know about IMPACT/ICROSS/COPHIA activities?

3. What services do you receive from the project?……

   ……

4. What services do you receive from the CHW?

Nursing care	……..	Medications	…….
Health education	……..	Counseling	…….
Nutrition care support	……..	Infection prevention	…….
Other	……..		

4. What benefits do you get from the services?……...

   ……

5. Has anyone in your household ever been to visit a VCT center?……..

   ……

6. What drugs do you take?

Name of drug	use	availability (sometimes/always)

7. Do you or your partner use condoms?

8. For what purpose do you or your partner use condoms?

EVALUATION OF USAID CARE AND SUPPORT PROGRAMS

Project:

Orphans and Vulnerable Children (OVC):

Date:

The following information on OVCs to be obtained from care-givers and family members

a. Source of psychosocial support, if any

b. Level of awareness of the effects of HIV/AIDS and related problems

c. Knowledge of COPHIA/IMPACT/ICROSS activities

d. Services received from projects

e. Benefits of such services

f. Enrollment in school

g. If there is any legal support, or if OVC requires legal support

h. If food supplies required are adequate

i. Nutritional status of OVC (determine by observation)

j. Vaccinations up to date

k. Clothing: Has …….Does not have……

l. The last time visited by a CHW and what the CHW did on that last visit

EVALUATION OF USAID CARE AND SUPPORT PROGRAMS

Project:
Women:
Date:

1. What do you know about activities related to the following projects?

   COPHIA……

   ICROSS……

   IMPACT……

2. Have you ever received services from these projects?

   VCT ……
   Post test club …….
   Income generating activity …….
   Home based care …….
   Nutritional care …….

3. Do you use condoms? …..yes …….no

   Explain……

4. Do you know how HIV can be transmitted to babies?

   Breast milk …….
   In utero/during delivery ……..
   Doesn't know ……..

5. Do you know how transmission of HIV can be prevented in babies?

   Drugs ……
   Do not breast feed ……..
   Doesn't know ……..