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Operational Challenges

Community Home Based Care (CHBC) for PLWHA in Multi-Country HIV/AIDS Programs (MAP) for Sub-Saharan Africa

AIDS Campaign Team for Africa (*ACTAfrica*)

Nadeem Mohammad
Juliet Gikonyo

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Operational Challenges Community Home Based Care (CHBC) for PLWHA in Multi-Country Aids Programs (MAP) in Africa

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Abstract

This paper is the first in a series of efforts to document the current practices of CHBC in the Multi-Country HIV/AIDS Program (MAP) for Africa, focusing on the operational challenges and limitations. In its design, the MAP is unprecedented in its flexibility, coverage and the emphasis it places on local, community-driven initiatives responding to the HIV/AIDS crisis. Country programs are designed to encompass all sectors and the full range of HIV/AIDS prevention, care and treatment activities. CHBC is an example of the community-driven initiatives focusing on HIV/AIDS care and treatment activities. Research shows that an effective and affordable CHBC for PLWHA, has the potential to positively impact the health and social status of patients, families and the community as a whole. However, research has also shown that CHBC area facing a multitude of challenges and limitations which not only adversely affect their ability to carry out their activities, but also have the potential to **exacerbate poverty and existing gender inequalities** among affected families and communities. This research was conducted by ACTAfrica to find out the current operational challenges and limitations faced by CHBC organizations, primarily CBOs, in selected MAP countries: Burkina Faso, Cameroon, Malawi, Mozambique, Nigeria, Senegal, Tanzania, Zambia. The principal findings of the research are the basis of the key recommendations cited in this paper.

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Authors' Affiliation and Sponsorship

Nadeem Mohammad nmohammad@worldbank.org

Juliet Gikonyo

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Preface

This paper documents the current operational challenges and limitations faced by Community Home-based care (CHBC) programs of primarily community based organizations (CBO) for people living with HIV/AIDS (PLWHA), in the World Bank's Multi-Country HIV/AIDS Program (MAP) in Africa.

This paper is the first in a series of efforts to document the current practices of CHBC in the MAP countries, focusing on operational challenges and limitations. Experience in various MAP countries show that simple logistics and operational bottlenecks severely affect the access to and provision of ART for the community based organizations. Some CBOs providing CHBC including ARV drug administration face problems from inconsistent supply of drugs to inadequate logistics costs. Various countries have put limits on the overhead costs to discourage misuse of the resources; however, they seldom realize the affects of such limitations when CHBC initiatives are undertaken.

There is documented research on the various activities carried out by CHBC and the successful strategies that have been implemented. However there is a lack of documented information on the root operational issues which contribute to the overall challenges and limitations. This paper aims to highlight these pervasive operational challenges and draw attention to the responsibility of the key players in CHBC. The principal findings of the research are the basis of the key recommendations for alleviating challenges and, hence improving the current situation of CHBC programs.

Acronyms

ACT <i>africa</i>	AIDS Campaign Team for Africa
AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-retroviral Therapy
ARV	Anti-retroviral
CBO	Community-Based Organization
CHW	Community Health Worker
CHBC	Community Home Based Care
CSO	Civil Society Organization
FBO	Faith-Based Organization
HIV	Human Immunodeficiency Virus
M&E	Monitoring and evaluation
MAP	Multi-Country HIV/AIDS Program for Africa
NAC	National AIDS Committee or Council
NGO	Non-Governmental Organization
OI	Opportunistic Infections
OVC	Orphans and Vulnerable Children
PLWHA	People living with HIV/AIDS
PMTCT	Prevention of mother-to-child Transmission
STI	Sexually Transmitted Infections
TB	Tuberculosis
TTL	Task Team Leader
UNAIDS	Joint United Nations Program on HIV/AIDS
VCT	Voluntary counseling and testing
WFP	World Food Program
WHO	World Health Organization

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1 EXECUTIVE SUMMARY

1.1 INTRODUCTION

1. Sub-Saharan Africa is disproportionately affected by the HIV/AIDS pandemic. With about 10% of the world's total population, Sub-Saharan Africa accounted for three-quarters of AIDS deaths worldwide and up to two-thirds of all people living with HIV/AIDS in 2004. African Leaders, the World Bank, and the international community at large have recognized the need for quick, forceful, and sustained action against the pandemic. Guided by these principles, the Bank and its partners designed the Multi-Country HIV/AIDS Program (MAP) for Africa, to support the national mobilization of Sub-Saharan African countries against the HIV/AIDS epidemic¹. As of June 2005, 28 African countries and three regional programs have received US\$ 1.1 billion within the MAP approach, and MAP projects are being prepared in another ten countries and other regional programs.

1.2 BACKGROUND

2. Undoubtedly, there is a **great need** for services and support provided by community home-based care (CHBC) program to persons infected and affected by HIV/AIDS. In Sub-Sahara Africa where the HIV/AIDS epidemic is of paramount concern, the nature of the disease, weak public health infrastructure, spiraling health costs, and lack of resources has made community home based care a necessity in the continuum of care in Sub-Saharan Africa. [Coleblunders et al., 2000] **However, mistakenly CHBC is seen as a lone option available for many HIV/AIDS patients.**

3. An effective CHBC program for PLWHA can yield major health and social benefits starting from the patients and their families, and consequently to the entire community. However, this can only be achieved through a **continual cohesive commitment between communities, governments, organizations and development agencies/donors.**

4. Experience in various MAP countries show that simple logistics and operational bottlenecks severely affect the access to and provision of ART for the community based organizations. Some CBOs providing CHBC including ARV drug administration face problems from inconsistent supply of drugs to inadequate logistics costs. Various countries have put limits² on the overhead costs to discourage misuse of the resources;

¹ Because mitigating the epidemic is a medium- to long-term challenge, the MAP will be phased over 12 to 15 years. Phase 1, over the first three to four years, would scale up existing programs in HIV/AIDS prevention, care and support, and mitigation and build capacity. Phase 2, following a rigorous stocktaking, would, over the next five years, mainstream those programs that have proved effective, attain nationwide coverage, and expand care, support and treatment interventions. Phase 3, by which time new infections are expected to decline, would permit a sharper focus of prevention on areas or groups where the spread of the epidemic continues. The number of AIDS cases will probably peak during Phase 3, requiring a maximum effort in care and support.

² World Bank does not prescribe any such limits under MAP.

however, they seldom realize the affects of such limitations when CHBC initiatives are undertaken.

1.3 JUSTIFICATION OF RESEARCH

5. It is imperative to rethink existing community home based care models in order not to **exacerbate poverty and existing gender inequalities** among affected families and communities [Akintola, 2004]. This research is conducted by ACT*africa* to find out the current operational challenges and limitations faced by CHBC organizations, primarily CBOs, in Sub-Saharan Africa.

1.4 METHODOLOGY AND OBJECTIVES

6. The eight MAP countries were selected using a criteria described later. Quantitative and qualitative data was collected from targeted key informants³ using three different questionnaires.

7. The goal of the research was to determine the implementation challenges faced by CHBC programs. To achieve this goal, the following objectives were outlined for the research:

- i. Document current practices of CHBC by community organization in selected MAP countries;
- ii. Determine the various approaches (including logistics), undertaken to deliver services to PLWHA with a concentration on support and adherence of ART by CHBC programs; and
- iii. To determine the existing expertise and knowledge and how it is disseminated from NGO, development partners and governments to CHBC programs.

1.5 PRINCIPAL FINDINGS

8. The research generated a number of findings, with the major ones under the following headings as being:

Definition of CHBC

- There is a general consensus on the definition of CHBC

Overview of Human Resources, Activities and Services

- ART support and adherence is **currently not a major activity of CHBC programs** as there are activities such as nutritional care, socio-economic and OVC that require more immediate attention.

Inputs of the Larger/International NGO's

- Direct funding and support to HBC programs at the community levels.

³ N=226 in 8 MAP countries: international organizations, grass roots organizations and individuals

- **Material and Supplies:** providing guidelines, manuals for training staff, drugs
- **Human Resources Support:** conducting training of staff & volunteers, refresher workshops, providing financial assistance for volunteers

I. Challenges and Limitations

- There is an **inherently weak referral system/links** between CHBC organizations and the public health sector;
- There are **few links between CHBC organizations and larger experienced NGOs** and agencies who have vast experience in socio-economic, nutritional and OVC's services for PLWHA;
- The **human resource** is a key challenge faced by CHBC programs and requires immediate attention in the areas of training, capacity building and technical expertise;
- **Volunteers**, who are essential to the sustainability of the CHBC, need to be encouraged and motivated. However their compensation and incentives is of ongoing debate;
- The CHBC programs are unable to implement and adequately deliver services to their clients due to **insufficient resources**, such as overhead funds, HBC kits, and education/informational material;
- **Transportation and logistics overheads** are major limiting factors in the ability of CHBC programs to carry out their activities, such as ART adherence support; and
- There are few **national guidelines** on CHBC.

II. Operational Issues

- **Human Resources:** The challenges in human resources are essentially due to the operational issues in the areas of training/capacity building and social/technical expertise. The CHBC providers are not properly trained and/or are too few to carry out the activities and services effectively. These issues can be alleviated through; (a) Government: Establishing and disseminating national guidelines on CHBC: Increasing public health sector involvement (b) International NGOs: Providing technical expertise & training; and (c) CHBC programs: Conducting baseline assessments; Generating community involvement: Identifying "local" volunteers.
- **Referral Systems/Links:** CHBC programs require a strong two way referral system and strong links to the public health sectors and Int. NGOs.
 - Government: Create the 'platform' to allow CHBC to create a referral system with local public health centers

- CHBC: Actively develop and maintain links with NGOs, especially for support of socioeconomic activities.
- **Institutional Resources/Logistics:** There is a lack of institutional resources/logistics for CHBC to deliver appropriate services
 - Government: Allow CHBC who receive funds to properly allocate funds for transportation within budget: Provide HBC kits and information/educational material
 - CHBC programs: Adopt innovative techniques to alleviate issues in transportation; utilize local resources to create HBC kits.

1.6 KEY RECOMMENDATIONS

9. Effective CHBC cannot be provided without **realistic financial support** for transportation, overheads and logistics.

10. CHBC programs need the **financial and technical support** from governments, NGOs and development agencies with a starting focus on the “**essential care**” activities. These essential care activities have the potential to positively impact the health and social status of the PLWHA and prolong their need for additional complex medical care. [PATH , 2001]

Table 1: Care and Support Activities for PLWHA, as Defined by WHO and UNAIDS 2000

Essential Care	Additional Activities of Intermediate Complexity and/or Cost	Additional Activities of High Complexity and/or Cost
<ul style="list-style-type: none"> • Nutrition Support • Nursing and medical care (treatment of common HIV – related infections, pain relief) • Psychosocial Support 	<ul style="list-style-type: none"> • Prevention and treatment for tuberculosis • Treatment of HIV-related malignancies, extensive herpes • Support for OVC 	<ul style="list-style-type: none"> • Laboratory monitoring of adherence to HAART • Treatment of HIV-related infections that are difficult to diagnose and/or expensive to treat, and malignancies • Community services to reduce the economic and social impacts of HIV infection
<ul style="list-style-type: none"> • Prevention of mother to child transmission • Community activities that reduce stigma and discrimination • Health Education 	<ul style="list-style-type: none"> • Income generating activities • Medical care for family members • Counseling on support and adherence to HAART 	

11. **Role and Responsibilities:** CHBC programs can not be successful unless they receive active support and participation from the Government, NGO’s & Communities. The following are therefore the roles and responsibilities each needs to assume:

- Incorporation of CHBC into district health service plans.
- Train and educate health care staff in the public health facilities on their necessary active participation in CHBC with an emphasis on the reduction of stigma and discrimination;

- A nationally recognized training program for volunteers;
- Involve and encourage the other public sector agencies dealing with social welfare, education, food and nutrition to be key players and share responsibilities in providing CHBC.
- Create less elaborate community care models (i.e. focus on the essential care activities in; **See Table 1.**) which can be implemented by government health facilities in resource-poor areas where donor funds are unavailable. For example

106. **NGO's, Development Agencies / Donors:** They can assist CHBC programs with the technical expertise in the areas of education and training the CHBC personnel, volunteer recruitment and motivation techniques, monitoring and evaluation of activities.

107. **Community Level:** The level of active participation of communities will differ from community to community, as the communities needs and resources will vary. Therefore the following are general recommendations;

- CHBC programs need to build and maintain a strong and dependable links through **active community participation** and **collaboration** between other CHBC organizations, NGO's/Development agencies, health facilities, and governmental agencies. A home based, offers many opportunities for public health education. Such care may also facilitate the readiness in communities to accept and act on prevention strategies.
- Encourage communities to initiate and develop their CHBC programs, actively participate in the recruitment, motivation and compensation of volunteers;

1.7 KEY LIMITATIONS OF THE STUDY

- The study used a convenience sample and therefore does not claim to be representative of all CHBC programs in Sub-Saharan Africa;
- The lack of information about the client satisfactions with the services and in particular, whether the services reflect their felt needs;
- An in-depth look at the possible methods of providing adequate nutrition as a major service provided within CHBC programs;
- The different roles and responsibilities of the personnel form the CHBC programs; and
- Reported funding or cost analysis of the CHBC programs.

2 INTRODUCTION

2.1 BACKGROUND

12. The HIV/AIDS epidemic has overwhelmed the fragile health systems of Sub-Saharan Africa, especially the poorest countries. The Sub-Saharan Africa remains by far the region worst-affected by the AIDS epidemic, with HIV prevalence rate of 7.5% among the adults and an estimated 2.2million AIDS related deaths in 2003 [UNAIDS, 2004]. The magnitude of AIDS-related deaths is simply too great for existing clinical infrastructures including hospitals and primary health care centers.

Table 2: Sub-Saharan Africa: Regional HIV and AIDS estimates, end 2003

(So: UNAIDS 2004 Report on the global AIDS Epidemic)

Adult (15 - 49) HIV prevalence rate	7.5% (range: 6.9 – 8.3%)
Adults (15-49) living with HIV	22 million
Adults and children (0–49) living with HIV	25 million
Women (15-49) living with HIV	13 million
Women (15-24) HIV prevalence rate	6.9% (range: 6.3% - 8.3%)
AIDS deaths (adults and children) in 2003	2.2 million

2.2 OVERVIEW OF COMMUNITY HOME BASED CARE

13. Home-based care has a variety of typologies, each representing a different delivery scheme, mix of services, staff and reach [PHR plus, 2004]. Some of the more identified types include facility-based, community-based (CHBC) and integrated [FHI, 2004; PHR, 2004]. The emphasis of each type of program tends to differ. For example, facility-based programs often focus on medical aspects of care involving teams including health professionals who can provide higher levels of care. CHBC programs emphasize psycho-social support to PLWHA and their families and deliver their services primarily through volunteer networks in the community together with program staff, not specifically health professionals [PHR plus, 2004].

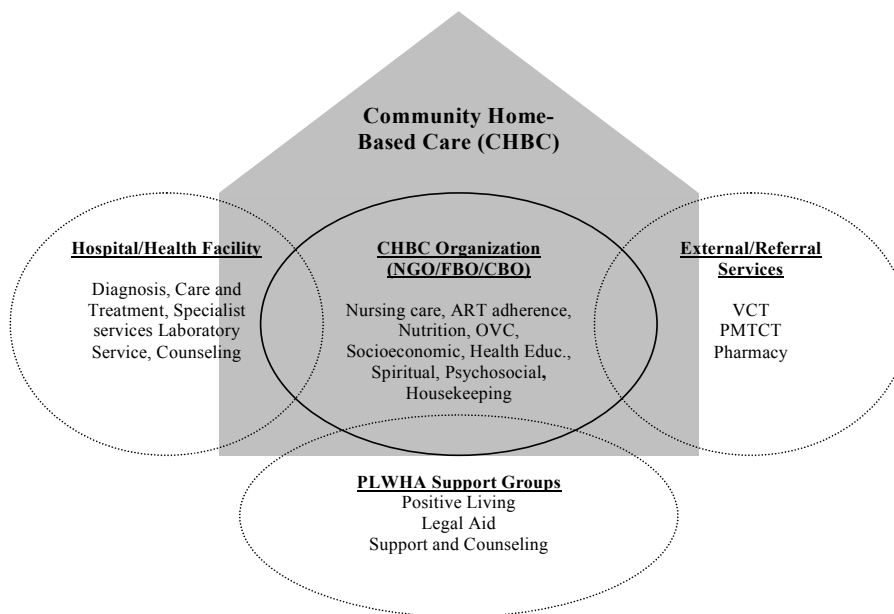
14. **Definition:** CHBC can be defined as the care given to an individual in his/her own environment (home) by his/her family and supported by skilled welfare officers and communities to meet not only the physical and health needs, but also the spiritual, material, and psychosocial needs [Gaborne Declaration on CHBC, 2001].

15. **‘Role’ of CHBC:** As the number of PLWHA increases, the gap continues to widen between the demand for, and the availability of health care services. Relying mainly on the family and community as caregivers, community home-based care (CHBC), has become a significant contributor in the treatment, care and support of those infected and affected by HIV/AIDS.

16. Though CHBC is provided in the home, it is part of an **integrated approach** in the care, support and treatment of HIV/AIDS. CHBC involves a variety of services, provided primarily by an organization (NGO/FBO/CBO) which is linked to various facilities/groups.

17. **Continuum of Care:** The need for CHBC is reflected in a number of current strategic plans of national AIDS programs in sub-Saharan African countries. However it is not explicitly stated where it is placed or how it is properly executed in the existing continuum of care. A clearer understanding of what services CHBC can and cannot provide, and more so the techniques used to carry out these services, will be invaluable information in carving a place for CHBC in the continuum of care.

Figure 1: Community Home Based Care (CHBC)



2.3 LITERATURE REVIEW OF CHBC

18. The current literature on CHBC, covers a variety of areas while examining a multitude of issues. Some of these areas/issues are briefly described below, signifying the importance of this study.

a) Cost Analysis/Effectiveness

19. Through describing the costs of establishing and operating a CHBC program to PLWHA, it is possible to project the full costs to the health care system of extending this care model [Uys & Hensher, 2002].

20. There are few documented estimates of the cost of HBC for HIV. Those studies that exist (carried out with different methodologies and contexts) show that HBC costs vary by location (rural and urban), service package, and program expansion and maturity. A study in Rwanda found that in HBC a facility-based approach has higher estimated costs per client than CHBC, with monthly costs per patient ranging from approximately \$31.20 to \$36.01 compared to \$12.75 to \$24.53 respectively [PHRplus, 2004]. Scale and program maturity also impacts costs of HBC: In Zimbabwe, the cost per home care visit decreased from US\$10 to US\$1 as the program expanded [Lee 1999] because,

although costs increased by 31 percent, the number of clients and visits also increased and the program became more efficient.

21. HBC for HIV/AIDS is increasingly looked to as more accessible and affordable than inpatient care, both for patients who are **unable to travel** to or pay for inpatient care as well as for **governments that must fund inpatient facilities** [PHRplus, 2004]. Notably, these costs are increased in rural areas where a **vehicle is required for staff/client transportation**. [Uys & Hensher, 2002].

b) Scaling-Up

22. “Scaling-up” is the process of expanding the scale of activities and institutions with the ultimate objective of increasing the numbers of people reached and/or impact on HIV/AIDS. Scaling up may entail; expanding coverage, altering the type or intensity of coverage, increasing impact or improving quality. While there is no precise definition, scaled up programs usually reach (or provide for) substantially more of the targeted population within a specified area.

23. Today’s challenge is not only deciding what to scale up, but how. To do so there are certain steps which need to be considered before scaling up⁴

- Vision/plan to scale up from the beginning of the project
- Determine the effectiveness of the approach
- Assess the potential to scale up
- Build a consensus to scale up
- Advocate for supportive policies
- Secure comprehensive funding
- Establish and maintain a monitoring and evaluation system
- Support institutional development scale.

24. In addition to the above steps, there are factors that affect the expansion and replication process lay community participation, **government commitment, donor support and program costs**. [Nsutebu, 2001]. In order to encourage government and donor support, an analysis of the services provided by CHBC and the operational strategies need to be investigated and therefore determine the gaps where the governments and donor community would be of greatest assistance.

25. Learning from experience. Any effort to achieve scale and increase the range of services available will benefit from hard-won “lessons learned” elsewhere. Knowledge transfer should support leaning from experience, especially in the dynamic environment surrounding the HIV/AIDS epidemic. New technologies and networks are now available to create communities and practices around critical areas. The scaling-up framework should include a learning framework that will help structure knowledge to be applied to problems encountered during scale-up⁵

26. **TB & HIV/AIDS Integration**: The increase in TB and HIV patients in many countries in Africa is outstripping the ability of public health services to cope. A possible way to scale up

^{4,5} For more information on Scaling-Up see **Turning Bureaucrats into Warriors: Preparing & Implementing MAP in Africa. A Generic Operations Manual**. World Bank 2004

existing HIV programs would be to integrate them into existing national TB program, which already delivery out reach services, and have the required infrastructure and institutional organization. The main barriers to this collaboration are poor communication, poor referral system and lack of knowledge and skills among health staff. [Wandwalo et al, 2004]. Some of these barriers may have specific operational problems which could be identified in this study and therefore pave the way for the possibility of TB & HIV/AIDS integration programs.

c) Challenges/Limitations

27. CHBC experience challenges in **providing pain relief** to their clients due to problem in/with drug availability and cost, transportation, government restrictions and lack of trained personnel to administer drugs. [Harding et al, 2001]. In Uganda, this has been tackled through an initiative to provide nationwide free oral morphine, while educating and sensitizing community health workers on its use [Ramsey, 2003]. Since a large percentage of AIDS patients suffer from pain, from this study it would be important to note if providing pain relief is noted as one of the major challenges and therefore the different ways CHBC programs are dealing with this issue.

28. In regards to **nutrition**, there has been emphasis on its significant influence on the success of ART. In resource limited settings, many PLWHA lack access to sufficient quantities of nutritious foods, which poses the challenges of affecting ART drug efficacy and adherence to drug regimes. [Castleman et al 2004]. For the severely malnourished, the use of ready-to-use food (RTUF) is a possibility, but warrants further exploration in the operational aspects of preparing RTUF locally and administering it in a variety of settings [Manary et al 2003]. Though the solution to providing adequate nutrition to PLWHA in CHBC is outside the scope of this study, some of the operational issues unearthed during the study may be relevant to alleviating the problem of nutrition.

29. **Care providers:** Caring for PLWHA is usually carried out by family members who serve as ‘primary caregivers’ and by community members who are recruited and trained to provide services as ‘volunteer caregivers’[Akintola, 2004]. Unfortunately caregivers experience poverty, social isolation, stigma, psychological distress, and lack basic care giving education. [Lindsay et al, 2003]. Receiving preparatory information, continued training and support from the health workers might be important components influencing coping and provision of quality care among home-care providers. Furthermore, different levels of health information may be associated with different coping strategies and quality care [Mbata &Seloilwe 2000]. This study will focus on the volunteer care givers and try to determine the challenges as well as the types of incentive/compensation and training they receive.

30. **Older women and girls are by far the majority responsible for HBC.** The burden of caring for PLWHA, as either ‘primary care givers’ and volunteers, is disproportionately provided by women. Men rarely assist with care giving [Akintola, 2004]. One study reported older women feeling overwhelmed with the magnitude and multiplicity of tasks they had to perform. Young girls often missed school and they were sexually and physically abused, sexually exploited and depressed. [Lindsay et al 2003].

31. There is also an increased effort to document the existing information on CHBC programs; guidelines, policy reports & papers, program management material, education and training manuals; and maintain a directory of CHBC organizations involved in caring for PLWHA (Annex 5)

2.4 REASONS FOR CONDUCTING THE RESEARCH

32. Primary reason of this research was to have an understanding of how HBC is being provided by various non-governmental organizations (large and small) and what implementation and operational challenges they face. At a later stage, it might be considered to develop a generic guideline. This guideline would be created from an array of existing guidelines, and target CHBC providers benefiting from the MAP financing. This will directly benefit MAP projects in Africa in improving local efficiency and approach. Other reasons include:

- There are a very large number of CHBC providers today in Africa, but little is known/documented on the operational challenges that are faced;
- As national and international funding and policy focus on HIV care for Sub-Saharan African populations is consistently increasing, it is imperative to research effective responses, and identify salient characteristics of HIV/AIDS CHBC programs and their successful strategies;
- Despite the increasing number of CHBC programs and such endeavors, statistics indicate an alarming rate of re-admission to hospital of patients with numerous complications, suggesting poor quality care at home;
- Several public and non-public organizations have been providing community home based care to PLWHA under MAP and other financing;
- With the introduction of ART, it is imperative to understand the role of CHBC and help alleviate some of the problems faced by CHBC programs so they do not interfere with support and adherence issues; and
- Various institutions, organizations, individuals and donors have substantial experience in this area. However, it is not clear how this expertise and knowledge is transferred to the smaller community organization or how it can be mainstreamed into the national AIDS strategies.

2.5 METHODOLOGY

33. The study was both quantitative and qualitative. It was conducted in selected MAP countries. These countries (listed in Table 2 below) met one of two selection criteria:

- Countries with prevalence rates above the average of Sub-Saharan Africa of 7.5%. (UNADIS, 2003). (**Rationale:** *Greater need of CHBC*)
- Countries with a higher prevalence compared to other countries in their geographic region (N/E/S/W Africa) (**Rationale:** *It is important to take into account language, cultural differences which are specific to regions and which will have an impact on HBC*)

39. Both the quantitative and qualitative data was collected through interviews/questionnaires of Key informants. The key informants of the study were divided into three groups in each country: (i) The local non-government organizations (including CBOs, NGOs, FBOs), (ii) International NGOs, Development agencies, and (iii) World Bank Task Team Leaders, Health professionals.

40. Questionnaires were sent to 226 key informants (183 randomly selected organizations, 43 individuals) Data was collected through three questionnaires tailored for the target respondents. Majority of the questionnaires were communicated via email, while some were answered through

personal or telephone interview. Interviews were informal, semi-structured and respondent led. All interviews were performed in English

41. The strengths of the study lie in the qualitative data that will be collected on (i) the challenges and limitations faced and some of the innovative solutions carried out by the CHBC programs to alleviated them, with a concentration on ART support and adherence; the quantitative data on (ii) the input of the larger NGO's specifically in training of volunteers, funding and resources (iii) the services provided by CHBC programs and the human resources required to carry out these services

42. The main limitations of the study are (i) it uses a convenience sample and therefore the results will not representative of all CHBC programs in Sub-Saharan Africa; (ii) it does not look at the current context/issues of CHBC in national AIDS strategies and (iii) information on client satisfactions with the services and in particular, whether the services reflect their felt needs;

43. The following table represents epidemiological data on the selected countries.

Table 3: Country Specific HIV/AIDS Data

(UNAIDS/WHO Epidemiological Fact Sheets on HIV/AIDS and Sexually Transmitted Infections– 2004 Update

Country	Official Language	Adult (15 – 49) HIV prevalence rate (%)*	Adults (15-49) living with HIV*	Adults and children (0–49) living with HIV*	Women (15-49) living with HIV*	AIDS deaths**	Orphans***
Burkina Faso	French	4.2 %	270,000	300,000	150,000	29,000	260,000
Cameroon	French	6.9%	520,000	560,000	290,000	49,000	240,000
Malawi	English	14.2%	810,000	900,000	460,000	84,000	500,000
Mozambique	Portuguese	12.2%	1,200,000	1,300,000	670,000	110,000	470,000
Nigeria	English	5.4%	3,300,000	3,600,000	1,900,000	310,000	1,800,000
Senegal	French	0.8%	41,000	44,000	23,000	3,500	17,000
Tanzania	English	8.8%	1,500,000	1,600,000	840,000	160,000	980,000
Zambia	English	16.5%	830,000	920,000	470,000	89,000	630,000

These estimates include all people with HIV infection, whether or not they have developed symptoms of AIDS, alive at the end of 2003

** *Estimated number of adults and children who died of AIDS during 2003*

*** *Estimated number of children who have lost their mother or father or both parents to AIDS and who were alive and under age of 17 at the end of 2003.*

3 FINDINGS

44. The findings are organized into the following categories, building from the definition of CHBC and closing with the various reported challenges and limitations.

- Definition of Community Home Based Care
- Overview of the Human Resources, Activities and Services of CHBC
- Inputs of the Larger/International NGO's:
- Challenges and Limitations
- Operational Issues

45. A Response rate of 46% of all key informants was achieved. In this chapter, from the results of the questionnaires, the respondent rate is represented as a percentage (%) and respondent numbers are represented as an average. The data was collected through Questionnaire 2 and 3.

3.1 DEFINITION OF COMMUNITY HOME BASED CARE

46. Target informants were asked if they agree with the below definition of CHBC, and if they had any proposed changes/additions. (*Questionnaire 2*)

“The care given to an individual in his/her own environment by his/her family and supported by skilled welfare officers and communities to meet not only the physical and health needs, but also the spiritual, material, and psychosocial needs” (Gaborne Declaration on CHBC, 2001).

47. All respondents agreed with this definition. There were some suggested additions to the definition such as *“providing communities with information on HIV/AIDS”*, *“care to affected family members”*, *“holistic care to patient”*, *“including neighbors, volunteers as care providers”* and *“emphasis that the responsibility of CHBC greatly lies with the Ministry of Health as well”*. There was a suggestion that the term *“skilled welfare officers”* should be replaced, as it implies *“professional health care officers”*.

48. This question of defining CHBC, gives a general idea of *what* CHBC is. It therefore creates the ‘platform’ for the next logical set of findings, which answer the question of *how* CHBC is carried out: Overview of human resources, activities and services of CHBC.

3.2 OVERVIEW OF THE HUMAN RESOURCES, ACTIVITIES AND SERVICES OF CHBC

49. The table below represents the personnel, activities and the services offered by the grassroots level organizations (respondents). (*Questionnaire 3*)

Table 4: Data on the Human Resources, Activities & Services of CHBC

Personnel	Activities	Services
<ul style="list-style-type: none"> ▪ Permanent Staff – This included administrative staff, community health workers. (avg. 4 staff/org). ▪ Volunteers – volunteers offered incentives/compensation/stipend.(avg. 68 volunteers/org) ▪ Health Professionals – Organizations reporting using a doctor/nurse to conduct medical home visits (27%). Some orgs compensated these health professional (2%) who carried out these medical visits on average every 3 months. 	<p><u>The following are activities for PLWHA</u></p> <p>Medical/Nursing care</p> <ul style="list-style-type: none"> • Treatment: STI /OI (90%) • TB DOTS (20%) • ART supply* (30%) • Bathing/toileting/other nursing care (53%) <p><u>The following are activities for PLWHA and family</u></p> <p>Health Education</p> <ul style="list-style-type: none"> • Adherence support of ART (87%) • Education on OI / STI prevention / control (60%) • Provision of condoms (60%) <p>Socioeconomic Support</p> <ul style="list-style-type: none"> • Micro credit/Income generating (53%) • Blanket/soap/consumables (47%) • Funeral arrangement (27%) • Support for children (60%) <p>Nutritional Support</p> <ul style="list-style-type: none"> • PLWHA (53%) <p>Psychosocial Support</p> <ul style="list-style-type: none"> • Spiritual support (67%) • Emotional support for PLWHA (67%) • Counseling (67%) • Counseling on Death and Dying (40%) <p>Housekeeping</p> <ul style="list-style-type: none"> • Cooking/Sweeping/Other duties (53%) • Fetching Firewood (40%) <p><u>The following are activities for the Family</u></p> <ul style="list-style-type: none"> • Medical/Nursing care (53%) 	<p>PLWHA receiving ART adherence support</p> <ul style="list-style-type: none"> • PLWHA receiving ART support – 32 PLWHA/org <p>Referral Services</p> <ul style="list-style-type: none"> • VCT • OVC • PMTCT • Health Facilities <p>Transportation to Health Facilities</p> <ul style="list-style-type: none"> • Vehicle owned by org (13%) • Cost of public transport (40%) • Personal accompaniment (40%)

* through a program/facility linked to the program

3.3 INPUTS OF THE LARGER NGOS

50. From the above Table 4, there are a number of services and activities which constitute/delivered by CHBC. The organizations receive assistance from larger NGO's to carry out these services and activities.

51. The following are an example of the types of assistance offered by the larger national/international NGOs to the grass-roots level CHBC organizations. (*Questionnaire 2*)

52. **Monetary Funding:** The first question on the different forms of assistance, targeted financial support. The respondents who answered 'YES' to directly funding, a grassroots level organization carrying out CHBC program(s) (**83%**).

53. **Material/Supplies:** Whether the respondents assisted the CHBC programs financially or not, the next question was the respondents who answered 'YES' to assisting a CHBC program(s) with the following. (listed in a descending order of respondent rate)

Table 5: Data Materials and Supplies: Assistance from Large NGO's to CHBC organizations

Guidelines on delivering CHBC	92%
Manual for training staff/volunteer who carry out CHBC	91%
Prescription drugs (STI/OI)	75%
Equipment	58%
ART medication	50%
Guidelines on ART support/adherence/monitoring in a CHBC setting	50%

54. **Human Resources:** Support provided to the CHBC program(s) with the following:

Table 6: Human Resources: Assistance from Large NGO's to CHBC organizations

Capacity building (training) for the CHBC program(s):	
• Staff	(83%)
• Volunteers	(83%)
Conducting workshops/refresher courses for staff	(67%) on average every 3 months
Financial assistance for volunteers through:	
• Pay/Stipend	(25%)
• Compensation/Incentives	(92%)
Technical assistance through personnel working on the ground to support the CHBC program(s)	(22%)

3.4 CHALLENGES AND LIMITATIONS

55. There was a range of challenges and limitations that were reported by the respondents. **Three main categories emerged**, under which the key challenges and limitations were listed according to the response rate (%) of the respondents. (See Table 7)

3.5 OPERATIONAL ISSUES

56. The challenge/limitations faced by CHBC are overwhelming. From the three categories identified within the structural organization of CHBC (See Table 7), the operational issues are drawn out. These operational challenges are discussed in detail in the next chapter.

- i. Human Resources: An apparent insufficient number of personnel can be traced to the operational challenges in the following:
 - **Training/Capacity Building:** There is apparently an insufficient number of properly trained personnel across the board of CHBC programs.

- **Technical expertise:** There is lack of technical expertise in key areas of monitoring and evaluation, program management, and implementation of activities/services in CHBC programs.
- ii. **Referral Systems/Links:** Effective CHBC programs require a strong two-way referral system, which can only be achieved through dealing with the operational challenges unique to the key players; Government, NGO/Development Partners, CHBC Programs
- iii. **Institutional Resources/Logistics:** The CHBC programs had various logistical issues, with transportation being the key uniform theme. There were a variety of logistical issues, which could be probably all traced back to the lack of funds. However the CHBC programs clearly identified the lack of resources such as HBC kits, telephones/internet access, educational/informational material and the means to transport personnel and/or clients.

Table 7: Challenges and Limitations

Category	Challenges/Limitations response rate (%)	Description	Specific examples from Participants
Organization and Management	Lack of Human Resources (70%)	The personnel required for CHBC programs are professional health workers such as nurses, community health workers (CHW) and volunteers.	<ul style="list-style-type: none"> • Insufficient number of CHW's to execute activities • Limited financial resources for adequate training, refresher courses of all personnel involved in CHBC activities • Insufficient incentives for volunteers. • Burn out, lack of motivation and commitment on part of volunteers • Lack of counseling for CHW's and volunteers • Lack of qualified personnel at managerial levels
	Limited Institutional Resources (60%)	The limited institutional resources impact the CHBC program's ability to deliver adequate services to the clients.	<ul style="list-style-type: none"> • Lack of transportation for the CHW's & volunteers impedes their ability to reach a greater number as well as remote clients. • Limited transportation for clients to and from health facilities for routine medical check-ups • In need of monitoring and evaluation methods to ensure quality care • Few CHBC medical kits, educational material and technical supplies • Insufficient logistical resources to implement activities. • Unavailable funds to improve and expand CHBC activities
	Poor Referral System/Linkages (54%)	A referral system to existing public primary health system and other organizations assisting PLWHA's	<ul style="list-style-type: none"> • Lack of coordination of CHBC activities between CBO's and health facilities • Lack of reference and counter reference with the health facilities in regards to PLWHA medical treatment.
Activities and Services	Inadequate ART support (80%)	Issues surrounding monitoring, adherence, accessibility	<ul style="list-style-type: none"> • Biological tests to monitor adherence and treatment are costly. Therefore programs rely on counting pills as the only method of monitoring adherence to ART • ART adherence counseling is time consuming and therefore is not properly delivered. • Lack of back-up methods when ART is unavailable • Lack of transport for clients to pick-up ART supply
	Lack of proper Nutritional Support for PLWHA (60%)	Challenges in assisting PLWHA meet their nutritional requirements	<ul style="list-style-type: none"> • Limited food security programs in the communities working alongside CHBC programs. • Lack of knowledge on the nutritional requirements on the part of the PLWHA, family members and volunteers.
	Limited Socioeconomic Initiatives (40%)	Activities to assist PLWHA with their socioeconomic status	<ul style="list-style-type: none"> • Few income generating opportunities available to PLWHA. • Lack of income generating opportunities leads to selling sex.
	Limited OVC Support (30%)	Assistance to OVC's	<ul style="list-style-type: none"> • Lack of financial resources to assist OVC's, especially in nutrition • Limited surrounding organization who deal with OVC to refer to
	Stigma and Discrimination (20%)	Stigma and discrimination are barriers to PLWHA seeking services from CHBC	<ul style="list-style-type: none"> • Lack of involvement of close relatives, or community in the care & treatment of PLWHA due to stigma.
	Lack of proper Health Education (10%)	Educating PLWHA and their family members on the prevention, care and treatment of HIV/AIDS	<ul style="list-style-type: none"> • Lack of information on nutritional requirements and support to positive living • The family members are not well informed on how to care for PLWHA or the side effects of the ART
External Factors	Medical supplies Health Facility Proximity	Limitations/Challenges which are not specific to CHBC but have an impact on the service delivery of CHBC	<ul style="list-style-type: none"> • Insufficient medical coverage services in some decentralized areas where civil society groups provide CHBC • Lack of constant availability of medicines for treatment of OI's/STI's/pain management • Condom availability • Frequent interruption in ART supply, which brings about the issue of resistance • Scarce reproductive health services, especially targeting men. • Lack of training of Traditional Healers. • Lack of support from Private Sector

4 DISCUSSION

57. In this study the **components of CHBC** were documented in order to understand and identify the key limitations and challenges. These key limitations and challenges were categorized into **structural organization, main activities and external factors**. In this section only the first two categories are further discussed. Thereafter the operational issues surrounding these challenges/limitations, and to conclude the recommendations brought forth from this research in the next chapter.

- a) Structural Organization of CHBC;
- b) The Main Activities/Interventions;
- c) The Operational Issues; and Possible Solutions
- d) Recommendations.

4.1 STRUCTURAL ORGANIZATION OF CHBC

(a) Human Resources

58. This was pervasive limitation throughout the research, with emphasis on the lack of community health workers, the high turn-over of volunteers and the extremely few health professionals working in conjunction with the CHBC programs. There was some mention of managerial staff and other technical expertise that is necessary for improved program delivery and expansion, which are also important factors to consider.

59. In terms of **health care professionals**, such as doctors and nurses, some organizations required their services for “the medical care of PLWHA who were bedridden and/or lived far from a health facility” or “nurses to constantly and frequently supervise the community care givers such as the volunteers”. The shortage of health care professionals working alongside CHBC programs stems from the root problem of a shortage of health care professionals across the board in the health infrastructure. Therefore this challenge is of greater magnitude, not unique to CHBC programs, and cannot be properly addressed within the scope of this study. However, it is worth mentioning as it is a challenge which impacts CHBC, especially when discussing strong referral networks to health facilities.

60. From the responses of the organizations, the **community health workers and volunteers** were the key human resources structure of the CHBC program. Both were mentioned consistently throughout the study, but at times it seemed as though the “titles” were used inter-changeably. There is a lack of clear understanding on duties and roles of the community health worker and volunteer.

61. The issue of **incentives/compensation/stipends** for volunteers differed among participants. Some of the responses “insufficient financial incentives for community volunteers,” “...volunteers are unpaid, which makes the work more difficult as they need to at least cover their subsistence

needs” were listed as some of the main challenges to CHBC. On the other hand it was reported “large incentives raises the issues of quality care and the purpose of a CHBC.” There was also mention on CHBC programs using “local” versus “visitor” volunteers. **Local volunteers** were an added advantage as they would understand the needs of the community and would not require transport. However they were then more likely to experience stigma, discrimination and social isolation due to the nature of their work.

62. The **motivation** of CHBC workers, especially volunteers needs to be addressed, and may be the one way to tackle the problem of their retention. Some possible solutions are visits to other CHBC programs and the opportunity to more specialized training (for instance in counseling). (Wegelin, KIT Royal Institute, 2005).

63. A better understanding of their **duties and roles** would shed light on their recruitment and training.

64. Programs reported needs for **technical assistance** in monitoring and evaluation. Such assistance will be required to strengthen measurement of program outcomes, quality and coverage.

(b) Referral System/ Links

65. If CHBC is a part of a comprehensive continuum of prevention, care, treatment and support services of HIV/AIDS, then it is imperative for CHBC programs to identify their place within this context and therefore their role in the community. From example, majority of the organizations that **reported assisting PLWHA** with their medical and nursing requirements **and listed health facilities** under the referral agencies, **they did not report** requiring health care professionals to make home visits. Similarly, one organization reported,

“When our CHBC programs are in areas served by other organizations such as World Food Program and Save the Children, we refer our clients to these organizations for assistance with nutrition and OVC respectively. However in other areas where our CHBC program are and these organizations are not present, the CHBC program has activities/services in place to deal with nutrition and OVC’s”

66. CHBC programs will need to have strong links to other organizations working in the vicinity, so as to assist them with the nutritional, socioeconomic, legal, child support services and other needs of the PLWHA and their families. This can be achieved through an open channel of communication between organizations and the support of the larger and more prominent organizations within the communities.

“During training, we invite faith-based organizations to discuss their beliefs in tolerance and acceptance and how it can be applied to PLWHA. Religious leaders have been found best in the role play of helping PLWHA. Religious leaders have been found best in the role play of helping people make the link between their religious beliefs and the stigmatization of PLWHA”

67. For a CHBC program to succeed in its goal it requires the community’s active stakeholder participation in the implementation and monitoring of programs to increase the impact and sustainability. This will involve PLWHA groups, local leaders and community groups such as faith based groups, youth groups etc. This may result in the community’s mobilization and advocacy efforts to organize resources for prevention, care, and support activities – such as orphan care, food support. However;

“Active involvement of the community does not automatically result in community mobilization for care etc. especially in communities with a high HIV prevalence and are therefore overwhelmed and do not easily take on other tasks. What will help community mobilization is effective linkages to external support services for orphan care, food support, income generating activities, loan and saving mechanisms” (Weglin, KIT Royal Institute, 2005)

(c) Institutional Resources

68. The one “institutional resource” that was apparently the main challenge of the organizations was the lack of transport. The transportation issue was divided into two categories; transport for the CHBC workers to the clients and transport for the clients to and from health facilities. To alleviate this challenge some of the organizations requested “*funds to pay for public transport of both the workers and the clients*”, or to “*purchase bicycles for the community health workers/volunteers*”.

69. Along side, was the reported problem of bed ridden clients who needed medical care, but were not near any public transport route. For this, some stated they required funds to purchase a vehicle, rent a vehicle, or purchase innovative vehicles such as an “ambulance bicycle”;

“Transport is a serious problem for the implementation of the activities, in general, but particularly for the transportation of the beneficiaries that are sick at home to the health units. Vehicles are extremely expensive and there are many donors that don’t pay for the acquisition of vehicles. To respond to this problem some projects are using bicycles to which is attached a litter to facilitate the transport of patients to the hospital. It could be a cheaper way of addressing the problem of transport especially in rural areas”

70. The need to transport bedridden patients was not a major theme, and therefore the transportation needs of the workers and other clients, is the more pressing problem.

71. The other challenges were the lack of supplies to carry out CHBC activities such as HBC kits, drugs for pain management, guidelines on CHBC, manuals on training personnel and other educational material.

4.2 MAIN ACTIVITIES AND SERVICES

72. The data on main activities and services was collected through questionnaire 3 which was completed by the grass-roots organizations. From the responses it is apparent, that these main activities and services surrounded two objectives. One objective was **ART Adherence Support** and the second was **Non ART Adherence Support**. Therefore, below are the reported challenges and limitations of the main activities and services, according to the specific objective.

(a) ART Adherence Support

73. From the research, majority of the organizations reported assisting PLWHA with ART adherence support. The PLWHA acquire these drugs from an external facility, usually a public hospital, and return to this same location for their refills. The role of the CHBC community health worker/volunteer is therefore to aid the PLWHA in complying with the strict drug regiment. This overwhelming task brings forth the following challenges/limitations:

- i. **Counseling:** For effective adherence to ART, PLWHA need to receive adequate counseling on a variety of issues such as the nature of the treatment, possible side effects and the disadvantages of poor adherence. It was reported that such counseling is time consuming and at times not properly executed as the CHWs/volunteers are not properly trained or supervised. It was also felt that the initial comprehensive counseling should be done at the health facility where the client receives the ARV drugs, or at the time of discharge from the hospital. The role of the CHW/volunteer would then be to supplement this counseling.

As importantly the family members who care for the PLWHA need to be receive counseling. More often counseling is carried out over a very short period of time, leaving the families inadequately prepared to face the agonies and pains that go with the care they provide to their ill relatives (Mbata & Seloilwe 2000)

- ii. **Monitoring:** The widely reported method of monitoring adherence was through pill counts. Due to a lack of financial resources on the part of the clients, few could access laboratory tests to monitor adherence. The organizations reported that the free access to ART should include subsidized laboratory tests; in addition the public hospitals which serve as the delivery point of the ART should be well equipped to serve the laboratory needs of people on ART. Complications in monitoring ART were further exacerbated if clients were hard to reach.

“Different NGOs have different opinions on the best way to assure adherence to medications. Most hope that health centers will have adequate physicians, nurses, counselors providing adherence counseling and support, therefore reserving CHBC programs for those with complex care needs”.(respondent)

- iii. **Stigma and Discrimination:** The rampant stigma and discrimination, forces PLWHA on ART to hide their medications from their family members. CHWs/volunteers can therefore not visit the home of these PLWHA to support them.
- iv. **Nutrition:** Due to the nature of the ART treatment and its related toxicity, PLWHA on ART needed to meet a certain nutritional standard. The vast responses from the organizations, indicates that a large number of PLWHA on ART are not reaching or maintaining this standard. Without the adequate nutrition, it is near impossible for the CHWs/volunteers to encourage them to comply with the therapy.
- v. **Socio-Economic:** The PLWHA require to be assisted with transport to and from the health facilities to pick up drugs and for routine medial treatment. In some cases when there is an interruption of supply within the public sector, where the drugs are provided freely, the PLWHA may require to purchase the drugs for that duration. Few organizations reported having any back up methods in the event of an interruption of the supply. Some of these few back-up methods included having strong links with other health facilities who could assist with the drugs or fundraising

(b) Non-Specific ART Adherence Support

74. Though majority of the organizations reported assisting PLWHA with ART adherence support, these were not the only clients that benefited from their programs. There were PLWHA who were not on ART who required assistance as well as their family members. The CHW/volunteers are therefore faced with the following challenges/limitations.

- i. **Nutrition:** While the nutrition of the PLWHA may be the core concern of the CHBC programs, it was irreconcilably tied with the nutrition of the entire family, especially the children. One organization reported

“We can not only feed our immediate clients (PLWHA), we also have to take into consideration the other family members. This means there are more mouths to feed and yet we do not have the food to feed them.”

- ii. **Socio Economic Support:** This was in reference to the financial support of the entire family unit. If the client was the bread winner of the family, the deterioration of their health resulted in their inability to work. This ultimately resulted in the decline of the family’s income. Unfortunately this meant that *“people (women/girls) were forced to into prostitution”*. Organizations reported the lack of funds or resources to implement income generating activities.
- iii. **Stigma and Discrimination:** The family members and care givers may not want to assist the PLWHA and therefore it becomes the sole task of the CHW/volunteer to care for the PLWHA. The CHW/volunteer end up spending a majority of the time carrying out housekeeping activities and less counseling.

4.3 OPERATIONAL ISSUES

75. As previously outlined, the operational challenges can be categorized as follows:

- i. Human Resources (Training/Capacity Building and Technical Expertise)
- ii. Referral Systems/Links
- iii. Institutional Resources/Logistics (Transportation, HBC Kits, Information/Educational Material)

76. Within each category, specific operational issues are can be traced to the different levels/key players (Government, NGO/Development Agencies, CHBC programs). Below is a detailed discussion of the operational issues specific to the different levels/key players, and the possible solutions as reported by the respondents.

Training/Capacity building and Technical Expertise

77. There is apparently an insufficient number of properly trained personnel across the board of CHBC programs, due to insufficient resources to conduct training, the lack of expertise to carry out training, problems in recruitment and retention of CHBC personnel, and the availability of guidelines and manuals. There is lack of technical expertise in key areas of monitoring and evaluation, program management, and implementation of activities/services in CHBC programs.

(a) Government:

78. *Establish and Disseminate National Guidelines on CHBC:* Few countries have existing national guidelines carrying out CHBC, and where present, they are not easily available/accessible to the CHBC programs in the country. The guidelines should be drawn up through a collaborative effort involving the key players of CHBC, which include training manuals targeting CHW’s/volunteers. The guidelines should be on the MOH website, in district hospitals and health facilities and actively distributed to CHBC programs.

79. *Increase Public Sector Involvement:* The management and health care staff in public facilities health facilities are not formally involved in CHBC programs. They require to be educated, trained and motivated on their roles and responsibilities in CHBC. This training could be offered as a continuing education class conducted at the hospital and/or integrated in the educational curricula of nursing and hospital management.

80. *Technical Expertise:* The CHBC programs require more support and guidance from the MOH. There should be an “office” in the MOH responsible for maintaining an extensive database of CHBC programs, developing a timetable to conduct workshops in the different areas, creating an email listing to encourage dialogue between the MOH and other CHBC programs.

(b) NGO/Development Agencies

81. *Support in Developing Guidelines:* In some countries, the CHBC programs were using guidelines on CHBC developed by NGO/Development Agencies. These organizations clearly have a vast wealth of knowledge on training, which can be used and would be of great importance to both the governments and the CHBC programs.

82. *Training Programs:* The CHBC programs are understaffed and therefore require assistance from the larger with training of the CHW’s/volunteers through workshops and refresher courses.

83. *Technical Expertise:* The NGO/Development Agencies should be more assist in training the staff of the CHBC through workshops and serve as information resource center to the CHBC programs by having an open door policy.

(c) CHBC Programs

84. *Baseline Assessment:* The lack of careful assessment on the needs of the communities results in inadequate activities and services of the CHBC program. It is imperative to identify these needs and recognize how and which ones can be addressed by the CHBC program.

85. *Generate Community Involvement:* Sustainability of the CHBC programs requires involving and encouraging the active participation of the communities through regular meetings with the leaders and groups. Stronger community involvement could inevitably result in greater adherence rates, decrease in stigma and discrimination and a better understanding of HIV/AIDS. Community leaders could visit communities where CHBC is well organized and active to encourage leaders.

86. *Identify CHBC Volunteers:* The volunteers should be from the community and therefore the community can determine ways to compensate and motivate the volunteers. Volunteers from outside the community address the problem of their transportation needs to visit clients. Community recognition of the role and responsibility of volunteers may decrease the stigma and discrimination associated with this work.

Referral Networks/Links

87. Since PLWHA require continual care, especially for Opportunistic Infections, the CHBC programs need **a strong two-way referral system** between the community and health facilities. This will allow CHBC programs to refer clients to local clinics or hospitals and allows hospital staff to link discharged patients back to CHBC programs.

88. This two-way referral system will need the support of the health care workers in health facilities, especially in the public hospitals which serve majority of the public’s medical needs. In addition, CHBC programs need too linked with other services/organizations in the community who

could support them with the various activities and services such as income-generating, nutrition and support of OVC's and legal aid.

(a) Government:

89. *Recognizing the importance of CHBC programs:* CHBC programs should be nationally recognized in the national continuum of care in the country, therefore CHBC services should be available in all/most communities hence planned for as part of district health services. This may change the perception of hospitals towards CHBC programs as “dumping grounds” for HIV/AIDS and increase the CHBC programs access to the MOH

90. *Community Links:* There should be a list in hospitals/MOH on existing CHBC programs, to which PLWHA are directed towards. From this it will become evident the areas which are not being served by or are inaccessible by CHBC programs.

91. *Introduction of other Sectors:* Since CHBC programs offer a variety of services targeting nutrition, OVC's and legal aid, the ministries/program within the government need to be to CHBC and actively support them.

(b) NGO/Development Agencies

92. *Access to Services:* There is a dire need for CHBC programs to offer income generating activities to their clients. With the lack of success associated with income generating activities, it is imperative for the CHBC programs to seek the assistance from the NGO/Development Agencies which are specifically dealing in this area, and therefore know how to properly implement them. For example, NGO's can assist CHBC programs in establishing linkages to micro-financing institutions. NGO/Development Agencies could offer instructional workshops to train the CHBC staff who will then educate the communities.

(c) CHBC programs

93. *Develop and Maintain a Referral System:* The major responsibility of maintaining a referral system with the health facilities lies mainly with the CHBC programs. CHBC programs need to create a list of the health facilities and names of key personnel at these health facilities who are responsible for the care and support of their clients. The clients of the CHBC programs should then be referred not only to a specific facility but more importantly to a specific person. Clients can be educated on their responsibility of keeping a “diary” of their visits to the health facility and report to the CHW/volunteer who visits them.

94. *Identify the health personnel from local health facilities:* By having a strong working relationship with a health professional in the area, the CHBC program can then call on them to visit bedridden patients. This may require recording the contact information of these health professional, which is made available to the lead CHW/volunteer.

Logistics: Transportation/Resources

95. The CHBC programs had various logistical issues, with transportation being the key uniform theme. There were a variety of logistical issues, which could be probably all traced back to the lack of funds. However the CHBC programs clearly identified the lack of resources such as HBC kits, telephones/internet access, educational/informational material and the means to transport personnel and/or clients.

(a) Government

96. *Transport Funding:* In most of the countries, the health facilities and ART delivery points are not well distributed within the country. The governments need to recognize the great need of the CHBC programs to assist their clients with transport, and therefore allow CHBC to allocated funds towards to transport within their budgets. Governments need to determine the location of CHBC and their proximity to district hospitals, public transport routes, and accessibility to reliable roads. From this information the governments can ascertain the type of transport needs required by the CHBC program. For example, a CHBC program in a remote rural area may require a vehicle, whereas a CHBC in an urban location may require only funds for public transport. Furthermore, using existing knowledge on the course of treatment for HIV/AIDS and data on periodic medical care-seeking, an approximate number of visits to the health facilities can be determined. Hence the calculated funds for transport per client.

97. *HBC Kits:* Governments can decide on whether HBC kits should be provided to the CHBC or if CHBC should be funded to procure their own HBC kits.

98. *Informational/Educational material:* There is a lack of printed material on CHBC. Governments are the key players in developing such material, which could detail positive living, nutritional requirements, ART support, adherence, benefits and side effects. This would greatly supplement the CHW/volunteers task in educating the family member/care givers. This would require, creating, printing and distribution of material on CHBC.

(b) CHBC Programs

99. *Budget for Transportation:* Though is was not clearly stated, insufficient funds for transportation could be due to the inadequate funds allocated during budgeting or the lack of proper assessment in the number and/or distance of potential beneficiaries.

100. *HBC kits:* CHBC programs need to determine the essential items of the HBC kits and alternatives using local materials.

101. *Access to phone/internet:* It is important for CHBC programs to be able to communicate with other organizations both local and international, MOH, health facilities and clients.

5 RECOMMENDATIONS

102. Unfortunately CHBC organizations are facing a variety of challenges which inexplicitly affect their ability to deliver adequate services to their clients. Consequently the CHBC programs are limited in their ability to carry out activities such as proper ART adherence and support. Hence, a renewed effort and commitment in community home-based care support is needed. The following chapter is a list of recommendations based on the findings of this research, which should be considered to help strengthen existing CHBC programs and pave the way for a higher level of services to PLWHA.

103. These recommendations are categorized into three steps:

I. **Step One: Research into the current CHBC programs** – There needs to be more research on the CHBC programs in the following areas

- **Main Activities and Services:** These have been documented, but there needs to be more information on their operations; how they are carried out, who carries them out. Additionally monitoring and evaluation of these main activities and services to determine if the clients needs are being met. Consistent measure will be required in order to systematically evaluate the feasibility and effectiveness of the diverse models and program configurations
- **Prevention:** Though not a main finding of this research, there are a number of CHBC programs which have integrated prevention as a key activity and promote VCT as part of the responsibilities of CHBC volunteers. Prevention as well as role of PLWHA support groups should be increasingly documented to encourage their active implementation within CHBC activities/services.
- **“Good Practices”:** How have they found success, and are they replicable? There are a number of CHBC programs which have been documented “good practices” in their success to achieve and maintain a high level of services and activities; motivation of volunteers, referral mechanisms, reduction of stigma and discrimination, high ART adherence rates. A proper analysis of these programs, documenting a step-by step approach, on how to attain the goals and deal with the imminent challenges.
- **Cost analysis of CHBC and financial sustainability:** The community contribution in terms of volunteers and infrastructure is far from minimal. However, in order to appreciate this, research is needed to evaluate the community’s contribution in monetary terms
- The one “threat” to the sustainability of these CHBC programs is the obvious dependency on external funds. **It is unrealistic to imagine that poverty stricken communities could one day supply the amount of financial resources required to sustain these CHBC programs.** Therefore the argument of financial sustainability should not be the deciding factor to the existence of CHBC programs. On the other hand, the human resource sustainability of the CHBC programs is feasible, granted the CHBC programs receive the necessary governmental and financial support.

II. Step two: Role and Responsibilities: From the finding of this and previous research, it is clear that CHBC programs can not be successful unless they receive active support and participation from the Government, NGO's, Development Agencies/Donors & Communities. The following are therefore the roles and responsibilities the need to assume:

- **Government:** Should assume a greater role in CHBC provision to ensure patients and families have access to high quality of care, treatment and support through the execution of the following:
 - i. Incorporate CHBC into district health service plans;
 - ii. Train and educate health care staff in the public health facilities on their necessary active participation in CHBC with an emphasis on the reduction of stigma and discrimination. Care of the terminally ill at home should not be left to the families alone. They should be assisted by health professionals;
 - iii. A nationally recognized training program for volunteers, which allows them to be certified in community home-based care, with the possibility of further training for placement within the health care system.
 - iv. Create the “platform” for a strong referral system, through forging partnerships with NGO's and CHBC programs, creating a directory, organizing conferences/seminars. Coordinate CHBC activities by different organizations at the district level;
 - v. Involve and encourage the other public sector agencies dealing with social welfare, education, food and nutrition to be key players and share responsibilities in providing CHBC. A comprehensive social welfare system needs to be put in place in order to assist the families to cope with burdens of care giving;
 - vi. Create less elaborate community care models (i.e. focus on the essential care activities in; **See Table 1.**) which can be implemented by government health facilities in resource-poor areas where donor funds are unavailable. For example
 - vii. Operational issues regarding ART (e.g. transportation and accompaniment to and from clinics) need to be addressed and solved in order to increase effectiveness of CHBC program
- **NGO's, Development Agencies / Donors:** The key strengths of these organizations lies in their technical expertise, financial assistance and vast knowledge/information on CHBC. They can assist CHBC programs with the technical expertise in the areas of Technical Expertise:

Educate and train the CHBC personnel on training methods, volunteer recruitment and motivation techniques, monitoring and evaluation of activities, proper record/report keeping and budgeting/financial methods. Referral networks and links; create the environment to foster networking and teach CHBC programs how to build other strong links.
- **Community Level:** The level of active participation of communities will differ from community to community, as the communities needs and resources will vary. Therefore the following are general recommendations;
 - i Encourage communities to initiate and develop their CHBC programs, actively participate in the recruitment, motivation and compensation of volunteers;
 - ii Create strong links, which can be depended upon, with other organizations and the MOH;

- iii Develop base-line assessments of the expected numbers of clients, which is annually recalculated to determine the available resources and therefore the necessary assistance required (from the government, NGOs etc)
- iv Encourage the families to be involved in the care of their ill relatives while in hospital so that they can understand their role and the ill persons condition.

III. Step 3: Future Considerations: Further research on the following

- **Scaling out of CHBC programs.** Home based care programs that scale-out their services are likely to be faced with a number of challenges. Programs may therefore face substantial challenges in maintaining a high quality of services. In addition management structures and systems are likely to become more bureaucratic, less flexible and responsive, and consequently less efficient. It would be useful for all key players to take these possible challenges in consideration, as the imminent question of scaling-up becomes more and more pervasive.
- **Development of generic guidelines:** Specifically for CHBC providers benefiting from the MAP financing. This will directly benefit MAP projects in Africa in improving local efficiency and approach.
- **Investigate** the availability of CHBC to pain relieving drugs, access to services, extent of coverage programs,
- **Identification of relevant needs,** determination of outcomes and the evaluation of the impact of CHBC programs. This presents particular challenges in selecting appropriate measures and methods. Relevant outcomes may include policy, strategy, sustainability, availability and utility of education and training, and integration of end-of-life care into health systems.

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ANNEX 1 PROTOCOL FOR RESEARCH

Title: Research on Practices in Providing Community Home-Based Care to People Living with HIV/AIDS by **Community groups**

1. Problem Statement

- Around 65% of adult medical in-patients are HIV-seropositive in urban hospitals of countries such as Zambia
- CHBC is the only option available for many HIV/AIDS patients because hospital care is unaffordable and inaccessible.
- Currently only a small proportion of people living with HIV/AIDS have access to CHBC services
- In resource-limited settings, palliative care typically requires an interdisciplinary team approach that includes both formal and informal caregivers
- It is estimated that 50% to 60% of people with HIV/AIDS worldwide have not access to professional healthcare workers to address their medical needs. For example in Uganda, 88% of the population lives more than 10 kilometers from any kind of health facility and the nurse to patient ratio is 1:4,300

2. What are the areas that need to be researched

- The various approaches to CHBC programs have not been well documented, especially best practices, challenges, and current programs carrying out ART.
- CHBC programs guidelines have either not been developed or implemented.
- Standard indicators for monitoring and evaluation of HBC programs are not being implemented on the grassroots level

3. Justification and Use of Results

- a) Several public and non-public organizations have been providing community home based care to PLWHA under Multi-Country HIV/AIDS Program for Africa (MAP) and other financing.
- b) Various institutions, organizations, individuals and donors have substantial experience in this area. However, it is not clear how this expertise and knowledge is transferred to the smaller CBOs and community groups.
- c) At a later stage, based on these findings, a guideline for CHBC for community based organizations and grassroots level community groups would be prepared. This will directly benefit MAP projects in Africa in improving local efficiency and approach.
- d) Goal: To research the practices of CHBC to PLWHA in the Sub-Saharan African MAP countries by community groups.
- e) Objectives
 - To document current practices CHBC to PLWHA by grass-root level organizations/groups in MAP countries
 - To determine the various approaches, including logistics, undertaken to provide ART in the context of CHBC to PLWHA by grassroots level community organizations/groups in MAP countries
 - To determine how existing expertise and knowledge on CHBC for PLWHA from NGO's & Development Partners is disseminated to the smaller grass-root level organizations/groups in the Sub-Saharan MAP countries

Indicators

Inputs	Process	Outputs
<ul style="list-style-type: none"> • Funds (<i>overheads, logistic costs</i>) • Supplies • Drugs (<i>ARV, Basic & Prescribed</i>) • Guidelines • Equipment • Personnel 	<ul style="list-style-type: none"> ❖ Training (<i>Staff, Volunteer</i>) ❖ Services (<i>Medical & Nursing, Socio-Economic, Human Rights/Legal Support, Psycho-Social Support</i>) 	<ul style="list-style-type: none"> ➤ Number Trained (<i>Staff/Volunteer</i>) ➤ Number of PLWHA support groups ➤ Number of PLWHA receiving ARV therapy

Goal	Objective	Indicators	Sources
To research the practices of CHBC to PLWHA in MAP countries by community groups.	To assess CHBC to PLWHA by grass-root level organizations/groups in MAP countries	Process - Training, Services Outcome - Number Trained (Staff, Volunteer), Number of PLWHA support groups	Key Informants
	To determine the various approaches undertaken to provide ART in the context of CHBC to PLWHA by grassroots level community organizations/groups in MAP countries	Process - Training, Services, Model Type Outcome - Number Trained (Staff, Volunteer), Number of PLWHA support groups, Number of PLWHA receiving ARV therapy	Key Informants
	To determine how existing expertise and knowledge on CHBC for PLWHA from NGO's, development Partners & Government Agencies is disseminated to the smaller grass-root level organizations/groups in the MAP countries	Inputs - Funds, Supplies, Drugs, Equipment, Guidelines, Personnel Process - Training	Key Informants

4. Specific tasks

- Conduct interviews with all relevant
 - World Bank MAP TTL's and other Bank professionals
 - NGOs and Development Partners
 - Country local NGO's, FBO's, CBO's and other grassroots level community groups/organization
- Review relevant websites, existing publications, guidelines and manuals produced on the subject;
- Prepare a detailed report based on the agreed outline
- Facilitate in conducting peer review consultations

5. Methodology

a) Type of Study and General Design

Case studies of the MAP countries: MAP countries were listed according to HIV rates and region. Case study countries were selected using the following criteria

Country Sampling Criteria:

- A. Countries with available HIV rates above the average of Sub-Saharan Africa of 7.5%. (UNADIS, 2003). **Rationale:** It is important to target the countries with the highest rate and therefore the greatest need of HBC

- B. Countries with the highest HIV rate in their geographic region. **Rationale:** It is important to take into account language, cultural differences which are specific to regions and which will have an impact on HBC

Case Study Countries:	Official Language
I. Zambia	English
II. Malawi	English
III. Burkina Faso	French
IV. Mozambique	Portuguese
V. Tanzania	English
VI. Cameroon*	French
VII. Senegal	French

Note

** Mali had the highest rate of HIV for northern Africa countries but the MAP funding has not yet been approved. The remaining countries had very low reported HIV rates and therefore would not have significant number of PLWHA and in turn low numbers of CHBC programs for PLWHA. Mali being a French speaking country, it was important to replace it with another French speaking country which did have high rates of HIV. According to the list, Cameroon was the best replacement.*

b) Data Collection, Instruments Used and Methods of Data Quality Control

Key Informants

Key informants are the main source of data and are contacted via email. Data will be collected using in-depth interviews using questionnaires. If possible a meeting date is scheduled for the interview. Otherwise the interview is conducted via phone or email.

- World Bank Task Team Leaders (TTL's) and other Bank professionals:
Selection Criteria: Selected using the a pre-existing list of TTL's within the Bank
Questionnaire 1
- Reputable International NGO's, Donor agencies:
Selection Criteria: Randomly selected through information gathered on existing CHBC programs.
Questionnaire 2
- Grassroots level organizations/groups (CBO's, FBO's, local NGO's)
Selection Criteria - To be determined through the course of research from interviews with key informants A. and B above
Questionnaire 3

c) Results and Data Analysis

- Tabulated information of key informants:
- Programs to be used SPSS, Excel

d) Timeline

Planning and design:	Jan 3 rd – Jan 17 th
Data collection :	Jan 18 th – March 1 st
Data Analysis:	March 2 nd – March 14 th
1 st Draft:	March 18 th
Final Draft	March 28 th

ANNEX 2. LETTERS TO ORGANIZATIONS

February 1st, 2005

Juliet Gikonyo
ACT Africa – Consultant
The World Bank
1818 H Street, NW
Washington, DC 20433

Dear Sir/Madam:

I am currently carrying out research on Community Home Based Care (CHBC) for People Living with HIV/AIDS (PLWHA) for the ACT Africa division of the World Bank. The goal of the research is to determine what problems CBO's, NGO's, FBO's and other grassroots level groups are encountering in regards to CHBC for PLWHA and therefore determine how best to assist them through the Multi-Country HIV-AIDS Program (MAP) for Africa. The countries of focus for this research are Nigeria, Senegal, Mozambique, Tanzania, Zambia, Cameroon, Burkina Faso, Malawi.

In order to achieve this goal the research has three objectives

- To document current practices CHBC to PLWHA by grass-root level organizations/groups.
- To determine the various approaches, including logistics, undertaken to provide/support ART in the context of CHBC to PLWHA by grassroots level community organizations/groups.
- To determine how existing expertise and knowledge on CHBC for PLWHA from Organizations & Development Partners is disseminated to the smaller grass-root level organizations/groups.

Your organization's experience and knowledge in CHBC for PLWHA would be of great benefit to the research and would be highly appreciated.

I have attached Questionnaires 2 and 3 to this email as well as copied them below. Please read the following criteria to determine which Questionnaire to answer

- Answer Questionnaire 2 if your organization funds/provides technical support to organizations providing CHBC for PLWHA.
- Answer Questionnaire 3 if your organization directly carries out CHBC for PLWHA.

Please answer each question and email the responses to jgikonyo@worldbank.org, or forward this email to the appropriate person in your organization (please copy me on the forward). The time period for data collection is Feb 1st -March 1st, 2005.

For further information or inquiries on the research please feel free to contact me.

I look forward to hearing from you.

Thank you
Juliet Gikonyo

ANNEX 3 QUESTIONNAIRES

Key Informant: Questionnaire 2 (NGO's, Development Partners)

Research on Practices in Providing Community Home-Based Care to People Living with HIV/AIDS by Community Groups. Research Conducted By: ACT Africa Consultant: Juliet Gikonyo

Thank you for participating in this research. Please fill in the blanks and answer the questions below (2 pages: 12 Questions) and email the responses to the above questions to jgikonyo@worldbank.org

Organization (name) : _____

Date: _____

Interviewee Name _____

Title _____

Contact tel/email address _____

Questions

Definition of CHBC: (The Gaborne Declaration on CHBC, March 2001) :care given to an individual in his/her own natural environment by his/her family and supported by skilled welfare officers and communities to meet not only the physical and health needs, but also the spiritual, material, and psychosocial needs"

1. Do you agree with the above definition?
2. Are there any other definitions or something you would like to add and/or remove from this definition?
3. Does your organization directly fund the above CHBC program?
4. Does your organization supply the above CHBC program with
 - a. ART
 - b. Prescription drugs (STI/OI)
 - c. Equipment
 - d. Guidelines on CHBC
 - e. Guidelines on CHBC ART support/adherence/monitoring
 - f. Manual for training staff/volunteer who carry out CHBC
 - g. Other Supplies
5. Are there any personnel from your organization working on the ground in conjunction with the above CHBC program?
6. Is your organization responsible for training the following for the above CBHC program?
 - a. Staff
 - b. Volunteers
7. (If answer to above is yes for 4 a. and/or 4 b.) Does your organization conduct workshops/refresher courses? How often are the workshops/refresher courses.
8. Are the volunteers
 - a. Paid
 - b. Compensated
9. To the best of your knowledge, what challenges is the above CHBC program facing
10. If the above CHBC program has an ART component, what challenges is it facing in regards to ART?
11. For the challenges listed in the above questions 9 & 10, what are the operational issues associated with each of the challenges and what are the possible solutions.
12. Further discussion (concerns/suggestions/recommendations)

For the purpose of collecting more in depth information, please forward Questionnaire 3 to one or more of the CHBC programs for PLWHA which your organizations funds/supports. (please copy my email address on the forward jgikonyo@worldbank.org)

Thank you for taking the time to answer these questions. Please email the responses to the above questions to Juliet Gikonyo jgikonyo@worldbank.org For further information or inquiries on the research please contact me on the above address.

Key Informant: Questionnaire 3 (NGO's, CBO's, FBO's, and other community groups)

Research on Practices in Providing Community Home-Based Care to People Living with HIV/AIDS by Community Groups Research Conducted By: ACT Africa Consultant: Juliet Gikonyo
Thank you for participating in this research.

Please fill in the blanks and answer the questions below (2 pages) and email the responses to jgikonyo@worldbank.org

Staff/Volunteer Interviewed (name, title, email address) _____

CHBC Program (name): _____

Country: _____ District/Location: _____

Type of Support Offered by your CHBC program:

Number Trained Staff _____

Volunteer _____

Number of PLWHA support groups _____

Number of PLWHA receiving ART _____

Does your organization provide the following to the **PLWHA**

Treatment for STI and OI Yes / No / Not applicable

TB DOTS Yes / No / Not applicable

ART Medication Yes / No / Not applicable (through the program/facility linked to the program) Adherence support of ART Yes / No / Not applicable

Bathing/toileting/other nursing care Yes / No / Not applicable

Nutritional Support for PLWHA Yes / No / Not applicable

Does your organization provide the following to the **PLWHA and/or Family members**

Counseling on adherence to ART Yes / No / Not applicable

Education on OI prevention/control Yes / No / Not applicable

Provision of condoms Yes / No / Not applicable

Emotional Support Yes / No / Not applicable

Spiritual Support Yes / No / Not applicable

Counseling on Death and Dying Yes / No / Not applicable

Cooking/Sweeping/Other duties Yes / No / Not applicable

Micro-credit/Income generating activities Yes / No / Not applicable

Assistance with funeral arrangements Yes / No / Not applicable

Blanket/Soap/Consumables Yes / No / Not applicable

Does your organization provide the following to the **Family members**

Medical care for family members Yes / No / Not applicable

Health education for family members Yes / No / Not applicable

VCT for family members Yes / No / Not applicable

Nutritional support for children (0-8yrs) Yes / No / Not applicable

Referral Agencies

Name Purpose

The following questions are in regards to challenges and ART

Please list the 5 main challenges of this CHBC program.

a)

.

.

List the 5 main challenges specific to ART support .

a)

.

For the challenges listed in the above questions 1 & 2, what are the operational issues associated with each of the challenges and what are the possible solutions.

Explain how your program monitors ART adherence.

Where to majority of the PLWHA or family members travel to collect the ART drugs? (please provide the name and location of the health facility)

Do MAJORITY of the PLWHA receive medical check-ups in the home OR do they travel to a health facility?

If PLWHA travel to a health facility for medical check-ups, does your program assist with

- a) Transport in a vehicle owned by the program Yes / No
- b) Transport costs for public transport Yes / No
- c) Personal accompaniment to and from the clinic Yes / No

If PLWHA receive medical check-ups in the home, please explain the following

- a) Who carries this out (nurse/doctor/other trained health care worker) and are they paid/receive compensation/volunteer
- b) How often are the medical check-ups done

Explain what methods are put into place when ART is interrupted/unavailable (what back-up plans if any are used to)

Thank you for taking the time to answer these questions. Please email the responses to the above questions to Juliet Gikonyo jgikonyo@worldbank.org

For further information or inquiries on the research please contact me on the above address.

Key Informant: Questionnaire 1 (For MAP Task Team Leaders/Assistants)

Research on Practices in Providing Community Home-Based Care to People Living with HIV/AIDS by Community Groups Research Conducted By: ACT Africa – Consultant: Juliet Gikonyo

Thank you for participating in this research. Please fill in the blanks and answer the questions below and email the responses to the above questions to *jgikonyo@worldbank.org*

(1 Page: 11 Questions)

Name: _____
Title : _____
Country(s): _____
Date: _____

Definition of CHBC: (The Gaborne Declaration on CHBC, March 2001) :care given to an individual in his/her own natural environment by his/her family and supported by skilled welfare officers and communities to meet not only the physical and health needs, but also the spiritual, material, and psychosocial needs”

Do you agree with the above definition?

Are there any other definitions or something you would like to add and/or remove from this definition?

Through MAP funding are there any programs for CHBC for PLWHA?

(If answer to above is yes) Do any of the MAP funded CHBC programs for PLWHA have an ART component/supporting PLWHA adherence to ART?

Are there national guidelines for CHBC for PLWHA?

Are there national guidelines for CHBC for PLWHA in regards to ART?

To the best of your knowledge, what the 5 main challenges CHBC programs for PLWHA facing?

If there are CHBC programs for PLWHA with an ART component, to the best of your knowledge, what are the 5 main challenges specific to ART delivery/support

What are your recommendations for CHBC for PLWHA?

Further discussion (recommendations/suggestions/concerns)

Below Only For information on the Case Study Countries (Nigeria, Zambia, Malawi, Burkina Faso, Mozambique, Tanzania, Cameroon, Senegal)

In order to gather information on practices in providing CHBC to PLWHA by grassroots community groups, please provide a contact person (name, title, email address, telephone number) for a CHBC program who can be interviewed (via telephone or email), AND/OR a contact person who can be of assistance in reaching the necessary person(s).

Thank you for taking the time to answer these questions. Please email the responses to the above questions to Juliet Gikonyo *jgikonyo@worldbank.org*

For further information or inquiries on the research please contact the above

Key Informant: Questionnaire 1b (Bank professionals/specialists)

Research on Practices in Providing Community Home-Based Care to People Living with HIV/AIDS by Community Groups. Research Conducted By: ACT Africa – Consultant: Juliet Gikonyo

Thank you for participating in this research. Please fill in the blanks and answer the questions below and email the responses to the above questions to jgikonyo@worldbank.org

(1 Page)

Name: _____
Title : _____
Country(s): _____
Date: _____

Definition of CHBC: (The Gaborne Declaration on CHBC, March 2001) :care given to an individual in his/her own natural environment by his/her family and supported by skilled welfare officers and communities to meet not only the physical and health needs, but also the spiritual, material, and psychosocial needs”

Do you agree with the above definition?

Are there any other definitions or something you would like to add and/or remove from this definition?

Discuss:

National guidelines for CHBC for PLWHA.

National guidelines for CHBC for PLWHA in regards to ART.

Challenges CHBC programs for PLWHA facing.

For CHBC programs for PLWHA with an ART component, challenges specific to ART delivery/support.

What are your recommendations for CHBC for PLWHA?

Further discussion (recommendations/suggestions/concerns)

Below Only For information on the Case Study Countries (Nigeria, Zambia, Malawi, Burkina Faso, Mozambique, Tanzania, Cameroon, Senegal)

In order to gather information on practices in providing CHBC to PLWHA by grassroots community groups, please provide a contact person (name, title, email address, telephone number) for a CHBC program who can be interviewed (via telephone or email), AND/OR a contact person who can be of assistance in reaching the necessary person(s).

Thank you for taking the time to answer these questions. Please email the responses to the above questions to Juliet Gikonyo jgikonyo@worldbank.org

For further information or inquiries on the research please contact the above

ANNEX 4 CONTACT LIST

The World Bank

<u>Name</u>	<u>Country</u>	<u>Title</u>
Task Team Leaders		
A Bach- Baouab	Ethiopia	
Bert Voetberg	Kenya	
Chris Walker	Eritrea	
Christine Kimes	Malawi	
Eileen Murray	Ghana	
Emmanuel Malangalila	Tanzania	
Gebre Okubagshi	Ethiopia	
Gylfi Palsson	Cape Verde	
Ibrahim Magazi	Guinea	
Jamomina P. de Regt	Mozambique	
Jean Delion	Cameroon & CAR	
John Elder	Nigeria	
John May	Gambia	
Johnston, Timothy	Burkina Faso	
Julie Van Domelen	Senegal	
Malonga Miatudila	Niger	
Michele Lioy	Chad	
Miriam Schneidman	Rwanda	
Muhammad Pate	Zambia	
Nadine Poupart	Madagascar	
Nicholas Ahouissoussi	Benin	
Peter Okwero	Uganda	
Sameh El-Saharty	Djibouti	
Serge Theunynck	Mauritania	
Son Nam Nguyen	Eritrea	
Task Team Assistants		
Abiodun Elfioye	Nigeria	
Astou Diaw-Ba	Senegal	
Bintou Sogodogo	Burkina Faso	
Evelyne Chytee Dora Kapyra	Tanzania	
Marta Tomazia Guimaraes		
Madeira	Mozambique	
Neta Mulenga Walima	Zambia	
Other Bank Professionals		
Alfred Sambirani Chirwa	Malawi	Population & Health Spec.
Elizabeth Lule	N/A	Adviser
Foluso Okunmadewa	Nigeria	Sr. Social Protection Spec.
Jane Miller	Nigeria	Sr. Health Spec.
	Cape Verde/Abidjan-Lagos Corridor	Sr. Program Assistant
Jocelyne do Sacramento	Project	
Khama Rogo	N/A	Lead Spec.
Ramesh Govindaraj	Malawi	Sr. Health Spec.
Ruth Kagia	N/A	Sector Director

International Organizations

<u>Country</u>	<u>Organization Name</u>	<u>Contact Person</u>	<u>email</u>
Botswana	African Comprehensive HIV/AIDS Partnerships (ACHAP)	Debbie Stanford	debbie@achap.org
Burkina Faso	Association African Solidarite (AAS) Project Orange		aas@fasonet.bf
Burkina Faso	Association Ammie	Beloum Cecile	ammie@fasonet.bf
Burkina Faso	Association Laafi La Vim (ALAVI)	Geoffroy Sawadogo	geoffroysawadogo@yahoo.fr
Burkina Faso	Centre de Cooperation International En Sante Et En Developpement (CCSISD)	Pierre Champagne	frederic.kintin@ccisd.bf
Burkina Faso	Initiative Privee Et Communautaire Contre Le VIH/SIDA	Milogo B. Price	ipcbf@cenatrin.bf
Burkina Faso	Network of People Living with HIV/AIDS	Roch Zogo	spcnls@fasonet.bf
Burkina Faso	Reseau African De Personnes Positive (RAP+)	Martine Somda	revs@fasonet.bf
Burkina Faso	Reseau National Des Personnes Vivant avec le VIH	Justine Korbeogo	Korbeogo_Justine@yahoo.fr
Burkina Faso	Responsabilite Espoir Vie Solidarite (REVS+)	Martine Somda Aime Arnaud Dabilgou	revs@fasonet.bf viepositive@hotmail.com
Burkina Faso	Vie Positive "Wake UP"		
Cameroon	Association Des Femmes Actives Et Solidaires (AFASO)	Pauline Angeline Mounton	afasocm@yahoo.fr
Cameroon	Association des Freres et Soeurs Unis por l'Espoir et la Solidarite (AFSUPES)	Solange Evodo	Ubsa_afsu_dla@yahoo.fr
Cameroon	Association des Freres et sourrs unis (AFSU)	Marie Joseph / Michel Ndjialeu	afsucameroon@yahoo.fr
Cameroon	Association pour la Sante, L;Information et la Vie au Cameroun (ASIVIC)	Roger Djihemine	asivicpositifs@yahoo.fr
Cameroon	Cameroon Link - Human Assistance Programme	James Achanyi-Fontem	camlink2001@yahoo.com
Cameroon	Centre D'Ecoute	Crepin Djemna	creps_117@yahoo.fr
Cameroon	Cercle des Jeunes Engages dans la Lutte contre le SIDA (CEJES)	Marie-Gisele Tientcheu Jean Jules	Cejes2002@yahoo.fr
Cameroon	Colibri	Kamegue	jean_juleskamgue@yahoo.fr
Cameroon	ESPOIR+	Josephine Batoum	As_espoir@yahoo.fr
Cameroon	Health and Solidarity	Linda Bihtaku Henriette Bikie,	bihlintaku@yahoo.com
Cameroon	Hope for African Children Initiative	Country Coordinator	bikie1henriette@hotmail.com
Cameroon	Hope is Rising Association (HIRASO)	James Clovis Kayo	hirasso@yahoo.fr
Cameroon	Project HOPE	Rev.Sister Breda Shigyan	gvngwa@yahoo.com

Cameroon	Society for Women and AIDS in Africa	Magdalene Wango	wangos@hotmail.com
Cameroon	Sun AIDS - Cameroon Network	Marie Mendene,	
Cameroon	UN Theme Group on HIV/AIDS, Chair	Lucie Tsamo	sunaids@nomade.fr
Kenya	African Medical and Research Foundation (AMREF)	Madani Tall	mtall@worldbank.org
Kenya	Association of People with AIDS in Kenya, The	Peter R. Ngatia	info@amrefhq.org
Kenya	Ecumenical Pharmaceutical Network	Rowlands G. Lenya	tapwak@kenyaonline.com
Kenya	Hope for African Children Initiative	Eva Ombaka	epn@wananchi.com
Kenya	ICROSS	Eileen Kwamboka	ekwamboka@africaonline.co.ke
Kenya	International Federation of Red Cross Kenya AIDS Intervention/Prevention Project Group	/ Helen Monteil	
Kenya	Kenya AIDS NGOs Consortium	Dr. Michael Elmore-Meegan	mikemeegan@icross-international.net
Kenya	Network of African People Living with HIV/AIDS (NAP+)	Patrick	ifrcke46@ifrc.org
Kenya	Policy Project	James Onyango	kaippg@africaonline.co.ke
Kenya	Women Fighting AIDS in Kenya (WOFAK)	Allan G. Ragi	kenaids@iconnect.co.ke
Malawi	Actionaid-Malawi	Michael Angaga	nap@wananchi.com
Malawi	Hope for African Children Initiative	Angeline Siparo	Asiparo@policy.or.ke
Malawi	Malawi AIDS Counselling & Resource Organisation (MACRO)	Dorothy Onyango	wofak@iconnect.co.ke
Malawi	Malawi Network of AIDS Service Organisations (MANASO)	Brenda Yamba, Country Coordinator	amsfa@sdpn.org.mw
Malawi	Malawi Network of PLWHA (MANET+) Secretariat	Katawa Hsowoya	scuscope@malawi.net
Malawi	Partners in Hope-ABC Community Clinic	Mrs. Francina Nyirenda	macro@malawi.net
Malawi	Policy Project Office	Mr. Victor Fidelis Kamanga	manaso@malawi.net
Malawi	Southern African AIDS Training Programme (SAT)	Mr. Victor Fidelis Kamanga	manet@malawi.net
Malawi	Umoyo Network	Perry Jansen	perry.jansen@sim.org
Malawi	Save the Children	Shawn Aldridge / Rita Chilongozi	saldridge@rti.org
Mozambique	ACCAO SIDA AIDS Action	Howard Kasiya	sat.malawi@satregional.org
Mozambique	Action AID		umoyo@malawi.net
Mozambique	Associacao Nivenyee De Pessoas Vivendo Com HIV/SIDA	Ana Novoa / Ricardo Barradas	chaggard@dc.savechildren.org
Mozambique	Hope for African Children Initiative	Fernanda Bernardo	medico@zebra.uem.mz
Mozambique	International Federation of Red Cross Mozambican Network of AIDS Services Organization (MONASO)	Silvio Saide	aamozhiv@teledata.mz
Mozambique		Sonia Romao, Country Co-ordinator	silsaide2003@yahoo.com.br
Mozambique		Fernanda Teixeira	mozvisitor@savechildren.org
Mozambique		Ana David	fernanda.teixeira@redcross.org.mz
Mozambique			AnaDavid@hotmail.com

Mozambique	Rede Nacional De Organizacoes De Pessoas Vivendo Com HIV/SIDA (RENSIDA)	Julio Ramos Mujojo	mudjasy@yahoo.com.br sat.mozambique@satregional.org
Mozambique	Southern African IADS Trainina Programme (SAT)	Gabriel de Barros	gabriel@satregional.org
Nigeria	African Council for Sustainable Health Development (ACOSHED)	Lola Dare, MD	acoshed@yahoo.com
Nigeria	Association of Students Against AIDS	Victori Ofen-Imu	zegidero@yahoo.com
Nigeria	Center for The Right to Health	Stella Iwuagwu	crhaid@stella.org
Nigeria	Centre for Adolescent Research Education and Sexuality (CARES)	Bode-law Faleyimu	cares@mail.com
Nigeria	Centre for Health, Education and Development Communication the (CHEDCOM)	Wumi Sina Falana	chedcom@yahoo.com
Nigeria	Child Health Organization	Vickie Njoku Onyekuru	childvicky32@yahoo.com
Nigeria	Family and Adolescent Health Initiative (FAHI)	Amechi Nweze	nwezea@unijos.edu.ng
Nigeria	Federal Ministry of Health (FMOH)	Dr. Salma Anas Kolo	salma_anas@linkserve.com
Nigeria	Friends of the Disabled	Chief. Mrs. A. C. Orduh	fotd2002@yahoo.com
Nigeria	GHAIN	Robert Chiegil	rchiegil@ghain.org
Nigeria	Global Health & Awareness Research Foundation (GHARF)	Obioma Nwaorgu	gharf@skannet.com
Nigeria	HIV/AIDS Concern Group	Ebun Onabanjo	hiv_aidscg@yahoo.com
Nigeria	Hope Worlwide Nigeria	Ola Clement	olacandido@yahoo.co.uk
Nigeria	Life Vanguard	Oluwole Odutolu	livanig@skannet.com.ng
Nigeria	Living Hope Care for People Living with HIV/AIDS	Ibiyemi Fakande	ukpong@skannet.com
Nigeria	Living Hope Organization	Jude Chidi Munaonye	livhorg@yahoo.com k.shettima.macarthur@skannet.com
Nigeria	Mac Arthur Foundation		macarthur@skannet.com
Nigeria	Mashiah Foundation	Pastor Bayo Oyebade	oyebades@yahoo.com
Nigeria	Organization of Nigeria Help-Line on HIV/AIDS	Pastor Michael O. Daniel	michon72@justice.com
Nigeria	Redeemed Christian Church of God/ Redeemed AIDS Programme Action Committee	Laide Adenuga	laideadenuga@yahoo.co.uk
Nigeria	Society for Women And AIDS in Africa (SWAAA)	Patricia Nzegwu	swaanigeria@yahoo.com stopaids@fordwa.linkserve.org
Nigeria	Stop AIDS		
Rwanda	Care	Andrew Jones	andrewj@care.org.rw
Rwanda	Care	Aliou Ayaba,	alioua@care.org.rw
Senegal	African Council of AIDS Service Organisations (AFRICASO)	Daouda Diouf	africaso@enda.sn

Senegal	African Network on Ethics, Law and HIV/AIDS		hivregun@telecom-plus.sn
Senegal	Association "AWA"	Seynaboo Ndovr	assoawa@sentoo.sn
Senegal	Association Clinique Conseil/SIDA	Ndongo Dione	accsembe2003@yahoo.fr
Senegal	Association Pour Le Developpement De L'Homme	Seriguebabacar Nodiaye	serignebnd@yahoo.fr
Senegal	Cellule D'accompagnement Des PVVIH	Ibrahim Diedhiou	hopndioum@sentoo.sn
Senegal	Centre De Cooperation Internatinal En Sante Et En Developpement (CCISD)	Rose N'Guessan	rdnguess@sentoo.sn
Senegal	Conseil National De La Jeunesse Du Senegal (CNJS)	Mohamed Habib Sarr	diopmalick@nomade.fr
Senegal	Enda Tiers Monde	Cheikh Hamidou Kane	se@enda.sn
Senegal	HIV Testing Centre		cpserv@sentoo.sn
Senegal	Hope for African Children Initiative	Alioune Fall, Country Coordinator	swaainter@sentoo.sn
Senegal	Oasis Solidarite Reseau National Des Personnes Vivant Avec Le VIH/SIDA (OASIS-RNP+)	Diethie Yacine Dieye	network@telecomplus.sn
Senegal	Programme National De Lutte Contre Le Sida (PNLS)	Ibrahim N'Doye	ibndoye@telecomplus.sn
Senegal	Promotion des Medecines Traditionnelles	Erick Vidjin Aghih	senegal@prometra.org
Senegal	SIDA Service	Gbodossou Paul Sagna	cpserv@sentoo.sn
Senegal	Society for Women and AIDS in Africa (SWAA)	Soukaye Dieng	swaa@telecomplus.sn
Senegal	Synergy For Childhood/Synergie Pour l'Enfance (SFC/SPE)	Ngagne MBAYE	ngagne@sentoo.sn
Tanzania	African Medical Research Foundation-Tanzania (AMREF)	Daraus Bukenya	info@amref.tz
Tanzania	African Regional Youth Initiative	Neema Mgana	arvi_2002@yahoo.com
Tanzania	Catholic Women of Tanzania Association (WAMATA)		nunzio@cats-net.com
Tanzania	Comprehensive Community Based Rehabilitation in Tazania (CCBRT)	Geert Vanneste	vanneste@intafrica.com
Tanzania	Kagera Development Trust Fund (KADETFU)		kadetfu@yahoo.com
Tanzania	Kivulini Women's Rights Organisation		lanizi@africaonline.co.tz
Tanzania	Lindi NGO Network (LINGONET)		lingonetlindi@yahoo.co.uk
Tanzania	OXFAM - Ireland	John Plastow	john@oxfam.ni.org.uk
Tanzania	Pathfinder International	Nelson Keyonzo	NKeyonzo@pathfind.org
Tanzania	Save the Children of Tarime (SACHITA)		mogabiri@africaonline.co.tz
Tanzania	Southern African AIDS Training Programme (SAT)	Adolf Mrema	sat.tanzania@satregional.org
Tanzania	Tanzania Network of People with HIV/AIDS (TANOPHA)	Julius Kaaya	tanopha@yahoo.co.uk

Tanzania	Union of NGOs in Morogoro (UNGO)		ungomoro@yahoo.co.uk
Tanzania	Women's Research and Documentation Project Association (WRDP)		wrdp@udsm.ac.tz
Tanzania	Zanzibar AIDS Commission	Bi Asha Abudulla Dr. Faith Alloba	asha.abdulla@zanlink.com
Tanzania	Zanzibar Association of PLWHA (ZAPHA+)	/Mr. Khamis Mbarouk	falloba@yahoo.com
Uganda	Uganda AIDS Prevention and Care Organization	Kyamuwendo Elijah Amoti	uapco@hotmail.com
USA	Medecins Sans Frontieres International	Rachel Cohen	rachel.cohen@newyork.msf.org
USA	Africare	Julius E. Coles	africare@africare.org
USA	AIDS Action	Andres Ilves	network@aidsaction.org
USA	Family Health International	Marie Coughlan	mcoughlan@fhi.org
USA	International HIV/AIDS Alliance		fsamuels@aidsalliance.org
USA	Pact	Dr. Polly Mott	reachgrants@pacthq.org
USA	Partners in Health	D. Moses	dmoses@pih.org
USA	Salvation Army World Office	Claire Boswell	Claire_Boswell@usn.salvationarmy.org
USA	Salvation Army World Office	Brawell Bailey	Bram_Bailey@usn.salvationarmy.org
USA	Salvation Army World Office	Mathew Smith	Matthew_Smith@usn.salvationarmy.org
Zambia	Bwafwano Community Home-based Care Organization	Beatrice M. Chola	bwafwano@hotmail.com
Zambia	Children in Distress - Kitwe Project, Zambia (CINDI)		cindi@zamnet.zm
Zambia	Churches Medical Association of Zambia	Dr. Simon Mphuca	mphuca@zamnet.zm
Zambia	Family Health Trust	John Musanje Elizabeth N.	fht@zamnet.zm
Zambia	Family Health Trust (FHT)	Mataka	fht@zamnet.zm
Zambia	Homecare Services (HCS)	Amos Nota	amosnota@yahoo.com
Zambia	Hope for African Children Initiative	Ricardo Lupenga, Country Coordinator	haci@zamnet.zm
Zambia	In-Community Care for Orphans (I-CCO)	Rev. Alfred G. Nyirenda	orphans@coppernet.zm
Zambia	Kenneth Kaunda Children Africa Foundation	Robert A Penney	kkfound@penn.com
Zambia	National AIDS Council	Dr. Golden Bolla / Dr.R.M Musonda	bollagk@zamnet.zm
Zambia	Ndola Catholic Diocese		diondola@zamnet.zm
Zambia	Network of Zambian People Living with AIDS (NZP+)	Kunyima Lifumbela Banda Catherine Ndashe	napnzp@zamnet.zm
Zambia	OneWorld.Net	Phiri	catherine.phiri@oneworld.net
Zambia	Project Concern International	Karen Romano	kromano@projectconcern.org
Zambia	Southern African AIDS Trust (SAT)	Judy Chikore	chikore@satregional.org

Zambia	UNAIDS Country Coordinator	Catherine Cozi cc Mobolaji Olokodana	csozi@who.org.zm
Zambia	United Nations Volunteers (UNV) Support for PLWHA		stpla@zamnet.zm
Zambia	Zambia National AIDS Network (ZNAN)	Mr. Listard Banda Chela Augustine / Mr. Joseph Bilali	znan@zamnet.zm
Zambia	Zambia Network of People Living with HIV/AIDS (NZP+)	KaTele	napnat@sn.apc.org

ANNEX 5 INFORMATION/EDUCATIONAL RESOURCES

Guidelines	
UNAIDS	<p>UNAIDS Best Practice: Technical Update on Palliative Care http://www.unaids.org/en/in+focus/topic+areas/home+and+community-based+care.asp</p>
US Dept of Health and Human Services	<p>A Clinical Guide to Supportive and Palliative Care for HIV/AIDS This manual is organized to address the many aspects of palliative care that are key in caring for the person living with HIV and AIDS. http://www.hab.hrsa.gov/tools/palliative/chap1.html</p>
CHBC workshop in Myanmar	<p>The Facilitators Guide for CHBC Orientation Workshop The facilitators guide provides instructions and materials for organizing and conducting a CHBC orientation workshop as well as concrete guidance on the steps that need to be taken after the workshop. Target participants from the public health sector, community representatives, civil society and private sector. http://hivinsite.ucsf.edu/pdf/cr08-bm-02.pdf</p>
Save the Children Federation (Malawi)	<p>A Community Mobilization Handbook for HIV/AIDS Prevention, Care and Mitigation: Save the Children USA Malawi Experience The handbook describes how STEPS (scaling up through expanded partnerships) worked in Malawi, and is designed to help users learn from the experience, adapt the STEPS approach to their own setting, help local people mobilize sustainable community-owned responses to the AIDS epidemic http://www.savethechildren.org/health/hiv_aids/images/malawimanual4.pdf</p>
Kenya MOH	<p>National home-based care for people living with HIV/AIDS : National home-based care policy guidelines -- Republic of Kenya These policy guidelines are intended to ensure that CHBC is thoroughly integrated into existing health services. It defines CHBC and presents the rational and guiding principles, spells out the components that CHBC programs are expected to compromise and outlines the programmatic standards and the requirements for service delivery. The policy describes the players, activities, training, referral mechanisms and support services, resources and monitoring and evaluation. The roles and responsibilities of PLWHA, family, the community, and the government in CHBC system. Target audience: policy makers, health care professionals, community health committees, AIDS control committees at all levels, program planners, coordinators and evaluators. http://www.dec.org/pdf_docs/PNACR140.pdf</p>
United Nations	<p>Living Well With HIV/AIDS: A Manual on Nutritional Care and Support for People Living with HIV/AIDS This manual provides home care agents and local service providers with practical recommendations for a healthy and well balanced diet for people living with HIV/AIDS. It deals with common complications that people living with HIV/AIDS are experiencing at different stages of infection and helps provide local solutions that emphasize using local food resources and home-based care and support. http://www.fao.org/documents/show_cdr.asp?url_file=/DOCREP/005/Y4168E/Y4168E00.HTM</p>
Child Protection Society (Zimbabwe)	<p>How Can We Help? Approaches to Community-Based Care This manual targets groups and organizations seeking to facilitate community based orphan cared initiatives in line with Government orphan care policy. It clearly explains the rationale for the strong emphasis on communities and shows why institutional care is not a viable/desirable option. It provides a practical step-by-step guide for NGO's wishing to engage with communities and assist them in finding their own solutions to the orphan crisis. The last section of the book is a tool kit, which contains useful technical information which can be used for producing training programs, assessing resources and understanding the law as it pertains to orphans. The manual is not only relevant to Zimbabwe but could have wide application throughout the Southern African region. Its authors encourage its adaptation for used in other countries and in the regard, its tool kit could be expanded to include locally relevant information. http://www.womenchildrenhiv.org/pdf/p09-of/of-03-05.pdf</p>

FHI	<p>Monitoring & Evaluation of CHBC Programs</p> <p>This training resource is designed to build skills for conducting quality monitoring and evaluation (M&E) activities. The course is anchored by three core modules: Introduction to M&E; Collecting, Analyzing and Using Monitoring Data; and Developing an M&E</p> <p>http://www.fhi.org/NR/rdonlyres/ehz3d4ozmhbvbjqijpcehueub57rj222dojlm6nvyodu4ljdambpht2ipj5mxelce7w4ctj3eyyl5dc/Mod04.pdf</p>
FHI	<p>Standard Operating Procedures for ART</p> <p><i>Standard Operating Procedures for Antiretroviral Therapy</i> is a guide for clinicians delivering antiretroviral therapy (ART) services at health facilities in low-resource settings. The report includes protocols for providing ART to adults and adolescents, adherence counseling and post-exposure prophylaxis (PEP)</p> <p>http://www.fhi.org/en/HIVAIDS/pub/guide/sopart.htm</p>
Partners in Health	<p>The PIH Guide to the Community-Based Treatment of HIV in Resource-Poor Settings</p> <p>This is a guide intended to be used as a resource for physician and other health care professionals who provide care and treatment to patients with HIV who live in resource-poor settings. The guide is divided into four parts; Initiating a comprehensive HIV prevention care program, Treatment guidelines for the management of patients with HIV/AIDS, Monitoring and Evaluation, Challenges.</p> <p>http://www.pih.org/library/aids/PIH_HIV_Handbook_Bangkok_edition.pdf</p>
Stepping Stones	<p>Stepping Stones</p> <p>Stepping stones has been used by many organisations to address a wide range of issues. These are issues which are universal and found in any community anywhere. But the manual does not impose imaginary experiences on participants from elsewhere. Instead it encourages participants to think about their <i>own</i> lived experiences in relation to these issues. Therefore each Stepping Stones workshop is unique, depending on the specific lived experiences of the participants in that particular community. This enables participants to develop their <i>own</i> solutions which are specifically relevant to their <i>own</i> concerns, which belong then to them.</p> <p>http://www.steppingstonesfeedback.org/issues.htm</p>
World Bank / Unicef / UNAIDS	<p>Operational Guidelines For Supporting Early Child Development (ECD) in Multi-Sectoral HIV/AIDS Programs in Africa</p> <p>These guidelines (1)provide guidance to develop national ECD policies, programs, and interventions that address young children affected by HIV/AIDS; multi-sectoral ECD approaches; and ways to advocate, implement, monitor, and evaluate these efforts (2) Include suggestions for interventions to support young children affected by HIV/AIDS (3) Serve as a resource for other national HIV/AIDS programs directly or indirectly concerned with ECD</p>
UNAIDS	<p>Techniques and Practices for Local Responses to HIV/AIDS</p>
Policy Reports, Papers	
Pop Council	<p>The Involvement of People Living with HIV/AIDS in Community-based Prevention, Care and Support Programs in Developing Countries: A Multi-Country Diagnostic Study- 2003</p> <p>Case countries – Burkina Faso, Ecuador, India, Zambia. Findings</p> <p>There are many ways for PLWHA to take part in the activities of NGO’s and there are 4 types of involvement; access, inclusion, participation, greater involvement.</p> <p>Recommendations: 1)Promote positive and non discriminatory attitudes and policies toward PLWHA 2)Build capacity of PLWHA for involvement 3)Offer psychological support, including peer support to PLWHA 4)Provide material support to PLWHA with few resourced 5)Network with other orgs and services to foster PLWHA involvement 6)Forming and sustaining support groups</p> <p>http://www.dec.org/pdf_docs/PNACW036.pdf</p>
International Center For Research for Woman	<p>Expanding the Care Continuum For HIV/AIDS: Bringing Carers into Focus - 2004</p> <p>This review applies the “care economy” lens to two key sectors, health and social protection and finds that while important strides are being made, much more needs to be known and done. The analysis suggests that (1) the international “care agenda” needs to incorporate an understanding of the care economy into its frame works and strategies for action, with a particular focus on the caregiver, (2) national to better integrate their services with those efforts being made by other social development sectors to help households survive (3)</p>

	<p>specific public sector roles and responsibilities need to be defined by national governments so that the viability of their populace can be protected or, in some cases re-established, and to provided governance in helping to shape the private and NGO sector roles. In conclusion, care provides fundamental public goods and therefore needs appropriate remuneration and support. A strategy of simply downloading responsibility for care onto women, families and communities can not longer be a viable appropriate or sustainable response.</p> <p>http://www.popcouncil.org/pdfs/horizons/xpndngcrcentnm.pdf</p>
Academy for Educational Development	<p>Multisectoral Responses to HIV/AIDS: A Compendium of Promising Practices from Africa - 2003</p> <p>This document brings together the “promising” practices identified by the PVO community. It details the many ideas and experiences of different organizations in different countries which seem likely to combat HIV/AIDS successfully. The topic areas are (1)Agriculture/Food Security/Nutrition (2)Capacity/Human Resources Development (3)Care & Support (4)Children (5)Conflict & Humanitarian Relief (6) Democracy and Governance (7)Economic Development/Microfinance (8)Education</p> <p>http://sara.aed.org/publications/hiv_aids/aids_in_africa/Multisectoral_Responses-oct03.pdf</p>
International AIDS Alliance and Glaxo Welcome	<p>Care, Involvement and Action: Mobilizing and Supporting Community Responses to HIV/AIDS Care and Support in Developing Countries - 2000</p> <p>This report shares the highlights and lessons learned in linking prevention to care and enhancing the quality of community care an support. The recommendations are directed towards the donors and policy makers and the NGO support programs</p> <p>http://www.aidsmap.com/en/docs/pdf/CareReport.pdf</p>
WHO	<p>Community Home-Based Care in Resource-Limited Settings: A Framework for Action</p> <p>This document provides a systematic framework for establishing and maintaining community home-based care (CHBC) in resource-limited settings for PLWHA and those with other chronic or disabling conditions. This framework is to guide government, national and international donor agencies and community-based organizations (including nongovernmental organizations, faith-based organizations and community groups) in developing or expanding CHBC programs.</p> <p>http://www.who.int/hiv/pub/prev_care/isbn9241562137.pdf</p>
World Alive Ministries International	<p>Community Responses 1: Mobilizing Men as Home-Based Care Volunteers</p>
AIDS Action	<p>Supporting Community Carers</p> <p>This issue of <i>AIDS Action</i> looks at practical ways to strengthen care in the community. This includes providing practical training and appropriate information to carers appropriate resources such as home-based care kits and emotional and spiritual support. This issue also looks at ways to encourage volunteers and especially to increase the number of men involved as carers.</p> <p>http://www.aidsaction.info/aa/aa50.html</p>
AIDS Action	<p>Home Care</p> <p>This issue looks into what is comprehensive care, planning home-based care and medicines & supplies</p> <p>http://www.aidsaction.info/aa/aa28.html</p>
AIDS Action	<p>Training for Health Workers</p> <p>Increasing skills and confidence for health workers. Home care training guidelines. Includes a special insert on teaching and training techniques</p> <p>http://www.aidsaction.info/aa/aa19.html</p>
Education and Training	
The Centre for Development and Population Activities	<p>Home Care for People Living with HIV/AIDS: The Power of Our Community</p> <p>This training manual provides the necessary information as well as tapping into the strength of the community and empowering participants to action. This manual offers PLWHA, OVC’s, families and community members knowledge about healthy living with HIV, about care and support, and death and dying.</p> <p>http://www.cedpa.org/publications/homecare/homecare.pdf</p>
John Hopkins	<p>How to Mobilize Communities for Health and Social Change</p>

University	This "how to" website, offers general steps, tools and approaches that many effective community mobilization programs have found useful. http://www.hcpartnership.org/Publications/Field_Guides/Mobilize/htmlDocs/introduction.htm
Academy for Educational Development	A Review of the Literature and Recommendations for Nutritional Care & Support in Sub-Saharan Africa This paper reviews research that indicates that in the early period of HIV infection, weight gain and/or maintenance might be achieved, and it addresses the extent to which nutrition counseling and interventions can slow or reverse the process and consequences of weight loss and wasting in PLWHA. It presents examples of a number of nutrition support program. The paper provides evidence-based nutrition care and support recommendations for four categories of PLWHA in Africa: asymptomatic individuals; individuals who are experiencing weight loss; adults with AIDS; and children suffering from HIV AIDS. Guidelines for the development of programs to provide nutritional care and support for PLWHA in Africa are also provided. http://www.pronutrition.org/files/HIVandNutrition.pdf
FHI	HIV/AIDS Care and Treatment: A Clinical Course for People Caring for Persons Living with HIV/AIDS (Facilitators and Participants) The <i>HIV/AIDS Care and Treatment Facilitator's Guide</i> presents new knowledge and skills for delivering and organizing clinical care and treatment services for people living with HIV/AIDS The <i>HIV/AIDS Care and Treatment Participant Guide</i> presents new knowledge and skills for delivering and organizing clinical care and treatment services for people living with HIV/AIDS http://www.fhi.org/en/HIVAIDS/pub/index.htm
International HIV/AIDS Alliance	ARV Treatment Fact Sheets The Alliance is developing a set of fact sheets and participatory tools to support community engagement for antiretroviral (ARV) treatment. The aim is to provide NGO/CBO staff with tools and information to support PLHA and their communities on ARV treatment. They are based on experience in supporting treatment programs in several countries. http://www.aidsalliance.org/sw19588.asp
Program Management Materials	
Save the Children	Care for Children Infected and Those Affected by HIV/AIDS: A Handbook for Community Health Workers This operationalization of the information in this handbook is intended to contribute to the goal of mitigating the psychosocial impact of HIV/AIDS on children in Uganda. In addition to providing basic information on HIV/AIDS, this handbook is primarily designed to assist carers for children affected/infected by HIV/AIDS in providing CHBC and counseling. This handbook can also be used as a resource for community health workers and other carers within communities. It provides guidance on how to confidently provide care in a manner that will alleviate the physical and psychological pain inflicted by HIV on children affected by HIV/AIDS. It can also be used as a source of information for PLWHA. http://hivinsite.ucsf.edu/pdf/kbr-CCI1.pdf
UNAIDS	Handbook on Access to HIV/AIDS-Related Treatment: A Collection of Information, Tools and Resources for NGOs, CBOs and PLWHA Groups A handbook to encourage groups already involved in HIV/AIDS care to extend the services they provide, and that it will encourage other groups (perhaps doing some other HIV-related activity, such as prevention and support, or in other fields of health, such as family planning and reproductive health) to get involved http://www.unaids.org/NetTools/Misc/DocInfo.aspx?href=http%3A%2F%2Fgva%2Ddoc%2Dowl%2FWEBcontent%2FDocuments%2Fpub%2FPublications%2FIRC%2Dpub02%2FJC897%2DHandbookAccess%5Fen%26%2346%3Bpdf
International Federation of Red Cross	Community Home-Based Care for People Living with HIV/AIDS This document provides the framework for National Red Cross and Red Crescent Societies that are working on the front line in the fight against HIV/AIDS – helping communities and families to strengthen their traditional coping mechanisms and addressing the needs of

	<p>people living with HIV/AIDS. Two documents – Orphans and other children made vulnerable by HIV/AIDS: Principles and operational guidelines for programming and this framework – provide a structure for the response to challenges faced by our community home-based care volunteers.</p> <p>http://www.ifrc.org/cgi/pdf_pubs.pl?health/hivaids/hbc.pdf</p>
Family Health International	<p>Establishing Referral Networks for Comprehensive HIV/AIDS Care The report <i>Establishing Referral Networks for Comprehensive HIV Care in Low-Resource Settings</i> offers guidance to help organizations and communities in low-resource settings create effective referral networks to provide comprehensive prevention, care, treatment and support for persons living with HIV/AIDS and their families and caregivers. The report's companion document, <i>Tools for Establishing Referral Networks for Comprehensive HIV Care in Low-Resource Settings</i>, provides a collection of pre-made referral forms and registers to help maintain accuracy, efficiency and consistency. These sample tools can be adapted for different settings.</p> <p>http://www.fhi.org/en/HIVAIDS/pub/guide/refnet.htm</p>
Family Health International	<p>HIV/AIDS Prevention and Care in Resource-Constrained Settings The <i>HIV/AIDS Prevention and Care in Resource-Constrained Settings: A Handbook for the Design and Management of Programs</i> offers state of the art knowledge on designing and managing HIV/AIDS programs. The handbook is intended to be used by program managers, technical and programmatic field staff, the staffs of donor and international partner agencies, health care providers, and field researchers.</p> <p>http://www.fhi.org/en/HIVAIDS/pub/guide/HIVAIDSPreventionCare.htm</p>
Patient and Community Education	
World Relief Corporation	<p>Hope At Home: Caring for Family With AIDS (Part 1) Pamphlet on giving comfort, giving care and particular problems for some people with AIDS</p> <p>http://hivinsite.ucsf.edu/pdf/kbr-HBC1.pdf</p>
FHI	<p>Catholic AIDS Action Manuals Offer Counseling Guidance for Children and Others Affected by HIV/AIDS <i>Community-based Counseling for People Affected by HIV/AIDS</i> is a 154-page, text that provides clear, easy-to-understand guidance on counseling. Its 13 chapters cover counseling techniques, substance abuse, mental health, grief and myriad other related issues <i>Building Resilience in Children Affected by HIV/AIDS</i> is a 150-page guide to psychosocial support for children. Its eight chapters are designed to help parents, caregivers and teachers understand children who are caring for a sick parent or who have lost a parent. It provides practical advice on supporting children who have experienced loss, and suggests helpful discussions and games.</p> <p>http://www.fhi.org/en/HIVAIDS/pub/guide/caacounseling.htm</p>
FHI	<p>Healthy Living: A Counseling Guide on ART <i>Healthy Living: A Counseling Guide for Health Workers on Opportunistic Infections, Antiretroviral Therapy (ART), Management of ART Side Effects</i> is a new collection of low-literacy guides and brochures covering ART and opportunistic infections, with both English and Swahili versions. The collection includes flip charts, booklets and brochures to help healthcare workers educate patients by using simple expressions and pictures</p> <p>http://www.fhi.org/en/HIVAIDS/country/Kenya/res_healthy.htm</p>

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