COMMUNITY CAREGIVERS: THE BACKBONE FOR ACCESSIBLE CARE AND SUPPORT
COMMUNITY CAREGIVERS:
THE BACKBONE FOR ACCESSIBLE CARE AND SUPPORT
MULTI-COUNTRY RESEARCH: MALAWI REPORT

Malawi research team members:
Winford Masanjala, Researcher, Chancellor College, Zomba - University of Malawi; Murphy Kajumi – independent researcher

Malawi Research Advisory Board members:
Annie Banda, Coalition of Women Living with HIV and AIDS in Malawi; Felix Kamowa, Kagwa Parish; Daneck Kathumba, Lighthouse; Maureen Luba, National Association for People Living with HIV and AIDS in Malawi; Joyce Mlotha, National Association for People Living with HIV and AIDS in Malawi; Agness Mussa, Lighthouse; Roreen Mzembe, VSO Malawi; Masiye Nyang’wa, Lilongwe Catholic Health Commission

Research Coordinators:
Carolien Aantjes, ETC Crystal; Tim Quinlan, Athena Institute - VU University Amsterdam

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<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIDS</td>
<td>Acquired immunodeficiency syndrome</td>
</tr>
<tr>
<td>ART</td>
<td>Antiretroviral therapy</td>
</tr>
<tr>
<td>CAN</td>
<td>Caregivers Action Network</td>
</tr>
<tr>
<td>CBO</td>
<td>Community-based organisation</td>
</tr>
<tr>
<td>CHBC</td>
<td>Community and home-based care</td>
</tr>
<tr>
<td>DHO</td>
<td>District health office</td>
</tr>
<tr>
<td>FBO</td>
<td>Faith-based organisation</td>
</tr>
<tr>
<td>HSA</td>
<td>Health surveillance assistant</td>
</tr>
<tr>
<td>HIV</td>
<td>Human immunodeficiency virus</td>
</tr>
<tr>
<td>HTC</td>
<td>HIV testing and counselling</td>
</tr>
<tr>
<td>LISAP</td>
<td>Livingstonia Synod AIDS Programme</td>
</tr>
<tr>
<td>NAC</td>
<td>National AIDS Commission</td>
</tr>
<tr>
<td>NASO</td>
<td>Nkhotakota AIDS Support Organisation</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-governmental organisation</td>
</tr>
<tr>
<td>OVC</td>
<td>Orphans and vulnerable children</td>
</tr>
<tr>
<td>PHC</td>
<td>Primary health care</td>
</tr>
<tr>
<td>UNAIDS</td>
<td>Joint United Nations Programme on HIV/AIDS</td>
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<td>WHO</td>
<td>World Health Organization</td>
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FOREWORD

This report is the result of research undertaken in Malawi as part of a broader multi-country research project commissioned by the Caregivers Action Network (CAN) to review community and home-based care (CHBC), especially in regards to HIV prevention, treatment, care and support.

CAN wishes to acknowledge the invaluable support provided by many actors involved in this multi-country research (Ethiopia, Malawi, South Africa and Zambia) both nationally and internationally.

This research would not have been possible without the information and insight provided by informants at the community and national level: the clients and their caregivers as well as key resource persons and representatives from the government and non-governmental organisations, including those implementing CHBC programmes. CAN is grateful for these contributions.

CAN also thanks the research coordinators from ETC Crystal and Athena Institute - VU University Amsterdam as well as the country-based researchers and members of research advisory boards in each country. The information collected has provided greater insight into the significant roles and responsibilities of community caregivers in the four case study countries with regard to the provision of accessible care and support and the need to continue investing in community care and support programmes.

In addition, CAN thanks the IAC Research Group members who started the dialogue around care and support research priorities and provided critical input and feedback in relation to the set-up of the research, its implementation and the preliminary findings of the research.

Gratitude is also due to the CAN co-facilitators (Cordaid, HelpAge International, Hope Development Initiative, the International HIV/AIDS Alliance and VSO International) as well as the Joint United Nations Programme on HIV/AIDS (UNAIDS) for providing guidance and input at all stages of the project process.

Finally, CAN thanks Cordaid and UNAIDS for funding this important research.
EXECUTIVE SUMMARY

This report is the result of research undertaken in Malawi as part of a broader multi-country research project commissioned by the Caregivers Action Network (CAN) to review community and home-based care (CHBC), especially in regards to HIV prevention, treatment, care and support. The other countries involved in the overall project were Ethiopia, South Africa and Zambia.

The research objectives were to:

- explore the adaptations and changes in caregiving at the community level since the rapid scale-up of antiretroviral therapy (ART), with a particular focus on the tasks of caregivers and the needs of their clients;
- assess how and to what extent caregiving by informal caregivers at community level has been integrated in the health system and is being recognized as part of primary health care (PHC) structures and policies;
- investigate the contributions of, potential role of and benefits for caregivers in the expansion of HIV prevention and treatment and PHC programmes; and
- assess the potential means for formal and informal community caregiver programmes to complement each other in the context of decentralisation of HIV treatment programmes, taking into account current initiatives and arrangements.

Interviews were conducted with key stakeholders active at the national and district level in CHBC service provision as well as with clients and caregivers. Moreover, three organisations implementing CHBC programmes were selected for in-depth review: the Mangochi Catholic Health Commission, the Nkhotakota AIDS Support Organisation (NASO) and the Livingstonia Synod AIDS Programme (LISAP), which is operated by the Church of Central African Presbytery (CCAP)-Livingstonia Synod.

Some of the key findings and observations from the research are summarized below.

Needs of people living with HIV

The needs of people living with HIV have changed with the advent of ART, evolving away from a primary focus on basic nursing care and treatment to psychosocial support, livelihood support and nutritional support. A range of socioeconomic and material needs (money, clothes, food supplies, blankets) currently form the core of client needs, in part due to the pervasive poverty conditions in the country and the increased vulnerabilities people face as a result of their HIV status. The research also found that although some needs were being addressed, at least to some extent—such as physical care (from caregivers), psychosocial support, basic nursing and clinical care, and pre- and post-ART counselling—the sheer magnitude of the challenges people face means that many persist. The research therefore found that the efforts by CBHC programmes to date have been commendable, but the comprehensive needs of clients are still not met. Increased support is needed if gaps in service provision are to be overcome.

Caregivers’ roles

Community caregivers are an essential resource in the delivery of PHC services. According to the government’s CHBC policy, the roles played by community caregivers include an extensive and wide-ranging array of activities and services, from identifying and recruiting clients requiring CHBC to providing basic nursing care and HIV treatment support and adherence monitoring. Caregivers also assist in seeking to reduce the stigmatisation and discrimination of people living with HIV and mobilising people for HIV testing and ART. Evidence from the research suggests these expectations are met to some extent. Community caregivers are engaged in home-based care activities such as basic nursing care as well as the wider range of treatment-related services such as monitoring medication adherence. ‘Health surveillance assistants’ (HSAs), who are trained and coordinated by the Ministry of Health, are responsible for supervising community caregivers on client care.
The major evolution in the role of caregivers has been two-fold: from basic nursing care to i) broader livelihood, nutritional and psychosocial support; and ii) toward key treatment-related support, including ensuring adherence to ART and monitoring.

**Service provision**

Community care and support is provided by several government departments, non-governmental organisations (NGOs) and communities themselves. The Ministry of Health sets out and regulates the framework for NGO service provision in line with the CHBC policy.

The Ministry of Health remains the largest single health service provider and is the main point of contact for treatment services. Faith-based organisations (FBOs) and other NGOs wishing to provide care and support services may do so provided they have trained health staff and work through and with community structures such as village health committees and support groups. This requirement was reflected in the range of services the three case study programmes offered at the establishment and programme level, as found during research for this report. The broad categories of services were treatment, prevention, capacity-building and support services. Services provided under treatment included provision of medication when clients visit mission hospitals and during home visits, procurement and distribution of drugs to community-based organisations (CBOs), and provision and restocking of CHBC kits. The programmes also provided services such as material support provision (clothes, blankets, nutritional support) and livelihood support (e.g., farm inputs such as seeds). Prevention services provided by the three programmes included HIV sensitization campaigns (including those focused on youth) and HIV testing and counselling (HTC) services through both static sites and via outreach. Capacity-building services under the programmes included training CBOs, provision of funding to support CHBC activities, technical assistance to CBOs in managing CHBC programmes activities, and nutritional education for secondary and primary caregivers.

**Health system integration**

Research indicates that CHBC is integrated into the PHC system conceptually and operationally. Both the CHBC policy and palliative care policies show that the roles of caregivers and other health workers include management of common ailments that are part of the government's Essential Health Package. With CHBC itself recognised as part of the Essential Health Package, it is clear that CHBC is firmly integrated in PHC. The degree and success of integration vary among districts due to differing capacities of stakeholders involved. Shortages of trained staff and inadequate resources for transportation were cited as the main challenges hampering effective integration.

**Decentralisation of HIV treatment**

The government of Malawi considers decentralisation of ART to be a priority. With regard to technical issues of treatment decentralisation and the role of CHBC and caregivers in this process, district health offices (DHOs) are critical because they implement CHBC policy, coordinate CHBC activities, mobilise resources and monitor the performance of CBOs in communities. Research findings indicate high levels of coordination between CHBC programmes and government extension workers, including HSAs, with regard to treatment at the community level.

**Caregivers’ potential**

Caregivers already have a role in encouraging testing, pre- and post-ART counselling and early initiation on ART, but there is significant scope for expansion. With the reduction in the number of bedridden clients and the shift in emphasis from basic nursing care and end-of-life care to more holistic, comprehensive care and support, caregivers are able to give an increasing focus to supporting clients in leading healthier and safer lives. They also could have expanded roles in providing information and education on HIV prevention and behaviour change, promoting HTC and distributing condoms.

With regard to ART, it seems clear that the role of caregivers in treatment is in a period of transition. Most providers of CHBC already offer some important services associated with treatment, including monitoring adherence to ART regimens, helping clients recognize and respond to side effects, and encouraging clients in the community and to get tested for HIV (which leads to increased initiation on
ART). Representatives from some, though not all, of the 11 organisations surveyed during the validation phase indicated that community caregivers associated with their organisations could conceivably be involved in a greater range of such services in the future if given the opportunity. However, research detected a general reluctance by health professionals to decentralise ART beyond health units to community-level structures such as CBOs, largely because of concerns with drug regulation difficulties and drug storage issues as well as worries about proliferation and illicit use.

**Complementarity between formal and informal community caregivers**

The CHBC and palliative care policies and guidelines of 2011 in principle recognise the role, contribution and complementarity between ‘formal’ (trained) community health workers and ‘informal’ community caregivers. In general, the findings of the research show that there has been acceptance and recognition of community caregivers as important partners in the delivery of PHC services, and especially CHBC services. Even trained health care workers at government district hospitals conceded that it would be near impossible to implement the CHBC services without community caregivers. This was because all home visits were planned within the context of CBOs and support groups under them. In addition, community caregivers are integrated in the formal case referral system of clients (to and from government health units).

**Challenges in CHBC service provision**

A number of important issues need to be considered if CHBC service provision is to help adequately cover the growing and changing demands of both clients and the government as well as address challenges that come with an expanded ART programme. One overall priority seems to be the need to redefine the roles and responsibilities of CHBC services from a predominantly health focus to also include essential non-health issues such as psychosocial and socioeconomic support. In an environment in which ART is only provided at health facilities and there are fewer bedridden clients, defining CHBC as a health intervention seems somewhat misplaced when the bulk of CHBC activities focus largely or exclusively on livelihood support, mitigation of the negative social impact of HIV, and supporting clients to live healthier lives in general.

Other challenges highlighted relate to coordination weaknesses; community participation in and nature of volunteer and unpaid work; drug stock-outs; the duplication of programmes and activities implemented by organisations; competition between organisations for the participation of community caregivers; and funding cuts faced by CHBC service providers, which has forced many to scale down their activities. Also of note are persistent human capacity constraints, which greatly limit the number of health care workers at health facilities and are responsible for a lack of adequate transportation to undertake home visits.
1 INTRODUCTION

This report is the result of research undertaken in Malawi as part of a broader multi-country research project commissioned by the Caregivers Action Network (CAN) to review community and home-based care (CHBC), especially in regards to HIV prevention, treatment, care and support. The other countries involved in the overall project were Ethiopia, South Africa and Zambia.¹

The research objectives were to:

- explore the adaptations and changes in caregiving at the community level since the rapid scale-up of antiretroviral therapy (ART), with a particular focus on the tasks of caregivers and the needs of their clients;
- assess how and to what extent caregiving by informal caregivers at community level has been integrated in the health system and is being recognized as part of primary health care (PHC) structures and policies;
- investigate the contributions of, potential role of and benefits for caregivers in the expansion of HIV prevention and treatment and PHC programmes; and
- assess the potential means for formal and informal community caregiver programmes² to complement each other in the context of decentralisation of HIV treatment programmes, taking into account current initiatives and arrangements.

This CAN report is based on research conducted between October 2011 and April 2012 by a Malawi-based research team and Research Advisory Board (see Annex 1) with support of ETC Crystal and Athena Institute - VU University Amsterdam.

The first section of this report presents the background to the Malawi country research and includes the findings of the desk review as well as a description of the research process. The bulk of the report, Section 2, presents the findings and analysis of the research. Section 3 contains a conclusion and lists some key challenges regarding CHBC service provision, based on the research findings.

Note on terminology used

The preferred term used in this report for men and women who provide CHBC services is ‘community caregiver’ (also referred to in this document as ‘caregivers’) for two reasons. First, this term includes both of the two main categories of individuals involved in caregiving at the community level: primary and secondary caregivers. ‘Primary caregivers’ can be defined as family and friends who provide immediate care to family members and/or loved ones. ‘Secondary caregivers’ are caregivers who work on an individual basis or as staff on a paid/ unpaid/ voluntary basis at clinics, for non-governmental organisations (NGOs) or for the government. As such, the term ‘secondary caregivers’ refers to both employees of health ministries and of NGOs, including faith-based organisations (FBOs), while ‘community caregivers’ refers to primary and secondary caregivers together. Secondly, the term ‘community caregiver’ is commonly used in the other countries included in this multi-country research. Using the same terminology makes it easier to make comparisons among the research countries. However, country-specific terms used for community caregivers are maintained in this report when direct reference is made to departments and agencies, policies and policy statements as well as information obtained from official documents. These country-specific terms are placed within single quotation marks. For example, when referring to paid government-employed community caregivers in this Malawi report, reference is made to ‘health surveillance assistants’ (HSAs).

While the term community caregiver refers to both primary and secondary caregivers, it is important to note that it has not been possible to adequately address primary caregivers’ role in this research.

¹. All CAN documents relating to the overall multi-country research, ‘Community caregivers: the backbone for accessible care and support’ can be downloaded from the CAN website at www.caregiversactionnetwork.org.
². As indicated in the note on terminology used, CAN gives preference to the use of the term ‘community caregiver’ rather than ‘community health worker’. Therefore the term ‘community health worker programmes’ as specified in the original research objectives has been replaced by ‘community caregiver programmes’.
Therefore, in this report, the community caregivers discussed do not include primary caregivers unless explicitly stated. CAN recognises that primary caregivers are a critical part of the delivery of care and support, and that there is a need for additional research focusing on their contribution to the HIV response.

1.1 RESEARCH PROCESS AND LIMITATIONS

Methodology

This report is based on findings from a number of approaches that were used in four phases of research. Phase 1 included a literature review, focus group discussions and interviews with policy makers. Phase 2 built on findings from Phase 1 and concentrated on consultations and qualitative interviews with key informants from community-based organisations (CBOs) that provide CHBC services as well as people living with HIV, caregivers, programme managers and district-level government officials. Phase 3 centred on analysis and synthesis of results from the first two phases and Phase 4 focused on validation of findings from the first two phases with policy makers and service providers, including other CHBC providers that were not part of the initial consultations.

An initial survey of the available literature was conducted concurrently with key informant interviews and focus group discussions. Prior to field work, three focus group meetings were held: the first with members of the National Community Home Based Care Alliance (NCHBCA), the second with members of the Research Advisory Board and the third with staff at Plan International-Malawi. While the focus group discussions in general sought to elicit views and further clarify issues and working relationships among CHBC stakeholders, the focus group discussion with the Research Advisory Board also sought to identify programmes that would meet eligibility criteria for inclusion in the in-depth study.

Semi-structured interviews, using interview guides, were held with a number of stakeholders—initially with policy makers at national level—to shed light on the evolution of CHBC in Malawi and paint a national picture of the evolution of the legal, policy and administrative frameworks related to CHBC (see Annex 2). Policy makers interviewed included those from the Ministry of Health, National AIDS Commission (NAC), National Association of People Living with HIV and AIDS in Malawi, and the Palliative Care Association of Malawi. Policy makers from the Department of Nutrition, HIV and AIDS within the Office of President and Cabinet (OPC) and the Ministry of Gender, Children and Social Welfare were consulted to validate the research findings. Interviews were also held with representatives of a number of NGOs, including ActionAid and Plan International-Malawi. Key informant interviews were conducted with district stakeholders linked to CHBC, including support groups comprising clients and primary caregivers, and subsequently a feedback session was held with the Research Advisory Board.3 The members of the board and their affiliations are listed in Annex 1.

From these interviews, three organisations implementing CHBC programmes were selected for in-depth review in the three districts of Mangochi, Nkhotakota and Mzimba: the Mangochi Catholic Health Commission, the Nkhotakota AIDS Support Organisation (NASO) and the Livingstonia Synod AIDS Programme (LISAP), which is operated by the Church of Central African Presbytery (CCAP)-Livingstone Synod. Selection of the case study programmes was based both on ensuring geographic variety and agreed criteria including having over 10 years of experience in CHBC. In addition, it was felt that the research could benefit from sociocultural differences that might affect evolution of CHBC in the communities. The Mangochi Catholic Health Commission operates a faith-based programme in an area predominantly inhabited by the Yao tribe, the majority of whom are Muslim and live in matriarchal societies in which fishing is the main occupation. NASO operates in an area of tribes of predominantly Muslim Nyanja people and Christian Tonga people. The lakeside people from both tribes are fishermen, although the Tonga area is also home to sugarcane farms and sugar mills. The Nyanja are matrilineal while the Tonga are patrilineal. LISAP was selected for this research as the programme operates in the northern region, in the upland district of Mzimba where the Presbyterian Church ministers to predominantly Tumbuka-speaking people of the Ngoni and Tumbuka tribes. Both tribes are both patrilineal and patrilocal.

3 This board was established with the purpose of monitoring the country research and providing input to the discussion on country findings.
Limitations
A major limitation of the research was the late commencement of field research due to a delay in getting ethical approval from the government’s Institutional Review Board. The initial application for approval was made on 12 September 2011 and, after addressing the board’s concerns, a resubmission was made on 9 February 2012. Approval was eventually granted on 28 February. In addition, actual field consultations were affected by state funeral activities following the death of the country’s president in early April 2012. Both constraints had the effect of significantly reducing the time available to complete the research, and thereby curtailed opportunities to back-check findings and conclusions with some of the respondents as originally planned.

This report provides an overview of the main outcomes of the research based on separate interim reports, which presented the findings from research Phases 1 and 2, as well as the outcomes of the validation phase.

1.2 DESK REVIEW
This sub-section provides a brief overview of the history of CHBC in Malawi as well as background information on the HIV epidemic and access to ART.

History of CHBC in Malawi
Although CHBC has long been practiced in Malawi, there is a lack of published studies on it. Exceptions are Zachariah et al. (2007) and doctoral dissertations by Munthali (2008) and Pindani (2008). Although these publications did not directly consider the dimensions of caregiving that this research focuses on, some findings were useful. In a study that compared the health outcomes of two groups of clients on ART—one on ART with CHBC support and a control group on ART without CHBC support—Zachariah et al. (2007) found that CHBC was associated with better outcomes. The findings indicated that over the period studied, 96 percent of clients who belonged to CHBC support groups had remained on ART and were alive. The comparable figure for those who had no links to CHBC programmes was far lower, 76 percent. The authors also found that death rates were lower among those receiving CHBC (3.5 percent) than for those in the control group (15.5 percent) and that ART adherence rates were higher among clients in the former group. Evaluations also seem to suggest that caregivers working in CHBC programmes have been effective in reaching clients with services ranging from physical and psychosocial care and support, information to raise awareness of HIV, promotion of HIV testing and counselling (HTC) services, and support for orphans and vulnerable children (OVC) (Phiri, 2010; CHC-Mangochi Diocese, 2011).

Munthali (2008) examined complementarity between formal national HIV responses and community-based arrangements and its impact on transaction costs of delivering CHBC and support to clients living with HIV. He found existence of conflict between the predominantly standardized and more rigid formal management techniques adopted by key stakeholders and institutions in the national response and the informal cultural techniques familiar to rural communities. He also found a lack of support and incentives in the CHBC structures as a key factor hindering CHBC capacities for providing sustainable service delivery.

Pindani (2008) examined the general feelings of people living with HIV towards life and their attitudes towards CHBC. Her research found that the majority of the people living with HIV expressed feelings of anxiety, worry and fear of death. They also complained about the burden of opportunistic infections and almost half of them carried a sense of guilt for burdening their families and complained of stigma and discrimination. A minority group of participants expressed less stress about their current situation and were more optimistic about the future. An interesting finding was that while most people living with HIV identified relatives as their primary care providers, they also cited them as a major source of HIV-related stigma.

Current status of the HIV epidemic
Malawi has a generalized HIV epidemic. The primary modes of HIV transmission are through heterosexual sex and mother-to-child transmission. After 1985 when the first case of AIDS was diagnosed, HIV prevalence increased significantly among persons aged 15-49; it rose to a peak of 16.4 percent in 1999 among persons aged 15-49, after which it started declining (Government of Malawi, 2012). According to the most recent estimates from the Joint United Nations Programme on HIV/AIDS (UNAIDS), as of 2011 Malawi was home to an estimated 910,000 people living with HIV. That corresponded to adult HIV prevalence of about 10 percent (UNAIDS, 2012).
Scale-up of ART

National policy documents and other literature including NAC programme-related reports illustrate how the scale-up of ART in Malawi since 2004 has necessitated changes in the policy landscape and led to the emergence of a more integrated policy framework for addressing HIV and emerging sub-sectoral issues (Government of Malawi, 2011). The Palliative Care Policy and Guidelines (released in 2005) and revised National CHBC Policy and Guidelines (2011) both acknowledge the continuing importance of CHBC. They also note the need for changes in CHBC and an increase in its provision due to an increased demand for community-based pre-ART services, an increase in the number of people enrolling in the ART programme, and the expanding range of eligibility criteria for CHBC. This has important implications for CHBC as both guidelines explicitly recognize the decisive role that CHBC plays in anchoring the ART programme.

When Malawi first developed its plans for scaling up ART, it proposed a programme that would cover 300,000 people in need of such treatment. However, that proposal was turned down by donors based on the assumption that Malawi’s health system did not have the capacity to administer such an ambitious programme. Instead, donors only provided resources for Malawi to begin gradually to cover 25,000 individuals. Yet since 2004, Malawi has quickly increased ART enrolment. The programme is generally regarded a success given Malawi’s health system and manpower capacity constraints. Table 1 and Figure 1 present trends in enrolment for ART in Malawi since 2003.

Table 1. ART coverage and enrolment figures for Malawi, 2003–2011

<table>
<thead>
<tr>
<th>Year</th>
<th>Total number on ART</th>
<th>Total number eligible for ART*</th>
<th>Total ART coverage**</th>
</tr>
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<tbody>
<tr>
<td>2003</td>
<td>3,100</td>
<td>205,295</td>
<td>2%</td>
</tr>
<tr>
<td>2004</td>
<td>13,183</td>
<td>216,531</td>
<td>6%</td>
</tr>
<tr>
<td>2005</td>
<td>29,087</td>
<td>226,512</td>
<td>13%</td>
</tr>
<tr>
<td>2006</td>
<td>59,980</td>
<td>235,715</td>
<td>25%</td>
</tr>
<tr>
<td>2007</td>
<td>100,649</td>
<td>258,829</td>
<td>39%</td>
</tr>
<tr>
<td>2008</td>
<td>147,497</td>
<td>273,499</td>
<td>54%</td>
</tr>
<tr>
<td>2009</td>
<td>198,846</td>
<td>420,895</td>
<td>47%</td>
</tr>
<tr>
<td>2010</td>
<td>250,987</td>
<td>461,158</td>
<td>54%</td>
</tr>
<tr>
<td>2011</td>
<td>322,209</td>
<td>478,904</td>
<td>67%</td>
</tr>
</tbody>
</table>

* Data relating to the total number eligible for ART prior to 2009 were based on eligibility criteria for a CD4 count of less than 200. Meanwhile, the data presented from 2009 onwards were based on eligibility criteria for a CD4 count of less than 350, as recommended by WHO in its most recent ART guidelines.

** The percentages refer to the share of all eligible for ART who were receiving it.

Source: WHO/UNAIDS 2011 estimates

Figure 1. ART uptake for eligible Malawians, 2003–2011*

* The percentages refer to the share of all eligible for ART who were receiving it.

Source: WHO/UNAIDS 2011 estimates
The decline in ART coverage between 2008 and 2009, as shown in both Table 1 and Figure 1, stemmed not from a reversal in ART scale-up but instead from a major revision in eligibility criteria. As noted in the Table 1 explanatory text, the data used prior to 2009 were based on eligibility criteria for a CD4 count of less than 200 while the data presented from 2009 onwards were based on eligibility criteria for a CD4 count of less than 350, as recommended by World Health Organization (WHO) in its most recent ART guidelines. The new criteria are based on growing evidence indicating that starting ART earlier in the course of HIV infection greatly reduces morbidity and mortality among people living with HIV and tuberculosis (a common co-infection among HIV-positive people, especially in sub-Saharan Africa) and reduces HIV and TB (tuberculosis) transmission. Malawi’s Ministry of Health officially adopted the new WHO-recommended guidelines in 2011, which means that all HIV-positive people with CD4 counts lower than 350 are now encouraged to begin ART. Among the consequences of the change is greater emphasis on community caregivers’ motivating people within their communities to go for HIV testing so that they know their status and are able to seek timely treatment if needed. Far too many Malawians are still accessing HIV testing and ART at a very late stage in the progression of their illness (usually due to the high level of stigmatisation).

The scale-up of ART has been unequally distributed. In particular, people living in some areas find it difficult to access ART services due to long distances from facilities where antiretroviral drugs are provided. This is exacerbated by transportation problems that constrain the ability of district health offices (DHOs) to reach people close to where they are.
2 RESEARCH FINDINGS

This section presents the findings of the research and associated analysis and is structured along the four research objectives. The complexity of the caregiver context means that some similar information and observations may be presented in multiple sub-sections.

2.1 HISTORY AND EVOLUTION OF COMMUNITY CARE AND SUPPORT

This sub-section explores the findings with particular reference to the adaptations and changes in caregiving that have occurred at the community level. Emphasis has been placed on changes with regard to the needs of people living with HIV, the roles of caregivers, service provision and the policy environment.

2.1.1 The needs of people living with HIV

Before ART first started in Malawi, the referral process was from the hospital and health facility to communities. Priority was placed on end-of-life care and ensuring dignified death with basic nursing care being provided by caregivers. People living with HIV needed services that included controlling pain from chronic illnesses and the management of opportunistic infections.

Based on consultations at the district and community levels, the research found that clients’ needs have evolved with the advent of ART. In general, needs of people living with HIV include not only end-of-life care but also clinical care, psychosocial support, livelihood support and nutritional support. The particularity of clients’ needs depends on whether they are on ART, how they are responding to treatment, and whether they are bedridden.

People living with HIV who are bedridden continue to require basic nursing care, periodic review by trained health staff to assess their condition and advice on how to maintain a measure of care that lessens pain and discomfort. A regular need related to clinical care is wound dressing and medicines, especially analgesics for people suffering from conditions that involve constant pain and drugs to treat opportunistic infections. Clients with conditions that limit their movement often need caregivers to assist them with turning in bed, bathing as well as other sanitary requirements.

A range of socioeconomic and material needs related to care and support were also highlighted. In rural Malawi, where poverty is fairly pervasive, these basic livelihood needs include money, food supplies, blankets and clothing. These needs arose for one or both of the following factors: i) clients were unable to provide for themselves due to illness and lack of savings or any reserves, and ii) their caregivers were equally materially or physically challenged due to old age or other reasons. These findings underscore the fact that lack of money and other resources is a major underlying concern. Clients and caregivers are often unable to meet livelihood challenges, to send children to school, and to buy basic necessities for themselves and family members. Although some of these needs are met via government-managed cash transfer programmes, such transfers do not cover everyone. In addition to the clients-centric need for socioeconomic assistance are needs for the care and support of OVC, who although not clients themselves are a constituency that both CBOs and support groups look after. The breadth of clients and vulnerable household needs are captured in the following statements from a primary caregiver:

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4 The definition used in Malawi for palliative care in official government reports corresponds with the ‘older’ general WHO definition of palliative care: “Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” CAN, however, recognises the fact that following the introduction of ART, the definition of ‘palliative care’ has gradually broadened, particularly in resource-poor settings, to reflect the expansion of the range of clients’ needs and the interventions delivered within comprehensive care and support services. The broader definition promoted by the Worldwide Palliative Care Alliance states that palliative care should not be seen only as end-of-life care. For the purposes of distinction between the older and newer definition the report will refer to ‘end-of-life care’ when the older definition of palliative care is used unless direct reference is made to the national palliative care policy.
There are a lot of needs … but the main one is the lack of basic necessities and the fact that I am old. My son should have been looking after me but now he is helpless. Food is never enough, even for myself as I can only produce so much. Most of the time the food stocks only last until October each year. When it finishes, we eat boiled leaves (from beans or pumpkins), but this is food that the patient does not like. Due to lack of money, clothes and beddings are also a problem. In addition, there are no care kits such as gloves and soap, and sometimes the patient is bathed without soap.

—Eighty-year-old primary caregiver, Mangochi District

Client interviews suggest some needs are more likely to be met than others. Physical care, spiritual encouragement, basic nursing and clinical care and ART counselling are often being provided by caregivers. Far less commonly available, according to clients, is material support—including for basic livelihood, housing for orphans, and overcoming food insecurity (i.e., lack of consistent access to sufficient food and nutrition).

According to Ministry of Health officials, ART access will remain a challenge for those who qualify—especially now that HIV treatment guidelines have been revised to make far more people eligible for ART (i.e., for all HIV-positive people with CD4 counts of 350 or below). This change has increased the total number of eligible clients in Malawi, thereby placing greater demand on the time and capacity of CHBC providers to meet the overall needs. Those initiated on treatment also need education in terms of how to deal with side effects as well as the full range of other support services all people living with HIV often require.

Caregivers themselves, the majority of whom are female, some living with HIV, have important needs that directly influence client needs. Across all three programmes that were the subject of the research, it was reported that because a number of primary caregivers were older and less capable of fending for themselves, there was little scope for their engagement in any productive activity and thus financial support was needed. Social cash transfers were provided largely via the government’s Social Welfare Department across the three case study districts. However, NGOs such as Plan International-Malawi also supported primary caregivers from vulnerable households with livelihood support.

2.1.2 Caregivers’ roles

In principle, Malawi’s CHBC policy has defined the role of caregivers in relation to CHBC service delivery around the ‘five “r”s’: readiness, retention, responsibility, referral and reporting (Government of Malawi, 2011). The policy’s guiding principles recognise that for caregivers to provide the requisite basic care and support to clients, caregivers need appropriate technical, supervisory and psychosocial support to prevent burn out and stress.

The structures and groups involved in provision of care and support are reflected in the government’s policy, which recognises the existence of three categories of CHBC providers:

- At the formal level: **trained health personnel in the clinics or extension workers**
- At the community level:
  - **primary caregivers**, who are almost always relatives who are not remunerated, and
  - **secondary caregivers**, who are involved in CHBC programmes yet who are not directly employed by the government. Secondary caregivers who are not remunerated for their work are generally referred to as ‘volunteers’

As the third category indicates, CHBC programmes also organise caregivers who primarily play a support role for Ministry of Health professionals based at health facilities and the ‘health surveillance assistants’ (HSAs) who are their agents in the communities.

According to the government’s CHBC policy, the roles played by community caregivers include the following: identifying and recruiting clients requiring CHBC as per prescribed criteria; providing basic nursing care; managing simple ailments such as cough, fever, diarrhoea and other common problems; providing psychosocial support and nutritional counselling to clients; referring clients to health and other support services; keeping clients’ records on care given and providing monthly reports to immediate supervisors; monitoring side effects and adherence/compliance for clients on ART and TB treatment; conducting follow-up visits for clients to reduce loss to follow up and retain clients in care; coaching and
mentoring family members of clients on the CHBC programme; educating clients and family members on prevention of HIV, TB and malaria as well as the importance of HIV testing; monitoring clients’ response to treatment and community-based care and support; and facilitating mobilisation of community transport for referral of clients from community to health facilities.

Some of these expectations are broadly met. According to research findings, primary caregivers bathed, fed and ensured that their clients took their medications. They supported clients who could not move on their own for sanitary issues and in moving to and from their beds (including helping them turn over). They also reported providing counselling to other relatives and taking clients to hospitals when they were very ill.

The roles of secondary caregivers include supporting primary caregivers with household chores that need to be done in addition to offering counselling, psychosocial support and referrals. Moreover, these caregivers offer adherence support and follow up those lost to care. Evidence from the research suggests that secondary caregivers bear a significant share of the burden alongside primary caregivers in terms of providing care and support to clients. Both categories of caregivers also play an important role in addressing HIV-related stigma and discrimination, which is a major problem that people living with HIV face regularly. They also motivate community members to go for HIV testing, even though there may be no signs of illness.

That effort is considered crucial in the drive to encourage more people to know their HIV status so they can seek (timely) treatment if they test positive. The link between the primary and secondary caregivers is captured by the following sentiment:

Apart from the material support that helps us meet some of the needs, the volunteers provide moral support to both the patient and ourselves who assist the patient. They also supply us with medicine when the patient is feeling pain (e.g., panadol) and we do not have it ourselves.

—Primary caregiver, Mangochi District

The Malawi research shows that the major evolution in the role of HIV caregivers has been two-fold: from basic nursing care to i) broader livelihood, nutritional and psychosocial support; and ii) toward key treatment-related support, including ensuring adherence to ART and monitoring. In many cases community groups have gone even further. For example, support groups formed under CBOs often help to encourage people living with HIV on ART to take their medication consistently and regularly. An interesting innovation in this area was seen in Nkhotakota, where caregivers associated with NASO are involved in the formation of post-test groups that seek to assist those who have undergone HTC—both those who have tested positive and not—to take measures to improve their own health and the health of others in their lives.

However, despite the diversification of client needs and caregiver roles, it is somewhat surprising that the government still officially considers CHBC in Malawi to be primarily a clinical, health intervention. That perception remains, as can be seen in text from the 2011 guidelines cited below, even though clear evidence exists that caregivers have long been involved in activities that are not directly related to direct health provision:

In Malawi care of chronically ill patients is a biomedical intervention. Mitigating the impact of disease at household level through non-biomedical interventions targeted at socioeconomic needs, food security and care of orphans and vulnerable children are addenda activities [that] are implemented by other sectors under the impact mitigation framework

—Government of Malawi (2011), National CHBC Policy and Guidelines

### 2.1.3 Service provision

The CHBC policy delineates the roles to be played by different stakeholders and field research confirmed the multiplicity of these stakeholders and associated roles. Community care and support is provided by several government departments, NGOs and communities themselves. The Ministry of Health sets out the framework for NGO service provision, with service providers only able to provide services that are within the Ministry of Health policy framework. These activities are also expected to be implemented in the context of approved district AIDS implementation plans within district development plans.

The Ministry of Health remains the largest single service provider and is the main point of contact for
treatment services. The National AIDS Commission (NAC), while not providing any direct services, is the intermediary organisation that funds activities related to care and support, treatment and capacity-building among all stakeholders. The Ministry of Health is responsible for the provision of the minimum package of CHBC, which includes basic nursing care; prevention, identification and management of common health ailments in the home; referral of clients with chronic illnesses including HIV and related diseases; end-of-life care; transfer of skills to the carer; infection prevention and control in the home; nutrition, education and food supplementation; provision of integrated outreach services; and monitoring of clients on ART and cotrimoxazole prophylaxis through discharge planning and referral services to appropriate services including for CD4 count, HIV testing and counselling; IEC to clients and family members on prevention of HIV, TB and malaria; assistance with socioeconomic needs of families; and food security and care of OVC (Government of Malawi, 2011).

However, as noted in Section 2.1.2 above, it is noteworthy that the wording in the government’s CHBC policy does not always seem to fully describe what is actually expected in regards to comprehensive CHBC provision. For example, the policy’s statement that “care of chronically ill patients is a biomedical intervention” is not reflected in the wide range of activities specified in the minimum package of CHBC outlined by the Ministry of Health. Many of those activities, including provision of IEC, are not normally categorized as biomedical interventions by most other observers.

The CHBC policy also stipulates that FBOs and other NGOs wishing to provide care and support services may do so provided they have trained health staff and work through and with community structures such as village health committees and support groups. The apparently loose interpretation of the overall CHBC policy and guidelines is further reflected in the broad categories of services provided by such NGOs. Research indicates that such services are grouped into four main categories: treatment, prevention, capacity-building and support services. Services provided under treatment included provision of medication when clients visit mission hospitals and during home visits, procurement and distribution of drugs, and provision and restocking of CHBC kits. The three programmes surveyed in detail for this research also provided support services such as material support provision (clothes, blankets, nutritional support) and livelihood support (e.g., farm inputs such as seeds). Prevention services provided by the three programmes included HIV sensitization campaigns (including those focused on youth) and HTC services (including through static sites and outreach).

Capacity-building services under the programmes included training CBOs, provision of funding to support CHBC activities, technical assistance to CBOs in managing CHBC programme activities, and nutritional education for community caregivers. The findings also indicated that in addition to CHBC services, some NGOs provide vocational training to youth affected by HIV. Innovations were observed for some of the services and activities delivered; for example, NASO has designed and extended its scope of services to reach special groups such as fishermen and sex workers. Moreover, research findings indicate that the concept of support groups for people living with HIV has been the consistent thread around which CHBC architecture has been woven, effectively defining a key role for community participation in CHBC and PHC. Support services provided by CBOs and affiliated support groups are strongly dependent on external funding received, for example from the National AIDS Commission. At times they are forced to discontinue these services as a result of funding cutbacks or changes in priorities set by the funding organisations.

CHBC programmes entail the mobilisation of community resources to improve the welfare of a community as well as individuals in need of health care. Resource mobilisation for and coordination of higher-level services such as social cash transfers, psychosocial support and OVC support fall under the responsibility of the Department of Social Welfare.

Given the residence patterns in Malawi, CHBC service providers are predominantly rural. Of the 10 organisations implementing CHBC programmes that were consulted during the validation phase, 80 percent served both rural and urban areas with the remainder concentrated on serving rural populations only. On average these organisations have been in operation for about 12.8 years and have 23 salaried staff and 716 volunteer and unpaid caregivers.

Table 2 below provides an overview of service provision by primary and secondary caregivers, as per research findings.

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5 The acronym IEC refers to ‘information, education and communication’.
Table 2. Service provision by primary and secondary caregivers within organisations providing CHBC services

<table>
<thead>
<tr>
<th>Type of services provided</th>
<th>Number and % of organisations questioned providing specified services through secondary caregivers</th>
<th>Number and % of organisations questioned providing specified services through primary caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>%</td>
</tr>
<tr>
<td><strong>Direct care and support to clients</strong>*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Basic nursing care: for people living with HIV</td>
<td>10</td>
<td>91</td>
</tr>
<tr>
<td>Basic nursing care: for elderly people</td>
<td>10</td>
<td>91</td>
</tr>
<tr>
<td>Basic nursing care: malaria</td>
<td>6</td>
<td>55</td>
</tr>
<tr>
<td>Basic nursing care: other diseases</td>
<td>9</td>
<td>89</td>
</tr>
<tr>
<td>Clinical care (e.g., taking blood pressure, weighing people) in organisation’s own facility</td>
<td>5</td>
<td>46</td>
</tr>
<tr>
<td>End-of-life care</td>
<td>10</td>
<td>91</td>
</tr>
<tr>
<td>Pain relief</td>
<td>8</td>
<td>73</td>
</tr>
<tr>
<td>Personal hygiene</td>
<td>11</td>
<td>100</td>
</tr>
<tr>
<td>In home/community: pre-ART client counselling</td>
<td>8</td>
<td>73</td>
</tr>
<tr>
<td>In home/community: ART adherence support</td>
<td>8</td>
<td>73</td>
</tr>
<tr>
<td>In home/community: recruitment of clients for VCT services</td>
<td>8</td>
<td>73</td>
</tr>
<tr>
<td>In home/community: recruitment of clients for ART services</td>
<td>6</td>
<td>54</td>
</tr>
<tr>
<td>In home/community: recruitment of pregnant women for PMTCT services</td>
<td>2</td>
<td>18</td>
</tr>
<tr>
<td>In home/community: HIV pre-test information</td>
<td>8</td>
<td>73</td>
</tr>
<tr>
<td>In home/community: HIV testing</td>
<td>10</td>
<td>91</td>
</tr>
<tr>
<td>In home/community: HIV post-test counselling</td>
<td>10</td>
<td>91</td>
</tr>
<tr>
<td>Health education: HIV</td>
<td>10</td>
<td>91</td>
</tr>
<tr>
<td>Health education: malaria</td>
<td>6</td>
<td>55</td>
</tr>
<tr>
<td>Health education: other diseases, e.g., TB and sexually transmitted infections (STIs)</td>
<td>11</td>
<td>100</td>
</tr>
<tr>
<td>Social support (e.g., shelter, clothing, assisting with accessing IDs or birth certificates, social workers, etc.)</td>
<td>10</td>
<td>91</td>
</tr>
<tr>
<td>Livelihood support (e.g., income-generating activities, savings groups)</td>
<td>10</td>
<td>91</td>
</tr>
<tr>
<td>Legal support</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>Nutritional support/referral for nutritional support</td>
<td>11</td>
<td>100</td>
</tr>
<tr>
<td>Spiritual and/or emotional support</td>
<td>9</td>
<td>82</td>
</tr>
<tr>
<td>OVC care</td>
<td>10</td>
<td>91</td>
</tr>
<tr>
<td>Referral of clients to clinical services (clinics, hospitals)</td>
<td>9</td>
<td>82</td>
</tr>
<tr>
<td>Organise or provide transport for health facility visits</td>
<td>8</td>
<td>73</td>
</tr>
<tr>
<td>Educating members of the client’s household</td>
<td>9</td>
<td>82</td>
</tr>
<tr>
<td><strong>Assistance to service provision in local health facility</strong>*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assistance in local health facility: pre-ART counselling</td>
<td>7</td>
<td>64</td>
</tr>
<tr>
<td>Assistance in local health facility: HIV pre-test information</td>
<td>8</td>
<td>73</td>
</tr>
<tr>
<td>Assistance in local health facility: HIV testing</td>
<td>9</td>
<td>82</td>
</tr>
<tr>
<td>Assistance in local health facility: HIV post-test counselling</td>
<td>7</td>
<td>64</td>
</tr>
<tr>
<td>Assistance in local health facility: administrative tasks</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>Assistance in local health facility: other</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td><strong>Specific types of support / activities</strong>*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Specific support for women: women and child protection and SRHR interventions***</td>
<td>3</td>
<td>30</td>
</tr>
<tr>
<td>Specific support for women: empowerment and self-reliance interventions</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Lobbying and advocacy activities</td>
<td>2</td>
<td>20</td>
</tr>
</tbody>
</table>

* Based on 11 organisations surveyed, except where otherwise noted
# Based on 10 organisations surveyed
** SRHR = sexual and reproductive health and rights
Source: CAN multi-country research – Malawi research, 2011–2012
The table shows that more than 90 percent of CHBC providers surveyed offer direct support to clients through secondary caregivers that includes basic nursing care for people living with HIV and the elderly and end-of-life care, and that the vast majority of all secondary caregivers are involved in providing personal hygiene support. Primary caregivers are involved in a range of care and support services including HIV testing, post-test counselling, health education and nutritional support and support to orphans and other vulnerable children. Co-infections also place a strong demand on CHBC services, with all service providers confirming that they offer health education on TB and sexually transmitted infections. Findings also indicate that CHBC service providers assist actual service provision at local health facilities. When they are involved at such sites, it is in the realm of IEC, especially pre-ART counselling and provision of pre- and post-test information and education.

2.1.4 Policy environment

Malawians have long mobilised and participated in community activities, especially those oriented around development and political parties (in both one-party and multi-party settings). This recognition of community participation has been justified on the basis of ownership and sustainability of development initiatives and services. The 1998 Malawi Local Government Act and the decentralisation policy (2000) provided a policy framework for community mobilisation and participation in local governance and development management. The local development planning and management framework includes village development committees that are expected to develop participatory village action plans that subsequently feed into area development plans and ultimately into district development plans. Over time these structures have been customised to accommodate new community challenges or opportunities as evidenced by the creation of village health committees and village AIDS committees for the national response to HIV.

A number of policies and guidelines provide direct and indirect guidance on CHBC in Malawi, including at least 15 related to community care and support (see Annex 3). While the Malawi Growth and Development Strategy (2011-2016) provides a broad overarching medium-term development framework, the National HIV and AIDS Policy of 2003 (updated in 2008) and the Malawi HIV and AIDS (Extended) National Action Framework (2005 and updated in 2009) set out the sectoral administrative and legal framework. A specific CHBC policy and guidelines, initially formulated in 2005 and updated in 2011, describe the purpose of CHBC programmes as follows: to improve the health status, environment and quality of life of chronically ill clients and vulnerable children; advocacy to improve the availability of, access to and use of comprehensive care services; and to strengthen the capacity of individuals, families, communities and institutions to deliver CHBC services.

The current CHBC policy reflects the changes that have occurred due to the advent of ART and other emerging issues including the need to recognise the role of caregivers, inclusion of other chronic diseases, and issues specific to the elderly, people with disabilities and OVC. The policy recognises the range of eligible clients. It states: “All chronically/terminally ill people (3 months or more) of all age groups in the community shall be eligible for CBHC. They include adults and children (0-18 years) living with HIV, TB, cancer, stroke and other chronic illnesses. Vulnerable groups of people in the community shall benefit from CHBC. They include people living with HIV, orphans and vulnerable children, at-risk pregnant women and the elderly” (Government of Malawi, 2011).

The effect of changes in the policy environment since the introduction and scale-up of ART has been to define and clarify the content of CHBC and stakeholder roles. While to a large extent the national policy environment was meant and seen to be facilitative of the work of partners, some NGOs also perceived that in some respects the new policy and operationalization mechanisms were restrictive. The following sentiment is illustrative of some of these concerns:

*Government policies (the pillars to national response to HIV) in programming are restrictive. The HIV and AIDS pillars promoted by the National AIDS Commission [NAC] are rigid with little room for manoeuvre regarding integration/expansion of service as one has to operate within the specified pillars if they are to access NAC funding. And NAC is a key source of funding.*

—Key informant, Nkhotakota
It was also noted that modifications to the national CHBC policy and guidelines resulted in changes in the way CHBC activities were being programmed and implemented. However, as implied in Sections 2.1.2 and 2.1.3, the new CHBC policy and guidelines are not necessarily viewed as rigid in terms of language and perceived expectations. Most CHBC service providers and their community caregivers offer a far greater range of services that encompass those not always (if ever) considered strictly or even partially biomedical. For example, based on their implementation experiences, some programmes such as the Livingstonia Synod AIDS Programme (LISAP) have retained in their programme elements that are no longer contained in the policy and guidelines. An example was the piloting of mixed support groups that bring together people living with HIV with others in communities as part of an effort to address HIV-related stigma.

There is also a national palliative care policy and set of guidelines that focus on the type of services and standards provided by different stakeholders as part of the national health sector response to HIV and other life-threatening conditions such as cancer. This policy provides direction on establishment and implementation of quality end-of-life care in institutions and communities, and on improving access to quality end-of-life care including pain and symptom control. Both the CHBC and palliative care policies acknowledge the linkages and connections with other national policies and guidelines such as the those regarding HIV in general, ART provision specifically, nutrition and community-integrated management of childhood diseases.

Although end-of-life care has always been part of the responsibility of the Ministry of Health because the agency covers all biomedical-related issues, an interesting case was the emergence of Lighthouse, the first provider of end-of-life care in Malawi (since 1997). Lighthouse’s services predate the palliative care policy. It was developed by clinicians to follow up on terminally ill clients who had been discharged; the developers had noted that once clients were sent home, communities were not adequately prepared to provide basic nursing care and other related services. Lighthouse volunteers have been trained and placed in communities implement CHBC activities, including support for bedridden and graduated clients (formerly bedridden clients), under what is called the Ndife Amodzi (‘We are One’) programme.

The existing policies highlighted above emphasise the central position of the Ministry of Health in defining the purpose and scope of CHBC programmes, which it considers to be part of PHC services in the country. Notably, CHBC is defined as a Ministry of Health service that serves its HIV programmes. The ‘community’ component of these programmes and projects is defined by the requirement that FBOs and other NGOs go through local government structures, including traditional authority and village committees as well as district executives and district development committees, to gain approval and, thereafter, to recruit community caregivers and define local service needs. The NGOs must also work with local AIDS management structures, which are similar to those of the local government as they use that hierarchy as a template.

2.2 HEALTH SYSTEM INTEGRATION

2.2.1 Primary health care structures

Three levels must be examined to ensure a comprehensive analysis of PHC in Malawi: the conceptual level, policy/regulatory framework level and the practical/implementation level. The institutional framework as described by the national CHBC policy and guidelines apportions roles and responsibilities among the potential players in CHBC from national scale to community level. The research confirmed that CHBC is indeed integrated into PHC at the conceptual level via a broad notion of PHC. A review of both the Palliative Care Policy and Guidelines and revised National CHBC Policy and Guidelines (2011) shows that the roles of community caregivers and health workers go beyond the confines of CHBC for HIV and include management of common ailments that are part of the government’s Essential Health Package.\(^6\)

The situation is similar in reverse. Physical care is firmly integrated in PHC because CHBC itself is part of the Essential Health Package. A case in point is Nkhotakota District, where primary health units provide technical expertise relating to CHBC and also assist with restocking the CHBC kits for community caregivers/CBOs under the NASO programme and offer support in the training of community caregivers. For its part, NASO periodically organises joint review meetings with health units, including the district
health office (DHO). As a result, NASO has become a referral organisation for care and support, with the DHO referring clients to the programme, especially those newly diagnosed with HIV. Similarly, community caregivers with whom NASO works provide support at the district hospital, especially in the nutrition and rehabilitation unit for children, and have also prepared a demonstration garden at the district hospital that is used to provide information on nutrition for clients. The caregivers have been trained through the United Nations Food and Agricultural Organization (FAO) on garden and food preparation and are now able to provide this information to new clients.

In Mzimba District, meanwhile, NGOs such as Plan Malawi and LISAP are assisting government health units with training in CHBC for community caregivers. LISAP in particular conducts refresher courses for community caregivers. The following statement is indicative of the extent to which integration seems to have been achieved:

*There is a very strong link between the primary health care system and community caregivers. This is done through the HSAs and the community nurses. [They] work directly with both primary and secondary caregivers during periodic home support visits.*

—Key informant, Mzimba North

There are also formal arrangements for reporting between district hospitals and local councils, as noted by the following statement:

*We send monthly and quarterly reports to the district council for the attention of the district AIDS coordinator. There are specific templates designed by the district health officer and the district AIDS coordinator that are used. The information is supposed to be entered into the district HIV and AIDS database. The forms to the district health officer are submitted on [a] quarterly basis.*

—Key informant, Nkhotakota

As noted previously, the Ministry of Health sets out the framework for NGO service provision. The CHBC services for instance have to fit within district implementation plan approved by local administrations and coordinated by district AIDS coordination committees. However, there is little consistency to date as to the extent to which this framework has been implemented across the districts and how effective it has been, in part due to differing capacities of those involved. For example, while in the Mangochi District there were frequent and structured CHBC home visits from the DHO through the CHBC coordinators, in the Nkhotakota and Mzimba districts such visits occurred more intermittently. Shortages of trained staff and inadequate resources for transportation were cited as the main reason for limited visits. It was noted that programme-level CHBC activities coordinated by the three programmes were carried out as planned, although achieving wider geographical coverage was a challenge.

2.2.2 Decentralisation of HIV treatment

Although the national HIV policy and CHBC policy and guidelines clearly define the link and boundaries between the formal health system and community caregivers in terms of CHBC, care and support, the devolution of roles and activities from the central government to communities follows the national government’s decentralisation policy. Under this policy all government ministries represented in a district are answerable to the district commissioner and are part of the district executive committee. Whereas the Ministry of Health provides overall technical leadership in CHBC policy implementation, at district level the district health office (DHO) gets guidance and indeed must work within the context of the overall decentralized local council planning and coordination framework. For technical issues of treatment, the DHOs are the most critical because they actually implement CHBC policy, coordinate CHBC activities, mobilise resources and monitor the performance of CBOs in communities. More importantly, district health officers chair the CHBC sub-committees of district AIDS coordinating committees. DHOs are linked to community activity through two avenues: through NGOs (including FBOs) and formally through ‘health surveillance assistants’ (HSAs). The Ministry of Health entry point into communities is health centres, which implement, monitor and supervise CHBC activities in their catchment areas and also develop referral systems for CHBC within their specific areas. Ideally at each health centre there

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6 In 2002, Malawi adopted the Essential Health Package (EHP), a clearly defined package of key interventions which serves as the basis for pooled funding to the health sector.
is supposed to be either a community nurse or environmental health officer who is responsible for a number of HSAs.

The involvement of an international NGO in the decentralisation of ART preceded the scale-up of ART services by the government. About a decade ago Médecins Sans Frontières (MSF) began offering ART in two districts of Thyolo and Chiradzulu. This service was provided through a government hospital and mission hospitals but was limited in coverage and had stringent qualification criteria. When the government decided to roll out ART, antiretroviral drugs were distributed only at district hospitals due to a need for laboratory testing. NGOs were instrumental in lobbying for extending geographical coverage of ART to rural areas. In Nkhotakota, it was found that there were 21 treatment sites at the time of the research, up from just one centre when ART started, while in Mangochi there were seven treatment sites providing ART. These sites are normally health centres that have been assessed by the Ministry of Health and certified as suitable to provide ART services on the basis of availability of staff trained in ART. The expansion of the number of ART sites in the country between December 2003 and December 2010 is depicted in Table 3 below.

Table 3. Increasing number of ART sites (public and private) in Malawi

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<tr>
<td>ART sites</td>
<td>9</td>
<td>24</td>
<td>83</td>
<td>141</td>
<td>163</td>
<td>221</td>
<td>377</td>
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However, the research also found that although there have been positive changes in terms of increasing ART coverage, people in some areas remain far removed from easily accessible ART services due to long distances. This was exacerbated by transportation problems that constrain the ability of DHOs to reach people in their communities.

The CBOs that were working with the selected programmes are conducting pre- and post-ART counselling and promoting adherence to ART via support groups, client monitoring and referral of clients who experience side effects and other negative reactions to drugs. In all three of programmes reviewed in-depth in this research, none of the CBOs were involved in dispensing antiretroviral drugs. While the NGOs consulted indicated this might be useful to facilitate increased and consistent access—provided quality assurance measures can be developed and followed—respondents from other sectors were largely reluctant to support this step. Many said they were concerned about potential inadequacy of storage infrastructure and quality at the community level, while others noted worries about proliferation and “illicit use”. As argued by one respondent in the following quote, allowing CBOs to directly dispense antiretroviral drugs would be “taking things too far”:

*We should bear in mind the fact that everywhere in the world drugs handling needs to be controlled and should meet the requirements of the Pharmacy and Poisons Board....To expect that treatment services can be taken to the community level is therefore taking things too far.*

—National key informant

Interviews during validation confirmed the high level of collaboration between CHBC programmes and government extension workers that was observed during the earlier phases of the research. All CHBC groups interviewed during the validation stage indicated that there was collaboration with HSAs. The need for expanding ART coverage to a wider canvas was reiterated, a step that requires additional sites be identified to provide ART. However, those surveyed during validation gave a mixed reaction to the idea of decentralising HIV treatment beyond health units.
2.3. CAREGIVERS’ POTENTIAL

2.3.1 HIV prevention and treatment programmes

In Malawi, HSAs, support groups and community caregivers are involved in HIV prevention through the provision of information, education and communication (IEC) in communities on prevention of HIV, TB and malaria as well as the importance of HIV testing. Through CBOs, they are actively involved in community sensitization campaigns on prevention, including the promotion of HIV testing and counselling (HTC) services. They educate community members on the advantages of HIV testing and provide post-test counselling and care, depending on the tests’ outcomes. Community caregivers consulted in the three case study programmes indicated that these activities have become an important part of their broader care and support work. For instance, under NASO in Nkhotakota, caregivers interact with sex workers, providing them with information on HIV prevention. Further, under both LISAP and Mangochi Catholic Health Commission, the core of programme activities focus on prevention of HIV transmission, with these services being delivered largely by community caregivers.

With the reduction in the number of bedridden clients and a shift in emphasis from easing the pain and terror of death to healthy and safe living, new and enhanced efforts are required in regards to behavioural change. NASO has diversified its services to include several HIV prevention interventions such as training for male and female initiation facilitators and fishermen. Meanwhile, LISAP and Mangochi Catholic Health Commission are focusing attention on prevention aspects of the national response with community caregivers as a key piece of their programme strategies. Within the broader context of the national HIV response, there is also an increasing focus on prevention aspects that can build upon the role of community caregivers—e.g., HIV prevention through education or distribution of female condoms.

The role of caregivers in treatment still remains to be clearly defined, and future direction and potential depend on how the health system copes with the additional number of people who qualify for ART. As noted previously, caregivers are currently involved in activities that assist in monitoring adherence to ART regimens and dealing with side effects of drugs as well as encouraging community members to get tested for HIV, leading to initiation on ART where necessary.

Results from the validation phase of the research show that some CHBC providers are already engaged in other important ART-related monitoring activities, including helping determine whether clients need to visit health facilities for a check-up and undertaking door-to-door voluntary counselling and testing. Representatives from some, though not all, of the 11 organisations surveyed during the validation phase indicated that both health professionals and volunteer caregivers associated with their organisations could conceivably be involved in a greater range of such services in the future if given the opportunity.

Although the Malawian government currently does not allow non-medical personnel to undertake direct treatment provision, CHBC programmes are variously involved more broadly in treatment services. In some communities, such as Nkhotakota and Mangochi, caregivers have been trained on how to administer prescribed dosages of antiretroviral drugs to clients alongside nutrition education, and thus are able to support both clients and other caregivers. Respondents indicated that though ART had not been decentralised to the CBO level, non-medical personnel could nonetheless play an increasing role if properly trained. As noted previously, interviews with health workers and other key informants suggested that concerns about inadequate drug storage and improper use of drugs constituted major challenges to decentralising ART to community-level structures such as CBOs. For example, there have been unconfirmed stories—in which people are said to sell antiretroviral drugs to be used to add potency to locally brewed beer—that seem to lend credence to these concerns.

2.3.2 Primary health care programmes

Community caregivers are an essential resource in the delivery of PHC services. Since by policy they are defined as part of PHC, the architecture also actively integrates ART and CHBC as services in the Essential Health Package. In practice the government provides PHC through its own hospitals, yet under the Essential Health Package it also provides PHC services to communities remote from government facilities through service-level agreements with private and mission hospitals. Under this arrangement
the government not only refunds such hospitals for any services, but it also subsidizes staff salaries, including those for any HIV coordinators who may be employed at the private facilities. In this context, staff involved in CHBC from LISAP and the Mangochi Catholic Health Commission were indirectly being funded by the government. Moreover, regardless of CBO or NGO affiliation, the government also provides CHBC kits and supplies, although programmes that were capable also procured and distributed such kits. Such supplies and support are often provided to meet the minimum package of CHBC services as defined by the Essential Health Package. The implication is that the delivery of the PHC and, hence, CHBC, is actively supported by the government.

Community caregivers are active in CHBC activities not only through and with NGOs, but also alongside ‘health surveillance assistants’ (HSAs) in disease-prevention activities. All programmes included a deliberate process of skills transfer through mentoring community caregivers as a precursor of ‘task-shifting’ in order for the caregivers to provide services such as physiotherapy, pressure area care, wound cleaning, mouth cleaning and feeding of clients. This is standard protocol for home visits from public health units, and is aimed at building the capacity of community caregivers to provide such services that would be ordinarily be provided by a trained community nurse. Further, community caregivers participate in health education, child immunization campaigns and water and sanitation education led by HSAs.

Malawi continues to face serious human capital constraints in the health sector and in the foreseeable future will continue to augment that shortfall with community caregivers. The main areas that community caregivers are likely to continue participating in include direct care provision, immunization campaigns, client monitoring (ART and other chronic illnesses), as well as environmental sanitation services. Caregivers can also be instrumental in community case management of diseases in collaboration with HSAs.

2.4 COMPLEMENTARITY BETWEEN FORMAL AND INFORMAL COMMUNITY CAREGIVERS

2.4.1 Recognition and acceptance

The CHBC and palliative care policies and guidelines of 2011 in principle recognise the roles and contributions of—and complementarity between—formal health personnel working in the clinics/extension workers and informal primary and secondary caregivers involved in CHBC programmes at the community level. It is important to recognise that the distinction between ‘formal’ and ‘informal’ is used loosely since government policies recognise the role of community-based workers and therefore it is not clear-cut whether they can be considered informal when, by policy, they are integrated within the health system. That notwithstanding, and as noted previously, the CHBC policy clearly underscores the fact that CHBC is a responsibility of the Ministry of Health and is an integral part of its biomedical-oriented interventions.

In reality, there is a measure of formal acceptance of caregivers, and this was confirmed at both the community and district levels. CHBC coordinators at district hospitals were fully aware that the policy explicitly recognises the community caregivers, and that it was such recognition of integration that justifies the Ministry of Health’s investment in providing basic training to community caregivers, given that community caregivers have been apportioned distinct roles. Even trained health care workers at government district hospitals conceded that it would be near impossible to implement the CHBC services without the community caregivers. This was because all home visits were planned within the context of CBOs and support groups under them. In addition, community caregivers are integrated in the formal case referral system of clients (to and from the formal government health units). The following statement lends evidence to these observations:

As noted already, we work closely with the public health services. There is a formal patient referral arrangement to and from the public health services on care aspects. Our cooperation is complementary. In addition, we as NASO contribute to strengthening coordination by facilitating joint meetings in care and support activities at the district level. NASO brings different players together. Government does not initiate such forums with others

—Key informant, Nkhotakota
Civil society representatives consulted during this research confirmed that the referral system was functioning properly, with clients referred to health units with referral letters treated as priority cases. Referred clients reportedly do not wait in line for service, much to the appreciation of the community caregivers. However, although community caregivers noted that while there was already widespread recognition and acceptance of their role within the community, certification could create greater credibility for their work. A certification process by the Ministry of Health for those trained as caregivers would essentially provide formal recognition of community caregivers’ services. Recognition also comes through the receipt of CHBC kits from the government at the community level. For instance, the research noted that CHBC kits, which contain basic drugs and care items, were provided to facilitate caregivers’ work. However, in practice, there were challenges with maintaining the full set of supplies in the CHBC kits, as either re-stocking took a long time or was not done at all after the initial provision.

In general, the findings of the research show that there has been formal acceptance of community caregivers as important partners in the delivery of PHC services, and especially CHBC services. Evidence was found of referral systems for clients from communities to health units and vice versa. However, there are neither formal remuneration nor career path opportunities for most of the ‘volunteers’. Attempts have been made to formulate and formalise an incentive structure that would eventually allow for compensation and integration of community caregivers in the formal health system. Under the auspices of VSO Malawi, and in conjunction with ActionAid-International Malawi, a draft ‘care for carers’ policy was formulated in 2010 and presented to the Ministry of Gender, Children and Social Welfare. At the time this research concluded, that draft policy was awaiting review and adoption by the government. It proposes integrating caregivers within the national health system and incentivising volunteers with a stipend. The following sentiment from one of the key informants at the national level seemed to illustrate the frustrations by NGOs in this connection:

> Community members participating as volunteers are given training, t-shirts, umbrellas and in some cases bicycles. Apart from this, there is no other form of remuneration. There are no other known incentives for the community caregivers apart from recognition in the community. Efforts to ensure there is some kind of remuneration for the volunteers seem not to be receiving adequate attention by policy makers.

—National-level key informant

### 2.4.2 Coordination regarding HIV care and support

Coordination of CHBC activities occurs at various levels with a complex web of monitoring and reporting structures, both formal and informal. The Ministry of Health has a leading role in the coordination of CHBC services at the district level. As the secretariat for the home-based care sub-committee of district AIDS coordination committees, the Ministry of Health is supposed to work with other stakeholders involved in treatment, care and support services such as mission hospitals and civil society.

There are distinct reporting lines for managerial and technical responsibilities at the district level. The Ministry of Gender, Children and Social Welfare, through the Department of Social Welfare, bears the responsibility for managing and ensuring proper functioning of CBOs to which community caregivers are attached. The Ministry of Health—through district health offices (DHOs) and, subordinately, ‘health surveillance assistants’ (HSAs)—takes the lead in regard to ensuring that community carers are providing the CHBC services at a minimum acceptable standard. DHOs are supposed to coordinate quarterly stakeholder review meetings, home visits and training in collaboration with other government officials such as district social welfare officers and district AIDS coordinators.

In the programmes evaluated, HIV coordinators at the mission health units provided support to CBOs and support groups. HSAs, who are trained and coordinated by the Ministry of Health, are responsible for supervising community caregivers on client care. They are expected to be based in the community and visit and support clients and their primary caregivers, providing information and skills to caregivers through on-the-job participation and observation, monitoring client conditions and assisting with physical care. HSAs also provide basic nursing care, support for treatment adherence, psychosocial support and maintaining records on clients under their care and on other CHBC activities in their catchment areas.
In some cases HSAs facilitate community mobilisation for CHBC programmes—i.e., activities such as the recruitment of caregivers, the involvement of people living with HIV and training according to the Ministry of Health standards.

Figure 2 below provides a basic schematic overview of linkages that exist in the organisation of HIV care and support services in Malawi. The organogram reflects the complex environment that exists in the country in relation to the organisation of these services and shows the involvement of various ministries, departments and committees.

**Figure 2. National organogram for care and support in Malawi**

The research underlined the existence of a formal reporting arrangement where all three selected case study organisations implementing CHBC programmes consulted, prepared and submitted reports to the DHOs and district AIDS coordinators. Using specific templates, monthly and quarterly reports are sent to district councils for the attention of district AIDS coordinator. The information provided is fed into the HIV and AIDS database used at district level, the Local Assembly HIV and AIDS Reporting Framework (LAHARF). In all districts, there was a CHBC Working Group, which was a sub-committee of the district executive committee that dealt with coordination of CHBC services. However, research for this report found that such committees were barely operational.

The HIV-related management structure mirrors the local governance structure, with district AIDS coordinating committees and village AIDS committees responsible for coordinating with CHBC committees. Sub-committees of district AIDS coordinating committees organise government CHBC activities and therefore work closely with NGOs engaged in such work.

The transfer of tasks and responsibility from the health system to communities is dictated by the requirement that FBOs and all other NGOs must work through and with the local government structures. As highlighted before, there is a three-tier hierarchy of local governance that includes the district administration, traditional authorities and village-level government. NGOs are directed into communities through the district, area (traditional authority) and village development committees. Community caregivers operate in a defined geographical area, and by virtue of their being identified by communities and leaders they are expected to be primarily accountable to the community leadership structures. In
this connection, community leaders such as village headpersons and group village headpersons’ play important roles in the ability of community caregivers to function.

Management of caregivers is done through established community structures such as CBOs and support groups. The Mangochi Diocese has 18 parishes and there is a health facility in all of them. For each health facility, the Mangochi Catholic Health Commission has an HIV coordinator who manages all the CHBC activities in collaboration with a steering committee and community caregivers. The entry point is existing CBOs that have been registered with the Department of Social Welfare at the district level. This is similar to the arrangement implemented by LISAP, which instituted dedicated HIV committees in each of its congregations to help manage HIV issues. This arrangement has now become an interdenominational initiative, reaching out to all people in the region, regardless of their religious affiliation. Through an interdenominational consortium, LISAP receives funding from various partners, including the National AIDS Commission and TearFund. In regards to CHBC, LISAP supports the work of support groups and CHBC committees under CBOs.

As an NGO that started as a support group, NASO is coordinating the CHBC referral network in Nkhata Bay and Nkhotakota districts, where it trains health workers and different partners. Unlike the two church-related programmes that are linked to mission health centres and hospitals, NASO has no health facilities. However, it has working links with St. Anne’s mission hospital in Nkhotakota District, which operates a referral service. Given the sociocultural characteristics of the populations that NASO serves, the programme recently extended its services to reach special groups such as sex workers and be engaged with key traditional initiation institutions by training gatekeepers such as female and male initiation facilitators (namkungwi, and ngaliba, respectively).

The existence of linkages between CHBC service providers and various ministries, authorities and other organisations has been underlined by the research. All 11 organisations surveyed in the Phase 4 validation exercise indicated that they collaborated with the Ministry of Health, while all but one organisation also collaborated with the Ministry of Agriculture and the Ministry of Gender, Children and Social Welfare. Research findings indicate that a third of CHBC service providers engage only with local authorities and a third with both local authorities and other CBOs. Areas of collaboration include the selection of caregivers, monitoring of care and support services and community mobilisation.

A more recent development in the country is the formation of the National Community Home Based Care Alliance (NCHBCA), which seeks to aggregate interest for civil society agencies involved in CHBC. During the research period for this report, the NCHBCA had just begun developing its own systems for identifying and mobilizing stakeholders involved in such services. These efforts are likely to provide further impetus towards greater recognition, coordination and representation of community caregivers.

2.4.3 Continuum of care and comprehensive care and support

The research identified attempts to ensure a continuum of care and provision of comprehensive care and support. Before the advent of ART a continuum of care was needed from diagnosis of HIV (due to co-infections and opportunistic infections) or clinical indication of AIDS to people becoming bedridden. Clients often would go through cycles of being admitted to and discharged from hospitals before being finally discharged for a final time to return to their homes for end-of-life care and support. In the era of ART, the cycle is the same, though with an intervening period of medication; therefore, death may be postponed for a long time and may not necessarily come about as a result of HIV infection. Respondents at both the community and district levels indicated that the work of support groups involved the identification and monitoring of clients for CHBC. According to the national CHBC policy and guidelines, chronically ill persons are expected to access comprehensive care and support across the continuum of care at the community level and at the health facility level when referred by community caregivers. The policy also highlights the importance of reverse referrals, with clients able to access care back in the community when referred from health units.

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7 A group village headperson oversees a cluster of between 7-12 villages while a village headperson looks after only one village. Community and other services, including caregiving, are organised around clusters of villages under the group village head.
With increased availability of HIV counselling and testing, diagnosis does not always happen in relation to the presence of opportunistic infections. Upon diagnosis with HIV, all clients can begin pre-ART care with some already eligible for ART. Access to CHBC services can therefore begin from health units upon diagnosis, where clients are referred to CHBC groups under CBOs, and vice versa when cases are observed at the community level. The care received depends on access to health service and clients’ quality of life is often dependent on access to nutritional support.

The service delivery by the Ministry of Health reflects this arrangement where a formal referral system is in place between community caregivers and health units. The role of government programmes in this area has been largely to build the capacity of the CBOs to undertake CHBC, as well as to assist households with chronically ill clients with livelihood support. Regarding HIV, the roles of caregivers in providing pre- and post-ART counselling reflect the need to provide the continuum of care. The contents of the national CHBC policy and guidelines reflect the importance of comprehensive care and support, and community caregivers interviewed were fully aware of what this involves. It was indicated that during sensitization meetings, people who are sick for a period are encouraged to undergo HIV testing and are subsequently followed up and referred to health units by community caregivers.

The reverse referral situation is also important to note. Clients who are diagnosed at health units were referred to organisations such as NASO for continuum of post-testing care and support. Throughout the period that clients are alive, they are provided with the necessary care and support, including clinical, psychosocial, physical, and in some cases material and nutritional support through the CHBC framework. In this connection, the research also found that through programme investments and activities of the three case programmes studied, substantial contributions were made to ensure a continuum of care and comprehensive care and support. The focus was towards ensuring comprehensive care and support for people with chronic illnesses. For instance, NASO indicated it provided human resources through multi-skilled teams that go to homes providing care and support services. It also procured drugs that it distributed directly to CBOs and support groups. Similarly, the Mangochi Catholic Health Commission and LISAP through their primary health care work provided resources and supplies for CHBC services to ensure continuum of care and comprehensive care and support. Both supported orphans as well as provided nutritional education and support.

It was noted, however, that the existence of this framework is not a guarantee for continuum of care due to the unreliable supply of drugs in the country as well as the lack of transport for health personnel and community caregivers. Such obstacles limited regular engagement with caregivers for all clients in need.
3 CONCLUSION

The evolution of CHBC in Malawi reflects the changing needs of clients and acceptance of realities on the ground. As the needs of people living with HIV have evolved, so too have roles of different stakeholders including community caregivers, CBOs, government departments and other institutions. Starting from the late 1980s when HIV first became a serious health, economic and social crisis—thus putting considerable stress on the country’s PHC systems in particular—there has been an increasing recognition of the value and importance of CHBC. Standardization of procedures means that CHBC has been formalized as part of the PHC system; as such, it is expected that CHBC will be critical in the future even as it adapts to changing realities.

The research noted that there is potential for caregivers to play an expanded role in responding to the growing needs of clients and new challenges that come with an expanded ART programme. The potential arises from the services that the community caregivers are already offering, such as their participation in HIV treatment and prevention programmes and the expansion PHC activities. Many of these services are not biomedical in nature, thereby indicating that the wording and emphasis in the government’s 2011 CHBC guidelines are perhaps best considered only a starting point for a more flexible and expansive interpretation in reality.

If CHBC is to continue to play an important and essential role in Malawi in terms of care and support service provision, a number of challenges will need to be addressed. Some of the practical challenges to CHBC relate to coordination, community participation and the nature of volunteer work. With regard to running projects in communities, general challenges include distance and lack of transport. Since many rural areas lack ART clinics, limited transport opportunities create and sustain inconsistencies in access and adherence to ART and sometimes this obstacle is the main reason clients drop out of care. Secondly, the work environment for caregivers is demanding given that most work in homes and care for sick people. Yet due to the fact that many caregivers are unpaid and lack other incentives, keeping them motivated is proving problematic, leading some to drop out and creating a need among CHBC programmes for continuous training. It is estimated that about 10 percent of volunteer and unpaid caregivers drop out soon after completion of training and many others do so over time. Thirdly, some professional health workers participating in this research said they doubted the service quality and accountability of certain CHBC programmes given their reliance on volunteer and unpaid caregivers.

Other notable challenges include the following:

- As noted regularly in this research, most of the work that forms part of CHBC in practice and on a daily basis can best be described as psychosocial and economic in nature, whereas the conception of CHBC in the government’s CHBC policy largely addresses biomedical issues. In an environment in which ART is only provided at health facilities and there are fewer bedridden clients, defining CHBC as a health intervention seems misplaced. This is especially true when the bulk of CHBC activities focus largely or exclusively on livelihood support, mitigation of the negative social impact of HIV, and supporting clients to live healthier lives in general.

- Health system challenges include intermittent supply of drugs. Drug stock-outs are becoming common, especially drugs for general pain (i.e., analgesics) and treatment of HIV-associated opportunistic infections and management of other chronic diseases. In this regard even assuring future availability of key medicines and supplies, including antiretroviral drugs, is proving difficult. Kits used by CHBC personnel are not easily replenished and recently there have been cases of stock-outs of supplies as basic as gloves, thus forcing caregivers to resort to using plastic bags.

- Due to the shift in approach that some international NGOs have recently adopted, a lot of work that was previously being done using government extension workers is now being done by partner NGOs that have their own extension workers. Some tensions have been observed at the district level where government staff believe that resources are being inappropriately channelled away from government systems to NGOs. Cooperation with government officers at the local level in this regard has been problematic.
• Coordination and consistency remain challenging. The lack of stakeholder coordination sometimes results in duplication and competition for the participation of community caregivers; this happens in part because while the CHBC policy defines the vertical relationship among different players in the CHBC landscape, there is no framework for NGO coordination. As such the horizontal relationship between and among NGOs is not well defined. A number of challenges are also particular to CBOs and other NGOs. For instance, issues of financial management are a concern in regards to many CBOs, with some that once received funding from the National AIDS Commission no longer eligible because of real or perceived poor record keeping and other accountability problems.

• Due to funding cuts from some of their donors, many non-governmental CHBC providers—including two of the three programmes focused on during the research, NASO and LISAP—have had to scale down their activities and reduce their staff. That has compromised outreach and service quality at a time when increasing numbers of people are in need of ART and other services. Meanwhile, rigid funding guidelines from the National AIDS Commission mean that there is little room for innovation and programmes may not qualify for funding if they deviate from prescribed formats.

• CHBC programmes are beset by capacity problems. Although each government health centre is supposed to have either a community nurse or an environmental health assistant to supervise ‘health surveillance assistants’ (HSAs) and oversee CHBC, the limited number of health care workers at most facilities and lack of transportation hinders the ability of trained health care workers to undertake home visits. At times, due to the lack of trained health workers to man health posts, HSAs have been forced to manage health centres to the detriment of their pivotal responsibility of supervising community workers and managing community programmes.

• Capacity constraints are a chronic problem across the country. Malawi continues to face serious human capital constraints in the health sector, and therefore must rely even more on community caregivers. In 2008, the country had just over 2,900 and 10,000 nursing professionals and HSAs, respectively (Africa Health Workforce Observatory, 2009). The massive shortfall is a huge problem in regards to scale-up of HIV services as well as health care more broadly, given that these cadres are critical to the provision of PHC programmes. Addressing such challenges will be difficult. Respondents indicated a number of directions for the future of CHBC in Malawi, including the need to train more health personnel in CHBC; the need to actualize the ‘care of carers’ concept in order to have a sustainable pool of caregivers and address current lack of training and support; the need to expand HTC services; and the need for more attention be put on continued capacity-building for CBOs.

• The effectiveness of CHBC in the future relies on caregivers receiving more training and information to make their work as relevant as possible. New and different needs and priorities have arisen among clients since the advent of ART and its rapid scale-up, which means different responses are expected from community caregivers. Caregivers, for example, now require more thorough training and information in regards to the provision of livelihood and nutrition support.
REFERENCES


ANNEX 1. COUNTRY RESEARCH PARTICIPANTS

Researchers:
- Winford Masanjala – Researcher Chancellor College, Zomba - University of Malawi
- Murphy Kajumi – independent researcher

Research Advisory Board members:
- Annie Banda – Coalition of Women Living with HIV and AIDS in Malawi (COWLHA)
- Felix Kamowa – Kagwa Parish
- Daneck Kathumba – Lighthouse
- Maureen Luba – National Association for People Living with HIV and AIDS in Malawi (NAPHAM)
- Joyce Mlotha – National Association for People Living with HIV and AIDS in Malawi (NAPHAM)
- Agness Mussa – Lighthouse
- Roreen Mzembe – VSO Malawi
- Masiye Nyang’wa – Lilongwe Catholic Health Commission
ANNEX 2. KEY INFORMANTS

Phase 1: Semi-structured interviews
Interviews with representatives of:
- ActionAid International (1)
- Lighthouse (1)
- Ministry of Health (2)
- National AIDS Commission (2)
- National Association for People Living with HIV and AIDS in Malawi (NAPHAM) (1)
- Oxfam (1)
- Plan International Malawi (5)

Phase 2: In-depth review of three community programme cases

Case 1: Mangochi Catholic Health Commission
Interviews with representatives of:
- Kapile Health Centre (1)
- Katuma Health Centre (1)
- Mangochi Catholic Health Commission (1)
- Mangochi District Council (1)
- Mulibwanji Community Hospital (1)
- Nankhwali Health Centre (1)

Interviews with:
- Primary caregivers (10)

Focus group discussions with:
- Primary caregivers from Chiphi, Katimbe, Machokola, Mpeya, Nasuluma, Nikisi and Tsamilani (13)
- Community members from the Mpeya community (10)

Case 2: Nkhotakota AIDS Support Organisation (NASO)

Interviews with representatives of:
- NASO (3)
- Nkhotakota District Health Office (1)
- Nkhotakota District Council (2)

Interviews with:
- Clients (8)
- Primary caregivers (4)

Focus group discussions with:
- Community caregivers, Tambala CBO (8)
- Community members (7)

Case 3: Livingstonia Synod AIDS Programme (LISAP)

Interviews with representatives of:
- LISAP (2)
- M’mbelwa District Council (1)
- Mzuzu Health Centre (1)
- Mzimba South District Social Welfare Office (1)
Interviews with:
- Clients (5)
- Primary caregivers (6)

Focus group discussions with:
- Community caregivers from Enukweni CBO (15)

Phase 4: Validation interviews/ questionnaire

Interviews with representatives of:
- ActionAid International (1)
- Department of Nutrition, HIV and AIDS (1)
- Ministry of Gender, Children and Social Welfare (1)
- National AIDS Commission (1)
- National Association of People Living with HIV and AIDS in Malawi (NAPHAM) (1)
- Palliative Care Association (1)

Organisations included in the questionnaire sample:
- Development Action for the Marginalised Rural Areas
- Emmanuel International
- Health workers living positively with HIV (HECAWLP)
- Livingstonia Synod AIDS Programme
- Mangochi Catholic Health Commission
- Namwera AIDS Coordinating Committee (NACC)
- NAPHAM Mangochi
- NAPHAM Mzuzu
- Nkhotakota AIDS Support Organisation
- Rumphi Catholic Health Commission
- Tovirane HIV/AIDS Organisation (THAO)
## ANNEX 3. POLICIES AND GUIDELINES WITH REFERENCE TO COMMUNITY CARE AND SUPPORT IN MALAWI

<table>
<thead>
<tr>
<th>#</th>
<th>Policies and Guidelines</th>
<th>Organisation</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>National HIV Policy</td>
<td>Ministry of Health</td>
<td>Overarching guiding document for implementation of HIV and AIDS activities in Malawi</td>
</tr>
<tr>
<td>2</td>
<td>National Community Home Based Care Policy</td>
<td>Ministry of Health</td>
<td>Policy and guidelines that define what CHBC providers should do in the home to improve health status, environmental quality of life of chronically/terminally ill clients and vulnerable children</td>
</tr>
<tr>
<td>3</td>
<td>Management of HIV-related Disease Guidelines</td>
<td>Ministry of Health</td>
<td>Guidelines for health practitioners and health workers in CHBC as they review and manage clients with HIV-related diseases</td>
</tr>
<tr>
<td>4</td>
<td>National Palliative Care Guidelines</td>
<td>Ministry of Health</td>
<td>Guidelines for health practitioners and others involved in the management and support of palliative care clients and families</td>
</tr>
<tr>
<td>5</td>
<td>National HIV testing and Counselling Guidelines</td>
<td>Ministry of Health</td>
<td>Views HIV testing and counselling in a continuum of care for HIV clients and is utilised on issues pertaining to HTC for CHBC clients</td>
</tr>
<tr>
<td>6</td>
<td>ARV Guidelines</td>
<td>Ministry of Health</td>
<td>Provides guidance on all antiretroviral drugs and client monitoring</td>
</tr>
<tr>
<td>7</td>
<td>Pre-ART Guidelines (Family HIV Clinic)</td>
<td>Ministry of Health</td>
<td>Guidelines to be used to ensure there is no delay in initiating ART and to be utilised on issues of pre-ART care issues for CHBC clients</td>
</tr>
<tr>
<td>8</td>
<td>Orphans and Vulnerable Child Care Policy and Guidelines</td>
<td>Ministry of Gender, Children and Social Welfare</td>
<td>OVC care is undertaken as part of comprehensive CHBC service</td>
</tr>
<tr>
<td>9</td>
<td>Early Childhood Development Policy and Guidelines</td>
<td>Ministry of Gender, Children and Social Welfare</td>
<td>Direct promotion of early childhood development (ECD) for all children and direction on community-based intervention for ECD</td>
</tr>
<tr>
<td>10</td>
<td>National policy and implementation strategy for community integrated management of childhood illness (IMCI)</td>
<td>Ministry of Health</td>
<td>Promote early identification of, treatment, care and referral of sick and chronically ill children in the home</td>
</tr>
<tr>
<td>11</td>
<td>PMTCT Guidelines</td>
<td>Ministry of Health</td>
<td>Provides direction on implementation of PMTCT interventions especially for chronically ill pregnant and postnatal mothers</td>
</tr>
<tr>
<td>12</td>
<td>Infection Prevention and Control Policy Guidelines</td>
<td>Ministry of Health</td>
<td>Provides guidelines on infection prevention and control measures while managing clients in any setting</td>
</tr>
<tr>
<td>13</td>
<td>Reproductive Health Guidelines</td>
<td>Ministry of Health</td>
<td>Apply to health practitioners and health care workers in CHBC during review and management of clients requiring reproductive health care referred by community care providers</td>
</tr>
<tr>
<td>14</td>
<td>Nutrition and HIV Guidelines</td>
<td>Department of Nutrition, HIV and AIDS (DNHA), within the Office of President and Cabinet (OPC)</td>
<td>Apply to health practitioners as they manage CHBC clients with nutritional-related diseases and apply to all providers of CHBC services during management of clients</td>
</tr>
<tr>
<td>15</td>
<td>Gender Guidelines</td>
<td>Ministry of Gender, Children and Social Welfare</td>
<td>Provide direction on gender issues while managing clients in any setting. CHBC providers are expected to use the guidelines during management of palliative care clients to ensure that gender issues are addressed</td>
</tr>
</tbody>
</table>

Source: CAN multi-country research – Malawi research, Phase 1 data