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Caregivers Action Network

COMMUNITY CAREGIVERS: THE BACKBONE FOR ACCESSIBLE CARE AND SUPPORT

MULTI-COUNTRY RESEARCH: **ZAMBIA REPORT**

Cordaid BUILDING FLOURISHING COMMUNITIES

COMMUNITY CAREGIVERS:
THE BACKBONE FOR ACCESSIBLE CARE AND SUPPORT
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Support provided by:
Caregivers Action Network (CAN) co-facilitators (Cordaid, HelpAge International, Hope Development Initiative, International HIV/AIDS Alliance and VSO International) and the Joint United Nations Programme on HIV/AIDS (UNAIDS). With additional support from the CAN IAC Research Group.

Date of publication: June 2013
Photography: Dare Cekelis/HelpAge International 2007
Design: Jessica Finkelstein Design

Recommended citation: Mwewa AM, Saili G and Simbaya J (2013). Multi country research on community caregivers: the backbone of accessible care and support – Zambia report. The Caregivers Action Network.

The multi-country research was commissioned by CAN, coordinated overall by Cordaid, implemented by ETC Crystal and Athena Institute – VU University Amsterdam in collaboration with the Country Research Teams and Research Advisory Board members, and financed by Cordaid and UNAIDS.

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ACRONYMS AND ABBREVIATIONS

AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral therapy
CAN	Caregivers Action Network
CHA	Community health assistant
CHBC	Community and home-based care
CPT	Care and prevention team
FBO	Faith-based organisation
HIV	Human immunodeficiency virus
NAC	National AIDS Council
NGO	Non-governmental organisation
NHC	Neighbourhood health committee
OVC	Orphans and vulnerable children
PHC	Primary health care
PMTCT	Prevention of mother-to-child transmission
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
VCT	Voluntary counselling and testing
WHO	World Health Organization

FOREWORD

This report is the result of research undertaken in Zambia 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.

Four research objectives guided the process and are reflected in this report. They 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.

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 lead researchers 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.

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 Zambia 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, Malawi and South Africa.

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 clients and caregivers. Moreover, three organisations implementing CHBC programmes were selected for in-depth study: Chikankata Health Services (run by the Salvation Army's Chikankata Mission Hospital); Bwafwano Integrated Home Based Care Organisation (run by Bwafwano Integrated Services Organisation); and Chipata Community Home Based Care programme (run by St. Paul's Parish, which is under the Archdiocese of Lusaka).

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

Needs of people living with HIV

The needs of people living with HIV have changed over time with the advent of ART. They have evolved from basic nursing care and end-of-life care to more wide-ranging care and support needs, including nutritional and economic needs. People living with HIV stated that their biggest need at present is food security – ensuring access to sufficient food and maintaining a healthy diet. Other challenges highlighted related to difficulties faced in accessing ART or other health services, in rural areas in particular. The research revealed a concern that if clients do not receive adequate support to meet their needs, in particular their socioeconomic and nutritional needs, they may face difficulties in adhering to their treatment and their health may decline.

Caregivers' roles

In line with the changes highlighted above, a similar shift has been observed in the type of services provided by community caregivers and through CHBC programmes—from services with a strong focus on nursing care to more comprehensive care and support services and programmes. Caregivers now have a role in record-keeping, linking of clients to services provided at facility level, health promotion activities, tracking clients living with HIV who are on treatment, encouraging defaulters to resume treatment, and educating family members on how to support their relatives to adhere to ART. Some caregivers reported additional roles such as counselling community members, testing individuals for HIV, and linking those living with HIV to treatment centres. The roles and responsibilities of caregivers are strongly defined by the scope of work of partner organisations and needs at facility level.

Service provision

The initial community-level response to HIV in the 1980s was driven by pragmatism and a sense of moral responsibility among many individuals to help those in need, This response was followed by efforts of non-governmental organisations (NGOs), including faith-based organisations (FBOs), to provide a more standardized and professionalised community-level care and support response. Increasingly, the government has engaged in the coordination and regulation of such services through the Ministry of Health, National AIDS Commission (NAC) and the development of various operational frameworks.

The main actors presently involved in the provision of care and support services in Zambia are line ministries and government departments, NGOs and communities. Health services in urban areas are accessed through a mix of public and private health institutions, while those in rural areas largely depend on institutions run by the government and NGOs. FBOs provide a significant percentage of health services through mission hospitals, which have links with other rural health facilities. Other local and international NGOs often provide community health care services on a smaller scale.

There are stronger sectoral and coordination linkages among stakeholders at the higher (national) level than at community level. That situation underscores the need for the government to play a stronger leadership role in coordinating and harmonising the activities of local and international partners involved in care and support programmes at the community level.

Health system integration

Zambia has a long history of involving community caregivers in the provision of health care at facility and community levels. It is widely accepted that community caregivers are linked to the health system primarily through the organisations they work for and these organisations links with specific health facilities. Moreover, Zambia's PHC structure recognises community caregivers as an important part of the health delivery system, as limited human resources constitute a major challenge to the effective and efficient functioning of PHC structures. Integration efforts continue as CHBC programmes are increasingly requested to report on their activities in communities through established national, sub-national and community structures. In a resource-constrained environment, there is recognition that national authorities require the support of NGOs and communities in the delivery of services.

The Zambian health sector does not necessarily define CHBC providers in terms of 'formal' and 'informal', although this distinction will be sharpened with the introduction by the government of a new category of specially trained and remunerated 'community health assistants' (CHAs) at the health post level in communities. It is envisaged that the primary functions of these individuals will be to engage in promotive and preventive health at the community level rather than curative work. CHAs are also being trained to have a broad disease focus by addressing conditions such as HIV, malaria, respiratory illnesses, diarrheal diseases and TB.

Decentralisation of HIV treatment

The scale-up of ART in Zambia, while not without challenges, has been positive. Community caregivers have been an integral part of this achievement. For example, there have been significant strides in decentralisation of HIV treatment that involve the active participation of community caregivers and their CHBC programmes. Most CHBC organisations now support clients with ART adherence and help monitor their check-ups and progress.

Many of the CHBC providers questioned indicated that they are able and willing to be trained to provide additional treatment-related services, including provision of antiretroviral drugs and diagnostic tests. Some respondents perceived the potential administration of ART by non-specialists at the community level as logical and critical to overcoming capacity limitations at health facilities. Others meanwhile—predominantly health professionals surveyed—are opposed to this idea because they believe CHBC providers do not and could not have the requisite skills and equipment needed to monitor clients closely enough. Government policy currently restricts such services to trained health specialists.

The national scale-up of government-run health posts as well as the introduction of mobile ART services offer future opportunities for the decentralisation of HIV treatment and making health services more broadly accessible to the population. Based on research responses, it appears that the decentralisation of ART in Zambia to the community level will likely take place in the near future but within limits. For example, non-specialists at the community level might become more engaged in different aspects of HIV treatment with the important exception of actually being able to disburse antiretroviral drugs to clients.

Challenges and concerns

Despite the many achievements related to care and support in Zambia, CHBC services and operations currently face a number of challenges, particularly in relation to: the coordination of CHBC programmes; funding for community health; variations in remuneration for community caregivers; addressing the needs of people living with HIV and other clients; the identification of clients in the community; and access to ART.

1 INTRODUCTION

This report is the result of research undertaken in Zambia 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, Malawi and South Africa.[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 programmes[2] 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 July 2012 by a Zambia-based research team with support from a Research Advisory Board (see Annex 1), ETC Crystal and Athena Institute – VU University Amsterdam.

The first section of this report presents the background to the Zambia country research and includes the findings of a desk review and a description of the first two research phases. The bulk of the report, Section 2, presents the findings and analysis of the research. Section 3 highlights challenges and concerns related to CHBC provision, while Section 4 contains a conclusion.

Note on terminology used

Within the Zambia context, many terms exist for those who work in the community and carry out one or more functions related to health care delivery and broader care and support. Terms used include, among others, treatment supporters, adherence support workers, lay counsellors, health promoters, community health advisors, outreach educators, community health representatives, peer health promoters, and peer health educators (Ministry of Health, 2010). Terminology used by the Ministry of Health in its National Health Strategic Plan (see Annex 2) also highlights the fact that drawing clear lines between different types of caregivers is difficult as many of their tasks and responsibilities tend to overlap.

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

1. All CAN documents relating to the 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'.

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, reference is made to 'community health assistants' (CHAs); similarly, another country-specific term is 'community-based volunteers' (CBVs), which is used when referring to unpaid primary and secondary community caregivers.

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. 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 research followed a basic exploratory qualitative approach. The rationale for electing this approach rested on the need to understand how health and other actors (key informants) in Zambia perceive and understand community care and support policy and ART strategies at national level. Phase 1 of the research was based on analysis of data collected at the national level and a review of policy-level literature on care and support in Zambia. Phase 2 involved analysis of the findings from three CHBC programmes being implemented in Zambia: Chikankata Health Services (run by the Salvation Army's Chikankata Mission Hospital); Bwafwano Integrated Home Based Care Organisation (run by Bwafwano Integrated Services Organisation); and Chipata Community Home Based Care (run by St. Paul's Parish, which is under the Archdiocese of Lusaka). The three case study programmes were selected as per pre-set criteria (see Annex 3) provided in the overall research framework and in consultation with a Research Advisory Board made up of local and national representatives engaged in care and support programming.

The first phase of the research included a document/literature review followed by semi-structured interviews with national-level actors engaged in policy formulation and interpretation. Semi-structured interviews were also used in discussions with key informants from small and medium-sized organisations (see Annex 4) working in care and support at national level. In terms of data collection, the research team manually and digitally recorded the in-depth interviews and focus group discussions. The recorded data were transcribed and coded using a pre-defined system and then analysed using qualitative analytical software (ATLAS.ti). Twelve national-level interviews were conducted with government policy actors and representatives from NGOs.

In Phase 2 of the research, 60 interviews were conducted with CHBC clients and community caregivers from the three CHBC programmes. Focus group discussions were conducted in all three programme sites with programme managers, staff, secondary caregivers and community representatives. The research team also conducted simple service observation in all three sites. Researchers accessed and reviewed secondary data provided by programme staff and examined care and support structures in each location. Policy documents and studies on HIV in Zambia were also reviewed for their relevance to training and support of caregivers. The team accessed and reviewed secondary data from online searches, conference papers and programme documents and reports from researchers on HIV and caregivers. Manuals and guidelines on HIV and CHBC were reviewed for contextual information. The research team also collected relevant information from donors, local and international NGOs and government agencies.

In order to verify and validate the data collected during fieldwork, researchers conducted additional semi-structured interviews based on the main findings of the research. Respondents included national-level participants interviewed in the initial phase and the three CHBC programmes investigated in this research. The Research Advisory Board assisted the researchers with the selection of an additional six

organisations providing CHBC for the validation phase in order to objectively include a broader range of actors engaged in care and support provision in Zambia and substantiate the findings from the three CHBC programmes. The organisations were selected based on the nature of their CHBC provision and the geographic area in which they operate. Findings from the interviews and questionnaires are incorporated in this report.

Limitations

Research limitations include the following:

- Logistics and resources determined the community locations where interviews were held. In Chikankata for instance, the research team was unable to reach some communities that had been selected within the catchment area because they were inaccessible due to impassable roads and time constraints.
- Programme staff and community leaders were not randomly sampled; they were chosen based on availability.
- In peri-urban areas (Bwafwano and Chipata), the research team noted that research fatigue among the respondents was a challenge as many have been exposed to numerous data collection exercises.
- The research team observed that there is a dearth of peer-reviewed literature in Zambia covering the relevant thematic areas. As a result, the bulk of resources relied upon, particularly in Phase 2 of the research, is unpublished. The research team also noted the following constraints in collecting literature on CHBC, caregivers and HIV: information was limited or not accessible within the timeframe, a central repository for information on the subject does not exist, and key respondents in some programmes were absent or unavailable.
- The timeframe to collect data and prepare the Phase 1 report was relatively short and compounded by initial delays in approvals from the Ethical Review Board and local authorities. The research team applied for ethical review in November 2011, but approval was only granted in February 2012. Following this approval, the research team requested approval from the Ministry of Health (as required), which was given in early March 2012.

1.2 DESK REVIEW

This sub-section provides a synthesis of literature reviewed (national and programme level) and background information on the current status of the HIV epidemic in Zambia and access to ART. It highlights Zambia's pioneering efforts in health reforms aimed at decentralising health care and the development of community-level social structures that are enabling participation of community caregivers in the provision of ART. It also considers some of the implications of the ART scale-up on CHBC, many of which are also referred to throughout this report.

History of CHBC in Zambia

A thorough understanding of the history and evolution of caregiving in Zambia requires recognition of the policy and structural reform process of the health sector from the late 1970s to the 1990s. The Alma-Ata Declaration[3] in 1978 provided the impetus and direction for the Zambian government to make primary health care the key channel for the delivery of health services. Prior to this, community participation was already a key feature of the Zambian health system as demonstrated by 30 percent of rural facilities being developed on a 'self-help basis'.[4] Existing policies at that time also included elements of free medical services (Kalumba et al., 1994). In response to management challenges in the health system, reform processes were provided for under the Medical Services Act of 1985, which framed the creation of semiautonomous hospital management boards for all major hospitals (Raken, 2004).

3 The Alma-Ata Declaration is considered a major milestone of the 20th century in the field of public health. It identified primary health care as the key to the attainment of the goal of 'health for all'. Additional information is available at www.who.int/social_determinants/tools/multimedia/alma_ata/en/index.html.

4 These are community-driven projects with little or no external support (e.g., from the government). In most cases, this involves community members using local materials (sand, water, bricks, etc.) to build the structures.

In 1991 the Ministry of Health began to promote community involvement as a means of bringing essential health care as close to the family as possible. Neighbourhood health committees (NHCs) were created to link clinics and communities and increase access to basic health services. Through this process, a "national community mobilization curriculum was developed and a training of trainers and roll-out methodology was adopted to strengthen and increase effectiveness of the more than 100,000 NHC members countrywide, with specific focus on NHCs learning health promotion and community mobilization skills" (Serlemitsos, 2006).

In March 1996, a new National Health Services Act came into operation that established the Central Board of Health (CBOH) (Melle, 2012). The CBOH was designed to monitor, integrate and coordinate the programmes of the health management boards, whereas the Ministry of Health was the main policy-making and regulatory body (Bossert et al., 2000; Foltz, 1997). The reorganised health delivery system was based on four levels with the Ministry of Health at the apex and the lowest level being the health centres/health posts. The reform programme also provided for local resource mobilisation and the creation of a number of structures for popular participation, including area health boards and health centre advisory committees (HCACs) (Bossert, 2000; Kalumba et al., 1994; Masiye et.al., 2008).

The 1996 law and Ministry of Health policy changes throughout the 1990s occurred as communities in Zambia were playing a key role in the delivery of health services. In the Zambian cultural context, families (nuclear and extended) have always been the unit of support for people with illness, as demonstrated in the response to the HIV epidemic in the 1980s and 1990s (Iliffe, 2006). In 1987 a hospital-based home care model, pioneered by the Salvation Army in southern Zambia to care for people living with tuberculosis (TB) and leprosy, was extended to people living with HIV (Iliffe, 2006). The initiative was a response to the lack of sufficient hospital beds for the growing number of people living with HIV in need of care and support (Malama, 1994; Myslik et al., 1997).

Between 1988 and 1990, the Catholic Church and Salvation Army established large CHBC programmes. By 1993, 22 mission hospitals were providing CHBC services to people living with HIV.[5] The model was easier to implement in urban areas due to lower travel costs and less staff time required from hospital-based caregivers (Iliffe, 2006). In some areas, clinical health workers were supplemented and in some cases replaced by trained 'lay' people based in the community. These non-medical community caregivers bridged the gap between medical institutions and family (primary) caregivers.

The HBC Forum was established in 2005 by key CHBC organisations and other stakeholders, with a priority responsibility to address the lack of guidelines and standards for CHBC. In 2007, several stakeholders including the National AIDS Council (NAC) and the HBC Forum developed the Zambia National Minimum Standards for Community and Home-Based Care Organisations. The guidelines were developed through a series of consultative processes facilitated by NAC and the HBC Forum.

Literature reviewed suggests that CHBC is now an integral part of Zambia's public health system. NGOs, including FBOs, provided the initial innovative community-level responses to HIV, but increasingly the government has engaged in coordination and regulation of such services through the Ministry of Health, NAC and the development of various operational frameworks. NGO-led programmes have continued to evolve due to resource constraints, changes in clients' needs, increased demands for services, introduction and scale-up of ART and enhanced involvement of communities. Although community caregivers were already an integral extension of the public health services prior to the introduction of ART, the scale-up has increased and expanded their roles and promoted the uptake of medical care for HIV (Cataldo et al., 2010).

Current status of the HIV epidemic

Zambia has a generalised HIV epidemic. The primary modes of HIV transmission are through heterosexual sex and mother-to-child transmission. Infection rates are highest in cities and towns along major transportation routes and lower in rural areas with low population density. According to the most recent estimates from the Joint United Nations Programme on HIV/AIDS (UNAIDS), as of 2011 Zambia was

5 In 1993, the distribution of health facilities in Zambia was as follows: Ministry of Health hospitals (43); other government health facilities (795); mission hospitals (29); other mission health facilities (69); private hospitals (11); and other private health facilities (139) (Berman, 1995).

home to an estimated 970,000 people living with HIV. That corresponded to an adult HIV prevalence of about 12.5 percent (UNAIDS, 2012).

Scale-up of ART

A major area of interest in this research was the impact of the rapid scale-up of ART on caregiving, the roles of caregivers and the needs of clients. Figure 1 provides a visual snapshot of the extent to which ART coverage has expanded in Zambia. As Table 1 indicates, remarkable progress has been made in the number of individuals receiving ART. In 2005, only 21 percent of those eligible for treatment had access. By 2011, the percentage had increased to 83 percent. The upsurge in the provision of treatment is linked closely to the government's introduction of free ART in 2003 and the expansion of ART provision in 2005 to include related services (UNGASS Zambia Country Report, 2011). Despite this progress, 17 percent of those in need of treatment still did not have it in 2011. Of the 502,432 people reported as eligible for treatment, more than 86,000 did not have access to ART.

Table 1. ART coverage and enrolment figures for Zambia, 2003-2011

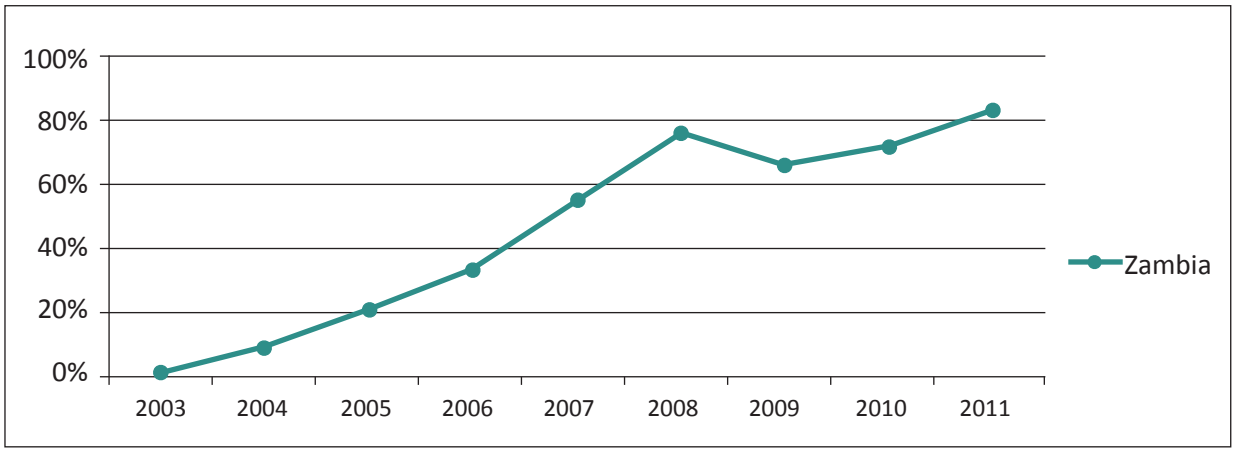
Year	Total number on ART	Total number eligible for ART*	Total ART coverage**
2003	1,121	222,964	1%
2004	20,000	227,747	9%
2005	48,585	234,940	21%
2006	82,030	245,721	33%
2007	151,199	272,468	55%
2008	219,576	289,519	76%
2009	283.863	431.488	66%
2010	344,407	479,138	72%
2011	415,685	502,432	83%

* *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 Zambians, 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 TB (a common co-infection among HIV-positive people, especially in sub-Saharan Africa) and reduces HIV and TB transmission.

2 RESEARCH FINDINGS

This section presents the findings of the research and associated analysis and is structured around 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. Particular 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

This research shows that the needs of people living with HIV have evolved over time. In the pre-ART era many people living with HIV were cared for in their homes. Their predominant needs related to nursing care and end-of-life care as well as support within the home environment. With the scale-up of ART programmes, other needs developed. Clients now state that their biggest challenge is ensuring access to sufficient food and maintaining a healthy diet. Clients mentioned that their drug regimens are most effective when they eat nutritional foodstuffs, but they are often unable to afford them.

Lack of adequate food for clients on ART and TB treatment was a problem identified by many CHBC programmes. From the perspective of primary caregivers, clients need nutritional support foremost. Focus group discussions with secondary caregivers and community representatives also stressed the importance of nutritional support. Respondents from across the spectrum observed that food insecurity—lack of sufficient food and nutrition—contributes to clients defaulting on treatment. In some instances, programmes have provided targeted nutritional support based on set criteria. However, this approach has its limitations. Some secondary caregivers observed that individuals on treatment who are not eligible for nutritional support have at times defaulted after expressing dissatisfaction with the targeted approach.

Although many clients stated that they are more productive as a result of ART, with a small number able to engage in economically productive activities, opportunities for generating an income are limited. As a result, many clients continue to rely on relatives and friends to support them, particularly in relation to their nutritional needs.

Transportation to access health services is another major challenge for clients. Such challenges are particularly severe in rural areas, such as the Chikankata research site. Many clients living far from the hospital struggle to access ART and other health services that have not been decentralised to the remote and rural locations of Chikankata.

Respondents questioned in relation to the three case study programmes reported shifts from the traditional CHBC services focused on nursing bedridden people living with HIV to the inclusion of ART adherence and comprehensive care and support including physical, psychosocial, socioeconomic, legal and human rights and nutritional support. Increasingly, clients are supported to engage in small income-generating activities. The research shows a concern that if clients do not receive adequate support to meet their changing needs, particularly in relation to economic wellbeing and nutrition, they may face difficulties in adhering to their treatment and their health may decline again.

2.1.2 Caregivers' roles

Caregivers associated with all three case study programmes noted that their work initially focused on providing support in terms of the management of symptoms such diarrhoea, coughs, skin conditions and throat problems as well as with bathing, cleaning homes and surroundings, caring for children, cooking

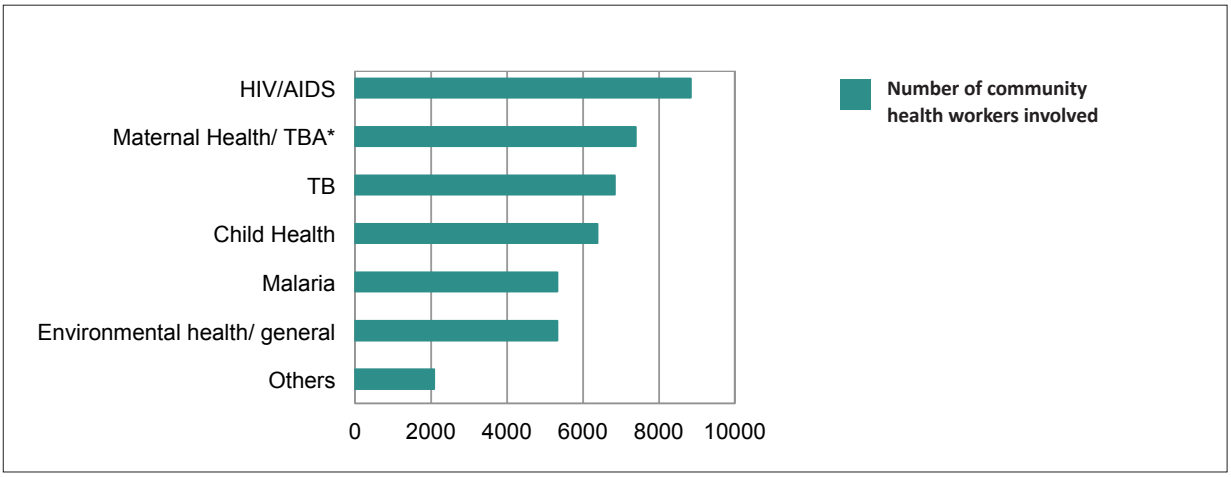
food and accessing drugs from health facilities. Most said that care and support in the traditional sense of caring for bedridden clients continues but to a relatively lesser degree. With the introduction of free antiretroviral drugs and the expansion of ART provision, caregivers have taken on new and additional roles and responsibilities, such as the tracking of clients on ART, encouraging defaulters to resume treatment, and educating family members on how to support their relatives to adhere to ART. Some caregivers reported additional roles such as record-keeping at facility level and in the community; health promotion; counselling community members; and linking HIV-positive individuals to treatment centres or linking community members to various services at facility level (e.g., for maternal and new-born child health services, including prevention of mother-to-child transmission [PMTCT] of HIV). In addition to direct treatment, care and support, community caregivers in HIV programmes are also involved in mobile voluntary counselling and testing (VCT) sessions, which are conducted by public health facilities aimed at decentralising access to these services.

Community representatives affirmed that the responsibilities of caregivers have increased over the years. They highlighted that their tasks now also include offering advice on medication, collecting antiretroviral drugs on behalf of clients and accompanying clients to health care facilities when the need arises. With regard to this new role of linking and tracking clients to ART centres, caregivers reported challenges in identifying clients in the community relative to the pre-ART period. In the past—with the assistance of community members and their own fieldwork—caregivers could identify potential clients who were usually bedridden or visibly sick. In the ART era, identification of clients requires stronger links with health facilities as clients become more ambulant and without overt signs of HIV-associated ailments.

Training opportunities provided to caregivers in the three case study programmes also highlight the broad range of services provided by caregivers. These training opportunities include behaviour change, leadership skills, hygiene, administration of DOTS (directly observed treatment, short course) for tuberculosis treatment, treatment adherence support, end-of-life care and nutrition advice. The caregivers themselves stated that the trainings provided, including the work they do, has added value in their roles as parents or guardians as they are able to use the information and new skills in family settings.

Evidence indicates that more community caregivers are engaged in HIV-related service programmes than in any other single health programme, as shown in Figure 2 below. The figure depicts the estimated number of community health workers (as defined by the Ministry of Health) who were active in health service programmes in 2012. Most were involved in health-related programmes, which focus on treatment, care and support for people living with HIV (8,846), followed by maternal health/TBA (7,399); TB (6,837); child health (6,382); malaria (5,329); environmental health/general (5,324) and other health-related issues (2,085).

Figure 2. Involvement of 'community health workers' (CHWs) in health service programmes



* *TBA = traditional birth attendant*
Source: Ministry of Health (2012)

2.1.3 Service provision

A number of line ministries are involved in the provision of care and support in Zambia. At the fore is the Ministry of Health, which provides PHC services through the various levels of the health care system—including health posts, health centres, level one hospitals, level two hospitals and level three hospitals. The lowest service provision point in the health sector is the health post, where community health care is provided.

The Ministry of Community Development, Mother and Child Health (MCDMCH) also provides services at the community level. It has an important role through its focus on prevention primarily related to maternal and child health, whereas the Ministry of Health is more focused on the curative aspects of health. The MCDMCH also provides social welfare assistance (including cash transfers) at the community level, particularly to support orphans and vulnerable children (OVC) and other vulnerable groups. The Ministry of Defence also provides some health services through military hospitals and clinics.

Health services in urban areas are accessed through a mix of public and private health institutions, while in rural areas services are provided by the government and NGOs, including FBOs. The Ministry of Health has a memorandum of understanding (MoU) with FBOs through the Churches Health Association of Zambia (CHAZ), an umbrella organisation. Through this agreement, the Ministry of Health provides grants and seconds skilled health workers to the FBOs. Such partnership is vital because FBOs provide a significant percentage of health services through the mission hospitals, which have links with other rural health facilities. For instance, Chikankata Mission Hospital is the main provider of care and support services in the Chikankata catchment area, which has limited government health facilities.

Other local and international NGOs often provide community health care services on a smaller scale. For instance, Bwafwano Integrated Health Services provides CHBC services to people living with HIV, TB clients and OVC. Recently Bwafwano has instituted a deliberate change in focus from "basic nursing care to more comprehensive care and support that includes counselling, referrals, medical care and support, logistical support to access diagnostic and treatment services and ART and TB treatment adherence support" (Bwafwano, 2011).

One of the biggest bottlenecks over the years to service provision is poor coordination and integration of care and support programmes, particularly high-impact interventions. Linked to that is the fact that limited human resources constitute a major challenge to the effective and efficient functioning of PHC structures.

Service provision by caregivers

Table 2 outlines the care and support services provided to clients by 'primary caregivers' and 'secondary caregivers' through nine CHBC-providing organisations questioned during the validation phase of the research. The table shows that primary caregivers predominantly provide direct care and support services to clients, whereas secondary caregivers also provide support in health facilities as well as implementing programmes to strengthen the knowledge, skills and self-esteem of their clients. Services such as HIV testing and the provision of pre- and post-test counselling and information are tasks that generally are not assigned to primary caregivers by the nine organisations surveyed. The roll-out of ART within the country has contributed to an expansion of services provided by secondary caregivers, in particular, to include the provision of support at health facilities, the tracking of clients in communities and supporting treatment adherence.

Table 2. Service provision by primary and secondary caregivers within organisations providing CHBC services*

Type of services provided	Number and % of organisations questioned providing specified services through secondary caregivers		Number and % of organisations questioned providing specified services through primary caregivers	
	Number	%	Number	%
Direct care and support to clients				
Basic nursing care: *for people living with HIV*	7	78	5	56
Basic nursing care: *elderly care*	6	67	3	33
Basic nursing care: *malaria*	7	78	3	33
Basic nursing care: *other diseases*	5	56	3	33
Clinical care (e.g., taking blood pressure, weighing people) in organisation's own facility	4	44	3	33
End-of-life care/palliative care	4	44	2	22
Pain relief	7	78	5	56
Personal hygiene	9	100	5	56
In home/community: *pre- ART patient counselling*	8	89	4	44
In home/community: *ART adherence support*	8	89	4	44
In home/community: *recruitment of patients for VCT services*	8	89	3	33
In home/community: *recruitment of patients for ART services*	8	89	3	33
In home/community: *recruitment of pregnant women for PMTCT services*	7	78	3	33
In home/community: *HIV pre-test information*	9	100	1	11
In home/community: *HIV testing*	7	78	1	11
In home/community: *HIV post-test counselling*	8	89	1	11
Health education : *HIV*	9	100	2	22
Health education: *malaria*	8	89	2	22
Health education: *other diseases, e.g., TB and STIs*	8	89	1	11
Social support (e.g., shelter, clothing, assisting with accessing IDs or birth certificates, social workers, etc)	7	78	4	44
Livelihood support (e.g., income-generating activities, savings groups)	7	78	2	22
Legal support	6	67	1	11
Nutritional support/referral for nutritional support	5	56	3	33
Spiritual and/or emotional support	8	89	1	11
OVC care	8	89	2	22
Referral of clients to clinical services (clinics, hospitals)	9	100	1	11
Organise or provide transport for health facility visits	6	67	3	33
Educating members of the client's household	8	89	1	11
Assistance to service provision in local health facility				
Assistance in local health facility: *pre-ART counselling*	7	78	1	11
Assistance in local health facility: *HIV pre-test information*	7	78	0	0
Assistance in local health facility: *HIV testing*	6	67	0	0
Assistance in local health facility: *HIV post-test counselling*	6	67	0	0
Assistance in local health facility: *administrative tasks*	7	78	1	11
Assistance in local health facility: *other*	7	78	1	11
Specific types of support / activities				
Specific support for women: *women and child protection and SRHR interventions*	5	56	1	11
Specific support for women: *empowerment and self-reliance interventions*	5	56	1	11
Lobbying and advocacy activities	6	67	1	11

* *Based on a survey of nine organisations providing CHBC services*
Source: CAN multi-country research – Zambia research, 2011-2012

The research findings show that CHBC organisations work primarily through secondary caregivers, although primary caregivers continue to provide critical care and support to family members on treatment. Primary caregivers in interviews highlighted the supportive role they play, particularly in the referral process by providing information to secondary caregivers regarding the condition of the client, levels of adherence and challenges faced. Additionally, primary caregivers listed emotional support as important in assisting the client to adhere to treatment. The most common task performed by primary caregivers as indicated in their responses is providing food and in some cases proving care and support to children within affected households.

2.1.4 Policy environment

The policy environment is shaped by various sector-specific and national-level policies. Since 1992, Zambia has been implementing wide-ranging health sector reforms aimed at attaining equity of access to cost-effective quality health services, as close to the family as possible. This vision is shared by health professionals and is shaping care and support services across the country.

The Sixth National Development Plan (SNDP) provides the overall national framework for all government social and development efforts. The health chapter in the plan lists four key priorities in the area of HIV. These priorities are also reflected in the National AIDS Strategic Framework (NASF) 2011-2015. Among the priorities listed in both the SNDP and the most recent strategic framework is a focus on accelerating universal access to ART and care and support for people living with HIV as well as their caregivers and families. Community care and support is recognised within the NASF as an integral component of the continuum of care, particularly in the context of ART.

As noted in Section 1.2, in 2005 the Ministry of Health and NAC, in partnership with other actors in the newly formed HBC Forum, recognised the need for standards for CHBC, including in regards to training of caregivers and in the provision of services. Through collaborative efforts, the Zambia National Minimum Standards for Community and Home-Based Care Organisations was launched in 2007 by NAC and the Ministry of Health. In line with the minimum standards, a package of eight modules (the National Community and Home Based Care – Training Package) was developed as a guide for the comprehensive training of community caregivers. The guidelines provide a framework for accrediting the operations of CHBC organisations and monitoring of programming.

The Ministry of Health and NAC stipulate that the accreditation to operate as a CHBC organisation is based on the 2007 national minimum standards for CHBC providers. The associated comprehensive training guide provides for both qualitative and quantitative monitoring of CHBC programming by NAC and the Ministry of Health.

The Joint Mid-term Review of the National AIDS Strategic Framework (2006-2010) indicates that the introduction of the minimum standards has contributed to an improvement in the quality of care provided to clients. Yet at the same time, the national HIV policy does not provide specific definitions of the types and roles of 'community-based volunteers'. The term 'caregiver' is not explicitly used in the text; however, the policy recognises that "community-based volunteers and support from FBOs, religious and health facilities form the backbone of these programmes." Moreover, the absence of a regulatory framework for incentives given to community caregivers has hampered effective management of community caregivers in the country, including guidance to FBOs and other NGOs on how to better support community caregivers—most of whom are volunteers and are not compensated for the important work that they do.

The 2009 NGO Act intended to address and clarify the registration of NGOs, including community-based organisations (CBOs). The full implications of the law for civil society are still unclear as it has not yet been fully implemented by the government.

2.2 HEALTH SYSTEM INTEGRATION

This sub-section assesses the extent to which community caregivers have been integrated into the state health system in practice as well as formally through state policies. It also identifies opportunities for further decentralisation of HIV treatment.

2.2.1 Primary health care structures

Zambia has a long history of involving community members as caregivers in the provision of health care at facility and community levels. Interestingly, it appears that no formal organogram exists that 'places' and defines the role of community caregivers within the health system. It is widely accepted that community caregivers are linked to the health system primarily through the organisations they work for and these organisations links with specific health facilities (e.g., in tracking and linking clients to ART clinics under FBOs and the public health system).

Community caregivers are recognised within PHC structures as key players in the delivery of health services. Community participation is fostered based on a policy framework that prioritizes the delivery of health services as close as possible to the family. 'Community-based volunteers' are linked to health facilities through social structures such as neighbourhood health committees (NHCs). To enhance access, the health sector has organised various geographical locations into smaller units called zones. Each of these zones is linked to a health facility. Community caregivers are drawn from these zones and are recognised as an integral part of the delivery of primary health services. There are indications that community caregivers are also assisting in selected hospitals and not only at health centres/posts. In all of these settings, their roles include record-keeping, tracking clients and assisting with taking vital signs.

In line with the PHC structures created under the public health system, all three case study CHBC programmes at the centre of this research have community caregivers who are a key part of the delivery of health services. At Bwafwano and St. Paul's these caregivers are ultimately linked to the public health facilities through the NHCs. Chikankata uses a different model, with caregivers linked to the mission hospital, which provides trainings and supervision. Chikankata Mission Hospital also has caregivers working within the hospital who assist with taking basic vital signs, filing and record-keeping, and routing clients around the hospital. In the peri-urban programmes, St. Paul's and Bwafwano, caregivers work closely with the clinics run by the organisations; however, these caregivers also link critically ill clients with the public health facilities. Although training is mainly provided through the programmes caregivers work with, they can sometimes access training led by public health facilities, e.g., adolescent ART training and adherence support.

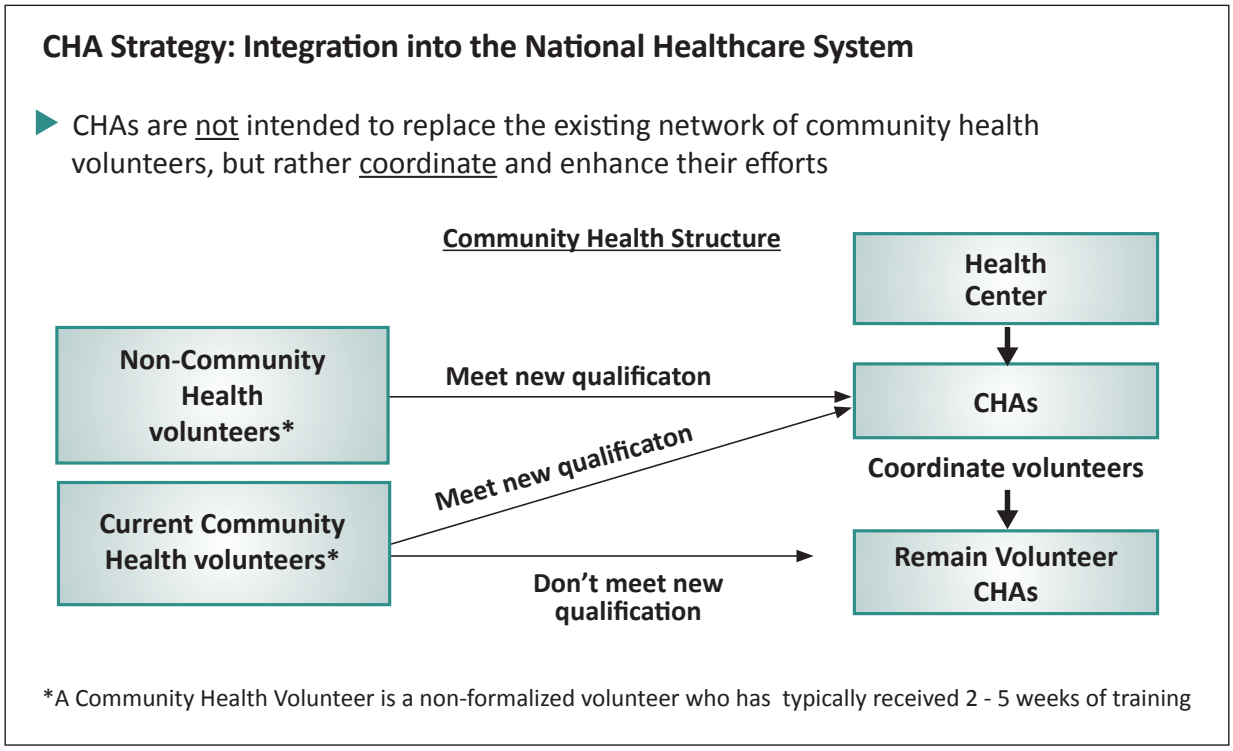
Although the Zambia Salvation Army runs the mission hospital in Chikankata, the hospital receives grants from the government, which also pays for some of the salaries of health professionals practicing at the institution and supplies delivered. This indicates that at the highest level there is recognition by the government that primary health care is not the preserve of public health institutions.

Even though caregivers have been involved in care and support service delivery for many years in Zambia, the effectiveness of this approach is constrained by a lack of formal linkages with the health system and no formal accreditation or remuneration for caregivers. The Ministry of Health is seeking to address this issue by introducing a new cadre of community-based health workers called 'community health assistants' (CHAs). The Health Professionals Council of Zambia will accredit these assistants, who will receive training for one year and regular (monthly) stipends. They will be stationed at health posts, the lowest health service delivery point in the health system. It is envisaged that the primary functions of the CHAs will be to engage in promotive and preventive health at the community level rather than curative work, including a broad disease focus encompassing HIV, malaria, respiratory illnesses, diarrheal diseases and TB.[6] CHAs will represent Zambia's first efforts to have 'formal' community health workers.

At the time of research, this initiative was in a pilot phase supported by donors and the government. However, if the introduction of CHAs at health posts proves to be a success, opportunities will increase to further integrate other community caregivers (referred to in Figure 3 below as 'community health volunteers') into the health system. This is based on the recognition that CHAs will contribute to the coordination of community caregivers linked to the health posts. Figure 3 illustrates the role that CHAs will play vis-à-vis other community caregivers.

6 After the conclusion of research for this report, the first batch of CHAs graduated from the one-year training and their position had been formally accredited (September 2012).

Figure 3. Integration of 'community health assistants' (CHAs) into the public health system



Source: Ministry of Health (2012)

At this point it is worth noting a concern expressed by respondents that the introduction of a regularly remunerated community cadre may create challenges and potentially tension in the management of the vast numbers of community caregivers who are not part of this cadre and therefore do not receive the same incentives. On the other hand, community leaders interviewed said that although most community caregivers are not regularly remunerated, most have a sense of satisfaction by seeing a healthier community.

2.2.2 Decentralisation of HIV treatment

Despite the impressive scale-up of ART across the country over recent years, there are still limitations in certain areas. For instance, in Chikankata ART prescription is only available at the mission hospital although the area has some (though only a few) government-run rural health facilities that could be used. The size of the area presents challenges as some clients must travel long distances to access drugs and services at the hospital. Programme staff at Chikankata noted that the further decentralisation of treatment to health facilities where ART is not yet provided is an important step to improving access to ART.

The Ministry of Health appears to recognize the need to address this barrier as it has been leading a process to make ART more accessible to communities. This has primarily included provision of both facility-based and mobile access to treatment. As reflected in the following statement, made by a key informant from the Ministry of Health, elements of the 'Treatment 2.0' framework developed by WHO and UNAIDS[7] are already integrated in the ministry's health programming:[8]

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7 As noted on the WHO website: "'Treatment 2.0' is an initiative that aims to catalyse the next phase of HIV treatment scale up through promoting innovation and efficiency gains. It will help countries to reach and sustain universal access to treatment, and capitalize on the preventive benefit of antiretroviral therapy through focused work in five priority areas: 1) optimize drug regimens; 2) provide point of care diagnosis; 3) reduce costs; 4) adapt delivery systems and 5) mobilize communities." More information about the overall initiative is available at www.who.int/hiv/topics/treatment2/en/index.html and www.who.int/hiv/topics/treatment2/en/index.html.

8 It should be noted that aside from this very specific comment about Treatment 2.0, the majority of respondents did not indicate specific knowledge about the strategy. Yet at the same time, the discussions and observations regarding decentralisation and increasing community engagement in HIV service delivery underscore the fact that stakeholders in the country already recognise and respect many of the main Treatment 2.0 principles.

> *Treatment 2.0 is a combination of different strategies that come together that should translate into better care, more quality effective care. So it talks about using fixed-drug combinations, which make the pill burden much easier on the patient but also much cheaper for the programme, because the programme does not have to think about transporting or storing tons of medicines. And community aspects are part of Treatment 2.0; among the questions is how you cultivate your community interventions to bring the best that you can for your patients. I think the ministry has bought into 2.0 and is already implementing; I think we have been doing this already and just do not call it 2.0.*

Generally, national guidelines and policies highlight the important role that communities play in assisting with the delivery of services, mobilisation of clients, and accountability of the national response. Guiding documents recognise that the scale-up of interventions in rural areas is different from urban areas. For instance, mobile services are effective in scaling up PMTCT, VCT and ART in rural and remote locations. However, for such services to be effective strong partnerships with community systems and structures are required.

Respondents had varied perspectives on the decentralisation of ART to community caregivers. Some respondents perceived the potential administration of ART by non-specialists at the community level as logical and critical to overcoming capacity limitations at health facilities. One policy level informant and an ART specialist indicated support for such decentralisation as follows:

> *The patients I saw today didn't need to see me and if I could find a way for them to actually get their drugs within the community that's something that can be explored—it could decongest my clinic. So I had to tell some patients that they don't need to see me every three months, but that they will see somebody every three months and they can see me every six months. So then, it opens up my calendar to see critically ill patients or with acute effects. So if there was a community hub that such patients could go to and this hub is able to cater to their basic needs and is able to track them and keep them engaged, that would be a good thing.*

Other respondents, though, worried that CHBC providers do not and could not have the requisite skills set and equipment needed to monitor clients closely. Based on responses in this research it appears that the decentralisation of ART in Zambia to the community level in the near future will likely take place but will have some limitations. For example, non-specialists at the community level might be more engaged in different aspects of HIV treatment with the important exception of actually being able to disburse antiretroviral drugs themselves to clients.

2.3 CAREGIVERS' POTENTIAL

This sub-section investigates the contributions and potential role of caregivers in the expansion of HIV prevention and treatment as well as in PHC programmes.

2.3.1 HIV prevention and treatment programmes

Community caregivers are actively engaged in HIV prevention programmes. They are taking advantage of opportunities while in households to provide information to clients and family members to raise awareness of HIV. Additionally, outreach activities organised by health facilities are being utilised by caregivers to share health education (including information on HIV) with community members. In some areas, caregivers also distribute condoms.

Within the Ministry of Health, HIV prevention programmes are coordinated under the Directorate of Public Health and Research. However, opportunities to further expand the roles and responsibilities of community caregivers in HIV prevention programmes are being explored and utilised by several other units within the Ministry of Health and partners. As noted earlier (in Section 2.2.1), an initiative being

implemented under the Directorate of Human Resources and Administration is the introduction a new formal cadre of community caregivers called CHAs. The introduction of CHAs in the community will provide a significant opportunity to coordinate prevention activities in HIV and more broadly. These formalised community health workers will spend 80 percent of their working time within the community and will focus on prevention activities. Respondents anticipated that members of this cadre, drawn from the local community, will have a deeper appreciation of challenges within the community and will serve as a link between the health facility and the community.

Task-shifting of responsibilities from nurses to community caregivers has been strongly supported by the government of Zambia (Morris & Chapula, 2009). As a result, caregivers are currently providing significant contributions to treatment programmes. Informants reported that these caregivers—who generally work on a voluntary basis and are not paid for the work they do—help with triaging, keeping records, tracking clients in the community, linking clients to different services, offering peer support, participating in health education talks including treatment adherence, and providing emotional support.

Ministry of Health officials also mentioned innovative initiatives being piloted in which community caregivers are providing health protection measures to individuals receiving HIV treatment. One informant stated:

> *We are piloting a different package of care for...patients with HIV instead of the usual soap and towel, because they are no longer bedridden; we are looking at preventing malaria, preventing diarrheal diseases. In that package, we have a water filter, treated mosquito nets and a few other items. The whole purpose is to prevent [such diseases] in people who are living with HIV because...their CD4 count [could] fall drastically. So, we have introduced this package, and with the help of our partners we are doing a pilot in Copperbelt and North-Western provinces to see how this package can assist to further care for people who are living with HIV.*

It was noted in Section 2.2.2 that discussions have begun regarding the possibility of expanding the role of community caregivers in HIV treatment. Currently, community caregivers are primarily involved in providing adherence advice to clients on ART, including identifying side effects of medications and linking clients in need with hospitals. Community leaders in Chikankata indicated during a focus group discussion that it is worth considering changing policies to allow caregivers to give medicines to clients in addition to the current roles they are performing. That suggestion was supported by some secondary caregivers working in that area who said that with appropriate training, the care and prevention teams (CPTs)[9] could be in the frontline in the administration of ART with the possibility of administering diagnostic tests (e.g., for CD4 counts) and interpreting results. Results from the validation phase of the research indicate that most CHBC providers are already engaged in important ART-related activities such as provision of pre-ART counselling and monitoring clients to determine whether they might need a check-up. Of note is that representatives from more than half of the nine organisations surveyed during this phase indicated that professionals and volunteers associated with their organisations could conceivably be involved in distributing antiretroviral drugs. This appears to underline their desire to be more engaged in all aspects of HIV treatment, care and support. However, most health professionals from the government sector remain opposed to allowing non-specialists to dispense these drugs directly and undertake specific medical tasks such as diagnostics.

It is notable in this regard too that one of the emerging issues in Zambia is the need to increase access to and uptake of paediatric HIV testing and treatment services in line with the drive to achieve Millennium Development Goal (MDG) 4. According to the Ministry of Health, some 130,000 children in Zambia are HIV-positive with 36,000 of them in immediate need of ART—yet at the end of 2011, only 30,700 children were receiving treatment. Given this apparent challenge facing the ministry, one of the opportunities identified by respondents is the need for increased community engagement by caregivers in the scale-up of paediatric ART.

9 CPTs are social structures developed by the Chikankata Mission Hospital that encompass various community-based agents providing care and support to people living with HIV in the community.

2.3.2 Primary health care programmes

As noted throughout this report, community caregivers in Zambia are already playing multifaceted roles in the delivery of health services in their communities. This has occurred in part because the acute shortage of skilled health workers has necessitated the participation of community caregivers, who are generally volunteers and not paid for the work they do, in the delivery of PHC services. With the policy focus on decentralised health services, many public health interventions are increasingly relying on community caregivers to take services closer to the people. Therefore, this pool of individuals and the organisations they work with complement the work of government-employed health workers. Hence, there is widespread agreement on their importance in helping improve access to and coverage of communities with health services and, consequently, bolster health outcomes (Ministry of Health, 2010).

One current challenge is that the majority of community caregivers appear to be focused on services for people living with HIV, even though there is a critical need for such support more broadly in the overall system. This is a significant weakness and challenge to the effective delivery of PHC programmes. Furthermore, it presents a disconnect between the PHC component and the community care and support structures in the sense that the linkages are invariably based on specific diseases such as HIV.

While there were suggestions that the roles and responsibilities of community caregivers could expand further, there are limitations given the constrained health sector resources. It is within this resource-constrained setting that the Ministry of Health is exploring the feasibility of employing formalised CHAs at community level and associated with health posts. The expectation is that improvement in the quality of services (preventive and promotive) delivered by these CHAs, in collaboration with other community caregivers, will lead to a reduction in the flow of cases of preventable illness. One hoped-for outcome is that this approach will allow health facilities to focus more on cases that require higher-level medical expertise, thus mitigating the impact of the clinician shortage (Ministry of Health, 2010).

It is anticipated by health sector actors that this new cadre of health workers will play a key role in the delivery of PHC services. An ART specialist highlighted this point:

> *Essentially, you are looking at a cadre who knows the people well and will be able to be a critical link between the facility and the community for some of these [important] services....They will be able to provide these services in a recognised way with a clear scope of work.*

Supervision and referral are key elements embedded in the new CHA approach. Respondents demonstrated awareness of the proposed supervision of CHAs—i.e., they will report to the nurses or the relevant individuals in charge at the health post and will be supervised at the nearest 'parent' health centre on a monthly basis. The Ministry of Health has said that supervisors in these parent health centres will be trained and equipped with a standard manual, tools and resources to facilitate regular supervisory visits (Ministry of Health, 2012).

A major limitation to the further integration of non-governmental community caregivers in the public health system is the absence of a national community information system (C-HMIS). Whereas local and international partners are collecting community-level data and have registers on community caregivers, to a large extent this information does not filter through to the national level. At district level, coordination of community-level activities is often the responsibility of environmental health officers. Therefore, in the absence of a fully dedicated 'community mobilisation officer' and an operational C-HMIS, the full integration of community caregivers will remain a challenge.

2.4 COMPLEMENTARITY BETWEEN FORMAL AND INFORMAL COMMUNITY CAREGIVERS

This sub-section assess the potential for 'formal' (state health system) and 'informal' (community caregivers in NGOs) programmes to complement each other.

2.4.1 Recognition and acceptance

Care and support initiatives led by NGOs (notably FBOs) have long been a key and widely accepted part of Zambia's public health system. An example of this strong complementarity includes support provided by government health workers during trainings organised by CHBC organisations. For example, government health workers regularly attend and support treatment adherence trainings provided by the Archdiocese of Lusaka. This contribution and support from the local health facilities validates the trainings and provides opportunities for standardisation of the trainings across all involved actors. Likewise, the existence of toolkits and guidelines developed by the Ministry of Health and NAC demonstrates the deeply embedded formal linkages between the community care system and the public health system. Examples of such tools include the standardised training package for CHBC providers and the minimum standards for CHBC.

The Zambian health sector does not necessarily define CHBC providers in terms of 'formal' and 'informal'. However, the introduction of the CHAs will constitute a new 'formalised' cadre, thereby presenting opportunities for complementarity with the different categories of community caregivers who will not receive the same training. CHAs based at health posts will coordinate and partner with community caregivers supervised by NGOs as well as other unpaid community caregivers working at health centres and at community level under Ministry of Health social structures (e.g., neighbourhood health committees [NHCs]). The expectation is that improvements in coordination, referral systems, supervision and reporting will ensure that CHAs at health posts work closely with other community-based caregivers.

However, as noted previously, it is important to recognise the potential for tension within communities given that CHAs will be remunerated and registered formally while other CHBC providers will continue to work under the same conditions as now—i.e., with irregular, in-kind incentives, short trainings and no formal registration or remuneration. Effectively recognising and managing such tensions, should they occur, is critical because the CHAs will not replace the existing categories of community caregivers. Instead, the majority of CHBC services will likely continue to be carried out in the same manner, and by the same category of caregivers, as now.

2.4.2 Coordination

The Ministry of Health has established national management units such as NAC for specific health programmes. Coordination of HIV programming within the ministry falls under two directorates: Public Health and Research, which handles HIV preventative structures or issues, and Clinical Care and Diagnostic Services, which handles ART and other treatment, care and support services. Provincial health offices and district health offices coordinate HIV services at the lower level.

Community structures are also critical in the coordination of these services. Sub-national level structures established through NAC provide opportunities for NGOs and communities to participate and contribute towards the national response to HIV. Forums for participation exist under the provincial, district and community AIDS task forces, which are part of provincial development coordination committees and district development coordination committees. Community groups can mobilise and participate in these local level structures, particularly the community AIDS task forces.

Lower-level community structures link with high-level formal and representative forums for all partners:government, private sector, cooperating partners, civil society, international NGOs, people living with HIV and organisations involved in the decentralised response to support the national response to HIV (NAC, 2010). Other line ministries such as the Ministry of Youth and Sports and the Ministry of Community Development, Mother and Child Health (MCDMCH) have lower-level structures

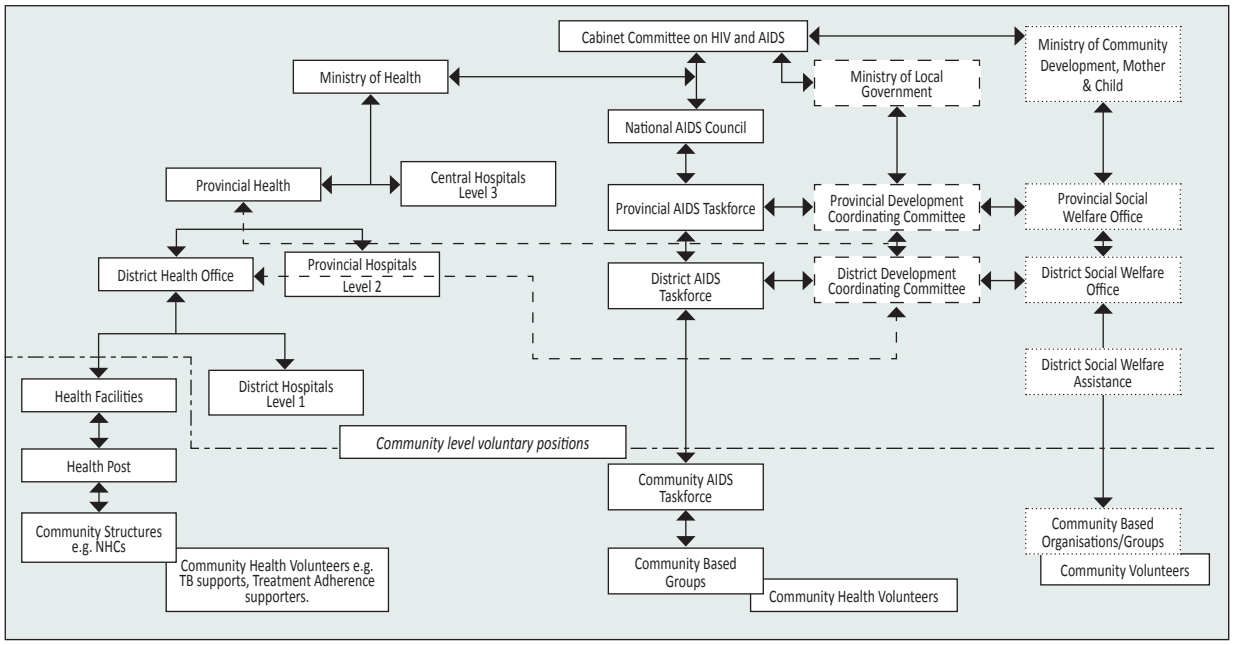
that facilitate community participation and mobilisation. For instance, HIV and social welfare activities are facilitated and coordinated through the district AIDS task forces and district welfare assistance committees. Community AIDS task forces and zonal AIDS task forces operate at community level and are linked to these structures. However, according to respondents these lower-level structures are not fully functional in certain geographical areas. It appears, there is stronger sectoral and coordination linkages at the higher (national) level than at community level.

The health facility is the hub under which community health care services are organised with the neighbourhood health committees (NHCs) and health centre advisory committees (HCACs) primarily providing the nexus between the community and the public health delivery system. The extent to which community caregivers are connected to NHCs and HCACs usually varies from one health facility to another.

Variations can also be observed in the way that community caregivers are managed. Most directly, they are coordinated through government-run health facilities. The health facility catchment areas are divided into zones, and in each zone there are 'community health workers' (CHWs) providing health promotion, education, and tracking of clients. NGOs also place community caregivers in health facilities, more commonly in ART centres. In such instances, implementing partners sometimes provide a monetary incentive to CHWs, who play a supervisory or coordination role. In addition, many of the CHBC programmes have also created community-level social structures as a means of coordinating volunteers such as the care and prevention teams (CPTs) in Chikankata. Whereas the CPTs are ultimately linked to the mission hospital, in the other two CHBC programmes (both peri-urban), volunteers have coordinators/supervisors based at the clinic who engage directly with the nearest government health facility.

Figure 4 below provides a comprehensive overview of the main HIV-related care and support structures in Zambia.

Figure 4. National organogram for care and support in Zambia



Source: CAN multi-country research – Zambia research, 2011-2012

Working together with partners, including networks of caregivers such as the National Community Home Based Care Alliance and the Zambia Grassroots Home Based Care Alliance, the government has provided frameworks and policy documents to guide the delivery of treatment, care and support services for people living with HIV. Increasingly, community care programmes are being requested to report on their activities in communities through established national, sub-national and community structures using reporting tools that have specifically been developed. However, it appears that the functionality and

coverage of some of the lower-level structures such the district and community AIDS task forces may still be weak, a situation that affects the extent to which community care and support programmes can be integrated into 'formal' community care and support structures.

All three case study CHBC programmes reviewed in this research link to the structures highlighted in Figure 4 to varying degrees and have adopted specific models for coordinating caregivers internally in their programmes. The structure at Bwafwano, for example, has caregivers divided into two main groups consisting of the supervisors who have been with the programme since inception and the general caregivers who focus on specific thematic areas. Chipata CHBC is similarly structured with coordinators/supervisors. It is organised so that the community is divided into sections, with 30 households making up one section. Each section nominates a caregiver according to the demand and needs of the area. As noted elsewhere in this report, Chikankata Health Services uses an innovative community-based structure based on care and prevention teams (CPTs) comprising various community-based agents who assist clients and are coordinated through a higher CPT board. The community itself mobilises volunteers.

Table 3 below summarizes some strengths and weaknesses of CHBC structures, based on the three case study programmes assessed in this research.

Table 3. Strengths and weaknesses of community care structures*

Strengths	Weaknesses
• Recognition that health service delivery goes beyond the bio-medical needs, includes social aspects	> Inadequate lateral linkages at lower levels compared to high level
• Various toolkits and guidelines for community care and support have been developed	> Insufficient information sharing between public health system and standalone initiatives supported by local and international partners
	> Inadequate leadership in the coordination and supervision of community-level activities undertaken by NGOs/CBOs
	> Lower-level structures face challenges in delivering and sustaining services being provided

* *Based on in-depth research conducted with the three CHBC programmes assessed in this research.*
Source: CAN multi-country research – Zambia research, 2011-2012

It appears that there are strong coordination linkages between government health facilities and CHBC programmes operating ART centres. In the two peri-urban programmes in this research, the public health centres that act as hubs for the community care programmes provide logistical and technical support for ART. Respondents indicated that the local clinics provide drugs and other supplies to the NGO clinics. The situation in Chikankata seems to be different in that the mission hospital provides logistical and technical support to the limited number of public health facilities located in the area.

To assess collaboration and support available to organisations providing care and support, representatives from nine organisations participating in the validation phase were asked whether they received any assistance from local authorities or other community-based organisations (CBOs). Most had received little or no support from either, although overall more assistance was reported from CBOs than from local authorities. Organisations that did receive support highlighted that it was in relation to the selection of caregivers (five organisations), receiving community contributions for clients in great need (five organisations), the monitoring of community care and support services (three organisations) and receiving assistance in community mobilisation for health promotion events (three organisations). An assessment of sectoral collaboration among the same organisations revealed that all nine organisations collaborated with the health sector (mainly, the Ministry of Health and health-related NGOs). In addition, four organisations reported collaborating with the education sector (both government and community schools), while two collaborated with the police and two with the agricultural sector.

The observations highlighted above provide further credence to responses from national-level actors suggesting that community or lower-level structures are not fully functional in certain geographical areas, whereas linkages and coordination at national level are stronger. In the HIV sub-sector, coordination efforts are hampered by weaknesses in the sharing of information by NGOs and resource tracking by the Ministry of Health/NAC of all partners. Currently, NAC is making efforts to collect data using various tools including Web-based technology.

2.4.3 Continuum of care and comprehensive care and support

As mentioned before, the Ministry of Health's vision is to bring health services as close as possible to the family. Based on this vision, Zambia's PHC system is organised as a pyramid structure in which promotive, preventive, curative and rehabilitation care services are delivered at various levels from community level up to the tertiary hospital level. Within this structure, which is operating in a resource-constrained setting, a referral system permits clients access to a continuum of care in which communities play a key role and hospitals provide specialised health care services.

Two of the three case study organisations featured in this report (Bwafwano and Chipata CHBC) fall under the catchment areas of public health facilities. As such, these NGOs complement the delivery of government health care services. A range of comprehensive services—including counselling and testing, clinical management, nursing care, and community-based social support—are offered from the community level, at local health centres and ultimately at larger hospitals located at district, provincial and national level. The system enables clients to receive services at community level, and caregivers to follow up cases after clients have visited public health facilities.

With the scale-up of ART in the country, a range of services is being offered to people living with HIV. CHBC is provided through local NGOs and their caregivers and families. PHC is mainly delivered through mobile health services and health posts/centres. Clients access specialised care at district and tertiary hospitals.

The CHBC initiatives studied in this research go beyond medical assistance to include broader care and support. Respondents provided examples of various livelihood activities aimed at assisting clients to be more economically self-sufficient. At Bwafwano, caregivers and clients are assisted with resources to engage in income-generating activities. Also, Chipata CHBC builds the capacity of clients and caregivers by enhancing their entrepreneurship skills.

3 CHALLENGES AND CONCERNS IN CHBC PROVISION

Despite the many achievements over the years, CHBC services and operations in Zambia face a number of challenges relating to the coordination of CHBC programmes; funding for community health; variations in remuneration for community caregivers; addressing the needs of people living with HIV and other clients; the identification of clients in the community; and access to ART. Each of these challenges is discussed below.

- **Coordination of CHBC programmes:** Respondents pointed to the gap in information sharing between the public health system and stand-alone initiatives supported by local and international partners that, in some cases, have different registers and reporting systems. Further concerns were raised with regard to a perceived lack of coordination and harmonisation of community-level activities being implemented by NGOs, a situation that has led to inconsistencies in relation to the type and scope of activities offered through CHBC programmes. There were suggestions that the government should play a stronger leadership role in coordinating and harmonising the activities of partners at the community level.

- **Funding for community health:** The public health sector has experienced reduced and delayed funding, including from international partners, in the last few years. This has had a negative impact on the extent to which health facilities, particularly in rural areas, have been able to engage in outreach activities, including community care and support services. CHBC programmes reported not being able to reach as many clients as planned due to funding constraints, even though they largely relied on predominantly volunteer and unpaid community caregivers. Many organisations have struggled to provide community caregivers with basic logistical support such as bicycles, boots and umbrellas and are unable to pay stipends. This has a negative effect on motivation and retention of community caregivers. Given funding challenges, there is a risk that innovative new strategies including the training and supporting of 'community health assistants' (CHAs)—the new cadre of remunerated caregivers at community level—will not be rolled out as extensively or effectively as hoped. This would represent a major missed opportunity for improved coordination and integration of CHBC.

- **Variations in remuneration for community caregivers:** Incentives provided by both government-owned facilities and implementing partner organisations vary considerably, both in terms of the type of incentives provided and their value. Monthly monetary incentives provided by partners to facility-based 'community health workers' (CHWs) range from $20-$40 per month, though in some cases partners provide about $100 to CHWs under their programmes (Ministry of Health, 2010). Others receive small stipends or only non-monetary incentives such as training certificates, bicycles, t-shirts, fertilizers (in rural farming communities), shoes/boots, and meals during training sessions or outreach activities. At least one of the CHBC programmes in this research supported caregivers with entrepreneurship training and start-up capital for income-generating activities.

  The absence of a regulatory framework for incentives given to community caregivers poses an enormous challenge. Most notably, variations in remuneration lead to tensions within communities and in regard to management as caregivers gravitate towards programmes that offer higher value incentives. Respondents noted that such tensions will inevitably increase with the introduction of regularly remunerated 'community health assistants' (CHAs) into environments where the vast numbers of community caregivers who are not part of this cadre do not receive the same incentives. A further concern raised by respondents is the short-term nature of most monetary incentives, which some believe erodes the spirit of volunteerism. CHBC programmes such as the one in Chikankata have opted, based on experiences, to not provide monetary incentives for volunteers with the aim of discouraging dependency.

- **Addressing the needs of people living with HIV and other clients**: Respondents from the three case study programmes as well as clients noted, in particular, that many people living with HIV experience food insecurity because they do not have access to adequate food or nutrition on a regular basis. As a result, some find it difficult to adhere to ART regimens. Poor adherence has major consequences on clients' health and increases the workload of caregivers seeking to provide comprehensive care and support to as many individuals and families as possible.

- **Identification of clients in the community:** Caregivers are facing challenges in identifying clients in the community. With a heightened focus since ART scale-up on their role in supporting people to adhere to ART, caregivers are expected to place greater focus on identifying potential clients who need care and support. The research shows that this process of identification was easier when clients were bedridden. This challenge points to the need for better coordination between ART clinics and CBHC programmes and the caregivers themselves.

- **Access to ART:** This remains a challenge in some parts of the country, due largely to lack of decentralisation and, consequently, the long distances many people must travel to health facilities where ART is available. Many clients have limited opportunities to generate income and therefore find it difficult to afford transport and other costs associated with obtaining consistent treatment. Some are forced to rely on relatives and friends who may not have many resources themselves.

4 CONCLUSION

Research indicates that the Ministry of Health, NAC and other government departments are making strides to harness and direct the functionality of community care and support services in Zambia. As reflected in this research, the government has developed a number of frameworks, guidelines and policies to guide and standardise the recruitment, training and supervision of community caregivers and other CHBC providers. Its efforts have helped create important national, provincial and district structures that are allowing and promoting the continued scale-up of ART and other HIV services.

This research confirms the well-documented fact that the needs of people living with HIV have changed in the era of ART and now include nutritional support, in particular to help ensure treatment adherence. As individuals become more ambulant, socioeconomic factors also come to the fore and CHBC programmes are making efforts to address important issues associated with the livelihood needs of clients.

In terms of caregiver roles, it is evident from the findings that although caregivers are still engaged in caring for bedridden clients, community mobilisation and health education, they are significantly expanding their roles to include tracking clients on treatment, supporting adherence, and supporting HIV testing and counselling. In terms of prevention, caregivers are using the household as entry points for sharing HIV prevention information and awareness raising. Although not fully explored in this research, community caregivers are also distributing public health commodities including condoms.

The Ministry of Health, NAC and other government departments recognise community care and support structures in Zambia. In collaboration with partners, the government has provided frameworks and policy documents to guide the delivery of treatment, care and support services for people living with HIV. Increasingly, community care and support programmes are being requested to report on their activities in communities through established national, sub-national and community structures. This research highlights the potential weaknesses in the functionality and coverage of some of the lower-level structures such the district and community AIDS task forces; such weaknesses affect the extent to which community care and support programmes can be integrated into formal community care and support structures.

The scale-up of ART in Zambia, while not without challenges, has been positive. Community caregivers are an integral part of this achievement. In particular, decentralisation efforts are being furthered by innovative approaches such as mobile ART clinics organised by district health management teams with the engagement of community caregivers who assist with the mobilisation of communities. There are varied viewpoints with regard to the role caregivers can play in the further decentralisation of ART provision. Some community respondents indicated that the role of caregivers should be further expanded to include administration of ART, especially given the fact that the scale-up of ART is hampered by the absence of skilled health workers and logistical support (particularly in rural and remote areas such as Chikankata). However, no evidence was found of the government exploring this possibility

There are strong indications that the distinctions between ‘informal’ and ‘formal’ caregivers in Zambia will be sharpened with the introduction of a new category of highly trained and remunerated community health workers—‘community health assistants’ (CHAs)—at the health post level. Although CHAs are expected to supervise and coordinate the work of community caregivers, it appears that there is limited knowledge and information of these plans within the community care and support programmes investigated. Moreover, the risks and implications of having two co-existing types of community-based caregivers are not yet clear. It is known that the number of CHAs will almost certainly be far fewer than community caregivers who are not employed by the government. Therefore, the majority of CHBC services will likely continue to be carried out in the same manner, and by the same category of caregivers.

Finally, an overarching conclusion is that community care and support structures and operations in Zambia require strengthening. Support services provided by other line ministries such as the Ministry

of Community Development, Mother and Child Health (MCDMCH) are not strongly linked at community level. Opportunities for strengthening coordination exist through bodies such as the provincial, district and community AIDS task forces and the newly formed MCDMCH, particularly in regards to preventive services and support. In addition, following the abolition of the Central Board of Health (CBOH), neighbourhood health communities (NHCs) need to be strengthened as they play a key role in anchoring community caregivers to health facilities.

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ANNEX 1. COUNTRY RESEARCH PARTICIPANTS

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ANNEX 2. TERMINOLOGY USED FOR COMMUNITY CAREGIVERS

A review of literature and data collected in this research suggests that there is lack of clarity in the terminologies being used for community caregivers. Terminology used by the Ministry of Health in its National Health Strategic Plan (NHSP) is reflected in Box 1.

Box 1. Ministry of Health definitions of community caregivers

CBV: A community-based volunteer (CBV) functions in a specific capacity (after an initial training), e.g., community-based distributors, home-based caregivers, malaria control agents, psychosocial counsellors, TB treatment supporters, area pump menders. These CBVs can be trained CHWs at the same time, but this is not always the case.

CHWs: Community health workers (CHWs) are lay members of communities who work either for pay or as volunteers in association with the local health care system in both urban and rural environments and usually share ethnicity, language, socioeconomic status and life experiences with the community members they serve.

CHWs: CHWs are lay people who have been trained in order to assist the formal health system in all its aspects (promotive, preventive and curative activities) and to assist the communities they work in to take responsibility for their own health (community empowerment). This definition includes community-based and facility-based (non-formal) workers and both volunteers and employed workers. It includes both general and service-specific workers, such as traditional birth attendants (TBAs).

CHWs: A CHW is a volunteer, selected by the community and trained in certain aspects of health and serves the same local community. The CHW is answerable to the community and is supported by the Neighbourhood Health Committee. The main functions are the promotive and preventive interventions of health that are initiated and accepted by the local people. One CHW should serve a population of 500 people in a catchment area. In order to realize the Ministry of Health vision of providing equity of access to cost effective quality health care as close to the family as possible, there is need to train the CHWs who can serve as a link between the community and the health system.

Source: 2008 mid-term review of the National Health Strategic Plan (NHSP)

The example above shows how difficult it is to clearly define different groups of caregivers and to make strict distinctions in terms of their roles and responsibilities. Such roles and responsibilities may overlap and tend to depend on the work of partner organisations and needs at facility level.

As noted in Section 1 a plethora of titles exist for individuals engaged in community caregiving in Zambia.[10]Several of these types of caregivers are a new phenomenon propagated by local and international partners. The variation in types of volunteers is a result of the different content, duration and particular thematic focus of the trainings provided by partner organisations.[11] This has resulted, as noted by the Ministry of Health, in a "confusing situation for both communities and formal health workers and the need for alignment and harmonization was identified" (Ministry of Health, 2010). The 2008 mid-term review of the National Health Strategic Plan observed that the current muddle is compounded by the fact that "the various health departments implement fragmented community health interventions that are not linked to one overall community approach".

The Ministry of Health's CHW handbook, released in 2005,[12] provides a detailed list of functions for the general 'community health workers' (CHWs) and provides a basis for defining a required community services package. The government developed this handbook to provide some guidelines for CHW work and training. Although the Ministry of Health has developed standardised training guidelines for CHWs and other community caregivers, its efforts are being undermined by the fragmented approach of partner organisations and the absence of a dedicated CHW desk or 'community health focal person'. Another obstacle is the lack of an official policy to guide the management of CHWs and other volunteers, as was cited in the 2008 mid-term review of the National Health Strategic Plan and other sources (Ministry of Health, 2010).

10 These include treatment supporters, adherence support workers, lay counsellors, health promoters, community health advisors, outreach educators, community health representatives, peer health promoters, and peer health educators (Ministry of Health, 2010).

11 These training opportunities include training programmes on behaviour change, leadership skills, hygiene, administration of DOTS (directly observed treatment, short course) for tuberculosis treatment, end-of-life care and nutrition, HIV testing, adherence support, child health, safe motherhood and so on.

12 The National Health Strategic Plan's 2008 mid-term review indicates that this handbook is now outdated, although it is still in use. The review noted that other manuals have been developed, including a manual for home-based care, a PMTCT reference manual for lay counsellors, and guidelines for nutrition programmes, among others.

ANNEX 3. SELECTION CRITERIA FOR CASE STUDY PROGRAMMES

The following criteria were specified in the overall research framework for the selection of case study CHBC programmes.

Core criteria:

- Programmes managed by different organisations
- Running for at least 10 years
- Representativeness of the selected programme
- Programmes offering diversity of services in care (not exclusively health), range of clients (HIV as well as other chronic illnesses), some integration in the health system

Secondary criteria:

- A Cordaid-linked programme
- Different yet representative models
- Inclusion of urban/rural locations

Tertiary criteria:

- If feasible, at least one programme to include rural and urban locations
- Government-run programme if there is such or NGO/CBO programme that relies on government funding and management

ANNEX 4. KEY INFORMANTS

Phase 1: Semi-structured interviews

Interviews with representatives of:

- Africare
- Concern Worldwide
- Catholic Relief Services
- Churches Health Association of Zambia
- Ministry of Community Development, Mother and Child Health
- Ministry of Health
- Ministry of Youth and Sport
- National AIDS Council
- Salvation Army
- Sustainability Through Economic Strengthening (STEPS) OVC
- UNAIDS
- World Health Organisation
- Zambia Interfaith Networking Group on HIV/ AIDS (ZINGO)

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

Case 1: Bwafwano Integrated HBC Programme

Interviews with representatives of:

- Bwafwano Integrated Home Based Care Organisation (BISO) (2)

Interviews with:

- Clients (10)
- Primary caregivers (10)

Focus group discussions with:

- Community representatives from Chazanga, Chimwemwe, Lumber Community Group and Lukasu (8)
- Programme staff – BISO (4)
- Secondary caregivers – BISO (12)

Case 2: Chikankata Health Services (CHBC Programme)

Interviews with representatives of:

- Chikankata Health Servicess – Community Based Orphan Support Programme (HARD) (2)
- Chikankata Health Services – Home-based care (1)
- Sustainability Through Economic Strengthening (STEPS) OVC (1)

Interviews with:

- Clients (10)
- Primary caregivers (10)

Focus group discussions with:

- Community representatives from Chikankata/Katuru (8)
- Secondary caregivers from Care and Prevention Team (CPT)/Chikankata (8)

Case 3: Chipata Community Home Based Care (St. Paul's Parish, Archdiocese of Lusaka)

Interviews with representatives of:

- Archdiocese of Lusaka (2)

Interviews with:

- Clients (10)
- Primary caregivers (10)

Focus group discussions with:

- Community representatives from NHC, St. Paul's Parish, WDC and zonal AIDS task force/ community AIDS task force (4)
- Programme staff from St. Paul's Parish (5)
- Secondary caregivers from Chipata Compound (9)

Phase 4: Validation interviews/ questionnaire

Interviews with representatives of:

- Africare (1)
- Churches Health Association of Zambia (1)
- Ministry of Health (2)
- Salvation Army (1)

Organisations included in the questionnaire sample:

- Bwafwano Integrated Home Based Care Organisation
- CARE Zambia (PRISM Project)
- Catholic Diocese of Ndola- Integrated AIDS Programme
- Catholic Diocese of Chipata
- Community Based Orphan Support Program (HARD), Chikankata Health Services
- Nangoma HBC
- St. Paul's Parish
- Truevine Community and HBC (OVC)
- VK Community Care Organisation

C·A·N

Caregivers Action Network

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