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Caregivers Action Network

COMMUNITY CAREGIVERS: THE BACKBONE FOR ACCESSIBLE CARE AND SUPPORT

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

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ACRONYMS AND ABBREVIATIONS

ART	Antiretroviral therapy
CAN	Caregivers Action Network
CBO	Community-based organisation
CHBC	Community and home-based care
CHW	Community health worker
FBO	Faith-based organisation
HAPCO	HIV/AIDS Prevention and Control Office (of Ethiopia)
NAC	National AIDS Council
NGO	Non-governmental organisation
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 presents a synthesis of the results of a four-country research project undertaken in Ethiopia, Malawi, South Africa and Zambia. It was commissioned by the Caregivers Action Network (CAN) to review community and home-based care (CHBC), especially in regards to HIV prevention, treatment, care and support.

CAN wishes to acknowledge the invaluable support provided by many actors involved in this multi-country research both nationally and internationally.

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

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

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

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 presents a synthesis of the results of a four-country research project undertaken in Ethiopia, Malawi, South Africa and Zambia on the development of community and home-based care (CHBC) in the context of HIV. The research was commissioned by the Caregivers Action Network (CAN) in 2011 to inform its advocacy agenda with regard to highlighting the importance of community care and support programmes.

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.

The field research was conducted from September 2011 to August 2012 and was carried out by local research teams. These teams conducted research on CHBC programmes and conducted interviews and focus group discussions with, among others, government officials at national, provincial and lower levels; community caregivers and their clients; and representatives from CHBC-providing organisations—most of which are non-governmental organisations (NGOs) in the countries studied.

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

History and evolution of CHBC programmes

The research shows that prior to but, notably, since the introduction of ART, CHBC programmes have positioned themselves to provide a wide range of HIV-related care and support services. People living with HIV were the predominant client population among the CHBC organisations surveyed, although many also provide services to HIV-negative clients with other chronic conditions (such as hypertension, diabetes and cancer), tuberculosis (TB) and sexually transmitted infections.

The introduction of ART has been a major factor influencing the development of community care and support in all four research countries, as it has generally contributed to an improved health status and productivity of those receiving HIV treatment. People living with HIV are now less likely to be bedridden and in need of end-of-life care, and far more likely to need a wide range of services such as support in adhering to ART, psychosocial support, assistance in identifying income-generating opportunities, and—critically—food security.

CHBC programmes have adjusted to the changing needs of their clients and as a result, caregivers' roles and the types of care and support services provided have changed. A wide and comprehensive set of CHBC services are provided by primary and secondary caregivers in communities. Caregivers' roles include the provision of care and support services such as basic nursing care, psychosocial support, socioeconomic support, care for OVC, counselling and testing support, adherence support, providing assistance in triaging, registration support, record-keeping, facilitating client flow in clinics, counting pills and tracking clients in communities and encouraging them back into care when necessary. They also play an important role in addressing the stigmatisation and discrimination of people living with HIV and in mobilising people for HIV testing. The focus is on providing a continuum of care and comprehensive care and support.

Another significant development identified in relation to the tasks and responsibilities of community caregivers and CHBC-providing organisations was the growing demand for CHBC and PHC programmes to accommodate a broader range of health care conditions. These demands are linked to the expansion of HIV treatment services. As ART services in particular have expanded, so has the knowledge of the scale and presence of other (non-communicable) diseases such as diabetes, hypertension and mental and physical disabilities.

The form and content of CHBC have also changed as a result of international agency and national government interventions to revitalise PHC services and elaborate social services to support those in need in communities. The research recorded changes in policy environments relating to care and support in all four countries. While the general trend is towards incorporating CHBC into government PHC structures and programmes, there are marked differences among the countries according to the extent to which they have adopted the World Health Organization (WHO) decentralisation model and, critically, whether health policies are aligned to national economic development policies and structures. Country differences can be observed with regards to the extent to which governments recognise and accept community caregivers and CHBC programmes as integral components of national health systems, the management of community caregivers, remuneration of community caregivers, and community participation and mobilisation.

According to the research findings, CHBC programmes have managed to persist because the organisations running them have developed sound mechanisms to mobilise communities to support members in need, ensure participation of members as community caregivers in their programmes, and adapt to the changing needs of their clients and local and national health care systems. Yet their ability to provide adequate and comprehensive services is threatened by funding cutbacks and uncertainty over their future roles and responsibilities as countries seek to expand government-run PHC structures and systems that rely on salaried personnel employed directly by the state. The general trend is to create professional/paid community caregivers to i) be the intermediaries between government medical personnel and CHBC programmes and their voluntary/unpaid community caregivers and ii) deliver PHC services. While most respondents welcome governments taking increased responsibility to meet the health care needs of citizens, some expressed concern that important community-level linkages and attention offered through CHBC programmes will be lost.

Health system integration

The research detected large variations in the extent to which governments view community caregivers and CHBC programmes as integral components of national health systems. In Ethiopia, CHBC programmes are acknowledged as a component of the health system but with responsibility for the 'non-clinical', social welfare aspects of health care; as such, they are not considered formally part of health services. Collaboration between government agencies and NGOs is accepted and encouraged but there is no intention to integrate CHBC programmes into health services or to place them within the remit of PHC. Zambia and Malawi recognise that community caregivers and CHBC programmes are essential components of their health systems and integral to their ART and PHC strategies. Although the Zambian Ministry of Health seeks to 'formalise' community caregiving, via the establishment of a new cadre of 'community health assistants' (CHAs), this is likely to be only in the sense of emulating Malawi's existing use of 'health surveillance assistants' (HSAs) to create firm links among health facilities, community caregivers and CHBC programmes. In both countries, coordination rather than integration of CHBC and PHC programmes is the practical agenda. In South Africa, the past lack of formal mechanisms for coordination of the Ministry of Health services and CHBC programmes and the multiplicity of different categories of community caregivers are driving a policy to restructure community caregiving and integrating it into PHC services.

Overall it is agreed that CHBC programmes and community caregivers are vital to national efforts to improve the uptake of HIV treatment services as well as retention of clients on ART. All four countries have made important strides in expanding access to treatment services for people living with HIV. HIV

treatment services have generally expanded to health centre levels. Not all health centres are equipped to provide ART, however, mainly due to restrictions allowing only specially trained health professions to prescribe and manage ART. With the exception of Zambia, where mobile sites provide access at community level, and current pilots in South Africa that experiment with dispensing drugs outside health facilities, there does not seem to be much impetus for further decentralisation of HIV treatment to lower-level health or non-health facilities in the near future.

Caregivers' potential

The research noted the important contribution of community caregivers in HIV prevention and treatment across the four research countries. They play a central role in mobilisation for HIV prevention campaigns and contribute to the drive for universal counselling and testing, with some even trained to conduct HIV tests directly. Their potential in promotion of health-seeking behaviour in general and uptake of HIV-related services, including prevention of mother-to-child transmission (PMTCT), by linking people to health facilities, is widely recognised and deployed in the countries studied. In relation to HIV treatment, community caregivers fulfil a vital role in tracing defaulters, improving the uptake of services and supporting clients to adhere to treatment. The research showed that ART programmes depend on the involvement of non-state employed community caregivers and that many would underperform, or possibly collapse, without their contribution. Mixed opinions were expressed in relation to the potential of caregivers to become actively involved in the administration of ART. Some research informants—in particular those representing CHBC-providing organisations—favoured that approach, as long as community caregivers receive adequate training and support. Others were opposed to the idea, however, stating for example that CHBC providers do not have the requisite skills set and equipment needed to monitor clients closely. Other potential areas for further involvement in treatment programmes, as suggested by research informants, included the detection of new clients, combined DOTS approach[1] for HIV/TB, increased involvement in pre-ART care and support for clients, and support to issues that affect adherence such as lack of nutritious food by creating vegetable gardens.

The research uncovered only limited evidence calling on community caregivers to contribute to the expansion of PHC programmes in the four countries, despite the fact that their tasks already extend into the domain of PHC services. The current trend is for governments to use their own cadres of 'community health workers' to deliver PHC services. However, there is a clear potential for caregivers to be more involved to supporting policy makers' plans and visions for PHC in the future.

The research shows that there is potential for further decentralisation of services using existing structures. For instance, scope exists for expanding links among health ministries, other government departments and CHBC programmes. The need to capitalise further on community-level resources in contexts of limited human and financial resources within governments and to meet the objectives of initiatives such as Treatment 2.0[2] could provide drivers for this to happen. In the immediate future, expansion and increased linkages will likely remain a challenge because of the retraction of CHBC programme services due to external funding cuts to NGOs and the inevitable, subsequent limitation of the ability of health ministries to sustain community participation in their 'outreach' projects.

Complementarity between formal and informal community caregivers

The necessity of CHBC programmes and community caregivers is fully acknowledged in the four research countries, yet variations can be observed with regard to the role of CHBC programmes in national HIV programmes and in the definition, role and conditions of service of community caregivers.

The research shows that the organisation of care and support services in all four research countries is complex and involves numerous ministries, departments, committees and organisations. A general

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1   DOTS refers to 'directly observed treatment, short course', a TB treatment and monitoring strategy recommended by the World Health Organization.
2   The Treatment 2.0 initiative, launched by the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization (WHO) in 2010, aims to guide the next phase of HIV treatment scale-up.

trend observed is to emphasise the need for coordination of government health services and CHBC programmes with professional/paid community caregivers as the hinge. Research findings underscore the need for NGO-run CHBC programmes to move beyond the notion of community and home-based care—and, as importantly, for government health ministries to move beyond bio-medical constructs of PHC—to establish and sustain 'community-oriented' health care systems. The changes to the form and content of CHBC programmes and PHC services indicate that this is happening but in different ways in the four countries. The general direction is towards PHC and CHBC programmes complementing each other but, inevitably, there are tensions and challenges. Tensions are expected to arise as governments move to 'formalising' community caregivers on the basis of wage employment contracts but in contexts where extensive use of volunteer community caregivers is still, and will continue to be, necessary in order to stay abreast of the changing demands on the public health services. Moreover, foreseeable developments such as a greater involvement of CHBC programmes in the elimination of mother-to-child transmission and paediatric HIV programmes will inevitably foster demands for further devolution of health care into communities. A key structural challenge is sustaining the generally effective means developed by NGOs, including FBOs, to mobilise communities and to ensure their participation in CHBC activities. This and other challenges pale, however, compared with the threat posed by the financial cutbacks to CHBC programmes, most of which result from the global financial crisis. The cutbacks have forced curtailment of many CHBC programmes activities which, in turn, has reduced the capacity of both NGOs and health ministries to continue expanding and elaborating community-oriented treatment, care and support services.

Existing conceptions of CHBC need to change in view of the evidence that community-level health services are in transition. The lack of clarity and consistency in terminology used to describe people and structures involved in the provision of care and support often leads to confusion. Such confusion and lack of specificity—due to the use of multiple terms for community caregiver and often blurred distinction between the different categories of caregivers in terms of roles and responsibilities—present challenges, in particular in terms of policy making and implementation in relation to community care and support. Likewise, the notions of 'formal' and 'informal' caregivers/caregiving, which are often used to distinguish civil society-led CHBC programmes and government health services, do not adequately reflect the sophisticated structures and mechanisms for delivery of community-oriented health care and the mechanisms-in-the-making for coordination of different health agencies' activities.

Conclusion

This research shows that a successful transition of health care service delivery at the community level requires investments in CHBC programmes and true recognition by national governments and other stakeholders of the expertise of CHBC programmes and those already providing care and support in their communities. Caregivers and CHBC-providing organisations can and in many cases already play a critical role in delivering a wide set of HIV, health and broader development services. Their engagement is crucial in terms of expanding access to ART and HIV prevention services, increasing and sustaining adherence to ART and other medicines, providing comprehensive care and support, and achieving broader PHC for all.

1 INTRODUCTION

This is a synthesis report of a four-country research project on the evolution of community and home-based care (CHBC) in the context of HIV. The focus countries are Ethiopia, Malawi, South Africa and Zambia. The research examined the evolution of CHBC, the extent to which CHBC programmes are integrated into national health systems, and their current and potential roles in expanded national HIV and primary health care (PHC) systems and structures. Additionally, the research aimed to obtain greater insight into what the opportunities and challenges associated with CHBC and the expansion of national HIV and PHC systems and structures might mean in relation to the implementation of the 'Treatment 2.0' agenda.[3] Fieldwork for the research project was conducted between September 2011 and August 2012.

As a synthesis document, this report summarises results from the country studies and focuses on what the research reveals with regard to the project's overall objectives. Readers are directed to the four individual country reports for more extensive details and discussion of the findings in each country.

The Caregivers Action Network (CAN) commissioned the project in recognition of the need for a strengthened evidence base to inform an international strategy and advocacy agenda the network is leading on the role of caregivers and the importance of care and support. CAN is a network open to organisations and individuals committed to realising a global health agenda that recognises, integrates and supports caregivers and community-based care and support as a fully resourced part of the health care system. The different parts of this research highlight priority developments, trends and factors that may be useful for policy making as well as strategy and advocacy decision-making.

This CAN publication is based on the findings and analysis highlighted in the four country research reports and a research synthesis report prepared in 2012 by Carolien Aantjes (ETC Crystal) and Tim Quinlan (Athena Institute - VU University Amsterdam). The publication is structured as follows. Section 1 provides a description of the background to the research, including objectives, scope, methodology, limitations and explanations on terminologies used. Section 2 discusses the research findings according to the main research objectives. Section 3 summarizes challenges and concerns observed in and highlighted by the research. Section 4 presents a discussion of the research findings, and Section 5 contains a conclusion.

1.1 BACKGROUND TO THE RESEARCH

In 1978, countries attending the International Conference on Primary Health Care signed the Alma-Ata Declaration, which established an international agenda to develop comprehensive PHC services with an emphasis on delivery of outpatient health care within communities at clinics.[4] Another priority emphasis was on interventions by a wide range of government agencies (i.e., in addition to health ministries) to improve social and economic conditions in communities.

One facet of the PHC agenda proposed at the 1978 conference was to improve the identification, referral and treatment of illnesses at 'local-level' health facilities. This was to happen through the training and deployment of 'community health workers' (CHWs), a term used to cover a variety of individuals involved in improving health care within communities. The following is a widely accepted definition of such individuals:

> [They] should be members of the community where they work, should be selected by the communities, should be answerable to the communities for their activities, should be supported by the health system but not necessarily part of its organisation, and have shorter training than professional workers.
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> —World Health Organization (WHO), 1989

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3   Launched by the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization (WHO) in 2010, the Treatment 2.0 initiative aims to guide the next phase of HIV treatment scale-up. More information on this initiative is available at www.who.int/hiv/topics/treatment2/en/index.html.

4   The text of the declaration is available online at www.who.int/publications/almaata_declaration_en.pdf (accessed 1 July 2013).

In many countries, 'community health worker' programmes were implemented in hasty, poorly planned and top-down manners. Their implementation ran parallel to donor-led structural adjustment programmes, which among other things forced countries to introduce user fees for health care—to the detriment of people's access to PHC (Weissman, 1990; Loewenson, 1993; Walt & Gilson, 1994). Instead of transforming health care services, CHW programmes ended up being under-resourced and undervalued, thereby leading to an overall decline in enthusiasm for them (Walt, 1990; Abbatt, 2005).

The HIV pandemic led to the revival of 'community health worker' programmes in the mid-1980s (WHO, 2006). The rationale was largely one of necessity in many developing countries that experienced burgeoning HIV epidemics. The burden of HIV-related illnesses in national populations was, and continues to be in many places, beyond the capacity of the public health services, particularly in sub-Saharan Africa. One recourse was to rely more on the contribution of 'community health workers', many of whom were volunteers and not paid for their work. Most were recruited and deployed through CHBC programmes that were organised largely by faith-based organisations (FBOs) and other non-government organisations (NGOs) (Rohde et al., 2008).

Before antiretroviral therapy (ART) became available for people living with HIV, community caregivers operating though these programmes focused on providing care and support to those who were bedridden. By taking much of the care burden from public health facilities, these programmes and their community caregivers supported the delivery of PHC services. Prior to but, notably, since the introduction of ART, CHBC programmes have positioned themselves to provide a range of HIV-related care and support services (Lindsey, 2002). In particular, the advent of national ART programmes (generally in the mid-2000s in sub-Saharan Africa) led CHBC programmes to expand their activities beyond basic nursing and end-of-life care.

As CHBC programmes expanded in scope and scale, there was widespread recognition of the need for community caregivers. Yet challenges also arose in regard to defining their place within national health systems, creating appropriate policies and legislation in some countries, and establishing effective supervision and training (Hermann et al., 2009; Schneider et al., 2008; Walt, 1988; WHO, 2007b). Additional challenges in some countries have stemmed from rigid bureaucratic structures within health ministries and the resistance of health professionals' councils (Zachariah et al., 2009). Thus, although community caregivers fulfilled (and still fulfil) an essential role in delivery of HIV services, they often receive limited recognition and compensation (Akintola, 2008b; Heymann et al., 2007; Hosegood et al., 2007; Kipp et al., 2006; Orner, 2006; Robson et al., 2006; Ogden et al., 2006; Akintola, 2011).

In 2008, many African countries declared a renewed commitment to the principles of Alma-Ata (WHO, 2009). The aims included achieving the health-related Millennium Development Goals (MDGs), using the PHC approach to strengthen health systems and to scale up universal access to health services (WHO, 2009). As discussed in this report, the formal revival of PHC has provided a foundation for strategic interventions by governments to align CHBC programmes with public health services and practical efforts to integrate community caregivers into PHC operations. Challenges remain, however, particularly in relation to concerns about how primary health care can and should deliver both preventive and therapeutic services (Rohde et al., 2008) and how it sustains community participation and intersectoral collaboration (Lawn et al., 2008). Several scholars have pointed out that CHBC programmes may currently face challenges similar to PHC in the 1980s and 1990s and have called for more empirical evidence on their contribution to the development of health systems and the challenges those systems face (El-Sadr et al., 2007; Schneider et al., 2008; South African Health Review, 2008; UNAIDS, 2011; Wringe et al., 2010; Yu et al., 2008).

1.2 RESEARCH INITIATION

The overview in Section 1.1 provides the context in which CAN commissioned further research on community care and support. This sub-section details how the research was initiated and developed. Discussions with like-minded organisations at the 18th International AIDS Conference in Vienna in July 2010, as well as at the Conference on Universal Access to Care and Support in London later the same

year[5], led to a consensus to gather evidence on the impact of community care and support programmes to present at the 19th International AIDS Conference, held in Washington, DC in July 2012.

On behalf of CAN, Cordaid invited interested networks and organisations present in Vienna and London to come together in an IAC Research Group to start a dialogue around care and support research priorities. After the establishment of the research group, Cordaid commissioned the development of a working document that identified five key thematic areas with insufficient evidence and data on care and support. This document served as the basis for discussions in the IAC Research Group, with members asked to identify their priority areas. The two main areas identified were the linkages with the public health system and community health care and the changing context of caregiving in the ART era. It was agreed that the selected themes would be further elaborated in a research proposal.

ETC Crystal and the Athena Institute at VU University in Amsterdam prepared a research proposal for discussion by the IAC Research Group members, who also provided feedback and support in developing research methods.

Country selection criteria included the presence of a generalised HIV epidemic, presence of firmly established care and support programmes at community level (for at least 10 to 15 years), and evidence of government commitment to revitalisation of PHC. On the basis of these criteria, Ethiopia and Malawi were selected to be included in the research. South Africa and Zambia were later added when increased funding was secured. The research was funded by Cordaid and UNAIDS, with the former being the contract holder on behalf of CAN. The combination of a focus on community care and support and the Treatment 2.0 agenda developed by UNAIDS and WHO resulted in objectives that focus on the role of caregivers in relation to health ministries and health services.

In each country, local research teams were identified through a tender process. Research advisory boards consisting of representatives of CHBC organisations, health/HIV programmes and caregivers were established in each country to provide advice to the research teams, to act as a sounding board to the research coordination group, to provide input to the research documents, and to support the dissemination of the research findings. ETC Crystal was contracted to coordinate the research project. The Athena Institute provided technical support to the research and ensured scientific rigour. During the implementation of the research, IAC Research Group members were kept up to date through communication briefs.

1.3 SCOPE OF THE RESEARCH

Four objectives were agreed for the research:

- 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 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[6] to complement each other in the context of decentralisation of HIV treatment programmes, taking into account current initiatives and arrangements.

5　The London conference took place in November 2010 and was organised by the UK Consortium Care and Support Initiative. Two notable publications from the conference are available at http://aidsconsortium.org.uk/wp-content/uploads/2011/11 CareSupportAdvocacyDoc2011Compressed.pdf and http://aidsconsortium.org.uk/wp-content/uploads/2011/12/ CareSupportRoadmapDoc20111.pdf.

6　As noted in Section 1.6, CAN gives preference to the use of the term 'community caregivers' over 'community health workers.' This explains why the term 'community health worker programmes', which was the term specified in the original research objectives, has been replaced in the report by 'community caregiver programmes.'

1.4 RESEARCH METHODOLOGY

The project was designed to be a qualitative descriptive research, using four country studies to enable comparative analysis. In essence, the research was a situational assessment of CHBC programmes.

The research consisted of eight phases (phases 0–7) in which document/literature study, semi-structured interviews, community mapping, focus group discussions and questionnaires featured as the main research methods. The phases are outlined below:

Phase 0: Defining of key issues

Phase 1: Exploration and preparation

Phase 2: In-depth study of selected cases

Phase 3: Analysis and integration of data of previous phases

Phase 4: Validation and consolidation

Phase 5: Analysis and comparison of all country data

Phase 6: Discussion on preliminary research findings

Phase 7: Publication of research findings

Phase 0 involved the dissemination by CAN of an online questionnaire among a sample of international experts in HIV and primary health care. The questionnaire sought to obtain the views of experts on the proposed research and their recommendations in regards to questions that would be pertinent to explore at country level. The results of this first step were combined into a brief 'Phase 0' report containing the findings and recommendations for issues that should be addressed in subsequent phases of the research. The findings were also used to inform the design of the research tools. Furthermore, the regional coordinator of the Athena Institute visited all four countries to provide further elaboration on the scope of the research and assisted in the contextualisation of the tools with the country research teams. Prior to Phase 1, the research teams submitted the research protocol to the appropriate ethical review boards in their respective countries.

Phase 1 consisted of a desk review of the available literature and semi-structured interviews conducted by the research teams. The desk review sought to retrieve all available literature from the specific countries related to CHBC and the research objectives. This involved scientific literature as well as grey literature, including national documents and reports from organisations involved in CHBC provision. The review was followed by semi-structured interviews with 8–10 key informants involved in community care and support policy and ART strategies at national level and 6–8 key informants working for medium-size to large care and support implementing organisations with offices operating at national level. The semi-structured interviews explored the in-country structures of caregiving; evolution in national policies, strategies, caregiving practices, in-country structures, linkages and networks; governments' policies regarding support for community (health) care delivery; involvement of lay workers; and the different implementation models for community care and support.

The second phase consisted of an in-depth study of three selected community programme cases. Firstly, the research teams conducted a document review on-site to retrieve relevant factual data from the organisations, such as number of clients enrolled and policies. Secondly, semi-structured interviews were arranged with 4–5 key informants and 2–3 external stakeholders per selected programme (such as district health officers and district AIDS taskforce coordinators). In addition, a number of trained caregivers compiled a community map of the structures and actors involved in care and support activities in their communities and the links among them. Within each selected programme, a minimum of three focus group discussions took place: one with a selection of programme staff, one with secondary caregivers and one with community representatives. The focus group discussion with programme staff included an exercise whereby important historical events (i.e., evolution) of the organisation were discussed and put in a timeline. Individual interviews, guided by a specific questionnaire, were conducted with some 30 clients and their primary caregivers. The questionnaire for clients covered questions on their needs and the type of comprehensive care and support they are receiving, while the questionnaire for their caregivers focused on their roles and responsibilities in caregiving and how they evolved over time. Lastly, service observations were conducted by means of a standardised checklist to acquire additional insight

into structures, forms of comprehensive care and support, organisation and practice at community level. The checklists focused on a minimum of two forms of comprehensive care and support provided by the selected programmes. The country research teams developed interim reports for each of the two phases, and these reports in turn provided the foundation for a formal country research report in which findings would be triangulated.

Phase 3 included the processing and content analysis of country data as well as a comparative analysis across cases and countries. The same analysis process was used for all countries to allow comparisons among countries. A structured coding model was developed with the input of the country research teams based on the objectives of this research and recurrent themes in the literature. The final coding guide (associated with the Atlas.ti software programme) was distributed to the teams and was used for the coding of all data. All interviews and focus group discussions were fully transcribed. The codes used for the content analysis served as a basis for country research and research synthesis reports.

A preliminary synthesis report of the country data was developed between Phases 3 and 4, as delays in the timeframe of the field research meant that all data collection phases were not completed prior to the July 2012 International AIDS Conference. This draft report was presented and discussed at an internal review meeting in Geneva in June 2012. The meeting was also used for planning activities at the Washington conference. IAC Research Group members (including UNAIDS, Cordaid and CAN representatives) were present at this meeting as well as the lead researchers and representatives from the in-country research teams and advisory boards. The discussions provided valuable input for revisions to the draft synthesis report.

Phase 4 sought to validate the country findings in a second round of interviews with key informants at national level and through the distribution of questionnaires among a sample of 59 care and support organisations across the four countries. The design of the questionnaire was based on key findings from the country analyses and sought to validate those findings with a wider range of community programmes/projects in each of the countries. The response rate was 78 percent. The findings were processed in SPSS software with results adjusted for missing data.

The output from Phase 5, analysis and triangulation of all country data, is contained in this report. Due to challenges with the timing of the research, the planned phases 6 (stakeholder meeting to discuss research findings) and 7 (development of a two-page brief on the research for dissemination at the 2012 International AIDS Conference) were brought forward and conducted in relation to the preliminary findings. The other component of Phase 7 is the write-up of a scientific publication to be submitted to a peer-reviewed journal. As of April 2013, a manuscript for submission was expected to be ready by mid-2013.

Country research teams and respective research advisory boards have facilitated national briefing meetings to exchange overall research findings and country findings with relevant stakeholders at policy and programme level in their respective countries.[7] These meetings are viewed as an important platform to advocate for recognition of the contribution of community caregivers to the country's health system and discuss ways to strengthen community systems.

1.5   RESEARCH LIMITATIONS

At the time of its conception, the project had an ambitious timeframe with the aim to present findings at the 2012 International AIDS Conference. This deadline allowed for one year to complete the research. Initially, only two countries were to take part in the research, Ethiopia and Malawi. With additional funding becoming available, South Africa and Zambia were added—but only in November 2011, which left their researchers limited time to conduct field research. Despite being one of the first selected countries, the Malawi research team encountered a long delay in commencing its field research as a result of a slow ethical approval process. The team was only able to start its field research in February 2012. Soon thereafter, the president of Malawi died, causing additional delays and limiting the research team's ability to finalise the Phase 1 interviews with government officials and to proceed with Phase 2.

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7   Such meetings had been held in Ethiopia, Malawi and South Africa as of May 2013. Zambia had yet to organise such a meeting pending approval of the country research document from the Ministry of Health.

Delays occurred in South Africa and Zambia as well, with research teams having to go through additional formalities (apart from ethical approval) to enable them to interview government officials. Moreover, Phase 2 of the field research encompassed an extensive range of data collection methods and informants that demanded sizable time investments from the research teams in terms of translation, transcription and coding of the data. Consequently, preliminary findings of the research were shared at the June 2012 Geneva meeting while data collection was still in progress.

Where feasible, the researchers brought in quantitative data to substantiate some of the findings. However, this was limited as data sets were either difficult to access or incomplete. While there is a clear need for research on costing CHBC activities, this research design did not include such a component, mostly for reasons of time limitations and restrictions in the available budget for the research. The research only touched lightly upon the roles of caregivers in, and the domain of, social welfare and 'non-health' sector services. This limitation has been acknowledged and results from how the project was conceptualised; as such, the findings may not do sufficient justice to the broad scope of caregiving and community participation in non-health domains.

1.6 NOTE ON TERMINOLOGY USED

HIV care and support: This report uses the definition of HIV care and support endorsed by UNAIDS in its 2011–2015 Strategy (UNAIDS, 2010b):

> *HIV care and support demands a comprehensive set of services, including psychosocial, physical, socioeconomic, nutritional and legal care and support. These services are crucial to the well-being and survival of people living with HIV and their caregivers as well as orphans and vulnerable children. Care and support services are needed from the point of diagnosis throughout the course of HIV-related illness regardless of ability to access ART.*

Community and home-based care (CHBC): This term is used to refer to the range of community-based services provided for people living with and affected by HIV in their homes. CHBC has largely been delivered by NGOs, including FBOs, using cadres of individuals working at the community level (usually referred to as secondary caregivers, as noted below) who support primary caregivers providing care and support to family members in their own homes. CHBC is also delivered by public health professionals such as government community health workers, nurses and doctors, particularly in better resourced areas.

Community caregivers: This term (also referred to in this document as 'caregivers') refers to individuals who provide care and support. The 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 NGOs or for the government. As such, the term 'secondary caregivers' refers to both employees of health ministries and of NGOs, including FBOs, while 'community caregivers' refers to primary and secondary caregivers together.

Research indicates that no one term can easily and clearly cover the range of caregiving functions, responsibilities and employment situations across the four focus countries and that justifications can be given for giving preference to the use of different terminology with regards to community care and support. In general, this report follows CAN's preference for the use of 'community caregiver' over 'community health worker'; this preference is based on the recognition that the latter term is often automatically, though not necessarily correctly, associated with paid work that is largely focused on the physical aspects of care and support and less on other services (e.g., socioeconomic support, nutrition, etc.). Country-specific terms used for specific groups of community caregivers are maintained in this report if direct reference is made to departments and agencies, policies and policy statements as well as information obtained from official documents. The country-specific terms have been placed within single quotation marks.

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, discussion of community caregivers is not meant to 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.

Palliative care: The term 'palliative care' and its definition have changed over time, in particular in resource-poor settings. Prior to the introduction of ART, the term referred to the physical and psychosocial end-of-life care that was provided for people dying of HIV-related illness. This narrow definition has only been slightly expanded beyond end-of-life care in the current general WHO definition: [8]

> *Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.*

However, following the introduction of ART, the definition of 'palliative care', particularly in resource-poor settings, gradually broadened to reflect the expansion of the range of client needs and the interventions delivered. The broader definition promoted by the Worldwide Palliative Care Alliance (WPCA) states that palliative care should not be seen only as end-of-life care. It asserts that palliative care should begin earlier rather than later for individuals facing life-threatening illnesses; should include social as well as medical interventions (e.g., "provision of social and legal support that will also assist with poverty alleviation, food security"); and be a "comprehensive" intervention to improve individuals' "quality of life" (WPCA, 2011). This broader definition is also now often reflected in national government and international health agency policies and strategies.

This report refers to the expanded definition of the term palliative care throughout the document. However, for the purposes of distinction between the older and newer definition, the report refers to the older, more restrictive definition as 'end-of-life care'.

Continuum of care and comprehensive care and support: The wide range of care and support interventions required by people living with HIV, their families, caregivers and communities are commonly referred to as comprehensive care and support. The term reflects the need for people living with HIV at any one and different points in time to receive a wide variety of services that are commonly summarised in terms of treatment, care and support. Continuum of care and support refers to the need for people living with HIV to receive a variety of different services over a long period of time— e.g., from HIV diagnosis to initiation of ART to adherence support—from a range of different sources. A continuum of care and support effectively links the individual to all the services he or she needs from health facilities to home.

Formal and informal care: When this research project was conceptualized and initiated, the term 'formal' care was used to refer to the activities of health professionals and public health services, while 'informal' care was used in reference to the activities of unpaid caregivers and CHBC programmes run by NGOs, including FBOs. The research results, however, show that distinctions on this basis misrepresent the role and place of CHBC programmes within the national health and social welfare systems of the countries where the research was conducted. CHBC programmes are integral features of national health systems, as government health services often rely on these programmes to assist with the management and operation of clinics and on unpaid caregivers for the delivery of services. Therefore the terms formal and informal and the distinctions among the different ways in which care and support are provided are not used in the research unless clear distinctions can be made in specific situations.

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8   Additional information about the WHO definition may be found at www.who.int/cancer/palliative/definition/en/.

2 RESEARCH FINDINGS

This section presents the key findings of the research and associated analysis. It is structured around the four research objectives outlined in Section 1, thereby following the same format as the individual country research reports. The complexity of the caregiver context means that some findings, information and observations may be presented in multiple sub-sections of this report.

2.1 HISTORY AND EVOLUTION OF COMMUNITY CARE AND SUPPORT

Research objective: 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.

2.1.1 Rapid scale-up of ART

The research shows that the introduction of ART has been a major factor influencing the development of community care and support in all four research countries, as it has generally contributed to improved health status and productivity of those receiving HIV treatment. ART was introduced in the four countries in and around 2004–2005. Since then, remarkable strides have been made in rapidly scaling up the provision of ART, as can be observed in Table 1 as well as Figure 1. Despite these achievements, large numbers of people living with HIV and in need of ART still do not have access: in 2011, more than 200,000 in Ethiopia; more than 150,000 in Malawi; more than 850,000 in South Africa; and more than 85,000 in Zambia (WHO/UNAIDS 2011 estimates).

Table 1. ART access in research countries, 2003–2011

	2003 (all ages)	2004 (all ages)	2005 (all ages)	2006 (all ages)	2007 (all ages)	2008 (all ages)	2009 (all ages)	2010 (all ages)	2011 (all ages)
Total number on ART									
Ethiopia	50	11,000	20,477	53,720	90,212	132,379	176.632	222,723	265,174
Malawi	3,100	13,183	29,087	59,980	100,649	147,497	198.846	250,987	322,209
South Africa	25,000	55,000	206,718	324,754	458,951	730,183	971.556	1,389,865	1,702,060
Zambia	1,121	20,000	48,585	82,030	151,199	219,576	283.863	344,407	415,685
Total number eligible for ART*									
Ethiopia	318,604	331,907	339,680	342,628	354,319	353,476	485.380	476,709	469,355
Malawi	205,295	216,531	226,512	235,715	258,829	273,499	420.895	461,158	478,904
South Africa	771,393	904,667	1,025,542	1,136,034	1,270,786	1,373,207	2.295.159	2,448,096	2,568,974
Zambia	222,964	227,747	234,940	245,721	272,468	289,519	431.488	479,138	502,432
Share of all eligible who are receiving ART									
Ethiopia	0%	3%	6%	16%	25%	37%	36%	47%	56%
Malawi	2%	6%	13%	25%	39%	54%	47%	54%	67%
South Africa	3%	6%	20%	29%	36%	53%	42%	57%	66%
Zambia	1%	9%	21%	33%	55%	76%	66%	72%	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.*
Source: WHO/UNAIDS 2011 estimates

Figure 1. ART coverage in research countries, 2003–2011*
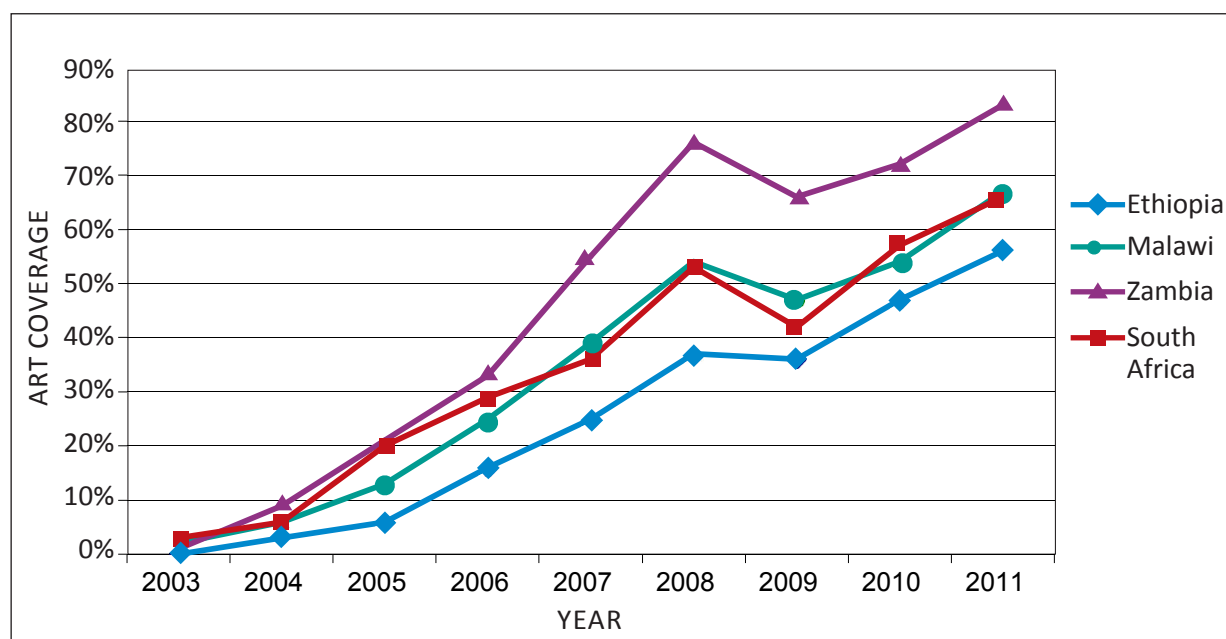
*   *The percentages in this figure refer to the share of all people clinically eligible for ART who were receiving it. That baseline is the reason a significant drop in ART coverage can be seen in all four countries in 2009. The data used prior to 2009 were based on eligibility criteria for a CD4 count 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 WHO in its most recent ART guidelines.*

Source: WHO/UNAIDS 2011 estimates

Regarding these data, it is important to note the significant increases in all four countries in the number of people eligible for ART. These increases are due to changing international standards in the latter part of the decade, culminating in the 2010 release by WHO of new guidelines recommending earlier ART initiation for adults and adolescents. The new criteria are based on growing evidence indicating that earlier initiation greatly reduces morbidity and mortality among people living with HIV and tuberculosis (a common co-infection especially in sub-Saharan Africa) and reduces HIV and TB transmission. The new ART guidelines recommend starting ART at a CD4 count of less than 350 rather than less than 200 as recommended before.

2.1.2 Needs of people living with HIV

The research shows that the needs of people living with HIV are changing, primarily due to increased ART access. Whereas the main needs of people living with HIV in the pre-ART era were basic nursing care, end-of-life care and psychological support, their present needs predominantly relate to care and support services that enable those on ART to recover from HIV-related illnesses and maintain their physical and mental health, as well as be engaged in productive/ income-generating activities. Nevertheless, a significant share of people living with HIV still require basic nursing care, end-of-life care and other forms of care and support within the home environment.

The examples below from the four research countries show not only how the needs of people living with HIV have changed over time but also reflect the breadth of care and support needs identified. Such needs range from physical care and support to psychosocial, socioeconomic, nutritional and legal care and support.[9]

In **Ethiopia** before the introduction of ART in 2005, people living with HIV fully depended on the goodwill of their communities and NGOs to support them during their illnesses and in mitigating

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9   The research investigated clients' needs as part of a questionnaire (which was generally administered by a researcher, sometimes with help of an interpreter) among people living with HIV and their primary caregivers for each of the three case study CHBC programmes that were studied in each country. Client needs were assessed in terms of both particular services or support required as well as those that were lacking or insufficient. Additional input regarding clients' needs was obtained during focus group discussions and interviews with respondents from government and other sectors.

as much pain and discomfort as possible as they died. The involvement of the government in HIV service provision has increased over the past several years as growing numbers of people living with HIV have obtained access to free ART and/or have enrolled into government-managed income-generating and food support programmes. The increased access to ART has resulted in a clear shift in the needs of people living with HIV from basic nursing care in the home to livelihood support, including the need for adequate and nutritional food, other material support, and means of income generation in the long run.

The needs of people living with HIV in **Malawi** have also changed with the advent of ART, evolving away from a primary focus on basic nursing care and treatment to psychosocial support, livelihood support and nutritional support. A range of socioeconomic and material needs (money, clothes, food supplies, blankets) currently form the core of client needs, in part due to the pervasive poverty conditions in the country and the increased vulnerabilities people face as a result of their HIV status. The research found that the efforts by CHBC programmes to date have been commendable as many needs of those infected with and/or affected by HIV are addressed. However, given the extensive needs of clients many are still not met. Increased support is needed if gaps in service provision are to be overcome.

The scale-up of ART in **South Africa**, which began in 2004, has meant a gradual shift in the needs of most people living with HIV from basic nursing care when bedridden to ensuring that those who need treatment have access; that their use of antiretroviral drugs is monitored; and that the possible side effects are monitored and managed. Moreover, clients surveyed expressed the need for central and accessible distribution points for ART, appropriate information about drug regimens and side effects, good care and treatment related to side effects, and (especially) the need to receive drugs reliably. Clients also frequently expressed dire socioeconomic needs, such as for food, adequate shelter and access to social security grants.

Likewise, the needs of people living with HIV in **Zambia** 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 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. Similar developments were observed in the other research countries.

Common needs expressed in the four research countries were food security, income-generating opportunities and psychosocial support as well as specific needs related to ART. Each of these priority areas is discussed in more detail below.

Food security

The need for food security derives from the fact that most individuals on ART require sufficient amounts of nutritious food to physically cope with antiretroviral medicines and benefit consistently from ART.[10] This observation was supported, for example, by the Zambia research. Respondents in that country raised the concern that if clients do not receive adequate support to meet their socioeconomic and nutritional needs, they may face difficulties in adhering to their treatment and their health may decline.

People living with HIV often rely on relatives and friends for support in meeting their nutritional needs. In addition, various programmes and activities have been developed by governments and NGOs to address this need, such as 'food by prescription' programmes at ART clinics,[11] community-driven food support programmes, and programmes that aim to support people living with HIV to start farming and business ventures that enable them to generate income and therefore to purchase nutritious food more reliably. However, the research shows that many of these programmes and activities are under pressure

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10 Research focused on availability of and access to "adequate nutrition", which was defined narrowly to refer to type of food. The term is associated with a broader term, "food security", which is used in the country reports to convey the wider and more comprehensive needs and concerns related to food access and availability.

11 As is the case in Ethiopia.

due to financial constraints or far greater demand than can currently be met. For example in the case of Ethiopia, food support programmes implemented by CHBC-providing organisations have either come to a complete stop or have been severely restricted due to financial cutbacks. Moreover, questions were raised by clients with regard to the accessibility of the 'food by prescription' services provided at ART clinics because the body mass index (BMI) is the only criterion used for selection of beneficiaries. As a result, some people in need of food support may be ineligible simply because they do not meet the requirements of this one benchmark.

These research findings underline the fact that adequate nutrition and nutrition-oriented services should be a distinct and key consideration for the design and operation of ART programmes and HIV clinical health services. Key issues that should be addressed in this regard include adequately trained health dieticians to institute appropriate education campaigns and interventions, assessments of individual client needs for diet supplements and provision of supplement packages. Equally, the need for adequate nutrition points to the importance of CHBC programmes including interventions to enable and enhance clients' access to food via agricultural and horticultural projects.

Income-generating opportunities

Respondents, including clients, caregivers and representatives of CHBC-providing organisations, expressed a need for creating opportunities for people living with HIV and their caregivers to be financially independent.

Psychosocial support

Findings show that the need for psychosocial support runs throughout the history of the HIV epidemic in the research countries. It was identified as a necessary aspect of care and support provided within the home environment in the days when end-of-life care was really the only form of care that could be provided and levels of stigma and discrimination against those infected with HIV were even higher than they are today. The need has remained but in different forms as the HIV epidemic has progressed.

> **South African** informants, for example, referred to the need for 'appropriate' counselling in the sense of counselling that serves clients' concerns and interests in relation to ART. Supervisors of HIV counsellors expressed a concern that the psychosocial needs of clients at times exceeded the capacity of counsellors, both in terms of their training and in terms of balancing the increasing burden of medically oriented tasks with the needs of clients for practical and emotional support. In the case of **Zambia**, the need for psychosocial support was voiced in relation to stigma and discrimination. The essence of the explanations was that although HIV-related societal prejudice had lessened, a development reflected in higher rates of voluntary testing, a major unmet need remains for counselling that supports and maintains growing popular confidence and knowledge of HIV and understanding of the benefits of ART and the importance of adhering to treatment regimens. This points to the importance of comprehensive 'pre-ART' counselling and services that break down myths about ART and HIV more broadly, and thereby prepare individuals for successful treatment uptake.

Needs related to ART

Care and support needs for those on ART were generally expressed in terms of treatment for opportunistic illnesses and side effects of treatment, as well as the development of diabetes, hypertension and different types of cancer that may be associated with long-term ART use.[12] The need for easier access to antiretroviral medication was also highlighted. Ongoing challenges in this regard relate to costs in time and money (e.g., for transport) to collect ART medicines every month, with inefficiencies at health facilities often cited as a regular barrier.

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12 This research only touched the surface of these issues. More information is becoming available on the impact of taking ART for life and how the negative effects might be recognized and addressed.

2.1.3 Caregivers' roles and the management of community caregivers

Much of the research focused on what caregivers do and how their roles and responsibilities have changed over time as well as the management of community caregivers and community mobilisation processes.

Caregivers' roles

The research shows that there has been a clear shift with regard to the roles of caregivers. Prior to the introduction of ART, CHBC predominantly focused on the provision of basic nursing care and psychosocial support to people who were dying from HIV-related illnesses. Following the introduction of ART, the range of services provided has expanded as the needs of people infected with and affected by HIV have changed (as highlighted in Section 2.1.2). Currently, caregivers generally provide a wide range of care and support services that are required to make ART programmes effective and able to adequately respond to the changing needs of people living with HIV. Caregivers' roles in helping achieve these broad goals include the provision of basic nursing care, psychosocial support, socioeconomic support, care for OVC, counselling and testing support, adherence support, providing assistance in triaging, registration support, record-keeping, facilitating client flow in clinics, counting pills and tracking clients and encouraging them to return to care when necessary. They also play important roles in addressing the stigmatisation and discrimination of people living with HIV and in mobilising people for HIV testing.

The examples below from the research illustrate the diversity in roles and responsibilities of community caregivers and the changes that have occurred over time in relation to their roles.

> The provision of care and support at community level in **Ethiopia** is predominantly carried out by civil society organisations that work with volunteers selected from communities, while government 'health extension workers' (HEWs) are responsible for the identification of people in need of clinical care and support and for referring them to the appropriate facilities. Community caregivers recruited by the civil society organisations include 'home-based care volunteers', 'ART adherence volunteers', 'counselling volunteers' and 'prevention of mother-to-child transmission (PMTCT) volunteers'. The roles of community caregivers changed remarkably with the scale-up of ART services. Following the significant reduction in the number of bedridden people living with HIV, the predominant focus shifted from basic nursing care and end-of-life care to, among other activities, the provision of support in enhancing adherence to treatment, provision of information on clients' medical history at health facilities, provision of support in terms of food preparation and personal hygiene, information and knowledge sharing on HIV and AIDS, teaching of primary caregivers and providing support in the preparation of funerals. Caregivers now also play a significant role, while conducting house visits, in convincing individual clients to be more open about their HIV status, especially if they have not disclosed to relevant health care providers, and to get enrolled in care and support programmes. The role of caregivers in voluntary counselling and testing (VCT), PMTCT and ART service uptake was noted to be significant as well.

> In **Malawi**, the CHBC policy has defined the roles of caregivers in relation to CHBC service delivery around the 'five "r"s': readiness, retention, responsibility, referral and reporting. The policy regards CHBC primarily as a clinical health intervention and distinguishes among the roles of health professionals, government-employed 'health surveillance assistants' (HSAs), support groups and community care workers. HSAs provide basic nursing care, support to treatment adherence for clients on ART and psychosocial support as well as maintaining records on clients under their care and on other CHBC activities in their catchment areas. HSAs are responsible for supervising volunteer care workers whose roles include identifying and recruiting clients requiring CHBC as per prescribed criteria; providing basic nursing care; managing common ailments such as coughs, fever, and diarrhoea; providing psychosocial support and nutritional counselling to clients; referring clients to health and other support services; keeping clients' records on care given; providing monthly reports to their supervisors; monitoring side effects of ART and adherence/compliance of clients to treatment (including TB regimes); conducting follow-up visits to clients to retain them in pre-ART and ART care; coaching and mentoring family members of clients; providing IEC (information, education and communication) to clients and family members on prevention of HIV, TB and malaria and the

importance of HIV testing; monitoring clients' responses to treatment and care; and facilitating mobilisation of community transport for referral of clients to health facilities.

In **South Africa**, caregivers' roles have shifted from general to specialised activities. Before the advent of HIV, caregivers' roles tended broadly to target health conditions related to poverty, social inequality and migrant lifestyles; however, these roles shifted to focus on basic nursing care and other support required by clients and their families within the home environment as the HIV epidemic worsened. Once ART became available, diversification and specialisation of roles occurred in the areas of testing, counselling and monitoring adherence to medication, in addition to care for OVC and the psychosocial and socioeconomic support for those living with and affected by HIV already being provided. Current policy moves are towards a more generalist 'community health worker' who will primarily play a surveillance and health promotion role in communities, map health conditions at a population level and advise and refer at-risk individuals and households to appropriate care, support and treatment.

Caregivers in **Zambia** noted that their roles in the past focused on bathing and cleaning clients and performing household chores. Most said that CHBC in the traditional sense of caring for bedridden clients continues but relatively to a lesser degree. More recently, new responsibilities have included tracking clients living with HIV and on treatment, encouraging defaulters to resume treatment, and educating family members on how to support their relatives to adhere to ART. Some caregivers work in health facilities where they assist professional nursing staff with triaging, registration, record-keeping and facilitating client flow in the clinics. Others provide health education talks, assist with the distribution of family planning products, provide counselling for community members, test individuals for HIV, and link clients to treatment centres. According to community representatives, caregivers have over the years increased their responsibility by offering advice on medication, collecting antiretroviral drugs on behalf of clients and escorting clients to health facilities when the need arises.

Among governmental and non-governmental CHBC providers there has been a tendency to create different categories of community caregivers depending on the type of care and support services provided, as reflected in the examples below for South Africa and Zambia.

In **South Africa**, many terms exist for those who work in communities, carry out one or more functions related to health care delivery and broader care and support, but usually have no formal, professional health care qualifications. Terms used include, among others, community caregiver, community care worker, community (based) health worker, home-based carer, lay counsellor, lay health worker, adherence counsellor, peer educator and DOTS supporter.[13] The common generic term used is 'community care worker' (CCW). A national audit estimated that there are some 72,000 CCWs active in South Africa and no fewer than nine categories in this line of work (Department of Health, 2011).[14] The agenda presently being promoted by the government is to deploy a cadre of 'community health workers' as part of primary health care outreach teams directed by the local, relevant health facilities and paid standard wages by the government. In the case of **Zambia**, terms used for community caregivers 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.

Although the caregivers' titles generally reflect their main tasks, caregivers are often involved in a wider range of activities. That is because their roles and responsibilities are defined not only by the scope of work of CHBC-providing organisations but also the needs that exist at health facilities and national policies developed in relation to CHBC. As a result, overlap often exists among the roles and responsibilities of different categories of caregivers.

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13 DOTS refers to 'directly observed treatment, short course', a TB treatment and monitoring strategy recommended by the World Health Organization.

14 The audit did not include child protection workers or OVC workers of the Department of Social Development. In some cases there is overlap and an OVC worker may also be paid as a CCW by the Department of Health. In that case they would have been counted in this particular audit.

This research supports the need for clarification and greater consistency of the terminology used to describe the different people and structures involved in the provision of care and support. The use of multiple terms for community caregivers and existence of many categories of community caregivers leads to confusion and presents challenges, in particular in terms of policy making and implementation with regard to CHBC. The blurred distinctions among the different categories of caregivers, both in the country's policy documents and the minds of key actors, clearly came out in Zambia during interviews with national-level officials. It is yet to be seen what lessons can be drawn in this regard from South Africa, with the government's new plans for organising community-based care and support through the deployment of 'community health workers' as part of PHC outreach teams.

Management structures

Changes in the roles of caregivers have led to different strategies for managing and organising community care and support provision. NGO-managed CHBC programmes generally have administrative structures with salaried, professional health staff coordinating and supervising voluntary community caregivers (in the case of Malawi this is obligatory, as mandated by the government). With the exception of South Africa, these community caregivers are selected through established community structures.

In **Ethiopia**, community caregivers generally receive training for about 10–12 days before being deployed by NGOs to provide care and support. One caregiver is allowed to work under a single caregiving organisation only. The caregivers are usually supervised by staff of the NGO that hires them. Supervisors generally receive monthly reports from every caregiver under their control. Reports are compiled and sent to the headquarters or regional branches, in the case of larger organisations, on a quarterly basis. Consolidated reports are ultimately received by funding organisations, the federal Ministry of Health and other governmental agencies. Moreover, the district health offices of the Ministry of Finance and Economic Development and the Ministry of Women's, Children's and Youth Affairs provide on-site supervisions to projects within their jurisdiction.

The management of community caregivers in **Malawi** is carried out through established community structures and support groups. All selected caregivers are trained and provided with the necessary equipment to do their work, while care and support organisations are required to have trained health professionals among their staff for support and management. At the district level, the Ministry of Gender, Children and Community Development bears the responsibility for managing and ensuring proper functioning of community-based organisations (CBOs) to which community caregivers are attached. The Ministry of Health, through district health officers, takes the lead with regard to ensuring that community caregivers are providing the CHBC services to a minimum acceptable standard. Structured periodic home visits by representatives from health units help both primary and secondary caregivers to acquire on-the-job skills through participation and observation as trained health workers perform home visits according to set protocols. Individual volunteers working on specific projects are identified via the local leadership and work under CBOs in support groups.

Management structures vary in the case of **South Africa** due to considerable differences across provinces in the interpretation of national and provincial policies and guidelines. This diversity is exacerbated by the origin (and hence specific requirements) of funding for NGOs, which may come from the Department of Health, the government's NGO[15] coordination unit, or donors such as the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), the Global Fund to Fight AIDS, Tuberculosis and Malaria, and the European Union. At the time the research was conducted, community caregivers were still to a large extent recruited, selected, supervised and paid by NGOs, which in turn had reporting obligations towards the Department of Health at district level. The Department of Health at provincial level has to assure services are indeed being rendered by NGOs in the districts and that stipends are paid out accordingly. The larger and better resourced NGOs appoint coordinators (e.g., professional nurses) to supervise their caregivers. In smaller NGOs, management structures tend to

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15 The term 'NGO' in the South African context deserves special attention. A different term for the same type of entity, 'non-profit organisation' (and its associated acronym, NPO) are more commonly used in South Africa and are in fact used in the country case study. For the sake of consistency and to avoid confusion, however, only one term—NGO—is used in this synthesis document, including when referring to South Africa. Of note as well is that NGO is the term used throughout the other three country research reports.

be non-hierarchical and there is little formal supervision of community caregivers. However, these structures co-existed with management structures evolving to accommodate the implementation of PHC outreach teams in pilot districts. A further complication is that the Department of Social Development has its own cadre of community caregivers with different funding and management structures, which also involves delegating the selection and management of caregivers to NGOs.

While state-employed community caregivers tend to receive salaries, the majority of those employed by CHBC-providing organisations (most of whom are women, many living with HIV) do not. They generally do receive non-monetary incentives such as training certificates, bicycles, t-shirts, farm inputs and shoes. Some also receive small financial incentives, such as per diems for attending training programmes and meetings or small stipends to pay for meals and transportation costs while working. Examples of remuneration and incentives provided are highlighted below.

In the case of **Ethiopia**, community caregivers receive incentives from their organisations in the form of financial and material support as well as capacity-building support through training programmes. Caregivers often receive small amounts of money to pay for transportation and food while working, with some also receiving per diems during trainings and meetings. The amounts vary from site to site, from time to time and from organisation to organisation. Training is another incentive provided to community caregivers. Most receive training on first aid, nutrition, basic nursing care, ART adherence, data collection and handling, and reporting and counselling. Caregivers also report receiving materials such as umbrellas, caps, shoes, notebooks, t-shirts and home-based care kits including gloves, soap, gowns and uniforms. Some organisations organise annual events to publicly voice appreciation for the work done by community caregivers. In general, it is understood that caregivers should not work longer than 18 months to two years on a voluntary basis in order to avoid burnout. After that period of time, depending on the organisations' operations, they should receive further training, a certificate and financial assistance to start up a business.

Different remuneration levels were also observed among state-funded caregivers in the case of **South Africa**. While some caregivers have already been incorporated into facility-based PHC outreach teams, the Department of Health also still funds a multitude of NGOs, which provide stipends for the community caregivers deployed from these organisations. An exception is in KwaZulu-Natal, where the provincial government has paid community caregivers directly since 2011. The national government provides the policy guidelines and structures through which caregivers are managed by NGOs, but provincial governments are responsible for the actual management of the operations of NGOs. The Department of Social Development has its own cadre of community caregivers with different funding and management structures, although it also delegates the selection and management of caregivers to NGOs. Community caregivers deployed by NGOs linked to the Department of Social Development focus on offering basic care and support, with priority on social support for OVC in the community, at drop-in centres and in children's homes. The stipends of community caregivers funded by the Department of Social Development are usually smaller than those provided by the Department of Health.

In **Zambia**, different incentive arrangements exist for voluntary community caregivers, depending on the organisation for which they work. NGOs often have their own policies for training, recruiting and remunerating community caregivers. Some organisations provide payments to community caregivers who are placed at health facilities while others provide small allowances for community outreach activities or the necessary means to carry out their work, such as bicycles, CHBC kits, shoes, bags and t-shirts. Other forms of incentives are appreciation and recognition at community gatherings and certificates on completion of various training courses. There are also NGOs that conduct training courses lasting from two to eleven weeks, assist caregivers with farming inputs and/ or provide spiritual/pastoral care to prevent burnout. Generally speaking, the principle in Zambia has been to not pay community caregivers. This principle stems from the early and influential CHBC programming designs of the Salvation Army and the Catholic Church. These stakeholders encouraged, and continue to encourage, an ethos of 'self-help' using resources within the communities backed by the material resources and organisational capacity that they can deploy.

The differences noted above in regards to remuneration underscore the finding that there is some ambiguity about the 'voluntary' nature of the work of community caregivers. Many NGOs prioritize and operate as per the principle of voluntarism. This is understood, as noted above in regards to Zambia in general, as meaning that community care work is undertaken by community residents and for no financial reward—although in practice (as noted above) most organisations provide incentives. Moreover, there is much debate about the relative merits of paid and volunteer caregivers. As one informant from a Malawian care and support programme observed, there are significant concerns for the welfare of volunteers:

> *The volunteers give so much. It seems we are only interested in what they are able to give and not what they can get out of the system. There should be some consideration.*

The established systems to sustain flows of volunteer community caregivers are now complemented by the introduction of state-paid community caregivers. Tensions are already apparent, and will likely increase, as governments move to 'formalise' community caregivers on the basis of wage employment contracts in contexts where extensive use of volunteer community caregivers is still, and will continue to be, necessary in order to stay abreast of the changing demands on public health services. The basis for such tensions is that incentives provided by both government-owned facilities and implementing partner organisations tend to vary considerably, both in terms of the type of incentives provided and their value. The absence of a regulatory framework for incentives given to community caregivers therefore poses an enormous challenge, including within communities as caregivers gravitate towards programmes that offer higher value incentives.

Community participation and mobilisation

The research shows that CHBC programmes have managed to persist because the organisations running them have developed sound mechanisms to mobilise communities to support members in need and to ensure participation of members as community caregivers in their programmes.

With the possible exception of South Africa, well-established means were identified to enable and ensure community participation in the research countries. These means are based on existing community structures and, importantly, they are designed to cultivate a 'community'. An important feature illustrating this situation is that CHBC programmes in Ethiopia, Malawi and Zambia align health care with local economic development so that CHBC initiatives incorporate an ethos and means to mobilise communities. In South Africa, however, CHBC programmes struggle to ensure the type and scope of community mobilisation that is so essential for sustaining CHBC programmes. One likely reason for this difference is that many 'communities' are congregations of displaced persons—this is due to the legacy of apartheid and, particularly in urban areas, is a consequence of rapid and uncontrolled growth of slums as people moved to places where there were employment opportunities. Put differently, CHBC programmes in South Africa developed similar ways to enable community participation as those in other countries, but they have struggled to ensure community mobilisation, which is so essential for sustaining CHBC programmes. An implication of the research findings is that CHBC needs to be grounded within communities and to support community-level development as much as individual and family-level health care. The findings below from the research countries show different strategies in community participation and mobilisation.

In **Ethiopia**, community conversations are the main tool used for mobilising community members. Idirs (local community-based organisations) and kebeles (municipalities) often use 'coffee ceremonies' as an entry point. This means of engaging communities is used to encourage participants to voluntarily test for HIV and to urge them to also encourage others. Community caregivers are selected within communities by a committee made up of the kebele administrator, idir members, representatives of caregiving organisations and people living with HIV based on criteria set by the committee. CHBC programmes are largely locally based initiatives involving local government administrators and NGOs, including FBOs and community organisations. Recent interventions by the Ministry of Health to engage more with CHBC programmes do not imply that there will be significant changes to the existing NGO-led system for promoting community participation and mobilisation.

In **Malawi,** community participation is dictated by the requirement that NGOs, including FBOs, must work through and with local government structures. There is a three-tier hierarchy that includes the district administration, traditional authorities and village-level government. NGOs are directed into communities through district, area (traditional authority) and village development committees and HIV and AIDS management structures—district AIDS coordinating committees and village AIDS committees. Community participation is organised according to how a CHBC programme or project is designed and planned in consultation with the relevant committees. 'Health surveillance assistants' (HSAs), who are trained and coordinated by the Ministry of Health, are responsible for supervising community caregivers on client care and facilitating community mobilisation for CHBC programmes (e.g., recruitment of volunteers, the involvement of people living with HIV, and training according to Ministry of Health standards).

Volunteer-based CHBC programmes were the norm in the 1990s in **South Africa**, but substantial criticism led to the introduction of stipends for volunteers. The main mechanism for promoting CHBC programmes became funding-focused partnerships that the government, largely via the Department of Health and Department of Social Development, arranged with NGOs. The foundations were i) the government's Expanded Public Works Programme, which supports financial payments for caregivers attached to CHBC programmes, and ii) a policy of using partnerships with NGOs, including FBOs, whereby the government provides financial grants to establish and run CHBC programmes, with participating NGOs recruiting local residents as community caregivers.. According to a 2011 audit, the bulk of the CHBC programmes (run by some 2,800 NGOs) included payments to some 72,000 community caregivers funded by the Department of Health, PEPFAR and the European Union.[16]

There is a strong heritage of community participation in the delivery of health services in **Zambia**. This system, which is threatened by the current financial cutbacks forced upon community care programmes, for many years has involved and continues to require ongoing mobilisation of community members to participate in these structures and mechanisms. The extensive scale of this process is reflected in the use of some 23,500 community caregivers, the majority of whom are volunteers involved in a wide range of comprehensive care and support activities in and beyond health facilities. It is also reflected in the much larger number of individuals who, as residents or as representatives of organisations, are members of various forums such as neighbourhood health committees, health centre advisory committees, community AIDS taskforces and, more generally, community-level committees. These structures provide resource support to local residents in need alongside other stakeholders such as caregiver NGOs, various other FBOs and CBOs, associations including those comprising people living with HIV, and youth clubs. The extensive participation of communities is the result of sustained commitment of the government and NGOs, since the late 1980s, to decentralising health care services to the community level and elaborating the roles of community members as health service needs and demands change. The deep and extensive network of structures that involve community members in the country's HIV programme and other health service programmes are being reinforced by the recent introduction of the new cadre of state-employed community caregivers, i.e., 'community health assistants' (CHAs).[17] The introduction of CHAs is a means to uphold the principle of decentralising health care and the longstanding commitment to community-oriented care.

Mixed impressions were obtained with regard to the deployment of community caregivers. On the one hand, respondents in Ethiopia indicated that the number of community members willing to volunteer for care and support services for people living with HIV has increased over time due to a decrease in HIV-related stigma and discrimination. On the other hand, the Malawi research revealed that many

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16 The Community Health Audit (2011) recorded the existence of 49,042 home-based carers or community caregivers, 15,206 lay counsellors, 2,010 adherence counsellors,2,740 DOTS supporters, 3,478 peer educators, 93 TB defaulter tracers, 109 high transmission area workers (HTA workers), 143 hospice workers and 18 mentors.

17 Community health assistants (CHAs) are paid employees of the state, receive a year's training before being deployed to coordinate voluntary community caregivers, and are formally recognised via registration with the Health Professionals Council of Zambia. They are expected to spend 80 percent of their time in communities and 20 percent at health posts. The associated development in this instance is the agenda to revitalise health posts, which are the lowest level of health facility and were created in the late 1980s as part of Zambia's endorsement of the WHO model of decentralised health care. Each of these facilities is supposed to be staffed by a nurse, but that often does not happen due to staff shortages and the debilitating consequences of the HIV epidemic.

CHBC-providing organisations were struggling to keep community caregivers motivated and involved in their programmes due to limited incentives provided, a situation that has increased drop-out rates and created a continuous need for training of community caregivers within CHBC programmes. In the case of Zambia, the loss or severe reduction in cash incentives, and even in resources such as bicycles, has reportedly led to many community caregivers withdrawing their services. Yet it is important to note that at the same time others reported that there are many caregivers who continue to provide their services on a voluntary basis regardless of the reduction in support.

2.1.4. Service provision

Another focus of the research was to identify which services CHBC programmes and government health systems provide as a means to describe the general structure of treatment, care and support in each country.

CHBC service provision structures

In all four countries, structures exist for the provision of community care and support services to those in need. CHBC is provided primarily by NGOs, guided by national policies that define national standards and guidelines for the training of community caregivers. Collectively, NGOs offer a wide range of services. Considerable variations, however, exist in the links between the operations of the NGOs and those of government ministries. As highlighted in Section 2.1.3, in Malawi it is mandatory for NGOs to work with 'health service assistants' (HSAs) who are their formal community-level link to government health services. In South Africa, the government still to a large extent 'outsources' community care and support services to NGOs via partnerships in the form of funding grants to conduct care programmes. In Ethiopia and Zambia, NGOs operate relatively independently of the government and, generally, they have informal working arrangements with government departments. In Zambia, there is a long history of NGOs being responsible for community care and support services and some also manage their own hospitals and clinics. Consequently, they interact directly with different government programmes and design cooperative arrangements as necessary. In Ethiopia, NGOs (including FBOs) must register their operations with government departments. After that, they establish their own cooperative arrangements with relevant state agencies.

Summaries of findings from the research countries in terms of service provision are highlighted below.

> Initially, care and support services for people living with HIV in **Ethiopia** were mainly delivered by individuals and NGOs, including FBOs. Caregiving organisations provided food items and cash, covered medical expenditures, and provided home-based nursing care and end-of life care to people living with HIV through community caregivers. Nowadays such services are provided by different actors, ranging from individuals to both local and national governmental entities and NGOs. Opportunities for involvement in income-generating activities are now provided by government institutions and food support by health offices and health facilities.

> A clear division exists in CHBC service provision in Ethiopia between clinical and non-clinical services. Non-clinical care consists of services such as psychosocial support, economic support, food and materials support, and other social supports. These services are generally provided by NGOs. The Ministry of Health generally provides clinical care at health facilities, including the services associated with ART provision, PMTCT and treatment adherence as well as early detection and treatment for opportunistic infections, etc.

> In **Malawi**, community care and support are provided by several government departments, civil society organisations and communities themselves. The Ministry of Health sets out the framework for NGO service provision, with service providers only able to provide services that are approved by local administrations and district AIDS coordination committees. The Ministry of Health remains the largest single health service provider and is the main point of contact for treatment services. FBOs and other NGOs wishing to provide care and support services may do so provided they have trained health staff and work through and with community structures such as village health committees and support groups. This requirement was reflected in the range of services that the

three case study programmes offered at the facility and programme level, as found during research for this report. The broad categories of services were in treatment, prevention, capacity-building and support services. Services provided under treatment included provision of medication when clients visit mission hospitals and during home visits, procurement and distribution of drugs to CBOs, and provision and restocking of CHBC kits. The programmes also provided support services such as material support provision (clothes, blankets, food) and livelihood support (farm inputs such as seeds). Prevention services provided by the three programmes included HIV sensitization campaigns and HIV testing and counselling (HTC) services through both static sites and via outreach. Capacity-building services under the programmes included training CBOs, provision of funding to support CHBC activities, technical assistance to CBOs in managing CHBC programme activities, and nutritional education for primary and secondary caregivers.

While the government in **South Africa** has started implementing new policy guidelines deploying state-paid 'community health workers' as part of PHC outreach teams operating from formal health facilities, services are still also delivered by health-related NGOs that enrol, supervise, manage and pay their own caregivers. The state provides funding, policy guidelines and resources, and it offers some skills-development capacity support through arranging training opportunities. Government structures are also responsible for coordinating the monitoring and evaluation of the delivery of services as well as for ensuring that protocols and targets are respected. Services are delivered at state clinics, in clients' homes and in communities. Two government agencies are involved in funding and supporting community care and support work in NGOs, namely the Department of Health and the Department of Social Development. Services currently provided by CHBC personnel include HIV services, TB services, family planning services and care and support activities within the home environment.

Different configurations were observed among the three case study organisations included in the South Africa research. The organisation operating in the Free State Province structured its services in vertical programmes: CHBC, including care and support for chronic conditions; HIV-related services (counselling and testing, adherence monitoring, verbal screening for TB); and OVC services. The organisation working in a rural setting within the Western Cape delivered holistic services including all of the above, apart from OVC services. The organisation working in an urban setting within the Western Cape focused on delivering lay counselling services in facilities, sub-divided into HIV testing and ART adherence counselling in general outpatient and maternity unit settings (with the majority of counsellors now trained to perform both roles). Referral to facilities and other sources of care and support (often offered by other NGOs) was an important service in all the organisations observed.

CHBC programmes in **Zambia** have evolved from early interventions in the late 1980s, which were largely set up by FBOs but with government policy support for community-based health care services to NGO-run CHBC programmes. These have grown in tandem with the government's strategy to decentralise health care through the establishment of three tiers of services (central, provincial, district) and the creation of health posts within districts to provide PHC services. In addition, a multisectoral response has been promoted—for example, through encouraging businesses (notably the large mining sector), traditional healers and parastatal organisations to develop HIV prevention and treatment initiatives. Currently, various line ministries are involved in the provision of care and support in the country. 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, and level one, two and three hospitals. The lowest service provision points in the health sector are health posts, where community health care is provided. Another government agency providing services at the community level is the Ministry of Community Development, Mother and Child Health. It now has an important role through its focus on prevention at the community level, primarily related to maternal and child health, whereas the Ministry of Health is now more focused on the curative aspects of health.

Health services in urban areas are accessed through a mix of public and private health institutions, while rural dwellers largely depend on institutions run by the government and 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 MoU, the Ministry of Health provides grants and seconds skilled health workers to these not-for-profit organisations. Such partnership is vital because FBOs provide a significant percentage of health services through mission hospitals, which have links with other rural health facilities. NGOs (local and international) on a smaller scale provide community health care services. For instance, one organisation surveyed provides CHBC services at community level to people living with HIV, TB clients and OVC. More recently, this organisation has instituted a deliberate change in focus from basic nursing care to more comprehensive care and support that includes counselling, referrals, logistical support to access diagnostic and treatment services, and ART/TB treatment adherence support.

Services provided

Table 2 below shows the main types of services provided by primary and secondary caregivers according to the 46 care and support organisations that responded to the Phase 4 questionnaire in regards to service provision.[18] The findings clearly illustrate the wide range of care and support services provided. Annex 1 offers a more elaborate and detailed overview of the services provided and illustrates the diverse roles of primary and secondary caregivers in service provision.

Table 2. Main care and support services provided by community caregivers*

- Basic nursing care
- Personal hygiene
- End-of-life care/ pain relief
- Social and/or livelihood support
- Nutritional support
- Spiritual and/or emotional support
- HIV prevention and treatment support within the home/ community environment
- Health education
- OVC care and support
- Referrals of clients to health facilities

*   Based on a survey of 46 medium-size and large care and support organisations providing CHBC services
Source: CAN multi-country research (Ethiopia, Malawi, South Africa and Zambia), 2011–2012

The shift towards the provision of more comprehensive care and support discussed above has included an increasing role for caregivers: record-keeping, linking of clients to services provided at facility levels, health promotion activities, counselling community members, testing individuals for HIV, linking HIV-positive individuals to treatment centres, tracking HIV-positive clients on treatment, encouraging defaulters to resume treatment, and educating family members on how to support their relatives to adhere to ART. While CHBC-providing organisations predominantly work with secondary caregivers, primary caregivers also provide critical care and support services—particularly in terms of basic nursing care, pain relief, personal hygiene, nutritional support and treatment support.

Expansion of services offered and client populations served

Another significant development identified in relation to providers responding to client needs is the growing demand for CHBC and PHC programmes to accommodate a broader range of health care conditions. These demands are linked to the expansion of HIV treatment services. As ART services in particular have expanded, so has the knowledge of the scale and presence of other (non-communicable) diseases such as diabetes, hypertension and mental and physical disabilities. In the South African case, other relatively common problems include extremely high levels of trauma induced by domestic and criminal violence and, particularly in urban areas, drug and alcohol addiction. Furthermore, CHBC

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18 Given that 59 organisations were approached and asked to fill in questionnaires, the 46 participating organisations represent a response rate of 78 percent.

programmes and government health services have opened the door to including many of these other conditions and challenges in their operations via interventions to incorporate support services for TB (often co-existing with HIV infection) and, more generally (particularly in Malawi and Zambia), commitment to community welfare and development.

CHBC programmes generally embody a broad conception of health and community welfare and, prior to recent financial cutbacks, the large care and support organisations had the resources and structures to begin developing projects to address these challenges. Government health services have also begun to broaden the scope of their PHC services in relation to HIV via a focus on paediatric treatment and sexual and reproductive health services. This has occurred in response to donor requests and is in accord with core imperatives of the Millennium Development Goals (MDGs), notably those related to maternal and child health, and the ongoing concerns about the welfare of OVC in the context of HIV.

FBOs and other NGOs have been at the forefront of these developments and, in some countries, government policies have encouraged the development of CHBC programmes that emphasise community and family welfare as well as individual treatment, comprehensive care and support. The situation is evolving as NGOs and governments continue to refine and/or restructure HIV-focused initiatives. A respondent from a South African HIV organisation[19] described the evolution of his organisation's activities in the following terms:

> *We were formed as an HIV organisation, as many were, but we…have been broadening consistently…. We've expanded our work from prevention, vertical transmission of HIV and breastfeeding, where we were focused before, to [now] include the whole road to health care, [such as] immunisation, developmental stages, child development, etc.*

The CHBC-providing organisations included in Phase 4 of the research predominantly served people living with HIV. Other clients served were individuals with chronic conditions such as hypertension, diabetes and cancer (Malawi, South Africa) and with TB and sexually transmitted infections (Ethiopia, Zambia).[20]

2.1.5 Policy environment

The research recorded changes in policy environments relating to care and support in all four countries. While the general trend is towards incorporating CHBC into government PHC structures and programmes, there are marked differences across the countries according to the extent to which they have adopted the WHO decentralisation model and, critically, whether health policies are aligned to national economic development policies and structures.[21] Variations observed relate to how (and if) governments have decentralised health care in the past and seek to do so in the future, as well as the extent to which governments recognise and accept community caregivers and CHBC programmes as integral components of national health systems.

Malawi and Zambia are among the countries that have a relatively long and stable history of government commitment to the decentralisation of health care and, specifically, to community-level services. In these countries, the revitalisation of PHC has introduced some tensions with regard to incorporating ART programmes and the relationship between PHC facilities and CHBC programmes. However, this revitalisation has occurred within a strong framework that acknowledges CHBC programmes as integral components of the national health system.

In the case of **Malawi**, a large number of policies and guidelines provide direct and indirect guidance on CHBC, including at least 15 related to community care and support. While the Malawi Growth

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19 The names of the three case study CHBC-providing organisations included in the South Africa research are not specified in this report. The reason is that the country researchers are of the opinion that the purpose of the research was not to showcase the work or these organisations but rather to obtain a better understanding of the environment in which CHBC-providing organisations operated.

20 Across all 46 organisations surveyed in the four countries, the average number of clients living with HIV was 1,778. By comparison, each organisation was serving (on average) 747 clients with other chronic conditions. Because these figures reflect averages only, there is a wide range between organisations with far fewer clients and those with far more.

21 The WHO decentralisation model refers to the common practice encouraged by WHO in the 1980s to devolve management of the delivery of health care (e.g., down to district level) coupled with expansion of PHC facilities at local level.

and Development Strategy (2011-2016) provides a broad overarching medium-term development framework, the National HIV and AIDS Policy of 2003 (updated in 2008) and the Malawi HIV and AIDS (Extended) National Action Framework (2005 and updated in 2009) set out the sectoral administrative and legal framework. A specific CHBC policy and related guidelines were formulated in 2005 and updated in 2010. The current CHBC policy reflects the changes that have occurred due to the advent of ART and other emerging issues including the need to recognise the role of caregivers, inclusion of other chronic diseases, and issues specific to the elderly, people with disabilities and OVC.

Zambia has a strong community care and support policy framework that is shaped by various sector-specific and national-level policies. The country has been implementing wide-ranging health sector reforms aimed at attaining equity of access to assured cost-effective quality health services, as close to the family as possible. 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. The Ministry of Health and the National AIDS Council (NAC), in partnership with other actors, recognised the need for standards for CHBC, including in regards to training of caregivers and in the provision of services. This resulted in the launching of the Zambia National Minimum Standards for Community and Home-Based Care Organisations in 2007. In line with the minimum standards, the National Community and Home Based Care Training Package, which includes eight modules, 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 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 situation in Ethiopia is different as government policies restrict the decentralisation of health care and emphasise distinct roles for PHC facilities (treatment and care) and CHBC programmes (comprehensive care and support). The coordination role of the HIV/AIDS Prevention and Control Office (HAPCO), and deployment of health extension workers to serve it, has yet to be well-defined with appropriate procedures and mechanisms. In the meantime NGOs continue to develop CHBC programmes, particularly in rural areas where government PHC services are lacking, and by doing so support the development of PHC operations. This process, however, is being halted or even scaled back due to lack of funding for many civil society groups.

The government's longstanding approach in **Ethiopia** to HIV is to have the Ministry of Health focus on the clinical aspects of HIV health care; as such, it views community-oriented health care as a social health issue and, therefore, not one of its principal responsibilities. CHBC programmes therefore are largely the domain of NGOs (including FBOs) operating independently of the health services. This situation has not changed substantively, although informal collaboration between NGOs and government health facilities has grown to enable cross referral of clients living with HIV. The principal change is that the Ministry of Health has begun to integrate its HIV treatment programme into its general health programmes and has directed HAPCO to coordinate CHBC programmes.

The current situation reflects Ethiopia's continued reliance on the HIV control and prevention policy developed in 1998. That policy covers the clinical care of HIV clients and was developed by the Ministry of Health. More recently, a national OVC policy was drafted and implemented by the Ministry of Women, Children and Youth Affairs to set out principles for the social welfare of children affected by the HIV epidemic. A multisectoral response is encouraged through each government ministry being required to incorporate HIV into its strategies and plans.

There has been organisational and operational restructuring of the national HIV response over the past decade, which amount to de facto policy changes. HAPCO, a separate arm of the Ministry of Health at national, regional and local levels of government, was the principal structure for managing

the country's interventions until 2010-2011. That responsibility now lies with the general health management structures—regional health bureaus (RHBs), zonal health departments (ZHDs) and woreda health offices (WrHOs)—and the health facilities that report to those agencies. HAPCO is, as mentioned, responsible for coordinating CHBC programmes. However, decentralisation of responsibilities includes the transfer of monitoring and evaluation functions of community programmes to district-level WrHOs. Along with RHBs and ZHDs, WrHOs work closely with care and support organisations in selection of project sites, capacity-building and reporting of activities. The complex political environment in which CHBC programmes operate is also clearly reflected in procedures that need to be followed to implement such initiatives.

The South African situation is noteworthy because of the new government policy of establishing a cadre of paid 'community health workers'. This represents fundamental changes to community-based care and support. At the time of the research, changes were only just beginning to take place, so this research cannot comment on the implementation of the new approach. Further detail regarding the proposed changes in South Africa is provided below.

> In **South Africa**, the National Department of Health launched in September 2011 a new set of policy guidelines envisaging a revitalised PHC approach with all community caregivers as state employees deployed in outreach teams to do community profiling, risk identification and referral to formal health facilities.[22] These guidelines come within a South African context where health needs associated with poverty, infectious disease, non-communicable disease and injury and violence amount to a quadruple burden of disease.
>
> The government's guidelines on re-engineering PHC emphasise a shift towards deploying more generalist 'community health workers' who will be trained to play primarily a surveillance and health promotion role in communities, mapping health conditions at a population level and advising and referring at-risk individuals and households to appropriate care, support and treatment. The idea is to focus initially on HIV, TB, and maternal and child health, and then to expand to other chronic illnesses and conditions resulting from injury and violence. Other important roles envisaged for the more generalist 'community health workers' are encouraging people to be tested for HIV and supporting HIV-positive clients' uptake of and adherence to treatment. The generalist 'community health workers' will be part of ward-based outreach teams operating from formal community-based health facilities (like PHC clinics) and will be directly employed by the National Department of Health.
>
> The proposed changes represent the South African government's response to the challenges emerging from a somewhat fragmented community care system. Changes are based on a national Community Health Worker Audit conducted by the National Department of Health in 2010–2011.
>
> The guidelines developed by the National Department of Health have been made available to the nine provinces for implementation. Uptake is not compulsory, however, and the provincial health departments have responded to the guidelines in different ways. For example, the North West Province has created a provincial task team and has started to implement the guidelines systematically; others, including the Free State and KwaZulu-Natal, are starting partial implementation, while the Western Cape is opting out but is nonetheless aligning existing programmes with national government guidelines.
>
> At the time of research it was unclear how the proposed changes would affect NGOs providing care and support services. Many representatives from the sector expressed uncertainty about the future of daily home-based care for long-term bedridden clients, time-consuming adherence support and dedicated psychosocial support programmes. The roles of NGOs in the new structure were also indistinct, and as a result many had begun to adjust their priorities from home-based care to managing access to ART and shifting their focus to the care and support of OVC and their primary caregivers.

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22 More information on the provincial guidelines set for the implementation of the three streams of PHC re-engineering is available at www.cmt.org.za/wp-content/uploads/2011/09/GUIDELINES-FOR-THE-IMPLEMENTATION-OF-THE-THREE-STREAMS-OF-PHC-4-Sept-2.pdf.

2.2 HEALTH SYSTEM INTEGRATION

Research objective: Assess how and to what extent caregiving by informal caregivers at community level has been integrated in the health system and is being recognised as part of primary health care structures and policies

2.2.1 Primary health care structures and policies

The research found large variations in the extent to which governments view community caregivers and CHBC programmes as integral components of national health systems. In Ethiopia, CHBC programmes are acknowledged as a component of the health system but with responsibility for the 'non-clinical', social welfare aspects of health care and, therefore, are not formally part of health services. Collaboration between government agencies and NGOs is accepted and encouraged but there is no intention to integrate CHBC programmes into the health services or to place them within the remit of PHC. Zambia and Malawi recognise that community caregivers and CHBC programmes are essential components of their health systems and integral to their ART and PHC strategies. Although the Zambian Ministry of Health seeks to 'formalise' community caregiving, via the establishment of a new cadre of 'community health assistants' (CHAs), this is likely to be only in the sense of emulating Malawi's existing use of 'health surveillance assistants' (HSAs) to create firm links among health facilities, community caregivers and CHBC programmes. In both countries, coordination rather than integration of CHBC and PHC programmes is the practical agenda. In South Africa, the previous lack of formal mechanisms for coordination of the Ministry of Health services and CHBC programmes and the multiplicity of different categories of community caregivers are driving a policy to restructure community caregiving and integrate it into PHC services.

> As noted in Section 2.1.5, the government in **Ethiopia** distinguishes health care from community-level caregiving on the basis of its bio-medical definition of the responsibility of the national health services. Accordingly, integration of CHBC into PHC services is neither projected nor expected. CHBC programmes are recognised as necessary interventions and the government has directed HAPCO to coordinate their operations, using 'health extension workers' (HEWs) to engage at the community level. However, there is no clarity on how this is to be done because there is no formal CHBC policy currently exists and the arrangements are not well defined; moreover, according to respondents, HAPCO has yet to set up mechanisms and procedures to fulfil its new responsibility. HEWs are supposed to coordinate the activities of community caregivers and to facilitate the delivery of PHC services. Unlike in other countries, their role will not be restricted to the coordination and supervision of existing community caregivers. Instead, HEWs, the majority of whom are nurses, are expected to work with community caregivers to improve the reach of the ART programme and to reduce the rate of clients who have stopped treatment. To date, this new system has been implemented primarily in the capital, Addis Ababa. Elsewhere, particularly in the rural areas, there are reports that PHC services exist by default through the activities of CHBC programmes. One concern is how this will work in practice, given that as HEWs are employees of HAPCO and not formally part of health facilities that are managed by regional health bureaus (RHBs) and woreda health offices (WrHOs).

> In **Malawi**, government policy views CHBC as an integral part of the country's primary health care services. CHBC is part of the Essential Health Package for citizens.[23] Health centres monitor, supervise and implement (with NGOs) CHBC activities and referral mechanisms for clients in their catchment areas. The Ministry of Health sets out the framework for NGO services in districts, in association with local government administrations and district AIDS coordination committees. There is also a mandatory requirement that NGOs have health professionals among their staff (often in supervisory and managerial roles). Government-employed 'health surveillance assistants' (HSAs) also act as agents of the local health facility to ensure coordination of community caregivers' activities and NGOs' programmes. While CHBC programmes are integrated into PHC services, both structures are closely aligned to local government and community structures that define local health and

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23 In 2002, the Malawi government adopted the Essential Health Package, a clearly defined package of key interventions that serves as the basis for pooled funding to the health sector.

community welfare priorities and interests. The limitation of this system is that it depends upon adequate staffing by health professionals in health facilities. In their absence, HSAs become de facto nurses and are confined to working in health facilities, focusing on treatment and care work.

National guidelines in **South Africa** at present favour using health facilities as a platform for creating ward-based community outreach teams to provide PHC services (wards are local government areas within districts or towns). As per new proposed policy guidelines (see Section 2.1.5), these teams are to be managed by health professionals and will deploy state-employed caregivers to enable identification and referral of clients for treatment, care and support. The agenda includes integration of TB and HIV services.

This approach is supported by policy drafts that dictate decentralisation of PHC and CHBC responsibilities to provincial governments. However, there are as yet no definitive policies and existing guidelines are being interpreted differently by provincial governments. One challenge of the changes is that not all 72,000 individuals currently providing community-based health services in South Africa will be employed by the state because of the cost. At the time of research it was unclear whether the provision of care and support services within the home environment would be included in the job descriptions of employed caregivers. Consequently, there are likely to be many community caregivers who would work 'outside' the system via small NGOs that secure external funding; these caregivers may remain unpaid.

Zambia's health services recognise that community caregivers are an integral part of their community-level health programmes. This is due to the well-established CHBC system that has been promoted by the government since the mid-1980s. The government first sought to exercise more control over CHBC programmes in the 1990s; more recently, it has revitalised that effort in the last 4–5 years through, for example, the development of new national standards for the training and delivery of care and support services and the 'formalisation' of caregiving by deployment of 'community health assistants' (CHAs). The stated agenda is that CHAs will coordinate community caregivers and also help to expand PHC services, focusing on malaria prevention, respiratory illnesses, diarrheal illnesses, TB, HIV and maternal and child health. They are not intended to replace the existing network of community caregivers and there is no expectation that CHBC programmes should be integrated into PHC structures. Consequently, the situation is one of two parallel structures, both working within broader government policies that emphasise commitment to improving community health and welfare but, generally, operating independently (including the CHBC programmes themselves).

Although the four countries represent different government strategies with regard to the principle of programme integration in relation to CHBC programmes and PHC services, the outcomes are not necessarily different. Integration is a key principle in Malawi and South Africa. It has been mostly achieved in Malawi but remains a challenge in South Africa. In the latter case, the problems relate to inconsistent interpretation of policy, an agenda that does not integrate health services into both community and district-level government structures, and a new system that will not recognise a great many volunteer community caregivers. The situation in Zambia is marginally different from Malawi, with the former soon to have a similar community care and support system in place via deployment of 'community health assistants' (CHAs). The principal difference will be that Zambia's national development and CHBC policies promote coordination rather than integration of CHBC programmes into the Ministry of Health framework.

Of note too are similarities between Ethiopia and South Africa. In both countries the actual mechanisms for the interaction between CHBC programmes and PHC services are not well defined. However, the expectation is that 'health extension workers' (HEWs), in the case of Ethiopia, and state-remunerated 'community health workers' in South Africa, are representatives of the health services and will liaise with community caregivers and NGO-run CHBC programmes to ensure greater reach of ART and other PHC services.

These similarities and contrasts reflect debates in the 1980s between 'selective' and 'comprehensive' PHC. Malawi and Zambia represent governments that have moved deliberately towards providing comprehensive PHC services. However, it is not yet possible to discern the core agenda of the Ethiopian and South African governments in this regard.

2.2.2 Decentralisation of HIV treatment

All four countries have made important strides in expanding access to treatment services for people living with HIV. The research found that HIV treatment services have generally expanded to health centre levels, although not all health centres are equipped to provide ART. This is mainly the result of restrictions allowing only specially trained health professions to prescribe and manage ART. With the exception of Zambia, where mobile sites provide access at community level, and current pilots in South Africa that experiment with dispensing drugs outside health facilities, there does not seem to be much impetus in Ethiopia or Malawi for further decentralisation of HIV treatment to lower-level health or non-health facilities in the near future.

The decentralisation of HIV treatment in **Ethiopia** is still in process, with first-line ART available at both hospitals and many health centres but second-line ART only available in hospitals. According to the government, all health centres should be providing first-line ART by 2015. Despite advocacy by NGOs to decentralise treatment to the health post level (to increase access among rural populations), interviews with respondents in key positions at national level revealed that further decentralisation is not expected.

Resistance, lack of adequate counselling and concerns about the timely detection of opportunistic infections were mentioned as obstacles to further decentralisation of services. Also, it is not always clear that decentralisation will remove bottlenecks at some higher-level facilities; for example, managers of ART clinics in hospitals expressed concern over the high influx of clients at their clinics despite having decentralised such services to health centres. Such influx persists despite the successful 'community conversation' strategies to tackle stigma and discrimination at community level because some clients still prefer to seek services outside their locality.

NGOs providing CHBC have a support role in treatment services. The majority of community caregivers are assisting the ART programme by promoting VCT and enrolment to ART services at community level. They monitor the adherence of clients, with some even visiting their clients twice a day to ensure intake of medication. In the event that clients are too ill to visit health facilities for their drug supply, caregivers are allowed to collect the drugs for them.

An illustration of how general policies can restrict the expansion of HIV treatment services is a recent government instruction that client files should be centralised within health facilities. Client cards formerly were located in the ART department but all cards are now stored in the 'card room'. As a result, clients have to wait longer for ART services than before because health staff need to collect their cards (which are sometimes misplaced or lost).

HIV treatment services in **Malawi** have been decentralised to district centres and selected health centres at district level. Free ART is also provided through private clinics and NGO hospitals, including those managed by the Christian Hospital Association of Malawi. There is a close coordination with community caregivers from CHBC programmes. ART is being provided by health care professionals and complemented by the involvement of community caregivers in identifying, recruiting and referring clients requiring treatment; monitoring clients' responses to treatment; monitoring side effects and adherence/compliance of clients, including those on cotrimoxazole prophylaxis and TB drugs; and conducting follow-up visits to retain clients on pre-ART and ART care. The role of community caregivers in dispensing treatment is minimal and this is expected to be the norm for the foreseeable future.

In general, **South Africa's** redesign of PHC services seeks to incorporate comprehensive care andsupport services for TB and HIV. The research revealed different approaches at provincial level. In Gauteng and the Free State the current focus is on HIV treatment being managed through 'health posts' in communities. In the Western Cape experiments for further decentralisation of HIV treatment services are planned, with some already running. One plan is to train HIV and TB clients in treatment readiness for two months and one month, respectively. After this training, a community caregiver will conduct a home visit to assess the level of treatment support in the household and determine whether the client qualifies for home treatment. Chronic medicine dispensing units exist in some communities so that clients do not have to travel to clinics for their medication. Distributing

ART drugs at these dispensing units is being considered. Furthermore, general chronic care support groups (incorporating HIV clients) are also conceived as possible points for dispensing HIV treatment along with other chronic medications. Caregivers and nurse coordinators wished to incorporate people living with HIV into their chronic care groups as a way of combating stigma and to make it easier for those individuals to access their antiretroviral medicines.

There is also considerable enthusiasm for ART 'clubs' run by nurses or counsellors that would allow stable and adherent clients to get quicker access to their treatment, either at a convenient community distribution point or in the local state facility. Adherent clients would also be allowed to pick up a larger amount of pills (e.g., for two or three months), which would reduce the number of times that they would have to collect new supplies.

ART services in **Zambia** have been decentralised to over 500 sites in the country, with the lowest level of provision being health centres and mobile sites. District health offices have been using mobile ART services to increase access of communities that are located far from health facilities. Community caregivers have been drawn into these services through various activities. One study conducted in rural Lusaka Province found that involvement of community members, via lay counsellors and support groups, increased the number of clients retained at the original site compared with hospitals, which normally have many referred cases (Dube et al., 2010). The decentralisation of ART to health centres and mobile sites has helped to decongest hospitals and reduce the distances clients have to travel to collect drugs. Trained health personnel who prescribe ART are complemented by community caregivers who provide adherence counselling and follow-up visits.

Current challenges in the decentralisation of ART services include a shortage of qualified human resources to prescribe and dispense ART as well as the absence of diagnostic capacity (e.g., for CD4 counts and liver function tests) at health centre level, which means that clients have to be referred to hospitals. The research revealed limited scope for decentralising treatment further down to community level in the immediate future in Zambia. This is due in part to the difficulty the Ministry of Health is facing in staffing its health posts with health professionals, a step that would be needed to provide the necessary supervision of community-oriented treatment services.

The research provides evidence that many of the principles of the Treatment 2.0 initiative are understood and being prioritised, although respondents did not explicitly use or know the term Treatment 2.0. For example, community caregivers are complementing clinical services by both promoting ART enrolment and supporting the retention of clients in care. Among the ways in which community caregivers are involved in HIV treatment service provision are adherence counselling and monitoring of drug intake and possible side effects. The integration of HIV treatment services in other health services was predominantly observed in TB services, with some innovative interventions projected to happen in South Africa—notably, integrating non-communicable disease with HIV treatment services.

Following the advent of ART, national health professionals gained a greater appreciation of the vital role played by community caregivers. In order to rapidly expand ART programmes, their engagement in adherence support proved indispensable for professional health providers. However, the decentralisation of HIV treatment in the four countries seems to have reached a point of official resistance. There does not seem to be scope for further decentralisation of ART in Ethiopia. The Zambian and Malawian context may provide some room but it is likely to be met by significant resistance from health professionals.

In South Africa, there is perhaps the most room to further experiment with different service delivery models through PHC structures because there is more sensitivity to civil society advocacy and a more flexible policy environment. As noted elsewhere, complementarity currently exists between community caregivers and health professionals in following clients on treatment. Yet even so, the example from South Africa—where a 'club' service is provided to stable clients—appears to be the only one that deviates from the prime delivery model of health facilities working on the basis of monthly returns by clients for check-ups and refills.

2.3 CAREGIVERS' POTENTIAL

Research objective: Investigate the contributions of, potential role of and benefits for caregivers in the expansion of HIV prevention, treatment and primary health care programmes.

2.3.1 HIV prevention and treatment programmes

Across the four countries, research results indicated that the contributions of community caregivers in HIV prevention were not just concentrated on the provision of health education. Caregivers play a central role in mobilisation for HIV prevention campaigns led by personnel of NGOs and government facilities. As such, they contribute to the drive for universal counselling and testing, with some even trained to conduct HIV tests directly. Their potential in promotion of health-seeking behaviour in general and uptake of HIV-related services, including PMTCT, by linking people to health facilities, is widely recognised and deployed in the four countries. Education messages change with the changing information needs of their clientele, with the provision of sexual and reproductive health (SRH) education being a prime example of how community caregivers have adapted to new situations.

ART programmes depend on the involvement of non-state employed community caregivers and many would underperform, or possibly collapse, without their contribution. As underscored by the research, these individuals are vital to efforts to improve the uptake of services as well as retention of clients on ART. They fulfil an essential role in tracing defaulters and supporting clients to adhere to treatment. Some of these caregivers have been stationed in health facilities, as seen in examples from Ethiopia and South Africa, and receive remuneration for their services. In such instances their role is restricted to assisting health professional staff and this is not likely to change in the near future.

Research data from the Phase 4 survey show that services related to HIV treatment have already become part of the daily tasks of community caregivers and components of many CHBC programmes. Table 3 summarises the relevant findings in relation to a question on HIV treatment services currently provided. As expected, only a minority indicated that voluntary community caregivers were currently involved in direct ART provision, although over 40 percent of all respondents (representing 19 organisations) from the four countries were in favour of these caregivers being given responsibility for distributing ART.

Table 3. Multi-country findings on current roles of voluntary community caregivers in HIV treatment programmes*

Type of service	Already providing this service
Monitoring the health of clients to check whether they need to visit health facilities for a check-up	80%
Monitoring clients to check whether they are taking their medicines	91%
Provision of pre-ART care and counselling	71%
Distributing antiretroviral medicines	22%
Door-to-door voluntary counselling and testing	53%
Recruitment of pregnant women for PMTCT services	78%

*   Based on a survey of 46 medium-size and large care and support organisations providing CHBC services
Source: CAN multi-country research (Ethiopia, Malawi, South Africa and Zambia), 2011–2012

Other potential areas for further involvement in treatment programmes, as suggested by research informants, include detection of new clients (Zambia), combined DOTS approach for HIV/TB (South Africa), increased involvement in pre-ART care and support for clients, and support to issues that affect adherence such as lack of nutritious food by creating vegetable gardens (Malawi).

> In **Ethiopia**, 'health extension workers' (HEWs) are expected to take up a preventive role and educate the community in which they work. Whether HEWs are also engaged in HIV-related prevention activities, such as community mobilisation and VCT, varies from area to area. Community caregivers

tend to be more engaged in HIV prevention. They provide HIV and sexual and reproductive health (SRH) education, provide (mobile) VCT services together with local health facility staff, communicate positive prevention messages and promote PMTCT services. As one Ethiopian respondent noted:

> *Currently, many services previously limited to the facility level are being handled in the community by volunteers who have received the relevant training.*

Although Ethiopian care and support NGOs advocate for decentralising treatment to health post level and support greater community involvement, the government has reservations about involving community caregivers in ART provision. As such, their increased involvement is currently only being tentatively explored with some caregivers having been assigned to hospitals. These 'ART promoters'—who receive a salary—monitor the treatment adherence of clients and undertake home visits, together with HEWs, to trace clients defaulting on their treatment. This experiment is a joint initiative of the national NGO Mekidim Ethiopia, Johns Hopkins University, Columbia University and the International Training and Education Center for Health (I-TECH), and is currently being implemented in different regions across the country.

Collaboration occurs between Ethiopian care and support organisations and HEWs at community level. For example, a current division of labour exists whereby PHC (mostly identification and referral) is the main responsibility of HEWs, while NGOs focus on providing comprehensive care and support activities for people living with HIV, OVC and clients with other chronic conditions. This may well be the result of local NGOs having a longstanding engagement in HIV care and support, while the HEW structure is relatively new. In Ethiopia, other categories of volunteers also work specifically on malaria ('malaria agents') and on SRH ('community-based reproductive health agents'). Despite the extensive involvement of CHBC programmes in PHC activities, there is no indication that the government intends to change the specialist categories or the diverse activities of CHBC programmes.

In **Malawi**, 'health surveillance assistants' (HSAs), support groups and community caregivers are involved in HIV prevention through the provision of information, education and communication (IEC) in communities on prevention of HIV, TB and malaria as well as the importance of HIV testing. HSAs are also responsible for preventive activities in regards to HIV (including PMTCT) and sexually transmitted infections. They also provide important family planning services. Support groups and community caregivers are increasingly involved in the promotion of positive living, uptake of HIV counselling and testing, and condom distribution. Their engagement may even extend to participation in village health days, campaigns in safe motherhood, child immunisation and VCT campaigns if they are members of village health committees. Community caregivers and support groups are already involved in conducting follow-up visits to track and to retain clients on ART and there is potential to increase their involvement in pre-ART care and support. In addition, given community caregivers' firm position within the continuum of care in Malawi, interviewees suggested that they could work more closely with community development assistants in addressing issues that affect ART adherence. This could include the provision of nutritional supplements or assistance with the creation of vegetable gardens and/or husbandry.

Malawi is faced with severe shortages of doctors and nurses. Therefore, community caregivers are essential for the delivery of PHC services and, more broadly, for assisting households with sick people to improve their livelihoods. Nevertheless, health professionals are reluctant to decentralise health-related tasks to community caregivers. Informants from care and support organisations have indicated their concerns about such 'task-shifting' but for different reasons. They emphasise the burden placed on them, even using terms such as 'abusing' caregivers who are primarily women and who work entirely on a voluntary basis.

Community caregivers in **South Africa** provide an important contribution to national VCT campaigns in the country. They prepare communities for outreach VCT teams by providing health education and by promoting health-seeking behaviour. Screening of households is promoted in CHBC programmes run according to PHC principles, and HIV counsellors are trained to perform HIV testing. With the move in the last two years to provider-initiated testing, these counsellors are being encouraged to meet stringent testing targets with an emphasis on offering testing to a wider range of clients attending facilities

There has been a marked emphasis within activist- and service-oriented NGOs on HIV education and literacy initiatives. The 'peer educator' and 'expert patient' paradigms are prominent in organisations such as the Treatment Action Campaign (TAC) and the Community Media Trust and are ways to increase knowledge in communities to promote behavioural change in communities. TAC's treatment literacy and prevention advocates support clients' ability to demand their right to adequate health care, including ART.

The current set-up in South Africa engages community caregivers in the home monitoring of people living with HIV who are on ART. There are attempts to expand the responsibilities of some cadres in HIV treatment programmes; to date, facility-based HIV counsellors have played the primary role in such programmes. In the case of the Western Cape, all HIV counsellors are gradually being trained to provide not only HIV counselling and testing, but also ART adherence support. This involves counselling clients in treatment preparedness and also doing additional work with people who are struggling with medication compliance. The research also revealed efforts to integrate disease-specific services at the point of delivery for TB, HIV and chronic conditions. Examples include the training of HIV counsellors in treatment adherence for TB medication in the case of co-infection and new service models implemented by some NGOs. These models make clients responsible for adhering to medication regimens, usually with the help of a 'treatment buddy', and encourage community caregivers to provide additional support and advice about side effects. These caregivers attend team meetings in their local state-run clinics where they coordinate and accept referrals from facility-based teams, including HIV counsellors.

In **Zambia**, community caregivers are actively engaged in HIV prevention programmes. They are taking advantage of opportunities while in households to provide awareness information to clients and family members. 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 contraceptives, including condoms.

As noted elsewhere in this report, an initiative being implemented under the Directorate of Human Resources and Administration is the introduction of a new cadre of 'community health assistants' (CHAs). At the time of research, this initiative was in a pilot phase supported by donors and the government. Once trained, CHAs will be stationed at health posts, the lowest health service delivery point in the health system. CHAs represent Zambia's efforts to have 'formal' community health workers at this level. They are expected to supervise and coordinate the work of community caregivers. The introduction of CHAs in communities will provide a significant opportunity to coordinate prevention activities beyond HIV. These formalised community health workers are expected to spend 80 percent of their working time within communities and will focus on prevention activities.

Discussions have begun regarding the possibility of expanding the role of caregivers in HIV treatment. Currently, caregivers are primarily involved in providing adherence advice to clients on ART, including identifying adverse effects of medication and linking clients in need to health facilities. The range of services offered was highlighted by one Zambian respondent:

> *In government clinics, even though volunteers are not getting remuneration or anything, they are doing the same things as in partner-supported facilities—such as patient registration, managing patient flow in the clinic, helping patients get to the right provider at the right time, weighing patients, helping the patients count through their pills, and offering adherence counselling. And if patients are missing clinic visits, they go out into the community and track the patients and bring them back into care.*

Several community caregivers contacted during this research supported changing government policies to allow caregivers to give medicines to clients in addition to the current roles they are performing. Many stated that with adequate training, community caregivers operating through CHBC programmes could effectively provide that service along with other essential treatment-related interventions, such as administering diagnostic tests and interpreting results. Yet despite many community stakeholders' enthusiasm for such a change, most health professionals from the government sector remain opposed to allowing non-specialists to dispense ART directly and undertake specific medical tasks such as diagnostics.

The research revealed attempts from both the government as well as NGOs to complement PHC with CHBC and vice versa. The Ministry of Health has introduced the provision of a broader care and support package for people living with HIV in the Copperbelt and North Western provinces whereby in addition to providing the usual soap and towels, community caregivers distribute water filters and insecticide-treated mosquito nets to prevent diarrheal diseases and malaria. An example from one of the studied FBO programmes are so-called care and prevention teams (CPTs). These teams are multi-disciplinary, community-owned and address not only health but general development problems in their communities. Each community ranks its own issues, develops a plan to address them and mobilises its own resources. That FBO, Chikankata Health Services, anticipates a major shift in terms of management of comprehensive care and support services largely due to the current efforts to empower communities by fostering self-reliance. The expectation is that the FBO will in due course scale back the number of staff engaged in community activities and only interact on a need-to-need basis.

Government cadres of community caregivers, such as 'community health assistants' in Zambia, 'health surveillance assistants' in Malawi, 'health extension workers' in Ethiopia and the new cadre of facility-based 'community health workers' forming part of outreach teams in South Africa, have a clear educational function. Yet the non-government employed community caregivers also contribute to increasing health knowledge within communities—with a number also operating within health facilities—on a wide range of topics in addition to HIV, and play an important role in the promotion of health-seeking behaviour. They are considered trusted, knowledgeable advisors in their communities. The South African case study provided the only example of the existence of 'community educators' who include a focus on clients' human rights.

2.3.2 Primary health care programmes

The research uncovered only limited evidence of community caregivers being called upon to contribute to the expansion of PHC programmes in the four countries, despite the fact that their tasks already extend into the domain of PHC services. The current trend is for governments to use their own cadre of 'community health workers' to deliver PHC services. However, there is a clear potential for caregivers to be involved, including in regards to supporting policy makers' plans and visions for PHC in the future. Such potential is reflected in the examples from the research below.

The potential roles of caregivers in PHC programmes in **Ethiopia** are highlighted by the fact NGOs working in care and support assist in increasing ART enrolment, ART adherence and PMTCT, which are primarily the responsibilities of the PHC system. Moreover, most of these organisations take part in provision of maternal and child health services (epidemiology, family planning, nutritional rehabilitation, malaria control and prevention, etc.) and environmental and personal hygiene services. In Ethiopia, there are specific community caregivers for several different health-focused programmes. For instance, community-based reproductive health agents (CBRHAs) work on reproductive health issues while malaria agents concentrate on malaria prevention and control activities. However, most CHBC programmes tend to focus on activities related to HIV.

'Health extension workers' (HEWs) at health posts collaborate with community caregivers associated with CHBC providers and other specialist community caregivers in addressing issues such as sexually transmitted infections (STIs), TB and ART adherence. HEWs may also link a client or family with a care and support organisation if a potential need of such organisations' services is identified during their home visits. However, participants in the focus group discussions comprising community caregivers generally agreed that HEWs are barely involved in HIV activities since they are mainly occupied with activities related to sanitation. It was also noted that HEWs do not provide counselling services, follow up on ART adherence or trace ART defaulters, although it was observed by some that they perform HIV testing. HEWs in Jimma were said to be closely working with Organization for Social Services for AIDS (OSSA) caregivers and taking part in meetings of stakeholders providing care and support.

Community caregivers in **Malawi** are an essential resource in the delivery of PHC services. Since by policy they are defined as part of PHC, the architecture also actively integrates ART and CHBC as services in the Essential Health Package. In practice the government provides PHC through its

own hospitals, yet under the Essential Health Package it also provides PHC services to communities remote from government facilities through service-level agreements with private and mission hospitals. Under this arrangement the government not only refunds such hospitals for any services, but it also subsidizes staff salaries, including those for any HIV coordinators who may be employed at private facilities. Moreover, regardless of CBO or NGO affiliation, the government also provides CHBC kits and supplies, although programmes that were capable also procured and distributed such kits. Such supplies and support are often provided to meet the minimum package of CHBC services as defined by the Essential Health Package. The implication is that the delivery of the PHC and, hence, CHBC, is actively supported by the government.

It was found that community caregivers were active in disease-prevention activities alongside 'health surveillance assistants' (HSAs). All programmes were involved in a deliberate process of skills transfer through mentoring both primary and secondary caregivers as a precursor of 'task shifting', with caregivers trained to provide services such as physiotherapy, pressure area care, wound cleaning, mouth cleaning and feeding. These services are part of the standard protocol for home visits from public health units, and the skills transfer process is aimed at building the capacity of community caregivers to deliver such services that would ordinarily be provided by trained community nurses. Further, community caregivers participate in health education, child immunization campaigns and water and sanitation education led by HSAs.

Malawi continues to face serious human capital constraints in the health sector and in the foreseeable future will continue to augment that shortfall with community caregivers. The roles the community caregivers are currently playing therefore remain relevant, and will likely continue in the following areas: CHBC; immunization campaigns; client monitoring (ART and other chronic illnesses); and environmental sanitation services. Caregivers can also be instrumental in community case management of diseases in collaboration with HSAs.

At the time of the research in **South Africa** there remained some concerns about the extent to which new 'community health workers' will be able to engage in the provision of comprehensive care and support as currently being delivered by NGO-deployed community caregivers. The future role of CHBC organisations and their caregivers therefore requires clarification. Most of the care and support focused organisations included in the research have a relatively strong degree of informal integration with state PHC structures. They offer promising potential models for delivering a broad range of services while working closely with the formal health system, and therefore concerns about their continued survival under the new dispensation are to be taken seriously. These organisations could, for example, offer services covering a wider range of infectious diseases, maternal and child health, and non-communicable diseases (thereby reflecting the disease burden in South Africa, where conditions such as hypertension and diabetes are regarded as epidemics alongside HIV). There are NGOs that already model the possibility of offering a comprehensive PHC programme through community-based services; one such organisation provides comprehensive services for many infectious and chronic conditions. The strengths of this approach include a supervisory system whereby community caregivers receive ongoing support and advice in the field from trained nurses, a referral system (up and down) between health facilities and CHBC programmes, and a functioning monitoring and evaluation system that tracks programmes' ability to offer comprehensive PHC services.

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. As a result, there is widespread agreement on their importance in helping improve access to and coverage of communities with health services and, consequently, bolster health outcomes.

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 'community health assistants' (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.

Another major limitation to the further integration of 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 and the government has limited data on the number of existing caregivers and where they are. In the absence of a fully dedicated 'community mobilisation officer' and an integrated C-HMIS, the full integration of community caregivers will remain a challenge.

The changes underway in South Africa offer great hope for improved PHC service delivery yet also raise the challenge of ensuring that hard-earned gains are not undermined. Findings indicate that there will be a migration of NGO-based community caregivers to formal positions within the Ministry of Health at PHC level. Both in South Africa and in the other research countries, there is little evidence of expanding PHC through the existing CHBC programmes, despite the fact that such programmes provide a wide range of PHC activities. The current trend is for governments to use their 'own' community caregivers to deliver PHC services.

This trend presents a potential challenge in terms of changing the foundation and means for 'community participation'. On the one hand, it seems clear that the trend is a means by which health ministries are substantiating their commitment to revitalising PHC services; on that basis, employment of community caregivers represents a positive development for community-oriented health care services. Nonetheless, there is legitimate cause for concern that this development ignores the effective systems for community participation and mobilisation that CHBC programmes have developed and risks establishing parallel systems.

2.4 COMPLEMENTARITY BETWEEN FORMAL AND INFORMAL COMMUNITY CAREGIVERS

Research objective: 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. [24]

2.4.1 Recognition and acceptance

The necessity of CHBC programmes and community caregivers is fully acknowledged in the four research countries. However, variations can be observed among the countries with regard to the role of CHBC programmes in national HIV programmes and in the definition, roles and conditions of service of community caregivers, as highlighted in the examples below.

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24 As stated in Section 1.6, when this research project was conceptualized and initiated, the term 'formal' care was used to refer to the activities of health professionals and public health services, while 'informal' care was used in reference to the activities of unpaid caregivers and CHBC programmes run by NGOs. The research results, however, show that distinctions on this basis misrepresent the role and place of CHBC programmes within national health and social welfare systems because CHBC programmes are often integral features of these systems.

Until recently, CHBC programmes in **Ethiopia** were not formally recognised by the national government, partly because there was no policy on CHBC. Nonetheless, their engagement has been acknowledged for many years via the system for registration of NGO programmes with the Ministry of Health, HAPCO and the Ministry of Finance and Economic Development. Of particular importance in this regard is the mechanism of memorandums of understanding (MoUs) by which CHBC programmes are approved by the Ministry of Health.

The situation has changed in the last 2–3 years to the extent that there are now guidelines on community care compiled by the federal Ministry of Health. Although these guidelines are seemingly not well known among health officials, they are being implemented by instruction to officials for restructuring the internal organisation and management of the national HIV programme. Notably, the Ministry of Health has begun to accommodate CHBC programmes by directing HAPCO to be responsible for coordinating the work of CHBC programmes. This de facto recognition of CHBC programmes stems from a heritage of informal interactions and arrangements for client referrals and mutual assistance between NGOs and Ministry of Health offices in the country's regions and districts.

In **Malawi**, the CHBC and palliative care policies and guidelines of 2011 recognise, at least in principle, the role and contribution of primary and secondary caregivers involved in CHBC programmes at the community level. They also acknowledge the complementarity between those 'informal' caregivers and 'formal' health personnel working in clinics/extension workers. The place and role of CHBC programmes has been largely defined by the national policy and guidelines developed in 2005. Notably, these documents defined CHBC as a responsibility of the Ministry of Health and as an integral part of its biomedical-oriented interventions leading to CHBC services being increasingly regarded as the responsibility of health professionals. The role of NGO-sponsored community caregivers is primarily to support state employees who work in communities—in particular the Ministry of Health's 'health surveillance assistants' (HSAs) and their equivalent in other agencies, such as social welfare assistants—to identify and refer people in need of health care to health facilities. The result is that CHBC programmes in any locality are linked into networks of the Ministry of Health and other ministries' auxiliaries. These networks define the terms for NGOs' community-level care and support activities. The Ministry of Health requirement that all NGO programmes must have health professionals (i.e., nurses) on their staff builds in a professional care capacity and, inevitably, a link between health facilities and CHBC programmes. In sum, there is a common structure for the establishment, operation and development of NGO initiatives. A consequence of this system for CHBC is that there is relatively little debate about principles and practice. Community caregivers are expected to be volunteers supporting community development as much as CHBC while nurses employed by NGOs, Ministry of Health HSAs and their equivalents in other ministries are paid local agents of the system.

In **South Africa**, current developments show that the government recognises the need for community caregivers and is framing their role as formal paid state employees. CHBC in South Africa is therefore being redefined as an 'outreach' activity of the health service, rather than as an NGO-based set of interventions. NGOs (including FBOs) working in this field generally accept this perspective on the grounds that such caregivers should receive payment for their services, which among other things might reduce the problem of volunteer attrition. Community caregivers themselves welcome the prospect of remuneration and the security that goes with having a 'regular' job. However, at the time of the research there remained a lack of clarity about the process for reshaping the form and content of CHBC in the country. Wide variation in the type of NGOs, the services they offer, and their relationship with government agencies in different parts of the country also had yet to be considered and addressed.

The NGO-founded community care system in **Zambia** has been recognised and accepted for many years throughout the country and by the government. It originates from the way the government implemented the WHO model of decentralised health care beginning in the 1980s, and is the result of the government's commitment to developing community-oriented health care through NGO-run CHBC programmes. The notion of formal and informal community caregiving programmes is a relatively recent concept (2010–2011). It has been propagated as a result of the Ministry of

Health agenda to 'formalise' the system by creating a cadre of 5,000 government-trained and paid 'community health assistants' (CHAs) and to integrate programmes into PHC structures. Although this initial number of CHAs is not especially large, the concept raises questions about the long-term future of the 'informal' system. Ministry of Health officials are emphasising that CHAs will not replace the existing structures and categories of community caregivers or the NGO programmes most are associated with. Instead, the claim is that CHAs will coordinate and supervise those caregivers from health posts, and that their overall work will be supported by professional nurses at those posts and at clinics. However, the logic of this agenda is to have all community health care programmes eventually integrated into the 'formal' health services (i.e., Ministry of Health structures). This would mean all CHBC programmes would be organised and directed by health professionals from health facilities.

Malawi represents perhaps the most stable policy environment at present in the sense that it has a well-developed policy framework and practice for coordination of health facility and CHBC programme operations. Ethiopia, meanwhile, is creating a system to manage the relationship between government health services and NGO-based community health care services. NGOs may continue to elaborate their CHBC programmes as they see fit and, indeed, the government health services recognise their dependence upon these programmes to expand the national ART programme. In this context, it is not appropriate to frame the arrangements and community caregivers in terms of 'formal' and 'informal' health care programmes. NGO-run CHBC programmes are a formal component of the health care system with responsibility for the specific aspects of HIV treatment and comprehensive care and support.

In South Africa there are now opportunities to build synergies between government-funded and NGO managed CHBC programmes. However, the current changes to PHC and CHBC will need to address the linkages between NGO programmes and the Departments of Health and Social Development. A potential challenge relates explicitly to the establishment of a new cadre of 'community health workers'. Because these workers are defined as employees who must be remunerated regularly, expectations and demands may follow to specify basic conditions of service and pay scales. In turn, the financial cost of employing community caregivers for both government agencies and NGOs is likely to lead to a reduction in the number of caregivers, thereby potentially leading to civil society organisations pursuing alternative measures to provide the range and scale of services required to enable access and adherence to ART. Whether the funding will be available for NGO-led interventions remains to be seen, and there is a real danger that the experience and expertise of NGOs may be lost from the public health system.

In the case of Zambia, officials may argue that the government agenda is not to replace community caregivers with 'community health assistants' (CHAs)—but only on the grounds that it is neither feasible nor practical in the short to medium term. It is highly unlikely that CHAs will be able to influence and guide the decisions and operations of the large and extensive CHBC programmes of NGOs that run hospitals and clinics and have hierarchies of programme directors and managers down to CHW supervisors, linked in to local village committees and neighbourhood health committees (NHCs) or their equivalent. However, the Ministry of Health has indicated its strong commitment to expanding PHC services by advertising in 2012 to employ 3,000 more nurses and 5,000 CHAs. Yet even taking into account that development, the public health services are not as prepared and experienced as NGOs to adapt to the ongoing changes in service needs and demands. It is true that the increase in number of persons on ART requires expansion of clinical services to monitor and adjust individuals' treatment regimes as necessary. Equally, however, there is need to expand interventions to ensure retention and adherence and nutritional support. These are non-clinical issues whose significance or priority in a locality is more easily determined and understood by NGO programmes than by health professionals and CHAs, as are the options and means to intervene effectively.

2.4.2 Coordination and collaboration

The form and content of coordination and collaboration among different government agencies and structures were considered in the research, in conjunction with exploration of the extent to which community care and support programmes are formally integrated into national health systems. Annex 2 includes organograms depicting the current set-up and hierarchy of community care and support at the

provincial or national level.[25] These models illustrate the intricacy and complexity of such systems in all countries surveyed.

Coordination

A general trend observed in the research countries is the need expressed by respondents for coordination of government health services and CHBC programmes with professional/paid community caregivers as the hinge. Tensions arise, however, as both governments and civil society organisations face the changing demands on public health services. First, there are different perspectives associated with bio-medical and social determinants of health frames of reference. Second, both governments and civil society organisations are grappling with defining the boundaries between primary health care and traditional public health interventions such as health promotion and disease surveillance. Third, both types of stakeholders are striving to develop what can be described as 'community-oriented', as opposed to 'community-based' health care systems. At the risk of simplifying the issue, these tensions can be summarised as the aspirations for, and difficulties with achieving, 'coordination' of government and non-government health initiatives.

Coordination requires extraordinary actions in the sense that it entails modifying established practices as well as the authority and autonomy of different stakeholders in the case of combining different initiatives (Buse & Walt, 1996; UNAIDS, 2004). The difficulties of coordinating CHBC and PHC programmes have been accentuated by the ever-changing conditions for delivery of health care. The introduction of ART was a catalyst for change and the process continues. Furthermore, as noted briefly earlier in this report, there are foreseeable developments such as more involvement of CHBC programmes in PMTCT and paediatric HIV programmes. Inevitably, these developments foster demands for further devolution of health care into communities. The current debates on how far ART delivery and management can be decentralised will have their parallels in the debates on the extent to which PMTCT and paediatric HIV services can be devolved to (appropriately trained) community caregivers and to CBOs.

Much of the content of the country researches revolved around the significance of the links and, as importantly, gaps among all the stakeholders involved in community health care. The 'silo' character of the hierarchies for management and delivery of health care in communities was a common refrain. The organograms presented below, which highlight the existing care and support structures in the research countries, show that there are substantive differences between Malawi and Zambia on the one hand and, on the other, Ethiopia and South Africa, with regard to policy directives on the coordination of health services and community welfare. In Malawi and Zambia, national policies explicitly incorporate health policies as one component of broader national development strategies and of community-level socioeconomic development. In Ethiopia and South Africa, the policy focus is primarily on individual and community health. However, in Ethiopia, there are NGOs that have emulated the approach of their counterparts in Malawi and Zambia by aligning their support services with local economic development projects.

> In **Ethiopia**, coordination of government health services and NGO-sponsored CHBC programmes is being established as part of the Ministry of Health's restructuring of the national ART programme. This is reflected in the way the ministry has begun to dismantle this single, vertically integrated programme that has been managed by HAPCO by transferring responsibility for the management of VCT, ART and PMTCT services to regional and district health offices. It is also reflected in HAPCO being given responsibility for coordinating the work of Ministry of Health staff and the CHBC programmes via the cadre of 'health extension workers' (HEWs).
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> Coordination of services and activities is evolving within the CHBC system in Ethiopia as well. Some NGOs have well-established structures to direct and manage different comprehensive care and support services, such as supervisors (usually professional nurses); programme managers and

25 AIDS denialism refers to a range of beliefs and actions that run counter to the scientific and epidemiological consensus around the world. In South Africa, former President Thabo Mbeki and members of his administration frequently expressed scepticism that HIV caused AIDS and that antiretroviral drugs were safe and effective for people living with HIV. As a result, his government resisted rolling out comprehensive HIV prevention and treatment programmes.

directors; and different 'departments' (e.g., counselling, social support, palliative care and ART support). Smaller NGO operations are less elaborate. For all, there is now the well-established practice of working with community organisations (churches and mosque congregations, as well as idirs) and local government administrations (kebeles) as well as establishing community-level organisations (e.g., 'anti-AIDS clubs'). It is a system that has adopted a broad perspective on health care in that it incorporates issues and needs associated with HIV prevention and, notably, local economic development, particularly food production. Both are critical components of a comprehensive effort to improve the efficacy of the national ART programme.

Another prominent feature of coordination of care and support activities in Ethiopia is the formation of forums and taskforces to facilitate collaboration among different actors, i.e., government sectors and NGOs (including FBOs). A challenge observed is the lack of a well-publicised and implemented community care policy amidst community care systems that have evolved rapidly in the past decade. Without this guidance, duplication of efforts as well as perceived competition among service providers can be observed on the ground.

See Figure 3 in Annex 2 for a basic schematic overview of linkages that exist in the organisation of HIV care and support services in Ethiopia.

Coordination of CHBC activities in **Malawi** occurs at various levels with a complex web of monitoring and reporting structures, both formal and informal. The Ministry of Health has a leading role in the coordination of CHBC services at the district level. Other key institutions are the National AIDS Council (NAC), district executive committees and district AIDS committees. As the secretariat for the home-based care sub-committee of district AIDS coordination committees, the Ministry of Health is supposed to work with other stakeholders involved in treatment, care and support services such as mission hospitals and civil society. There are distinct reporting lines for managerial and technical responsibilities at the district level. The Ministry of Gender, Children and Social Welfare, through the Department of Social Welfare, bears the responsibility for managing and ensuring proper functioning of CBOs to which community caregivers are attached. The Ministry of Health—through district health offices (DHOs) and, subordinately, 'health surveillance assistants' (HSAs)—takes the lead in regard to ensuring that community carers are providing CHBC services at a minimum acceptable standard. DHOs are supposed to coordinate quarterly stakeholder review meetings, home visits and training in collaboration with other government officials such as district social welfare officers and district AIDS coordinators.

Of note is that the constitution of the NAC and its various forums support the engagement of representatives of the Ministry of Health and other ministries, the private sector, donors and civil society. As a result, cross-sector communication is strongly supported. Also important is the presence of programmatic and structural links between the Ministry of Health, the Ministry of Local Government and Rural Development, and the Ministry of Gender, Children and Social Welfare and their common presence in district AIDS committees. A notable structural efficiency stems from the simple and quick way in which NGOs may enter the CHBC system via district local government administrations and district AIDS committees.

Furthermore, there are established mechanisms for coordinating the interests of different sectors. This is reflected in the work of the Malawi Business Coalition Against HIV/AIDS (MBCA) for the private sector, the Malawi Network of People Living with HIV/AIDS (MANET+) for all organisations comprising and working with people living with HIV, the Malawi Network of AIDS Service Organisations (MANASO) for local and international NGOs working in this field, and the Malawi Interfaith AIDS Association (MIAA) for FBOs.

Finally, effectiveness in coordination is enhanced by local government structures and, in particular, the community-level government and development mechanisms that direct the work of NGOs in different localities. 'Health surveillance assistants' (HSAs) are a key means to link the treatment-oriented work of government health facility work with the comprehensive care and support work of NGOs' CHBC programmes.

The Malawi research also revealed that a lack of stakeholder coordination at times results in duplication of service provision and competition for the participation of community caregivers. While the CHBC policy defines the vertical relationship among different players in the CHBC landscape, there is no framework for NGO coordination and as such the horizontal relationships among NGOs are not well defined. This, however, is expected to improve due to the formation of the National Community Home Based Care Alliance (NCHBCA) in 2011, a network of civil society agencies involved in CHBC in Malawi.

See figure 4 in Annex 2 for a basic schematic overview of linkages that exist in the organisation of HIV care and support services in Malawi.

In the case of **South Africa**, research underscores the fact that greater collaboration between the National Department of Health and other ministries, in particular the National Department of Social Development, is crucial since the two departments will each be deploying cadres of community caregivers. Moreover, as the National Department of Social Development has learned from its experience in overseeing the delivery of psychosocial support, such caregivers should be included in any plan to develop a broad-based formal national programme for South Africa. 'Community health workers' who are part of the outreach teams will be required to work in schools and, as such, collaboration between the National Department of Health, the National Department of Social Development and the National Department of Basic Education will be needed.

Until now, there has been limited coordination of different health programmes, including CHBC programmes. There is clear intent and clarity about the logic and principles of the agenda to create ward-based teams of 'community health workers' working from within formal health facilities with health professionals and for NGOs to align their initiatives with them. However, the principle and practice of coordination has yet to be entrenched at the national level of government. The South African National AIDS Council (SANAC) was sidelined for many years as a result of the politically driven 'AIDS denialist' policies of a former presidential administration[26], and as a result, it is still in the process of increasing its effectiveness as the national body coordinating HIV programmes. Likewise, further effort is needed to increase the influence of provincial, district and municipal AIDS councils. There are formal links among different government departments at national, provincial and local levels but huge variations exist across the country in the extent to which they are used substantively to forge and drive coordinated interventions. As stated above, the Department of Health and the Department of Social Development are nominally the two agencies that should coordinate their cadres of caregivers, but the current national proposals exclude caregivers managed by the latter department.

The inference is that the Department of Health will only support the employment of community caregivers that work through its proposed system of health facility and ward-based outreach teams. It is possible therefore that there will continue to be different cadres of caregivers operating with different agendas determined by the two departments. Furthermore, there will be marked differences among the provinces in how the principle of coordination is applied due to the fact that provincial governments are interpreting the Department of Health proposals differently.

See figures 5 and 6 in Annex 2 for a basic schematic overview of linkages that exist in the organisation of HIV care and support services in the two provinces and three case study organisations in which the field research for South Africa was conducted. Each province has its own set-up in terms of organisational structures; therefore, the organograms depict provincial overviews rather than a national one in regards to the involvement of various ministries, departments and committees.

In **Zambia**, the apex for coordination is the National AIDS Council (NAC). The council is relatively effective in practice. It has several established forums with representatives from different government agencies and civil society organisations and has conceived strategies and means to address clinical and non-clinical aspects of the national response. The NAC has produced standards

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26 AIDS denialism refers to a range of beliefs and actions that run counter to the scientific and epidemiological consensus around the world. In South Africa, former President Thabo Mbeki and members of his administration frequently expressed scepticism that HIV caused AIDS and that antiretroviral drugs were safe and effective for people living with HIV. As a result, his government resisted rolling out comprehensive HIV prevention and treatment programmes.

and guidelines for training community caregivers and for implementing CHBC services. The ministry of Health is attempting to exert more control over the strong NGO-driven CHBC programmes as well as the effective and well-regarded NAC but lacks the necessary internal systems to coordinate CHBC programmes. For instance, it has a register of CHBC services by different organisations but monitoring of activities is limited (reports are compiled at district level). There is no designated position in district health offices to oversee the activities of community caregivers. Of the two national-level directorates within the Ministry of Health that manage HIV interventions, the Clinical Care and Diagnostic Services Directorate appears to be dominant in view of its authority for managing and coordinating the delivery of treatment, comprehensive care and support through the health facility hierarchy.[27] One indication of this directorate's sensitivity to the changing demands regarding services (and thus in regards to future demands for coordination) is that it has begun to focus attention on paediatric HIV and adolescent ART services. AIDS taskforces and coordinator posts at provincial and district level have provided a defined structure for coordination of different facets of the HIV programme.

Zambia's recent move to revitalise health posts and to create 'community health assistants' (CHAs) represents the NAC's commitment to i) define the relationship between the public health services and CHBC programmes and their caregivers and ii) coordinate delivery of the wide range of clinical and non-clinical activities that are now required in an era of managing HIV epidemics. The approach reflects a Ministry of Health agenda (promoted in 2005 with the disbanding of the Central Board of Health) to be central to the evolution of treatment, comprehensive care and support programmes and with the expectation that such programmes will be components of PHC in the country. The principal shortcomings of this agenda are the lack of staff to fill key posts such as programme coordinators and nurses, especially in rural areas. In regards to nurses especially, there is also a shortage in terms of the skills and means to both guide the work of CHAs and implement the clinical and non-clinical components of the ever growing and changing service needs (e.g., paediatric HIV, adolescent sexual and reproductive health, and emerging needs such as disability and mental health services). However, as noted elsewhere in this report, the government in 2012 embarked on an intensive recruitment drive for 3,000 nurses and 5,000 CHAs to counter this limitation.

See figure 7 in Annex 2 for a schematic overview of linkages that exist in the organisation of HIV care and support services in Zambia. The organogram shows the involvement of various ministries, departments and committees.

The extent of coordination within and among CHBC programmes varies. There are some large NGO programmes that also run hospitals and clinics and have defined structures for managing and coordinating different comprehensive care and support services. These include positions such as supervisors and site coordinators to manage the different types of caregivers who primarily provide support within communities and to health facilities. There are also many smaller operations that do not have such elaborate structures. General indicators of the scale and type of coordination within the CHBC system include the variety of caregivers; the links between the programmes and community representative structures such as village committees, which support the recruitment and work of community caregivers; and, in the case of one large programme, creation of care and prevention teams (CPTs). These CPTs address broader health and economic development challenges on the basis of priorities set by the communities themselves and, at a very practical level, the provision and use of material resources such as bicycles and umbrellas to facilitate community caregivers' work.

The two systems (public and non-governmental) have complemented each other to date. This has been achieved in part by design through the government's commitment to the decentralisation of health care services with an emphasis on community-level participation in the delivery of health care. It has also been achieved partly by default as the decentralisation of services coincided with the explosion of the country's HIV epidemic and was shaped in practice by rapid growth of NGO-sponsored CHBC programmes and their approaches to community health care.

A gap in information sharing was noted between the public health system and stand-alone initiatives supported by local and international partners that, in some cases, have different registers and

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27 The other directorate is the Public Health and Research Directorate.

reporting systems. The research also highlighted inconsistencies in relation to the type and scope of activities offered through CHBC programmes due to a lack of coordination and harmonisation of community-level activities being implemented by NGOs. There are stronger sectoral and coordination linkages among these stakeholders at the higher (national) level than at community level, thus pointing to 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. As stated by one respondent in Zambia:

> *I think at all levels we are all equally guilty of not coordinating. Instead of building on, we are coming in and adding on another service with a different bureaucracy in the system. The whole system is a bit of a mess and I think the government needs to sort it out.*

Collaboration

Representatives of CHBC organisations[28] were asked to indicate whether their organisations collaborated with others (i.e., within the sector, with other sectors, with local authorities and with other CBOs) in the field of care and support. As can be observed from the examples below, the research findings show that collaboration in practice varied widely among CHBC programmes (within and across the four countries) and indicate that there is room for greater collaboration.

A prominent feature of coordination of care and support activities in **Ethiopia** is the formation of forums to facilitate collaboration among different actors. The National Partnership Forum (NPF) was established in 2004 to increase collaboration among organisations working on care and support for people living with HIV. Forums also exist at lower levels. In the Hawassa area, for example, 53 NGOs have created a forum for collaboration. The collaboration helps, among other things, to make sure that an individual is not receiving the same kind of support from more than one organisation and that two or more organisations do not implement the same programme in a certain locality. Strong collaboration also exists between community care and support organisations and 'health extension workers' (HEWs). Seven out of ten caregiving organisations that participated in the research validation phase indicated that they collaborated with government HEWs. Two of the organisations collaborated with extension workers from the Ministry of Finance and Economic Development while one collaborated with extension workers from the Ministry of Agriculture.

The **Malawi** research shows extensive links between CHBC service providers and various ministries, authorities and other organisations. All 11 organisations that responded to the Phase 4 questionnaire indicated that they collaborated with the Ministry of Health, while all but one organisation also collaborated with the Ministry of Agriculture and the Ministry of Women, Gender and Social Welfare. Research findings also indicate that a third of CHBC service-providers respondents engage only with local authorities, while another third collaborate both with local authorities and other CBOs. Collaboration occurs on a range of issues and activities including in selection of caregivers, monitoring of care and support services and community mobilisation.

In **South Africa**, research findings affirmed a lack of intersectoral collaboration in community care and support work. Representatives from 13 organisations indicated that there was no intersectoral collaboration in community care work, while two collaborated with the health sector and one with the agricultural sector. Data collected in relation to the involvement of local authorities and other CBOs in the work of these organisations show that little assistance was received from local authorities such as ward councillors or the municipality. Assistance received, if any, generally came from other CBOs—for example in assisting in community mobilisation for health promotion events (five organisations), contributing community resources for clients in great need (four organisations), and the selection of caregivers (three organisations).

In the case of **Zambia**, most CHBC-providing organisations that participated in the research validation phase reported receiving some support from local authorities or other CBOs, with more

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28 The number of organisations surveyed in each country was as follows: Ethiopia (10), Malawi (11), South Africa (16) and Zambia (9). These 46 total organisations were those that responded of the 59 originally approached, thus representing an overall response rate of 78 percent.

assistance overall reported from CBOs than 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. 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 country study results were intriguing in that collaboration was a key principle for setting up and running CHBC programmes, and there were well-established mechanisms (particularly in Malawi) for creating and maintaining CHBC programmes via collaboration with various government agencies. The mechanisms include engagement of 'non-health' ministries in CHBC, which this research recognised but did not explore in detail. Ethiopia and South Africa revealed a lower level of sectoral collaboration and integration of CHBC programmes compared with Malawi and Zambia. At the same time, the impression was obtained that there was little evidence of collaboration among CHBC programmes operating in the same areas, and the extent of collaboration in practice varied widely among different CHBC programmes (within and across the four countries).

2.4.3 Continuum of care and comprehensive care and support

A continuum of care and comprehensive care and support are central principles of HIV treatment. A continuum of care refers to the need for different forms of care for people living with HIV over time—to recover and maintain their health, to deal with occasional relapses as a result of opportunistic illnesses, and so on. Comprehensive care and support refers to the need for a wide variety of interventions to support people living with HIV, including physical, psychosocial, socioeconomic and legal care and support. Both principles are reflected in the operations of ART and CHBC programmes in the four countries but there are different emphases among them.

In **Ethiopia**, the government health services focus on providing a continuum of clinical-related care. The CHBC system is expected to be, and has the means to provide, comprehensive care and support. In urban areas government and CHBC systems overlap. In rural areas, there is a clearer division of focus because of the limited reach of government health services; in such areas, NGOs have established a stronger presence as part of their efforts to support expansion of the national HIV programme. A particular characteristic of the Ethiopian case is that the government is not elaborating the principle of decentralisation nor is it really incorporating CHBC to complement the expansion of its PHC structures.

Currently, the situation in **Malawi** reflects a focus on providing comprehensive care and support. This is highlighted in the priorities of the still-used Malawi Growth and Development Strategy (MGDS) 2006 to 2011 (e.g., its inclusion of 'prevention and management of nutrition disorders' as one priority) and the Ministry of Health's dictation of the form of CHBC programmes. Also of note in this regard are agendas of other government entities—e.g., the HIV-focused interventions of the Department of Nutrition, HIV and AIDS within the Office of President and Cabinet (OPC); and the Department of Community Development within the Ministry of Gender, Children and Social Welfare.

The projected form of state-run CHBC programmes in **South Africa**, as outlined in the new approach by the National Department of Health, is based on an effort to ensure comprehensive care and support and an improved continuum of care. Research revealed that senior government officials had a clear understanding of the principles and logic of the agenda to create facility and ward-based teams of caregivers but that understanding of the contexts for the application and actual nature of many CHBC programmes remains somewhat limited. Many CHBC programmes have established and expanded their range of services in response to the challenging situation in South Africa. They are largely reactive responses and, in essence, a form of disaster management. Yet at the same time, they often employ professional nursing staff who provide a foundation for the organisations to provide some medical treatment as necessary, to create ties with local public health service

facilities and, in general, to mitigate the challenges that many of the people experience with regard to accessing health care.

In **Zambia**, the government's public health system has promoted both the principles of, and practices associated with, a continuum of care and comprehensive care and support. This has been done at the level of strategies and policy (as noted elsewhere in this report) through to its current initiatives to incorporate CHBC into PHC structures and to expand the latter to provide a broader range of services. The NGO-based CHBC system has over time taken on a wide range of comprehensive care and support services, as well as providing support to public health programmes and including a focus on promoting local economic development within CHBC programmes. There are differences of degree and form between the two systems. Generally, the government's recent initiatives—including consideration of emerging demands such as expanded paediatric HIV services and adolescent sexual and reproductive health (SRH) services—reflect a focus on promoting a continuum of care to accommodate the rise in number of both people in need of treatment and on treatment. However, the government seeks to embellish its commitment to comprehensive care and support by making more use of CHBC programmes. NGOs, meanwhile, provide various forms of support to public health service facilities to address the critical issues of recruitment, adherence and retention of ART clients. It is arguable whether their focus on promoting an ethos of 'community' and 'self help' along with a focus on local economic development represents a qualitatively different and broader perspective on health care than the government health services.

In summary, CHBC programmes have provided the foundation for comprehensive care and support. The current agenda of health ministries in Zambia, South Africa and Malawi to incorporate CHBC into their PHC programmes underscores the ongoing efforts to provide comprehensive care and support. NGO-run CHBC programmes are also increasingly focused on broadening the practice of comprehensive care and support and complementing services currently provided by governments.

3 CHALLENGES AND CONCERNS IN CHBC PROVISION

Significant and substantial benefits and potential future opportunities were identified in regards to community care and support provision in the four countries, many of which are discussed throughout the report. The research also revealed a number of overarching challenges and areas of concern, including from the perspective of individuals and organisations directly engaged in caregiving and the provision of care and support. This section discusses in detail some of these challenges and concerns such as a lack of clarity and consistency in terminology used; tensions within communities and among community caregivers; human capacity constraints in primary health care systems; funding/financial constraints; lack of coordination and collaboration among stakeholders implementing CHBC programmes; and uncertainty about the future roles of community caregivers and CHBC-providing organisations. Country-specific challenges and concerns are discussed in the country research reports.

Lack of clarity and consistency in terminology used

Confusion often results from the use of multiple terms for community caregivers, the existence of many different categories of community caregivers and the often blurred distinctions among the different categories in terms of roles and responsibilities. Such confusion and lack of specificity present challenges, in particular in terms of policy making and implementation with regard to community care and support. A need therefore was observed for greater clarity and consistency in terminology used to describe people and structures involved in the provision of care and support. Likewise, the notions of 'formal' and 'informal' caregivers/caregiving, often used to distinguish civil society-led CHBC programmes and government health services, do not adequately reflect the sophisticated structures and mechanisms for delivery of community-oriented health care and the mechanisms-in-the-making for coordination of different health agencies' activities.

Tensions within communities and among community caregivers

Incentives provided to community caregivers tend to vary considerably, not only between governments and NGOs in a country but also among NGOs, both in terms of the type of incentives provided and their value. This can be ascribed to the fact that regulatory frameworks are generally non-existent in this field. Variations in remuneration lead to tensions within communities and among caregivers as caregivers gravitate towards programmes that offer higher value incentives. As a result, CHBC organisations experience difficulties in retaining community caregivers, many of whom they have trained. Organisations therefore have to invest in training of new caregivers even while resources are restricted.

In addition, the introduction of state-employed community caregivers by health ministries creates a division between those who are part of this cadre and those who are not. For example, in the case of South Africa, it is unlikely that all 72,000 community caregivers presently active in the country will be taken on by the Ministry of Health under the currently proposed policy to create 'generalist' community caregivers who are remunerated. Neither the state nor NGOs, even if working together, will be able to meet the cost of paying this number of caregivers. Therefore, it is likely that NGOs will continue to run CHBC programmes with volunteer caregivers who are not recognised by the health service and operate independently of it. The persistence of such a two-tiered system could cause resentment among those not able to obtain paid employment. One consequence could be erosion of the ethos of voluntary work; another could be the diminishment of respect for unpaid caregivers simply because they are not paid, even if and when they provide essential and exemplary service.

## Human capacity constraints in primary health care systems

Questions were raised in Ethiopia, Malawi and South Africa in relation to the government's abilities to address the wide range and specific care and support needs of clients, in particular in remote and rural areas, without the substantial support of NGOs. This concern seems particularly important with regard to efforts to revitalise PHC systems.

In **Ethiopia** reference was made to the fact that PHC facilities are already overstretched and the supervision of community caregivers would present an additional burden. Research findings indicate that there will be a continued role for NGOs, including FBOs, in meeting the social needs of clients. Concerns were also raised about capacity problems faced at health centres in the case of **Malawi**. Although each government health centre is supposed to have either a community nurse or an environmental health assistant to supervise 'health surveillance assistants' (HSAs) and oversee CHBC, the limited number of health care workers at most facilities and lack of transportation hinders the ability of trained health care workers to undertake home visits. At times, due to lack of sufficient numbers of trained health workers to staff health posts, HSAs have been forced to manage health centres to the detriment of their pivotal responsibility of supervising community workers and managing community programmes. In the case of **South Africa**, questions were raised in relation to the ability of the state health care services to provide adequate supervision, by professional nurses, for 'community health workers' employed by the state. Additional concerns were raised in relation to PHC clinics' capacity to handle potentially larger numbers of clients identified by outreach teams; how the new government plans will deal with the time-consuming physical and psychosocial needs of clients; and the transition of care and support services that are presently provided by community caregivers not employed by the state. In **Zambia**, 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 and that strong partnerships with community systems and structures are required to be effective.

Funding/financial constraints

Financial constraints were a challenge common to all four countries. In the Phase 4 survey to which 46 CHBC organisations responded, most agreed that funding cuts are a particularly serious and ongoing problem and are making it difficult to meet all the care and support needs of the communities they serve. Figure 2 below shows the proportion of organisations in each country in the Phase 4 survey that stated they had experienced funding cuts in the year prior to being surveyed for this research.

Figure 2. Percentage of CHBC organisations reporting funding cuts in the past year*
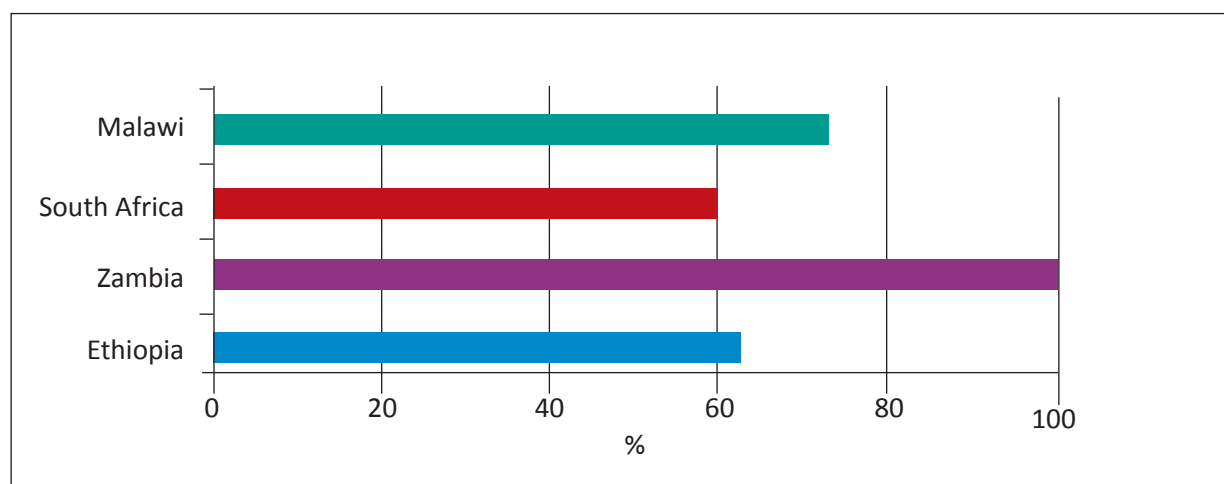
* Based on a total of 46 responses from organisations. The number of organisations surveyed in each country was as follows: Ethiopia (10), Malawi (11), South Africa (16) and Zambia (9).
Source: CAN multi-country research (Ethiopia, Malawi, South Africa and Zambia), 2011–2012

All the responding CHBC organisations in **Zambia** stated that they have faced funding cuts due to changing donor priorities. In Malawi, organisations indicated that they could no longer expect funding for CHBC through the National AIDS Council or from Pact **Malawi**, a high-profile international NGO. Most noted that the consequences of these cuts included reductions in the number of staff and CHBC activities and poorer quality of services provided. Examples noted during the research included less or non-existent supportive supervision for caregivers, a reduction in training opportunities, a reduction of

care and support services for clients, less monitoring of ART clients, and fewer programmes and activities enabling people living with HIV to obtain sufficient and quality food. The funding cuts experienced by several of the main care organisations in **Ethiopia** represent a heavy blow to community care services as well as to ART programmes. NGOs that are still active reported increasing requests from people for support as a result of other programmes closing down or scaling back their CHBC services. There have been some attempts to maintain services; for example, the Zonal Health Department in Jimma has begun to work with community caregivers who previously worked for a local NGO to maintain the work of tracking clients on ART. The **South Africa** research noted decreasing funding support for CHBC provision in general and a lack of funding support in particular for programmes and activities enabling people living with HIV to obtain sufficient and quality food.

Lack of coordination and collaboration among stakeholders implementing CHBC programmes

The research explored the linkages among stakeholders involved in CHBC initiatives and the presence of mechanisms for coordination and collaboration. Other than at the national level, the research did not reveal substantive formal links between NGOs running CHBC programmes and those involved in other sectors such as agriculture nor, indeed, in the health sector other than HIV. This is a concern because lack of stakeholder coordination and collaboration often brings about, among other consequences, duplication of efforts, inconsistencies in the type and scope of activities offered through CHBC programmes, and competition for the participation of community caregivers. The country research reports also showed that there were few lateral links among different government ministries. This is not to deny, however, that there are informal links or that there is increasing involvement of a range of 'non-health' government agencies in community-level projects that also support CHBC programmes, directly and indirectly.

Much of the content of the country researches revolved around the significance of links and, as importantly, gaps among stakeholders involved in community health care. The 'silo' character of the hierarchies for management and delivery of health care in communities was a common refrain. The difficulties of coordinating CHBC and PHC programmes have been accentuated by the ever-changing conditions for delivery of health care. The introduction of ART was a catalyst for change and the process continues. Foreseeable developments such as more involvement of CHBC programmes in PMTCT and paediatric HIV programmes foster demands for further devolution of health care into communities.

However, it is important to also note that the country researches revealed positive developments in terms of achieving greater coordination and collaboration among different stakeholders involved in CHBC-provision, such as the formation of forums and taskforces in all case study countries and national CHBC alliances in Malawi and Zambia to facilitate the process.

Uncertainty about the future roles of community caregivers and CHBC-providing organisations

At present, much uncertainty exists about the future of a broad range of services currently offered by community caregivers based in NGOs. In general, there seems to be some debate within health services and among NGOs, including FBOs, about using health professionals to manage and supervise volunteer and unpaid community caregivers, and there are different perspectives with regard to the future role of community caregivers. On the one hand, an argument has been made for more skilled community caregivers to support, in particular, the clinical health components of ART programmes. Governments in all four research countries support this approach, which would create more 'professional' community caregivers who have some form of clinical health training. Steps toward building cadres of such personnel have already begun in all countries. On the other hand, another viable argument has been made for maintaining the broader conception of health care and differentiation of comprehensive care and support. This approach would ensure a more distinct and extensive role for NGOs in the operation and implementation of community caregiving services.

4 DISCUSSION

This section highlights a number of issues arising from the research that merit further discussion.

4.1 OVERVIEW: HEALTH CARE IN TRANSITION

This research has highlighted the rapidly evolving demands on national health systems as ART programmes are expanding and as the needs of clients change. It has also highlighted the evolution of health systems, using the cases of Ethiopia, Malawi, South Africa and Zambia, to illustrate common and particular developments across the four countries. Common developments include broad strategic initiatives to re-invigorate the concept and practice of primary health care by incorporating ART programmes and by re-introducing the use of community caregivers as a key principle. The original principles and aims of PHC, as adopted in the 1978 Alma-Ata Declaration, have been re-asserted largely through the growth of CHBC programmes to meet the challenges of HIV. Particular developments in each country include variations in approach and perspective within governments and civil society with regard to the meaning of PHC, the role and status of community caregivers, and the responsibilities of government health services and NGO CHBC programmes.

The research shows how health care is being redefined and practiced in the context of the HIV epidemic. Five key observations are detailed below:

- The introduction of national ART programmes was a catalyst for continuing adaptation and change in public health services and in CHBC programmes. ART access has generated the need for interventions to ensure adherence and retention of clients on treatment, which has led to CHBC programmes developing a broader range of social support-oriented activities in addition to physical care. Basic nursing and end-of-life care are no longer the primary focus of CHBC due to an improved health status of those enrolled on ART, but they remain crucial for those without access to ART and in particular times of ill health for others. Though not discussed in this report, paediatric HIV treatment programmes have inevitably been established and scaled up in the wake of ART programmes. It seems clear that their effectiveness will require development of mother and child-oriented support services within CHBC programmes

- PHC is being promoted to accommodate changes in client needs and to help achieve 'universal' health coverage. Elaboration of PHC services is driven by an imperative for public health services to secure and promote the health of the overall population (WHO, 2008). Efforts are substantiated by the principles of comprehensive care and a continuum of care. The principle of comprehensive care informs efforts to enable ART clients to recover and maintain their health. This is reflected in the growth of support services in CHBC programmes alongside continuation of traditional home-based care to assist infirm HIV-positive individuals. Meanwhile, the principle of a continuum of care is necessary in view of the lack of a cure for HIV infection and the need for ART clients to stay on treatment all their lives. Largely for this reason chronic care, which was first promoted by WHO in 2002, is emerging as a broader framework for organising and managing the HIV treatment aspects of PHC services (WHO, 2002).

- Changes in the definitions and meaning of common concepts of care and support also reflect the fact that health care is in transition. For example, the definition of 'palliative care' has broadened following the introduction of ART, particularly in resource-poor settings. The term chronic care may possibly even become the more commonly used concept of care and support for people living with HIV in the future due to the fact that HIV is becoming a chronic manageable condition and the (rapid) emergence of other chronic diseases, such as diabetes, in low- and middle-income countries. Also, as explained in Section 1.6, this report has used 'community caregiver' as a generic term to cover a wide range of posts and roles taken on by individuals who provide care and support services at the community level. However, understandings and uses of this term are changing and differ among countries. The research reflects the need for clarity and greater consistency of terminology used to describe the different people involved in the provision of care and support and services provided.

- The conceptual changes highlighted above reflect the redefinition of 'community health' and 'health care' as a result of the evolution of CHBC programmes and elaboration of PHC services. As has been discussed in this report, 'community health' and 'health care' refer not only to bio-medical interventions and health ministry responsibilities. They include the much broader domain of social services and interventions that support the delivery, management and organisation of bio-medical services. For example, caregivers in CHBC programmes still identify ART clients and support adherence and retention to ART but are also expected to deliver the critical psychosocial, socioeconomic, nutritional and legal and support that is necessary to make ART effective and for clients' improved quality of life. Increasingly, government employees are taking on greater responsibility for delivering and supervising such services in some countries, especially as health ministries deploy staff to the community level. Of note as well is that government agencies engaged at this level include not only health ministries but also 'non-health' ministries such as those focusing on social welfare and economic development.

- The interplay of the social and bio-medical demands on health services informs the recent strategic initiatives to strengthen health systems (Samb et al., 2010; Harries et al., 2009; El-Sadr & De Cock, 2009; Oomman et al., 2008; WHO, 2007a). In practice, this amounts to re-emphasising the principles of integration and coordination within health services and between health services and other sectors (for example, social services). Current efforts to place ART and CHBC programmes under the rubric of PHC services represent a move away from vertical HIV programmes, incorporating them into general health services (Ford et al., 2011; Topp et al., 2010; Sweeney et al., 2012).

The dynamics outlined above provide a frame for the following discussion on the relationship between CHBC programmes and public health services.

4.2 THE GROWING SIGNIFICANCE OF CHBC SUPPORT SERVICES

This report highlights the marked increase in demand for non-medical care and support services by people living with and affected by HIV. As more people receive treatment, a growing number look for and need support to help them recover and maintain their health. Their needs have expanded and now include psychosocial support, nutritional support, socioeconomic support and legal support, all of which are critical to large numbers of clients. CHBC programmes have evolved to meet these needs directly or through referrals. This has led in part to the creation of different categories of community caregivers within CHBC programmes.

The emerging significance of this broader set of services was highlighted by interviews with people on ART, with the need for food security being the primary example. ART clients' focus on nutritional needs reaffirms the fact that people living with HIV fare better overall, including in regards to tolerating some treatment regimens, when they have reliable, consistent access to appropriate amounts and type of food. Furthermore, it is probable that many had experienced the damaging physical effects of HIV infection and would have been well aware of the need for adequate food to recover their health once on ART. The broadening of services also became apparent in Ethiopia and Zambia, where research noted assistance provided to clients to improve their farming and horticultural enterprises and to start new businesses. Sixty-five percent of the 46 care and support organisations that responded to the Phase 4 questionnaire provided some sort of livelihood support to their clients, while up to 85 percent reported offering social, spiritual and emotional support. In sum, provision of a broader range of non-medical services has become a distinct feature of CHBC programmes alongside physical care and support.

4.3 REVITALISING PRIMARY HEALTH CARE: AN UNEASY FIT FOR CHBC?

The principles and general agenda for revitalising PHC are closely aligned to the principles and practice of CHBC programmes. The general strategy, as expressed in the Ouagadougou Declaration of 2009 (WHO, 2010), is to elaborate the role of community-level health facilities (e.g., clinics, health centres, health posts) to increase the number and skills of health service staff in these facilities and to incorporate CHBC programmes into the broader PHC approach. The ideals and goals of the Ouagadougou Declaration include community participation, intersectoral collaboration, creation and use of 'community health

workers' and widespread reach of effective and efficient health services (Frenk, 2009; Lawn et al., 2008; WHO, 2010). As such, the expanded conception of PHC and a 'social development/welfare' approach to community care and support presumes intersectoral collaboration. The research findings, however, show limited collaboration within CHBC systems (i.e., links among programmes) as well as among different ministries, although the situation seems to be changing. Moreover, there are clear differences in the ways health ministries have been implementing this agenda. The research shows that the governments of Malawi and South Africa have adopted a more bio-medical approach while Ethiopia and Zambia focus more on a social development/welfare approach.

There is widespread agreement within health services and CHBC programmes about the benefits of using health professionals (usually nurses) to manage and supervise community caregivers. There is also common interest in creating and deploying more skilled caregivers to serve the changing demands upon health systems arising from ART programmes. There are, however, different approaches with regard to the current and future role and place of community caregivers. Most CHBC programmes have opted for different types of caregivers to serve specific functions, with many acquiring skills through experience, appropriate training and guidance from supervisors. Large CHBC programmes have management hierarchies in place to organise programmes. Government delivery of PHC favours training and deployment of both nurses as supervisors and also state-paid caregivers who have some form of clinical health training—e.g., Zambia's one-year-trained 'community health assistants'; Ethiopia's 'health extension workers', who are usually (for now) nurses in urban areas; Malawi's 'health surveillance assistants' (nurse auxiliaries); and South Africa's proposed, state-paid generalist 'community health workers'. In the case of South Africa, 'community health workers' are not envisaged as managers of other caregivers but they themselves are to be managed by professional nurses.

Both CHBC programmes and health ministries are enmeshed in a process of broadening the concept of health care and redefining the meaning of 'community health'. This is indicated in the diverse support roles of community caregivers and, in Zambia and Malawi, endorsement of CHBC programmes that serve local-level development and health priorities. In Malawi, there is an evident bio-medical orientation, indicated by the way professional health staff at PHC facilities reach into communities via 'health surveillance assistants' to manage and deliver HIV services. However, their reach and the efficacy of their work depend on the dense network of community-level employees from different ministries who interact with each other and CHBC programme caregivers. In Zambia, many large CHBC programmes operate virtually in parallel with government services and therefore there is a heritage of resistance to efforts by the Ministry of Health to exert more control over CHBC programmes. Nonetheless, the Zambia Ministry of Health is following a similar approach to that taken in Malawi by training a cadre of 'community health assistants', who will have supervisory roles over community caregivers at the local levels. In Ethiopia, of note is the limited expansion and deployment of 'health extension workers' and a policy ethos of collaboration with, rather than supervision and management of, NGO-led CHBC programmes.

The country research findings also show that there is a subtle difference between health ministries' and NGOs' understanding of community participation. Health ministries tend to adopt a perspective of 'community outreach' whereas NGOs favour 'community inreach' (Drimie & Quinlan, 2011). NGOs have tended to develop CHBC programmes that are embedded in communities whereas health ministries have sought to co-opt community residents for mutually beneficial purposes. In other words, NGOs ensure the ongoing involvement of community members in their CHBC programmes by engaging large numbers as volunteers. They use organisational structures such as village/neighbourhood-level committees, traditional authorities and local government offices, which enable recruitment of volunteers and access to and use of local resources. The NGOs' 'inreach' is also expressed in designing CHBC projects to serve development as well as health aims within which individuals benefit. In contrast, Ministry of Health efforts are directed to expanding the public sector's health presence in communities and to draw people to facilities. They pay less attention to community participation and mobilisation. The trend to create and employ a cadre of community caregivers with wage incentives who work within communities is a means to encourage the participation of community caregivers. This difference need not be contradictory, as the evidence from Malawi shows, that health ministry and NGO approaches to CHBC can complement each other.

There are also concerns about how community caregivers are treated and supported following the introduction of salaried community caregivers. The consequences could be problematic in regards to coordination and provision of quality services. One such concern is that community caregivers who work on a voluntary and unpaid basis would be working under conditions that restrict their ability and inclination to serve their communities as thoroughly and effectively as possible. This could ensue due to lack of support, training, equipment or other small incentives for the caregivers; lack of accountability of PHC services and staff to communities; and lack of commitment to community-level welfare and development. Another concern centres around the actual status and roles of paid community caregivers. Formal employment is a means to counter criticisms that volunteers are exploited and that governments fail to invest in human resources within communities. However, as health ministry employees, these paid caregivers may see themselves primarily as extensions of health facilities, as is the case in Ethiopia, and therefore ignore a core purpose of their deployment: to coordinate health ministry and NGO activities in communities.

4.4 DECENTRALISATION OF ART WITH THE SUPPORT OF CHBC PROGRAMMES

A current, topical debate revolves around the question of how far HIV services, and ART in particular, can be further decentralised. The research reflects calls within communities to improve access to ART by decentralising distribution and monitoring of clients to the community level, on the grounds of cost-effectiveness and efficiency. These calls are also supported by health staff, often based on the desire to free up staff time at clinics. However, the way PHC services are being expanded seems to encourage and prioritize the decentralisation of ART only to the point of clinics and no further (e.g., to community-level 'health posts'). Officials from health ministries and other government agencies commonly cite the following reasons for their reluctance or refusal to move beyond that level: concern about capability of any individuals or organisations (even with training) to do the work of professional health staff, administrative challenges such as creating and maintaining systems for distribution of medicines to CBOs and other stakeholders within communities, and doubts about the security of medicine stocks within communities.

There are, of course, broader structural factors underpinning both opinions. CHBC programmes often already have the structure and means to support such decentralisation. Many have evolved to deal with the social dimensions of HIV-related health care, including the work that brackets clinical treatment of people living with HIV—e.g., recruitment of clients to initiate ART and support for adherence and retention. Such programmes already provide assistance within as well as beyond clinics for these purposes. Furthermore, the larger NGOs have defined management hierarchies to facilitate administration of the services they deliver. Consequently, for them to take on management of distribution of medicines and monitoring of clients seems an obvious and feasible extension of their work.

Health officials' strategic thinking, meanwhile, is dictated by the costs of revitalising PHC. This agenda presumes significant investment in more professional health staff, nurses in particular, to enable expansion of clinical services and also in administration systems to enable the management and coordination of treatment, care and support work within communities. Yet for health ministries, a practical constraint is the limited financial resources devoted to health care in national government budgets. They may therefore consider a hybrid approach in the short- to medium-term. Based on the premise that nurses can manage and supervise the delivery of health care in communities, health ministries may commit to investing in more nurses, although numbers would be limited, and reducing overall costs by training and employing community caregivers. The wages of such caregivers are less than those of nurses and they can do the work of coordinating the delivery of different services in communities.

Findings suggest that the debate over decentralisation of ART beyond health facilities reflects broader uncertainty about the meaning and content of 'community health care' in a context of rapidly changing conditions and demands for the delivery of health care. That underscores the difference of perspective arising from the inclination of CBHC programmes to emphasise the social determinants of health whereas health ministries emphasise the bio-medical determinants of health. The differences run

deeper, however. CHBC programmes stress the importance of creating a social environment within communities to enable adaptation and addition of services as health care demands change, while health ministries focus on their mandate to deliver clinical health care and to increase delivery capacity. CHBC programmes seek to build skills and resources within communities to provide different forms of health care whereas health ministries focus on the narrower notion of 'task-shifting' to defray resource costs. CHBC programmes collaborate with health ministries and other government departments with social welfare responsibilities (e.g., departments of 'social/community development' and their equivalents), whereas health ministries have limited links to those departments, at least in the four countries covered by this research.

The research shows that there is potential for further decentralisation of services using existing structures. For instance, scope exists for expanding links among health ministries, other government departments and CHBC programmes. The need to capitalise further on community-level resources in contexts of limited human and financial resources within governments and to meet the objectives of initiatives such as Treatment 2.0 could provide drivers for this to happen. In the immediate future, expansion and increased linkages will likely remain a challenge because of the retraction of CHBC programme services due to external funding cuts to NGOs and the inevitable, subsequent limitation of the ability of health ministries to sustain community participation in their 'outreach' projects.

4.5 COORDINATION AND COLLABORATION BETWEEN CHBC AND PRIMARY HEALTH CARE PROGRAMMES

The introduction of health ministries' paid community caregivers has to date led to different outcomes. In Malawi, 'health surveillance assistants' (HSAs) have been in place for several years. They are essentially nurse auxiliaries whose job is to help identify and refer clients to clinics. However, through interaction with NGOs as they reoriented their CHBC programmes following the advent of ART, HSAs have informally acquired a coordination role. In Ethiopia, nurses are often employed as 'health extension workers' (HEWs) in urban areas; in rural areas, however, HEWs are primarily specially trained non-professionals and their coordination work is limited compared with Malawi's HSAs.[29] The Ethiopian HEWs provide basic nursing care training among selected primary caregivers and then guide them to transfer that knowledge and assist five other primary caregivers from households in circumstances similar to their own. In Zambia, the effects of introducing 'community health assistants' (CHAs) have yet to be seen since the first cadre was only recently deployed (in 2012). It is probable that they will play a significant coordination role as they have been trained specifically to include this role in their work and because there are some large NGOs that run substantial CHBC programmes as well as health clinics and hospitals. The situation in South Africa is unclear due to the current ongoing changes to PHC.

The addition of a coordinating role for the government-paid community caregivers has introduced a new dynamic to the evolution of CHBC and PHC programmes. They challenge the status and work of NGO supervisors and managers of caregivers who work on an unpaid basis and there is some concern around undermining the spirit of volunteerism. The reliance on unpaid community caregivers means responsibility for the delivery of care and support has often been borne by those who can least afford it—i.e., the poor, and usually women and girls. This situation has not changed significantly in most communities, although there have been some improvements in support being provided to community caregivers, in terms of incentives. Also of note is that government-paid caregivers/health workers may become, as in the case of ´health surveillance assistants' (HSAs) in Malawi, simply part of a network of community caregivers in localities whose work is governed largely by NGOs' CHBC supervisors and managers, providing one link to health facilities. Alternatively, if health ministries prioritize the primary status and role of public health facilities in directing CHBC programmes, there are several challenges to the work and relative strengths of CHBC programmes.

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29 There is also a recent anecdotal report that a new Ministry of Health project is to create an additional cadre of community caregivers in Ethiopia known as the 'health development army'. These caregivers, who would serve on a voluntary basis, would be teams of four to five locally influential women who are meant to help health professionals to improve maternal and child health. Such a proposal stems from concerns over the lack of improvement in maternal mortality indicators in the country.

The core challenge is to define the different support responsibilities of clinics and NGOs and decide whether both types of entities have the capacity to fulfil those responsibilities and can meet the demand for support services. As government clinics and staff expand into communities, a challenge for NGOs could be withdrawal of funding for care and support activities. Cutbacks in such funding would reduce NGOs' ability to meet their responsibilities. This is a concern because an as-yet-unanswered question in most contexts is whether government health services can and are willing to make up the shortfall either by funding NGOs to continue their interventions or by taking over care and support responsibilities. Capacity limitations, both human and financial, are likely to be the major obstacle to the effective and efficient expansion of government-run caregiving activities and programmes. As such, complementary governmental and non-governmental systems, in which NGO-run CHBC programmes remain prominent, offer the best option to reach those in need, at least in the short and medium term.

As these current and potential challenges indicate, the difficulties of coordinating CHBC and PHC programmes have been accentuated by the ever-changing conditions for health care delivery. The introduction of ART was a catalyst for change and the process continues. There is a need for greater distinction and recognition of the different—and more extensive—types of care and support intervention needed by clients who are now receiving 'chronic care'. Furthermore, as noted in Section 2.4.2, there are foreseeable developments such as more involvement of CHBC programmes in PMTCT and paediatric HIV programmes. Inevitably, these developments foster demands for further decentralisation of health care into communities.

5 CONCLUSION

This multi-country research shows that health care at the community level is in transition in sub-Saharan Africa. Ambitious, internationally driven strategic initiatives to improve the reach of public health services are being interpreted differently by health officials in different countries. National policies, in turn, are being developed and implemented in ways that change and challenge longstanding interactions between governments and NGOs operating CHBC programmes.

Such government policy changes have occurred as the roles and responsibilities of CHBC programmes and community caregivers have transformed in line with the changing needs of their clients. Community caregivers now provide a broad range of non-medical care and support services in addition to basic nursing care, end-of-life care and psychosocial support. Existing conceptions of CHBC are often outdated, however, as they do not reflect the substantive changes to the form and content of CHBC programmes that have emerged since the introduction of national ART programmes, including a focus on broader health issues.

The findings suggest that national governments recognise the necessity of CHBC programmes and are attempting to create systems for community-orientated health care services. However, health ministries that drive this agenda do not always recognise and support what is required to mobilise communities and to sustain community participation in the delivery of services in the same way as NGOs are able to. The general trend of health ministries to create cadres of caregivers employed by the state and primarily accountable to health officials threatens to dispense with the experience and expertise in community-oriented health care that countries have acquired in large part through NGO, including FBO, initiatives in the context of HIV. The research points out the need to recognise and incorporate services provided by CHBC programmes when revitalising the principles and practice of PHC. Efforts to expand the presence of public health services within communities should strengthen and coordinate with the existing effective structures operating at the community level for CHBC programmes. Likewise, recruitment of state-employed community caregivers to strengthen capacity for the delivery of health care at the community level should draw on the expertise already present at the community level and the generally effective means developed by NGOs to ensure community participation in CHBC activities should be sustained.

The research shows how different actors are struggling to deal with the changing environment around CHBC. Both government and civil society stakeholders are grappling with defining what 'community health care' means in situations that require ongoing expansion of national ART programmes that have generated and continue to generate new demands on health care services. Health ministries face the growing need and requirement to accommodate social and economic determinants of health and health care in their operations. Such changes require them to modify their bio-medical perspective. NGOs involved in CHBC are dealing with the imperative for more and better coordination of their activities with government health services.

The difficulties underlying these changes and adaptations reflect the transition of health interventions from 'community-based' care to 'community-oriented' care. The limitations of 'community-based' care have been widely acknowledged since the mid-2000s; among the most notable are the great burden of care placed on those who can least afford it, usually women and girls. What was evident from the research was the host of efforts to resolve these limitations over recent years. The strategic and practical efforts by some African governments to revitalise PHC since 2009 represent promotion of 'community-oriented' health care. The Zambian case study provided the most graphic illustration of substantive investment in this direction.

The research also underlines the importance of continuous and sufficient funding support for CHBC programmes to avoid reduction of community services and thereby undermine current efforts by national governments and international donors to revitalise PHC as well as achieve universal ART coverage. Concerns about the future funding of CHBC programmes, voiced in the early days of the global financial crisis, predicted that many would have to curtail activities that were evolving in response to changing health care demands and were seen as crucial for the expansion of national ART programmes.

The results of this research show that the financial cutbacks experienced by many CHBC programmes are a significant threat to their viability and, indeed, to the current efforts of national governments to revitalise and expand PHC services and implement effective ART programmes. Such impacts of funding and financing limitations represent a major obstacle to implementing the Treatment 2.0 agenda, which requires increased resources in the short- to medium-term to enable lower costs further down the line.

Another notable finding in this regard is that the current investment focus within the health care sector is on employing medical personnel to revitalise and expand PHC services. This research draws attention to the fact that extending direct provision of antiretroviral drugs and other medicines to community-level stakeholders (and incorporating systems for security, management and distribution of medicines) would entail further investment in health service administrations too. Decentralising such services to the community level is a major component of the Treatment 2.0 agenda, thereby underscoring again the consequences of reduced or flat investment in such efforts.

Financial concerns are not the only ones with the potential to block decentralisation, however. Although the research shows that, overall, there is potential for further decentralisation of ART services to include the direct engagement of CBOs (and, perhaps, CHBC programmes), differing perceptions exist regarding the feasibility of doing so. CHBC programme staff and their clients see such engagement as a viable option and a necessary development to improve efficient and equitable access to treatment for those who need to take such medicines for the rest of their lives if they want to stay healthy. Yet government health authorities and medical personnel are generally sceptical of decentralising ART provision to the community level in this way because of concerns about the quality and sustainability of such services being provided by 'non-professionals'. Many argue that even with training, NGOs and their staff and community caregivers will be unable to monitor clients properly, including in regards to changing to different treatment regimens in cases of adverse side effects or lack of previous regimens' effectiveness. The current debates on how far ART delivery and management can be decentralised will have their parallels in the debates on the extent to which PMTCT and paediatric HIV services can be decentralised to (appropriately trained) community caregivers and CBOs.

In regards to the existence of country-level policies that can accommodate decentralisation of treatment programmes, as recommended by the Treatment 2.0 agenda, policy frameworks seem to be more accommodative in Malawi and Zambia, and one seems to be emerging in South Africa. It is expected that implementation of the Treatment 2.0 initiative in Ethiopia will be more challenging due to the fact that HIV treatment is still guided by a policy dating back to pre-ART days and the Ministry of Health's continued separation of 'health care' (its own responsibility) and 'community care' (a civil society responsibility). In regards to 'optimizing' HIV treatment,' the research observed the need for sound supply chain management systems to be in place to eliminate instances of medicine stock-outs at clinics and other health facilities.

This research also brought out a number areas which deserve further attention, such as the need to study the impact of the transition of health interventions—from 'community-based' care to 'community-oriented' care—on NGOs providing CHBC; the involvement of non-health ministries and sectors in community health care and, conversely, the roles of caregivers in social welfare and other 'non-health' sector services; the costing of CHBC activities, including in regards to cost-effectiveness and efficiency; and the implications of people taking ART for life on health care systems.

Caregivers and CHBC-providing organisations active in sub-Saharan Africa can and in many cases already play a critical role in delivering a wide set of HIV, health and broader development services. Their services are crucial in terms of expanding ART access and adherence, providing comprehensive care and support, HIV prevention, and broader PHC. It is appropriate to conclude that community caregivers are the backbone for accessible care and support and that successful transition and improvement of health care at the community level requires investment in CHBC programmes and true recognition by the national government and other stakeholders of the expertise of CHBC programmes and those already providing care and support in their communities.

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ANNEX 1. SERVICE PROVISION BY PRIMARY AND SECONDARY CAREGIVERS

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*	37	80	21	46
Basic nursing care: *elderly care*	33	72	15	33
Basic nursing care: *malaria*	15	33	9	20
Basic nursing care: *other diseases*	28	61	15	33
Clinical care (e.g., taking blood pressure, weighing people) in organisation's own facility	21	46	6	13
End-of-life care	29	63	7	15
Pain relief	29	63	9	20
Personal hygiene	39	85	19	41
In home/community: *pre- ART patient counselling*	38	83	10	22
In home/community: *ART adherence support*	40	87	10	22
In home/community: *recruitment of patients for VCT services*	38	83	4	9
In home/community: *recruitment of patients for ART services*	34	74	6	13
In home/community: *recruitment of pregnant women for PMTCT services*	36	78	5	11
In home/community: *HIV pre-test information*	28	61	5	11
In home/community: *HIV testing*	23	50	4	9
In home/community: *HIV post-test counselling*	27	59	5	11
Health education : *HIV*	43	93	8	17
Health education: *malaria*	20	43	5	11
Health education: *other diseases, e.g., TB and sexually transmitted infections (STIs)*	37	80	4	9
Social support (e.g., shelter, clothing, assisting with accessing IDs or birth certificates, social workers, etc)	39	85	5	11
Livelihood support (e.g., income-generating activities, savings groups)	30	65	6	13
Legal support	17	37	2	4
Nutritional support/referral for nutritional support	36	78	7	15
Spiritual and/or emotional support	39	85	5	11
OVC care	40	87	5	11
Referral of clients to clinical services (clinics, hospitals)	41	89	4	9
Organise or provide transport for health facility visits	30	65	5	11
Educating members of the client's household	41	89	4	9
Assistance to service provision in local health facility*				
Assistance in local health facility: *pre-ART counselling*	21	46	6	13
Assistance in local health facility: *HIV pre-test information*	20	43	4	9
Assistance in local health facility: *HIV testing*	19	41	3	6
Assistance in local health facility: *HIV post-test counselling*	18	39	3	6
Assistance in local health facility: *administrative tasks*	11	24	4	9
Assistance in local health facility: *other*	14	30	2	4
Specific types of support / activities**				
Specific support for women: *women and child protection and SRHR interventions ****	17	38	1	2
Specific support for women: *empowerment and self-reliance interventions*	10	22	1	2
Lobbying and advocacy activities	15	33	1	2

*   *Based on a survey of 46 organisations providing CHBC services*
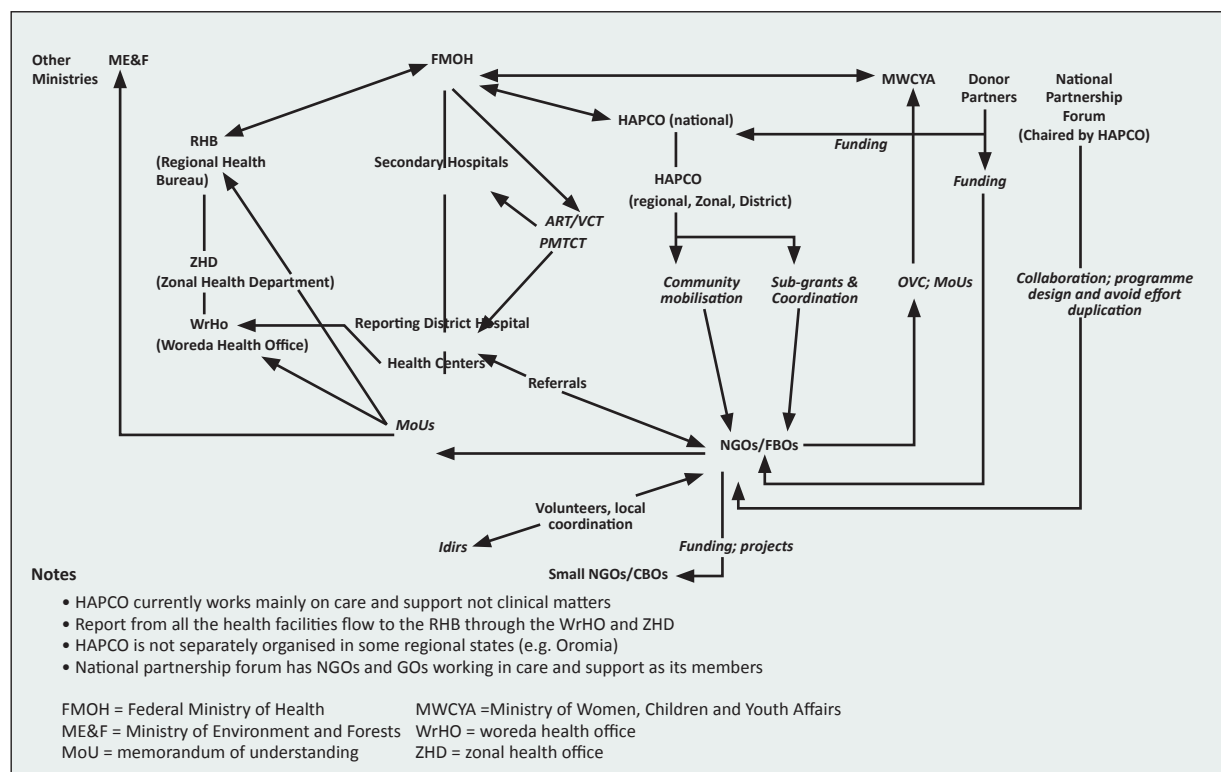**   *Based on a survey of 45 organisations providing CHBC services*
*** *SRHR = sexual and reproductive health and rights*
Source: CAN multi-country research (Ethiopia, Malawi, South Africa and Zambia), 2011–2012

ANNEX 2. ORGANOGRAMS OF NATIONAL AND PROVINCIAL HIV CARE AND SUPPORT STRUCTURES

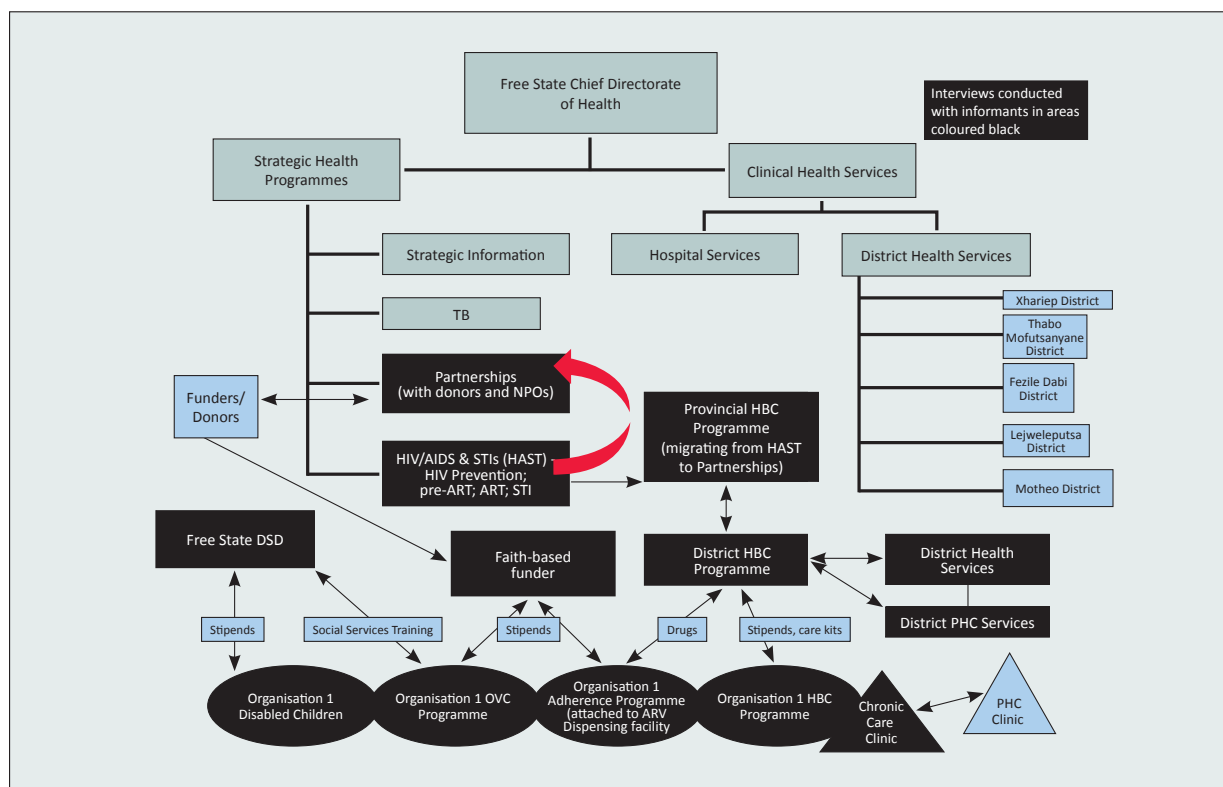**Figure 3. National organogram for care and support structures in Ethiopia**

Notes
- HAPCO currently works mainly on care and support not clinical matters
- Report from all the health facilities flow to the RHB through the WrHO and ZHD
- HAPCO is not separately organised in some regional states (e.g. Oromia)
- National partnership forum has NGOs and GOs working in care and support as its members

FMOH = Federal Ministry of Health
ME&F = Ministry of Environment and Forests
MoU = memorandum of understanding

MWCYA =Ministry of Women, Children and Youth Affairs
WrHO = woreda health office
ZHD = zonal health office

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

Figure 4. National organogram for care and support structures in Malawi
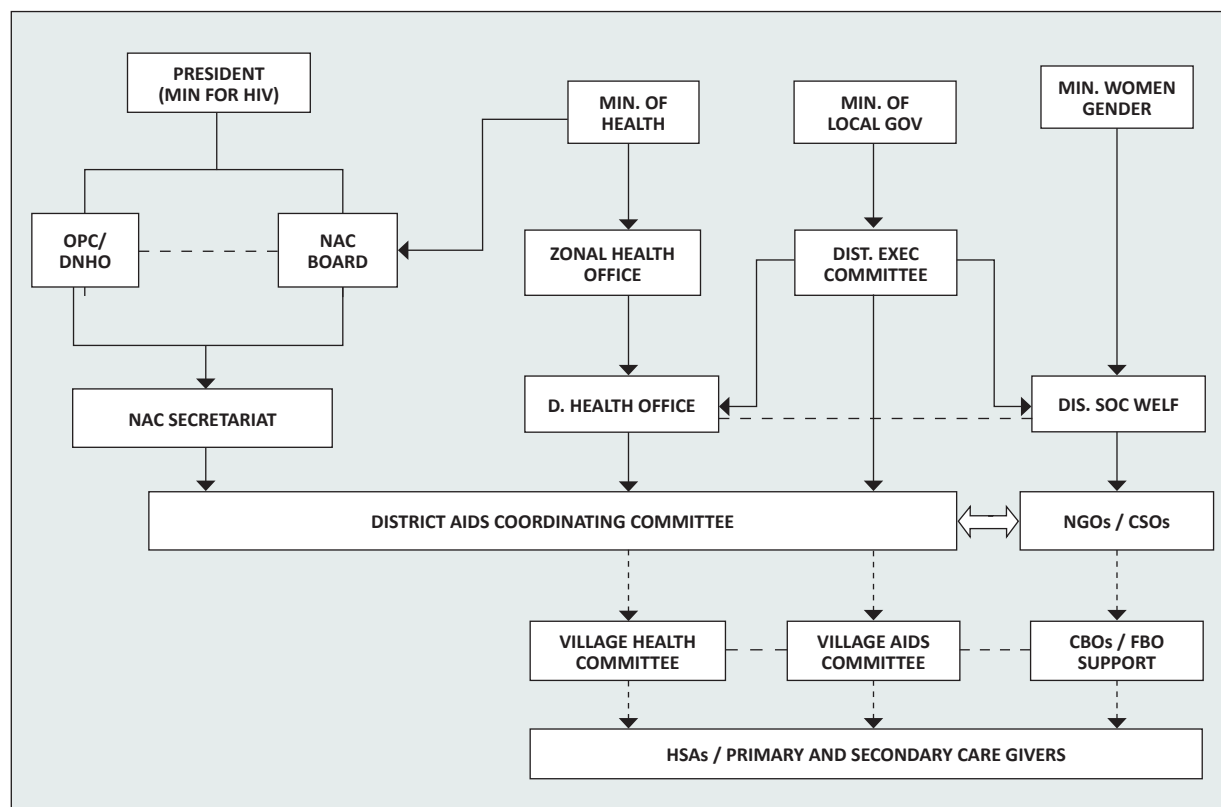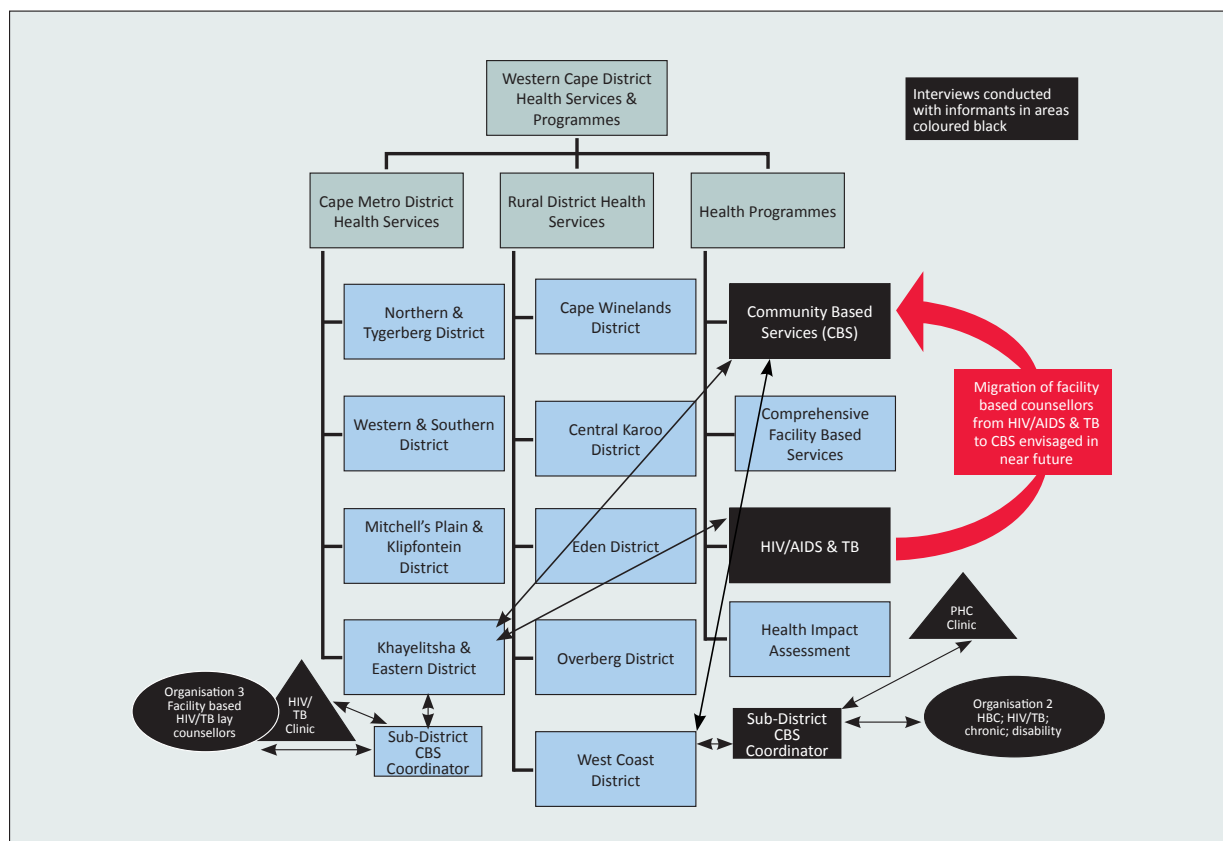

Source: CAN multi-country research – Malawi research, 2011–2012

Figure 5. Provincial organogram for care and support structures in the Western Cape, South Africa (including case organisations 2 and 3)
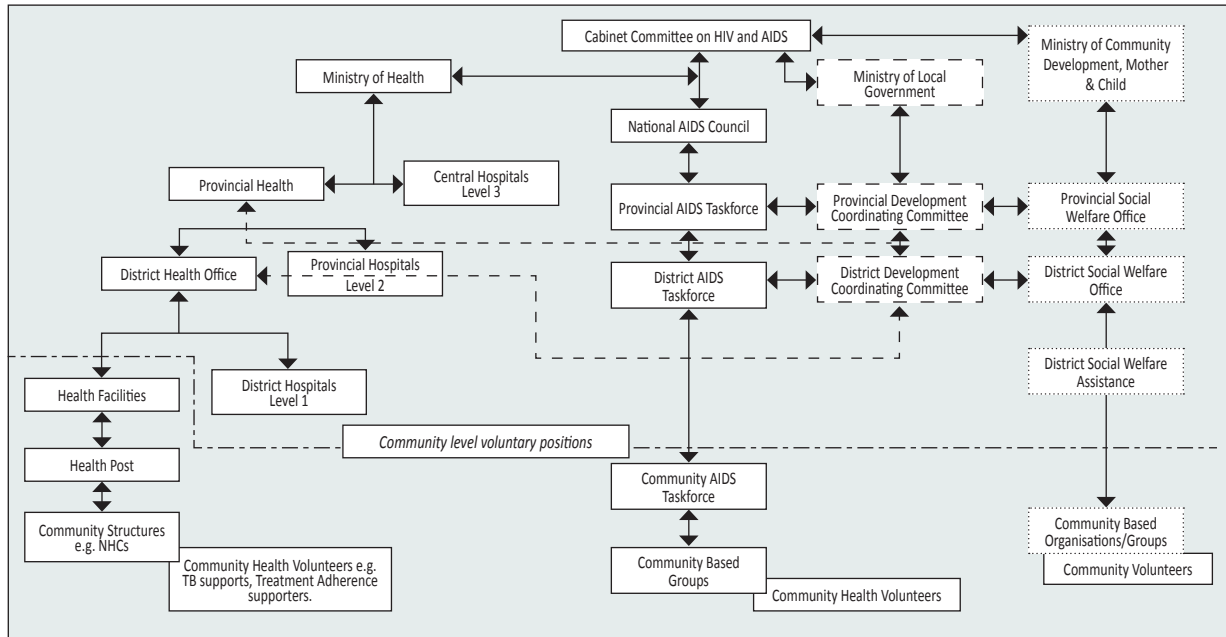

Source: CAN multi-country research – South Africa research, 2011–2012

Figure 6. Provincial organogram for care and support structures in the Western Cape, South Africa (including case organisations 2 and 3)

Source: CAN multi-country research – South Africa research, 2011–2012

Figure 7. National organogram for care and support structures in Zambia

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