

## COMMUNITY CAREGIVERS: THE BACKBONE FOR ACCESSIBLE CARE AND SUPPORT



# COMMUNITY CAREGIVERS: THE BACKBONE FOR ACCESSIBLE CARE AND SUPPORT MULTI-COUNTRY RESEARCH: SOUTH AFRICA REPORT

## South Africa research team members:

Ermien van Pletzen, University of Cape Town; Hayley MacGregor, Institute of Development Studies

## South Africa Research Advisory Board members:

Melanie Alperstein, University of Cape Town; Raymond Bokako, Thusang Community Care / Community Care workers' Forum; Anna Genu, South African Christian Leadership Assembly / Community Care Workers' Forum; Ntombuzuko Kraai, AIDS Response / Wellness Foundation; Lawrence Mbalati, AIDS & Rights Alliance for Southern Africa; Nokwanele Mbewu, Philani Child Health and Nutrition Centre; Penny Morrell, freelance project practitioner; Mavis Nonkuzi, TB/HIV Care Association

## Research Coordinators:

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

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# ACRONYMS AND ABBREVIATIONS

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AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral therapy
CAN	Caregivers Action Network
CBO	Community-based organisation
CHBC	Community and home-based care
DOTs	Directly observed treatment, short course
FBO	Faith-based organisation
HIV	Human immunodeficiency virus
M&e	Monitoring and evaluation
MSF	Médecins Sans Frontières
NPO	Non-profit organisation
OVC	Orphans and vulnerable children
PHC	Primary health care
PMTCT	Prevention of mother-to-child transmission
TAC	Treatment Action Campaign
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization

# FOREWORD

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

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

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

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

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

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

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

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

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

# EXECUTIVE SUMMARY

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

The research objectives were to:

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

The main focus of the South African research was on three organisations implementing CHBC programmes that were selected for in-depth study: a faith-based organisation (FBO) operating in a peri-urban/semi-rural setting within the Free State Province, a non-profit organisation (NPO) operating in a peri-urban/rural setting within the Western Cape Province, and an NPO operating in an urban setting within the Western Cape Province. The research further comprised an extensive literature review, interviews with government and other civil society stakeholders, and a validation questionnaire completed by 16 organisations providing CHBC services nationwide.

Fundamental changes affecting community-based care work in South Africa were under way at the time the research was conducted (December 2011 to August 2012). These arose from the announcement by the National Department of Health in 2010 of far-reaching new policy guidelines on re-engineering primary health care (PHC), which included new arrangements for the delivery of CHBC. However, implementation of the new policy arrangements had not been widespread at the time the research was concluded, and most CHBC programmes were still managed and shaped by the NPO sector, in loose partnership with the national government. This means that the data presented in this report are necessarily highly selective and time bound and cannot be regarded as a comprehensive overview of CHBC in its current or future form in the country as a whole.

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

## History and evolution of community care

South Africa has a long history of community participation and mobilisation organised through civil society structures as well as community care provision to vulnerable communities through CHBC programmes. Community caregiver programmes played an important role in supplementing and redressing the effects of apartheid and in supporting the process of reforming the health system in the period before the democratic election in 1994. While the new democratic government did not implement a national community caregiver programme post-1994, there was a large increase in community caregiver activity in response to the HIV epidemic and the overburdened public health system in the late 1990s and early 2000s.

Until recently the South African national government has relied mainly on partnerships with a wide array of NPOs to deploy community caregivers in impoverished communities. Thus, while the government has striven to provide enabling environments and funding, many NPOs operating at community level still take on basic care delivery, as well as the tasks of enrolling, training and managing community caregivers; paying their stipends or salaries; and integrating their services within existing health and other social structures. These NPOs range from small community-based organisations (CBOs) performing basic care and support services within the home environment in resource-constrained communities to well-resourced national and international NPOs offering care and support or fulfilling training and managerial roles. Across the nine provinces there has been considerable variation in the conditions of service of community caregivers, the extent of formalisation of their employment, the location of their work within or outside health facilities and in their remuneration. They provide a broad spectrum of health-related as well as social services, including more targeted specialised care.

### **Policy changes and new guidelines**

In recent years, the National Department of Health has identified a number of problems with existing CHBC programmes run by the NPO sector. The following were among those problems: inadequate training, support and supervision of community caregivers; random distribution of services leading to uneven coverage; poor integration of CHBC programmes with services offered by formal health facilities; and inadequate accountability of the NPO sector. At the same time, the National Department of Health was determined to tackle the continued poor health outcomes of the South African population, especially in relation to the HIV epidemic,

A new set of policy guidelines was launched from 2010 onwards to address these problems and concerns. These guidelines envisage a revitalised PHC approach with generalist 'community health workers' employed by the state and deployed in outreach teams supervised by professional nurses and linked to formal health facilities in each electoral ward. Their main roles were defined as community profiling, risk identification, health promotion and education, and referral of clients to appropriate health services. 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 focus of the revitalised PHC approach will initially be on HIV, TB, and maternal and child health, expanding subsequently to chronic illnesses and conditions resulting from injury and violence. Other important roles envisaged for the state-employed 'community health workers' are to encourage people to test for HIV and TB and to support their uptake of and adherence to treatment. Policy implementation guidelines made available to provincial governments in 2011 state that funding for employing 'community health workers' would no longer be made available to NPOs, since the state would employ all 'community health workers' in future. NPOs would instead be funded to undertake social mobilisation and other community-level activities that would complement the work of the PHC outreach teams.

### **Needs of people living with HIV**

The scale-up of ART, which began slowly in 2004 but gathered momentum from 2009 onwards, has meant a gradual shift in the needs of most people living with HIV from basic nursing and end-of-life care when terminally ill to the need for access to treatment. There has been an accompanying shift that underscores the increased priority among clients for support for monitoring and managing comprehensive ART provision, including in regards to the drugs' effectiveness and possible side effects.

Clients surveyed in the study 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 particularly the need to receive drugs reliably. In the three South African case study organisations, clients also frequently expressed dire socioeconomic needs, such as for food, income-generating activities, adequate shelter and access to social security grants.

Clients further observed that their ability to access care and support would improve if HIV-related stigma were reduced, which could help remove obstacles to testing for HIV and taking up treatment.

Likewise, the research revealed that unless community participation, mobilisation and leadership are strengthened significantly at ward and district level, especially in rural areas, the access of clients to services may be compromised by the clients' and their primary caregivers' current lack of agency in expressing clients' needs and rights.

## Caregivers' roles

Caregivers' roles have tended to shift from generalist to specialist, and back to generalist, in response to the contours of the HIV epidemic, as well as to the ways in which funding has prioritised the pandemic over other illnesses. Before the advent of HIV, caregivers' roles in South Africa tended broadly to target health conditions related to poverty, social inequality and migrant lifestyles, but these roles shifted to focus on basic physical care and other support required by clients and their families within the home environment as the HIV epidemic worsened during the 1990s. Once ART became more available from around 2004, a diversification and specialisation of roles occurred in the areas of testing, counselling and monitoring adherence to medication, in addition to services already provided such as psychosocial support, care for orphans and vulnerable children (OVC) and socioeconomic support for those infected with and affected by HIV. More recent policy moves by the National Department of Health have again been 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. On the whole there is a trend towards integration of specialist roles and incorporation of conditions other than HIV/AIDS, most notably the integration of HIV and TB services.

Research respondents raised concerns about the focus on state-employed 'community health workers' under new government policy, in light of the broad range of care and support roles that are currently being offered by community caregivers based in NPOs (largely funded by the Department of Health). A concern was that some elements of the spectrum of care and support, most notably home-based care, may no longer be provided if 'community health workers' became the only cadre of workers funded by the Department of Health. These roles include day-to-day basic physical care and support of long-term bedridden and terminally ill clients within their home environment, long-term psychosocial support, assistance with securing livelihoods through accessing social grants or generating income, counselling and regular drug adherence support in cases where it is necessary.

## Service provision

As in the case of caregivers' roles, the structures and modes of service provision in CHBC work are diverse and vary across provinces and organisations in South Africa. At present NPOs and the community caregivers they enrol deliver an important range of services for people living with HIV and other conditions. In this transitional period the state still provides funding, policy guidelines and resources, as well as some skills-development and capacity support to NPOs providing services. Government structures are also responsible for coordinating the monitoring and evaluation (M&E) of the delivery of services as well as for ensuring that protocols and targets are respected. Two government agencies are involved in funding and supporting CHBC in NPOs, namely the Department of Health and the Department of Social Development, at both national and provincial level.

Within the new policy context of the National Department of Health, it was uncertain at the time research for this report was conducted whether NPOs will continue to receive state funding from the Department of Health for CHBC services not covered by the PHC outreach teams. As a result it is also unclear whether CHBC services provided by such NPOs will be sustainable in the future. The new policy guidelines do not extensively address NPOs and CHBC services funded through the Department of Social Development, which presumably will continue for the time being without being changed. In this respect, the 2011 provincial policy implementation guidelines envisage that outreach teams would provide psychosocial support in collaboration with community caregivers supported by the Department of Social Development.

## Caregivers' potential

**The research highlights the important roles played by caregivers in health promotion programmes, counselling and testing, client advocacy, stigma mitigation and community mobilisation**—all of which contribute to prevention of HIV or increased uptake of treatment. Moreover, caregivers are increasingly playing an important role in connecting clients to treatment sites and monitoring adherence to ART. Likewise, they are becoming increasingly involved in surveillance for TB and other opportunistic infections, as well as monitoring side effects of ART. Caregivers clearly have the potential to effectively contribute to an expansion of HIV prevention, treatment and primary care programmes, provided they receive adequate support, including supervision and training.

Organisations focusing on care and support offer promising potential models for delivering a broad range of services at local level while working closely with the formal health system. They can, for example, offer services covering a wider range of infectious diseases, maternal and child health, and non-communicable diseases. Additionally, they can offer services that could be utilised for the implementation of the 'Treatment 2.0' framework, one objective of which is to increase the use of HIV prevention and treatment services through community-based approaches, provided that caregivers receive the required support and training. Several care organisations expressed an interest in expanding services, including direct ART provision.

## Complementarity between formal and informal community caregivers

Relationships between the formal health system and informal community caregiver programmes run by NPOs have not in the past been highly structured and often they depend on the individual efforts of staff in organisations and facilities. This limited degree of complementarity between formal and informal services is one of the problem areas that the National Department of Health identified and aims to address through its new policy guidelines. The new arrangements proposed and already being implemented will in effect 'formalise' the work of 'community health workers' by integrating their work into the services provided by formal health facilities in communities. This research revealed that there were expectations among government and NPO respondents alike that informal, NPO-based community caregiver programmes would continue to operate alongside the outreach teams under the new PHC model, for instance to provide home-based care or support for OVC. How to ensure that these programmes complement the work of 'community health workers' in the PHC outreach teams is as yet not clear, but respondents felt that it is necessary to define, strengthen and regulate the relationships between formal and informal care workers, whether they are to be based at formal system facilities or in NPOs. Greater collaboration between the Departments of Health and Social Development, the main departments funding and supporting community caregivers in South Africa, was mentioned by NPO respondents as a crucial requirement for developing closer complementarity.

Because of the history of CHBC in South Africa, much experience and expertise in providing community-based care lies with non-formal NPO-led programmes. It is important for this experience and expertise not to be lost. As described at present, the outreach teams will be supervised by professional nurses, an expectation that may not be realistic in the near future given the critical shortage of trained health professionals in South Africa as well as many professional nurses' lack of experience in managing 'lay' staff working outside facilities and in the field. Given human resources constraints and the history of largely unstructured relationships between formal health professionals and community caregivers, it has been recommended by research respondents from government and NPOs that experienced community caregivers or NPO managers should be considered alongside professional nurses for supervisory posts in the field. If necessary, professional nurses who end up as supervisors of 'community health workers' in outreach teams should be additionally trained and supported in managing staff in the field.

## Challenges and concerns

The future of CHBC service-providing organisations under the government's new plans for organising community-based care and support is not clear. While the need for recognition, standardisation and monitoring of community care work is widely recognised by government and civil society, there is concern that the new Department of Health policy guidelines on PHC outreach teams do not sufficiently spell out the future of NPOs in the system. They also exclude some forms of CHBC: For instance, they do not sufficiently highlight the need for ongoing psychosocial support and there are concerns as to whether the generalist 'community health worker' will be able to provide some of the time-consuming care and support services such as home-based care that are presently being provided by community caregivers.

These issues remain serious gaps in the current policy environment. Moreover, if government policy is to be implemented strictly, there is a risk that the considerable knowledge and experience of NPOs, especially in the field of HIV care and support, but also in more general CHBC, will be lost. This may be especially the case for smaller community-based organisations that may not be able to reposition themselves as organisations delivering training, supervisory or capacity-building services. It also remains to be seen whether state-employed 'community health workers' organised in outreach teams will function better in the PHC structures of the health system than some of the current organisations with a high degree of informal integration with PHC structures.

Research participants also raised concerns about i) the formal health system's capacity to provide staff qualified to supervise outreach teams and manage the transitional period; ii) PHC clinics' capacity to handle potentially larger numbers of clients identified by the outreach teams; and iii) decreasing funding support for CHBC provision in South Africa 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.

## Conclusion

After a long and complex history, CHBC programmes are at an important new point of departure in South Africa, with the National Department of Health providing new policy guidelines on formalising care work in communities. Implementation of guidelines through provincial and district departments has begun, but many NPO-run CHBC programmes still continue to be offered in many parts of the country. At the time this research was finalised it was too early to comment on the implementation process and its implications for CHBC in the country, particularly for civil society organisations and their caregivers that offer care services falling outside the scope of services defined for state-employed PHC outreach teams.

A number of challenges and concerns emerged from the study. In consultation with the South African Research Advisory Board, a list of advocacy priorities based on these challenges and concerns was developed. One notable overall priority is for close collaboration during the transition period of policy implementation between relevant government departments, as well as between government and civil society. Collaborative efforts should be wide-ranging so as to include poorly resourced community-based organisations in marginalised parts of the country and the community caregivers that have provided CHBC in South Africa, some of them for many years. Their engagement is critical to ensure that existing forms of care, caregivers' experience, managerial expertise, understandings of client needs and networks for mobilising communities are not lost to the implementation process.

# 1 INTRODUCTION

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

The research objectives were to:

- explore the adaptations and changes in caregiving at the community level since the rapid scale-up of antiretroviral therapy (ART), with a particular focus on the tasks of caregivers and the needs of their clients;
- assess how and to what extent caregiving by informal caregivers at community level has been integrated in the health system and is being recognized as part of primary health care (PHC) structures and policies;
- investigate the contributions of, potential role of and benefits for caregivers in the expansion of HIV prevention and treatment and PHC programmes; and
- assess the potential means for formal and informal community caregiver<sup>2</sup> programmes to complement each other in the context of decentralisation of HIV treatment programmes, taking into account current initiatives and arrangements.

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

The first section of this report presents the background to the South African country research and includes a description of the research process as well as the findings of the desk review. The bulk of the report, Section 2, presents the findings and analysis of the research. Section 3 contains a conclusion, including advocacy points for community care work in the country.

## Note on terminology used

Within the South African context, many terms exist for those who work in the community. These workers 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.<sup>3</sup> 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<sup>4</sup> supporter.

The preferred term used in this report for men and women who provide CHBC services is 'community caregivers' (also referred to in this document as 'caregivers') for two reasons. First, this term includes both of the two main categories of individuals involved in caregiving at the community level: primary and secondary caregivers. 'Primary caregivers' can be defined as family and friends who provide immediate care to family members and/or loved ones. 'Secondary caregivers' are caregivers who work on an individual basis or as staff on a paid/ unpaid/ voluntary basis at clinics, for NPOs or for the government. As such, the term 'secondary caregivers' refers to both employees of health ministries and of NGOs, including faith-based organisations (FBOs), while 'community caregivers' refers to primary and secondary caregivers together, although in this report mainly to secondary caregivers, as explained below.

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1 All CAN documents relating to the overall multi-country research, 'Community caregivers: the backbone for accessible care and support', can be downloaded from the CAN website at [www.caregiversactionnetwork.org](http://www.caregiversactionnetwork.org).

2 As indicated in the note on terminology used, CAN gives preference to the use of the term 'community caregiver' rather than 'community health worker'. Therefore the term 'community health worker programmes' as specified in the original research objectives has been replaced by 'community caregiver programmes'.

3 Cameron, S, Coetzee, L and Ngidi, N (2009). Chapter 11, Community caregivers. Legal Aspects of Palliative Care: 99-106 Hospice Palliative Care Association of South Africa

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

Secondly, the term ‘community caregiver’ is commonly used in the other countries included in this multi-country research. Using the same terminology makes it easier to make comparisons among the research countries. However, country-specific terms used for community caregivers are maintained in this report when direct reference is made to departments and agencies, policies and policy statements as well as information obtained from official documentation. These country-specific terms are placed within single quotation marks. For example, when referring to the community caregivers deployed through the revitalised PHC policy currently unrolling in South Africa, the term ‘community health workers’ is used, while some specialist terms like ‘lay counsellors’ and ‘home-based carers’ are also used when referring to community caregivers performing such specialised tasks.

While the term ‘community caregiver’ refers to both primary and secondary caregivers, it is important to note that it has not been possible to adequately address primary caregivers’ role in this research. Therefore, in this report, the community caregivers discussed do not include primary caregivers unless explicitly stated. CAN recognises that primary caregivers are a critical part of the delivery of care and support, and that there is a need for additional research focusing on their contribution to the HIV response.

The term ‘non-profit organisation’ and its associated acronym, NPO, are used in this report instead of a more commonly recognized term for similar entities: ‘non-governmental organisation’, or NGO. The decision is based on the specific wording used in the South African government’s 1997 act, which referred to “non-profit organisations”. Non-governmental organisation (NGO) is used elsewhere in the overall CAN multi-country research.

## 1.1 RESEARCH PROCESS AND LIMITATIONS

### Methodology

Phase 1 of the research consisted of a desk review of the available literature and semi-structured interviews. The desk review focused on information related to CHBC and the research objectives. This involved scientific literature as well as national documents and reports from organisations involved in CHBC. The review was followed by semi-structured interviews with key informants involved with community care and support policies and ART strategies at national and provincial level in government, as well as key informants from civil society working for medium-sized to large care and support organisations with offices operating at national level. These interviews explored the in-country structures of caregiving; evolution in national policies, strategies, caregiving practices, in-country linkages and networks; the government’s position towards and support to community (health) care and support delivery; involvement of lay workers; and the different implementation models for community care and support.

To capture a sense of the variability of CHBC across the provinces, interviews were conducted with informants not only at the National Department of Health, but also at the two provincial Departments of Health in the Free State and Western Cape provinces. These provinces were selected as they are home to the case study organisations in research Phase 2. Interviews were also conducted with staff from five large national NPOs offering care and support services (see Annex 2).

Phase 2 consisted of an in-depth study of three organisations providing CHBC<sup>5</sup> that were selected with the guidance of the Research Advisory Board formed to assist and review the research. The three organisations reviewed were: a FBO operating in a peri-urban/semi-rural setting within the Free State Province; an NPO operating in a peri-urban/rural setting within the Western Cape Province; and an NPO operating in an urban setting in the Western Cape Province. The FBO in the Free State runs a number of separate programmes, including a facility providing HIV testing and counselling, HIV treatment and adherence monitoring, an OVC programme with a drop-in centre, a day care centre for children with disabilities and an informal home-based care programme attached to a private clinic. The peri-urban/rural NPO in the Western Cape Province is home-based care organisation which offers care and support to clients referred by state clinics or hospitals. A wide range of services covering infectious and chronic

<sup>5</sup> The names of the three case study organisations have not been mentioned by the researchers as the purpose of the research is not to showcase the work of these organisations but rather to obtain a better understanding of the environment in which organisations providing CHBC in South Africa operate.

illnesses, maternal and child health, injury, disability and mental illness are provided in clients' homes and at the NPO's premises. The urban NPO in the Western Cape Province is a voluntary counselling and testing organisation focusing on HIV, although integration with TB services is gradually being phased in. The NPO's 'lay counsellors' are based at state day clinics and day hospitals, where they assist clients visiting these facilities. Annex 3 contains additional information on the three case study organisations.

These organisations were chosen because they represent different contexts and types of CHBC work, ranging from generalist CHBC programmes with strong psychosocial dimensions (or even a psychosocial focus) to specialised HIV testing, counselling and treatment programmes. Selection also took into account the variability in implementation of new government policy guidelines across the nine provinces of the country. As such, one province (the Free State) had started implementation processes, while the other (the Western Cape) had opted out of the new framework but undertook to align its programmes to the policy guidelines.

In addition to the literature review and interviews, at least three focus group discussions took place per selected programme: one with a selection of programme staff, one with community caregivers and one with community representatives. Individual interviews, guided by questionnaires, were also conducted with clients and their primary caregivers for each programme.

Fieldwork for Phases 1 and 2 was completed by the end of April 2012. Consent forms were signed by all key informants, and data were collected in four languages: English, South Sotho, Xhosa and a regional Afrikaans dialect. Phase 3 included the processing and content analysis of data as well as a comparative analysis between cases and the four countries involved in the research. The analysis process was standardised for all countries, with a view to structuring data in the same manner to enable comparison. A structured coding model was developed, based on the objectives of this study and recurrent themes in the literature. This coding guide was distributed to the research teams for a compatibility check and input, whereupon it was used to simplify the synthesis of the data. All focus group discussions and interviews were fully transcribed. The codes were used for the content analysis, which in turn served as a basis for Phase 1 and Phase 2 interim reports, final country reports (based on the two interim reports) and a final four-country synthesis report.

The final data collection phase at the country level (Phase 4) focused on validating the country findings in a second round of interviews with key informants at national level and in the distribution of a questionnaire among a sample of care and support organisations. The design of the questionnaire was based on key findings from all four research countries and sought to validate these with a wider range of community programmes/projects. The response rate in South Africa from the 16 organisations surveyed was 100 percent. The findings were processed in SPSS software with results adjusted for missing data.

The South African component of the research received ethical approval from the University of Cape Town's Faculty of Health Sciences Research Ethics Committee on 14 October 2011. Further approval to conduct interviews with government officials was received from the National Department of Health, the Free State Department of Health, the Free State Department of Social Development, and the Western Cape Department of Health.

## Limitations

The research set out to investigate the current arrangements and nature of CHBC work in South Africa as well as to capture a sense of the transitional moment being experienced in the country. This was an ambitious task, and the challenges were exacerbated by stringent budgetary and time constraints and the vast distances to be travelled. As such, the research could not hope to be comprehensive and was subject to a number of limitations.

One limitation encountered during fieldwork occurred as a result of high levels of HIV-related stigma and ethical considerations. This meant that home visits to people living with HIV were not possible in most cases, and arrangements were made to interview these individuals and their primary caregivers at facilities where they were ensured a larger degree of anonymity.

Another limitation was associated with the significant changes in the policy environment taking place at the time of the research and the different interpretations of this policy in various provinces. This was

compounded by the vast and decentralised nature of the district health system in South Africa, as well as the large number of NPOs that, despite policy changes, were still the major providers of CHBC at the time the research was conducted. In addition, while this research focused on HIV, it was conducted in a context where the vertical programming dedicated to HIV and TB was being shifted to more horizontal integrated service provision that is inclusive of the many other conditions that beset a country with significant poverty and inequality.

A further limitation was that given the vastness and complexity of the environment in the health sector that the research team was attempting to cover, the scope of the project did not allow the inclusion of organisations and cadres of community caregivers supported by the Department of Social Development. Despite instances of overlap and collaboration between the Department of Health and the Department of Social Development (for instance around the policy framework of 2009), the caregivers supported by these two departments to a large extent remain two different cadres. Only passing reference is made to the Department of Social Development, and only one provincial official of that agency was interviewed (since one of the selected organisations was receiving funding and support from both the departments of Health and Social Development).

And finally, in-depth case studies of just three organisations can only give a limited view of CHBC in South Africa and thus should not be viewed as representative of what is happening in the country as a whole. While the validation interviews that encompassed another 13 organisations and another three provinces (see Annex 2) go some way towards addressing this limitation, it was extremely difficult to capture and present a full or coherent picture of CHBC nationwide.

While these limitations necessarily limit the generalizability of the findings, an important strength of this project remains that it focused in large part on collecting data from community caregivers themselves as well as from their organisations, their clients and the clients' primary caregivers in the home. While analysis of these data may again result in limited findings that may not be generalizable, the research still captures the nature of CHBC and role of caregivers in a way that would not be possible by focusing on analysis of policy guidelines, implementation plans and processes, or interviews with government officials.

## 1.2 DESK REVIEW

### History of CHBC in South Africa

In South Africa organised CHBC programmes played an important role in trying to redress the effects of the highly inequitable health system during apartheid and in supporting the process of reforming the health system in the period before the first democratic elections in 1994 (Van Ginneken et al., 2010). Paradoxically, programme numbers dwindled post-1994 with the new government's adoption of a PHC approach within a district health system that did not include the development of a national community health worker programme (Friedman, 2005). Since the late 1990s, however, there has been resurgence in CHBC activity, primarily in response to the HIV epidemic and the overburdened public health system (Schneider et al., 2008). This can be viewed as part of a general upward trend in the number of civil society organisations documented in Southern Africa over this time (Birdsall & Kelly, 2007). Around 2004, the Departments of Health, Social Development and Basic Education, in collaboration with the Social Sector of the government's Expanded Public Works Programme, supported the development of CHBC programmes in an attempt to expand the delivery of health and social services, to build skill and capacity among the unemployed, and to relieve widespread poverty (Friedman, 2005; Schneider et al., 2008).

The development of post-apartheid CHBC programmes was enabled by government legislation—in particular the Non-profit Organisations Act of 1997—but the government relied from the outset on partnerships with a wide array of NPOs. Thus, while the government has striven to provide enabling environments and funding, many NPOs operating at community level have taken on delivery of care and support and CHBC as well as the tasks of enrolling, training and managing community caregivers; paying their stipends or salaries; and integrating their services within existing health and other social structures. These NPOs range from small community-based organisations (CBOs) performing basic home-based care in impoverished communities to well-resourced national and international NPOs offering care and

support or fulfilling training and managerial roles (Van Pletzen et al., 2009). Across the country's nine provinces there has been considerable variation in the conditions of service of community caregivers, the extent of formalisation of their employment, the location of their work within or outside health facilities and in their remuneration. They provide a broad spectrum of health-related as well as social services, including more targeted specialised care and support. While many prioritise HIV-related care and support—given the priority need and the funding earmarked for this work—a significant number continue to provide a broader range of services, often with minimal resourcing.

Since the initial appearance in 2004 of the National Department of Health's draft 'Community health worker policy framework', public policy makers have been grappling with the process of providing guidelines for the management and deployment of different cadres of 'lay health workers'<sup>6</sup> in this extremely complex organisational and social environment. A follow-up document, the 'Community care worker policy management framework' (2009), produced by the National Department of Health and the National Department of Social Development, suggested that the rapid growth in numbers of lay workers and existing management models had produced unfortunate consequences both for 'care workers' and associated NPOs. Particular problems identified were interruptions in the flow of funding from government sources to CHBC workers via partner NPOs and the persistence of fragmented, programme-specific approaches to service delivery instead of integrated, comprehensive approaches (Lehmann & Sanders, 2007; Health Systems Trust, 2011). In addition, the vertical programming that focused narrowly on HIV and TB in particular (driven largely by the structure of funding) meant that other areas of significant importance—specifically non-communicable and chronic illnesses—were in danger of being neglected.

## Policy guidelines

Coupled with the problems identified with the provision of CHBC through NPOs, the National Department of Health expressed determination from late 2008 onwards to tackle the continued poor health outcomes of the South African population, especially in relation to the HIV epidemic. A new set of policy guidelines started emerging in 2010 (Barron et al., 2010), envisaging a revitalised PHC approach with generalist 'community health workers' employed by the state and deployed in outreach teams supervised by professional nurses and linked to formal health facilities in each electoral ward. Derived to some extent from the Brazilian model, these outreach teams are considered to be the cornerstone of community-based PHC services (Pillay & Barron, 2012). The main roles of the 'community health workers' in these outreach team were defined as community profiling, risk identification, health promotion and education, and referral of clients to appropriate health services. These guidelines came within a South African context where health needs associated with poverty, infectious disease, non-communicable disease and injury and violence amounted to a quadruple burden of disease (*The Lancet Health in South Africa Series*, 2009). Other important roles envisaged for the state-employed 'community health workers' are to encourage people to test for HIV and TB and to support their uptake of and adherence to treatment.

As part of implementing the process of re-engineering PHC, the National Department of Health undertook a national 'Community health worker audit' in 2010-2011 (2011a). This revealed that at the time of the audit, 2,800 NPOs and 72,839 people were providing community-based health services in South Africa (National Department of Health, 2011a). The following categories and numbers of individuals were reported: 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'; 143 'hospice workers' and 18 'mentors'.

There were great variations in the numbers of care providers, the services rendered and employment conditions across the nine provinces. Key policy recommendations made in the audit were as follows:

- The many different categories of workers referred to above should be reduced to 'community health workers', 'home-based carers' and 'counsellors'.

<sup>6</sup> Lay health workers have been defined as any health worker carrying out functions related to health care delivery; trained in some way in the context of the intervention; and having no formal professional or para-professional certification or tertiary education. They can be found in almost every primary health care system across the world, carrying out a range of tasks including end-of-life care, counselling, health promotion, treatment support, breastfeeding support, etc. (Daniels et al., 2012)

- These categories of worker should be integrated into the formal health services as well as the human resource planning of the health sector.
- All categories of worker should have the same conditions of service, benefits and obligations as other health sector employees.
- Recruitment of the new categories of worker should be from the existing pool of 'community-based health workers'.
- All categories of worker will receive remuneration.

There has been broad consensus between government and civil society about the need to make community care and support provision more coherent in the country, as well as the need to improve the conditions of employment of community caregivers. Concurrently with policy developments at national and provincial levels, two important national symposia organised by the South African National AIDS Council (SANAC), attended mainly by civil society representatives but also by government officials, took place in 2010 and 2011; at both meetings the future roles and employment conditions of community caregivers were discussed. At the first—the Community Care Worker Symposium held in April-May 2010—consensus was reached that community caregivers and their services should be located in a revitalised PHC system. The follow-up symposium, held in September 2011, sought to inform civil society of the new policy guidelines and plans for implementation contained in re-engineering PHC, to comment on these, and to assert the centrality of a partnership between government and civil society if these plans were to be realised. The large number of government delegates attending this meeting was regarded as a promising sign of possible collaboration between the two sectors in formalising CHBC work.

Policy implementation guidelines were made available to provincial governments in 2011 (National Department of Health, 2011c) outlining that funding for employing 'community health workers' would no longer be made available to NPOs, since the state would employ all 'community health workers' in the future. NPOs would instead be funded to undertake social mobilisation and other community-level activities that would complement the work of the PHC outreach teams. The guidelines recommend collaborating with NPOs in order to improve their efficiency and to strengthen their interaction with formal facilities and sub-district managerial levels. A further area of collaboration mentioned is in the area of psychosocial support. The guidelines envisage that outreach teams would provide psychosocial support in collaboration with community caregivers supported by the Department of Social Development.

Uptake of these implementation guidelines is not compulsory, and the provincial Departments of Health have responded to the guidelines in different ways. At the time the research was concluded, the North West Province had created a provincial task team and had started to implement the guidelines systematically; others, including the Free State and KwaZulu-Natal, were starting partial implementation in different ways, while the Western Cape was undertaking to align existing programmes to national government guidelines. It is at this stage too early to comment on the implementation process and its implications for CHBC in the country, particularly for civil society organisations and their caregivers that offer overlapping services or other services falling outside the scope defined for state-employed PHC outreach teams.

### Current status of the HIV epidemic

South Africa has a generalised HIV epidemic, which has stabilised over the past few years. According to the most recent estimates from the Joint United Nations Programme on HIV/AIDS (UNAIDS), as of 2011 South Africa was home to an estimated 5,600,000 people living with HIV. That corresponded to adult HIV prevalence of about 17.3 percent (UNAIDS, 2012). South Africa currently ranks the third highest in the world in terms of TB burden, with an incidence that has increased by 400 percent over the past 15 years. There is a wide variation in HIV and TB prevalence across age, race, gender, socioeconomic status and geographical location (South African National AIDS Council, 2011).

## Scale-up of ART

The South African government was slow in making ART available to the population in the late 1990s and early 2000s. This occurred due to AIDS ‘denialism’ on the part of some leading policy makers (including a former president and national health minister) and concerns about the affordability of making this treatment available to all in need.<sup>7</sup> In the early 2000s, ART coverage was extremely low as antiretroviral drugs were not supplied within the state health sector. The country’s first public treatment site was a prevention of mother-to-child transmission (PMTCT) pilot started in 1999 by the Western Cape provincial government in collaboration with Médecins Sans Frontières (MSF) in Khayelitsha, part of the City of Cape Town.

Khayelitsha was also the place where, in 2001, the first clients received ART at a primary level in South Africa. Strong lobbying by civil society, especially the Treatment Action Campaign (TAC),<sup>8</sup> resulted in ART becoming more generally available, with the national HIV Treatment and Prevention Plan being approved in late 2003. ART became available in the public health system in 2004, starting in Gauteng, and by 2005 there was at least one service point for ART distribution in each of the country’s health districts. In 2006 a new five-year National Strategic Plan was adopted urging a multisectoral approach and stronger reliance on ART. Scale-up of ART gained momentum in 2009 with the national government’s announcement of new eligibility criteria for selected high-risk groups, making it possible to access ART in public health facilities with a CD4 count below 350 instead of below 200 as before. The government also announced a massive national counselling and testing (HCT) campaign that aimed to test 15 million people. The new eligibility criteria for receiving ART were extended to all HIV-positive people in 2011—thus complying with updated World Health Organization (WHO) ART guidelines—and the National Department of Health prepared many additional public ART facilities to deal with the scale-up in 2010 and 2011 (Pillay, 2012).

Table 1 and Figure 1 below provide an overview of ART coverage in South Africa since 2003.

**Table 1. ART coverage and enrolment figures for South Africa, 2003-2011**

Year	Total number on ART	Total number eligible for ART*	Total ART coverage**
2003	25,000	771,393	3%
2004	55,000	904,667	6%
2005	206,718	1,025,542	20%
2006	324,754	1,136,034	29%
2007	458,951	1,270,786	36%
2008	730,183	1,373,207	53%
2009	971,556	2,295,159	42%
2010	1,389,865	2,448,096	57%
2011	1,702,060	2,568,974	66%

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

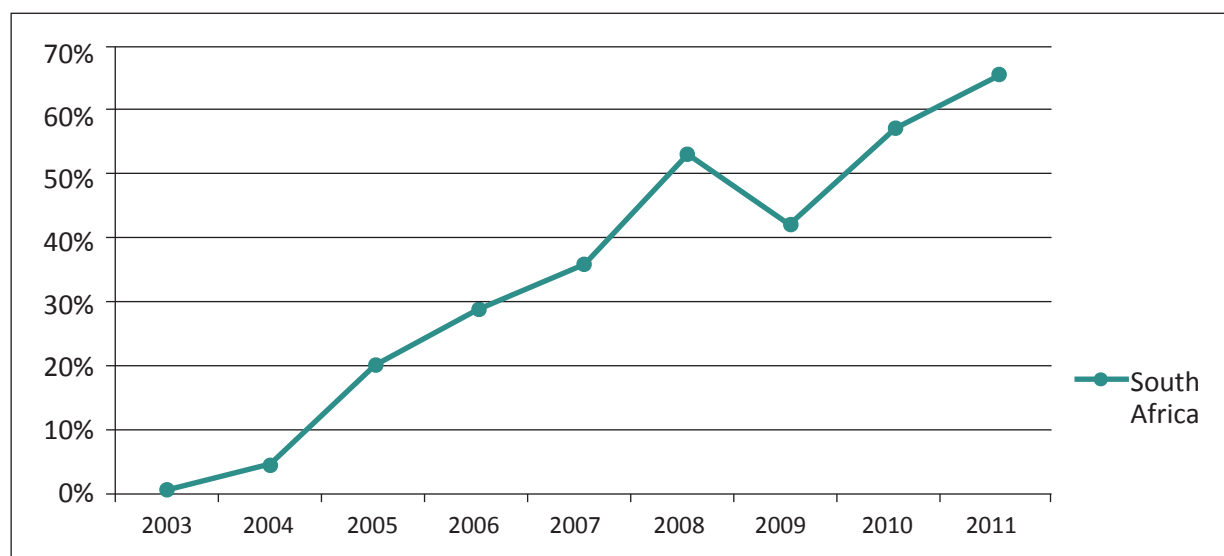
\*\* The percentages refer to the share of all eligible for ART who were receiving it.

Source: WHO/UNAIDS 2011 estimates

7 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.

8 South Africa has a long history of community participation and mobilisation organised through civil society structures. In the Western Cape organisations such as TAC and the Community Media Trust (CMT) play an important role in mobilising communities and raising awareness. TAC has its own support groups and an extensive organisational network of local offices through which advocacy work is done and advice dispensed, and where local people can go to lodge complaints or discuss issues. Advocates associated with TAC regularly engage in monitoring service delivery. Activist organisations tend to be based in urban areas, however, and rural communities tend to have few participatory or mobilising structures at their disposal.

**Figure 1. ART uptake for eligible South Africans, 2003-2011\***



\* The percentages refer to the share of all eligible for ART who were receiving it.  
Source: WHO/UNAIDS 2011 estimates

It is important to note that the decline in ART coverage between 2008 and 2009, as shown in both Table 1 and Figure 1, stemmed not from a reversal in ART scale-up but instead from a major revision in eligibility criteria. As noted in the Table 1 explanatory text, the data used prior to 2009 were based on eligibility criteria for a CD4 count of less than 200 while the data presented from 2009 onwards were based on eligibility criteria for a CD4 count of less than 350, as recommended by WHO in its most recent ART guidelines. The new criteria are based on growing evidence indicating that starting ART earlier in the course of HIV infection greatly reduces morbidity and mortality among people living with HIV and tuberculosis (a common co-infection among HIV-positive people, especially in sub-Saharan Africa) and reduces HIV and TB (tuberculosis) transmission.<sup>9</sup>

The data presented in Table 1 give a clear sense of the overall escalation of the HIV epidemic in South Africa and the impressive progress made by the national government in providing treatment. The data further give a sense of the magnitude of the shift that occurred in the availability of ART. This fundamentally underlies the shift in client needs and in the nature of CHBC work described elsewhere in this report.

<sup>9</sup> The South African government announced the change in eligibility criteria for selected vulnerable groups in December 2009 and for the general population in August 2011 (Pillay 2012). Using 2009 as the year when eligibility criteria changed makes the South African estimates comparable to the other countries, including the other three countries' covered by the multi-country research.

## 2 RESEARCH FINDINGS

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

### 2.1 HISTORY AND EVOLUTION OF COMMUNITY CARE AND SUPPORT

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

#### 2.1.1 The needs of people living with HIV

##### Historical context

The advent of HIV and the development of a full-scale epidemic in South Africa in the mid- to late 1990s intensified the scope and scale of health care needs of people living with the heritage of apartheid inequities. The epidemic had an adverse impact on the young democratic government's aims to replace the fragmented and unequal health system of apartheid with a functioning district health system implemented along the principles of comprehensive PHC services.

AIDS denialism during most of the years when Thabo Mbeki was president (from 1999 to 2008) meant that the needs of people living with HIV were gravely neglected. During that period, it was to a large measure left to a range of civil society organisations—including large NPOs, FBOs and local CBOs—to provide care and support to ill and dying clients within their home environment. Once ART became available in 1999, it was again left to organisations like MSF to meet clients' needs for HIV treatment. Activist organisations such as TAC started mobilising people living with HIV to demand that the state provide affordable access to treatment for themselves, their families and communities, as well as medicines to prevent mother-to-child transmission of HIV.

The systematic provision of ART in the public health system from 2004 onwards and the impressive scale-up following new treatment protocols announced in 2009 and 2011 (Pillay, 2012) have meant a gradual shift in the needs of most people living with HIV away from basic nursing care and other support when they were ill and often bedridden. Priority needs now include broader kinds of support such as access to treatment, especially when clinically eligible, and support for monitoring and managing comprehensive ART provision, including in regards to drugs' effectiveness and possible side effects.

##### Needs expressed by clients

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 particularly the need to receive drugs reliably. In the three case study organisations, clients also frequently described their dire socioeconomic needs, such as for food, adequate shelter and access to social security grants. Many frail or bedridden clients and their primary caregivers indicated that they would struggle to cope without the broad spectrum of support they are receiving from caregivers in the home. Such services include direct physical care (e.g., wound dressing), psychosocial support and support related to poverty alleviation. Primary caregivers looking after family members or friends further indicated a need for assistance with applications for disability and child support grants.

Moreover, the research found a need for better information about healthy living and better financial and geographic access to health services, especially in rural areas. With regards to physical disability, client observations underscored the need for rehabilitation, which is at present not adequately available. It was also evident that clients who were virtually housebound valued the social contact with a visiting caregiver and those who lived alone requested favours, such as small purchases of groceries. On the

whole, there seemed to be a need for client empowerment. Most clients were grateful for receiving services from community caregivers, but few thought they could ask for more or better care and support.

Many client respondents also said their ability to access care would improve if HIV-related stigma were reduced. This remains a pervasive problem in South African communities, especially in rural areas. While client needs were found to be fairly strongly represented by activist organisations in urban areas (as for instance by TAC in Khayelitsha), community mobilisation around human rights in rural areas was less vibrant and clients in rural areas frequently did not have organisational or political support for their needs. Many rural clients and/or primary caregivers approached by the researchers expressed feelings of social isolation and demoralisation due in large part to HIV-related stigma and seemed unaware of their own or their family members' rights. Similarly, clients of 'lay counsellors' working in facilities expressed a need to be treated with respect and for confidentiality to be ensured.

### **Client needs as viewed by government officials**

Government officials interviewed did not comment much on client needs apart from referring fairly generally to the country's heavy burden of disease, comprising mainly infectious but also non-communicable diseases. They spoke mainly in abstract terms about client needs and commented largely from the perspective of the structures, programmes and services put in place to meet them. Government respondents identified prevention and promotion activities for the general public as well as for high-risk populations as a specific area of need. Other areas mentioned included i) knowledge and understanding of HIV testing (including pre- and post-counselling and the actual testing process); ii) treatment readiness; iii) the existence of adherence support and other support groups and clubs; iv) accessing social security grants; and v) addressing psychosocial needs of OVC and their families.

Other health-related needs highlighted by government respondents were TB-related (such as the need for integrated programmes in HIV and TB treatment support for co-infected individuals); needs pertaining to maternal and child health (such as mother-to-child transmission of HIV); and needs of the bedridden, terminally ill and elderly, most of whom require basic care and support in the home, such as washing, feeding and wound dressing.

### **Client needs as viewed by respondents from large care and support focused organisations**

These respondents emphasised the need for the full range of care, support, prevention, treatment and impact mitigation interventions. Several informants noted health-related needs beyond HIV, particularly related to other chronic illnesses such as diabetes and hypertension. They stressed the importance of identifying needs at a community level—for instance through community dialogues and close contact with small CBOs. An emphasis on a need for public health and treatment literacy education was noteworthy among some representatives from the organisations questioned in the first phase of the research.

## **2.1.2 Caregivers' roles**

### **Changes in roles ascribed to caregivers**

Caregivers' roles in South Africa have shifted from generalist to specialist in response to the contours of the HIV epidemic as well as to the ways in which funding has prioritised the pandemic over other illnesses. Before the advent of HIV, caregivers tended to focus broadly on individuals experiencing health conditions related to poverty and social inequality—such as TB, diarrhoea in children and malnutrition—and health conditions often related to migrant lifestyles, such as sexually transmitted infections (STIs). As the HIV epidemic worsened, caregivers' roles started to shift more toward providing basic care and other means of support required by clients and their families within the home environment. Once ART became available, a diversification and specialisation of roles occurred in the areas of testing, counselling and adherence monitoring to medication, as well as in psychosocial care and support for OVC as the social impact of HIV on families and communities became evident. Present policy moves are towards a more 'generalist community health worker', but specialist categories and vertical interventions remain prominent in CHBC programmes.

In two of the three case study organisations, caregivers' roles were still separated to a large extent, with caregivers providing either distinct care and support within the home environment, or adherence support, or OVC support, or HIV counselling, and so forth—but rarely providing more than one such specialized service. In one of the organisations there was a drive towards integration of roles, with caregivers performing a mixture of basic care for bedridden clients, adherence support, promoting and supporting income-generating activities, chronic care and post-partum care. In that organisation, the emphasis has also broadened over time to include conditions other than HIV. In all the organisations, caregivers fulfil health promotion roles at times, for instance taking part in door-to-door campaigns initiated mainly by the national or provincial government. Respondents from several of the large care organisations interviewed in the first phase of the research stipulated that they see an increasing need to offer training curricula that can, in particular, increase the biomedical knowledge of community caregivers, both in HIV medicine but also in other illnesses. The objective aims to enable them to play a substantial role themselves in general health education and early detection and disease surveillance.

Respondents working at community level expressed various challenges in the work they are doing. 'Lay counsellors' and 'home-based carers' expressed concern about members of the community testing very late for HIV and TB, as well as for chronic conditions like diabetes and hypertension. As a result, community members often arrive at health care facilities when they are already seriously ill. Counsellors and other caregivers talked of a (sometimes overwhelming) range of physical and psychosocial needs presented to them on a daily basis by clients. They also spoke of having to deal with a range of social circumstances that affected treatment adherence, such as substance abuse and difficulties with disclosure of HIV status. 'Lay counsellors' also particularly mentioned the emphasis on meeting clinic targets, which made them feel squeezed for time to provide adequate and thorough psychosocial counselling. Supervisors of caregivers expressed concern that the increasing expectation of caregivers to perform more and more tasks was undermining their ability to address time-consuming physical and psychosocial needs such as providing basic physical care to seriously ill clients or emotional/spiritual counselling to people suffering through illness and poverty. They expressed the same concern about an increase in tasks with a narrow biomedical focus.

### Caregivers' roles under the new PHC model

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 test and supporting their uptake of and adherence to treatment. The generalist 'community health workers' will be part of a ward-based outreach team and will be directly employed by the National Department of Health. Informants saw this as involving expansion of service provision beyond the previous vertical focus on HIV, as already occurs in some NPOs, and placing considerable emphasis on early detection of illness and surveillance.

Respondents expressed a lack of clarity regarding the place of basic home-based care for bedridden clients in relation to the new generalist state-supported 'community health worker'. An informant from the National Department of Health noted that such care remains important as generalist 'community health workers' should be able to refer clients to NPO-managed 'home-based carers'. Likewise, civil society respondents argued that basic care provision for clients in their home environment should remain integral to the scope of practice of a generalist 'community health worker'. This is seen in practice in the early implementation of the outreach model in KwaZulu-Natal, where the two roles are combined in contradiction to the nationally proposed model. National task teams are currently working to delineate the scope of practice for 'community health workers', who will form the PHC outreach team, as well as to develop training for this new cadre of 'community health workers'.

Different viewpoints also emerged as to the future role and location of 'HIV counsellors'. Government respondents from the Western Cape in particular argued that in urban areas counsellors should remain in facilities, liaising closely with treatment supporters deployed in communities. In rural areas these roles could be fused.

Despite government informants' good knowledge of the move in policy guidelines towards integrating roles into more generalised categories of 'community health workers', government respondents tended to refer to 'specialist' categories of caregivers, usually dominated by the specialist roles currently performed around the infectious diseases of TB and HIV, such as 'lay counsellors' and 'adherence monitors'. They also focused mostly on biomedical and physical care roles. Only the official from a provincial Department of Social Development integrated biomedical and psychosocial care and support roles in one category of caregiver, while Department of Health officials saw these as separate orientations that should be linked through referral from one department to the other. The 2011 implementation guidelines state that outreach teams should provide psychosocial care and support in collaboration with community caregivers supported by the Department of Social Development (National Department of Health, 2011c). On the whole, research respondents did not refer to such collaboration; nor did they elaborate on referral mechanisms that could be put in place to ensure that clients continue to receive psychosocial care and support.

## 2.1.3 Service provision

### Historical context

South Africa has a long history of service delivery to poor communities through civil society organisations that mostly responded to health conditions related to poverty and the apartheid government's neglect of services to black people. Many of these organisations were politically progressive and/or had religious ties. Although the post-1994 democratic government has tried to reach impoverished communities through its district health system and PHC approach, a backlog in services, sometimes contradictory leadership, and a lack of resources (in some significant cases, a result of poor or mismanagement) has meant that civil society organisations have continued to deliver services in South Africa.

The advent of HIV increased the pressure on the National Department of Health for the delivery of services and further stimulated the growth of civil society health provision. This was heightened in the late 1990s and early 2000s by the government's AIDS denialist stance, which resulted in the rise of strong advocacy and mobilising organisations like TAC while also effectively placing the burden of much of the HIV-related service delivery on civil society organisations. Once the government started taking responsibility for ART from 2004 onwards, civil society continued to play a role, and a powerful, not always easy, synergy between the state and civil society came into being in South Africa.

### Structures and modes of service provision

The structures and modes of service provision in CHBC work are diverse and vary across provinces and organisations. Since implementation of the new policy is still in progress, services are still to a large extent delivered by health-related NPOs that enrol, supervise, manage and pay their own caregivers. The state provides funding, policy guidelines and resources, as well as some skills-development and capacity support through arranging training opportunities. Government structures are also responsible for coordinating the monitoring and evaluation (M&E) of service delivery, as well as for ensuring that protocols are adhered to and targets are met.

Services are delivered at state clinics, in clients' homes and in communities. As mentioned before, two government agencies are involved in funding and supporting community care work in NPOs, namely the Department of Health and Department of Social Development. Community caregivers deployed by NPOs 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.<sup>10</sup> Some organisations fund and support community caregivers through resources received from donors. Work independent of government is undertaken by organisations such as TAC. That organisation employs community-based workers called 'treatment literacy and patient advocates' who do health education, predominantly around HIV and TB, in state health facilities.

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<sup>10</sup> As noted under the section highlighting the limitations of this research, limited reference is made to caregivers employed by the Department of Social Development. This is due to the fact that given the vastness and complexity of the environment in the health sector that the research team was attempting to cover, the scope of the project did not allow the inclusion of organisations and cadres of community caregivers supported by the Department of Social Development.

NPOs supported by the Department of Health usually respond to tenders to provide services covering particular geographical locations. These can be large national NPOs or medium-sized or smaller FBOs or local CBOs. Some large national NPOs also channel funding to smaller CBOs or assist them with capacity-building and setting up M&E systems in order for them to be eligible to apply for and retain Department of Health funding for community-level service provision. NPOs under the governance of the national and provincial Departments of Social Development tend to have poorer resources than those operating under the governance of the Departments of Health. While not much information was gathered from the national and provincial Departments of Social Development themselves, there is clearly still a lack of integration with respect to community-based services offered by these two government departments.

The following services were mentioned by most government informants from the national and provincial Departments of Health as among those that are currently provided by CHBC personnel:

- HIV services: testing (on-site at clinics and through community-based outreach campaigns), pre- and post-test counselling, ART adherence monitoring and support, support for retention in care and treatment, PMTCT, prevention and promotion in high transmission areas, peer education training, support groups
- TB services: support for DOTS, defaulter tracing, integrated HIV/TB adherence support, prevention and promotion services
- Family planning services
- Other key caring services including physical, health, psychosocial, material and spiritual care and support services relating to HIV and TB as well as other conditions.

Care and support services provided in relation to OVC, as highlighted by a respondent from a provincial Department of Social Development, included: services provided at drop-in centres (such as food provision and educational support for OVC); home visits; providing assistance to OVC to obtain identity documents and social grants; helping OVC and their caretakers develop income-generating activities and food security gardens; and supporting health promotion initiatives in schools.

The three case study organisations observed for this research described delivering services in different ways from one another. The organisation operating in the Free State 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. The organisation working in a peri-urban/rural setting within the Western Cape delivered holistic services including all of the above, apart from OVC services, while 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 NPOs) was an important service in all the organisations observed.

The Phase 4 research collected additional survey data on services provided by 16 care and support focused organisations through community caregivers. The sample included medium-sized NPOs in five provinces. These provided services in both rural and urban locations, and included staff working under various employment conditions. Table 2 below summarises the geographic coverage of staff in the NPOs surveyed. The mean period of operation of the NPOs was approximately 18 years, which indicates that they were all well-established and had offered services at various stages of the HIV epidemic and through degrees of treatment availability.

**Table 2. Operational coverage of organisations providing CHBC services included in the research sample**

Operational coverage	Number of organisations per area
Urban	4
Rural	8
Both urban and rural	4

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

Table 3 below summarises the range of services provided by these organisations, as well as the extent to which organisations drew on primary caregivers to address the needs of family members and friends.

**Table 3. Services provided by surveyed care and support organisations<sup>+</sup> using paid and unpaid community caregivers**

Type of services provided	Number and % of organisations using paid secondary caregivers*		Number and % of organisations using unpaid primary caregivers**	
	Number	%	Number	%
<b>Direct care and support to clients</b>				
Basic nursing care: <i>for people living with HIV</i>	12	75	10	63
Basic nursing care: <i>elderly care</i>	10	63	8	50
Basic nursing care: <i>malaria</i>	1	6	1	6
Basic nursing care: <i>other diseases</i>	11	69	6	38
Clinical care (e.g., taking blood pressure, weighing people) in organisation's own facility	10	63	0	0
End-of-life care	10	63	4	25
Pain relief	7	44	0	0
Personal hygiene	11	69	8	50
In home/community: <i>pre- ART patient counselling</i>	12	75	0	0
In home/community: <i>ART adherence support</i>	15	94	1	6
In home/community: <i>recruitment of patients for VCT services</i>	14	88	0	0
In home/community: <i>recruitment of patients for ART services</i>	12	75	0	0
In home/community: <i>recruitment of pregnant women for PMTCT services</i>	14	88	0	0
In home/community: <i>HIV pre-test information</i>	6	38	0	0
In home/community: <i>HIV testing</i>	6	38	0	0
In home/community: <i>HIV post-test counselling</i>	6	38	0	0
Health education : <i>HIV</i>	16	100	0	0
Health education: <i>malaria</i>	1	6	0	0
Health education: <i>other diseases, e.g., TB and STIs</i>	12	75	0	0
Social support (e.g., shelter, clothing, assisting with accessing IDs or birth certificates, social workers, etc)	14	88	0	0
Livelihood support (e.g., income-generating activities, savings groups)	6	38	0	0
Legal support	4	25	0	0
Nutritional support/referral for nutritional support	14	88	0	0
Spiritual and/or emotional support	14	88	0	0
OVC care	12	75	0	0
Referral of clients to clinical services (clinics, hospitals)	15	94	0	0
Organise or provide transport for health facility visits	10	63	0	0
Educating members of the client's household	15	94	0	0
<b>Assistance to service provision in local health facility</b>				
Assistance in local health facility: <i>pre-ART counselling</i>	4	25	0	0
Assistance in local health facility: <i>HIV pre-test information</i>	3	19	0	0
Assistance in local health facility: <i>HIV testing</i>	3	19	0	0
Assistance in local health facility: <i>HIV post-test counselling</i>	3	19	0	0
Assistance in local health facility: <i>administrative tasks</i>	3	19	0	0
Assistance in local health facility: <i>other</i>	3	19	0	0
<b>Specific types of support / activities</b>				
Specific support for women: <i>women and child protection and SRHR interventions</i>	7	44	0	0
Specific support for women: <i>empowerment and self-reliance interventions</i>	1	6	0	0
Lobbying and advocacy activities	5	31	0	0

+ Based on 16 organisations surveyed overall

++ SRHR = sexual and reproductive health and rights

\* Refers to secondary caregivers who work in communities or as staff at clinics, for NPOs or for the government.

\*\* Refers to family and friends who provide immediate care to family members and/or loved ones.

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

The findings in the table above indicate that most organisations were engaged in a wide range of direct care and support activities, including basic HIV and other physical care, as well as social, emotional, spiritual and nutritional support, mainly through making use of stipended community caregivers. Apart from basic physical and hygiene care, few organisations delivered services through structured use of primary caregivers. Moreover, all of the organisations included in the sample were engaged in health education and most also offered care and support services to people not living with HIV. This observation is supported by data presented in Table 4, which show that (in 2012) almost 45 percent of clients receiving care and support from the 16 care organisations surveyed did not have HIV.

**Table 4. Mean number (per organisation) of clients with and without HIV receiving care and support from organisations surveyed in 2012\***

	Mean
Living with HIV	905.8
Not living with HIV	700.87

\* Based on 16 organisations surveyed overall  
 Source: CAN multi-country research - South Africa research, 2011-2012

## Future outlook

The status of current programmes, mainly delivered by a multitude of NPOs in the country, is in flux. Likewise, the future roles of NPOs are also unclear and many CHBC organisations have adjusted by changing focus and priorities. Respondents from large NPOs spoke of developing a future role for themselves by expanding the services that they provide with respect to the training of community caregivers and the refining of M&E systems.

## 2.1.4 Policy environment

### Historical context

Policy developed and implemented at the time of the 1994 transition to democracy in South Africa focused on forging one health system from the fragmented and unequal services left behind by almost 50 years of apartheid governance. Unlike other African, South American and Asian governments, however, the South African government did not implement a systematic community caregiver programme through either the district health system or the PHC approach adopted.

As a result, the place of community caregivers in the national health system remained undefined in the 1990s and early 2000s. Civil society organisations were largely instrumental in providing access to health care to impoverished communities through deploying community caregivers as volunteers or as lay workers on small stipends, especially as the HIV epidemic gained momentum and the government continued to deny the scale and impact of the epidemic and the need for care, support and treatment of those affected. As mentioned before, the government’s main contribution at this stage was to create enabling environments for civil society organisations, after which it partnered with civil society in the organisation of community care work by providing training and capacity-building opportunities as well as funding for selected programmes. This approach has led to the development of an extremely variable sector of community care and support provision in South Africa.

The overwhelming health needs—including beyond HIV—of a large section of the uninsured South African population have prompted the National Department of Health’s policy guidelines to re-engineer PHC, partly through ward-based outreach teams that will map client needs at a population level, identify individuals and families at risk in the community, and link them to the appropriate level of treatment, care and support through referral systems. The research found an awareness among government officials of the quadruple disease burden,<sup>11</sup> and especially the increasing need for health and social care responses to morbidity (and indeed disability) associated with non-communicable diseases. The need of a large sector of the population for access to health care that is affordable is currently being examined

11 The quadruple burden includes communicable, non-communicable, perinatal and maternal, and injury-related disorders.

in the proposals for national health insurance. This reflects the government's determination to address the historical inequities that exist in the country in terms of the overall distribution of health resources across the population and between the private and public health sectors.

The policy environment around community care work is particularly vibrant at present. A number of symposia and policy documents reveal consensus between the state and civil society about the need for a 'national community caregiver programme' in South Africa. However, implementation of policy guidelines has started while many details still have to be worked out. This has raised anxiety and concern about various aspects of service delivery, as well as the roles of different kinds of 'caregivers'. Among respondents based at the three case study organisations, knowledge of the new policy guidelines on community care work was poor and often confusing, as will be discussed in more detail in the next sub-section.

## 2.2 HEALTH SYSTEM INTEGRATION

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

### 2.2.1 Primary health care structures

The new government policy guidelines presuppose a high level of formal integration of community care work into the state health system. The idea of outreach teams mapping health at a population level and referring at-risk individuals and households to formal health services suggests that the concept of PHC adopted in policy guidelines is a fairly specific interpretation of PHC that focuses on specific public health functions.

#### Knowledge of the new PHC model

On the whole, the research showed that government officials<sup>12</sup> are well-informed about the re-engineering plans. However, there is still a large measure of uncertainty about aspects of the process, predominantly about the continued role of NPOs—e.g., what they will be expected to do and whether they will continue to receive funding for care and support services presently provided. Government officials tended to view traditional home-based care for bedridden clients as the main role envisaged for NPOs, while the capacity-building engagement of large care organisations was also mentioned as an important activity that should continue. National government informants emphasised that the role of supervising and monitoring the work of 'community health workers' in outreach teams should be transferred to state-employed professional nurses.

Representatives of the large care organisations interviewed were also knowledgeable about the new policy guidelines and expressed some anxiety and uncertainty about their future roles and services provided such as daily home-based care and household support for long-term bedridden clients, time-consuming adherence support and dedicated psychosocial care. Knowledge of the new policy guidelines, however, varied among respondents from the three case study organisations. There was a sense—for example, among those at the Western Cape peri-urban/rural organisation—that the government would employ all community caregivers in the future (and great excitement about the perceived prospect of higher pay for caregivers). However, there was no knowledge of the government's new policy guidelines among respondents at the Free State organisation, which is threatened by closure as a result of possible cessation of funding in 2013. The concept of 'community health workers' being deployed in ward-based outreach teams and supervised by state nurses as envisaged in new government policy guidelines is not widely known among NPOs at present, apart from among the leadership of large care organisations involved directly in the dialogues about the new plans. There is no indication of how the rich experience of civil society organisations or the long tradition of CHBC provided by community caregivers will fit into the government's conception of PHC structures.

<sup>12</sup> All key government informants from the health departments interviewed as part of this research—but notably not the informant from the National Department of Social Development—referred to the process of re-engineering PHC.

Consistent with its choice not to implement national policy but to align its CHBC programmes, the Western Cape Department of Health has explicitly stated that in urban areas with high HIV prevalence, integrated HIV and TB adherence support would be developed as a targeted intervention for specialist (rather than generalist) care providers.

### Expectations and concerns

Some caregivers see the new government policy as an opportunity to gain the same employment benefits as the health professionals operating alongside them in state facilities. ‘Lay counsellors’ questioned at the case study organisation operating in the urban Western Cape setting expressed quite vociferous discontent at what they perceived as slow progress toward integration, which they said is necessary to shake off some of the stigma of their ‘lay’ status. The ‘lay counsellors’ did, however, state their appreciation for the fortnightly supervision sessions that they received from a psychologist through the NPO. On balance they sought a future situation where they had the benefits of higher salaries and state benefits, but the support as currently received from the NPO. This group of counsellors also expressed a sense of powerlessness to voice their opinion about proposed changes and a desire to be incorporated into some form of employment union.

Besides the expectations and concerns mentioned above, research respondents—in particular representatives of care and support focused organisations and caregivers—raised a number of additional concerns in relation to the formal integration of community care work into the state health system:

- The re-engineered PHC guidelines do not respond to the needs that clients expressed for more direct and individualised physical and psychosocial care. Likewise, home-based care and general psychosocial support and counselling are not identified as part of the new dispensation in any amount of detail, and if taken on board these services could be interrupted if the transition from organisation-based to team-based services is not managed seamlessly. Mental health problems are also not high on the agenda in discussions of the burden of disease, despite the likelihood that mental disorders, including substance abuse, are implicated in difficulties in adhering to treatment and behavioural change programmes.
- As the PHC outreach model is launched, it is uncertain whether NPOs will continue to receive funding for care and support services provided. It is expected that generalist ‘community health workers’ will not be able to sustain specialist and often time-consuming roles such as caring for long-term bedridden or terminally ill clients. Moreover, it will take time for team-based ‘community health workers’ to develop the full range of skills to deliver a suite of services comprising health surveillance, identification of a wide range of risks and referral systems. These developments could imply that specific sets of services would for the time being have to be offered by a separate cadre of caregivers based in NPOs (i.e., they would not become state employees).
- The state-provided outreach services will need to be acceptable to the community. These services will inevitably be different from those provided by an NPO, with issues of accountability and perceptions of being responsive to local needs being factors. If services that individual clients and their families want—such as psychosocial, curative and other services provided within the home environment—are no longer provided, or are provided in a different form and by government-employed health workers, these services may be less accepted in communities or population-based surveillance services may be seen as intrusive.

Annex 4 contains a more extensive list of challenges and concerns expressed by different stakeholders with regard to community care work, in particular in relation to HIV prevention, treatment, care and support and the new PHC model.

## 2.2.2 Decentralisation of HIV treatment

The potential for decentralisation of HIV treatment undoubtedly exists, and in some places it has been a reality for many years. As stated before, with the advent of ART, community caregivers started playing important roles in connecting clients to treatment sites and monitoring adherence and side effects to ART as well as doing surveillance for TB and other opportunistic infections. Results from the validation phase of this research (Phase 4) show that a majority of the 16 care organisations surveyed already

offer services through community caregivers who are not health professionals, such as: recruitment of women for PMTCT services (14 organisations); health monitoring of clients to check whether they need to visit health facilities for check-ups (12 organisations); and provision of pre-ART care and counselling (12 organisations). Several organisations stated that direct ART provision was a service they would like to offer.

The case study organisations on which this research focused have already succeeded in developing decentralised HIV treatment centres. The FBO in the Free State runs its own ART dispensing programme in a peri-urban/semi-rural community. Community members expressed their appreciation for this service, saying that it offers treatment in a less stigmatised environment than the government clinics and district hospital in the region. To be successful, however, representatives of the organisation noted that community caregivers require supervision and ongoing training, as they may lack independent initiative in referring new clients to the ART programme or spotting non-adherence and other issues that may undermine clients' health or treatment. Caregivers in the peri-urban/rural Western Cape case study organisation reported that their clients living with HIV frequently expressed their preference for community-based settings (outside government clinics) for drug distribution and adherence monitoring. While treatment clubs for diabetes and hypertension are already being run in the organisation in conjunction with the pharmacy at the local clinic (with drug distribution and basic monitoring being done by the nurse coordinator and the community caregivers from the NPO facilities), ART provision for the community was still being managed from the district hospital in the region. The challenge is whether ART provision will also eventually occur in decentralized ways in this sub-district.

The developments highlighted above are positive in light of the 'Treatment 2.0' framework developed by WHO and UNAIDS and the envisaged role for communities in the strategy.<sup>13</sup> The considerable and valuable experience of a number of NPOs and their staff in ART roll-out could serve this initiative well, along with the fact that several care and support organisations expressed an interest in expanding their services to also include direct ART provision. Their ability to offer such a service would, however, depend on caregivers' receiving the required support, including supervision and training.

There continues to be much innovative thinking regarding the decentralisation of treatment through treatment clubs and home-based treatment support in Khayelitsha, where South Africa's first public treatment site was located. Much of this initiative has been spearheaded from the clinic that used to be run by MSF and which still has a strong link with the organisation. The integration of HIV and TB treatment support is currently being implemented in a community-based model, which may also serve as a template for other chronic diseases. Treatment clubs have been set up in several clinics so that clients on ART are able to collect medication less frequently and do not have to wait in long lines at pharmacies. In addition, one of the clinics is also piloting community distribution units, which are like clubs but take place in public spaces such as libraries. In addition, there are plans to also run treatment clubs from clients' homes.

Decentralised services are more likely to be effective in environments with strong infrastructure and supervised settings. The model being pioneered by MSF in rural Mozambique (Médecins Sans Frontières, 2012) is worth noting for comparable settings in South Africa. This model draws on the notion of 'expert patients' supporting each other in groups in rural areas, with a rotating treatment collector who travels to the clinic.

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

## 2.3 CAREGIVERS' POTENTIAL

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

### 2.3.1 HIV prevention and treatment programmes

A multitude of organisations have shown that CHBC programmes can play a significant role in HIV prevention and treatment in South Africa, as the task of providing such services initially fell on the shoulders of NPOs. Additionally, civil society organisations with a strong advocacy focus have played an important role in shaping an ideology that promotes a paradigm of care and support based on motivating clients to take primary responsibility for adherence and lifestyle change.

Community caregivers have also engaged with and have the potential to support health promotion programmes (including health promotion and condom distribution programmes), counselling and testing, connecting clients to treatment sites, monitoring adherence to ART, surveillance for TB and other opportunistic infections, monitoring side effects of ART, client advocacy, stigma mitigation and community mobilisation—all of which contribute to prevention of HIV or increased uptake of treatment. Given their engagement to date, the expertise and experience of existing CHBC programmes with regard to HIV prevention and treatment offer excellent opportunities for integration into and collaboration with the new PHC outreach teams. In this respect, the government's provincial implementation guidelines (National Department of Health, 2011c) describe possible areas of collaboration and capacity-building.

### 2.3.2 Primary health care programmes

Because of the nature and scale of the HIV epidemic and the way funding has been targeted, many CHBC organisations in South Africa have developed a specialist focus on HIV. Nonetheless, there are also many generalist organisations with experience in providing services for chronic conditions and maternal and child health (for instance, the peri-urban/rural Western Cape organisation selected for this research). These tend more to an integrated horizontal PHC model than a vertical programme focusing on HIV.

The care and support organisations observed 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. These organisations could, for example, offer services covering a wider range of infectious diseases, maternal and child health, and non-communicable diseases (which reflect the disease burden in South Africa, where conditions like hypertension and diabetes are regarded as epidemics alongside HIV). The same may not apply to the outreach teams envisaged in the new policy guidelines, which are an integral part of the PHC programme. Their focus on community profiling, health promotion and referral at a population level may imply that they will not be able to engage to the same extent in direct care, support and treatment, all of which NPOs have been offering.

## 2.4 COMPLEMENTARITY BETWEEN FORMAL AND INFORMAL COMMUNITY CAREGIVERS

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

### 2.4.1 Recognition and acceptance

The terms 'formal' and 'informal' are loosely used, as highlighted below in this section. At the time research was conducted for this report there were not many community caregiver programmes in South Africa that could be strictly described as 'formal' in the sense that they are part of the formal state-funded health system (there are for example cadres of DOTS supporters based at public health facilities). Given the long history of deployment of community caregivers through NPOs, however, they have tended to form a kind of parallel system through the long-standing, well-established and often essential services

provided to the communities they serve. These are not ‘informal’ per se, though they are provisionally resourced and not part of the central system, and in this sense could be called ‘informal’.

Many NPOs do have strong and constructive links with provincial governments, especially at a district and sub-district level. Government officials interviewed for this research valued the work of the NPOs and regarded their contributions to community-based care as vital. However, they could not be clear about future funding arrangements for these organisations once the new policy guidelines on revitalising PHC were implemented, although all of them wanted the NPOs to continue with their work.

Many NPOs also have strong links with formal health facilities, especially with local PHC clinics in their districts. While in some cases the contribution of community caregivers was highly valued, accepted and recognised by staff at these clinics, the quality of these relationships seemed to depend on particular individuals in the health system and on the links formed between individual formal and informal workers, and not on a clearly defined set of structural arrangements that could be properly monitored. Many community caregivers interviewed for the research felt that formal health facility staff looked down on them, did not accept their referrals of clients, and did not value their contributions to the health of the community. Some staff members from formal facilities complained about the attitudes and behaviour of community caregivers, saying that they were not professional enough in their conduct.

The limited degree of complementarity between the formal and informal services is one of the problem areas that the National Department of Health identified and aimed to address through its new policy guidelines. The new arrangements proposed and already being implemented in effect ‘formalise’ the work of ‘community health workers’ by integrating their work into the services provided by formal health facilities in communities. Mechanisms to ensure that programmes provided by NPOs complement the work of ‘community health workers’ in the PHC outreach teams are as yet not clear or in place, but respondents felt that it would be necessary to define, strengthen and regulate the relationships between formal and informal care workers, whether they were to be based at formal system facilities or in NPOs. Addressing the relationship at this interface will be central to the successful implementation of the envisaged PHC outreach teams. There is a danger that the inclusion (and recognition) of some ‘caregivers’ into the formal system could have the unintended consequence of developing a tiered system comprising those ‘in the formal system’ and those who are not. The question is how to ensure that the work of those who may continue to be employed by NPOs—who already are and presumably would be providing care as part of the ‘informal’ system—is properly recognised.

## 2.4.2 Coordination

### Linkages

NPOs providing community care are generally linked to the PHC directorate at a district or sub-district level, given the services they are contracted to deliver (refer to Annex 5 for organograms on the arrangement of community care work in the Free State and Western Cape). The type of linkages built and degrees of integration may vary widely among NPOs. Some have strong links with state, provincial, district and sub-district community-based services as well as local PHC clinics (e.g., in the Western Cape cases observed). Others are more autonomous, e.g., in the Free State case observed, although other organisations in the Free State link more closely with government structures at a provincial and district level. As noted elsewhere, guidelines are being interpreted and implemented differently across the nine provinces, and it is too early to assess the extent to which outreach teams may fulfil the ideal version of integration into PHC structures envisaged by policy.<sup>14</sup>

The autonomous interpretations of the national policy guidelines by the provincial health departments are resulting in a wide range of management structures. The community health worker audit of 2010–2011 revealed that the majority of health-related NPOs (1,260, involving stipends for 40,767 caregivers) were funded by the National Department of Health from a variety of sources, and by donor agencies such as the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR) and the European Union (Department of Health, 2011a).

<sup>14</sup> Conflicting opinions were expressed in the key informant interviews about the supposed early effects of the incorporation of ‘community health workers’ into state structures in provinces such as KwaZulu-Natal and the North West.

Partly because of this variability in funding structures, the management structures of community care provision were found to be located within a network of interrelationships among national and provincial government agencies, district teams, donors, NPOs and other stakeholders. The Department of Health was not directly managing community caregivers at the time of the research, but rather providing mechanisms for this to take place.

The complexity of management structures also had an impact on reporting structures. The process of re-engineering PHC has brought about further complication to structures. At times, provincial officials felt that they had been left out of important planning and implementation processes already taking place at a district level.

## Intersectoral collaboration

One of the cornerstones of PHC is intersectoral collaboration. Progress still needs to be made in this area as little evidence of collaboration was found in the interviews conducted for this research. The 2009 policy framework called for large-scale collaboration between the National Department of Health and the National Department of Social Development in their arrangement of community care provision, but research respondents did not in general emphasise the need for collaboration. In the Free State it was found that officials from these departments collaborated in a limited way, checking funding arrangements to organisations in order to avoid overlap. There was also some evidence of collaboration on the ground in the Western Cape, with quarterly meetings and particular areas targeted for collaborative effort (e.g., early childhood development, home-based care for bedridden clients, intellectual disability and care of the elderly). In the peri-urban/rural Western Cape district selected for this study, the Provincial Department of Social Development played a role in some of the Provincial Department of Health's promotion and prevention campaigns.

The general lack of intersectoral collaboration in community care work was affirmed by findings from informants representing the 16 care organisations included in the validation phase of the research. Representatives from 13 organisations (81 percent) said they had experienced no intersectoral collaboration in community care work, while two collaborated with the health sector and one with the agricultural sector. Moreover, 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 with 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).

## Community participation

Formal community participation structures arranged at the level of government were found to be limited in the areas observed, especially in rural areas.<sup>15</sup> Local clinic councils, AIDS councils and ward councillors were all mentioned as potential participatory structures in communities, but these were regarded as functioning poorly or not at all as they often lacked the knowledge and skills to support strong community participation, were uninterested in health issues and/or were dysfunctional. It often remained for civil society to provide or enliven these structures. This was, however, not the case in the urban case study (in the Western Cape), where a health forum was seen to play an important role. Respondents from this case study organisation as well as other local stakeholders in civil society and government mentioned regular meetings and joint planning, for example for health promotion efforts and campaigns.

<sup>15</sup> An important point with regards to community participation is that although community caregivers mostly live in the communities where they work, they are generally not selected by communities and therefore are not necessarily seen as representing them in health issues. Many NPOs do have boards elected by the communities they serve, however, which offers some opportunity for community participation. One of the large care organisations surveyed for Phase 1 of this research encouraged smaller CBOs to initiate community dialogues to discuss health-related issues with community members, local politicians and traditional authorities. Some organisations are also involved in community development programmes, for instance income-generating projects, poverty alleviation through distribution of food and clothing, and cultural projects (especially for children). Such initiatives usually depend on the motivation and resources of individuals or small interest groups, and therefore do not necessarily ensure wide-ranging or consistent levels of community participation or mobilisation.

## Deployment and supervision of community caregivers

In both provinces observed, community caregivers were generally recruited, selected, supervised and paid by NPOs themselves, which had reporting obligations towards the provincial health department at a district level. While all community caregivers in the organisations selected for this research received stipends, that is not necessarily the case in all organisations. Government officials explained that organisations only received funding for stipends if they had been awarded a tender from the relevant provincial Department of Health or Department of Social Development or through donor funding. Many small CBOs did not have the capacity to respond to tenders or apply for external funding.

Despite the links with the public sector, research indicates that the majority of community caregivers are deployed not from formal health facilities but from NPO premises. They perform most of their work in clients' homes or while walking in the community. While some organisations employ nurses or retired nurses as supervisors, many of the small organisations have a flat structure or non-professional managers. In the Free State case study organisation, the Roman Catholic Church plays an important managerial role, yet professional nurses supervise HIV testing and counselling, the ART dispensing clinic and adherence programmes. An informant from the provincial government's community-based services (CBS) programme in the Western Cape mentioned that professional nurses working for facilities or NPOs do not necessarily have the time to supervise community caregivers, and that non-professional supervisors are therefore employed in some NPOs. In the Western Cape, CBS facilitators at the district and sub-district levels were observed playing strong coordinating roles between NPOs and the Provincial Department of Health. In a Phase 4 interview with an official in the Western Cape Department of Health, the point was made that current staffing levels in the state health sector do not make it feasible to allocate professional nurses from facilities to supervise community caregivers. The informant outlined a hypothetical situation whereby the province would recruit retired professional nurses to act as nurse coordinators employed by the NPOs to supervise community caregivers, with a strong relationship envisaged between these nurse coordinators and the sub-district CBS facilitators. This was indeed the situation in the peri-urban/rural Western Cape organisation observed, where one of the nurse coordinators had been invited to take up this NPO position after retirement, and was working closely with the sub-district CBS facilitator (a former nurse coordinator of the organisation).

At present community caregivers are supervised in some NPOs by professional nurses, but in many others by non-professionals. Some of the non-professionals may be experienced community caregivers while others are managers not experienced in the health professions but with varying degrees of training and experience in management and administration. As foreseen at present, the intention in the new PHC model is that the 'community health workers' in the outreach teams are supervised by a nurse. Many civil society stakeholders recognise the importance of clinical support in the field but do not necessarily think this proposed structure is ideal. Not only are nurses in short supply in South Africa but they are ill-equipped to undertake the daily management of a cadre of workers deployed in the field, with all the non-clinical issues this can entail. In addition there have also been cases of adversarial relationships between formal health professionals and community caregivers, as noted elsewhere in this report. Some civil society respondents therefore support instead a combination of experienced caregivers and nurses, with the former doing daily on-site supervision in the field and nurses providing crucial clinical support in cases where it is needed.

In the Free State a number of 'DOTS supporters' and 'lay counsellors' are based in clinics and hospitals, although outreach services are often provided into the community. Similarly, some NPOs in the Western Cape place 'lay counsellors' at facilities to provide HIV and TB services. These caregivers based in facilities are partially supervised by formal health facility staff members such as professional nurses. Research indicates that the facility-based 'lay counsellors' in the urban Western Cape organisation experience difficulties with the ambiguity of line management in their jobs, given that both the state facility managers and the NPO site coordinators exert authority over them and do not always concur. Examples of differences included a dispute when a facility manager insisted that 'lay counsellors' should remain in the same facility and build up long-term relationships with clients, whereas the NPO manager wished to have the flexibility to shift counsellors among facilities depending on workload and staff shortages.

## Coordination related challenges and concerns highlighted in relation to the new PHC model

**Greater collaboration between the** National Department of Health and other departments, in particular the National Department of Social Development, is considered crucial since they are both deploying cadres of community caregivers. Moreover, as the National Department of Social Development has experience in delivering psychosocial support, such caregivers should be included in any plan to develop a broad-based formal ‘national community caregiver programme’ for South Africa. The National Department of Health acknowledged the importance of such collaboration in its provincial implementation guidelines (2011c). Furthermore, ‘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 and National Department of Basic Education will be needed.

Additionally, given the many different types of relationships between ‘formal’ and ‘informal’ health programmes that currently exist, questions persist about the health system’s capacity to coordinate and supervise a state-run community care and support system consisting of ward-based outreach teams as described in the government’s new policy guidelines. If ‘community health workers’ in the outreach teams were all state employees—with the direct client care services being provided by contracted NPOs—the capacity might be sufficient, although still challenging. A more likely scenario, in the short term at least, seems to comprise a continuation of various forms of employment and service provision across the nine provinces. A recommendation of this research would be that a change management plan be put in place to define, strengthen and regulate the relationship between formal and informal personnel in the field. Once ‘community health workers’ start being deployed on a large scale in formal outreach teams, the relationship between the health facilities and these teams will have to be formalised by developing new procedures and guidelines in a collaborative manner, involving staff in the health facilities, ‘community health workers’ in outreach teams, and community caregivers in NPOs.

### 2.4.3 Continuum of care and comprehensive care and support

A number of models of CHBC programmes with the potential to cover all phases of illness throughout a person’s lifespan were observed in this research. These models differ significantly from each other.

The case study organisation in the peri-urban/rural Western Cape deploys generalist community caregivers offering a broad spectrum of interventions ranging from supporting TB clients and providing care and support to clients within their home environment, to supporting and educating post-partum mothers and undertaking regular health campaigns covering both infectious and non-communicable diseases. Another organisation (in peri-urban/semi-rural Free State) also covered a broad spectrum, including dispensing decentralised ART, adherence support and care and support for OVC and disabled children. This organisation deployed specialist community caregivers in separate (but loosely interconnected) programmes in the organisation. Both of these programmes were regarded as invaluable by government officials interviewed, and they both had links with large care and support focused organisations and religious institutions with long traditions in community care work. However, the future of these divergent but ‘successful’ models of providing community treatment, care and support is not certain under the government’s new plans for re-organising CHBC provision.

The organisation in the urban Western Cape supervising ‘HIV counsellors’ was following state guidelines and targets aimed at providing a continuum of care and retention in treatment programmes for clients with HIV, or dual infection with TB. The ongoing deployment of ‘TB/HIV adherence supporters’ in the communities surrounding the clinics where these ‘HIV counsellors’ work should substantially improve the ability to follow up clients who do not return to the clinics. The counsellors spoke of the pivotal role of other NPOs in the sub-district that provide specialist services and thus make it possible for clients with problems (such as relational difficulties or alcoholism) to be referred for further support.

## 3 CONCLUSION

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After a long and complex history, CHBC programmes are at an important new point of departure in South Africa. This has been motivated by the National Department of Health's new policy guidelines on formalising care work in communities to counteract some of the weaknesses identified in the previous arrangement of CHBC being run largely by NPOs in partnership with government. Implementation of guidelines through provincial and district departments has begun, while many NPO-run CHBC programmes still continue to be offered in many parts of the country. At the time this research was published it was too early to comment on the implementation process and its implications for CHBC in the country. In general though, the commitment of the national government to the creation of a more systematic 'national community health worker programme' should be lauded. It forms part of its determination in 2009 to tackle the relatively poor health indicators of the South African population and its impressive track record of rapid scale-up of ART from 2009 onwards. The new policy guidelines open up important opportunities for collaboration between government departments, as well as between the state and civil society, in the provision of community-based care.

Despite the promising nature of this new development, a number of issues about the future of CHBC in South Africa remain unclear. As signalled by this research, the following are of particular concern:

- the formal health system's capacity to provide staff qualified to supervise outreach teams and manage the transitional period;
- PHC clinics' capacity to handle potentially larger numbers of clients identified by the outreach teams;
- the future of a broad range of services<sup>16</sup> currently offered by community caregivers based in NPOs, especially ones that are excluded from the scope of work of state-employed 'community health workers' under the new government policy;
- the future of NPOs (and their funding) in providing CHBC services; and
- the possibility of decreasing funding support for CHBC provision in South Africa 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.

In consultation with the South African Research Advisory Board, a list of advocacy priorities based on these challenges and concerns was developed. In summary, close collaboration during the transitional period between relevant government departments is recommended, as well as between government and civil society. Collaborative efforts should be wide-ranging so as to include poorly resourced community-based organisations in marginalised parts of the country and the community caregivers that have provided CHBC in South Africa, some of them for many years. Their engagement is critical to ensure that existing forms of care, caregivers' experience, managerial expertise, understandings of patient needs and networks for mobilising communities are not lost to the implementation process.

### Advocacy priorities

Table 5 below summarises the key advocacy priorities arising from the research in relation to the government's new plans for organising community-based care and support. The recommendations are presented with regard to the National Department of Health's 'community health worker' programme in particular, as this is the current main focus of CHBC service provision. However, many of the issues discussed are of similar relevance to community workers engaged in caregiving through NPOs. The more inclusive term 'community caregiver' is therefore used in this table whenever such inclusivity should be denoted.

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<sup>16</sup> Such services include day-to-day care of long-term bedridden and terminally ill clients within the home environment, long-term psychosocial care and support, counselling, end-of-life care, and daily adherence support in cases where it is necessary.

**Table 5. Advocacy priorities for community care and support work in South Africa**

HEALTH SYSTEM ISSUES	
Funding	Adequate funding should be provided for implementing a more comprehensive national community caregiver programme. This should include allocations to NPOs to continue to support social mobilisation processes as well as provide CHBC services that complement the work of the PHC outreach teams, such as providing psychosocial support.
Integration	Departments responsible for community care work—namely the Department of Health and the Department of Social Development—should coordinate their efforts to i) ensure that psychosocial and socioeconomic support initiatives are available and ii) avoid duplication when both departments may be offering similar services.
Role of NPOs	The role of NPOs and their staff in the provision of CHBC services needs to be clarified, especially with regard to the deployment of ‘community health workers’ planned under the National Department of Health’s new re-engineered PHC guidelines.
Human resources for health	Given that HIV and TB continue to be prominent health issues in South Africa, the expertise and experience contained in existing CHBC programmes should not be lost, whether they are retained inside or outside the government’s envisaged structures for community care work.
Participative local structures	Regular forums should be organised where communities receiving care and support and representatives from all types of health personnel—including those based in NPOs—meet to review various aspects of the delivery of PHC services.
Communication	Two-way communication, including the dissemination of proposed policies and approaches, should be improved so that community caregivers and the other health workers with whom they interact are involved in decision-making processes and equipped with relevant information.
Referrals and relationships	Staff in the facilities who receive referrals from community caregivers, and who refer clients to them, should understand and value the roles of these community-based workers—be they state-employed or from NPOs.
M&E	A robust monitoring and evaluation system needs to be implemented to ensure that issues are addressed and quality services are delivered to communities served by community caregivers.
COMMUNITY CAREGIVERS’ ISSUES	
Entry requirements	‘Community health workers’ for the PHC outreach teams should be drawn from the current cadre of caregivers, and minimum qualification standards should take into account long-standing experienced caregivers who may not be formally or highly educated but whose service the system should seek to retain.
Remuneration	Community caregivers should be properly remunerated.
Conditions of service	Community caregivers should be employed on decent conditions of service, including measures to ensure their health and safety.
Psychosocial support	Psychosocial support for community caregivers—and their supervisors—should be integral to the structure of their jobs.
Scope of work	The scope of work of different categories of caregiver where they exist (e.g., ‘community health workers’, ‘home-based carers’ and ‘counsellors’)—needs to be clarified. The specifications should be realistic and aimed at ensuring that a continuum of care is available.
Home-based carers	‘Home-based carers’ need to be included in the community-based health services—and included in state budgets.
Stigma and discrimination	Reducing the stigma and discrimination that can obstruct people’s access to health services should be part of the scope of work of community caregivers. This is required to strengthen community mobilisation and awareness, and can help increase health service uptake.
Biomedical knowledge	Suitable biomedical knowledge needs to be included in training programmes and procedures for community caregivers. This is required to inform screening and referrals and to enable community caregivers to provide appropriate home-based care where required.
Training	Suitable accredited standardised training should be made available in accessible ways to community caregivers.
Career paths	Realistic and feasible career paths should be identified for community caregivers.
Supervision	Daily supervision of community-based caregivers can be undertaken by experienced caregivers rather than nurses, as currently proposed. Clinical support and supervision should be carried out by a nurse, however, as necessary and as far as possible.

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

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## ANNEX 1. COUNTRY RESEARCH PARTICIPANTS

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### Researchers:

- Hayley MacGregor – Institute of Development Studies (IDS), United Kingdom
- Ermien van Pletzen – University of Cape Town, South Africa

### Research Advisory Board members (Cape Town):

- Melanie Alperstein – Faculty of Health Sciences, University of Cape Town
- Raymond Bokako – Thusang Community Care; Community Care Workers' Forum
- Anna Genu – South African Christian Leadership Assembly (SACLA); Community Care Workers' Forum
- Ntombozuko Kraai – AIDS Response/Wellness Foundation
- Lawrence Mbalati – AIDS & Rights Alliance for Southern Africa (ARASA)
- Nokwanele Mbewu – Philani Child Health & Nutrition Centre
- Penny Morrell – Freelance project practitioner working in public health and social justice (Chair of the advisory board)
- Mavis Nonkuzi – TB/HIV Care Association

## ANNEX 2. KEY INFORMANTS

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### Phase 1: Semi-structured interviews

Interviews were conducted with representatives from the following two main sectors.

Government officials:

- National Department of Health (2)
- Free State Department of Health (3)
- Free State Department of Social Development (1)
- Western Cape Department of Health (2)
- District Office, Free State Department of Health (1)

Large (not for profit) care organisations:

- AIDS Foundation (1)
- Community Media Trust (1)
- Wits Reproductive Health and HIV Institute (1)
- TB/HIV Care Association (1)
- Treatment Action Campaign (1)

### Phase 2: In-depth review of three case study CHBC programmes

#### Case 1: FBO in peri-urban/semi-rural Free State

Interviews with representatives of:

- FBO (3)
- District Office, Free State Department of Health (2)
- Catholic Office, Free State (1)

Interviews with:

- Clients (5)
- Primary caregivers (8)

Focus group discussions with:

- Caregivers in ART and CHBC programmes (6 participants)
- Caregivers in OVC and disabled children programmes (7 participants)
- Community representatives (6 participants)

#### Case 2: Home-based care NPO in peri-urban/rural Western Cape

Interviews with representatives of:

- NPO (2)
- Western Cape Department of Health (1)
- Sub-district local PHC clinic (1)

Interviews with:

- Clients (9)
- Primary caregivers (11)

Focus group discussions with:

- Caregivers (11 participants)
- Community representatives including a church minister, member of local municipality, teachers and nurses (6 participants)

### **Case 3: Voluntary counselling and testing NPO in urban Western Cape**

Interviews with representatives of:

- Counselling NPO (3)
- Médecins Sans Frontières (1)
- State-employed nurse (Department of Health) (1)
- Treatment Action Campaign (1)
- TB/HIV Care Association (1)

Interviews with:

- Clients (10)

Focus group discussions with:

- Counsellors in NPO (4 participants)

### **Phase 4: Validation interviews/ questionnaire**

**Interviews with representatives of:**

- Free State Department of Health (2)
- National Department of Health (1)
- TB/HIV Care Association (1)
- Western Cape Department of Health (1)
- Wits Reproductive Health and HIV Institute (1)

**Care organisations included in the questionnaire sample:**

- Bhekuzulu – KwaZulu-Natal
- Elungelo – KwaZulu-Natal
- Groeneweide – Western Cape
- HIV counselling organisation (case study organisation) – Western Cape
- Hlokomela – Limpopo
- Keth'Impilo – Eastern Cape
- Khanya – Free State
- Kriste ka Thorollo – Free State
- Mfesane – Western Cape
- FBO (case study organisation, ART project) – Free State
- FBO (case study organisation, OVC project) – Free State
- Philani – Eastern Cape
- South African Christian Leadership Assembly (SACLA) – Western Cape
- Sego – Limpopo
- TB/HIV Care Association – Western Cape
- West Coast home-based care organisation (case study organisation) – Western Cape

## ANNEX 3. BACKGROUND INFORMATION ON THE THREE CASE STUDY ORGANISATIONS

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### Free State FBO in peri-urban/semi-rural area

This organisation operates in a black peri-urban township situated 60 kilometres (37 miles) from the capital of the province. Although it is described as peri-urban, the township is largely rural and under-resourced. People are overwhelmingly poor, and many of their needs are related to the quadruple burden of disease experienced by many poor people in South Africa. HIV prevalence in the relevant district is estimated at 27.8 percent (Department of Health, 2010a); that figure may be much higher (up to 38 percent for some groups) in the municipality in which the organisation is located (Hattingh et al., 2009). The number of clients on ART in this township of approximately 177,000 people was 3,673 in 2008; 4,572 in 2009; and 6,206 in 2010 (figures provided in person by the Free State Department of Health in 2010). In 2011 the official unemployment rate was 56 percent (Mangaung Metropolitan Municipality – Economic Data review, 2011).

This FBO runs the following semi-autonomous programmes, each with distinct funding and management structures:

1. an HIV testing and HIV treatment and support programme with an informal link to
2. a home-based care programme, as well as
3. an OVC programme with
4. a day care centre for disabled children attached to it.

The organisation operated under the auspices of the Roman Catholic Church and was funded mainly by the South African Catholic Bishops' Conference, with some additional support from the National Department of Health and National Department of Social Development. It participates in a sophisticated M&E system, capturing daily data for both the HIV treatment and support programme and OVC programme. These data are shared with the National Department of Health. (See Annex 5, Figure 2 for an organogram of this organisation and its relationship with community care worker structures in the provincial and district health departments.)

A professional nurse acts as manager of the four programmes, although each programme runs semi-autonomously. The structure, staffing and client numbers of the programmes are as follows:

1. The HIV treatment and support programme employs a nurse (full time) and a doctor who visits one day per week to perform clinical work; a project coordinator and assistant; two data capturers; a pharmacy assistant; five full-time counsellors; and seven adherence monitors. Approximately 1,000 clients are enrolled in this programme.
2. The home-based care programme comprises five 'home-based carers' working loosely with a neighbouring private chronic care clinic with a professional nursing sister in charge. These carers look after a varying number of clients. The programme is very informal and loosely structured, and in a state of change. When funding becomes restricted in the HIV treatment and support programme, staff tend to find limited employment and remuneration in the home-based care programme.
3. The OVC programme employs a project coordinator, five carers and five cooks. Approximately 250 children are supported in a drop-in centre providing food and help with homework and psychosocial issues; a further 250 children are supported at home.
4. The day care centre for disabled children shares the OVC project coordinator and employs four staff members who care for 20 children with varying disabilities.

### Home-based care NPO in peri-urban/rural Western Cape

This organisation is based in a large provincial town situated in farmlands, 66 kilometres (41 miles) from Cape Town, the capital of the Western Cape Province. There are limited employment possibilities,

including seasonal labour on the surrounding farms. The town is still fairly segregated, with white, coloured and black African people largely living in separate areas. (These racial categories are regrettably still a reality of South African existence, and researchers emphasise that they are treated throughout the report as social constructs. Many people in South Africa, however, still self-identify with one of these categories.) Black African people are generally still regarded as ‘newcomers’ to this area and tend to be the worst off economically. Many of them live in shacks in an informal settlement on the margins of the residential area formerly designated for coloured people (during apartheid years). By contrast, the former (but still mainly) coloured area consists of areas of low-income brick housing but also some larger and more affluent neighbourhoods. The CHBC organisation is situated in this residential area and serves mainly coloured and black people. The coloured community caregivers seem to tend to coloured clients while black community care workers tend to black clients.

The relevant district is large and sparsely populated, having only 4.9 percent of the population of the Western Cape Province as a whole (Western Cape Government Provincial Treasury, 2011). In 2007 the population of the sub-district (where the organisation is located) was 77,522—just over a quarter of the 286,748 in the entire district. In 2007 the literacy rate in the district was 76.1 percent, six percentage points behind the province as a whole (Western Cape Government Provincial Treasury, 2011).

Compared with other parts of the province, however, the district has been assessed as having good provision of health facilities, especially in rural areas. In June 2011 the ART client load for the district as a whole was 3,205, with the highest number of these clients (1,039) in the municipality where the organisation is situated (Western Cape Government Provincial Treasury, 2011).

The organisation is one of two CHBC organisations in the sub-district. As it is regarded by the Department of Health as a well-functioning organisation, it was funded to extend its services to a larger geographic area in the sub-district (taking over from organisations that were not performing so well). It reports to the sub-district community-based services coordinator. The organisation gets its clients through referrals from the nearby state clinic and the sub-district’s referral hospital, situated close by in the same town.

At present the mainstay of the organisation’s funding is from the Department of Health, although small amounts of funding and ad hoc support are received from other sources; for example, a project vehicle was bought from lottery funding.

The organisation comprises one project manager, one administrator and two nurse coordinators (staff nurses) in charge of 48 community caregivers. One of the nurse coordinators runs the rural outreach team to extend services to more isolated rural areas where access is a problem. The other nurse coordinator oversees the caregivers who are allocated clients in the town. At present the organisation serves approximately 2,000 clients, 70 percent of whom are elderly. About 150 are HIV clients who are all referred from the treatment programme at the sub-district hospital. (See Annex 5, Figure 3 for an organogram of the organisation and its relationship with community care worker structures in the Western Cape and in the peri-urban/rural district health departments.)

### **Voluntary counselling and testing non-profit organisation in urban Western Cape**

The organisation is based in a large township area of the City of Cape Town) of the Western Cape Province. The vast majority of the population is isiXhosa-speaking, many of whom migrated from the Eastern Cape.

Since 1994 there has been a gradual increase in serviced housing in the sub-district, initially through schemes such as the Reconstruction and Development Programme. In the most recent published census data from 2001, the population was estimated at 329,000 (although the growth since then suggests it is closer to half a million), with 64 percent of the population reported to be living in shacks and 50.8 percent unemployed (Western Cape Government, 2005). In 2011 the first in-patient hospital facility was opened in the township. The burden of disease is high as is usual in low-income settlements: antenatal HIV prevalence in 2010 was 26 percent, significantly higher than the provincial prevalence of 18.5 percent (National Department of Health, 2010a). In 2009, the infant mortality was 35 per 1,000 live births (Médecins Sans Frontières et al., 2011). While controlling infectious disease in the township remains a significant challenge, gains are being reported in combating the linked challenges of HIV and

TB infection through, for example, increases in the number of people tested for HIV, initiated onto ART, and retained in treatment programmes, as well as earlier detection of TB through integration of care (Médecins Sans Frontières et al., 2011).

This non-profit organisation is a national counselling organisation with a long history of promoting training and supervision of largely volunteer 'lay counsellors' to provide counselling of a general nature, both by telephone and face-to-face. Although it did not have a long history of HIV counselling specifically, it won the Western Cape provincial government tender to contract and supervise HIV counsellors in the state facilities, in parts of the sub-district.

The organisation's office in the township selects applicants to do a personal growth course that is run on site. From these participants, people are selected for further general counselling training and to work as volunteer counsellors, seeing community members at the township offices. It is from among these volunteers that applicants are drawn to apply for the paid positions as HIV counsellors in the facilities in the township. They are then sent for a 30-day HIV counselling and testing (HCT) training course run by the AIDS Training, Information and Counselling Centre (ATICC), the provincial training body.

The structure of the organisation at the time of fieldwork in April 2012 is given in Annex 5, Figure 3, an organogram of the organisation and its relationship with community care worker structures in the Western Cape and City of Cape Town health departments.

During Phase 2 of the research—when information was being gathered—the organisation had an HIV manager and three coordinators assigned to supervise counsellors in the various facilities. There was also one office assistant. A social worker was employed but only to support the general counselling work at the organisation's township office. These staff members also assisted with training of the volunteer counsellors, with support from the organisation's central Cape Town office.

Also during Phase 2, the organisation employed 54 HIV counsellors, all of whom worked in the state day clinics and day hospitals in the township, including in the midwife obstetric units. The counsellors tended to work in a particular facility, but could be moved among different facilities in the township, depending on work load, staffing shortages and so forth. None visited clients in their homes or did follow-up work beyond the facilities.

Eleven of the counsellors were only trained to do HCT in the facilities, while 43 counsellors received a further 10 days of training from ATICC to qualify as adherence counsellors. A plan was in place to gradually train all the HIV counsellors in both HCT and adherence counselling so that they all would be able to move between both types of work, depending on need. In addition, all counsellors were gradually being trained in a TB/HIV integration protocol. During Phase 2 of the research, 25 counsellors were doing HCT work and the remainder were placed in ART clinics doing adherence work and running treatment clubs. They are all meant to do education work in the waiting rooms in the facilities, encouraging people to test for HIV.

The Phase 4 interviews revealed that between April and early August 2012, another NPO had taken over the management and employment of a proportion of the 'lay counsellors' working in facilities in the sub-district. As of August 2012 the case study organisation was still employing one manager, one office assistant and one social worker. However, there was one fewer coordinator and only 27 HIV counsellors, of whom all but 4 were jointly trained in HCT and adherence counselling. There were also 12 volunteers doing general counselling at the offices of the NPO.

The contract between the province and the NPO stipulates the targets for the work of the counsellors in the facilities, and the work of the counsellors is fully integrated into the work of the clinic, with all the referrals originating from state employees in the clinics. With respect to the monitoring of the HIV counselling work, the NPO coordinator reports to the sub-district provincial health offices based also in the township and to the HAST (HIV and AIDS / STI / TB) coordinator.

## ANNEX 4. CHALLENGES AND CONCERNS RELATING TO COMMUNITY CARE AND SUPPORT SERVICE PROVISION

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This section lists a wide range of challenges and concerns expressed by different stakeholders with regard to community care work, in particular in relation to HIV prevention, treatment, care and support and the new PHC model.

### Government officials

- Finding adequate funding for implementing the envisaged national ‘community health worker’ programme
- Continued lack of integration between the two large national ministries responsible for community care work, the Department of Health and Department of Social Development
- Lack of clarity with respect to the role of NPOs in the deployment of ‘community health workers’ under the new re-engineering PHC guidelines
- Lack of clarity about the future of ‘home-based care services’ as opposed to the proposed surveillance/profiling/health promotion and prevention services that may have a more ‘bureaucratic’ slant
- Providing adequate training for ‘community health workers’, as well as standardisation and accreditation of training
- Providing appropriate supervisory structures for ‘community health workers’ in outreach teams, especially given the shortage of doctors and professional nurses in the country
- “Getting rid of the boundaries between professionals and ‘community health workers’ to get a team functioning”
- Career pathing for ‘community care workers’
- Whether the proposed increased formalisation of community health work under state governance could create distance between these ‘workers’ and the communities they work in
- Perceived inactivity of local community structures like clinic councils and AIDS councils
- Making reliable assessments of client needs and matching client needs to resources, especially in impoverished and remote areas of the country
- Supplying functional M&E systems
- Managing “constant changes in leadership” which “are not good for service delivery”, a particular problem noted in certain provincial departments

### Managers of large care organisations

- The extensive number of roles that generalist ‘care workers’ will be expected to fulfil in the new PHC teams
- The future of the basic role of CHBC (e.g., providing home-based care to bedridden clients in home environments)
- While large care organisations had relationships with the Department of Health, they had much less contact with the Department of Social Development. Broader care and support activities have thus received less attention than more medically orientated roles. There is concern that this medical focus will narrow further in future as the Department of Social Development has not been greatly involved in the new policy discussions
- The future of facility-based ‘counsellors’ in the new plans. In particular, there is concern that the psychosocial support role will be de-emphasised as counselling comes increasingly to be defined by testing targets and retention in treatment programmes, with numerical performance indicators that might devalue the care and support offered by ‘counsellors’ and the role they play in helping clients negotiate systems in state clinics
- Caregivers may lose their niche roles and be drawn instead into doing lower-skilled clinic jobs such as filing for the nursing staff. Some of the informants suggested that this had already happened in provinces where the state had taken over the management of ‘care workers’, and that ‘care workers’ in these instances had been observed spending increasing amounts of time in the facilities and less time in the community

- The ability of the state health care services to provide adequate supervision for ‘community health workers’ employed by the state
- The smaller CBOs may not be able to survive if the state takes over their role of contracting and supervising community ‘care/health workers’
- The large care organisations that were involved in grant making for CBOs are going to have to shift their focus and find new roles. Greater involvement in training appears to be an option for several large care organisations
- The importance of training for ‘community health workers’ to enable them to impart adequate medical knowledge if they are to play a role in early detection of disease. This view of community ‘care/health worker’ training emphasises that lay people can be expected to assimilate considerable biomedical knowledge
- Discussions about minimum qualification standards for people to train as ‘health workers’ in future; this could mean that long-standing, experienced caregivers who fall short of these standards could lose their jobs. This has already been observed in the Western Cape in the implementation of the policy to retrain TB ‘DOTS supporters’ as integrated ‘TB/HIV adherence supporters’
- Maintaining an ethic of care as systems and processes become more formalised under the new policies was a concern across the board of large care organisations
- The importance of robust M&E systems was raised as a challenge, with innovations in information and communication technologies for health suggested as one means to ensure a quality service. Good training and supervision were highlighted as essential in this regard

### Management operating in the three case study organisations

- Community caregivers’ lack of independent initiative when it comes to referring new clients from the community to the ART programme or spotting non-adherence or other issues that may undermine clients’ health or treatment
- The continued stigma surrounding HIV and TB, which prevents clients from accessing health services and is an obstacle to better adherence
- The quality of care offered by workers perceived by clinic staff as lacking ‘professional’ training and a ‘professional’ ethic of care
- Concerns that the new government policy might lead to outreach teams flooding clinics with referrals that they as clinics will not be able to manage with their present staffing
- The unstable funding environment
- The fast turnover of government officials, which hampers achieving continuity in dealing with stakeholders
- Managing anxiety about adapting to changes in programmes due to new directives from the Department of Health
- Developing appropriate responses to discontent among caregivers about new tasks being added to their scope of practice while their salaries remain unchanged

### Caregivers operating in the three case study organisations

- The low level of pay received by community caregivers and no prospects of higher paying jobs or more satisfying career paths
- The expansion of roles (for instance the addition of post-partum care to mothers and babies and frequent door-to-door campaigns)
- The struggle to maintain boundaries in impoverished environments where clients and their families need community caregivers for important psychosocial care and support, including poverty alleviation
- Assimilating new medical knowledge when drug regimens and treatment guidelines are constantly shifting—for example, remaining up-to-date with complex TB and HIV drug regimens and drug interactions, changing guidelines for the initiation of ART, and changing advice for breastfeeding
- The stress of monthly performance targets for facility-based counsellors and the perception that there is less time to talk to clients and address broader needs
- The emotional burden of feeling responsible for addressing non-adherence in ART programmes when underlying structural factors are to blame (e.g., drug stock-outs)

- Clients' late presentation for HIV and TB testing and treatment; non-adherence
- Dealing with stigma and difficulties with disclosure of HIV status
- Apathy on the part of ward councillors who do not seem to take an interest in the local community's health issues or the work of health-related programmes and organisations

As indicated in Section 2.1.2, 'lay counsellors' and 'home-based caregivers' indicated that they were concerned by the fact that many clients often do not visit health care facilities until they are already seriously ill. Moreover, they highlighted the sometimes overwhelming range of physical and psychosocial needs presented to them on a daily basis as well as the need to deal with a range of social circumstances that affected treatment adherence, including substance abuse and difficulties with disclosure. 'Lay counsellors' mentioned that the emphasis on meeting clinic targets meant that they found it difficult to allocate sufficient time to effectively meet the need for psychosocial counselling.

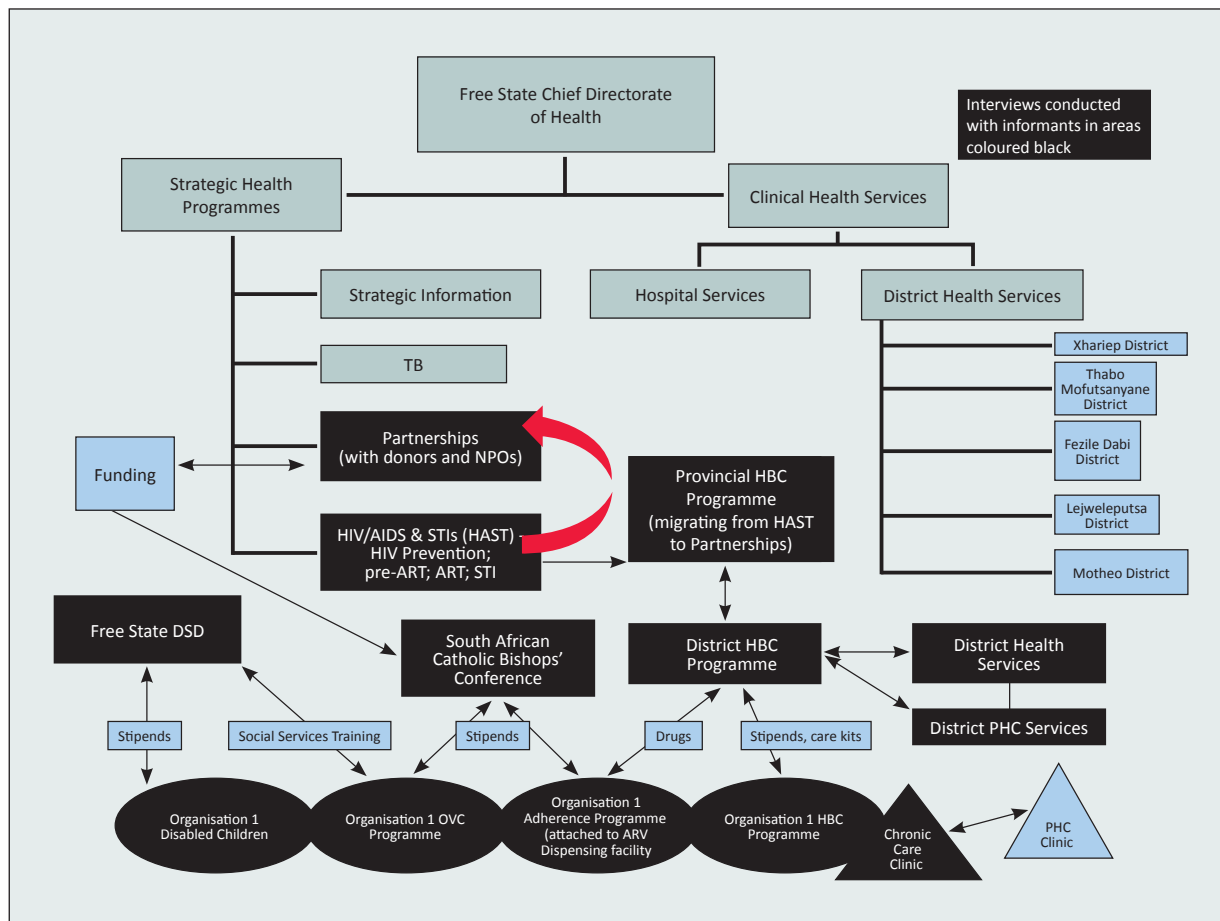
Supervisors of caregivers expressed concern that the increasing expectation of caregivers to perform more and more tasks was undermining their ability to address time-consuming physical and psychosocial needs such as providing basic physical care to bedridden or seriously ill clients and emotional/spiritual counselling to people experiencing serious illness and poverty. They expressed the same concern about an increase in tasks with a narrow biomedical focus.

Concerns about funding are especially notable in regards to the future of CHBC provision in South Africa. In the questionnaires, representatives from the three case study organisations were asked about their future outlook in terms of funding. The peri-urban/rural Western Cape organisation was largely supported by the Provincial Department of Health, but additional funds were also required. The coordinator noted that the organisation was experiencing greater difficulty obtaining funding for CHBC provision. The urban Western Cape organisation reported experiencing a reduction in funding and that a few adjustments had to be made. For example, the hours of the office assistant had been reduced, and the organisation had rationalised office space to reduce rent of the premises. The Free State case study organisation had suffered significantly from funding cuts in 2011 and had to negotiate for the state to provide some of its medications. Caregivers had also been retrenched.

Finally, in relation to funding, it was noted that funders would support HIV programmes but that the greatest need of all, namely funding for food, was not included.

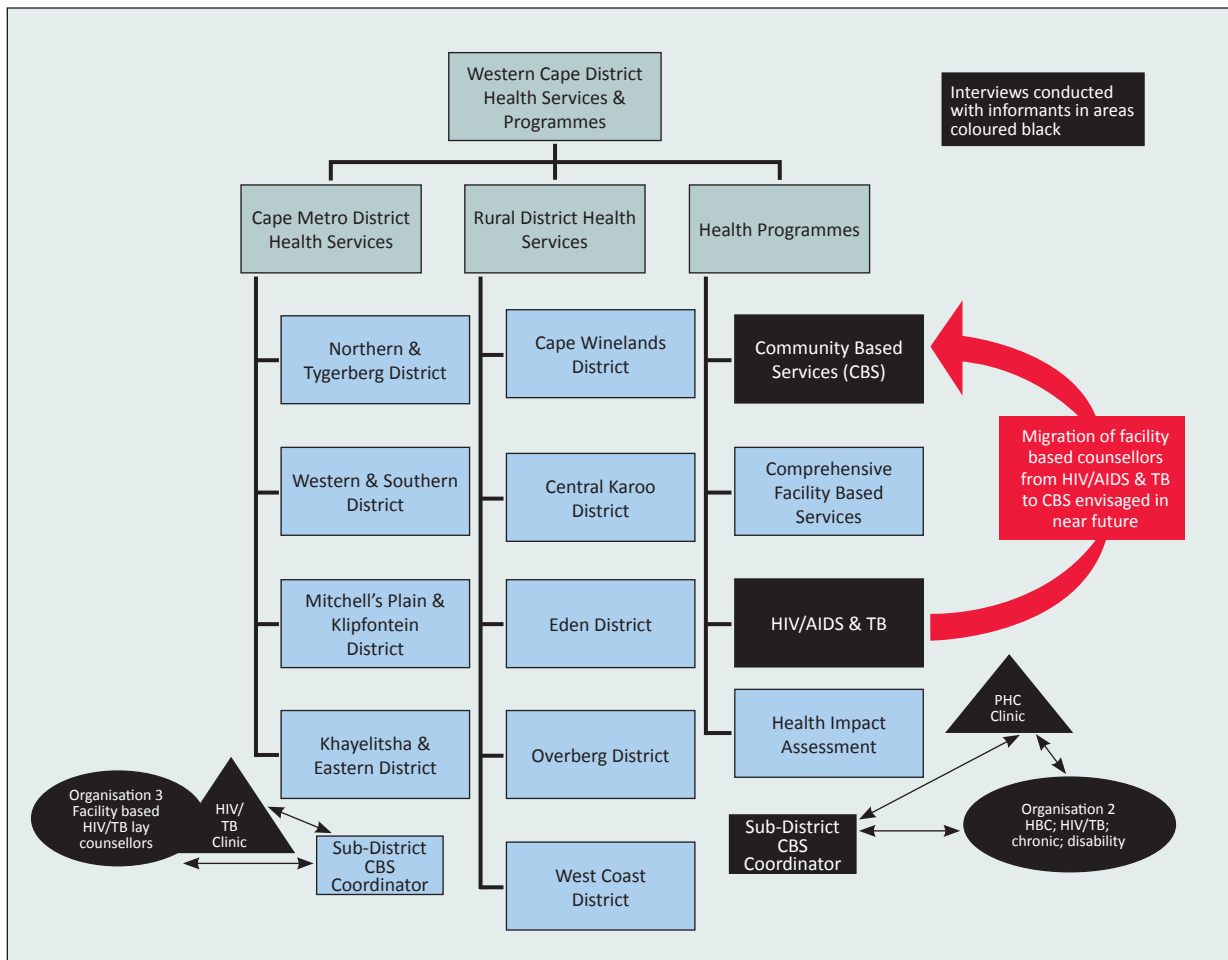
# ANNEX 5. PROVINCIAL ORGANOGRAMS FOR CARE AND SUPPORT STRUCTURES

Figure 2. Provincial organogram for care and support structures in the Free State , including case organisation 1



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

**Figure 3. Provincial organogram for care and support structures in the Western Cape, including case organisations 2 and 3**



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



Caregivers Action Network

[www.caregiversactionnetwork.org](http://www.caregiversactionnetwork.org)