

**COMMUNITY HEALTH WORKERS, COMMUNITY PARTICIPATION
AND COMMUNITY LEVEL INTER-SECTORAL ACTION: THE
CHALLENGES OF IMPLEMENTING PRIMARY HEALTH CARE
OUTREACH SERVICES**

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of

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Declaration

I, Nonhlanhla Lynette Nxumalo, declare that this thesis is my own work. It is being submitted for the degree of Doctor of Philosophy in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

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To Jabulani Nxumalo, Mirriam Nxumalo and Sibusiso Nxumalo

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Abstract

Background: The recognition of growing health disparities globally and, in particular Sub-Saharan's continued poor health outcomes, has been responded to with a call to revitalise primary health care (PHC) 30 years after the Alma-Ata Declaration. Despite some limitations, and although not the only solution, community health workers (CHWs) have been shown to be able to reduce factors that can act as barriers to accessing care. However, CHW programmes (often provided by non-governmental organisations in South Africa) have historically been poorly regulated and fragmented. The South African government has proposed to address the health inequities through a series of health system reforms. One of these has been a current attempt to strengthen PHC through the use CHWs in order to reach underserved communities. The capacity of CHWs to provide effective outreach services remains unclear. This work examined the experiences of CHWs in their efforts to improve access to care through community participation and outreach services that work across sectors.

Aim: The study aimed to examine the implementation of community health worker-provided services through the comparison of three case studies in order to identify enabling and constraining factors.

Methodology: A case study method was used to compare three CHW programmes. Qualitative methods such as key informant interviews, participant observations, focus group discussions and network maps, were used to collect data. A thematic content analysis was used to identify *a priori* and emergent themes.

Results: CHWs operate in communities with multifaceted needs (food, transport, health and social welfare services) requiring a comprehensive approach. The experiences of households in this thesis illustrate the various barriers to accessing services. The success and sustainability of CHW programmes depends on the ongoing commitment of resources, including investment in quality training, supervision, mentoring and organizational support. Furthermore, government institutional contexts with poor cross-sectoral integration, conflicting departmental mandates and poor accountability constrain the efforts of CHWs at local level. Operating within a community with strong social cohesion and social capital provided an enabling environment for CHWs to mobilise the community and facilitate community participation, which is crucial for implementation of cross-sectoral outreach activities.

Conclusion: The study indicates that CHWs provide services in communities that live in poverty which results in multiple problems that contribute to ill health. The study goes further to illustrate that in order to strengthen outreach services across relevant sectors, the role of central government is crucial. These findings indicate a need for greater understanding about how to strengthen institutional contexts both in government and in non-governmental organisations.

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Nomenclature

ARV	Antiretroviral
AIDS	Acquired Immune Deficiency Syndrome
CBO	Community-Based Organisation
CHC	Community Health Centre
CoJ	City of Johannesburg
CPHC	Comprehensive Primary Health Care
DOH	Department of Health
DOTS	Directly Observed Therapy – Short Course
GP	General Practitioner
HIV	Human Immunodeficiency Syndrome
HiAP	Health in All Policies
ID	Identity document
IDP	Integrated Development Plan
KII	Key Informant Interviews
NGO	Non-Governmental Organisation
RDP	Reconstruction and Development Programme
SDH	Social Determinants of Health
STI	Sexually Transmitted Infection
VCT	Voluntary Counselling & Testing

CHAPTER 1

1.0 Background and Introduction

In the 30 years since the Alma Ata Declaration, challenges to various efforts to implement primary health care (PHC) have limited the ability to achieve the core values of the Declaration of, better health for all, the right to participation and solidarity, and social justice [1]. To address the growing health disparities, specifically in developing countries, there is increasing effort internationally to revitalize the practice of PHC values [2, 3] . Although mostly prescribed, the Millennium Development Goals (MDGs) constitute explicit health –related goals that resonate with the principles in the Declaration [4, 5]. They are a reflection of the global recognition of health inequities that still exist. Some countries are striving to integrate the strengths of their vertical programmes with more comprehensive programmes to strengthen health systems. This has been coupled with emerging discourse regarding a comprehensive health care system approach [1].

According to the MDGs Report of 2008 [5] , both developed and developing countries has been made progress in meeting some of the MDGs. Deaths from measles declined from more than 750 000 in the year 2000 to less than 250 000 in 2006. Approximately 80% of children in developing countries presently receive a measles vaccine. With the growth in the availability of antiretroviral treatment, there is a noticeable decline in number of people dying from AIDS, from 2.2 million in 2005 to 2 million in 2007. An estimated 2.7 million people were newly infected in 2007, down

from 3 million in 2001. The use of insecticide-treated nets in malaria prevention has expanded, with 16 out of 20 countries having tripled since 2000.

Despite this reported progress, sub – Saharan Africa continues to experience poor health outcomes. Half of the deaths of children under the age of 5 years in developing countries are found there. Maternal mortality remains significantly high across the majority of developing regions, where 99% of these deaths occur, with Southern Asia and Sub-Saharan Africa accounting for 86% of the deaths . In fact, it is now predicted that Africa will only achieve the MDGs’ aim of reducing child mortality by two-thirds from 1990-2015 in 2065 [6].

The practice of PHC recognises that health depends on other non-health sectors to address the health and wellbeing needs of a society in a comprehensive way. International policy debates recognise that biomedical interventions (that are often of the health sector) alone cannot address issues of health and disease. The burden of illness in communities is the result of their social conditions. Policies and programmes that aim to improve health outcomes therefore need to include programmes in other areas such as water, sanitation, housing and social protection, and not just health programmes [1, 4] and require inter-sectoral action. Comprehensive health systems constitute therapeutic and rehabilitative, preventative and promotive components to deal respectively with the effects of a health problem, the cause of the health problem at an individual level and the cause of the problem at the societal level [7]. The renewed interest in comprehensive PHC is largely because it aims to address the social determinants of health through establishing community structures that develop linkages with key sectors such as education, agriculture and housing [8]. A comprehensive or holistic approach to health care also ensures the involvement of communities in defining their own health needs. Although the involvement of communities is a complex process that requires influencing factors such as social

cohesion and social capital [9], community participation has the potential to build a health system that can respond to changing health needs and is resilient to those changes [8, 10].

Community health workers (CHWs) are best positioned to create a link between coordinated services that can ensure this comprehensive approach and underserved communities who are less likely to reach those services. They have the potential to provide greater community outreach services that address the social determinants of health and strengthen comprehensive PHC. Particularly in rural settings and more so in sub-Saharan Africa where health systems are weak and fragmented, CHWs have been one of the ways used to improve equity in access to health care, by extending reach and linking vulnerable populations to the public health system [11]. Through the outreach nature of their work, CHWs have been shown to reduce factors that can act as barriers to accessing care [6]. There is ample evidence that, despite some limitations and although not the only solution, CHWs can be effective in providing a range of services to poor communities [6, 12, 13].

In South Africa, following the first democratic elections in 1994 the new government initiated a series of health system reforms to address health inequities. One of these was to alleviate the burden within tertiary levels of care in hospitals by encouraging preventative modes of care at PHC levels and moving the focus from the curative approach [14]. Part of this endeavour has been to conduct an overview of the CHW and/or community-based sector and explore ways of using the workforce to extend priority health care interventions to underserved communities. Consequently, in light of the increasing shortage of skilled health professionals in the health sector, some of these priority programmes have relied on the expansion of CHWs to provide outreach services. However, it is currently unclear to what extent these community workers are providing outreach PHC services.

The primary aspect of my study is the role of CHWs in contributing to the implementation of PHC. The study aims to examine the experiences of CHWs in providing outreach services to support comprehensive PHC. It goes further to examine the experience of a CHW that works within a comprehensive PHC model as opposed to the traditional PHC. The former is distinctive in that it provides outreach services that incorporate community participation using an empowerment approach and community level inter-sectoral action. As a primary mechanism to support comprehensive PHC, CHWs facilitate inter-sectoral action at community level, which is in the form of outreach services that work across sectors. In so doing, they assist patients and/or households to access services provided by other sectors (besides health) that deal with social determinants of health, thereby adopting a comprehensive approach. The latter, PHC, is whereby CHWs operate within the health sector only with limited or no links with other non-sectors and does not involve the community in the effort to provide services. Consequently, this approach does not contribute to supporting comprehensive activities that incorporate social determinants of health. Although inter-sectoral action is considered a macro function that is beyond the role of CHWs, this thesis asserts that CHWs, by the nature of their outreach activities, also have to work across sectors in order to enable households to access multiple sectors to address multiple needs. It is for this reason that in the thesis, I use outreach services to refer to community-level inter-sectoral action (and use the terms interchangeably). This also applies to PHC. Although CHWs do not directly implement PHC services, their outreach services have the potential to support PHC services, hence my reference throughout the thesis to outreach PHC services. Moreover, I reflect on the CHWs' community participation and outreach services in order to examine the extent to which they support PHC and in the process, also identify the enablers and constraints of their efforts.

1.1. Statement of originality

This study emphasises that there is a greater need for literature to document the local context within which research is based. The rich depth of description in this particular study has shown the weakness of current literature. There is very limited description in most studies on CHWs, of the difficulties and the realities of rendering CHW programmes in poor communities and what is required to make those programmes successful. My study highlights that the nuances that exist in the different contexts need to be carefully understood so that researchers, policy-makers and implementers are able to engage with the complexities presented. It highlights the impact and consequences of urban marginalisation in relation to health and health services. It also challenges the commonly held belief that urban settlements, despite their poverty, provide better opportunities and access because of their geographical proximity to services. The study shows the micro-reality of poverty and how important the details of this reality are if one is to address these needs successfully. In light of the limited level of this detail in the literature, the thesis provides an important contribution to the understanding of poverty in South Africa.

The thesis highlights how the Alma Ata declaration has described the ideal role for CHWs and how they are different to those conceptualised within government-initiated programmes. The Declaration envisages a CHW that empowers the community, has agency, holds government accountable and challenges authoritarian figures. In contrast, government-initiated programmes work on the premise that CHWs should have their roles prescribed, as opposed to CHWs that define their own roles according to the needs of the community. The thesis however highlights the complexity of CHWs retaining the original principles of agency. In reality, as shown in the

study, CHWs will always be remunerated by government and this dependency influences the nature of the relationship. Although the Eden programme is funded by an NGO, the case study shows the ways in which CHWs can advocate for the needs of the community. The case study highlights the support necessary to facilitate the ability of CHWs to be advocates. Furthermore, the study engages with the current PHC re-engineering process in South Africa. In light of this, the thesis provides some lessons on how to create sufficient flexibility for the government to respond and therefore be able to focus on broader needs despite the complex context of the community.

This research has also made a theoretical contribution, which is highlighted in the revised conceptual framework (Chapter 10, Page 281, section 10.6, figure 10.1). Here, the study recognizes and places the CHW as the central player, which the literature rarely does. The revised conceptual framework examines the CHWs as central players and in the process details in boxes the enabling and constraining factors to providing outreach services, which is often limited in the literature.

1.2. Problem statement

Much research exists on CHWs and the programmes that foster community-based services rendered by CHWs. However, the majority of the studies focus on the description of the programmes and have limited detail on the experiences of CHWs in their efforts to provide outreach PHC services. This study addresses the major problem of too much focus on describing CHW programmes with limited research geared at understanding the factors that constrain and enable CHWs in their delivery of outreach services to support comprehensive PHC.

1.3. Justification of the study

Since developing countries are striving to meet the MDGs and the global community strengthens PHC to support efforts to meet these targets, this study could not be more relevant. It is important to understand the factors that either constraints or enable CHWs to provide holistic services that address the social determinants of health. Moving beyond describing the functions of this workforce will assist to strengthen CHWs' contribution to comprehensive approaches to PHC.

South Africa is currently in the process of health sector reform. Its mission to improve access to care and to address the growing disparities in health has led to the current health policy revisions. This included amending the policies regarding CHWs. Simultaneously, there is a significant international phenomenon to strengthen and utilise CHWs to provide community-based services. The methods previously used in most evaluations of CHW programmes have focussed on the outputs rather than the key implementation experiences of the CHWs and lessons learned from those programmes. While the Cochrane review for instance, provides a broad overview of the scope of CHWs programmes globally, a weakness with the reviewed studies is the lack of qualitative analysis to explore the contextual factors that may have contributed to the outcomes [15]. Furthermore, the analyses in these studies do not explain the factors that lead to the successes and failures of the programmes. According to Walt [16], the use of randomised controlled studies for instance does not provide the space to address policy relevant questions such the factors needed for successful implementation of these programmes. My study focuses on these crucial questions by using more qualitative methods to gain an in-depth understanding of the experiences of CHWs, thus contributing to the knowledge in this area.

1.4. Aims and objectives of the study

1.3.1 Overall aim

The aim of this study is to examine the implementation of community health worker-provided services through the comparison of three case studies in order to identify enabling and constraining factors.

1.3.2 Specific objectives

The objectives of the study are:

1. To describe and compare three non-governmental organisations providing CHW services, their institutional setting, community context, and to explore patient experiences of these services
2. To examine social cohesion and social capital within the community contexts which CHWs operate and how this impacts on community participation
3. To examine the policy environment and institutional setting and how this impacts on the facilitation of community level inter-sectoral services
4. To reconsider how these issues are conceptualised in order to inform policy and implementation

1.5. Structure of the thesis

This thesis is by monograph divided into 11 chapters. The first chapter provides a background of the thesis and includes the problem statement. The second chapter presents a review of the literature regarding the different models of PHC and the debates involved regarding these differences, including the history of CHWs in PHC internationally. The section also reviews the

experiences of inter-sectoral action and community participation internationally and briefly presents modern mechanisms that potentially can provide guidance to addressing the social determinants of ill health in the current context. Chapter 3 presents an overview of the context in South Africa, including the history and current status of PHC and CHWs in the country. Chapter 4 addresses the methodology of the study, which includes an overview on the selection of the case studies, sampling and the piloting of the study. Chapters 5 to 9 present the findings, where Chapter 5 gives an in-depth description of the communities, the households and their context within which the three organisations provide services. Chapter 6 provides an in-depth overview of the organisational contexts of each organisation and its programmes. Chapter 7 covers the experiences of both the CHWs and the clients as they interact in the community, relating how the CHWs provide their services and how households receive them. Chapter 8 explores the experiences of the CHWs as they attempt to facilitate community participation and looks at the extent to which they are able to use any available community participation structures in their respective communities in order to provide services. The final chapter of the findings examines the extent to which the CHWs facilitate inter-sectoral outreach services, relating the theme to the extent to which there are community participation mechanisms. Chapter 10 provides a synthesis of the findings, looking at the key aspects and implications in relation to current literature. The final chapter is the conclusion and provides recommendations, including suggestions on potential future studies.

CHAPTER 2

2.0 Literature review

This chapter outlines the scope of the thesis by reviewing the literature that describes comprehensive PHC and more importantly, the role of CHWs in PHC. The chapter pays attention to four main areas. The first part describes the history of PHC before discussing the motivation for the model's current recognition and re-evaluation, looking mainly at the social determinants of health. The third part focuses on the role of CHWs in PHC and the fourth section looks at the two key principles of comprehensive PHC, inter-sectoral action and community participation. In both these latter sections, I review empirical studies that describe the implementation of PHC through CHWs. In addition, the studies assist to contextualise the role of CHWs in PHC, inter-sectoral action and community participation. I then conclude the chapter by describing the conceptual framework that emanates from the literature. The framework provides the theoretical basis of the PhD and describes how the key components that relate to PHC and CHWs link together.

2.1. The global context - The history of primary health care

The Alma-Ata conference in 1978 provided a platform for the changes of ideas about health care especially with regards to developing countries. At this conference, health was recognised as a human right and the goal to achieve health for all was established [8, 17]. At the brink of significant health inequity between and within developing and developed countries, the Alma-Ata Declaration on Primary Health Care was launched to provide guidelines for achieving the goals to address basic health care needs. The PHC approach included comprehensive

programmes with a key focus on disease prevention and health promotion, community participation, inter-sectoral collaboration for health, universal accessibility and coverage, and attention to cost-effective intervention and appropriate technology [17, 18]. This broad approach had social justice as a central principle [4, 17, 19].

After Alma-Ata, there was a shift away from the comprehensive aspect of PHC to a more selective approach. The justification for this more focussed move was that a comprehensive approach was too complex for most governments and that it would be more realistic to target scarce resources to specific diseases [20]. This selective approach led to the support of a few low cost interventions, mostly in child health care [17]. The predominance of these vertical health programmes, where health services targeted specific diseases accounting for high mortality and morbidity, led to the narrow implementation of PHC subsequently termed selective PHC, which ignored the social determinants of health [17].

Despite the rekindled interest for a more comprehensive PHC approach, the confusion regarding its interpretation remains, as clearly outlined in one of the articles in the Global Health Watch 3 [21]. For example, Rohde et al [22] refers to the comprehensiveness of PHC as a broader or increased range of a set of selective, clinical interventions which are primarily facility-based and curative. This approach disregards the core elements that make PHC comprehensive, namely, community participation and inter-sectoral action, including preventive, promotive and rehabilitative services. Even more concerning is the fact that it considers the use of community-based resources such as CHWs as a temporary measure to increase coverage with the aim to extend the health care function to more skilled workers. This undermines the involvement and empowerment of the community to take responsibility for its own health care [21]. However, in

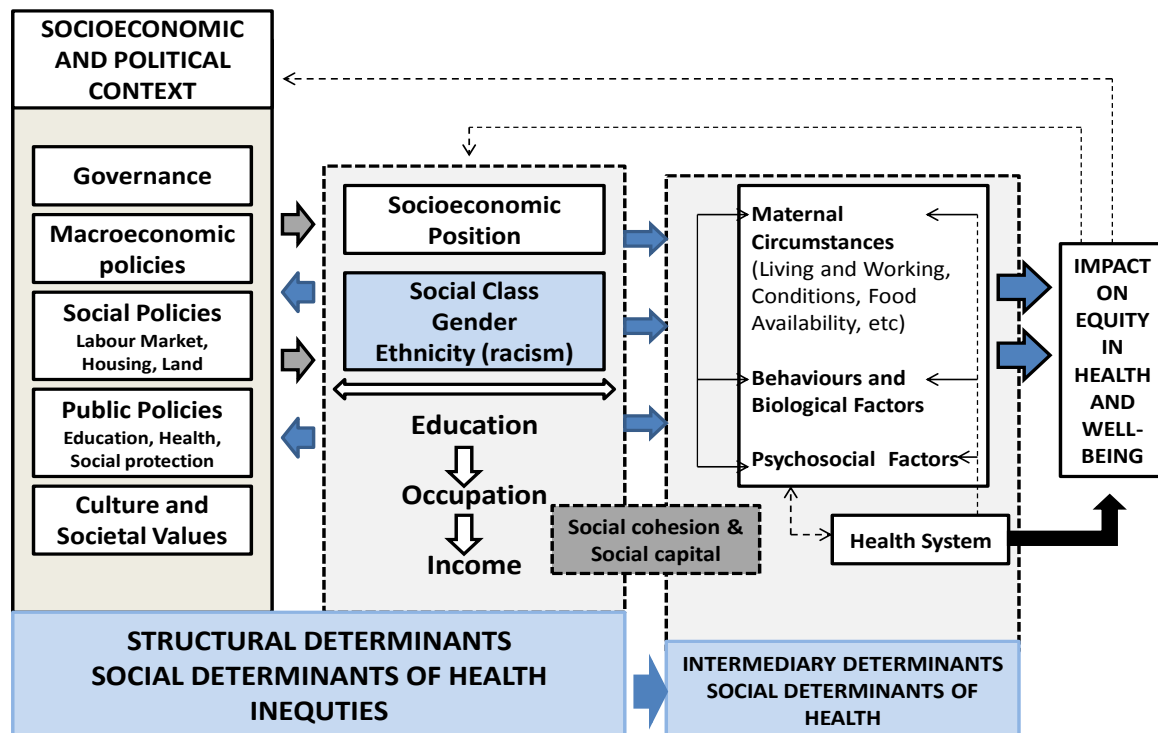
contrast other articles in the series, such as Lawn et. al. [4] and Rosato et. al. [10] both acknowledge the value of mobilising communities and inter-sectoral action.

Moreover, the effort by the World Health Organisation (WHO) in the 2008 report [1] to revisit PHC also digresses from the original comprehensive nature of PHC to the more ‘mechanistic’ and ‘supply-side’ [21]. In fact, the report tends to interchange the terms ‘primary care’ and ‘primary health care’, exposing its bias to PHC that focuses more on health services [21].

Overall, the renewed interest in the late 2000s in PHC is coupled with the focus of moving away from the narrow, medically-related approach to one that recognises the strong influence of social factors on health status. It is in this light that the PHC and the social determinants of health share a common platform, hence Wilkinson and Marmot [23] regard it as the one influencing the other, where better health can influence other social factors such as education, and economic development and visa versa. It therefore follows that a PHC system needs to have an approach that recognises the macro/structural and intermediary elements. In addition, the core principles of this comprehensive approach to PHC, inter-sectoral action and community participation are considered to be the important mechanisms to address the social determinants of health. These two elements are a prominent feature of this thesis and the findings are embedded in the social determinants of health.

2.1.1 A description of the conceptual framework of the social determinants of health

Figure 2.1: The CSDH conceptual framework



Source: Solar O, Irwin A. A conceptual framework for action on the social determinants of health. Social Determinants of Health Discussion Paper 2 (Policy and Practice). Geneva: World Health Organization 2010.

There is a plethora of evidence which agrees that the primary cause of the bulk of the global burden of disease and health inequities is due to the conditions in which people reside, work and grow [24]. Addressing those social factors calls for action that is beyond a health sector focus, with the need for interventions across sectors [2, 24]. The currently consolidated conceptual framework (Figure 2.1) of the Commission on Social Determinants of Health (CSDH) [25] has helped to contextualise this and will be able to guide the envisaged implementation of

comprehensive PHC in South Africa and in other developing countries . Moreover, it attempts to justify the need for a health system that adopts a social determinant approach.

The framework indicates that the socio-economic and political **context** is a strong influence of stratification within society. Some of the factors that determine this stratification and therefore contribute to health inequities are the nature of policies, hence, any attempt to address health inequities cannot be without looking at the existing or absent policies. The CSDH framework describes those mechanisms that stratify and cause social division as the **structural determinants**. These determinants influence the distribution of aspects such as *income* or *education* according to *gender*, *race* or *disability*. Consequently, it is also these mechanisms that determine the socio-economic status on the basis of access to and extent of *resources* and *power*. Moreover, formal and informal *governance structures*, *education systems*, and/or *social protection* develop and assist to maintain these differential social positions or address the inequities through progressive policies.

The differential social hierarchies and/or positions are the cause of inequities in health status and health outcomes. This is primarily because they affect aspects such as *living conditions*, *food security*, *psychosocial conditions* and *behavioural* and/or *biological factors*. According to the CSDH framework, these are the **intermediary determinants** and more importantly, the *health system* is included as part of these intermediary determinants. In order to have an impact on or improve some of these determinants, such as the health system, and certainly to reduce health inequities, a social determinants approach is needed. This approach strongly requires inter-sectoral action, where the sectors that influence the intermediary mechanisms can act in a coordinated and collaborative manner. Improvement of the social determinants can contribute to improved health, which can therefore have an impact on social factors such as social cohesion

and social capital, access to resources such as education and social protection. In short, equity in health cannot improve without action on both health and its determinants.

It is for this reason that I have used Solar and Irwin's [25] CSDH conceptual framework (Figure 2.1) to inform my understanding and analysis of the findings. As a result, I have incorporated it in my conceptual framework (Fig 2.3), which attempts to provide a theoretical basis of the study.

2.1.2 The debate about the link between primary health care and the social determinants of health

The discourse regarding the role of PHC in addressing health inequities has not been without some concerns. The view is that both these approaches, PHC and the social determinants of health, share a common factor, they are key strategies to focus on health equity through a lens of policy and core values. However, due to the experience of selective PHC being biased towards curative health care rather than on the other influences on health outcomes, those who advocate for a social determinants approach question whether PHC has the ability and competence to guide and facilitate inter-sectoral action or even move beyond the narrow curative approach [2]. Regardless of this doubt, some authors such as Gilson et. al. [26] are of the view that a strengthened health care system is crucial to address health inequities and in addition should guide the process of establishing linkages across sectors. Furthermore, those favouring a more social determinants of health approach fear that the focus on developing a well-functioning health care system may divert the attention towards strengthening PHC principles rather than moving beyond the health system paradigm [2]. The concern from those advocating for attention to PHC is that the health sector has broad priorities such that prioritising social determinants of health in a comprehensive PHC response may reduce the effort to strengthen an already neglected level of health care. Ultimately, Rasanathan, Montesinos et al. [2] believe that

setting the two approaches against each other is likely to achieve very little. Rather, it is important to acknowledge that PHC and social determinants of health both have the potential address health inequities and challenges. Furthermore, PHC is merely an approach to strengthening the health system and addressing health inequities, but in doing this, it requires the support of other sectors which influence social factors that contribute to illness and disease. In fact, according to the CSDH framework, the health sector is considered one of the determinants of health equity/inequity and is not by any means a separate and privileged entity [25].

2.1.3 The urban context – a lens to examine the social determinants of health

My study is based on the social and economic dynamics that exist in an urban context. The urban reality and its complex social, environmental and service factors indicate even better that the determinants of ill-health are beyond the scope of the health paradigm. In fact, these determinants can be complex and multiple, particularly in urban settings and /or cities. Urban settings have been documented to be the ideal lens through which to examine the impact of the social determinants of health [27] as they are. It is a setting that is more likely to have a higher rate of inequities, socially and economically. Urban areas are more likely to be densely populated, hence higher health risks, higher potential to transmit infectious diseases and higher demand for resources. They are also more likely to have poorer households and minority groups, and due to the high density and socioeconomic disparities it is likely to create more barriers to care for those of lower socio-economic status and strain the health care system. In addition, the poorer living and working conditions where there is high rate of urbanisation leads to more chronic illnesses. It is for this reason that there is reference to the ‘double burden’ of disease resting on those in urban settings [27].

In fact, Geronimus [28] emphasises the value of the CSDH framework, citing that to address the underlying causes of the differential urban morbidity and mortality, policymakers have to tackle the structural factors such as income inequality, racism and overall poverty. In light of this, efforts to address health inequities have to incorporate both the social determinants of health and PHC. As a result, the current view is that inter-sectoral action and the involvement of communities remain crucial strategies to implement these approaches [2, 10].

The overall message is that the current discourse regarding PHC remains plagued with differing definitions of its implementation. My study examines the potential of CHWs in two provinces to contribute to a comprehensive approach of PHC. CHWs have enabled countries such as Thailand, Iran and Brazil [21, 29] to provide comprehensive health care services to large proportions of their populations, ensuring maximum coverage. This workforce has been considered an integral aspect of PHC and has the potential to facilitate community participation and inter-sectoral outreach services [29]. Comprehensive PHC emphasises factors such as universal access and coverage based on need, comprehensive care that focuses on the prevention of disease and health promotion, the participation of individuals and the community including self-reliance, inter-sectoral collaboration in order to deal with issues of determinants of health and relevant technology and resources that are cost-effective [4]. My study examines this comprehensiveness via the two core principles, community participation and community level inter-sectoral action.

2.1.4 Central players in primary health care – community health workers

There are a number of definitions of CHWs. A WHO Study Group [30], defined CHWs as a cadre of workers that “ should be selected by the communities, should be answerable to the communities for their activities, should be supported by the health system but not necessarily a

part of its organisation, and have shorter training than professional workers.” For the purpose of this thesis, I will use the definition by Lewin, Dick et al. [31] found in their Cochrane systematic review of CHWs: “Any health worker (paid or voluntary) carrying out functions related to health care delivery; trained in some way in the context of the intervention; and having no formal professional or paraprofessional certified or degreed tertiary education” [31] . I have chosen the latter because it captures the essence of the principles of comprehensive PHC which include functions that are “related to health care delivery as opposed to ones that are supported by the health system”. In my view, the WHO definition confines the CHWs’ functions to health rather than those that also relate to health, such as the social determinants. It is however important to note that as much as Lewin, Dick et al’s [31] definition alludes to a comprehensive approach, part of the definition, “trained in some way in the context of the *intervention*”, is a reflection of the how the evaluation of CHW programmes have been historically confined to selective clinical interventions rather than broader approaches. My study aims to indicate that the role of CHWs extends beyond that of specific interventions.

The examples of PHC programmes provided further in this section are only just a few amongst a sea of other diverse services that are provided by CHWs around the world. The type of CHW and their titles are as diverse as their functions. Whether they are referred to as “Community Health Volunteers” in Malawi, “Lady Health Workers” in Pakistan or “Brigadista” in Nicaragua, CHWs offer more than a singular function that is related to health care provision [32]. Moreover, this cadre has progressively proven to be an effective link between marginalised communities and the formal health and social services system [33] and have proven their ability to extend services to those difficult-to-reach areas and/or populations. Over time, many countries have recognised the

value of CHWs and respective governments have begun to invest in financing and implementing CHW programme policies [33]. South Africa is embarking on a similar endeavour. As I discuss the various PHC and development programmes, it is important to keep in mind that their implementation efforts have relied on community volunteers, whether as part of a state programme or an independent NGO. In addition, the success and/or failure of these workers to support the implementation of effective PHC has relied on key factors. These include the extent and nature of training, supervision and the support offered to enable them to negotiate their respective and often complex contexts [32, 34-37]. Considering that most CHWs in South Africa function within the organisational context of an NGO, it is important that an organisation has the capacity to fulfil this supportive role and facilitate these enabling factors. As I illustrate the experiences of the CHWs in my study, these factors will be important to consider as I examine the extent to which they were able to provide outreach PHC that are holistic.

2.1.5 Programmes that illustrate the different attempts of implementing primary health care

A number of countries have strived to roll out models of PHC. I highlight these programmes to illustrate the key components of PHC, community participation and inter-sectoral action, and to show how they can support comprehensive PHC. In this way, I also show how this approach has the potential to improve health outcomes. Part of this section demonstrates how CHWs have been the central role-players in supporting PHC programmes through their outreach services.

Although much of the discourse around revisiting PHC has occurred three decades after the Alma-Ata Declaration, it is important to highlight that several programmes had already pioneered the implementation of comprehensive approaches to providing primary health care services. Community-oriented primary care, which evolved through initiatives by the Karks',

went on to influence church-based and NGOs initiatives in apartheid South Africa in the 1940's and 1950's [38]. Even though the principles are more symbolic than having influenced policy in the country, their involvement went on to contribute to the discourse related to community-based care and PHC [39]. The barefoot doctor programme in China during the mid-1950's was exemplary of the wide provision of basic health care by lay volunteers [40], and subsequently inspired other countries to explore the use of village health workers [12].

Regardless of these early comprehensive initiatives, much has been said about the failure of many selective PHC programmes to improve health outcomes subsequent to the PHC conference. In contrast, Bangladesh illustrates how the ICDDR, B (Box 1) moved from using selective programmes to a more comprehensive approach. Consequently, the country is currently considered one of several that have managed to reduce their maternal, infant and child mortality rates [41, 42].

Box 1: Delivery of selective PHC approach in Bangladesh

A non-governmental organisation, The International Center for Diarrhoeal Disease Research, (ICDDR,B) provided specific PHC services, maternal and child health and family planning services in one of the country's rural areas [42]. With the aim of providing community-based family planning services using trained (volunteer) traditional birth attendants, the programme expanded to include other selected services such as acute respiratory infection treatment. Over time, it included other preventive and health promoting services. In addition to the programme, the country went on to incorporate other services to improve the socio-economic status of women such as micro-credit, improved education, access to water and increased food availability [43]. Furthermore, the reduction in the country's maternal mortality was reportedly associated with improved access to services such as midwifery, emergency obstetric care and safer pregnancy termination, including the overall improvement of women's education and social indicators [42].

Source: Chowdhury, Botlero et. al. (2007) [42]

Despite Bangladesh's initial implementation of vertical programmes to address maternal and child health problems, the ICDDR, B programmes progressed to embody the principles of comprehensive PHC which considered the need address the social issues that impacted on the health of these two groups. In addition, the community's involvement through the use of traditional birth attendants ensured that the community was self-reliant in addressing maternal and child health issues. Consequently this also increased the coverage of these services. India's Jamkhed Comprehensive Rural Health Project (Box 2) is another programme that embraced the key principles of PHC before Alma Ata. More importantly, it illustrated the value of community involvement in taking up its own health care services.

Box 2: The Jamkhed Rural Health Project in India

In 1970, a PHC programme was started in the rural area in India called Jamkhed [44, 45]. The project used community participation to establish farmers' and women's clubs, and other community activities by mobilising the villages together. These were coordinated and organised by the core component of the project, the trained village health workers (VHWs). The first activity involved the clubs identifying problems in the community. This resulted in the clubs' decision to focus on improving water supplies and sanitation. The clubs transitioned into women's development organisations which embarked on activities ranging from identifying women to be trained as village health workers (VHWs), establishing funds for women with household health emergencies and food crises through to micro-credit schemes. Using the VHWs, the project expanded to other villages to cover a wide population of over 250 000. In the first 20 years of its existence, it has showed a decrease in the infant mortality, birth rate and malnutrition and has almost reached a universal coverage in antenatal care, safe delivery and immunisation services [45]. The initial objective was for the project to call on midwives and nurses to reside in the villages and provide health care. However, due to lack of trust of outsiders, the community workers have been an essential factor of the project [46].

Source: Arole and Arole, (1975) [44]; Arole and Arole (2000) [45]

Similar to the Indian comprehensive programme, Thailand also relied on community-based implementation through its CHWs (Box 3). The nationwide network of Village Health Volunteers (VHVs) managed to achieve high universal coverage. However it is also important to note that the development of a sustainable PHC system is arguably also dependent on the political will and support of government [47]. The key PHC principles in Thailand were translated into policies. To strengthen community participation, the “Determining Plans and Process of Decentralisation” law was passed [46] . This resulted in a significant move of the national budget to rural areas with a portion of the fund from the sub-district allocated to health promotion and disease prevention activities. Moreover, a committee of community members with at least one VHV supervises a fund for health promotion activities and local community leaders and VHVs are trained in health planning. This strategy recognised that community members are important role players fulfilling positions within the PHC system with some level of influence.

Box 3: Delivery of comprehensive PHC in Thailand

The success of Thailand’s PHC programme has largely been attained through its Village Health Volunteers (VHVs), currently numbering more than 800, 000 across the country. PHC programmes in Thailand addressed the eight elements as recommended by the WHO and included another six in order to address the health needs of the country: promotion of mental health, dental health, health consumer protection, environmental health, substance abuse and HIV prevention. This approach achieved successes such as the improvement of both the management of child nutrition and nutritional status [29]. This was the result of the training in nutrition provided to VHVs, women’s groups and community leaders. The country has sustained its high coverage of immunization and skilled birth attendance, ensuring low inequity [22]. It progressively developed its district health system, which acted as a foundation for comprehensive provision of maternal, newborn and child health care. A large proportion of its implementation involved community participation, where VHVs were effective in

developing this aspect. The programme developed community self-reliance to such an extent that communities in villages are able to identify their own health needs. Another aspect of comprehensive PHC that characterised the Thailand PHC programmes was its focus on inter-sectoral action. The Ministry of Public health introduced the “Quality of Life for All” goal, to encourage shared responsibilities among sectors such as agriculture, education and health.

Source: Rohde, Cousens et. al. (2008) [22]

The examples of attempts to implement comprehensive PHC illustrate how community participation and inter-sectoral action are inter-dependent principles that are essential in the quest to address the social determinants of health. My study is based on this premise. However, in order to understand the experiences of the CHWs in my study, it is important to understand the nuances involved within these two components. I deal with this in the following sections.

2.2 Community participation in PHC: why does it matter?

The importance of community participation is based on the premise that for any community to achieve the health gains that are promised by the Declaration (that is, “Health for all by the year 2000”), communities should exercise the right to plan and implement their own health care programmes [48], in collaboration with the state. Considering the multitude of definitions, my study refers to community participation as defined in the Alma Ata PHC report: “The process by which individuals and families assume responsibility for their own health and welfare and those of the community, and develop the capacity to contribute to their and the community’s development” [49]. Within the discourse regarding community participation, there is a common perspective that the involvement of the community ensures self-reliance, health promotion, empowerment and collective action. Some have argued that due to greater control of the community, more resources can be provided, often appropriately in response to the ‘voiced’

needs [10, 50, 51]. In fact, community involvement in health has found wide political acceptance especially in developing countries because it was recognised as not only to be a cost effective strategy, but also a favourable way to provide comprehensive strategies to public health problems [52].

The benefit of a community's involvement in its own decisions and implementation of programmes has been validated by the Indian Jamkhed and the Kenyan Kisumu projects (Box 3, and 4), that have shown improved health outcomes. Community participation was a pivotal strategy in both these programmes. Despite the support and acknowledgement of the role of community participation in the implementation of comprehensive PHC, including evidence to indicate the potential of communities to ensure improved health care, the extent to which a community's involvement can really change policies to commit to equity in health care still remains unknown. It is also evident that projects of this nature are difficult to scale up, where once part of a national programmes, the top-down and bureaucratic nature of government changes the nature of community participation [10]. Because community participation needs to be a process of capacity-building within which individuals and/ or communities are ultimately empowered, authorities in higher levels of institutions such as governments may fail to realise that past successes of community participation programmes were often because they allowed the process to unfold and not by placing emphasis on achieving performance targets [10]. The unhurried nature of engaging with communities, which is flexible and responsive to their varied contexts, allows growth to be generated from within the community rather than from external financing [50, 53].

It is important to highlight that because CHWs are agents of community participation, it is even more important to consider their role in this component of comprehensive PHC. However,

CHWs can either be agents of community participation, empowered individuals to empower the larger community, or be used as a means of meeting the policy needs and delivery of targets of government in relation to the provision of PHC. These different approaches to community participation are more formally defined. The *empowerment model* is where community participation is used as a strategy to empower a community to take responsibility and make decisions regarding its health [54], while the *utilitarian model* is where governments utilise participation by using community resources (such as land, labour) to counteract the costs of providing services [55]. The use of CHWs as the facilitators of community participation can by definition cater for both models; however, it also illustrates the tension between these two modes of community participation practices [56]. The role of a CHW has its benefits, as it can lead to empowerment of the individual. From a South African perspective for instance, there is evidence that the CHW is able to gain a range of skills and knowledge, through training, which can provide an avenue to access other forms of formal employment [32, 57]. In other countries, the CHW can gain status through political and social prestige [56, 58]. However, the utilitarian aspect of the role of community participation is reflected in policies where CHWs are expected to create a bridge between their communities and the formal ('biomedical') health system, while also being able to balance the two paradigms of community (traditional practices of participation and health care) and the formal sector/s. This tension between these two forms of community participation contributes to the challenges that are encountered in the use of community participation to provide services to poor communities. Policies continue to lean towards a more utilitarian form of community participation, where in practice, it remains merely rhetoric [56]. This form of community participation is termed a resource dependency approach by Zakus [55], where a government would integrate community participation into the health service delivery

system, rather than using a community that has organically organised itself in the provision of its own health services. By definition, the resource dependency approach to community participation means that organisational behaviour is influenced by various environmental factors which are external to the organisation including how they are perceived, interpreted or enacted by the organization [55]. The author illustrated this form of community participation by an example implemented in Oaxaca, one of the Mexican states. The Ministry responded to its policy needs by merely co-opting various communities and individuals to provide health related services on its behalf, thus utilising the ‘environment external to the organisation’. The health service structures themselves, rather than the community, initiated many of the components of the programme. A health Ministry representative, usually a nurse, selected the volunteers (VHWs), the health committees and stimulated community participation activities. Due to the extent of control from the Ministry, the community (the health committees and auxiliaries in the local health facilities) remained dependent on the government structure and not much decision-making occurred within the community. Key decisions over training and control over resources for instance, remained at higher levels of government. With inadequate training of VHWs and therefore little regard and recognition by the community (due to lack of skills), community participation in this area of Mexico remained low and the quality of services by VHWs, including the committees and the auxiliaries, remained questionable.

Another perspective regarding the lack of clarity regarding the role of CHWs in community participation was highlighted in the 1980s. Community participation was viewed as a way of mobilising community resources, whether it be people, money or material, while another perspective leaned towards the practice being a strategy to improve people’s control over multiple factors that determined their health [59]. These varying perceptions regarding what

community participation actually is manifests in the way it is factored into the implementation and provision of services in various countries. More often than not, it has led to minimal successes.

Highlighting the factors documented in the literature as enablers to successful implementation is useful to show how various CHW programmes often remain unsustainable. The most common enabler of sustainable community participation is the small scale of the programmes initiated within and by communities with the aid of an NGO for instance [32]. A strengthening factor that enables communities to facilitate involvement is the extent to which their mobilising precedes the establishment of a CHW programme. This is as opposed to a CHW programme that is established in isolation of the larger community but rather occurs in conjunction with other community activities. This ensures the participation of the whole community rather than the CHWs being the sole source of community participation. The Western Kenya Kisumu PHC project [60] (Box 4) illustrates this, where community participation was generated within the community through the use of trained CHWs. Due to this the spirit of involvement has sustained without the formal project. Portes and Landolt [61] and Portes and Itzigsohn [62] explain this view through Latin America's efforts to institutionalise community economic initiatives. Policies to enable informal community grass-roots markets to trade with formal markets showed that it is important to develop policies and initiatives from what exists in the community rather than imposing external agents. They argue that 'outsiders' are often not *au fait* with the historical and social contexts that govern that community and this can bear challenges [61, 62].

Box 4: The Kisumu PHC (KPHC) project

The project is in Kisumu, Kenya's third largest town, in three of its adjacent rural areas. Due to poor water supply, there were frequent cholera outbreaks, a scourge of diarrhoea and malnutrition among young children. The town's inadequate roads rendered essential drug supplies often unreliable and inadequate. Community participation was central from the beginning of the KPHC project. Community members identified their needs, contributed money for the construction and maintenance of various facilities such as water sources and selected their own health workers. Committees were established to select, train and coordinate volunteers, mainly CHWs, TBAs and village health committee members. The village health committees were gradually used to secure support from government, donors, the church and NGOs to contribute to the training of CHWs. With the support of community nurses, the CHWs operated from both static and mobile clinics and conducted home visits where they promoted various health services such as child and maternal health. The project encouraged the community to take responsibility for their water sources. They identified groups that needed new water points, provided construction material, maintained, protected and cleaned the water sources. This created a greater sense of responsibility. To address drug supply problems, the CHWs were trained to participate in a drug distribution scheme where they learned basic skills in diagnosis and treatment and the use of seven generic drugs. Although the KPHC Project no longer operates in the area, important components of the project have been sustained with most of the CHWs continuing the work and new ones have been trained [60].

Source: Sohani and Fox (2004) [60]

These examples of PHC models that incorporate community participation illustrate the value of involving communities in PHC programmes. All of them show that involving communities ensures the extension of health issues beyond the health paradigm and places them closer to those social issues that affect communities and have an impact on health. However, there is a dearth of programmes that have been successful and sustainable, particularly through CHW programmes [32, 54] primarily because community participation is a complex and delicate process [50]. It is also important to highlight that, although community participation has

potential benefits, the understanding of it is contested. Not only is there the challenge of defining it, there are also the difficulties of power relations within communities. Community participation has been defined as a strategy for those in authority to utilise resources in the most efficient way [52, 63]. In some instances, it is seen as a form of empowerment where a community can find solutions and make decisions about its challenges and needs [64-66]. In light of these varied definitions, Rifkin [67] explains that attempts to define this strategy have been in vain, as it is a dynamic process that is determined by the context. Numerous experiences have highlighted the difficulties of facilitating community participation. Part of this has been the assumption that a 'community' is a homogenous structure [68]. Lessons have shown us that communities are made up of factions and conflicting interest, which often manifest in local politics and power dynamics [69, 70]. In such cases, patterns of power or powerlessness can determine who has influence, preference and/or is excluded [71].

Regardless of these limitations, community participation remains an important component for the success of CHW programmes and the delivery of comprehensive PHC. Its benefits of community participation are invaluable: people are more likely to respond positively to health services because they have been involved in the decision-making process about the services. Furthermore, they are more likely to change their risky health behaviour when they have participated in deciding how that change might occur. Added to this, individual and collective resources can be used to contribute towards activities to improve health in the community. Moreover, there is an element of empowerment where people (such as CHWs) who can facilitate this mechanism, gain skills, information and experience, so they are ultimately able to challenge their social systems [51]. Through community participation, communities have the opportunity to realise their ability to solve their own problems collectively [72, 73].

On the basis of the demonstrated value of this PHC principle, I further explore its complexity and discuss the factors that have the potential to ensure that community participation achieves the intended outcomes.

2.2.1 Factors involved in community participation

Although these studies above on CHW programmes provide lessons regarding the value of community participation, they fall short of explaining and exploring why and what determines the extent to which communities can mobilise to impact on their own services. As mentioned, community participation has been rendered a “complex and delicate process” [50] and as a result, various factors have been explored to explain this complexity. Terms such as “social cohesion”, “social networks” and “social capital” have been discussed interchangeably by a range of authors and scholars, as a means to understand the nature of communities and the existing factors that motivate them to participate. Since my study is embedded within the context of communities, I explore these factors (social cohesion, social capital and social networks) to understand the community dynamics that were involved in the case studies in my study.

2.2.1.1. Social cohesion

Social cohesion relates to the extent of engagement and the sense of trust that individuals have within their communities [74]. A more cohesive society, where there is a strong sense of group identity tends to be more sensitive to common wellbeing [75]. A sense of community generates the extent to which individuals feel that they have an influence on their immediate environment [76, 77]. Amongst the plethora of early studies regarding the phenomenon of a “community” and what it constitutes, there are a few that stimulated subsequent attempts to understand the dynamics involved in influencing individuals to participate in community development. Although not all were intended for understanding and examining participation in relation to

health, their theories and concepts can easily be extended to this paradigm. For instance, out of the many theories to explain and understand social cohesion from sociologists and psychologists, Chavis and Wandersman [76] developed and tested a model that illustrated the relationships involved in determining how a sense of community influences participation. They proposed three components which they considered to influence an individual's participation. Firstly, an individual's perception of the environment: this involves one's judgment about their environment. If those perception are negative, they may cause stress and/or arousal [78] and even withdrawal [79]. However, negative perception of one's environment can also motivate action. A study by Florin and Wandersman [80] indicated that one's perception of the environment can motivate one to participate in an organisation that has been formed to improve the community. Secondly, one's perception of one's social relations: this involves the interactions that occur amongst neighbours. A sense of community influences people to interact with those in their neighbourhood. This allows for the establishment of social networks, which then allow for individuals to support one another. For instance, strong social interactions allow for the transmission and sharing of past experiences of health facilities, health professionals, drugs and illnesses [75], thus extending the process of health information. Thirdly, the perception of one's level of control and empowerment within the community: this relates to an individual's perception of their likelihood that their efforts or collective effort can solve a community's problem [81], which illustrates how empowerment is an important factor. In Chavis and Wandersman's [76] study to test this model, the findings supported the notion that the three components played a significant role in influencing people's level of participation. They indicated that when people have a strong sense of community, they are likely to feel more secure with their neighbours, have a positive perception of their environment and are then more likely to

feel comfortable with attending their first meeting. The findings also supported the model by showing that the relations amongst neighbours contributed more than any other items used to predict the level of participation. The findings also suggested that a sense of community contributed to community development in that individuals and groups felt that more empowered to act collectively to address shared needs. The study indicated that when individuals shared a strong sense of community, they felt more motivated and empowered to change their circumstances. However, Heller [82] cautioned that empowerment had, in earlier times, progressed to be considered an individualistic process rather than both an individual and collective dynamic. This is an interesting notion, as the author states that if discourse regarding empowerment remains with the former connotation, it could constrain the efforts of the community development field to influence collective strategies for achieving power for marginalised groups [82]. This observation is very relevant, especially if one considers that in most CHW programmes, particularly those that are institutionalised, those in the system, for instance nurses, conduct training and capacity building. Only those selected individuals (CHWs) of the community gain skills through community participation. How far this empowerment extends to the larger community, thus serving the core principle of community participation, is questionable. Despite this concern, an important aspect which relates to this component is how participants must have the opportunity to develop and gain skills, in order for action to be effective. Those in authority, whether it be government or a community agency, play a role in providing this support [76].

Given the complexity that often results from the dynamics in individual-group associations, the elements that influence behaviour are multifaceted. McMillan and Chavis [77] indicate that those “reinforcements” maintain a positive sense of togetherness. Some of the reinforcements, as

multifaceted and difficult to pinpoint as they are, stand out. The *competence* of group members brings members closer together. People are attracted by people and groups that offer the most benefits [77]. In my view, this could be expanded to the importance of competence amongst CHWs. A community that has confidence in their competence and skills is likely to respond more positively to their services. Since it is part of the value of training, competence certainly legitimises their social standing in the community [13]. The extent to which a group *shares values* will determine their ability to organise and prioritise to meet their needs [77]. So, the level at which individuals in a community share an emotional connection, based on a shared history, facilitates or inhibits the strength of the community [77]. These “reinforcements”, as termed by the authors, provide some of the factors to explore when discussing the status and quality of the communities involved in my study. Furthermore, the concept of social cohesion is also important to my study because of the notion that a healthy society needs an ability and culture of collective action. However this can most likely be determined by a community that has shared experiences. Consequently, these collective experiences can potentially strengthen collective solidarity which can lead to action [83].

At this juncture, it is important to highlight the value of social networks and shared experiences in the discourse on urbanisation and the relocation of communities in major cities. The rural – urban differentiation is part of the context of my study. The quality of social networks in rural areas certainly stands in stark contrast to those in urban areas. More specifically, rural communities commonly have more homogeneous and dense social networks, long existing social ties and shared histories and experiences, hence solidarity and a culture of reciprocating is normal practice [84]. Much has been said regarding what contributes to urban health inequities and poverty. Part of it has been related to the social fragmentation [27]. In South Africa, for

instance, instead of improving or upgrading existing informal settlements, communities in urban slum areas are subjected to frequent relocations. This has resulted in the break of already weak social networks and existing informally developed community organisations [85]. In fact, efforts to implement community development interventions that aim to build on existing community structures have been met with challenges [85].

A case study to evaluate a change in social cohesion to improve health status is illustrated by a community-based intervention to address child nutrition in two Kenyan villages (Box 5). This programme further indicated some of the factors that can constrain social cohesion and therefore reduce the potential for collective participation. These included illiteracy, conflict, poor leadership and lack of access to and control of resources. [83]. Interestingly, another component which was considered to have resulted in the poor performance of one of the districts was diversity, which constrains social cohesion [86].

Box 5: The Community-Based Nutrition Programme (CBNP) – Kenya

The CBNP implemented a social educational process to improve the nutritional status of children in two districts in Kenya (Makueni and Kwale). The Participatory Approach to Nutrition Security (PANS) involved participatory learning and action techniques. Although there were other components, the PANS process included activities such as the identification of causes of malnutrition. Community members working in peer groups conducted the process and presented the analysis through various participatory learning techniques and visualisations. They presented and discussed these visuals in a community meeting. This resulted in the identification of what the community perceived to be the causes of malnutrition and illness in children.

Some of the key factors that were identified as causes of malnutrition were, what the community termed “social disunity”. They attributed this to the weakening of social bonds due to the disappearance of social support systems and the migration of men to towns for labour and returning with new illnesses and lifestyles. They perceived these factors to erode the social fabric and result in the breakdown of

family structures and support for child care. Furthermore, the community viewed these factors as increasing single, female headed households, and reducing the amount and quality of childcare because families were no longer able to assist each other.

A subsequent process in PANS was for the community to identify solutions to address the causes of childhood malnutrition. As the primary developers and implementers of community action plans, the community prioritised social disunity as the immediate problem to address. The PANS process was used to identify the factors attributed to the health outcomes. During the implementation of action plans for solutions, informal discussions and observations indicated that communities with a stronger pre-established social fabric were more able to embark on their action plans and implement them. Another factor was what the community called congruence building, which referred to social cohesion and this factor was a result of the participation process and the activities that were implemented through the community action plans. These components were stronger in the Makuela district than in the Kwale district. The latter District was more ethnically diverse and the literacy levels were lower in both women and men. In addition, the movement of squatters into the District, which occupied valuable land, resulted in conflict regarding access and control of resources. These differences further highlight the factors that contributed to the differences in health outcomes related to the CBNP intervention.

Source: Havenmann and Pridmore (2005) [83]

The case in Kenya (Box 5) illustrates how communities with strong social cohesion are better able to mobilize themselves more efficiently to challenge their circumstances [83, 87]. In fact, the efficiency and sense of unity within a community contributes to its ability to mobilise resources such as funds for an ill member to access a health service. These collective assets that can be accessed and utilised by a group or a community, is termed social capital. The extent of social cohesion determines the level of sharing of these collective assets. Consequently, social cohesion is a necessary characteristic to generate social capital.

2.2.1.2 Social capital

Although an integral component in the discourse regarding community participation and/or community development, social capital is a concept that is discussed as a more sophisticated

combination of social cohesion, social networks and social integration [9, 88, 89]. Berkman [9] notes that a key feature in a cohesive community is a strong level of social capital. As a result, scientists used this to measure the extent of available resources in a community. In relation to the social determinants of health, the public health community continues to grapple with the manner in which social factors interact with those that are economic ones. Consequently, this has generated an interest in the concept of social capital [90].

Although considered an important factor, similar to the notion of community participation, there is still contestation about its definition. Social capital generally refer to the notion that sociability, ‘connection’ and participation in groups has benefits for the individual and the community [91]. The definition has evolved over time, however, the theme or premise remains common in all its variations. Some authors have defined social capital in terms of the presence of social networks or structures mostly embedded within informal relationships which generate or allow individuals or groups access to resources ([61, 92, 93]. Other scholars have related it to civic participation or organisation through which decision-making and policy formulation can occur. This form of civic engagement can be a mechanism to establish community development, hence the need for cohesion at community or societal level [94-96]. My study used the term ‘social capital’ to focus on the extent to which mobilisation, whether through formal or informal community structures, generates the potential to access resources and services. Based on this lens, I use a combination of the two perspectives, which relates to the existence of civic participation, including the role of social cohesion in generating this form of engagement. The thesis also focuses on the role of the levels of social and civic trust in communities, including the existence of social networks, as these factors influence coordination and cooperation for mutual gain [9, 90].

The ultimate message is that social capital is a mechanism for social support [97]. Therefore, it is beneficial for and can be incorporated within the discourse regarding health. However, considering there are some in the political arena who believe that social capital may allow states to withdraw or limit social support, while others believe that state support is important for the growth of social capital, the different interpretations indicate that the benefit of social capital on health remains disputed. A more current interpretation though advocates for the establishment of health promoting communities through a process of strengthening social and economic conditions [90]. Regardless of these perspectives, social capital is a subject that is awash with complexity and subjectivity primarily because it is a construct of components such as participation, trust, networks and cooperation. What remains evident is that it is a component that can be cultivated in cohesive communities where there is a group identity based on trust, which can establish healthy social networks. In order to sustain this cohesive nature in a community, social capital requires constant maintenance and regeneration, as it represents social trust through social networks, civic organisations and general association in life [95]. Family, friends and acquaintances can create a valuable asset base that can contribute to the health and well-being of individuals and communities. These social networks or relationships are implicit in the broader structural contexts such as health care and educational systems and political institutions [86]. At an intrapersonal level, it affirms a sense of belonging, worth and dignity, some of the factors that have been attributed to action beyond the self [98].

The value of strong social networks that individuals and groups can reach out to for resources and support has been an underestimated ingredient in the participation of communities in social, political and economic systems [99]. Furthermore, social capital performs other social functions which were emphasised by Putman [95, 100]. Bonding social capital typically occurs in more

homogeneous networks such as families and is considered to form strong closer bonds which are a strong source of social support. Bridging social capital is one that happens in more diverse networks which bridge social differences but are weaker due to the heterogeneous ties [95]. Although bonding social capital purportedly forms stronger networks, it is the bridging type that allows individuals and communities to form linkages across their communities and /or cultures outside the confined of common bonds. Bridging social capital allows one to access resources (e.g. information about how to access health care or job opportunities), which are different from the resources that a family network could provide [95, 101]. The two can, however, be generated and/or strengthened exogenously in order to achieve overall effect. For instance, one of the world's most violent cities, Cali in Columbia, implemented a social capital intervention for its youth, the most affected population [27, 102, 103]. The programme strengthened relations amongst young people (bonding social capital) and between the youth and institutions (bridging social capital). Consequently, social capital was retained over three years in the evaluation population while it reduced in the control community, with violence-related indicators improving in the evaluation community as compared to the control population [102].

Social capital is key to the discourse regarding community participation because it can be strongly reinforced by participation. Participation in networks and groups enhances the possibility to access information and to increase social support. In this way it also reduces some of the constraints that are brought about by the lack of general and/or financial resources [104]. In fact, it is when resources are lacking that social capital and strong social linkages can enable vulnerable communities to deal with social factors that determine vulnerability, as has been the lesson from a South African study [105]. Strengthening elements such as social networks, trust and social cohesion, which are associated with social capital enhances the possibility of active

participation [104]. However, it is important to recognise that generating social networks and social capital is likely to be difficult in communities that have to endure the manifestations of poverty such as powerlessness, dependency and poor social fabric [106]. Portes and Landolt [61] make an important assertion that ‘engineering’ social networks and/or social capital has not received much support because the communities where this is attempted often have poor social relationships due to the dynamics alluded to in the discussion above, such as poverty, and recent settlement. On the other hand, if there are attempts to generate social capital it may be useful to strengthen it from within the community where there is some established trust with the agent that leads the intervention. The Cali programme in Columbia, for instance, was implemented by a long-existing NGO [102]. This is particularly useful for communities that are insecure and lack trust towards outsiders. In fact, this notion reinforces Portes and Landolt’s [61] view that it is beneficial to use existing structures for such interventions rather than outside imposition.

Despite the difficulty in finding favourable conditions to nurture social capital in the quest to achieve a culture of community participation, there is still merit in considering it as a valuable tool to facilitate social cohesion and social networks. Social capital provides poor communities with collective assets that can be enablers to accessing resources. Those assets lie within relationships that have been born out of interaction and participation [107], hence the strong link between community participation and social capital. In fact, the discourse has expanded to consider social capital as part of a policy instrument in the efforts to increase community participation and therefore provide equitable health care [108, 109]. Not only are there benefits for governments in supporting programmes that highlight the role of poor communities in finding solutions to their ill health, particular community programmes that allude to the same

philosophy have illustrated how social cohesion should be part of any health program that aims to improve community health [83].

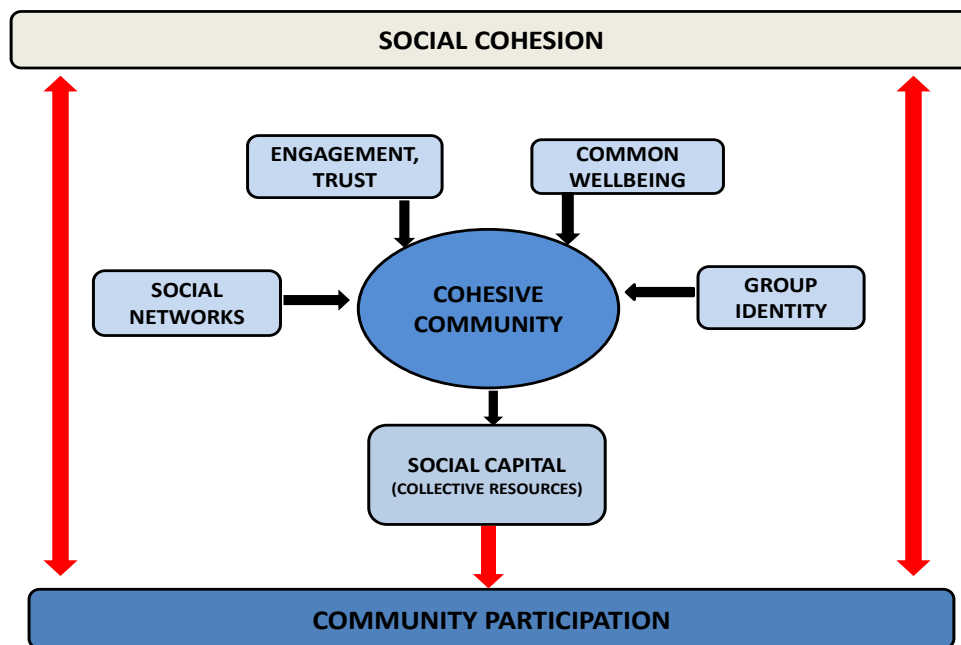
One of the reasons community participation should be an area of focus for any government that seeks to enable communities to challenge and address their own social systems, especially with regards to issues of health, is the fact that community participation provides favourable opportunities for different groups, such as community organisations to interact and increase their networks and therefore diversify the resources available [99]. Based on the discussion regarding community participation and its benefits, it is my view that diverse interaction can take place at an informal level, but it can also be valuable at a higher level where multiple sectors network and interact to address health and /or social issues within a community.

The Kenya example (Box 5) illustrates that a community with a diverse range of networks can galvanise a range of resources to strengthen social capital and to achieve improved health outcomes. The successful District, Makuela in Kenya had established a strong social fabric. This contributed to two important elements: Firstly, the mobilisation of a diverse range of members who contributed to various skills, and secondly the ability to pool resources from different sources, ranging from the individual community members to the municipality. This latter element strengthened a sense of control of resources including the access to those resources, in contrast to the Kwale District where there was conflict over resources due to the diverse ethnic groups which did not constitute a cohesive well-established community.

It is important to note that despite the definitions provided for community participation, social cohesion and social capital, the findings in this thesis show that how these concepts play out in reality is influenced by the different contexts and the heterogeneous nature of the communities.

This discussion highlights that, community participation is relies on three key factors, the social networks in the community, the extent of social cohesion and social capital. However, the discourse does indicate that the relationships between these factors are neither linear nor as simple as my graphic in figure 2.2, which visually illustrates these key components, as guided by the literature.

Figure 2.2: Key components of community participation



In the discussion above it is acknowledged that participation of local communities ensures that communities have some influence over access to services and resources. In the effort to constantly remain conscious of the impact of social factors on the health of communities, community participation has emerged as a key mechanism to galvanise communities to hold the sectors that play a role in addressing the social determinants of health accountable. However, what is apparent from the discussion is that the extent of community participation relies on the

extent of organisation and the degree to which there are representative organisations in a country. From the examples that I have provided, it is evident that NGOs have played a major role in implementing community and CHW programmes. They also indicate the crucial role of such institutions. The effectiveness to provide services using community participation as a resource is also dependent on the nature of the relationships NGOs establish with other institutions, such as government. This notion is discussed further below.

2.2.2 Non-governmental organisations and the State – relationship dynamics

The discourse above shows that the involvement of a community is often in response to what government is not able to provide, whether it be resources or services. Part of this response has been within institutions such as community-based organisations or NGOs. The programmes mentioned above are a reflection of NGOs' and/or CHWs' responses to the need to address the health problems of their respective societies. Moreover, they are an indication of the massive role that NGOs have played in filling a gap that governments have failed to or have had limited capacity to fill. This is more so in developing countries. It is reported that NGOs in these countries have influenced the lives of 250 million people through interventions and agendas targeting issues ranging from human rights, development, landlessness, gender and the environment [110, 111]. Although most of the programmes cited are mainly through independent organisations such as Jamkhed in India (Box 2) and the KPHC project in Kenya (Box 4) while some are state-based community agents such as the VHWs in Thailand (Box 3), all are community initiatives that interact with the government to some extent. Consequently, NGOs have progressively fulfilled the role of providing external support in various endeavours which are often those of the state [110]. It is in this light that the dynamics of power and the

nature of the relationship between these two entities is important to consider or at least keep in mind.

Although government can have administrative and resource capacity from which NGOs can draw from, its level of power is also known for its domineering and ‘co-opting’ nature [112]. If NGOs are to function according to their own mandates and provide effective and intended services, they need to function as autonomous and independent agencies. The period of observing top –bottom approaches, during the early 1970s, showed that the state’s total control over the functions of community level initiatives limited the achievements expected from development interventions [112]. In fact, it has provided a lesson on the need for the two entities to co-operate due to their respective strengths and advantages. While the state has the financial and policy decision-making muscle, NGOs have a closer relationship with communities, enabling them to provide relevant and needed services. For development initiatives, one cannot be effective without the other [113]. To avoid a relationship with the state from becoming one that reduces the legitimacy of NGOs in their communities, they need to ensure co-operative autonomy, where the relationship establishes a collaborative synergy between the ‘top’ institutions and those at the ‘bottom’ [113]. NGOs such as Proshika in Bangladesh [114] and the Self-Employed Women’s Association in India [115] which had co-operative relationships with the state show that the success of this relationship was due to the policy/legislative support from government and the capacity to generate funding within the respective organisations [115], hence reducing financial dependency.

My study was based on the extent to which NGOs, which employ CHWs, are able to provide effective services. Considering that they function and exist within an environment where they interact with the state; whether as partners or service providers, it is important to understand the

potential nuances involved in this relationship. Consequently, this background will allow us to understand the experiences of CHWs and the NGOs discussed in this thesis in their interaction with organs of the state. In addition, in understand these experiences, the background also highlights the nuances that exist within communities that can either enable or constrain the functions of CHWs, such as the extent of social cohesion, social capital and how that influences the community participation.

2.3 Community level inter-sectoral action – why does it matter?

Inter-sectoral action has been defined by the WHO as “a recognized relationship between part or parts of the health sector with part or parts of another sector which has been formed to take action on an issue to achieve health outcomes (or intermediate health outcomes) in a way that is more effective, efficient or sustainable than could be achieved by the health sector acting alone” [116]. It is based on the premise that the health of a nation cannot rely only upon the health sector, primarily because health to a large extent is determined by social and economic factors [1]. The effort to work across sectors grew in the 1990’s with the growth in the knowledge of the social determinant of health.

Inter-sectoral action has been an important strategy to address the SDH and health inequities in various countries (which are highlighted in this section). I draw from the discussion above (section 2.1) in order to explore the dynamics regarding inter-sectoral action and its purpose in comprehensive PHC. More importantly, this section will assist me to interrogate and understand the experiences of the participants in my study.

Although the conceptual framework of the social determinants of health (fig. 2.1) by Solar and Irwin [25] provides a range of complex mechanisms to explain how health is affected by other social factors, the notion is generally overt. Take the simple example of the context of the workplace. Any changes introduced in this area, for instance, the loss of employment, can cause an elevation in blood pressure and therefore can have an adverse impact on health [1]. The fact of the matter is that the health sector cannot on its own accord change labour relations or employment arrangements nor can it independently increase taxes on alcohol or regulate rural migration. Although these measures have the potential to achieve positive health outcomes, they are not within the control of the health sector [1]. They lie within the domains of other sectors. For this reason, it remains crucial for the health sector to collaborate with other sectors, not to establish collaboration to address pre-identified priority health issues, but to ensure that non-health sectors understand and recognize that health is a socially acknowledged outcome that is embedded in all policies [1].

2.2.2 Poverty – a key factor to understand inequity in health and access to services

My study is embedded in the experiences of CHWs in an urban setting while using a rural setting as a comparative. It is important to highlight from the literature, the conditions and circumstances that require effective community level inter-sectoral action. This will shed light on the participants' experiences of inter-sectoral outreach services and contextualize the findings.

From the discussion above regarding the social factors that contribute to ill health, it is clear that the mechanisms leading to inequitable health and access to resources are inter-related and influence one another in a complex manner. Consequently, the framework on the SDH [25] (fig.2.1) is particularly relevant because it provides a means to illustrate the overall context

within which my study is based. While a range of factors interact to cause health inequities as seen in the framework, for the purpose of my study, I focus on poverty as a lens to explore these other social factors. The foreword illustrated in Box 6 appropriately sums up this assertion.

Box 6: Definition of poverty

“Poverty creates ill-health because it forces people to live in environments that make them sick, without decent **shelter, clean water or adequate sanitation**. Poverty creates hunger, which in turn leaves people **vulnerable to disease**. Poverty denies people **access** to reliable health services and affordable medicines, and causes children to miss out on routine vaccinations. Poverty creates illiteracy, leaving people poorly informed about health risks and forced into dangerous jobs that harm their health.” Foreword by Ann Kern (WHO) & Jo Ritzen (World Bank) in Dodd and Munck (2002) [117]

There is broad agreement that poverty is a structural mechanism that relates to a lack of those basic elements that are necessary for one to endure a basic living standard. There is also agreement that there are degrees of poverty. “Absolute poverty” is a lack of the basic material that meets the basic means for survival [23, 118]. It has an impact an adverse impact on food security, the ability to access health care services, education, clean water and sanitation, shelter and basic necessities such as clothing [118]. “Moderate poverty” is a life where the “basic needs are met, but just barely” [119], whereas relative poverty is when one is significantly poorer than the average proportion in society [23]. In light of these perspectives, it is evident that poverty is defined in varying and debatable ways because the term itself can be understood in a narrow sense, meaning the lack of income or a broader sense, which considers multi-dimensional issues such as housing, health, education, access to services and, the ability to access social power relations and alternative avenues of accessing resources [120]. The latter understanding certainly embodies those social factors that determine one’s health status. In spite of this variability, it is

evident that poverty creates barriers to accessing not only health but other services and opportunities as well. Moreover, it is a state in which one is more likely to be exposed to health risks [121]. A plethora of studies show how the structural drivers to ill health, such as unemployment, manifest in these barriers. The cost burdens (such as transport costs) of accessing services or for repeat visits to health facilities [122-125] lack of access to food to ensure that one takes chronic medication [126, 127], poor social and/or support structures [123], and cultural dynamics (such as patriarchy) that occur within households and/or community [128] all impede the potential for households to benefit from the comprehensive efforts to address and reduce health inequities. Moreover, as discussed above, people that are affected by poverty experience these barriers regardless of the traditional urban-rural distinction. Urban settings, despite the assumed better proximity to and availability of resources, present with a complex set of access issues. This is more so in the poorest parts of urban areas, the informal settlements. This is where one finds “not only the high concentration of poverty and substandard living conditions..., but also the insecurity of tenure and marginalisation from the formal sector, including basic health services” [129]. Inter-sectoral action has been widely proposed as a key strategy to addressing health inequities as a means of responding to these complex dynamics.

2.3.1 Strategies to address health inequities – Inter- sectoral action

The nature of the SDH are evidently *multi-sectoral*; hence ill health has been associated with illiteracy, lack of clean water or lack of adequate housing, for instance [27]. They are also *multi-level* in the sense that policy decisions made at higher levels of government have an impact on what occurs at community level and in addition, where one lives, and those community – level factors also have an impact on health [27]. Recent efforts of inter-sectoral action, which provide a range of strategies, particularly with regards to policy intervention, have recognized these

complex dynamics and these are reflected in how they have been implemented at various levels of government and various levels of society. Although there have been macro level inter-sectoral action efforts to address inter-country health inequities, such as those driven by the WHO or United Nations agencies [130], it is those national level efforts that provide lessons to successful implementation. It is evident from those efforts that each of the countries have approached this strategy according to their respective contexts. Malaysia's attempt to address the health of its population included the emphasis on inter-sectoral action as a strategy to implement PHC [131]. Although coordinated from central government, the principle of inter-sectoral action translated across all levels of government through the implementation of Healthy Public Policies [131]. Cuba also illustrates how inter-sectoral action has been central to its national health system (Box 7) [132].

Box 7: Inter-sectoral action in Cuba

In the effort to improve the health care system, Cuba has experienced a gradual process of incorporating an inter-sectoral approach to health care. This has developed over many years from the **1960s** when the initial approach was to increase coverage, access and social participation. The country established health committees which are inter-sectoral and community bodies that are sourced from social and community organizations. Economic and social sectors involved included environmental services at community level, the water system sector, agriculture, education, health, amongst others and it involved activities such as environmental health, hygiene and domestic comfort, vaccination and others.

The **1970s and 80s** involved the establishment of comprehensive and community clinics and the introduction of family medicine programmes. These institutions strived to achieve greater coverage, targeting populations with specific risks and strengthen the concepts of universality, social participation and inter-sectoral action. A number of projects remain primary examples of activities that demanded and facilitated the involvement of communities and inter-sectoral participation in health problems at a *broader level: **The Turquito Manati Plan***: Targeting populations that resided in mountainous regions,

the agricultural sector was in charge of assigning different sectors. The construction and agricultural sectors were responsible for building sanitary services inside houses while the agricultural sector and small farmers were tasked with the responsibility of increasing the production of garden fruit and vegetable gardens to address nutritional issues in people that resided in the mountains.

The Cuban Commission on Health and the Quality of Life: This was established to promote public health and to co-ordinate relevant activities thereof. Membership of the commission came from sectors such as health, education, business, transportation, media, science and technology, public food supply, water resources sector, social security, including other social organizations. This project has resulted in a reduction in mortality due to accidents, improved the supplies of vegetables and reduced malnutrition among at-risk populations. Despite the indication of existing problems from the evaluation, such as drinking amongst teenagers and inadequate environmental hygiene due to illegal dumping, the inter-sectoral strategies have seen some effective outcomes.

Source: Serrate, Lausanne et al (2007) [132]

New Zealand has adopted inter-sectoral action in order to address its health inequities through whole-of-government approach by utilizing a deprivation index. This multi-level approach resonates with the notion that inter-sectoral action is a mechanism that can be used to target health issues at several levels and for various issues. Although coordinated from central government, the key feature of these inter-sectoral action initiatives was the involvement of communities (Box 8). The New Zealand Ministry of Health for instance selected three different categories of inter-sectoral action activities. These initiatives involved community level activities that created links and networks at local level. The categories reflect the diverse and multifaceted factors that are involved in determining the health of communities and populations and even more importantly, they attempt to approach the context through various settings, namely at the more macro level setting, at a more issues-based level and at a micro case level [133].

Box 8: Inter-sectoral action – New Zealand

Inter-sectoral action in New Zealand was based on three initiative categories.

1. *The over-arching area or settings-based initiatives*: These were based in rural or city settings. An example of a city based programme was the internationally renowned Healthy Cities programme, which mobilised agencies and citizens to identify and facilitate actions such as child injury prevention and environmental health. A programme which was the longest running and considered the most successful was in Manukau. Some of the factors that were attributed to the success of this initiative were for instance, the establishment of a common understanding amongst the different agencies and local organisations by drawing up a Charter, ensuring a public declaration of a commitment to the endeavour. Another enabling factor was the project's ability to establish strong links between the different sectors and its strong community participation component.
2. *The Issues-based inter-sectoral action initiatives* were programmes such as those that addressed alcoholism. Various projects under this category were established, with varying results. Since the main aim of the projects were to coordinate existing resources (organisations) rather than establish new ones, the projects that achieved successful outcomes such as a community alcohol action project specific to the Maori community, based their strength on establishing strong cooperative partnerships with existing agencies, such as the local police and community members who assumed higher roles within the community.
3. *Case-Management Initiatives* involved programmes such as the Strengthening Families Initiatives to improve the overall well-being of families. The primary efforts went into strengthening collaborative relationships between sectors such as welfare, education and health, nationally and locally. The initiative established a variety of projects. One of them was the Collaborative Case management. The primary mechanism was the facilitation of joint meetings with the involved agencies and the families and an evaluation indicated an overall strengthening of already established collaborative relationships prior to the establishment of the project. The evaluation also indicated related improvement outcomes for families.

Source: Maskill and Hodges (2001) [133]

Although promoted by a globally based organisation such as the WHO, the Healthy City initiative appeared to foster a similar mechanism to that in New Zealand, where inter-sectoral action can be established at various levels and settings. Moreover, it resonates with the efforts to

address complex multi-level and sectoral urban health issues where municipalities and local level structures struggled with an increasing population due to urbanisation. This placed-based strategy in cities was meant to enable the facilitation of multi-sector projects at specific settings such as schools [27]. In fact, the strategy had several aims: to increase community participation; increase awareness of health issues in urban development interventions; strengthen capacity at municipalities to cope with increased pressure from the demands for services; enable urban municipalities to form partnerships with community-based organisations and communities and to generate networks of cities to share resources such as information [27].

The inter-sectoral action strategies above illustrate that this mechanism has the potential to address health equity but moreover, they enable us to examine the factors that influence successful or poor implementation. These key factors are expanded on in the section below.

2.3.1.1 Influential factors in inter-sectoral action

a. Organisational culture

Similar to community participation, the context and cultural environment is important for the success of inter-sectoral initiatives. It is therefore crucial for the different sectors to understand how others operate particularly from a structural point of view. In other words, approaches that achieve results for one sector may not achieve the same results for another sector [130]. What remains important is the recognition that different organisational cultures and their use of their own ‘language’ can make inter-sectoral action difficult to carry out [26]. For example, from presentations on health promotion in schools, Rowling & Jeffreys [134] indicated how the challenges in the collaboration between health and education were due to factors such as the

professional diversity of views, competing priorities and the differing decision-making processes. Health research believed that health promotion mechanisms were effective in all schools while educational research indicated that schools have widely different cultures (such as rural school compared to inner city schools). This indicated that partners need mutually recognition of the benefits, feasible implementation mechanisms and compatible monitoring and evaluation strategies [134].

b. Political support

The road to successful inter-sectoral collaboration requires political support [24, 130], as indicated in the Manukau Healthy Cities project (Box 8). A clear mandate and a supportive environment can contribute to effective inter-sectoral initiatives, as is evident in Sri Lanka, where there was explicit support for inter-sectoral initiatives through the formation of a new structure called the National Health Development Network which was formed to support the National Health Council. The network was established to act as a mechanism to facilitate and ensure political commitment to inter-sectoral action at national and provincial levels [135]. In fact, legislation has been commonly used to formalise institutional arrangements amongst sectors.

c. Lack of skills and capacity

Despite the mechanisms to facilitate inter-sectoral action, Lock and McKee [136] report that a lack of capacity to implement can hamper inter-sectoral initiatives. This lack of capacity was evident in a study on formal community participation mechanisms (such as health committees) that structurally encourage the involvement of a diverse range of sectors and community members. Due to consistent withdrawal of members and absenteeism, some of the health committees often had to function with very few members which resulted in infrequent meetings,

poor functioning of the community structure and poor community participation initiatives [137] . This shortcoming can hamper the process and sustainability of inter-sectoral collaborations. Similarly, findings from a participatory action research in Zimbabwe indicated that poor capacity resulted because of inadequately trained and poorly resourced Village Community Workers and Environmental Health Technicians, which limited their role in community mobilisation and inter-sectoral action [138].

d. Accountability

A shared sense of accountability across all those involved in the different sectors is a factor for successful inter-sectoral action [24]. For this reason, the Canadian Agency report [130] recommends the establishment of an agreed upon accountability framework, as accountability requirements are different for different sectors. Inter-sectoral collaboration is never self-generating and needs mechanisms to facilitate this process, however a vested interest in this initiative is often a positive start. So, inter-sectoral collaboration may be more successful at community level, where there are fewer personal interests to protect one's own sector in relation to, for instance, limited budgets. In addition, social cohesion at community level can play a crucial role in fostering effective inter-sectoral action. It requires complex collaborative efforts to address multifaceted issues that have an impact on health [139] and a community-based structure of social networks is one of the necessary ingredients to achieving this.

Despite there being a drive for collaborative efforts, Stahl [140] suggests that inter-sectoral action should be strengthened within the health sector which should lead the collaboration process. However, this requires sufficient capacity within the sector to deal with, for instance, administrative and public health training. This is more so because other sectors require input from the health sector to guide the process that will allow health implications to be taken into

account [140]. Therefore, any efforts to address health inequities require a strengthened health care system [26], which requires strengthened PHC [2]. With enough support inter-sectoral action can be most effective at community level. This support can be through the promotion of local action and application of political pressure on the higher levels of government to comply. Furthermore, the critical factor also includes connecting community groups with public health personnel [135]. Sri Lanka has been exemplary in this regard, by creating structures that liaise with non-governmental actors and assist in coordinating their initiatives [135]. In fact, the WHO emphasises this point by noting that non-governmental organisations can play a crucial role in implementing policies that are developed through inter-sectoral approaches [141].

e. Government structures and the policy terrain

Considering that inter-sectoral action initiatives also occur within broader social and political settings, it is also important to explore some of the more fundamental factors that determine the extent to which they occur. The political context of inter-sectoral action means that it involves different levels of government [142]. However, the complex government structures have been considered a contributor to the challenges of inter-sectoral action implementation [142]. This is primarily because the nature of the relationship between these different levels, determine the extent to which joint action is translated amongst the different levels, within and amongst multiple sectors. A lack of clarity regarding where the responsibility for issues on the determinants of health lies makes for unclear regulation, which in turn have an impacts on inter-sectoral action. Inter-sectoral action efforts at provincial and national levels in Canada for instance, have highlighted the complexity mostly embedded within the policy context. Different levels of government have different responsibilities for health and the social determinants of health such as education and labour and the differences in the division of responsibilities are also

between its provinces. This is a constraining factor for the implementation of any national initiatives [142]. A similar political and/or policy context presents a barrier to the implementation of its macro comprehensive policy framework. In Belgium, entities responsible for addressing its various social determinants of health are distributed differently amongst the local, provincial and national levels of government [142]. In the same country, public health services such as prevention and health promotion are located at regional level while health care related to treatment are at national level. In this context, discourse regarding inter-sectoral action initiatives is based only at regional and local levels [142], hence lacking a holistic perspective in this regard.

An inter-sectoral approach needs to be incorporated at a macro level for it to be regarded as important across all levels of society. Chile is exemplary and illustrates the essence of this notion. When the democratic government replaced the military one, it established several special programmes with social welfare objectives which required collaborative action across the government sectors within national, regional and local social networks. The establishment of this principle was translated across all levels of society [142]. Likewise, as a strategy to reduce the gap in its health inequalities, the state of South Australia adopted the “Health in All Policies” (HiAP) approach [143]. Established as a centrally coordinated process, the state uses its main planning document, the South Australian Strategic Plan, to explore and foster inter-linkages of various targets within the planning document [143]. Through this approach, various projects have involved different sectors. Its success was linked to the prominent cross-government focus, a central government involvement and support and the use of methods of inquiry that are adaptable across sectors but use a health focus [143].

This drives home the point that the principle of inter-sectoral action cannot be far reaching if it is not translated with similar objectives, strategies and commitment across different levels. In England for instance, the establishment of a joined-up-government approach to address its health inequalities achieved limited outcomes. The horizontal integration which originated and strengthened at national level was not transferred to local levels, resulting in poorer, more vertical approaches and inconsistent inter-sectoral action mechanisms at local levels [142, 144, 145]. Cuba's reported varying outcomes of its inter-sectoral action efforts have been attributed to the disjuncture between national and local levels of society. Limited involvement, consultation and lack of support at local level for professionals and community members resulted in mixed inter-sectoral action impact, despite there being strong national support [142]. This indicates that the disconnection between levels of government makes it difficult for actors in each level and in each sector to observe and understand each other's contexts. Mechanisms to approach inter-sectoral action at national level may not be similar to those of other levels of government and therefore difficult to translate to local level circumstances. It is therefore necessary for national inter-sectoral action strategies to be informed by local level issues and contexts, to avoid the top-down approach of inter-sectoral action development and implementation [142].

Inter-sectoral action initiatives at local levels are recognised to achieve better gains in terms of implementation. The principle of community participation plays a strong role in this regard. The one community in the Makueni District of Kenya (Box 5) illustrates this. In Ecuador, the municipal government in one of its regions organised an assembly which was attended by community participants. This gathering facilitated the identification of the main lines for regional planning and development. This activity established an inter-sectoral process [142]. The activity has reportedly achieved improved health outcomes; reflected by the lower incidence of maternal

and child deaths in over three years [142]. In this case, local government played the primary role of facilitating the initial process of mobilising the community and providing support in the process of inter-sectoral action. An important element to note here is that all of these initiatives can occur with limited or without the support of national government, however, strong local government support is essential, especially when there is an empowerment aspect to the process. Despite the success that has been demonstrated by this bottom-up approach, it is important to acknowledge that there are even better gains in collaborative work between the different levels of government. That is, there is benefit in working through both top-down and bottom-up, although strong local level inter-sectoral action initiatives can influence inter-sectoral action at higher levels as illustrated in India's sex worker project, the Durbar Mahila Samanwaya Committee Theory and Action for Health Research Team (DMSC)[146] (Box 9).

Box 9 Inter-sectoral action in India – Sonagachi red-light area

A WHO funded study on sex workers in a city of India, Kolkata, which showed a low prevalence rate of HIV at 1% but that 80% of sex workers reported STI symptoms, with condom use at 1%. The All India Institute of Hygiene and Public Health (AIHPH) established the Sonagachi HIV/AIDS Intervention Project (SHIP) as a public sector initiative (which eventually became Durbar Mahila Samanwaya Committee (DMSC). The project focussed on STI treatment, condom promotion and peer health education, mainly to decrease the high levels of STIs and increase the use of condoms amongst the marginalised group of sex workers in the main red-light district of Kolkata called Sonagachi. The project started at a small scale with a few peer educators (PEs) who were trained sex workers to conduct health education and condom distribution and a small clinic in the district. With the core driver being the sex workers themselves (PEs), the project expanded to include interventions such as; vaccination and treatment programmes for the children of sex workers, literacy classes for sex workers and their children, political activism for workers' rights, advocacy drives linking them to political leaders and law enforcement, community mobilisation, micro-credit schemes and cultural activities The DMSC established its own financial cooperative which offered savings schemes and micro-credit to

sex workers. By the time of the evaluation in 2007, it had more than 2000 sex workers as members with affiliations of five different organisations with different functions.

Source: DMSC (2007) [146]

The sex workers, including the community, had to establish and illustrate a powerful level of organisation. They had to generate skills that positioned them as independent and knowledgeable community members. These factors rendered them independent from higher government levels, however, the establishment of their own micro credit and banking facility required government recognition. Their established status as an empowered group that incorporates advocacy principles earned them state recognition and thus the right to control their own economic resources [146]. The nature of this bottom-up approach eventually influenced higher levels of government. Through this buy-in, DMSC was able to incorporate government officials in other activities of the organisation such as advisory boards to involve them in inter-sectoral action activities. This demonstrates that each level has different resources and powers to share, but a stronger involvement of communities results in the recognition and demand for an integrated perspective on health issues, as opposed to the more siloed approach of higher level government [142, 146]. Moreover, enabling communities to approach health issues inter-sectorally challenges these siloed approaches and structures of government sectors [142]. To highlight this notion, the DMSC's (Box 9) initial objectives were primarily focused on HIV/AIDS prevention [146]. However, as with any community, dynamics are never one dimensional. The organisation responded to sex workers' other social needs such that the organisation organically evolved its approach to an integrated one requiring inter-sectoral activities [146]. With advocacy principles embedded in these activities, the role of DMSC applied inter-sectoral action demands on the state. In addition, an important factor which is echoed in this organisation was the strong social

capital that was cultivated due to the level of mobilisation and participation by the group. The organisation established strong informal social networks from which the sex workers could draw on for their activities, from legal experts to those who could provide physical space and logistical assistance [146]. Although they are an example of a sub-community within a larger one, the sex workers illustrate how an organised community that recognises its own potential can offer and enforce inter-sectoral action at the local level while influencing higher levels of government. This also supports the position that a strong and mobilised community can function and sustain itself independently from the higher levels of government.

Because of the level of independence by this community in Sonagachi (Box 9) and thus the strong bottom-up approach to inter-sectoral action, local level efforts were minimally affected by the government's varying level of commitment and support. This echoes Barr's [142] view that this approach protects local level efforts from any changes in government.

The discussion above indicates that NGOs and communities have a significant role to play in facilitating inter-sectoral action at local level. With sufficient capacity, they not only have the potential to address specific issues affecting the community, but also have the ability to influence policies that can have national impact, as illustrated by the DMSC in India (Box 9). Brazil (Box 10) also offers a lens into the benefits of involving communities in influencing higher level issues. In fact, the role of community participation was an integral part of the country's constitution [142], with communities playing a strong role in demanding the PHC service from its municipalities [147].

Box 10: Primary health care – Ceara, Brazil

A PHC programme was established in one of Brazil's poorest states, Ceara, to improve universality with regards to access to basic health care and to improve the state's poor health outcomes. The Family Health Program's (FHP) core implementers were trained villagers, called rural health assistants or health agents in municipalities. Through a process of decentralisation, municipalities had the opportunity to secure control of funds for the programme. However this was determined by specific conditions: The community in a municipality had to show strong demand and interest for the programme so that funds would be released to employ a nurse. A growth in the program to other municipalities was driven by the general public's observation of its success in the municipalities that were implementing.

The health agents conduct home visits to households within their assigned communities while receiving supervision from nurses based at the local clinic. The agents provide services ranging from immunisation and diarrhoea treatment and have now expanded to providing services such as promoting cancer screening, water and sanitation promotion, and in a few municipalities, in the promotion of early childhood development.

A key success to the programme was in the selection of the health agent: The first factor was that communities were only included in the programme if they had established a leadership committee, with a local business leader, a church representative and trade unionist. These committees were responsible for deciding on the agents to employ. The second factor to its success was the quality of the supervision and training. Both aspects were conducted by the nurse and most importantly, to ensure inter-sectoral action in the programme's implementation, the training factored in the local concerns of the agents and clinic staff.

Inter-sectoral action was also ensured through the decentralisation of some areas of government administration to municipalities. Through extensive training of municipal authorities, the administration process involved shared decision making with other sectors such as NGOs, through the municipal health councils. The programme has made strides in providing universal coverage of the states priority health issues with the involvement of the community and inter-sectoral action. Now in its period of expansion, the FHP reportedly provides services beyond medical care, with its main services organised according to its population needs [148]

Source: Svitone, Garfield et al. (2000) [147]

Despite the illustrated value of inter-sectoral action and the factors involved, the examples of country implementation also provide a range of practical approaches which move beyond the theoretical factors thus far discussed. The ‘how’ of inter-sectoral action implementation can determine the extent to which it is successful or not.

f. Organisational/ government structures

One of the factors that were prominent in the implementation of inter-sectoral activities were the structures involved in its organisation. Creating organised structures to support inter-sectoral action at local level, but particularly in government, provides authority to the targeted health issues/s and strengthens the cooperative nature of addressing health inequities [142]. However, organisational structures, especially those in government can typically be complex and bureaucratic. Norway dealt with this complexity by incorporating the policy process of its National Strategy to Reduce Social Inequalities in Health on existing government structures, as opposed to creating separate structures for inter-sectoral action. The strategy was implemented through the reorientation of existing activities and budget allocations, instead of a separate budget with its own action plans [149].

The complexity of structural organisation also manifests itself in inter-sectoral action in the fostering of collaboration of diverse sectors. Simply bringing different sectors together across all levels of government may not necessarily foster inter-sectoral action. The enabling factor is how those different sectors assume their active roles. For instance, in the India DMSC initiative, the importance of ensuring that a wide range of sectors were involved in the process was primary, however, they were involved at different levels for different needs. The active involvement of municipal government was instrumental in some of its achievements, such as establishing its financial entity. However, besides this level of involvement, the state participated mostly at an

advisory level. This was also evident in the role of its inter-sectoral action committees, ranging from being responsible for the policy process to an advisory role. This approach enabled the sex workers' organisation to manage its diverse partnerships and collaborators [142]. What remains important is that for inter-sectoral action initiatives to be effective, appropriate linkages between levels within the sectors, particularly between the local and higher levels and across sectors need to be established [24, 150].

g. The Role of the Health Sector in inter-sectoral action

The health sector is considered to have the potential to play an important role in facilitating inter-sectoral action and thus can have a strong impact on the broader socio-political environment [26]. It can provide leadership in the development of processes and mechanisms that facilitate inter-sectoral action, particularly because it is in a more informed position to provide a theoretical framework and rationale to leverage the work related to inter-sectoral activities [26, 130, 142]. The nature of the health sector can however be a hindrance to strengthening and retaining the types of partnerships that are required for successful inter-sectoral action. The fact that it is based on a biomedical model of health, focussing on curative interventions, can often result in it functioning outside of the established mandate and agreed parameters of those relationships [24, 26, 142]. This can develop into an environment where the leadership takes on a more domineering role and thus isolating other sectors. Consequently, this can result in a situation where inter-sectoral action efforts only address the narrow objectives rather than the broader social, economic and historical aspects involved [142]. Despite the indicated importance of the leadership of the health sector, it is not in all instances that it can and should take a central role. Logically if dealing with an issue that is within the knowledge, experience and is related to programmes delivered by the health system, it is best that the health sector takes a leadership role.

However, issues beyond the scope of the health sector, such as those relating to the social determinants of ill health (e.g. poverty), the sector can play a role as a policy partner where it can be involved in the development and implementation of the policy rather than lead the process. The extent of the role of the health sector can therefore vary, however, it is evident that it remains crucial that it is visible and active in most inter-sectoral action efforts. For instance, Malaysia's national strategy to target social and environmental determinants was led by the economic development, education and housing sectors [131], which were more appropriate for this endeavour, although the active role of the health sector remained crucial. A message in relation to leadership in inter-sectoral action is primarily that it requires a central player to facilitate the process. Interestingly, South Australia's Health in All Policies (HiAPs) approach has placed that central role at the government of the country, where all relevant sectors have to play a key role in inter-sectoral action efforts without imposing the primary responsibility on the health system. Nonetheless, health is incorporated and adapted according to the specific inter-sectoral action project [143].

A key component of a centralised role of government in inter-sectoral action resonates with *the joined – up government* approach. This approach is based on the premise that in order for priority services to be addressed in a coherent manner, agencies cannot operate independently [151]. The Healthy City initiative by the WHO is illustrative of this approach [27]. Closely related to it is *systems thinking* which refers to how effective health managerial practices require a supportive environment in which the health system is effectively interconnected. It allows one to understand and appreciate the characteristics and relationships within systems [152]. In an effort to understand health systems, de Savigny and Adam [152] provide a Framework for Action which constitutes components that make up the health system in a coordinated fashion. These

components, which are termed the health system building blocks, include: governance, information, financing, service delivery, human resources and medical technologies. All of these building blocks have an effect on one another and at the centre of this system there are people. Placing people in the centre of this system drives the premise that primary health care should be built on fairness, social justice, participation and inter-sectoral collaboration [152]. South Africa has a similar mechanism to encourage civil servant commitment to public service called Batho Pele, a South African approach meaning “people first”, which aims to get public servants committed to serving people and to find ways to improve service delivery [153]. This is an indication that there are some existing tools to work with in the effort to involve committed individuals in the provision of PHC. In addition, it is people that can drive efforts that contribute to effective systems, such as collaborative approaches. It is in this light that the core of my study was based, that is, the different layers that make up the health care system in Gauteng province can have an effect on each other. Part of the aim of examining the institutional contexts of the different agencies with whom CHWs interact with was to focus on how they are interconnected to one another.

These two areas (joined-up government and systems thinking) have offered the space in which to explore and facilitate inter-sectoral action across and between various levels of organisations. Consequently, I have briefly included them in the discussion as a way of acknowledging that current attempts at inter-sectoral action are being explored through specific mechanisms and languages.

What also remains evident from all the practical experiences of the country examples is that establishing a strong PHC system can create an environment that can influence the development of inter-sectoral initiatives at local level [142]. In fact, PHC purports to be “an approach to

organising society, including health systems, with the aim of achieving health equity” [154]. Inter-sectoral action therefore mainly lies at the helm of the health system whose responsibility it is to reach out to society to advocate for ways that can support its efforts to reduce health inequities [2]. With an enabling environment where there is strengthened PHC, CHW programmes have proven to play a crucial role particularly with regards to a bottom-up approach to community level inter-sectoral action.

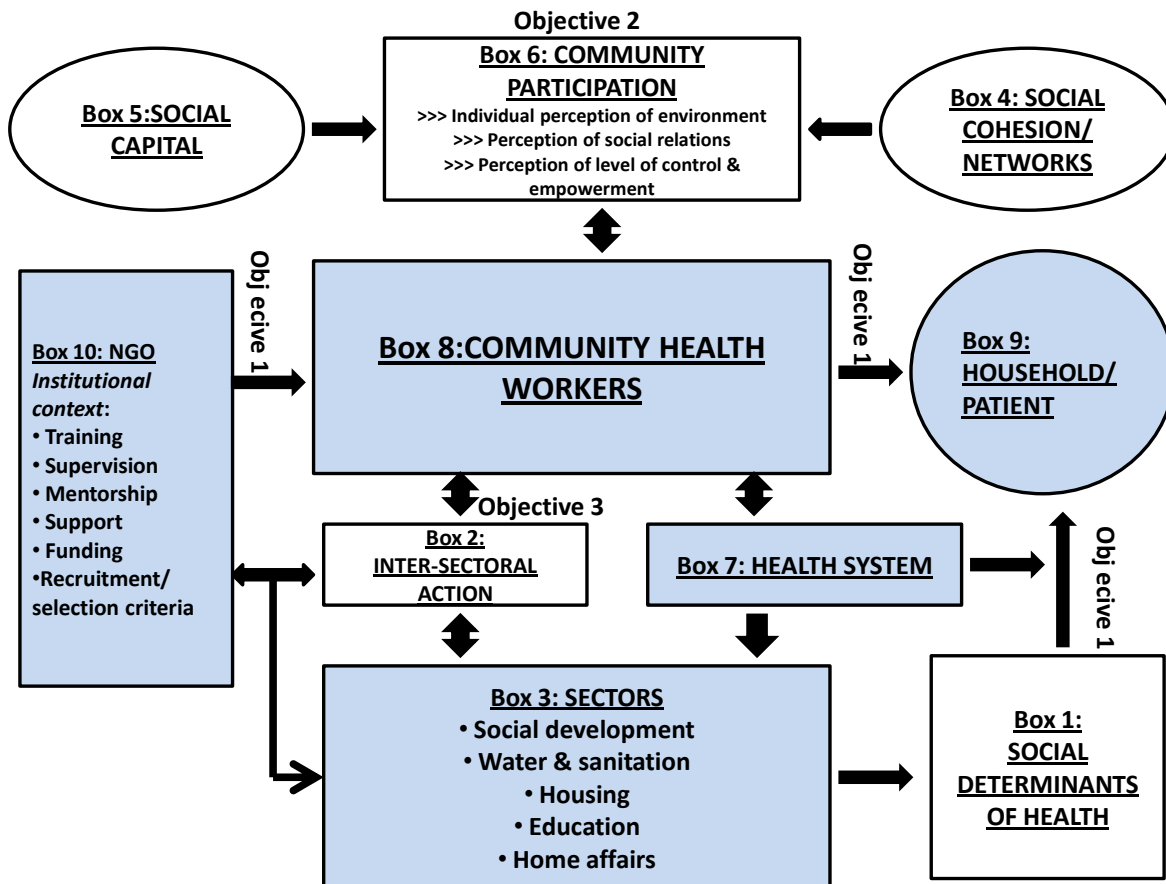
It is also evident from the discussion above that effective and sustainable inter-sectoral collaboration needs effective and strengthened structures of community participation. These also need to be embedded in effective accountability mechanisms and supported through resources and legislative strategies. Inter-sectoral action is complex, involving multiple players and requiring all sectors involved to engage within a spirit of common interest and shared values. In addition, strengthened social cohesion and social capital, where there is collaborative effort to achieve positive health status for communities, plays a key role in inter-sectoral action. Despite the literature highlighting these factors at a broader and macro level, there is a common understanding and motivation that community organisations such as CHWs can play a crucial role in driving these two components of comprehensive PHC. However, community level inter-sectoral action and community participation requires that they are part of the organisational culture at all levels of society.

2.4 The Conceptual Framework

The section above has been an overview of the theory and discourse regarding comprehensive PHC and the role of CHWs. In this section, I present and describe the various components and

hypothesised linkages that constitute my conceptual framework (Figure 2.3). It therefore provides the basis in which to explore the various issues that have emerged in the PhD study.

Figure 2.3 Factors in comprehensive primary health care and community health workers



Source: Author's own adaptation of comprehensive PHC from the literature

I have developed the conceptual framework by consolidating the key issues that are related to comprehensive PHC and CHWs found in the literature. The framework represents the pathways, possible linkages and the environment in which CHWs provide services. The shaded boxes represent the actors, while the non-shaded ones indicate the processes and/ or concepts. In the quest to address the **social determinants of health** (Box 1), community health workers have the

potential to facilitate **inter-sectoral action** (Box 2) in communities, so as to link them to the different **sectoral departments** (Box 3). CHWs rely on a variety of components to ensure such an endeavour. An active and cohesive community (**Social Cohesion/Networks** - Box 4) that has sufficient **social capital** (Box 5), that is, community assets from which to mobilise resources to act and support households. Both these components influence the extent of **community participation** (Box 6) which CHWs can use to deliver outreach services. At an individual level, three factors influence a person to participate. His/her perception of the environment, his/her perception of their social relations and his perception of his level of control and empowerment within his community [76]. Furthermore, CHWs require an effective **health system** (Box 7) which is able to reach, refer and provide a range of services to communities. However, communities need to access those services easily and sufficiently. Within this ideal environment, **community health workers** (Box 8) have the potential to provide comprehensive services to communities and households (**Household/Patient** - Box 9), within the scope of comprehensive PHC, if they function within a supportive institutional context (**NGO** - Box 10). In addition, the range of components derived from the literature relate to the objectives of the thesis as indicated in the framework. The study, embedded within this framework in the discussion below, considers and incorporates the framework as it delves into the stories presented in the case studies and households. The methodology in Chapter 4 has been utilised in order to explore the issues proposed for the study.

CHAPTER 3

3.0 The South African context

3.1. Current population and health outcomes

South Africa's history has had a significant impact on the health of its population, its health policies and its services. Fifteen years after apartheid-related discriminatory and restrictive laws and policies, inequity continues to permeate development efforts across all aspects of its society. These inequalities also exist in health status where a disproportionate burden of ill-health is in black African and rural households [155-157]. Despite various policy changes, the country's government has struggled to realise improved health outcomes. South Africa is currently experiencing four concurrent epidemics [158]. The burden of non-communicable diseases continue to grow while illnesses related to poverty, such as infectious diseases, malnutrition and maternal deaths are prevalent [159]. HIV and tuberculosis are concomitant epidemics and a major public health challenge. South Africa accounted for 17% of the global burden of HIV infection in 2007, with approximately 5.5 million people [160, 161].

South Africa is a middle-income country with worse health outcomes than several low income countries. This is partly due to the level of poverty and derelict environment, particularly in rural, peri-urban and informal dwellings, as well as the effects of HIV/AIDS [162, 163]. Rather than seeing a decline in child mortality since the Millennium Development Goals baseline was established in 1990, the country has experienced an increase, with 69 deaths under the age of 5 years per 100 000 live births [164]. The maternal mortality rate for HIV-negative women is 34

per 100 000 live births, which is similar to other middle-income countries such as Brazil and Thailand, however, the rate is ten times higher in HIV-positive women [165].

These major epidemics overshadow other public health challenges that affect the current health outcomes of South Africa. According to WHO estimates, the burden of non-communicable diseases in South Africa is two to three times higher than that of developed countries, and similar to that found in some sub-Saharan countries [166, 167].

Despite non-communicable diseases traditionally being considered as diseases of affluence, the distribution indicates socio-economic disparities. The heaviest burden is in poor communities, increasingly in rural areas and disproportionately affecting the poor in urban areas [166, 168].

Despite the establishment of progressive health care policies by the post-apartheid government in 1994 such as free PHC, the anticipated benefits have not materialised. This is partly due to the inadequate quality of health care and inequitable access to services [169, 170]. Another contributor is the upstream determinants of health that are beyond the role and capacity of the health sector, such as those related to social and economic factors that lead to poor health [166, 171].

The public health issues and health outcomes facing South Africa, particularly within its poor communities, set the context for this study. I expand on the underlying factors that drive these public health issues and highlight the very important role of comprehensive PHC and CHWs below.

3.2 The South African settlement situation and policy context

Informal settlements, homelessness, unemployment, and the lack of access to basic services such as health, are but some of the stark features of poverty that post-apartheid South Africa has inherited which remains one of its core challenge. In fact most of these features manifest even more prominently in South Africa's major cities, where 16% of the total population reside in informal settlements, an estimated 2.4 million households countrywide [172]. Almost one million of these informal settlements are located in the nine major cities of South Africa [173]. A quarter of the City of Johannesburg's informal households are within and on the outskirts of its urban areas [174]. Internal and cross-border migration into Johannesburg has contributed to increasing urbanisation and municipalities are increasingly incapable of responding to the multiple needs of these communities [175, 176]. Consequently, the South African approach to addressing informal settlements has in the past, been the market-driven model, where residents are relocated to 'greenfield' sites. According to Huchzermeyer [85] this process of moving communities undermines existing community structures, prospects and ideals for self and community improvement and the vulnerable livelihoods that rely on these informally established community networks and land-use patterns.

Although this study attempts to provide a general scope of PHC in Gauteng, its focus is at a local government level as this is where the responsibility of PHC implementation lies [176]. Government itself has reflected on the lack of capacity for local government to respond to the pressures of service demand and the limited achievements of this sphere of government to implement the developmental mandate [177]. The limited

capacity has been linked to its complexity, lack of skills and funding and the lack of the means and information to carry it out [178, 179].

3.3 Contextual challenges

A democratic South Africa emerged during an economic context when discourse on development policy leaned towards the liberalisation of economic markets. Consequently, the adoption of these policies has had a significant effect on employment and income amongst poor households. Furthermore, without dealing with this context, addressing health and social inequities will be a challenge [180].

Despite the range of poverty alleviation policies, South Africa is considered to be one of the most inequitable in the world [181-183]. It is estimated that over 20 million South Africans live in poverty [184]. The disparities are embedded within racial, gender, spatial and age dimensions, a direct consequence of colonial, segregationist and apartheid regimes and policies [181, 183]. Poverty therefore is predominantly with black Africans, in women, those who reside in rural areas (including urban informal settlements) and black youth [119]. Contextualising this poverty, in comparison to other middle-income countries, South Africa's social indicators such as life expectancy at birth, infant mortality, adult literacy, total fertility and access to clean water are relatively poor for a country that is considered an upper-middle income country. This is largely due to its skewed distribution of income [185] as reflected in its Gini coefficient. Where a measure of 0 denotes complete equality and 100 indicates extreme inequality, South Africa stood at 57.8 in 2010 [186] . The extent of inequality highlights even further the levels of socio-economic disparities in South African society, where currently, the poorest 10% of the population accounts for just over 0.2% of income, while the richest 10% of the population

accounts for 51% of income [187]. This consideration of the extent of poverty in South Africa and its definition/s [23, 118, 119] is necessary to provide perspective and context for the case studies and most of the households involved in this research study.

The levels of poverty and inequity have been accompanied by unemployment. The fourth Quarterly Labour Force Survey (QLFS) in 2010 indicated an unemployment rate of about 24%, (only those actively seeking employment) and was the highest amongst the Black population at 28.1%, followed by the Coloured population group at 21.3%, with the Indian and the White population groups at 7.9% and 5.5%, respectively [188]. The survey indicates that unemployment was higher than the national average among women and the youth. If one considers the broader definition of unemployment, that includes all those who are not employed and are looking for work and those who have given up on seeking for work, the rate rises to approximately 37% [189]

3.4 The policies to address health and social inequities in South Africa

Since 1994, the new government has made efforts to address these disparities through a series of policies [119, 155]. This ethos is found in health care, housing, social security and education policies [119]. For instance, the national system of social grants has been a major source of relief against the impact of poverty for millions of South Africans [155]. The new government restructured and de-racialised social security and introduced new grants, the old pension and raised the child support grant (CSG) from children younger than nine years to children up the age of 18 years [190, 191]. About 12.4 million beneficiaries received social grants in 2007/2008, increasing from 2.4 million in 1996/1997, mostly due to the introduction of the CSG, which in 2012 currently has about 10 million beneficiaries [191].

Other interventions to redress the social inequalities of the country came through the public education and health. From 1996 to 1997, salaries for teachers increased and moved onto a single consolidated scale [192]. The redistribution of an education and health budget formerly biased towards the white population, resulted in poor households benefiting from the introduction of free public education and public health care (for some groups such as women and children). Despite this effort, the quality of education for poor children remains a concern [119].

Having considered the role of the South African government in addressing the existing social disparities of the country, it is important to understand how the systems of government operate to implement these interventions, particularly for CHWs who function at the lowest level of service delivery and are therefore affected.

3.5 Different tiers of government

Although community-based activities primarily occur at local level and ideally should collaborate with local government structures to foster effective community level inter-sectoral action and community participation efforts, local government is still part of a three-tiered structure of government. The responsibility of the National Department of Health is to develop policies and to oversee the overall coordination of the health system while the provincial departments mainly provide health services through hospitals and PHC clinics [156]. Local government provides environmental health services and some facility-based PHC services. Non-governmental organisations (NGOs) and government employ CHWs to support the provision of PHC through their outreach services.

3.5.1 The recognition of local government

Local government is regarded as playing an important role as “a vehicle to realise national goals of transformation and inequality for all South Africans...” [193]. While local government is an organ of state that is at the interface of service delivery demands and burdens, policies and legislation to refine its mandates and functions, major challenges have emerged. The HIV epidemic has highlighted these challenges as it has affected households, institutions, the economy and national development efforts [194]. Consequently, government introduced a systematic mechanism of operation across called intergovernmental relations (IGR) via the constitution and legislation [194]. This was to support efforts for efficient service delivery across all sectors. However, putting the IGR into effect using integrated development plans (IDPs) has been complex. Envisaged as an ambitious but practical tool to enable the different spheres of government to align their planning, budgeting and execution of services and ultimately to work across sectoral and hierarchical networks, this endeavour has not realised its potential [194]. This challenge is at the heart of the constraints that are apparent in the efforts of CHWs to provide comprehensive PHC outreach services. Differences in institutional capacities and mandates across the different sectors complicated and limited efforts to ensure inter-sectoral collaboration. Part of establishing IDPs was also to encourage the participation of communities and community organisations and therefore be able hold local government entities accountable. Furthermore, the intension was also to involve communities in formulating budgets, planning and prioritising processes [195]. Through local government legislation local authorities established ward committees which are democratic participatory systems at local level [196]. They are an effort to increase the link between local government (through municipalities) and the communities. Moreover, they can be used as a platform to keep abreast of local problems,

aspirations and needs of communities. Ward Committees therefore have an important role to play in facilitating the process and functions of the IDPs and other local government functions [195]. This also implies that they can be a useful resource in enabling communities to facilitate community level inter-sectoral action, which is pertinent to my study. The role of community-based initiatives in South Africa and how they have to operate within these systems of government provides a basis for the understanding of the experiences of CHWs. It is important to mention though that the implementation and functioning of ward committees has been poor.

3.6 History and experiences of Primary Health Care and CHW programmes

This section which deals with the history of CHWs and PHC in South Africa is followed by a review of the current PHC and CHWs experiences.

South Africa established a National Community Health Worker Programme in 2004 which was integrated into the National Public Works Programme to improve PHC services in South Africa, particularly in light of the HIV and AIDS epidemic as well as to increase the human resources within the health system [57]. The Expanded Public Works Programme (EPWP) is a government strategy to address unemployment. It facilitates employment opportunities in the different government sectors for South Africans, who receive training and gain skills while earning an income. This strategy also addressed the aim of improving the support and career opportunities for the volunteer workforce within the health sector. The Department of Health of the Gauteng Province launched its Community Health Worker Programme, as a sub-programme of the EPWP in 2004 [197]. Over the years the programme has relied mostly on NGOs and/or Community Based Organisations (CBOs) to coordinate and manage the activities of CHWs who provide a range of services with a primary focus on HIV/AIDS and TB care. The EPWP has played a

critical and cost effective role in the delivery of holistic HIV/AIDS and TB-related services. However, with the focus on HIV/AIDS and TB, the broader functions of CHWs have been sidelined, such as engaging with the community on issues such as water disposal, clean water, family planning and nutrition [198]. Seven years later, this still remains the case.

In its efforts to overhaul the health system, the post apartheid government ensured that primary health care, delivered through the district health system, was the central aspect of its health policy [155]. The principles of PHC, as promoted in the Alma Ata Declaration, are reflected in the policy whereby children less than six years of age and pregnant mothers receive free treatment, through a system that is based on community health centres [155]. Additionally, the historical legacy of profound inequalities in health and health care influenced the South African government's policy of selective PHC (SPHC) which allowed it to focus on immediate needs and disparities [199]. Government aimed to use these selected programs, such as HIV/AIDS, TB and nutrition) as foundations to develop the district health system and to prioritise PHC services. The country has made considerable investment in PHC through increased infrastructure, rapid expansion of TB, HIV and maternal health related programmatic interventions. This was coupled with an increase in utilization of services and numbers of CHWs [200]. However, as in the tradition of SPHC, this approach leads to a shift away from the broader determinants of health to focus on technical health care such as antiretroviral treatment [8].

As with other governments that have attempted to transform their health system and implement PHC, the South African government has faced challenges. These include a shortage of health professionals, the historical inequity in the distribution of resources and weak managerial capacity and health system leadership [201]. Civil society, through mostly NGOs, has emerged to response to the inefficiencies and the neglect of the remnants of apartheid.

However, over the years, attempts to implement PHC through the support of CHW programmes have not been very successful. Some of the reasons cited for this have included poor training, supervision and support [202, 203] and poor integration of PHC services [204, 205]. In light of this, it is evident that how South Africa practices and applies PHC directly affects the ability of CHWs to function and foster the values of PHC. Clearly, CHWs need a supportive and efficient PHC system that recognizes the principles of comprehensive and coordinated services. This is the case to not only ensure the quality of service provision and their ability to respond to the changing needs of communities, but also to ensure effective implementation of comprehensive PHC. Interestingly, the current CHW policy framework defines CHWs as “community-based generalist health workers who will combine competencies in health promotion, primary health care and health-resource networking and coordination.” [206]ⁱ. This study sheds light on the experiences and the extent to which CHWs are able to fulfil this role.

3.7 Current reforms: Primary Health Care and community health workers in South Africa

Despite the challenges in South Africa, there is visible continuation of the efforts to strengthen PHC. Central to the efforts of the revitalisation of PHC was the service agreement that was signed between the Minister of Health and the President of South Africa in October 2010 [207]. A further output of the efforts was reflected when the Minister of Health established a task team to provide advice on the re-engineering of PHC in South Africa [208]. Part of this re-engineering will reportedly include community-based services, a shift away from the current PHC model where the health system waits for users to access the health system. The revitalised model is

ⁱ The CHW policy framework has recently been under review. I am referring to the aforementioned policy as that was the version that was in implementation at the time of the data collection.

planned to constitute a PHC outreach team made up of one professional nurse leading the team, a staff nurse, a health promoter, an environmental officer and six CHWs in the frontline, actively going to communities and households [209, 210].

Despite this ambitious plan to include this workforce, a mapping exercise of CHWs in South Africa by Van Pletzen, Colvin et al. [203] provides insight into the extent of reform that will be necessary to enable CHWs to support effective PHC outreach services. CHW roles still vary significantly and are not formalised or refined. In reality, this workforce largely provides more specific services such as HIV/TB-related activities than the more generalist home-based carer [32]. Their functions become even more complex and blurred when one considers that the roles that they are mandated to perform by the formal sector vary widely from the needs of patients and households [203]. Although they also act as advocates for households to demand better services from local service providers, this role is unrecognised, unofficial and in fact if pursued, has been reported to lead to conflict with formal sector providers [203].

Community health workers, referred to as Community Care Workers in the policy currently under review [211]ⁱⁱ, are crucial to the provision of PHC and a range of other caring services [203]. During data collection for my study, a parallel process to the revitalisation of PHC was the revision of the CHW policy that is still underway. What the reviewed policy framework highlights is that CHWs are envisaged to take on a more integrated role. According to their competencies, this cadre is intended to play a role in, mobilising communities to be more responsible for their health and social needs, advocating improving health and wellbeing, facilitating access of other disciplines of health and social sectors into households, providing

ⁱⁱ This policy was not official during data collection

health and social security information, providing health promotion and psychosocial support, transferring health and wellness skills and referring to other sectors beyond the scope of their work [211].

The discussion above highlights the various and complex aspects that form part of the CHWs' context which they are required to navigate provide outreach comprehensive PHC outreach services. Moreover, in light of the South African situation, where the country is looking at revitalising PHC and the role of CHWs, I will focus particularly on the institutional contexts of the NGOs, the types of services that CHWs provide, the extent and nature of community level inter-sectoral action within these services and the extent and nature of community participation.

In view of the overall literature and the conceptual framework derived from it, this thesis makes a contribution by describing what is required to ensure that CHWs fulfil their role in providing comprehensive services. In considering the feasibility of these PHC reforms, it also highlights that these requirement are necessary for implementing strengthened PHC. Merely modifying the status and tasks of this workforce will not assist to achieve this.

3.8 Synthesis of the literature

Overall, the literature highlights a series of interconnected issues. PHC over time and currently has been influenced by the principles emerging from the Alma Ata conference. To address health and health inequities, there needs to be recognition of the role of the social factors that affect health, hence the need for inter-sectoral action. It also highlights the need for communities to participate to ensure self-sufficiency and decision-making, even amongst vulnerable communities. Using CHWs as a lens to examine the practices of providing outreach services, I review the experiences of CHW programmes within the provision of PHC; internationally and

locally. A synthesis of the range of literature shows the importance of providing support. It shows that providing this support is manageable in small scale CHW programmes, however, this becomes more difficult once they grow to large-scale implementation. The literature also points to the need for CHW programmes to adapt to the contextual changes within communities, so as to maintain the capacity to meet the needs. Many of the examples of CHW programmes often fail to adapt to the context of communities as they expand and become more involved with higher level functions - proving to be detached from local changes. This has often resulted in programs that do not align to the local needs. It is through these experiences that I am able to recognise and highlight the gaps in the literature as highlighted in the following section.

3.8.1 Key gaps in the literature

The literature is limited in its recognition of the importance of understanding the context within which outreach services are provided, especially for low income communities. The range of literature on PHC and CHW programmes, such as those reviewed in this thesis, only focus on evaluating the programmes. They lack the depth of providing the finer contextual details involved that affect how CHW provide outreach services. My study contributes to the discourse on what is crucial in understanding the nuances involved in attempting to provide integrated services to poor communities. The thesis fills this gap by providing a vivid picture of the role of the context as a major factor limiting the extent to which CHWs are able to provide outreach services. This is expanded upon in the section on the ‘Statement of originality’ (Chapter 1, Page 5, section 1.1).

CHAPTER 4

4.0 METHODOLOGY

This chapter describes the methods used to examine the experiences and factors involved in providing PHC outreach services by CHWs. I also provide an overview of the study design that guided the research process. I then describe the study sites and the selection of the case studies. I follow up with a brief description and reasons for their selection. I describe the data collection methods and measures taken to ensure methodological rigour, and explain the data analysis process. I then conclude by addressing the ethical considerations of the study.

4.1 Comparative case study design

To explore the various issues proposed for the study (as illustrated in the conceptual framework in fig. 2.3), I used a comparative case study design to collect data on the experiences of CHWs to compare and contrast the different CHW programmes in the Gauteng and the Eastern Cape provinces in South Africa. This method allowed me to understand the institutional dynamics and nuances of CHW programmes in supporting the implementation of PHC. I could describe and explore the dynamics in a more intimate setting, and understand the processes involved in facilitating community participation and community level inter-sectoral action for providing comprehensive PHC outreach services. The case study method allows one to explore and learn about the stories and experiences of the persons involved in those case studies. Pertinently so, Stake [212] adds that the main importance of a case study is to learn at a more in-depth level. The choice to use case studies was because I was particularly interested in learning whether the uniqueness of their respective individuality (of the CHW programmes) influences the extent of

holistic outreach services. It is recognized that each selected case study is an integrated system [212-214] with relationships and interactions which may function well and not so well. I was therefore interested in how these relationships, or lack thereof, influenced the implementation of comprehensive PHC outreach services, if at all. If one is seeking accuracy and depth, and exploring a naturally occurring phenomena while seeking to answer the “how” and “why” within this natural setting, then a case study method is a natural choice [213, 215].

It is also important consider the definition of the case study. Rule and John [216] propose that there are three types. A case can be “a person, a classroom, a programme, a process, a series of developments, an institution or even a country” and here its defining feature would be its singular form. It can also be “a circumstance or problem that requires investigation, or it could be a body of evidence that supports a conclusion or judgement” [217]. In this study, I relate my definition of a case study to the first type. I define each case study to include the community, the NGO and the programme implemented by each NGO. To allow a rich description and in-depth understanding of the interactions and dynamics within the case studies, I used a range of qualitative methods. They included key informant interviews, focus group discussions, participant observations and network maps. I expand on these methods further below.

4.2 Study sites and selection of case studies

4.2.1 Study sites and case studies

I identified NGOs (which in South Africa are commonly the employers of CHWs) in two South African provinces (Gauteng and the Eastern Cape) as the study sites. Gauteng was selected as a study site primarily because of the province’s rich characteristics of urbanisation and the growth of informal settlements. Although it is noted that this context is similar in many other areas in South Africa, hence I could have selected from those regions, it is important to note that about

31% of people who live in informal settlements live in Gauteng Province [218]. This area is therefore a rich environment to explore understand the contextual nuances that exist in informal settlements. Moreover it made more sense to access the regions that are in close proximity to the research institution where I am based, allowing for the flexibility to access and verify information during data collection. Furthermore, it is an area of the country that I am most familiar with.

I was also of the view that informal settlements would provide in-depth insight into the social determinants of ill health and if CHWs' efforts address these conditions. To better understand the reasons for success and failure, I selected one successful organisation situated in the Eastern Cape to compare with the Gauteng programmes. Therefore, the experiences primarily apply to the Gauteng Province case studies, while the Eastern Cape case study provides a comparative reference. Identifying the case studies occurred in two stages. The first stage was to identify all the NGOs in the Gauteng Province which employed CHWs and the second stage was to select NGOs with characteristics that fulfilled the criteria for selection (described below). I then conducted pre-visits to the proposed NGOs. This stage allowed me to finally select the two NGOs which would be the case studies.

4.2.2 Stage 1: Selection of case studies

A representative from the Gauteng Department of Health (GP-DOH) assisted me in selecting the case studies since the department is one of the main sources of funding for the NGOs in the province. The representative was responsible for the coordination and management of all identified NGOs in the province that are funded by the department, however, even those that were not funded were listed on the database. I was confident that the representative had significant insight and information on the types of NGOs in the province and that this would

provide valuable guidance in terms of selecting the case studies. The representative provided a database with a wide range of NGOs, however, since all the NGOs are spread out across the province, I limited the selection to those located in the largest district in the province, the City of Johannesburg. Because of the wide variety of contextual needs of communities in this city, there is also a diversity of NGOs that attempt to cater to this range of needs. As a result, I was able to select NGOs that had programmes that cater to these different needs. I developed the following criteria to guide my selection prior to selecting the two case studies:

- The NGO had to employ more than 10 CHWs to ensure a generous pool of CHWs to choose from when conducting data collection. A reasonably large group would provide some CHWs with stronger qualities than others, such as the ability to easily communicate information. Too small a pool would yield a limited range for selection.
- The NGO was required to have CHWs that provided services on a daily basis and to a wide variety of patients. This would ensure a rich context from which to collect data, rather than a scenario where the CHWs did not often provide services due to a low number of patients;
- The NGO was required to have a manager. This decision was based on the assumption that a person in a position of some sort of authority would be able to provide details about the organisation such as the history, the funding and financial arrangements, the organisational objectives, the recruitment processes and overall management processes. These criteria would also allow me to identify variation in management processes and if any, to examine and compare how they affect the ability of CHWs to provide outreach services; and
- It needed to receive funding from government or other sources. This would allow me to examine the relationship between an NGO and its funder/s how this has any impact on the ability and capacity of the organisation to support CHWs in their provision of outreach

services. Furthermore, without funding, the NGO would have been involved in a very limited range of activities, hence not being suitable for the study.

In addition, in order to ensure a wide range of input with regard to the recommendation of the NGOs, I also contacted various stakeholders involved in the NGO terrain in Gauteng who worked with NGOs and had practical knowledge about them. One informant was a representative from Reproductive Health Research Unit (now known as the Wits Reproductive and HIV Institute) who was involved in community-based services and the different NGOs. To narrow the focus, I also contacted local government NGO coordinators to obtain further input. The informants echoed and confirmed the Department of Health representative's list and from these recommendations, I chose seven NGOs.

4.2.3 Second stage: Pre-visits to non-governmental organizations

Once the seven NGOs were selected, I contacted the relevant individuals to introduce and explain the study. Following positive responses, I visited each of the seven NGOs where I conducted informal interviews with the NGO managers to gather information and confirm whether the recommendations of the stakeholders were adequate. I held informal discussions with the CHWs in each NGO to obtain information regarding the types of services and cases they consulted. After the exploratory visits, only one organisation out of the seven met the required selection criteria. Interestingly, despite being on the provincial database, the other six NGOs lacked a range of characteristics that were assumed to be present. One issue was that the majority of them had not been receiving funding from the province for several years. As a result, the NGOs had lost CHWs over the years, some remaining with as little as two. Many of the NGO managers/representatives reported that the lack of funding made it difficult for them to pay the CHWs regularly, hence the high turnover. The lack of funding had other implications. Although

still employed by the NGOs, the remaining CHWs were often unable to travel to work because they could not afford to pay costs of public transport. Consequently, they often did not provide the limited services they were meant to render. In fact, on several occasions during a visit, the CHWs arrived to work at the NGO, only to remain in the premises rather than go out into the community. In such instances, the NGOs that primarily provided home-based care services, which often required resources such as gloves, soap and detergent were not able to supply CHWs with such equipment. Consequently, this limited the extent of services, for instance for bedridden patients. During my visits to some NGOs, I found the CHWs either making clothes or other objects that they could sell to generate money, while in others they conversed amongst themselves until the end of the day. Another limitation the NGOs experienced was the lack of premises; some of them functioned from rented garages in private houses. One of them was using a garage of the manager's house as an office.

Rather than returning to the database, I explored cases where trusting relationships had been built previously which could provide easier access which led to the second and third case studies. As with the first case study, the second case study met the selection criteria: it had more than 10 CHWs, had a manager and the CHW provided services on a daily basis to a range of beneficiaries. As it was a pilot project which still had to be rolled out in the province, it was not included in the provincial database. The South African National AIDS Council (SANAC) identified and documented the third case study's good practice of providing comprehensive services. I selected this NGO as a comparative case study to better understand the reasons for success (and failure).

In Chapter 6, I provide more detail about each case study and for the purpose of confidentiality, I have used a pseudonym for each organisation (including their geographical place names): The

Khanya programme (Case study 1) and the Zola programme (Case study 2) in Gauteng and the Eden programme (Case study 3) in the Eastern Cape. I selected the organisations for the differences in their institutional contexts:

1. The Khanya programme is a small, independent organisation separate from government and is under-resourced, receiving local government funding;
2. The Zola programme is a government programme run by an NGO with limited resources, receiving direct funding from the Gauteng Province; and
3. The Eden programme is an NGO which is part of a larger umbrella body and is well resourced and receives international funding.

These organisational contexts provide a basis from which to examine the extent to which the CHWs support PHC.

Although I will offer a more detailed description of the case studies in Chapter 6, a brief account of why the three case studies were selected is provided below:

4.2.4 The selected case studies

4.2.4.1 *The Khanya programme*

The Khanya programme is located in an area called Oxford, which captures the wide contrasts of the City of Johannesburg metropolitan area. Despite the area being in close proximity to the centre of urban Johannesburg, the NGO services an area that has rural characteristics such as farms and houses that are widely distributed with large distances between each house. Another aspect that rendered this an ideal case study was the manager of the NGO. From the initial meeting and informal interview, it was evident that she would offer an open and willing space to conduct the study, thus adding to the convenience of data collection. The CHW service model,

reportedly being implemented by the NGO, also offered a potentially rich environment to explore CHW services and the way in which their outreach services support PHC implementation. This ideally entailed integrated services such as home-based care, treatment defaulter tracing, health information dissemination, referrals to other sectors and psychosocial support. In addition to the context, the area made for minimal travel for me, therefore creating easier access for data collection. Although the NGO seemed to be typical of many others in this municipality, the contextual factors within which it operated differentiated it from other possibly similar NGOs in other areas. In fact, the NGO was the only one providing services in the informal settlement of Oxford. These contextual factors are expanded on and described in chapter 5. After meeting the CHWs in a focus group discussion, I was satisfied that both the number of CHWs employed and the wide range of skills and personalities would offer a sufficient pool of CHWs to choose from for data collection purposes.

4.2.4.2 The Zola programme

This programme is an existing project in an area where fellow researchers had conducted work. After consulting various stakeholders, including the researchers, I decided to explore it, firstly because it met the selection criteria and secondly because it provided a specific community-based service model. This model mainly involved the dissemination of information to households, ranging from information on the priority diseases to information on how to access other sectors. The organisation therefore offered a different context for comparison with the other service models. The NGO was located in the outskirts of urban Johannesburg, known as Harvard. The manager of the NGO was often absent and the NGO almost non-functional, which led to a representative of the local Department of Health (DOH) taking over the role of manager. After conducting an informal interview with this manager and an informal interview with the manager of the NGO, it became evident that the most appropriate individual to consider as the

manager of the NGO was the municipal Department of Health representative. I considered this an advantage because the DOH representative was able to offer valuable information with regard to the inception and purpose of the project (implemented through the NGO). Another aspect which made access to this project and the NGO convenient was the fact that the province and the local government needed to evaluate the project. I established this after conducting an introduction and briefing meeting to request permission for access with the Director of the HIV/AIDS Directorate in the City of Johannesburg. The organisation is located within this unit as a core project. Although my study was using one NGO to explore the model and/or project, the district health authority believed that it would provide in-depth information regarding the status of implementation of this particular model.

In addition, the informal focus group discussion with the NGO's volunteers indicated that the number and wide range of individuals would offer a sufficient selection pool for conducting data collection.

4.2.4.3 The Eden programme

To understand the factors that contribute to the successful provision of comprehensive PHC outreach services, I was of the view that evaluating a successful NGO can offer valuable lessons for drawing up recommendations to inform policy. SANAC identified this organisation as a good practice at responding to the needs of orphans and vulnerable children in 2009. This organisation was ideal for me to examine the institutional factors that lead to successful provision of holistic services. The organisation is located in the Eastern Cape Province in an area called Selby.

4.3 Description of the participants

I conducted key informant interviews with 23 participants from a variety of institutions across the three case studies. Tables 4.1 and 4.2 provide a summary of the participants from government

sectors and the case studies respectively. The representatives were from institutions that are involved with the NGO sector who provided their insight and experience of the services of the CHWs. This process supplemented the data collected through participant observations with 74 households across the three case studies and network maps, to develop a holistic perspective on the services that are provided by this workforce. I provide a detailed description of the households included in the participant observations in Chapter 5.

Table 4.1 Government department respondents:

Department	Participant designation
Department of Health	National (2), Province (1), District (2)
Department of Housing	Regional (1)
Department of Social Development	Regional (2)

Table 4.2 Case study respondents

KHANYA PROGRAMME	ZOLA PROGRAMME	EDEN PROGRAMME
• CHW Focus group discussions (2) • NGO project manager • NGO coordinator • Clinic nurses (2) • Community representative (from clinic committee) (1) • Community representative (Community Development Worker (1) • Local health authority district representative (Health promoter) • Local government representative (Ward councillor)	• CHW Focus group discussion (1) • NGO coordinator • Regional NGO coordinator • Clinic nurse (1)	• CHW Focus group discussion (1) • National NGO representative • NGO /project coordinator • Project mentor • Project supervisor

4.4 Data tools development and piloting

The literature and the conceptual framework (Fig.2.3) guided and influenced my development of the data collection tools. In order to explore the objectives that have been linked to the conceptual framework, I developed themes and/or questions that would allow me to explore the possible linkages and pathways between the concepts such as community participation, social cohesion and social capital and the actors that are meant to facilitate the processes between these pathways and relationships. The questions are highlighted in the objectives and the objectives assist to capture the essence of what is illustrated in the conceptual framework. As indicated in all the interview guidelines (see appendixes) and parallel to the conceptual framework, I developed questions that would help to explore the relationships between the different actors at the different spheres of government, including the CHW sector. The conceptual framework primarily captures the possible relationships, however, the questions developed to collect rich data went further to explore the nuances that possibly exist between and within these relationships. This was mostly explored through the open-ended questions regarding the perceptions of the respondents regarding the range of concepts and elements that are illustrated in the conceptual framework, such as the role of the health system and community participation structures in CHW services.

Prior to conducting data collection, all the tools were pre-tested. I piloted them in another district health authority of Johannesburg. The NGO that was selected for the piloting process reportedly had a close and long-term relationship with the Gauteng Department of Health representative (NGO co-ordinator and manager mentioned above). This allowed for ease of access and therefore was convenient.

The pilot highlighted the concern that conducting in-depth interviews with patients without the CHWs being present would be a challenge, largely because most of the areas that they visit are not considered safe. In fact, the CHWs themselves worked in pairs, particularly because they were women. I therefore decided to use the participant observations (through the spontaneous conversations that would occur during the home visits) to gather the information that I would otherwise have gathered during the patient in-depth interviews. The participant observations provided for a more natural setting, ease of conversation (of which I was part of), and established rapport which made it convenient to pose some of the key questions. The participant observations during the pilot also allowed me to refine the process of data collection. I gathered that it was advantageous to enter a patient's household as an objective observer rather than a debriefed one with preconceived notions provided by the CHWs. I gathered more detailed information after the observation process. The semi-structured interview guidelines proved to be long and the questions were thereafter refined to be more open ended, thus reducing the number of questions. It was, however, positive to learn that the questionnaire explored the pertinent issues efficiently because the respondents provided information that related to the objectives of the study

4.5 Data collection methods

This section describes the methods used in data collection as summarised in Table 4.3.

Table 4.3 Methods of study and objectives

Objective	Methods	Themes explored
1. To describe and compare three NGOs providing CHW services, their institutional setting and community context, and to explore patient experiences of these services	▪ Participant observation ▪ Key informant interviews ▪ Focus group discussions	▪ Types of services provided ▪ Organisational structure ▪ Institutional support (training, supervision, recruitment process) ▪ Needs of the community ▪ Existing services and resources/infrastructure (clinics, hospitals, transport, churches, NGOs)
2. To examine social cohesion and social capital within the community contexts where CHWs operate and how this impacts on community participation	▪ Participant observations ▪ Key informant interviews ▪ Focus group discussions ▪ Network maps	▪ History of the community and the area ▪ Profile of community and households ▪ Existing community participation structures (ward councillor, ward committee, other) ▪ Existing community resources ▪ Existing and types of community leaders and/ representatives ▪ Enablers and/or constraints of community participation
3. To examine the policy environment and institutional setting and how this impacts on the facilitation of community level inter-sectoral action	▪ Participant observations ▪ Key informant interviews ▪ Focus group discussions	▪ Institutional/departmental structures and mechanisms to facilitate inter-sectoral action (in government) ▪ NGO mechanisms to facilitate community level inter-sectoral action ▪ Enablers and/or constraints of community level inter-sectoral action
4. To reconsider how these issues are conceptualised in order to inform policy and implementation	▪ Thematic content analysis (Atlas. Ti)	▪ Enabling and constraining factors of implementation of CHW-provided services

4.5.1 Key informant interviews

I had initial ideas regarding the specific respondents required to interview across all case studies. However, upon pre-visits and discussions with the different people involved in the sector, it was evident that the key informants would differ with each case study as some of the categories of key informants played a more prominent role in one case and not in another. The most helpful

key informants in all the case studies were the *managers of the NGOs*. I drew much of the information about the context and dynamics of the areas in which the NGOs were located from these interviews. The purpose of interviewing the NGO managers was to obtain information regarding the institutional contexts of the NGO such as recruitment, training, and supervision. I also interviewed managers to obtain information regarding the NGOs' relationship with the community, the different government sectors, especially the health sector and other NGOs in the area. I intended the *nurses* working in the local clinics in both the case studies to be key informants. They proved to be valuable informants with regard to the profile of patients and the types of diseases in the area, and more importantly the nature of the clinics' relationship and level of interaction with the organisations.

Policy makers from the national and provincial Department of Health were crucial with regard to gathering information about status of CHWs in the province (Gauteng) and the implementation of services, particularly PHC and their views and perceptions on community participation and inter-sectoral action. I identified a range of additional key informants through the other methods, especially the participant observations. The participant observations (explained further below) offered an opportunity to identify the needs of patients and the households which could be dealt with by various sectors, and allowed me to identify representatives who could answer questions that emerged during the participant observations. Such key informants were representatives from the different government sectors at local level. For instance, in the Khanya programme case study, the lack of housing and the challenges related to grants and sexual abuse emerging from data collection led to the decision to interview representatives from the Department of Social Development and the Department of Housing. However, interviewing a Department of Health manager from the municipal health authority was an obvious decision, considering the

challenges faced by the clinic in the area. Despite the issues that emerged regarding labour issues (pertinent for the farm workers in the Khanya programme households as described in Chapter 5) and access to formal documentation (such as IDs), obtaining access for interviews with representatives from the Department of Home Affairs and the Department of Labour proved to be difficult. However, because these interviews aimed to gather information regarding the organizational dynamics of the sectors, the role and extent of inter-sectoral collaboration and community participation, interviewing the other sectors provided sufficient information. In the Zola programme case study, the needs were also similar; I identified representatives from the Department of Housing, the Department of Human Development (local level derivative of the Department of Social Development) and the Department of Health at district health authority level. The district health authority (as opposed to the local Department of Health which is a level below) was responsible for the Zola programme, hence it made more sense to hold a formal interview with the Director of the HIV/AIDS unit of the City of Johannesburg (the district health authority) rather than an individual from the local Department of Health. I conducted the interview with the Director after completing data collection in this site (Zola programme case study) because I needed to clarify issues that emerged during data collection, such as the future of the project and management issues (recruitment, supervision, training, the future of the volunteers). It must be noted that I interviewed the representative from the local DOH in her capacity as the manager of the NGO (Zola programme).

Other key informants recommended some of the identified respondents. For instance, in the Khanya programme case study, some key informants felt that it would be beneficial to interview the ward councillorⁱⁱⁱ of the area. This informant provided information regarding the extent of

ⁱⁱⁱ The 'ward' is the smallest geographical unit in South Africa; it consists of a ward committee which is made up of community members and is chaired by the ward councillor.

community participation and the community participation structures. This interview was important because it also identified the political and power dynamics related to community participation and in particular to government-community participation structures. Following recommendations, I interviewed other community members in Oxford who were active in the formal community structures as key informants.

For the comparative case study, I conducted key informant interviews mainly with representatives of the organisation which included the coordinators, mentors and supervisors of the Eden programme. It should be noted that this was because I was interested in the institutional context of the organisation and how it navigated the community in the process of providing services.

Each individual interview commenced with me introducing the study and providing information about its purpose prior to the actual day of the interview. I then repeated the process on the day of the interview when I handed out an information sheet (Appendixes 1, 2 and 3). After indicating that they understood the purpose of the study, I handed the interviewee a consent form (Appendix 4) to sign which gave approval for me to proceed with the interview. I followed a similar process requesting their consent to tape record the interview (Appendix 5). I used an interview guide with open-ended questions (Appendixes 6 to 13) to guide the interview. All respondents indicated their understanding of the study and readily gave consent. Interviews took between 45 – 90 minutes. Although I used the questionnaire to guide the interview, I often allowed the interviewees to guide the conversation, particularly when I deemed the issues as important for the richness of the data. Despite using a tape recorder, I always took notes during the process to record the context at the time of the interview. This helped during the transcription of the interviews, as the notes explained some of the ‘unusual’ responses which could often be

explained by the situation at the time. For example, in the first few minutes of the interview with a nurse at an extremely busy clinic, the nurse would apologise and leave the interview to assist the nurse that was working alone. The interview eventually continued without interruption when another nurse arrived. The notes helped to explain the lack of coherence from one sentence to another in parts of the recorded interview.

4.5.2 Focus group discussions

I conducted focus group discussions (FDGs) with the CHWs. My prior knowledge was that CHWs are a mixed cadre; one category consists of women who volunteered in their communities before the CHW sector was formalised through the establishment of the CHW policy. Some of these women reportedly have little or no education. The second category comprised young women who had either completed or partially completed school and were seeking ways to further their skills and/or education. Being a CHW is considered an avenue towards a better career or a vehicle to gather skills. I decided to split the FDGs into two groups of CHWs: those that were younger and had just started working as CHWs and those that were older and had been in the sector for longer. However, in all the case studies, this proved not to be the case. All of the women were ‘young’ in terms of years in service (ranging from one year to five years), with partial and completed education. In the Khanya programme, most of the CHWs had been working with the organisation for at least five years. They had all completed the formal, national standard training course for CHWs, and were therefore receiving a stipend. The ‘younger’ CHWs (in years of service) were still considered volunteers as they had not undergone the training and were not receiving a stipend, even though some of them had been volunteers for the NGO for at least two years. I conducted the FDGs with these two distinct groups and this is the only case study where I did so. In the Zola programme, all of the CHWs had been employed by the NGO for periods ranging from eight months to five years. In this case study, because all of

the CHWs had undergone training that was specific to this model and were all receiving a stipend, I held the FGD with one group. In the Eden programme, there was not much variation in terms of length of service and I conducted the FGD with one group of CHWs there as well, where variation was mostly related to level of qualification. The FGDs were conducted at the premises of the NGOs in all the case studies. I also ensured that they took place away from the presence of senior members of the organisation, such as the managers, for ease of engagement and confidentiality. Depending on the case study, the FGDs included between eight and ten CHWs. Each session was an hour to an hour and a half in duration. The FGDs were conducted mostly in English, but there was the occasional use of Zulu and Xhosa. Because Zulu is my mother tongue and Xhosa is very similar. I was able to translate while simultaneously transcribing the recordings.

The aim of the FGDs was mainly to obtain information regarding the experiences of the CHWs in providing services to their respective communities; successes and challenges in assisting patients to access various services; their experiences regarding management (recruitment, training, supervision, career-pathing); the types of households and individuals to whom they provide services; and their perceptions and experiences regarding community participation and inter-sectoral outreach services. I used the FGDs to identify three CHWs from each case study for the participant observations. I selected CHWs who were outgoing and forthcoming with information, thus proving that they would allow for ease of data collection and access to information. I explained the process of FGDs prior to the actual process, requested consent (Appendix 14), including to tape record the discussion (Appendix 5) and included an information sheet (Appendix 15). I requested consent to take notes during the discussion and explained the purpose of this exercise. I also explained that the participants would remain anonymous (that no

names would be used in the notes or in the final report). The CHWs had freedom to converse in any language they preferred. Fortunately, I was conversant in all the languages used, and I translated the interviews. Using a guide (Appendix 16), the FGDs took between 60 - 90 minutes. As with the open-ended questions in the key informant interviews, I allowed the CHWs to guide some of the issues discussed, particularly when these related to the context of their work in the community.

4.5.3 Participant observations

A participant observation is an ethnographic method in which a researcher becomes part of the natural and social context of the area which is related to the research [219]. It is during this process that the researcher can observe the daily activities as influenced by this natural environment. This method allows the researcher to observe behaviour that is influenced by the dynamics of the natural settings, hence providing a richer explanation of the issues, behaviours and themes that emerge for the data collection. There are however different ways to conduct participant observations. In one, the researcher is completely immersed in the activities of those researched and fully participates, as a participant who is an observer. Another is where a researcher observes more than participates, while another is when one only observes with no participation [219].

I adopted the observer as participant approach which allowed me to participate, although the main role was to collect data. This approach allows one to establish relationships and be involved in some activities while being explicit about one's aim to observe, hence one's observation activities is known to the people being studied [220, 221]. My involvement mainly included functioning in exactly the way CHWs functioned daily. This allowed me to gain an understanding of the experiences of the CHWs and therefore what had an impact on their

functioning [220, 222]. For instance, walking long distances to a patient's house or waiting for hours for a nurse to attend to inquiries regarding patients. In addition, I participated in some of the conversations that occurred during the household visits, particularly when I was interested in more detail regarding the issues discussed. However, I made sure not to interfere with the natural flow of the CHW's visits and work. I conducted the participant observations with three CHWs from each case study. The observations were mostly of their daily interactions and visits, primarily to the households of their clients and the clinics (in the Gauteng case studies). Before each household participant observation took place, I provided each CHW with an information sheet (Appendix 17) and I requested consent to observe them (Appendix 18). The CHWs thereafter explained the study to the household member/s and sought permission for the researcher to observe the meeting as part of the research. I repeated this process on each visit with an information sheet (Appendix 19) and confirmed the consent of the participant/client/members of household (Appendix 20). My observations only proceeded after I had consent from the patients/clients and the members of the households. I did not use a tape recorder during the participant observations and this is explained in this section below. I followed a similar process was followed at each of the health facilities (such as clinics) that the CHWs anticipated visiting during the researcher's presence. This was supplemented with introductory meetings with staff members of the facilities.

I ultimately spent between three to five days with each CHW. In all the case studies, the CHWs would gather in the morning and thereafter disperse to their respective household. In the Khanya programme case study, because the NGO is located in a clinic, the CHWs would first consult with the nurse on which patients required delivery of medication or tracing. The CHWs in this case study primarily provided services to the informal settlement and the farms in the

surrounding area. The CHWs travelled in pairs for security, while the selected CHW was the 'leader' for the week that she was being observed. The informal settlement close to the NGO was in walking distance. The farms, however, were extremely far and walking to each household took hours. When reaching the household, the CHWs would introduce me, having followed all the procedures of requesting consent from the household and the patient/client. Although the process was interactive with natural conversations, I mostly observed and asked questions where necessary.

The process in the Zola programme case study was fairly similar. The CHWs walked in groups of three and each would take turns to lead the conversation with the households as their core service was to disseminate information. The selected CHWs were however in the groups. The process of observation was similar. I observed while in the household and then clarified issues that emerged during the visit with the lead CHW as we walked to another household.

In the Eden programme case study, the process was similar except that the CHWs conducted their home visits individually. Some of the CHWs walked to the respective households, while others were provided with transport. The CHW introduced me to each home subsequent to the CHW having obtained consent.

The participant observations allowed me to not only observe the activities of the CHWs within their work settings (as in a clinic or household), but also within the contexts of their communities. This method allowed me to understand how the institutional and social contexts influenced and/or affected the extent to which they provided their outreach services. In this way, I was also able to examine the factors that enable and/or constrain their ability to provide holistic services. Through this method, I was privy to the daily social interactions amongst community members and the relationships the CHWs had with individuals in the community. To avoid

having to interfere with the natural setting within which spontaneous interaction occurred between the CHWs and their clients and other contacts, I chose not to use a tape recorder. I took notes during every encounter and used the note taking as a daily diary to take note of issues that fell outside of the subject of the study, but appeared important to understand the context. After each visit, I immediately wrote the notes clearly and in full to ensure that there were no gaps.

4.5.4 Network Maps

One of many factors that ensure one's ability to function and derive support from one's community is determined by the extent to which social networks exist, that one can draw from. Without these "effective contacts" or networks, [one would find it] "harder to negotiate [one's] place in the world" [223]. Social networks can play an important role in the work of CHWs as they can use them to support their efforts to provide services to their communities.

Network maps are a visual representation of the networks that exist within an area or a community [221]. I used the network maps to obtain visual information as a means to reflect the extent of interaction with people they interacted with on a daily basis that either hindered or assisted their provision of services. I intended the CHWs to provide the network maps in this study. However this was difficult as all of the CHWs from the Gauteng case studies found it difficult to identify any networks because they felt that they did not have any. After some probing, we drew a visual map (in Chapter 9 – Images 4, 5 and 6), which detailed the various interactions that they had with various individuals/groups/institutions in the community. The method also assisted to identify community members for the key informant interviews. The NGO manager in the Khanya programme also provided more information with regard to the different networks. The CHWs in the Zola programme particularly found it difficult to name any social networks and connections; however, through much probing, they were able to recall some

contacts, albeit very few. The CHWs from the Eden programme collectively named several contacts and enthusiastically developed their network map. I discuss the aspect of social networks and relationships in the community further in Chapter 9.

All participants had the opportunity to refuse an interview or to be observed without prejudice. Participants' names were not recorded and respondents were assured that all information that they had provided was confidential and would be used only for the purposes of the study. This was also emphasized during the FGDs with the CHWs. In addition, the names of the programmes and geographical place names described in the thesis have been replaced with pseudonyms.

4.6 Data Management

All the interviews were tape recorded and then saved in audio files in a secure computer to which only I had access. I kept all written notes and the fieldwork diary in a secure place accessible only to me. I transcribed all the data since most of the interviews were in a mixture of English and other languages. This required me to transcribe and translate at the same time. I back translated the interviews that were translated into English to the original languages. To ensure that I did not miss any information, I confirmed all the transcriptions as I listened to the audio tapes. Each transcript was given unique identifiers by coding them according to the type of method used and the category of the interviewee, for example "CHW1" or "Gauteng DOH representative". The transcripts were recorded on Microsoft Word 2007 and imported into Atlas.ti WIN 6.0) software.

4.7 Analysis and data quality control

I conducted analysis through the coding of key themes using Atlas.ti to assist with the identification of *a priori* and emerging themes in each of the case studies. I compared the data within and between cases. After examining themes comprehensively, I returned to the original data to test the emerging analyses. Furthermore, I examined in-depth the divergent evidence. To substantiate and confirm unexpected themes, I used my fieldwork diary notes to understand the relevance of these themes to the core of the study. This process of ensuring good data quality is regarded as applying ‘interpretive judgment’, when at identifying contradictory data, one returns to review the initial interpretations made by the respondents [224]. Part of the process of ensuring the validity of the data was to continue to re-check the themes from each method used to collect the data (fieldwork diary, notes and recorded interviews), particularly with the use of the tape recordings. This process, which is an active process of iterative questioning and checking during the analysis, allowed me to enquire how and why certain episodes occurred [225]. This was another way of ensuring quality data. The triangulation of the multiple methods assisted to ensure validity of the findings because they highlighted contradictions between the data within each method. Moreover, they helped to confirm the findings and facts shared by the respondents. Using the findings from all these sources, I developed the major themes as the core of the study. After independently identifying the core themes, I shared selected transcripts with the research team (my supervisor and co-supervisor) during which we collectively agreed on the themes. To ensure reliability of the results, this collective decision regarding emerging themes was facilitated through regular meetings as part of the analysis process. A further process of ensuring quality and rigour of the research was to follow a logical process, ensuring that each step fed into another and making sure that there is efficiency in the documentation of all the details, hence allowing dependability of the data. I also provided for confirmability by constantly

ensuring that the data confirmed the general findings. As mentioned in the selection process of the case studies, the case studies were similar to the context in other regions in the country. In light of this, the depth of the findings was examined to provide perspectives that could be transferable to other settings which share common contextual features. To ensure the trustworthiness of the data, I ensured that my review and reconstruction of the findings matched the views of the respondents. Despite the attempts to ensure quality and rigour of my data, I acknowledge that my bias would have influenced the interpretation of the data.

I represent the experiences and views of the participants in the Chapters on findings using quotes. In some instances, I have edited some of the quotes for more clarity without compromising the integrity, reliability and accuracy of the verbatim quote. Most of the edited parts were to preserve the confidentiality of the respondents. The context-based reflections of households (from the participant observations) are illustrated in boxes which depict my observations and what was expressed during the interactions. Moreover, I used vivid descriptions of the situations during the observation to reflect the experiences of those observed. From these views and experiences I drew my analytical interpretations as reflected in Chapters 5 – 9 with the implications of my interpretations of the findings in Chapter 10.

4.8 Limitations of the data collection methods

A major limitation of some of the methods used was ensuring the accuracy of information provided. Although participant observations allow for a more natural setting where people are less likely to limit their natural behaviour, natural settings can prove to be difficult to control. For instance, in some of the visits, some of the conversations between the family and the CHWs would lead to members of the family disclosing the illness of the patient/client, although this is

considered confidential. Despite the CHWs mentioning that they did not need to disclose any information that the patient/client would not want disclosed, some family members would do so without the approval of the patient, often speaking on their behalf. I was also not able to assess whether CHWs deliberately selected the households to visit, possibly to show me the extreme nature of their work in the hope that their ‘plight’ might reach the powers that be. To circumvent this possibility, I also confirmed with the NGO managers whether the households visited were those within the CHWs’ regular scope of weekly visits. The NGO managers confirmed this in all the three case studies. Although I strived not to interfere in the work flow of the CHWs during their visits, it is possible that I could have influenced the conversations, as the CHWs already had pre-conceived ideas regarding the information I was looking for. To minimise this, I always had discussions with the CHWs pre- and post the visits to explain that the best way to get a true reflection of their and experiences and those of their patients was to continue as if I were not there and to allow for the conversations and interactions to proceed as usual. An observer often adds an unnatural element to the natural setting, hence participants are likely to modify their behaviour. The length of time spent with the CHWs helped to alleviate this limitation as they became more comfortable with me over time.

4.9 Ethical Considerations

The study was approved by the University of the Witwatersrand Human Research Ethics Committee (Medical) - **Clearance Certificate M090237** (Appendix 21). I requested permission to conduct the study with the NGOs (funded by the Province) in the Gauteng Province from the relevant authorities such as the Gauteng Province – Department of Health. I also sought permission from the province which would give permission to the local health authority district

for the study. Because the NGO in the Eastern Cape was autonomous and not funded or accountable to the Eastern Cape Province, I sought and received ethical approval from the NGO.

CHAPTER 5 The community, the households and their context

This chapter provides an overview of the communities that form the basis of the findings in this thesis. It is also an introduction for the rest of the findings in subsequent chapters and I describe the communities within which the CHWs provided services. Chapter 6 describes the organisations as found during data collection and the factors making up the organisational contexts of each NGO. Chapter 7 gives an account of the experiences of the CHWs and the communities and/or households to which they provide services. As a result of this interaction and experiences, Chapters 8 and 9 show how, in the quest of the CHWs to provide outreach services to support PHC, the facilitation of community participation and community level inter-sectoral action unfolds in light of the experiences. The chapters are drawn together in the discussion of the findings in light of the literature in Chapters 2 and 3.

5.1 The communities across the three case studies

This chapter describes the communities and the patients/clients of CHW services across the three case studies. These descriptions and the narratives of community and client experiences emerge mainly from the participant observations in the households across all three case studies, supplemented by the respondents' comments in the key informant interviews and the FGDs.

The description of the participants from the participant observations portray the characteristics of the communities, the households and the context within which they reside. From this contextual description, a series of core themes illustrate the context within which the CHWs provide their services, the nature of these services and how patients/clients receive and experience the services.

This provides a basis for explaining the working environment of CHWs. The section depicts stories of the beneficiaries from the case studies to illustrate how their context influences the nature and extent of CHW services and their experiences thereof. As a result, the described context allows me to show later in the thesis how it affects the extent to which the outreach services of CHWs support PHC, including the enabling and disabling factors. It also portrays the interaction between CHWs, the community and their patients/clients and how efforts of CHWs to provide services play out in reality.

Before proceeding, it is important to explain the different titles for community-based workers used in the different case studies. In the Khanya programme, they are referred to as CHWs because they are funded by the Department of Health and offer services that are primarily health-related. In the Zola programme, they are actually referred to as volunteers and are mandated to focus on information dissemination on a range of issues, hence they are not sector specific. In the Eden programme, they are actually referred to as child and youth community workers (CYCWs) because their primary focus is on children and the youth. In addition, the CHW policy framework is currently being revised [211] and the draft version refers to CHWs as Community Care Workers (CCWs). For the sake of consistency in this thesis, I use the term CHW to refer to all three cadres. It is also important to note that because this chapter refers to households across the case studies, not all patients in the households are regarded as such in all the programmes. In light of this, I refer to them as “clients” rather than “patients” in the rest of the chapters.

5.2 The stories behind the households

The contextual factors within which the CHWs operate help to understand the types of services they provide and how these play out in the reality. The context also explains the complex environment within which the CHWs are expected to provide these services and consequently,

how their services are received and experienced by their clients. Having provided the definitions of poverty in the literature review [23, 118, 119], a large proportion, if not all, of the households lived in what one would describe as *absolute poverty*. This was even more so for all households in the Gauteng case studies. A few households in the Eastern Cape case study fell in the category of *moderate poverty* while the rest experienced *absolute poverty*. In other words, in one way or another, they all experienced varying levels of poverty, some worse than others. The various stories and life experiences referred to in the text are all embedded in and are a consequence of poverty.

From a broader perspective, the fact that most of the households referred to in this study lived in conditions of deprivation has led to the clients of the CHWs to experience a level of isolation from participating and interacting with the normal social systems. This includes systems such as residing in adequate shelter, accessing basic services such health care, education, social services, employment, regular clean water, sanitation and exercising the right to elect those in the spheres of government. In addition, this social condition or status prevents them from exercising their power to challenge those in positions of authority in relation to issues such as service delivery.

The households referred to in the following discussion represent the range of household contexts and experiences that I documented during data collection. The profiles of each household are specified according to several criteria: the level of poverty, the extent of access to services, the illness/es encountered (if at all), the members that constitute each household and the extent to which they were linked to the community and/or social networks.

The profiles of the households are illustrated in boxes within the text. While not all households and/or clients observed in the study were included in this chapter, those that were selected represent a spectrum of the contexts and experiences of all the households. These experiences

range from those who have better managed to survive and cope to those households that are destitute and in absolute poverty. A brief introduction to the households is provided in the boxes below, obtained from participant observations and FGDs. Although this section discusses the households and their experiences collectively, I describe the context of the communities within each case study separately. This illustrates how the CHWs navigate the unique contextual circumstances related to their respective communities. While there were commonalities across the three case studies, the households in the thesis represent a range of profiles. They are described as follows:

There were households that experienced absolute poverty, experienced multiple barriers to access and were in dire need of a range of services (Box 1 and 2). Other homes had families that came from other provinces to seek work in the Gauteng Province. It was typical that they had lost communication with their families who live in other provinces in the country (Box 1 and 2). Some were headed by unemployed single mothers, often faced with a chronic illness such as HIV or TB (Box 3 and 4). Other households had families that had immigrated to South Africa, experienced absolute poverty and struggled to access basic services. Unlike those in Box 2, these households experienced access barriers that were more complex due to their status as foreigners (Box 5). Some households had members with disabilities which illustrate the general difficulties experienced by those with disabilities and their caregivers when living in poor communities (Box 6). I have included examples in Box 7 and 8 to illustrate further the types of cases and households the CHWs dealt with. More importantly, they clearly illustrate the nature of services and skills required to navigate a difficult environment. Some CHWs were exemplary in this regard. In addition, the household in Box 9 is important because it illustrates the complex nature of poverty and how it compromises the quality and nature of services provided by the CHWs.

It is important to note that the unequal distribution of wealth in South Africa is the main cause of deep poverty. This includes the inequitable nature in which services are delivered and the commitment to ensure this equity. It is important to be mindful of this dynamic because if we ignore it, we would be ignoring a factor that has significant effect on marginalised communities.

5.2.1 Description of households in the respective case studies

5.2.1.1 Households serviced by the Khanya programme

The structure of the community

The informal settlement serviced by the Khanya programme is a large stretch of land with shacks that have reportedly been there for the past 10 - 14 years. The informal settlement is about a five-minute walk from the clinic and the CHWs provided services to this community. The settlement continues to grow due to ongoing migration into the Gauteng province.

The CHWs also provided services to an area that was part of the Reconstruction and Development Programme (RDP), a South African national low income housing programme to provide houses for people who reside in informal settlements and who are identified as low-income earners (hence the houses are referred to as 'RDP houses'). This particular area was called Townsview, whose residents were mostly those who had been moved from the informal settlement. During data collection, some of the houses were still under construction, with most of the roads only partially completed. The RDP houses consist of two rooms; one of the rooms is used as kitchen and the other the other a bedroom, and a toilet. Many of the household have manually erected a partition in the one room (with a curtain, cloth or a cardboard) to create an additional 'room' such as a 'lounge' area. Many of those out of these households have remained as clients of the CHWs.

Collectively, these communities endure profound poverty, high unemployment and have a wide range of illnesses. Common illnesses are reportedly TB, HIV/AIDS, diabetes, and high-blood pressure and various disabilities.

The infrastructure (Image 1)

The communities were distant from formal infrastructure such as transport services and/or basic services. These included the major hospitals and regional health facilities such as community health centres which have better resources and offer more services than the respective clinic^{iv} in the case study. During data collection, it was evident and reported by most respondents that public transport such as taxis (public mini-busses) were scarcely available. Reportedly, one would pass by on the main road in the morning and in the evening. The area surrounded by these residents was not a formal transport route, and no government buses drove past this area. People often stood along the main road to hitch rides in cars.

Illegitimate citizens

The Khanya programmes serviced a community largely made up of migrants from various provinces in South Africa and other neighbouring countries such as Mozambique, Zimbabwe and Lesotho. The area was historically a commercial farming area in Johannesburg. Consequently, besides the owners of the farms (who were also the employers), the majority of the households were subsequent generations of those who first arrived in pursuit of work. While the farm employers resided on the farms, the majority of the residents lived in the informal settlements located on the margins of the farms, while a few employees resided on farm property. Most of these houses (in the farm property) were also not formal houses but primarily houses and/or

^{iv} A community health centre is defined as a health facility which provides a wide range of PHC services are provided and is open 24 hours a day, 7 days a week and also provides accident and emergency and midwifery services. It does not offer surgery under general anaesthetic. A clinic is a permanent facility that offers a broad range of PHC services. These are provided at least 8 hours a day and at least 4 days a week.

cottages that had been reportedly abandoned by the previous owners of the farms. As abandoned houses, they were disconnected from the normal systems and services of the main farms over time, thus rendering them with no access to basic utilities such as tap water, sanitation and electricity. Most of the residents in the abandoned houses and informal settlements were unemployed, however they occasionally got day jobs on the farms for a minimal stipend. Some of the women in this area, including those living on the boundary of the farms, were able to secure a “washing” (of laundry) job for a day or two with the farm owners. The “*elderly couple*” in Box 1 represent the farm labour communities that occupied these abandoned houses. In the midst of apartheid, the majority of these farm workers were illegally employed and therefore did not have legal documentation such as work permits and identity documents throughout the duration of employment. As a result, the illegitimate status of people in this community hindered them from accessing a range of government services. Despite being born in South Africa, many of the households who were of second and third generations inherited an ‘illegal status’. The lack of legal documents such as birth certificates and identity documents meant that these individuals continued to experience access barriers. The reality of this illegitimate status is illustrated by the household in Box 5 (“*The woodcutter*”). Struggling to obtain birth certificates for her children, the woman was not able to access a child care grant for each of them to financially provide basic needs such as food and clothing. Although the difficulty of obtaining birth certificates is not unique to those individuals from outside of the country, the process of applying for birth certificates was arduous. A language barrier was a common factor cited as a key barrier to the woman accessing and receiving a service.

She says she has problems travelling to the departments and even then when she gets there, she struggles to communicate with them. (Notes from participant observations regarding “The woodcutter” [Box 5])

In fact, the CHWs reported that it was a common difficulty for many migrant households. Had the woman been able to obtain the birth certificates, she would have been able to apply for the cash grants, which would in turn address issues of affordability in accessing services and resources. Moreover, due to the fear of exposing their illegal status, the residents were voiceless citizens, remaining disempowered. This resulted in the communities' inability to participate and function as citizens of a country in which they were born or had lived in for many years.

“This community does not even have formal forums where they meet. You see at the moment, in this informal settlement, especially this year, there are a lot of Malawians, Zimbabweans, guys from Mozambique so...what can they say? They are scared. They are not here legally. They struggle to get IDs. They are just grateful that they have that shack...some shelter and that is alright. With regard to what happens in terms of services, they don't bother.” (KII – Health promoter – Khanya programme)

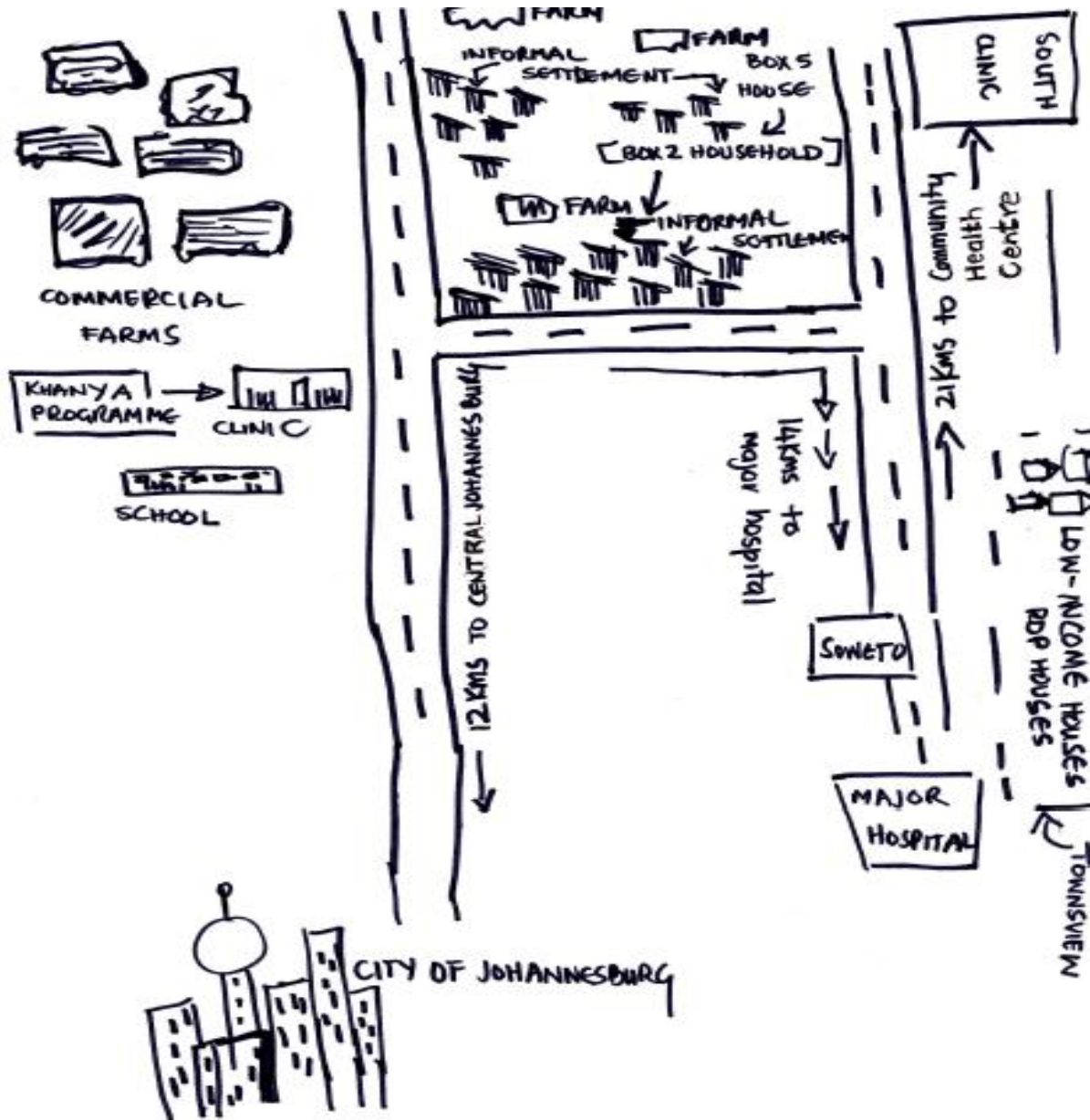
Although access is a problem for many of these marginalised households, these examples show the how being a migrant presents with more complex nuances that manifest as barriers to accessing services.

Most of the older community members who had been employed on these farms were laid off because they were considered to be unable to continue with the physical nature of the work. However, this was without the formal benefits of retirement. The farms in the Khanya programme case study are widely spread out and are long distances from the main roads. Despite this, the residents often have to walk to destinations such as clinics, hospitals and shops which are far from the area. Due to the level of poverty, partly a consequence of unemployment and their illegitimate status, most of this population reside in abandoned buildings or shacks in an informal settlement. One of the respondents explained the situation:

“They came from Lesotho and the children were born here. But it's so difficult for them to get IDs because the parents don't have IDs themselves. Secondly, people are working in these farms

and as they are ageing and with the new government coming in, the previous owners moved out and these people were left behind. They lost their homes because they were told that they can't stay there anymore because their employer is no longer there. That is why they don't have an adequate place to stay. Most of the new people that take over the farms come in with their own employees and that is why they have to leave their homes which are in the farms. This becomes a problem because once they are told to go off, they are not working, they don't have any income, and they don't have a place to stay." (KII - Health promoter – Khanya programme)

Image 1: Oxford



5.2.1.2 Households serviced by the Zola programme

The community serviced by the Zola programme is almost identical to that of the Khanya programme; however, I will deal with the unique differences further in this section. The community in this case study is in an area identified by the Gauteng province for building low-income ('RDP') houses.

The structure of the community

The area is a combination of informal settlements and RDP houses in a former mining area called Harvard. It is on the far edges of South West Johannesburg, between Soweto and a large and affluent suburb and commercial area called Glassview. When the mine closed down, the employers reportedly assisted some of the employees to erect shacks on land close to the mine. When entering the area, one immediately sees a stretch of shiny silver shacks that make up the informal settlement. These shacks are close to other abandoned buildings that were reportedly the homes of the mine authorities. The buildings still have the white paint that renders them conspicuous compared to the rest of the shelters. They were reportedly dilapidated with no electricity, water and sanitation. These buildings were also occupied by some of the residents of Harvard.

When the RDP houses were constructed, communities from other informal settlements were transported to this area. However, while waiting for the houses to be completed, they were advised by the province to live in the shacks. Over time, the number of shacks accumulated beyond the original number of residents, generating a growing informal settlement. Consequently, this resulted in more households than originally planned for the low-income houses. Once the houses were completed, there were already more people in the informal

settlement needing housing than was available in the new houses. This informal settlement was eventually occupied by a combination of the original people from different informal settlements in the province and by others who erected shacks after the first group of arrivals. Moreover, some were from other provinces in South Africa, while a minority were from neighbouring countries such as Zimbabwe and Mozambique.

The infrastructure (Image 2)

Gravel roads surround the entire area of Harvard, making driving a vehicle a challenge. According to one of the residents, three years ago a ward councillor had announced that the local authority needed to complete the roads before installing electrical infrastructure. The area still has no electricity. Many of the low-income households visited during data collection used portable paraffin stoves while others who could afford rechargeable car batteries, used these to connect utensils such as televisions and radios.

Those who lived in the shacks were often found with a fire outside or using a paraffin-stove. Although the low-income houses have indoor water and sanitation infrastructure, the houses that I visited had malfunctioning toilets and indoor taps. In many of the houses I was shown taps over a sink without a drainage system. In this case, people disposed of grey water in their yards or in the streets. Some toilets were not connected to any sewerage system or the municipal pipes were blocked, so when used, they reportedly clogged up. In contrast, infrastructure in the informal settlement in this area was more limited if not lacking. The residents living in the shacks shared communal toilets erected within the settlement. Although dilapidated, with a few requiring repair, reportedly only certain individuals had access to keys for the ones that were functional (in photo 1, those with the doors) and it was not clear how these keys were allocated. Access to

clean water was through a communal water source/tank and/or tap (illustrated in photo 3 and 4 respectively).

Photo 1: Communal toilets at Harvard informal settlement, broken or locked (photo by Sian Singh OFaolain)

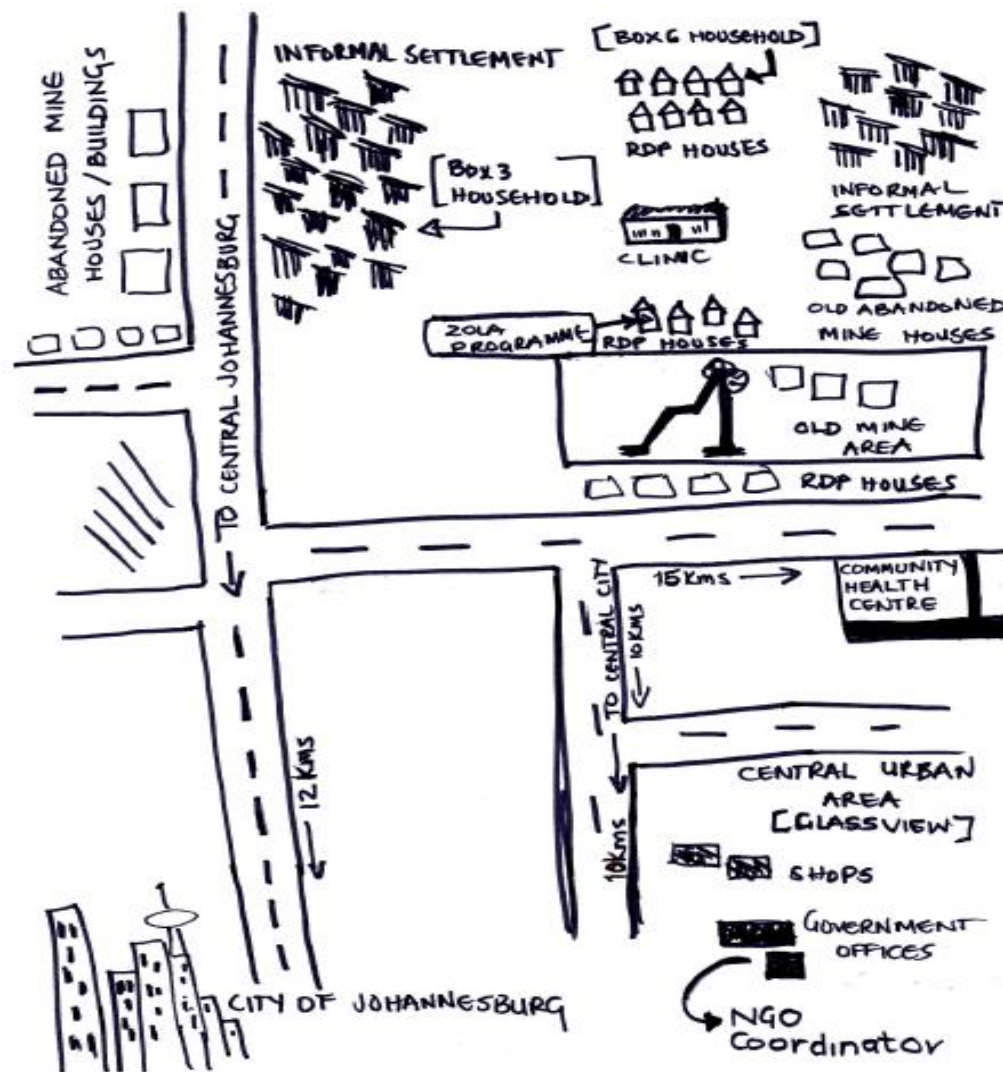


Due to the growth of the community, the local government reportedly decided to provide a mobile clinic. However, other communities from areas surrounding Harvard also started to access it. As a result, it was upgraded to be a permanent facility which is described further below.

A large proportion of this community was reportedly unemployed and endured high levels of poverty. The main illnesses were reportedly HIV/AIDS, TB and high blood pressure. Although Harvard is part of central Johannesburg, it is located on the outskirts of the city and requires formal transport to access basic services such as shops and various government services, as they

are far. During data collection, some people from the area would be seen taking the 40-minute walk to the nearest suburb and commercial area (Glassview). This mode of accessing services was not favourable for those who were ill, the elderly and for women, also due to safety reasons. I would often see mostly young men walking towards the city. Most of the services, particularly government services, were not situated in a single area or facility. Residents would reportedly go to one department, only to be referred to another department which was either further away or in another part of Johannesburg, rendering the walk futile. The closest referral health facility, a community health centre, was also a 40 minute walk away. Due to lack of doctors in the local clinic, it was the main point of referral.

Image 2: Harvard



The case studies highlight the absence of preconditions for basic health such as water and sanitation, as well as limited access to public facilities such as education and medical services.

5.2.1.1 Households serviced by the Eden programme

The structure of the community

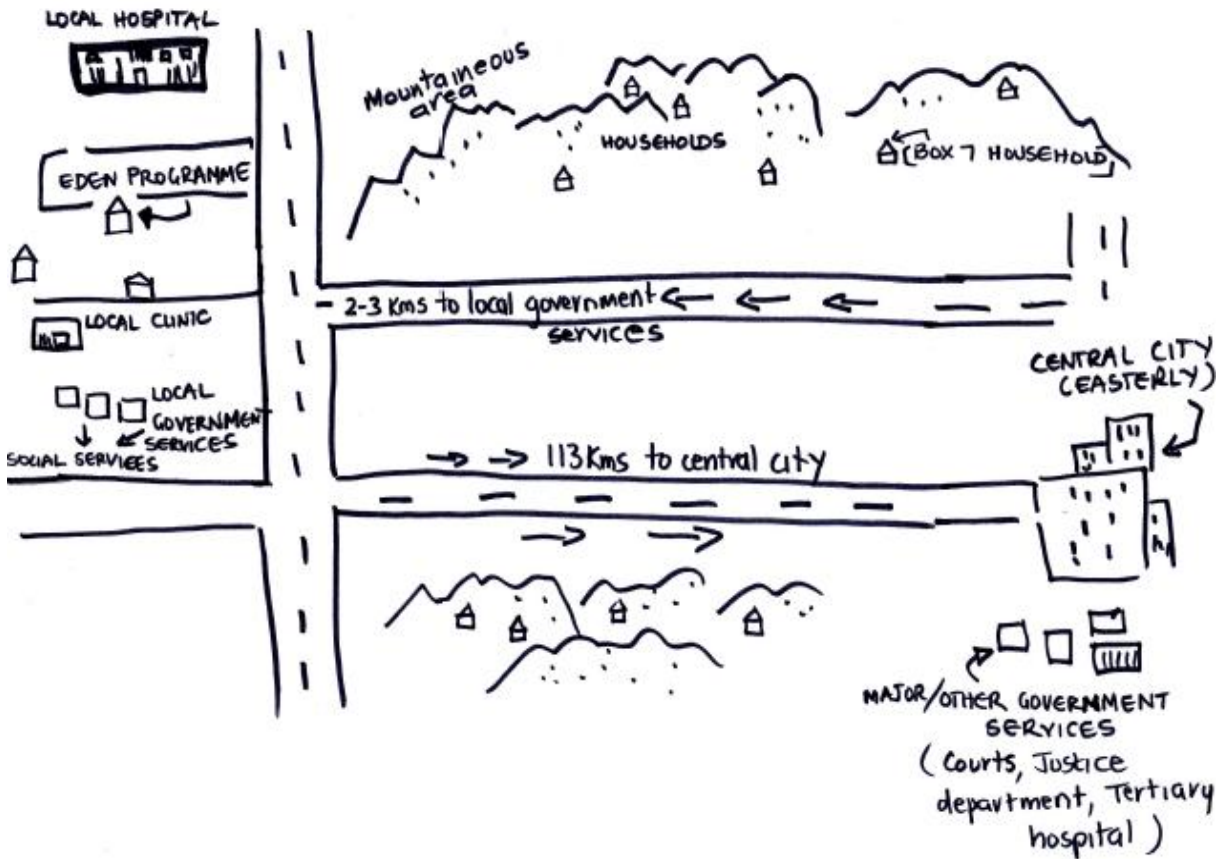
The Eden programme services a community in a small town called Selby. In contrast to the previous case studies, the dense rural settlements were established during the apartheid

government's separate development policy. The community residing in Selby accessed basic government services at the local government offices, about 2-3 kms away. These were primarily; health care services through the local clinic and hospital and social services through the local social development offices, which has several social workers. Most of the other services are in other areas, such as the major city of Easterly, about 113kms from the town, such as the Department of Justice & Constitutional Development. This department was central to the services provided by the CHWs in this case study as it related to the legal aspects that involve children. It is important to note that the services of this department played a crucial role in the wellbeing of the CHWs' clients and often required great effort by the clients and the CHWs to access it.

The infrastructure (Image 3)

All of the houses in this community are old constructions that have existed since the apartheid era 'homelands'. These houses are extremely small with two rooms which in most homes have been partitioned into a kitchen and a bedroom with the toilet on the outside. Some households have extended the small structures with either an extra room or a garage. One of the homes we visited used a coal stove for cooking and to generate warmth while the others did not have any internal heating, despite the regular sub-zero ambient temperatures during winter. The CHW indicated that many of the households could not afford to purchase coal. The households in this area are widely dispersed, with some distance between them. The roads in the residential areas are not tarred, , rendering them unfavourable for vehicles and difficult to travel on during rainy days. The CHWs could not conduct home visits one rainy day because the muddy state of the roads was dangerous to walk and/or drive on, and data collection could not take place. This was reportedly common practice during such weather conditions.

Image 3: Selby



As a long settled area, many of the families had been resident in the area for some time. A substantial proportion of those in the community depended on remittances from migrants working in other provinces. From my general observation and verbal confirmation from those that I held informal conversations with, I gathered that a large proportion of those that remained in the community were not of employment age, were ill or were elderly. In essence, the community of this small town reportedly remains stable, with many residents who have observed the political transition of the country remaining in the area.

The previous section provided a description of the communities that are serviced by the CHWs in the three case studies. The remaining sections will provide a description of the context of the

households and the environment within which the CHWs have to function. I deal with this collectively, across the case studies.

5.3 The context

Box 1 “The elderly couple”

Together with the CHW we enter a damp and very dark house to visit an elderly couple who had been farm employees. ***Laid off with no formal employment benefits, the couple lived in a makeshift building without water and sanitation. They rely on scraps of food from neighbours, who are equally poor.*** The elderly woman seated on the mattress has extremely swollen feet which are sticking out of a door. She was too sickly to walk to the nearest clinic. The old man mentioned that at times he walks up to the road to stop a taxi so that it can drive inland to collect the old woman. The CHW inquires if they buy food, because there was no sign of food in the house.

The couple mentions that they both receive a pension grant but they often cannot go to collect it at the government offices because they cannot afford it and do not have the strength to walk to the main road for public transport. The main road is about a 15-20 minute walk from their home.

The CHW attends to the woman. She says her feet are painful and finds it difficult to walk hence she sits the whole day. After looking for a tap or a source of water around the yard to wash her feet, ***the old man mentions that the only way they manage to access some water is to walk up to a hose that extends to the fields to sprinkle the produce in the main farm. He says that he places a bucket under a leaking part of the hose and waits until it fills up with the water.*** We walk up to the hose and do the same. The CHW then finds an old rag and proceeds to wash her feet. In an effort to appease the elderly woman, the CHW says: ***“We will try to come back and fetch you with a car,”*** in order to take her to the clinic for the nurses to assess her feet and her blood pressure. But that is not certain as access to transport is not guaranteed. (Notes from participant observations)

Photo 2: Home of “Elderly couple” (photo taken by author)



Box 2 “*The South African immigrant*”

We find a 65-year-old man sleeping in a shack that is built with corrugated iron, hence is extremely cold. He reportedly came to Johannesburg 46 years ago from Mount Frere (Eastern Cape province) in search of work. He is the CHW’s TB patient and she monitors his treatment and ensures that he takes his medication. The shack is bare with no sign of any food except for a jug filled with what he says is a sweetened drink. There appears to be no facility/basin to wash. ***There is no sign of a tap nearby. The nearest is a communal water tank within walking distance from his house, a difficult task for him due to his illness and consequent weakness.***

The CHW inquires why he is sleeping during the day (it is 11.23am). He says he has just returned from the local clinic because he felt weak and needed to fetch his treatment. When he arrived there, he felt worse. Close to his bed there is a small table that is full of containers with tablets from several months ago indicating that he does not take his medication regularly. This also meant that he is given a new supply each time he visits the clinic as it occurred today. [This indicates that he is not monitored by the clinic or the CHWs]. The CHW asks why he has not taken any of this other medication. ***He replied that he often does not have any food and it is very difficult and unpleasant to take the medication on an empty stomach.*** There are two dry slices of bread on the table which he says he was given by a

neighbour so that he could take the tablets he was given today; however, the bread is too dry to swallow. The CHW gives him a banana which she had just bought as we were walking because she felt lightheaded. She watches as the man eats the banana and then helps him take the tablets with the drink. She spends a few more minutes with him, talking and asking him about life in general. (*Notes from participant observations*)

5.3.1 The journey to Gauteng

Although the clients across all the cases studies are part of communities that are situated in different geographical areas, poverty contributed to their common experience of various services as illustrated by *The elderly couple* (Box 1, Photo 2) and *The South African immigrant* (Box 2). Both illustrate the typical levels of poverty experienced by the range of households that the CHWs visited across the case studies. The majority of the households resided in informal settlements, with varying degrees of ‘informality’. The households in Box 1 and Box 2 represent the experience of internal immigrants, where people historically moved to Johannesburg from other provinces in search of work many years ago. “*The woodcutter*” (Box 5) is an illustration of families who are immigrants from other countries and eventually became naturalised citizens.

Personal accounts which were not recorded verbatim were provided by some of the CHWs, where they explained how they came to live in the informal settlements (in both case studies). Their narratives indicated that the journey to residing in these areas and types of households takes shape through various avenues. A CHW originally from the Eastern Cape Province mentioned how after completing high school, she was unable to find employment there. She then decided to come to Johannesburg after being told by friends and relatives that there were better job prospects. She heard about the informal settlement by word of mouth, where on her arrival she was accommodated by a friend until she had gathered enough material (corrugated iron sheets) to erect her own shack. Other CHWs mentioned similar experiences, where they knew

either relatives or friends who had already moved to the settlement and therefore had prior knowledge of where they would live whilst they sought work and settled in a new area. This appropriately illustrates that the use of pre-existing social networks could act as a form of social capital. The provision of temporary accommodation while seeking employment and personal shelter created a context in which the CHWs could cope with their move into a new area. This was, however, not the case with many of the households residing in the farm communities served by the Khanya programme such as *The South African immigrant* (Box 2) and *The wood cutter* (Box 5). These households did not have the comfort of using existing social networks such as relatives and friends since most started their families in the country (South Africa) or in the area they moved to from another province. The lack of social networks and its consequent limitations was clearly illustrated by the woman in Box 5 (*The woodcutter*). From my observation and confirmation by the CHWs, she was isolated from the rest of the community, and also lacked access to basic information and resources such as those one could receive from a neighbour or the community.

5.3.2 The harsh conditions

For some of the households, living conditions were often what one would describe as squalid and unfavourable for any human habitation. The “*elderly couple*” in Box 1 and “*The woodcutter mother*” in Box 5 provide an illustration of households that are typical of this context. For the “*elderly couple*”, the single-room home served most purposes, where they ate and slept in the same space. Limited access to water made it difficult to maintain any level of cleanliness. Many of the households in these informal settlement communities arranged their lives within cramped spaces, either sharing a shack with extended family members or creating extra “rooms” to rent out to generate some income. Part of the data collection occurred during the winter season and

many of the shacks were often extremely cold and damp. One household visited typified this context:

The home is a shack occupied by 11 people. Some are related and some share the space as a means of saving costs. From the outside, the shack looks like one single large shack, but when one enters, one notices that there are different “rooms” which are separated by a combination of sheets, wooden doors, cardboard and steel objects. The room closest to the entrance is full of wood and an indoor fire is being prepared. All the rooms look damp, cold and dusty. (A shack in a Zola programme visit – Notes from participant observation)

Some households made a fire in a corrugated iron bucket and kept it in the rooms in an effort to keep warm. The rooms were therefore often filled with smoke.

Makeshift toilets and communal taps

Due to lack of formal water and sanitation systems, it was common in most of the informal households to share a communal toilets and water source or tank and/or tap water (photos 1, 3 and 4 respectively) which in most cases were not fully functional. This was illustrated in one of the households visited, “*The rats vs the single mother*” in Box 3.

She immediately apologizes for the stench that is exacerbated by the wind. She tells us that “government” came to take “their” portable [bucket] toilets about a month ago and people have been using the bush behind her shack as an alternative. (Notes from participant observations – “The rats vs single mother” - Box 3).

Although portable toilets were available, some of the households in the informal settlements lived far from any visible ones. Some households had resorted to erecting their own makeshift pit toilets, as illustrated in photo 5. In fact, informal settlements served by the Khanya programme had a few portable (bucket) toilets distributed in the area; however, there were too few to serve the entire community. Some of them were reportedly not functional. This was a similar case with regard to access to water where in one household, “*The South African immigrant*” (Box 2), the

ailing client was unable to fetch water from the communal water source/tank as it was far from his shack (photo 3).

Photo 3: Communal water tank/ in the Khanya programme community (photo taken by author)



Photo 4: Communal tap in the Zola programme community (photo taken by Sian Singh OFaolain)



Photo 5: Makeshift toilet (photo taken by author)



These examples highlight how the depth of poverty not only manifests acts as a barrier at the point of accessing. It is an indication of how poverty permeates all aspects of an individual and a community and thus highlights the need for a comprehensive approach to addressing needs.

The sense of insecurity and vulnerability

In a community with high levels of violence and crime, it is not surprising that all of the informal households visited gave a sense of vulnerability. This was evident from the lack of physical security, especially for the women who lived by themselves or in households headed by women. The shacks were made out of an array of corrugated iron, with some attempting to create a sense of security by using wires, old padlocks and a variety of objects to secure fragile doors to create an impression that they were safely locked. Many of the households were headed by women who expressed a great sense of insecurity as seen in the household where a single mother lives in the shack with her daughter and her granddaughter, *“The rats vs the single mother”* (Box 3). A similar sentiment was expressed by one of the key informants who sometimes conducted home

visits with the CHWs: *“People are being raped in their shacks. People just come, remove part of a shack while people are sleeping and they go in.”* (KII – Clinic manager, Khanya programme).

Box 3 *The rats vs the single mother*

We approach a woman in the yard of her shack. Inside, it is damp and one of the CHWs asks whether it was the rain. She says that every time the clouds start to gather she gets anxious because she knows that her home will be flooded and her belongings will be damaged. ***“Rats come in and die in our pots,”*** comments the woman. She also reports that they are scared to sleep. ***“When I hear a taxi hooting in the morning, I thank God that I’ve lived to see another day.”*** She reports that an old man next door to her was killed: ***“Imagine sleeping, knowing that someone was being killed while you were snoring away? Is this the life?”*** One of the CHWs inquires about her HIV treatment and asks where she collects her treatment. She replies that she fetches it at a community health centre that is approximately 12kms from the area. Currently the community’s local clinic, as with all other clinics, does not supply ARV treatment). ***She says it is a struggle, but her daughter helps her out with transport money from the temporary jobs she occasionally secures.***

The family mostly relies on the Child Support grants of her two grandchildren. She reflects on how she came to Harvard together with one of the CHWs and that she is still on a waiting list for a house. She reports that a house with the same number as the house she was allocated is now occupied by someone else. The community representative who is assigned to book and allocate people houses from Harvard’s Housing Department office allegedly gives houses to people he is close to and those who are prepared to pay. This representative is also allegedly well acquainted with the ward councillor who is meant to oversee the process and intervene in such matters. The ward councillor is allegedly only responsive to a few individuals. The residents (CHWs and the woman concerned) allege that the councillor often holds meetings with certain groups outside official meetings. They also allege that he is a member of a certain political party and responds only to those who are supporters or members of that party. The woman reports that she has been inquiring about her house so often that she feels powerless. *(Notes from participant observations)*

The account in Box 3 also illustrates the vulnerability through exposure to the damaging effects of natural elements such as rain which often flooded homes and yards. Here, the family has had to live in a shack since 2002 while waiting for a low-income house.

Despite the contrast between residents who lived in the secure shelter of formal low-income houses and those living in the informal settlements, all households across the case studies faced similar circumstances with regard to needs and daily struggles. Those in the low-income households, for instance, still lived in cramped spaces, where poverty was a core component of life, thus evidently no different from those in the informal settlements. A CHW provided an account of one of the family's life in one of the old houses in Selby which was serviced by the Eden programme

“I worked for 2 years in that family with the one child I was assisting. The hygiene in this family was very bad, because they are staying in a small house and they are more than 14 or 15 in the house.” (FDG – Eden programme)

Unemployment: The quest to survive poverty

Many of the formal homes the CHWs visited showed what many experience in the informal settlements including a lack of food security, unemployment and limited basic services such as water and electricity. For instance, while the *“HIV positive mother & son”* in Box 4 resided in a low-income house, the mother was unemployed and struggled to deal with living with her own and her young son's HIV infection. Living in a secure shelter did not prevent her from the other experiences manifested by poverty.

In fact, very few of the households across all case studies reported having a regular income, and the majority of adult household members recounted they had been unemployed for almost their entire lives. For this reason, most of the clients in these households eked out an irregular living from either handouts from neighbours, temporary jobs for a few days and for the fortunate, a monthly social security grant. Survival on a grant was often found in households with single mothers, as illustrated by the households *“The rats vs the single mother”* (Box 3) and *“The HIV*

positive mother & son” (Box 4). Both homes depended entirely on the social security grants for the children in the house.

Box 4 “*The HIV positive mother & son*”

We visit an HIV positive woman who stays with her 6-year-old son, who is also HIV positive. The son has just started taking his treatment which is collected from Chris Hani Baragwanath Hospital, one of the major hospitals in Johannesburg, about 14kms from their home. She started taking treatment but decided to stop after a few months, saying that she preferred to take traditional medication and herbs instead.

One CHW asks how she has been advised to administer the treatment to her son. She replies that she is not sure and adds that she collected the medication a day ago at the clinic. She says she cannot read and therefore is not sure about the dosage. The CHW starts to read the instructions and explains and shows how she should be administering the medication. ***One of the CHWs inquires if it was not explained to her at the hospital. She adds that the nurse that was attending to her was speaking mostly in a language she does not understand.***

As the CHW explains that if she were to take her ARVs, all the symptoms that make her feel ill and weak would be alleviated, the woman says she just believes that she now has AIDS and she would rather die. The CHW explains that she does not have AIDS yet and that she is just suffering from HIV symptoms and that the purpose of the ARVs is to prevent these symptoms. The woman refuses to get onto treatment and says that she would rather die and leave her child. She adds that her parents both died and she managed to grow up on her own. ***“He will be fine...he will survive.” She says that half the time she has no food and has had enough with taking tablets on an empty stomach. “Those tablets make you terribly hungry.”*** The CHW explains that once she’s on ARVs, she’ll receive a grant so that she can buy food. She appears not to be convinced. She continues to mention that she is also tired of taking her son to the clinic. ***“They [health care providers] often never help even when his treatment is not effective.”*** (Notes from participant observations)

Some of the households reportedly survived on handouts from neighbours and assistance from the CHWs. A young man who lived by himself was unemployed and was on ARV treatment. Since he lacked financial means, he often struggled to fetch his treatment regularly:

“He however finds it difficult to fetch his treatment regularly because of transport issues. He relies on neighbours for money; sometimes [he] manages to get money from a one or two day job and he sometimes borrows from the CHWs themselves.” (Notes from participant observations - Household serviced by the Khanya programme)

In some cases households survived by generating income through informal activities:

“These people absolutely struggle. Some of them do “piece jobs” [small/temporary jobs] and others will work here in the field in the farms and afterwards, the farmers...the owners will give them a cabbage or whatever they grow in the fields...sometimes maybe R10 (USD 1.20^v) for the day.” (KII - Health promoter- Khanya programme)

Some of those efforts involved innovative means to generate some income. The household in Box 5 (*“The woodcutter”*) conducted various activities in this regard. The woman would burn wood and sell it to the community for fire-making.

Box 5 *“The woodcutter”*

We enter a yard with a shack and it is visibly damp from the rain. The shack is close to an open field and the woman who resides in the shack is chopping burned wood. The CHWs inform me that she makes a living by burning wood and selling it and people use it as coal. She has completed her TB treatment; however, the CHWs continue to monitor her during their house-visits. She is from Mozambique and came to South Africa 13 years ago. The CHWs together with the NGO’s project coordinator assisted her to obtain an ID. They report that this was successful because it occurred on the one occasion when the local Home Affairs department brought a mobile unit to the area and they assisted all those in the community that needed IDs. This was the only time that some people managed to receive these essential documents. Under normal circumstances, the CHWs mention that it would have not been the case. Many others struggle to access this service. She has three children, aged 4, 7 and 12 and is in the process of getting a social security grant for them. ***The woman says she is struggling to get birth certificates for all of them so that they can apply for Child Care grants which could assist to provide them with some food and clothing. She says it is a challenge to travel to the departments, and when she does manage to get there, she struggles to communicate with the staff*** (she does not speak the local languages and has a limited command of English). In addition, she mentions that she no longer has decent clothing

^v 1 ZAR = USD 0.12 [14 December 2012]. Please note that this applies to all other subsequent currency rates in the thesis

because of the nature of her work. ***“Iyo! I look like this every day; can you imagine me going anywhere looking like this...like a witch?”*** [She laughs...]. The CHWs mentions that their manager always brings clothing to distribute. They assure her that they will bring some clothes for her and the children when she delivers some in the future. (Notes from participant observations)

In an effort to survive, some of the women reportedly resorted to practices and/or risky survival strategies which impacted their lives in ways that manifested beyond health:

*“The one time this young girl said to me, “Uncle, my mother comes home late on a Friday, drunk, she comes in with this guy and then without any privacy they will do whatever they do then the following day, I don’t see that guy anymore, but **I see another guy the next time.** And when I try to talk to my mother, she tells me that **whatever I eat in this house is brought by those people I’m complaining about**”. So this child is being taught that this is the only way to survive.”* (KII – NGO representative – Khanya programme)

Children reportedly learn the various ways that are adopted by parents to survive. This manifests in social problems such as teenage pregnancy and sexually transmitted diseases and infections, which are reportedly prevalent in the Khanya programme community:

“There is a problem of teenage pregnancies. Why do these girls fall pregnant so early? We go to the school to talk to them especially about this issue. It goes back to one thing, finance. Poverty plays a part. They will tell you that the older men promise them material items and give them things that their fathers cannot afford. They sometimes use this money to support the whole family. So these girls have to give something in exchange for all this. According to them, they are not prostitutes. Their reasoning is that they don’t go to the streets although, yes, they do sleep with them.” (KII – NGO representative – Khanya programme)

Living on the margins of society: Access to services

Although all of these households, particularly in the Gauteng case studies, were situated reasonably close to the cities, they were in reality on the periphery. The impact of unemployment and poverty made it difficult to travel and get to areas with better resources and more services. Not only were these central business areas far to reach because they require transportation, the

households were far from formal transport routes or from adequate transport infrastructure. For this reason, most of the clients raised the difficulty of travelling to access services, with the exception of the community serviced by the Eden programme. Even though the nearest city is about 113kms away, the local government departments are geared for the rural context and offer satellite services which are more accessible. However, circumstances that required higher level interventions or services, such as courts for legal issues or tertiary hospitals, required the locals to travel to the distant city. In contrast, the communities in the Gauteng case studies had to travel to access any basic services and many reportedly requested transport along the main road to the city. Most of the households could not afford the costs of travel.

Oxford (serviced by the Khanya programme), for instance, is an area situated in the centre of the official geographical boundaries and it is often is not recognised as part of any official sub-area. Although it is part of a large sub-district in the City of Johannesburg (fig. 6.2), its geographical boundaries are blurred, resulting in residents ultimately not receiving services. This confusion was reportedly a common and long standing experience in the community; however, it was not clear to me whether it was one that the authorities were unaware of or one that was not attended to so that it became the norm for the community. I expand on this in Chapter 9, when I discuss how communities struggled to access comprehensive services.

The area where this community (serviced by Khanya programme) resides was along a main road that is not part of the official transport route of the sub-district. The closest major hospital is about 14kms away and the closest community health centre was about 21kms away. None of the common transport sources travelled along this route. As a result, people in the community resorted to walking 20 minutes to a transport route, while some often requested transport from willing strangers in passing cars. One of the respondents explained:

“...they can’t reach some of the areas that we refer them to because of the geographic area. There are no public taxis (public transport). The transport system here is the poorest. There’s only one taxi that is functioning for everyone. If you miss that taxi for the morning, that’s it. The taxi passes through all the farms and comes by the clinic. If you’ve missed it, you have to hike^{vi}! People hike here...which is not safe. Failing which, you have to walk...” (KII – Clinic Manager – Khanya programme)

Although the communities in the Gauteng case studies were located in areas that were seemingly close to central areas, as opposed to the 113km distance for those in the Eden programme community, travelling to services still remained a primary challenge for these communities living on the periphery. The Zola programme community better articulates this underestimation. Even though the intention of the Gauteng province was to place this community in an area that was presumably close to the formal transport route, the reality is that the community is on the margins of one of Johannesburg’s central urban areas. The main transport route is approximately a 10- minute walk and the closest central urban area is about 10kms away. For this community, there were costs involved to reaching these areas. One respondent confirmed this:

“But in terms of services...You see these areas are far from services...that is why we targeted Harvard (with this dissemination programme). We were looking at areas or communities with limited access to information and services. But it’s very difficult for those people to access services.”(KII – City of Joburg representative, in reference to the Zola programme community)

Consequently, the isolation resulted in limited exposure to other basic services, evident across the three case studies.

“They need recreational facilities, youth groups, to get them to do something where they can occupy themselves, such as shopping centres....just basic infrastructure. Decent streets where you can walk and drive and not worry that you’ll fall into some ditch or damage your car. Electricity... a community library, I think it’s necessary. A big problem here is also an ambulance. The response is so poor. Remember we [the clinic] don’t have a phone line and because the roads are so bad and there is no signage, they get lost and they often leave after a while if they don’t get the house or the clinic they are meant to go to. People even ask: “Where is

^{vi} Local term meaning to stop a car on the side of the road to request a ride

this Harvard?” as if it never existed all these years.” (KII- Clinic nurse – Zola programme case study)

The community in Selby (Eden programme) was very different to the Gauteng case studies. Reportedly situated in one of the most poorly performing provinces in the country in terms of service provision, the small town had local level basic services - one local clinic, one hospital, and a satellite Department of Social Development. Other major departments such as tertiary hospitals and public legal services (often needed by the Eden programme CHWs for cases of child abuse) were quite out of reach for the households in the town. One respondent provided their view of the context:

“Selby...because of the social context... because it was in the former homeland of the Ciskei...because although it is near services like Easterly, the services are somehow limited or of no easy access and the resources are too difficult to come across.” (KII – Eden programme coordinator)

Interestingly, even though the community in the Eden programme case study had geographical barriers of distance compared to the distances in the Gauteng case studies, all three communities experience similar access barriers. This, in my view, tested the commonly held view that rural communities encounter far worse access challenges than those in the urban areas.

The local services: the extent to which they coped

All of the households across the case studies had local health services available, for instance clinics that had been provided to accommodate the lack of transport. The Khanya programme community used the premises of the local clinic, a very small facility that in reality was too small to accommodate the large numbers of residents that visited daily. The clinic has a small waiting area with the space offering very limited privacy for the patients. The reception is in the same

area and adjacent to the waiting area, and within it a small corner has been designated for the weighing of babies. This corner was also where a health promoter gave “health talks”. There was, however, a second and larger waiting room which was the outer part of the clinic and was used when the clinic inside was full and when it was not raining or cold. The Khanya programme NGO mostly used this waiting room for its meetings. The clinic built this outer extension to accommodate more private consultations and for Voluntary Counselling and Testing (VCT), including clinical assessments. Over time, the clinic acquired two ‘containers’ (portable and/or mobile rooms) which were used as consultation rooms. The one container reportedly became a room to attend to TB patients, where one nurse managed all the testing and counselling. During data collection, one would find a number of patients waiting outside to be attended to by the nurse. Since the nurse was operating alone, many often remained unattended to and had to return the following day. The second container was used as an office for the head of the clinic. The health facility did not have a telephone or a fax machine. As a result, the staff members shared a mobile phone which the clinic manager kept; however, this was often not functional. This clinic provided services mainly for the community from the surrounding informal settlements and the farming community. As is usual for local clinics, it provided a variety of primary care basic services such as assessments, weighing of children, and monitoring and treatment for chronic diseases such as high blood pressure. Patients requiring other higher level interventions would be referred to tertiary levels of care.

After being relocated to Harvard, the community serviced by the Zola programme was reportedly provided a local clinic a long time after settling in the area. The clinic consisted of two portable/mobile rooms (‘containers’), initially unfenced, located in the middle of the community. The one room was the main clinic and the other was an administrative office, with the senior

nurse's office. The clinic did not have a telephone and/or a fax machine. The only option for the staff to communicate with other services or facilities was to use their personal mobile phones. During data collection, the clinic had three nurses and no doctor. At the beginning of the study, some of the VCT counsellors had reportedly left, and the one remaining was on maternity leave. Due to lack of electricity and after several months of enduring cold weather, the clinic reportedly requested for a generator. Since it had no waiting area, people had to sit outside while waiting which was a challenge on rainy days. Similar to the Khanya programme case study, the facility was small and under-resourced for the population that it served. This was mostly because, although it was intended to provide services only to the community of Harvard, other informal settlement areas surrounding the community also used the services to avoid travelling to other health facilities which were further away. One of the nurses described the situation:

“...Without electricity? We do what we have to do. We decided to go and talk with the big bosses, asking them to close the clinic because it was too cold. I mean it's a container, we didn't even have shelter where we attend to people because not everyone can fit in the container, so when it was raining, it would be a disaster. We also closed because we needed other things like water supply, there was not enough water supply. We needed fencing because we were completely exposed.” (KII – Clinic nurse – Zola programme case study)

Consequently, the service at the local clinics, more evidently in the Gauteng case studies, remained mostly ill-equipped to cope with the needs of the communities.

“The nurses in this clinic are very few because they don't only attend to people from here only. People from other informal settlements surrounding Harvard come here and they never get to see all the people in a day. It's not easy to get help there. You go there as early as possible, but you'll still need to return the following day. The thing is we are sharing a service with people that are really sick. There is a high rate of TB in the area, including HIV.” (FGD – CHW – Zola programme)

In light of the access barriers cited, the residents who needed interventions from higher levels of care were often unable to reach those facilities. This was illustrated by one of the households in Harvard where a child with a severe disability was cared for by his mother (“Mother & the

disabled son” - Box 6). In fact, the presence of an unemployed woman who attended to an ailing family member was a common feature in these communities. “*The rats vs the single mother*” (Box 3), “*The HIV positive mother & son*” (Box 4) and “*The woodcutter*” (Box 5) illustrate this reality.

Box 6 “*The mother & the disabled son*”

We visit a woman who is a guardian to her deceased sister’s two children and her own disabled son. The CHWs ask her how she survives and how she fends for the family. She mentions that she is living on a child support grant for the two children. The CHW asks if her son is receiving a disability grant. The woman reports that her son used to receive a disability grant but it was stopped when he turned 18 years old. She was told that her son needs an ID so that the grant can be registered as his own. She has not been able to go with him because if she uses a public taxi, they charge her, her son and the wheelchair as it takes up a lot of space. ***She says she needs to save up for the trip to go to the Home Affairs department to apply for the ID. The CHW mentions that it will not only be money for the travelling costs. There may be costs for other documents that will be required to apply for a disability grant.*** She says that she will need a letter from a doctor that gives a diagnosis of her son’s disability and the level of severity. We enter the disabled son’s room. The boy looks very small for an 18 year old. He has cerebral palsy. The CHW comments that he has still not managed to gain weight. The mother responds, saying that she really struggles to feed him as his mouth is quite tight and he grinds his teeth and struggles to swallow. The CHW asks why she never brings him out of the house so that he can sit in the sun anymore. She mentions that he has been sick. She says she took him to the clinic but by the time she had prepared him and placed him on his wheelchair, it was late and the clinic was full. She adds that they waited but they did not get to see any nurse as the clinic had to close. She says she will try again.

As we stand up to leave, I inquire whether it was explained to her what her son’s condition is or whether she consulted a specialist who deals with children with disabilities. She says ***she gave birth in the Eastern Cape and was just told that her child was disabled and that he would need special care.*** I asked if she had been to any of the community health centres where one can find a physiotherapist who can show her how to feed her son. She says she has not been to anywhere else but a clinic when he is ill. The CHWs mention that if she gets an ID perhaps she can find a way to take him to some of the community health centres that have “***this type of doctor***” [says one of the CHWs]. From the response, I get the impression that the CHWs may not be informed about health professionals such as occupational therapists, physiotherapists, speech therapists, etc. (Notes from participant observations)

5.3.3 The common factor/s across the three case studies

It is evident from the communities in the three case studies that various factors are common in all of them. There is pervading poverty of varying degrees and the households attempted to cope in a number of ways, ranging from relying on neighbours to engaging in transactional sex. A common feature in all the communities across the three case studies was one of poverty and an existence along the margins of society in the respective areas. The households struggled to navigate the formal health care system and equally important, other essential sectors of government. This was due to a range of barriers, such as financial, distance of services, illegal status and the limited extent to which services could cope with the demand. This context impacted on the extent to which CHWs could provide quality services, including their ability to facilitate outreach services across sectors for the range of services required as part of their institutional objectives, and to utilise community structures to facilitate community participation.

The sense and texture of a community can to some extent influence how communities deal with their struggles. How a community tackles its own issues and struggles and the extent to which it participates in making decisions is commonly known to be stronger in communities that share a history of existence and thus have a strong sense of social cohesion. The two communities in Gauteng shared a common factor: they both constituted people who joined the community at different periods, from other communities in another part of the country and other countries. I reported earlier that the communities in the Khanya programme case study were reluctant to participate in any community structures as most of them had illegal status and thus lived in fear of being identified. The community in the Zola programme case study also depicted a community constituted of recently settled households with conflicting aspirations and needs.

Consequently, it emerged that different ‘informal factions’ took the responsibility of challenging the more formal community structures such as ward committees. The various factions had different leaders who often assisted community members with some of their challenges rather than channelling them through formal government structures. The poor sense of community contributed little to alleviating the experiences that were a manifestation of poverty.

In contrast, the community in the Eden programme case study had shared a long history of living together and survived the transition from the apartheid government to the current one. Judging from the extent and nature of participation reported, there appeared to be a strong sense of cohesion where, for instance, neighbours were easily willing to take over the guardianship of orphans or needy children in their neighbourhood. Consequently, the ward committee in this case study was reportedly more active and in accord with the community, while the ward counsellor was regarded as being much more visible and in direct contact with the community. I will expand on this in the chapters below.

It is within this context and in these aforementioned communities that the CHWs provided their services. In order to understand and explain the work of the CHWs in the respective case studies, the following chapter describes in detail the organisations that employ these CHWs, including other organisational factors that contribute to the extent of their ability to provide these services.

In short, drawing from these case studies and the respective communities, I have illustrated the range of needs that the households have with respect to access. Moreover, I have shown how their vulnerable, marginal and excluded status influences their ability to access basic services. The following chapters will discuss the findings in an attempt to relate them to the context presented in this chapter.

CHAPTER 6 The organisations and their contexts

As described in the methods chapter (Chapter 4), case studies were selected primarily based on their organisational contexts. Community-based organisations such as those in my study are often embedded in the communities to which they provide services. In this regard, they also face the realities and contexts of those communities. These organisations, however, are also institutions with structures and as with any other organisation, their respective institutional contexts determine the extent, nature and quality of their functions and outputs. In this chapter, I describe the unique organisational contexts of each case study and attempt to understand how and why the CHWs from each organisation experienced and managed (or did not), to provide outreach services in their respective communities. I provide the geographic location and general details of each case study, and describe the structure and the operational details including the staff establishment and the type of services actually rendered (as opposed to intended). I describe the extent and type of management (and/or administration) and leadership. I provide details on the recruitment process of CHWs, the training and supervision and resources (funding, premises, and transport). I conclude by describing the social networks using the network maps of the respective communities to show the community context within which the CHWs provide services. I introduce this component towards the end of the description of the case studies on the premise that over and above the content of the institutional context of each organization, how the communities function and interact as a collective also determines the extent to which the CHWs are able to use the existing community participation structures and practices to facilitate community level inter-sectoral action.

The following table captures some of the components in the organisations.

Table 6.1: Comparison between the organisational components of the case studies

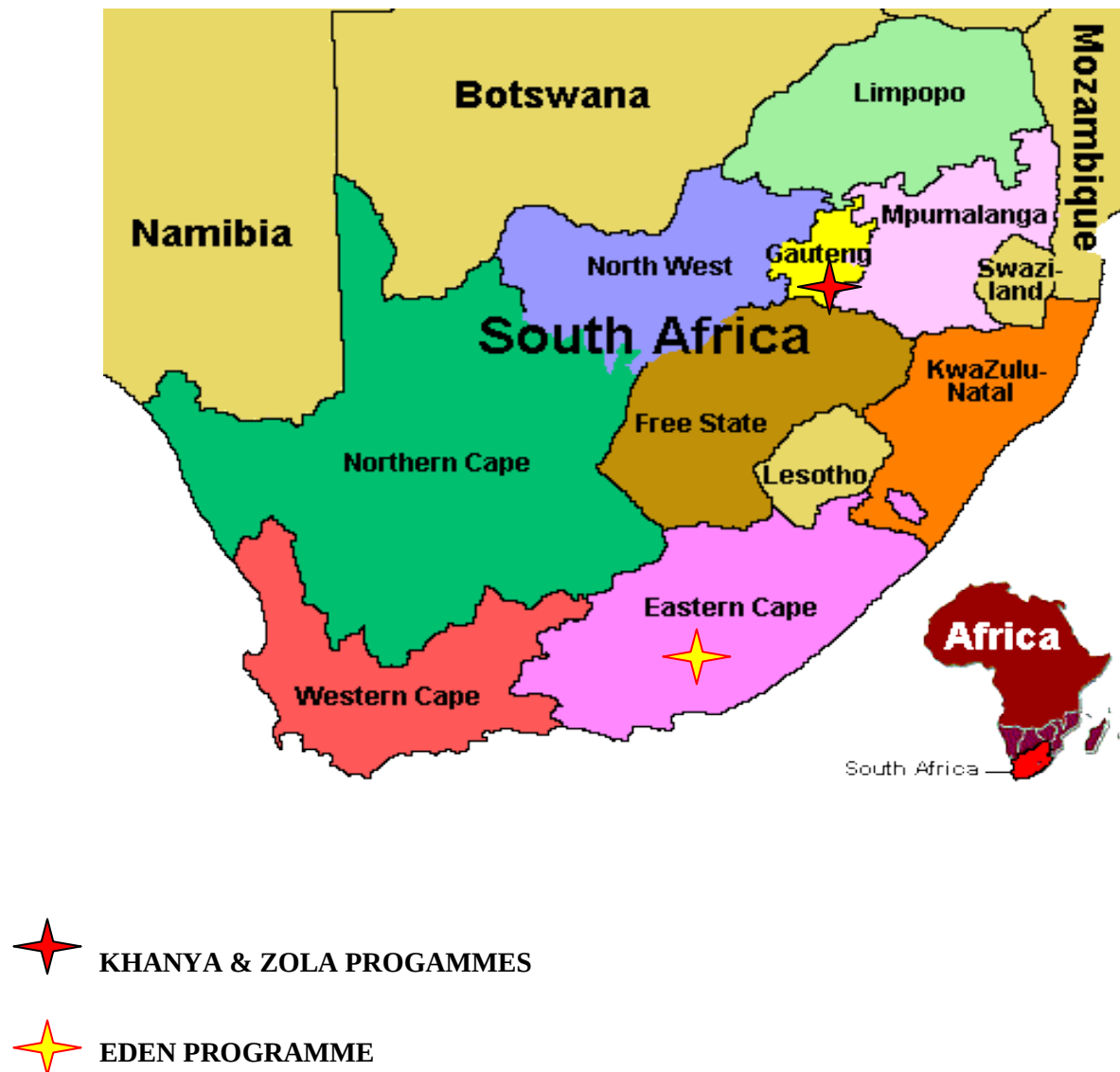
Component	Khanya programme	Zola programme	Eden programme
Types of services rendered	Deliver medication, patient tracing, home-based care, social/psycho-social support	Health promotion, referrals to other sectors and advice on required documentation e.g. how to apply for a grant. Do not provide care (information dissemination)	Child & youth care focus. Social support for vulnerable children (home based care, support access to school, food, social grants, & provide safe after-school facilities)
Funding/financial stability	Moderate – mostly provincial funding and other sources (in the form of donations, but this was secure)	Weak – temporary funding and sustainability is based on availability of funding at province level	Strong – primarily international donor
History of the organisation	Revived from an old NGO with similar funding structures	New programme established by Gauteng province DOH as a district programme. The NGO is one of a few pilot projects in the district	Part of a long existing umbrella NGO – it is one of several other branches across the country
History of the settlement/community served	Different groups of people from different S.A. provinces and other neighbouring countries settled at different periods over less than 10 years	Different groups of people from different S.A. provinces and other neighbouring countries settled at different periods over less than 10 years	Long standing community of over 10 years' existence, settled during apartheid era, comprising rural villages.
Management	Moderate	Weak	Strong
Human resources & management	Operations of organisations conducted by two individuals: <u>NGO manager</u> – for institutional functions; and the <u>project co-ordinator</u> (and assistant) mainly for management of CHWs and other administrative functions. A provincial health promoter assisted CHWs with clients on an ad hoc basis Moderate management of CHWs	One individual placed at the sub-district level, not in the same location as the CHWs. Responsible for managing all other NGOs in the district, including the Zola programme Poor management of CHWs	A range of individuals responsible for various functions. A hierarchy of NGO coordinators responsible for oversight of programme (equipment, salaries, finances, etc); mentor for supervisors and CHWs; Supervisors for onsite supervision and training Strong management of CHWs

Component	Khanya programme	Zola programme	Eden programme
Resources (NGO premises, cell phones, transport allowance, remuneration, equipment for nature of service)	Limited - No institutional premises, mostly no transport, manager and health promoter used their own on an ad hoc basis). Intermittent remuneration from province, limited equipment	Limited resources – a scarcely furnished office for gatherings	Range of resources – Allowance for CHW transport, allowance for mobile phone vouchers, equipment (books, toys, as per needs of the household), regular remuneration, premises for administrative functions and premises for actual functions (play therapy and counselling for clients)
Mentoring	Moderate	Non-existent	Strong
Training	Moderate: Once off 69-day training workshop on home-based care, TB DOTS, disabilities, child & family health, pregnancy and preparedness for disease outbreaks	Poor: 5-day training course on HIV/AIDS, TB and cancer.	Strong: 14 training modules over 2 years. Content includes basics of child & youth care work, behaviour management, and lifespan development
Supervision	Moderate	Non-existent	Very strong; supervision internally and onsite supervision (i.e. with client)
Career prospects for CHWs	Poor	Poor	Strong
CHW support mechanisms (e.g. Care-of-the care, personal support)	Poor – some support provided by the manager and the health promoter (but ad hoc).	Non-existent	Strong – provided by mentors, supervisors and peer support, including care-for-the carer programme
Nature of community serviced	Farm labourers including laid off farm labourers because of illegal status and trapped	Largely unemployed Economic migrants (internal and external and migrants) looking for work in the city	Dependants on remittance of migrant workers
	Peri –urban informal settlement with poor access to formal services	Peri-urban informal settlement, relocated from other informal settlements with poor access to formal services	Rural small town with poor access to formal services
Markers of social cohesion & social capital	Lack of community structures	Lack of community structures	Evidence of community structures such as: - Women's groups - Churches
	Ward councillor not representative of community	Ward councillor inactive – biased interaction with political party supporters	Ward councillor active & involved

Component	Khanya programme	Zola programme	Eden programme
	Lack of other community representatives	‘Illegitimate’ community representatives emerged due to dissatisfaction with state initiatives that provided limited services	Traditional chief involved in consultations such as decision-making processes
	Lack of active NGOs	Lack of active NGOs	Range of active NGOs
	Poor social cohesion – lack of trust and fear of being identified as ‘illegal immigrants’	Poor social cohesion – conflict in community, due to conflicting needs and lack of shared experiences	Strong social cohesion – shared history and experiences

It is important to note that the descriptions of the case studies' contexts have been approached individually solely for the purpose of relating them to the respective institutional contexts. However, the discussion of the findings will continue in the form of a cross case analysis in Chapter 7, 8 and 9. Figure 6.1 presents a visual overview of the location of the three case studies in South Africa

Figure 6.1 Location of case studies on South African map



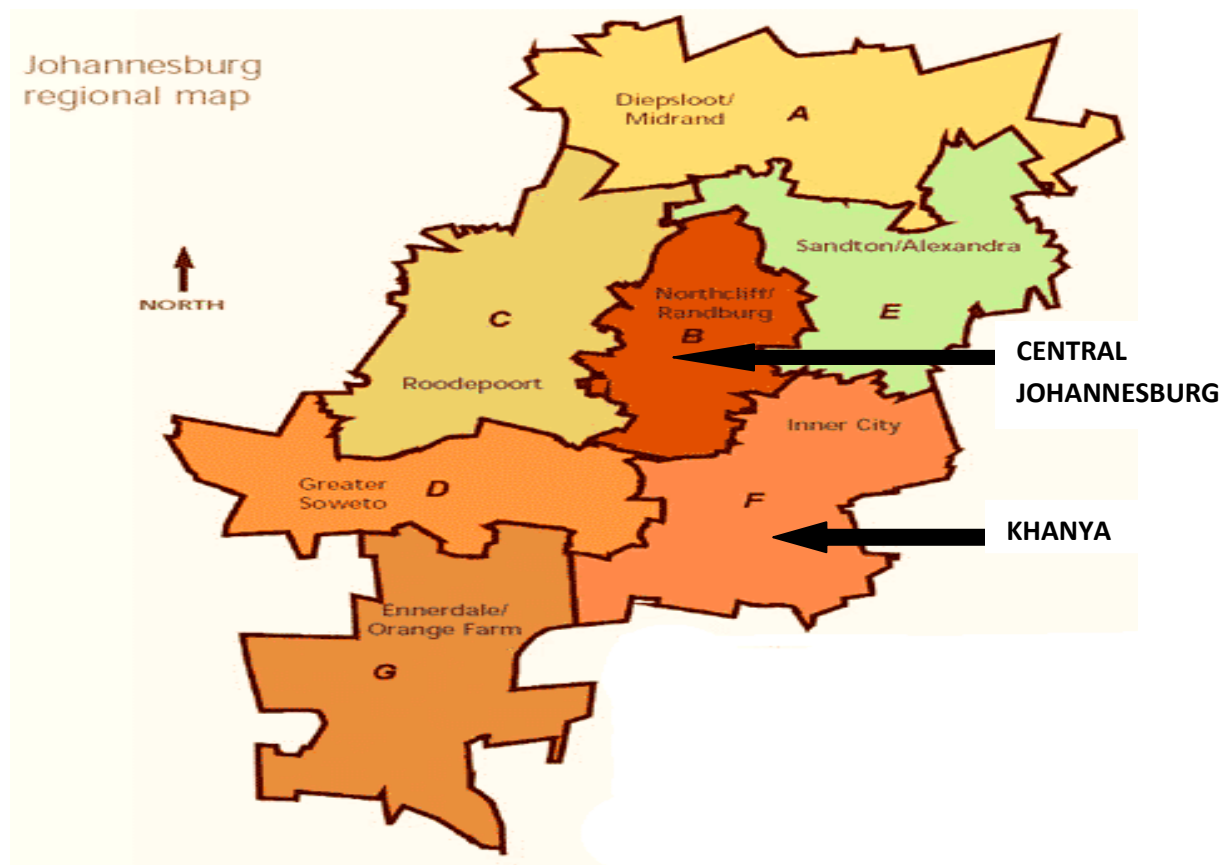
Source: <http://maps-africa.blogspot.com/2012/05/south-africa-map-pictures.html>

6.1 The Khanya programme

6.1.1 Geographical area

The Khanya programme is an NGO situated in the sub-district of Region F (Fig 6.2), in the south of the City of Johannesburg district (CoJ). The sub-district is an area of contrasts. It ranges from the more stable commercial suburb called Brighton and old existing degraded residential areas such as Bentley, to the more affluent middle- and upper-income suburbs of Glen Valley, Oaksview and Austen along the sub-district's southern boundary. It also has a large area of farms that have existed since the apartheid government and continue to function. The organisation is in the centre of these farming communities and some members live in the informal settlements on the margins of the farms in Oxford.

Figure 6.2 Khanya programme area profile



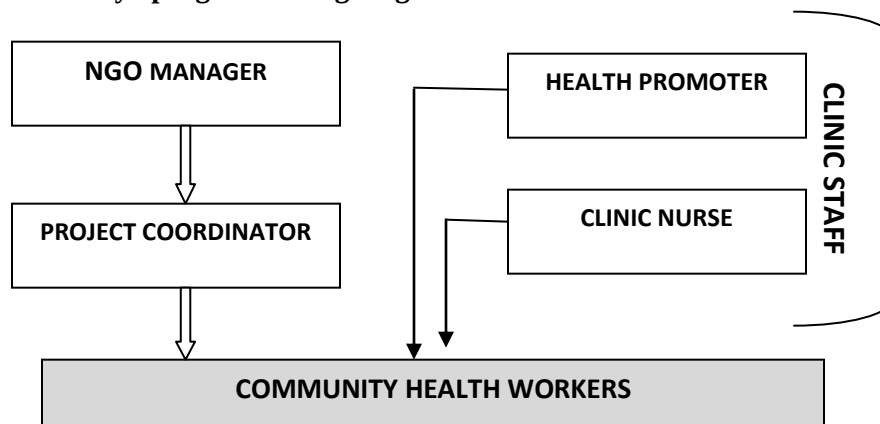
Source: www.joburg.org.za/regions

6.1.2 General information

During data collection, the organisation was located within a clinic, with no formal working premises or space. The district assisted the manager of the NGO to identify this clinic as a “temporary” location while in the process of looking for a formal office. The NGO had been using the location since its inception in 2004. According to the manager, because the clinic was not conducive for the formal functioning of the NGO’s activities, it was mainly used as a gathering place for the CHWs before they headed off for household visits and other activities. The NGO also used the venue for meetings throughout the year, which were conducted in the patient waiting area in the evening when patients had left or early in the morning before patients arrived. The clinic itself was originally a private house which was bought by the province and transformed into a clinic. This explained the inadequate space for both clinic staff and patients. The NGO’s files and administrative materials were kept on a shelf in the clinic manager’s office. The organization had employed 15 CHWs; however, three were still considered volunteers. The organogram below (Fig 6.3) provides a visual representation of the organisation.

6.1.3 Structure and operational details of the organisation

Figure 6.3: The Khanya programme organogram



6.1.3.1 Who is in the organization?

The *project manager* headed the Khanya programme and was responsible for the key functions of the organization. This entailed fundraising, operational management, as well as supervision and mentorship of the CHWs. She also sometimes made an effort to assist the CHWs with resources if available, for instance, by providing them with transport when they were visiting clients that were far away.

The *project coordinator* was responsible for the administrative functions of the organization. He ensured that the CHWs reported to work at the beginning of each week, and that they received their monthly reporting forms for submission at the end of each month. During meetings which often developed into training sessions, he assisted the CHWs to complete the forms appropriately. The coordinator also monitored whether the CHWs reported on “actual” visits to homes by keeping abreast of what they reported on in previous months. In addition, the coordinator provided support to the CHWs for other ad hoc functions, such as advising clients on the requirements for applying for documents such as birth certificates, identity documents and social security grants. Due to his experience of engaging in community development work, he was well informed about how government sectors function, particularly the key departments which the organisation’s clients often needed to access such as the Departments of Social Development, Home Affairs and Health. Consequently, he often acted as an advisor for some of the clients that CHWs identified who automatically became clients in the clinic. He was also qualified in Voluntary Counselling and Testing (VCT). He offered this service not only for the clients that were identified by the CHWs, but for those that attended the clinic. The coordinator adopted these roles fluidly as and when it was required.

The NGO also utilized the services of a *health promoter* employed by the district (Department of Health) to consult at the clinic. The clinic and the NGO therefore shared her services. The health promoter often acted as the coordinator when he was not available to accompany the CHWs on home visits. She was equally well versed in the processes and systems involved in other sectors such as the Departments of Home Affairs and Social Development with regard to application processes. The health promoter played a significant role in providing transport for the CHWs which was a constant limitation for them. She was able to request a government car from the province which was sometimes used to transport the CHWs to clients who were far away. She also used the car to transport clients who, during the home visits, appeared to require urgent attention. However, this occurred opportunistically because the health promoter could not guarantee the car's availability as it was part of a shared pool of vehicles in the district. In addition, during data collection, the health promoter also appeared to adopt the informal role of a confidante to the CHWs, offering support when needed.

Although the *nurses* in the clinic were not part of the NGO itself, they had progressively become a close component of the organization's referral network. By virtue of their shared premises, the NGO and the clinic developed an efficient client referral process. The nurse that worked in close proximity to the CHWs was responsible for the treatment, management and care of clients with tuberculosis. Other nurses managed illnesses such as diabetes and high blood pressure at different times. The nurses randomly took on the informal supervision of the CHWs when they brought clients in to the clinic (having accompanied them from their homes).

The core component of the organization was the group of 15 *Community Health Workers*. All were female and of ages ranging from 18 to 38 years. Ten of the CHWs had been with the organization since its inception. They had been absorbed from a previous NGO in the same

vicinity which closed down due to lack of funds. Twelve of the CHWs received a stipend of R1000 (\$117.40) per month. This stipend was prescribed by the Gauteng Province (but the rates varied across provinces) and was irrespective of the level of qualification and/or the amount of courses one had completed. At the time of data collection, the remaining three CHWs were considered to be volunteers because they had not as yet undergone the standard national training course for CHWs known as the 69-day training course (details of the course are further below). Although not formal policy, the organisation devised this to differentiate between the CHWs who were formally trained and practicing and those who were not trained and therefore not formally providing services. The volunteers only received a stipend after completing the 69-day training, when they would be able to provide services in their community. During the volunteering period, they would be paired with the more experienced CHWs to give them the opportunity to observe.

All of the CHWs lived in the community where they provided services. They all shared the same history in terms of how they settled in the community from other provinces. The CHWs had lived in the Oxford informal settlement prior to the launch of the NGO, and had provided services to this community. As part of the Reconstruction and Development Programme (RDP), which was the 1994 government's socio-economic policy to address poverty [226], low-income houses were constructed from 2007. When the new NGO took over the services and recruited the existing CHWs, the organization assisted them to apply for the new houses. During the time of data collection, ten of the CHWs had already moved into their new homes and the remaining five were still residing in the shacks in the informal settlement. The CHWs continued to provide services to those in the informal settlement and those in the low-income houses. I discuss the experiences and the types of services rendered by the CHWs in both these communities in the following section below.

6.1.3.2 What type of services does the organisation provide?

The CHWs were ideally meant to provide a range of comprehensive outreach services mostly related to health promotion, prevention and resource coordination and networking services (as reported by the project manager). Despite not following the CHW policy framework, the organisation's objectives were similar to it (as defined in Chapter 3). Although they did render some of these services, the extent varied and the manner in which the services played out in reality made it difficult to categorise them formally. Much of this was influenced by the context of both the clients and the CHWs. I will deal with this aspect in more detail in Chapters 7, 8 and 9. The CHWs mostly provided home-based care and the types of services were a vague combination of preventative, health promotive services and attempts to link clients to other resources and non-health services. The outreach services included activities such as regularly ensuring that clients completed their treatment for TB and other chronic illnesses such as diabetes, high blood pressure and HIV. The latter service is illustrated in one of the households that we visited where a young man, who was identified by the CHWs when he was gravely ill, was successfully assisted to start taking ARVs^{vii} and was being regularly monitored for adherence. They provided a similar service to the single mother in "*The HIV positive mother & son*" (Box 4). The households in both these examples had clients who were on ARV medication. It must be noted that at the time of data collection, CHWs were not allowed to fetch this medication for clients. Only the clients themselves or their next-of-kin could do this. In addition, ARVs were only available at hospitals and not in PHC facilities. However, the CHWs' role in the Khanya programme fulfilled a somewhat clinical role. When they visited a household, they would inquire about the client's experiences with regard to taking treatment. This included side

^{vii} HIV treatment

effects, problems with adherence and/or challenges with accessing their treatment regularly. They would then refer the clients to an appropriate service provider if or when necessary.

The services of the CHWs also insured continuity of care. A nurse at the clinic would communicate with a CHW regarding, for instance, a discharged TB client who was on TB treatment. The CHW would then monitor that client's treatment until completion. This also included clients who had not returned to the clinic to fetch their subsequent cycle of medication. The CHWs in this programme would trace such clients at their homes to assess the situation. Depending on the status, the CHWs would continue to monitor a particular client as guided by the nurse. "*The South African immigrant*" (Box 2) illustrates some of the TB clients whom the CHWs traced and monitored.

The CHWs also assisted HIV positive patients on ARVs to organise support groups in their communities, hence assisting them to link with community resources. In one of the households we visited, the CHWs were assisting their client to assemble a group of HIV positive individuals in the same area. This outreach service was regarded as one that contributed to the continuity of care and as one that enabled clients to be independent and to rely on one another (communicated by one of the CHWs). The purpose of the groups would be to assist the clients to deal with their infection within a supportive community. During a participant observation, one of the CHWs explained that they were in the process of recruiting a group of people who were HIV positive to be part of this group. She added that one constraint was a place to meet which would be accessible to all of them. Another was being able to maintain contact with those they had already contacted as they did not have phones themselves and the clients also struggled with airtime vouchers for cell phones. Although they experienced some limitations, this example illustrates

that the CHWs assisted patients outside of the clinical setting in order for them to adhere to their treatment.

The CHWs often worked in households where the entire family required a range of outreach services. In such a case, additional CHWs would visit together to assist with the other clients in the house. In one of the households, a CHW provided a service to a mother who was on TB treatment, an elderly man who had diabetes and was on treatment for high blood pressure and a young man who was respectively, the son and grandson to the two clients. He was HIV positive and in need of ARV medication. Although not explicit, this range of outreach services were partly preventative and health promotive, where for instance, the CHWs engaged with the HIV positive client on the need for and the benefits of ARVs, and the role of a disability grant in maintaining his livelihood.

6.1.4 Management (administrative) and leadership of the organization

6.1.4.1 Recruitment process

During the period of data collection, the policy framework (including the one currently under revision), stipulated that community representative structures should be involved in the selection of CHWs [211, 227]. Despite this proposal, it appeared that the organisation was not following the policy. In fact, the manager mentioned that they did not have the official policy document. Consequently, the organisation established its own recruitment system and conducted its own internal recruitment without community representatives. In the same vein, although the CHW policy requirement for recruitment was that a CHW had to have at least a secondary school qualification in order to complete the official provincial training course or a course related to home-based care, this NGO had recruited three CHWs with completed secondary schooling while the rest did not. The rationale given by the project manager was that they gave an

individual the opportunity to prove that they were able to cope, not only with the practical work, but also the academic aspect of it. The only way they reportedly could judge this was through the 69-day training course. If they exhibited capacity to cope with the work but did not successfully complete the training course, their applications were considered unsuccessful and they were not recruited. In addition, the volunteers were reportedly given the opportunity to be exposed to the nature of the work (as unpaid volunteers) by being paired with a qualified CHW for three months, so that the team (project manager and coordinator) could assess whether they were suitable and according to the manager *“to decide whether this is the type of work they want to do.”* (KII- Khanya programme manager).

The process however was not as fluid as intended. Three months after recruiting the three volunteers, the organisation was still waiting for the Province to contact them regarding the availability of a 69-day course and to request for candidates. The volunteers reported that they had been working without pay for six months. They explained that they were told that the Province had not as yet requested for candidates to attend this particular training. As a result, the women had to work as volunteers with no pay in the hope that they would be called to attend the course. How they performed in the course would determine whether they would ultimately be employed. One volunteer expressed her frustration with the recruitment process:

“Every morning, my husband complains about how I wake up every morning to go to a job that does not pay instead of using up that time to look for a job that pays. I don’t know how much longer my family can put up with me” (FGD – Volunteer - Khanya programme)

One of the volunteers informally mentioned that the availability of the 69-day courses was not as regular as they had expected. The Province called to ask for candidates as and when the course was available, but that reportedly took many months of waiting. This illustrates how the

recruitment processes at organisational level are compromised by the ad hoc approach of the province. In light of this, it may be an indication of similar experiences of other NGOs that rely on the province for CHWs training.

6.1.4.2 Training & Supervision

The 12 CHWs completed the 69-day training course. The curriculum included home-based care, TB-DOTS, disabilities, child and family health, pregnancy and preparedness for disease outbreaks [228]. In addition to this course, most of them had already attended basic certificate courses on home-based care and/or HIV/AIDS. The remaining three volunteers only had high school certificates and one had completed a certificate course on HIV/AIDS. The CHWs were, however, given the opportunity to upgrade their skills and knowledge by attending courses within the National Qualifications Framework (NQF)^{viii}. During data collection, some of the CHWs would go away for a week or two to attend NQF courses geared towards qualifying to apply for a course in Auxiliary Nursing. It was not clear whether this was the route the CHWs should be taking. They furthered their education on an ad hoc basis as courses became available on community work and home-based care, with components such as the different priority diseases such as TB, HIV/AIDS, and diabetes. Generally, NGOs had random notification about courses which was reportedly not regular. In this organisation, the project manager would select the CHWs to attend the courses. Moreover, training took place through in-service training where the project manager and the coordinator would identify a gap in the knowledge of the CHWs. For instance, in the early stages of data collection, the manager of the NGO invited a representative from the Department of Home Affairs to conduct a workshop on issues such as the

^{viii} A national system for the classification, registration and publication of quality-assured national qualifications under the South African Qualifications Act (SAQA Act 58 of 1995)

required documentation when applying for a birth certificate, identity documents or work permits.

Although the CHW policy currently under revision mentions that an NGO employing CHWs should have a staff complement that includes a supervisor [227] , it does not have details on the required background, qualifications or guidelines regarding this function. Consequently, the project manager in this NGO was meant to supervise the CHWs, who reportedly had a basic certificate in home-based care and HIV/AIDS. During the participant observations, the supervision was not very apparent and was often informal. Clinical supervision was minimal because the nurses at the clinic were not officially part of the organisation. In addition, this negligible interaction was in the form of conversations and/or advice about specific clients that the CHWs attended to. This engagement only took place at the clinic premises as opposed to in the clients' homes because transport constraints prevented them from accompanying the CHWs.

The lack of access to transport impacted on the organisation's ability to provide services to households as a multidisciplinary team as reportedly intended. Consequently, the health promoter and the project coordinator were also often not able to join the CHWs. Some of the supervision was conducted during the monthly meetings where the CHWs had joint meetings with the NGO coordinator, the health promoter and sometimes the project manager. During the meetings, of which I was invited to one, the CHWs would raise issues about their respective clients and seek advice. These sometimes led to general discussions about core issues, such as how to manage bed-sores on an adult client or what to do when household members of the client are in denial of the client's illness or are hostile towards the CHW. Supervision would also occur opportunistically during the days for completing and submitting the monthly reporting forms (what they referred to as "stats" forms) to the Province.

6.1.4.3 Resources

The NGO functioned with limited resources. It did not have its own premises, hence it did not have office equipment such as furniture, telephones, a fax machine, shelves to store records or an area to conduct regular meetings and training activities. However, by virtue of being located within a clinic, the organisation informally utilised its office space and some of the furniture. The clinic nursing staff was reportedly also considered a resource as they could conduct direct referrals to and from the CHWs.

Although the primary function of the CHWs was to conduct home visits, the NGO only had one vehicle which was the project manager's personal car. It was sometimes used to transport some of the CHWs who had patients living extremely far from the clinic; however, that was during emergency situations or when the project manager was available (which was seldom). The only other source of transport that CHWs relied on was the official government car used by the health promoter. However, this was during the few times that she came to the clinic, as she was the only health promoter for the whole region and therefore could not consult at the clinic regularly.

The NGOs sought funding from various sources, however these were limited and not regular. The primary source was the Gauteng Department of Health, although it also received some funding from corporate businesses, mostly as sponsorship for specific activities and/or events. The funding from the Department of Health required an annual submission of applications. Upon approval and a subsequent phased transfer of funds, the NGO was required to submit periodic records of its expenditures. Transfer of these funds was however not as regular. During data collection, the NGO had not received the expected tranche of funds and the CHWs had not received stipends for three months. The CHWs relied on the stipend to finance travel costs to work. As a result, in an effort ensure the continuation of services, the project manager provided

the CHWs with a small stipend from her personal funds to cover travel costs for that period. According to one policy-maker, this interruption of payment was often due to the late submission of due documents such as monthly statistics or incomplete applications forms.

“If me as an NGO and the 20 other NGOs are delayed on processes like that, I delay the five other NGOs that are on time to be paid. If we as five NGOs delay, we delay the other 20...so we delay the whole district, because the districts cannot be signing a cheque for one NGO. It just delays the whole process.” (KII – National DOH representative)

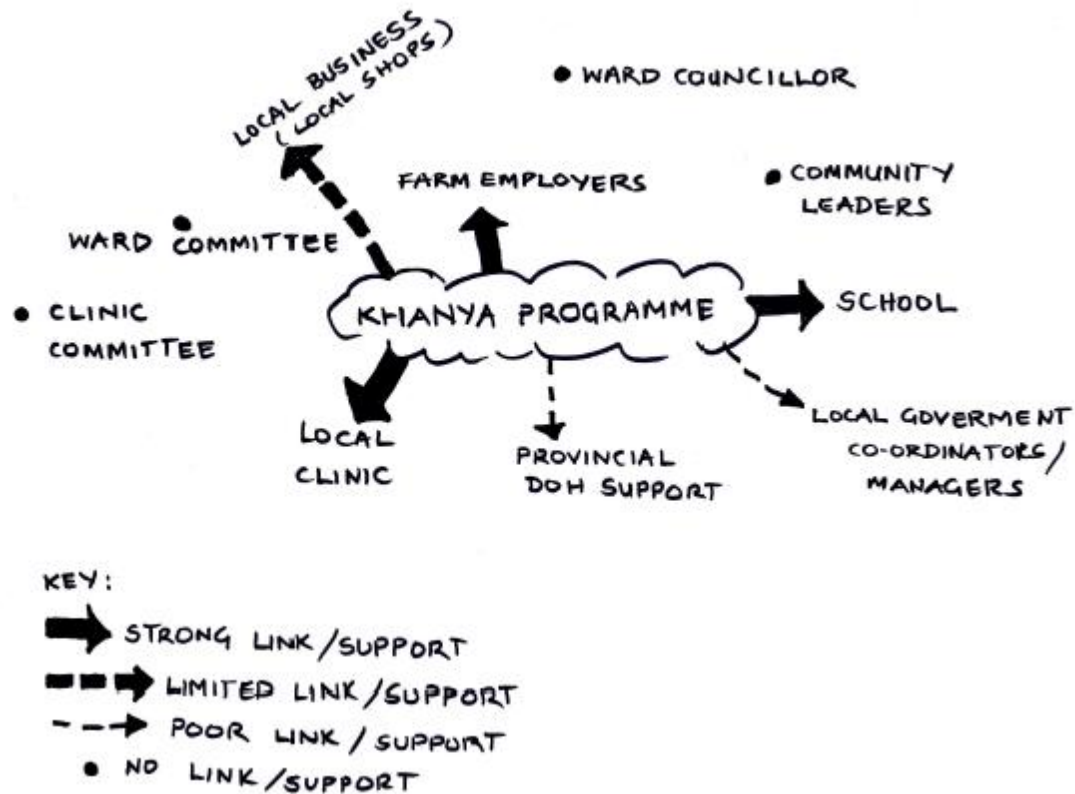
Consequently, NGOs that were reliant on state funding were therefore required to abide by the processes of government, such as the indicators to report on in the reporting mechanisms.

6.1.4.4 Social networks

Social networks form part of social capital, a complex concept which relates to “those features of social structures – such as interpersonal trust and norms of reciprocity and mutual aid – which act as resources for individuals and facilitate collective action.” [229]. Judging from the network map provided by the CHWs in the Khanya programme (Image 4), it is evident that even though there were some individuals and groups to interact with, very few provided a supportive and enabling role. Rather, community members offered an enabling environment for the CHWs. In contrast, support from the spheres of government was poorer and even more sparse in the higher government levels such as the Province. According to the CHWs, the most supportive entities in the community were two farm employers who reportedly allowed CHWs to give health talks and to monitor their clients who were on treatment. The other strong network existed at the school adjacent to the clinic. The CHWs reported regular interaction with the principal who allowed them to conduct various activities in the school. The local community participation structures were evidently weak, with the ward councillor and the clinic committee failed to offer support to

the CHWs' efforts to provide outreach services. I expand on this aspect in Chapter 8 on community participation.

Image 4: Network Map of the Khanya programme



The Khanya programme is an example of several NGOs that aim to provide services to their communities within a range of constraints. This case study however also indicates how some level of support for the CHWs from the organisation can be an enabling factor towards providing outreach services. It also indicates that although the aim of the service model of the organisation was geared at being outreach, what was actually provided was determined by the institutional context of the organisation. The Zola programme described below has a different institutional context to the Khanya programme.

6.2 The Zola programme

6.2.1 Geographical information

The Zola programme was in another sub-district of the City of Johannesburg (CoJ) called Region C (Fig.6.4). It is located within a larger area called Glassview in the west of Johannesburg surrounded by major areas such as Soweto, and is about a 12kms to the inner city. The community in this area was placed in a settlement that is a combination of formal low-income houses (RDP houses) and informal settlements in Harvard.

Fig. 6.4 Zola programme area profile



Source: www.joburg.org.za/regions

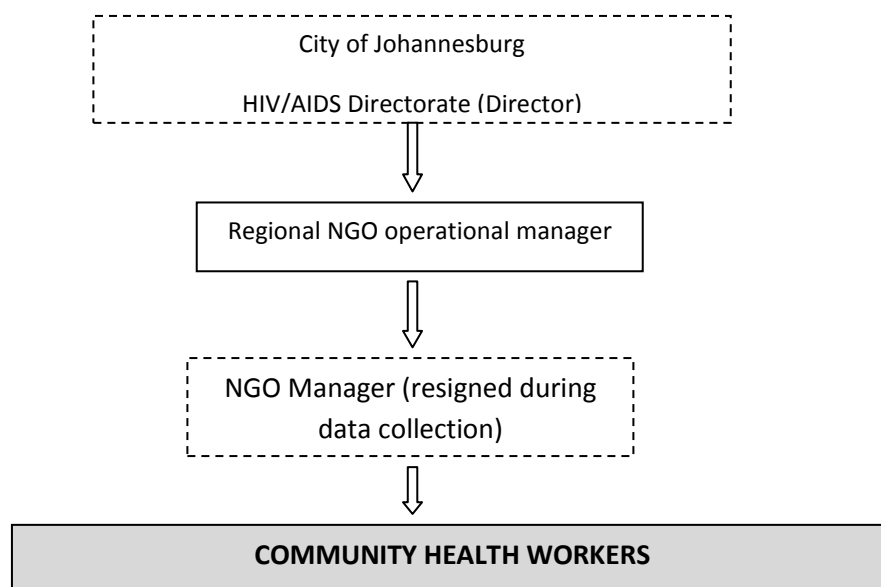
6.2.2 General information

This case study had its own office, a rented house in the centre of Harvard. The CHWs used it for meetings and to gather in the morning before they dispersed to their respective house-to-house visits. They were employed by the City of Johannesburg district and at the time, the programme was a pilot programme of the HIV/AIDS Directorate of the district health authority. Established in 2005, the programme was to be implemented over five years with the aim of evaluating it and depending on the results, to roll it out in other provinces. The programme employed CHWs who were managed by the sub-district (local health authority) and although also funded by the provincial Department of Health, they were paid directly by the province and not through a transfer of funds as was the case with the Khanya programme. Despite this internal structure, which can be considered an advantage since it is embedded within a state entity, the CHWs remained isolated from the local health authority offices due to the distance. The only opportunity to interact with the local health authority was through the manager who visited as and when it was possible, which was seldom.

6.2.3 Structure and operational details of the organisation

6.2.3.1 Who is in the organisation?

Figure 6.5 Zola programme organogram



The *regional NGO operational manager* of all the NGOs in the local government (Regional coordinator) managed the programme. She was responsible for the monitoring and supervision of all the NGOs, including the organisation that implemented the Zola programme, which meant that she was ‘spread too thin’. Consequently, she could barely manage and assist the CHWs. She was reportedly meant to consult with the group at least monthly to assist them with the completion of the reporting forms and to manage issues regarding payment and recruitment. However, as opposed to the intended monthly meetings, the manager paid random visits when she was close to the area. Ideally, she was also meant to assist the CHWs on issues or problems identified during the house visits. This did not occur during data collection.

This case study also had a *coordinator* who was part of the NGO that the district identified as the implementer of the programme. This individual had a history of advocacy in the field of HIV/AIDS and reported to be living with HIV, hence his mission was to “*educate, inform and advocate for people living with HIV/AIDS*” (*KII- NGO Coordinator*). At the time of data collection, he was employed by the local government Department of Health as a CHW in the programme but adopted the role of the coordinator. Although this role was not clear, he attended to a range of tasks, such as assisting the CHWs to complete their reporting forms and with problems that the workers identified during their house visits. However, during the period of data collection, the coordinator disclosed that he was planning to leave. In fact, he was often absent during my data collection visits. A few months into the data collection process, he resigned from the programme.

The core establishment of the programme comprised 11 CHWs. They received a monthly stipend of R500 (\$61.34), however, two months into data collection, the stipend was increased to

R800 (\$98.14) per month. All the CHWs were residents at Harvard and were all owners of the new low-income houses. The CHWs had been part of a group of residents relocated by the local government from another informal settlement area once they qualified to receive the houses in 2002. They had all occupied shacks erected with the assistance of the local housing authority while they waited for their houses to be completed. This was reportedly because by the time they arrived, the houses were incomplete for occupation. The first few members of the community in these shacks eventually moved into the houses a year later in 2003, including all the CHWs. At that time they were unemployed, while two of the 11 were CHWs of a home-based care NGO close to the Zola programme office. This neighbouring NGO closed down immediately after the programme was established due to an unsuccessful attempt to apply for the continuation of funding. All the CHWs in this programme were women between the ages of 18 and 45 years old, with the eldest assuming the role of a mother figure. The only male staff member resigned during data collection.

6.2.3.2 What type of services does the organisation provide?

Ideally, the project had been solely established to disseminate information and educate communities about HIV/AIDS and TB, and to inform households about basic services such as how to access social security grants and how to apply for an identify document. Furthermore, they had to educate households about other illnesses such as cancer, diabetes and high blood pressure. The project also aimed to facilitate community development projects, specifically mobilizing communities to grow food gardens. The main objective of the programme was to facilitate outreach services that work across sectors by informing households about services and/or sectors that have an impact on health in relation to HIV/AIDS.

The City of Johannesburg launched the programme in 2004 as part of its HIV/AIDS strategy and the need to address the social determinants of ill health through collaboration of sectors. The programme implementation commenced in 2005, initially in six informal settlements as pilot sites in the region (a level below a province). Harvard, where this case study is situated, was one of the pilot sites.

In reality, the CHWs routinely conducted house-to-house visits and disseminated information ranging from cervical cancer to HIV/AIDS. The CHWs also inquired if the household members encountered any challenges that they could assist with. Although their other primary objective was to provide households with information regarding other available government sector services than the health sector, this was limited. I describe the experiences of attempting to facilitate this objective in more detail in Chapters 8 and 9.

Harvard had no other NGOs in the area, and the only one that operated closed down as mentioned above. The CHWs had, however, established a working relationship with one of the nurses that worked in the clinic for a longer period. Due to lack of home-based care programmes in the area, the CHWs took on some of the roles and occasionally fetched and delivered medication for individuals who were not able to walk to the clinic. This included elderly people and those who were not feeling well and had requested the CHWs to assist. This function was random and occurred quite seldom, hence the programme really only provided health promotive services.

Again, due to the absence of other NGOs such as home-based care programmes, some of the CHWs also attempted to assist the households with illnesses. If they had identified an ill person or people in the households, they communicated with the nurse/s in the local clinic at Harvard.

Even though the nurses did not conduct home visits, they reportedly went to the households when there was an emergency.

In practice, the CHWs tended to visit a household only once and then returned to it after a period of time, based on the assumption that information had been provided and any subsequent visits would be to provide new information and to review what was “discussed” before. This routine was reportedly primarily to avoid monotony. The regular exercise of the door-to-door visits started with the initial gathering of the CHWs at the office in the morning to sign a register of attendance and to collect boxes of condoms which they distributed to the various informal shops in the community with condom dispensers. They would then split into groups based on the respective areas to visit on the specific day. Each group decided on who would lead the discussion once they arrived at a household. Once at a house, the lead person would conduct the introductions and explain the purpose of their visit. The approach varied from house to house. Sometimes, an individual in the house would prompt a discussion after being informed about the type of information the group would talk about. The household members would pose a question that would initiate a discussion. Some households required the CHWs to introduce a topic and ask people if they knew about the subject, thus initiating a conversation. Sometimes the CHWs influenced the type of information to talk about after they identified issues in the household. For instance, when they found a child with a disability, they first asked if the child had a birth certificate and an identity document, which would be a point of entry for the subject of discussion. The “*mother & the disabled son*” in Box 6 illustrates this encounter and the process during a home visit.

6.2.4 Management (administrative) and leadership of the organization

6.2.4.1 Recruitment process

After the ward councillor announced the programme at a meeting attended by the community members, the CHWs applied to work in the programme. Most of them met the requirements for application, which was to have a minimum qualification of a Grade 8 (incomplete high school qualification) and some knowledge of HIV/AIDS. The programme employed 15 CHWs; however four reportedly resigned over the course of the programme. The number of volunteers was capped at the remaining 11 because it was a pilot programme and there was no guarantee of further funding and whether it would be extended.

6.2.4.2 Training & Supervision

The CHWs completed a five-day formal training course as part of the induction. The course training covered HIV/AIDS, TB and cancer as well as strategies to support the community's access to other services. There was no further training during the period of data collection. The CHWs had basic high school qualifications, some with certificates in HIV/AIDS and basic skills in typing, project management and computers. The lowest qualification was a Grade 6 (the first level of high school) and the highest was a Grade 12 (the final year of high school). Two of the 11 CHWs, however, had prior training in home-based care while some had undergone certificate courses in areas which were not necessarily related to their career advancement. These included HIV/AIDS, basic computers and project management. The CHWs did not receive any formal supervision. When they needed assistance, they would contact the regional operational manager for advice or assistance which was often not successful due to the lack of telephones. In addition, if their query was related to clinical issues, they would consult with the nurses at the clinic. The CHWs mostly relied on each other when uncertain of specific information.

6.2.4.3 Resources

The rented house which the CHWs used as an office had two rooms with chairs only. There were no administrative resources such as phones and desks. In addition to being a gathering place before setting off to the community each morning, they used the house to hold their weekly meetings on Fridays. An A4 size book served as their register. The only form of communication resource they had for contacting relevant people was their mobile phones, which often did not work because they could not afford to purchase airtime vouchers regularly. At the time of data collection, there were only two CHWs with mobile phones that actually worked. Most of the others cited that their phones were not functional and often remained that way because they could either not afford to repair them or they were waiting to receive their stipends to use to purchase vouchers.

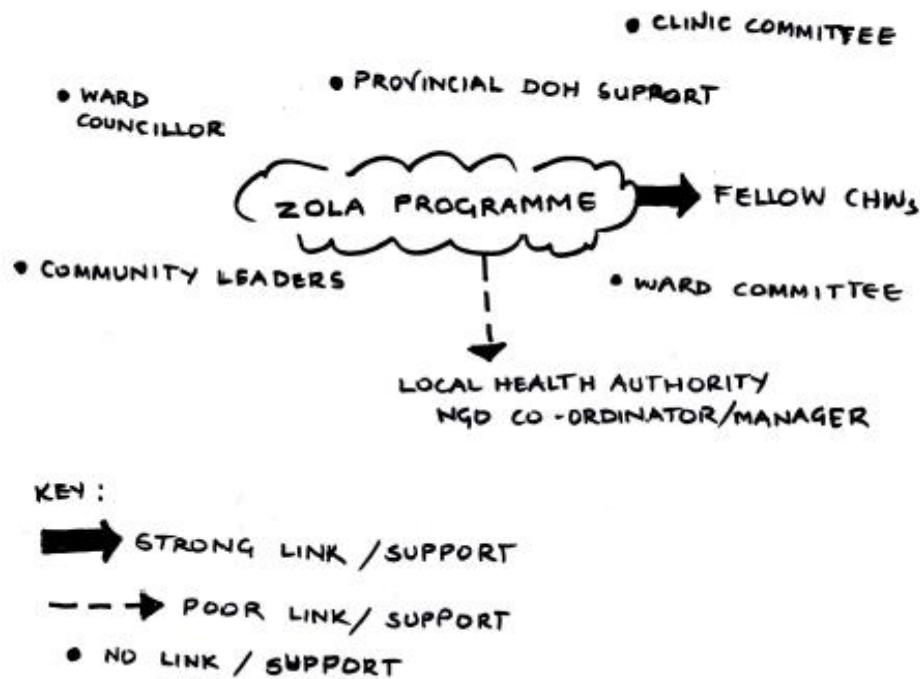
The CHWs did not have any form of transportation. The core of their work was based in their community and it was assumed that they did not require any transport. However, part of the work often required them to accompany clients in need of assistance to various government departments. Consequently, this function (and need by community members) was compromised since they lacked transport and the means to pay for public transport. This limitation compromised the extent to which they could assist clients to negotiate access to service/s in a particular department, constrained their effectiveness and the extent to which the client could benefit from the service.

6.2.4.4 Social networks

Social networks were almost nonexistent in this community (Image 5). The CHWs reportedly could only rely on each other and occasionally the regional coordinator when she visited, but this was often for completing the monthly reporting forms. A lack of this component evidently had

an impact on community participation and therefore the outreach services that worked with multiple sectors, as discussed in the Chapters 8 and 9.

Image 5: Network map of the Zola programme



6.3 The Eden programme

6.3.1 Geographical information

The case study was in the Eastern Cape Province in a municipality called Selby (Fig. 6.6). This Province was initially part of the apartheid government's policy to relegate black ethnic groups to separate homelands. It is in these areas that that government believed that black South Africans would eventually grow to be independent through self-governing structures, allowing this population to reside in "White South Africa" only for the purposes of labour. The identified homelands were often barren areas, far from the central areas of services.

Selby is mountainous with houses significant distances from another. Very few of the roads had tarmac such that rainy days made it difficult for vehicles to travel. The area primarily has a rural population with 20% of the population residing in urban areas^{ix}.

The Eden programme was located in a designated office on land provided by the local government. The office, which was portable/removable structure (similar to the clinic in the Khanya programme) as opposed to being a formal brick and mortar building, was a central location for the staff members and the CHWs. The 'parent' organisation had other satellite offices in the area where the CHWs were designated on a daily basis and they only visited the central office for meetings, supervision and other organisational functions. I expand on the functions of the satellite offices below.

Figure 6.6 Eden programme area profile



^{ix} <http://www.easterncapebusiness.co.za/municipalities> (accessed in 1 June 2012)

6.3.2 General information

The Eden programme was a satellite organisation of a ‘parent’ national child and youth care NGO. This particular case study is one of 64 around the country and was established through an extensive process. As part of the aim to provide child and youth care services in communities, the NGO, in partnership with the Department of Social Development in the Eastern Cape Province, identified a partner that would be responsible for the implementation of the programme. With the assistance of some social workers, they identified the local Anglican Church as the appropriate implementing partner (and employer) because one of its priests in Selby was significantly involved in providing services for orphans. The NGO believed the programme was necessary because of the context in the area, especially regarding the limited availability and access of basic services. There were reportedly also an increasing number of orphans in the area due to HIV/AIDS. After the NGO approached the church, they held a series of meetings with different stakeholders in the area including a neighbours’ association and the ministers of other local churches. The meeting was conducted to present the implementation model of the programme and to assess if the community was interested in the programme. After much interest, a steering committee consisting of a representative from the neighbourhood association, a ward councillor, a minister and representatives from two of the local churches and a representative from the national NGO was established. This committee was to continue establishing what the needs of the community were, and to inform the community of the envisaged programme.

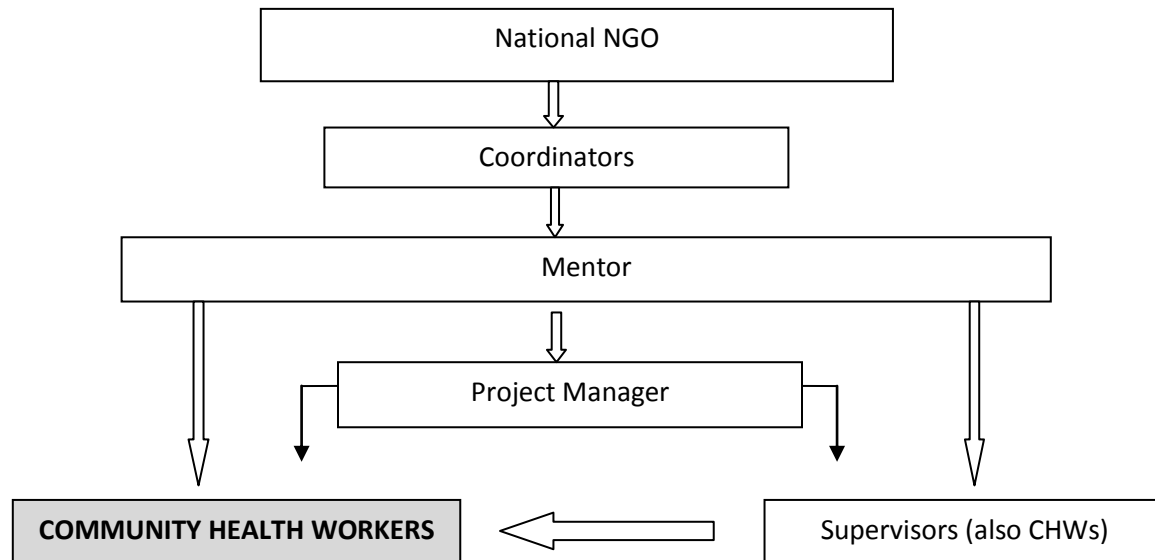
The Eden programme had 16 CHWs at the time of data collection. I discussed the beneficiaries of the services of these CHWs in Chapter 5. The CHWs mainly provide services in households of the clients, including play therapy. The programme also provides space for the children to

interact in what they called *Safe Parks*. I expand on this in the section on the types of services provided.

6.3.3 Structure and operational details

6.3.3.1 Who is in the organisation?

Figure 6.7 The Eden programme organogram



The local church *coordinated* and implemented the Eden programme. The two representatives from this body (who were the coordinators) were responsible for overseeing the overall functioning of the programme. They received the funding from the ‘parent’ NGO (which received funding from the President’s Emergency Plan for AIDS Relief (Pepfar) for a range of purposes. For instance, over and above funding the usual institutional costs of an organisation such as salaries, the CHWs were provided stipends to pay for transport when needing to travel to households and to accompany clients to government departments. Moreover, the coordinators also ensured that the *Safe Parks* and the premises in the *Safe Parks* were well equipped. They

also responded to any other needs that the CHWs raised in terms of resources. I expand on this in the section on resources.

The programme had a *mentor* who was responsible for the overall training and supervision of the CHWs. She identified any gaps that the CHWs had in terms of skills and addressed them through further training or in-service training workshops. She was also responsible for mentoring all the CHWs in other branches of the *Safe Parks* in the area. She also took on the role of a mentor for the personal needs of each of the CHWs. The mentor monitored and coordinated the training and was responsible for the curriculum.

The *project manager* was responsible for the daily functioning of the programme including the management of any administrative requirements. Over and above that, as a CHW she also had her own clients which she consulted in the households, hence she was also supervised by the mentor. She received a stipend of R1, 500 (\$184.32)

The *supervisors* also had their own clients, however, they assisted in the supervision of the other CHWs by conducting on-site individual supervision during home visits. They also conducted monthly meetings where the CHWs held joint discussions regarding their respective cases. The supervisors received a stipend of R1, 400 (\$172.02).

The 16 *CHWs* were a combination of those that had just started on the programme and had only completed Module 1 and 3 (I explain this in the discussion on training below). They were paired with a more experienced CHW who had successfully completed other modules. The more experienced CHWs received a stipend of R1, 200 (\$147.45) and those who had completed the first two modules received a stipend of R1000 (\$122. 87).The CHWs were based where they lived and only met at the main office when there was a meeting or a particular activity. They all had a high school qualification and had a background of activism in their communities, as was

the requirement of the national NGO. The CHWs in this case study were all women of ages ranging from 21 to mid-40s.

6.3.3.2 What type of services does the organisation provide?

The CHWs provided a range of services that focused on child and youth care needs, requiring specialized skills due to the developmental aspects of young children and the youth. However, even though their primary focus was the child and youth, they also attended to the needs of respective family members because the principle of the programme was also to assist to sustain the family unit. One of the ways to ensure that families were involved was to facilitate family meetings together with the CHWs:

“We usually go and conduct some meetings. For instance, we have just called members of one family and made a family conference with them and together in that forum we talk to the ill person to understand. So at the moment the CHW is now still visiting the family and is looking after the children.” (FGDβ – Eden programme)

The care workers conducted daily home visits to their designated houses mostly to attend to a child that was a client or one recently identified to be in need. The needs ranged from issues relating to physical abuse and/or neglect, learning disabilities or challenges, physical disabilities to a loss of a parent/s. They also attended to ailing parents. This required the CHWs to supervise the rest of the family on how to attend to the ailing family member. The core of their work included ensuring that children and their families accessed basic services such as health care, social services, and addressed issues that required services from departments such as housing, when a family was considered homeless. This often required the workers to negotiate with service providers across sectors when the patient was likely to encounter challenges. One CHW described how she ensured that her client was attended to by negotiating with service providers:

“There was a case of a child that was abused physically...a 4-year-old that was abused by the grandmother. We took the child to the local clinic, and the nurse saw the child and said the child has to be taken to the police station so that we can get a form to the doctor at the hospital. When we arrived there because the parents of the child are not here in Selby, we talked with the doctor to accommodate the child...to admit the child for some few days so that we could connect with the parents of the child because we could not take the child back to the grandmother.” (FDG – Eden programme)

The CHWs also provided home-based care services. This included washing ill patients, cleaning the house if the children were still very young, and ensuring that an ill parent had medication. However, they reportedly referred most cases to appropriate NGOs in the area if this service was the only primary need of the household. They assisted and monitored the treatment of any individual in the family, from ensuring adherence to ARVs to the completion of TB treatment. They helped with funerals when the parents of a client had died. Part of the aim of the programme was to maintain a family unit. Therefore, in instances where there was conflict, or when a child had been orphaned, they would trace other family members in the effort to encourage them to take over guardianship.

During home visits, the CHWs conducted play therapy with the child/ren in the household, where they assessed and kept abreast of the child’s progress and assessed their problem/s. They used the space to also provide grief therapy through a technique called the Memory Box for children who had lost a parent/s to diseases such as HIV/AIDS. This is a tool to assist the child to preserve memories of their parent/s and to assist them through the grieving process by allowing them to talk about their loss. In child-headed homes where a family member/s had not been identified, they assisted with the daily functioning of the home. They arrived early in the morning to ensure that the children were washed and made breakfast together with the children. Thereafter, if the children were quite young, the CHWs would walk the child/children to school. At the end of the day, they would fetch the child from school, assist with homework and ensure

that they cooked supper before leaving. During instances when a child was either abused, or had lost their parents and they had not managed to find an alternative family member, they consulted social workers to ensure that they removed the child from the abusive environment and placed them in a place of safety or a home, until a foster parent was identified. The CHWs conducted their home visit during the first half of the day. After this activity, they then returned to the *Safe Parks* (Photo 6). This facility is part of the programme where children from the community play and participate in various activities. The park was an open field with swings, slides and a field where children could play a range of activities such as sports, games, cultural events and games. It also had mobile premises equipped with toys and other resources for conducting therapy and other activities appropriate for a range of age groups (Photo 7). Because the households that the NGO services are widely distributed, the *Safe Parks* were located in other areas such as satellite/network offices, to ensure that children that reside far from the main NGO office had access to the CHWs' services through the *Safe Parks*. This also ensured that the community workers residing in those distant areas could provide services at an office nearer to them and only travel to the central office for administrative functions. The children visiting the *Safe Parks* were often those that the CHWs visited in their homes, but the park provided space for the CHWs to continue the work they conducted at home with them. The CHWs also used the *Safe Parks* to assess other children that may have problems who were new in the park. They communicated with them by asking them questions to assess if there were needs or problems. The CHWs used this facility to assess any developmental needs, disabilities or challenges encountered by the children. "*The orphaned boy*" in Box 7 captures the nature of care and type of activities conducted by CHWs in this case study.

Box 7 *“The orphaned boy”*

The 7-year-old boy was left by his mother to live with his grandmother to go work in Johannesburg. The mother reportedly later died from AIDS. A headmaster at the local crèche reported to the CHWs that his attendance was irregular and that he seemed ill. One of the CHWs went to the boy's home after he reportedly had stopped attending crèche because of regular bouts of illness and from being admitted to hospital. It was found out the boy was living with a grandmother who was gradually becoming blind. After being informed about his mother's death, the CHW assisted the child to go for an HIV test. She assisted the child to receive ARV treatment. Throughout the process, the CHW was gradually counselling the grandmother to relent care to her daughter (the boy's aunt), in light of her progressive blindness. Due to the grandmother's reluctance, the CHW eventually arranged a family meeting where she explained to the aunt and the grandmother about the benefits of the aunt taking care of the child. She assured the grandmother her grandson would still be able to visit her because the aunt lived close by.

After the grandmother agreed to let the child stay with the aunt, the CHW assisted the aunt (who is unemployed) to apply for a Foster Child grant^x. She assisted the aunt with the court processes and after a long period accompanied her to social services to apply for the grant. As soon as the child fostered by the aunt, the grandmother's Child Care grant^{xi} was withdrawn. The CHW then assisted the grandmother to receive a Disability Grant^{xii} because she was not as yet eligible to receive an old age pension. The CHW familiarised the aunt with the routine of fetching ARVs for the child. The CHW adds that during the process of discussing with the aunt and her agreeing to stay with the child, she asked the aunt to come with her to the local clinic where the boy was tested so that the nurse at the clinic would officially disclose to her about her nephew's HIV status. She mentions that the nurse explained details about HIV and AIDS, how the virus affects a child, how to care for a child with HIV. As the boy was moved to the Eastern Cape, he did not understand why he was moved and the subsequent loss of his mother. The CHW therefore conducted grief work and provided him the space to talk about his mother through play and by using a tool called a memory box, where the child kept memorabilia and objects that are reminder of his mother, such as pictures and items she used to carry with her. During each visit, he would produce the memory box and they would select the items and talk about them.

The visit to the boy's home

The home is about 10kms from the central office of the Eden programme along the hilly part of Selby. The road is still quite muddy from the previous day's rain. We visit a two-roomed house with most of the household members huddled in the kitchen. There are four young children in the kitchen and two women sitting around a small table. The house is ice-cold (The CHW explains to me after the visit that most families cannot afford to purchase coal for the stoves). The CHW's client quickly runs to the bedroom and emerges back with a book to show her. The boy mentions that he has finished colouring all the drawings they had started on the last time they were together. The CHW praises the boy and asks if

^x A grant provided for the care of “a child who has been placed in (one's) custody by a court as a result of being: orphaned, abandoned, at risk, abused, neglected.”

^{xi} A grant for a primary caregiver (parent, grandparent or a child over 16 years who heads a household) who requires financial assistance to care for a child.

^{xii} A grant “for persons with a physical or mental disability which makes them unfit to work”

Source: <http://www.services.gov.za/services/content/Home/ServicesForPeople/Socialbenefits/>

the other children have completed theirs. They respond in unison that they have and they fetch their books. She then sits on the floor with the children and starts to talk and laugh with them. She explains after the visit that even though play therapy is for the sake of the client, she also involves the other children in the house or family, to avoid stigma. The CHW plays with the children while strategically focussing on the client. She inquires about school, what he likes to eat (nutrition) and other family dynamics. After a while, she leaves them to play while she engages with the aunt, generally talking about his treatment and his condition and how they are coping.

Photo 6: Safe parks for therapy and play – Eden programme (Photo taken by author)



Photo 7: During play therapy with a CHW (Photo taken by author)



Interestingly, during data collection, some CHWs had just completed a course in Early Childhood Development and were preparing to accept the first children of below five years of age. This training was in collaboration with the Department of Social Development. The CHWs also provided a youth programme called the Teenage Development Programme which included various activities such as camping, where the youth were taken outside of their context to other parts of the province for a number of days. The CHWs facilitated the workshops and activities in those excursions. On the last day of data collection, a team of CHWs had gathered at the main office and were preparing to take a group of girls who were their clients and some from the community to camp in another town. The trip targeted the girls because the CHWs wanted to focus on issues that affected them as girls during that time. In fact, during that morning it rained

so heavily such that I inquired if they would continue with the activity. One of the CHWs confirmed that they would go camping:

“The girls have been looking forward to this trip all these months. You should see the excitement right now...we cannot disappoint them.” (CHW- informal conversation)

Although the services of the Eden programme hinge on one health paradigm; HIV/AIDS, they used this as an entry point to provide a wider spectrum of services that related to the social context of the community. Their approach differentiated them from the Gauteng case studies which will be clear in the sections that delve into community level inter-sectoral action and community participation.

6.3.4 Management (administrative) and leadership of the organization

6.3.4.1 Recruitment process

The steering committee, established at the beginning of the programme in Selby, coordinated the initial process of recruiting the first batch of CHWs. Members placed adverts in public places such as shops, community facilities, clinics, schools and churches. In terms of the selection criteria, the adverts stipulated that the applicant had to be someone of good standing in the community with a history of activism, was recognized for their honesty, competence, sense of responsibility, ability to work in a team, and had a passion to work with children, the youth and families. The person also had to have the ability and passion to overcome the challenges encountered when working in communities, including networking and facilitating communication in difficult situations such as family conflicts. The person also had to submit a letter of recommendation from a community representative. The steering committee shortlisted the applications and those selected after the interviews had to attend the first training comprising Module 1 and Module 3. This initial training determined whether the selected person would be

formally recruited into the programme, as it was here that assessors were able to assess if the person would cope with the rest of the modules. Those unsuccessful with training were not accepted to continue with the recruitment process. The ones that were successful proceeded to a second interview when the steering committee selected a project manager, the supervisors and the first group of CHWs. This extensive recruitment process has subsequently remained the same to date.

6.3.4.2 Training and Supervision

The selected CHWs were required to complete 14 training modules and ongoing assessments over two years. The content of the modules included the basics of child and youth care work, children's rights, behaviour management and lifespan development. Module 1 focused on "The basics of child and youth care work" and Module 3 on "Children's rights", which was the core part of their work. Due to their involvement with children and the youth, the CHWs often had to deal with issues that involved the Child Justice Act^{xiii} which aims to protect children and vulnerable groups. Only after successfully completing these modules and being selected as CHWs could they start working in the community. They completed the other modules in a phased system, and during data collection, the CHWs were at different stages of training, based on their experience and length of service. They could only progress to the next module once they had completed a module and applied it in their daily work.

The programme had designated supervisors who also functioned as CHWs and consulted their own clients as well as supervised CHWs. This supervision took place on site at the client's household, and during regular meetings where all the CHWs gathered to discuss their respective cases. In addition, the CHWs had their own 'peer support' at meetings held without the

^{xiii} www.justice.gov.za (accessed 6 July 2011)

supervisor. The mentor conducted overall supervision and oversight of the supervision process during individual monthly meetings with the supervisors to monitor their own work. She also conducted meetings with the rest of the CHWs to monitor their work and assist with any key and/or difficult cases.

6.3.4.3 Resources

The implementers or *co-ordinators* of the programme (the church) identified a piece of land where they erected the main administrative office in Selby, consisting of three mobile rooms for the staff members. The premises were equipped with furniture such as shelves for files and extra resources such as a fax machine, a telephone and books. The second room was an office where the CHWs conducted therapy, play and other interventions with a range of items for children appropriate for their age groups such as toys, crayons, dolls, equipment to build objects, and blackboards. The third office was a space for meetings, workshops and group discussions. Although the CHWs had the designated office area where they gathered prior to their daily activities, they conducted the core of their work in the homes of the clients and the Safe Parks.

Because their work also involved supporting families with issues such as visiting government services, the CHWs would often accompany individuals there. A CHW was therefore able to apply for money to cover transport expenses. In contrast to the CHWs in the Gauteng case studies, the NGO did not expect these CHWs to use their own stipends to assist their clients. They also received an amount to cover items such as airtime for mobile phones when they needed to contact their supervisors for assistance or advice while in the field or at government departments negotiating access for their clients.

This is evident from an account one day during data collection when a CHW needed to travel with a client to a provincial department in the city, a 113kms from Selby. Prior to the trip, she

had formally submitted a budget for a stipend for the costs of transport for both herself and the client, and airtime for her mobile phone to ensure that she was able to contact her supervisor if necessary.

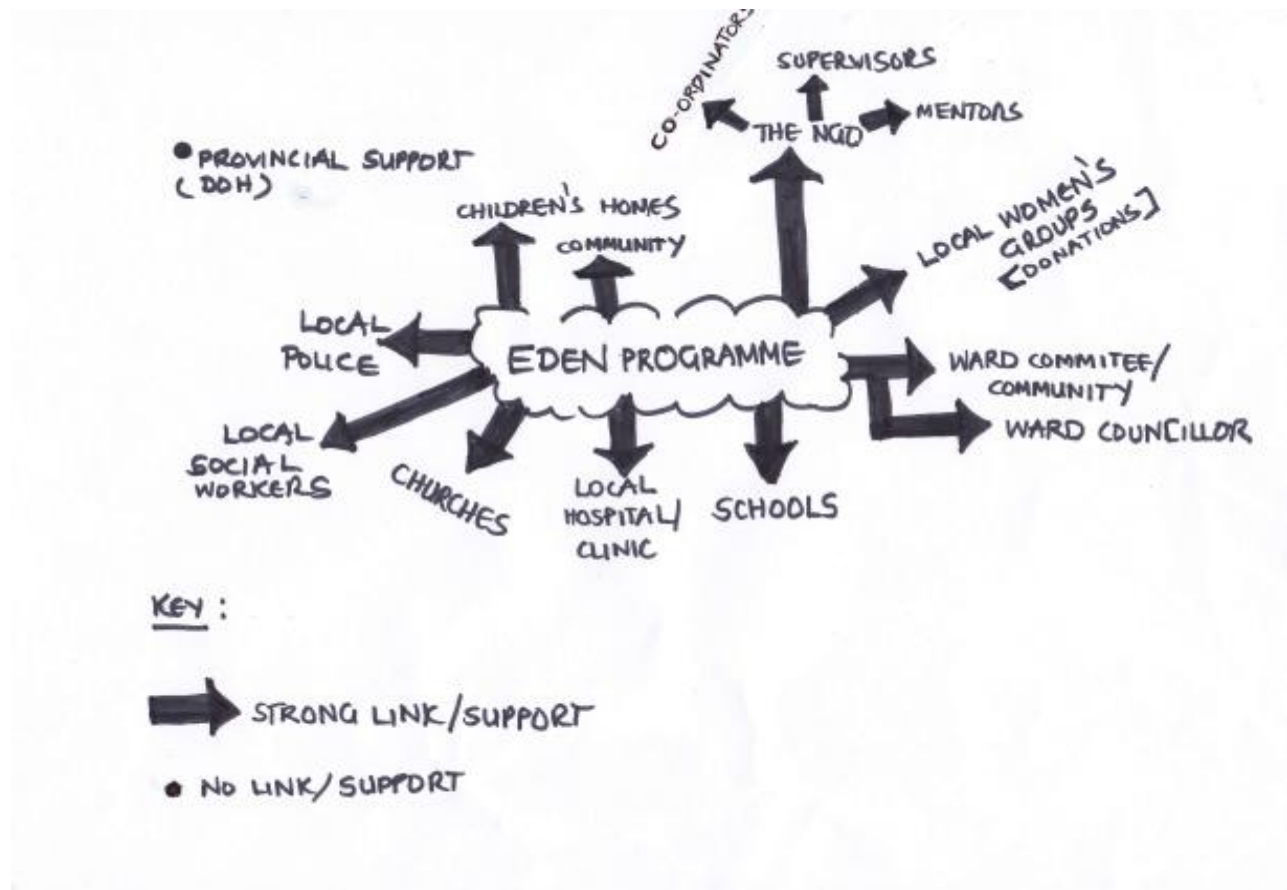
Moreover, partly as a supportive resource for the care workers and partly as recognition of their difficult backgrounds and working environments with challenging cases, the programme established a Care-for-the-Carer programme. At a specific time during the year, the CHWs were taken away from their work where they attended therapy and a workshop involving group sessions to discuss their encounters and difficulties. The group I met during the period of data collection had attended a similar workshop. I discuss this in Chapter 8. This activity was supplemented by regular consultations between each CHW, the supervisors and the mentor, where they had the opportunity to communicate any challenges or personal issues.

6.3.4.4 Social networks

In contrast to the two Gauteng case studies, it was interesting to observe the social dynamics within which the Eden programme CHWs operated. The social resources and networks were evidently richer in this case study (Image 6). They had a range of sources to rely on for providing services to the community, and had many links and networks that were strongly supportive. The churches donated items such as clothes and food for their clients and needy community members. Some individuals were also cited as being strong supporters who often allowed orphaned children to live with them. In addition, the CHWs indicated that the community was open to guardianship of children that had lost their parents. The police were often instrumental in identifying children in need during their patrols. The ward committee, together with the ward councillor, was active in mobilising the community and the CHWs confirmed that they used this platform to report some of their cases. They cited that schools were often key sources for

identifying children in need of a range of services. Teachers identified children who either showed poor attendance and/or performance, or seemed to show signs of neglect. However, the most strongly cited source of support was the organisation itself, and the CHWs expressed high levels of support from different members of the organisation. This evidently made CHWs that were secure and satisfied with the work they provided to the community.

Image 6: A Network map of the Eden programme



Overall, the description of the institutional context including the models of services (Table 6.1) indicates that various factors within the organisation influenced how the CHWs functioned to facilitate community participation and foster inter-sectoral outreach services. Some of the key factors include the role that management plays in ensuring the stability of the organisation regarding the availability of adequate resources. As illustrated in the Eden programme, this

evidently provides a level of support for the CHWs which determine the extent to which they can function in poor communities. The sense of security generated by supervision and adequate training seemingly enhances the ability of the care workers to determine solutions and follow through with the services they provide to their clients. The knowledge gained from training, as illustrated by the CHWs in the Eastern Cape case study, ensures a level of empowerment that equips them with a sense of authority to challenge service providers in the various sectors. Another key factor that is apparent from the case study is that the nature of the community and the extent of its participation in community activities and issues, determine the extent to which the CHWs can use that as a resource to provide their services and more importantly to mobilise the community to contribute to its own well-being. The lack of social capital and networks in the Gauteng case studies is manifested in its poor participation in community activities. I expand on this aspect in Chapter 7. However, what remains important to explore and discuss even further is how the components discussed in the previous sections play out in reality within the context of the interaction between the CHWs and the community.

CHAPTER 7 The interaction between community health workers and the clients

Only 18 years ago, South Africans lived in areas divided by race, where black communities had mostly poor quality infrastructure and services [183] . This reality has manifested in the poverty that is still visible in most communities around South Africa, and it is these communities where the CHWs provide their services. The existing CHW policy framework, currently in the process of revision, stipulates that this workforce should facilitate a variety of activities in households and communities as an extension of the health care system. More importantly, it also stipulates that “their future roles are envisaged to support an integrated and multidimensional service” [230]. Describing the context within which the CHWs operate helps to broaden our understanding of the constraints of providing this support, how their efforts unfold within the contexts, and how their clients receive the services. This section discusses how the CHWs manage to function within this environment. Part of the description will link back to the community experiences and descriptions (in boxes) of the households provided in Chapter 5.

7.1 The nature of interaction between CHW and client

The nature of relationships and interactions between the clients and the CHWs varied across the case studies. The CHWs in the Khanya programme had to some extent established relationships with their clients because the nature of their work involved regular visits to their homes. Moreover, the type of services they provided were of an intimate nature, often involving either washing, feeding or asking and looking through personal belongings when cleaning up. This was evident in the households of “*The elderly couple*” in Box 1, the “*The South African immigrant*” in Box 2 and “*The HIV positive mother & son*” in Box 4 where the CHWs and the clients appeared to be comfortable with each other across most of the households. Furthermore, the

interaction involved the disclosure of the illnesses such as HIV and TB. The type of services they provided determined the nature and depth of the relationships with their clients. The more regular the consultations were, the more the interaction established closer relationships. This was also apparent in the Eden programme. The CHWs in this programme spent extended periods in homes with their clients, where the nature of the service was therapeutic which ultimately created a bond. For example, the relationship between the CHW and the “*The orphaned boy*” in Box 7 illustrates one that was close, where the worker was able to ask sensitive questions regarding the child’s deceased mother.

The way in which the type of services influenced the nature of the relationships was even more evident in the Zola programme where, in contrast, very few relationships were forged between the CHWs and the members of the households. In this case, the interaction between the CHWs and their clients were, in my observation, often formal and sometimes strained. This may have been because they visited the households once or twice a year. This was illustrated during the visit to “*The mother and the disabled son*” in Box 6, where the mother appeared uncomfortable and almost unwelcoming, constantly apologising for the “mess” in her home which indicated her discomfort. When one of the CHWs insisted on showing me the woman’s disabled son, it appeared this was an imposition, rather than acceptable. After all, their work in this case study was only to provide information, allowing limited opportunity to establish relationships with households. The mother knew that CHWs offered little beyond information and would not offer any other tangible assistance such as spending time and caring for the disabled boy. The fact that they offered limited services was reportedly the general perception in the community about the CHWs in this programme. Despite this, there were occasions which proved contrary. Our visit to the home in Box 3 (“*The rats vs the single mother*”), revealed CHWs who had established a relationship with the mother in the household. Here, the nature of the service moved beyond

information dissemination. Since they had visited her home several times, they managed to establish a space in which to discuss more personal issues, and they discussed her illness comfortably. This resulted in a ‘softer’ relationship for more comfortable interaction. The services in this programme often did not require the CHWs to return to the same household, as would be the case with for instance the Khanya programme and the Eden programme, where one is caring for an ill individual who requires regular contact. However, despite the limitation of the Zola programme, the needs sometimes required the CHWs to extend their mandate, albeit very seldom due to resource constraints. In *“The rats vs the single mother”*, the CHWs explained that in the woman’s attempts to find out about the closest health care facility to collect her ARVs after being moved to this area, they continued to visit her on a regular basis to find out whether she was successful with the information they had given her. This subsequently created an opportunity for extended conversations beyond issues related to her treatment. In instances where the CHW visits were not regular, as was the norm this case study, the reception in some of the homes was more of hesitance and scepticism.

The type and level of interaction between clients, including other factors, shaped the space within which the CHWs could provide services. As rapport with their clients grew, the CHWs could probe their clients’ needs more comfortably, allowing them to provide other necessary services such as merely talking and inquiring (as in the Khanya and Eden programme). Although a range of factors are necessary to enable the clients to benefit from the services, the relationships and the nature in which the services were received played a crucial role. However, what also remains important is the extent to which the nature of this interaction influenced the types of outreach services rendered and whether those supported the objectives of comprehensive PHC. The section below delves into this aspect.

7.2 Nature of CHW services

7.2.1 The extent of comprehensiveness of the outreach services

The CHWs across the case studies provided a range of outreach services which varied in comprehensiveness depending on the type of services the case study aimed to provide. All of the case studies provided information to households, either regarding certain health issues, how to take treatment or on the availability of particular services and/or on how to access them, as illustrated in *Box 4* (“*The HIV mother & son*”). Often, the services extended to providing secondary services such as cleaning a client’s home. However, in the one case study, secondary services were purposeful and were specifically part of the intervention to ensure that the clients were self-sufficient and independent. A CHW explained this:

“If the parent is sick and maybe he’s got two or three children, I visit there as early as possible, maybe 6am or 6.30am, where you prepare the children for school. I clean the house but also showing the children how to clean the house before they go to school so that they know that you are coming as a CHW, but you don’t want them to depend on you. I want them to be independent so I show them how to wash the dishes, how to clean the house, how to prepare themselves for school then I just help them with the homework because the mother is sick.” (FGD - Eden programme)

It may be difficult to claim that the outreach services provided by the Eden CHWs were formally comprehensive. However, they made an effort to address the needs of households through a holistic approach without being confined by the definition of services within comprehensive PHC. In light of this, it may be argued that they provided outreach services that supported the principles of a comprehensive approach.

7.2.2 The extent of follow-through

As mentioned above regarding the limitations of the CHW services in the Zola programme, the most that the Gauteng case studies could do was refer clients to the appropriate service provider. This was often without the ability to follow through and monitor the outcome of the referral. Consequently, this generated little community trust in the value of the CHWs' services.

“The clients usually say that where we referred them did not offer any assistance. They say that it's either because we don't know the correct information or that we do not discuss with the people we refer them to. We do try our best but once we have referred them, we really can't guarantee that they will receive any help or find anyone who is relevant to help them with their problem.” (FGD – Zola programme).

The CHWs in the Khanya programme were often not able to follow through with clients because of a lack of transport, as seen in the encounter with the *“The elderly couple”* in Box 1. After realising that the elderly woman required intervention beyond their competence and that they would not be able to return immediately, one CHW tried to comfort the woman by cleaning her wound and said, *“We will try to come back and fetch you with a car.”* Consequently, the lack of transport limited the opportunity to follow through with most of their cases.

In contrast, most of the cases in the Eden programme resulted in referrals and follow-through to conclusion. *“The orphaned boy”* in Box 7 indicates a service where the CHWs not only attended to the boy, but also to the range of needs that would eventually lead to a successful intervention for the boy. This required assisting the grandmother and the aunt with the social service grants and linking the aunt with the clinic so that the boy's long-term treatment could be continued. Overseeing all the needs ensured a complete follow-through of the service to the households.

7.2.2.1 Utilising alternative resources and problem resolution

The CHWs' involvement of the community was part of the effort to provide more comprehensive outreach services. In the Eden programme, this mechanism was more collaborative. The CHWs ensured that they addressed all primary needs of the household (Box 8) by using a variety of avenues, such as the community. Because the family had wide-ranging needs, they realised that these needs would not be addressed through a single source. In this case, as illustrated in the CHW's account of the "*Granny, the community ...a new home*" in Box 8, the workers did not only access formal services such as the grants from the government department, but they also sought the assistance of the community as a resource. The example illustrates that the CHW services are holistic in that they ensure overall benefit for their clients. This therefore implies that their outreach services did not necessarily have to align to the traditional categories as defined in comprehensive PHC in order to support its implementation. They identified a community member to oversee the guardianship of the children, ensured that the guardian secured a grant to enable her to care for those children, and also arranged the building of a new home for the grandmother. In my view, these interventions certainly relate to the broader perspective of what a more comprehensive model of PHC entails; that it is one in which a community is involved, where multi-sectoral services are coordinated and involved in order to improve health and social wellbeing [4, 21]. In fact, according to my observation, the CHWs in this case study provided holistic outreach services that had the potential to ensure the general wellbeing. Consequently, for them to fulfil this role efficiently, they were required to problem-solve and with the support of the organisation, work out alternative strategies to address the needs of this household. One of the CHWs describes their experience with an elderly woman and how the collective efforts of the community provided her a new home:

Box 8: “Granny, the community...a new home”

“I had a case where a grandmother was 88-years-old and she had two grandchildren. They were temporarily staying in someone’s house...so they did not have a place to stay. I started looking for a place to stay for them, so that they can have their own place. I made an appointment with the chairperson of the of the community forum and mentioned that I have identified this problem in the community. **The chairperson organized a meeting with the community members and after that, the community helped to identify a site on where to build a house.** Then I spoke to the coordinators (of the programme) and my supervisors to arrange building material for them. After organising the material, the community and we built a house for them. The children stayed there with the grandmother but it was difficult financially. I went to Social Development to help her to apply the Foster Care grant. There is where I got stuck, because they said these children have got different fathers. The older one still has a father and the other one is an orphan. So they said she could not apply for the grant because “uMakhulu” [*Xhosa for grandmother*] was old enough to look after the children...but also not old enough to get an old age pension grant. She could not access both grants and there was no other person to look after these children. She was only the only next-of-kin of these children. Then I was stuck at this point with Social Development until this year...this was about seven months ago. I found a neighbour who will be taking over the care of the children so that they can get the foster care grant. So during the time when the grandmother was struggling to take care of the children, I eventually found the neighbour.... **I just asked the neighbour if she could take over the care of the family and the children.** You see we work with MDT [Multi-disciplinary Therapy]... You MUST ask the neighbours if the family does not have another family around; you ask the neighbours as community members to look after the family and the children. Because as CHWs, we have got a boundary. Our service is time bound. You cannot work in the family for a long time. The neighbour agreed, so they are now processing the foster care grant as we speak.” (FGD – Eden programme)

7.2.3 Community health workers - a link to formal services

CHWs across all the case studies played a role in exposing and linking communities to a range of formal services that they otherwise would not have managed to access, although the extent and quality varied for each case study. The role of the CHWs to link communities to the formal health system including other sectors was so central to their work that even the weaker CHWs from the Gauteng province managed, in a few occasions, to do so. One CHW explained how they sometimes managed to link clients to one of the least likely services in their community. This was after the CHWs indicated that ambulance services were often reluctant to enter informal settlements. In the case described below, they found one of their clients in her house, weak and delirious. After the ambulance arrived and took her to one of the tertiary hospitals, the

client was assessed to be in the advanced stages of HIV and was immediately put on ARV treatment.

“When we were conducting our door-to-door campaigns a year ago, we found her bed-ridden and close to death. We arranged for an ambulance, which, through the assistance of the clinic manager, eventually arrived. Although it took at least 24 hours, it was better than the usual, where it doesn’t arrive. (Notes from participant observation- Khanya programme – A CHWs account of finding a woman we had visited.)

The role also included being an extension of health care facilities and providing services which nurses were meant to provide in the community. One of these services entailed the tracing of those individuals who defaulted on their treatment.

“Oh yes, there would be a difference. I’ll tell you how I used to measure this. There was a time when we did not have CHWs at all. Our defaulter rate was so high, which brought down our TB statistics of those who (were) supposed to have been cured.... Their presence makes a difference as far as tracing those patients that we cannot find and those that are defaulters. (KII - Khanya programme- Clinic representative)

Both these examples illustrate how there is room to strengthen the potential of this workforce to be instrumental in ensuring that households are linked to cross-sectoral services.

Despite these efforts and due to a range of constraints, the Gauteng CHWs were often not able to facilitate access to services in most of the households. Consequently, they often resorted to providing basic support. For instance, in one case in the Khanya programme, the CHW and I visited a home with three clients. One was a woman with TB (who was not available on that day) whom the CHW monitored for adherence to her TB treatment. The second patient was a young man in his mid-20s who was the woman’s son. He was HIV positive but due to financial constraints, was unable to start treatment because he could not afford to travel to a hospital. The third patient was an elderly man (the young man’s grandfather) who had diabetes and gangrene

on one of his legs. Similarly, he could not afford to travel to the clinic for an assessment and management of his condition. After several reported attempts to call an ambulance for both clients, the least the CHW could provide, in the meantime, was minimum care. The CHW expressed that she could only comfort the client because she could not do anything beyond that. This level of service is again demonstrated in their encounter with the “*Elderly couple*” (Box 1), where all that they could do was wash the client’s feet, despite the need for more advanced clinical attention. The lack of resources, both of the CHWs and the households in these case studies, limited the extent of the services. Consequently, informal psychosocial support was the common form of service for the CHWs in the Khanya and the Zola programmes. In such instances, they therefore superficially supplemented the formal services that ordinarily sectors such as social services and health should provide. Interestingly, some of the comments by the CHWs reflect their perception of the effectiveness of the services. The notion that the main purpose of the visits was merely to provide comfort compromised the quality and impact of their service, more so because it was clear that the condition of their clients often remained the same. The nature of the regular visits to “*The HIV mother positive and son*” (Box 4) was mostly of a CHW who could only provide advice and communicate (at length) with the mother; evidently the type of care that had little impact on the health outcome of both clients.

The CHWs mention that they check up on her regularly mostly to give her reassurance that someone is there to assist even though she lives alone. They also do this so that they can monitor her health. Upon my observation of the lack of food in the house, I inquire whether they are not concerned about her nutrition. They mention that when they have brought food, she says she has no appetite. They mention that they suspect that she is depressed. They add that most of their services to this woman are to provide support for her and her son, by providing her with information and regularly making sure that her son receives treatment and that they both are nurtured with food. They add they cannot assist with her depression. “Maybe she needs counselling. She may be finding it difficult to cope with her illness.” (Notes from participant observation – CHW - Khanya programme)

In some cases though, the CHWs provided psychosocial support as a principled part of their services. Over and above the actual service, CHWs in the Eden programme indicated that providing support to other members of the family who were not necessarily the primary client was an important factor to achieving a positive outcome with the main client.

Most of the households across the case studies had clients affected or infected with chronic illnesses such as HIV/AIDS. The CHWs in the Eastern Cape case study extended psychosocial support in the form of grief work for those that lost family members from the disease and other illnesses as illustrated in Box 7, *“The orphaned boy”*.

There were also instances when the CHWs were able to assist their clients (especially in the Khanya and Eden programmes), by exploring other avenues such as requesting assistance from their managers or supervisors. The institutional support enabled them to link their clients to formal services. For instance, the experience with the *“The woodcutter”* in Box 5 shows how the CHWs assisted the client to go through the laborious process of obtaining an identity document, by harnessing assistance from their managers.

Interestingly, some of the Eden CHW services went beyond that of care when they played an advocacy role to ensure that their clients accessed the required services. Furthermore, the level of support from the organisation appeared to give them the confidence to take on this role. Consequently, the outcome of pushing their own boundaries and holding service providers accountable ensured that a client could access treatment and avoid interruption (of this treatment). Moreover, the CHWs were able to change the policy regarding the provision of treatment for the benefit of many other people in the community.

“...we used to get ARVs from Easterly (city which is 113kms from Selby). I had to be up at 4am rushing to get the ambulance at the hospital. I would sometimes sleep over there, so that they can take my client to the Easterly hospital. Then one day, the child and I arrived on time to find the dispensary closed. The child was there. No treatment. I mean, they say once a person is on ARVs, they cannot stay even a day without that treatment. I then called the coordinators to tell them of the changes. The coordinators arranged for me to get a Daily Dispatch journalist, who went and witnessed this in the Easterly hospital. It was in the Daily Dispatch the following day. That was the day they started to have the ARVs here in our town, because she and the journalist exposed them. Because of the type of support we have to speak out on services, we don't only have to collect ARVs in distant hospitals like we used to.”(FGDλ – Eden programme)

7.2.3.1 The extent of the link to formal services – compromised quality of care

Undoubtedly, the difficulties encountered by the Gauteng CHWs to access transport and a range of services meant that a few of the clients who had specialized needs were even less likely to access this care. Some of the cases had disabilities which the CHWs were unfamiliar with. Due to the lack of adequate knowledge, the unavailability of adequate services for these disabilities and the lack of means to access services, households had difficulty with coping. In fact, some of the clients seemed to have accepted their condition such that they did not seek further ways to address the problem particularly because the local health services were not sufficiently equipped to offer services needed by those with disabilities. Consequently, the CHWs in the Zola programme seemed to have taken a similar position. For instance, the mother of the client in Box 6 *“The mother & the disabled son”* expressed that she was at a point where she only went to the clinic only when her son was sick (and not to seek disability services). Financial constraints delayed all other efforts to address her son's disability.

In the same vein, there were a few households that had clients with mental illnesses who did not have access to the most basic treatment such as medication. The lack of services in the clinic close to their homes and limited information restricted the potential to access services that catered to their needs. Even if they were informed of the available services, they would still be unable to access those services due to a lack of formal documents such as identity documents and

birth certificates that are required to access government services. This was often because they could not afford to travel or use other means to reach the services to access those essential documents. “*The elderly man and his silent son*” (Box 9) illustrates the complexity of accessing a range of services. The fact that the communities across the three case studies were placed at the margins of or far from more formal areas, where there was limited formal infrastructure such as transport routes, resulted in their inability to deal with these issues. One client, a young woman with a supposedly psychiatric illness and/or intellectual challenge, was left unassisted by the CHWs from the Khanya programme. The young men in the settlement took advantage of her ‘disability’ by reportedly often raping her over weekends, with nobody to assist. In this case, the CHWs appeared to be completely helpless. One of the CHWs explained that this woman’s situation made it complex to intervene. Her family reportedly rejected her because they did not understand her illness and perceived her as “*bewitched and therefore insane*”. This made it difficult for her to call social services or an ambulance because she could not confirm where the woman lived or what her name was, often because she was incoherent. The CHWs mentioned that they had considered calling an ambulance to give her access to a health facility for assessment and appropriate referral. She added that the community seemed to have a neglectful attitude (often making fun of her), leaving the CHWs short of avenues to assist. Consequently, it is in such cases that the institutional support provided by the Eden programme could have enabled CHWs to deal with such complex cases.

Box 9 “The elderly man and his silent son”

We enter a household that has a 30-year-old male whom the father (70 years) believes has a psychiatric problem. He mentions that he has not spoken ever since he was assaulted six years ago. The father indicates that he is from Zimbabwe. **He reports how he is unable to get his son to hospital for an assessment because he does not have an ID for him.** The father has an ID. He mentions that even if his son did have one as well, he cannot afford to get as far as the hospital for him to get an assessment and he also cannot conduct the errands that he needs to follow up for him to get an ID for him. He says that, because his son is unable to speak, he has no choice but to travel with him to assist with the process. **He however cannot afford to pay for both of them for public transport.** He mentions that **“If I had to die now, I’m worried that he (his son) will just eventually die himself...he cannot fend for himself.”** He says he wishes that he could just get him an ID so that he can apply for a grant. That way he can have some money to provide the basics for himself. He explained that his frustration is that everything requires money. To go to home affairs to apply for a grant and to get him to hospital for a psychiatric assessment. (Notes from participant observation, Khanya programme)

7.2.4 The interface between poverty and extent of care

Poverty for most of the clients across the case studies had an impact on a variety of aspects of their lives. Lack of access to food meant that many of them were not able to take necessary medication, consequently often resulting in non-adherence to treatment as indicated by the “*The South African immigrant*” in Box 2 and “*The HIV positive mother & son*” in Box 4. Both the elderly man and the mother were unable to take their TB and ARV treatment, respectively, because they reportedly experienced severe hunger after taking the treatment. Lack of access to food made the efforts of the CHWs to enable access to the treatment and care futile.

“We have got a lot of our patients coming back and saying, you know what...I want to take the treatment, but because I don’t have food...I can’t take it regularly...it just irritates my tummy...I can’t take it.” (KII – Health promoter –Khanya programme)

During one of the participant observations, I observed a similar experience:

The house belongs to a couple that is HIV positive. We found the wife sitting outside. The house looks very bare with just one chair inside. She looks very emaciated and weak. The patient reports that she has not eaten in four days. Sometimes the husband goes away to try to look for work. They are both unemployed. It is during those times that she will not have any means of finding anything to eat. A CHW mentions that: “This is when it becomes difficult for me to assist any further. Everything requires financial means and I can’t help with that.” (Notes from participant observation – Khanya programme)

Poverty also made it difficult for the communities in the Gauteng case studies to negotiate adequate services. The lack of access to sources of influence within the community rendered them powerless. The household in Box 3 (*“The rats vs the single mother”*) is an example of how a family was forced to live in inadequate shelter despite having successfully applied for a house. This was reportedly due to not having good relations with the local person who was “given the authority” to allocate the houses. The woman had no avenues to query the issue at higher levels of government and the CHWs were in the same disempowered position. In contrast, the community in the Eastern Cape case study used a range of resources to negotiate access to services. This mostly relates to the nature of the community, which I discuss in the Chapter 8.

Despite the diverse needs of the clients in most of the households across the case studies, it was evident that the households which the Gauteng CHWs served received the least comprehensive outreach services. The Khanya programme households received mainly informal psychosocial support from the CHWs, identification of ill clients, the tracing of treatment defaulters and in a few cases, assistance to access other formal services such as social grants, TB and/or ARV treatment. However, the poverty level of the households compromised the quality of those services. For instance, the complex circumstances of the *“Elderly couple”* in Box 1 prevented the extent to which the CHW’s could provide care. The lack of water, food, decent housing and the financial means to travel to basic services meant that the services they provided could not achieve much of an outcome. The services in the Zola programme were even more limited, mostly focusing on providing information and referrals and not much else. The principle of this programme provided the CHWs with limited avenues to ensure that the provided information was followed through.

In contrast to the Gauteng case studies, the CHWs in the Eden programme provided more holistic outreach services. The principles of their model were not restricted to a health paradigm, but towards addressing the broader needs of a household, allowing them to focus on a range of factors. More importantly, the comprehensive nature of their approach ensured that their services achieved positive outcomes, even though they functioned in similarly poor families as the Gauteng programmes. This flexible approach allowed them to circumvent the compromising effects of poverty on the impact of the services. The CHW assistance to the families in Box 7 (*“The orphaned boy”*) and Box 8 (*“Granny, the community...a new home”*) illustrate this. Their ability to utilise and rely on the resources of the rest of the community rather than only those within the households enabled them to facilitate outreach services that eventually achieved the expected outcomes. Added to this, although their services targeted children and the youth infected and affected by HIV and AIDS, this model of intervention recognizes that the adult and family play a significant role in the wellbeing of a child.

“We focus on those with HIV/AIDS because lots of families are affected. We work with those families because those children are also at risk.” (FGD – Eden programme)

In contrast, the Khanya programme focussed on health issues, even though the CHWs were aware of other influencing issues which they often failed to address. The Zola programme was even narrower where the CHWs provided even fewer services, focusing on a single paradigm of care; where when opportunity emerged, they would identify and refer households to pertinent services, sometimes to dissatisfaction of those the households. As one CHW described:

“We usually inform people and refer them to social services....but they usually always have to go back because they need this document and that document and it becomes a long process. Despite that, they often don’t get help when they eventually get there anyway...They usually say that where we referred them did not offer any assistance and suspect that we don’t know the correct

information. We do try our best but once we have referred them, we really can't guarantee that they will receive any help or find anyone who is relevant to deal with their problems.” (FGD – Zola programme)

Despite most of the homes in the Gauteng case studies being relatively closer to the cities than their counterparts in the Eastern Cape, they were unable to reach those services as they lacked financial capacity to travel to those services. Even in the few instances when they reached those services, they reportedly would not receive immediate assistance. This was primarily because these services were not available in a single area and therefore required several visits to different departments. This was explained by the “*The elderly man and his silent son*” in Box 9 where he could not obtain an identity document for his son which required accessing a range of departments such as the police for an affidavit and a psychiatric hospital for an assessment to confirm his son's condition. Both of these services were kilometres away from each other.

Another client in Gauteng had a similar experience:

The woman reported to have high blood pressure but has been unable to continue with treatment in the Oxford clinic because they told the granddaughter who went to fetch the medication for her that she is required to personally return for a check-up. For transport, she cannot walk to the taxi route hence she sometime asks one of the boys in the neighbourhood to carry her in a wheelbarrow to the main road so that she can catch a taxi to the clinic. She has not been able to do that so far, therefore she has stayed without medication for a while. (Notes from participant observation – Khanya programme)

The interface between poverty and the nature of treatment that CHWs could provide was evidently a constraining factor. In most instances in the Gauteng case studies, even if the CHW provided the best service and care, the clients' level of poverty often rendered their services unsustainable, as illustrated in Box 1 (“*The elderly couple*”). The client in this household had so many needs such that whatever services rendered at that time proved unsustainable and therefore had little impact on outcome of the intervention.

Interestingly, barriers to access manifested in basic ways. Lack of adequate clothing prevented the woman in Box 5, “*The woodcutter*”, from seeking services. In a similar experience, lack of access to water to wash resulted in the reluctance of a CHW to refer a client to the clinic due to lack of hygiene:

After examining the woman’s foot, the CHW decides that she will need to go to the clinic for attention, as she has a severe cut. Although we had transport to take her to the clinic, the CHW was concerned that the nurses would refuse to attend to her because she had not washed, saying: “You know you need to get yourself cleaned up. There is no way that Nurse X will see you in this state...she’ll just complain...you know that”. To which the client responded: “We have not received water [which the Department of Environment was meant to deliver monthly] for the entire week. We haven’t been able to wash...” (Notes from participant observation – Khanya programme)

This episode clearly indicates that most of the time, the context and the circumstances of poor communities determine their decision to access services. The woman in Box 5, “*The woodcutter*”, expressed how she felt uncomfortable accessing services at formal facilities because she lacked decent clothing.

7.2.5 The disjuncture between patient need and health system policies

In most cases, even when the clients had finally managed to access services, they faced the apathy of service providers. In fact, the policies of some of the sectors reflected the lack of recognition of the plight of the poor. During data collection, most of the HIV positive clients needing treatment reported how they were required to attend a three-day adherence session before being considered eligible to commence treatment. Most of those clients were evidently unable to afford to travel for three consecutive days to attend the sessions. Since CHWs in the Gauteng studies had no resources to assist in this regard, this resulted in most of the clients not accessing the required treatment.

“This system in itself is a barrier for patients who cannot afford to travel back and forth for three days. That means for this patient, she may eventually fall very ill because she cannot access treatment due to the policy of attending adherence sessions only at hospital, rather than allowing this to be provided at clinic level as well where it can be accessible because it is closer.” (FGD∞ – Khanya programme)

The experience was different for the CHWs in the Eden programme. They not only informed and referred their clients to the necessary services, but also ensured that they reached those services by providing various means, either by mobilising the community, using the authoritative advantage of their seniors or by using the resources that the organisation provided, such as financial assistance. The overall element that ensured a positive experience and outcome for clients in this organisation was that the CHWs carried services through to fruition. This was despite the fact that the communities in the case studies shared similar contextual circumstances of poverty. The household contexts shaped the extent to which the CHWs’ outreach services could achieve positive outcomes. However, other factors such as the institutional support, the competence of the CHWs to utilise their resources innovatively, and the ability to navigate fragmented government services ensured that the contextual aspects of poverty did not compromise the comprehensive nature and intended outcomes of their services.

Even with the varied contexts and circumstances in the communities across all case studies, it was clear that despite the CHWs’ respective models of care, all the clients in the households observed required services beyond the scope of the health sector. To ensure an outcome of general wellbeing and health, the CHWs needed to provide outreach services requiring community-level inter-sectoral action. The majority of cases across the case studies evidently called for multiple services. However, the two cases in Gauteng fell short of adhering to this principle that supports comprehensive PHC, in contrast to the Eden programme. From the discussion above and the household stories, the nature of the community was clearly a factor

which provided an enabling environment (or not) for the CHW to provide these outreach services that worked across sectors. In light of how the outreach services in the Eastern Cape case study unfolded, this component seems to determine the extent to which a community mobilises to facilitate services. I consequently discuss community participation further in Chapter 8.

CHAPTER 8 The woes of community participation - a vehicle to community level inter-sectoral action?

“From the earliest rhetoric of global Primary Health Care, the role of community participation has been considered one of several key ingredients required to improve community health” [231]. This section discusses the dynamics of community participation. It explores the factors that both enabled its facilitation and use as a vehicle to provide inter-sectoral outreach services to poor households, and those factors that constrained it. The chapter looks at the value of social cohesion and social capital, and explores how community participation contributes to the extent to which CHWs can support comprehensive PHC.

8.1 What structures exist to facilitate community participation?

Formal structures existed in the communities across all the case studies. The most prominent ones were the ward committees that ward councillors ideally coordinated to generate community participation at local level. It is where the different sectors (health, social development, home affairs, environment, agriculture, emergency services, etc.) are meant to meet with communities to address needs and challenges, thus fostering inter-sectoral action at community level. The ward councillor is supposedly the central point of contact between the community and these sectors, while the ward committee should be accountable to the ward councillor and the community. Other tools, which were alluded to by those in authority, were the Integrated Development Plans (IDPs). These were established to foster community participation and inter-sectoral action and were theoretically meant to be functional in these communities. However, they were not evident and reportedly a distant concept to the communities and the CHWs.

Other formal structures which were much more evident across these case studies were the health committees, which are also meant to mobilise the community regarding health issues and to hold service providers accountable. These committees are obliged to constitute a range of representatives such as those from the community, local churches, local businesses, health care providers and the ward councillor. However, they existed and functioned at varying levels across the communities. I deal with this in the rest of the discussion below.

8.2 Who were the main active groups?

Despite the existence of formal structures for community participation across the communities in the three case studies, there were informal structures that developed organically in the effort to address existing needs in the respective communities. These informal efforts emerged mainly due to the perception that the formal structures were ineffective. Regardless of the existence of both, these structures differed in their degree of functionality and impact. The most formal ones were NGOs that offered a range of services, but their effectiveness varied across the case studies. The Gauteng case studies had the least amount of other community-based structures, except the study organisations themselves, which made it difficult for the CHWs to refer and establish referral networks. The only community structures identified in the Khanya programme case study were for places of safety for orphaned children. However, these services were mostly informal because they were homes of elderly women who took in needy children. They were only formal in the sense that they received funding from the government which they applied for and received by virtue of being registered as NGOs. A respondent explained:

“We have quite a number of ‘places of safety’. There are ladies who take these kids and stay with them. We’ve got one who takes in children who are sexually abused and another who takes in children who are disabled and mentally challenged. I’m not really sure why they take it upon themselves to do this, but they provide a service that would otherwise be absolutely zero here.” (KII – Health promoter –Khanya programme).

During data collection, I, together with the CHWs, visited one home that accommodated and provided care for children with disabilities. The owner was an elderly woman who lived on a farm and had extended her home to the children that she had taken in over the years. The CHWs referred any children identified during home visits to her home. In fact, it was the only facility closest to the community that catered for this need. Although not an ideal situation, the community member provided the CHWs with an opportunity to use her as an existing resource to establish social networks and provide services.

Other attempts of community participation were the efforts to resuscitate an existing clinic committee in the Khanya programme. However, poor attendance by the community members rendered it weak and ineffectual, leaving the community with no platform to voice opinions and concerns on the health services of the clinic. During the participant observations, I unexpectedly met a community member who was part of a recently established cadre of community workers called the Community Development Workers (CDWs). A government construct of community participation, the province developed and managed this cadre to monitor the inter-sectoral needs of communities. The only one in the Khanya programme's community, the CDW was however considered ineffective and almost non-existent by some community members.

The Zola programme had no other formal community-based structures except the organisation itself and a ward committee. There were no other NGOs to refer to. Interestingly, there were various isolated informal community structures which different (not unified) individuals initiated in frustration at the lack of services in the community. These structures reportedly perceived the ward councillor and the CHWs from the Zola programme as state funded entities that are ineffective structures. The CHWs explained to me that one of these 'community representatives'

was of the view that the CHWs were well resourced, that is, received funding, but failed to assist those in need in the community. They informed me that this particular community leader (“X”) was not in favour of the Zola programme because the local health authority reportedly took CHWs from an existing NGO and placed them in this programme. This left the original NGO without support or funding, hence it later closed down. He reportedly perceived the CHWs as part of the problem of the government’s poor effort to provide services. According to a nurse in the local clinic, this individual took matters into his own hands and helped those that sought assistance from him. She mentioned how a particular “self-proclaimed community leader” was resourceful in assisting community members to access services when they struggle to do so by themselves. She however mentioned that there was animosity between this individual and the CHWs because he seemed to perceive this group of workers as agents of a state that did not care about the welfare of the community:

“I must say X is very resourceful because he is also involved in social services. If I’m struggling...for instance, there are those people that cannot do birth registrations because they don’t have ID, I go through him at times so that he can assist people to go to Home Affairs. For example, for patients that do not have parents, he goes and stands there with them and signs for them in his capacity as a community leader. But then again as I said, this community cannot work as a team. This one wants to be in charge and that one wants to be in charge. If they all worked together, they would have been able to use X’s ability to get responses from the departments, but I don’t think they want to work together.” (KII – Health professional, Zola programme clinic)

After many failed attempts to contact and meet this individual, the CHWs informed me that he indicated that he did not wish to meet me. They mentioned that they suspected that it was because he associated me with the programme. Upon reflection, this incident was not only an indication of the lack of unity in the community which hampered community participation

efforts, it was also an interesting indication of the disdain in which marginalised communities responded to formal attempts by government to foster community-based efforts.

In contrast, I found the most varied and unified efforts of community participation in the community of the Eden programme. In this case study, the CHWs interacted and referred to various NGOs that provided home-based care for clients with health needs:

“...We referred the case to the home-based care worker, but also you are hands-on because you cannot say ‘Ok, I’m referring this and I’ll just leave the parent and focus on the child’...because then you have missed the point. We follow up with our referrals, even if it involves the relative of the child.” (FGD – Eden programme)

The community in this case study also had an active and visible ward councillor and ward committee. Moreover, the community often mobilised to address various areas of community needs through the committee. I expand on this in the following discussion.

8.3 How did the institutions and groups work in reality?

The existence of community participation forums such as ward committees and clinic committees is a reflection of the recognition by the Province of the challenges of attaining inter-sectoral collaboration between and amongst departments. These formal structures are meant to foster inter-sectoral action and provide communities with platforms to hold service providers accountable. It is these vehicles that CHWs can utilize to facilitate community-level inter-sectoral action. Community participation is therefore potentially an important component towards driving and achieving comprehensive and coordinated services. The CHWs can use the participation platforms to ensure that their communities and service providers know and recognise them. This can indirectly empower them as important agents of the community, as seen in the Eastern Cape community:

“...There are ward committees and that is what we use to communicate with the community. For instance, when they wanted to open a Safe Park in these locations (local areas), they worked hand-in-hand with the ward committees and with the councillor. It was the councillor who called a meeting and called the coordinators together with the team leaders of the NGO. So everything was worked through with the councillor.”(FGD – Eden programme)

However, the potential benefit of community participation was not realised in the Gauteng communities. Challenges to achieving this were due to a range of factors outlined below.

8.3.1 An ineffective ward committee

The lack of active community participation structures meant that the communities did not have the opportunity to engage amongst themselves or with those meant to provide them with services. For instance, in an incident where a young girl was sexually abused in her home, the lack of an effective community structure left the CHWs with limited avenues to seek assistance for her:

“She cannot report to anyone in the family. If you put yourself in that child’s shoes, do you think you would cope? She then contemplated suicide...three times. Social services have done nothing to assist. I mean it’s sad, when your own family can turn against you to defend someone who hurts you. Who do you go to? We really all have failed this child. If at least there was a functional ward committee where you could vent and report these issues and engage with people that are supposed to deal with these issues, then that would at least help. But we sometimes don’t hear from Mr X [ward councillor] for months. I am yet to hear of any ward committee meeting taking place” (KII - Clinic representative, Khanya programme)

8.3.2 Political affiliation compromises the commitment of ward councillors

Respondents from both case studies in Gauteng expressed concern with regard to the ward councillors, believing that their lack of contribution was due to their political involvement. They felt that the ability to access different sectors and services in their respective areas would be possible if the ward councillors were active and fulfilled their mandates. In both case studies, the CHWs struggled without success to involve ward councillors:

“Politically our ward councillor is a... (name of political party) councillor, so it’s difficult to get him on board. He can’t relate to the issues.” (KII – NGO manager, Khanya programme)

The negative influence of politics was apparent in both provinces, where the Eden programme reportedly strived to operate far from the political dynamics of government by operating with agencies at a more local level.

“You hear constantly that the community complains that the things don’t get done unless you know so and so or you are related to the councillor, the ward councillor, that is the deep reality which we are in Selby. There is no political accountability because the vote of the people is still a vote for a party and that party ends up choosing or deploying someone. We as a community do not vote for this councillor.” (KII – NGO coordinator – Eden programme)

These concerns included the fact that the reporting lines of these community structures were not aligned and people were answerable to various individuals, which weakened accountability:

“If your ward committees were well functioning and then link that with all those community based cadres - the CDWs, the DOT supporters, the CHWs...because really that is where you have access to the different sectors, then we’d be able to address health issues and other issues for that matter. It’s just that our structures are not aligned and then you’re not able to achieve the impact that an integrated structure would be able to achieve.” (KII – Gauteng DOH – Local government representative)

In addition, the ward councillors were perceived to have conflicted loyalties, thus compromising their ability to address the needs of the community. One of the CHWs in expressed their frustration:

“Most of the time, the councillor calls meetings with his own people and they make their own decisions without calling the rest of us and the community. We are the ones that go from door-to-door and hear people’s problems about the clinic, but they have the audacity to call their own people who don’t walk around here and hear people’s grievances. He has cliques that he hangs around with. He is a member of the... (name of political party) so he tends to engage with those that are ...(name of political party) members. What is he then? Is he here to rally members or is he a councillor to deal with issues of the community?” (FGD – Zola programme)

8.3.3 Poor communities have more pressing needs... and struggle to participate

Some of the respondents concurred that ensuring outreach inter-sectoral action required a strong level of involvement of the community; however fostering this aspect especially amongst poor communities was a challenge. One of the CHWs in the Zola programme indicated how there was always better response from the community when the meeting was about housing issues than one on health services. Ensuring that members participated regularly was a constant battle as it was felt that individuals had more pressing priorities:

“I’ve been trying to mobilise a clinic committee. People do not come to meetings because sometimes some of them get employment and they have to work. And you know, being a poor community, people want to do something for something in return. I remember when the notice was put up about looking for people to form a clinic committee, people used to come in and ask if there was some sort of stipend and when I said no, they never came back.” (KII – clinic nurse-Zola programme)

8.3.4 Lack of recognition of the Community health workers

Another aspect which impacted on the ability of the CHWs to use community structures to foster inter-sectoral outreach services was the limited extent to which individuals and institutions recognized them as valuable actors in the system of service delivery. The poor outcomes of many clients of the Gauteng CHWs revealed their poor influence as community agents resulting in a poor response from those in the various state departments. Since their services were not valued or recognised, the CHWs often failed to provide comprehensive outreach services. In fact, despite the better reputation of the CHWs in the Eastern Cape, higher organs of the state were not responsive to their efforts. One CHW explains how this affected efforts to address the needs of their clients:

“We wrote some letters to the prosecutor, telling him that he cannot put this child in the same stand with the perpetrator (abuser). There was also a letter from the school. But this man refused to read the letters or consider what we had suggested. He put them together in the same stand and now the child has regressed. She’s wetting herself, when you talk it’s as if you are talking to this wall. She just looks at you. We are having that challenge. Even the courts and the Department of Justice is not doing any justice for that child.” (FGD - Eden programme)

The poor recognition and reception of the CHWs by those in higher authority also resulted in a lack of responsibility towards clients. Some of the health professionals did not refer back to CHWs, therefore limiting the opportunity for continuity of care:

“...The expectation is that once our facilities have managed an individual and they find that further care can be done at home, they are supposed to refer this to the NGOs in the area so that they manage them further. This doesn’t always happen that way. Most of the time, our professionals don’t respect the community services enough to refer to the NGOs. The referral is mostly from the NGO side to our facilities. And that’s an area of challenge.” (KII - Gauteng Provincial representative)

8.4 What do the case study organisations add to community participation?

As evident in the discussion above, the organisations could potentially use the community participation structures as platforms to advance their own work in the community. After all, these structures are ideally meant to hold service providers and the state accountable. However, the weaknesses found in the community participation structures made it difficult for the CHWs to use them and mobilise the community. On the other hand, it is also clear that, when functional, the structures are effective channels to facilitate community level inter-sectoral action. The experience of the “*Granny, the community...a new home*” in Box 8 is exemplary. The CHWs here were able to use the community both as a resource to identify people who would take over the guardianship of an orphan, and mobilise it to provide an adequate housing for the family.

8.5 What do the network maps indicate?

The nature of social cohesion in communities provides an enabling environment for community participation. This is manifested in the Eastern Cape case study where the community shares a long history and has managed to forge strong bonds over time. As illustrated in Box 8 (*“The granny, the community ...a new home”*), the established networks allowed the community to recognise its collective needs as opposed to those at the individual level, thus generating and allowing them to draw from social capital. Collective resources offered the CHWs in this case study an enabling environment to provide services that address the multi-sectoral needs of its community. Involving the various local government services also forced these sectors to act in a coordinated manner. The stark differences in the range of social networks established the case studies (Images 4, 5 and 6), illustrate how a more extensive profile of social networks and strong social cohesion provides a richer environment for community-based organisations to render multifaceted services. The two case studies in Gauteng evidently had weaker social cohesion and social capital and therefore failed to facilitate community participation. In this regard, they also failed to foster inter-sectoral outreach services which potentially could offer holistic services. Admittedly, the failure of the Gauteng case studies also demonstrated that CHWs would find it more difficult to mobilise communities which do not have pre-existing social cohesion, established social networks and strengthened social capital. In fact, this notion encourages the question: who then should take the responsibility of community building in order to strengthen social cohesion and generate social capital in poor communities?

The discussion on community participation illustrated a range of constraining and enabling factors. The presence of community structures, formal and/or informal has the potential to provide an environment that encourages this mechanism. Three factors were, however, evident in the CHWs’ attempts to use community participation as a mechanism to provide services.

Firstly, there needs to be a unified front in a community's attempts at mobilisation. Secondly, poor communities have immediate and sometimes conflicting needs and participation can be the least of their priorities. Thirdly, a community that has common ground and a shared experience, strong social cohesion and collective resources enables community participation. In addition, such a community is able to recognise those resources and use them efficiently for CHWs to provide effective outreach services.

The discussion shows that CHWs require an environment with a mobilised community to provide outreach services that function across sectors. For instance, despite the existence of community structures in the Gauteng communities, their fragmented nature affected the extent to which the CHWs could link households to the various sectors. It is in this light that community level inter-sectoral action frequently failed to occur in these case studies. More importantly, the CHWs in the Eden programme demonstrated that they, with the community, could use existing community structures to facilitate inter-sectoral outreach services. How and why this component is important to their work is discussed in Chapter 9.

CHAPTER 9 The nature and extent of community level inter-sectoral action

A WHO sponsored conference in Canada in 1987 defined inter-sectoral action as “...a recognised relationship between part or parts of the health sector with part or parts of another sector that has been formed to take action on an issue to achieve health outcomes...” [116]. The definition pertinently provides a clearer perspective to the discussion in this chapter. In view of the circumstances of the communities across the three case studies, their experiences of the CHW services and the contexts within which the services were provided, it is evident that their needs and experiences require effective outreach services that adopt an inter-sectoral approach. It is also clear that one of the key mechanisms that enable community level inter-sectoral action is community participation. The issues illustrated in these communities call for the CHWs to link them not only to health care services, but also to other non-health services that have an impact on health and well-being. However, the discussion above also shows that efforts to foster inter-sectoral outreach services in the Gauteng cases studies was limited and often not achieved. This chapter discusses themes from the data that reflect on why this was the case. In the chapter, I also focus on the instances when community level inter-sectoral action did occur and explore the factors that enabled it. This is illustrated mainly in the Eastern Cape case study. The themes that emerge and explain why outreach services, which work across sectors, did manage to occur will be used to develop a repertoire of lessons learned.

9.1 Conceptualizing the role of CHWs with respect to the social determinants of health

Conceptualization of the social determinants as a cause of poor health is key to the shaping the role of the CHW. The CHWs' programmes in Gauteng were conceptualized within the health sector and therefore CHW activities were confined to health-related issues. The CHW programme in the Eastern Cape aimed to meet the needs of children affected by the HIV epidemic. This required CHW to respond to health problems via other sectors, often addressing broader household needs, and although child-focused, services targeted the range of problems identified in a household:

“The intervention was extended beyond that of focusing on children with HIV/AIDS...if there is alcohol abuse in the family, it leads to the possibility of being infected with HIV/AIDS so we do early intervention to those families. (FGD – Eden programme)

Furthermore, the Eden programme had specifically recruited community members who had already been working in the community and understood from experience the need to respond to the broader range of determinants of health to be able to assist community members. Moreover, the CHWs *“had other specific training with other service providers...it is not only health, sometimes they receive special training through other service providers, to help them to address the multifaceted things that happen in social service.” (KII- project coordinator from Eden programme).*

9.2 Community level inter-sectoral action is resource intensive – the capacity to provide institutional support

Considering that CHWs across all case studies assumed very limited power to influence government level processes and practices, the institutional support gave them the leverage and ability to explore different avenues for providing effective services to their clients. Investing in resources such as training, supervision and other forms of support such as financial support for transport was an advantage for the CHWs in the Eastern Cape case study.

9.2.1 The training and supervision

Some of that support can materialise in the type and quality of training provided and related to this, the extent to which it makes them competent to cope with the complex context within which they function. In most cases, the CHWs in the Gauteng case studies were unable to identify alternatives in their efforts to assist their clients. The type of training they received could have caused this, resulting in their limited ability to deal with the complex cases and situations. The complex nature of multiple needs presented in the household in Box 1(*“The elderly couple”*) illustrates this. These CHWs often faced clients that required a range of services. Better quality training would have afforded them the skills to deal with some of the issues.

In contrast, the Eastern Cape case study was successful partly due to the resources invested in ongoing training, supervision and mentoring of CHWs to assist with the development of problem solving skills. In fact, the CHWs regarded their training as an enabling component to dealing with their cases and providing services that had positive outcomes. This, according to them, was especially so regarding their ability to explore various avenues to link clients to a range of services:

“The training does help them to be able to problem-solve and refer, when to refer and know who to refer to. We give them that kind of training so that they can look at the situation, do assessments as professional child and youth care workers and be able to look at the needs and refer when they need to. So over and above the 14 modules, they have additional training because of the context in which they work. It is not only health. They receive the special training with other service providers. They help them to address the multifaceted things that happen in social service.” (KII- project coordinator – Eden programme)

In this case study, the CHWs considered the training to be instrumental in their ability to communicate with services providers. Consequently, this competence is usually a necessity when negotiating services for clients. It reportedly also enables them to explore interventions that are unique to each client:

“The training helps us a lot. Because firstly, you are being trained on how to communicate: it gives you the communication skills and you have to observe. You observe, you assess, then you design the programme that is suitable for this family.” (FGD – Eden programme)

The extent and quality of supervision enabled the CHWs in the Eden programme to deal with the multi-sectoral needs of their cases. Inter-sectoral outreach services require varied knowledge and a multitude of skills. This could range from how to circumvent a complex referral system to deciding which service would be appropriate for the problem at hand, or which service/intervention within the choice of services would have a better effect on the client’s status and progress. Consequently, supervision across the three case studies occurred in different forms, all leading to different outcomes with regard to community level inter-sectoral action. The value of supervision was that it enabled the CHWs to appreciate outreach services that work across sectors and how to facilitate them. In fact, the supervision in the Eastern Cape NGO required supervisors to conduct supervision within the household where they could examine and monitor all the needs of the home.

This was different in the Gauteng programmes. For instance, the project coordinator conducted most of the supervision in the Khanya programme during the monthly sessions where they would review reporting forms. The process involved discussions regarding the progress and status of the CHWs' clients. Although the coordinator would follow up to assist with some of the cases, much of the supervision was in the form of advice, leaving the CHWs to problem-solve on their own.

In contrast to the Khanya programme, the CHWs in the Zola programme received no supervision. This lack of supervision and limited assistance prevented them from being able to link their households to different sectors and addressing their multi-faceted needs. In short, the supervision in the Eastern Cape NGO contributed to a large extent to the ability of the CHWs to problem-solve and determine avenues and alternatives to conducting inter-sectoral outreach services, but even more importantly, to realize the outcome of this action.

9.2.2 Organisational support – resources

The CHWs in the Gauteng province struggled to ensure that their clients were not only able to access multiple services, but also to reach those services. This was primarily because of the lack of resources such as transport, or the means to reach the referral services, which included transport costs. Added to this was the CHWs' inability to communicate with their supervisors or managers that were in a more influential position to negotiate with government departments on their behalf:

“We have no support. If there was at least someone who is a bit above us who has the power or the influence to go to those offices for us so that we can help people, that would make a difference but we are really standing on our own feet....Or if there was some way the department can help with providing transport so that we can accompany those people...for them to at least get there. We are part of an NGO but really we are on our own” (FGD – Zola programme)

“Requesting for an ambulance to come through takes a long time, sometimes weeks. We often rely on “S” (project manager) to organize it. We are powerless to do it ourselves.” (Notes from participant observation – Khanya programme)

Consequently, the lack of institutional support epitomised by the lack of transport or financial means to accompany clients to services constrained the potential of CHWs in the Gauteng case studies to refer clients to a range of sectors and ensure that there was follow through if and once they accessed the services. The lack of transport meant most clients were left to their own devices after being referred by the CHWs. Consequently, the CHWs often failed to follow through with their clients’ referrals to the outcome. This was strongly evident with *“The elderly couple”* in Box 1, where the CHWs suggested that the ill woman go to a clinic to address her problem. Their constraint to take her to the clinic themselves limited the extent to which they could assist the client. The same applies to the *“The mother & the disabled son”* in Box 6. The best that the CHWs could do in this case was to refer them to the furthest community health centre for onward referral to an appropriate specialist to address the son’s problem. It was evident that the mother would find it difficult to travel with her son because of his disability and would struggle to pay for the costs of transport. Both households (Box 1 and 6) had clients with a range of limitations which inhibited the ability of the CHWs to follow and/or address them to their ultimate outcomes. The lack of the institutional capacity to support them exacerbated their struggle to support the two households.

In addition, the lack of financial support placed a burden on the CHWs to provide finance - a workforce that receives a stipend rather than a salary:

“Most of the time they delay the process and take long to eventually get there. Sometimes you try and lend them R5 (\$0.6) or so but they usually always have to go back because they need this document and that document...” (FGD – Zola programme)

In the Eastern Cape NGO, support to the CHWs was embedded in the organisational culture. When experiencing difficulty, the CHWs had sufficient options within the organisation to seek assistance:

“The supervisors are always supportive. If you are not sure along the way, you go back to the supervisors. The supervisors will meet with the project manager and the project manager; if the CHW still doesn’t understand they will involve the mentor and they will ask the mentor what should be done and they will work together with the CHW. So you don’t do something you are not sure of. You know that you can get help.” (FGD – Eden programme)

In addition, as previously indicated in the description of this organisation, financial support was part of the culture of support:

“If, for instance you have a child that needs to go to a department in the city and you know that you will need airtime to communicate while you are away, you submit an expenditure form so that you get money that will cover airtime and transport for both me and the client.” (FGD – Eden programme)

The extent of support in this case study also enabled the CHWs to facilitate inter-sectoral outreach services by exploring a variety of avenues. For instance, they also played an advocacy role to ensure that government services were accountable to those who needed the services. Constraints from other sectors were challenged in various forms, for example, by using the influence of the media, an approach which the CHWs in the other case studies would unlikely be able to foster without that support.

The Eastern Cape organisation also extended the scope of support to focusing on the wellbeing of the CHWs by providing a care-of-the-carer programme:

“We did some grief work for a week when we went away as a group. You’ll find that the reason that we are attracted to the work that we do is because of our own baggage that we went through. So the psychologist helped us a lot. Our coordinators made a plan that we stay there, away from this context. We were all together and we were sharing and it opened us up so much.” (FGD –Eden programme)

However, even with limited resources, the Khanya programme illustrated how merely receiving some level of support enabled the CHWs to assist their clients to access certain services. The manager, the health promoter and the co-ordinator all played various roles in providing some support. For instance, the project co-ordinator would sometimes accompany the CHWs to households where they felt that he would offer better assistance and influence, especially with issues that related to accessing formal documents such as IDs. The health promoter, although not part of the organisation but a representative for the province, would on some occasions provide transport in emergency situations:

“I work with them, for instance if they have got a problem with somebody who is very sick, who needs assistance and cannot walk or whatever, I will go and see how we best can help. If that person is very ill, I will take him and bring him to the clinic, where he will be seen and then I will take him back. With the cases such as sexual abuse and so forth, we sit down and work out where we should refer.” (KII – Health promoter –Khanya programme)

The failure to invest in resources and to provide support for CHWs can limit the extent to which they can foster community level inter-sectoral action. An institutional context that offers support to CHWs can empower them to influence spheres of government, which may otherwise be inaccessible to them and to their clients. As illustrated above, the availability of resources, whether organisational support or practical resources such as transport, gave the CHWs in the Eastern Cape the leverage to foster outreach services that function across sectors.

9.3 Measuring progress

In the Eastern Cape case study, the CHWs reported on the activities and progress for each household on case by case basis. This ensured that the CHW took a holistic approach to meeting a client's needs. In contrast, CHWs in the Gauteng case studies were limited to reporting on the number and type of cases, and the number of houses visited. Given the expectation to meet a specific quota per month, the CHWs were not able to address the multiple needs of their clients which would have required time consuming access to multi-sectoral services. It was apparent that the reporting system was not used to enable the CHWs to understand and internalize the principles of inter-sectoral outreach which go beyond the health paradigm. The value of the reporting system to guide CHWs to incorporate outreach services that employ an inter-sectoral action approach was more evident in the Eden programme, where their reports emphasised what and how a service was adopted for each household and the outcomes thereof.

However, difficulties to ensuring community-level inter-sectoral action extend beyond the micro-level factors, such as the institutional contexts of the organisations, to the macro level factors, such as the various sectors from which clients required services.

9.4 Response from the sectors

With a project manager in the Khanya programme that had the drive and initiative to provide the needed services in the community, one would have assumed that the CHWs would be able to follow through with their work. However, despite the ability to facilitate some local level inter-sectoral outreach services, the project manager, in an attempt to support and assist the CHWs, was constantly faced with poor agency from the different department such as Social services and the Department of Home Affairs. Most clients across all the case studies had complex circumstances which required the attention of higher levels of government in different sectors.

For instance, most of the clients in both cases in Gauteng were either migrants or people who had moved from other provinces to look for employment. The lack of formal documents was a manifestation of the context within which they live and the history of the country:

“We need Home Affairs, which really seems to be challenged when it comes to those people who have a long history and lineage of a lack of legal documents. The representatives come and explain to us why they can’t give the people IDs. They said if they are from Lesotho, they have to have documents from Lesotho but still they can’t give them IDs even if a child was born here...” (KII – Health promoter- Khanya programme)

Many households in these Gauteng case studies were then unable to receive assistance from various departments and in turn, the CHWs were unable to assist either. Attempts to communicate with the respective departments were often met either with promises or by referring them to other individuals:

“We invited The Department of Labour and they came. They then promised that we’ll have an appointment with them and that we’ll visit them. That was it. Now they are impossible to get a hold of. Department of Agriculture, we invited them to our meeting several times. None of them have ever responded or showed up.” (KII – Clinic manager – Khanya programme)

The lack of response from the various sectors compromised the level of trust the community had in the services of the CHWs, who expressed how clients responded with either contempt or doubts about the purpose of their work:

“That patient will wait for that food parcel until next month. We promise patients food parcels and they never arrive. It’s so uncomfortable now. People say we play big and promise things we can’t deliver.” (FGD - Khanya programme)

The extent to which the organisations and the CHWs facilitated community level inter-sectoral action is also dependent on the level of response by the different sectors. Poor responses from

other spheres of government constrained the extent to which the CHWs could assist their clients to access the services. However, what is important to note is that in the Eastern Cape case study, despite poor responses from government departments, they managed to establish good relationships with different sectors because of the hands-on approach of the CHWs. The ability of the CHWs to accompany their clients to the service providers in the various sectors ensured their visibility and familiarity with the people they encountered which enabled them to forge relationships. In addition, the CHWs strengthened relationships and networks at a local level such that they did not necessarily have to deal with the macro level dynamics of the higher spheres of government:

“The team has formed really good relationships with the police, the school principals, with some of the key people in the hospital and people in the clinics, so they have networked. Those people they have a relationship and there are lot of referrals.” (KII - NGO coordinators – Eden programme)

However, a factor that I have referred to earlier seemed to reinforce the Eastern Cape CHWs’ ability to provide services regardless of the poor responses from government sectors. They had the ability to problem-solve. When faced with poor response and service from government, the CHWs had the competence to explore other avenues:

“...there is no response to the client. The CHW will problem-solve and go to wherever they need to go to, to access whatever they need whether it’s grant or ID.” (KII – NGO coordinators – Eden programme)

Self-sufficiency enabled the CHWs to provide services to clients when the departments that were meant to fulfil that role failed to do so.

The findings highlight that in order for CHWs to address the overarching social determinants of ill health, particular enabling factors are necessary. At an organisational level, providing sufficient training, supervision and organisational support in the form of resources such as transport can ensure follow through of their services. At a macro level, a poor level of agency from government sectors contributes to the difficulties that this workforce already experiences in assisting households to access comprehensive outreach services.

Besides the factors discussed above, another element resonated as a contributor to better inter-sectoral outreach services, not only during the participant observations, but also with some of the respondents. An integrated system ensures that clients are able to receive multiple services at the same point service. A coordinated system goes even further by ensuring synergy and organized management for users. Instead, the CHWs and their clients across the case studies navigated a fragmented system.

9.5 Integration and coordination

One of the most prominent factors that accounted for the limited extent of community-level inter-sectoral action across the case studies was the poor integration within and between a range of sectors. Most of the cases that the CHWs dealt with evidently required a diverse range of services from both health and non-health sectors. A single household typically had a client with multi-faceted needs, including adequate housing, frail care, and access to financial grants to cover food and travel to access other services. “*The elderly couple*” in Box 1 and “*The South African immigrant*” in Box 2 are such examples. Most of the respondents from the government departments cited conflicting mandates regarding accountability as one of the constraining factors to inter-sectoral action. The majority indicated that at government level, they were required to achieve specific targets. Most of these targets were specific to the respective

departments and/or sectors and were not coordinated and aligned to other departments that addressed similar or related issues:

“In terms of the extent of coordination amongst all these sectors, that is a challenge. I think the problem is that there is lack of coordination, not only internally but at other levels of government as well. You can go to National and you see that sectors still function as silos. This is the same in the Province. It is difficult to translate coordination to the lower levels if it is not established in the higher level (KII – Gauteng Local government- Department of Health representative)

It was equally expressed that this was more so due to the fact that this policy was enforced and translated from the higher spheres of government:

“I think that coordination can only be achieved if the higher levels are coordinated. If those people that designed the key performance targets for the specific departments ensured that they speak to one another, it would be so much easier to coordinate at the bottom, because the coordination would already have been established and developed at the top.”(KII – Regional Department of Human Development representative – Gauteng Province)

“...Maybe it requires a big drive from the premier’s office (central provincial level of government) to get everybody working together.” (KII – Regional Department of Health representative – Gauteng Province)

The conflicting reporting lines of accountability (in terms of who one reports to) were also perceived to contribute to poor coordination amongst the different sectors. In addition, some of the spheres of government have reportedly adopted a business model in which performance is based on score cards. The conflicting targets and lines of accountability made it even more difficult to foster any collaboration and coordination of services. One respondent explained:

“It is not because people do not want to work in a coordinated manner. The difficulty is that the City (of Johannesburg) works on a score card which is a business model. Each department operates on targets which have to be met. If the target that I have to achieve does not match the one from the department of health in a particular month, it is often difficult to rope that department in because they probably have their own target to meet during the same month. The interesting thing is that because some of our targets tend to be similar, health will organise

themselves and then the other sectors will need to meet the same target during another month. They will be contacting us to join them and by that time, we would have completed the project.” (KII – Department of Human Development representative – Gauteng Province)

The lack of accountability in the spheres of government also affected the ability to communicate with those in higher levels of authority. Vagueness and lack of clarity on who was responsible for a particular service had a notable impact on the ability of the organisations to function and provide services at local level:

“I requested the health promoter to go to Social Services to see the person who is in charge. She could not get the person in charge. She asked for the name and contact numbers and they gave her details of someone else. The person in charge was not known. So we ended up not communicating with anyone. So I don’t even have to explain how CHWs struggle to connect their clients to these departments. We struggle...what more them?” (KII – Clinic manager- Khanya programme)

In addition, some of the participants felt that the lack of clear lines of accountability made it much more difficult to know who to report to or to hold individuals accountable. Some expressed the fact that they were often dealing with faceless people in the various departments:

“We never know who to go to. We don’t even know who to contact so as to hold the people accountable. Who do you complain to when you don’t get responses from these people? We don’t know. People take these positions and promise that they’ll help the community.” (KII - Health promoter – Khanya programme)

The government system of meeting targets and mandates based on priorities that were unaligned to other sectors had an adverse impact on the implementation of mechanisms meant to foster integration and community level inter-sectoral action. Some of the informants were concerned that these tools were misunderstood and not implemented because departments were only

concerned about meeting their targets rather than using the tools to foster integration and inter-sectoral action:

“We have Integrated Development Plans (IDPs) which all departments have to work with and submit, but because it is about meeting targets, each department is just concerned about meeting their targets. People don’t realize that IDPs are a tool to assist departments to work together and identify areas and issues where they should work together, but it is not the case. And because of this, implementation is also a challenge because departments are not focused on how they are going to implement these grand plans which are identified in the IDPs but just on meeting their targets.” (KII – Regional Department of Human Development- Gauteng Province)

Interestingly, attempts to foster inter-sectoral action were often based on specific calendar events such as World AIDS Day or Cancer Awareness Day. However, this was often an ad hoc approach:

“When we had a joint campaign with the Department of Health during Women’s month, it went very well because we had the same Key Performance targets during that month. You did not have to chase anyone for anything, if there was a planning meeting, we were all there. (KII – Regional Department of Human Development- Gauteng Province)

In one case, fostering inter-sectoral action was successful when there was a ‘champion’ who led the process. The individual reportedly offered leadership and took stock of the rest of the sectors:

“I can tell you of a recent case where there was coordination and we managed to achieve some of the deliverables. Last week there was a fire in one of the squatter camps. In such emergency situations, you need most of the sectors. People are without shelter so you need housing to come on board. There are people who are injured during the event, therefore you definitely need the emergency services. You also have people who are on chronic medication, therefore you need the local health facilities to step in. If it was not because there was an active ward councillor in the community, not much would have been achieved.” (KII – Regional Department of Human Development- Gauteng Province)

Moreover, other respondents added that the solution was for the health sector to take on the leadership role in this endeavour:

“We need one lead department to make sure that things DO happen because if you can wait for everybody to do it, nobody will bother. So we are taking responsibility to make sure that, through health, we can bring other sectors in.”(KII -District health representative – Gauteng Province)JK

This lack of coordination manifested in the poor recognition of the complex environment that households have to navigate in their attempts to access multi-faceted services. In most of the cases, clients were required to access different departments to achieve a single purpose such as applying for an identity document. For instance, if a client was from another province, s/he was required to provide proof that s/he was born in the country. Most of the clients across all the case studies did not have birth certificates as proof. They were then required to visit their primary school for a letter stating they attended the school. Most clients, especially in the case studies in Gauteng, had not completed schooling or had never been to school. If they had, they had no means to travel to the schools. For those from another country, the requirements would be even more complex, requiring them to travel back to their country of birth for documents. As result, a household with multiple issues had to follow a lengthy process that required travelling to multiple sectors that were often in different locations.

Furthermore, the geographical area served by local government offices varied from one service to another. Due to the lack of alignment of demarcated areas of jurisdiction, service providers often denied clients and CHWs services with the explanation that a particular department was not responsible for the area that a client resided in. Clients thus went from one office and department to another, often failing to obtain any service at all:

“Our referral system here is just not working well...We don’t know where to refer. One minute, you refer patients to the South Clinic [nearest Community Health Centre in the area...about 21kms]; they say to them ‘No, you have to go to Vereena [about 20kms from Oxford]’ because of this demarcation of services.” (KII - NGO representative – Khanya programme)

Poor coordination and integration amongst the different departments contributed to the difficulties that CHWs experienced in trying to foster outreach services that worked across sectors. However, the more detailed components of all these sectors, such as systemic challenges, posed even more of a challenge to achieving this.

9.6 Nature of relationship with health & non – health sectors

Some of the factors that contributed to limited community level inter-sectoral action were related to broader issues within and between sectors. For instance, in the Gauteng case studies, it emerged that the Department of Social Development decided to remove the social workers in clinics and relocated them to skills centres. This consequently required clients to travel to them, whereas previously, the social workers were an available resource at local clinic. The nature of their work required them to link clients to other sectors. This change in their function, from being service providers closely linked (and placed) to health care services to being separate entities operating as a separate sector, was an indication of the isolated manner in which the different departments function:

“We had a social worker who was based here at the clinic but then she was placed in another office. Right now we don’t know where to send these clients to.” (KII – Clinic representative, Zola programme)

This isolation and compartmentalized nature of operating resulted in departments executing decisions that did not consider the context in which services and clients had to function:

“We usually refer them to social services. It used to be easier before they removed the social worker from the clinic. Now the process takes so long because firstly they have to go to the offices in Roodepoort and the only way they can get there is by walking. The clients delay the process and take long to eventually get there.” (Participant observation – CHW – Zola programme)

Overall, a fragmented and uncoordinated environment, with weak social cohesion and social capital and therefore poor community participation, poses as a significant barrier for CHWs to foster inter-sectoral action outreach services. The outcome in most cases was that a large proportion of clients remained unassisted and unable to navigate the complex system to access basic service.

From the complex needs of the communities in my study, it is evident why community level inter-sectoral action is one of the important mechanisms to support PHC. It acknowledges that health is determined and should be addressed not only by health but by non-health sectors as well. However, a range of factors can compromise the access communities have to health and non-health sectors, as indicated in the findings. In addition, the findings also highlight the glaring absence of an explicit policy that guides or encourages inter-sectoral action, albeit some mechanisms that attempt to incorporate the strategy (such as the IDPs).

9.7 Overall analysis of the findings

The findings highlight the impact that context has on the extent to which CHWs can provide inter-sectoral outreach services, and poverty, as a central theme of the context, determines the extent to which households benefit from CHW services. In addition, the capacity of the organisation to support CHWs is crucial, as are the organisational structures of government that either constrain or enable CHWs to navigate a difficult environment. Furthermore, the context of the communities can also act as a constraining or enabling component. The theories regarding the provision of comprehensive PHC remain relevant, but the findings in this thesis highlight the need to consider the detailed context and micro-realities within which CHWs function. These local and household factors lead to difficult dynamics that are not usually understood or made explicit. Overall these findings highlight the importance of understanding the detailed context to

further understand how to successfully provide inter-sectoral outreach services. This is the major contribution of this research.

The complex environment that is reflected in the findings in this thesis call for CHW programmes that recognise and attempt to deal with these complexities. Furthermore, they show how the ideal roles of CHWs as envisaged in the Alma Ata declaration, require revision. The traditional government-initiated CHW programmes fail to understand these nuances or the need for flexibility in their approach. This is reflected in the findings.

To therefore consolidate the discussion above regarding CHWs and their role in supporting comprehensive PHC, several factors are necessary to achieve the important components of this model (community participation and inter-sectoral action outreach services). These are summarised in Table 10.1 in Chapter 10.

CHAPTER 10 Discussion

The purpose of this study was to examine the implementation of community health worker-provided outreach services by comparing three case studies to identify enabling and constraining factors. The thesis is based on the themes and sub-themes drawn from the literature review and findings in Chapters 5, 6, 7, 8 and 9 that reflect these factors. Furthermore, the study aimed to explore if there were key enabling factors that are necessary for CHWs to provide outreach services aligned to PHC its policies. In this chapter, I reflect on the findings in light of the literature.

Primary health care has been recognised as the key global strategy to address health inequities and achieving optimal health [232]. This approach, since its original inception at the Alma Ata conference in 1978, has centred on key principles that make it a comprehensive way of addressing health. Two of these are central to this study, namely inter-sectoral action for health and community participation. A call for the revitalisation of PHC mostly by civil society and groups such as the People's Health Movement [2, 3] has been met with a myriad of responses by institutions and/or policymakers such as WHO. Most of those responses have been a combination of enquiries and evaluations of the successes and failures of the various PHC approaches. Some have queried the effectiveness of community health workers in supporting the implementation of PHC. The evaluations, conducted globally over the past 30 years, have examined whether the range of PHC approaches have improved health outcomes, particularly in developing countries.

Part of this thesis finds that CHWs are a crucial part of the implementation of comprehensive PHC. The results in Chapters 7, 8 and 9 show that in order for this workforce to add value to this health care model, a number of enabling factors play a contributing role. Some of the key factors

are an organisational context that invests in institutional resources which can provide support to CHWs; community participation is more feasible in communities that are cohesive and have social capital; and community participation is a critical component of effective community level inter-sectoral action. In this chapter, in reflecting on the findings, I summarise the enabling and constraining factors by contextualising them within the broader literature. I also discuss the implications of these factors in light of the revitalisation of PHC in South Africa and internationally.

In addition, I present these factors in the form of five key themes: The first part describes and examines how poverty calls for a desperate need for inter-sectoral outreach services; the second theme discusses how the institutional context of the state can either hinder or enable CHWs; the third part of the chapter explains how organisational contexts can enable or constrain CHWs; the fourth considers if community participation is a critical component for effective community level inter-sectoral action; and the fifth theme explores the value of institutional relationships in comprehensive PHC. As a means of consolidating these key themes, I present a revised conceptual framework (Fig. 10.1), which is a modification of the framework in Chapter 3 (Fig. 2.3). The revised framework highlights the enabling and constraining factors in light of the findings, albeit influenced by the current literature.

10.1 Poverty calls for a desperate need for inter-sectoral outreach services

Key findings

- The primary social determinant of ill health in this study is poverty
- A major city such as Johannesburg struggles to respond to poverty and manifesting health needs due to urbanisation
- The social welfare sector has a key role to play in addressing social determinants in order to address social inequities
- The health sector has a role in guiding and motivating inter-sectoral action to address health inequities. This calls for the strengthening of the health system through PHC.
- The poverty in which CHWs operate undermines the extent to which households benefit from their services

10.1.1 Social factors determine health status

As indicated in Chapter 3, the inequities that continue to exist in South Africa manifest in the social, economic and health realm of society. The health status of South Africans is disproportionately distributed across racial and geographical spheres. Moreover, in spite of this geographical variation, the urban poor demonstrate similar, if not worse, exposure to poor health compared to their rural counterparts, despite the supposed proximity to resources. In the literature reflected in Chapters 2 and 3, I cite how the process of urbanisation limits the poor's access to resources while major cities in my case studies failed to respond to poverty and the manifesting health needs. The case studies in this thesis illustrate this notion.

The findings in this study show that CHWs operate within an environment where households have needs that transcend health and health services. The challenges they encountered in their efforts to support PHC services showed that no single sector, particularly the health sector, could act alone. In the findings, the “*elderly couple*” (Box 1) with their multi-faceted needs illustrates this. In fact, the findings reveal a principle embedded in comprehensive PHC, that the health status of a population is predominantly determined by multiple social factors, more recently

termed the Social Determinants of Health [171]. In other words, a population's broad social conditions determine the extent of its experience of health problems. Some studies have even indicated that the social determinants of health influence how health status is distributed along a socio-economic spectrum, contributing more to health inequalities than those caused by the health system [121, 171]. In my study, it is clear that poor households experience illnesses that are largely attributed to complex social factors relating to economic constraints. To emphasise this notion, a recent study aimed to assess health inequality in South Africa [233]. Aptly enough, it found a strong adverse association between socio-economic status (SES) and ill-health amongst most of the health conditions the authors investigated, as do other international studies [234, 235]. For instance, those of lower SES experienced more disability than wealthier people, while HIV and diarrhoea affected the bottom 40% of the population at 56%, compared to those in the top 40% at 11%. Moreover, as my findings demonstrate, the health care system exacerbates the spread and extent of those health problems as it is unable to ensure that those social factors are addressed. For instance, although part of the health sector, the CHWs in the Gauteng case studies were not able to ensure that their patients were able to access food, adequate sanitation or financial means to enable them to access other health care services.

Poverty is the root of all evil...but policies can be the cause

As described in Chapter 5, all households across the three case studies had a range of needs that required a response from multiple sectors. In this light, I argue that the poverty and other concomitant upstream factors that accompany this context, such as unemployment and lack of access to adequate housing, in these communities demonstrate the urgent need for services that employ an inter-sectoral action approach. In fact, my study goes further to show that indeed poverty has an intricate way of contributing to the poor health outcomes of these communities in that it creates barriers that manifest through people's everyday lives. Households experienced

barriers to access due limited basic resources; however, studies show that social and economic policies exacerbate these barriers. Although not a prominent feature in my findings, it is important to recognise the adverse effect of macro level policies. In other words, policies have the capacity to manifest as the social factors that determine, for example, unemployment and lack of access resources [236]. To a certain extent, though, there were some experiences reflected in the findings that indicated how policies could have an influence at local level. The account of the client on ARVs in the Eastern Cape (Chapter 7) illustrates this. At the time of data collection, the policy stipulated that patients were to collect their medication only at major hospitals rather than clinics. As a result, only those that had the means to travel to the hospitals could access treatment. Even though the policy was revised later on, it is a relevant example of how policies contribute to these social factors that determine health outcomes. In fact, this experience makes Marmot's [236] sentiment even more convincing, that "policies have not been pursued as if they had people's basic needs in mind" [237]. In this particular case, I clarify the good intentions of the policy; the DOH's aim was to ensure that patients received their monthly regimen in accredited health facilities. However, the policy fell short of taking clients' basic needs into account, such as the means to travel for these regular visits to the hospitals. Consequently, Marmot [236] notes further that taking action to address these effects will achieve very little if there is limited understanding of how policies affect health.

In addressing the upstream factors, there is consensus that a health care system itself is a social determinant of health. One that is inadequate, inaccessible and unaffordable has an impact on other social determinants [26, 171]. It therefore follows that due to the combination of barriers experienced by the households in this study, the rationale for ensuring that there are CHWs in poor communities is exactly to ensure that through outreach services they can identify and link ill persons, including those who have other social needs, to formal services. In addition, the

clients can have the opportunity to benefit from their preventative and promotive services, particularly in the context of structural poverty. A health care system that is not able to ensure that other sectors function in an integrated manner to achieve this endeavour can only result in the failures that were experienced in the Gauteng case studies. In fact, in the Commission on Social Determinants of Health's final report [171] on advocacy for the need for universal coverage, it is also states that a health care system that is based on a PHC model focussing on locally related action across the range of social determinants has better health outcomes.

Interestingly, the CHWs in the case study in the Eastern Cape were able to facilitate the integration of the various sectors and circumvent the barriers cited above due to various enabling factors. My study indicates that in order to enable poor communities to benefit from integrated services and to deal with socially determined health problems, it is important to emphasise those social factors as a catalyst to addressing health problems. The Eden programme CHWs harnessed mostly socially based enablers to facilitate inter-sectoral outreach services and therefore address the multifaceted needs of clients. Firstly, they functioned in a cohesive community that had strong social networks, with established collective resources to share. Secondly, they were part of an organisation that had established cooperative relationships with a diverse range of stakeholders. Thirdly, they operated within a supportive organisation that offered an enabling institutional environment through its socially relevant training, supervision and organisational support. However, despite this social approach, Gilson, Doherty et al [26] emphasise that in order to address the health needs of poor communities such as those in informal settlements, in addition to addressing the upstream determinants, one needs to strengthen the health care system. They believe that access to a well-functioning health care system addresses morbidity, which in turn affects development outcomes, as households can pursue and deal with other facets to development and livelihood sustainability such as education and employment.

Understanding of the social factors and how to take action

In view of this, some hold that the health sector should therefore take the lead in advocating and guiding other sectors to deal with the social determinants of ill health. Added to this, the broader literature indicates that inter-sectoral action is more likely to be successfully facilitated if the health sector takes a leading role [26, 130, 142], primarily because it is more likely to understand the nuances of social determinants and how they affect health. Although this notion is not contested, the findings in my study seemed to agree with a more flexible perspective alluded to in Chapter 2: with issues that are beyond the health sector,, it is better for the sectors directly concerned to take the lead in facilitating inter-sectoral action with the guidance of the health sector. For instance, in my study, the CHWs were able to address the social determinants of ill health and facilitate community level inter-sectoral action without much leadership from the health sector. This lesson therefore builds on the view that the principles of comprehensive PHC do not necessarily have to be confined within the health sector and a health care paradigm. It also resonates with the authors [2, 24, 27] referred to in Chapter 2, who believe that the health sector does not have to act alone to foster policies based on social determinants. It is in fact the responsibility of all sectors to incorporate health in their policies, such as in South Australia [143]. My study was a good example of this, showing that the social sector (the Eden programme) played a stronger role at different stages and contexts in poor communities. More importantly, poor communities residing in informal settlements such as those in my study may have dire social needs, rendering it difficult to prioritise health. I reflect on this in Chapter 8 (section 8.3.3), where it is indicated that community members were more inclined to deal and attend meetings on issues such as housing than health services. As indicated in Chapter 2, Russell and Schneider [238] indicate how people living with HIV and AIDS were more concerned with the livelihood and security of their children than medical issues related to HIV.

This was exemplified by the Malaysia national strategy to address the social and environmental determinants of health. Although led by the economic, education and housing sectors, the role of the health sector remained important [131]. In my study, the organisation based more within the social sector than health proved to have the potential to deal with the social factors that impacted on the health of households.

Whose role is it then to lead inter-sectoral action?

Regarding the extent of the role of the health sector versus the non-health sector in facilitating inter-sectoral action, I believe it is important not to lose sight of Adeleye and Ofili's [239] assertion that the health sector is ideally placed to give better insight on how other non-health departments have an impact on health. In a similar vein, the respondents in my study responded favourably to the notion that the health sector has a significant role to play in leading this process because it can inform other sectors on the need for and rationale of inter-sectoral action: "*We need one lead department to make sure that things DO happen...*" (KII - District DOH representative – Gauteng) (Chapter 9, 9.5). The role of the health sector in providing leadership by, for instance, developing enabling mechanisms for inter-sectoral action have been exemplified by various country experiences such as Malaysia and Cuba [142]. In both these countries, the health sector took responsibility for co-ordinating inter-sectoral activities. Similarly, in my study a Department of Health representative narrated how during an emergency due to a fire in a Johannesburg informal settlement, the presence of a "champion" who personally pulled all the relevant sectors together ensured that the problem was dealt with effectively. This example indicates two enabling factors; that inter-sectoral action requires the guidance of the health sector that understands the impact of the social determinants of health and the drivers of health inequity, and a leader to drive the process. Gilson, Doherty, et al. [240] make an important assertion, that inter-sectoral action "requires dynamic leaders who are able to

work across sectors, draw in communities and manage different interests.” This, in my view, should be a guide for government institutions that attempt to improve their capacity. More importantly, because inter-sectoral action requires sectors to adapt the way they engage with one another which requires some changes in respective policies, Kingdon’s theory [241] is relevant for policy change. The author asserts that three primary factors - the problem, the policy and the politics - are required to interact in order to stimulate a window of opportunity for this change to occur [241]. This notion provides a lesson for South Africa. In principle, the problems (health inequity), the policy (PHC) and the politics certainly offer that window of opportunity.

However, the success of the Eden programme in fostering inter-sectoral outreach services indicates that my study leans more towards a more flexible approach with regard to roles of leadership for inter-sectoral action. Despite this perspective, I am not proposing that the role of the social sector in leading inter-sectoral action should supersede that of the health sector. In fact, the findings consolidate the discourse regarding PHC and the social determinants’ approach. They support the view that for one to successfully address health inequity, it is essential to strengthen the health care system through strengthened PHC [2]. In this way other non-health sectors, such as the social sector as reflected in the Eden programme, have room to implement policies that incorporate health related services/interventions (such as food parcels and grants), in an enabling health policy space. It is here that the findings resonate and contribute to the efforts to revitalise PHC in South Africa. To what extent will strengthened PHC enable the health system to respond to non-health sectors in formulating health-related policies and therefore contribute to inter-sectoral action? In my view, this is where the role of central government to ensure “Health in All Policies” (HiAP) [143] is crucial.

This section above is key to the rest of the subsequent discussion in this chapter. It lays out the context within which the CHWs in the study function. More importantly, I use this context to emphasise its central connection to the social factors that determine health. The social and economic poverty that determines factors such as unemployment, social class and socio-economic status, that were explicit in the narratives, had an impact on the psycho-social context, access to resources such as food and adequate housing and the extent of social networks. These factors therefore had an impact on the health status of individuals and households.

The findings represent the typical “vicious circle” in which the social conditions of the communities across the case studies have a direct impact on their health status, hence a weakness in addressing the social determinants that have an impact on health [23]. All of these determinants are aptly reflected in Solar and Irwin’s [25] conceptual framework of the social determinants of health, referred to in Chapter 2. Furthermore, the most prominent social determinant of health in my study that encompasses and manifests in the above-mentioned components is poverty. Consequently, my study affirms the need to address poverty as a determinant of health.

10.2 Government institutional context can enable or constrain CHWs

Key findings

- **Inter-sectoral action should be promoted from central government so that it is a multi-sectoral responsibility**
- **Health in All Policies approach enables government to facilitate inter-sectoral action**
- **Reporting mechanisms can guide and enable CHW to facilitate inter-sectoral action at local level**
- **Inter-sectoral action requires leadership and accountability in all involved institutions**

From this discussion on the context and the need for a social determinant approach to health and therefore inter-sectoral action, it follows that there is a parallel need to understand how to

facilitate this strategy. My findings indicate that the difficulties in facilitating inter-sectoral action at government level were largely due to barriers created by the institutional contexts of government departments. These included issues such as the lack of resources, the lack of leadership, lack of accountability and conflicting mandates. Although from a broader perspective, documented experiences from other studies indicated similar barriers [242, 243]. In this section, I discuss these factors more specifically in relation to the findings in my study and in a context of poverty.

Respondents viewed the lack of integration within and between government sectors as a bureaucratic culture resulting from government departments functioning in silos. My study highlights that this lack of integration at national and provincial levels of government acts as a constraint for those at district and/or local levels of the system to facilitate community level inter-sectoral action. In addition, this weakness in government structures resulted in sectors acting on unaligned priorities and mandates. In relating the urbanisation feature in my study to Harpharm's [27] in Chapter 2, I echo her sentiment that social determinants should be considered as manifesting via multi-sectoral and multi-level determinants. Consequently, these determinants call for governance structures that can deal with this complexity.

Even developed countries that have attempted inter-sectoral action have experienced the lack of integration and therefore the challenge of institutions working individually. In one of Canada's experiences with inter-sectoral action, the implementation of a Quebec Public Health Law encountered difficulties where some sectors were unwilling to work together [242]. The reality is that different government departments have different and conflicting key goals. Gilson, Doherty, et al. [26] additionally note that this conflict is seen when, for instance, departments use their own 'languages' and have department-specific organisational cultures that more often than not

limit communication between sectors. Stronks and Gunning-Schepers [244] aptly explain that “In inter-sectoral action, conflicts between the goal of equality in health and goals in other policy fields, especially economic policies, are...to be expected”. What remains important and relevant for this thesis are the key lessons learned (in Canada) to overcome this constraint. One of them was the health sector’s realisation that inter-sectoral action requires common ground with other sectors by framing issues in ways that related to other sectors [242]. In South Australia, its Health in All Policies approach [143] not only ensured that all non-health sectors engaged in the efforts to address the social determinants of ill health, but that inter-sectoral action was not only the sole responsibility of the health sector. This contrasts with my findings. The respondents in the Gauteng case studies gave examples when the health sector approached other sectors after establishing its mandate and finalising its plans, in the hope that they would collaborate: *“Health will organise themselves and then the other sectors will need to meet the same target during another month. They will be contacting us to join them and by that time, we would have completed the project.”* (KII – Department of Human Development representative – Gauteng). This proves to be the practice in other cases as well. Failure of the health sector to act as a guide to other sectors was expressed at a South African event organised to examine the challenges of implementing an integrated response to HIV/AIDS. One representative pointed that one of the reasons there was poor collaboration amongst the different sectors was because HIV/AIDS was viewed as solely a health issue [245] and hence acted on its own. As indicated in the Canadian experience [242], the inability of the health sector to engage with other sectors in a language that they can relate to often results in poor inter-sectoral action and collaboration. There is therefore a need for common goals or targets. In essence, the evidence reflected in Chapter 2 from South Australia [143] and Canada provide us with a summation of what inter-sectoral action mechanisms are required if to be applied in the context represented by my study. Firstly,

government departments need to address conflicting goals and mandates by seeing health and its determinants as a common issue across department. Secondly, the health sector needs to guide other sectors by using mechanisms that all sectors can understand. Consequently, a key message remains relevant for the findings in my study: That the NGOs and the CHWs, located in the centre, need to be surrounded by a health system, other departments and other stakeholders with common goals. All of these synergies of common goals should be facilitated at government level to benefit the community and households. Moreover, although inter-sectoral action is viewed as a macro-level function, it is evident from the findings in my study that the outreach services of CHWs (in the Eden programme) act across sectors, thereby facilitating community level inter-sectoral action. This is exemplified by the Sonagachi red-light area project (Box 9 in Chapter 2) where sex-workers worked across diverse sectors to address health issues within their community [146]. However, what also appears crucial as an enabling factor for CHWs (alluded to by the respondents) is a government that also functions in an inter-sectoral manner and is therefore able to translate that at community level.

10.2.1 The role of reporting mechanisms in guiding inter-sectoral outreach services

From the discussion above, what remains important to consider is that poor integration between and within spheres of government can affect inter-sectoral action at the community level. Even though not explicitly expressed by the respondents in the case studies, the indicators used in the reporting mechanisms for the CHWs clearly influenced their practice of inter-sectoral outreach services. Reporting mechanisms reflect the scope of work of CHWs as stipulated in the CHW policy. These areas of work could potentially relate to the principles of comprehensive PHC, inter-sectoral action and community participation. My findings indicate that reporting mechanisms can either act as a constraint or an enabler to implementing these core principles. The Gauteng case studies, the Khanya and Zola programmes, illustrated the former. Their

reporting indicators were confined to a health paradigm, requiring them to report the number of households attended to as opposed to the approach or intervention employed in each household. These expectations constrained the CHWs from realising their purpose in the community, which was to enable households to access wider services beyond those of health. Consequently, they could not act as agents that mobilise the community so as to enable it to generate and collectively use its own resources to access those services. The Eden programme illustrated the potential for reporting mechanisms to guide CHWs to incorporate the principle of inter-sectoral action in their services. Here, the CHWs were required to report on the interventions and/or services provided and the outcomes achieved for each household or client attended to. The value of this practice was that the CHWs invested the time and effort to each of their clients and followed them through to their outcome. This process required that they address all aspects of the clients' problems within a household, which often meant referring and engaging with multi-sectoral issues and services, thus facilitating community level inter-sectoral action. Unfortunately, various studies [11, 12, 246] that have evaluated CHW programmes consider reporting mechanisms as only a tool for monitoring and evaluation, which admittedly does assist to monitor the outcome and effectiveness of the interventions. However, this narrow approach only focuses on health outcome rather than other social factors that have an impact on health. My study, however, shows that reporting mechanisms can be used to incorporate the principles of comprehensive PHC to enable community level inter-sectoral action and, more importantly, to facilitate engagement and support.

10.2.2 Lack of institutional accountability can affect inter-sectoral action

The lack of accountability within governmental entities exacerbated poor community level inter-sectoral action. The limited extent to which government departments take responsibility for their respective functions makes it difficult for community-based institutions to demand and hold the

various departments accountable for services. The CHWs across the three case studies often had to deal with unresponsive departments, therefore constraining efforts to facilitate inter-sectoral outreach services. The important lesson from the Canadian experience [130, 242], which was evidently lacking across all the case studies, is that in order to ensure accountability, it is the responsibility of those involved in inter-sectoral initiatives to clarify authority and responsibility. This is often the role of the lead sector [242]. In contrast, some of the respondents in my study indicated that people in government positions change regularly, thus making it difficult to know those responsible. A study on inter-sectoral action in Iran [247] showed that clarity regarding these roles alleviated the negative impact of this endeavour.

The findings in my study clearly echo the discourse regarding inter-sectoral action, that it is difficult. As alluded to earlier in this chapter, my study also surmises that although the health sector has an important role to play in “educating” other sectors on the importance of inter-sectoral action, all relevant sectors are responsible for the strategy and for central government to lead the process through policy. My findings also confirm that a range of enabling factors can contribute to inter-sectoral action. The institutional contexts of government such as leadership, accountability and the extent of integration between and within departments, are contributing factors to its success. Furthermore, the success of inter-sectoral action relies on the relationships between and within different sectors which have different and varying roles to play. The extent of these enabling factors, however, also influences the extent to which NGOs and CHWs can respond to community needs through community level inter-sectoral action.

10.3 The organisational context can enable or constrain CHWs

Key findings:

- The capacity of NGOs to support CHWs to achieve their goals determines the extent to which they provide comprehensive PHC outreach services
- Capacitating mechanisms such as ongoing training, regular supervision that is aligned to inter-sectoral action principles is crucial
- A clear career path for CHWs instils commitment and assists to retain skills in the community
- Providing travel and cell phone allowance provides needed support for CHWs to engage and link clients to multi-sectoral service providers
- Presence and intervention of senior NGO members enable CHWs to negotiate a difficult and subordinating environment

The previous section takes into account the role of the institutional context of government in influencing the capacity of CHWs. The organisational context of the NGOs is as crucial, and this section examines what this entails. CHWs in South Africa generally operate within NGOs which often play the role of the employer. The findings in my study illustrate how the institutional contexts of these organisations determine the extent to which this cadre can negotiate the environment within which it operates. This is particularly at micro level where CHWs deal with the organisational issues but also the issues at community level. The institutional context of an organisation in my study related to a range of key components: training, supervision and general support. It indicates how these factors contribute to the success of CHWs in providing outreach services for clients in their communities.

10.3.1 The nature of training for Community health workers

A range of studies have emphasised the value and importance of training and continuing education, and have illustrated how a lack of this component often acts as a barrier to effective CHW performance of CHWs [34, 35, 37]. My study echoes the recognition that this component contributes to the extent to which CHWs provide effective services and illustrates that training

can capacitate and empower CHWs in various areas. A number of authors concluded that one of the main barriers to care is the poor responsiveness of service providers [26, 248, 249]. The competence of the CHWs in the Eden programme indicated how it enables them to problem-solve and gives them a sense of confidence which allows them to challenge authority on behalf of their clients and the community, thus practicing advocacy. The CHWs from this case study illustrate the value that a trained and knowledgeable CHW has to offer. They are able to function independently and challenge those actors who in normal circumstances are considered the authority and therefore deemed unchallengeable. Even though most CHW programmes vary dramatically on the type, length, depth, and approach to training [32], the Eden programme has its own independent approach which the CHWs viewed as an enabling factor. They are required to progress and complete the initial training as they continue to work and gain experience in the community, thus applying the knowledge received from the training. The training occurred at various stages of the CHWs' career, extensively at entry level and then throughout the transition as they progressed in their work. Few studies have provided guidelines regarding training; however, Curtale, et al. [250] have suggested providing three training days regularly per year as a mechanism to improve the quality of service. Although not similar, the Eden programme provided regular training which was embedded into the supervision sessions.

On the contrary, the CHWs in the Gauteng cases studies only received the initial training provided for one to qualify as a CHW. After the training, they have to rely on the knowledge received from that single learning exposure to function in their environment and provide services to households. This is reportedly the general experience of CHWs in the country. In a mapping exercise of the scope of CHW functions in South Africa, Van Pletzen, Colvin et al. [203] found that there were no continuing education courses of even refresher or skills development courses subsequent to the CHW core training. Consequently, the CHWs in Gauteng showed limited

ability to solve problems, execute alternative solutions for their clients or follow through on their services. Although the ability to conduct this range of functions is certainly not solely determined by the training, the scope of knowledge that training can provide can prepare and enable a CHW to negotiate a difficult environment that often requires some ability to problem-solve and facilitate alternative solutions. This difficult environment was evident in the findings and only the CHWs in the Eastern Cape case study were able to deal with it. Moreover, their level of training was reportedly sufficiently advanced to ensure a tertiary qualification. This clearly is in contrast with the training commonly provided to this workforce. A study in Colombia and Tanzania [35] illustrates that because the skills learned during the training were linked to the communities' health issues, this allowed for a strengthening of the workforce, including connections with the community while also improving their standing as service providers. However, training can also, more often than not, be technical, pedantic and not applicable to the context. Gilson, Walt et al. [251] indicated that prevalent complaints were that the methods were often "too theoretical, too classroom based, and too complicated". A possible reason to regard the Eden programme's training method as an enabling factor was that regular supervision was embedded in it and it was closely related to the context. This rationale relates to the findings in studies by Gilson, Walt et al [37], Robinson and Larsen [35], Kaseje [34] and Walt [13] that for CHWs to be effective, the training has to be regular, continuous and most importantly, relate to the needs of the community.

10.3.2 The nature of supervision for community health workers

The Eastern Cape NGO closely linked the training to its systematic supervision of CHWs to ensure training was regular and facilitated various levels of learning. Firstly, they received training during their contact with clients in the households, in agreement with Robinson and Larsen [35] who assert that training should be conducted in the community. Secondly, training

occurred through peer discussions where the CHWs would offer advice to each other and thirdly, during a more detailed process at regular meetings with supervisors where each individual CHW would discuss each case with their supervisor. This ensured that the knowledge from the training went beyond the technical nature and delved into the contextual aspects of the work. In addition, the supervision in this case study was conducted by the NGO's staff members who were trained in the field, had moved up the ranks and had a better understanding of the nature of the work of CHWs. This is in contrast to most CHW supervision models (not only in South Africa), which often use health facility staff (such as nurses) to supervise. The study by Gilson, Walt et al [37] indicates this limitation, that the staff in the health services tend not to understand the role of the CHWs or their own role in this regard. While the CHWs in the Khanya programme received supervision during regular meetings, this occurred mainly at a general level rather than at a client and context specific level. At ad hoc meetings, there would be discussions regarding a specific household or client. The CHWs in the Zola programme received no supervision. In light of this, the value of supervision reflected the glaring differences between the performance and conduct of the CHWs in the Gauteng case studies and those in the Eastern Cape. The strong level of supervision (in the Eastern Cape case study), which was a continuation of the extensive training, resulted in CHWs that acted beyond their designated roles. Admittedly, this may not have been only due to the training; however, it does appear that due to the content of the training, which incorporates the social factors that CHWs encounter as they consult their clients, the training enabled these CHWs to address issues far better than could the CHWs in Gauteng. Granted, the given context required them to act beyond their traditional roles; however, the training and capacity building efforts enabled them to negotiate the context. Consequently, the Eastern Cape CHWs fulfilled an advocacy role as clearly illustrated in the findings in Chapter 7 (7.2.3 - FGDλ), and the role of a negotiator within the family and with a range of service providers

(Chapter 6 – 6.3.3.2 - FGDβ). CHWs are called to respond to contexts which often means conducting functions that are outside the scope of their work and/or training [203]. These authors add that the reality is that the CHW sector is one in which their roles vary significantly and are not formalised or refined. In my view, this is also largely because of ad hoc, undefined needs of poor communities. The Eastern Cape was able to deal with these ad hoc functions due to two factors. Firstly, the CHWs conducted the ‘additional functions’ as part of the training and the organisation recognised and rewarded these functions. Secondly, these workers had initiative, a sense of self-confidence and through the process of supervision, had witnessed other peers taking the initiative. This is contrary to other NGOs and the experiences of CHWs, where their roles and wider functions are blurred and complex, and yet remain unofficial and unrecognised [203].

An important aspect regarding the value of training, which differentiated the CHWs in the Eastern Cape case study from those in Gauteng, is the structure of the capacity building process. The training aims to facilitate a clear career path for the workers. In this case study there was progression through the ranks. A CHW was required to complete several modules of the course, then progress to practical experience by working in the community, then after measured experience, they could become one of the supervisors and then be a mentor. This clear process instilled commitment to the work and certainly assisted in retaining the skills within the organisation and the community. The general discourse is that CHWs often are motivated to conduct their work because of the knowledge they acquire legitimises their status in the community and also assists them to progress in their careers [13]. However, in most parts of South Africa, career path strategy is reportedly not clear, and strengthening PHC will require much focus in this area. As seen in the Eden programme, a clear career path for CHWs is likely to assist in managing, retaining and developing the skills of a sector that struggles with a high turnover of workers. [32]. Evidence shows that CHWs who receive more extensive standardised

training and certification as a form of furthering their careers provide more effective services [33].

10.3.3 Other support Community health workers need

Along with the technical support such as training and supervision, CHWs require other forms of support that enable them to execute their work at a client and community level. The findings across all the case studies highlighted the value of the availability of transport. Although the general principle is that CHWs provide services in their own communities, often the nature of their work requires that they travel. In areas where households are widely distributed such as that in the Eastern Cape case study, the ability to travel was crucial due to the geographical distribution of the houses. However, this was not only to reach clients for home visits, but as indicated in the findings, also to pay for and accompany their clients to negotiate access to various services on their behalf. Unquestionably, this implies that clients are disempowered such that they are unable to negotiate access for themselves. Unfortunately, my study seems to show power imbalances at play across all the areas, rural and urban. Consequently, although the Gauteng case studies did not have a wide distribution of households, the need for the CHWs to travel with their clients was equally necessary. An organisation able to provide this type of support creates an environment where the CHWs are able to execute their interventions. For instance, due to lack of transport, the CHWs in the Gauteng case studies were often not able to conclude the services provided to the households, and the clients were therefore unable to benefit from those services. The need of clients to access multiple government services that affect their health such as access to food, was often not realised because of lack of transport. Moreover, the CHWs could not address this barrier to complete the service. On the other hand, the CHWs in the Eden programme were able to follow through on the services offered to households because the organisation provided resources such as transport and/or travel allowances to ensure that clients

accessed the referral services. This concurs with other studies [32, 36, 252] where the availability of logistics and infrastructure support, such as drugs, equipment and transport was illustrated as integral to CHWs' effectiveness. In fact, lack of such resources was cited not only to have an impact on the effectiveness of CHW services, but also on the credibility of the CHWs in the community. The findings in my study clearly show that the lack of transport meant that CHWs in the Gauteng case studies were unable to conduct regular visits to households, accompany clients to other referred services to ensure they received attention, and/or facilitate their attendance at clinics. This resulted in a lack of confidence in the CHWs, thus undermining their standing in the community.

In light of this argument, it is also important to note further how the implications of supporting CHWs determine the extent to which they can address the social determinants of ill health within their respective communities and households. In fact, failure to do so is clearly a result of poor implementation of inter-sectoral outreach services, which consequently prevents poor households from benefiting from the CHW efforts to support PHC services. For instance, poor access to food resulted in patients being unable to take their medication (Chapter 7, 7.2.4, KII - Health promoter). Often chronic medicine needs to be taken with food, or results in an increased appetite which led most patients to refuse treatment due to a lack of food. Similar findings are noted in studies in South Africa and internationally [126, 127, 253]. Consequently, the lack of and high cost of transport led most clients to give up and not access treatment or follow up on appointments. This barrier had a more concerning impact on clients with chronic illnesses, who had to conduct repeated visits to health services and had to take medication more frequently. A South African study to examine the experiences of poor households in their attempts to access chronic care showed that the cost burdens for repeated visits to health care services can be significantly high [125]. The effect of the lack of transport for poor households has been

indicated in a series of studies [123, 124, 254, 255]. It certainly remains one of the main barriers that significantly undermine the potential benefits of health care services and, in the case of my study, that of PHC outreach services to poor households. Considering this poor concentration of multiple services in one area or one site, it could follow that the proposed ward-based PHC outreach teams in the envisaged revitalisation of PHC in South Africa could address this deficiency. However, despite the multi-disciplinary make up, it will also be important for the state to consider how households and CHWs will overcome barriers to accessing those services that are beyond the skills of the team. Indeed the team will be able to refer to other services; however, this was the bane of the CHWs' experiences. The CHWs expressed their frustration of not being able to follow through with their referrals because clients were not able to travel to those services (Chapter 7). The implementation of PHC services will indeed have to consider this issue.

Although other studies mentioned above indicate that support provided to CHWs translates into a range of components – technical, logistical and in the form of infrastructure - the findings in my study additionally show the importance of an involved manager or senior member of the organisation to assist CHWs when necessary. This cadre of workers occupies a subordinate position within the health system, which often makes it difficult for them to assert themselves with those in authority in the various sectors, and to negotiate access and/or services for their clients. The findings illustrate how the CHWs in the organisations with managers that could intervene when necessary were often able to follow through on their services compared to those who did not have an authority in the organisation to assist. A study by Parlato and Favin [256] showed how creating a close link between the CHWs and an expert or a person of higher authority raises the status of the health worker. This can ensure that government officials recognise CHWs as legitimate health workers and respond to their requests. The CHWs in the

Khanya and Eden programmes thrived because the presence and intervention of a higher level member of the organisation enabled them to negotiate the context within which they operated. As described in the findings, this included providing effective PHC outreach services to poor and marginalised communities who endure a range of social factors which act as barriers to accessing formal services and contribute to populations' poor health and well-being. Generally, CHWs in South Africa reportedly receives very limited organisational support [203].

My study has highlighted particular organisational factors as enablers for CHWs to function effectively in these contexts. The provision of basic resources such as means to travel and cell phones for direct access to senior support and possible intervention proved to be crucial. As South Africa anticipates strengthening PHC [210, 257] , it is important to consider how the health sector will provide similar support to CHWs as exemplified by the Eden programme.

10.4 Community participation for community level inter-sectoral action

Key findings

- **Well-trained and confident CHWs have the potential to mobilise the community**
- **CHWs with capacity to problem-solve and adapt how they use community structures to facilitate community level inter-sectoral action have the potential to generate and build up social capital**
- **Communities with strong social networks can generate social capital – this enables CHWs to mobilise resources and facilitate inter-sectoral outreach services.**
- **The urbanisation and relocation of those in informal settlements results in the breakdown of established social links and community structures – a constraining environment for CHWs to use community participation for community level inter-sectoral action.**
- **It is possible to facilitate community level inter-sectoral action at the lowest level without skilled capacity in e.g. ward committees – as long as there are strong social networks**

The previous section indicates that despite an enabling organisational environment, other basic components contribute to the extent to which CHWs facilitate effective inter-sectoral outreach services in order to support PHC. The context beyond the institutions is just as important. The involvement of the community can evidently assist CHWs to facilitate effective inter-sectoral outreach services. I expand on this in this section.

This study documents community participation as an enabling factor to successful community level inter-sectoral action. Findings depict how using existing community structures, formal and/or informal, can facilitate this endeavour. In fact, it highlights that CHWs with a good standing in the community have the potential to generate a community response that can assist them to provide and assist households. In addition, in the process of using existing social groups to generate this response, my work also shows that well-trained and confident CHWs have the potential to mobilise communities to respond to their own needs. Examples from programmes in Nepal, Bangladesh and Kenya are exemplary of community responses and the extent of mobilisation [43, 83, 258]. As cited in Chapter 2, all of these programmes managed to address infant, neonatal, under-5 and maternal deaths through the participation of community members via the use of CHWs and participatory action techniques. The process of mobilising communities to identify and solve community problems generated community involvement and contributed to the improvement of health outcomes. The Eastern Cape case study described how the CHWs used community participation structures of local government and the informal social networks in the community to merge services and interventions from existing resources from multiple sectors, including those from the community. The impact of using various community structures to reach out to various sectors is aptly documented in a Zimbabwean study [138]. As a result, the CHWs in this Zimbabwean programme illustrated that communities can use community participation to collectively solve their own problems, as alluded to by other authors [72, 73].

The CHWs in the Eden programme illustrate this in Chapter 8 (8.3) where they mobilise both the formal structures of local government (ward committees) and the community to provide the children of the community with a safe space to play.

10.4.1 Social networks and social capital

The use of community structures in my study highlighted the importance not only of the role of social networks that co-exist between and within government and communities, but also the existence of collective resources within communities that can be drawn from to assist households. Consequently, my study illustrates that social capital can develop from diverse and active social networks, and that both these components can be utilised by communities to support households. This is in line with findings in other research that suggests that communities with strong social networks are more likely to be able to address poverty and other factors that result in vulnerability [87]. More importantly, my study echoes the lesson from various South African micro-credit projects, that while other forms of capital may be scarce, social capital can provide a cushion to vulnerable communities to overcome social and economic barriers [105, 259]. In order to deal with the lack of response and agency from government departments, the CHWs in the Eden programme mobilised community assets. These ranged from neighbours offering to take over guardianship of orphaned children to local government authorities providing shelter for poor families. A prominent feature in the CHWs' ability to mobilise their community was their sense of empowerment and the confidence to utilise the various partnerships. The Eastern Cape CHWs illustrate this in Chapter 8, for example, where they had the confidence to assert themselves with government representatives such as the ward councillor as well as community members in their effort to mobilise resources. Interestingly, the CHWs in this case study were able to initiate new partnerships in accordance with the context and the circumstances, thereby creating new and additional forms of social capital in the community. For instance, in the

example from the Eden programme in Chapter 7 (7.2.3), the CHWs reported the health facility practices around patients' ARV collections to the community newspaper. Potentially, this meant that they created a resource for the community to voice their frustrations when disillusioned with government service providers. This highlights their ability to problem-solve and generate solutions for a diverse range of issues, as illustrated in the findings.

Although in this study empowerment is reflected through the CHWs, it is important to also notice that the manner in which community members contribute their knowledge, resources and time indicates a community sufficiently empowered to challenge its social system. In fact, this relates to Bandura's [81] notion (in Chapter 2) of the extent to which an individual or a group feels that their effort is likely to address the community's problems, that is, one's perception of their control and empowerment within their community [76, 81]. Moreover, community empowerment has emerged as a prominent feature in various experiences of community interventions, where social networks have been used to access existing social capital [51, 259, 260]. In addition, it is important to remember the view that the institutional make-up of small scale community-based projects allow for an organic "unhurried", flexible process of capacity-building which manifests to the wider community as growth and empowerment [10, 50]. It is also now that I reflect on the role of CHWs in the type of community participation that takes place. Among the proposed community participation models, the Eden programme appears to align with the empowerment model where the CHWs used their skills to mobilise the community to take ownership of their decisions around health and other social interventions [54]. The Gauteng case studies, on the other hand, leaned towards the utilitarian model, where the government used the CHWs as community resources to provide services that it should be providing, similar to the resource dependency approach [55]. As South Africa forges ahead with revitalising its PHC and involving CHWs and/or organisations, two aspects have to be kept in

mind. Firstly, the recognition that scaling-up (or interfering) with this nature of community participation in the Eden programme, especially in organisations that are effective, is likely to compromise this empowerment process. Secondly, that in considering the policy regarding CHWs, empowerment of communities adds more value than integrating community participation mechanisms into the health system as an add-on. The latter, as indicated by [55], removes decision-making powers from the community where the aspects such as training and resources remain within the control of government. This was illustrated by the volunteer programme in one of Mexico's states, Oaxaca [55].

Overall, the Eden programme supports Putnam's [95] notion of both bridging and bonding social capital as discussed in Chapter 2. Despite its weaker heterogeneous networks, bridging social capital enables communities to form networks across communities and cultures, thus allowing better access to resources. In addition, the CHWs that generated it hence could practice advocacy for community level change. However, a combination of both is evident in the narrative of Box 8 (Chapter 7: "*Granny, the community and a new home*"). Through their family focussed interventions, where they first attempted to resolve an issue through the family of a client, the CHWs explored any existing family networks and support in their quest to assist an orphaned child. They then consulted the community by requesting a neighbour to take over guardianship of a child in the community. This combination of social capital was echoed in the Cali intervention in Columbia [27].

On the other hand, not all communities have active and effective social networks. My study shows that social networks can flourish in a community with strong social cohesion. The nature of the community in the respective case studies in my study determined the extent of social cohesion, which then established the extent to which the communities mobilised to assist each

other. The less social cohesion, the less the CHWs found space to create, use and mobilise community participation structures. In fact, some authors are of the view that the extent of poverty, unemployment, segregation and the constant episodes of moving and being displaced erodes any possibility of developing social networks [261]. Added to this, conflict, poor leadership and lack of control of resources exacerbates the poor potential for collective involvement [83]. This was certainly the case in the Gauteng communities where similar factors existed, as described in Chapter 5 (5.2.1.1 and 5.2.1.2). Although the community in the Eastern Cape experienced similar poverty and unemployment, the permanence and the presence of sustained generations contributed to the ongoing generation of social networks, which strengthened the extent of social cohesion. In contrast, the communities in the Gauteng case studies comprised residents that moved in at different times, from different parts of the country and other countries and this evidently resulted in weak social networks. Although their basic needs were the same, the fact that they had differing experiences, histories and needs resulted in communities and households with conflicting priorities. The communities in Gauteng found it difficult to function collectively, and efforts to enable them to create and use community participation structures often failed because of this weakness. Weak social networks made it difficult for the communities in these two case studies to mobilise collective resources or social capital to support one another (Chapter 8, 8.2, KII - Health professional, Zola programme). As mentioned in Chapter 2 (Box 5), the Community-Based Nutrition Programme (CBNP) in Kenya [83] illustrates the negative impact that diverse communities of this nature (similar to those in the Gauteng case studies) are likely to have on social cohesion [86]. Weak social capital resulted not only from weak social networks but also from the lack of existing community resources. One factor the Gauteng case studies illustrate is that social networks are difficult to generate in communities that have to endure what King, Samii, et al. [106] refer to as the “non-material

outcomes” of poverty. These are; “powerlessness, the breakdown of social fabric and dependency”, or what Peter Costello termed “non-monetary things such as trust and tolerance” in his address at the Sydney Institute, July 2003 [262]. What illustrated this most clearly was the case of the Gauteng communities. The community served by the Khanya programme consisted of illegal residents who were insecure to join community participation processes. The Zola programme’s community constituted of households from different areas and/or provinces of the country and therefore had conflicting priorities and needs. Discourse regarding social capital alludes to the notion that its nature is influenced by the availability of resources which are generated by social networks [91]. This aspect is relevant because it highlights the importance of empowerment of a community in any intervention to improve people’s ability to access resources through social cohesion. However, in the same light, much of it, as expressed by Beyers, Brown, et al. [261] points to the fact that the richness of social capital results from the quality of social networks. The outcome of such networks is indicated by the existence of mutual trust, cooperation and shared norms [77, 95, 261]. A limited existence of these factors in the Gauteng communities was a constraining environment for the CHWs. A similar experience is documented in a study on a social capital generation intervention in rural South Africa, where community mobilisation activities were poor in areas where there was lack of trust between members [259].

On the contrary, the Eastern Cape case study was exemplary of how, when in an enabling environment, community participation structures and a mobilised community could act as an enabler for CHWs to facilitate community level inter-sectoral action and therefore provide PHC outreach services. Notably, this community was more cohesive than the case studies in Gauteng. This was a community made up of generations of households with a shared history and experience of living through apartheid, and which had retained its cultural principles (such as

language and trust) with regard to collectively attending to each other's needs. As mentioned in Chapter 2, these factors are viewed as key to determining the strength of a community [77]. In addition, it is important to note that the difference in the extent of social capital between the case studies in Gauteng and the Eastern Cape can also be explained by urbanisation where the emergence of informal settlements through the relocation of households results in the breakdown of already fragile social networks and community structures [27, 85]. While the communities in Gauteng had left their cohesive structures in other provinces and/or neighbouring countries to seek employment, those in the more rural Eastern Cape communities continued to maintain the long-standing cohesion, thus nurturing the social capital. In fact, strengthened social networks and shared life experiences have resulted in instances where reciprocity and sharing is viewed as the norm in rural areas [84].

The CHWs in the Eastern Cape case study were often able to mobilise the community through formal community participation structures to advance their work and provide services. Interestingly these formal structures (ward committees) blended very closely with the informal forums (community cultural gatherings). Much of what the CHWs communicated in this case study transpired where the ward counsellor of the area operated between the two spheres of existing forums. For instance, the conversation involving the grandmother and her grandchildren (Chapter 7 - *“Granny, the community...a new home”* (Box 8)) who were assisted to secure a home occurred at an informal community forum, but was led by the ward counsellor, giving this a more formal status. This episode indicates that it is wise to use existing social structures, relationships and support (as opposed to impose) through more formal mechanisms, for instance ward committees [61, 62]. What is clear here is that the CHWs in the Eden programme used the informal networks (the neighbours) and the formal relationships such as the ward councillor. Despite the poor responses from government departments, the CHWs were able to use the social

capital of the community to assist households. This aspect (of social capital) was offered in various forms such as offering guardianship of orphaned children, a responsibility that lies with the social development sector, and identifying land for a homeless family by the community, a responsibility for local government. Interestingly, my study highlights the fact that a community with strong social networks and established social capital can use shared assets and resources to support one another with little or no support from the higher spheres of government.

10.4.2 Formal community participation structures can also act as a hindrance to community participation

The previous section shows how the CHWs from the Eastern Cape managed to cope with limited support from government departments. However, the three case studies in my study show how some of these formal structures can constrain community participation. Despite the presence of ward councillors in the Gauteng case studies, their role as political party representatives compromised their commitment to being community leaders. For instance, the Khanya programme respondents perceived that formal forums such as the ward committee, which are supposed to be led by the ward councillors, were used for political activities by those aligned to the ward councillor's political party as opposed to using them as a platform for general community activities. From the general perception of community members in both Gauteng case studies, it was evident that the fact that ward councillors were political representatives compromised the extent to which they responded to general community needs. Instead, they attended to the needs of those who were members of their political party. The PHC program in Northern Brazil apparently recognised the general impact of the socio-political context since the state retained the central control of the payment and employment of local personnel [147]. This strategy to prevent the local politicians from manipulating the programme emphasises the

challenges experienced by the communities in the Gauteng case studies, where politicians based their decisions regarding addressing community issues on political allegiance.

The ward councillors' conduct in these two Gauteng communities created an environment where community members were suspicious and had limited faith and trust in the formal participation structures established by government. This suspicion and lack of trust gave rise to informal community structures and/or representatives that acted as the voice of those who struggled to access government services. Since these representatives were usually individuals who took matters into their own hands, they often worked in isolation and in an exclusionary fashion rather than in unison with other community structures, rendering conflicting actions and priorities. This development ironically points to the damaging side of social networks and the possible negative implications of social capital [263].

My study indicates that the political position and/or involvement of ward councillors can compromise their role as representatives of community participation structures, such that they fail to act as expected. This phenomenon needs exploration, particularly with regard to district services. However, I do not take for granted the fact that strong social networks can have adverse outcomes which can hinder development. Various scholars acknowledge that networks can also be used to discriminate, exclude and corrupt [263, 264]. Nevertheless, what my study does show, although not explicitly, is that through social ties, communities can generate fertile ground for social mobilisation and this, as Gilson, Doherty, et al. [26] point out, can be linked to ways of holding those in authority, such as ward councillors, more accountable. In addition, the Eastern Cape case study illustrates that with established social capital, there is potential to facilitate inter-sectoral action at the lowest level of communities with little skilled capacity, as found in members in ward committees.

It should also be noted that, although my findings support the role of social capital, I am aware of the contesting discourse [90] regarding its benefit and value as indicated in my discussion on social capital in Chapter 2. Indeed, some argue that social capital or its extent can allow an ineffective state to neglect or abuse poor communities or abdicate its responsibility [90]. In addition, as alluded to in Chapter 2, attempts to generate social capital in communities have to recognise that imposing social dynamics have not received much support and success [61]. It is worth taking note of this in efforts to ‘engineer’ or build social networks as a means of generating community resources. Despite this view, the potential for the existence and viability of social capital in vulnerable poor communities, particularly to contribute to effective implementation of community interventions, cannot be taken lightly.

More importantly, although CHWs are partly meant to facilitate community level inter-sectoral action, I am of the view that it is short-sighted to expect them to implement government interventions in poor communities without acknowledging the factors that constrain these efforts and how different communities have different dynamics.

10.5 The value of institutional relationships in comprehensive primary health care

Key findings

- **Crucial to addressing the social determinants of ill health and health inequities is the strengthening of institutional relationships between multiple stakeholders**
- **The dominating nature of the state compromises NGOs and CHWs ability to provide intended outreach services**
- **CHWs have potential to provide effective PHC outreach services where the state and NGOs are equal partners and NGOs retain their autonomy and flexibility within the relationship**
- **Government that is sensitive to community needs renders it an enabling partner for NGOs**

This study highlights a factor that encompasses all the components discussed in the findings and the section above, which is that institutional relationships are crucial in interventions that aim to

achieve effective comprehensive PHC. The role of the institutional contexts in government, NGOs, and communities directs us towards the importance of establishing and strengthening relationships and partnerships within and between those spaces. In fact, my study illustrates that even though some of the problems that encouraged the drive towards PHC at the Alma – Ata conference have remained relatively similar, it is worthwhile to consider that the context has somehow changed. For instance, the scope and patterns of illness and mortality in developing countries has certainly changed. A good example is how in South Africa, the introduction and wider access to HIV treatment has altered the needs of those who are infected, particularly the poor and women. As a result of the treatment, people are living longer with the disease, and there is now a greater need to access multi-sectoral services (such as housing, clean water, electricity, etc) other than those in the health sector [265]. Furthermore, the global socio-political dynamics notably reflect that poverty and inequity have intensified globally and in South Africa [155, 156, 266]. These dynamics are evident in the findings in my study. I therefore believe that current and modern discourse regarding this area has introduced new approaches or mechanisms to addressing the need for integration such as the ‘joined-up government’ approach [27, 151]. This entails a more integrated engagement between and within government department and sectors. The focus on the need for interconnectedness within the health system and other sectors is potentially a modern way of engaging with the concept of inter-sectoral action because it allows us to understand the complex nature of relationships and characteristics within systems, hence also the discourse regarding ‘systems thinking’ [152]. This notion of institutional relationships is closely linked to what emerged in my study findings on social networks and the challenges experienced in generating collective action and social capital in the Gauteng case studies. In light of the constraints (indicated in the findings) which concur with Beyer, Brown et al [261] that poverty, unemployment and displacement often result in limited trust, poor community

participation and diminished social networks within communities, it is possible to consider that government interventions aiming to achieve community development are more likely to fail. Poor communities have limited assets to share. This offers an environment that is not conducive for community-based approaches for development and improving health and well-being of populations. Therefore, it could be of value to explore innovative ways of enabling poor communities to establish social capital or community assets by utilising government resources that do not consequently render them dependent on the state. The Eastern Cape case study illustrates this, and introduces an interesting aspect which, in my view, was a key contributor to the success of this case study, namely the collaborative relationship between the organisation and the state. I discuss this further in the section below.

10.5.1 The relationship between the state and Non- Government Organisations

One aspect that was apparent between the case studies in Gauteng and the Eastern Cape was the nature of their relationship with the state or the spheres of government. The distance between the two entities determined the nature and the roles that each party adopted within the relationship. Moreover, the status determined the extent to which the organisations provided services to their communities according to their own objectives. To explain this, I will refer to the Eastern Cape case study. The organisation managed to establish a close link with the different levels of government, varying these links according to its needs. For instance, when CHWs were mobilising resources for their clients or household, they facilitated cooperation or a partnership with the local government through the local ward councillor. *“The Granny, the community...a new home”* (Box 8) in Chapter 8 aptly illustrates this point. The CHWs utilised the close relationship they had established with the ward councillor to facilitate the building of a new home for the family. Although the relationship between the local state and the NGO was close, there was a culture of cooperation as opposed to the typical power dynamics that often exist

between these two parties where the state dictates the agenda because it is providing resources. Authors such as Sanyal [112, 113] and Schurman, et al. [267] captured the discourse regarding this phenomenon. The emergence of NGOs as independent agencies that provided services which the state failed to provide generated discourse around the need for NGOs to retain autonomy and independence. It was argued that cooperating with the state, particularly where it provided resources such as funding, often resulted in NGOs being controlled by the political sphere and thus losing their autonomy and legitimacy [112]. The author asserts that government entities are often far removed from the realities of local communities such that their bureaucratic approaches to, for instance, poverty alleviation, often frustrate the non-bureaucratic styles of NGO processes which are community-based. Furthermore, because NGOs are less bureaucratic, they are far more able to respond to needs of the community than the state could [113, 268]. The interaction between the Eden programme and the local government was based on a mutual understanding of roles without the state dictating to the other, a process Sanyal [113] termed “cooperative autonomy”. The organisation fostered a strategic link with the state without having to be constantly dependent on these linkages for all functions. This factor is considered an enabler to the success of an NGO to providing its services. The Self-Employed Women’s Association (SEWA) in India [115, 269] depicts this NGO-State cooperation. Here, the organisation distributed credit to women, while the government purchased products the women made and sold them in government-owned stores. The Eastern Cape case study reinforced the sentiment by Fowler [270] and Cernea [271] that the state and NGOs can work together in a manner that utilises and draws on their respective strengths. In this case study, the state was closer to the community through the local government structures. The councillor was able to provide the resources and the NGO was able to utilise its position within the community to mobilise community members to assist households, without the state exercising its authority on

how the resources would be used and without the councillor compromising the objectives of the organisation.

The Eastern Cape case study drew on the strength of the state on other levels as well. It engaged the state at provincial and/or national levels, for instance when dealing with particular policy issues, as illustrated in Chapter 7, 7.2.3 - FGDλ. In all these examples, the power dynamics between the state and the organisation were based on equal positions of power. Despite the ‘might’ of government, the organisation continued to adhere to its own mandate. In other words, regardless of this close link between the two, the organisation managed to retain its autonomy and independence. In fact, this autonomy and independence was in my view reinforced by the capacity of the organisation to raise its own funds therefore limiting its reliance on government funding. I refer to the report of van Pletzen, et al [203] regarding this dynamic. In it, what is also evident is that the NGO’s role influences the extent to which a CHW can negotiate a complex environment. The authors stress that one key component that cushions this workforce to deal with their contexts is the capacity and power of the NGO. That is, “its ability to raise funds and disburse stipends regularly, and its willingness to mediate relationships with formal sector providers, and provide support systems, debriefing opportunities, training and career advancement” [272]. The impact of the poor capacity to raise funds is illustrated by the Gauteng case studies which I discuss further in this section. The Eastern Cape case study was able to ensure that the state valued its view and recognised it as a partner for fostering a cooperative relationship. Werner [273] and Sanyal [113] consider these aspects as important elements that facilitate an effective relationship between the two parties. Moreover, when an NGO shows its added value and its openness to making a difference as opposed to the resistant and confrontational manner that has often been the nature of such agencies, it provides an opportunity to facilitate this cooperation [270]. The fact that the CHWs were adding value via

the programme and the *Safe Parks* to the community might also have enhanced the relationship between the Eastern Cape case study and government.

On the contrary, the case studies in Gauteng illustrated that the nature of the institutional linkages between the state and the NGOs could also have a negative effect, particularly on the NGOs. The Gauteng case studies lacked the institutional capacity to interact with the state at an equal level, particularly so for the Zola programme because it existed ‘within’ the state, proving to be a compromising position to occupy. Moreover, this was exacerbated by the wide distance within which the state interacted with the community. As described in Chapter 6, in reality, the Gauteng programmes only interacted with the state during the months they submitted the reporting forms. The organisations therefore interacted with a government that had a limited perspective of the community context. The tenuous link between the state and the Gauteng case studies resulted in organisations that merely complied with the state’s bureaucratic procedures, thus affecting the nature of the CHWs’ services. As captured in Chapter 6, both organisations had to comply with a quota-specific reporting mechanism. Consequently, the eventual focus of the CHWs was to ensure that they honoured the stipulated number of cases consulted during the month rather than their core function, which was to deal with the type of cases seen and therefore the interventions implemented. The NGOs’ dependence on the state compromised the CHWs’ autonomy to focus on the specialised needs of their clients, in fear of not meeting the demands of the state. The weakened position of the NGOs to exercise their independence and legitimacy alludes to the ‘usual’ poor institutional capacity that Lillehammer [274] refers to. The author mentions that NGOs often tend to have poor capacity and occupy a weakened position in relation to actors such as the state. She adds that this weakened status means that they lack the power and the skills to negotiate, and also do not have the appropriate systems to interact with government institutions. This indicates the reality of the lack of adequate systems that enable NGO to access

the state in a non-compromising and non-bureaucratic manner [274]. Similarly, the Gauteng case studies, particularly the Zola programme, lacked this institutional capacity in various ways. Firstly, the poor leadership and skills to engage with the state forced them to play a subordinate role, abiding by government's demands, rather than playing a cooperative role. Secondly, their weak financial independence fostered a submissive position where the organisations were obliged to render activities that were dictated by the state, for instance via the reporting mechanisms.

It is important to recognise the existence of power dynamics between the state and NGOs and how this can influence the way in which NGOs function on the ground. The dependent status of the Gauteng case studies illustrates this point. Their obligation to the Provincial Department of Health was to ensure that they fulfilled the required quota of household visits each month, which superseded their core objectives of providing care and information, respectively. Admittedly, it is crucial to monitor the work that the CHWs provide, particularly to assess the extent to which they reach those households that actually need assistance. Interestingly, the Eden programme monitored this by ensuring that the CHWs covered the required needs of a household and ensured that they resolve the issue over a particular period: *"...As CHWs, we have got a boundary. Our work is bound. You cannot work in the family for a long time."* (FGD cited in Box 8, Chapter 7). This also ensured that there is follow through and that they move on to other households.

Instead, the CHWs in Gauteng acted as the "lackeys" of the state rather than the "liberator" of their communities as referred and discussed in Chapter 2. The weakened position of the Gauteng case studies reduced their flexibility to determine the depth at which they interacted with government whereas, the Eastern Cape case study's independence enabled the organisation to

determine the nature of the relationship, including the ability to avoid the power the state could impose over it. Consequently, the CHWs in this case study could exercise their roles as advocates of their community, while cooperating with the state to draw from its resources. The relationship between the two parties was close enough to ensure consensus and cooperation, but not to allow its co-option by the state.

In light of the discourse regarding the re-engineering of PHC in South Africa, the current status of the relationships between the state and NGOs and/or the CHWs will determine the role that they occupy in the implementation of PHC. Important questions then are: Will NGOs and/or CHWs be co-opted as civil servants and therefore implement government policy, thus conceding their independence or will they act as independent equal partners in the endeavour to strengthen PHC in South Africa? Which of these arrangements will work best in the effort to achieve this policy plan?

Furthermore, the data in my study provides an opportunity to inquire what the role of CHWs is likely to be in the process of revitalising PHC of the country, given the current discourse regarding the policy and the approach. The CHWs in the Eden programme employed an advocacy role, which often allowed them to challenge the policies of the state that they deemed to disadvantage their clients. Their role extended beyond that of a service provider to that of “liberators” [273] of their community. The nature of the organisation’s relationship with the state enabled cooperation as equal partners while retaining an advocacy role to challenge and interrogate government policy, but also acting with government to provide services to its communities (Chapter 7 – 7.2.3 FGDλ). The Gauteng case studies struggled to play a similar role. Their dependence on the state rendered the organisations as its patrons, mostly to provide services according to the government’s objectives rather than their own, and “lackeys” [273] of

the state. Their weak autonomy and independence placed them in a compromised position whereby they were unable to challenge or question state policies in meeting their core objectives or those that disadvantaged their clients (Chapter 7 – 7.2.5 – FGD[∞], Khanya programme). They were therefore unable to act as advocates compared to their counterparts in the Eden programme. The role of the CHWs clearly needs to be one where they represent the community to government. The findings in this thesis indicate that the Eastern Cape case study's independence and its role as a legitimate representative of the community reinforces the importance of a bottom-up approach coexisting with a top-down approach. More specifically, the findings resonate with Sanyal's [112] sentiment that as history has proven, the state cannot implement community-based policies without engaging with community-based agencies, just as community-based initiatives cannot sustain without the involvement of government. Both have strengths to offer. It therefore follows that in the discourse regarding the revitalisation of PHC and the involvement of CHWs in the policy in South Africa, it will be important to consider how communities and NGOs will be involved in the process. Will they have the policy space to function in a way that ensures that their relationship with the state is one that facilitates effective bottom-up and top-down approaches within the relationship? In addition, there will be a need to interrogate the implications of neglecting the role of NGOs to facilitate community involvement that can potentially ensure mobilisation in communities on the one hand, and on the other community level inter-sectoral action. The weakened role of NGOs as equal partners in the implementation of PHC outreach services can affect the ability CHWs to draw in the services of different stakeholders that have the potential to ensure a comprehensive approach.

Despite the fact that this thesis shows the potential value that NGOs can add in the strengthening of PHC, I do note that in South Africa, NGOs in this CHW sector are generally small, with poor management systems. Fragmentation results in the duplication of services that, in some cases, are

poorly aligned to national priorities. However, given that local government services are weak, the Eden programme's services provide not only important relief to the communities it serves, but the organisation provides a valuable example of better practice in the management of CHW programmes.

This thesis has illustrated through the Eastern Cape case study that CHWs have the potential to thrive when they can use a diverse range of institutional partnerships. In this way, Evans [275] and Pronyk, Harpham, et al [259] pronounce that this allows the potential to enhance social capital, but also, in my view, to strengthen their capacity to be equal key players to implement comprehensive community-based outreach services. This finding also highlights the fact that the ability of CHWs to provide effective PHC outreach services relies on relationships, formal and/or informal. Moreover, the nature of these relationships can determine the extent to which they function effectively to support PHC implementation.

Consequently, the findings from my study elicit an important enquiry, particularly in light of the aforementioned mechanisms and concepts such as joined-up government and systems thinking. What type of institutional context is necessary to ensure that the relationship between various stakeholders, such as the state and NGOs, is effective and therefore drives comprehensive PHC? The discussion above has indicated that there needs to be a type of “cooperative autonomy” [113], where parties draw from each other's strengths. For the purpose of the revitalisation of PHC in South Africa, it is important to examine how to establish this. The Eastern Cape case study provides lessons to learn.

In summary, the table below (Table 10.1) provides a summary of the factors that acted as enablers to the CHWs' outreach PHC services, based on the findings from one of the case studies

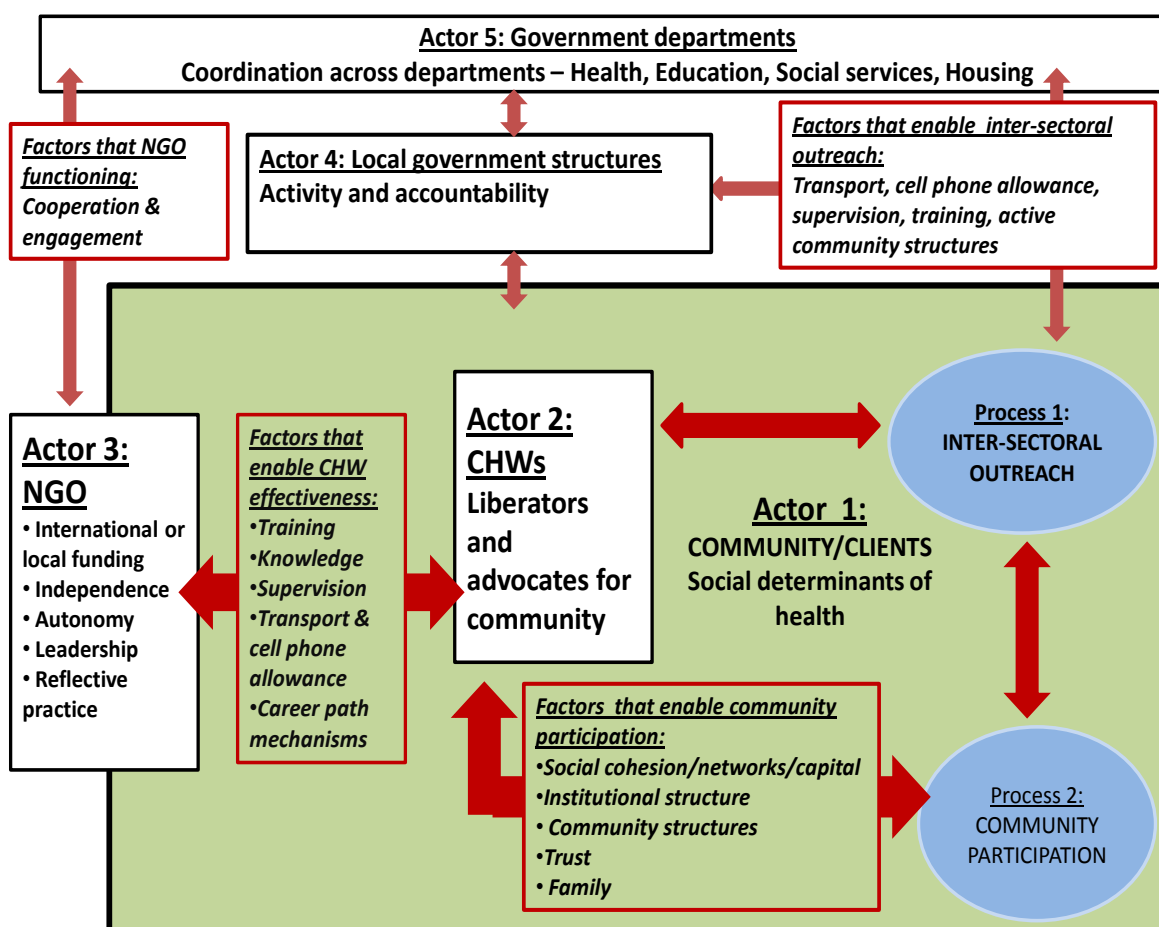
(Eden programme). What remains important is that for services at the micro-level to be effective, the other levels at macro level also need to be effective.

Table 10.1: Key factors for comprehensive PHC – Inter-sectoral action & community participation

INTER-SECTORAL ACTION AT MICRO LEVEL	
Organisational autonomy from the state	➤ Flexibility ➤ Decision-making independence ➤ Retaining of legitimacy in the community
Organisational capacity to support CHWs	➤ Sufficient funding
	➤ Managerial support when dealing with higher levels of government
	➤ Quality and sufficient training – updating of information and knowledge relevant to the work and community needs
	➤ Quality supervision – on-site and in-service training
	➤ Providing stipends to support clients (travel, airtime)
	➤ Resources such as modes of communication
	➤ Reporting indicators related to inter-sectoral outreach services
Strong social cohesion	➤ Strong sense of community
	➤ Nurturing of social capital to draw from
Efficient community structures (formal and informal)	➤ Extent of unity with the structures
	➤ Active and politically unaffiliated ward councillors
Support to local structures	➤ Skills , infrastructure
INTER-SECTORAL ACTION AT MACRO LEVEL	
Integration and coordination -	➤ Effective coordination and communication between and within ➤ Aligned management (and reporting) structures
Accountability	➤ A specific individual to hold accountable
A champion of the cause	➤ A specific individual to lead inter-sectoral action processes
Sector leadership	➤ A particular sector to lead inter-sectoral action efforts according to the specific endeavour.

10.6 The conceptual framework in light of the findings

Figure 10.1 Revised conceptual framework – enabling factors for community level inter-sector action and community participation



Contrary to the initial conceptual framework developed at the outset of this thesis in figure 2.3, the findings in this study confirm that factors beyond the mere existence of the various entities (such as government departments, NGOs and the community (that are depicted in the framework) determine the ability of NGOs and CHWs to provide effective outreach PHC services, and for CHWs to negotiate a complex context. The adapted framework (Fig.10.1) shows that the nature of the relationships between the NGOs and the stakeholders can provide an

enabling environment for CHWs. The framework indicates that even though an NGO [Actor 3] may have a close relationship with the state [Actor 5] through its various organs, its independence and extent of autonomy ensure its ability to remain self-sufficient and to become an active and equal partner that fosters a cooperative relationship. It recognises that primarily international funding is an important institutional component that contributes to an organisation's autonomy. This level of independence allows an organisation to offer institutional support that is adapted to the CHWs and the community's contextual needs, such a leadership and reflective practice as CHWs conduct their work. An NGO's autonomous status allows flexible engagement with the state, without allowing the state to dominate and dictate its agenda, thus maintaining its legitimacy in the community. The framework also illustrates that the relationship and distance between the state and the community [Actor 4] needs to be active and close enough to ensure that government (for instance, the ward councillors and the ward committees) is sensitive to community needs and therefore can provide support and resources accordingly. The framework confirms that NGOs require a range of strong links and interactions amongst various components to facilitate community level inter-sectoral action and provide outreach services to address the social determinants of ill health: An NGO needs the capacity to provide intensive organisational support to CHWs. This support should include the following components:

- Leadership provided through mentoring. As is evident in the findings, this nurtures independent and confident CHWs that are able to negotiate the context in which they work.
- Reflective practice in the training and supervision for enabling CHWs to provide services that are relative to the community's needs.
- Provision of resources such as transport and mobile phones for enabling CHWs to access and mobilise multi-sectoral stakeholders, and facilitate inter-sectoral outreach services. In

addition, it enables them to follow through with their services by not abandoning clients to negotiate with government officials.

- A career path that ensures job-satisfaction and retention of CHWs in the NGO.

Consequently, this level of support allows CHWs [Actor 2] that are equipped to act as advocates and “liberators” in their community. The CHWs can be effective within a community that has tangible social networks, which strengthens social cohesion and social capital. This includes the institutional (organisational) context within which the CHWs function and its capacity to support them, the viability and capacity of community structures, the extent of trust in the community and the contribution of families in working with the CHWs to assist household members. These factors foster strong community participation [Process 2], which the CHWs can use to foster coordinated efforts from a range of sectors to address the range of needs of communities, hence facilitating community level inter-sectoral action [Process 1]. However, what is crucial in this interaction is the level of coordination that exists across the different departments in government [Actor 5]. As illustrated by the Eastern Cape case study, although based in a rural community often known to be under-resourced, the CHWs fostered relationships with diverse people and stakeholders in the community, hence contributing to the successful inter-sectoral outreach services and allowing them to address the social determinants of health that evidently had an impact on the central focus of the CHWs; the community and/or clients [Actor 1].

These enabling factors depicted in this framework reflect the factors that were active in the Eastern Cape case study, and comparatively that were lacking in the Gauteng cases studies. As a result, the Eastern Cape case study provides a framework of factors that are necessary for CHWs to provide outreach PHC services.

This framework contributes to the discourse to revitalise PHC in South Africa, and allows me to interrogate how the South African government envisages the role of NGOs and CHWs. In light of the enabling factors that have been reflected in the framework, the planning and discourse regarding PHC will have to consider a range of factors. Firstly, NGOs have played a historical role in the management of CHWs. My case studies illustrate the extent to which they have provided supportive and enabling organisational contexts for CHWs, which differs widely from one NGO to another. It will therefore be important to consider the role of NGOs in the management of CHWs. In addition, it will also be important to consider whether the varied capacity to provide the support and management will solely be the responsibility of the NGOs or whether the state will play a role. Whether it is the former or the latter, government will have consider devising mechanisms to offer support to those NGOs with poor capacity to provide enabling organisational support for CHWs. Furthermore, the Eastern Cape case study has revealed much about the effective institutional mechanisms required to co-ordinate an inter-sectoral response to poor communities. Secondly, and in addition to required institutional support, it was evident in my study that although CHWs operate in their own communities where they reside, in order to facilitate inter-sectoral outreach services and to support their clients, they still need to travel to the stakeholders to whom they refer clients. The South African government will need to consider how and whether it will be able to provide such resources as highlighted in the Eden programme. These resources are particularly crucial in geographical environments that are typical of this case study, where widely dispersed households require extensive travelling. Lack of transport would reduce the extent of coverage of households. This was the finding in the Khanya programme, where CHWs were unable to access households in the farm areas because of their distance. Thirdly, depending on the nature of the relationship between the state and the NGOs and in light of the findings from this study, both parties will need to consider how to

ensure that NGOs develop and retain their level of independence and autonomy to exercise their mandate without state interference. Fourthly, the findings in my study indicate that implementing community-based policies and services in poor communities with scarce resources, poor social cohesion and therefore lack social capital makes for a context in which CHWs find it difficult to support those policies. My study indicates that a community lacking these components renders CHWs with poor capacity to facilitate community level inter-sectoral action and therefore provide holistic outreach services. On this basis, to what extent will the state assist poor communities to strengthen the social capital in order to develop social networks and improve community participation in the effort to strengthen PHC? Moreover, how will it utilise the CHW workforce to play a role in addressing the social factors that have an obvious impact on the health status of communities, as the CHWs in the Eastern Cape case study have illustrated?

The initial conceptual framework (Fig 2.3) in my study indicates that effective PHC outreach services require the involvement of multiple institutions and/or role players. However, the findings highlight the weakness of this framework in that it does not reflect how these role players impact on the CHWs and NGOs in their effort to provide services. The current framework (Fig 10.1) illustrates that key factors enable and/or constrain CHWs to provide PHC outreach services. Emerging from the findings, it recognises that CHWs that function in an NGO environment that is obligated to government and unsupportive, makes it extremely difficult for them to engage with the community and with the various institutions that function within that space. Poor integration within government which translates to the local context, and poor support from the NGOs results in poor contribution to PHC. The conceptual framework in Fig. 10.1 is a realistic reflection of the lessons that the Eastern Case study provided in its effort to provide PHC outreach services and facilitate community level inter-sectoral action and community participation.

10.7 Study limitations

Because of the constraints regarding securing data from the users of the CHW services, I based the study on the views of the service providers, which limits the understanding of the programmes' weaknesses from the users' perspectives. It also limits those who develop community-based services to interventions that are based on service-provider perceptions regarding what poor households require in terms of services. This study provides lessons learned from a single successful case study, which limits our knowledge of factors that facilitated community level inter-sectoral action. A range of successful models would have provided a more comprehensive understanding. Furthermore, the study would have been stronger had I selected a well-functioning urban case study in order to maintain the similar contexts, for a better comparative analysis. The choice of a very different contextual setting of the rural case study may have distracted the strong features of urban poverty. In addition, presenting the Eden programme as a 'good example' without more reflection on aspects of the organisation that may have not worked well may make the case of a well-functioning rural organisation unconvincing. It is important to mention that I referred to other evaluations of the organisation's model and they do not refer or focus on the weaknesses or challenges, which may have been present. It may also be that I selected an organisation that functions well or that the time spent collecting data in this case study was not sufficient enough for me to identify the weaknesses.

In the selection of the case studies, I should have, in theory, returned to the database of the NGOs in Gauteng. However, I chose to select case studies that met the criteria but also because they were based where there were established trusting relationships and previous knowledge that they would be useful.

10.8 Study strengths

Although many studies have assessed the nature of CHW programmes, this thesis has adopted more in-depth method to gain a deeper understanding of CHWs' experiences in their pursuit to ensure that communities have access to a range of services. Beyond understanding the technical aspects of CHW programmes, this thesis has attempted to examine the components that enable CHWs to navigate poor communities with complex health and social problems through in-depth qualitative methods.

Furthermore, this thesis has managed to dissect the finer components that potentially contribute to the ability of CHWs to negotiate the difficult circumstances faced by poor households. It motivates that to strengthen of the capacity of CHWs in the health system, it is crucial for those in authority to prioritise their training, their supervision and the level of institutional support provided. The study further asserts that poor communities, where CHWs often have to provide their services, need other multifaceted development services which will enable CHWs to provide more effective services to improve the health and wellbeing of marginalised communities. Furthermore, the study indicates that while inter-sectoral action is regarded as a macro level function, the Eastern Cape case study shows that CHWs provide services that work across sectors while facilitating inter-sectoral action through outreach services at the community level. The broader literature does not consider this dynamic. As South Africa pursues its implementation of PHC, the study explains that it is important to consider the role of CHWs in a currently complex policy environment. The lessons in this thesis offer some areas to consider.

CHAPTER 11 Conclusions, recommendations and further research

11.1 Conclusions and recommendations

This study aimed to examine the extent to which CHWs contribute to comprehensive PHC through community participation and community level inter-sectoral action, and to explore the factors that enable and constrain them in achieving this. Table 10.1 illustrates the factors that were enablers to providing PHC outreach services, based on the findings from one of the case studies (the Eden programme). My study indicates that CHWs provide services in communities that live in poverty and therefore face multiple problems that contribute to ill health. This study emphasises what literature has been documenting for many years: these health problems, commonly found in poor communities, are a manifestation of the social factors within the environment. It further adds to the discourse that the health sector cannot address these problems on its own. The stories from the households illustrate that a social determinants approach is required to address the social determinants of health and health inequities, hence the importance of inter-sectoral action. The community context documented in this thesis has significant implications not only for policies that relate to PHC and CHWs, but also in terms of the macro context. Poverty and unemployment exacerbates vulnerability to various social factors. The experiences of households in this thesis illustrate the various barriers to accessing services. There is a range of research [276-278] that has explored the constraints to implementing pro – poor policies such as social security mechanisms. Despite this, there is clearly a need for more in-depth methods, similar to those used in this study, which can explain how and why households continue to face significant challenges in benefiting from those policies. Further research in this area of work needs to focus more on the contextual factors that make the provision of PHC

outreach services all the more difficult. Research that examines the micro-realities of vulnerable communities can play a role in providing a better understanding of how this context affects implementation of PHC services. As captured in the thesis, it is clear that most of the difficulties that are experienced by the CHWs is partly due to the failure of the state to deal with the complexities that exist in poor communities. In addition, there is a fundamental difference between the roles of CHWs in outreach programmes that have been conceptualised by government and those that were envisaged in the Alma Ata declaration. In the process of trying to think about the role of CHWs in supporting the implementation of comprehensive PHC and its revitalisation, it is important to have a better understanding of these shifts in roles and objectives. The role of research is therefore to provide studies that explore and examine the nuances that are manifested by complex contexts, such as those found in poor communities in the thesis. The research can therefore provide lessons on how governments can navigate these nuances through the use of flexible strategies such as those exemplified by one of the case studies (the Eden programme). Research should explore CHW programmes that indicate ways in which government can enable CHWs to provide outreach services - that adapt to the needs of vulnerable communities through flexible approaches, potentially to inform CHW/PHC policy so that it is relevant to the context.

The study goes further to indicate that the institutional contexts of both government and the NGOs (that employ CHWs) are important in determining the extent to which they provide effective services. I opine that government institutions that have poor integration, conflicting mandates and little accountability result in the transferral of those weaknesses to the local level. I expand by illustrating that the role of central government is crucial for harnessing inter-sectoral action across relevant sectors. 'Health in All Policies' enforced across sectors alleviates the traditional notion and burden that inter-sectoral action, a complex strategy, is the primary role of

the health sector. A practical example of how government could incorporate inter-sectoral action principles in all sectors is, for instance, in the reporting mechanisms at all levels (for example, government departments and NGOs). The Eastern Cape case study exemplified this by including inter-sectoral action in their reporting systems and in the training and supervision processes. My study also demonstrates the value of NGOs in supporting CHWs to function in a complex environment. I found that ongoing training and supervision that incorporates the principles of inter-sectoral action empowers CHWs to execute their mandate of providing comprehensive services. I also highlighted the importance of NGOs in providing basic resources such as transport and cell phone allowance, which enable CHWs to travel to and accompany their clients to referred services. This allows them the opportunity to negotiate and ensure that disempowered clients access the intended services and enables them to follow through on their own services to households.

In light of the South African Department of Health's plan to revitalise PHC and its envisaged aspiration to absorb CHWs into the health system, it is important to query the sector's capacity to offer sufficient institutional support to these workers, as shown in the Eastern Cape case study. These findings call for more evidence-based interventions to learn how to strengthen institutional contexts both in government and in community-based organisations.

The study also shows that in order for CHWs to advance their efforts of community level inter-sectoral action, they require a community with strong social ties and effective social networks. However, this assertion also indicates that these two aspects rely on the extent of social capital. The Eastern Cape case study illustrated that it is possible to have inter-sectoral action functioning in a community with diverse range community structures, formal and informal. In contrast, we see from the Gauteng case studies that urbanisation and increased informal settlements in major

cities and consequent relocation by municipalities has affected the established social links and community structures. Poor communities with limited resources to share have poor social networks and pressing priorities that make it difficult to participate. As a result, the CHWs in both these case studies struggled to use community participation structures to facilitate community level inter-sectoral action. Consequently, the findings highlight a strong need for government to explore community development interventions that incorporate mechanisms for improving the socio-economic status of poor communities. These could include micro-credit schemes which South African projects demonstrated have potential to improve social capital in marginalised communities [259, 279].

Furthermore, my study emphasises the importance of institutional relationships, including the nature of such relationships in implementing community-based interventions in poor communities. An NGO's institutional context influences how it relates to the state. The more independent and self-sufficient it is, the more it is able to retain its autonomy, as seen in the Eden programme. Likewise, the distance (gap) between the state and NGOs (including the community) can influence how NGOs and CHWs function at local level. The Eastern Cape case study illustrated that an independent NGO can determine how close its relationship with government can be while avoiding the disempowering nature of government. If PHC is to achieve its goals of addressing health inequities in South Africa, the role of NGOs remains crucial. An important question emerges from these findings: what will be the nature of the relationship between NGOs and how will the state ensure that it does not have an impact on the intended mandate of community-based interventions?

In summary (Table 10.1), this study indicates that comprehensive PHC requires strong NGO institutional capacity, firstly, to offer institutional support to CHWs to enable them to negotiate

the environments and secondly, to establish and sustain autonomous relationships within, across and between sectors and other stakeholders. My study indicates that to address the social determinants of health, we need an approach that takes into cognisance the social factors that contribute to health problems. While my study acknowledges the role of the health sector in motivating and guiding other sectors to appreciate the importance of inter-sectoral action, it highlights the greater need for a ‘sector-wide’ approach of central government, as seen in South Australia regarding HiAPs [143].

In closing, I quote from the Commission on Social Determinants of Health: *“Where systematic differences in health are judged to be avoidable by reasonable action they are, quite simply, unfair. Putting right these inequities – the huge and remediable differences in health between and within countries – is a matter of social justice...Social injustice is killing people on a grand scale.”*[171]

This quote highlights that despite the efforts of CHWs to provide holistic outreach services, the scope of their impact will be limited by this broader context within which they work. Furthermore, it captures the essence of this thesis which is that we may be dealing with local level issues and complexities, but there are underlying macro-level factors of inequity between the rich developed countries and those that are poor.

11.2 Future research

This study has shown that one of the ways to learn about CHW programmes and the health care models they are expected to deliver is to adopt a more in-depth approach, to understand the experiences of CHWs and those who receive the services. Despite this level of depth, there is a crucial need for more in-depth research regarding the experience of the users of CHW services.

In fact, there is already other research which is exploring a broader range of CHW initiatives which can also be taken further. For instance, there are currently various studies taking place in the pilot sites to evaluate PHC outreach teams in which CHWs are central. The CHW research studies or assessments could be extended beyond the life of the pilot site evaluations.

Another area requiring further research is the exploration of mechanisms that address the social determinants of ill health in a more multi-faceted and integrated approach, such as Health in All Policies. A detailed analysis is needed of the implementation failures of various policies (as documented in this thesis) meant to address the factors that render poor households vulnerable. As many countries continue to explore ways of providing effective outreach services, it would also be useful to examine mechanisms of ensuring the independence and decision-making space of CHWs and /or NGOs as they work within or in partnership with the state. As shown in my study, independence enables them to act as advocates of the community who work as equal partners of the state. Currently in South Africa, the autonomy of community-based structures remains unclear and unexplored.

My study confirms that the capacity of NGOs to provide institutional support is crucial for CHWs to function effectively. Research is necessary on how to equip NGOs with the skills to utilise the resources for supporting CHWs to function in a complex context. Factors such as adequate training, supervision, transport are neglected support mechanisms. The extent and ways of facilitating these support strategies need further investigation.

As proven in the findings, weak functioning at the macro-level makes it difficult to ensure effectiveness at the micro-level. Further research is necessary to examine ways to equip government institutions and sectors to function in an integrated and coordinated manner, particularly for effective inter-sectoral action. Other studies have attempted to explore this

aspect, however, these mostly targeted macro level entities. Research that explores strategies for coordinated government functions should explore this in unison with the micro level. Research at the district /local level has the potential to identify useful lessons. What is important, as alluded to in the discussion, is that community level outreach services need an effective macro level government to function effectively across sectors.

Finally, the study recommends that community-based services that aim to address the social determinants of ill health such as comprehensive PHC should explore ways of incorporating mechanisms to improve social capital in poor communities. There have been projects that have tried to examine such strategies, as highlighted in the literature in this thesis. However, as seen with in the three case studies in this research, different communities have different dynamics and needs. Further research needs to examine varied mechanisms in a range of different communities. This can potentially provide lessons on how to match community development interventions to different communities and their unique dynamics. Furthermore, part of this exercise would also be to investigate innovative ways of integrating these mechanisms into existing community structures or initiatives, instead of imposing them.

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Appendices

Appendix 1: Information sheet for non-governmental organisation manager/representative

Information sheet: CBO/NGO Manager

Good day. My name is (name of researcher) and I am a member of a research team from the Centre for Health Policy (CHP) (University of Witwatersrand in Johannesburg). I would like to interview you to obtain from you an overview of the work of your organisation, specifically the work that you do with community health workers. I would also like to hear your views on the community health worker programme and your experience with working with the DOH. I hope that you will share with me your experiences of working in your community and the challenges and successes that you face and have faced in the past.

Background

CHP has been granted funding for a project to evaluate the CHWP in Gauteng. I am mostly interested to know how CHWs provide their services and your role in the services of CHWs and the ways in which you go about managing them as individuals who work in the community. I am also interested in knowing what drives you to do the work that you do and to know about your community and your role in the community. To obtain this information, I will also examine the referral processes between the health facilities and your organisation; I will examine the different services that the organisation and the CHWs provide and also examine the perceptions of CHWs with regards to the factors that assist them to do their work and the factors that make it difficult to do their work..

To gain a better understanding of CHWs and your role I will be conducting a number of interviews and other activities to get a better sense of your experiences. I will be interviewing other managers of CBOs/NGOs; nurses in the local clinics; the clinic and hospital managers; district managers and patients. I will also be travelling with each of the selected CHWs for 2-3 days to observe the types of activities and interactions they engage in. All of these activities will be conducted subsequent to receiving permission from those in authority such as yourself and the DOH.

You have been selected to participate because we believe that you will be able to provide us with valuable information about the CHWP; the CHWs and the nature of your work as an organisation

I would like to invite you to participate in this study and to ask your permission to conduct an interview with you.

Why we want to interview you?

I am interviewing a number of other CBO/NGO managers who work with CHWs and are familiar with their services. I would like to hear your story about your experience of working with them and the DOH. I would also like to hear what your views are on CHWs, your relationships with them and your management processes with regards to them.

Consent

Permission to carry out this project has been obtained from the provincial department of health. Ethical approval for this study has been obtained from the University of the Witwatersrand Ethics Committee for Research on Human Subjects (medical).

Will there be any benefit from participating?

You will not benefit directly from participating in this study.

Will there be any harm from participating?

No harm will come to you from participating in the study, as all information will be kept confidential and no one in the department will know what you have said. Similarly there will be no negative consequences for individuals who do not want to be interviewed.

During the interview you have the right to decline to answer any of the questions, or stop the interview at any time. The fact that you have done this will not be reported to anybody, will not be recorded in the research report and will not have any negative consequences for you.

Permission to tape the interviews: To make the interview easier for us, I will also ask if I can tape the interview. If you do not want the interview to be taped that is your right, and it will not influence the interview or the research in any way. If you give me permission to tape the interview I will listen to the tape and write down everything that you say but not use your name. I will keep the tapes under lock and key for two years, after which they will be destroyed.

Confidentiality

As a participant in the research you can expect that all the information you provide will be treated in a confidential way. The names of facilities and individuals will not be used in the research report. We will keep all information that people provide confidential. If necessary a member of the research team may contact you to check that you are happy with what has been written, and are not worried that you can be identified.

The Interview

The interview will take about an hour each. It will be carried out in English unless you would prefer it to be in your own language. The interview will be carried out a time and place that are convenient to you, and will not interfere with your duties in the organisation.

Contact Details of the Principal Investigators of the Research Project

If you have any further questions, or any complaints about the way that the study is being implemented you can contact the Principal Investigators of the project.

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Similarly you can also contact the Human Research Ethics Committee (Medical) which oversees the ethical aspects of this study. Members of this committee can be contacted through Ms Anisa Keshav on 011 717 1234.

Appendix 2: Information sheet for Department of Health representative

Information sheet: Department of Health Representative

Good day. My name is (Name of researcher) and I am a member of a research team from the Centre for Health Policy (CHP) (University of Witwatersrand in Johannesburg). As per our initial communication with regards to the study on the community health worker programme (CHWP), I would like to interview you to obtain from you an overview of the programme, your views on the community health workers (CHWs) in the programme as a collective and the organizations that manage the CHWs. This will include information on the role of the Department of Health (DOH) in the CHWP and what it provides for Community-Based Organizations (CBOs) or Non-governmental Organizations (NGOs). Here is some information about the study and the information that we are hoping to discuss with you.

Background

CHP has been granted funding for a project to evaluate the CHWP in Gauteng. I am mostly interested in the extent to which CHWs provide comprehensive services in their communities and the enablers and constraints to provide these services. To obtain this information, I also need examine the referral processes between the different entities involved in the programme, I will examine the different services that CHWs provide and also examine the perceptions of CHWs with regards to constraints and enabling factors.

To gain a better understanding of the CHWP and the constraining and enabling factors encountered by CHWs, I will conduct multiple methods to collect the data. I will be interviewing managers of CBOs/NGOs, nurses in the local clinics, the clinic and/or hospital managers, district managers and patients. I will also be travelling with each of the selected CHWs for 2-3 days to observe the types of activities and interactions they engage in. All of these activities will be conducted subsequent to receiving permission from those in authority, including the DOH.

I am asking you to participate because I believe that you will be able to provide me with valuable information about the CHWP and that you will guide me in the selection of NGO/CBOs to use as case studies.

I would like to invite you to participate in this study and to ask your permission to conduct an interview with you.

Consent

Permission to carry out this project has been obtained from the provincial department of health. Ethical approval for this study has been obtained from the University of the Witwatersrand Ethics Committee for Research on Human Subjects (medical).

Will there be any benefit from participating?

You will not benefit directly from participating in this study.

Will there be any harm from participating?

No harm will come to you from participating in the study, as all information will be kept confidential and no one in the department will know what you have said. Similarly there will be no negative consequences for individuals who do not want to be interviewed.

During the interview you have the right to decline to answer any of the questions, or stop the interview at any time. The fact that you have done this will not be reported to anybody, will not be recorded in the research report and will not have any negative consequences for you.

Permission to tape the interviews: To make the interview easier for us, I will also ask if I can tape the interview. If you do not want the interview to be taped that is your right, and it will not influence the interview or the research in any way. If you give me permission to tape the interview I will listen to the tape and write down everything that you say but not use your name. I will keep the tapes under lock and key for two years, after which they will be destroyed.

Confidentiality

As a participant in the research you can expect that all the information you provide will be treated in a confidential way. The names of facilities and individuals will not be used in the research report. I will keep all information that people provide confidential. If necessary a member of the research team may contact you to check that you are happy with what has been written, and are not worried that you can be identified.

The Interview

The interview will take about an hour . It can be carried out in your own language or in English. The interview will be carried out a time and place that are convenient to you, and will not interfere with your duties in the department/work.

Contact Details of the Principal Investigators of the Research Project.

If you have any further questions, or any complaints about the way that the study is being implemented you can contact the Principal Investigators of the project.

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Similarly you can also contact the Human Research Ethics Committee (Medical) which oversees the ethical aspects of this study. Members of this committee can be contacted through Ms Anisa Keshav on 011 717 1234.

Appendix 3: Information sheet for ward councillor

Information sheet: Ward Councillor

Good day. My name is (name of researcher) and I am a member of a research team from the Centre for Health Policy (CHP), University of Witwatersrand in Johannesburg. I am currently conducting a study on community Health workers (CHWs) and the extent to which the PHC service they provide is comprehensive. I would like to interview you to obtain from you an overview of the Community Health Worker Programme (CHWP), your views on the community health workers (CHWs) in the programme as a collective and the organizations that manage the CHWs. This will include information on the role of the Department of Health (DOH) in the CHWP and what it provides for Community-Based Organizations (CBOs) or Non-governmental Organizations (NGOs). Here is some information about the study and the information that we are hoping to discuss with you.

Background

CHP has been granted funding for a project to evaluate the CHWP in Gauteng. I am mostly interested in the extent to which CHWs provide comprehensive services in their communities and the enablers and constraints to provide these services. To obtain this information, I also need examine the referral processes between the different entities involved in the programme. I will examine the different services that CHWs provide and also examine the perceptions of CHWs with regards to constraints and enabling factors.

To gain a better understanding of the CHWP and the constraining and enabling factors encountered by CHWs, I will conduct multiple methods to collect the data. I will be interviewing managers of CBOs/NGOs, nurses in the local clinics, the clinic and/or hospital managers, and patients that are not based in the health facilities that are or have used CHW services. I will also be travelling with each of the selected CHWs for 2-3 days to observe the types of activities and interactions they engage in. All of these activities will be conducted subsequent to receiving permission from those in authority, including the DOH.

I am asking you to participate because I believe that you will be able to provide me with valuable information about the health status and health services of the district, including the role that you think the CHWs fulfil in providing these services.

I would like to invite you to participate in this study and to ask your permission to conduct an interview with you.

Consent

Permission to carry out this project has been obtained from the provincial Department of Health. Ethical approval for this study has been obtained from the University of the Witwatersrand Ethics Committee for Research on Human Subjects (medical).

Will there be any benefit from participating?

You will not benefit directly from participating in this study.

Will there be any harm from participating?

No harm will come to you from participating in the study, as all information will be kept confidential and no one in the department will know what you have said. Similarly there will be no negative consequences for individuals who do not want to be interviewed.

During the interview you have the right to decline to answer any of the questions, or stop the interview at any time. The fact that you have done this will not be reported to anybody, will not be recorded in the research report and will not have any negative consequences for you.

Permission to tape the interviews: To make the interview easier for me and to capture accurate information, I will also ask if I can tape the interview. If you do not want the interview to be taped that is your right, and it will not influence the interview or the research in any way. If you give me permission to tape the interview I will listen to the tape and write down everything that you say but not use your name. I will keep the tapes for two years under lock and key, after which they will be destroyed.

Confidentiality

As a participant in the research you can expect that all the information you provide will be treated in a confidential way. The names of facilities and individuals will not be used in the research report. I will keep all information that people provide confidential. If necessary a member of the research team may contact you to check that you are happy with what has been written, and are not worried that you can be identified.

The Interview

The interview will take about an hour. It will be carried out in English unless you would prefer it to be in your own language. The interview will be carried out a time and place that are convenient to you, and will not interfere with your duties in the department/work.

Contact Details of the Principal Investigators of the Research Project.

If you have any further questions, or any complaints about the way that the study is being implemented you can contact the Principal Investigators of the project.

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Similarly you can also contact the Human Research Ethics Committee (Medical) which oversees the ethical aspects of this study. Members of this committee can be contacted through Ms Anisa Keshav on 011 717 1234.

Appendix 4: Consent Form for Key Informant Interviews

I have been given the Information Sheet on the study on community health workers in Gauteng. I have read and understood the Information Sheet and all my questions have been answered satisfactorily.

I understand that it is up to me whether or not I would like to participate in the interview and that there will be no negative consequences if I decide not to participate. I also understand that I do not have to answer any questions that I am uncomfortable with and that I can stop the interview at any time.

I understand that the researcher/s involved in this project will make every effort to ensure confidentiality and that my name will not be used in the study reports, and that comments that I make will not be reported back to anybody else.

I consent voluntarily to be interviewed for this study.

Interviewee's signature: _____ Date: _____

Interviewer's signature: _____ Date: _____

Interviewer's name
(please print): _____ Date: _____

Appendix 5: Consent to tape record interview /Focus group discussion

I have read the project information sheet, and I understand that it is up to me whether or not the interview is tape-recorded. It will not affect in any way how the interviewer treats me if I do not want the interview to be tape-recorded.

I understand that if the interview is tape-recorded that the tape will be destroyed two years after the interview.

I understand that I can ask the person interviewing me to stop tape recording, and to stop the interview altogether, at anytime.

I understand that the information that I give will be treated in the strictest confidence and that my name will not be used when the interviews are typed up.

Yes, I give my permission for the interview to be tape recorded	☐
No, I do not give my permission for the interview to be tape recorded	☐

Interviewee's signature: _____ Date: _____

Interviewer's signature: _____ Date: _____

Interviewer's name
(please print): _____ Date: _____

Appendix 6: Interview Guide

Key informant interview – Department of Health Representative (National)

SECTION 1: BIOGRAPHICAL INFORMATION

1. Age

2. Gender

3. Home language

SECTION 2: THE DEPARTMENT OF HEALTH AND NGOs/CBOs

Interview question:

Because the Department of Health (DOH) plays an important role in the work of CHWs and the community health worker programme (CHWP), I would like to understand the structure, function, the role of the DOH with regards to the CBO/NGOs, from the provincial level down to the district level (you could draw a diagram if that would help). Please describe the structure and function of the Gauteng Province –D OH- District Health System with regards to the CHWP and your experiences with implementing the programme. Perhaps you can also describe your interaction with CBOs/NGOs and the dynamics thereof.

Issues to cover:

- Role of this office
- Role of District Health System managers & district office
- Formal meetings
- Selection as to which CBO/NGO to fund
- Training and supervision
- Stipends
- Monitoring and evaluation

Probe:

- Can you describe and give me some examples of interactions with NGOs, where things have gone well, and other examples where difficult issues have arisen.
- Can you describe for me some of the challenges that you have faced and some of the successes of the CHWP. If possible giving specific examples.

Interview question 2:

You work with different CBOs/NGOs in the province. Can you give an overview of the contexts that some of these CBOs/NGOs operate in. For instance, some function in very poor areas where there is much apathy and lack of community cohesion, or where CHWs are not really accepted because of issues of stigma, but you find other areas that are mobilized and are active even though poor, so you find the NGOs functioning well and are accepted.

Issues to cover:

- The community within which the CBOs/NGOs are operating
- Funding dynamics
- Size of the organization
- How they decide whether an CBO/NGO is a best practice or is doing well
- Intersectoral collaboration
- Community participation
- Social cohesion

Probe:

- What dynamics do CBOs/NGOs have to deal within their communities
- What issues do organizations have to deal with as organizations
- Comment on the level of community participation in the province [highlight different areas]
- Comment on the level of intersectoral collaboration in the different districts in the province

SECTION 3: THE COMMUNITY HEALTH WORKER PROGRAMME**Interview question:**

Can you describe some of the interactions and activities that happen within the CHWP or that relate to the work of CHWs such as with other government sectors, for instance, social services or home affairs? Also include activities that somehow involve the community with regards to for

instance, forums where issues are discussed and decisions are made about health in their communities.

Issues to cover:

- Other government sectors involved in the CHWP or CHW related work
- Formal guidelines/policies for intersectoral collaborations
- Examples of successes and challenges to intersectoral collaborations
- Activities and structures for community involvement
- Formal processes that support and facilitate community participation
- Community structures that are functioning in the community linked to the CHWP

Probe:

- How is intersectoral action facilitated and incorporated within the CHWP from the higher levels of the health sector **[is it incorporated in the training?]**
- How is community participation facilitated and supported within the CHWP?
- Are there any formal guidelines/policies available with regards to intersectoral collaborations that the different government sectors can follow or refer to? Please describe
- How do you measure/monitor whether intersectoral action is happening at local level (especially with community-based sectors)?
- What are the challenges and or successes of Intersectoral collaboration (examples)
- What health issues that have an impact on health do you think the communities face that you think may need the intervention of other government sectors? Please describe?
- What are the challenges/successes to community participation (examples)

Interview question:

I also wish to understand some of the dynamics/challenges of working with CHWs. Please provide an overview of some of the difficulties or even examples.

Issues to cover:

- Varying literacy levels and possible impact on quality of service
- Acceptance dynamics of CHWs by some of the health personnel
-

Probe:

- Are there systems to monitor the level of quality of services by CHWs, especially with regard to their varying literacy levels
- Are the systems to monitor whether all CHWs working in the community have undergone some training.

SECTION 4: REFERRALS AND TYPES OF SERVICES

Interview question:

Can you describe the referral processes that occur within the CHWP, where most of the referrals are to and from, and how well they work? Can you describe some specific problems that have occurred? Can you also describe the type of health services that CHWs provide and touch on the guidelines that may be available that detail the type of activities they are required to carry out.

Issues to cover:

- Job descriptions/guidelines for CHWs on types of services
- Referral processes and challenges/successes

Probe:

- What are the dynamics around referrals with regards to the CHWP
- What are the types of health services that CHWs provide and how do they meant to work with the guidelines if they are available?
- Please describe the challenges and successes of working with CHWs

Interview question:

Please can you identify the NGO/CBOs involved in the CHWP in the province that you view as successful or a best practice, and explain why you choose those ones

Issues to cover:

- Criteria used to judge/measure best practice

Probe:

- Explain how you decide whether an organization is best practice or is doing well? [Give some examples of some of those organizations]
- Which organizations do you personally know or have heard of that seem to interact and use the resources and services of other sectors besides health and at the same time, are actively engaged in mobilising the community to participate in the row health care. For instance, by having high visibility in the health committees and ward committees, etc.

Thank you for your time

Appendix 7: Interview Guide

Key informant interview – Department of Health – District health manager

SECTION 1: BIOGRAPHICAL INFORMATION

1. Age

2. Gender

3. Home language

SECTION 2: THE CHWP AND THE ROLE OF THE DISTRICT

Interview question 1:

In the effort to understand the CHWP and the work that CHWs provide, I wish to understand your role within this programme. Can you please describe the structure and function of this district office with regards to the CHWP?

Issues to cover:

- General role of the district office with regards to CHW services

Interview question 2:

Because of the existence of NGOs/CBOs in your district, can you also provide me with an overview of the NGOs.CBOs that operate in your district with regards to their history, the type of services that they provide and perhaps what your role is in supporting these organizations.

Issues to cover:

- Support to organizations

- Challenges of supporting NGO (example)
- Recommendations on what would enhance your ability to support NGOs
- Selection criteria on which organizations to fund
- Stipend
- Training
- Supervision
- Monitoring & Evaluation of the organizations you engage with
- Health services provided by CBOs/NGOs
- Availability of guidelines for CHWs

Interview question 3:

Perhaps you can also touch on your experiences in implementing the CHWP and in working with the organizations that employ CHWs. Whilst we are still on the overview of the organizations, can you please also provide me with your view on which NGOs are the ones that are doing well and which ones are the weaker one and provide input as to why you hold that view for either.

Issues to cover:

- Challenges faced by CBO/NGOs in the district [example/s]
- Challenges faced by CHWs [example/s]

Probe:

- What have been the successes and challenges of working with CBOs/NGOs with regards to the CHWP and community based work generally?
- What have been the challenges of implementing the CHWP
- How much of the principles of inter-sectoral action are incorporated in CHW training?
- What do you think are some of the factors that could assist NGOs to function better?
- What do you think are some of the factors that could assist CHWs to function better?

SECTION 3: REFERRALS, COMMUNITY PARTICIPATION AND INTERSECTORAL COLLABORATION/ACTION

Interview question 1:

I would like to find out how the rest of the system and the structures in the community work within the CHWP. Can you please describe the referral processes with regards to the CHWP and give a view on whether it works or not and perhaps suggestions as to how you think it would work better if at all.

Issues to cover:

- Referrals between health services
- Referrals with other sectors

- Referrals between other NGOs that offer different services

Probe:

- Describe with examples some of the challenges with referrals
- Describe instances where they have worked well [please give examples]
- What do you think would make the referrals of patient to be more effective if you feel that they are not.

Interview question 2:

I would also like you to describe any of the community structures that exist in the community that allow the community to be involved in discussions and making decisions about their health. For instance, what do health committees and/or ward committees interact in issues of health and how does the community great involved, especially the CHWs.

Issues to cover:

- Community involvement structure
- Support from district to facilitate community involvement
- Examples of community activities

Interview question 3:

In that same vein, can you provide your own view on the nature of the community in your district with regards to cohesiveness and the rate of their involvement in community activities and issues.

Issues to cover:

- The community structures that exist in the district that are self initiated [not linked to government but may have an impact on services]
- Level of involvement in community structures
- How community structures are held accountable
- Experience of communities in community participation activities [do community participants/leaders receive any training to capacitate them with skills to participate/lead a committee?]

Probe:

- Describe with examples some of the challenges and successes with community participation

Interview question 4:

Can you explain and describe some of the linkages that the CBOs/NGOs have with other government sectors? Perhaps you can provide an example of an event where different sectors had a joint initiative. Explain how this was initiated and the purpose of the initiative (what problem was it meant to address?) and the outcome of the initiative. Did it achieve what it was planned to achieve? If not, why do think that is? If it was successful, what do you think contributed to the success?

Issues to cover:

- Formal mechanisms that facilitate this linkage, if at all
- Any general policy/guideline that facilitates and supports inter-sectoral collaboration

Probe:

- How is inter-sectoral action facilitated and incorporated within the CHWP from the higher levels of the health sector **[is it incorporated in the training?]**
- What are the challenges in ensuring and sustaining the interaction/linkage?
- Can you provide some examples of successes in inter-sectoral collaboration? How do you measure/monitor whether inter-sectoral action is happening at local level (especially with community-based sectors)?
- Can you provide some recommendations to improve these linkages and inter-sectoral action in general?
- What health issues that have an impact on health do you think the community faces that you think may need the intervention of other government sectors? Please describe?

Thank you for your time

Appendix 8: Interview Guide

Department of Health: City of Johannesburg - HIV/AIDS Directorate

SECTION 1: GENERAL & BIORAPHICAL INFORMATION

1. Age

2. Gender

3. Home language

4. How many year have you been employed by the organization?

5. What is your position in the organization?

OVERVIEW & FUNCTION OF JOZI IHLOMILE

I have been conducting fieldwork at [name of geographical place] for the past three months and have been kindly embraced by the volunteers of [name of programme]. I have also spent almost the same amount of time with the CHWs from the [name of programme].

1. What is the role of the [name of programme] volunteers?

2. Can you please touch on what the objectives of [name of programme] that the city wanted to achieve?
3. From what you have received with regards to reports of the work of volunteers from [name of programme], what do you think are the successes of the programme.
4. What do you think are the main issues that they encounter in their interaction with the community?
 - What challenges do the volunteers experience in addressing these challenges?
 - What systems or mechanisms are in place or available for the volunteers to use when encountering these challenges?

INTERSECTORAL ACTION & COMMUNITY PARTICIPATION

5. From the field work that I conducted, some of the issues that the volunteers identify in households at [name of area] often require the intervention of other government departments such as Home Affairs, Social Services, Housing, Environmental services (water & sanitation) and Health, what mechanisms are available that volunteers can tap into so as to assist community members to access these services?
 - How do IDPs play a role and assist in this regard if at all?
 - To what extent does the training of the volunteers include their role in helping community members to access the various sectors
 - How integral is the role of the volunteers in health services, especially clinics because they are placed at the same level. What is their role in relation to identifying ill people in households. E.g. do they refer?
6. To what extent do different services/sectors function in an integrated manner at metro, regional and local level?
 - If there is a level of integration at the metro, regional and local level, how is this facilitated? (Is there a policy, strategic plan, etc??)
 - If there is no integration, why do you think that is so and what do you think needs to be done to encourage the different sector to function in an integrated fashion at each level?
7. According to your insight, what issues, specifically related to the various sectors, which the volunteers have identified do you think are most urgent and significant for the [name of geographical place] community which you feel have not been addressed adequately?
 - How do you think these issues can be addressed?
8. What mechanisms are available which encourage and facilitate community participation?
 - The role of the ward/political councillor

- Ward Committees
- Clinic Committees, etc
- What are the challenges of ensuring that communities participate in issues/areas that affect them (g, health, education, clean water & sanitation
- In your view, to what extent is there community participation at [name of geographical place]?

SUCSESSES /CHALLENGES OF [NAME OF PROGRAMME]

9. To what extent is [name of geographical place] typical of other areas that [name of programme] provides services. Are the other pilots similar to the one at [name of geographical place]?

10. I know that you are familiar with the [name of programme]. What do you think are the differences between the two programmes looking at aspects such as he services each provides, the training involved, management, scope of work of the CHWs or volunteers?

11. With regard to the purpose and objectives of [name of programme], what is your view regarding whether the project has been able to achieve these objectives at [name of geographical area]?
 - Elaborate on these achieved objectives.
 - What are the challenges of implementing a project such as [name of programme]? [Is it about capacity, training, leadership, stipends, management and also the scope of practice? [Name of programme] provide a variety of services, whereas [name of programme] health promotion. Is the [name of programme] model too narrow?]
 - What do you think is necessary to alleviate or even prevent these challenges?
 - What are some of the successes that you can think of that have experienced by [name of programme]?
 - What do you think enabled those successes?

12. Do you think the [name of programme] is a model that should or could be replicated?, If you think so, why? What could be changed if at all?

13. From the fieldwork, I have come across a range of community-based initiatives/cadres. Child caregivers, Community Development Workers, CHWs and the [name of programme] volunteers. How are these cadres meant to work in the communities, if at all?

[NAME OF PROGRAMME] VOLUNTEERS

14. Let's talk about the [name of programme] volunteers. What is the nature of training for individuals who want to volunteer in the project?
- Nature of further training and updating knowledge and information
 - Nature of supervision if there is any
15. What is your view on the scope of service that the volunteers provide (health promotion only)?
- Please give an opinion on whether the services they provide to the community is sufficient
16. What are the plans for [name of programme] for next year?
- Where do you foresee [name of programme] next, regarding funding and rollout?
 - What are the plans for the volunteers? (Career pathing system, further training, etc)

Thank you for your time!

Appendix 9: Interview Guide

Key informant interview – Provincial Department of Health, District Health Services (DHSS) Support

SECTION 1: GENERAL & DEMOGRAPHICAL INFORMATION

1. Age

2. Gender

3. Home language

4. How many years have you been employed by the department specifically this unit?

5. How long have you been doing this job?

6. What is it that you do?

OVERVIEW & FUNCTION OF DHSS

7. Can you please give an overview of the role of DHSS with regards to NGOs and/or community-based services in the province?

Probe:

- Relationship between the DHSS and the NGOs in the province (purely financial, managerial, etc?).
- What is the nature of the link/relationship between the health services (clinics) and the CHWs?
- That relationship is facilitated by NGOs. How effective is this relationship and how sustainable is it?

- The CHW policy has been revised. Was the old policy a problem and if so, why was it a problem?
8. Now that the DoH has merged/partnered with Social Development, how has this affected the CHW programme and the NGO terrain, if it has? How do you envisage this relationship affecting the implementation of the policy?
- Probe:
- CHWs have different service packages depending on whether they are from Health and Social Development and they clearly overlap and this plays out in households and communities where you find 2-3 cadres all providing the same service. How is this overlap and/or duplication currently managed and how do you think it can be managed overtime, considering this integration between the two departments?
 - What is your opinion of the training of CHWs currently?
 - How do you envisage it being adapted to the revised policy and relationship with social development?
9. From what you have received with regards to reports of the work of CHWs in the province, what do you think are the main issues that they encounter in their interaction with the community?
- What challenges do the volunteers experience in addressing these challenges?
10. What systems or mechanisms are in place or available for the volunteers to use when encountering these challenges? I will need you to comment on this in relation to:
- The training
 - The supervision of CHWs
 - The reporting arrangements. That is, what indicators do they have to report on and thus provide services according to those indicators? To what extent do these indicators or components that they have to fulfill allow them to provide comprehensive care
11. As mentioned, I have been using case studies from an NGO at [name of geographical place] and one at [name of geographical place], the [name of programme] project. How representative are these two NGOs of others in the Province?

INTERSECTORAL ACTION & COMMUNITY PARTICIPATION

12. a. The NGO Act encourages the relationship between departments and organizations by saying all organs of states must coordinate the implementation of its policies in a manner that supports the capacity of NGOs. How effectively do you think this works and what are the constraints?

b. What mechanisms are available that NGOs and CHWs can tap into so as to assist community members to access services from different sectors? For instance, is there a policy that facilitates this?

c. *[Give example of domestic abuse where a person needs to access SAPS, clinic and justice/court. Often people approach these departments as silos and at different times because they act in a non-coordinated manner]*

What is your opinion on the extent of integration between different departments (sectors) and what do you think can be done to encourage and enable different sectors to function in an integrated fashion?

13. According to your insight, what issues which NGOs and CHWs have identified do you think are most urgent and significant for the community which they serve, which you feel have not been addressed adequately?

- How do you think these issues can be addressed?

14. What mechanisms are available which encourage and facilitate community participation?

- Ward Committees
- Clinic Committees, etc
- What are the challenges of ensuring that communities participate in issues/areas that affect them (e.g. health, education, clean water & sanitation)

15. With regard to sustainability, what is the thinking regarding CHW services in the future in terms of the health system. Is this a programme that seeks to retain workers on a voluntary or stipend basis or is there a plan with regards to the current career-pathing system?

Thank you for your time

Appendix 10: Interview Guide

Key informant interview – NGO managers/representatives

SECTION 1: GENERAL & DEMOGRAPHICAL INFORMATION

1. Age

2. Gender

3. Home language

4. How many year have you been employed by the organization?

5. What is your position in the organization?

SECTION 2: INFORMATION ABOUT THE ORGANISATION

Interview question 1:

In the effort to understand the work that you and CHWs do and your experiences of working in the community, it is important for me to know more about the structures that you all work with. Can you tell me a bit about your organization? Its history, who it employs, the types of

services it provides, about how you are funded and who you refer and receive patients to and from?

Issues to cover:

- Organogram of NGO
- Length of funding grants
- Description of actual services provided?
- The nature of your relationship with the local health facilities with regards to CHWs
- Challenges and successes of referrals – provide examples

Probe:

- With regards to funding, roughly, what are your total yearly costs?
- Are you dependant on one funder, or do you have several that you rely on? Who is (are) the funder/s
- Why and how do you decide on the type of services to provide?

Interview question 2:

I also wish to know if there are other ways that the community participates in what you are doing, whether there are other ways that you engage with the community, for instance, finding out about other problems in the community or where you are members of other community organisations. How well does this work and what are the problems? Perhaps comment on the nature of your community as to how well it works together (how cohesive it is) and how active it is in getting involved in community issues and activities. ***Perhaps you can provide an example of an event that involved the community: What was its aim? Who facilitated and coordinated it? What was the outcome? Did it achieve what it was meant to achieve? What were some of the challenges?***

Issues to cover:

- Community participation activities (challenges and successes)
- Nature of linkages with other community organizations such as Health Committees/ Ward Committees
- The length of existence of the community

Probes:

- Other than home visits, do you or the CHWs engage with the community in other ways?
- To what extent are you involved in Health Committees, Community Advisory Boards and/or Ward Committees?
- How does the community engage and deal with its own issues, e.g. a health facility that does not offer a satisfactory service. How does the community address this?

Interview question 3:

Working in the community and being involved in community activities and functions requires different people to take on different roles. This also means that people who occupy those roles need to be accountable for their responsibilities. Can you provide an example of how it is ensured that members of the organization are accountable for what they are entrusted with? ***For instance, an example of how each CHW in your organization is held accountable for their patients and the work that they have to deliver? Provide your opinion of whether the system or the mechanism is effective or not and provide an example that confirms your opinion.***

Issues to cover:

- Accountability and the mechanisms in place
- Reporting issues

Probes:

- How in the past have people that seem not to do their work been dealt with in the community organizations that you are members of?
- Who as an organization are you accountable to (who do you report to?)

SECTION 3: VIEWS ON THE GAUTENG COMMUNITY HEALTH WORKER PROGRAMME

Interview question 1:

The CHWs engage with or function within the CHWP and I would like to understand the dynamics around implementing this programme. Can you tell me how you perhaps engage or are involved with the policy? Please describe your relationship with the Department of Health if there is any and if there is some engagement, perhaps describe the relationship, who you engage with the most and the role of this person/s is. I would also like to hear your general views on the CHWP; what its benefits are; the guidelines available if at all and your positive and/or negative experiences of implementing the programme.

Issues to cover:

- Formal meetings
- Reporting
- Guidelines of the CHWP

Probes:

- An example of a success in implementing the CHWP
- An example of the challenges of implementing the CHWP
- With regards to the CHWP, how do you engage with it? That is, does it influence and guide what you do?

- How do you engage with Department of Health, if at all?

Interview question 2:

If you were to rate yourself in terms of performance in providing the services that you are meant to provide, what would you say: Doing well, could do better, not doing very well?

Please explain why you hold this view.

Probe:

- What do you think has led you to this position?
- What do you think could help you to do better or improve?

Interview Question 3:

You have managed to provide the services that you provide throughout the period that you have existed. Considering all the issues and experiences throughout this time, why do you think that is the case?

Issues to cover:

- Coping strategies
- Resources
- Enablers
- Constrainers

Probe:

- During difficult times, who or what do you rely on help you out? [An example or an incident when you had a particular problem and you relied on a particular resource or strategy to address the problem. What was the outcome?
- What are things that make a bit easier for you to do the work that you do? What are the things that make it difficult? Please give an example of both.

SECTION 4: INFORMATION ON COMMUNITY HEALTH WORKERS

Interview question:

You obviously work closely with CHWs. Please tell me about the CHWs that work here with regards to their background, how many they are in the organization. I also wish to know issues around how they are selected, their stipends, their training, contracts and their supervision.

Issues to cover:

- Recruitment system
- Formal contracts
- Decision on amount of stipends
- Training provider, monitoring of training
- Provision of supervision, monitoring of supervision
- Career pathing /growth

Probes:

- What are the issues around stipends?
- What are the issues around training?
- What are the issues around supervision?
- How do you think the CHWP addressed the issue of career growth for CHWs, if at all?

SECTION 5: INTERSECTORAL COLLABORATION/ACTION

Interview question:

You obviously have some kind of relationships with different structures in the community. Can you please tell me a bit about that, especially with regards to the local health facilities and other government sectors (such as the Department of Home Affairs, Social Development or the department that deals with clean water and sanitation)? Can you please give an example of a specific joint event/s or activity/s which involved other government sectors? Perhaps you can describe how it came about (who initiated it), what its purpose was and how it was initiated. How did working together with other sectors work out? What were the challenges and what was the outcome of the event/s?

Issues to cover:

- Nature of linkages with government sectors, such as Department of Home Affairs, Department of Social Development, the department that deals with issues of clean water and sanitation
- Government sector/s worked with the most
- Challenges of working with other sectors – example
- Successes of working with other sectors – examples
- Strategies used to link with other sectors [how and why they made the decision to link with the sector/s]

Probe:

- What are the challenges of linking with other government sectors?
- Name some of the government sectors you have worked with
- Which government sectors have responded to your needs – example
- What avenues are there to address and link up with other sectors that have an impact on the community's health?

- Describe the nature of your interaction with other government sectors with regards to CHWs if at all
- Is there anything else that you would like to tell me about our conversation that you think may be useful or helpful?

Thank you for your time

Appendix 11: Interview Guide

Key informant interview – Clinic/Health facility manager & nurse

SECTION 1: GENERAL & DEMOGRAPHICAL INFORMATION

1. Age

2. Gender

3. Home language

4. How long have you worked in this service (in years)?

SECTION 2: WORKING WITH COMMUNITY HEALTH WORKERS

Interview question 1:

In order to understand the work that you do in relation to CHWs and the NGOs, can you please describe to me your experiences of working with the NGOs in the community and the role that you play with the CHWs. Please give examples of some of the challenges and even successes that you have experienced with the CHWP and also give your view on the programme itself with regards to implementation in the district.

Issues to cover:

- General views on CHWs
- Benefits and successes of working with CHWs– please give examples
- Challenges of working with CHWs – examples
- Purpose of the relationship

Probe:

- What is your relationship with the NGO that you work with (refer patients to etc) and how do they facilitate communication and/interaction (meetings, etc)
- Give an example of your experience of working with NGOs and/or CHWs
- Which other health professionals are involved in the CHWP and what are their roles?

Interview question 2:

I also wish to learn more about the referral system within the programme and your views about it. Also include an overview on other government sectors that you refer to or interact with. Can you please give an example of a specific joint event/s or activity/s which involved other sectors? Perhaps you can describe how it came about (who initiated it), what its purpose was and how it was initiated. How did working together with other sectors work out? What were the challenges and what was the outcome of the event/s?

Issues to cover:

- Any challenges with the referrals
- Successes and benefits of referral system

Probe:

- What challenges have you experienced regarding the referral processes
- What benefit/successes have you experienced regarding the referral processes?
- What would you recommend with regards to improving the referral processes?
- Which other sectors, for example, social workers (if any) does the c\hospital collaborate with? Please provide details of the interaction
- What health issues that have an impact on health do you think the community faces that you think may need the intervention of other government sectors? Please describe?

Interview question 3:

Describe your interaction with other community structures in the district such as ward committees, Health committees. Perhaps provide your experiences with these structures and your view on how they support and facilitate community participation. Also tell me some of the challenges you think these structure face with regards to encouraging and facilitating communities to participate. Can you please give an example of a specific joint event/s or activity/s which involved other community structures? Perhaps you can describe how it came about (who initiated it), what its purpose was and how it was initiated. How did working together with other community structures work out? What were the challenges and what was the outcome of the event/s?

Issues to cover:

- Type of involvement with community structures
- Types of community structures the facility interacts with and the nature of interaction

Probe:

- What are some of the challenges of being involved and interacting with community structures
- What type of community structures do you interact with
- What are the processes/activities of the structures that you are involved in (e.g. meetings, campaigns, etc.)

Thank you for your time

Appendix 12: Interview Guide

Key informant interview – Ward councillor

SECTION 1: GENERAL & DEMOGRAPHICAL INFORMATION

1. Age

2. Gender

3. Home language

4. Do you live in the community?

Yes	
No	

5. How long have you been involved in the ward committee? (In years)

SECTION 2: OVERVIEW AND WORK OF THE COMMITTEE

Interview question 1:

In order for me to understand the work that you do in the community and the relationships you have with community-based structures such as local clinics, the NGOs, I wonder if you can give me an overview of the ward committee.

Issues to cover:

- Purpose of the committee;
- how many members and who they are/they represent,
- Different roles on committee;
- Frequency of meetings

Probe:

- What are the main topics of discussion in your meetings?
- How often do you meet?
- What are the challenges that you face as a committee especially with ensuring that you fulfill your purpose in the community
- How do you engage with the community? And how do you engage with the health facilities? Can you give me specific examples to illustrate how things work?
- Please describe your activities in the committee. What is it that you actually do?

Interview question 2a:

Please describe some of the ways that you facilitate community involvement in addressing community issues (such as health).

Interview question 2b:

Can you touch on your relationship or interaction you might have had, if any, with health committee (X clinic) of this region. Please provide your own view on their (health committee/s in general) function and abilities in assisting to address health issues in the community. Please provide an example of the function and benefits/challenges that you have faced when working with these committees

Interview question 2c:

Can you please give an example of a specific joint event/s or activity/s which involved other community structures? For example, a community forum involving all sectors and stakeholders at [name of geographical place]. Perhaps you can describe how it came about (who initiated it), what its purpose was and how it was initiated. How did working together with other community structures work out? What were the challenges and what was the outcome of the event/s?

Issues to cover:

- Nature of engagement with the community health committee (s)
- Types of issues that they have engaged in with community health committees
- Interaction with other government structures

Probe:

- Comment on the extent of community participation in your area and indicate the role of CHWs in community participation.

- To what extent are CHWs involved in facilitating community participation?

Interview question 4:

Also provide your opinion on the nature of this community and its strength or lack of, in working together including its level of activism. Please provide an example to demonstrate your response.

Issues to cover:

- Challenges of involving community in community activities

Probe:

- Does the community get involved in health related issues? Can you give me some examples?
- What do you think are the challenges to ensure that the community becomes more involved?
- How can the community's involvement be broadened
- What community activities are you aware of that facilitate community participation?
- Are there formal structures exist and function as structures for community participation

Interview question 5:

The health status of communities is sometimes affected by other elements such as lack of clean water and sanitation or lack of access to government resources such as grants which can assist people to access health services. Can you give your view of how other government sectors function in the region, if they active at all? Please give an example of how different sectors of government function and provide services that indirectly contribute to the health status of communities.

Issues to cover:

- How you and the committee engages with the various sectors (the nature of your relationship)
- Views on referral system with regards to the different sectors (constraints, successes)
- Views on the ability of the various sectors in responding to community needs (e.g. water and sanitation; social services, home affairs, etc.)
- The extent of the ability of the different government sectors to engage and collaborate
- Challenges of working with different sectors [example]
- Success (es) of working with different sectors [example]

Probe:

- What are your views on the referral processes that exist between the health facilitates/ government sectors and the community-based structures?
- What are the challenges that you think community structures face with regards to accessing the different sectors (specifically focusing on area demarcations).

- How do you think the referral system (between the different sectors) that is currently functioning can be improved (considering the area demarcations that exist)?
- What health issues that have an impact on health do you think the community faces that you think may need the intervention of other government sectors and which government sectors are those? Please describe or provide an example of such interactions if they exist or have been done.

Interview question 5b:

Can you please give an example of a specific joint event/s or activity/s which involved other sectors? Perhaps you can describe how it came about (who initiated it), what its purpose was and how it was initiated. How did working together with other sectors work out? What were the challenges and what was the outcome of the event/s?

Interview question 6:

Working in the community and being involved in community activities and functions requires different people to take on different roles. This also means that people who occupy those roles need to be accountable for their responsibilities. Can you provide an example of how it is ensured that members of the committee are accountable for what they are entrusted with? ***For instance, an example of how each member of your organization is held accountable for the work that they have to deliver? Provide your opinion of whether the system or the mechanism is effective or not and provide an example that confirms your opinion.***

Issues to cover:

- Accountability and the mechanisms in place
- Reporting issues
- Unresolved community issues

Probes:

- How in the past have people that seem not to do their work been dealt with in the committee?
- Who as a committee are you accountable to (who do you report to?)
- How are disagreements managed in the committee
- How are unresolved issues that are reported by the community dealt with? Is there a higher position that the committee can see a solution?

Thank you for your time

Appendix 13: Interview Guide

Key informant interview – Representative from Sectors/Department – Department of Social services/ Department of Housing

SECTION 1: GENERAL & DEMOGRAPHICAL INFORMATION

1. Age

2. Gender

3. Home language

4. How many year have you been employed by the organization?

5. What is your position in the organization?

SECTION 2: GENERAL INFORMATION

6. Can you please go through the levels of the district / region from a sector point of view?
[Metro, Region, Local]

Probe:

- At which level does the department function so that local communities can have access to it?
7. What are the functions of the department towards communities such as [geographical place], especially those that relate to health priorities, if there are any?
 - Any regard to issues around determinants of health?
 8. Under what principle/s did the two departments (health and social services) decide to merge / why did the two departments decide to merge?
 - Thus far, what do you think are the advantages of merging? Can you give an example where the partnership achieved a certain goal especially in the community (e.g. campaign, community event, etc)
 - What are the challenges of merging these departments? Please give an example that reflects these challenges
 9. While on that note of working with other sectors, to what extent does your department engage with other sectors, especially those that have an impact on the health and wellbeing of poor communities e.g. water & sanitation, environment, housing, etc.
 - What mechanisms are used to facilitate this engagement, if any?
 - To what extent does your department participate in the ward committees of this area? What is your role with regards to ward committees?
 - What other formal structures exist that have been established to form a link between your department and the community?
 10. Please provide any example of joint events/activities with other sectors that take place/have taken place at community level which enable community members to engage with your department and other sectors?
 - What other forums/structures exist for the various sectors to engage, if at all?
 - What are the challenges of ensuring that these forums function and continue to function?
 - What are the challenges of forming partnerships with other departments?
 - What have been the challenges of ensuring that multiple sectors engage at local level on a regular basis?
 - In your opinion, what is it that ensures coordination within different sectors and to what extent do you think has happened?
 11. What is your sense of IDPs and what value has it added to the coordination between the different departments?
 12. What sectors do you think are important to forge a relationship with when working in a community such as [geographical place]?

13. How does your department relate to community-based organizations in communities such as [name of programme]? (e.g. CHWs, CDWs, volunteers, etc).

- What is the role of the department with regards to NGOs?
- Please provide any information with regards to any formal referral mechanisms that may be in place for these various community workers to refer clients that are in need of your services?

Thank you for your time

Appendix 14: Consent form for Focus Group Discussions with community health workers

Consent Form for Focus Group Discussion participant

I have been given the Information Sheet on the study on community health workers in Gauteng. I have read and understood the Information Sheet and all my questions have been answered satisfactorily.

I understand that it is up to me whether or not I would like to participate in the interview and that there will be no negative consequences if I decide not to participate. I also understand that I do not have to answer any questions that I am uncomfortable with and that I can withdraw from the focus group discussion at any time.

I understand that the researchers involved in this project will make every effort to ensure confidentiality and that my name will not be used in the study reports, and that comments that I make will not be reported back to anybody else.

I consent voluntarily to participate in the focus group discussion for this study.

Participant's signature: _____ Date: _____

Interviewer/ facilitator's
signature: _____ Date: _____

Interviewer/facilitator's
name (please print): _____ Date: _____

Appendix 15: Focus Group Discussion information sheet

Information sheet: Focus Group Discussion - Community Health Worker (CHW)

Good day. My name is [Name of researcher] and I am a member of a research team from the Centre for Health Policy (CHP), University of Witwatersrand in Johannesburg. I would like to obtain from you an overview of the work that you do in your community. I would also like to hear your views on the community health worker programme (CHWP) and your experience on working in your organisation. I hope that you will share with me your experiences of working in your community and the challenges and successes that you face and have faced in the past.

Background

CHP has been granted funding for a project to evaluate the CHWP in Gauteng. I am mostly interested to know how you go about doing your work, who you relate to on a day to day basis, who you depend on to help your patients and your community. I am also interested in knowing what drives you to do the work that you do and your opinion on what makes it difficult for you to do your work and also what makes it easier to do your work.

To gain a better understanding of the work that you do and the challenges that you face, I will be conducting a focus group discussion with other CHWs that you work with (with you included), where you will discuss and share your experiences of working in the community as a CHW.

You have been selected to participate because I believe that you will be able to provide me with valuable information about the nature of the work that you do and the challenges and successes that you face, about the CHWP and the nature of your relationship with other agencies in the community, such as the clinic, the NGO and other community structures.

I would like to invite you to participate in this study and to ask your permission discuss with you and ask questions in a group with other CHWs.

About the focus group discussion process

You will be in a group with other CHWs where I will pose some questions which you can discuss in a group.

Consent

Permission to carry out this project has been obtained from the provincial Department of Health and the organisation that you work for [name of organisation]. Ethical approval for this study has been obtained from the University of the Witwatersrand Ethics Committee for Research on Human Subjects (medical).

Will there be any benefit from participating?

You will not benefit directly from participating in this study.

Will there be any harm from participating?

No harm will come to you from participating in the study, as all information will be kept confidential and no one in the organisation/community/department will know what you have said. Similarly there will be no negative consequences for individuals who do not want to be interviewed.

During the discussion, you have the right to decline to answer any of the questions or to withdraw from the discussion at any time. The fact that you have done this will not be reported to anybody, will not be recorded in the research report and will not have any negative consequences for you.

Permission to take notes during the focus group discussion: To make it easier for me to recall all the details and interactions that occur during the discussion, I will need to take down notes which will help me to write down the exact information from the discussion. Taking notes also makes it easier for me to make sure that I do not miss the whole discussion just in case the tape recorder does not work. If you give me permission to write notes I will look through the notes later and write them in detail, but I will not use your name. I will keep the notes for two years under lock and key, after which they will be destroyed.

Permission to tape the focus group discussion: To make the interview easier for me, I will also ask if we can tape the interview. If you do not want the interview to be taped that is your right, and it will not influence the interview or the research in any way. If you give me permission to tape the interview I will listen to the tape and write down everything that you say in the group, but not use your names. I will keep the tapes for two years under lock and key, after which they will be destroyed.

At the end of the research project I will write up a report. This report will include information that I noted during the discussion, but your names will not be used. No one apart from the researchers involved in the study will know that it was any of you who were in the group.

Confidentiality

As a participant in the research you can expect that all the information you provide will be treated in a confidential way. The names of facilities and individuals will not be used in the research report. I will keep all information that people provide confidential. If necessary a member of the research team may contact you to check that you are happy with what has been written, and are not worried that you can be identified.

Contact Details of the Principal Investigators of the Research Project.

If you have any further questions, or any complaints about the way that the study is being implemented you can contact the Principal Investigators of the project.

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Similarly you can also contact the Human Research Ethics Committee (Medical) which oversees the ethical aspects of this study. Members of this committee can be contacted through Ms Anisa Keshav on 011 717 1234.

Appendix 16: Focus Group Discussion Guide

FOCUS GROUP DISCUSSION GUIDELINE

SECTION 1: INFORMATION SHEET

How the process will work:

- We will hold the discussion in a group where I will ask some questions. Anyone has the right to respond but each person should try to give another person the opportunity to complete their response before responding.
- Let us try to respect each other's comments
- We will be sharing confidential information amongst the group. I need to request everyone to keep this information confidential so that we can ensure that everyone is able to speak freely. I personally and the other researcher will keep all information confidential and the recorded discussion will be shared between only myself and the other researchers and the tapes will be kept in a safe and locked place until they are destroyed after two years. I however cannot guarantee that everyone else in the group will exercise confidentiality. This is solely dependent on each one of you to protect each other.
- You can ask a question at any point in the discussion if you need clarification or an explanation
- Please keep cell phones off for the duration of the discussion

SECTION 2: VIEWS AND EXPERIENCES OF COMMUNITY WORK AND THE CHWP

Interview question 1:

In order for me to understand the work that you do and to know about your experiences of working in the community, I wish to know more about the services you provide to the community, the type of clients you see, how you get to meet your patients and the challenges of working with patients especially your experiences of working in the clinics with the nurses and in patients' homes.

Issues to cover:

- Type of clients seen
- Guidelines available on providing the services

- Challenges of your work - examples

Probe:

- What have been some of your experiences in working as CHWs and providing health services in the community?
- Describe some of your roles and experiences of working in the local health facilities
- Difficulties of working with nurses in the health facilities?
- Benefits of working with the nurse in the health facilities
- What are the difficulties of working with patients?

Interview question 2:

Perhaps you can also provide some examples of how you have been successful with some of your patients and some where you feel you were not so successful.

Issues to cover:

- Challenges where you were not successful and why
- Successes – examples

Probe:

- What have been some of successes when working with your patients?
- Who do you report to in times of emergencies? [for instance, if a patient has a certain episode and you need advice]
- Please provide an example of times where you have had problems or grievances with anything or anyone in other government sectors (such as department of home affairs, social services, etc.)
 - What process did you follow to voice your complaint?
 - Was your complaint taken care of? Please explain

Interview question 4:

You obviously function within the CHWP. I would like to hear your general views on the programme, what its benefits are, the guidelines available if at all and your positive and/or negative experiences of implementing the programme.

Issues to cover:

- Strengths of the programme – examples
- Weaknesses of the programme - Please give some examples
- Benefits
- Career path opportunities
- Training
- Supervision

Probe:

- Have you been informed about the CHWP? If yes, what do you know about it?
- What is your opinion on the CHWP?
- What are some of the benefits of the CHWP on you as a CHW?
- What are some of the benefits of the CHWP on the patients that you see?
- What are the disadvantages of the programme for both you the CHW and the patient?

I would take the material out of the section above on their views of the programme...and put it together in a separate question

Interview question 5:

Please describe some of your experiences in the referrals of patients. Describe how and who refers patients to you and how and to whom you also refer patients. Perhaps provide your views on whether the referral system is working or not and why you think so.

Issues to cover:

- Who refers to CHWs
- To who do CHWs refer to
- Example/s of challenges experienced with referrals

Probe:

- What are some of the difficulties and/or successes with the referral system?
- In your experience, what do you think would work best so that patients are referred appropriately?

Interview question 6:

Also explain and describe how and whether you interact with other government sectors to assist your patients, for instance, social services, home affair, etc. Describe the nature of your interaction and perhaps who you deal with the most. Also add your experiences by giving some examples of your experiences with one of the departments.

Issues to cover:

- Government sector/s worked with the most
- Challenges of working with other sectors – example
- Successes of working with other sectors – examples
- Strategies used to link with other sectors [how and why they made the decision to link with the sector/s]

Probe:

- What are the challenges of linking with other government sectors?
- Name some of the government sectors you have worked with
- Which government sectors have responded to your needs – example
- What avenues are there to address and link up with other sectors that have an impact on the community's health?

Interview question 7a:

Besides the work you do in the community in terms of healthcare provision, what other community activities are you involved in that involve other community structures? In that description, please provide your views and explanation on any interactions you may have with the ward committee or health committee or other community structures and what the nature of your interaction is with these community organizations. Please mention if there are other community committees that are not linked to government and comment if or why they are different.

Interview question 7b:

Please provide an example of times where you have had problems or grievances with anything or anyone in the health facilities and used some of these community structures to facilitate some action.

Issues to cover:

- Nature of involvement in community structures
- Type of activities CHWs participate in
- Awareness of the community structure and how they utilize them

Probe:

- What are views on the community structures in your community that allow the community to be involved in health issues and decisions?
- What do you think are the challenges of the community participating in community issues?
- What challenges do you think these community structures face to encourage and support the community to participate?
- What could be done differently that would improve community participation?

Thank you for your time

Appendix 17: CHW information sheet on participant observations

Information sheet: Community Health Worker

Good day. My name is [name of researcher] and I am a member of a research team from the Centre for Health Policy (CHP) (University of Witwatersrand in Johannesburg). I would like to obtain from you an overview of the work that you do in your community. I would also like to hear your views on the community health worker programme (CHWP) and your experience with working in your organisation. I hope that you will share with me your experiences of working in your community and the challenges and successes that you face and have faced in the past.

Background

CHP has been granted funding for a project to evaluate the CHWP in Gauteng. We are mostly interested to know how you go about doing your work; who you relate to on a day to day basis; who you depend on to help your patients and your community. We are also interested in knowing what drives you to do the work that you do and your opinion on what makes it difficult to do your work and also what makes it difficult to do your work.

To gain a better understanding of the work that you do and the challenges that you face, I will be travelling with you as you go about doing your work in the community.

You have been selected to participate because we believe that you will be able to provide us with valuable information about the nature work that you do as a CHW and the challenges and successes you face, about the CHWP and the nature of your relationship with other agencies in the community, such as the clinic, the NGO and other community structures.

I would like to invite you to participate in this study and to ask your permission to allow me to travel with you over 2-3 days as you go about your work in the community.

Why we want to observe you?

I am observing a number of other CHWs who work in other organisations who are involved in the work that you do. I would like to observe your experience of working with the community and other government sectors. I would also like to hear your views about what makes your work difficult and what makes it easier.

About the observation process

I would like to observe you as you go about doing your work in the community. I will be coming with you to all the people and institutions that you visit on a day to day basis to get a sense and a better understanding of the people that you interact with in your work. I will also need to come

with you when you do your home visits to your patients. I will also need you to select two patients that you have provided services to. One should be one that you feel that you have been successful in assisting them and the other should be one who you feel you were not so successful with in assisting. I will thereafter need you to ask permission from the patient and/or his/her family to come to their home and observe as you assist them. Before the visit, I will provide you an information sheet which you/ the patient can read so that they can understand what the visit will be about and I will also provide you with a consent form which the patient will have to sign to say whether they permit me or do not permit me to come to their home to observe.

The observation will take place over 2-3 days. During those observations, I can assist you if you need me to, but I will interfere with your work and your interactions. Before the observation, I will also request that you draw up a map of all the places and people you regularly interact with on a daily basis to do your work. You will be provided with an information sheet and a consent form for this activity.

Consent

Permission to carry out this project has been obtained from the provincial Department of Health and the organisation that you work for [name of organisation]. Ethical approval for this study has been obtained from the University of the Witwatersrand Ethics Committee for Research on Human Subjects (medical).

Will there be any benefit from participating?

You will not benefit directly from participating in this study.

Will there be any harm from participating?

No harm will come to you from participating in the study, as all information will be kept confidential and no one in the organisation/community/department will know what you have said. Similarly there will be no negative consequences for individuals who do not want to be interviewed.

During the observation you have the right to decline to answer any of the questions or stop being observed at any time. The fact that you have done this will not be reported to anybody, will not be recorded in the research report and will not have any negative consequences for you.

Permission to take notes during the observation: To make it easier for me to recall all the details and interactions that occur during the observation, I will need to take down notes which will help me to write down the exact information from the observation. If you do not want the researcher to take down any notes, that is your right, and it will not influence the observation or the research in any way. You also have the right to request to read the notes or for someone to read or explain the content of the notes to you. If you give me permission to write notes I will look through the notes later and write them in detail, but I will not use your name. I will keep the notes for two years under lock and key, after which they will be destroyed.

At the end of the research project I will write up a report. This report will include information that I noted during the observation, but your name will not be used. No one apart from the researchers involved in the study will know that it was you who was being observed.

Confidentiality

As a participant in the research you can expect that all the information you provide will be treated in a confidential way. The names of facilities and individuals will not be used in the research report. We will keep all information that people provide confidential. If necessary a member of the research team may contact you to check that you are happy with what has been written, and are not worried that you can be identified.

Contact Details of the Principal Investigators of the Research Project

If you have any further questions, or any complaints about the way that the study is being implemented you can contact the Principal Investigators of the project.

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Similarly you can also contact the Human Research Ethics Committee (Medical) which oversees the ethical aspects of this study. Members of this committee can be contacted through Ms Anisa Keshav on 011 717 1234.

Appendix 18: Community health worker consent form for participant observations

CONSENT TO OBSERVE CHW DURING DAILY ACTIVITIES

I have read the project information sheet and have been briefed by the researcher prior to the observations and I give my consent for the researcher to come with me observe my daily activities for the next 2 - 3 days.

I am aware that the researcher will travel with me as I conduct my work in the community. I am aware that the researcher will be taking notes during the observations. I am aware that these notes will be fully written in a report which will be read in the future by those that are involved in the work of CHWs, such as the managers of NGOs, those that are in the Department of Health, by us the CHWs and other agencies. I am also aware that my name will not be used in the report. The notes from the observation may also be used as part of a book that documents the experiences of CHWs and those that use their services. The notes will not be used for commercial purposes.

Yes, I give permission to be observed as I conduct my work in the community	☐
No, I do not give permission to be observed as I conduct my work in the community	☐

CHW's signature: _____ Date: _____

Researcher's signature: _____ Date: _____

Researcher's name
(please print): _____ Date: _____

Appendix 19: Information sheet for client/household member to be observed

Information sheet: Clients – Participant Observation

Good day. My name is [name of researcher] and I am a member of a research team from the Centre for Health Policy (CHP), University of Witwatersrand in Johannesburg. I would like to invite you to participate in a study about community health workers and your experience of being assisted by them. Here is some information about the study and the information that we are hoping to find from you.

Background

CHP is evaluating the Community Health Worker Programme (CHWP) and to see how the work that CHWs provide for you and the community assists you in your daily lives. To gain a better understanding of what CHWs do and how they do it, we have chosen you and other people who use their services so that we can understand how they assist you.

I would like to invite you to be observed by myself, the researcher during your interaction with the CHW so that I can gain more understanding of how they assist you with your health and/or other areas of your life.

Why I want to observe you?

I am observing you and a number of other people who have used the services of CHWs. I would like to see how you and your CHW interact with each other and how the CHW helps you in your home.

I am requesting permission from you and your family to come and visit your home during the days and times that the CHW comes to do her visits to your home. I will visit for one day and observe throughout the time that the CHW is with you.

About the observation process

I would like to observe you and the CHW for the time that s/he spends with you. The observation will be in your home during the CHW's home visit to you. During the observation, I will be taking notes of which I will ask for your permission to do so. There will be times when I help out if the CHW needs me to but I will not interfere with your regular interaction with her/him. If it makes you feel more comfortable, you are welcome to ask questions during the process.

Consent

It is entirely up to you whether or not you are observed. It is your right to refuse to be observed and that will not impact on the care that you receive in any way. The researcher who carries out the observation does not work at any hospital/clinic/CHW organisations and cannot influence the care that you get in any way.

If you do agree to be observed, you are free to stop the observation at any time and that will not be a problem in any way.

Will there be any benefit from participating?

You will not benefit directly from participating in this study, although we hope that our overall findings will help to improve the services that you get from CHWs.

Will there be any harm from participating?

No harm will come to you from participating in the study, as all information will be kept confidential and no one at the facility will know what you have said.

Confidentiality

The information that is noted during the observation will be kept confidential. The researcher who works on the research project is not a staff member at any hospital/clinic/CHW organisation. She will not report what you said to anyone who works at the hospital/clinic/CHW organisation.

Permission to take notes during the observation: To make it easier for me to recall all the details and interactions that occur during the observation, I will need to take down notes which will help me to write down the exact information from the observation. If you do not want the researcher to take down any notes, that is your right, and it will not influence the observation or the research in any way. You also have the right to request to read the notes or for someone to read or explain the content of the notes to you. If you give me permission to write notes I will look through the notes later and write them in detail, but I will not use your name. I will keep the notes for two years, after which they will be destroyed.

At the end of the research project I will write up a report. This report will include information that I noted during the observation, but your name will not be used. No one apart from the researchers involved in the study will know that it was you who was being observed.

If you have any further questions or complaints

You can contact the Principal Investigators of the project.

Contact Details of the Principal Investigators of the Research Project.

If you have any further questions, or any complaints about the way that the study is being implemented you can contact the Principal Investigators of the project.

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Similarly you can also contact the Human Research Ethics Committee (Medical) which oversees the ethical aspects of this study. Members of this committee can be contacted through Ms Anisa Keshav on 011 717 1234.

Appendix 20: Consent form to observe during client home visit (from client/household member)

CONSENT TO OBSERVE DURING PATIENT/CLIENT HOME VISIT

I have read the project information sheet and have been briefed by the community health workers (CHW) prior to the observation and I give my consent for the researcher to come to my home and observe my home and my interaction with the CHW.

I am aware that a researcher will visit my home for a day with a CHW. I am also aware that the researcher will be taking notes during the observation. I am aware that these notes will be fully written in a report which will be read in the future by those that are involved in the work of CHWs, such as the managers of NGOs, those that are in the Department of Health, by the CHWs themselves and other agencies. I am also aware that my name will not be used in the report. The notes from the observation may also be used as part of a book that documents the experiences of CHWs and those that use their services. The notes will not be used for commercial purposes.

Yes, I give permission for my home to be visited and for me to be observed	☐
No, I do not give permission for my home to be visited and for me to be observed	☐

Client/household member's signature: _____ Date: _____

Researcher's signature: _____ Date: _____

Researcher's name (please print): _____ Date: _____

Appendix 21: Ethical Clearance Certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

R14/49 Miss Nonhlanhla Nxumalo

CLEARANCE CERTIFICATE

M090237

PROJECT

The Gauteng Province Community Health Worker Programme: The Extent to which it Contributes to the Provision of Comprehensive....

INVESTIGATORS

Miss Nonhlanhla Nxumalo.

DEPARTMENT

School of Public Health/Centre for Health Policy

DATE CONSIDERED

09.02.27

DECISION OF THE COMMITTEE*

Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE

09.03.23

CHAIRPERSON



(Professor P E Cleaton Jones)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : Prof J Goudge

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and ONE COPY returned to the Secretary at Room 10004, 10th Floor, Senate House, University.

I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. I agree to a completion of a yearly progress report.

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...