

# **Alleviating the Burden of Responsibility: Report on a Study of Men as Providers of Community-Based HIV/AIDS Care and Support in Lesotho**

**Lesotho Ministry of Health and Social Welfare  
in Collaboration with The Capacity Project**

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*The views expressed in this document do not necessarily reflect the views of the United States Agency for International Development or the United States Government.*

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## **Abbreviations and Acronyms**

CHAL	Christian Health Association of Lesotho
CHBC	Community Home-Based Care
CHW	Community Health Worker
DHI	District Health Inspector
DHS	Demographic Health Survey
DMO	District Medical Officer
DPHN	District Public Health Nurse
FGD	Focus Group Discussion
GOL	Government of Lesotho
HC	Health Center
KII	Key Informant Interview
LENEPWHA	Lesotho Network of People Living with HIV/AIDS
MDA	Miners Development Agency
MOHSW	Ministry of Health and Social Welfare
NC	Nurse Clinician
NGO	Nongovernmental Organization
PHC	Primary Health Care
PLHIV	People Living with HIV and AIDS
TEBA	The Employment Bureau of Africa
VSO	Voluntary Service Overseas
WLSA	Women and Law in Southern Africa

## Foreword

Gender disparities need to be addressed in human resources for health (HRH) policy and planning, workforce development and performance support to assure that men and women contribute to and benefit from social and economic development on an equal basis. The desired outcomes of all gender-related actions in HRH are improved service delivery and health—for workers and for the communities they serve. As it works to strengthen HRH systems to implement quality health programs in developing countries, the Capacity Project—a USAID-funded global project that focuses on planning, developing and supporting the health workforce—is concerned with how differences and inequalities affect women’s and men’s opportunities for education, training and occupational choice. The Project promotes interventions that are deliberate in addressing gender disparities, working from the following strategic framework:

- **Purpose:** Reduce gender barriers to women’s and men’s participation in the health workforce by addressing inequalities that affect workforce entry, safety, professional satisfaction, mobility, rights at work and retention
- **Strategic objectives:** (1) Strengthen HRH policy and planning to promote gender equality; (2) increase gender integration in education, training and work; (3) create supportive, fair and safe work environments.

Gender segregation of occupations, which typically assigns caring/nurturing jobs to women and technical/managerial jobs to men, has been recognized as a major source of inequality worldwide with implications for the development of robust health workforces. Gender segregation in HRH tends to differentially restrict access to health occupations, positions and tasks for interested men and women. Stereotypical conceptions of women and men, which sustain occupational and task segregation, may be embedded in educational or occupational recruitment strategies, educational curricula and institutional hiring policies that impact would-be health service providers from the time they enter primary school to the time they complete professional education or enter a health occupation. Gender segregation of health occupations in the era of HIV/AIDS, in combination with the problem of “brain drain,” makes for inefficiencies and missed opportunities that are highly problematic because they create barriers to workforce entry and hence, the fullest possible pool of formal and nonformal health workers. The Capacity Project assisted the Lesotho Ministry of Health and Social Welfare to strengthen its capacity to respond to the HIV/AIDS pandemic by addressing gender segregation in nonformal caregiving through the active engagement of men as providers of community and home-based HIV/AIDS care and support.

Most men in Lesotho have been attracted to mining in South Africa, but as these jobs have disappeared, and as the demand for more workers to respond to community-based HIV/AIDS care and support needs has increased, there is increasing awareness of the need to move beyond traditional divisions of labor, multiply the number of hands to do the work of caregiving and “alleviate the burden of responsibility” (Government of Lesotho. Gender and Development Policy, 2003). The Capacity Project conducted a study to understand the gendered division of labor and the dynamics of caregiving in

three districts of Lesotho and to identify sustainable, *gender redistributive*<sup>1</sup> approaches to recruit, train, support and retain men in jobs traditionally considered the province of women. The study had an additional aim, which was to offer alternatives to male unemployment while addressing the critical shortage of health workers in Lesotho. The study's central questions were: *To what extent can men be attracted into caregiving jobs traditionally considered the province of women? What will it take to increase the numbers of male HIV caregivers and to address barriers that may keep the potential pool of male HIV caregivers low?* The recommendations of this report focus on ways to reduce gender segregation in HIV/AIDS caregiving through health workforce policy and planning, development and support efforts.

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<sup>1</sup> The Lesotho Gender and Development Policy defines “redistributive” approaches as “Interventions intended to *transform* existing stereotypes to ensure gender equity and equality by a more even redistribution of resources, responsibilities, and power between and among men and women, girls, and boys.”

## Executive Summary

Early in 2008 researchers conducted 25 individual interviews and 31 focus groups with 264 respondents in villages, health clinics and hospitals across the three districts in Lesotho chosen to represent two ecological zones, to contain both rural and urban sites and to achieve Ministry of Health and Social Welfare and Christian Health Association of Lesotho representation. The study collected a range of perspectives about gender and HIV/AIDS care from those participating in and potentially affected by health care initiatives.

The objectives of the study were as follows:

1. Determine the need to bring men into community-based HIV/AIDS care and support
2. Determine the feasibility of engaging men as providers of community-based HIV/AIDS care and support, especially the gender-related and cultural factors that need to be addressed to increase male involvement in community-based care, based on an analysis of gender relations in Lesotho
3. Identify factors that facilitate or hinder substantive and sustained male involvement in community-based HIV/AIDS care and support
4. Make recommendations for feasible gender-redistributive recruitment, training, support or retention strategies to increase the number of male community-based providers of HIV/AIDS care and support in Lesotho.

Analysis of these interviews has determined that there is a need, and it is feasible, to involve men in community home-based care (CHBC) in Lesotho. The study used gender analysis techniques to learn how gender relations might influence the involvement of men in CHBC. It formulated recommendations consistent with Lesotho's 2003 Gender and Development Policy, asking how interventions might affect gender relations and whether proposed recruitment, training, incentive and retention strategies were "gender redistributive."

The study found that:

- Caregiving is a gender-segregated job. A nexus of gender stereotypes about essential "male" and "female" traits, status beliefs and perceptions of men and of caregiving kept women in voluntary HIV/AIDS caregiving and kept men out of it. In the long run, increasing and sustaining men's participation in home-based care appears untenable as long as women's continued volunteer labor is expected to fill the breach.
- It is feasible to involve men in CHBC, since the Basotho men and women in the study sample demonstrated psychological and social flexibility in taking on the domestic and household tasks ascribed to the other gender.
- Male respondents emphasized the technical aspects of caregiving, identified with more powerful male tasks and groups (first aid, miners) and represented this

work as more “masculine” by using male-identified traits, such as bravery, courage, dignity and discretion.

- Training can mitigate negative stereotypes of men, assuage women’s fears about men’s potential for sexual exploitation and increase men’s skills. Training for male and female community health workers (CHWs) should involve critical reflection on gender roles and responsibilities.
- Men stand to lose respect from other men and discretionary time by entering CHBC, but stand to gain economically by entering the now-remunerated CHW cadre. While men’s participation in CHBC can alleviate the disproportionate burden of HIV/AIDS care, women stand to lose the benefit of social recognition and may face competition from men in the CHW job.
- Standardized working conditions, such as financial and nonfinancial incentives, supplies and equipment, income generation activities, water and food security are essential elements of a increased response to community-based HIV/AIDS care and support needs.

The Government of Lesotho, nongovernmental organizations and donors have an opportunity to increase the pool of community and home-based HIV/AIDS caregivers of both sexes through resourced CHBC. CHBC policies and programs should address existing inequalities through explicitly gender “redistributive” and egalitarian policies, messages and recruiting, training and incentives practices (Government of Lesotho, Gender and Development Policy, 2003). Study recommendations targeted national policy, district and community-level interventions:

1. To reduce gender segregation in health work, national health, HIV/AIDS and CHBC and human resources policies should be *gender redistributive* and explicitly promote a more equal division of responsibilities between women and men, in general and in the context of HIV/AIDS care and support. The Lesotho government and other stakeholders involved in CHBC should simultaneously continue to strengthen women’s capacity to care for those affected by HIV/AIDS through gender-responsive policies, budgets and initiatives.
2. Gender redistributive HIV/AIDS and CHBC policies should be promulgated through training curricula, job descriptions and protocols. The national CHBC training curriculum should include skills training, critical reflection on masculine and feminine gender roles and gender equality in caregiving, communication, HIV/AIDS education, service ethics, gender-based violence and an introduction to male role models already engaged in CHBC.
3. Organizations should adopt a “Volunteer Charter” for CHWs and home-based caregivers to address conditions of work including standardized resources and protections with standardized working hours and remuneration; psychosocial support; response to harassment and violence; tangible protections such as pensions and child-support grants; and supplies needed to cope effectively.

4. CHBC programs operating at district or village levels should be designed or redesigned to be “redistributive.” Explicitly promote the equal sharing of responsibilities between women and men in training and supervision and in the recruitment of men. Interventions to recruit men for CHBC should not reinforce stereotypes or expectations of masculinity that might exacerbate existing gender inequalities.

We hope this study will help human resources for health practitioners in Lesotho and elsewhere to think about ways to reduce gender segregation in health occupations and tasks, to alleviate the burden of care on women and to address the shortage of nonformal health workers involved in HIV/AIDS prevention, care and support.

## **Introduction**

Lesotho is a small country with an area of 30,355 square kilometers and a population of 1.8 million, landlocked and enclaved within South Africa. The country has four distinct ecological zones: the lowlands, foothills, mountains and the Senqu valley. The country is mountainous and more than 80% of the land is 1,800 km above sea level. This topography and a climate of often severe winters present challenges to health service delivery (GOL Gender and Development Policy, 2003).

### **Economy**

Lesotho is a resource-poor country with a large percentage of the population (76.2%) residing in rural areas, where poverty is most prevalent. The country depends mainly on subsistence farming, manufacturing and remittances from migrant labor in South African mines.

### **Population**

Lesotho has a young population, 40% of which is under 15 years of age. The current annual population growth is estimated at 25% and in 33 years the population is expected to double, 76.2% of the population reside in the rural areas where poverty is most prevalent (Health and Demographic Survey, 2004).

### **Health Care System**

Primary health care (PHC) was adopted as a strategy for health service provision in Lesotho in 1979. Eighteen health service areas were delineated on the basis of the catchment populations. The nineteenth health service area is served by the Lesotho flying doctor service, providing assistance to the most remote areas of the country.

Public health care and social welfare services are administered by the Ministry of Health and Social Welfare (MOHSW). The GOL also subsidizes the provision of health services by the Christian Health Association of Lesotho (CHAL) and a limited number of other nongovernmental organizations (NGOs). CHAL provides approximately one-third of health care through a network of eight health service area hospitals and 73 health centers (HCs). CHAL facilities tend to be located in sparsely populated, remote and underserved populations.

In 1997 the local government established administrative districts that were charged with overseeing the provision of health and social welfare services. The decentralization affects the delivery of health services, and there are often overlaps in service management. It is not clear how district level HIV/AIDS councils relate to MOHSW health service areas.

## **Disease Burden**

Lesotho has the third highest HIV prevalence rate in the world, at 23%. It also has the fourth highest rate of tuberculosis incidence and a growing problem of multi-drug-resistant tuberculosis. These high rates create a heavy burden and severe adverse impacts on socioeconomic indices of the population.

The Demographic and Health Survey (DHS) measures of attitudes of acceptance toward those living with HIV include the following: 87% of women and 79% of men are willing to care for a family member with the AIDS virus in the respondent's home; and 64% of women and 66% of men would not want to keep secret that a family member was infected with the AIDS virus, though women's and men's acceptance on five attitude measures was low (24% of women and 20% of men).

UNAIDS estimated 23,000 annual deaths in Lesotho due to AIDS in 2003. The Lesotho Network of People Living with HIV/AIDS (LENEPWHA) Five-Year Strategic Plan states that "the number of people living with HIV/AIDS is high and steadily growing," with about 55% (146,300) of cases in 2005 being females aged 15-49, of which 75% were aged 15-29. Of the 270,000 Basotho living with HIV in 2005, 14% were receiving ARVs. Life expectancy in Lesotho fell from 60 years in 1989 to just 39 years by 2005.

The impact of the HIV/AIDS epidemic has resulted in an increased burden on the health care system. It directly affects the health of large numbers of people in society and reduces the overall health status and wellbeing of the nation contributing to increased morbidity and mortality and placing stress on already overstretched health care system (National AIDS Policy, 2006).

The most basic level of PHC service provision is at the community/village level where an estimated 4,800 volunteer community health workers (CHWs) are the first line health providers (Human Resource Needs Assessment Survey, 2004). LENEPWHA notes that many of these women, who are primary family caregivers, will experience early mortality. Among AIDS deaths in 2005, 54% were women and 46% were men, 97,000 children were orphaned as a result of AIDS and other causes and with an increase in children-headed households. This suggests that children and adults needing care, psychosocial support and community mobilization will likewise increase. A 2004 UNAIDS report estimated that in Africa, only approximately 12% of HIV-positive people in need of home-based care actually received it.

This study supports two strategic options included in the GOL's 2006-2010 National HIV/AIDS Strategic Plan: promoting the involvement of men in home-based care; and recognizing and supporting caregiving services offered by women and girls to HIV/AIDS patients. The study was conducted on behalf of the Lesotho MOHSW's Family Health Division and its partner, the Capacity Project, in order to find out what it would take to attract, train, support and retain men as providers of community-based, home-based HIV/AIDS care and support.

The study utilized a gender analysis framework to explore the gendered division of labor (including the tasks related to HIV/AIDS care and support that are currently female-identified tasks), how time is spent and where, how stereotypes about men keep them from taking on HIV/AIDS care and support tasks and how stereotypes about women keep them performing these HIV/AIDS care and support tasks, in order to recommend gender-equitable strategies to attract, retain and support men that are favorable to both men and women and consistent with the GOL's gender policy. The goal is to strengthen the capacity of Lesotho's health system to address the HIV/AIDS pandemic at the community level by increasing the active engagement of men as providers of community home-based health care. The results of this study are meant to be disseminated at national, district and community levels, in order to shape policy, strategy, behavior change communication, program development and implementation and resource mobilization.

### **Relevance of the Study**

The study results contribute to the 2006 National HIV/AIDS Strategic Plan in the following areas:

- Strategic Focus Three: Treatment Care and Support, Strategic Option 1.11.1.2 k) Promotion of the involvement of men in home-based care
- Strategic Focus Four: Impact Mitigation, Strategic Option 1.12.3.2h) Recognizing and supporting caregiving services offered by women and girls to HIV and AIDS patients.

This study will also contribute to the following GOL HIV/AIDS Strategic Monitoring and Evaluation indicators:

- 012: Number of caregivers trained to provide home-based care
- 013: Number of caregivers that are providing home-based care
- 015: Number of caregivers that have been trained to provide care and support to orphans and vulnerable children.

## Context and Justification

In this section, recent findings from research in the sub-Saharan Africa region are presented and rationales formulated to explain why we studied men as potential providers of community-based HIV/AIDS care and support in Lesotho, a job traditionally considered the province of women. It should be noted that in Lesotho there are more male traditional healers than females and that in professional spheres there are more male doctors, while females comprise the majority of the workforce in fields where caring is dominant (e.g. nursing, teaching and home economics) because these are traditionally believed to be the female domain.

### Burden of Care on Women

“The burden of HIV and AIDS care has dehumanized women; it has feminized poverty and turned women into workhorses in the name of volunteering and caring for the community” (Augustine Chella, Voluntary Service Overseas [VSO], Zambia).

It has been estimated that two-thirds of primary caregivers in households surveyed in Southern Africa are female (one quarter of whom are over 60 years of age); another study puts the estimate as high as 91%. The NGO VSO in Zambia reported in an influential policy brief that the increasing demands placed on communities to provide community and home-based care—mostly by women and girls—results from “a complex interaction of factors, including: gender inequality, traditionally gendered roles, weak public health systems, health care worker shortages and migration, insufficient donor and national funds, weak social security systems and poverty and structural adjustment policies of earlier decades that reduced the public sector mandate and capacity.” In many countries, this situation has resulted in what amounts to a crisis of care and an unsustainable burden on women and girls.

### Impacts of an Unshared Burden of Care

The impacts of an unshared burden of care on women include social, physical and psychological/emotional stress, and lost opportunities for education, careers and income. A recent study in South Africa found that 40% of caregivers had to take time off from work, resulting in lost income and deepened poverty. Further, where women are the main agricultural producers, this productive function is undermined when women and girls become caregivers. In general, home-based caregivers’ experience of stress/distress, as well as their vulnerability to infection, are exacerbated by the lack of adequate training, mentoring and support. A study in Botswana also reflects the above findings and adds the following: older women were overwhelmed by the multiplicity and scope of caregiving tasks, felt depressed and exhausted and neglected their own health; while young girls, in addition to frequently missing school, were sexually and physically abused, sexually exploited and depressed. Both age groups experienced poverty, social isolation, stigma, psychological distress and lack of caregiving education (Lindsey et al, 2003). In light of the foregoing, it is imperative to address the unequal burden of care on women and girls, stated both in Lesotho’s gender and development and national

HIV/AIDS policies, by conducting research into ways to increase the pool of caregivers, since it will not be sustainable to “try to achieve universal access through continuing to exploit women’s unpaid labor.”

### **Gender Segregation of Health Occupations and Tasks: The Feasibility and Advantages of Involving Men in Community-Based Care and Support**

The International Labor Organization has determined that gender segregation in health occupations, by which caring/nurturing jobs are assigned to women and technical/managerial jobs to men on the basis of cultural stereotypes, is a source of inequality worldwide. Cultural stereotypes are related to seemingly intractable presumptions about essential gender-specific skills, proclivities and tastes that guide the gendered division of labor in households and at work and impede the crossover of women into male-identified jobs and men into female-identified occupations.

Gender segregation in health occupations in the era of HIV/AIDS in combination with the problem of “brain drain” makes inefficiencies and missed opportunities highly problematic because it creates barriers to the fullest possible pool of formal and nonformal health workers. The problem of sex stereotyping in occupations has been fully recognized by the GOL’s 2003 Gender and Development Policy, which states that gender stereotypes limit the capacity of boys and girls “to venture into non-traditional careers like medicine and politics for girls and catering and nursing for boys.” The increased involvement of men and boys in HIV/AIDS care would mean more hands to do the work, and in the words of one CHW, a “united effort brings the bull to the ground.”

To this end, Lesotho’s Gender and Development Policy urges the government to “advocate for the improvement and expansion of gender-sensitive home-based health care service delivery with particular attention to HIV/AIDS affected and infected persons *to alleviate the burden of responsibility on women.*” At the 2007 National Symposium on Community-Based Worker Systems, the first lady of Lesotho noted that 92% of community-based workers are women, which “points to the challenges and gender dynamics of the subject of community-based work in Lesotho, a situation I hope will be addressed in the nearby future.”

### **Feasibility of Changing Gender-Stereotyped Roles and Tasks to Increase Men’s Participation in CHBC**

**Positive evidence:** In some countries, gender stereotyping and occupational segregation by gender are very rigid; in others, occupations have become less gender-segregated or more so as a result of historical processes. For example, men had already entered the ranks of nursing in South Africa in the context of war and as a part of the mining industry in the first four decades of the last century, though this path was blocked to men after 1948 (Burns, 1998). Lupton found that men’s entry to female-dominated occupations is less linked to masculine gender roles than to the promise of social mobility (Lupton, 2006). Recent research from Zambia demonstrated that trained

male and female caregivers provide similar types of care to people living with HIV and AIDS (PLHIV), including personal care tasks and housework—which are often perceived to be women’s tasks — if they are given adequate training, support (including warm meals) and access to community partnerships (William, 2006).

There are also recent success stories on male involvement in HIV/AIDS care provision from Zimbabwe (AED, 2003), Kenya (Astrid, 2006), Botswana (Lindsey, 2003), Ethiopia (the USAID-funded High Risk Corridor Initiative) and South Africa (Akintola, 2006; and UN Department of Economic and Social Affairs/DAW July 2008).

The extent of rigidity of gender roles and related occupational gender segregation of HIV/AIDS care and support work is as yet undetermined in Lesotho. Information gathered in the planning phase of this study indicated that women are disproportionately responsible for HIV/AIDS caregiving: a source at LENEPHWA reported that only 20% of their PLHIV caregivers were men (personal interview, 2007). However, the return from mining jobs in South Africa, in circumstances where the HIV/AIDS pandemic requires a reconstituted workforce, may in fact represent a period of opportunity and experimentation for some retrenched men returning to Lesotho. Further, it is possible that the previously cited DHS finding in which 79% of Basotho men were willing to care for family member with the AIDS virus in the respondent’s home reflects men’s openness to providing home-based care *themselves*, with training and support. Finally, a study conducted by the organization Women and Law in Southern Africa (WLSA) in 1998, which identified areas in which Basotho women had already taken on economic provider roles traditionally performed by men, in other ways drew distinctions between customary ideals and current practice and concluded that “custom is not made up of hard and fast rules, but is flexible and changes as circumstances demand” (Leduka, 1998). These were some of the questions explored by the study.

**Potential limiting factors:** Exploring the extent to which Basotho men will perform female-identified CHBC tasks requires consideration of potential limiting factors in the more equitable redistribution of these tasks. Sociological research posits that gender plays a role in the fundamental organization of social relations between individuals derived from the stereotypes, status assumptions and cognitive biases that result from gender roles (Ridgeway, 2006). If this is so, then attempts to transform men’s and women’s gender identities and gender roles may meet with resistance and might need particular kinds of social support to effect and sustain transformation.

In light of the challenge to masculine and feminine identities that men’s involvement in CHBC might represent, we also used the concept of “identity work” as a tool to understand the challenges that men may face in becoming involved in CHBC. Because societal pressure and personal desire to embody masculinity seems incompatible with traditionally “female” jobs or tasks, Lupton used the term “identity work” to describe coping strategies that men have used when crossing gender boundaries into “female occupations” in order to deal with a challenge to sexuality or to affirm their masculinity. Lupton observed that “identity work” strategies construct masculine identities and reinforce the gender order rather than subvert it and include:

- Emphasizing career prospects
- Disassociating (oneself) from job the when outside workplace
- Identifying with more powerful male groups
- Representing the work as more masculine.

Societal pressure to embody masculinity appears to be incompatible with working in traditionally “women’s jobs.” Other research found that because “women’s jobs” are undervalued and undercompensated, men are less likely to want to enter the field and that female students were less likely to stereotype professions by gender than males (Careers Scotland, 2004). This suggests that men may feel a stronger demand to restrict themselves to “male” jobs.

### **Advantages to Recruiting Men as Providers of HIV/AIDS Care and Support**

Regardless of limiting factors, recent research in Africa and elsewhere points to the feasibility and benefits of men’s participation in CHBC. Below are a summary of advantages to recruiting men as providers of HIV/AIDS care.

- Recruiting men into jobs traditionally considered the province of women not only addresses the shortage of community-based health workforce; it also alleviates the burden of care on hospitals and the burden carried by women and girls in the community.
- Recruiting and training men as HIV/AIDS care providers may increase the perceived quality of care, especially for clients of home-based care who want a same-sex provider to help with intimate activities of daily living. Patient care will actually improve as human resources are more plentiful.
- Men have influence in communities as traditional leaders and decision-makers and can channel leadership and advocacy to support families affected by AIDS and women and girls inequitably burdened by caregiving. In these capacities, men can also serve as role models for younger men.
- Men and women working together are better able to fight stigma and fear of discrimination.
- Information about what it would take to increase the numbers of men in community-based HIV/AIDS care and support in Lesotho may have broader uses, such as informing policies and programs to increase entry of both men and women into other gender-segregated jobs in Lesotho, e.g., the nursing assistant cadre for men, medicine for women.

# Goal, Purpose and Objectives

## Goal

To strengthen the capacity of Lesotho's health system to address the HIV/AIDS pandemic at the community level by increasing the active engagement of men as providers of community home-based health care.

## Purpose

To identify sustainable, gender redistributive practices to recruit, train, support and retain men in community-based HIV/AIDS home-based care and support jobs traditionally considered the province of women in three districts in Lesotho.

## Objectives

1. To determine the need to bring men into community-based HIV/AIDS care and support
2. To determine the feasibility of engaging men as providers of community-based HIV/AIDS care and support, especially the gender-related and cultural factors that need to be addressed in order to increase male involvement in community-based HIV/AIDS care and support, based on an analysis of gender relations in Lesotho
3. To identify factors that facilitate or hinder substantive and sustained male involvement in community-based HIV/AIDS care and support
4. To make recommendations for feasible gender-redistributive recruitment, training, support or retention strategies to increase the number of male community-based providers of HIV/AIDS care and support in Lesotho
5. To disseminate study results in such a way as to ensure applicability at national, district and community levels of the health system.

## Methodology and Data Analysis

The study investigated the need for, feasibility of and hindering and facilitating factors related to men's substantive engagement in community HIV/AIDS home-based care and support in three districts of Lesotho. The study made use of qualitative and quantitative research methods to collect and analyze data. In interviews and analysis attention was paid to the ways that respondents understand the role of caring as a gendered role and how gendered perceptions of caring labor affected men and women's participation in CHBC, particularly with regard to caring for persons living with HIV/AIDS.

### Data Collection Methods

**Key informant interviews (KIIs):** Key informant interviewing is a preferred method for eliciting in-depth information on little-understood topics by eliciting responses from informants who provide the richest and most detailed content possible in relation to his or her own experiences. The flexible probing, according to the answers and interests of the informant, allows for a deeper understanding of a phenomenon. KIIs are particularly useful with information gatekeepers, community leaders and decision-makers who can provide insight into the complex processes used in implementing health care delivery systems and are used with individuals who are presumed to have special knowledge of a subject. KIIs were conducted for the following: village chiefs, HC nurse clinicians (NCs), health service area officials (e.g., district public health nurse [DPHN], medical superintendent, district medical officer and district health inspector [DHI]) and district health officials (district administrators and district HIV/AIDS officers).

**Focus group guides:** Focus groups are another qualitative method preferred for obtaining a wide range of responses from a homogenous group of people in an area of interest. By using multiple focus groups we can obtain input from a much larger group of people more efficiently than with individual interviews. The group discussions allow deeper exploration into cultural phenomena, such as the gendered division of domestic and household labor and *incentives*, with participants reacting to each others' interpretations, challenging each others' stereotypes and clarifying individual vs. group beliefs, perceptions and values. Focus groups can elicit a wider range of experience and memories, which often reduces the positive response bias compared to individual interviews. Focus group discussions (FGDs) were conducted for the following groups: women and men CHWs (which included ex-miners); and HIV-positive men and women.

### Data Collection Location and Tools

Semistructured data collection tools were created to guide both KIIs and FGDs (see Annex A). The tools were designed to reflect the study objectives. Particular emphasis was placed on eliciting information on the gender-related and cultural factors that need to be addressed to increase male involvement, information that could be used for an analysis of gender relations in Lesotho.

**Study location and district selection criteria:** The districts of Maseru, Thaba Tseka and Quthing were purposively chosen to represent two of Lesotho’s ecological zones (lowland and highland areas), to contain both rural (underserved and remote) and urban sites and to achieve MOHSW and CHAL representation (see Annex C).

**Sample characteristics:** Twenty-five individual interviews and 31 focus group interviews were conducted with 264 respondents in villages, health clinics and hospitals across the districts of Maseru, Thaba Tseka and Quthing (See Table 1). 70% of respondents were women and the average age of respondents was 49 years. Fifteen percent of focus group attendees were ex-miners and 14% were PLHIV. Ex-miners were chosen because they represent a source of unemployed males, which is a target group for possible community home-based care (CHBC) provider recruitment.

**Table 1: Study Participants**

Level	Key Informants	Number of KIIs N=25	Focus Group Participants	Number of FGDs N=31
<b>District</b>	District Admin (3), District HIV/AIDS Officer (2)	5	HIV+ men HIV+ women HIV+ both	3 2 1
<b>Health Service Area</b>	DPHN (3), Medical Superintendent (2), TB Officer, DMO, DHI, PHC Dir	9		
<b>Health Center</b>	NCs	5	CHW's	9
<b>Village</b>	Chief	6	Village men Village women	8 8

**Selection and training of data collectors:** Data collection tools were translated into Sesotho. Data collectors were recruited from among the pool of experienced data collectors in Lesotho and were trained in the techniques they were going to apply. A three-day training workshop was conducted to develop or reinforce the data collectors’ capacity to collect data using qualitative methods. Various techniques were used, including: review and analysis of tools; short exposés; questions and answers; and brainstorming and role plays with feedback on the behavioral/interpersonal aspects.

**Pretest of tools:** Immediately following the data collectors’ training workshop, interviewers pretested data collection tools in the district of Maseru with key informants (local government representatives, public health team members, village chiefs and NC supervisors) using a semistructured field guide. Data collection tools were finalized according to pretest findings.

**Data collection:** KII and FGD data were collected in the three districts of Thaba Tseka, Quthing and Maseru during January and February, 2008. A team of six data collectors had data collection maps and interview instruments for each class of respondents in Sesotho and English. The maps guided the field team to respondents in

each district that were divided into district and HC level. Data were recorded in the local language during KII (n=25) and FGDs (n=31), and later transcribed at each district and filed. Data were then translated from Sesotho to English.

**Informed consent:** In light of the importance of strict ethical standards for research, especially in the area of HIV and AIDS, each data collection tool contained a written informed consent clause, read to each respondent or group of respondents with the following content adapted to the methods and type of respondent:

“This study was approved by the Ministry of Health and by an Ethical Review Committee. We would like to ask you some questions about the possibility of involving men in HIV/AIDS care and support activities at the community level in order to assist the Ministry of Health plan to improve community-based HIV/AIDS service delivery in Lesotho. You will not be contacted in the future. We will not write your name down and all names mentioned will be deleted from FGD transcripts. Your answers will remain confidential. During the study, the questionnaires and audio-tapes will be kept in the Study Managers’ office in a locked drawer. The only persons who see or handle the questionnaires or audio-tapes are those who work on the study.”

Consent was obtained from all participants before data collection.

## **Data Analysis Methods**

KII and focus group results were translated to English in Lesotho by the study manager and entered into NVivo8 qualitative data analysis software by a consultant data analyst based in Chapel Hill, North Carolina. A code book of thematic categories of analysis was generated by the consultant according to the four primary project objectives noted earlier and the six domains outlined in Annex B. Codes were created for demographic (gender, status) and geographic categories (region, social level). Code categories were also derived from a close reading of themes in respondents’ narrative language to elicit indigenous categories of meaning and local knowledge about gender, caring, and HIV/AIDS.

All interview and focus group texts were coded according to the thematic categories and, where appropriate, multiple codes were used to capture answers to all study questions. The content of the code-categories were then examined by the data analyst to identify patterns and relationships relevant to determining the need to bring men into community-based HIV/AIDS care. Gender-related and other cultural factors expressed by respondents that would facilitate or hinder substantive and sustained male involvement were identified and analyzed in relationship to structural factors such as access to and distribution of resources which enable or limit the capacity of local men and women to provide CHBC. Finally, interview narratives were examined to identify and make recommendations for feasible gender-redistributive recruitment, training, support or retention strategies to increase the number of male community-based providers of HIV/AIDS care and support in Lesotho.

Demographic, economic and labor-time data were quantified by the data analyst from the interview transcripts and records, then compiled and entered into spreadsheet tables in Microsoft Excel 2002 for comparative analysis according to project objectives.

### **Objective 1: Need to Involve Men in CHBC**

To determine the need to involve men in CHBC, study participants were asked a variety of questions regarding real (typical, customary) HIV/AIDS caregiving in their communities and the need to increase the number of people (and men) involved in this.

**What happens when a family member gets sick in the community:** In many of the FGDs (both men and women) there was a reported lack of information about the rate of local HIV/AIDS infection, how many people were affected, the virus's paths of infection and/or treatment and prognosis knowledge<sup>2</sup>. The lack of knowledge many expressed is related by respondents to the shame and secrecy surrounding HIV/AIDS that hinders the exchange of information and resources on HIV/AIDS prevention and care.

“We heard that they are there, we don't know them. We only hear about them as people talk. We are aware of the so called Support Groups meaning they are supporting them. We have seen them going to district hospital to collect their pills supply. But we don't know them. They will tell you that they are suffering from TB, but you will see that they have it.” (community men's FGD)

“No, we have not seen them yet sir, we have not heard of them. The reason is that it is a sickness which is kept secret by the patient and the doctor, unless one is a relative of the family, that is where one could know. We hear that certain person is infected with this but we have no evidence.” (community men's FGD)

Fear of HIV and AIDS stigma and discrimination are prevalent and are manifest through fear of disclosure of one's status, keeping the illness secret and avoiding care from CHWs and support groups.

“At the moment members of the families are still keeping it a secret. So they are not yet free to talk to us Support Groups. However, as support group members who have been trained, we do see if someone is living with this infection. Where possible, we approach them and encourage them to go for testing. But it is difficult when the family does not receive us.” (female PLHIV FGD)

“It is said that he is going for counseling. One is clear that it is HIV/AIDS but he hides it. There is a situation which people take they hide and keep the secret and then it passes on to other people because he was afraid of telling the truth.” (community women's FGD)

“It seems he is shunned in the family, he is segregated even the villagers point fingers at him saying 'He is infected with HIV.'” (CHW)

**A range of caregiving strategies is used:** Respondents described a wide range of strategies they use in the event of illness. Family members, medical personnel, CHWs,

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<sup>2</sup> This was evident both in the responses to the “ice breaker questions” where men and women frequently did not know who or how many people in the area were HIV positive, and in responses that repeatedly emphasized a need for training and workshops about both individual status and protection, as well as HIV/AIDS care skills.

support groups and traditional healers were variously reported to be providing care to the sick at home or by referring them to health facilities:

“Relatives of the sick person are the first ones to provide care. Then we help the group helpers or CHWs who have had some training. They pay visits to families with sick people, where they assist to bathe the sick. But at times you will find that the sick person does not like the help of those CHWs, so that when they take their rounds among the sick, they find the doors closed.” (NC interview)

“Yes madam, actually the sick people are being taken care of by other members of the family, especially a woman/mother if she is present in such a household always takes care of the sick. We do pay her a visit from time to time.” (CHW FGD)

“It differs within families because somewhere you find that they support him and bring him in, they have treatment supporter, they come with them here to take ARV for the sick and in most cases I have seen patients sending them, they have support. They support them in their homes.” (district HIV/AIDS officer)

### **CHWs and support groups play roles in providing care:**

“I believe it is a matter of us being known in the village, for our work... The patient chooses himself the person who will provide care for him in his problems. It is someone he trusts, in whom he has placed hope that this person will help him with his problem. Yes sir, in providing care one of the relatives must be there so that they can discuss what to do with the caregiver.” (CHW FGD)

“I think because they are functional at village level, when they notice such illness, they will ask for help from the home-based-giver, when there is need. Apart from that the family is visited by a CHW to find out about any progress. They are very secretive about this illness. They don't want any outsider to know their patient.” (PHC director interview).

“It depends on how much the people in the village trust you with their patient.” (CHW FGD)

“The practices at present, people run for help from what is called *support groups*. They are the people who seem to be helping patients because concerning this sickness I am aware that the patients are no longer kept in hospitals. They are discharged, so their families try to help them. They help them through the support groups.” (district administrator interview)

**Use of traditional medicine:** Apart from family and friends, there appear to be two systems of care utilized in response to family illness—the western system of care represented by nurses, doctors and community health care workers, and a traditional system of care provided by traditional healers, who are both men and women. Traditional healers utilize herbs and perform certain rituals in accordance with what is believed to be the cause of the illness. Traditional healers may consult oracles and use herbal medicines, scarification and the sacrifice of animals to help people infected with HIV/AIDS.

“Most of the time people still prefer to use traditional medicines...Basotho still continue to use those approaches even if it is not necessary.” (community women FGD)

“They take them to the clinic, although will first start like people do, by taking them to the traditional healers.” (tuberculosis officer interview)

“Well, it is true we still continue to provide tradition-based therapies like, consulting the oracles, performing ‘scarification’ and preparing mixtures of roots and herbs. It is me together with ‘support’

here in the village. Me as a mother/woman am in-charge of the sick in my household.” (community women’s FGD)

**Need to increase the number of people involved in CHBC:** In the preceding section we presented evidence to suggest that study participants do not know how many people in their communities are living with HIV and AIDS. However, the following responses indicate a general awareness that there is a need to increase the corps of CHWs to deal with the “heavy workload” from increasing numbers of patients and that not enough labor power has “overloaded” the volunteer CHWs. Respondents describe the problem of some villages with zero or one CHW, leaving gaps in care provision. Respondents repeatedly described how being a volunteer CHW made it difficult for them to provide for their own families, while others said that young volunteers often got “fed up” from being overworked and undersupplied. A frequent comment was that it took a great deal of time to care for the sick, leaving them with little time to earn money or provide for their own families. CHWs especially expressed the need to increase the number of people involved in caring for sick people including people affected by HIV/AIDS—truly, a need for “more hands to do the work.”

“That workload is heavy, because as it is we also serve that other village because there are no CHWs there. Let me mention the tasks and problems we usually have to handle: You could be called to go and assist a delivering woman, while you are still dealing with that, you are told that a group of men were involved in a quarrel and sustained injuries which require quick attention. Your family needs have to be attended to as well. Then in the end one is overloaded that none of these tasks is completed satisfactorily.” (CHW FGD)

“Yes madam, it is necessary to increase their numbers.” (CHW FGD)

“If it could be noted that women are the ones who have excess load then male CHWs should be increased in number.” (CHW FGD)

“Yes madam. I see a need to increase them because they are few whereas there are many patients. You will notice that in one village two care providers have been chosen to care for many patients. Our villages are far apart hence they fail to visit patients in one day at the right time.” (community women’s FGD)

“Yes sir, there is a need to increase them. But we do not know how many are practicing, but yes they should be increased. You see, a number of sick people is increasing fast.” (community men’s FGD)

“Yes sir, I think they should be increased, because you find that infection continued to spread because most families are still ignorant.... Yes they should, because they live with them in the villages. It is true that given their other responsibilities, their work-load is too much, it leaves them with little or no time to attend to their family needs. In the end it disturbs peace in the family.” (NC interview)

“Yes.... You see with this illness (HIV/AIDS) increasing in this high rate, work proves to be too much for us CHWs, especially when we come across a male patient, it is rather difficult to convince them to relax.” (CHW interview)

“I think people can be happy if increased because the women have difficulty with male patients when they have to be turned. This is where men become even more important. Even men will feel free being turned by other men.” (village chief interview)

## **Objective 2: Feasibility of Men's Participation in CHBC**

To determine the feasibility of men's increased participation in community-based HIV/AIDS care and support, the study explored various issues across key informants and focus groups of men, women, CHWs and PLHIV, including:

- Men's and women's actual domestic/household and caregiving practices and participation. These data are intended to identify actual household/domestic labor performed by men and women.
- Men's and women's knowledge, beliefs and perceptions related to men's caregiving and support potential. These data are intended to determine if men are perceived as willing and acceptable caregivers and capable of becoming (more) involved in CHBC.
- Men and women's community activities. These data are intended to identify opportunities for men's involvement in CHBC, including their availability.

**Men's and women's actual household/domestic labor:** We asked groups of men, women and CHWs to indicate by raising their hands which of the following tasks they were responsible for at home: obtain food; obtain water; obtain firewood; earn money; prepare food; wash clothes; care for children; care for sick (in the family); work in the fields; and tend to livestock. In this section, we focus on those tasks that may be associated with CHBC.

**Men:** Male respondents reported that they carried the following tasks in high numbers: obtaining water; obtaining firewood; preparing food; washing clothes. Around half of the male respondents said they cared for children, while far fewer reported caring for the sick in the family. The data showed that men already do engage in tasks associated with CHBC, some at high rates.

**Women:** Female respondents reported obtaining water and firewood, preparing food, washing clothes and caring for children in very high numbers, while about two-thirds reported caring for the sick in the family. These data show that women engage in tasks associated with CHBC, at higher rates than men.

Together, the data suggest that there is gender integration of some domestic and household tasks associated with CHBC, which represents an opportunity to reinforce men's practice and skills in these areas.

**Ideal vs. real labor:** The role of breadwinner is associated with men. The analysis of self-reported household and domestic labor suggests that women have taken on the male-identified task of earning money, assuming the breadwinner role at very high rates, and at higher levels than men, through diverse strategies:

- About one-quarter of the female respondents reported selling an animal once in a while

- About one-quarter of the female respondents had a child (son or daughter) who gives her money monthly
- About one-quarter of the female respondents earned money by sewing
- About one-quarter of respondents reported selling vegetables in the streets.

Women's activities bring in income at different rates:

"We hoe for other people or we gather wood or to brew some beer." (community women's FGD)

"The money we are working is for cooking and feeding primary school children and we do not get it on time, we get it after four months." (CHW FGD)

These data suggest a gap between ideal and real gendered division of domestic and household labor in relation to both women and men. Despite the widely held belief that domestic labor is "women's work," men are already involved in female-identified domestic and household tasks associated with CHBC; and women are already involved in breadwinning.

**Men's and women's knowledge, beliefs and perceptions related to caregiving:** We asked questions to groups of men, women and CHWs to assess the feasibility of involving men in CHBC. The queries included assessing who is involved in caregiving, whether men are perceived as capable of becoming (more) involved in CHBC, the advantages and disadvantages of involving men in CHBC and hindering factors for men's participation in CHBC.

**Women as caregivers by nature:** The belief that women are *natural caregivers* because they have particular character traits and skills was widely expressed across all groups of respondents, regardless of whether they were professionals, administrators or community members and lay-persons:

"Yes. You see women naturally are kind and patient. Even in is Sesotho we say, 'A mother holds a knife on the cutting side/edge.'" (female PLHIV FGD)

"Yes, women have courage, sympathy and patience. They do not choose people, but help anybody who needs care. They also are capable of keeping secrets concerning people's illnesses." (village chief interview)

"Yes madam, women are very important people in the provision of care for the sick because they are able to bring up a child, therefore they are able to sweet-talk patients because many-a-times patients refuse to take medication, they refuse to be touched, they say they feel pain, they are handled painfully, you do this and that which they dislike so women are good at begging them submissively till he does what he is asked to do. Men are people who are angry quickly and they get fed-up." (community women's FGD)

**Women are socialized for caregiving:** There was a recognition that women are *socialized* to be caregivers, and that men are not. When asked why men are not more involved in CHBC, respondents remarked:

“The male taking care of the sick? They are there but they are very rare. Very rare. It is not many times you could find a male caregiver; you will find him giving care if it is a male who is sick. Yes, like you it may be your son who is sick you find that the father is trying.” (district HIV/AIDS officer interview)

“The tradition was that providing care is women’s work, I believe. The beliefs and we ourselves have grown up with these beliefs, that is what I say. Ever since we grew up, we know that sick people have been cared for by women in the families, they are doing it with all their strength. Because it has been like that, men are not interested if they do they are very few. Men have to go out and bring money home. Their tasks take them away from home. I believe it is one of the causes.” (district nurse interview)

“Women in nature are nurturing. They have the responsibility of bringing up children, taking care of the home. So traditionally, they have been given that responsibility of taking care of the sick. But it doesn’t mean that men don’t equally have the same skills, it’s just that they haven’t been practicing them.... It is the same as wanting to know why men do not cook. Traditionally, that has always been a woman’s role. It does not mean that there is anything I could prevent them from doing it. It’s just that they don’t perceive it as their own.” (district hospital superintendent interview)

## **Comparison of Women’s and Men’s Caregiving: Which Tasks Can Women or Men Do Better**

**What women can do better:** Respondents identified the following tasks that women can do better than men in caring for PLHIV:

- Bathing a sick person
- Washing soiled linen and clothes
- Cooking
- Feeding patients
- Sweeping/cleaning the house
- Ensuring that their patients take medications appropriately
- Speaking kindly and persuasively (“sweet talking”) to patients.

“There is work which women do better than men. Women are able to wash the patients’ clothes, they sweep the house, bathe the patient and cook for him/her.” (women’s FGD)

“Women are more skilled than men in caring for sick people in general. Women know how to bathe a sick person better than men. Men don’t have patience or a skilled touch.” (men’s FGD)

“They (men) have greater physical strength for lifting a heavy patient, that is all. Yes, just physical strength.” (women’s FGD)

“Yes, women are good in caring for the sick. They are able to cook and they know that they can cook better than men and they can provide care for the sick as required.” (village chief interview)

**What tasks men can do better:** Respondents generally identified the following tasks men can do better than women in caring for PLHIV:

- Undressing and dressing a man
- Bathing a man
- Feeding, assuring medications, toileting
- Lifting and turning patients regardless of whether patient is a man or woman
- Carrying and transporting patients from one place to another
- First aid.

Men were asked in focus groups if they knew other men who provided care to the sick (including HIV/AIDS clients), what caregiving tasks they performed and what tasks men could do better than women:

“Men are troublesome; one would feel comfortable given care by another man who would help bathe him and other things and not a woman.” (district HIV/AIDS officer interview)

“A man can transport you to the hospital, when he comes to visit you in the morning he brings you food only. A woman comes in the morning to bathe/wash you, see that you eat soft porridge and that things are all in place. Yes, men...they can only drive you to hospital and not to do anything beyond that.” (district HIV/AIDS officer interview)

“Yes madam, men do have work they do better than women especially if you take a person who is seriously ill. They are able to carry him to the vehicle. Men are able to carry a patient safely better than women.” (CHW FGD)

“Men can care for other men better than women would because a male would want to be bathed by another male. So good training for men can make the care for men better.” (men/miner’s FGD)

“Yes there is sir. Carrying a sick person from one place to another is done by men while women always ask for help that men should help the patient stand up to exercise his body. Men are able to keep secrets whereas women cannot because most of them have not been to circumcision/initiation schools. They lie.” (village chief)

“Imagine, these women work in the factories. They leave homes at 6 am and come back at 8 pm. On coming back they find that all household chores have been completed. So men can do more than women.” (male PLHIV FGD)

Overall, caregiving with its wide range of tasks is recognized as “women’s work,” both by nature (an essentialist view) and by socialization. This is a source of competence, power and identity for Basotho women. Both women and men see men’s essential and comparative advantages in lifting and bathing men, though men self-report a wider range of caregiving capabilities than women.

It should also be noted in the narratives below that some men, especially those with experience in mining employment or who had been trained in first-response and aid, expressed no stigma in relation to men’s caregiving knowledge and practice in the context of first aid. In fact, caregiving in the context of first aid is described in a matter-of-fact way as a male-identified technical skill different from women’s natural caregiving and the domestic sphere, and indeed, something that men do better than women:

“...when there is a problem, I will not call other women to come and help me. I learned at the mine how I can support a person. I must support her in a way that I am to help her before we find those people who will help her, I will have helped her.”

“It is not like that that they [women] surpass us with the provision of care. The remaining point is that some of them even run away from that kind of work which they are supposed to do. Here in Lesotho the problem is that we leave the neighboring country having been given some hints and tools and knowledge which we are coming to use, the tools for this work done by nurses. When we get to Lesotho, someone gets hurt. I help him. I prepare him and send him to the hospital properly bandaged.”

“Here in Lesotho it seems unacceptable but with us who have been given workshops in such things, we just enter and provide care for a woman as a patient irrespective of what he/she looks like, I give him/her care. I have the courage to do that.”

In the village men’s and miners’ responses that follow, men’s first aid experience in safety and the control of bleeding give men a comparative advantage and superiority over women:

“Women know nothing about safety so we are above them.” (men/miners FGD)

“Yes sir. You see men even know “First Aid” which is why they know which blood vessels to close in order to control bleeding. That way they save lives.” (men/miners FGD)

“Men are very brave but they cannot handle a patient, but their courage makes them excel.” (community men’s FGD)

“I like them for keeping secrets. Men keep secrets. They know how to close the eyes of someone who is dying.” (community men’s FGD)

Tasks related to the masculine characteristics of physical strength, bravery, courage, discretion and dignity are perceived by some men as a source of competence, even superiority to women and apparently compatible with some Basotho men’s current gender identity.

When study participants were asked why men were not more involved or unwilling to be involved in CHBC, they pointed to several factors, including a tradition of women’s voluntary caregiving, reticence in the face of not having been “called” (recruited), the lack of financial incentives and a belief that new times demand new responses from men and women together:

“In our tradition, there are things which are a responsibility of women and caring for sick people is one such thing. It is obvious though that because of changing times and new diseases, both men and women should unite against HIV/AIDS.” (men/miners FGD)

“I think we have a tendency to choose women all the time. I really cannot blame them. I think if men can be recruited they will join.” (NC interview)

“No, they do not refuse, the main point is that community health workers are chosen and are women. As for men, it has not yet been done that is, to include them.” (community men’s FGD)

“Women should stop being pompous and accept that we too can provide care to sick people just as they can. They should ignore political inclinations and unite as one work-group. They should be respectful and humble.” (male PLHIV FGD)

“It looks like men have a problem because caring for the sick is done by volunteers. Men want to be paid for whatever work they do. At present there is no pay. People are working for nothing. That is why they cannot provide care without pay, because they are the ones who fend for the families.” (community women’s FGD)

Male respondents seemed to interpret community home-based caregiving as something that CHWs do, not as something that families and friends do. They also underlined the perceived importance for men of having been *selected* or *chosen*. There is some sense that women have been privileged in CHW recruitment, training and certification. Women also involved in CHBC described their entry into the role of CHW as having been selected to volunteer while men repeatedly claimed that they had never been asked. This may reveal a pattern of CHW recruiting practices that may have inadvertently excluded some willing men from the CHBC movement, since they were not chosen or “called” to these positions, while women were. Some administrators admitted participation in this cultural bias favoring women in caring positions. However, it is likely that women are selected as CHWs not only because they are seen as naturally equipped for caregiving, but also because women have volunteered these services (i.e., work for free), while men’s expectation of incentives or pay for work impedes their serving as CHWs even when they are unemployed.

With regard to feasibility, the foregoing data reflect respondents’, predominantly men’s, capability for and acceptance of the caregiver role under certain conditions (being chosen, being paid), which would render men’s participation in CHBC feasible.

### **Advantages and Disadvantages of Involving Men in CHBC**

**Advantages:** Women largely identified men’s ability to *lift* patients and *transport* them, as well as interact with male patients in ways that women felt they should not, as being the greatest advantages of men’s participation in CHBC. This relates to men’s physical strength, the ease of communication and having a same-sex caregiver for intimate tasks.

Women also described the advantage of general *prevention* where, if men participate in HIV/AIDS care, they would have the courage to test and know their status. In turn they would encourage their fellow men to do the same. According to women respondents, men can venture into dangerous and risky places whereas women would need to be accompanied by men. Again, this relates to the physical strength of men. Women also expressed the importance of working with men as *sharing* of the work load of caring for the sick and *sharing ideas*, a sense of sharing and solidarity between men and women.

Women respondents feel men naturally and culturally have power and authority to influence things to happen; therefore women say if men are involved in CHBC, the community would listen to them.

The following illustrate the range of advantages perceived by women:

“They will have a way of approaching other men so they at least check their HIV status. And also advise them to attend check-up when they do not feel well.” (female PLHIV interview)

“The greatest success in dealing with HIV/AIDS in Lesotho can be achieved if men can truly be involved, know their HIV status and disclose.” (female PLHIV FGD)

“After all, male clients would prefer to be cared for by other men.” (CHW FGD)

“We maintain that it is alright and that people will accept them. Men are relatively dignified. People can easily choose them instead of us. Their voice is always heard as compared to ours. They can even walk in dangerous places, whereas we would require escorts.” (CHW FGD)

“A man has no problem rather than men hiding their sickness and it be found that they have a sickness that affects the genitals, then I am able to take him to a male caregiver if I am to care for him. The other man will look at him to find out what the problem is because it is visible that he has a problem but there is somewhere where he is hiding his sickness, then I would ask a man to inspect him for me to find out his condition.” (CHW FGD)

Male respondents indicated that it is more appropriate and advantageous to have men as caregivers in certain situations, including:

- When the patient is male and must be bathed, lifted, turned or moved
- When there is an emergency first-aid situation or in transporting a patient.

**Disadvantages:** It is not surprising that the majority of respondents felt that there were limits to what men could do in providing CHBC. Female respondents placed themselves in the role of the patient when considering men’s participation in CHBC and expressed a high degree of modesty and anxiety about their bodies being exposed to men in general, and to men’s sexual desires in particular:

“It is not acceptable, especially because a female patient will not be comfortable with male home-based-givers reaching for her private parts in any way. All the same, a male patient on the other hand would not mind if a woman outsider can touch him that way.” (community women’s FGD)

“It is because men misbehave, that is how God has created them, he is capable of doing the mistake and mention that he is helping the female patient.” (community women’s FGD)

“Yes madam, the challenges as we have mentioned is that men are dishonest...men have promiscuous minds, they think of nothing but adultery when they see women.” (community womens’ FGD)

“When he is not trained it is a problem because a man gets tempted when he has to clean the private parts of a woman. Sometimes problems, men can bring in problems because when he gets to the patient if he finds her recovering and in a better situation he can be attracted and then creep into the patient’s blankets.” (community women’s FGD)

If the patient is a father-in-law of a woman, or vice versa, she/he should not be providing care in the absence of others or any care that requires the patient to be undressed.

“It has not been acceptable yet that men can provide care for women because of our culture; the daughter-in-law cannot touch the father-in-law because of the respect attached and the father-in-law cannot touch the daughter-in-law vice versa. Now that respect does not give them chance to do this

work with freely.” (village chief interview)

“According to our custom, a man can not be able to provide care for his daughter-in-law and those are destructive challenges.” (community women’s FGD)

“Yes madam it is true that is not acceptable, a man can help his wife only not any other person in the family, except if it is some male neighbor.” (community women’s FGD)

Respondents also mentioned traditional prohibitions against men’s being near a woman who has just given birth (in a room or house) or in “off limits” women’s gatherings:

“A man is not allowed in a room of a newly delivered nursing mother.” (female PLHIV FGD)

“Yes, we are Basotho; when a person has just given birth, men are still not allowed to enter.” (village chief interview)

“Yes madam in our families we have customs and traditions, as we are Basotho; men do not enter a house where the woman has just given birth. Where there is a newly born baby, they enter when the child is some time old.” (community women’s FGD)

Table 2 below summarizes perceptions related to the feasibility of involving men in CHBC.

**Table 2: Perceptions of Comparative Performance, Advantages and Disadvantages of Men as HIV/AIDS Caregivers**

<b>1. Women can do better</b>	<b>2. Men can do better</b>	<b>3. Advantages of involving men</b>	<b>4. Disadvantages of involving men</b>
Bathe a sick person	Bathe a man	Men’s physical strength (W/M)	Men’s dishonesty/ womanizing/ untrustworthiness /promiscuity (W)
Wash soiled linen and clothes	Undress/dress a man	Safe mobility (W)	Men’s perceived tendency to sexualize care situations (M/W)
Cook	Toileting	Influencing other men to test and give care to other men (W)	Women’s sense of modesty/decorum (W)
Feed patients	Feed patients	Ease of communication with other men (W)	Traditional prohibitions against entering spaces where women need to be alone; or that father-in-law cannot care for daughter in law (M/W)
Ensure medications taken properly	Ensure medications taken properly	Intimate tasks with men (W/M)	Male breadwinner status/unwillingness to work without financial incentives (M/W)
Sweep/smear floors/ clean house	Lifting and turning regardless of whether male or female	Sharing and solidarity with women (W)	
Speak kindly and persuasively to patients (“sweet talking,” “submissive begging”)	Carrying/transporting patients	Transport (M)	
	First aid (controlling bleeding, safety)	Men can keep secrets (M)	

The perceived advantages and disadvantages of men as caregivers indicate a strong preference for involving men as same-sex providers for men and for not involving men as providers of intimate care for women outside their families.

## **Factors That Might Influence or Prevent Men from Becoming Involved in CHBC**

The study explored negative perceptions men might have about the CHW job, positive and negative reactions that men might face from the community if they became involved in caring for sick people and other challenges in participating in CHBC.

**Gender role expectations of men:** The first set of responses below show that, despite men's actual participation in female-identified domestic and household tasks (see Table I, above) and despite their comparatively low participation in male-identified money earning activities (18% as compared with women's 64%), the expectation that men be *money earners* serves as a social and psychological barrier to men's participation in CHBC, even in times of unemployment. For example:

"The job without incentives is a mockery." (community men's FGD)

"Men are always breadwinners for their families, so if home-based care is offered freely, men will not participate. In fact, the main incentive they are looking for is money. It very sad when a father gets home at the end of the day claiming to have been doing some work, yet he is not going to get a pay to take care of his family." (community men's FGD)

"It looks like men have a problem because caring for the sick is done by volunteers. Men want to be paid for whatever work they do. At present there is no pay. People are working for nothing. That is why they cannot provide care without pay, because they are the ones who fend for the families." (community women's FGD)

Men are breadwinners and symbolically fulfill their role in the home, or in caring for the sick, by "donating" money, even if it is a small amount. Volunteer caregiving is a "mockery" for men and this may be because it is associated with the lower status of women's unpaid household labor; i.e., women may work for free, but men will not. Women's responses indicate that they recognize that money will be a key factor in men's participation in CHBC, though giving money is not necessarily seen as a sufficient contribution to caregiving. The evidence suggests that men might engage in CHBC on the condition that it is linked to earning money, which would then qualify CHBC as worthy of men's time, if not exactly "men's work."

**Ridicule as an inhibitor of men's participation in CHBC:** Despite previous evidence that men engage in caregiving and that both men and women would accept men as providers of CHBC, ridicule is used to keep men away from *public* displays of caregiving.

First, ridicule for masquerading as nurses:

"I do not think that of late families are choosy because they volunteer. Some people in the villages ridicule them saying they are inquisitive and pretending to be nurse who are not paid, who cannot provide medication for them. Such sayings de-motivate them." (public health nurse interview)

Men are also ridiculed for being effeminate when they are involved in tasks associated with “women’s work,” or they may fear being stigmatized in this way. Sources of ridicule are both men and women. However, much evidence points to the existence of adverse pressure by peers who tease men who publically cross into a “ridiculous” social identity of caregiving (associated with the feminine gender identity) and who become unavailable for masculine pursuits (e.g., going to drink beer). For example:

“I once heard men ridicule another for taking an ‘under 5’ child for immunizations. ‘What have you done with her mother, where is she?’ And they were laughing. So, next time he will have to ask his sister to take a child to the clinic.” (PHC director interview)

“We should stop passing remarks that scare them. Again I believe we should allow them to approach sick people without saying ‘that one is your child.’ This makes him feel like sometimes his work is stigmatized.” (PHC director interview)

“I think sometimes he can meet problems from other men, who would say he likes women’s work, he is running about with women, he doesn’t have time for other men, for going to drink beer etc., things that are meant to discourage him.” (CHW FGD)

However, women may resist men’s involvement by expressing threat (or mock threat) that men are taking tasks associated with their feminine social identity:

“They’re being laughed at by other men. There are other women who also laugh at them.”

“Other women ridicule them saying they take women’s work and it is theirs.” (CHW FGD)

Or from fear of its consequences:

“The destructive things would be remarks like ‘now my husband will come with the infection in the family.’ ‘Please don’t go there, we still need you.’” (community women’s FGD)

### **Mistrust of men’s motives as an inhibitor of men’s participation in CHBC:**

Consistent with women’s perceptions of men’s untrustworthiness in relation to sex already detailed above, men who participate in CHBC may also face contempt and suspicion from both men and women that their motives are really to “womanize.” When asked what might be some positive or negative reactions to men’s participation in CHBC, male and female respondents stated:

“Men are discouraged by being mistaken as lovers to sick women. ‘There comes your.... So we have to provide privacy for you and your....’ It looks like men are not able to stand such accusations.” (women’s FGD)

“Yes there could, because this gentleman you seeing with us here today has been ridiculed. ‘Is it not the one who runs around with women?’ They despise him. That’s the problem. If we could have a two-week workshop, men would not come saying their livestock would be left unattended. They speak ill of him saying he a womanizer.” (CHW FGD)

### **Objective 3: Identify Factors That Hinder or Facilitate Substantive and Sustained Male Involvement in CHBC**

The study asked various groups of respondents questions about hindering and facilitating factors related to men's participation in CHBC, including factors to be accounted for in male recruitment, training, support and retention. While this section focuses on factors that would prevent men's participation in CHBC, it seems evident that many of these challenges are shared by women already working in CHBC.

#### **Factors That Might Prevent Participation in CHBC**

**Lack of resources:** Most respondents already involved with CHBC or HIV/AIDS care identified a lack of resources preventing them from providing, or clients from receiving, appropriate care whether they were men or women, including:

- Lack of money
- Inadequacy of the supplies necessary for caring such as medicines, gloves, soaps and toiletries such as Vaseline
- Lack of food and food packages, to the extent that caregivers feel impelled to share the little food they have with their patients or the sick; lack of gardening tools
- Inadequate water supply, since in the absence of sufficient water even the simplest strategy of infection control, such as washing hands, cannot be implemented
- Caregivers' unreimbursed, out-of-pocket travel expenses.

"It is difficult when there are no resources but if they are obtainable things it is better. Sometimes I have to bring soap, Vaseline and bread with me because the family really has nothing. It is heartbreaking in some families." (CHW FGD)

"As support groups, we visit that patient to help him by bathing him, by feeding him, helping him with medicines but you will find that we do not have medicines. We ask for medicines from the community health workers who are Ministry of Health people. Sometimes they also have run short. They do not have any." (community women's FGD)

"To me it would be some food handouts because these sick people are also starving. It is very hurting to look after someone who does not have food. I do not have enough food myself, but most of the time I am forced to share the little that I have with people I care for in the village." (female PLHIV FGD)

"I think if water, it is the biggest challenge, when people are sick with diarrhea have to be washed and bathed, water must be available on site, and this support which I see us getting which is that sometimes we get medicines will help patients, things like gloves and others which helps people to see to it that they are not exposed while helping during the cause of their helping clients at home." (NC interview)

"Ache! ...honestly and unfortunately some of them travel and you will find that a person has put his hand into his pocket and at the end of the day not being reimbursed. The only person that we had

recently over a year or something, was that of Community Health Central Services, whom we gave 40% out of the sales. But now since the advent of free health services that was also stopped but there was a promise that we'd be given some money and some incentives what is called wages.” (community mens' FGD).

“There is a trained group which was to help in the homes. They have not been paid. They are still asking to be paid. But the agreement was that they will be paid. You know I am not sure whether they are still working or not. They seem to have lost hope. Even this very day, they had come to ask when they were going to be paid.” (government clinic DPHN interview)

The responses point to a sense of urgency in the lack of all the resources needed in order for CHWs, families and communities to care for people affected by HIV and AIDS: food; water; money; supplies; and medications.

**Lack of information:** Respondents also identified a lack of information/knowledge about HIV/AIDS transmission, existence of HIV/AIDS and how to handle disclosure, as significant barriers to men's disclosing their status and thus seeking and giving care for HIV/AIDS:

“Disagreements among family members of the sick, where one of them decides to approach us about the newly diagnosed HIV/AIDS persons. When we go there as support group, we find the rest of the family is not yet ready to disclose. As a result we are sent away. That's very bad. It is like we are imposing.” (miners' FGD)

“Actually, men are not yet prepared to get involved. Even to disclose that they are HIV positive, they do it when it's late already and they have started to appear sick. Therefore, they cannot approach those who are infected.” (PLHIV women's FGD)

When asked how male caregivers differ from those who do not help, one study participants had this to say:

“What shall I say [laughs]. I have seen that they are men with a special understanding, who have patience for the sick whereas those who do not help are those who do not believe that there is something called HIV/AIDS. Those who help have a firm belief that it exists.... Men are people who do not believe, who do not accept that this thing exists that is why they do not care for the sick, they cannot take any step for helping the sick because they do not accept that this thing exists.” (community men's FGD)

“The greatest success in dealing with HIV/AIDS in Lesotho can be achieved if men can truly be involved, know their HIV status and disclose.” (female PLHIV FGD)

**Beliefs about HIV transmission contribute to stigma:** Study respondents sometimes identified the promiscuous behavior of the opposite sex as a vector of transmission and attributed to the spread of HIV/AIDS to moral causes. Some men identified women as carriers of the disease, and some women identified men as the ones who are always falling sick from it and the women are left to care for them. There were no consistent patterns identifying one or the other gender as a vector for the disease. This is a sample of *women's* statements about women's and men's beliefs about HIV/AIDS transmission:

Q: To what extent would training men to do these tasks help them do them as well as women?

A: “They are not good at heart as they think their wives are carriers whereas they are the people who sleep with many women. Living without knowledge makes men hasten their deaths hence this position in statistics. Their problem from which they have to be rescued, is that they hunt for HIV-negative women hoping having sex with them will remove their HIV status, because of their stubbornness they refuse to wear condoms and other protective clothes hence they saw HIV/AIDS.” (CHW FGD)

The general association of HIV/AIDS with promiscuous and irresponsible behavior corresponded to an association between caring behaviors and high moral and spiritual character—the two were ideologically opposed to each other—of the caregiver and the patient. This association might facilitate the stigma attached to PLHIV. Stigma and a lack of knowledge about HIV/AIDS transmission contribute to a significant communication barrier preventing people from disclosing their status and seeking and giving care for HIV/AIDS.

### **Factors That Might Facilitate Men’s Participation in CHBC**

**Training and increased knowledge:** Evidence suggests that training men as providers of CHBC can offset fear that men will sexualize caregiving and will increase their acceptability by association with the skill and professionalism of nursing. Many responses indicate that if men can be trained, encouraged and motivated by incentives, they may become more widely accepted as caregivers and may become more interested in the job.

“Yes madam, it can happen because there are places where we have heard that male care providers are there and the male support group members are there nearby in a village near here. It is a matter of them being trained and encouraged. Perhaps women could give a desire to men, their husbands, they should give them hope and encouragement to give care to patients.” (community women’s FGD)

“You will meet no problem in the village if you help a woman, provided we are trained because you will be going there with your head high as you have the required knowledge for that work.” (community men’s FGD)

“Once they are known to have gotten some training, yes they can be accepted.” (village chief interview)

“They should be trained and be informed on what actually happens good or bad. If training is well arranged they will understand and participate.” (NC interview)

“Yes sir, I think for the sake of this item we are discussing, of health working, which is providing care for a woman, I must not be afraid of her or a man. What can be great is that we be sent for training and be able to know about the nurses directly—male and female nurses—and these men should be given their order of how they should work, if the woman does not know those people working in the hospitals. If men could be taught this way, we will join and do this thing we will be able to join to help women and men.” (community men’s FGD)

Training can thus play a key role in rendering CHBC acceptable to both men and women as a more professional (and professionalizing) male endeavor, and this illustrates the feasibility of increasing men’s participation in CHBC. The role of men’s interest in the job, incentives, women’s hope and encouragement and supervision also emerge are key support elements in men’s participation in CHBC.

## Targeted Recruitment

**Recruitment:** We asked respondents if there were public places where men meet and might be recruited to work as providers of HIV/AIDS care and support. All respondents repeatedly identified the village chief's court as the most suitable place because this is where men traditionally meet to discuss village issues. Also, only the chief has the authority to convene a public gathering, to which practice Basotho men have always adhered. Usually a public gathering is convened at the chief's court, where the community nominates people who will assume caregiving roles. Criteria for CHWs include the ability to read and write Sesotho.

"A public gathering is usually convened where people would be informed about the affairs which concern them. Their opinions are shared and they take decisions." (village chief interview)

Other recruiting grounds included the church, already working CHWs, men's circumcision schools/ceremonial groups and the clinics where the study interviews were conducted. Networking through existing social relationships with men in positions in CHBC also attracted men into such labor. The following conversation took place in a CHW FGD:

"Yes madam, unless they meet at the chief's place—in court."

"I think there is such a place—at the circumcision school. I think someone could help explain matters relating to HIV/AIDS especially when they know that one of the boys must bring his own razor blade, then someone could elaborate on that."

"I do not disagree but I think the best place is the chief's place."

The last response suggests both a need and opportunity to introduce HIV/AIDS prevention and caregiving in a context where youth learn about healthy manhood. Youth associations were also mentioned as venues to attract energetic and enthusiastic young men:

"It could be nice; now the problem is that the youth are facing challenges of unemployment. You find that hunger drives them from their communities to where they have hope of finding jobs. When they get there, it could be worthwhile if they helped in youth associations. We have a number of youth associations. These are people who are interested and understanding regarding disease." (district administrator interview)

**Incentives:** In this section, we describe respondents' preferences for incentives to facilitate both women's and men's participation in CHBC. Men, women and CHWs were asked to *rank* a series of incentives previously used in other country program contexts, and to indicate what the *minimum* preferred financial remuneration would be.

**Table 3: Preferred Financial and Nonfinancial Incentives by Sex  
(Women, Men and CHWs)**

	<b>WOMEN</b>	<b>MEN</b>	<b>CHWs</b>
<b>NONFINANCIAL INCENTIVES</b>			
Health care equipment/materials	X	X	X
Free medicines	X	X	X
Additional training/workshops	X	X	X
Water/food	X	X	X
Transportation	X	X	X
Opportunity for job promotion	X		X
Child care	X		X
Counseling	X	X	
Job training		X	X
Farming equipment/animals/ gardens/trees		X	X
Recognition/encouragement from community		X	X
Assistance with burials		X	
Working with other health workers (peer support)		X	
Toilets/sewage pits		X	
<b>FINANCIAL INCENTIVES</b>			
Money/allowance	X	X	X
Travel costs	X	X	X
Reimbursement for out-of-pocket expenses		X	X
Retain part of \$ earned selling health products	X	X	
Work project to generate income	X	X	
Supplies to start own business			X
Clinic in village			X
<b>RANGE OF REMUNERATION</b>	m500-1000/ month	m300- 1000/ month	m1000/ month

There were significant similarities in male, female and CHWs' preferred *nonfinancial incentives*: health care equipment and materials; free medicines; training; water; food; and transportation. Women's preferences diverged to include employment in health care, selling home-based care products to generate income, domesticated livestock for food sustainability, food packages and childcare. Men's preferred incentives diverged to include job training, farming equipment, recognition/encouragement from the community, assistance with burials, peer support and sanitation. All the foregoing are nonfinancial incentives that would have costs for the government.

Female respondents suggested a higher minimum *financial remuneration* (500 maloti or \$71) than men (300 maloti or \$43), though all respondents preferred 1000 maloti per month (or about \$143), which may be seen as a wage rather than an incentive. After the study data collection was completed, the MOHSW established a financial incentive for CHWs at \$43 per month, which presumably will attract more men into this job. Neither men nor women in this study seem to have adequate access to money or food. In light of the foregoing, government, donor and NGO responses should target income generation opportunities and the development of economic networks for both women and men.

## Discussion

In this section, we provide a brief summary of important evidence, draw conclusions about study findings, show where findings are consistent or inconsistent with research and identify the implications for theory, policy and programs. We frame the discussion of findings by keeping in mind two questions:

- How does gender influence the achievement of men's participation in CHBC?
- How would interventions (i.e., strategies to recruit, train, resource and incentivize men) affect gender relations? Would they exacerbate existing inequalities or transform relations towards greater equity and equality?

### Gendered Division of Labor

The problem of “sex stereotyping” in occupations is fully recognized by the Government of Lesotho's 2003 Gender and Development Policy, and these study findings support the notion that women in Lesotho currently bear a disproportionate burden of unpaid HIV/AIDS care and support. Based on FGDs and interviews with a range of health professionals and community members, there is a definite need to increase the number of people currently providing CHBC. The participants in all groups confirmed the notion that most care providers still are women. Women serving as CHWs report being overextended by their responsibilities, including increased caregiving to people living with HIV and AIDS. These findings are consistent with those from other countries in sub-Saharan Africa, where women's willingness to volunteer caregiving has had some negative consequences for them.

However, evidence on men's and women's domestic and household tasks and HIV/AIDS caregiving also suggests that there has been some gender integration of hitherto gender segregated jobs (i.e., men crossing into caregiving, women crossing into breadwinning), and thus, some shift in traditional Basotho conceptions of *gendered division of labor*. This is consistent with the 1998 WLSA study, which identified areas in which Basotho women had already taken on economic provider roles traditionally performed by men; drew distinctions between customary ideals and current practice; and concluded that “Custom is not made up of hard and fast rules, but is flexible and changes as circumstances demand.” To the extent that this is so, the Government of Lesotho, NGOs and donors have an opportunity to increase the pool of community and home-based HIV/AIDS caregivers of both sexes through resourced CHBC. CHBC policies and programs should address existing inequalities through explicitly gender redistributive and egalitarian messages and practices for recruiting, training and incentives.

Study respondents perceive particular advantages to involving men, ranging from physical strength to same-sex care provision for intimate tasks, as “more hands to do the work.” Where men are involved in providing care, it is often when they are infected already and are members of support groups. When women are caregivers, they tend to have a wider range of potential patients compared with men. The tasks respondents felt a man could not do was enter the room of a woman who had given birth (and provide

care) and provide care for his mother in law (NB: A woman is likewise constrained from giving care to her father-in-law). Both men and women preferred same-sex caregivers for bathing.

## **Gender Stereotypes**

Stereotypes of what is normal male behavior—earning money and womanizing—seem to serve as barriers to men’s participation in CHBC. A web of gender stereotypes about essential “male” and “female” traits, status beliefs and perceptions of men and of caregiving keep women in voluntary HIV/AIDS caregiving and keep men out of it. Men stand to lose respect from other men and discretionary time by entering CHBC but stand to gain economically by entering the now-remunerated CHW cadre, which aligns it with the male-identified responsibility of earning money.

- a) While men’s participation in CHBC can alleviate the disproportionate burden of HIV/AIDS care, women stand to lose the benefit of social recognition and may face competition from men in the CHW job.
- b) Earning money is a task that has already been assumed by most of the women in the study sample; the value of monetary incentives in increasing participation in CHBC applies to women as well.

In any case, the chances of increasing and sustaining men’s participation in home-based care (to some level or at equal levels) would appear untenable as long as women’s continued volunteer labor is expected to entirely “fill the breach.”

Nevertheless, the study concludes that it is feasible to involve men in CHBC based on the following findings:

- Men already perform household and domestic tasks that constitute CHBC tasks at some level. Men are already perceived—and perceive themselves—as capable of performing many CHBC tasks. Men with prior mining experience are especially at ease with caregiving (especially with tasks that are “masculine” by association with first aid or the skill mastery of nursing and with specifically masculine-identified characteristics such as strength and courage). This may offset the perception of caregiving as “women’s work.” Furthermore there is a perception that the advent of HIV/AIDS requires new thinking.
- It is feasible to involve men in CHBC, in that the Basotho men and women in the study sample demonstrated psychological and social flexibility in taking on the domestic and household tasks ascribed to the other gender. Men appear to have discretionary time that is currently spent on recreational activities.
- Despite the perceived disadvantages of men’s participation in CHBC, both women and men appreciate the advantages, especially in performing tasks requiring strength and intimate (bathing) tasks.
- Training can mitigate negative stereotypes of men, assuage women’s fears about men’s potential for sexual exploitation and promiscuity and increase men’s skills.

Training can also serve as a nonfinancial (though not sufficient) incentive to involvement. Training for male and female CHWs needs to involve critical reflection on gender roles and responsibilities.

- Financial and nonfinancial incentives can increase men’s interest in CHBC by aligning it with the male-identified responsibility of earning money (a task that has already been assumed by most of the women in the study sample).
- Men appear to have greater mobility, more social networks and political participation, with the ability to influence decisions in chief’s councils. These present opportunities for recruitment, social support and dialogue for social change.
- The key to involving men in CHBC is their ownership of and belief in the disease through HIV/AIDS education.

## **Caveats**

The health system will greatly benefit from the active participation of men in CHBC. However, there are lessons learned from initiatives that have recruited men into traditionally “female” occupations. In attempts to increase the perceived value of women’s work and thereby attract men, it should be recognized that caregiving is currently a source of power for women in their families and perceived competence in their communities. Therefore, care should be taken that interventions not undermine women’s current sources of competence, even as they attempt to attract men into caregiving or transform gender relations toward a more equitable redistribution of caregiving tasks. Rigorous evaluation of the impact of increasing the number of men in female-dominated professions is essential. Caveats from previous efforts include the following:

- Male caregivers may perpetuate gender stereotypes by only performing “male” tasks (e.g., transporting patients to health facilities, lifting them; avoiding “emotional” tasks like counseling or messy tasks like washing soiled linen).
- Women may be subject to greater and unfair competition for leadership roles and job openings.
  - Men sometimes carry gender privileges and status advantages with them into female-concentrated occupations, which may reinforce gender hierarchies.
  - Advancement into management and higher pay may accrue faster to men than women in female-dominated occupations.
  - Compensation for men may disadvantage women—program managers should not pay men to do jobs that women do for free, or offer breadwinner benefits only to men.

Neither men nor women in the study sample seem to have adequate access to money or food, though women engage in income generation activities at higher rates than men. In light of the needs expressed by respondents, government, donor and NGO responses

should target income generation opportunities and develop economic networks and opportunities for both women and men.

### **Limitations of the Study/Need for Further Research**

Time and resource constraints limited the information that could be collected. We do not have quantitative and comparative information on male and female labor. In asking why men are not involved in home-based care, we did not measure how many caretaker-headed households there were, nor did we measure men's absence in HIV/AIDS caregiving. Is it also associated with male out-migration, abandonment, death of a spouse or divorce? (In Akintola's 2006 research, partner abandonment emerged as a subtle but effective and pervasive mechanism for avoiding care roles in South Africa. Most of the women in her study had nonresident partners who did not feel obligated to assist in providing care.) Finally, this study brought to the fore prohibitions against men entering a room where a nursing mother resides. Does this prohibition attach to proximity with newborn babies and, if so, what are the implications for men's participation in prevention of mother-to-child transmission services? These are all information needs that might be addressed by further research.

### **Implications for Policy and Programs**

The "government...realizes that household poverty lies more heavily on women than on men, as they are the pillars of all types of households.... This [poverty] is also compounded by the HIV/AIDS pandemic whose care-giving lies solely in the hands of women surviving on woefully inadequate resources completely expended to care-giving" (Government of Lesotho Gender and Development Policy, 2003). This study demonstrates the feasibility of actively pursuing the government's gender equality commitments in HIV and AIDS policies and programs and commitment to "advocate for the improvement and expansion of gender-sensitive home-based health care service delivery with particular attention to HIV/AIDS affected and infected persons *to alleviate the burden of responsibility on women*" (Gender and Development Policy). Alleviating the burden of responsibility on women requires that men shoulder some of this burden.

Interventions should support gender equality, recognizing that unequal gender relations are the source of women's current and probable future disproportionate burden of caregiving (i.e., all caregiving, not only HIV/AIDS caregiving). Following Lesotho's Gender and Development Policy, interventions should improve the conditions of caregiving work by those already involved in it, making it a feasible undertaking for both women and men. "Gender redistributive" approaches in policy and program responses are recommended, those "intended to *transform* existing stereotypes to ensure gender equity and equality by a more even redistribution of resources, responsibilities, and power between and among men and women, girls, and boys." The use of gender redistributive approaches implies the avoidance of approaches that use, exploit or exacerbate gender inequalities and stereotypes in pursuit of health and development objectives (USAID Interagency Gender Working Group, 2006). Exploitative approaches reinforce inequalities between men and women typically using stereotypical images or

ideas—for example, by perpetuating stereotypes of what is appropriate in women’s behavior, such as passivity in relation to her own health or women’s superior nurturing abilities, or of men’s promiscuity or superior reasoning powers. To this end, CHBC policies and programs should increase the pool of community and home-based HIV/AIDS male caregivers and support those existing and mostly female caregivers, by explicitly gender “redistributive” and egalitarian messages, recruiting, training and incentives practices.

## Study Recommendations

Over the *long term*, women, families and communities cannot alone provide a viable, appropriate or sustainable response to the HIV/AIDS crisis. The Government of Lesotho, NGOs and donors have an opportunity to increase the pool of community and home-based HIV/AIDS caregivers of both sexes through resourced CHBC. CHBC policies and programs should address existing inequalities through explicitly gender “redistributive” and egalitarian policies, messages and recruiting, training and incentives practices (Government of Lesotho, Gender and Development Policy, 2003). Study recommendations targeted national policy, district and community-level interventions are as follows; recommendations with greatest impact on health workforce development and support are marked with an asterisk (\*).

### *National and Policy-Level Recommendations*

1. \* To reduce gender segregation in health work, national health, HIV/AIDS and CHBC and human resources policies should be *gender redistributive*<sup>3</sup> and explicitly promote a more equal division of responsibilities between women and men, in general and in the context of HIV/AIDS care and support. While pursuing gender redistributive policies and actions, the Lesotho government and other stakeholders involved in CHBC should continue to strengthen women’s capacity to care for those affected by HIV/AIDS through gender-responsive policies, budgets and initiatives.
2. \* Gender redistributive HIV/AIDS and CHBC policies should be promulgated through training curricula, job descriptions and protocols. The national CHBC training curriculum should include skills training, critical reflection on masculine and feminine gender roles and gender equality in caregiving, communication, HIV/AIDS education, service ethics, gender-based violence and an introduction to male role models already engaged in CHBC.
3. A long-term goal of male involvement in CHBC in Lesotho should be put in place to reduce the transmission of HIV/AIDS by altering personal, social and cultural views surrounding HIV/AIDS care and support for healthy and socially and economically viable communities.

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<sup>3</sup> The Lesotho Gender and Development Policy defines “redistributive” approaches as “Interventions intended to transform existing stereotypes to ensure gender equity and equality by a more even redistribution of resources, responsibilities, and power between and among men and women, girls, and boys.”

4. Public, private and nongovernmental sector partners should work together at national and district levels to ensure the protection and survival of households affected by HIV and AIDS, and also increase accountability, coordination, resource mobilization and effectiveness of CHBC policies and programs.
5. Government should actively seek to involve the public sector, local businesses/ corporate organizations and international donors to work together to provide financial and infrastructure support to address chronic malnutrition and hunger of HIV/AIDS caregivers and PLHIV.
6. Study results should be disseminated to a range of multisectoral partners to be used at national, district and community levels.
7. \* Organizations should adopt a “Volunteer Charter” for CHWs and home-based caregivers to address conditions of work including standardized resources and protections:
  - a. Standardized working hours and remuneration
  - b. Psychosocial support
  - c. Response to harassment and violence
  - d. Tangible protections such as pensions, child-support grants
  - e. Supplies needed to cope effectively.
8. \* The MOHSW and the ministries of education and gender should work together to improve and ensure the gender sensitivity of the content of the CHBC Manual, and of other health curricula.
9. The MOHSW and CHAL should partner with the Ministry of Labor and the International Labor Organizations’ “Decent Work Program” and MDA and/or TEBA to design, pilot and evaluate a program for ex-mine workers and their wives and young unemployed men and women in the three study districts, to respond to employment needs and men’s and women’s preference for same-sex caregivers for intimate tasks.
10. HIV/AIDS and domestic caregiving should be made more attractive to men and boys through a media campaign that communicates the value of HIV/AIDS (and all) caregiving to society.

#### *District and Community-Level Recommendations*

1. Continuing public education campaigns should include strategies to raise awareness about the disproportionate burden of labor carried by women, and the importance of men’s role in HIV/AIDS prevention and care and support.
2. \* CHBC programs should be designed or redesigned to be “redistributive.” For example, they should explicitly promote the equal sharing of responsibilities between women and men in training and supervision and in the recruitment of men. Interventions to recruit men for CHBC should not reinforce stereotypes or expectations of masculinity that might exacerbate existing gender inequalities.
3. Male caregivers should not be paid, or paid more, for jobs that women are doing on a volunteer basis.

4. CHBC programs should include options and strategies to address poverty. These can range from IGAs to the formal registration of CHW groups.
5. Influential community members should be mobilized to offer social support through traditional structures (e.g., chief's court, community councils, etc.).
6. Men should be recruited as CHWs and promoted as family and community caregivers through public gatherings at a chief's court, at health clinics, sporting events or church meetings.
7. Education about HIV prevention and men's caregiving should be introduced in initiation schools.
8. There should be community mobilization targeting beliefs, perceptions and norms that currently constrain men's participation in CHBC and equitable sharing of caregiving responsibilities. An example of such a mass mobilization technique is "Stepping Stones," which has been effectively and widely used in sub-Saharan Africa to transform social norms and relationships.

## Annex A: Data Collection Tools

### Focus Group Discussion Guides and KII Guides

#### CHW Focus Group Discussion Guide

**Introduction:** The MOHSW would like to strengthen the capacity of Lesotho's health system to address the HIV/AIDS pandemic at the community level by increasing the active engagement of men as providers of community home-based health care. In this study, we would like to identify ways to recruit, train, support and retain men in community-based HIV/AIDS home-based care and support jobs which have traditionally been considered the province of women.

**Purpose:** The purposes of this Focus Group Discussion are to: determine the **need to** bring men into community-based HIV/AIDS care and support; determine the **feasibility** of engaging men as providers of community based HIV/AIDS care and support, in particular the **gender-related and cultural factors** that need to be addressed in order to increase male involvement in community-based HIV/AIDS care and support; and identify CHW perceptions of the **advantages or disadvantages** to male involvement in community home based care and support.

**Estimated Time:** 2 ½ hours

#### Informed Consent Statement

After introducing the purposes of the study and the focus group as well as the members of the research team, the FGD facilitator reads this statement:

This study was approved by the Ministry of Health and by an Ethical Review Committee. We would like to ask you some questions about the possibility of involving men in HIV/AIDS care and support activities at the community level in order to assist the Ministry of Health plan to improve community-based HIV/AIDS service delivery in Lesotho. You will not be contacted in the future. We will not write your name down, nor will it be on the transcript of the audiotape, and all names mentioned will be deleted from the transcript. Only the district and code number will appear on the question. Your answers will remain confidential. During the study, the questionnaires and audiotapes will be kept in the Study Managers' office in a locked drawer. The only persons who see the results are those who work on the study.

Your participation in the focus group is entirely voluntary and you may choose not to answer a question, or to leave the group at any time. We very much appreciate your help in this study, even though we will not be able to pay you. Although you may not immediately benefit from the study, the results will be used to improve health care delivery in your community and in other communities in Lesotho. However, we will be able to offer you a snack, a cold drink, and a small transport reimbursement. Please

remember that our conversation is confidential, so we'd like to underscore the importance of not communicating the specifics of what you discussed in this group to others.

If you have any questions, please contact (Name and telephone number of Study Manager).

**May we begin?**

After reading the foregoing consent declaration, tick off below for every respondent that agrees to participate.

Tick off below for every respondent who does **not** agree to participate in the focus group.

**Record: (Please record for all 10-12 FGD participants)**

1. Ages:
2. Sex:
3. Year trained as CHW:
4. Number of years working as a CHW:
5. Are you also an HIV/AIDS caregiver/support group member?
6. Interviewer \_\_\_\_\_
7. Date \_\_\_\_\_
8. Region \_\_\_\_\_
9. District \_\_\_\_\_

**ICEBREAKER**

\*What motivated you to become a CHW? Was the choice voluntary? (OR)

\*Are there people in this community living with HIV/AIDS?

**NEED TO BRING MEN INTO COMMUNITY HOME-BASED CARE (CHBC)**

*(REAL) PRACTICES AND PARTICIPATION)*

\*What typically happens when a family member gets sick with HIV/AIDS in your community?

\*Are there *customary* ways families take care of sick people? Does this apply to care of PLHIV?

- o Who *actually* takes care of the sick person?
- o If the caregiver is a *female* family or community member, what is usually her relationship to the sick person? (Probe for all caregivers, such as “mother of the sick person” and follow up by asking “Who else?” until no other caregivers are mentioned).

- If the caregiver is a *male* family member, what is usually his relationship with the sick person (Probe for all caregivers, such as “friend of the sick person” and follow up by asking “Who else?” until no other caregivers are mentioned):
  - Are the caregivers paid to take care of sick people or do they volunteer their time?

\*What home-based care and support tasks do you actually do, or have you done as a part of your job of CHW (Refer to **Attachment I, Home-Based HIV/AIDS Care and Support Tasks**, to prompt as necessary and record all that are mentioned)?

**Note to facilitator and notetaker:** In the next part of the discussion, we want to understand the workloads of CHWs by 1) asking them to confirm the tasks listed below 2) finding out if the task is performed daily and how much time it takes 3) and for tasks that are not performed daily, finding out how many times a week the task is performed. After introducing the question, follow the steps (1 a-c) for all of the tasks shown in the first example below:

\*Now I’m going to ask you about tasks you are responsible for at home. Do you

1. Obtain food for the family--How many of you do this task? (Count hands)
  - a. For those of you who obtain food for the family, how many of you do this every day? (Count hands)
  - b. For those of you who obtain food for the family every day, how much time do you spend on this every day? (Write the amounts of time)
  - c. For those of you who obtain food for the family but not every day, how often do you do this task each week? (Write the number of times per week)
2. Get water--How many of you do this task? (Count hands) etc.
3. Collecting firewood (Count hands) etc.
4. Earning money (Count hands) etc.
5. Preparing meals (Count hands) etc.
6. Washing clothes (Count hands) etc.
7. Care/supervision of children in your household (Count hands) etc.
8. Caring for sick family members (Count hands) etc.
9. Working in the field (Count hands) etc.
10. Taking care of livestock (pigs, chickens, horses, etc) (Count hands) etc.

\*Who if anyone shares the responsibility for doing these tasks?

\*Apart from these household tasks, what other tasks are you responsible for in the community (social, religious, traditional)?

\*Do you personally know any men who are involved in caring for sick people (including those affected with HIV/AIDS), either in their own households or in the community?

- How are these men who care for sick people different from those who do not? In personal qualities? In their family circumstances? In their financial circumstances?

\*Do you think there is a need to increase the number of people involved in providing HIV/AIDS care and support to families in this community? Why?

- Do you think there is a need to increase the number of men? Why?

## **FEASIBILITY OF ENGAGING MEN AS PROVIDERS OF CHBC/GENDER AND CULTURAL FACTORS THAT NEED TO BE ADDRESSED**

*(KNOWLEDGE, BELIEFS, PERCEPTIONS ABOUT/RELATED TO CARE AND SUPPORT)*

\*Should CHWs be doing home-based HIV/AIDS care and support tasks?

- To what extent is this feasible, given their other CHW responsibilities?

\*Why do you think most men are not getting involved in HIV/AIDS care in their families or in the community?

\*Do you believe there are tasks that **women can do better than men** in caring for PLHIV? (Refer to tasks mentioned in Attachment I)? What tasks?

- What makes women better at these tasks?
- To what extent would training men to do these tasks help them do them as well as women?

\*Are there tasks that **men can do better than women** in caring for PLHIV? What tasks?

- What makes men better at these tasks?

\*Is it considered acceptable for a *woman* to provide care for anyone who is sick and needs care, regardless of whether the sick person is a man or a woman? Why? Why not?

\*How acceptable would it be for a *man* to provide care for anyone who is sick and needs care, regardless of whether the sick person is a man or a woman? Why? Why not?

- What reactions—positive or negative--would men face from the community if they became involved in caring for sick people?

\*Is there anything that would prevent men getting involved in caring for sick people at home or in the community? Probe why or why not.

*(USE OF TIME AND SPACE)*

\*Are there any household spaces that are considered “off limits” to men?

\*In some places, women or girls have experienced violence or exploitation when they provided home-based care. How much of a problem is this for women or girls in your communities?

- Do such risks exist for boys and men?

\*Are there public places where men meet and might be recruited to work as providers of HIV/AIDS care and support?

*(SOCIAL OR MENTORING SUPPORT NEEDED FOR CHANGE)*

\* Would it be possible for *men* to change their attitudes and behavior and get more involved in caring for sick people at home or in the community? If so, what would make this change possible?

\*In what ways do *women* need to change in order for men to get involved in caring for sick people at home or in the community?

\*Who in the community could help change current attitudes or practices related to men’s involvement in caring for PLHIV?

\*Would you refer a male caregiver to a family member, friend or neighbor who is sick? Why? Why not?

**\*Note to facilitator and notetaker:** In the next part of the discussion, we want to find out what incentives would be valued by CHWs, incentives which would attract new CHWs or retain those currently working in the CHW job, by 1) asking them to select the top three (3) **financial** incentives from a list of incentives; and then asking them to select the top three (3) **non-financial** incentives from a list presented. It may be necessary to develop cards with pictures or locally recognizable symbols to help people remember the incentives.

**A. Here are 6 types of financial incentives that have been offered to CHWs in other programs:** 1) Allowance 2) reimbursement for out-of-pocket expenses 3) transportation costs 4) retaining part of the money earned from selling a health product (for example, vitamins, contraceptives) 5) housing and 6) electricity.

Think of three (3) out of all these financial incentives which would be most important to you.

*Raise your hand if one of your top three financial incentives is:*

- **Allowance in Rand** (Count hands for those who have this in their top three).

- Ask them how many Rand per month would be minimally preferred.

*Raise your hand if one of your top three incentives is*

- **Reimbursement for out-of-pocket expenses** (Count hands for those who have this in their top three).

*Raise your hand if one of your top three incentives is*

- **Transportation costs** (Count hands for those who have this in their top three)

*Raise your hand if one of your top three incentives is*

- **Retaining a part of the money earned by selling a health product to the community** (Count hands for those who have this in their top three)

*Raise your hand if one of your top three incentives is*

- **Housing** (Count hands for those who have this in their top three)

*Raise your hand if one of your top three incentives is*

- **Electricity** (Count hands for those who have this in their top three)

**B. Here are 9 types of non-financial incentives that have been offered to CHWs in other programs.** 1) Having work experience which counts towards getting a better job with an organization after a period of time (career path) 2) formal recognition by the community 3) cooked meals 4) vegetables or other foodstuffs 5) skills training; 6) working more closely with other CHWs or with the HC nurse; 7) free medicines or health care; 8) childcare; and 9) being provided all the materials necessary to do the job.

Think of your top three (3) **non-financial incentives**, the three out of all these that would be most important to you.

*Raise your hand if one of your top three non-financial incentives is:*

- Experience and opportunity to get a better job with an organization after a period of time (Count hands for those who have this in their top three)
- Formal recognition by the community (Count hands for those who have this in their top three)
- Cooked meal (Count hands for those who have this in their top three)
- Vegetables or other foodstuffs(Count hands for those who have this in their top three)
- Skills training (Count hands for those who have this in their top three)
- Working more closely with other CHWs or with the HC nurse (Count hands for those who have this in their top three)
- Access to free medicines or health care (Count hands for those who have this in their top three)
- Childcare (Count hands for those who have this in their top three)
- Being provided all the materials necessary to do the job (Count hands for those who have this in their top three)

What incentives have we not mentioned already that would in your top three financial incentives? Non-financial incentives?

### **PERCEPTIONS OF ADVANTAGES AND DISADVANTAGES TO MEN’S INVOLVEMENT IN CHBC**

\*Are there any *disadvantages* if men if they became involved in providing community-based care and support? Probe disadvantages to men, to women, to family or community)

\*Are there any *advantages* if men became involved in providing community-based care and support? (Probe advantages to men, to women, to family or community)

**Thank you!**

## ATTACHMENT I: HOME-BASED HIV/AIDS CARE AND SUPPORT TASKS

- Bathing the sick person \_\_\_\_
- Turning the sick person in their beds\_\_
- Lifting the sick person\_\_\_\_\_
- Cooking\_\_\_\_\_
- Feeding the sick person \_\_\_\_\_
- Caring for the sick person's mouth \_\_\_\_
- Toileting the sick person\_\_\_\_\_
- Supervising the sick person's children \_\_\_\_\_
- Sweeping the compound\_\_\_\_\_
- Fetching water\_\_\_\_
- Washing clothes\_\_\_\_\_
- Massaging the sick person or giving pain relief\_\_\_\_\_
- Dressing pressure sores\_\_\_\_\_
- Emotional support\_\_\_\_
- Finding out if the family needs financial or material support\_\_\_\_
- Transporting the sick person to the HC/hospital\_\_\_\_
- Getting medicines for the sick person\_\_\_\_\_
- Teaching family members how to do the tasks mentioned above\_\_\_\_
- Helping the family plan for the future of a widow(er) or children (i.e., making a will, consulting a paralegal, getting welfare benefits)
- Helping the family preparing a garden to improve nutrition or family finances

## Community Women Focus Group Discussion Guide

**Introduction:** The MOHSW would like to strengthen the capacity of Lesotho's health system to address the HIV/AIDS pandemic at the community level by increasing the active engagement of men as providers of community home-based health care. In this study, we would like to identify ways to recruit, train, support and retain men in community-based HIV/AIDS home-based care and support jobs which have traditionally been considered the province of women.

**Purpose:** The purposes of this Focus Group Discussion are to: determine the **need to** bring men into community-based HIV/AIDS care and support; determine the **feasibility** of engaging men as providers of community based HIV/AIDS care and support, in particular the **gender-related and cultural factors** that need to be addressed in order to increase male involvement in community-based HIV/AIDS care and support; and identify women's perceptions of the **advantages or disadvantages** to male involvement in community home based care and support.

**Estimated Time:** 2 ½ hours

### Informed Consent Statement

After introducing the purpose of the study and the research team, the FGD facilitator reads this statement:

This study was approved by the Ministry of Health and by an Ethical Review Committee. We would like to ask you some questions about the possibility of involving men in HIV/AIDS care and support activities at the community level in order to assist the Ministry of Health plan to improve community-based HIV/AIDS service delivery in Lesotho. You will not be contacted in the future. We will not write your name down. Your answers will remain confidential. During the study, the results will be kept in the Study Managers' office in a locked drawer. The only persons who see the results are those who work on the study.

Your participation in the focus group is entirely voluntary and you may choose not to answer a question, or to leave the group at any time. We very much appreciate your help in this study, even though we will not be able to pay you. Although you may not immediately benefit from the study, the results will be used to improve health care delivery in your community and in other communities in Lesotho. However, we will be able to offer you a snack, a cold drink, and a small transport reimbursement. Please remember that our conversation is confidential, so we'd like to underscore the importance of not communicating the specifics of what you discussed in this group to others.

If you have any questions, please contact (Name and telephone number of Study Manager).

**May we begin?**

After reading the foregoing consent declaration, tick off below for every respondent that agrees to participate.

Tick off below for every respondent who does **not** agree to participate in the focus group.

**Record for all 10-12 FGD participants**

1. Ages:

2. Number of children:

3. Number of ex-miners' wives:

4. Are you a member of an HIV/AIDS caregiver/support group?

5. Interviewer \_\_\_\_\_

6. Date \_\_\_\_\_

7. Region \_\_\_\_\_

District \_\_\_\_\_

**ICEBREAKER**

\*Are there people in this community living with HIV/AIDS?

**NEED TO BRING MEN INTO COMMUNITY HOME-BASED CARE (CHBC)**

*(REAL) PRACTICES AND PARTICIPATION*

\*What typically happens when a family member gets sick with HIV/AIDS in your community?

\*Are there *customary* ways families take care of sick people? Does this apply to care of PLHIV?

- Who *actually* takes care of the sick person?
- If the caregiver is a *female* family or community member, what is usually her relationship to the sick person? (Probe for all caregivers, such as “mother of the sick person” and follow up by asking “Who else?” until no other caregivers are mentioned).

- If the caregiver is a *male* family member, what is usually his relationship with the sick person (Probe for all caregivers, such as “friend of the sick person” and follow up by asking “Who else?” until no other caregivers are mentioned).
  - Are the caregivers paid to take care of sick people or do they volunteer their time?

\*What home-based care and support tasks do you actually do, or have you done on behalf of a family member or friend who is sick (Refer to **Attachment 1, Home-Based HIV/AIDS Care and Support Tasks**, to prompt as necessary and record all that are mentioned)?

**\* Note to facilitator and notetaker:** In the next part of the discussion, we want to understand the workloads of women by 1) asking them to confirm the tasks listed below 2) finding out if the task is performed daily and how much time it takes; 3) and for tasks that are not performed daily, finding out how many times a week the task is performed. After introducing the question, follow the steps (1 a-c) for all of the tasks shown in the first example below:

\*Now I’m going to ask you about tasks you are responsible for at home? Do you

1. Obtain food for the family--How many of you do this task? (Count hands)
  - a. For those of you who obtain food for the family, how many of you do this every day? (Count hands)
  - b. For those of you who obtain food for the family every day, how much time do you spend on this every day? (Write the amounts of time)
  - c. For those of you who obtain food for the family but not every day, how often do you do this task each week? (Write the number of times per week)
2. Get water--How many of you do this task? (Count hands) etc.
3. Collecting firewood (Count hands) etc.
4. Earning money (Count hands) etc.
5. Preparing meals (Count hands) etc.
6. Washing clothes (Count hands) etc.
7. Care/supervision of children in your household (Count hands) etc.
8. Caring for sick family members (Count hands) etc.
9. Working in the field (Count hands) etc.
10. Taking care of livestock (pigs, chickens, horses, etc) (Count hands) etc.

\*Who if anyone shares the responsibility for doing these tasks?

- Are your menfolk responsible for or involved in carrying out any of these tasks?
- Do you think the menfolk should take responsibility for some of these household tasks?

\*Apart from these household tasks, what other tasks are you responsible for in the community (social, religious, traditional)?

\*Do you personally know any men who are involved in caring for sick people (including people affected by HIV/AIDS), either in their own households or in the community?

- How are these men who care for sick people different from those who do not? In personal qualities? In their family circumstances? In their financial circumstances?

\*Do you think there is a need to increase the number of people involved in providing HIV/AIDS care and support to families in this community? Why?

- Do you think there is a need to increase the number of men? Why?

## **FEASIBILITY OF ENGAGING MEN AS PROVIDERS OF CHBC/GENDER AND CULTURAL FACTORS THAT NEED TO BE ADDRESSED**

*(KNOWLEDGE, BELIEFS, PERCEPTIONS ABOUT/RELATED TO CARE AND SUPPORT)*

\*Why do you think most men are not getting involved in HIV/AIDS care in their families or in the community?

\*Do you believe there are tasks that **women can do better than men** in caring for PLHIV? (Refer to tasks listed in Attachment 1)? What tasks?

- What makes women better at these tasks?
- To what extent would training men to do these tasks help them do them as well as women?

Are there tasks that **men can do better than women** in caring for PLHIV? What tasks?

- What makes men better at these tasks?
- Is this ability due to the way men are raised or is it because they are born with these skills?
- Do men have specific knowledge that can make them good at these tasks?

\*Is it considered acceptable for a *woman* to provide care for anyone who is sick and needs care, regardless of whether the sick person is a man or a woman? Why? Why not?

\*How acceptable would it be for a *man* to provide care for anyone who is sick and needs care, regardless of whether the sick person is a man or a woman? Why? Why not?

- What reactions—positive and negative--would men face from the community if they became involved in caring for sick people?

\*Is there anything that would prevent men getting involved in caring for sick people at home or in the community? Probe why or why not.

(USE OF TIME AND SPACE)

\*Are there any household spaces that are considered “off limits” to men?

\*In some places, women or girls have experienced violence or exploitation when they provided home-based care. How much of a problem is this for women or girls in your communities?

- Do such risks exist for boys and men?

\*Are there public places where men meet and might be recruited to work as providers of HIV/AIDS care and support?

(SOCIAL OR MENTORING SUPPORT NEEDED FOR CHANGE)

\* Would it be possible for *men* to change their attitudes and behavior and get more involved in caring for sick people at home or in the community? If so, what would make this change possible?

\*In what ways do *women* need to change in order for men to get involved in caring for sick people at home or in the community?

\*Who in the community could help change current attitudes or practices related to men’s involvement in caring for PLHIV?

\*Under what circumstances would you refer a male caregiver to a family member, friend or neighbor who is sick? Why? Why not?

## **PERCEPTIONS OF ADVANTAGES AND DISADVANTAGES TO MEN’S INVOLVEMENT IN CHBC**

\*Are there any *advantages* if men became involved in providing community-based care and support? (Probe advantages to men, to women, to family or community)

\*Are there any *disadvantages* if men if they became involved in providing community-based care and support? Probe disadvantages to men, to women, to family or community)

**Thank you!**

## **ATTACHMENT I: HOME-BASED HIV/AIDS CARE AND SUPPORT TASKS**

- Bathing the sick person \_\_\_\_
- Turning the sick person in their beds\_\_
- Lifting the sick person\_\_\_\_\_
- Cooking\_\_\_\_\_
- Feeding the sick person \_\_\_\_\_
- Caring for the sick person's mouth\_\_\_\_
- Toileting the sick person\_\_\_\_\_
- Supervising the sick person's children\_\_\_\_\_
- Sweeping the compound\_\_\_\_\_
- Fetching water\_\_\_\_
- Washing clothes\_\_\_\_\_
- Massaging the sick person or giving pain relief\_\_\_\_\_
- Dressing pressure sores\_\_\_\_\_
- Emotional support\_\_\_\_
- Finding out if the family needs financial or material support\_\_\_\_
- Transporting the sick person to the HC/hospital\_\_\_\_
- Getting medicines for the sick person\_\_\_\_\_
- Teaching family members how to do the tasks mentioned above\_\_\_\_
- Helping the family plan for the future of a widow(er) or children (i.e., making a will, consulting a paralegal, getting welfare benefits)
- Helping the family preparing a garden to improve nutrition or family finances

## **Community Men Focus Group Discussion Guide (Also to be used for the Miners Focus Group Discussion)**

**Introduction:** The MOHSW would like to strengthen the capacity of Lesotho's health system to address the HIV/AIDS pandemic at the community level by increasing the active engagement of men as providers of community home-based health care. In this study, we would like to identify ways to recruit, train, support and retain men in community-based HIV/AIDS home-based care and support jobs which have traditionally been considered the province of women.

**Purpose:** The purposes of this Focus Group Discussion are to: determine the **need to** bring men into community-based HIV/AIDS care and support; determine the **feasibility** of engaging men as providers of community based HIV/AIDS care and support, in particular the **gender-related and cultural factors** that need to be addressed in order to increase male involvement in community-based HIV/AIDS care and support; identify men's perceptions of the **advantages or disadvantages** to male involvement in community home based care and support; and men's training, mentoring and support needs (including incentives).

**Estimated Time:** 2 1/2 hours

### **Informed Consent Statement**

After introducing the purpose of the study and the research team, the FGD facilitator reads this statement:

«This study was approved by the Ministry of Health and by an Ethical Review Committee. We would like to ask you some questions about the possibility of involving men in HIV/AIDS care and support activities at the community level in order to assist the Ministry of Health plan to improve community-based HIV/AIDS service delivery in Lesotho. You will not be contacted in the future. We will not write your name down. Your answers will remain confidential. During the study, the results will be kept in the Study Managers' office in a locked drawer. The only persons who see the results are those who work on the study.

Your participation in the focus group is entirely voluntary and you may choose not to answer a question, or to leave the group at any time. We very much appreciate your help in this study, even though we will not be able to pay you. Although you may not immediately benefit from the study, the results will be used to improve health care delivery in your community and in other communities in Lesotho. However, we will be able to offer you a snack, a cold drink, and a small transport reimbursement. Please remember that our conversation is confidential, so we'd like to underscore the importance of not communicating the specifics of what you discussed in this group to others.

If you have any questions, please contact (Name and telephone number of Study Manager).

**May we begin?**

After reading the foregoing consent declaration, tick off below for every respondent that agrees to participate.

Tick off below for every respondent who does **not** agree to participate in the focus group.

**Record for all 10-12 FGD participants**

- 1. Ages:
- 2. Number of children:
- 3. Number of ex-miners:
- 4. Are you a member of an HIV/AIDS caregiver/support group?
- 5. Interviewer \_\_\_\_\_
- 6. Date \_\_\_\_\_
- 7. Region \_\_\_\_\_
- 8. District \_\_\_\_\_

**ICEBREAKER**

\*Are there people in this community living with HIV/AIDS?

**NEED TO BRING MEN INTO COMMUNITY HOME-BASED CARE (CHBC)**

*(REAL) PRACTICES AND PARTICIPATION*

\*What typically happens when a family member gets sick with HIV/AIDS in your community?

\*Are there *customary* ways families take care of sick people? Does this apply to care of PLHIV?

- o Who *actually* takes care of the sick person?

- If the caregiver is a *female* family or community member, what is usually her relationship to the sick person? (Probe for all caregivers, such as “mother of the sick person” and follow up by asking “Who else?” until no other caregivers are mentioned).
- If the caregiver is a *male* family member, what is usually his relationship with the sick person (Probe for all caregivers, such as “friend of the sick person” and follow up by asking “Who else?” until no other caregivers are mentioned):
  - Are the caregivers paid to take care of sick people or do they volunteer their time?

\*Do you think there is a need to increase the number of people involved in providing HIV/AIDS care and support to families in this community? Why?

- Do you think there is a need to increase the number of men? Why?

## **FEASIBILITY OF ENGAGING MEN AS PROVIDERS OF CHBC/GENDER AND CULTURAL FACTORS THAT NEED TO BE ADDRESSED**

*(ACTUAL PRACTICE AND PARTICIPATION)*

\*What home-based care and support tasks do you actually do, or have you done on behalf of a sick friend or family member (Refer to **Attachment I, Home-Based HIV/AIDS Care and Support Tasks**, to prompt as necessary and record all that are mentioned)?

**\* Note to facilitator and notetaker:** In the next part of the discussion, we want to understand the workloads of men by 1) asking them to confirm the tasks listed below 2) finding out if the task is performed daily and how much time it takes; 3) and for tasks that are not performed daily, finding out how many times a week the task is performed. After introducing the question, follow the steps (I a-c) for all of the tasks shown in the first example below:

\*Now I’m going to ask you about tasks you are responsible for at home. Do you:

1. Obtain food for the family--How many of you do this task? (Count hands)
  - a. For those of you who obtain food for the family, how many of you do this every day? (Count hands)
  - b. For those of you who obtain food for the family every day, how much time do you spend on this every day? (Write the amounts of time)
  - c. For those of you who obtain food for the family but not every day, how often do you do this task each week? (Write the number of times per week)
2. Get water--How many of you do this task? (Count hands) etc.
3. Collecting firewood (Count hands) etc.
4. Earning money (Count hands) etc.

5. Preparing meals (Count hands) etc.
6. Washing clothes (Count hands) etc.
7. Care/supervision of children in your household (Count hands) etc.
8. Caring for sick family members (Count hands) etc.
9. Working in the field (Count hands) etc.
10. Taking care of livestock (pigs, chickens, horses, etc) (Count hands) etc.

**\*Note to facilitator and notetaker:** In the next part of the discussion, we want to find out what incentives would be valued by men and which would attract them to work in a caregiving job such as the CHW job, by 1) asking them to select the top three (3) **financial** incentives from a list of incentives; and then asking them to select the top three (3) **non-financial** incentives from a list presented. It may be necessary to develop cards with pictures or locally recognizable symbols to help people remember the incentives.

**A. Here are 6 types of financial incentives that have been offered to CHWs in other programs:** 1) Allowance 2) reimbursement for out-of-pocket expenses 3) transportation costs 4) retaining part of the money earned from selling a health product (for example, vitamins, contraceptives) 5) housing and 6) electricity.

Think of three (3) out of all these financial incentives which would be most important to you.

*Raise your hand if one of your top three financial incentives is:*

- **Allowance in Rand** (Count hands for those who have this in their top three).
  - Ask them how many Rand per month would be minimally preferred.

*Raise your hand if one of your top three incentives is*

- **Reimbursement for out-of-pocket expenses** (Count hands for those who have this in their top three).

*Raise your hand if one of your top three incentives is*

- **Transportation costs** (Count hands for those who have this in their top three)

*Raise your hand if one of your top three incentives is*

- **Retaining a part of the money earned by selling a health product to the community** (Count hands for those who have this in their top three)

*Raise your hand if one of your top three incentives is*

- **Housing** (Count hands for those who have this in their top three)

*Raise your hand if one of your top three incentives is*

- **Electricity** (Count hands for those who have this in their top three)

**B. Here are 9 types of non-financial incentives that have been offered to CHWs in other programs.** 1) Having work experience which counts towards getting a better job with an organization after a period of time (career path) 2) formal recognition by the community 3) cooked meals 4) vegetables or other foodstuffs 5) skills training; 6) working more closely with other CHWs or with the HC nurse; 7) free medicines or health care; 8) childcare; and 9) being provided all the materials necessary to do the job.

Think of your top three (3) **non-financial incentives**, the three out of all these that would be most important to you.

*Raise your hand if one of your top three non-financial incentives is:*

- Experience and opportunity to get a better job with an organization after a period of time (Count hands for those who have this in their top three)
- Formal recognition by the community (Count hands for those who have this in their top three)
- Cooked meal (Count hands for those who have this in their top three)
- Vegetables or other foodstuffs(Count hands for those who have this in their top three)
- Skills training (Count hands for those who have this in their top three)
- Working more closely with other CHWs or with the HC nurse (Count hands for those who have this in their top three)
- Access to free medicines or health care (Count hands for those who have this in their top three)
- Childcare (Count hands for those who have this in their top three)
- Being provided all the materials necessary to do the job (Count hands for those who have this in their top three)

\*What incentives have we not mentioned already that would in your top three financial incentives? Non-financial incentives?

\*Who if anyone shares the responsibility for doing these tasks?

\*Apart from these household tasks, what tasks are you responsible for (religious, traditional)?

*(USE OF TIME AND SPACE)*

\*In what other types of activities do men get involved in your community? (Probe: Social? Sports? Other?)?

\*Are there any *household* spaces that are considered “off limits” to men?

\*Are there public places where men meet and might be recruited to work as providers of HIV/AIDS care and support?

*(KNOWLEDGE, BELIEFS, PERCEPTIONS ABOUT/RELATED TO CARE AND SUPPORT)*

\*Do you believe there are some tasks that **women can do better than men** in caring for PLHIV? What tasks?

- What makes women better at these tasks?
- To what extent would training men to do these tasks help them do them as well as women?

Are there some tasks that **men can do better than women** in caring for PLHIV? What tasks?

- What makes men better at these tasks?

\*Do you personally know any men who are involved in caring for sick people (including those affected with HIV/AIDS), either in their own households or in the community?

- How are these men who care for sick people different from those who do not? In personal qualities? In their family circumstances? In their financial circumstances?

\*Why do you think most men are not getting involved in HIV/AIDS care in their families or in the community?

\*How acceptable would it be for a *man* to provide care for anyone who is sick and needs care, regardless of whether the sick person is a man or a woman? Why? Why not?

- What reactions—positive or negative--would men face from the community if they became involved in caring for sick people?

\*In some places, women or girls have experienced violence or exploitation when they provided home-based care. How much of a problem is this for women or girls in your communities?

- Do such risks exist for boys and men?

\*Is there anything that would prevent men getting involved in caring for sick people at home or in the community? Probe what and why.

\*Under what circumstances would you refer a male caregiver to a family member, friend or neighbor who is sick? Why? Why not?

\*Can you tell us some negative views men might have about the CHW job?

- Are there any potential attractions for men to work in a caregiving job such as the CHW job?
- What would make the CHW job more attractive to you?

**Note to facilitator and notetaker:** In the next part of the discussion, we want to find out what incentives would be valued by men and which would attract them to work in a caregiving job such as the CHW job, by 1) asking them to select the top three (3) **financial** incentives from a list of incentives; and then asking them to select the top three (3) **non-financial** incentives from a list presented. It may be necessary to develop cards with pictures or locally recognizable symbols to help people remember the incentives.

**A. Here are six types of financial incentives that have been offered to CHWs in other programs:** 1) Allowance 2) reimbursement for out-of-pocket expenses 3) transportation costs 4) retaining part of the money earned from selling a health product (for example, vitamins, contraceptives) 5) housing and 6) electricity.

Think of three (3) out of all these financial incentives which would be most important to you.

*Raise your hand if one of your top three financial incentives is:*

- **Allowance in Rand** (Count hands for those who have this in their top three).
  - Ask them how many Rand per month would be minimally preferred.

*Raise your hand if one of your top three incentives is*

- **Reimbursement for out-of-pocket expenses** (Count hands for those who have this in their top three).

*Raise your hand if one of your top three incentives is*

- **Transportation costs** (Count hands for those who have this in their top three)

*Raise your hand if one of your top three incentives is*

- **Retaining a part of the money earned by selling a health product to the community** (Count hands for those who have this in their top three)

*Raise your hand if one of your top three incentives is*

- **Housing** (Count hands for those who have this in their top three)

*Raise your hand if one of your top three incentives is*

- **Electricity** (Count hands for those who have this in their top three)

**B. Here are 9 types of non-financial incentives that have been offered to CHWs in other programs.** 1) Having work experience which counts towards getting a better job with an organization after a period of time (career path) 2) formal recognition by the community 3) cooked meals 4) vegetables or other foodstuffs 5) skills training; 6) working more closely with other CHWs or with the health HC nurse; 7) free medicines or health care; 8) childcare; and 9) being provided all the materials necessary to do the job.

Think of your top three (3) **non-financial incentives**, the three out of all these that would be most important to you.

*Raise your hand if one of your top three non-financial incentives is:*

- Experience and opportunity to get a better job with an organization after a period of time (Count hands for those who have this in their top three)
- Formal recognition by the community (Count hands for those who have this in their top three)
- Cooked meal (Count hands for those who have this in their top three)
- Vegetables or other foodstuffs(Count hands for those who have this in their top three)

- Skills training (Count hands for those who have this in their top three)
- Working more closely with other CHWs or with the HC nurse (Count hands for those who have this in their top three)
- Access to free medicines or health care (Count hands for those who have this in their top three)
- Childcare (Count hands for those who have this in their top three)
- Being provided all the materials necessary to do the job (Count hands for those who have this in their top three)

\*What incentives have we not mentioned already that would in your top three financial incentives? Non-financial incentives?

*(SOCIAL OR MENTORING SUPPORT NEEDED FOR CHANGE)*

\* Would it be possible for *men* to change their attitudes and behaviors and get more involved in caring for sick people at home or in the community? If so, what would make this change possible?

\*If you were to consider getting involved in community home-based care for HIV/AIDS, what do you think would be the biggest challenge to deal with?

- What kind of (non-financial) support would you need, from whom, to deal with these challenges? (Probe training, group social support, technical support, mentoring)?

\*In what ways do *women* need to change in order for men to get involved in caring for sick people at home or in the community?

\*Who in the community could help change current attitudes or practices related to men's involvement in caring for PLHIV?

## **PERCEPTIONS OF ADVANTAGES AND DISADVANTAGES TO MEN'S INVOLVEMENT IN CHBC**

\*Are there any *disadvantages* if men if they became involved in providing community-based care and support? Probe disadvantages to men, to women, to family or community)

\*Are there any *advantages* to men's becoming (more) involved in providing community-based care and support? (Probe advantages to men, to women, to family or community)

**Thank you!**

## ATTACHMENT 1: HIV/AIDS HOME-BASED CARE AND SUPPORT TASKS

- Bathing the sick person \_\_\_\_
- Turning the sick person in their beds\_\_
- Lifting the sick person\_\_\_\_\_
- Cooking\_\_\_\_\_
- Feeding the sick person \_\_\_\_\_
- Caring for the sick person's mouth\_\_\_\_
- Toileting the sick person\_\_\_\_\_
- Supervising the sick person's children\_\_\_\_\_
- Sweeping the compound\_\_\_\_\_
- Fetching water\_\_\_\_
- Washing clothes\_\_\_\_\_
- Massaging the sick person or giving pain relief\_\_\_\_\_
- Dressing pressure sores\_\_\_\_\_
- Emotional support\_\_\_\_
- Finding out if the family needs financial or material support\_\_\_\_
- Transporting the sick person to the HC/hospital\_\_\_\_
- Getting medicines for the sick person\_\_\_\_\_
- Teaching family members how to do the tasks mentioned above\_\_\_\_
- Helping the family plan for the future of a widow(er) or children (i.e., making a will, consulting a paralegal, getting welfare benefits)
- Helping the family preparing a garden to improve nutrition or family finances

## PLHIV Focus Group Discussion Guide

**Introduction:** The MOHSW would like to strengthen the capacity of Lesotho's health system to address the HIV/AIDS pandemic at the community level by increasing the active engagement of men as providers of community home-based health care. In this study, we would like to identify ways to recruit, train, support and retain men in community-based HIV/AIDS home-based care and support jobs which have traditionally been considered the province of women.

**Purpose:** The purposes of this Focus Group Discussion are to: determine the **need to** bring HIV positive men into community-based HIV/AIDS care and support; determine the **feasibility** of engaging HIV-positive men as providers of community based HIV/AIDS care and support, including the **gender-related** and **cultural factors** that need to be addressed; identify perceptions of the **advantages** or **disadvantages** to male involvement in community home based care and support; and HIV-positive men's training, mentoring and support needs (including incentives).

**Estimated Time:** 2 ½ hours

### Informed Consent Statement

After introducing the purpose of the study and the research team, the FGD facilitator reads this statement:

«This study was approved by the Ministry of Health, by LENEPHWA and by an Ethical Review Committee. We would like to ask you some questions about the possibility of involving men in HIV/AIDS care and support activities at the community level in order to assist the Ministry of Health plan to improve community-based HIV/AIDS service delivery in Lesotho. You will not be contacted in the future. We will not write your name down. Your answers will remain confidential. During the study, the results will be kept in the Study Managers' office in a locked drawer. The only persons who see the results are those who work on the study.

Your participation in the focus group is entirely voluntary and you may choose not to answer a question, or to leave the group at any time. We very much appreciate your help in this study, even though we will not be able to pay you. Although you may not immediately benefit from the study, the results will be used to improve health care delivery in your community and in other communities in Lesotho. However, we will be able to offer you a snack, a cold drink, and a small transport reimbursement. Please remember that our conversation is confidential, so we'd like to underscore the importance of not communicating the specifics of what you discussed in this group to others.

If you have any questions, please contact (Name and telephone number of Study Manager).

**May we begin?**

After reading the foregoing consent declaration, tick off below for every respondent that agrees to participate.

Tick off below for every respondent who does **not** agree to participate in the focus group.

**Record for all 10-12 FGD participants**

- 1. Ages:
- 2. Number of children:
- 3. Number of ex-miners’ or ex-miners’ wives:
- 4. Are you a member of an HIV/AIDS caregiver/support group?
- 5. Interviewer \_\_\_\_\_
- 6. Date \_\_\_\_\_
- 7. Region \_\_\_\_\_
- 8. District \_\_\_\_\_

**ICEBREAKER**

\*Are there people in this community living with HIV/AIDS?

**NEED TO BRING MEN INTO COMMUNITY HOME-BASED CARE (CHBC)**

\*What typically happens when a family member gets sick with HIV/AIDS in your community?

\*Are there *customary* ways families take care of sick people? Does this apply to care of PLHIV?

- o Who *actually* takes care of the sick person?
- o If the caregiver is a *female* family or community member, what is usually her relationship to the sick person? (Probe for all caregivers, such as “mother of the sick person” and follow up by asking “Who else?” until no other caregivers are mentioned).

- If the caregiver is a *male* family member, what is usually his relationship with the sick person (Probe for all caregivers, such as “friend of the sick person” and follow up by asking “Who else?” until no other caregivers are mentioned).
  - Are the caregivers paid to take care of sick people or do they volunteer their time?

\*Do you think there is a need to increase the number of HIV-positive people involved in providing HIV/AIDS care and support to families in this community?

\*Do you personally know any men who are already involved in caring for sick people (including people affected by HIV/AIDS), in this community?

- How are these men who care for sick people different from those who do not? In personal qualities? In their family circumstances? In their financial circumstances?
- What are the personal characteristics you expect from a person providing home-based care for PLHIV?

\*Why do you think most HIV-positive men are not getting involved in HIV/AIDS care in their families or in the community?

\*How acceptable would it be to you to have a man provide care for you? Why? Why not?

\*What reactions—positive or negative--would an HIV-positive man face from the community if he became involved in caring for PLHIV? Why?

- Are there any potential attractions for HIV-positive men to work as HIV/AIDS caregivers, either as a CHW or as a member of a support group?
- What would make the provision of HIV/AIDS care and support more attractive to HIV-positive men?

\*In some places, women or girls have experienced violence or exploitation when they provided home-based care. How much of a problem is this for women or girls in your communities?

- Do such risks exist for boys and men?

\*Is there anything that would prevent (HIV-positive) men from getting involved in HIV/AIDS home-based care and support? In what ways—if any--does this differ from the experience of HIV-positive women?

**Note to facilitator and notetaker:** In the next part of the discussion, we want to find out what incentives would be valued by men and women living with HIV and AIDS, and which would attract them to provide home-based care and support, by 1) asking them to select the top three (3) **financial** incentives from a list of incentives; and then asking them to select the top three (3) **non-financial** incentives from a list presented. It may be necessary to develop cards with pictures or locally recognizable symbols to help people remember the incentives.

**A. Here are 6 types of financial incentives that have been offered to CHWs in other programs:** 1) Allowance 2) reimbursement for out-of-pocket expenses 3) transportation costs 4) retaining part of the money earned from selling a health product (for example, vitamins, contraceptives) 5) housing and 6) electricity.

Think of three (3) out of all these financial incentives which would be most important to you.

*Raise your hand if one of your top three financial incentives is:*

- **Allowance in Rand** (Count hands for those who have this in their top three).
  - Ask them how many Rand per month would be minimally preferred.

*Raise your hand if one of your top three incentives is*

- **Reimbursement for out-of-pocket expenses** (Count hands for those who have this in their top three).

*Raise your hand if one of your top three incentives is*

- **Transportation costs** (Count hands for those who have this in their top three)

*Raise your hand if one of your top three incentives is*

- **Retaining a part of the money earned by selling a health product to the community** (Count hands for those who have this in their top three)

*Raise your hand if one of your top three incentives is*

- **Housing** (Count hands for those who have this in their top three)

*Raise your hand if one of your top three incentives is*

- **Electricity** (Count hands for those who have this in their top three)

**B. Here are 9 types of non-financial incentives that have been offered to CHWs in other programs.** 1) Having work experience which counts towards getting a better job with an organization after a period of time (career path) 2) formal recognition by the community 3) cooked meals 4) vegetables or other foodstuffs 5) skills training; 6) working more closely with other CHWs or with the HC nurse; 7) free medicines or health care; 8) childcare; and 9) being provided all the materials necessary to do the job.

Think of your top three (3) **non-financial incentives**, the three out of all these that would be most important to you.

*Raise your hand if one of your top three non-financial incentives is:*

- Experience and opportunity to get a better job with an organization after a period of time (Count hands for those who have this in their top three)
- Formal recognition by the community (Count hands for those who have this in their top three)
- Cooked meal (Count hands for those who have this in their top three)
- Vegetables or other foodstuffs (Count hands for those who have this in their top three)
- Skills training (Count hands for those who have this in their top three)

- Working more closely with other CHWs or with the HC nurse (Count hands for those who have this in their top three)
- Access to free medicines or health care (Count hands for those who have this in their top three)
- Childcare (Count hands for those who have this in their top three)
- Being provided all the materials necessary to do the job (Count hands for those who have this in their top three)

\*What incentives have we not mentioned already that would in your top three financial incentives? Non-financial incentives?

## **FEASIBILITY OF ENGAGING MEN AS PROVIDERS OF CHBC/GENDER AND CULTURAL FACTORS THAT NEED TO BE ADDRESSED**

*(REAL PRACTICE AND PARTICIPATION)*

\*What home-based care and support tasks do you actually do, or have you done on behalf of yourself, a family member or friend who is sick (Refer to **Attachment I, Home-Based HIV/AIDS Care and Support Tasks**, to prompt as necessary and record all that are mentioned)?

*(USE OF TIME AND SPACE)*

**\*Note to facilitator and notetaker:** In the next part of the discussion, we want to understand the workloads of PLHIV by 1) asking them to confirm the tasks listed below 2) finding out if the task is performed daily and how much time it takes 3) and for tasks that are not performed daily, find out how many times a week the task is performed. After introducing the question, follow the steps (1 a-c) for all of the tasks shown in the first example below:

\*Now I'm going to ask you about tasks you are responsible for at home. Do you

1. Obtain food for the family--How many of you do this task? (Count hands)
  - a. For those of you who obtain food for the family, how many of you do this every day? (Count hands)
  - b. For those of you who obtain food for the family every day, how much time do you spend on this every day? (Write the amounts of time)
  - c. For those of you who obtain food for the family but not every day, how often do you do this task each week? (Write the number of times per week)
2. Get water--How many of you do this task? (Count hands) etc.
3. Collecting firewood (Count hands) etc.
4. Earning money (Count hands) etc.

5. Preparing meals (Count hands) etc.
6. Washing clothes (Count hands) etc.
7. Care/supervision of children in your household (Count hands) etc.
8. Caring for sick family members (Count hands) etc.
9. Working in the field (Count hands) etc.
10. Taking care of livestock (pigs, chickens, horses, etc) (Count hands) etc.

\*Who if anyone shares the responsibility for doing these tasks?

*(KNOWLEDGE, BELIEFS, PERCEPTIONS ABOUT/RELATED TO CARE AND SUPPORT)*

\*Do you believe there are some tasks that **women can do better than men** in caring for PLHIV? What tasks?

- What makes women better at these tasks?
- To what extent would training men to do these tasks help them do them as well as women?

\*Are there some tasks that **men can do better than women** in caring for PLHIV? What tasks?

- What makes men better at these tasks?

\*Under what circumstances would you refer a male caregiver to a family member, friend or neighbor who is living with HIV/AIDS? Why? Why not?

\*Are there any *household* spaces that are considered “off limits” to men?

\*Are there public places where HIV-positive men meet and might be recruited to work as providers of home-based HIV/AIDS care and support?

*(SOCIAL OR MENTORING SUPPORT NEEDED FOR CHANGE)*

\* Do you think it would be possible for *men* to change their attitudes and behaviors and get more involved in caring for sick people at home or in the community? If so, what would make this change possible?

\*If you were to consider getting involved in community home-based care for HIV/AIDS, what do you think would be the biggest challenge to deal with?

- What kind of (non-financial) support would you need, from whom, to deal with these challenges? (Probe training, group social support, technical support, mentoring)?

\*In what ways do *women* need to change in order for men to get involved in caring for sick people at home or in the community?

\*Who in the community could help change current attitudes or practices related to men's involvement in caring for PLHIV?

## **PERCEPTIONS OF ADVANTAGES AND DISADVANTAGES TO MEN'S INVOLVEMENT IN CHBC**

\*Are there any *disadvantages* if HIV-positive men if they became involved in providing community-based care and support? (Probe disadvantages to men, to women, to family or community)

\*Are there any *advantages* if HIV-positive men became more involved in providing community-based care and support? (Probe advantages to men, to women, to family or community)

**Thank you!**

## ATTACHMENT 1: HOME-BASED HIV/AIDS CARE AND SUPPORT TASKS

- Bathing the sick person \_\_\_\_
- Turning the sick person in their beds\_\_
- Lifting the sick person\_\_\_\_\_
- Cooking\_\_\_\_\_
- Feeding the sick person \_\_\_\_\_
- Caring for the sick person's mouth\_\_\_\_
- Toileting the sick person\_\_\_\_\_
- Supervising the sick person's children\_\_\_\_\_
- Sweeping the compound\_\_\_\_\_
- Fetching water\_\_\_\_
- Washing clothes\_\_\_\_\_
- Massaging the sick person or giving pain relief\_\_\_\_\_
- Dressing pressure sores\_\_\_\_\_
- Emotional support\_\_\_\_
- Finding out if the family needs financial or material support\_\_\_\_
- Transporting the sick person to the HC/hospital\_\_\_\_
- Getting medicines for the sick person\_\_\_\_\_
- Teaching family members how to do the tasks mentioned above\_\_\_\_
- Helping the family plan for the future of a widow(er) or children (i.e., making a will, consulting a paralegal, getting welfare benefits)
- Helping the family preparing a garden to improve nutrition or family finances

## **Interview with Local Government, Primary Health Team and NCs/CHW Supervisors**

**Introduction:** The MOHSW would like to strengthen the capacity of Lesotho's health system to address the HIV/AIDS pandemic at the community level by increasing the active engagement of men as providers of community home-based health care. In this study, we would like to identify ways to recruit, train, support and retain men in community-based HIV/AIDS home-based care and support jobs which have traditionally been considered the province of women.

The purpose of this interview is to: Determine the **need to** bring men into community-based HIV/AIDS care and support; determine the **feasibility** of engaging men as providers of community based HIV/AIDS care and support; identify **factors** which **facilitate** or **hinder** substantive and sustained male involvement in community-based HIV/AIDS care and support, such as: perceptions of the **advantages or disadvantages to** male involvement, **appropriate** recruitment and training curricula; and ways to meet mentoring, support and retention **needs** (including existing or needed **incentives**) in a gender-re-distributive <sup>4</sup> way.

**Estimated Time:** 1.5 hours

### **Informed Consent Statement**

After introducing the purpose of the study and the research team, the interviewer reads this statement:

«This study was approved by the Ministry of Health and by an Ethical Review Committee. We would like to ask you some questions about the possibility of involving men in HIV/AIDS care and support activities at the community level in order to assist the Ministry of Health plan to improve community-based HIV/AIDS service delivery in Lesotho. You will not be contacted in the future. We will not write your name down Only the district and code number will appear on the questionnaire (Your answers will remain confidential. During the study, the questionnaires will be kept in the Study Managers' office in a locked drawer. The only persons who see or handle the results are those who work on the study.

Your participation in the interview is entirely voluntary and you may choose not to answer a question, or to leave the interview at any time. We very much appreciate your help in this study, even though we will not be able to pay you. Although you may not immediately benefit from the study, the results will be used to improve health care delivery in your community and in other communities in Lesotho.

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<sup>4</sup> **Gender-redistributive** is defined by the Lesotho Gender and Development Policy as "Interventions intended to transform existing stereotypes to ensure gender equity and equality by a more even redistribution of resources, responsibilities and power between and among women and men, girls and boys."

If you have any questions, please contact (Name and telephone number of Study Manager).

**May we begin?**

After reading the foregoing consent declaration, tick off below for every respondent that agrees to participate.

Tick off below for every respondent who does **not** agree to participate in the interview.

**Record:**

1. Interviewer \_\_\_\_\_

2. Date \_\_\_\_\_

3. Region \_\_\_\_\_

4. District \_\_\_\_\_

## ICEBREAKER

\*Are there people in this community living with HIV/AIDS?

- Do you know how many of these people require home-based care and support?

## NEED TO BRING MEN INTO COMMUNITY HOME-BASED CARE (CHBC)

*(REAL PRACTICE AND PARTICIPATION)*

\*What typically happens when a family member gets sick with HIV/AIDS in this district?

\*Are there *customary* ways families take care of sick people? Does this apply to care of PLHIV?

- Who *actually* takes care of the sick person?
- If the caregiver is a *female* family or community member, what is usually her relationship to the sick person? (Probe for all caregivers, such as “mother of the sick person” and follow up by asking “Who else?” until no other caregivers are mentioned).
- If the caregiver is a *male* family member, what is usually his relationship with the sick person (Probe for all caregivers, such as “friend of the sick person” and follow up by asking “Who else?” until no other caregivers are mentioned):
  - Are the caregivers paid to take care of sick people or do they volunteer their time?

\*Do you think there is a need to increase the number of people offering home-based care and support to families in this community? Why, why not?

- Do you think there is a need to increase the number of men? Why, why not?

\*Under what circumstances would you refer a male CHW to a family in need of HIV/AIDS care and support?

## FEASIBILITY OF ENGAGING MEN AS PROVIDERS OF CHBC/GENDER/CULTURAL/OTHER FACTORS THAT NEED TO BE ADDRESSED

*(KNOWLEDGE, BELIEFS, PERCEPTIONS ABOUT/RELATED TO CARE AND SUPPORT)*

\*Should CHWs be doing home-based HIV/AIDS care and support tasks? Is this feasible given their other responsibilities?

\*Do you personally know men who are involved in caring for sick people (including people affected by HIV/AIDS), either in their households or in the community?

- How are men who care for sick people different from those who do not? In personal qualities? In their family circumstances? In their financial circumstances?

\*Why do you think most men are not getting involved in HIV/AIDS care in their families or in the community?

\*Do you believe there are tasks that **women can do better than men** in caring for PLHIV? (Refer to tasks mentioned in Attachment 1)? What tasks?

\*Are there tasks that **men can do better than women** in caring for PLHIV? What tasks? What makes men better at these tasks?

\*Is it considered acceptable for a *woman* to provide care for anyone who is sick and needs care, regardless of whether the sick person is a man or a woman? Why? Why not?

\*How acceptable would it be for a *man* to provide care for anyone who is sick and needs care, regardless of whether the sick person is a man or a woman? Why? Why not?

\*Is there anything that would prevent men in this district getting involved in caring for sick people at home or in the community? Probe.

## **FACILITATING AND HINDERING FACTORS**

\*In some places, women or girls have experienced violence or exploitation when they provided home-based care. How much of a problem is this for women or girls in your communities?

- Do such risks exist for boys and men?

\* \*What might community reactions be to a man who wanted to get involved in providing care and support to PLHIV, either as a CHW or as a caregiver in a support group?

- Would families around here allow male CHWs enter their homes to provide HIV/AIDS care?
- Are there some parts of a household are considered “off limits” to men?
- How could any negative community attitudes about men’s involvement in HIV/AIDS care be changed?

\*Who in the community could help change current attitudes or practices related to men’s involvement in caring for PLHIV?

\*What might be the biggest challenges for a man who is considering becoming a CHW?

\*What kind of (non-financial) support is needed, from whom, to deal with these challenges? For example:

- What kind of training is needed for male CHWs to perform well? Is this need the same for female CHWs?

- What topics would be important in training men as future CHWs offering HIV/AIDS care and support?
- What kind of peer support would be needed for male CHWs to perform well? Is this need the same for female CHWs?

*(RECRUITMENT)*

\*In what kinds of (social, business and religious) activities do men get involved in this district?

\*What is the process of recruiting new CHWs? (Probe: where are they found, how are they approved)?

\*What is the process of recruiting HIV/AIDS caregivers (Probe: where are they found, how are they approved)?

\*What would be the best places to find men who might be willing to work as CHWs or HIV/AIDS caregivers?

\* What things might be important in getting men interested in working in HIV/AIDS care and support in their homes or their communities?

\*What things (e.g., work conditions, financial or non-financial incentives) would keep a person in the job of CHW once they have started working? Are these things the same for women and for men?

**SOCIAL OR MENTORING SUPPORT NEEDED FOR CHANGE/INCENTIVES**

\* Would it be possible for *men* to change their attitudes and behavior and get more involved in caring for sick people at home or in the community? If so, what would make this change possible?

\*In what ways do *women* need to change in order for men to get involved in caring for sick people at home or in the community?

\*What kinds of community resources are available for CHWs who are caring for people affected by HIV/AIDS? (Prompt: Church groups, LENEPWA/PLHIV support groups, District AIDS Commission, Social Welfare officers, MDA, TEBA-Development office, Village Health Committee, etc).

- Do you think CHWs are aware of the community resources in this district?
- What are the best ways to link up CHWs with these community resources?

\*What kind of incentives –financial and non-financial--could this district support to increase men’s involvement in community health work, including HIV/AIDS home-based care and support? (Refer to Attachment 1, for prompting and clarifications).

\*Who should contribute to a CHW incentives package:

- National government
- Local government
- NGOs
- Community

***Thank you!***

## **ATTACHMENT I: INCENTIVES**

### Financial:

- Allowance (How many Rand per month is minimally preferred)?
- Reimbursement for out-of-pocket expenses
- Transportation costs
- Retaining a part of the money earned by selling a health product to the community (vitamins, contraceptives)
- Housing
- Electricity

### Non-Financial:

- Work experience that counts towards getting a better job with an organization after a period of time (career path)
- Formal recognition by the community
- Cooked meal
- Vegetables or other foodstuffs
- Skills training
- Working more closely with other CHWs or with the HC nurse
- Access to free medicines or health care
- Childcare
- Being provided all the materials necessary to do the job

## Interview with Village Chiefs

**Introduction:** The MOHSW would like to strengthen the capacity of Lesotho's health system to address the HIV/AIDS pandemic at the community level by increasing the active engagement of men as providers of community home-based health care. In this study, we would like to identify ways to recruit, train, support and retain men in community-based HIV/AIDS home-based care and support jobs which have traditionally been considered the province of women.

The purpose of this interview is to determine the need to bring men into community-based HIV/AIDS care and support; determine the feasibility of engaging men as providers of community based HIV/AIDS care and support; identify factors which facilitate or hinder substantive and sustained male involvement in community-based HIV/AIDS care and support, such as: perceptions of the advantages or disadvantages to male involvement, and ways to meet mentoring, support and retention needs (including existing or needed incentives) in a gender-re-distributive<sup>5</sup> way.

**Estimated Time:** 1.5 hours

### Informed Consent Statement

After introducing the purpose of the study and the research team, the interviewer reads this statement:

«This study was approved by the Ministry of Health and by an Ethical Review Committee. We would like to ask you some questions about the possibility of involving men in HIV/AIDS care and support activities at the community level in order to assist the Ministry of Health plan to improve community-based HIV/AIDS service delivery in Lesotho. You will not be contacted in the future. We will not write your name down on the questionnaire. Your answers will remain confidential. During the study, the questionnaires will be kept in the Study Managers' office in a locked drawer. The only persons who handle the questionnaires or see the results are those who work on the study.

Your participation in the interview is entirely voluntary and you may choose not to answer a question, or to leave the interview at any time. We very much appreciate your help in this study, even though we will not be able to pay you. Although you may not

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<sup>5</sup> **Gender-redistributive** is defined by the Lesotho Gender and Development Policy as "Interventions intended to transform existing stereotypes to ensure gender equity and equality by a more even redistribution of resources, responsibilities and power between and among women and men, girls and boys."

immediately benefit from the study, the results will be used to improve health care delivery in your community and in other communities in Lesotho.

If you have any questions, please contact (Name and telephone number of Study Manager).

### **May we begin?**

After reading the foregoing consent declaration, tick off below for every respondent that agrees to participate.

Tick off below for every respondent who does **not** agree to participate in the interview.

### **Record:**

1. Interviewer \_\_\_\_\_
2. Date \_\_\_\_\_
3. Region \_\_\_\_\_
4. District \_\_\_\_\_

### **ICEBREAKER**

\*Are there people in this community living with HIV/AIDS?

### **NEED TO BRING MEN INTO COMMUNITY HOME-BASED CARE (CHBC)**

\*What typically happens when a family member gets sick with HIV/AIDS in your community?

\*Are there *customary* ways families take care of sick people? Does this apply to care of PLHIV?

- Who *actually* takes care of the sick person?
- If the caregiver is a *female* family or community member, what is usually her relationship to the sick person? (Probe for all caregivers, such as “mother of the sick person” and follow up by asking “Who else?” until no other caregivers are mentioned).
- If the caregiver is a *male* family member, what is usually his relationship with the sick person (Probe for all caregivers, such as “friend of the sick person” and follow up by asking “Who else?” until no other caregivers are mentioned):
  - Are the caregivers paid to take care of sick people or do they volunteer their time?

\*Do you think there is a need to increase the number of people involved in providing HIV/AIDS care and support to families in this community? Why, why not?

Do you think there is a need to increase the number of men involved in providing HIV/AIDS care and support to families in this community? Why, why not?

\*In some places, women or girls have experienced violence or exploitation when they provided home-based care. How much of a problem is this for women or girls in your communities?

- Do such risks exist for boys and men?

## **FEASIBILITY OF ENGAGING MEN AS PROVIDERS OF CHBC/GENDER/CULTURAL/OTHER FACTORS THAT NEED TO BE ADDRESSED**

*(KNOWLEDGE, BELIEFS, PERCEPTIONS ABOUT/RELATED TO CARE AND SUPPORT)*

\*Do you personally know other men who are involved in caring for sick people (including people affected by HIV/AIDS) in this community?

- How are men who care for sick people different from those who do not? In personal qualities? In their family circumstances? In their financial circumstances?

\*Why do you think *most* men are not getting involved in HIV/AIDS care in their families or in the community?

\*Do you believe there are tasks that women can do better than men in caring for PLHIV? (Can refer to tasks mentioned in Attachment 1)? Why? What tasks?

\*Are there tasks that men can do better than women in caring for PLHIV? What makes men better at these tasks?

\*In your custom, how acceptable is it for a *man* to provide care for anyone who is sick and needs care, regardless of whether the sick person is a man or a woman? Why? Why not?

\*Is there anything in customary law or practice that would prevent men from getting involved in caring for sick people at home or in the community?

\*What might community reactions be to a man who wanted to get involved in providing care and support to PLHIV, either as a CHW or as a caregiver in a support group?

- Would families around here allow male CHWs enter their homes to provide HIV/AIDS care?
- Are there some parts of a household are considered “off limits” to men?
- How could negative community attitudes about men’s involvement in HIV/AIDS care be changed?

- Under what circumstances would you refer a male CHW to a family in need of HIV/AIDS care and support?

(RECRUITMENT)

\*What kind of (social, business and religious) activities do men get involved in?

\*Where would we be able to find men who might be willing to be recruited for work as CHWs or providers of home-based care and support?

\*What are the most important personal characteristics you look for in nominating someone to be a CHW? Are these the same for men and women?

\*What would be the best places to find men who are willing to work as CHWs or HIV/AIDS caregivers?

\* What things might be important in getting men interested in working in HIV/AIDS care and support in their homes or their communities?

### **SOCIAL OR MENTORING SUPPORT NEEDED FOR CHANGE**

\* Would it be possible for *men* to change their attitudes and behaviors and get more involved in caring for sick people at home or in the community? If so, what would make this change possible?

\*In what ways do *women* need to change in order for men to get involved in caring for sick people at home or in the community?

\*Who in the community could help change current attitudes or practices related to men's involvement in caring for PLHIV?

***Thank you!***

## Interview with Male CHWs

**Introduction:** The MOHSW would like to strengthen the capacity of Lesotho's health system to address the HIV/AIDS pandemic at the community level by increasing the active engagement of men as providers of community home-based health care. In this study, we would like to identify ways to recruit, train, support and retain men in community-based HIV/AIDS home-based care and support jobs which have traditionally been considered the province of women.

The purpose of this interview is to: Determine the need to bring men into community-based HIV/AIDS care and support; determine the feasibility of engaging men as providers of community based HIV/AIDS care and support; identify factors which facilitate or hinder substantive and sustained male involvement in community-based HIV/AIDS care and support, such as: perceptions of the advantages or disadvantages to male involvement, appropriate recruitment and training curricula; and ways to meet mentoring, support and retention *needs* (including existing or needed incentives) in a gender-re-distributive <sup>6</sup> way.

**Estimated Time:** 1.5 hours

### Informed Consent Statement

After introducing the purpose of the study and the research team, the interviewer reads this statement:

«This study was approved by the Ministry of Health and by an Ethical Review Committee. We would like to ask you some questions about the possibility of involving men in HIV/AIDS care and support activities at the community level in order to assist the Ministry of Health plan to improve community-based HIV/AIDS service delivery in Lesotho. You will not be contacted in the future. We will not write your name down on the questionnaire. Your answers will remain confidential. During the study, the questionnaires will be kept in the Study Managers' office in a locked drawer. The only persons who handle the questionnaires or see the results are those who work on the study.

Your participation in the interview is entirely voluntary and you may choose not to answer a question, or to leave the interview at any time. We very much appreciate your help in this study, even though we will not be able to pay you. Although you may not immediately benefit from the study, the results will be used to improve health care delivery in your community and in other communities in Lesotho.

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<sup>6</sup> **Gender-redistributive** is defined by the Lesotho Gender and Development Policy as "Interventions intended to transform existing stereotypes to ensure gender equity and equality by a more even redistribution of resources, responsibilities and power between and among women and men, girls and boys."

If you have any questions, please contact (Name and telephone number of Study Manager).

**May we begin?**

After reading the foregoing consent declaration, tick off below for every respondent that agrees to participate.

Tick off below for every respondent who does **not** agree to participate in the interview.

**Record:**

1. Age\_\_\_\_\_

2. Year trained as CHW\_\_\_\_\_

3. Number of years working as a CHW\_\_\_\_\_

4. Are you also a caregiver/support group member?

5. Interviewer\_\_\_\_\_

6. Date\_\_\_\_\_

7. Region\_\_\_\_\_

8. District\_\_\_\_\_

**ICEBREAKER**

\*What motivated you to become a CHW? Was the choice voluntary?

**NEED TO BRING MEN INTO COMMUNITY HOME-BASED CARE (CHBC)**

*(ACTUAL PRACTICE AND PARTICIPATION)*

\*Are there people in this community living with HIV/AIDS?

\*As a part of your CHW job, do you take care of PLHIV?

\*What typically happens when a family member gets sick with HIV/AIDS in your community?

\*Are there *customary* ways families take care of sick people? Does this apply to care of PLHIV?

- Who *actually* takes care of the sick person?
- If the caregiver is a *female* family or community member, what is usually her relationship to the sick person? (Probe for all caregivers, such as “mother of the sick person” and follow up by asking “Who else?” until no other caregivers are mentioned).
- If the caregiver is a *male* family member, what is usually his relationship with the sick person (Probe for all caregivers, such as “friend of the sick person” and follow up by asking “Who else?” until no other caregivers are mentioned):
  - Are the caregivers paid to take care of sick people or do they volunteer their time?

\*What home-based care and support tasks do you actually do, or have you done as a part of your job of CHW:

- Bathing the sick person \_\_\_\_
- Turning the sick person in their beds\_\_
- Lifting the sick person\_\_\_\_
- Cooking\_\_\_\_
- Feeding the sick person \_\_\_\_
- Caring for the sick person’s mouth\_\_\_\_
- Toileting the sick person\_\_\_\_
- Supervising the sick person’s children\_\_\_\_
- Sweeping the compound\_\_\_\_
- Fetching water\_\_\_\_
- Washing clothes\_\_\_\_
- Massaging the sick person or giving pain relief\_\_\_\_
- Dressing pressure sores\_\_\_\_
- Emotional support\_\_\_\_
- Finding out if the family needs financial or material support\_\_\_\_
- Transporting the sick person to the HC/hospital\_\_\_\_
- Getting medicines for the sick person\_\_\_\_
- Teaching family members how to do the tasks mentioned above\_\_\_\_
- Helping the family plan for the future of a widow(er) or children (i.e., making a will, consulting a paralegal, getting welfare benefits)
- Helping the family preparing a garden to improve nutrition or family finances

(USE OF TIME AND SPACE)

\*Now I’m going to ask you about other tasks you are responsible for. In addition to all the tasks you do for your job as CHW, what tasks are you responsible for at home? Do you

I. **Obtain food for the family?** Yes\_\_ No\_\_

--Do you do this every day? Yes\_\_ No\_\_

--How much time do you spend on this every day? \_\_\_\_\_

--If you obtain food for the family but not every day, how often do you do this task each week? \_\_\_\_\_per week

2. **Get water?** Yes\_\_No\_\_

--Do you do this every day? Yes\_\_No\_\_

--How much time do you spend on this every day? \_\_\_\_\_

--If you get water for the family but not every day, how often do you do this task each week? \_\_\_\_\_per week

3. **Collect firewood?** Yes\_\_No\_\_

--Do you do this every day? Yes\_\_No\_\_

--How much time do you spend on this every day? \_\_\_\_\_

--If you collect firewood but not every day, how often do you do this task each week? \_\_\_\_\_per week

4. **Earn money?**Yes\_\_No\_\_

--Do you do this every day? Yes\_\_No\_\_

--How much time do you spend on this every day? \_\_\_\_\_

--If you earn money but not every day, how often do you do this task each week? \_\_\_\_\_per week

5. **Prepare meals for the family?** Yes\_\_No\_\_

--Do you do this every day? Yes\_\_No\_\_

--How much time do you spend on this every day? \_\_\_\_\_

--If you prepare meals for the family but not every day, how often do you do this task each week? \_\_\_\_\_per week

6. **Wash clothes?**Yes\_\_No\_\_

--Do you do this every day? Yes\_\_No\_\_

--How much time do you spend on this every day? \_\_\_\_\_

--If you wash clothes for the family but not every day, how often do you do this task each week? \_\_\_\_\_per week

**7. Care/supervision of children in your household--Yes\_\_No\_\_**

--Do you do this every day? Yes\_\_No\_\_

--How much time do you spend on this every day? \_\_\_\_\_

--If you care for/supervise children but not every day, how often do you do this task each week? \_\_\_\_\_per week

**8. Care for sick family members?Yes\_\_No\_\_**

--Do you do this every day? Yes\_\_No\_\_

--How much time do you spend on this every day? \_\_\_\_\_

--If you care for sick family members but not every day, how often do you do this task each week? \_\_\_\_\_per week

**9. Work in the field?Yes\_\_No\_\_**

--Do you do this every day? Yes\_\_No\_\_

--How much time do you spend on this every day? \_\_\_\_\_

--If you work in the field but not every day, how often do you do this task each week? \_\_\_\_\_per week

**10. Take care of livestock (pigs, chickens, horses, etc)? Yes\_\_No\_\_**

--Do you do this every day? Yes\_\_No\_\_

--How much time do you spend on this every day? \_\_\_\_\_

--If you take care of livestock but not every day, how often do you do this task each week? \_\_\_\_\_per week

\*Who if anyone shares the responsibility for doing these tasks?

\*Apart from these household tasks, what other tasks are you responsible for in the community (social, religious, traditional)?

\*Do you think there is a need to increase the number of people involved in providing HIV/AIDS care and support to families in this community? Why, or why not?

- Do you think there is a need to increase the number of men? Why?

## FEASIBILITY OF ENGAGING MEN AS PROVIDERS OF CHBC/GENDER AND CULTURAL FACTORS THAT NEED TO BE ADDRESSED

(KNOWLEDGE, BELIEFS, PERCEPTIONS ABOUT/RELATED TO CARE AND SUPPORT)

\*Should CHWs be doing home-based HIV/AIDS care and support tasks?

- How feasible is this given their other responsibilities?

\*Do you personally know other men who are involved in caring for sick people (including people affected by HIV/AIDS), either in their households or in the community?

- How are men who care for sick people different from those who do not? In personal qualities? In their family circumstances? In their financial circumstances?

\*Why do you think most men are not getting involved in HIV/AIDS care in their families or in the community especially in light of the care needs brought about by HIV/AIDS pandemic?

\*Do you believe there are tasks that **women can do better than men** in caring for PLHIV? (refer to tasks mentioned in Attachment 1)? What tasks?

- What makes women better at these tasks?
- To what extent would training men to do these tasks help them do them as well as women?

\*Are there tasks that **men can do better than women** in caring for PLHIV? What tasks? What makes men better at these tasks?

\*How acceptable is it for a *man* to provide care for anyone who is sick and needs care, regardless of whether the sick person is a man or a woman? Why? Why not?

\*Is there anything that would prevent men getting involved in caring for sick people at home or in the community? Probe why or why not.

(BECOMING A CHW)

\*Did you ever have any concerns about working as a CHW?

\*What reaction did you face from your family or the community when you became a CHW? (Explore positive and negative reactions)

Positive reactions:

Negative reactions:

\*What were the biggest challenges you dealt with in becoming a CHW?

\*What kind of (non-financial) support was or is needed, from whom, to deal with these challenges?

- What kind of training is needed for male CHWs to perform well? Is this need the same for female CHWs?
  - What topics would be important in training men as future workers in HIV/AIDS care and support?
- What kind of peer support is needed for male CHWs to perform well? Is this need the same for female CHWs?
- What kind of supervision is needed for a male CHW to perform well? Is this need the same for female CHWs?

\* What things might be important in getting other men interested in working in HIV/AIDS care and support in their homes or their communities?

\*What things would keep a person in the job of CHW or HIV/AIDS care provider once they have started working? Are these things the same for women and for men?

\*What did you see as the advantages of becoming a CHW?

\*In some places, women or girls have experienced violence or exploitation when they provided home-based care. How much of a problem is this for women or girls in your communities?

- Do such risks exist for boys and men?

\*Is there anything that would prevent other men from becoming a CHW or getting involved in caring for sick people at home or in the community? Probe

*(USE OF TIME AND SPACE)*

\* In your job as a CHW, have you found that some parts of a household are considered “off limits” to men?

## **INCENTIVES/SOCIAL OR MENTORING SUPPORT NEEDED FOR CHANGE**

**\*Note to facilitator and notetaker:** In the next part of the discussion, we want to find out what incentives would be valued by men and which would attract them to work in a caregiving job such as the CHW job, by 1) asking them to select the top three (3) **financial** incentives from a list of incentives; and then asking them to select the top three (3) **non-financial** incentives from a list presented. It may be necessary to let the CHW see the list as he ranks his priority incentives.

**A. Here are 6 types of financial incentives that have been offered to CHWs in other programs:** 1) Allowance 2) reimbursement for out-of-pocket expenses 3) transportation costs 4) retaining part of the money earned from selling a health product (for example, vitamins, contraceptives) 5) housing and 6) electricity.

Choose three (3) out of all these financial incentives which would be most important to you. Put a 1, 2 and 3 next to the three which are most important, in the order of their importance:

- **Allowance in Rand**
  - Ask them how many Rand per month would be minimally preferred.  
\_\_\_\_Rand/Month
- **Reimbursement for out-of-pocket expenses**
- **Transportation costs Retaining a part of the money earned by selling a health product to the community**
- **Housing**
- **Electricity**

**B. Here are 9 types of non-financial incentives that have been offered to CHWs in other programs.** 1) Having work experience which counts towards getting a better job with an organization after a period of time (career path) 2) formal recognition by the community 3) cooked meals 4) vegetables or other foodstuffs 5) skills training 6) working more closely with other CHWs or with the HC nurse 7) free medicines or health care; 8) childcare; and 9) being provided all the materials necessary to do the job.

Choose three (3) **non-financial incentives** out of all these which would be most important to you. Put a 1, 2 and 3 next to the three which are most important, in the order of their importance:

- Experience and opportunity to get a better job with an organization after a period of time
- Formal recognition by the community
- Cooked meal
- Vegetables or other foodstuffs
- Skills training
- Working more closely with other CHWs or with the HC nurse
- Access to free medicines or health care
- Childcare
- Being provided all the materials necessary to do the job

\*What incentives have we not mentioned already that would in your top three financial incentives? Non-financial incentives?

\* Do you think it would be possible for *men* to change their attitudes and behavior and get more involved in caring for sick people at home or in the community? If so, what would make this change possible?

\*In what ways do *women* need to change in order for men to get involved in caring for sick people at home or in the community?

\*Who in the community could help change current attitudes or practices related to men's involvement in caring for PLHIV?

## Annex B: Gender Analysis Domains

(From the work of Deborah Caro and Deborah Rubin, Cultural Practice Ltd, through the Interagency Gender Working Group of the US Agency for International Development)

1. **Access** (to resources): Refers to the ability to access and use the resources necessary to be a fully active and productive participant (socially, economically, and politically) in society.
2. **Knowledge, Beliefs, and Perceptions:** Refers to *gender ideologies* that may shape individual or group beliefs about the personal qualities and aspirations appropriate to men and women. Ideology includes gender-specific norms and stereotypes about how men and women should behave, which may differ from real behavior. This domain also captures different types of knowledge, diverse beliefs and perceptions attributed to men and women.
3. **Practices and Participation:** Refers to peoples' behaviors and actions in life – the roles they play, what they actually do – and how this varies by gender. This includes the gendered division of domestic/household, reproductive and productive labor; current patterns of action and activity, such as the way that men and women engage in community, health or development activities (e.g., differentially attend meetings, training courses or give, accept or seek out services).
4. **Time and Space:** Gender often structures the availability of time and where time is spent. This domain is closely related to the preceding domain—practices and participation—but can illuminate gendered spaces in a household or in public places, and how time is used during the day, week, month, or year, and in different seasons—as people engage in the gendered division of labor.
5. **Legal Rights and Status:** Refers to how people in different gender categories are regarded and treated by both the customary and formal legal codes and judicial systems. This domain encompasses access to legal documentation (identity cards, voter registration) as well as rights to inheritance, employment, redress of wrongs and representation; includes the capacity to vote, run for office, be an active legislator, and to enter into legal contracts.
6. **Power:** The ability of a person to decide, to influence, to control, to enforce decisions and to exercise power in household, community, municipality or state affairs. It includes power to/over: ones' body; children; use of individual or household economic resources; choice of employment; conditions of work; mobility and social networks; to sign a contract; to run for office or legislate.

## **Annex C: Study Sites**

### **Thaba-Tseka District**

Paray Hospital	CHAL
Mokoto Health Center	Government
Government Health Center ( Reserve)	Government
Mohlanapeng Health Center	CHAL

### **Maseru District**

Scott Hospital	CHAL
Matsieng Health Center	Government
Sekameng Health Centre	Government
Motsekuoa Health centre	CHAL

### **Quthing District**

Quthing Hospital	Government
St Matheus	CHAL
Villa maria Health Center	Government
St Gabriel Health Center	CHAL

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- Improving workforce planning and leadership
- Developing better education and training programs for the workforce
- Strengthening systems to support workforce performance.

### ***The Capacity Project Partnership***



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