# Workshop on Integration of Water, Sanitation and Hygiene into HIV/AIDS Home-Based Care Strategies

Lilongwe, Malawi: Oct 29 – Nov 1, 2007

# **Background Paper**<sup>1</sup>

#### Introduction

Today, more than 39 million people around the world are living with HIV and AIDS (UNAIDS, 2006). One key strategy in mitigating the effects of this epidemic is the provision of community home-based care (HBC), defined as "care given to an individual in his/her own natural environment by his/her family and supported by skilled social welfare officers and communities to meet not only the physical and health needs, but also the spiritual, material, and psychosocial needs." (Southern African Regional Community HBC Conference, 2001). The goal of home-based care is "to provide hope through high-quality and appropriate care that helps ill people and families to maintain their independence and achieve the best possible quality of life" (WHO 2002).

Adequate access to water and sanitation, as well as practicing good hygiene behaviors, are important components of home-based care. Above and beyond the needs of the general population, households affected by HIV and AIDS require a greater quantity of water for bathing, washing and taking medicine, adapted sanitation facilities that meet the unique needs of the chronically ill and excellent hygiene to prevent opportunistic infections. Despite these changing needs, however, access to these services may in fact become more difficult for households caring for PLWHA due to declining physical health, worsening economic status and/or stigma.

While many of the linkages between HIV/AIDS and water, sanitation and hygiene (WSH) have been identified, little research has focused specifically on this area. Information and program guidance on the WSH needs of home-based care programming has been particularly limited. To address this gap, the World Health Organization and the United States Agency for International Development (USAID) sponsored studies in six countries (China, Malawi, Nigeria, South Africa, Vietnam, and Zambia) to explore the "Adequacy of Water, Sanitation and Hygiene in Relation to Home-based Care Strategies for People Living with HIV/AIDS". Conducted during the first half of 2006, these assessments combined household level data collection with key informant interviews of national and local policymakers to identify both the specific WSH needs of home based care and the gaps in relevant policies and program design.

This week's workshop was planned in response to a specific recommendation by the Malawi assessment team to organize a conference of key stakeholders from the HBC and water/sanitation sectors. The goal of the meeting is to move the WSH/HBC agenda forward by building on the international body of information and research conducted to date and using the lessons learned from the WHO/USAID assessments to modify existing approaches and policies, improving integration. The specific objectives of this meeting include:

1. To present lessons learned from the studies commissioned by WHO to investigate the "Adequacy of Water, Sanitation and Hygiene in Relation to Home-based Care Strategies for People Living with HIV/AIDS".

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- 2. To develop country specific policy and program recommendations for Malawi.
- 3. To outline a strategic approach for enhancing the profile of HIV/AIDS and WSH integration in the international community.

This paper serves as an introduction for the workshop. It begins with a brief background section, including information on the current status of the HIV/AIDS epidemic in Malawi, the country's water, sanitation and hygiene situation and an outline of the key linkages between these two sectors. A second section focuses on common findings and recommendations from the six WHO/USAID country assessments. Additional Malawi-specific findings are also presented. A third section highlights key lessons learned and recommendations. Finally, a series of issues requiring further discussion are presented. Complementing this paper are additional documents, including a more in-depth literature review, a broader exploration of the intersection between water, sanitation hygiene and HIV/AIDS and draft policy recommendations for Malawi.

It should be recognized that although the role of WSH in HIV/AIDS programs, and especially in HBC situations, has not yet been fully developed, a considerable amount of interest and effort has occurred on this subject in recent years. There is a growing body of literature involving both field implementation and advocacy for integrating WSH into HBC strategies at both the project and national levels. A partial list of these documents can be found at the end of this Background Paper. Organizations that have been leading these efforts include the World Bank Water and Sanitation programme, IRC, UNICEF and USAID. The accumulation of practical experience has yet to be compiled into general guidelines that are readily accessible to national governments, donor agencies and implementing organizations. This workshop, although limited to issues relevant to Southern Africa and Malawi, should be seen as a contribution to the emerging consensus that WSH has a crucial role in the delivery of appropriate HBC to HIV/AIDS patients and that greater attention is needed to make this integration as effective as possible.

# **Background**

Malawi is located in southern Africa and is bordered by Zambia, Tanzania, Mozambique and Lake Malawi. The country ranks 165<sup>th</sup> out of 177 nations on the Human Development Index, and next to last for GDP per capita (UNDP, 2005). More than 70% of Malawi's 13.6 million inhabitants live below the poverty line and in 2004 almost 50% of children under five were stunted, a figure virtually unchanged since the 1930's (UNDP, 2005; NSO and ORC Macro, 2005; Quinn 1994). Eighty percent of the population is involved in agriculture, farming primarily maize (54% of planted acreage). However, farms are typically less than 1 hectare and one-third of the population is unable to meet subsistence food requirements through farming, requiring that these households supplement their own production with a variety of coping strategies (Malawi VAC 2006).

As of 2006, an estimated 940,000 Malawians were living with HIV and AIDS, an adult (15-49) prevalence of 14.1%. More than 200,000 children have been orphaned by the disease. Although infection levels have plateaued over the past 5 years, urban and semi-urban sentinel sites reported a 7-10% decline between 1999 and 2005, suggesting increased infections in rural areas. Geographically, the HIV epidemic is most severe in the country's southern region where the prevalence rate (17.6%) is three times higher than in the central region and double that of the northern region. However, it is in this northern region where HIV is spreading fastest. Since 1998, HIV prevalence rates in this area have tripled (UNAIDS, 2006).

Given the large numbers of Malawians affected by HIV and AIDS, a diverse array of both formal and informal home-based care activities have been initiated. Informal activities include family caregiving and community support groups. More formal interventions typically involve home visits by trained HBC volunteers. Both types of caregivers provide a range of different caring activities: basic physical care

(washing, bathing, feeding), palliative care for the terminally ill, psychosocial support and counseling and care of children infected and affected by HIV (Lindsey 2002). More established programs also include education components, the distribution of basic medical supplies, medical referrals and overall case management for the chronically ill. However, while no national level data on HBC coverage in Malawi is available, anecdotal evidence indicates that a large and unmet need for these services exists.

Water, sanitation and hygiene are also pressing issues. Childhood mortality in Malawi remains high (125 deaths per 1,000 live births) and the prevalence of childhood diarrheal disease increased nearly 5% between 2000 and 2004 (UNICEF 2007; DHS 2004).

Access to water is defined by the World Health Organization as "the availability of 20 liters per capita per day at a distance no longer than 1,000 meters" (WHO/UNICEF 2000). According to the most recent Demographic and Health Survey, 62% of the Malawian population has access to an improved water source: 44% from protected wells and 20% from private and public taps (NSO and ORC Macro 2005). However, measuring access can be quite difficult and, as a result, DHS surveys only collect information on the type of water source utilized by survey respondents. The distance to the source, the quantities of water available and seasonal changes in usage are not considered. This makes the water supply situation in Malawi somewhat less clear. For example, while almost two-thirds of the population is defined as having access to an improved source, 58% of Malawians must travel more than 15 minutes to reach these sources, thus exceeding the WHO standard (NSO and ORC Macro 2005).

An examination of access to sanitation raises similar issues. While the 2004 Malawi DHS found that 80% of the population had access to improved sanitation, a mid-term evaluation of progress towards the Millennium Development Goal's water and sanitation targets reported that coverage stood at 46%, reflecting significant differences in how improved sanitation is defined (NSO and ORD Macro 2005; WHO/UNICEF 2004). However, despite these measurement issues, there is consensus that for access to both water and sanitation, large disparities exist between urban and rural populations and between the richest and poorest portions of the Malawian population (NSO and ORD Macro 2005; WHO/UNICEF 2004).

In addition to the issues facing these individual sectors, a small but growing body of literature has identified a series of linkages between water, sanitation and hygiene and HIV/AIDS. First, opportunistic infections, resulting from a combination of environmental pathogens and the suppression of immune function in People Living with HIV and AIDS (PLWHA), have negative effects on PLWHA's quality of life and can hasten the progression of HIV to AIDS (Chaisson et al 1998; Seage et al 2002). The frequency of these infections is closely tied to the level of water and sanitation services available to households affected by the disease as well as the hygiene practices of household members.

Second, mothers infected with HIV can transmit the virus to their children through breastmilk. Therefore, when feasible, the WHO recommends that breastmilk be fully replaced with formula. However, this requires both access to adequate quantities of potable water and hygienic preparation in order to prevent water related diarrheal disease.

Third, water and sanitation services which are located in close proximity to HIV affected households can have important labor saving effects, reducing the burden of caregiving and allowing more time for other activities, including school and income generation.

Fourth, access to water for productive purposes can improve household food security by allowing for food production and participation in certain income generating activities. Additionally, potable drinking water is often used to soften foods, making them more palatable for the chronically ill.

Fifth, water, sanitation and hygiene are closely linked to the provision of home-based care. Most prominently, caregivers play a key role in the prevention of opportunistic infections. Their success depends on (a) access to potable water, (b) access to sanitation facilities which are appropriate for use by the chronically ill and knowledge of both (c) water treatment techniques and (d) good hygiene practices. In addition, it is crucial that these improved hygiene practices be successfully introduced to and taken up by other household members. In Uganda, the successful introduction of the Safe Water System, a socially marketed home chlorination process, reduced both the number of diarrhea episodes and the number of days with diarrhea among persons with HIV (Lule et al, 2005).

And finally, households caring for the chronically ill also require a greater quantity of water than other households for medicine taking and additional washing and bathing. This adds to the existing burden on caregivers to collect water.

Unfortunately, despite the changing (and in many cases, increasing) water and sanitation needs of PLWHA, access to these services often declines as a result of lost income, physical disability and/or stigma associated with the disease. In southern India, for example, PLWHA were found to have better hygiene knowledge and behaviors than the general population as a result of NGO programming. However, despite these interventions, PLWHA reported more water borne illness, less access to water and sanitation facilities, and greater economic constraints related to purchasing water and fuel (for boiling water) (WSP, 2007).

Aside from the above study conducted by the World Bank-sponsored Water and Sanitation Programme (WSP), little research has attempted to address the relationship between water, sanitation and hygiene and home-based care. As a result programming and policy rarely reflect a conscious integration of these two sectors. In fact, few national home-based care and HIV/AIDS policies even mention these issues. Zimbabwe is a notable exception. It's *Water and Sanitation Sector HIV/AIDS Response* is the most comprehensive government policy linking these two sectors. Malawi does not have this type of unified document, nor does its national HIV/AIDS policy address water and sanitation issues. However, its *National Community Home Based Care Policy and Guidelines* (MOH 2005) does include some key guidance for caregivers related to water and sanitation. Its recommendations include:

- That water for PLWHA shall be obtained from a protected source and safety measures taken to avoid contamination.
- That during home visits caregivers should assess general cleanliness of home surroundings, waste disposal, availability of safe water and its utilization and intervene where necessary

In addition, the 2006 National Sanitation Policy for Malawi requires that sanitation policy and planning be "HIV and AIDS aware" and includes an appendix detailing the linkages between water, sanitation, hygiene and HIV/AIDS (MIWD 2006).

#### WHO/USAID Field Assessments

To address the lack of research on linkages between home-based care and water sanitation and hygiene, the World Health Organization, with support from USAID, requested proposals to investigate the "Adequacy of Water, Sanitation and Hygiene in Relation to Home-based Care Strategies for People Living with HIV/AIDS". Assessments were conducted in China (National Centre for Rural Water Supply), Malawi (Catholic Relief Services, CRS), Nigeria (WaterAid), South Africa (University of Venda), Vietnam (National Institute of Hygiene and Epidemiology) and Zambia (CRS). These assessments combined a review of relevant literature with qualitative and quantitative data collection. At the national, sub-national and local levels, key informant interviews were conducted with government officials. Topics discussed included the level of water, sanitation and home-based care coverage, barriers preventing access to these services and the relevance of current policies to the water, sanitation and

hygiene issues raised by home-based care provision. At the community level, similar issues were covered through a combination of focus group discussions and household interviews with PLWHA and caregivers. All six country assessments surveyed both urban and rural communities.

The six countries where assessments were conducted represent very different HIV/AIDS contexts, with adult prevalence rates ranging from 0.2% to 30% (UNAIDS 2005). Water supply coverage also varies greatly (55-87%), while access to improved sanitation is generally low (less than 45% for 5 of the 6 countries) (WHO/UNICEF 2004). However, despite these differences the assessments shared a number of common themes. These include:

#### Lack of policy relevance

• Current national policies for HIV/AIDS do not adequately reflect the linkages between water, sanitation and hygiene and home-based care. (6 countries)

#### Barriers to improved water supply

- High water tariffs in urban areas (5 countries)
- Long distances between homes and water points in rural areas (5 countries)
- Seasonal changes in water availability and quality (3 countries)
- Stigma prevents PLWHA from using community water points (3 countries)
- Poor water quality, including high salinity and iron content (4 countries)
- Limited treatment and disinfection of water at the household level, despite questionable water quality (4 countries)
- Poor maintenance of water points (3 countries)
- Limited number of water sources leading to long lines (2 countries)

#### Barriers to improved sanitation

- The poor, generally including PLWHA, cannot afford to construct improved latrines without subsidy (6 countries)
- Most existing latrines are simple pit toilets which are often unsanitary (4 countries).
- Unlined pit latrines frequently collapse due to the sandy soil, particularly during the rainy season (4 countries)
- Stigma prevents PLWHA from using community facilities (3 countries)

#### Barriers to good hygiene

- Low levels of good handwashing behavior (3 countries)
- Significant proportion of latrines were contaminated with fecal matter (4 countries)
- Limited hygiene education (2 countries)

#### Barriers to Home-Based Care provision

- Coverage of home-based care is very low (4 countries)
- Home-based care volunteers are poorly trained (4 countries), particularly with regard to hygiene (2 countries)

#### Additional Malawi specific findings

- All HBC clients reported some health problems in the last week including more than 40% who reported diarrhea.
- Most HBC clients (72%) reported at least one visit per month from a volunteer caregiver. 44% reported at least two visits.
- Almost all HBC clients (97%) had a latrine, most commonly a simple pit.
- Household survey respondents demonstrated good handwashing knowledge, although there was a gap between this knowledge and actual handwashing behavior.

• Key informants reported that donors seemed less interested in funding sanitation programs than water supply projects.

# **Key Lessons Learned and General Conclusions**

The findings of the WHO/USAID assessments, in combination with existing literature on the linkages between water, sanitation and hygiene and HIV/AIDS suggest three broad lessons. First, HBC clients are often unable to access basic water and sanitation services. Second, HBC clients have a number of additional needs beyond the provision of basic services, which are also typically unmet. And third, that home-based care services, when available, do not adequately address the water, sanitation and hygiene needs of their clients, due to a combination of limited training and supervision, a lack of necessary water and sanitation infrastructure and time constraints. More specific conclusions include the following:

#### General

- Clarify the linkages between water, sanitation and hygiene and HIV and AIDS (including home-based care) within national policies.
- Promote integrated programming among government ministries and NGOs working within the two sectors
- Include PLWHA and caregivers in community water, sanitation and hygiene planning processes.
- Disseminate accurate information on routes of HIV transmission to reduce community concern with sharing water and sanitation facilities with PLWHA.
- Invest in community level water, sanitation and hygiene programming to improve access for all.

#### Home-based care programming

- Expand coverage of home-based care services
- Improve both hygiene promotion training for HBC volunteers and volunteer supervision.
- Add soap and chlorine solution for household treatment of drinking water (and, if relevant, information on other water treatment options) to HBC kits.

#### Access to improved water supply for HBC clients

- When planning water systems, allocate additional water for households caring for PLWHA to meet increased needs.
- Explore the potential impacts and feasibility of water tariff subsidies for households affected by HIV and AIDS as a means of ensuring that these households can access an adequate quantity of water.
- If feasible, promote rainwater harvesting by HBC client households as a source of additional water in close proximity to the home.
- In areas where water is only available at long distances, investigate the effectiveness of labor saving water collection devices like the Q-Drum.
- Explore the use of hand pumps, solar pumps and play pumps to reduce the burden of drawing water from wells.
- Promote water saving devices and practices to make efficient use of available water supply. Possibilities include "tippy taps" for handwashing, the use of easily cleanable bedding materials (e.g. plastic sheets) and drip kits for home gardening (nutrition and income generation).
- Identify and promote appropriate household water treatment options including chlorination, filtration, solar treatment and, in some cases, iron removal. While treatment at the source is ideal, this requires both resources and ongoing community management. When this approach is not feasible, home-based water treatment (e.g. the CDC Safe Water System) should be promoted.

#### Access to improved sanitation for HBC clients

• Support latrine modification for households caring for PLWHA to make these facilities safer and more accessible. Suggestions include:

- o Double size latrine structures to give caregivers room to assist patients in using the toilet.
- o Bars or poles installed inside latrines for weak patients to hold on to while defecating.
- o Lining latrine pits with cement or other materials to prevent collapse.
- Explore the feasibility of latrine construction programs or subsidies in order to facilitate these improvements and provide latrines for those HIV affected household without access to sanitation.
- Provide chamber pots and bedpans for HBC clients too weak to access latrines.

## **Issues for Further Discussion**

1. Addressing knowledge gaps – The WHO/USAID assessments of water, sanitation hygiene and home-based care made an important empirical contribution to what was largely an anecdotal and theoretical literature. In particular, they provide specific information on the water and sanitation needs and the hygiene behaviors of home-based care clients. However important questions remain and further research is needed in order to fully inform program design and policy making in Malawi.

Most critically, more specific information on PLWHA's access to water, sanitation and hygiene *relative* to their neighbors is needed. Only one assessment collected data on control households and, therefore, while the special WSH needs of the chronically ill have been well established, it is unclear whether their access to these services is better or worse than their non-HIV affected neighbors. This information is crucial in developing a response. For example, a number of assessment recommendations proposed interventions to improve access to basic sanitation (e.g. latrine subsidies or construction). But the assessment also found that 97% of HBC client households already had a latrine. When compared with national sanitation statistics (46-80% coverage of the general population), the assessment findings suggest that a well-designed program focused on HBC clients might avoid latrine construction and focus on other needs. However, without more specific information, drawing conclusions is difficult.

Other areas which merit additional exploration include the specific magnitude of HBC client household's increased domestic water needs (i.e., 5 extra litres per day or 20 litres per person per day) and the role of productive water (e.g. irrigation, livestock watering) in these households.

Further attention to the needs of PLWHA will undoubtedly identify additional knowledge gaps affecting both policies and programs. The future direction of water, sanitation and hygiene in HBC strategies, therefore, will depend upon the following questions:

- What other knowledge gaps related to the linkages between WSH and HBC exist?
- What type of research is needed to answer these questions? A large household survey? A small number of detailed 24 hour water use diaries or observations?
- What is the feasibility of these different types of studies?
- 2. Choosing an entry point: basic needs vs. special needs Households caring for the chronically ill require two groups of services related to water, sanitation and hygiene. First, they share with the general population a need for basic services, including access to safe drinking water, access to hygienic and safe sanitation facilities and knowledge of proper hygiene behavior. As noted by the WHO, the provision of effective HBC depends on basic services like these being in place (Lindsey 2002). A second group of needs are specific to households providing home-based care (e.g., handrails, additional water for caregiving, HBC-related hygiene education).

When addressing water, sanitation and hygiene within HBC programs, program designers should identify which group of services is lacking (possibly both) as this is an important factor in formulating a programmatic response. For example, in a community with good access to basic services, an intervention which focused on the special needs of HBC clients could be integrated into existing HBC programming.

On the other hand, in areas where basic service provision is broadly inadequate, a partnership with the water sector to improve services for the entire community would be more appropriate.

#### Key questions

- In Malawi, are the basic water and sanitation needs of HBC clients being met? Which are most critical?
- What plans does the GoM have for improving community access to these services?
- How can collaboration between the HBC and water sectors complement existing government plans while improving service delivery for PLWHA?
- In Malawi, are the special needs of HBC clients being met? Which are most critical?
- How can the HBC sector modify its approach to help meet these needs?
- 3. The feasibility of subsidies The topic of subsidizing water and sanitation services for HBC clients is raised in all six WHO/USAID assessments. In two countries, subsidies already exist, although not specifically aimed at caregiving households. South Africa and China both cover latrine construction costs for poor households and the South African government also subsidizes water fees for low income groups through progressive rate increases for higher income households. For urban HBC client households, reduced water fees could increase the quantity of water available, leading to improvements in care for the chronically ill. Meanwhile, funds for the construction of latrines could benefit both rural and urban client households by facilitating the construction of otherwise cost prohibitive sanitation facilities. However, both types of proposed subsidies raise a questions related to cost, targeting, administration and equity which require further discussion.

#### Key questions:

- How would subsidies be targeted? By income? By HBC client status? By need?
- How large of a subsidy would be provided? And for how long?
- Given that water and sanitation coverage in Malawi is generally low, how might a subsidy program for HBC clients be perceived by the larger community?
- Under what circumstances might a broad subsidy (e.g., for all poor households) be a better option? (Note the growing controversy about subsidies for sanitation. For example, UNICEF/WSP do not promote subsidies, but rather the sanitation ladder encouraging communities to construct latrines at whatever level they can afford (e.g., simple pit latrine) and upgrading when possible in addition to enhancing the supply of low-cost sanitation products.)
- How might such a program be funded and administered?
- **4. Integrating WSH into HBC programming** There is an urgent need for identifying, demonstrating best practices for integration of WSH into HBC programming, and training HBC providers and water and sanitation implementers in how to implement such programming. Issues for discussion include the following:
  - What specific programming guidance on integration of WSH into HBC should be given to HBC providers and water and sanitation implementers?
  - What kind of policies and procedures need to be established in implementing organizations to manage integration of WSH into HBC programming?
  - What kind of training is needed to facilitate integration and for whom (e.g., HBC managers and volunteers, PLWHA, water and sanitation implementers)?
  - What kinds of resources are needed to ensure the success of these programs (e.g., water treatment products, soap, tippy taps, etc.)?
- 5. Defining and modifying policy Finally, the issue of policy development and revision deserves consideration. Currently, the linkages between water, sanitation, hygiene and home based care are

referenced in the Malawi national policies for home-based care and sanitation. However, little specific guidance on addressing these issues is provided and the topic receives no mention in the National AIDS and National Water policies.

#### *Key questions:*

- Based on the assessment findings and a discussion of the issues raised above, what policies require changes?
- How should they be modified?
- Which revisions are most critical? Why?

# **Moving Forward**

Together, the issues highlighted above aim to provide a starting point for a broad discussion of water, sanitation, hygiene and home-based care in Malawi. However, in addition to exploring the questions raised in this paper, workshop participants should also be sure to draw on their own experiences and share relevant linkages, concerns and potential solutions not covered here. Only through this type of fully engaged problem solving can the opportunity of this week's workshop be fully realized and a plan for moving forward be developed.

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