# EXAMINING THE LINK BETWEEN HIV/AIDS AND SLUM HOUSEHOLDS IN KAMPALA: CASE STUDY OF NAGURU 2 PARISH

STUDY COMISSIONED BY SHELTER AND SETTLEMENTS ALTERNATIVES February 08

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Sincerely yours,

Deborah Kaijuka

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#### March 12

#### I. INTRODUCTION

In 1982, the first AIDS cases were identified on the shores of Lake Victoria in Uganda. "Slim", as AIDS was first known, predominantly affected adults who appeared to gradually waste away and did not respond well to treatment used to alleviate other common illnesses. Uganda's national average prevalence rate climbed to 9% of the total adult population by the late 1980s, when nearly all districts of the country had reported cases of auto-immune deficiency syndrome (AIDS), which became recognized to be the final and fatal stage of the human immunodeficiency virus (HIV). By 1992, infection rates in Uganda peaked and the worst hit urban areas reported rates of over 30%. The national HIV/AIDS prevalence rate in Uganda has since declined to 6% of the total population, but the global epidemic has inflicted a devastating socioeconomic impact at the individual, household, and community levels.<sup>2</sup> The morbidity and mortality of HIV/AIDS has wreaked havoc on Uganda, causing most affected families to lose their jobs and, along with losing their incomes, are left to spend what remains of their household savings to care for the sick and dying. As a result, many of the infected and affected in urban centers, where the cost of living is relatively higher than rural areas, are forced to seek refuge in low income slum areas. This societal shift leads to dramatic declines in productivity, and negatively aggravates existing conditions of poverty.<sup>3</sup>

In light of the hard realities of the HIV/AIDS epidemic and its impact on Ugandan society, this study aims to examine the impact of HIV/AIDS on slum households, particularly those within informal settlements in Kampala, Uganda. For purposes of this analysis, slum households are defined here as "a group of individuals living under the same roof who lack one or more (in some cities, two or more) of the following conditions: security of tenure, structural quality and durability of housing, access to safe water, access to sanitation facilities and sufficient living area." Informal settlements can be understood to mean "areas where groups of housing units have been constructed on land that the occupants have no legal claim to, or occupy illegally" and/or "unplanned settlements and areas where housing is not in compliance with current planning and building regulations (unauthorized housing)." Human settlements, more broadly, are defined by UN Habitat as an "integrative concept that comprises (a) physical components of

<sup>4</sup> "Slum household." *United Nations Statistics Division – Millennium Indicators*. http://milleniumindicators.un.org/unsd/mifre/mi\_dict\_xrxx.asp?def\_code=504

<sup>&</sup>lt;sup>1</sup> Uganda AIDS Commission Secretariat. HIV/AIDS in Uganda: The Epidemic and the Response, 2002.

<sup>&</sup>lt;sup>2</sup> "HIV/AIDS in Uganda." Uganda AIDS Commission. <a href="http://www.aidsuganda.org/HIVug.htm">http://www.aidsuganda.org/HIVug.htm</a>

<sup>&</sup>lt;sup>3</sup> Uganda AIDS Commission Secretariat (2002)

<sup>&</sup>lt;sup>5</sup> Note: It is noted here that slum households and informal settlements are terms that are often used interchangeably, including in this research study, due to the conceptual linkage whereby a slum household can be a group of individuals living under the same roof who lack security of tenure and an informal settlement refers to households constructed in areas of insecure tenure.

<sup>&</sup>lt;sup>6</sup> "Informal settlements." *United Nations Statistics Division – Environment Statistics*. http://unstats.un.org/unsd/environmentgl/gesform.asp?getitem=665

shelter and infrastructure and (b) services to which the physical elements provide support, that is to say, community services such as education, health, culture, welfare, recreation and nutrition."<sup>7</sup>

#### II. PROBLEM STATEMENT

HIV/AIDS is more than a just a health issue. Aside from being one of Uganda's leading causes of illness and mortality, the epidemic has become one of the country's greatest socioeconomic challenges. The burden of the disease disproportionately affects slum households and, especially, AIDS widows and orphaned children who are more vulnerable to losing access to basic provisions which are critical to their survival, including water, sanitation, and secure tenure. In effect, HIV/AIDS has increasingly become a housing issue. The analysis of the impact of HIV/AIDS on human settlements can be based on a multi-dimensional conceptual framework, whereby the occurrence of HIV/AIDS in a slum household in an informal settlement (as the primary units of analyses) triggers a series of changes. These changes perpetuate a cycle of poverty in affected human settlements and exert negative pressure on national productivity as the country experiences tremendous labor force losses (both in terms of quality and size), which has grave implications for the national economy. Yet, despite the severity of the impact of the epidemic on society, a lack of literature exists that critically examines the link between HIV/AIDS and human settlements.

#### III. PURPOSE

In 2006, with the support of Rooftops Canada, Shelter & Settlements Alternatives (SSA) participated in the World Urban Forum in Vancouver, Canada, along with several other African and Canadian housing groups, cooperatives, community organizations, and non-governmental organizations. The Forum provided a good platform for participants to share ideas and knowledge on issues concerning housing and HIV/AIDS. The main objective of the three-day workshop was to build a shared perspective in the emerging field of multi-sectoral responses to HIV and AIDS. More specifically, participants aimed at sharing their experiences and resources to better understand and address the impact of HIV/AIDS on human settlements, to facilitate ongoing networking of ideas, resources and relevant horizontal exchanges towards enhancing the participants' capabilities to address the issues and develop appropriate responses, and to explore programme agendas and directions of individual organizations and/or the collective network. Based on the discussion outcomes of the 2006 World Urban Forum, SSA decided to commission this research study with the aim of drawing direct attention to the critical link between HIV/AIDS and human settlements, and advocating for national and local leaders to give due priority to the challenges facing slum households in informal settlements in Kampala in the fight against HIV/AIDS.

The purpose of this study is to fill in a gap in research that addresses the link between HIV/AIDS and human settlements. While it is now better recognized that improved access to safe water and adequate or acceptable sanitation improves the overall health and status of people living with HIV and AIDS (such as that over half of people infected by AIDS develop serious and chronic diarrhea and other water-borne infections) and that lack of access to safe water and poor sanitation puts HIV positive individuals at greater risk of opportunistic infection that leads to

<sup>&</sup>lt;sup>7</sup> "Human settlements." *United Nations Statistics Division – Environment Glossary*. <a href="http://unstats.un.org/unsd/environmentgl/gesform.asp?getitem=629">http://unstats.un.org/unsd/environmentgl/gesform.asp?getitem=629</a>

<sup>&</sup>lt;sup>8</sup> Uganda AIDS Commission Secretariat (2002).

rapid progression to AIDS,9 little in-depth research has been undertaken to analyze and substantiate the link between HIV/AIDS and housing (namely the link to factors including security of tenure, structural quality and durability of housing, and sufficient living area). Examining this link means assessing not only the impact of housing on people affected and infected by HIV and AIDS, but also to assess how HIV and AIDS impacts the housing situations of households affected and infected by the disease. And, although vulnerable housing and settlement conditions have been correlated with HIV prevalence and also that inadequate access to services, insecure tenure, and poor housing conditions put HIV positive individuals at greater risk of opportunistic infections, development policymakers and implementers alike still perceive HIV and AIDS to fall within the realm of the health sector's responsibility. 10 Sadly, the reality is that people living with and/or affected by HIV and AIDS are more likely to end up living in slum conditions, for a number of reasons that are explored in the Section VII of this research report, which is beyond the health sector's scope and control.

"In the midst of the HIV/AIDS pandemic", Professor Richard Tomlinson notes, "it is striking how little attention has been paid to the shelter and services needs of families with members who have an AIDS-related illness, AIDS, or who recently have died from such an illness." Searches on the UNAIDS and UN HABITAT best practices websites, for example, elicit no mention of such topics, nor on the UNDP or World Bank websites. 12 In an effort to fill in this disappointing gap in research and analysis, the main objective of this study is to examine, demonstrate and underline the link between HIV/AIDS and informal settlements or, more specifically, the link between HIV/AIDS and slum households in Kampala, Uganda, to get the attention of policymakers and leaders to recognize and address this problematic link. SSA is advocating all stakeholders to tackle poverty and inequality - the root causes of HIV and AIDS - in order to make a real difference in the fight against the pandemic. 13

#### IV. **METHODOLOGY**

The study design was threefold: First, relevant literature was reviewed to acquire an overview of the human settlements sector, with particular focus on how HIV/AIDS impacts slum households. For a complete list of the literature reviewed and references sourced, please refer to Annexes 1 and 2. Second, interviews were carried out with key stakeholders in the sectors of human settlements (including housing and land) and HIV/AIDS in order to gain an understanding of the set up of the respective sectors. Third, focus group discussions and key informant interviews were conducted with people living with HIV/AIDS and key HIV/AIDS service organizations in Uganda to gather information on the impact of HIV/AIDS on slum households in Kampala.

The Post-Test Club in Naguru 11 Parish was selected as the focus group for the study because the group was: 1) from an area that provided a good representative sample of a typical Kampala slum; 2) located within an informal settlement in Kampala, which is the focus area of the study at hand; 3) well-established in terms of longevity and organization level, including having

<sup>&</sup>lt;sup>9</sup> United Nations Settlements Programme. "HIV/AIDS Checklist: For Water and Sanitation Projects," UN *Habitat* (August 2006), p. 5.

<sup>&</sup>lt;sup>10</sup> Ambert, C. "Repositioning the Poverty Agenda in Informal Settlement Policy and Implementation: The HIV and AIDS Lens," Development Works, p. 1.

<sup>&</sup>lt;sup>11</sup> Tomlinson, R. "An Exploration of the Shelter and Services Needs Arising From HIV/AIDS?" University of Witwatersrand (2007), p. 1.

<sup>&</sup>lt;sup>13</sup> Canadian International Development Agency. CIDA Takes Action Against HIV/AIDS Around the World (June 2002). p. 2.

established a drama group to deliver behavior change and awareness raising campaigns to communities throughout Kampala; 4) relatively open about their HIV status, which eased information collection during group discussions; and 5) made up of individuals with both negative and positive HIV sero status.

Key stakeholder and informant interviews were conducted with selected representatives from key organizations in the HIV/AIDS and human settlements sectors based in Kampala, Uganda. When interviewees were unavailable to meet in person, informants completed and submitted a structured questionnaire based on the interview framework to ensure consistency in gathering data. To review a complete list of people/organizations interviewed, please refer to Annexes 3, 4 and 5. To see a copy of the questionnaire provided for the key informant interviews and a copy of the interview guide for the key stakeholder interviews, please refer to Annex 7 and 8.

This study first provides a brief background of Uganda's response to HIV/AIDS prevention, and outlines the key actors, policies (see full list in Annex, and framework of the human settlement sector in Uganda. Second, this study gives an overview of the key dimensions that define slum households in the Ugandan context. Third, this study analyzes the link between HIV/AIDS and slum households. Fourth, this study presents the findings of the individual interviews and the group focus discussions to substantiate the link between HIV/AIDS and housing in Kampala's slum households. Lastly, this study draws conclusions based on the research findings and provides final policy recommendations.

#### V. COUNTRY BACKGROUND

#### **HIV/AIDS Sector**

In the 1980s, during the initial outbreak, Uganda's national response to HIV/AIDS was largely confined to the health sector and the response was handled like any other epidemic.<sup>14</sup> In 1986, the Ugandan Health Minister openly announced the occurrence of HIV/AIDS in the country while attending the World Health Assembly in Geneva, which came to mark the first step towards mainstreaming the disease in Ugandan society and the trigger for mass awareness campaigns led by President Museveni's National Resistance Movement. The same year, the first AIDS Control Programme was implemented in the Ministry of Health, which was important to Uganda because it was both the country's first structural response to the disease, and the foundation for the country's response to the epidemic. 15 The Programme also attracted the support of the international community, which helped to make substantial progress in the areas of epidemiology, surveillance, health and AIDS education, and blood transfusion services. Soon thereafter, the Government of Uganda came to recognize AIDS as more than just a public health problem, and began to approach the epidemic as a socioeconomic disaster which they felt required a multisectoral intervention. This recognition led to the creation and implementation of the National AIDS Policy in 1992 which called on a comprehensive nationwide approach of all constituents or self-coordinating entities to control the outbreak of HIV/AIDS, including the active involvement of national government ministries, multilateral and bilateral organizations, the business sector, development partners, NGOs (national and international), CBOs, networks for people living with HIV and AIDS (PLHA), faith-based organizations (FBOs), research, academia, science, and community members. To see a list of stakeholders involved in HIV/AIDS activities in Kampala District, please refer to Annex 6.

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<sup>&</sup>lt;sup>14</sup> Uganda AIDS Commission Secretariat (2002).

<sup>15</sup> ibid.

In 1992, the government-appointed National Task Force on AIDS launched the Uganda AIDS Commission (UAC), which was implemented within the Office of the President with the mandate to lead the unified multisectoral response to combat the epidemic. More specifically, UAC was established to "bring together partners to review progress, identify gaps and set national priorities and strategies for implementation to ensure timely delivery and even coverage of prevention and care services." To ensure the effective coordination of this multisectoral approach to HIV/AIDS, the Uganda AIDS Commission has mandated the Directorate of Planning and Monitoring with addressing the challenge of monitoring and evaluation activities by tracking the successes and constraints of HIV/AIDS programmes throughout the country. The aim of Uganda's collective response is not only to prevent the spread of HIV and strengthen national and sectoral capacity in gathering information, planning policy and conducting research, but, more importantly, to actively respond and manage all perceived consequences of the epidemic, including mitigating the adverse health and socioeconomic impact of the disease. The Government of Uganda has taken a significant step by recognizing HIV/AIDS as a development and crosscutting issue and even integrating the epidemic into the pillars of the country's national Poverty Eradication Action Plan (PEAP), which means that the Government will fund a portion of all HIV/AIDS activities at all levels through the Poverty Action Fund, which finances PEAP priority programmes.<sup>17</sup>

Membership of the HIV/AIDS Partnership Committee consists of representatives of each selfcoordinating agency who are elected to participate in the Committee in order to share information, plan and coordinate issues in their constituencies through a monthly meeting chaired by the UAC. Permanent seats on the Committee have been assigned to the Ministries of Health and Finance, Gender, Labour and Social Development, UNAIDS, and the UAC Secretariat. A representative from the Parliamentary Standing Committee on HIV/AIDS also sits on the Committee. All members of the agencies meet annually at the HIV/AIDS Partnership Forum to review progress of the Committee and set priorities for the following year. Coordination costs are covered by the HIV/AIDS Partnership Fund, which is jointly managed by the Committee and the UAC. As an innovative and systematic national-level coordination mechanism, the Uganda HIV/AIDS Partnership Committee is assigned to setting the agenda to update, implement and monitor the National Strategic Framework on HIV/AIDS, to facilitate and harmonize HIV/AIDS policies, programmes and plans, and to spearhead resource mobilization. Through this function, the Committee aims to: 1) minimize wasteful duplication; 2) maximize potential for synergies, harmonization, learning and peer support; and 3) pool efforts for scaling up the response to the epidemic.<sup>18</sup>

#### **Human Settlements Sector**

The human settlements sector in Uganda is based at the central or national level. Following the decentralization of government in Uganda, the housing sector was originally placed within the Ministry of Public Works, Housing and Communications because the central government felt that the primary issue concerning human settlements and housing was the construction of roadways. Today, the housing sector is based within the Ministry of Lands, Housing and Urban Development. This Ministry is mandated with adopting, translating and localizing international resolutions, drafting and formulating national policies and standards, and responsible for monitoring and evaluation. A Parliamentary Committee on housing has been formed to supervise the housing sector. Housing was placed at the national, as opposed to the local, government level

<sup>16</sup> ibid.

<sup>&</sup>lt;sup>17</sup> Uganda AIDS Commission Secretariat (2002).

<sup>&</sup>lt;sup>18</sup> "The Uganda AIDS Partnership." *The Uganda AIDS Commission* (September 2003).

in Uganda because housing is still considered to be a matter that is the responsibility of the individual home owner and, therefore, should not directly involve government interference or intervention. Housing in Uganda has become more of a private sector issue, rather than a public government concern.

The Ministry of Lands, Housing and Urban Development acts as the sector's parent ministry and liaises with several stakeholders at different levels, including liaising with international bodies such as bilateral organizations and the UN on resolutions, programs, campaigns, and financing. The Ministry also collaborates with other national ministries primarily on issues of finance, health, water, and education, and works with sub-state agencies, including the National Housing & Construction Company (NHCC), the Housing Finance Company of Uganda (HFCU), the National Water and Sewage Corporation (NW & SC), and Umeme (an electricity and solar thermal heating company) to provide public goods and services related to housing. At the lowest level, the stakeholders which are responsible for the provision and delivery of housing products to the public includes non-governmental organizations, community-based organizations, the private sector, individual home owners, and faith-based organizations. Slum Aid Project, the Federation for Slum Dwellers in Uganda, and Slum Dwellers International are a few examples of non-governmental organizations working in the area of slum settlements in Kampala.

The National Shelter Strategy (NSS) has been employed as the primary policy for the housing sector in Uganda since 1992. This policy was formulated in response as a rehabilitative program during the post-Amin years in an effort to reconstruct housing infrastructure and improve provision of adequate shelter services in urban areas. The NSS recognized major stakeholders in the housing sector, which include individuals, the private sector, non-governmental organizations and financial institutions. Key partners in Uganda's housing sector include: UN Habitat, the UNDP, DFID which supports the C3 program (City, Community Challenge program), and private sector companies (i.e. Akright, Jomayi, and Kenington, etc).

As the NSS is now outdated, a new national housing policy is currently being drafted by the central government. Current policies concerning human settlements focus on responding to the challenge of limited land by encouraging vertical construction, such as the enactment of the condominium law. The government has implemented policies focused on encouraging savings and to increase the supply of housing mortgages. There are also efforts underway to implement initiatives focused on upgrading slums, but housing is still not included as a key element in Uganda's Poverty Eradication Action Plan (PEAP). Several stakeholders noted that the exclusion of human settlements and housing issues as primary challenges faced in Uganda's PEAP is problematic and needs to be addressed. In the wider human settlements sector, key policies include the Land Act (1998), the Public Health Act (1964), the National Health Policy (1995/1997), the Water Act (1995), and the National Water Policy (1996).

#### VI. OVERVIEW OF SLUM SETTLEMENTS

As noted in the introduction, slum households are defined here as "a group of individuals living under the same roof who lack one or more (in some cities, two or more) of the following conditions: security of tenure, structural quality and durability of housing, access to safe water, access to sanitation facilities and sufficient living area." For purposes of this analysis, this section will explain each of these conditions, in turn, which may be lacking in slum households according to their formal definition.

<sup>&</sup>lt;sup>19</sup> "Slum household." *United Nations Statistics Division – Millennium Indicators*. http://milleniumindicators.un.org/unsd/mifre/mi\_dict\_xrxx.asp?def\_code=504

#### 1. Security of Tenure

According to the Office of the High Commissioner for Human Rights, the right to adequate housing states that all persons should possess a degree of security of tenure which guarantees legal protection against forced eviction, harassment, and other threats.<sup>20</sup> "The practice of forced eviction involves the involuntary removal of persons from their homes or land, directly or indirectly attributable to the State. It entails the effective elimination of the possibility of an individual or group living in a particular house, residence or place, and the assisted (in the case of resettlement) or unassisted (without resettlement) movement of evicted persons or groups to other areas."<sup>21</sup> Therefore, secure tenure ensures the rights of all individuals and groups to de facto or perceived (effective) protection by the state against arbitrary unlawful evictions, based on legal documentation that evidences land/residence occupation including official title deeds or other written tenancy agreements (i.e. occupancy licenses, certificates, permits, documentation of municipal taxes or water bills, etc). Based on these documentation requirements, UN Habitat recognizes that informal settlements by their very nature do not possess formal secure tenure. As a result, most developing countries in the world lack information on the security of tenure in slum areas.

However, while it is very difficult to assess the security of tenure in slum households in informal settlements in real terms, UN Habitat has noted that secure tenure should not be understood narrowly as a question of access to land and one roof. Rather, the UN maintains that secure tenure should be conceptualized as a platform for development, and as having long term implications for security, housing investments, planning, and other socioeconomic indicators. The granting of secure tenure is therefore an important catalyst to stabilize communities, improve shelter conditions, reduce social services, leverage corporate and individual investment, and protect urban environments. By this measure, it is important to consider the security of tenure in informal settlements as a key human rights indicator as it concerns human settlements.

It is noted here that the 1995 Constitution of Uganda protects the right of every person to own property individually or in association with others, and ensures that no one is deprived of his/her personal property without compensation.<sup>23</sup> Similarly, the Land Act provides a legislative framework for the equitable ownership of land, including declaring null and void all customs that prevent women and children from inheriting land, and mandating land commissions with protecting the interests of vulnerable groups, including women, children, and people with disabilities.<sup>24</sup>

According to the 2005/06 Uganda National Household Survey, more than 60% of occupancy tenure of dwelling units in Kampala were rented, with less than 30% being owner occupied. It is

 $\underline{http://64.233.167.104/search?q=cache:6LXfMw1DZuYJ:www.chr.up.ac.za/hr\ docs/constitutions/docs/UgandaC(rev).doc+uganda+constitution+1995\&hl=en\&ct=clnk\&cd=2\&gl=ug$ 

<sup>&</sup>lt;sup>20</sup> General Comment No. 4 (1991), Common Economic, Social and Cultural Rights. Office of the High Commissioner for Human Rights.

<sup>&</sup>lt;sup>21</sup> Fact Sheet No. 25, Forced Evictions and Human Rights. <a href="http://www.unhchr.ch/html/menu6/2/fs25.htm">http://www.unhchr.ch/html/menu6/2/fs25.htm</a> "Slums of the World: The Face of Urban Poverty in the New Millennium?" United Nations Human Settlements Programme (UN-Habitat), 2003. p. 50-51.

<sup>&</sup>lt;sup>23</sup> Uganda Constitution (1995).

<sup>&</sup>lt;sup>24</sup> Uganda Land Act (1998). Equal Employment Opportunities for Women and Men. http://www2.ilo.org/public/english/employment/gems/eeo/law/uganda/la.htm

noted that ownership of a dwelling unit represents security of tenure of a household.<sup>25</sup> Based on the 2005/06 survey, it is clear that Kampala has a higher amount of tenure insecurity, as compared to the amount of secure ownership.

#### 2. Structural Quality and Durability of Housing

According to UN Habitat, the structural quality and durability of one's housing depends on the surroundings of the household and the community, including the condition of the dwellings adjacent to the housing unit and whether the housing unit is dilapidated beyond repair, is dilapidated but repairable, or is under construction. The quality of housing can also be measured by the adequacy of ventilation, particularly as it concerns cooking and heating. Because internal air pollution is an important aspect of environmental health and is closely related to acute respiratory disease, UN Habitat classifies single room dwellings without ventilation as slum dwellings.<sup>26</sup>

A house is considered "durable" by UN Habitat if it is built on a non-hazardous location (i.e. not on or near toxic waste, flood plain, steep slope, or dangerous right of way, including a railway, highway, airport or power line), has a permanent structure, and is adequate enough to protect its inhabitants from the extremes of climate conditions (including rain, heat, cold and humidity). Therefore, based on this definition, the following factors determine the structural quality and durability of housing: permanency of structure, use of permanent building materials for the walls/roof/floor, compliance to building codes, level of dilapidation, assessment for need of repair(s), and the location of the house. It is important to note that construction materials not only indicate the durability and permanency of a dwelling unit, but also denote the economic status of a household based on the affordability or purchasing power of a given resident(s).

It is noted that, according to the 2005/06 National Household Survey in Uganda, most households in Kampala (64.3%) were residing in tenements (run down apartment houses that barely meet minimum housing standards).<sup>27</sup> The same survey revealed that the following materials were predominantly used to construct dwelling units in Uganda's urban areas: iron sheet roofs (82.7%), brick walls (79.2%), and cement floors (68.6%).<sup>28</sup>

#### 3. Access to Safe Water

According to UN Habitat, a household can be considered to have access to improved drinking water if it has a sufficient amount of water (20 Litres/person/day) for family use, at an affordable price (under 10% of the total household income), available to household members without being subject to extreme effort (no more than one hour per day for the minimum sufficient quantity), particularly for women and children. Access to safe water can be measured by the following factors: piped connection to a house or plot, a public stand pipe that serves a maximum of five households, a bore hole, a protected dug well, a protected spring, and/or rain water collection. <sup>29</sup> "Improved" provision for water, on the other hand, is often classified by governments as having a public tap or water source within 200 metres of the dwelling unit, which is often shared by

<sup>&</sup>lt;sup>25</sup> Uganda National Household Survey 2005/2006: Report on the Socio-Economic Module. Uganda Bureau of Statistics (December 2006). p. 102-103.

<sup>&</sup>lt;sup>26</sup> ibid. p. 50.

<sup>&</sup>lt;sup>27</sup> Uganda National Household Survey 05/06, p. 101-102.

<sup>&</sup>lt;sup>28</sup> ibid. 106.

<sup>&</sup>quot;Tenement." <a href="http://wordnet.princeton.edu/perl/webwn?s=tenement">http://wordnet.princeton.edu/perl/webwn?s=tenement</a>

<sup>&</sup>lt;sup>29</sup> Slums of the World, 19.

several hundred people with an intermittent supply of water, of not necessarily good water quality. Access to improved water is often gauged using the household technology which is adopted to get the water, and, whereby, the technology for water retrieval is assessed based on its level or standard for environmental health.<sup>30</sup>

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In Uganda's 2005/2006 National Household Survey, 13.2% of urban households reported that they did not have access to safe water. According to the survey, increasing concern exists that, despite improved access to safe water supplies, the quality of water – once it is finally consumed – is frequently diminished due to poor hygiene practices in maintaining safe water chains.<sup>31</sup> In the same survey, it was reported that 4.1% of residents needed to travel between 1 and 5 kilometers to access their main water source.<sup>32</sup>

#### 4. Access to Sanitation Facilities

UN Habitat states that a household can be considered to have access to improved sanitation if an excreta disposal system, either in the form of a private toilet or a public toilet shared with a reasonable number of people, is available to household members. Measures of improved access to sanitation facilities include: direction connection to a public sewer that is not contaminated, direct connection to a septic tank, a pour flush latrine, and/or a ventilated improved pit latrine. <sup>33</sup>

"Improved" access to sanitation can often mean no more than access to a latrine, to which access is often difficult when shared among many households. Like access to water, improved access to sanitation is also measured by the type of technology employed by households to dispose of human waste. For example, access to an inoperable flush toilet is unacceptable, yet it is difficult for household surveys to account for whether an accessible toilet is functioning or permanently out of order. Similarly, the adequacy of service for sanitation facilities does not account for the cost of accessing the public latrine, the waiting time to use the facility, nor the maintenance and cleanliness of the toilets.<sup>34</sup>

The 2005/06 Ugandan National Household Survey pointed out that the use of appropriate toilet facilities is important in preventing hygiene-related illnesses, such as diarrhea, intestinal infections and cholera, among others. Based on the survey results, about 1% of households in Kampala did not have any access to toilet facilities. The majority of residents in Kampala (about 86%) reported that they used pit latrines as their main toilet facility. The remaining residents used ventilated improved pit latrines (4.6%), while only 9.1% reportedly had access to flush toilets, which means that only one in ten Kampala households surveyed used flush toilets as their main sanitation facility.<sup>35</sup>

#### 5. Sufficient Living Area

UN Habitat considers a dwelling unit to provide sufficient living area for household members if there are fewer than three people per habitable room. Other indicators of overcrowding include: area-level indicators, including average in-house living area per person or the number of

<sup>31</sup> Uganda National Household Survey 05/06, p. 110.

<sup>&</sup>lt;sup>30</sup> ibid. 50.

<sup>&</sup>lt;sup>32</sup> ibid. 111.

<sup>&</sup>lt;sup>33</sup> Slums of the World, 19.

<sup>&</sup>lt;sup>34</sup> ibid. 50.

<sup>&</sup>lt;sup>35</sup> Uganda National Household Survey 2005/2006, p. 108-109.

households per area, and/or housing-unit level indicators, including the number of persons per bed or the number of children under five per room.<sup>36</sup>

It has been shown that the number of persons per room correlates with adverse health risks.<sup>37</sup> In the 2005/2006 Uganda Household Survey, it was found that 73.6% or about three quarters of households in Kampala reported that they only had one room to use for sleeping, with 3.1 persons sleeping in the room on average.<sup>38</sup> These survey results demonstrate, by UN Habitat's standards, a problem of overcrowding in the typical Kampala household.

#### VII. UNDERSTANDING THE LINK: HIV/AIDS AND SLUM HOUSEHOLDS

The impact of HIV/AIDS on affected families can be devastating. Increases in medical expenses, food and transport costs for care and treatment drains the household savings of affected families. In addition, families are doubly burdened by losses in income because family members are unable to work often leaves families with no remaining disposable income to pay housing-related costs. Burial costs further deplete the resources of the extended family and household affected by the death of loved ones to AIDS. In many developing countries, including Uganda, governments are unable or unwilling to provide subsidized housing or other forms of social support for those in need, especially for the sick. As a result, children are forced to miss school to care for their sick parents and, when their parents die, orphans are quite often left homeless or with elderly grandparents who are unable to properly care for them. Lacking protection for their tenure and inheritance rights and facing stigmatization, surviving family members and orphans are most often unable to afford rent or mortgage payments to pay for housing and/or are forcibly evicted from their homes. When they are forced to move, the families frequently lose one or more sources of income which they were relying on to sustain their livelihoods.

When household members become sick, it is frequently necessary for the family to sell vital physical and/or productive assets, such as their homes and their land, in order to pay for expensive medical care and treatment and later funerals, and for the hire of replacement labor. Often, families are forced to sell their land at artificially low prices out of distress. Liquidation of assets is a coping method to generate lost income. These households, which are already suffering because their family members are infected and affected by HIV and AIDS, are left landless and homeless, and, as a result, must turn to the streets or to informal settlements for shelter.

Widowed, teenage and child-headed households cope with particular difficulty in securing enough money to pay for basic services, such as electricity, water, and sanitation, while still being able to afford food, school fees, medical treatment and rent for themselves and their dependents. These vulnerable groups end up living in the slums or on the streets because they have no where else to go. In many cases, such vulnerable persons, particularly women and young girls, are forced to turn to prostitution to generate income to survive, which puts them at further risk for contracting or spreading HIV/AIDS. Others are forced to abandon their regular income generating activities, including roasting cassava and maize, hairdressing, brewing local alcohols, running small retail shops and restaurants or bars, selling water and sodas, making handicrafts, or

<sup>38</sup> Uganda National Household Survey 2005/2006, p. 104-105.

<sup>&</sup>lt;sup>36</sup> Slums of the World, 19.

<sup>37</sup> ibid

<sup>&</sup>lt;sup>39</sup> Ambert, 1.

<sup>&</sup>lt;sup>40</sup> "Cameroon, Kenya, South Africa, Tanzania, Zimbabwe: HIV/AIDS is a Housing Issue!" *Rooftops Canada* (2003-04), p.6.

<sup>&</sup>lt;sup>41</sup> United Nations Settlements Programme, 6.

selling agricultural produce, because community members stigmatize and ostracize them as being contagious. This troubled situation is compounded by the fact that affected children and youth usually are forced to drop out of school in order to stay home and care for their sick family members, and to save on educational expenses and to increase household labor capacity. Unfortunately, this household shift results in the loss of educational training and paid employment opportunities, which later translates into a severe loss in the future-earning potential of the affected individuals and the family household more generally. In short, a context of HIV and AIDS is one in which housing affordability is systematically undermined.

Sadly, the risks for HIV+ persons contracting opportunistic infections, including both viral and bacterial respiratory infections like pneumonia and tuberculosis, greatly increase without access to adequate water supply and proper sanitation facilities, particularly for those without sufficient nourishment. It is especially hard for sick individuals and people caring for the sick, which usually means women and grandparents, to travel and/or spend time to manage and/or access water supplies. Exposure to unsafe water supplies, dirty toilets, and poor nourishment levels contribute to increasing individual levels of immunodeficiency and further compromises their immune systems to catching opportunistic infections. For example, if an infected person and their household cannot wash easily and lack access to hygienic sanitation, they face a greater risk of contracting serious and chronic diarrhea, water-borne diseases and skin infections. Without access to clean water, mothers with HIV/AIDS are unable to safely bottle feed their children, and are otherwise at risk for mother-to-child transmission of the disease if they are forced to breast feed their babies.

In terms of the problem of overcrowding, the majority of slum households tend to be one-room units which are shared with several extended family members. Overcrowding occurs as a result of both being forced into cheaper shared accommodation and as a result of household members becoming more dependent on each other as the number of productive family members decrease and the number of dependents increase when people fall sick. Young adults and children who are living in shared rooms with adults are at higher exposure to both sexual activity and sexual abuse (including rape and defilement) at an earlier age, which leads to increased chances of spreading and contracting HIV/AIDS and other sexually transmitted infections.

Based on these realities, HIV sufferers who are living in dire conditions of poverty in the slums or are homeless are much more likely to experience a faster decline into AIDS-related illnesses. <sup>46</sup> It is no wonder, therefore, that it has been widely argued that HIV infection and AIDS impacts thrive in conditions of socio-economic vulnerability and inequity, such as living in an informal settlement without proper access to secure tenure, health services (including treatment and management services for sexually transmitted diseases) and housing. <sup>47</sup>

<sup>&</sup>lt;sup>42</sup> ibid. 13.

<sup>&</sup>lt;sup>43</sup> Ambert, 2.

<sup>&</sup>lt;sup>44</sup> United Nations Settlements Programme, 5.

<sup>&</sup>lt;sup>45</sup> Tomlinson, R. 3.

<sup>46 &</sup>quot;Housing is a Health Issue!" Adequate Housing Sustains Health! (Rooftops Canada)

<sup>&</sup>lt;sup>47</sup> Ambert, 2.

#### VIII. SUBSTANIATING THE LINK: HIV/AIDS AND SLUM HOUSEHOLDS IN NAGURU 2 PARISH

#### 1. Insecurity of tenure

Most PLWHAs interviewed in Kampala were low income tenants, rather than owners of their homes, which created more tenure insecurity. Land owners, on the other hand, are faced with tenure insecurity because they are uncertain whether they will need to sell their assets to purchase medicine.

PLWHAs in Naguru 2 reported that some landlords evicted people they found out were living with HIV/AIDS because they feared that the PLWHAs would either infect others, be unable to pay their rent because of their conditions, or would die in their homes. They felt that they were often treated like undesirable, dirty people. Several people reported that they were unsure how long they would be able to stay in their houses because their landlords were not forthcoming about the status of the land on which the property existed. Some PLWHAs in Naguru 2 parish were told or heard threats from other community members that they were staying on land reserved for road construction and would soon be evicted. One female resident of Naguru 2 parish reported that she fears being thrown out of the house that her brother provided to her because she recently lost her husband to AIDS.

Many of the PLWHAs interviewed expressed their fears and insecurities about eventually losing their homes and their land when they die or their family members die, leaving their orphaned children or widowed spouses behind with no where to live. A representative from the National Community of Women Living with HIV/AIDS in Uganda reported cases when PLWHAs sell their homes to pay for quality medical treatment, which puts them at risk of ending up homeless because some of the women had their marital homes grabbed by their in-laws. This was common among discordant couples when the HIV positive spouse was thrown out of the home by the spouse who tested negative. This was also common in cases when in-laws grabbed the land from their widowed daughters-in-law who did not have wills to ensure security of tenure, or in cases when orphans were left with no rights or money to stay in their homes. Some of the PLWHAs reported that they ended up living in the slums of Kampala because they were forced to flee their village homes when others threatened that they were a health risk for spreading the virus to others. In five reported cases, PLWHAs reported being homeless because they were blocked from entering their homes and were left to rely on generous neighbors for food and shelter.

A major challenge facing PLWHAs living in informal settlements in Kampala is that they lack knowledge of or access to legal services to seek recourse in cases when they are wrongfully or illegally evicted from their homes, particularly in cases when in-laws or relatives grab the land of AIDS widows and orphans. The legal centers that do exist are inadequate and poorly distributed, which makes them difficult for most people to access. Few legal agencies provide inexpensive or free services to PLWHAs.

#### 2. Poor structural quality and durability of housing

Deteriorated health and resultant unemployment was blamed by PLWHAs interviewed when asked to explain why they were unable to save the money to build their own homes or rent decent homes. PLWHAs reported that they were forced to live in poor housing conditions because they could not afford to live in better areas while they continued to spend money on other more important expenditures, such as their medical treatment.

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On average, people living in Naguru 2 zone reported renting housing units in the price range from 20,000 to 25,000 UGX per month without electricity, and 40,000 UGX per month for those with electricity. Many of the PLWHAs interviewed in this area reported leaky roofs and that their houses were made from poor quality materials, such as mud and wattle. Several individuals reported that the mere passing of a rat caused a large amount of dust and soil to fall from the structure of the house, which was an indication of the poor structural quality and durability of the housing.

#### 3. Lack of access to safe water

As noted earlier, a household can be considered to have access to improved drinking water if it has a sufficient amount of water (20 Litres/person/day) for family use, at an affordable price (under 10% of the total household income), available to household members without being subject to extreme effort (no more than one hour per day for the minimum sufficient quantity), particularly for women and children. The findings of the study confirm that, although water may be accessible, the quality and quantity of water available to the households determines their patterns and frequency of water usage. The respondents interviewed reported that water sold in Kampala amounted to 50 to 100 Ugandan Shillings (UGX) per jerrycan, but up to 150 UGX or more per jerrycan during periods of water shortage. In Naguru 2 parish, the PLWHAs interviewed reported that they used six to twelve jerrycans per day on average, with the exception of a few small businesses which used more water (twenty-three jerrycans on average per day) to supplement their income-generating activities, such as brewing waragi. These same households reported average monthly incomes between 30,000 to 90,000 UGX.

In the lowest income household during a period of extreme water shortage and maximum water consumption, this means that the families must spend up to 150 UGX twelve times per day, at a total cost of 1800 UGX per day or 54,000 UGX per month, which would exceed their average 30,000 UGX monthly income by nearly double the amount. Even when water is plentiful and these same families are only paying 50 UGX, at the minimum of six times on average per day, at a total cost of 300 UGX per day or 9,000 UGX per month, their water expenditure totals 30% of their total household income. Even this conservative figure amounts to three times of the acceptable amount to be considered to be a household with sufficient access to drinking water.

For the PLWHAs who reported attempts at engaging in income generating activities, it was found that stigmas surrounding their sero status negatively impacted their business endeavors because some people rejected purchasing their products. In Naguru 2, an elderly woman reported that nearby residents shunned her locally-made brew for allegedly being contaminated with AIDS. As a result, this woman is forced to hire boda bodas to transport her to Kireka (another district) to pay another individual to sell her products on her behalf. She must return to Kireka on another day (and pay again for transport) to collect the sales profits. A young woman living with HIV/AIDS in Naguru 2 reported that she was forced to close her restaurant business which she had just set up with all of her long-term savings because residents spread rumors and started propaganda that she has cut herself while chopping meat for the restaurant which they alleged has contaminated the food with AIDS. Unlike the older woman, the younger woman is unable to supplement the costs incurred of hiring transport and middlemen sales persons to continue her business in another district.

It was generally reported that the poor, especially PLWHAs, found it difficult to access tap water on a daily basis because they needed to spend most of their money on medical treatment and nutrition. When it is not possible for these households to buy water due to insufficient funds or problems with water shortages, they must travel three kilometers to collect water from a spring

well or purchase the water from boda boda drivers at 1,500 UGX per two jerrycans. For most PLWHAs, they reported that, in most cases, they are not strong enough to carry the jerrycans for the three km distance three times per day (they use six jerry cans per day on average). As a result, they must pay the hefty cost of having water brought to them, or go without water. In addition, PLWHAs reported that they are discriminated against by local residents when they attempt to collect water from nearby springs where safe water is available. These other residents claim that they fear coming into contact with the same water source which the PLWHAs have used to collect their water. Faced with these stigmas, PLWHAs find it even more difficult to access water supplies.

Even in cases when they have easier access to water supplies, PLWHAs reported that they often do not have the energy to maintain the cleanliness of the water storage facilities. Several PLWHAs also reported that, because they are caring for several orphans and other dependents who consume more of the household's water supply, the households often do not have sufficient water supplies to clean utensils/dishes or to bathe. This situation comprises their level of hygiene and puts them at increased risk of contracting opportunistic infections.

#### 4. Lack of access to sanitation facilities

Given that a household can be considered to have access to improved sanitation if an excreta disposal system, either in the form of a private toilet or a public toilet shared with a reasonable number of people, is available to household members, this was generally not found to be the case for most households with PWLHAs in Naguru 2 parish.

Affected households blamed low income generation and unemployment, due to low productivity levels resulting from deterioration of health, as the primary cause of poor sanitation and hygiene conditions. For example, a young woman in Naguru 2 parish could no longer continue her work as a seamstress because it required her to sit working for long periods of time, which reportedly caused chest pains and general weakness. Another young woman had to stop selling maize, which was her primary income source, because she felt cold and feverish when sitting next to the charcoal stove fire to roast and sell her maize. She said that she needed to have younger children sell the maize for her in order to continue making money to survive, but often buyers took advantage of the children's young age and cheated them of their full payment.

Most PLWHAs reported that they lacked the funds to construct good toilets and renters were residing in cheaper housing units with poor toilet facilities. The PLWHAs interviewed reported that their toilets are full in most cases and landlords empty them in nearby drainages. In Naguru 2, PLWHAs reported that, on average, twenty-eight people were sharing the same toilet. For those residing in a "barracks" zone, more than forty people were sharing one toilet. In addition, PLWHAs reportedly suffered from diarrhea due to their poor health, which worsened the sanitation level of the shared toilet. In the same location, a nearby night bar led to patrons drinking large amounts and using the shared toilet to defecate, vomit and urinate all over the facility, putting the PLWHAs at increased risk for opportunistic infection.

Even in situations where decent sanitation facilities were available, it was reported that, as parents became weak due to the disease, children were unable to maintain the cleanliness and sanitation of the homes. For example, in cases when households were able to access and buy water, often they were unable to afford to buy charcoal which they needed to boil the water for drinking because they saved the charcoal that could be afforded for cooking their food.

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In Naguru 2 parish, Kampala City Council constructed public toilets which could be accessed at a cost of 100 UGX per person per use. The PLWHAs reported that this was a costly expenditure, given their already limited financial situations. For example, due to their deteriorating health conditions, some of the PLWHAs reported having to go to the toilet more than twelve times per day, which would mean that they would need to spend 1,200 UGX per day to use the public toilet. Because they were unable to afford to use the available public toilet facilities, some people reported that they were forced to defecate into polythene bags, which were later disposed of by throwing the bags of waste onto nearby rooftops. It was also reported that rainwater later filtered this waste off the roofs to contaminate local water supplies, creating a dangerous oral-faecal cycle that would put all residents' health at risk.

In some cases, landlords reported that they had no toilet facilities for their tenants due to shortage of land to construct facilities. In these cases, landlords created temporary dumping bins for toilet use, which were later emptied into local drainage channels during rainy seasons or late at night when the landlord would be less likely to be charged with illegal dumping. This situation demonstrates how poor or lacking sanitation facilities are a primary cause of contamination of water and living areas, which poses tremendous health risks for all nearby residents.

#### 5. Insufficient living area

As mentioned, UN Habitat considers a dwelling unit to provide sufficient living area for household members if there are fewer than three people per habitable room. However, this study found that most families of PLWHAs were occupants in overcrowded one-room units, far above the acceptable average number of people per room based on UN Habitat standards. None of the PLWHAs in Naguru 2 parish reported less than six people per room, and, on average, PLWHAs reported eight people per room. The interviewees explained that the reason for the high number of residents per household was due to the high number of AIDS-orphaned children and relatives homeless due to losing family members to AIDS. Many households reported sharing rooms with individual family members who were of marrying age. In one case, a female PLWHA reported that she was sharing a single room with fourteen people, including her husband, and three of the occupants were of marrying age. As demonstrated in the previous section, overcrowding, like in Naguru 2 parish, contributes to the increased spread of infections and poses a health risk to PLWHAs who are more susceptible to contracting and succumbing to opportunistic infection.

#### IX. CONCLUSIONS

By focusing on the causal relationship between slum households and HIV/AIDS, this study has shown how the five key elements of a slum household (specifically insecurity of tenure, poor structural quality and durability of housing, lack of access to safe water and proper sanitation facilities, and insufficient living area) have a negative impact on people living with HIV/AIDS and people affected by HIV/AIDS, as well as how slum households present increased risks of exposure to those not yet infected with HIV/AIDS. And, alternatively, this study has also shown the negative socioeconomic impacts of the HIV/AIDS epidemic on affected families, which increases their chances of being forced to live in slum housing within informal settlements.

The impact of HIV/AIDS on slum households is mainly felt due to the loss in income as family members are no longer able to continue working because they are either too sick, unable to secure employment due to stigmas associated with being HIV positive or must stay home and care for the sick, dying and other dependents, at the same time that the entire household copes with substantial increases in expenditures related to care and treatment (and, as may be necessary, burial costs) for sick family members. Add to this a lack of protection for their tenure and

inheritance rights and facing stigmatization, surviving family members and orphans frequently cannot afford better housing than one-room units in slum areas.

Sadly, living in these slum households means increased exposure to unsafe water supplies, dirty toilets, poor nourishment, and dilapidated, overcrowded living conditions which contribute to increasing individual levels of immunodeficiency and further compromises their immune systems to catching opportunistic infections. And, unfortunately, it is increasingly evident that women and children, the most vulnerable members of the household, bear the brunt of the disease's impact on the households as they struggle to care for their family members and pay for the household's basic necessities, including the rent, food, school fees, and medical care and treatment, and, as a result, are often left with little other choice but to turn to prostitution to generate income to survive, which puts them at further risk for contracting or spreading HIV/AIDS.

The research presented point to a two-way relationship between HIV/AIDS and slum households. HIV/AIDS sufferers are more likely to end up living in slum households due to the heavy costs incurred by the impacts of the HIV/AIDS epidemic, while slum dwellers are exposed to increased risks of either contracting HIV/AIDS or succumbing to AIDS-related opportunistic infections. In short, this study has demonstrated that the impact of HIV/AIDS on affected families can be devastating and the impact of living in slum conditions has the potential to permanently alter the health and wellbeing of local residents, as experienced by those interviewed in Naguru 2 parish. With this reality in mind, the last section of this study presents recommendations for moving forward to effect change in Kampala's slum households. It is noted here that SSA recommends further research, which was beyond the scope of this research study, to examine and assess the effectiveness of nongovernmental and community organizations working towards improving the lives of PLWHAs and slum dwellers in Naguru 2 parish.

#### X. RECOMMENDATIONS

The following recommendations are based on the information collected from the literature review, focus group discussions and key informant interviews. Based on the research findings obtained through undertaking this study, *Shelter & Settlements Alternatives* supports immediate action on the following recommendations by the Government of Uganda in order to prevent the further spread of HIV/AIDS and to improve the living conditions of all Ugandans, with particular emphasis on the need for improving the security of tenure, structural quality and durability of housing, access to safe water and proper sanitation facilities, and sufficiency of living area for slum households in Kampala. For purposes of organizational clarity, the recommendations have been organized into five thematic areas of focus which should together form the government's main objectives: supporting the economic empowerment of PLWHAs, strengthening national infrastructural and institutional capacity, raising community awareness, fostering partnerships, and developing policies and programming that mainstreams HIV/AIDS.

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Based on the research findings presented in this study, SSA recommends that the Government of Uganda move forward by focusing on:

1. Supporting the Economic Empowerment of PLWHAs

The Government of Uganda should support economic empowerment of PLWHAs by implementing policies and programs that support:

- increased access to housing loans for constructing decent shelters;
- programs for income generating activities at the community level;
- incentives for registering in small savings programs; and
- housing grants.
- 2. Strengthening National Infrastructural and Institutional Capacity

The Government of Uganda should support strengthening national infrastructural and institutional capacity by implementing:

- Slum upgrading programs that take PLWHAs into consideration;
- Resettlement programs for AIDS orphans;
- Public sanitation facilities that take the needs of PLWHAs into consideration;
- Sensitization programs for financial institutions on dealing with PLWHAs;
- Youth Forums for facilitating dialogue and exchanging ideas, innovations, lessons learned, and challenges in preventing the spread of HIV/AIDS; and
- Shelter projects led by organizations for PLWHA.

#### 3. Raising Community Awareness

The Government of Uganda should raise community awareness by supporting education programs aimed at:

- Increasing PLWHAs' awareness and knowledge of their rights to adequate housing and secure tenure of land, including education programs focused on effective advocacy methods;
- Providing information and referral systems for accessing affordable and adequate housing;

- Providing instruction on the proper maintenance of household and public toilets, including information on safe methods for disposal of waste from sanitation facilities:
- Increasing PLWHAs' awareness and knowledge of their rights to access safe water and proper sanitation;
- Increasing PLWHAs' awareness and knowledge of housing safety standards;
- Sensitizing all community members on their tenant rights;
- Encouraging and teaching PLWHAs to make wills; and
- Promoting HIV/AIDS education and prevention, including combating stigmas and common myths about the disease.

#### 4. Fostering Partnerships

The Government of Uganda should focus on fostering partnerships with key stakeholders, including:

- Relevant government ministries and departments;
- National Forum of People Living with HIV/AIDS Networks in Uganda;
- National Community of Women Living with HIV/AIDS in Uganda;
- Uganda Young Positives;
- National umbrella organizations, including the Ugandan Network for HIV/AIDS Service Organizations; and
- Community-based organizations for people living with HIV/AIDS and for slum dwellers in Kampala.

#### 5. Developing Policies and Programming that Mainstreams HIV/AIDS

The Government of Uganda should develop policies and programming that mainstreams HIV/AIDS, including:

- Building mobile Ecosan toilets in congested urban areas experiencing land shortages:
- Gender-sensitizing national housing and land policy provisions as it concerns PLWHAs;
- Reforming national policies on pensions and social security to approve PLWHAs
  to access contributions, given reasonable claims for medical and/or housing
  expenses;
- Providing housing subsidies for PLWHAs subject to long wait times for ARV treatment; and
- Providing special housing subsidies for child-headed households and households headed by older persons that are afflicted and/or affected by HIV/AIDS.

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ANNEX 3: KEY INFORMANT INTERVIEWS

(listed in alphabetical order by organization)

NAME	POSITION	ORGANIZAT ION	MANDATE	SERVICES PROVIDED
Mr. John Okumu	Manager, Loans Origination	Housing Finance Co. (U) Ltd.	Housing Finance Company of Uganda Ltd was incorporated as a private company under the Companies Act on 7 December 1967. The company is currently owned by the National Housing and Construction Corporation (NHCC) (5%), the National Social Security Fund (NSSF) (50%) and the Government of Uganda (45%).	To advance money to any person upon provision of security by way of mortgage of land including any building erected or constructed thereon in any gazetted town in Uganda upon such terms and conditions as the company may think fit; To receive money on deposit or loan and borrow and raise money in such a manner as the company may think fit; To manage land, buildings, and other property situated in Uganda, whether belonging to the company or not and collect rent or income therefrom.
Mr. Nelson S.	Monitoring and Evaluation Officer	Kamwokya Christian Caring Community	To enhance the capacities of families and communities in impoverished and low-resourced areas in Kampala district in a sustainable way to address their social, economic, health, spiritual, cultural and development needs	Primary health care; youth development and HIV/AIDS prevention; orphans and vulnerable children's welfare; advocacy rights and community empowerment; formal and technical education; credit and productive assets.
Mr. Edward Mugimba	HIV/AIDS Focal Point Person	Ministry of Gender, Labour and Social Development	The Ministry is enjoined to operationalise Chapter 4 of the Constitution (especially Articles 31 through 42), which focus on affirmative action and promotion of fundamental human rights of the people of Uganda, with a particular emphasis on marginalised groups. The mandate of the Ministry is to empower communities	The Ministry is the lead agency in the Social Development Sector. In collaboration with other stakeholders, the ministry is responsible for community mobilisation and empowerment, promotion of rights and social protection.

			to harness their potential through cultural growth, skills development and labour productivity for sustainable and gender-responsive development.	
Mr. Dennis Obbo	Principal Information Scientist	Ministry of Lands, Housing and Urban Development		
Mr. Samuel Mabala	Assistant Commission er for Human Settlements	Ministry of Lands, Housing and Urban Development		
Ms. Martha Were	Programme Officer	National Community for Women Living with HIV/AIDS in Uganda	To promote positive living for women living with HIV in Uganda through psychosocial support, economic empowerment and access to essential services.	Counseling, succession planning, and documented family history; income generating activities; survival training; life planning.
Ms. Sarah Mbabazi	HIV Services Manager	Population Services International (PSI)	The mission of PSI is to measurably improve the health of poor and vulnerable people in the developing world, principally through social marketing of family planning and health products and services, and health communications. Social marketing engages private sector resources and uses private sector techniques to encourage healthy behavior and make markets work for the poor.	PSI is a nonprofit organization based in Washington, D.C. that harnesses the vitality of the private sector to address the health problems of low-income and vulnerable populations in more than 60 developing countries. With programs in malaria, reproductive health, child survival and HIV, PSI promotes products, services and healthy behavior that enable low-income and vulnerable people to lead healthier lives. Products and services are sold at subsidized prices rather than given away in order to motivate commercial sector involvement.

Mr. Richard Serunkuma	National Coordinator	The Positive Men's Union	To create a concerted and organised effort in order to uplift the health and social economic status of men infected with HIV	Sensitization programs and health education.
Mr. David Oyat Abang	Capacity Building and Development Officer	The National Forum of PLWHAs Networks in Uganda	To improve coordination and develop strong partnerships including systems and structures and capacity building	Coordination, sharing information and experiences, identification of PLWHAs related gaps in districts, and devise mechanisms for strengthening partnerships and bridging gaps.
Ms. Rose Kabugo	Programme Officer, Decentralised Response	Uganda AIDS Commission	To oversee, plan and coordinate AIDS prevention and control activities throughout Uganda	Guide policy formulation and establishment of programme priorities; Take the lead in national planning and monitoring; Spearhead advocacy for HIV/AIDS activities; Identify obstacles to the national response; Mobilize and monitor resource allocation and utilization; Foster linkages among partners; Gather and disseminate information; Promote HIV/AIDS related research
Mr. Edward Were	Data Manager	Uganda AIDS Commission	To oversee, plan and coordinate AIDS prevention and control activities throughout Uganda	Guide policy formulation and establishment of programme priorities; Take the lead in national planning and monitoring; Spearhead advocacy for HIV/AIDS activities; Identify obstacles to the national response; Mobilize and monitor resource allocation and utilization; Foster linkages among partners; Gather and disseminate information; Promote HIV/AIDS related research
Mr. Joram Musinguzi	Project Officer, HIV/AIDS Home Care	Uganda Red Cross Society	To improve the quality of life of the most vulnerable people in Uganda as an effective and efficient humanitarian organization	Health and care; disaster management and response
Mr. Sam Ocen	National Coordinator	Uganda Young Positives	To provide support for young people living with HIV/AIDS	Positive living and positive prevention support
Ms. Alimpa Ritah	Programme Officer	Uganda Young Positives	To provide support for young people living with HIV/AIDS	Positive living and positive prevention support

ANNEX 4: FOCUS GROUP
MEMBERS OF POST-TEST CLUB IN NAGURU 2 PARISH

No.	Name	Designation/Occupation
1	Richard Serunkuuma	National Coordinator, Positive Men's Union
2	Babiry P.	
3	Akello Agnes	
4	Obama Josephine	Counselor
5	Lalam Florence	
6	Akello Christine	
7	Akwiri Alice	
8	Korina Aleena	
9	Masika Grace	
10	Lamunu Grance	
11	Onyanwo Garret	
12	Abeja Josephine	
13	Rhema Mwajuma	
14	Twembeze Jane	
15	Joram Musinluuz	Uganda Red Cross (Home Care Office)
16	Tustime Andrew	Uganda Red Cross (Home Care Volunteer)
17	Rehema M.	
18	Amony Aisha	
19	Anek Pamel	
20	Lamaro Betty	
21	Asaba Hellen	H.C.F.
22	Judith Arach	Member
23	Acayo Mary	H.C.F.
24	Akelo Sylvia	Member
25	Tumwebaze Jane	Member
26	Naguwa Winnie	
27	Achuir Grace	Member
28	Joram Musuiguzi	Home Care Officer, Uganda Red Cross
29	Tussiime Andrew	Uganda Red Cross Volunteer

#### ANNEX 5: KEY STAKEHOLDER INTERVIEWS

In order of sector and listed alphabetically according to organization name. Presented by name, position, organization, mandate, and services provided.

#### **HIV/AIDS Sector**

Ellen K. Bajenja	Programme Support Officer	Agency for Co-operation and Research in Development	African social movements	Facilitate learning, research, analysis and advocacy, both locally and globally, by linking area programmes to each other and to other organisations in the South and in the North; Thematic areas of focus include: gender and social discrimination, livelihoods, conflict, HIV/AIDS.
Mr. Drake Katungole	Branch Manager	AIDS Information Centre Headquarters and Kampala Branch	a model of excellence in the	Mobile and Home based HIV counseling and testing; community owned HIV counseling and testing; youth friendly services; testing and treatment for syphilis; septrine prophylaxis; CD4 and CD8 count tests; birth control and family planning services; post test club; couples club; training services; resource centre
Mr. Peter Ogenga	Advocacy & Information Officer	Community Health and Information Network	To promote the empowerment of people living with HIV	Capacity building for organizations of people living with HIV, uniformed forces, NGOs/CBOs, and, in particular, the Great Lakes region.  Advocate for greater accessibility and affordability of treatments for HIV infection and AIDS related illnesses.  Promote treatment awareness and education.  Provide community-based response for OVC to improve their quality of life.  Provide uptodate information on infectious diseases through resource centre.  Initiate and support prevention, treatment and care programmes in Great Lakes region.  Empower community leaders, youth, women, OVC and general public on HIV/AIDS issues and how they can engage effectively in policy development.
Dr. Andrew D Kambugu	O. Head, Clinical Services	Infectious Disease Institute, Makerere University	To build capacity in Africa for the delivery of sustainable, high quality HIV/AIDS care and prevention through training and research.	Creativity initiative for PLWHAs; urban care; paediatrics; core laboratory; training and AIDS treatment information centre;
Sr. Businge Molly	Nursing Officer	Kiswa Health Centre	Health centre of Kampala City Council	HIV/AIDS testing, counseling, treatment; reproductive health and family planning; prevention of mother to child transmission; ARVs; drug adherence counseling; health education

Ms. Esther Awino	Centre Manager, Owino Centre	Marie Stopes Uganda	To deliver high quality, affordable sexual and reproductive healthcare for men and women.	Family planning
Ms. Sandra Kyagaba	Public Relations	Women Living with	To promote positive living for women living with HIV in Uganda through psychosocial support, economic empowerment and access to essential services.	Counseling, succession planning, and documented family history; income generating activities; survival training; life planning.
Dr. Allan Ahimbisibwe	Training Manager	Pediatric Infectious Disease Centre	Health ward of Mulago Hospital	Voluntary counseling and testing; training of health providers; patient care and treatment; clinical services; food provision; clinical monitoring; CT scans; home based care and support
Mr. Kasuzi Vianney; Mr. Mathias Bukare Obonvo	Head Counselor; Counselor	The AIDS Support Organisation Uganda Limited	To contribute to a process of restoring hope and improving the quality of life of persons and communities affected by HIV infection and disease.	HIV/AIDS counseling; medical care; social support; training and capacity building; community mobilization and education; advocacy and networking
	Project Coordinator	Market Vendors AIDS Project	To create healthier and more productive market communities.	Mobilisation and sensitization; HIV VCT and STI testing and treatment through referral system; ABC prevention education; capacity building of peer educators and market leaders; provision of ARVs and treatment of opportunistic infections in partnership; monitoring and evaluation
Mr. Damon Kamese	Public Relations Assistant	The Mildmay Centre	train health care providers in the principles and practices of AIDS	Psychiatric clinic; dental services; reproductive health and family planning services; nursing; manage school fees for sponsored children; children's play therapy; adolescent programme; social support for patients receiving care; handling family issues that impact on care; treatment; physiotherapy; occupational therapy; counseling; pastoral care; adherence and outreach; training and education, including degree/diploma in HIV/AIDS Care and Managment
Dr. John Paul Odongo	Physician, Owino Centre	Uganda Cares	To save and improve lives by working in collaboration for quality antiretroviral treatment, care and support services.	Free opportunistic infection treatment; free ARV treatment; CD4 testing; laboratory investigation; counseling and testing education; technical assistance
Ms. Florence Ayo	Capacity Building Officer		To ensure HIV/AIDS prevention, quality care and support services through coordinating and strengthening HIV/AIDS service organizations in Uganda.	Information generation and sharing; capacity building for NGOs/CBOs; advocacy and lobbying; district networking and collaboration

			31	
Mr. Alex Orikushaba	Permanent Secretary	Organization Uganda	people with essential knowledge and skills for their health,	Prevention and control; training in counseling and psychosocial support, peer education, community prevention and management of TB, project planning and management, entrepreneurship and development, prevention of malaria in pregnant mothers and children; conferences and workshops
Human Settler	ments Sector			
Mr. E. Mukubwa Byaruhanga	Consultant - Dev. Planning		Professional consulting firm	Professional consulting services
Mr. Charles	Chairman		To empower the peoples of	Sensitization; self help programs and

and projects; social services; promotion of use Ofwono Rural Housing Uganda, particularly rural communities, to acquire and/or of environmental friendly technology; access better housing with advocacy; seminars and workshops; enough space, ventilation and promotion of education; networking; sanitation facilities through self property dealings help programs. To work towards poverty **Project** Community

and civil society empowerment.

Ms. Patience Nyangoma Manager Integrated eradication and creation of self Development sustaining communities in **Initiatives** integrated technical and material protection, improvement of drainage support in broad areas of channels sustainable agriculture, water and sanitation, environmental protection, income generation

1. Water and Sanitation: community based water management and education, community based sanitation education and Uganda through the provision of garbage management, spring water

> 2. Agriculture: sustainable agriculture and technology development, farm business education and marketing, food storage, post harvest handling and processing, market research and market linkages

3. Environmental management: community based activities for environmental awareness and protection, agro-forestry, sustainable use and management of natural resources

- 4. Health Care and HIV/AIDS: nutrition and gender, HIV/AIDS awareness and counseling, income generating activities for **PLWHAs**
- 5. Micro Finance: loans, savings, and credit facilities, entrepreneurial- skill development, institutional reserve fund 6. Lobbying, Advocacy and Networking: human rights awareness, conflict prevention and peace building, water and sanitation in IDP camps

Mr. Richard Busingye	Programme Officer – Accounts – CBP	and Sanitation	To work towards achieving universal safe access to safe water and improved sanitation.	Sector/NGO coordination, information sharing; representation in government for a; platform for members' voice and participation, capacity building, skills and knowledge, pilot projects, hosted projects
Mr. Abilu Charles Ateman	Programme Officer – Networking and Membership Development	and Sanitation	To work towards achieving universal safe access to safe water and improved sanitation.	Sector/NGO coordination, information sharing; representation in government for a; platform for members' voice and participation, capacity building, skills and knowledge, pilot projects, hosted projects
<b>Land Sector</b>				
Mr. Eddie Nsamba- Gayiiya	Consultant	Consultant Surveyors and Planners	Professional consultant firm	Professional consulting services
Ms. Judy Aturi Adoko	Programme Coordinator	The Land and Equity	civil society organisations,	Research; policy analysis; Grassroots work: LEMU is currently working with traditional institutions in Lango and Teso regions (in Northern and Eastern Uganda), to help them understand how they need to adapt to new economic and legal realities in the 21st century. By analysing with them the problems which are arising, LEMU has helped them to identify ways forward. Ordinances have been drafted, giving procedures to be followed when customary land is sold, and to re-establish traditional courts to hear land disputes; LEMU also gives occasional legal advice, both to individuals and to District Councils, helping to protect land rights.
Ms. Rose Mwebaza	Coordinator	Uganda Land Alliance	To enhance access, control and ownership of land by the poor women, men, children and marginalized groups through the promotion of fair policies and laws for the protection of land rights.	Research and documentation; advocacy; networking and information sharing; capacity building

rights.

## **Legal Sector**

Ms. Zaria	Project	The Uganda	To work with the poor and	Conflict and dispute management (strategic
Ddamulira;Mr.	. Manager;	Association of	vulnerable communities,	litigation, mediation, arbitration, child
Eric Naigambi	Head	Women	especially women and children,	rights, legal aid services for PLWHAs,
	Information,	Lawyers	to achieve justice, equality and	while you wait sessions, social counseling);
	Education, and		equity. This is achieved through	research, advocacy and networking;
	Documentatio		legal aid service provision, legal	information and education (including para
	n		and human rights education,	legal training, gender and human rights
			research and advocacy,	resource centre, legal awareness);
			networking and coalition	membership and staff development
			building.	
Mr. Tito	Executive	Uganda Law	To become a leading provider of	Legal information and advice; medication,
Byenkya	Director	Society -	legal services of choice in order	negotiation, and other alternative dispute
		Legal Aid	to ensure access to justice for	resolution services; court representation;
		Project	the poor and vulnerable people	training para legals; legal and human rights
			so as to promote the	awareness; human and legal rights
			socieconomic development of	information provision; lobbying and
			Uganda.	advocacy for pro poor laws; research

## Women's Sector

Ms. Peace Kyamureku	Secretary General	National Association for Women's Organizations in Uganda	C	Networking and information sharing; visibility and information generation; advocacy and representation; training and capacity building; support to member organizations
Ms. Caroline Bunga Idembe	Advocacy Officer	Uganda Women's Network	To promote and enhance networking, collective visioning and membership, and with different actors working towards development and the transformation of unequal gender relations in the Ugandan society.	Policy advocacy, networking, information management; institutional training and capacity building

## ANNEX 6: LIST OF STAKEHOLDERS INVOLVED IN HIV/AIDS ACTIVITIES IN KAMPALA DISTRICT\*

Academic Alliance

Action Aid Uganda

African Medical Research Foundation

African Youth Alliance

Agricultural Cooperative Development

International

Agency for Cooperation and Research in

Development

**AIDS Information Centre** 

Bukasa Chai Project

**Bukoto Development Association** 

Butabika Community Based Care and

Support to Orphans

Butabika Orphan and HIV Care Helper

Project

Child for Development Women's Group

Child Rights and Advocacy (Makerere)

Child Rights and Advocating

Christian Women Living with HIV/AIDS

Church of the Living Saviour, Naguru

Church Human Services AIDS Prevention

Programme

Community Health and Information

Network

**Embassy of Ireland** 

Family Planning Association of Uganda

Focus on Children International

Friends of Life Bwaise I HIV/AIDS

Initiative

Ggaba Community Based Care

Ggaba HIV/AIDS Support Group

Good Hope Organization

Hope Counseling Center

Infectious Disease Institute

Kabowa Ogutageganya Community

Association

Kasanga Health Care

Katwe Community Elderly, Widows and

**Orphans** 

Katwe Home Care

Katwe II West Zone Health Centre

Kera Community Counseling Service

Kibuli Parish Action on HIV/AIDS

Kikaya Bwakedde HIV/AIDS

Kiswa Health Centre

Kiswa Parish Action Metro-Health Chai

Project

Komamboga HIV/AIDS Community

Ministry of Health

Marie Stopes International – Uganda

Mutungo HIV/AIDS Initiative

National Community of Women Living with

HIV/AIDS

Naguru Orphans Muslim Association

Naguru Teenage Centre

Nakawa Parish Peri Urban Chai Support

Organization

Nakinyuguzi Teenage Anti AIDS Association

Nakulabye Guardians of AIDS Orphans

Namirembe-Bakuli Parish Youth AIDS Project

Namuwongo HIV Support Project

Nsambya Home Care

Nsambya Orphans Care and Family Support

Nsambya West Orphans and Widows Association

O.C.A.P.

Orphan and Guardian Kazo Angola

Orphans and Widows of AIDS Uganda

Pathfinder International

Pediatric Infectious Disease Centre

Plan Uganda

Prayer Player

Reach Out HIV/AIDS Initiative, Mbuya

Rescue Orphans, Widows of War and AIDS

Elderly

Salaama Family Help Group

Save the Children – Uganda

Sustainable Development

Taifa Community Care

The AIDS Integrated Model District Programme

The AIDS Support Organization

The National Forum of Alpha Networks in

Uganda

The United Nations World Food Programme

Traditional and Modern Health Practitioners

Together Against AIDS

Tukolenyo Women's Group

Tukolere Wamu Women, Widows and Orphans

Group

Uganda Badiira Herbal Medicine

Uganda Blood Transfusion Service, Nakasero

Uganda Cares

Uganda Protestant Medical Bureau

Uganda Red Cross Society

Uganda Youth Anti AIDS Association

Uganda Muslim Supreme Council

UNACO

Initiatives Subproject Uganda Network of AIDS Service Organizations Lubya Parish HIV/AIDS Initiative United Nations Children's Fund Lubya Parish HIV/AIDS Subproject Watoto Child Care Ministries Luzira Parish Community Based HIV/AIDS Women Alive HIV/AIDS Initiative World Health Organization Care World Vision International Marie Stopes Uganda Market Vendors AIDS Project Youth Health Organization Uganda Mbuyu Barracks Community HIV/AIDS Care Mbuya Family Helper Project **Meeting Point** Mildmay Centre Ministry of Education and Sports Ministry of Finance and Economic Development

<sup>\*</sup> NOTE: This list is not exhaustive. SSA regrets any errors or omissions that may have been made in the compilation of this list, as changes may have occurred since the original preparation of this research paper.

#### ANNEX 7: QUESTIONNAIRE FOR KEY INFORMANT INTERVIEWS

- 1. Which problems do homes with people infected or affected by HIV/AIDS meet in their attempts to access and/or ensure
  - affordable and decent shelter
  - housing finance
  - land for housing
  - clean and safe water
  - security of tenure (i.e. not being evicted from their places of abode)
  - sewers and good sanitation around their homes

as compared to those that are not infected or affected by HIV/AIDS?

- 2. Which problems do homes with people infected or affected by HIV/AIDS confront when they are trying to fit into their respective communities, as compared to those that are not infected or affected by HIV/AIDS?
- 3. Are you aware of any cases in which people are rendered homeless because of HIV/AIDS? Please explain.
- 4. How does HIV/AIDS impact homes and family structures? Please explain.
- 5. In general, how does HIV/AIDS affect the economic livelihoods of households? Please explain.
- 6. Does your organization have any programmes or activities aimed at trying to prevent the problems mentioned in the questions above? Please briefly explain.
- 7. Which organizations provide activities or programmes that try to prevent the above listed problems faced by homes and families affected by HIV/AIDS when trying to access affordable and decent shelter? Please explain.
- 8. What do you think could be done by your organization or other organizations to ensure that homes and families affected by HIV/AIDS are able to access decent and affordable shelter?

#### ANNEX 8: INTERVIEW GUIDE FOR KEY STAKEHOLDER INTERVIEWS

- 1. In your own words, please briefly explain your role in your organization, how you become involved in your work and how long you have been working in your current position.
- 2. What is the mandate and services provided by your organization? What major projects and initiatives are you currently working on?
- 3. Can you provide a general overview of the set up of the sector that you work within?
- 4. Who are the major stakeholders in your sector?
- 5. Which are the key partnerships in your sector and who are your organization's major partners? Funding sources?
- 6. Can you explain the implementation framework for your sector and your organization?
- 7. Can you identify the key policies for your sector and for your organization?
- 8. Please list and explain the major challenges faced by your organization. What challenges do you face in your day-to-day work?
- 9. What do you think are the major gaps in your sector?
- 10. Please provide any additional information you think may be useful to this study.
- 11. Who are the key contacts in your sector and/or organization that may be relevant/useful to this research study?

#### ANNEX 9: KEY POLICIES IN HUMAN SETTLEMENTS SECTOR IN UGANDA\*

Land Act (1998) National Health Policy (1995/1997) National Shelter Strategy (1992) National Water Policy (1996) Poverty Eradication Action Plan Public Health Act (1964) Water Act (1995)

\* NOTE: This list is not exhaustive. SSA regrets any errors or omissions that may have been made in the compilation of this list.