AIDS STIGMA AND DISCRIMINATION IN PUBLIC SCHOOLS: A CASE STUDY OF HIV-POSITIVE CHILDREN IN KENYA

(Spine Title: AIDS Stigma and Discrimination in Kenyan Public Schools)

(Thesis Format: Monograph)

By

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Graduate Program in Education

A thesis submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy

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ABSTRACT

The advancement of the antiretroviral therapy (ARV) has extended life expectancy for children born with HIV, allowing them to live longer, healthier lives and to attend school. Conversely, medical evidence indicates that it is unlikely for HIV transmission to occur during social interactions, and therefore exclusion of HIV-positive children (CLWHA) from school is unwarranted. Kenya's education policy guarantees every child the right to education and protection from all forms of discrimination. However, due to social misconstructions about HIV/AIDS, CLWHA's continue to face various forms of stigmatization. Therefore, the aim of this study was to examine the manifestation and experiences of AIDS stigma and discrimination in Kenyan public schools. It specifically explored how these experiences affected social interactions and learning of CLWHA.

This ethnographic qualitative case study utilized social stigma theories (Goffman, 1963) to illuminate the educational realities of CLWHA and divulge relevant implications. The study utilized purposeful criteria sampling to select 22 participants. Data were collected using qualitative in-depth interviews, participant observation and document analysis. Emerging data from the interviews and observations were analyzed into themes. Owing to the participants' vulnerability and the sensitive nature of this study, confidentiality was maintained at all levels and pseudonyms were assigned to all the participants and institutions.

The results indicated that stigma and discrimination were visible in the school milieu and negatively impacted the social interactions and learning of CLWHA. Lack of empowerment and inadequate resources suggested that CLWHA received limited support and stigma and discrimination were poorly addressed. The study however demonstrated that support was critical in enhancing learning and social integration of CLWHA into public schools. Based on the study findings, collaborative efforts and policies are necessary to enhance effective interventions aimed at reducing S& D in schools, and for directing government and school-based policies and practices towards improving CLWHA's right to education, empowerment and support.

Key words: AIDS stigma and discrimination, HIV-positive children, empowerment and support, socialization and learning

DEDICATION

This work is especially dedicated to all HIV-positive children in Kenya

ACKNOWLEDGEMENT

Through his grace and mercy, God has raised me up to more than I can be. Glory to you Lord!

I am extremely grateful to Dr. Aniko Varpalotai, my supervisor for diligently guiding me through this work and for making me believe in myself. Your inspirational insights, invaluable support and mentorship molded me to become a scholar. Sincere thanks to Dr. Alan Leschied, my committee member, for your unwavering support, constructive advice and encouragement that constantly reminded me how important this research was. I can never thank you enough! Thank you Dr. Suzanne Majhanovich, my committee member, for your continuous support and for making an outstanding contribution to this study. I count myself lucky to have worked with such a committed team. You are and will always be true blessings in my life!

I am most grateful to the HIV-positive children and the administrators of Kivuli Children's Home, the teachers and the administrator of Karibu School, who participated in this study. You generously entrusted me with your stories, without which, this work would not have been completed. May God continue to bless you abundantly.

Many thanks to the faculty members for the immense wealth of knowledge I have gained from each one of you. I deeply appreciate the care and support I have received from Dr. Immaculate Namukasa and Drs. Suzanne and Ljubo Majhanovich. Thanks to Linda Kulak, Tina Beynen, Karen Kueneman, and Bob McMillan. You worked behind the scenes, but in so many ways you have been instrumental in my academic achievement. A big thank you to the library and IT teams for providing up-to-date literature and efficient technology that supported my graduate work. Without Ruth Burger's contagious smile, our graduate work would have been most ineffective. Keep up the spirit Ruth!

I thank Lucy and Jerry Sollazzo, the family that welcomed me to Canada and provided me with a cozy home. I will always relish your kindness. I am indeed grateful to Lucy Karanja and Melanie Katsivo for your friendship and support throughout my study. I cannot forget to thank Nazia, Alfred and Jane Gichuru, for their support and encouragement during my graduate studies. I extend my profound gratitude to Raphael Sone for your friendship and for sacrificing valuable time to proof-read several drafts of my thesis with extreme patience.

I am indebted to the members of the Rotary Club of London West, particularly Karen and Eric Auzins, Barbara, Tom Telfer, Dennis and Jean Urbach and Ken Wilmott. Thanks to Malcolm and Barb Robin for ensuring that my stay in Canada was enjoyable and productive. Many thanks to the Assumption Sisters of Nairobi for allowing me time out to pursue my doctoral studies. I am truly grateful to my family and friends back in Kenya, Jamaica, and here in Canada, for all your support and most importantly, for lifting my needs to the Lord in prayer. Your kind words of encouragement, e-mails and occasional phone calls helped me maintain my academic focus.

I am grateful to the members of the Rotary Club of Black River for sponsoring me to come to study in Canada. Finally, I thank Rotary International Foundation, the University of Western Ontario and Margaret McNamara Memorial Fund for financing my studies.

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CHAPTER ONE: INTRODUCTION

Many people suffering from AIDS not killed by the disease itself are killed by the stigma surrounding everybody who has HIV/AIDS
(Former South African President Nelson Mandela-Barcelona Conference, July, 2002)

Stigma was perceived as a social construct long before Goffman (1963) provided a concrete definition. However, in his book *Stigma: Notes on the management of spoiled identity*, Goffman (1963) defined stigma as "an attribute that is deeply discrediting" (p. 3). Therefore, an individual possessing a characteristic that appears different may be considered undesirable in the eyes of the society, particularly when the person is perceived as "bad, or dangerous, or weak." Consequently, the person with this attribute is "reduced in our mind from a whole and usual person to a tainted, discounted one" (Goffman, 1963, p.3). He further emphasized that it is the society's belief that "the person with a stigma is not quite human" (p. 5).

Since the onset of HIV in the 1980s, a similar social construction of stigma has been directed at people living with HIV/AIDS (PLWHA), who by virtue of possessing HIV or AIDS are perceived to be different, and therefore undesirable. Owing to HIV/AIDS status, PLWHA have often been associated with immorality and other practices. This perceived "difference has been manifested in various acts of discrimination that often accompanies stigma, thereafter directed towards specific groups or individuals, who are perceived to be living with HIV/AIDS" (Parker & Aggleton, 2002, p. 14).

HIV/AIDS stigma and discrimination came into the limelight when Jonathan Mann (then Director of WHO) described three phases of the HIV pandemic explaining its impact on the society. In the first phase he demonstrated the form, which the pandemic

would take long before it was fully understood. In the second phase it was proposed that HIV would gradually develop into AIDS. The third phase which Mann considered the most important would be "characterised above all, by exceptionally high levels of stigma, discrimination and, at times collective denial that are as central to the global AIDS challenge as the disease itself" (Mann, 1987, cited in Parker & Aggleton, 2003, p. 13). Similarly, and over a decade later than Mann, Peter Piot (2000, cited in (Parker & Aggleton, 2003), the executive director of UNAIDS, stated that stigma was a "continuing challenge" and called upon the "global community to engage in rigorous action in order to combat stigma" (p. 14). Additionally, Brown et al (2003) argued that the "HIV/AIDS pandemic [had] evoked a wide range of reactions from individuals, communities, and even nations, from sympathy and caring to silence, denial, fear, anger, and violence"(p. 51). Consequently, the increase of HIV/AIDS cases to a staggering 33.3 million globally, AIDS and the accompanying stigma and discrimination continue to be a huge challenge in the society. Furthermore, infection rates continue to be particularly high in most African countries where resources to address the problem are low (UNAIDS, 2005).

Stigma and discrimination of PLWHA is exacerbated by ignorance about the disease, misconceptions about how HIV is transmitted, limited access to treatment, irresponsible media reporting, incurability of the disease and fears and prejudices relating to socially sensitive issues, including sexuality (www.avert.org). These differences in perception also hinge on the belief that HIV/AIDS is a life-threatening disease, with the commonly held view by the society that "PLWHA are sometimes perceived as invasive agents in a healthy society" (Sontag cited in Varas-Diaz et al., 2005, p. 170). These social differences have evoked "various forms of negative treatment including social exclusion,

rejection and denial of much needed support in the belief that they get what they deserve" (Parker & Aggleton, 2002, p. 13). Likewise, the "early AIDS metaphors such as death, horror, punishment, guilt, shame and otherness have aggravated these fears, reinforcing and legitimizing stigmatization and discrimination" (ibid).

As a global phenomenon, AIDS stigma and discrimination occur in various milieus including family settings, communities, religious organizations, work places, health care centres and educational institutions (Nwanna, 2005; Nyblade & Carr, 2011; Stutterheim et al., 2009). Avert (2010) however noted that stigma and discrimination are manifested differently in different countries; even within the same country, reaction to HIV/AIDS varies between individuals and groups. AIDS stigma, which leads to discrimination is also expressed through legislation with those in authority justifying as necessary to protect the society. Examples of legislated discrimination include forced HIV testing and treatment, forced disclosure of one's status, restriction from entering certain professions and forced seclusion (Herek, 1999). It is worth noting however, that AIDS-related stigma is not static, but changes over time as infection levels decrease and increased knowledge of the disease and improved treatment become available.

White and Carr (2005) attested to the fact that AIDS stigma and discrimination have severe consequences on the physical, emotional and psychological well-being of PLWHA. Furthermore, stigma and discrimination are major barriers to HIV prevention, access to treatment, care and support, and the pursuit of an education or vocation (Parker & Aggleton, 2002). Consequently, stigma and discrimination negatively affect how well PLWHA adapt to the disease and adjust to their status, thus making them susceptible to further stigmatization. Most PLWHAs who internalize stigma encounter difficulties in

socializing with members of the family and acquaintances, which in turn further affects their psychological well-being. Similarly, AIDS stigma, as a major barrier in the fight against HIV/AIDS, negatively impacts the ability of nations to combat the disease (Piot, 2000, cited by Parker & Aggleton, 2002, P. 1).

Governments and stakeholders have taken stringent measures to reduce the spread of HIV and decrease stigma and discrimination. In these efforts, some countries have initiated and implemented laws and educational programs and that involve PLWHA as a way of creating awareness, clarifying misconceptions and providing accurate information about HIV/AIDS in order to facilitate positive attitude and acceptance of PLWHA (Parker & Aggleton, 2002). In some countries, PLWHAs face mandatory HIV testing, particularly when seeking work permits, a visitor's visa or medical coverage. PLWHA who reside in foreign countries have also been forced to leave. In some countries, those responsible for spreading the HIV virus by not disclosing their condition to their partners are subjected to prosecution (Kenya HIV/AIDS Prevention and Control Act law, 2006, Kirp & Bayer, 1992, Gostin & Lazzarini, 1997, cited in Parker & Aggleton, 2002, p. 5). Although these preventive measures are geared towards the protection of the general public, they contravene the rights of PLWHA, which itself is a form of discrimination (Watney, 2000).

An encouraging development in the management of HIV/AIDS is the availability of antiretroviral drugs (ARV). Not so long ago, children diagnosed with HIV were expected to die before their fifth birthday. However, medical advances have greatly extended the life expectancy of many Children Living With HIV/AIDS (CLWHA) by transforming HIV from being an acute terminal illness to a chronic condition (Foster &

Lyall, 2005; Gibb et al., 2003). Consequently, CLWHA are surviving long enough and are able to attend school (Cooper et al., 2007, p. 103). As a result, the education of HIV positive children and the related stigma has become an issue that can no longer be ignored.

Kenya has a large number of CLWHA who have benefitted from ART and as a result, survival rates are now reasonably high. Unfortunately, however, the need for education in regards to the disease has been virtually overlooked. Silence on the part of the government regarding the education of CLWHA, has been used as a justification by some school administrators to deny admission to these children, consequently denying them a chance to realize their educational dream. Despite clear HIV/AIDS and education policy guidelines that guarantee CLWHA's right to education and protection, a significant number of children continue to be denied access to, or are forced out of schools in Kenya. Concerned about the plight of Kenyan CLWHA, UNICEF Director, Ann Veneman (UNICEF, 2007) stressed that meeting the needs of CLWHA and orphaned children must become a priority globally. On a similar note, Mr. Chris Ouma (UN Children's Fund Project officer) suggested that schools initiate programs to educate parents and sensitize them to the right of all children to education (UNICEF, 2006).

In Kenya, the matter concerning CLWHA's need for education did not receive media attention until 2004 when Kivuli Children's Home sued the government for denying HIV orphans access to education in various public schools on the basis of their health condition (Marc, 2004). Based on this law case, this study examines the experiences of AIDS stigma and discrimination of CLWHA from Kivuli in Kenyan public schools.

The Rationale of the Study

AIDS is redefining the very meaning of childhood for millions, depriving children of many of their human rights
(Sarah Epstein, UNAIDS, UNICEF, WHO, 2007 *UNICEF, 2007, p.1).*

Kenya is one of the African countries with a high prevalence rate of HIV/AIDS. Over 1.42 million Kenyans are living with HIV/AIDS including 150, 000 infected children (Kenya AIDS Indicator Surveillance Survey [KAIS], 2009, p. 1). Similar to other countries, stigma and discrimination of people infected by HIV/AIDS is a common phenomenon in Kenya as evidenced by extensive media citations of various forms of harassment, rejection, labelling, bullying, death threats and even death of those associated with them. These reports illustrated that people known to be infected or perceived to be HIV-positive risk losing jobs, property, family support and social relationships (Kenya Times Newspaper, January, Monday 22nd 2007, p. 1).

The majority of those highly stigmatized include sex workers and members of the gay community, whose sexual practices are not only considered offensive and immoral but also illegal in Kenya, "punishable by up to 14 years in jail" (BBC News, October, Thursday 29th 2009). Due to fear of ostracization by the public, this cohort has declined disclosing their status, and as a consequence, they lack the care and support enjoyed by other Kenyans. Other stigmatized groups include HIV-infected and affected children and their families, and women whom the society hold responsible for spreading the virus.

The introduction of antiretroviral treatment (ARV) was believed to positively influence public attitudes towards PLWHA. However, reports continue to suggest that stigma and discrimination are rife in Kenya. For example, in a study conducted in Kibera Slums in Nairobi, Kenya, almost 43% of the respondents were said to have experienced

stigma and discrimination (Odindo & Mwanthi, 2008). Other observations confirm that the occurrence of stigma and discrimination is more common among HIV-positive women in Kenya, particularly in health care centers. The Federation of Women Lawyers (FIDA-Kenya, 2010) recounted how HIV-positive women are isolated or treated differently by health care professionals by denying them adequate health care services and assistance during child-birth because they believe women with HIV should not have children. Such treatment contravenes the Protective Act that received presidential assent on December 30th 2006, mandating appropriate treatment, counselling, and care for persons infected or at risk of HIV/AIDS infection (www.avert.org, 2010). Usawa ni Haki Newsletter (2010; http://ncpwd.go.ke/usawa-na-haki-newsletter/), an organization that fights for the equal rights of people who experience unjustified treatment reported that young women living with HIV/AIDS were mistreated by members of the community, while their families sent them away from their homes in addition to denying them a right to property ownership.

Minimal attention has been accorded to research in the area of AIDS stigma and discrimination in Kenya. However, the few reports available have focused on adult populations of PLWHA with minimal consideration given to the experiences of CLWHA. Yet, close to 150,000 children are infected with HIV/AIDS, more than 10 per cent of the 15 million children are orphans, and in excess of 650,000 have lost parents to HIV/AIDS (KAIS, 2009). Understanding their predicament while they attempt to negotiate their place in society among non-infected peers and how they cope with the disease and the accompanying stigma is central to this study.

Kenyans perceive orphanhood as a 'bad omen', and with the onset of the HIV/AIDS epidemic, it has increasingly become an anathema. As a result, discrimination against orphans has been observed to occur frequently (Beegle et al., 2006). Moroever, when people draw conclusions that the children are orphaned due to HIV/AIDS, they are additionally stigmatized. Children labelled as orphans are therefore treated with scorn by family, while society unjustifiably shuns and discriminates against these voiceless children. Similarly, threats against and actual death of CLWHA has also been reported. For example, a 15-year old orphan boy was brutally murdered by his uncle because of his HIV status (Kenya Times Newspaper, January, Monday 22nd 2007, p. 1).

CLWHA, who are partial or complete orphans, are often excluded from public schooling in Kenya. The Integrated Regional Information Network Report indicated that many CLWHA, the majority of whom are orphans, attend public school; however, theirs is an untold story since they often face harassment through stoning, isolation, bullying by peers and taunting by their teachers (UNICEF, 2006). According to Ruto et al (2009), some media reports highlighted incidences of CLWHA being treated differently by teachers and peers. This study confirmed that many people including teachers avoided close proximity with sickly-looking HIV infected children for fear of contracting the disease. The authors however observed that when physical symptoms such as rashes disappeared, the instances of isolation lessened. The discrimination and isolation was found to be a cause of anxiety for the CLWHA, especially when it occurred at school. Consequently, most CLWHA appeared depressed, did not mix with other children and exhibited learning difficulties in class. Their depression was linked to being orphaned as well as the physical and verbal abuses from their peers (ibid). As observed by Cooper et

al (2007), “without protection, these children may drop out of school” (p. 106). These incidences clearly demonstrate the dilemma CLWHA constantly face while confronted with issues of stigma and discrimination within the school setting and in their communities.

One important observation by KAIS (2009) revealed that the Kenya Ministry of Education Science and Technology (MOEST) lacks official records of the actual number of CLWHA attending public or private schools, meaning that they relied on records of absenteeism and the deteriorating physical appearance of a child. Another study by Human Rights Watch (HRW, 2007-2008) of five provinces of Kenya (Nyanza, Western, Rift Valley, Nairobi and Coast provinces) reported a general lack of acknowledgment of CLWHA and blamed the Kenya AIDS Indicator Survey (KAIS) for entirely excluding data about children under age 15 in their reports. Confirming these reports, teachers in Nairobi schools highlighted that the number of CLWHA could be higher in some schools. The teachers further observed that in the slums of Nairobi, there was an increasing number of CLWHA in the lower grade levels. They attributed this increase to the lack of detailed information from the family regarding the health status of the pupils due to stigma. This was consistent with Ruto et al’s (2009) findings that orphaned and vulnerable children (OVC) lacked basic amenities and support despite the Kenya education policy acknowledging that OVC’s have special needs. Similarly, Mbugua (2004) noted though Kenya had some of the best programs for combating the spread of HIV/AIDS, few programs were designed specifically to address the needs of HIV/AIDS orphans. As such, “a gap existed in meeting the special needs of affected and infected orphans, especially their education and psychosocial needs” (p. 305).

To combat the spread of the virus, most school education programs focuses primarily on providing information on basics of HIV, which include the causes of HIV, routes of transmission and preventative measures (Njue et al. 2009).. Human Rights Watch (2007-2008) however suggested that in order to promote fair treatment of children who are victims of stigma and discrimination, particularly when in school, there was a need to reinforce child protection mechanisms, and in the case of CLWHA, protection from stigmatization and discrimination.

The majority of teachers in one of the Nairobi schools decried a lack of resources, skills, and proper guidelines necessary to handle HIV/AIDS-related issues (Ruto et al., 2009, p. 133). Teachers' inability to address the needs of these children and to perform their duties conscientiously and in a sensitive and responsive manner signifies that OVC and in particular CLWHA, "are deprived of life chances, including quality education and accrued future benefits" (Ruto et al., 2009, p. 132). Gachuhi (cited in Mbugua, 2004, p.304) reteriated that it was critical to combat HIV/AIDS, with the education sector at the frontline. Therefore, greater effort, along with school-based policies that will ascertain a more conducive and inclusive atmosphere for all learners are required for schools to sufficiently address these needs.

A number of studies exploring AIDS stigma and discrimination in North America, Africa and the Caribbean have been published (Bharat et al., 2001; Deacon et al., 2007; Earnshaw & Chaudoir, 2009; Mead & Hamilton, 2005; Skinner & Mfecane, 2004; Ogunjuyigbe et al., 2009). Most of these studies focused on the attitudes of the non-infected towards PLWHA, the effects of HIV/AIDS disease on non-infected orphans, HIV/AIDS interventions, and attitudes towards HIV that result in stigma and

discrimination mainly among the adult population. Consequently, understanding the experiences of AIDS stigma and discrimination towards CLWHA has been based primarily on observations and perceptions relating to adults. However, Deacon and Stephney (2005) cautioned that "research on adults cannot be extrapolated to children because children are likely to be affected by stigma and discrimination in different ways from adults" (p. 7). The authors further noted that unlike adults, "children are developing cognitively, physically and socially, and may interpret, express, and react to stigma in different ways from adults" (ibid). Moroever, "owing to CLWHA's vulnerability, their experiences of stigma and discrimination might be more intense than that of adults because they have little control of their circumstances compared to the adults and, therefore, lack knowledge of their rights, hence they are unable to assert their rights" (Cree et al., 2004, p. 74).

In this study, I investigated how AIDS stigma and discrimination are manifested and experienced by CLWHA from Kivuli Children's Home in Kenyan public schools, and how these experiences affect social interactions and learning. These children (CLWHA) were integrated into the public education system after an intensive and successful court case in Nairobi, Kenya. The court order allowed CLWHA to access free education, and as a result, they became 'pioneers' in public schools in 2004. Important findings emerging from CLWHA's experiences have the potential to provide guidance on how specific issues and concerns pertaining to stigma and discrimination can be appropriately addressed.

Research Questions

The aim of this study was to investigate AIDS stigma and discrimination in Kenyan public schools. Specifically, I sought to understand the experiences of CLWHA from Kivuli Children's Home in Nairobi, Kenya. In order to collect sufficient data from the participants, I was guided by three "grand tour" questions also referred to primary questions as and three sub-questions. Spradley (1979) emphasized that "answers from grand tour questions often place events in a larger context and elicit data that one would never have thought to ask, while sub-questions supplement questions that further focus on grand-tour answers" (p. 87). This study was guided by three primary research questions and three sub-research questions that enabled the participants to elaborate on the meanings that emanated from their experiences. It followed Lincoln and Guba's (1985) remarks regarding 'grand tour questions', where the researcher approaches the study "… not knowing what is not known" (p. 235). I used questions to address the underlying concerns regarding AIDS stigma and discrimination as experienced by CLWHA in Kenyan public schools. The main source of this concern was the scarcity of literature on the experiences of CLWHA and lack of proper guiding policies on AIDS stigma and discrimination. The following research questions guided this inquiry:

Primary Research Questions

1. In what ways are HIV/AIDS stigma and discrimination manifested in Kenyan public schools?
2. In what ways do HIV-positive children experience stigma and discrimination in public schools in Kenya?
3. How do these experiences affect their social interactions and learning?

Sub-Research Questions

1. What coping strategies do CLWHA employ to deal with stigma and discrimination in Kenyan public schools?
2. What resources exist in the school that provide material and psychological support and/or empower CLWHA to deal with stigma and discrimination?
3. How are non-infected children and teachers educated or encouraged to support their infected peers?

These questions illuminated the challenges of AIDS stigma and discrimination experienced by CLWHA in Kenyan public schools. They also provided an informed basis for intervention strategies necessary to improve the educational experiences of CLWHA.

Kivuli Children's Home

"Kivuli" (pseudonym) is a Kiswahili word that means "Shelter." Kivuli Children's Home is a model home that was specifically designed to provide special care to CLWHA. It was established in 1992 as a response to the increasing number of abandoned and homeless HIV-positive children by parents or family members after the death of their parents. In acknowledgement, the National AIDS Control Programme (NASCOP, 2005) reported that infected and affected orphans find difficulties settling down after the deaths of their parents. Although culturally orphaned children are the responsibility of the extended family, with the onset of HIV/AIDS, there has been a remarkable increase in the number of orphans in the country with no one to care for them. Fear of the disease, and the additional financial demands of caring for extra children, have compelled many families to surrender the orphans to the institutions.

The manager of Kivuli, Mr. Chrisy (pseudonym), gave some of the reasons why relatives found it difficult to accept CLWHA or even provide them with a home:

> Often, when other family members take in AIDS orphans, they really do not want to associate with that child. They are worried that they and their children could get infected (Mr. Chrisy-interviewed on November 20th 2010).

Although the intention to surrender CLWHA to the institutions might be good for families, the children may interpret this as rejection.

Kivuli Children were the first to benefit from the antiretroviral drugs (ARV) when they became available at the beginning of 2000. They were fortunate because the director of the Home, a psychiatrist by profession, had links with medical organizations in the United States of America that supplied the children with the drugs (Marc, 2004). The drugs had significant effects on the lives of CLWHA children, which not only brought them hope for healthier lives but also resulted in higher survival rates. Unlike other children's homes, Kivuli has fully skilled medical personnel and a team of social workers that provide ongoing medical care and emotional support to CLWHA.

The introduction of antiretroviral drugs coincided with the government's declaration of free education for all and fore-grounded the educational issues of CLWHA. Responding to the good news, the director of Kivuli sought admission for CLWHA into the public schools; however, this move was met with strong opposition by school administrators and parents. Prior to 2004, Kivuli spent over US $14,000 yearly to educate 41 children who were in private schools. With the death rate decreasing and the number of CLWHA increasing, it was critical that these children should benefit from free primary education like all other Kenyan children.

Kenya has ratified non-discriminatory laws and policies on the rights of the child to education, but school administrators disregarded them and proceeded to deny vulnerable children their right. Employing legal mechanisms, the Kivuli director brought the Ministry of Education Science and Technology (MOEST) to court accusing MOEST of discriminating and violating the rights of CLWHA by denying them access to free primary education. Following the court ruling in 2004, the government ordered all public schools in the country to enrol CLWHA without discrimination. This resulted in the first seven CLWHA being admitted in class one at Karibu School[1]. One lawyer hailing the court's decision noted: "This is a resounding victory for life, liberty and justice over prejudice, stigma and fear" (Marc, 2004, p.1).

Karibu Primary School

Karibu (Meaning "Welcome") Primary School is one of the public schools under the jurisdiction of the Nairobi City Council. Due to its exemplary performance in national examinations, it is popular among parents and pupils, and as result, it has a large population of over one thousand pupils drawn from Langata division and the surrounding areas. It is one of the public primary schools that had initially declined to admit HIV-positive children from Kivuli Children's Home because their HIV status was known to the public. The administration considered it increasingly risky to have CLWHA learning in the same facility with other pupils. However, in adhering to the directives of the Ministry of Education Science and Technology ordering all schools to admit all children including CLWHA irrespective of their HIV status, Karibu School became the first school to accept CLWHA. Due to prior resistance by the school administrator, a change

[1] Karibu School- One of the city council schools in Nairobi where children participating in this study attended school.

in senior administration had to be effected to facilitate the integration of these children. Consequently, the principal and a significant number of teachers who had colluded with him to reject CLWHA were transferred to other schools. The new principal, together with a group of the new teachers, paved the way to welcome the first seven HIV-positive children into the school. Later in the year, one child died, but the other six who were in grade 7 at the time of data collection participated in the study. Over the years, the number of children at the school has grown. Currently, there are over 40 HIV-positive children from Kivuli Children's Home learning at Karibu School from grade one to eight.

It is worth noting that there are a number of children's homes in the areas surrounding Karibu Schoo that provide care to orphaned children, but Kivuli Home is unique in that it specifically cares for HIV- positive orphans. Some of the orphans from these homes attend Karibu School as well. While conducting the study, I learned that a small number of HIV- positive children from regular homes attended Karibu School. The incumbent school administrator was extremely instrumental in the admission of CLWHA into the public education system. The administrator and the majority of the teachers I interviewed joined the teaching staff almost at the same time as the CLWHA.

Significance of the Study

The main objective of this study was to investigate how AIDS stigma and discrimination impacts on CLWHA's social interactions and learning in Kenyan public schools. Using a case study, I focused on the experiences of Kivuli Children who represent many silent voices of CLWHA worldwide, and whose experiences of stigma and discrimination remain untold. Yet, AIDS stigma and discrimination have been recognized as a major problem that demands to be addressed by initiating some strategic

mechanisms. While Deacon and Stepheney (2005) have acknowledged that literature on children and HIV/AIDS is extensive, they warned that there is a dearth of research specifically focusing on AIDS stigma and children (p. 62). This is in spite of the numerous incidents reported involving stigmatization, isolation, prejudice, and discrimination, social ostracizing, harassment, and rejection and of CLWHA being consistently denied access to education due to their serostatus (Fan et al., 2004).

Additional studies have emphasized bullying and violent attacks on CLWHA even when the symptoms are absent to confirm their serostatus (Marc, 2004; Ruto et al., 2009). Other studies have established that some teachers view CLWHA as a risk to other children in the classroom (Fan et al., 2004), and as a result, these teachers threaten the children, making it clear that they are not welcome into the classroom. Several scholars have blamed the escalation of incidences of stigmatization of CLWHA on the scarcity of resources to meet their needs and the lack of proper policies to protect them. Other studies highlighted teachers' feelings of inadequacy when dealing with CLWHA as a result of fear and other misconceptions attached to the disease. As a consequence, CLWHA receive limited or absolutely no form of support from teachers and peers (Obare et al., 2009).

I concur with Roberts (2000) arguement that "a school is essential for children because it is the place where they spend a considerable amount of time, learning, developing relationships and deepening their understanding of the world beyond the context of their homes" (p. 35). These interactions with peers significantly shape CLWHA's perceptions and identity. This study therefore seeks to unearth the CLWHA experience of living with a chronic disease amidst a prevailing stigmatizing environment

that has the potential to affect socialization and learning. Most importantly, my goal in this is to give voice to the CLWHA by providing them with a forum where they can reflect and express their experiences. This observation is consistent with the Committee on the Rights of the Child (CRC, 2003) that states: "Children have rights to express an opinion in matters that affect them and the right to be heard" (Article 12, p.11). Finally, these experiences will help to conceptualize the needs of CLWHA within the school context and suggest ways in which they can be addressed.

Justification of the Study

This study paid special attention to the CLWHA's experiences of AIDS stigma and discrimination and investigated their impact on social interactions and learning particularly in Kenyan public schools. In order to delve into these experiences, I employed social stigma theory by Ervin Goffman (1963) and symbolic interactionism (SI) theory by Herbert Blumer (1969), both of which are sociological theoretical frameworks that can be used as lenses through which to appreciate lived experiences.

Unlike other theories, these sociological theories provide an improved grasp of individual behaviours; hence their utilization enhanced my understanding of CLWHA's experiences of living with a highly stigmatized chronic disease and how the process of stigmatization altered personal perceptions and identities. This study also utilized ethnographic methodology and qualitative methods including interviews and participant-observation to investigate the challenges these children face in their day-to-day encounters while in school, and comprehend what mechanisms they employ to cope with the challenges. Through this inquiry, comprehensive descriptions of their experiences that have not been unearthed due to limited research among CLWHA were revealed.

Insights gained from their experiences will aid in the development of programs and policies that will hopefully meet the educational needs of children living with HIV/AIDS. The end results of this research will contribute significant knowledge that education policy makers might draw from in designing responsive policies that are specific to the educational needs of CLWHA. This is in addition to augmenting the body of literature on AIDS stigma and discrimination that is fundamental in social sciences and education research.

Locating Myself in the Research

The inspiration to investigate AIDS stigma and discrimination in Kenyan public schools came from many years of my high school and college teaching experiences in Kenya and Jamaica, West Indies. Additionally, my experience of seven years as the coordinator of an HIV/AIDS project in Jamaica exposed me to the sufferings HIV-positive children endured, which also significantly shaped and informed this study. Therefore, I view HIV/AIDS as a personal and painful journey that has challenged my life directly as well as my profession.

In the year 2000, I painfully watched an HIV positive female colleague in the last stage of AIDS. She struggled to maintain her job as a teacher in order to support her children. I observed how she harnessed her diminishing energy to keep her students and classes going. However, after one single session in the classroom, she was too exhausted to continue. The fear and lack of understanding of how HIV is transmitted resulted in both students and teachers distancing themselves from her, which served to isolate her at a time when she needed support the most. Her condition loosened all of the links she had with other teachers, the majority of whom were “born again” Christians, who passed

judgment on the morality of the disease and concluded that she deserved her "punishment".

It is with sad memories that I approached this research as I recalled the agony and despair written in the faces of family members, friends and colleagues as they watched their loved ones languishing under the horror of HIV/AIDS. As a classroom teacher, I occasionally dealt with orphans whose pain and loss was unbearable and who could barely concentrate on learning. It was then that the true meaning of the proverb "Only the wearer knows where the shoe pinches" made sense to me. Given my limited knowledge about HIV/AIDS and lack of skills at the time to address their emotional and psychological concerns, I was only modestly equipped to ease their pain.

When I moved to Jamaica in 2001 and worked with people living with HIV/AIDS, I gained a new appreciation of the disease and the prevailing social attitudes that were directed towards PLWHA. I witnessed first-hand men, women and children being ostracized, harassed and threatened with death by close members of the family including friends who became as enemies after learning about their plight. Innocent CLWHA were oblivious as to why their peers had all of a sudden turned a cold shoulder to them. Gripped by a feeling of insecurity, they tearfully clung to their mother's arms for reassurance and a feeling that all would be well. But, in my opinion, all was not well:

- When the public refused to board the same taxi with PLWHA.
- When taxi drivers refused to drive PLWHA to the hospital and left them to die.
- When doctors declined to treat HIV patients leaving them hopeless.
- When nurses breached confidentiality and spread rumours about PLWHA who sought comfort in counselling.

- When drivers refused to drive an infected child to school.
- When schools sent children home on suspicion that they or their parents were infected.
- When CLWHA were teased by teachers and peers thus making schooling experience unbearably painful.
- When church sisters and brothers avoided sitting in the same pew with a PLWHA for fear of being contaminated.
- When PLWHA became the talk of the village and made to feel like second class citizens and, therefore, less human and unworthy.
- When they were rejected, abused, physically attacked and threatened with death.
- When family members contemptuously refused to attend funerals of PLWHA, accord them a decent burial and bid them last goodbyes (Personal observations: 2001-2007).

While adult PLWHA could adjust and, with time, design strategies to cope with stigmatizing experiences, HIV-positive children continued to silently live with the insults from every corner; insults from peers and ridicule from teachers. Unfortunately, these experiences had long lasting psychological effects on these children. The daily realities of CLWHA definitely challenge and question the administrative and leadership role of schools in promoting an inclusive learning environment for all learners regardless of their HIV status. This is consistent with Conway's (2005) observation that "schools remain an important part of a child's life since by their very nature, they provide a supportive caring environment and should be interested in promoting the voices, interest and well-being of all children in every aspect of their lives" (p. 3). But, in a society where HIV was

envisioned as a punishment for violating social norms, stigma and discrimination has rendered the powerless CLWHA defenceless.

Another important aspect that has significantly influenced my research choice was my Christian belief in the right to equality and the respect for the dignity of every human person irrespective of their status. From this perspective, my study pays special attention to how the educational rights of CLWHA have been violated due to their HIV status regardless of policies stipulating that "every child … regardless of whether he or she is infected or affected by HIV/AIDS, is entitled not only to an education, but also to care and protection just like any other child" (Government of Kenya, 2004, cited by Ruto et al., 2009, p. 132).

These experiences and others prompted me to question the role of the school in accepting, integrating and promoting the educational goals of HIV-positive children. I believe the insights gained from this study will help policy makers to facilitate the integration of CLWHA into public schools.

Definition of Terms

Definitions of key terms used in this study are provided below:

Human Immunodeficiency Virus (HIV): Human Immunodeficiency Virus (HIV) is a virus that attacks the immune system, which is the body's natural defense system. Both the virus and the infection it causes are referred to as HIV. The virus invades certain white blood cells called $CD4^+$ that are an important part of the immune system. If too many $CD4^+$ cells are destroyed, the body lacks the ability to defend itself against infections and to fighting off disease. As a result, the immune system deteriorates, and a variety of life-threatening complications begin to surface (www.MedicinceNet.com).

Acquired Immunodeficiency Syndrome (AIDS): means a condition characterised by a combination of signs and symptoms, resulting from depletion of the immune system caused by infection with the Human Immunodeficiency Virus (HIV) (The HIV/AIDS Prevention and Control Act, 2006, p. 1).

Seropositive status: Seropositive status describes particular antibodies that are present in the body. It means that someone who has these antibodies has been producing antibodies for HIV. These antibodies can be detected with an HIV antibody test, which is the most common type of HIV test in use today (www.ehowhealth).

AIDS Related stigma: HIV/AIDS stigma is a real or perceived negative response to a person or persons by individuals, communities or society. It is characterized by rejection, denial and discrediting, disregarding, underrating and social distance. It frequently leads to discrimination and violation of human rights (Agency for Cooperation and Research Development (ACORD, 2004), p. 122).

Discrimination: Refers to any form of arbitrary distinction, exclusion, or restriction affecting a person, usually but not only by virtue of an inherent personal characteristic or perceived belonging to a particular group-in the case of HIV and AIDS, a person's confirmed or suspected HIV-positive status-irrespective of whether or not there is any justification for these measures (UNAIDS, 2000, cited in UNAIDS, 2005, p. 9).

The stigmatized group: According to Alonzo and Reynolds (1995), "these are a category of people who are pejoratively regarded by the broader society, and who are devalued, shunned or otherwise lessened in their life chances and in access to the humanizing benefit of free and unfettered social intercourse. The stigmatized perceive

themselves to be members of a stigmatized group, whether it is obvious to those around them or not, often experience psychological distress and may view themselves contemptuously" (p. 304).

$CD4^+$ or T-Cells: White blood cells that orchestrate the immune response, signalling other cells in the immune system to perform their special functions. These cells are killed or disabled during HIV infection (Day & Walker, 2003, p. 1396).

Antiretroviral**:** Refers "to a drug that counters or acts against a retrovirus, usually understood to be HIV; FDA-approved antiretrovirals include reverse transcriptase inhibitors, nucleoside analogues and protease inhibitors" (www.thefreedictionary.com/antiretroviral).

Empowerment: It is the process of increasing personal, interpersonal, or political power so that an individual can take action to improve their situation (Gutierrez, 1990, p. 149).

Outline of the Study

This thesis contains six chapters. Chapter 1 provides an overview of AIDS stigma and discrimination, the rationale of the study, the background of Kivuli Children's Home and Karibu School, the significance, justification of the study and the research questions.

Chapter two comprises two sections. Section one presents the social stigma theoretical framework. This theory provide a lens through which CLWHA's experiences of AIDS stigma and discrimination in public schools affect social interaction and learning, individual perceptions and self-identity. Section two presents a comprehensive review of literature on HIV/AIDS, defines types of stigmas, manifestation of stigma in different contexts including educational institutions, functions of stigma, the effects of

HIV, stigma and discrimination on CLWHA and finally, a discussion focusing on the different interventions that are aimed at reducing HIV stigma and discrimination in Kenya.

Chapter three contains a description of the ethnographic methodology and methods relevant to this study. The rationale for using qualitative research methods (in-depth interviews, participant observation and document analysis) for data collection and the data analysis procedure are also discussed.

Chapter four provides participants' profiles and detailed accounts of their experiences of stigma and discrimination at Karibu School. Chapter five discusses the research findings. It describes the educational experiences of HIV-positive children, school resources and educational initiatives, CLWHA's support, empowerment of teachers and CLWHA's career aspirations. Chapter six contains the analysis and discussion of the research findings. In addition, recommendations for future research that address the educational needs of CLWHA and the limitation of the study are discussed.

CHAPTER TWO: THEORETICAL FRAMEWORK AND LITERATURE REVIEW

This chapter is divided into two sections. Section one discusses in depth the social stigma theory by Ervin Goffman (1963). Section two is a review of literature that is relevant to the understanding of AIDS stigma & discrimination experienced by people living with HIV/AIDS. In the first part of section two, I provide a global overview of HIV/AIDS, including Africa with a special focus on Kenya. I also discuss the various modes of HIV transmission and the prevention measures employed by the Kenyan government to combat the spread of HIV/AIDS, including, HIV education and HIV policy. The second part of section two discusses issues of significance to the understanding of the types of stigmas, the functions of stigma and discrimination, the effects and strategies PLWHA use to cope with these stigmas, and finally, the mitigation of stigma and discrimination.

Social Stigma Theory

The term stigma is derived from the Greek language, and refers to a bodily mark that was engraved on the skin of criminals, slaves, or traitors as a way of identifying them. Herek (1990) observed that "the mark signified social ostracism, disgrace, shame or condemnation" (p. 2). Hence, in the minds of the society, these persons were considered "polluted" and were avoided by the society (Goffman, 1963, p.1). Emile Durkheim first discussed the notion of stigma in 1895 (cited in Herek & Glunt, 1988), and demonstrated how society justifies the treatment it accords to those who engage in activities that society disapproved of:

> …faults, which appear venial to the layman, create the same scandal that the ordinary offense does in ordinary consciousnesses. If then, this society has the

> power to judge and punish, it will define these acts as criminal (or deviant) and will treat them as such (Herek & Glunt, 1988, p. 25).

Attempts to define the term stigma have been ongoing throughout history. However, in 1963, Erving Goffman developed one of the best theoretical definitions of stigma that many contemporary scholars still deem relevant. In his book *Stigma: Notes on the management of spoiled identity*, Goffman defined stigma as "an attribute that is deeply discrediting" (p.3). He argued that "persons who possess certain characteristics are considered socially undesirable and acquire a "spoiled" identity" (ibid). Discredited persons are considered different from others and are therefore perceived to be "bad, dangerous or weak". Consequently, they are "reduced in our minds from a whole and usual person to a tainted one" (ibid). In fact, any person possessing a stigma is considered "not quite human" [since] the person deviates from what is perceived as 'normal'" (Goffman, 1963, p.5). As Herek (1990) noted, the difference between social expectations and the reality is more apparent during social interactions when the individual's attribute fails to meet social normative expectations (p. 2). To illustrate the occurrence of this difference, he provided a couple of examples. He argued that "being black" may be a source of stigma in the company of whites only. Additionally, persons living with HIV/AIDS may feel stigmatized in the company of non-infected persons but feel more comfortable in a social network with others who share similar stigma (p. 2). These scenarios make the individuals to feel inferior and they may experience a sense of discrimination. Goffman (1963) referring to Riesman (1951) notes: "inferiority accounts for the danger he/she represents, sometimes rationalizing an animosity based on other differences, such as those of social class" (p. 5).

While stressing the role of discrepancy in relation to how one is perceived by others, Goffman (1963) warned that stigma as an attribute should be understood "as a language of relationships" that occur as persons interact with each other (p.3). He pointed to the fact that language plays a key role in day-to-day discourses during which stigma is defined and specific stigma ascribed to those perceived to bear the "attribute". As a follow up, stigma then "legitimatizes" the treatment we accord those bearing the mark of difference. As Goffman (1963) indicates, we treat them in "less humane ways than those without the mark" (p. 5).

Goffman (1963) argued that people who bear a stigma fall into two categories, that of discredited and discreditable attributes, which the stigmatized individual has to contend with. Being discredited implies that the stigmatized individual assumes his differentness is known or is evident, while discreditable is where the person assumes that his/her stigma is not immediately perceived by those around him (p. 4).

Goffman (1963) identified three different stigma types that define those possessing the "mark":

> First there are abominations of the body-the various physical deformities. Next there are the blemishes of individual character perceived as weak will, domineering or unnatural passions, treacherous and rigid beliefs, and dishonesty, these being inferred from a known record of, for example, mental disorder, imprisonment, addition, alcoholism, homosexuality, unemployment, suicide attempts, and radical political behavior. Finally there are the tribal stigma of race, nation, and religion, these being stigma that can be transmitted through lineages and equally contaminate all the members of a family (p.4).

Using these stigma types, Goffman (1963) made distinctions between the "normals", who did not bear the stigma and the stigmatized. Expounding on these stigma types, Campbell and Deacon (2006), added that, first, the "overt or external deformities" may refer to

chronic illness like leprosy, which was dreadful to the society and resulted in stigmatization. Second, stigma of known personal traits or deviations similar to those Goffman (1963) cited is associated to the already negatively stereotyped groups, such as individuals who engage in injecting drugs and homosexuality. Third, the tribal stigma illustrates national, religious, or race affiliations, Islam, being black, the castes of India. Following Campbell and Deacon (2006), stigma associated with HIV/AIDS can be said to add to other types of stigma in our contemporary world.

Gofffman (1963) pointed out that stigmatized persons share similar beliefs with the rest of society and perceive themselves as normal "human beings" (p. 7). However when they deviate from the normal expectations of the society and acquire a stigma, their expectations change because other people are not ready to make contact with them on "equal grounds" (p. 7). Consequently, feelings of shame due to blame by others are gradually internalized magnifying the reality of who he/she ought to be. Goffman (1963) emphasizes how "shame becomes a central possibility, arising from the individual's perception of one of his own attributes as being a defiling thing to possess, and one he can readily see himself as not possessing" (p.7). Some people however hold on to personal identity beliefs that are expected of them and in turn consider others as not normal or the ones with the problem (p. 6). Although this is outright denial of the reality, others confirm this reality by refusing to treat him/her with the respect deserved by normal persons, and instead accord him/her the treatment of a contaminated person, which the stigmatized embraces or denies (Goffman, 1963, pp. 8-9).

An important component of stigma theory is labeling and ascribing labels to those supposed to be different. Becker (1963), referred to the labeled as "outsiders" because of

their involvement in acts of deviance. He noted that labels could possibly mould the behavior of the individual especially when they conform to the label *(http://www.historylearningsite.co.uk/labelling_theory.htm).* Similarly, Falk (2001) acknowledged that labels could cast individuals with a common stigma into a group membership or category. To illustrate further, Goffman (1963) emphasized that when a stigmatized group meets "they may both modify their treatment of each other by virtue of believing that they each belong to the same 'group" (p. 23). Link and Phelan (2001) proposed four specific components of the labeling process:

> In the first component, people distinguish and label human differences. In the second, dominant cultural beliefs link labelled persons to undesirable characteristics—to negative stereotypes. In the third, labelled persons are placed in distinct categories so as to accomplish some degree of separation of "us" from "them." In the fourth, labelled persons experience status loss and discrimination that lead to unequal outcomes. Finally, stigmatization is entirely contingent on access to social, economic, and political power that allows the identification of differentness, the construction of stereotypes, the separation of labelled persons into distinct categories, and the full execution of disapproval, rejection, exclusion, and discrimination (p. 367).

The authors suggested that stigma applies "when elements of labelling, stereotyping, separation, status loss, and discrimination co-occur in a power situation that allows the components of stigma to unfold" (ibid). In summary, Goffman (1963) and Becker (1963) were cognizant that both stigma and labeling affected individual's or groups' behaviour, and especially their self-perception.

Goffman (1963) also illustrated that stigma affects individuals and once they assess the situation, they respond to it accordingly. He cited examples to show how stigmatized individuals endeavour to change their situation by attempting to correct the deformity, through various means (p. 9). Accompanying stigma were feelings of fear, insecurity, inferiority and anxiety, constantly being unsure of how the "normals" would

identify and treat the person, and whether they would reject or accept the person (p. 13). These uncertainties are explained by Goffman (1963), "thus in the stigmatized arises the sense of not knowing what the others present are 'really' thinking about him" (p. 14). Consequently, the individual might expect to be discriminated against, which may affect his/her behavior, resulting in social withdrawal and other subsequent disadvantages (Mills, 2004, cited in Deacon, 2006, p. 421).

USAID (2006) stated that stigma is not unique to HIV/AIDS since throughout history stigma has been experienced in "relation to other diseases, including tuberculosis, syphilis, and leprosy, which are associated with the transgressions of social norms" (p. 2). The social stigma concept has been explored in various fields, for example, stigma has been associated with mental disorders and physical conditions such as physical disability, visual blindness, deafness and obesity (Yanos et al., 2001). Lazare (2000) pointed out that cancer patients experienced shame and humiliation due to their illness and related treatment(s). Additionally, Cheng et al (2011) found that family members of elderly people diagnosed with Alzheimer's disease experienced similar feelings of shame, some refusing to call it Alzheimer's but referring to the disease as forgetfulness or dementia (Cheng et al., 2011). Asserting similar observations, Charmez (1991) pointed to the fact that chronically ill persons are socially ostracized or ignored because of the disease.

Questions have been raised as to why certain chronic conditions are not subjected to the same stigma as HIV/AIDS. Jones et al (1984) correlated Goffman's two types of stigma namely: discredited and discreditable by developing six dimensions of stigma that explains why some individuals face stigmatization, and in particular those with conditions such as HIV/AIDS that are:

- Concealable - extent to which others can see the stigma.
- Course of the mark - whether the stigma becomes more prominent over time.
- Disruptiveness - the degree to which the stigma gets in the way of social interactions.
- Aesthetics - other's reactions to the stigma.
- Origin - whether others think the stigma is present at birth, accidental, or deliberate.
- Peril - the apparent danger of the stigma to others. (Jones et al., 1984).

Herek and Glunt (1988, cited in USAID, 2001) acknowledged that "the stigma attached to HIV/AIDS as illness is layered upon pre-existing stigma" (p. 2), for example, social behaviours that contravene social norms, including 'promiscuous' people, [such as] gay men, commercial sex workers and women, in general" (Deacon, 2006, p. 421). In an attempt to apply the six dimensions to HIV/AIDS, Jones et al (1984) summarized the six dimensions to four characteristics to explain why stigma is highly stigmatized:

- Stigma is often attached to a disease whose cause is perceived to be the bearer's responsibility.
- The disease is associated with the risk of death.
- Perceptions of danger and fear of contagion have surrounded AIDS since the beginning.
- The disease is concealable to others (it disrupts or hinders social interactions).

These perceptions demonstrated by Jones et al (1984) resonate with the society's justification in using stigma and discrimination of certain individuals with similar characteristics such as those living with HIV/AIDS.

The modern derivation of AIDS stigma and discrimination used in this study was developed by the Agency for Cooperation and Research Development (ACORD, 2004). It defined stigma and discrimination as follows:

> HIV/AIDS stigma is a real or perceived negative response to a person or persons by individuals, communities or society. It is characterized by rejection, denial and discrediting, disregarding, underrating and social distance. It frequently leads to discrimination and violation of human rights (p. 122).

Numerous researchers have used the social stigma lens in understanding the experiences of stigma and discrimination of PLWHA across various populations worldwide. Attitudes towards PLWHA and the impact on their psychological well-being have been explored by a number of scholars including Irungu et al (2008); González-Rivera & Bauermeister (2007); Varas-Diaz et al (2005); African Caribbean Council on HIV/AIDS in Ontario (ACCHO, 2006) and Castle (2004). Mlobeli (2007), for example, employed the social stigma theory to investigate the perspectives and experiences of PLWHA in South Africa, while Zhou (2008) focused on the experiences of stigma and discrimination on women PLWHA from China. The findings from a wide range of literature have confirmed that the majority of PLWHA experience various forms of stigma and discrimination in a variety of contexts including educational institutions. The findings from the literature further confirm that the belief that HIV/AIDS is contracted through immoral behaviour is often a factor that the majority of people use to treat PLWHA differently. In addition, misconceptions about HIV routes of transmission reinforce these misconceptions. The use of the social stigma concept with children or adolescents has focused mainly on attitudes towards peers or the general PLWHA population and solicit information about HIV/AIDS knowledge.

ACORD (2004) highlights that sources of stigma and discrimination underlie illness and the perception that HIV/AIDS is a fatal disease. As such the majority of people in the society believe that once an individual is diagnosed and is living with HIV, death is imminent. Consequently, HIV/AIDS is equated to dying and therefore remains a strong reminder of death and mortality for many PLWHA (Stoddard, 1994).

This study involves CLWHA learning in a public school. Most Kenyans living in Nairobi have a general knowledge about Kivuli Children's Home and associate it with HIV/AIDS. Owing to the CLWHA serostatus, they conform to the characteristics described by Jones et al (1984). The fact that these children are HIV-positive, the society perceives them as "tainted" and therefore possess a "spoiled" identity (Goffman, 1963). On this basis using the social stigma lens could shed light on peers and teacher perceptions of CLWHA. Assuming that their condition is known, peers may consider them as "discredited" and therefore blame them for bringing a dangerous disease to the school. In short, they may be considered a disgrace to the school and in this case viewed as a "bad apple", which could raise fears of contagion among peers, and subsequently result in isolation. This knowledge may cause different forms of stigma and discrimination to occur particularly during interactions, while playing or learning, or when participating in extra-curricular activities such as games. During these times physical marks (skin rashes) resulting from the disease may be exposed to peers, triggering isolation or rejection and animosity. Similarly, teachers' and peers' perception of the disease may not differ from the common social beliefs held by the society. It is possible that teachers could use these beliefs to legitimately treat CLWHA in a manner that would stigmatize them. Consequently, this kind of treatment may have a direct impact on CLWHA's psychological well-being and educational focus. The theory will also unravel the realities of CLWHA's experiences as they gradually become integrated into the public school system. Link and Phelan (2001, cited in Deacon, 2006) argue that stigma is a process, where "elements of labelling, stereotyping and, separation, status loss and discrimination co-occur in a power situation that allow them to unfold" (p. 420).

Considering that stigmatizers perceive themselves in control and place the stigmatized in a subjective position, this theoretical concept will facilitate our understanding of how these negative experiences could threaten CLWHA's interpersonal relationships with peers and their academic pursuit.

Staggs (2007) has attested to the fact that the mark of an illness does not need to be physically visible for someone to be stigmatized and can occur to people with other health conditions; in particular PLWHA may look completely healthy, but still be stigmatized. CLWHA in this study have been on antiretroviral drugs for several years; therefore, it might be difficult to detect their HIV status since they may physically appear healthy. Using the social stigma lens, factors other than physical appearance that might increase the likelihood of stigmatization for CLWHA in public schools will be explored.

In Kenya, PLWHA are prescribed labels according to their physical appearance. Some reference labels that are commonly used include "Mukingo" signifying "long neck" and "skinny" meaning extremely slim. While labels are intended to distinguish the stigmatized from the "normal", they also justify the marginalization of the stigmatized (Goffman, 1963, p. 6). Falk's (2001) work is explicit about categorization of those perceived to be different. They are considered 'outsiders', a label that amplifies the difference. This difference is characterized by positive or negative emotions, for example hate for the other (Falk, 2001). Children living with HIV/AIDS in this study attend school as a group. It is worth investigating whether the school community has ascribed labels to CLWHA, and assess the impact this has on them.

The theory is cognizant that social interactions provide avenues for social categorization and labelling where CLWHA fit into the category of a "stigmatized group"

or are labelled as a distinct group in the school. Through the process of labelling, CLWHA may become aware of others' judgment of them, recognizing both positive and negative labels. Likewise, they may gradually understand the rewards and consequences of these labels. Receiving an undesirable label affirms what others think about them According to Link and Phelan (2001), expectations of devaluation become personally relevant once official labeling occurs during contact with treatment. Subsequently, labeled individuals tend to conform to the essential meaning of that judgment, because once the label is fixed, the individual automatically assumes the label relevant to HIV and the person remains stigmatized (Goffman, 1963). It is therefore worth investigating what specific labels are used to refer to CLWHA and the extent to which they conform to these labels.

Literature Review

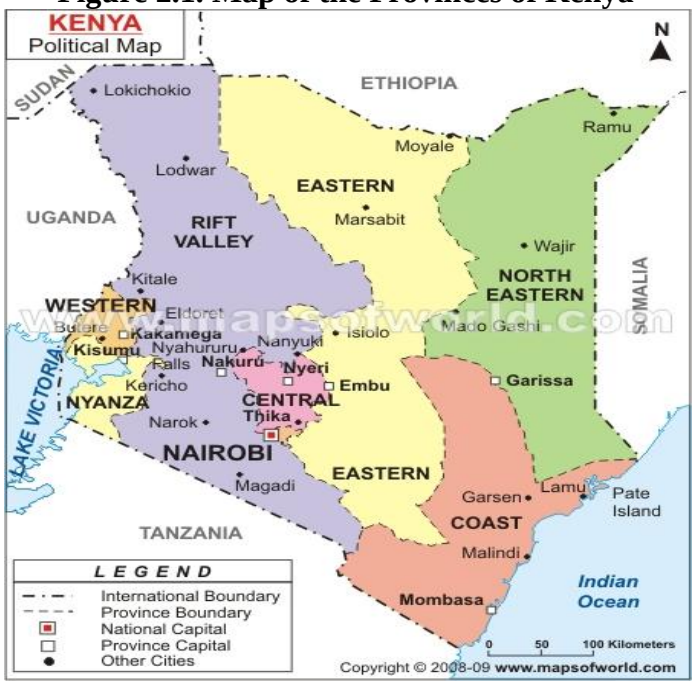
In this section of the chapter, I provide an overview of Kenya and discuss the literature that is relevant to the HIV/AIDS pandemic as well as issues pertaining to stigma and discrimination.

Overview of Kenya.

Kenya, a former British colony, became an independent republic in December 1963. It has a land area of 580,000 square kilometres. The population of 38 million comprises 42 different ethnic communities and cultures, including the Bantus, the Nilotes and the Hamitic groups (Kenya Bureau of Statistics (KBS), 2010). Named after Mount Kenya, which is the second highest of Africa's mountain peaks, it is located in East Africa, on the equatorial latitude, with the Indian Ocean to its south-east. Uganda is to the

west, Tanzania to the south, Ethiopia to the north, South Sudan to the north-west, and Somalia is to the north-east (Country Profile: Kenya, 2007, p.7).

Figure 2.1. Map of the Provinces of Kenya



(http://www.mapsofworld.com/kenya/kenya-political-map.html)

Kenya is one of the most important countries in Africa politically and financially. Compared to neighbouring countries, it has been relatively peaceful. A democratic country, Kenya had previously been comprised of eight provinces that were each headed by a Provincial Commissioner, who was appointed by the President. It is now divided into 47 counties. Each county has its own semi-autonomous government headed by an elected governor (http://kenyayetu.comxa.com/devolved-government.html). Agriculture is the largest contributor to Kenya's GDP. Kenyan coffee and tea are enjoyed world-wide and recently, the country began exporting fresh flowers to Europe. Kenya is a leading exporter of fresh produce such as cabbages, onions and mangoes. Tourism is also an

important industry – the country's world-famous wildlife reserves attract visitors from all over the world (Country Profile: Kenya, 2007, pp. 9-14).

The capital city is Nairobi. It is the most populous city in East Africa, and has an estimate of about 3 million (Kenya Bureau of Statistics (KBS), Census, 2010). Urban migration to Nairobi from other areas of the country continues to add to the city's growth. As the 12th largest city in Africa, Nairobi has the largest economy by GDP in East and Central Africa. The Nairobi Stock Exchange (NSE) is Africa's fourth largest stock exchange with respect to trading volumes, and fifth in terms of market capitalization as a percentage of GDP (http//www.NSE Millenniumit.com, 2006). The Globalization and World Cities Study Group and Network has identified Nairobi as a major social centre (Bauk, 2007)

Although the country has made outstanding socio-economic progress, it still faces enormous challenges related to high rates of unemployment, high levels of poverty, a large population living with HIV/AIDS and high rates of maternal mortality. As a regional business center, Nairobi is home to some of the largest businesses in Kenya. The United Nations Environment Programme (UNEP), which is also the headquarters for the UN in Africa and the Middle East, is one of over 100 major companies and organizations that have offices in the city Bauk, 2007).

Global overview of HIV/AIDS pandemic.

The first case of HIV/AIDS was identified in the United States of America in 1981. In 1982, the disease was named Gay Related Immune Deficiency (GRID) because it was thought to be contracted almost exclusively by gay men. With new cases being diagnosed among female and male heterosexuals, intravenous drug users, and

haemophiliacs however, it became understood that the syndrome was caused by an infectious agent, and was possibly spread through exchange of body fluids. GRID was then renamed Acquired Immune Deficiency Syndrome (AIDS) (http://www.avert.org/aids-history-america.htm). In sub-Saharan Africa, Latin America, and the Caribbean, heterosexual intercourse, blood transfusions and prenatal transmission became known factors in HIV transmission. In Eastern Europe, the Middle East, North Africa, Asia and the Pacific, it became prevalent mostly among those engaged in high risk behaviours (WHO/UNAIDS, 2010). An estimated 33.4 million people, including 15.5 million women and 2 million children under 15 years of age are presently living with HIV/AIDS globally (UNAIDS, 2010).

HIV/AIDS in Africa.

The first case of HIV in sub-Saharan Africa was reported in the 1980s (http://www.aidsandafrica.com) and was mainly spread through social mobility, sexual activities, the use of intravenous drugs and blood products (http://www.avert.org/hiv-aids-africa.htm). Sub-Saharan Africa has 10% of the world's population, but over 70% of the world's AIDS cases – an estimated 22.5 million cases are found in the continent. Additionally, approximately 40% of the women living with the disease world-wide reside in sub-Saharan Africa. In 2009 alone, an estimated total of 1.8 million adults and about 370,000 children became infected. Most of the infected children had acquired the virus during their infected mother's pregnancy, labour or delivery, or through breast milk (UNAIDS, 2010). An estimated 1.3 million people have died from AIDS-related illnesses in sub-Saharan Africa. The prevalence of HIV among adults varies across the African continent with rates as low as 0.2% in Madagascar and as high as almost 26% in

Swaziland (http://www.aidsandafrica.com). About half of those with HIV became infected before age 25, thus, HIV is considered the most common cause of death among 20-24 year olds (http://www.aidsandafrica.com).

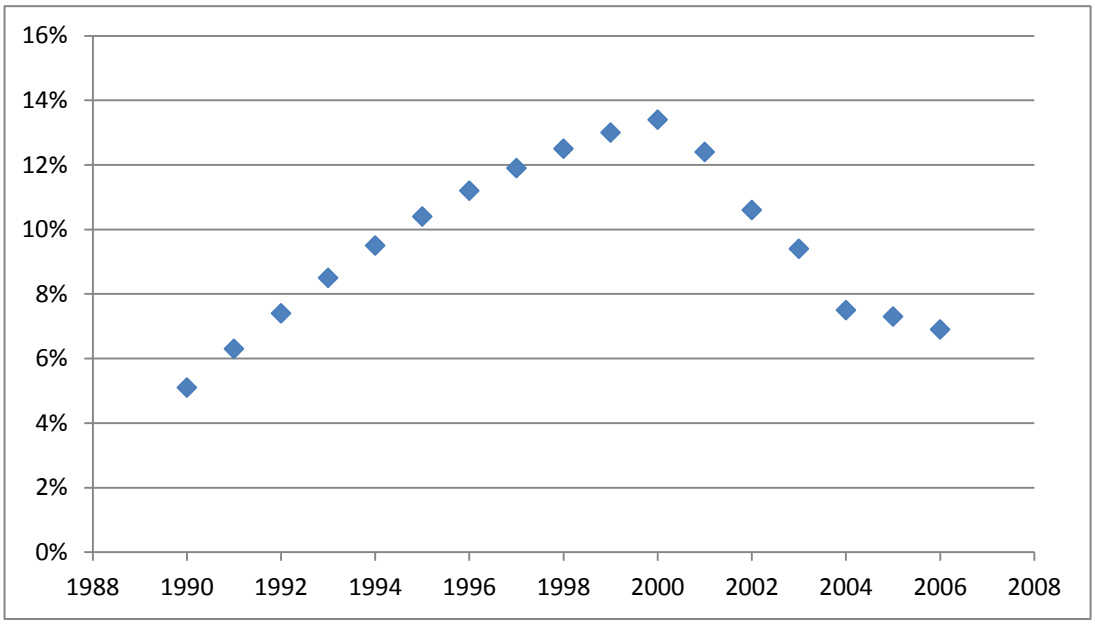
Since the first case of the epidemic was first diagnosed in sub-Saharan Africa, 15 million children have lost a parent or both parents to the deadly virus. Of these 11.4 million are from sub-Saharan Africa (UNAIDS, 2010). The HIV epidemic in sub-Saharan Africa appears to be stabilizing due to the use of antiretroviral treatment, education and awareness programs, along with the availability of counselling and testing services. The pandemic continues to be a great threat to many communities in spite of these efforts (UNAIDS, 2004), hence the need to implement further interventions.

HIV/AIDS in Kenya.

An estimated 1.42 million people are living with HIV/AIDS in Kenya, including 110,000 children (8%), 570,000 men (40%) and 740,000 women (52%) (KAIS, 2009). The first cases of HIV were reported in 1984 among 26 sex workers in Nairobi. By 1985 the prevalence among sex workers had increased to 59%, indicating that AIDS was also spread through heterosexual practices (http://www.avert.org/hiv-aids-kenya.htm). At the end of 1986, an average of four new AIDS cases each month were being reported to the World Health Organizations. In 1987, 286 cases were reported, of which 38 proved fatal. By the end of that same year, an estimated 1-2% of adults in Nairobi were reported to be infected with HIV. Between 1989 and 1991, HIV prevalence among pregnant women in Nairobi had increased from 6.5 % to 13 % and by 1994 about 100,000 people had already died from AIDS-related illnesses and about one in ten adults were infected with HIV (KAIS, 2009). HIV prevalence continued to increase from 5.3% in 1990, to its highest

peak at 13.4% in 2000 before it began to decline and stabilize. In 2006, HIV prevalence decreased to 6.9% and by the end of 2009, prevalence had declined to 6.3 % (http://www.avert.org/hiv-aids-kenya.htm). Decline in HIV in infection rates resulted from education awareness and preventative interventions that started in 2000, and behaviour changes due to the increased use of condoms. The decline was also attributed to the deaths from AIDS, which totalled 150,000 in 2003 (Cheluget et al., 2006, p. 4). Figure 2.2 illustrates HIV prevalence trends in Kenya between 1990-2006.

Figure 2.2. Estimated National HIV Prevalence in Kenya: 1990-2006



Source: KAIS (2009)

HIV rates were higher among some groups and differed by location, gender and age. For example, HIV prevalence was at 8.7% nationally for women between 25-29 years and 4.6% for men. Rates for young females aged 15-24 years were four times higher at 5.6% than they were males of the same age group. Their infection rate was

1.4%. Violent sexual contact was found to be a contributing factor to the high prevalence of HIV among Kenyan women (KAIS, 2009, p. 3).

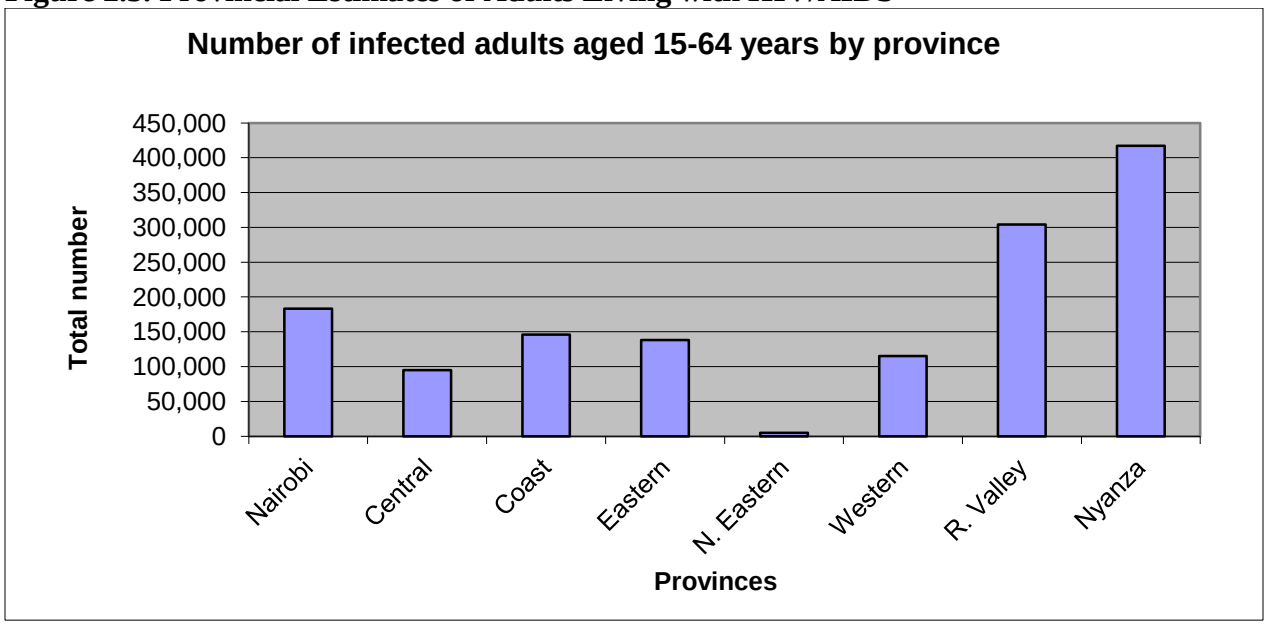
The Kenya National AIDS/STD Control Program (NASCOP, 2005) found that 10% of all pregnant women in Kenya were HIV positive. The risk of HIV transmission from mother to child during pregnancy, birth and breastfeeding was rated between 20-40%. Colton (2005, p. 2) observed that as a result of this trend, between 50,000 to 60,000 infants in Kenya became infected with HIV each year. The large number of women, girls and children infected with HIV/AIDS and the 1.1 million children orphaned in 2005 have proven to be major challenges for Kenya. Extra costs associated with orphanages, medical care, drugs and funerals have caused an economic strain on the country (NASCOP, 2008).

A report by KAIS (2009) indicated that HIV/AIDS was major cause of death of children. About 15% of all children's deaths in Kenya were attributed to the disease. The study also revealed a 3.8% infection rate among 15-24 year olds. Although those aged 50-64 years were considered to have low risk for HIV, their rate of infection was at 5.0%. Uncircumcised men aged 15-64 years had infection rates three times greater than that of circumcised men (13.2% vs. 3.9%). HIV prevalence among adults aged 15-64 years in urban areas was measured at 8.4%, while in rural settings the prevalence rate was 6.7% (p. 32).

There are significant differences in HIV infection rates across Kenya's eight provinces. According to the KAIS sentinel surveillance report 2009, infection rates were as low as 0.81% in the North Eastern province, while the Nyanza province experienced rates at 14.9%. While provinces may have experienced epidemics at different times, the

report showed that Nyanza province had the highest number of HIV cases totalling to 417,000. The Rift Valley had 304, 000, Nairobi had 183,000, the Coast had 146,000, the Eastern province had 138,000, the Western province had 115,000 and the North Eastern province with the lowest number of cases recorded, had 5,000 (pp.37-38). Figure 2.3 shows the estimated number of persons infected with HIV/AIDS in the eight provinces of Kenya.

Figure 2.3. Provincial Estimates of Adults Living with HIV/AIDS



Source: KAIS (2009)

HIV/AIDS pandemic in Nairobi Province.

The most recent figures show that an estimated 183,000 (12%) of the urban population living with HIV/AIDS resides in Nairobi Province. Although it ranks third in population among the Kenya's eight provinces, it has the highest HIV prevalence rate of 8% among the urban centres (KAIS, 2009, p.37). The Kibera slum, adjacent to Nairobi City, has an estimated population of 700,000. It is thought to be Africa's second largest

slum, and has been expanding due to rural-urban migration (Kenya Bureau of Statistics, 2010). With a high level of unemployment, most residents of the Kibera slum live in extreme poverty, and earn less than $1.00 per day. Cases of assault and rape are common and health care services are inadequate, thus creating a fertile ground for HIV and AIDS. There has been a noted increase in HIV transmission from mother to child. As a result, the incidence of HIV in the slums is higher compared to the rest of Nairobi province (Madise et al., 2008, p. 4). A large number of children from Kibera slum and the surrounding areas attend Karibu School. Due to HIV/AIDS, there is an increase in the number of orphaned and mostly abandoned children, who often end up in orphanages.

The number of infected and affected orphans in Nairobi has been growing as a result of children losing one or both parents to HIV/AIDS. Because of the fear of stigmatization from the community, and because insufficient resources prevent relatives from being able to support additional children, Nairobi province now has a large number of orphanages, including Kivuli Children's Home, that provide care and education to HIV-positive orphans (Togom, 2009, p. 20).

Modes of HIV transmission.

Blood transfusion.

In the early 1980s, when AIDS cases were first being discovered and reported, the cause of the condition was unknown. It was not understood at the time that HIV could be transmitted via the blood of an infected individual (http://www.avert.org/hiv-aids-kenya.htm). As Mati (1997) pointed out, young adults have the highest prevalence of HIV infection, and they are the age-group most likely to donate blood. Additionally, due to malnutrition and other endemic diseases, the need for blood transfusions is

considerably higher in Africa than other continents, and by the time that a screening test was developed, and contaminated blood from donated stockpiles were isolated, thousands of people who had received blood for health care reasons had already been infected. Because no treatment existed at the time, many of these people rapidly became ill with HIV. Today, donated blood is effectively screened in almost every country in the world. Consequently, the number of people developing AIDS as a result of receiving infected blood has declined dramatically (UNAIDS/WHO/UNICEF, 2011)

Sexual transfer between partners.

In most of Africa and the Caribbean, a large percentage of HIV infection occurs through sexual transmission (UNAIDS, 2010). Studies link sexual transmissions particularly in Africa with lower socioeconomic status, sexual activity without the use of any protective measure, lack of circumcision, inadequate education and preventive programs (Denis & Becker, 2006, p. 45). Global statistics indicate that sexually active young adults who often engage in sex without barrier protection have the highest rates of infection (ibid). Although this may be partly due to the lack of funds to purchase condoms, to a greater extent, cultural practices play a significant role (Rodriguez & Hayes, 2001, p. 9).

Mother-to-child transmission (MTCT).

After the first cases of HIV were reported among homosexual populations in the United States, similar cases began to emerge in newborns who quickly developed infections, became sick and died (http://www.avert.org/aids-history-america.htm). Colton (2005) also noted a drug use link and concluded that sex partners transmitted the virus to drug partners who then transmitted the virus to other sex or drug partners. Women who

became infected through their sex or drug partners were having babies, and one in four of these babies also became infected (p. 2). The WHO/UNAIDS (2004) report estimated that 630,000 children world-wide were infected with HIV in 2003, most likely through mother-to-child-transmission (MTCT).

MTCT rates are higher in developing countries than in the developed countries, illustrating growing inequalities in global health. This has been attributed to the availability of anti-retroviral therapy (ARV) and other medical facilities and services, resulting in MTCT rates in developed countries being less than 2% (Colton, 2005, p.3, UNAIDS, 2004). In contrast to this, in sub-Saharan Africa for example, many births are conducted outside health care facilities, with traditional birth attendants and other non-professionals assisting in deliveries. In this process, birth attendants use sharp unsterilized objects to cut the umbilical cord and their bare hands to handle the placenta, thus exposing them to blood. If the mother or birth attendant is seropositive, viral transmission could occur to either of them (De Bruyn, 1992; Egwuatu, 1986).

In poorer countries like Kenya, the majority of those infected include young women, 15- 49 years old. A survey conducted by the Kenya National AIDS/STD Control Program (NASCOP, 2008) indicated that about 10% of pregnant women in Kenya were HIV positive; hence, there was a 30-40% chance that in the absence of proper health care services, an HIV-positive breastfeeding mother would pass the virus to her child. As Colton (2005) observed, about 50,000 to 60,000 infants become infected with HIV each year in Kenya as a result of MTCT. These statistics explain why the number of babies being born with HIV was exceedingly high (p. 3).

Other methods of HIV transmission.

Apart from mother-to-child transmission, a recent study established that horizontal acquired HIV infections do occur among children due to puncture from suspected malaria, injections and dental surgery (Kilewo et al., 2009, p.854). A few cases of children having contracted HIV through sex have also been reported (WHO/UNAIDS, 2004). Consequently, to lower transmission rates, it is critical that as many women as possible receive mother-child health (MSC) services and are instructed in prevention approaches and procedures. Ritual operations using contaminated equipment have not been evaluated, but it may be possible that contaminated blood could readily transmit the virus from one person to another during both male and female genital mutilation (Brady, 1999, cited by Kinuthia, 2010, p. 2).

Combating HIV/AIDS in Kenya.

UNAIDS (2006) has emphasized that AIDS related stigma and discrimination need to be by everyone in a position of leadership in the society since HIV infection has been spreading at an alarming rate and remains "the world's greatest threat to health and communities, as it has killed millions of people of all ages and ethnicities" (Kalichman, 2003, cited in Mlobeli, 2007, p. 10). Particularly in developed countries, governments have undertaken medical research to find a cure for HIV, and have formulated policies to protect individuals from social stigma and discrimination. These initiatives resulted in two important breakthroughs in HIV treatment and related infections. The first breakthrough, documented in 1994, was the discovery of the antiretroviral drug (ARV) that could reduce the rate of mother-to-child infection from 25% to 8%. It was also discovered that by using combinations of ART to reduce the amount of HIV (viral load)

in the mother's system during pregnancy and childbirth, that HIV transmission rates could be reduced considerably. Effective treatments for infected newborn babies were also developed, resulting in a much better survival rate among them. In order for treatment to be effective, mothers receive counselling (Colton, 2005, p. 8).

The second breakthrough was the introduction of the Highly Active Antiretroviral Therapy (HAART) in 1996-7, which is a treatment that delays the onset of AIDS (Krauss et al., 2006). While some countries, including Uganda, vigorously designed approaches to address HIV/AIDS and related stigma through collaborative efforts with government and non-governmental organizations, Kenya's response to the crisis was incredibly slow because the government was concerned that the pandemic could discourage tourists from visiting the country. At the same time however, the government was also slow to promote preventative measures, such as the use of condoms, as a way to reduce the incidence of infections (http://www.avert.org/hiv-aids-kenya.htm). As a result, HIV infection rates were escalating and its impact was being felt in many productive sectors of the economy. After finally becoming cognizant of the impact of HIV/AIDS on Kenyan society, the government prepared an HIV/AIDS policy, initiated HIV/AIDS education and awareness programs, and embarked on using HIV sentinel surveillances in order to monitor the spread of the HIV virus. It was not until the end of 1990 however that the Ministry of Health through the Nations AIDS and the STI Control Program (NASCOP) established the HIV/STI surveillance system (Ministry of Health (MOH), 2003).

In 1997, a multi-sectoral approach to control the epidemic was initiated by the Kenya National AIDS Control Council (NACC). This was followed by the release of the first policy paper on AIDS entitled "Seasonal Paper No. 4" (MOH, 2005). In 1999,

Daniel Arap Moi, then president of Kenya, declared HIV/AIDS a national disaster saying:

> AIDS is not just a serious threat to our social and economic development, it is a real threat to our very existence…AIDS has reduced many families to the status of beggars… no family in Kenya remains untouched by the suffering and death caused by AIDS. AIDS related illnesses are the highest cause of mortality within the country and it is estimated that 700 Kenyans die daily from the disease. The real solution to the spread of AIDS lies with each and every one of us (NACC, 2002, p. 8).

That same year, President Moi encouraged the use condoms citing AIDS as a huge threat to the Kenyan population (MOH, 2003). Thereafter, the National Condom Policy and Strategy (NACC, 2005) promoted the education of Kenyans on prevention techniques and on making condoms widely available and affordable throughout the country. In 2003, in an effort to continue fighting the pandemic, President Kibaki appointed a committee to deal with HIV-related issues. In December, 2006, the rights based law, Kenya's HIV/AIDS Prevention and Control Act, was passed by Parliament making it a crime for an HIV-positive person to intentionally transmit the disease to someone else (www.healthpolicyinitiative.com). In the same year antiretroviral drugs became available in all public health centres allowing PLWHA to access them free of cost (http://www.avert.org/hiv-aids-kenya.htm). In 2005/6-2009/10, the Kenyan National HIV and AIDS Strategic Plan was established with the aim of reducing the number of HIV infections (NACC, 2005/6-2009/10).

The Kenyan government embarked on nationwide educational awareness programs, to various age groups in order to address HIV/AIDS and related stigma (NACC, 2005/6-2009/2010). In addition, 10 million condoms were distributed in 2004 and 124.5 million were distributed in 2008 (www. Avert.org). Although the government

promoted the use of condoms to reduce the spread of the virus, this move was opposed by some religious leaders, thereby sending conflicting messages about condoms to the public. Opposition from leaders prevented people from accessing or from wanting to use them (IRIN, 2008). Starting in the year 2000, Voluntary Counselling and Testing centres (VCT) were established and expanded throughout the country with a target of testing 2 million Kenyans for HIV by the year 2010. To achieve this goal, a door-to-door program for HIV testing and counselling services for people living in remote areas with little access to health care was launched in 2009. Additionally, the Prevention of Mother-to-Child Transmission (PMTCT) services were expanded in over 3,397 health care facilities country-wide (www.avert.org/hiv-aids-kenya.htm).

Surveillance of tracking the infection levels of pregnant women has been ongoing since 1992 and surveillance on HIV and STDs that had begun in 1991 was expanded to 2003 in both urban and sub-urban areas (UNGASS, 2010). In spite of the availability of the treatment, 22,259 new child infections through mother-to-child transmissions were recorded. This was partly a result of PMTCT services only being available to 50% of pregnant women in Kenya, leaving 81,000 women without access to the drugs (UNGASS, 2010).

HIV/AIDS education in Kenya.

Kenya ranks 9th among the countries worst affected by the HIV pandemic. (http://www.rnjournal.com/hiv_crisis_in_africa.htm). Owing to the fact that HIV has largely affected young people between ages 15-24 years old, on whom the future of Kenya depends, it is imperative for the country to establish mechanisms of addressing the pandemic, and most importantly to focus specifically on this vulnerable cohort. While

several intervention measures have been designed and are being implemented, the Kenyan government has realized that it is only through education that young people can be reached effectively, because in the long run it will provide them with adequate knowledge and skills that will allow them to confront the HIV pandemic sufficiently. Researchers Vandemoortele and Delamonica (2002) are in full agreement with this and observed that "the changing social profile of the AIDS pandemic makes a compelling case for using education as one of the most powerful tools for slowing and reversing the spread of HIV" (p. 11). Similar sentiments were expressed by Mannah (2002), who stated that:

> Education is one of our most powerful weapons against HIV/AIDS, it is also a sector that is human resource intensive and therefore most vulnerable to the disease. As the AIDS pandemic ravages, it becomes imperative for countries to rethink education and education systems in order to curb the onslaught of the disease (p. 157).

Kelly (2000a, cited in Mannah, 2002) further suggested that:

> Education in a world of AIDS must be different from education in an AIDS free world. The content, process, methodology, role and organization of school education in a world with HIV/AIDS must be radically altered. The entire educational edifice must be dismantled (p. 157).

The adaptation of education as a response to the HIV/AIDS pandemic has been embraced across the globe with many countries borrowing the concept proposed in the article by Vandemoortele and Delamonica (2002) namely, "Education Vaccine Against HIV". Additionally, Duflo et al (2007) stated that "children between the ages 5 and 14 have been referred to as a 'window of hope'" (p. 2) because of their low infection rates and little or no sexual behaviour, and thus signify the urgency of addressing the pandemic from the early years of a child's life.

As a follow up of the guidelines provided by these scholars, many countries have designed appropriate education programs that are currently being implemented in both primary and secondary schools. This is consistent with Kelly (2000; Bundy, 2002 cited in Duflo et al. 2007). The authors argued that "the majority of children in Africa attend at least some primary school, and schools offer an opportunity to reach these children" (p.2). Although debates on HIV/AIDS education programs have been on-going, it is not yet clear how effective they are in reducing the spread of HIV/AIDS particularly among the young people (ibid).

The magnitude of the HIV pandemic was realized in Kenya in 1999 and confirmed in a Kenyan report on the impact of HIV/AIDS in 2000, which stated: "AIDS will also affect the process and content of education in Kenya. The seriousness of HIV/AIDS means that it needs to be integrated into curriculum for students throughout the country" (Republic of Kenya, 2000, p. 18). In 1999, the HIV/AIDS education curriculum designed by the Ministry of Education was introduced in all primary and secondary schools in 2000 (Njue, et al., 2009, p. 169). The aim of the curriculum was to equip learners with knowledge and skills that would enable them to address issues pertaining to HIV/AIDS and STI infections (Njue et al, 2009, p. 170). It was also intended to encourage learners to adapt preventive practices such as abstinence (p. 170). Duflo et al (2007) pointed to the fact that the curriculum focused on "HIV transmission, prevention, and care for people living with HIV/AIDS" (p. 6). In primary schools, HIV/AIDS topics were incorporated into the existing subjects, while in high schools they were included in the biology course (p. 170). Books on HIV/AIDS to guide teachers on the teaching of HIV/AIDS education were provided to all the schools countrywide by the

Ministry of Education. Factors causing problems in the implementation of the curriculum were mainly related to inadequate knowledge about HIV/AIDS, particularly among women and men aged 15-54 years (ROK, 2000, p. 19).

Although the implementation of HIV/AIDS education curriculum in Kenya was successful, questions exist about its impact on learners' knowledge. An evaluative study by Njue et al (2009) involving 21 primary and 9 secondary schools, revealed numerous shortcomings suggesting the need to review the curriculum in order to meet its objectives (p. 170). A summary of the study showed that HIV/AIDS lessons were not a priority in most schools since there was no specific time allocated to the topic unlike for examinable subjects, and as a result, teachers were not motivated to spend much time teaching about HIV/AIDS. Teachers lacked sufficient pedagogical approaches to address the subject because of its sensitive nature, which compelled them to omit some topics from the curriculum, thus affecting its delivery and impact (Njue et al., 2009, p. 172). Similarly, Duflo et al (2007) noted that teachers found it challenging to debate issues touching on the use of condoms since they had no training on how to address the topic (p. 6).

All these factors confirm that although the curriculum is important in transmitting the necessary information to the young in Kenyan schools, its intended impact is limited because little attention is being accorded to the subject (Njue et al., 2009). An important factor was the increased workload for teachers in primary schools after the introduction of free primary education in 2003 that saw school enrolment grow from 5.9 million in 2002 to 7.2 million in 2003 (Kenya, Ministry of Education, 2004, cited in Njue et al., 2009, p. 172).

The curriculum was designed before many CLWHA survived long enough to join public schools; therefore, the extent to which teachers feel comfortable teaching about

HIV/AIDS in a class with CLWHA, might explain why some omit the subject altogether. Additionally, HIV curriculum focus on AIDS stigma and discrimination is limited, yet such information is critical for reducing stigma and discrimination and to foster acceptance of CLWHA in Kenyan schools.

Issues of stigma and discrimination affecting people living with HIV/AIDS.

This section is a review of empirical literature that is relevant to this study. This literature explores the discourse of stigma and discrimination, types of stigma, functions of stigma, manifestation of stigma and discrimination in educational institutions, effects of stigma, the strategies PLWHA employ to cope with stigma and discrimination and finally, a discussion on the efforts to reduce AIDS stigma and discrimination.

Stigma and discrimination discourse.

Nyblade and Carr (2011) defined stigma as "prejudice, discounting, discrediting and discrimination", and "a daily reality for people living with HIV/AIDS and their families" (p.1). They state that as a global phenomenon, "HIV stigma is prevalent in all facets of life since it occurs within families, communities, institutions such as health care facilities, places of employment, in the social media, and in government policies" (Ogden & Nyblade, 2005, cited in Nyblade & Carr, 2011, p. 2). Discrimination however has been understood as the end result of the process of stigma, which includes negative acts being directed to those whom society deems deserving of stigmatization. Nyblade and Carr (2011) argued that as a result of stigma and discrimination, many "PLWHA are subjected to job loss, school expulsion, ostracism, violence, lack of care and support, and loss of property" (p. 2). The relationship between stigma and discrimination is well

explained by Nelkin and Gilman (1988), who emphasized that stigma and discrimination often follow the existing realities of social marginalization or social exclusion:

> Categories of blame often reflect deep social-class biases. Illness is frequently associated with poverty and becomes justification for social inequities. …disease is frequently associated with the 'other', be it the other race, the other class, the other ethnic group. Inevitably the locus of blame is also tied to specific ideological, political and social concerns (pp.362-363).

Incidences of stigma and discrimination have been demonstrated at the global level indicating that it is a more common occurrence among groups that are already marginalized. In Africa, for example, women have been blamed for transmitting HIV (Nwanna, 2005).

Researchers have shown that stigma associated with HIV/AIDS is manifested in diverse settings worldwide including, China, Mexico, Jamaica, South Africa, United States and India (Mahendra et al., 2006; Nwanna, 2005; Nyblade et al., 2003, Mead & Hamilton, 2005). These scholars revealed that PLWHA experience all forms of stigma and discrimination in health care centres, educational institutions, family settings and work places. Reports have shown that some health care professionals sometimes refuse to provide health care services, admit or seek informed consent from PLWHA before testing (Mahendra et al., 2006, cited in Nyblade & Carr, 2011; Ogunjuyigbe et al., 2009). As a result of the stigma and discrimination, PLWHA often refrain from seeking treatment which in turn compromises their well-being.

Contemporary researchers have illustrated the various ways in which stigma and discrimination are manifested (Nyblade et al. 2003; Brown et al., 2003; Herek & Capitanio, 1998; Malcolm et al., 1998; Nwanna, 2005). Qualitative studies by Steward et al (2008) exploring HIV-related stigma in India and by Yebei et al (2008) investigating

stigma among rural and urban PLWHA in Kenya revealed three distinct types of stigmas experienced by PLWHA namely, enacted stigma (discrimination), felt stigma and internalized stigma.

Types of stigma

External stigma.

Numerous researchers have taken interest in exploring enacted stigma. For example, Deacon (2006) extensively reviewed literature related to HIV-related stigma. Brown et al (2001) stated that "enacted (actual) stigma, on the other hand, refers to the real experience of discrimination" (p. 4). She suggested that the definition of external stigma be limited "to the process of othering, blaming, and shaming" (p. 418). Enacted stigma, which is also described as discrimination is manifested in various forms and in different settings and has been researched extensively in educational institutions, health care centres, religious places, work places and in family settings (Family Health International (FHI), 2008; Nyblade et al., 2003; Nyblade & Carr, 2011, Nwanna, 2005; Varas-Diaz et al., 2005, Makoae et al., 2008). The participants in these studies, reported social isolation by family and friends, exclusion from health care services, insults and taunts, ostracization and denied opportunities etc. In an attempt to explain why PLWHA experience external stigma, Muyinda et al (1997), pointed to the general perception that HIV is contracted through voluntary behaviours that justifies acts of stigmatization. Parker and Aggleton (2003) citing several scholars indicated that "the general populace believes PLWHA deserve avoidance and ostracism because of their illness, and are often in favour of severe policies that threaten their human rights" (p. 15). It has also been established that PLWHA with physical limitations associated to HIV/AIDS face more

stigma and discrimination. For example, "one South African study revealed that community members who had lost weight, experienced hair loss, had a cough, had body or facial sores, or showed changes in complexion were assumed to be HIV-positive and were stigmatized" (Centre for the Study of AIDS, 2004, cited in USAID, 2006, p. 4). In this study, the participating CLWHA reside in an institution exclusively for HIV children, which is a strong motivation for stigmatization within the school setting. Therefore, it is critical that this study establishes the basis of stigmatization for CLWHA in public schools.

Internalized and felt stigma.

"Internal stigma"--also described as felt, imagined, or self-stigma-- is the product of the internalization of shame, blame, hopelessness, guilt and fear of discrimination associated with being HIV positive" (USAID, 2006, p. 1). Numerous studies focusing on internalized stigma found that it is mainly defined by fear, shame, guilt, denial, loss of hope, loneliness, self-isolation and depression (Banteyerga et al., 2003; Hong et al., 2008; Koku, 2010). USAID (2006) claimed that "the process of internalizing stigma is complex, and any person diagnosed as HIV-positive experiences some form of it" (p. 2).

Felt stigma has been described as the fear of being discriminated against as a result of one's status (USAID, 2006). Chapman (2000) and Yebei et al (2008) observed that individuals suffer from felt stigma when they internalize negative perceptions that society holds about them. Being aware of these attitudes, they hold them to be true. Accepting and internalizing the society's negative characterizations, may result in individuals feeling that they deserve mistreatment (Herek & Capitanio, 1998).

Consequently, experiencing the three types of stigma may have dire consequences on the socio-economic and psychological well-being of a majority of PLWHA.

Courtesy stigma.

Deacon and Stephney (2005) argued that "courtesy stigma is stigma attached to people because of their association with HIV/AIDS or HIV-positive people, for example stigmatization of family members of a person identified as having HIV/AIDS, or stigmatization of health care workers who work with people living with HIV/AIDS (PLWHA)" (p. 5). Although it does not use the term "courtesy stigma" but includes it under "internal stigma", USAID (2006) stated that this type of stigma also referred to as secondary stigma affect[s] "partners, family members, friends, professionals, and volunteers associated with affected groups" (p. 4). Snyder et al (1999) shared similar observations but further noted that due to courtesy stigma, caregivers or acquaintances disassociate themselves from the stigmatized person, withdrawing their support. A study involving male doctors in Mexico revealed that they sometimes avoided providing medical care to male AIDS patients, due to fear of being associated with homosexuality (USAID, 2006, p. 4).

Research has identified lack of awareness and knowledge about HIV/AIDS, fear of contracting the HIV virus and of being linked with immorality as some of the main forces driving stigma and discrimination (Nyblade & Carr, 2011, p. 3). In their study, Yebei et al (2008) found that external and internalized stigma was intense in rural areas and lower in urban centres.

Functions of stigma.

Stein (2003) argued that AIDS stigma serves social and psychological functions because the disease is subject to more prejudice than other diseases. Koku (2010) stated that HIV/AIDS is associated with promiscuity and deviant sexual relations (p. 4). Stein (2003) summarizing studies by Muyinda et al (1997) and Ross and Levine (2002) emphasized that there is a strong belief that HIV/AIDS is "contracted not only through voluntary behaviours, but also through immoral behaviours" (p. 7).

Unlike other diseases HIV/AIDS is highly contagious and incurable and its fatal nature causes fear and anxiety in society (Stein, 2003). Further observations showed that the early metaphors depicting HIV/AIDS "as death, as horror, as punishment, as guilt, as shame, as otherness-have exacerbated these fears, reinforcing and legitimizing stigmatization and discrimination" (Horizons, 2002, p. 1) still persist today. As a result, society adapts measures such as, distancing, isolation, blaming, etc., to help them maintain a sense of security. By blaming PLWHA for their failure, society feels safe because, unlike the infected person, they feel they have done nothing wrong to deserve HIV. Joffe (1999, cited in Stein, 2003) concluded that stigma as a defense mechanism serves to alleviate anxiety in the face of danger (p. 18).

Other sources of stigma have been discussed by Moon et al (2002, cited in Stein, 2003) with regard to family members' resentment towards PLWHA, who they accuse of making no economic contribution but continue to depend on what is considered limited resources. Since this is a common phenomenon in Africa, where HIV infection rates are high, economic strain may result in family members withdrawing their support (p. 8). In a paper entitled "I have an evil child at my house..." Campbell, et al. (2005, p. 808), the

authors illustrated how society justifies their discriminatory actions towards a specific group of people. Campbell et al (2005) argue that this is considered an effective form of "social psychological policing", which society used to punish social deviants who engage in unacceptable behavior (Campbell et al., 2005, p. 808). Conclusively, Ngozi et al (2009) pointed to the consequences of these measures, arguing that it is responsible for increased rates of HIV since it discourages PLWHA from disclosing their status or from seeking proper treatment.

Stigma and discrimination in educational institutions.

Stigma and discrimination by parents.

Different forms of AIDS-related stigma and discrimination have been occurring in schools across the world. Numerous reports have demonstrated how parents of CLWHA struggle to obtain admission for their children in different schools with little success (Mead & Hamilton, 2005). Family Health International (2008) reported that parents had to submit registration application forms several times before their children were admitted into the school. Research focusing on the attitudes of the parents of healthy children regarding access to education for infected children expressed reluctance to having their children share the same facilities with CLWHA. Several studies noted that parents suggested that CLWHA should be taught in separate rooms, be forced to stay at home, or should learn at special facilities away from the school (Conway, 2005; Mead & Hamilton, 2005).

A report by *Time World Newspaper* (Monday, August 24th, 2009), cited similar sentiments where Vietnamese parents and the local people strongly opposed the admission of CLWHA into the school. This resulted in two CLWHA being taught

separately. In the same report, parents forced the administrators to send CLWHA away from school after they had been admitted. Apparently, when their demand was not met, some parents withdrew their children from the school emphasizing that they would never allow their children to learn in the same classrooms with CLWHA. While taking her child away one parent stated: "It is better to stop our children's schooling than to let them sit next to AIDS infected children" (p.1). One grandparent emphasized: "We survived the French bombings and the American bombings. I'd rather be bombed to death than die slowly of AIDS" (ibid). A similar reaction by one parent in Vietnam stated:

> I will not send my children to a school receiving children with HIV/AIDS. One class with about 40 to 50 children is managed and cared for by two or three teachers. I think it is too difficult for them to make sure all children are safe when they live, eat, play and sleep together with those infected with HIV (*Time World* Newspaper, Monday, August 24th 2009, p. 1).

Ironically, the rights to equality and non-discrimination of people living with HIV/AIDS, and in particular CLWHA's right to education are explicit in the policy document. However, the scenario reported above is an indication that a gap exists between what is spelled out in the policy and actual practice (Vietnam Policy Report, 2003).

Similar observations by Pryor et al (1999) showed parents' demand for the removal of an HIV-infected child from the school resulted in the harassment of the child by classmates. In their study exploring the attitudes of parents towards CLWHA in Jamaica, Mead and Hamilton (2005) observed that parents considered CLWHA "contaminated", which they used as justification to segregate them (p. 5). The fear that HIV transmission would occur during interactions was apparent as one parent noted: "An HIV student might breathe and others might get it. Moreover, an infected student and a

non-infected student can fall in love leading to sexual relations and transfer the virus" (ibid). Another parent stated: "A student can share syringes, or even worse, an HIV-positive student might intentionally transmit the virus to others by means of a syringe, blade or other weapon". Yet another concerned parent asked, "What will we do if children bite each other?" (p. 6). These perceptions and utterances were driven by ignorance and portrayed CLWHA as having "an immoral character and prone to risky and dangerous behaviour" (ibid). These were mere speculations from the parents since there is no medical evidence to prove that transmission can take place in casual contact. Such comments however are extremely damaging to the targeted children. Besides, since the onset of HIV, most schools now apply universal precautionary practices with the students irrespective of their health status in order to avoid discrimination.

It was reported that some school administrators enrolled CLWHA into the school in the belief that they posed no risks to other children. However, some reports indicated that as soon as the parents found out the children's status or that of their parents, they demanded their expulsion from the school. The same report showed that parents acting from fear confronted CLWHA and told them exactly why they discriminated against them (*Time World Newspaper,* Monday, August 24th 2009, p. 1). Surprised by the turn of events, some CLWHA sought answers from the school administrator: "Why are our classmate's parents angry with us? Why don't they let us go to school? What is wrong with us?" Commending CLWHA's excellent performance and passion for school, he quoted what a seven-year-old CLWHA said to him: "I know I won't live long. Please let me go to school normally like other children of my age. I promise I'll not let my infection spread to anybody (*Time World Newspaper,* Monday, August 24th, p. 1)." Such negative

reactions by parents had dire psychological and emotional effects on CLWHA; as a consequence some were reportedly upset and some refused to eat. Stigmatizing attitudes evidenced by parents indicate that fear of HIV transmission remains a powerful barrier to CLWHA's access to education.

Stigma by teachers and peers.

Research on HIV-positive children has mainly focused on the clinical, social and psychological impacts of HIV and related stigma (Conway, 2006; Gibb, et al., 2003; Thorne et al., 2002). Consequently, there is a limited body of literature with regard to teachers' and peers' attitude towards CLWHA in educational institutions. However, the little that exists provides evidence that such attitudes have negative implications on the lives of CLWHA. Some studies have indicated that when CLWHA's identity is known it impacts on how they learn and socialize because they lack acceptance and support from the school community.

Hong et al (2008) discussed extensively issues pertaining to HIV transmission noting that even after CLWHA were admitted into the schools, teachers constantly feared that they would transmit the virus to the other children. There are a few examples that illustrate similar incidents. A study by the Human Rights Watch (2004) documented expulsion of CLWHA by teachers after learning that they or their parents were HIV-positive. In the UK, Thornton (2008) described a CLWHA as young as four years old being turned away from school while others were excluded from both primary and secondary schools. In India, reports indicated that children are expelled from schools by teachers. For example, two HIV-positive boys were barred from attending school for one year after the school where they had sought admission denied them entry. Parents who sought admission

for their CLWHA complained that the process of integrating CLWHA into the school system was almost impossible and only occurred after a long struggle.

Macek and Matkovic (2005) described teachers' indifference in enrolling young CLWHA in the kindergarten classes, which was mandatory for primary school entry. The authors confirmed that attempts to seek admission in other schools became futile because some parents from the former school alerted the teachers in other schools, who in turn rejected CLWHA. In a similar scenario, a17-year-old Ugandan girl tearfully described her experiences of stigma by friends and teachers. She explained:

> When I went to boarding school in Primary six, there was a lot of stigma and discrimination in the school, especially by the matron and some children who made life hard for me. I remember someone confronting me, asking me if it was true that I had HIV (World Vision, 2008, p. 1).

A report by UNHCR in Vietnam cited several examples of discrimination of young CLWHA by teachers who denied them admission into the school refusing to allow them to learn with other children. For example, one girl recounted her experience with the teacher:

> Previously, my teacher loved me very much. She sometimes asked me to help my classmates. When I asked my friends why they did not let me play with them, they answered that the teacher had told them not to because I was ill. When I wanted my friends to share a book with me, they did not agree (*Time World Newspaper*, Monday, August, 24th 2009, p.1).

The BBC reported that some schools in Tanzania forced HIV-positive children to wear red ribbons on their shirts for identification while in school. The head teacher in one school stated: "Our school has pupils who are suffering from various diseases. The school and the society at large have decided to label pupils' uniforms" (BBC, Monday, March 15th 2012). In addition, The National AIDS Trust (2010) reported bullying of CLWHA by teachers, which in turn compelled CLWHA to abandon schooling altogether.

A consensus from numerous studies has highlighted students' unwillingness to interact with their HIV-positive peers. For instance, a study conducted in Iran by Tavoosi et al (2004) indicated that high school students would avoid sitting next to an HIV-positive student. Some students however were of the opinion that HIV-positive students should be banned from joining public schools. In their study, Huang et al (2005) reported that a third of the students who participated in a study in Hong Kong stated that they would avoid close contacts with an infected student.

Related studies also explored teachers' confidentiality with regard to the serostatus of HIV-positive children. Studies in the UK, for example, highlighted that teachers erroneously assumed the diagnoses of CLWHA and compromised their confidentiality (Conway, 2005). A report presented by representatives from the East African countries in Arusha, Tanzania in 2010, indicated that teachers' lack of confidentiality resulted in teachers' questioning HIV-positive children about their sickness, absence from school and about the medication they were taking, which caused anxiety to the children and disrupted their studies. Some CLWHA reportedly refused to attend school because they could not concentrate on learning. Some refrained from taking medication when in school, while others stopped taking medication altogether. A10-years-old HIV-positive girl in Uganda illustrated a similar incident:

> I was able to go back to school but adhering to medication was rather hard because of the fear to be seen taking drugs. Timing was also difficult. I could not share with anyone (World Vision Report, 2009, p. 1).

Baguma (2008) and other scholars have pointed out that lack of antiretroviral (ARV) intake by CLWHA has serious implications on their health.

A report presented in Arusha in 2010 emphasized that while overt discrimination in Kenyan schools is somewhat reduced, CLWHA continue to face all forms of discrimination, with many of them feeling the need to hide their HIV status from teachers and fellow students. These stories and others demonstrate that discriminative treatments of CLWHA in schools prevent them from freely discussing their sickness or disclosing their HIV status, leaving them to suffer alone.

The status of CLWHA is disclosed to school administrators to allow for the necessary support to the children, but complaints of violations of confidentiality have been reported. Regarding disclosure, Cohen et al (1997) described that parents found it difficult to maintain confidentiality especially when the school personnel had not been informed about the status of the child. Before considering disclosing, parents had to weigh the benefits of disclosure and the loss of privacy and discrimination of their children (p. 4). In a similar scenario, Thornton (2008) cited a case where a parent transferred an HIV-positive child to a different school after the administration told her that the auxiliary staff would have to be informed about the child's HIV status in case there was an accident. The mother, not believing that her child's condition was a risk to other children, and because the child did not yet know of her condition, did not want the information passed on to others (Cohen et al., 1997, p. 4). Cohen et al (1997) concluded that issues of disclosure were particularly critical in compromising the education of CLWHA due to the absence of protective policies in educational institutions (ibid).

Studies investigating the relationship between HIV/AIDS knowledge and stigma have been conducted globally. A study involving all male high school students in Saudi Arabia showed that ignorance about HIV resulted in high levels of stigma towards HIV-

infected individuals. A study by Badahdah (2010) suggested that "students who knew less about HIV/AIDS were more likely to stigmatize persons living with HIV/AIDS than those who knew more" (p. 390). The participants stated that PLWHA should be ashamed of the disease and while 76% favoured the idea of isolating them, another 59% said they would terminate PLWHA from employment (ibid). Another study by El-Gadi et al (2008) found similar attitudes towards PLWHA among Libyan students. However, girls showed stronger stigmatizing attitudes compared to boys, while students from the rural areas showed less stigmatizing attitudes. This study contradicted Yebei et al's (2008) study that indicated stigmatizing attitudes were more prevalent in rural areas. These attitudes were influenced by conservative Muslim beliefs that forbid practices that are associated with HIV-infection. In spite of the high level of stigma in the school, a vast majority of students felt that PLWHA should be provided with free health care. This was due to the compassion, kindness and mercy that are highly valued virtues in Islam, especially towards the sick, weak, and the old (p. 388). Buseh et al's (2006) study indicated that boys were less sympathetic to PLWHA than girls, meaning that stigmatizing attitudes were higher in this cohort.

The majority of the studies have established that attitudinal problems show a strong association between misinformation, lack of education about HIV/AIDS and beliefs, which in turn facilitate stigmatization of PLWHA. Agrawal et al's (1999) study in India showed a strong correlation between HIV/AIDS knowledge and attitude. They observed that a third of the Indian students' attitudes towards PLWHA emanated from the common taboo of sex. Another study by Maughan-Brown (2006) in South Africa showed that the prevalence of negative judgments and fear of HIV infection was greater

than negative behaviour towards PLWHA. A study aimed at assessing attitudes of college students in Tanzania towards PLWHA, concluded that due to high levels of stigmatizing attitudes among the students, there was a need for intervention programs such as voluntary counselling and testing (VCT) services and HIV/AIDS educational programs tailored to colleges students' needs that would assist in reducing stigma towards PLWHA (Maswanya et al., 2009).

Huang et al (2005) noted that knowledge of HIV/AIDS among Chinese university students was limited. Although the students could easily identify HIV transmission routes, they had considerable misconceptions about the modes of HIV transmission, which resulted in stigmatizing attitudes toward their infected peers. In a similar study, Zhang et al (2008) found that Chinese students who held misconceptions and limited knowledge about how HIV was transmitted were most likely to stigmatize PLWHA including their peers. Zhang et al (2008) noted that students who held misconceptions about HIV transmission routes stated that they would shun PLWHA and that they should not have the same rights regarding education and employment as everyone else. This implies that misconceptions about HIV/AIDS and its modes of transmission facilitate the stigmatization of PLWHA (p. 140).

Further findings by Castle (2004) in Mali confirmed that school teachers' and children's stigmatizing attitudes were associated with misconceptions, for example, the belief that it is possible to contract HIV through social contact. Incidentally, he found that community elders, parents, and school teachers held similar views, which to an extent influenced the children's attitudes towards their infected peers (pp. 6-8). A study by Macek and Matkovic (2005) in Croatia established a correlation between education, and

stigmatization. The authors noted that persons with higher education had low negative attitudes toward HIV-positive students, meaning that knowledge contributed to their sensitivity regarding the needs of young children living with HIV/AIDS in school. Age and HIV knowledge were important factors in stigma and discrimination as Lau and Tsui (2005) established. The authors found that in general, the younger, single Chinese population in Hong Kong with more education had less stigmatizing attitudes towards PLWHA. However, the general population considered PLWHA immoral and believed they were receiving the punishment they deserved (p.118).

Another study conducted in US schools showed a relationship between the length of time a teacher had spent in the profession and time spent interacting with PLWHA. These two factors determined a teacher's willingness to interact with an HIV-positive student (Little, 1991). This finding concurred with my study's selection criteria for participating classroom teachers since studies have confirmed that the length of time teachers interact with CHLWA has a tremendous impact on teachers' attitudes.

The effects of HIV disease on HIV-positive children.

In spite of the availability of the Antiretroviral drugs allowing the majority of CLWHA to live longer, Aldrovandi (2005, cited in Cooper et al., 2007) observed that "although these children were surviving, they were usually stunted in growth and showed a history of frequent illnesses throughout childhood. They were also affected neurologically, with learning difficulties and slowed intellectual responses" (p. 103). Similarly, Blanchette et al (2002); Wolters & Brouwers 2005, cited in Cooper et al (2007) stated that "the infected child is, in addition, likely to be small for their age, often with mildly inflamed skin and dull hair. They may have frequent cough, often loose and

bubbly, and a tendency to suffer from diarrhoea" (p.105).The authors also noted that "infected children have a range of intellectual abilities, like all children, but HIV infection does affect cognitive function, and on average there is delay in development" (ibid). These observations could result in stigmatization of CLWHA by peers, teachers and even the community.

Medical studies show that children born with HIV have insufficient immune systems, and as a result they are vulnerable to opportunistic infections and pain, which was a common attribute of HIV/AIDS (Brown & Lourie, 2000; McComsey & Leonard, 2004; Lolekha et al., 2004). UNAIDS (2005) indicated that requiring the child to stay home, or hospitalization resulted in frequent absences from school. HIV symptoms and absenteeism made CLWHA feel more stigmatized. Similarly, ARVs caused side effects from time to time and given their young age, children were likely to follow the treatment for longer periods of time.

Other studies have found a relationship between HIV disease and depression (Kalichman et al., 2000). The effects of the HIV disease and related stigma and discrimination on learning and social interaction for CLWHA in Kenyan public schools are yet to be explored.

Effects of stigma and discrimination on people living with HIV/AIDS.

Numerous studies showed that frequent incidents of stigma and discrimination occurred in various settings, among family and friends, in health care centres, at work and religious places (Family Health International (FHI), 2008). Studies exploring the effects of stigma and discrimination illustrated that social exclusion and rejection were persistently sources of social and psychological stress, which led to low motivation, poor

self-perception, low esteem, loss of status and limited social interactions (Nyblade et al., 2003; Zhou, 2008; Hong et al., 2008; Koku, 2010; Varas-Diaz et al., 2005). Fear of stigma prevented PLWHA from proactively managing their health concerns because, being unwilling to disclose their status, they may not seek HIV testing or pursue proper treatment, which is detrimental to their well-being (Brown et al., 2001, p. 421). Examining the social consequences of the disease Link and Phelan (2001) observed that "labelled persons experience status loss and discrimination that lead to unequal outcomes" (p. 367). Labels negatively affect the quality of life of PLWHA making it difficult for them to cope with the disease and resulting in the individual withdrawing from the stigmatizing situations (ibid).

Nyblade et al's (2003) study in Ethiopia found that internalized stigma for PLWHA was often characterized by guilt and shame, resulting in the abandonment of one's aspirations and goals. "The loss of hope, combined with fear and anger sometimes resulted in suicidal thoughts and attempts." (p. 8). In addition, Anderson et al's (2004) study on stigma and discrimination of HIV-positive Caribbean people in the UK indicated that feelings emanating from internal stigma were characterized by depression and alcoholism. In a study conducted in Nairobi schools in Kenya, infected orphaned children appeared depressed, did not mix freely with other children and exhibited learning difficulties in class. Teachers reported that the cause of the depression hinged on being an orphan as well as the physical and verbal abuse they experienced from peers (Ruto et al., 2009, pp. 137-138). In addition, some CLWHA had fresh memories of rejection and denial of educational opportunity by the school authorities. The children participating in this study have suffered a double blow - that of being an orphan as well

as the experience of living with a chronic disease. Therefore, in this study, I investigate how these reactions affect social interactions and academic performance.

Stigma and discrimination were found to be the reasons parents and guardians preferred not to disclose the child's status, leaving the child to discover their status on their own. As Thornton (2008) highlighted, because of lack of clear knowledge of their HIV status, the majority of the children did not understand the reasons for occasional medical check-ups and why they had to take medications regularly. Consequently, the children lacked the skills to deal with the disease as well as other unpleasant experiences related to their condition.

Physical signs of the disease promote avoidance by family and the community as observed by Varas-Diaz et al (2005), particularly when the signs of bodily deterioration begin to show. The authors noted that "these signs placed strains in the process of establishing effective communication pattern with others" (p. 176). It is worth noting that CLWHA with more visible physical symptoms are more vulnerable to stigmatization, making socialization with peers more difficult, even in the absence of anticipated risk. However, in their study, Ruto et al (2009) reporting on children with HIV-related symptoms confirmed that when physical symptoms cleared up and the isolation ceased, the effect of past isolation on the child remained a serious matter. Teachers in the study also confirmed that isolation was a significant cause of anxiety for a majority of CLWHA, especially when it happened in school (p. 138).

The above literature illustrates that PLWHA experience various stigmas and have reduced opportunities as a result of discrimination. Most often, their sense of worthlessness disempowers them to an extent that their will to live is shattered. This

study will explore the effects of stigma and discrimination on CLWHA, and investigate the extent to which they receive empowerment from the school, and in what form.

Strategies for coping with AIDS stigma and discrimination.

Coping refers to "cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p. 41). Ebersohn and Eloff (2002) provided a list of coping strategies that a person being faced with a demanding situation engages. The authors suggested that "coping implies adaptation by an individual to demands" (pp. 79-80). There are numerous studies that have explored distinct ways PLWHAs cope with HIV-related stigma. For example, Nyblade et al (2003) summarized the coping mechanisms employed by PLWHA in Ethiopia. These included HIV disclosure and non-disclosure, denial, turning to God and prayer, and avoiding socialization. Some however sought support from PLWHA networks, or were actively involved in advocacy and HIV/AIDS education (p. 10). A study involving PLWHAs from five African countries by Makoae et al (2008) identified some of the coping strategies PLWHAs employed, including thinking positively about oneself, avoidance, social distancing, letting it be, humour, seeking counselling, changing lifestyle and joining social networks etc. (pp. 4-8). Additionally, similar findings by Carr (2002) in Jamaica and Tarwireyi (2005) in rural Zimbabwe indicated that PLWHAs turned to God in prayer and engaged in religious practices for solace. In my view, turning to God and hope for a cure was particularly common in countries where Christianity is the common practiced faith, including Jamaica and most parts of the sub-African continent.

Physical symptoms did not necessarily cause avoidance. Anderson et al (2009) found that PLWHA of Caribbean origin in the UK coped with stigma by refusing to enter into a relationship because they did not wish to deceive or lie about their status; however, practicing safe sex with the partner was an alternative mechanism that they used to cope with stigma. Additionally, they used avoidance and limited social interaction with friends (pp. 7-8). Jones et al (1984, cited in Siegel et al., 1998) stated that while challenging the term that defines them as "discreditable", stigmatized groups "may take the form of banding together with fellow targets, . . . withdrawing from one social environment and embracing another, and redefining an attribute of the self" (p. 6). In their study examining the strategies gay men employed to cope with HIV-related stigma, Siegel et al (1998), found that the participants concealed the truth about their serostatus and opted to "live a lie" in spite of it being very painful. In an attempt to control information, they presented themselves to their acquaintances as healthy (p. 11). This was consistent with what Goffman (1963, cited in Siegel et al., 1998) referred to as "passing" which participants used to protect themselves while maintaining normal social relations (ibid).

Reeves (2001) found that youths in particular, used the internet to seek support, empowerment and knowledge. Internet self-education provided them with a greater sense of control, enhanced self-esteem and self-confidence (pp. 713-714). This study will explore how CLWHA manage stigma and discrimination and what strategies they employ.

CHAPTER THREE: METHODOLOGY AND METHODS

Ethnographic Methodology

The focus of this study is the experiences and perceptions of CLWHA in a specific context, namely, Karibu School. Therefore, using ethnography as a qualitative technique fits the objectives of this research, since it provides me with an effective approach to appreciate the experiences of children living with HIV/AIDS (CLWHA), who reside in Kivuli Children's Home and are educated at Karibu School. Ethnographic methodology is popular with researchers interested in exploring the lived experiences of vulnerable children in various circumstances. For example, Nieuwenhuys (2008) attempted to understand the lived experiences of street children and violence in Haiti. Lopez's (1999) study focused on migrant children both at home and in school. Other scholars, for instance, James (2007) and Friedl (2004) used ethnography as a way of entering the children's world in order to conceptualize the meaning of childhood. Gregory & Mahera (2011) introduce the "insider/outsider" concept of the researcher's dilemma and how meanings unfold when working with young children and their families in cross-cultural contexts. The significance of the tenets of ethnography is illustrated in how it provides the researcher with a lens through which he/she observes and discovers hidden nuances. More importantly, while researching children, ethnographers are "sensitive to issues of power and abuse" and are reflective of the ethics involved in social science research (Jones & Watt, 2010, p. 9).

Van Manen (1988) provided a broad definition of ethnography as a written presentation of selected aspects of a culture defining the uniqueness of a specific group. Culture therefore refers to the "knowledge members of a group share with one another"

(p.3). Culture is expressed in the words and actions of its members; therefore, a researcher would have to be immersed in the culture in order "to hear, to see, to understand, and most importantly write what he/she witnessed in the field" (ibid). Emerson (1983) described ethnography as "the process of describing the activities and realities of other people" (p. 19), while Berreman (1968, cited in Emerson, 1983) argues that ethnography as a research methodology provides "a description of the way of life, or culture, of a society [that identifies] the behaviours and the beliefs, understandings, attitudes, and values they imply found in that social world" (ibid). Moreover, it provides "thick descriptions" of cultural and social activities" [and] "presents in close detail the context and meanings of events and scenes that are relevant to those involved in them" (Geertz, 1976, cited in Emerson, 1983, p. 24).

Van Manen (1988) cautions researchers about the responsibilities tied to the practice of ethnography by pointing to the fact that spending time in the field is critical in order to "share firsthand the environment, problems, background, language rituals, and social relations" (p. 3) with a specific group before embarking on actual research. Similarly, Emerson (1983) points to the need of the researcher to plan wisely to spend a reasonable amount of time in order to maintain "face-to-face contact with the people being studied in the natural setting of their daily lives" (p. 63).

While discussing the importance of institutional ethnography, Campbell and Gregor (2002) emphasized the need for locating oneself in "a distinct terrain of inquiry" (p. 17) in order to conceptualize people's everyday lives and experiences, since "people's lives happen in real time and in real locations to real people" (ibid). For the researcher to make sense of people's lived experiences, he/she must be strategically

positioned to explore in depth the "actual world in which things happen, where people live, work, love, laugh, and cry" (p. 17).

I assumed the position of an enthusiastic researcher interested in the lives of the research participants in two specific settings, namely Kivuli Children's Home and Karibu School. Following the advice stipulated in the work of Campbell and Gregor (2002), I spent a period of over three months in these settings, familiarizing myself with the participants' day to day programs, while at the same time observing and conducting interviews. This was a discovery period that enabled me to observe and understand the life experiences, interactions, peer relationships, attitudes and beliefs held by students and teachers. I was also guided by Miller and Kaiser (2001), who suggested that "no research design could enable a researcher to fully understand the experience of another person, but utilizing qualitative research design would bring out a rich, in-depth, and detailed description of each participant's experience" (p. 21). The ethnographic lens allowed me to capture peer interactions, on-going relationships, and other significant factors that contributed to the study.

As a researcher, I am aware that familiarity with the language of the study-group is a vital tool in data collection that may not be understood by observation alone, particularly by outsiders. Besides sharing a common nationality and the Swahili language, I could not ignore the fact that Kenya has 42 distinct languages and numerous diverse cultures. However, having been away from Kenya for the last 10 years meant that I was unfamiliar with the current changes in culture and language. Further, urban youth tend to use "Sheng" (a mixture of English and local languages) that distinguishes them from other age groups. Undoubtedly, comprehending insinuations and constructing

meaning from “Sheng” made me feel more of an outsider than an insider. Other cultural aspects that I could not disregard were the age gap, professional experience and interests, which could potentially affect ways of communication and understanding. To overcome these hurdles, I maintained a low profile while building rapport with the participants and at the same time learned a few innuendos, and sought clarification without being too invasive.

Rationale for Case Study

The study utilized an ethnographic case study approach. This methodology allowed me to study the participants in their everyday life contexts; namely, at Karibu School and in the Kivuli Children’s Home. This was in an effort to understand the events that the participants were involved in and how they perceived them. Yin (1984, cited in Merriam, 1988) argues that “case study is a design particularly suited to situations where it is impossible to separate the phenomenon’s variables from their context” (p. 10). The choice of these settings for my study was supported by Merriam (1988), who argued that the choice of a case study design hinges on the fact that the researcher is “interested in insight, discovery, and interpretation rather than hypothesis testing” (ibid). Furthermore, “case study seeks holistic descriptions and explanations” (ibid).

According to Merriam (1988), four specific characteristics distinguish a qualitative case study; “particularistic, descriptive, heuristic, and inductive” (p. 11). These features were important guides for the study. For example, selecting the specific study site and the participants enabled me to focus on a “particular situation, event, program[s], or phenomenon” (ibid), which were going on at Kivuli Children’s Home and Karibu Primary School. Shaw (1978, cited in Merriam, 1988) stated that choosing a case

study allows the researcher to "concentrate attention on the way particular groups of people confront specific problems, taking a holistic view of the situation" (ibid). By singularizing this group, my aim was to understanding their experiences of AIDS stigma and discrimination in Kenyan public schools. Children residing at Kivuli Children's Home and learning at Karibu School have explicit characteristics and lived experiences that I found significant and unique for this study. Similarly, Karibu School encompasses substantial information regarding the challenges encountered in the process of integrating CLWHA, who were initially turned away by other schools.

As a novice researcher, I was cognizant that investigating the lived experiences of CLWHA and attempting to interpret them in a manner that represents and reflects their own views was important. I could not claim to fully understand their experiences. However, my aim as a researcher was to describe these children and their experiences using their own words in the text without speaking for them. To do so efficiently, I utilized certain skills from my work experience, particularly those gained from teaching, serving in a HIV/AIDS coordinating position, as well the insights I had gained at the University of Western Ontario. Most importantly, my aim was to ensure that the participants' voices took precedence in the investigation.

Combining ethnography and case study methodology aligned with my study objectives. This methodology allowed me to capture in greater depth the complex issues related to CLWHA's experiences, perceptions, interpersonal relationships, and issues of teacher-pupil and pupil-pupil relationships. The use of semi-structured interviews, participant-observation, and document analysis was consistent with Hakim's (1987) argument that the "use of multiple sources of data allows case studies to present a more

rounded and complete account of social issues and processes" (p. 63). Moreover, use of multiple sources of evidence makes the case study one of the most powerful research designs (Hakim, 1987, http://ilhamjournals.wordpress.com).

Accessing the Research Setting and the Role of Gatekeepers

Cohen et al (2007) hinted that access to the study site and the participants is not automatic, pointing out that the presence of a researcher might raise questions especially if the study takes a long period of time, or demands that the participants give up some of their time (p. 55). The authors also pointed out that the reception accorded to the research varies considerably from individuals to groups. Therefore, seeking permission before embarking on the research is essential.

Before venturing into field research, I had to reflect on the different approaches that I would employ to bargain my entry into the two research settings, namely Kivuli Children's Home and Karibu Primary School. I realized that understanding the views of gatekeepers, particularly the administrators of Kivuli Chidren's Home and the principal and the teachers at Karibu School was important for bargaining and maintaining access in these settings. Miller and Bell (2002 as cited in Cohen, et al., 2007) argue that "gatekeepers play a significant role in research, particularly in ethnographic research" (p. 123). I was also aware that gaining access and conducting research with vulnerable participants, specifically CLWHA required more than seeking permission. This is because as someone coming from a Canadian university, the participants as well as the administrators considered me an intruder or outsider with little in common with those being researched. This is in spite of the advantage of being a Kenyan, speaking the same language, and sharing a similar culture. My presence held the potential to be viewed as an

intrusion that would disrupt the school program or interfere with the schedule of the lessons. Adler and Adler (1994, cited in Kawulich, 2005) pointed to the fact that a researcher remains an "outsider" and may be considered an intruder into the privacy of those being researched. However, the authors argue that "acquiring the peripheral membership role would enable one to observe and interact closely enough with members to establish an insider's identity without participating in those activities constituting the core of group membership" (p. 11).

Owing to the sensitive nature of the study topic and the vulnerability of some of the participants involved, I anticipated a certain degree of resistance from the gatekeepers. For example, it was the sole responsibility of Kivuli administrators to protect CLWHA from any form of stigmatization. Besides, they were also concerned that allowing CLWHA to participate in this research could not only disclose sensitive information but would also trigger unpleasant psychological and emotional feelings. This was consistent with what Cohen et al (2007) argued, that "the greater the sensitivity of the information, the more safeguards are called for to protect the privacy of the participants" (p. 63). Additionally, I was cognizant about teachers' personal anxieties about the disease. Hence, after clarifying the issue of privacy and confidentiality with regard to the information they were to provide, I gave them the option to participate or decline taking part in the interviews. As Kimmel (1988 cited in Cohen et al., 2007) noted, "some potential respondents in research on sensitive topics will refuse to cooperate when an assurance of confidentiality is weak, vague, not understood, or thought likely to be breached" (p. 65). I had therefore to assure all the participants that whatever information they shared would remain confidential. Similarly, Devers and Fraenkel (2000) noted that

the greater the sensitivity of the information, the greater the reluctance to compromise these individuals' privacy. They emphasized that:

> Gate-keepers share common concerns, including: the time, resources, and disruption involved in their organization's participation in the study; fear that they will be shown to be "bad" or "wrong"; exposure of proprietary or competitive information; and privacy and confidentiality for their organization, its employees, or people it serves (p. 266).

The two authors however suggested three ways that can be used to facilitate easier access:

> First, social networks can be useful for obtaining basic information and facilitating entry. Second, using a personal contact who can 'vouch' for the researcher or write a letter of support can be critical, and third, researchers can involve themselves in settings where subjects are likely to be located in some other capacity (p. 266).

Walford (2001, cited in Cohen et al, 2007) further warned that "gaining access and becoming accepted is a slow process" (p. 121).

Given the importance of this study, it was fundamental to ensure easier access to the research setting and the participants in order to garner meaningful data. Soon after completing the proposal requirements, I e-mailed the director of Kivuli Children's Home introducing myself and briefing her about the objectives of my study. Consequently, in her e-mail response, she introduced me to the Principal of Karibu School, whom I later contacted via telephone. Both administrators were very supportive about my intended study and promised their support throughout the data collection period.

After arriving in Kenya, I contacted both administrators and scheduled a meeting with each. During the meeting, I explained the objective of the study and provided any necessary clarifications. I also handed each of them a copy of the ethical clearance from UWO and a letter from the National Council for Science and Technology (Appendix B) allowing me to conduct research in a public school. After meeting with the administrators,

each administrator took time to introduce me to the participants. The reception by the administrators and the participants was warm and reassuring.

In order to establish trust and gain access to CLWHA, I arranged with the director to participate in the activities of Kivuli Children's Home in becoming a volunteer for the entire period of data collection. The period of volunteering commenced in mid-August 2010 when Karibu School was in recess. Kivuli Children however followed a school-like program that was facilitated by volunteers. Volunteership involved teaching several subjects in different classes, sharing meals with the children in their cottages, playing games, and sometimes watching television and movies. I also joined the ancillary staff in the morning prayers and participated in the prayer service every Sunday. Interacting and participating in all of these activities helped build trust with the CLWHA and establish genuine relationships, which played a key role during interviewing. Familiarization, establishing trust and friendships was equally reassuring for the CLWHA, which made my shifting to the school for observation less threatening. Similarly, volunteering provided me with an opportunity to understand and make comparisons of CLWHA's behaviour while at the home and at school. In addition, Hammersley and Atkinson (1983) suggested that "gaining access not only is a practical matter but also provides insights into the social organization of the setting" (p. 121). At the beginning of the third term in September, 2010, I briefed the classroom teachers about my research and specified their anticipated role in the study. I used a similar approach with CLWHA in grades 4, 5, 6, and 7. After explaining the study objectives to CLWHA, I asked them to volunteer to participate in the study and, based on the specified criteria requirement, selected 12 CLWHA.

Data collection commenced in mid-September to the end of November 2010. Throughout this period, I interacted and maintained a cordial relationship with the teachers, especially in the staff room during tea and lunch breaks. When interacting with teachers, I questioned them about general issues pertaining to stigma and discrimination, the HIV/AIDS curriculum and also the challenges they had encountered as a result of having CLWHA in the school. Occasionally, teachers asked for my assistance with class work whenever there was need. For example, I often stepped in to assist teachers with lessons or in managing the classes whenever an urgent matter they had to attend to arose. This was consistent with Burgess (1991), who suggested that access to the participants should be based on a set of relationships that the researcher establishes and maintains throughout the research process (p. 43). I also interacted and conversed with the pupils inside and outside the classroom, while paying special attention to how CLWHA behaved and interacted with other pupils. I was however careful not to single out the CLWHA.

I joined pupils in discussions, played with them during P.E. and responded to some of their queries, most of which were out of curiosity. For example, some children wanted to know what I do and where I live. While I made sure that each child received adequate attention, I was careful not to associate with one group of children over another. This was consistent with Denvers and Fraenkel (2000), who stressed that "researchers must show interest, concern and sensitivity, without over identifying with one group" (p. 267). Through conversational exchanges with teachers, pupils and personal observations of the on-goings in the school, I was able to analyze the teachers' and pupils' perceptions of CLWHA. The opportunity enabled me to visualize how well CLWHA had been integrated into the public school system.

Sampling and Recruitment of Participants

I recruited research participants using the method of purposeful sampling. This method allowed me to select specific individuals whom I believed would offer information and insights that were central to the research objectives (Cohen et al., 2007). As Ball, 1990, cited in Cohen et al, 2007) further stated, "purposeful sampling is used in order to access 'knowledgeable people' i.e., those who have in-depth knowledge about particular issues, maybe by virtue of their professional role, power, access to networks, expertise or experience" (p. 115). In addition, the method is useful in selecting unique participants "that are especially informative" from "a difficult-to-reach, specialized population" (Neuman, 1997, p. 206). In their study, Marc et al (2005) highlighted that purposeful sampling is a useful method to investigate the specific experiences of PLWHA. Using the principles of purposeful sampling, I selected 22 participants. This group included 12 HIV-positive children, 8 classroom teachers and 2 administrators, one from Kivuli and the other from Karibu School.

The criteria for selecting teacher participants was based on their role as classroom teachers, teaching at Karibu School for at least two years, possession of relevant knowledge about the subject matter and in particular issues pertaining to HIV and related stigma that would enrich the study, and their willingness to participate in the study. The 12 HIV-positive children were selected from a group of volunteers that showed interest in participating in the study. Those selected met the following sampling criteria: being an orphan and HIV-positive, residing at Kivuli Children's Home, attending Karibu School for at least two years, and being in grades 4, 5, 6, and 7. Administrators were selected on

the basis of their office portfolio and also on their involvement in the educational pursuits of CLWHA.

Initially, my plan was to interview 27 participants (5 teachers and 10 children from grades 4 to 8). But after arriving at Karibu School, the administrator informed me that CLWHAs were in grades 1 to 7. This fact necessitated increasing the number of participants in each class rather than the initially proposed two participants per class, which brought the total number of CLWHA participants to12. Similarly, after a lengthy meeting with the school administrator, I considered including classroom teachers from grades 1 and 2 who were not part of the initial sample. These teachers possessed valuable information since they were the first to encounter CLWHA when they were admitted in the school and spent adequate amount of time working with them in the classroom. Their contributions were also crucial because they were based on personal experiences and observations of CLWHA in their early years in school. In fact, during the interviews, teacher participants offered rich information based on their observations and experiences both in the classroom and outside. The following are summaries of the participants' demographics.

Table 3.1. Research Participants - Classroom Teachers in Karibu School

Classroom Teachers	Gender	Grade	Total Years of Teaching Experience	Years of Teaching at Karibu School
Mrs. Sewe	F	1	24	8
Mrs. Kisu	F	2	34	18
Mrs. Siti	F	4	35	7
Mrs. Were	F	6	15	7
Mrs. Mwega	F	7	25	2
Mr. Hose	M	8	35	30
Mrs. Tini	F	5	18	7
Mr. Maua	M	8	20	20

Table 3.2. Research Participants – Children living with HIV/AIDS at Karibu School

CLWHA	**Gender**	**Age**	Class
Tindi	F	10	4
Makena	M	12	4
Trina	F	13	5
Beata	F	13	5
Kariuki	M	14	5
Sidi	M	14	6
Kairu	M	14	6
Gatarina	F	14	6
Kamweru	F	15	7
Kakubwa	F	15	7
Kalee	M	15	7
Lekule	M	14	7

Table 3.3. Research Participants - Administrators

Name	**Gender**	**Years of Service**
Mrs. Nuru (Karibu School)	F	15
Mr. Chrisy (Kivuli Children's Home)	M	14

**All the names used are pseudonyms*

Importance of interviews.

Through interviews, the researcher explores and gathers experiential narrative materials to use as a resource for developing a richer and deeper understanding of a human phenomenon. Additionally, interviews encourage face-to-face conversation between the researcher and interviewees, providing further understanding of the participants' experience (Van Manen, 1990). Mischler (1986) reported that through the structure of asking and answering interview questions, discourse is shaped and organized. Mischler (1986) defined interviews as follows:

> An interview is a joint product of what interviewees and interviewers talk about together and how they talk with each other. The record of an interview that we researchers make and then use in our work of analysis and interpretation is a representation of that talk
> (p. 26).

I chose this method since interviews provided the opportunity to gather data through direct oral interaction with the participants. I used open ended interviews because they allow the participants great flexibility when addressing and answering questions and encourage them to express themselves in their own way (Verma & Mallick, 1999, p. 123). In their study with children, Freeman and Mathison (2009) observed that structured interviews "give freedom to interview participants to answer in their own way, using their own terms, and making their own connections to the interview topic" (p. 91). I found interviews to be especially useful with children because their unique needs differ considerably from those of adults (Freeman & Mathison, 2009). They have lower concentration spans, but also the ability to recall life experiences that they consider important. By engaging children personally in the interview process, I established trust over the period of time I volunteered, and did everything I could to put the children at ease. I did so by creating a friendly and enjoyable environment to ensure that the child was less distracted (Arksey and Knight, 1999, cited in Cohen et al., 2007).

Interviewing process.

Before engaging the participants in the interview process, I sought out suggestions from experienced researchers on how to conduct interviews with children, and in particular vulnerable children living with HIV/AIDS. I followed Freeman and Mathison's (2009) suggestions on the structure of the interviews including how to ask questions as a way of obtaining the necessary information while ensuring that the environment was

conducive for the child to share personal issues freely. I designed three sets of semi-structured interview questions (guide) that were deemed sensitive to the emotional and psychological needs and appropriate to the age of the participants (Appendix E), particularly CLWHA. The guide helped me ensure that all questions were asked in straightforward, simple language. I following Freeman and Mathison's (2009) advice of:

> Knowing how to phrase questions that encourage participants to provide elaborate, detailed (rather than brief) responses; and asking questions that elicit the participant's own views and experiences as opposed to reflecting the convictions of the interviewer. Relevant techniques include asking one question at a time, verifying unclear responses, asking open-ended questions, avoiding leading questions, and using follow-ups and probes (p. 41).

All 12 CLWHA were interviewed at Kivuli Children's Home on weekends. Interviews with eight classroom teachers took place within the vicinity of the school, while the administrators were interviewed in their respective offices. The reason for choosing Kivuli Home for the interviews was to ascertain that CLWHA were in a natural and familiar setting that would ensure maximum comfort and would motivate them to speak freely.

Face-to-face interviews were conducted in English and Swahili although prior to each interview session, I gave each child the option to use either language. Since the majority of CLWHA had a good command of the English language, they all preferred to respond in English even though they used the two languages interchangeably. Before embarking on the interviews, I introduced myself to the participants and explained the purpose of the study. I employed simple strategies such as appearing natural, allowing for some informal exchange before the interview, and then focused on their interests before engaging them in an interview discussion. During the interviews, my introductory question with CLWHA mainly focused on Kivuli Home because it was more familiar to

them. Issues of personal interest were followed by questions related to their experiences at Karibu School. Questions were asked according to the responses each child provided and not necessarily in accordance with the outline. However, all questions were similar to those outlined in the interview guide. I framed the questions in simple language that was commensurate with each CLWHA's age and level of understanding. To ensure the clarity of the questions, particulatly with CLWHA, I repeated it in both English and Swahili throughout the interview sessions. However, all the teachers were interviewed in English.

While I remained attentive to each child's responses, I also listened to their questions and checked to confirm with them in order to avoid contradictions and to insure that I fully understood their responses to the questions. Assuring that the participant's perspectives are well understood by the researcher confirms the validity of the data (Freeman & Mathison, 2009, p. 40). Additionally, to encourage the children to speak freely and remain focused on the topic, I used motivational prompts and probes. Permitting interviewees to speak freely allows them to remain close to their experiences and to explore those experiences as though the experiences are being relived (Van Manen, 1990).

Interviews with CLWHA lasted between 30-60 minutes. Interviews with teachers and administrators lasted for approximately 60 minutes or more. Interview questions were semi-structured, sought demographic information of the participants and some focused on the research themes. Maintaining gender balance among the classroom teachers was a challenge since, out of 27 teachers in the school, only three were male. Therefore I interviewed two male and six female teachers. In order to maximize understanding from the interviews and to make the process less strenuous, I participated

in some of the children's activities. At the same time I scheduled interviews after play or learning sessions in which I participated. The importance of engaging in children's activities is in line with Van Manen (1990), who stated that "to gain access to the experience of young children, it may be important to play with them, talk with them, puppeteer, paint, draw, follow them in to their play spaces and into the things they do while you remain attentively aware of the way it is for the children" (p. 68). The three months I spent at Kivuli volunteering not only helped develop interpersonal relationships but also bolstered trust with CLWHAs, making the process of data collection less complicated.

Participant observation.

DeWalt & DeWalt (2002, cited in Kawulich, 2005) defined "participant observation as reflecting the process of enabling researchers to learn about the activities of the people under study in the natural setting through observing and participating in those activities" (p. 2). The aim of the participant observer is to develop a profound familiarity with the participants by becoming intensively involved in their activities within their natural environment over an extended period of time. This process allows the research to understand the participants, appreciate their thoughts and behaviours and finally describes their situation (Erlandson, Harris, Edward et al., 1993, as cited by Kawulich, 2005, p. 2).

Being physically present in the study site in order to observe and interact with the participants was emphasized by Robson (2002). Furthermore, as Van Manen (1990) noted, "the best way to enter a person's lifeworld is to participate in it" (p. 69) because it minimizes the distance between the researcher and the participants whose experiences are

of interest to the study (ibid). Kawulich (2005) summarizes the advantage of observation for a period of time:

> To conduct participant observation, one must live in the context to facilitate prolonged engagement; prolonged engagement is one of the activities listed by Lincoln and Guba (1994) to establish trustworthiness. The findings are considered to be more trustworthy, when the researcher can show that he/she spent a considerable amount of time in the setting, as this prolonged interaction with the community enables the researcher to have more opportunities to observe and participate in a variety of activities over time (p. 21).

In addition, "observing young children would create various forms of experiences that would be impossible to gain from written documents or interviews" (p. 68). Although participant observation is governed by the topic of study, Goetz and Lecompte (1984, cited in Merriam, 1988) point to the importance of interactions with the study participants. They argue that "the data begin to emerge as the ethnographer [researcher] interacts in the daily flow of events and activities, and the intuitive reactions and hunches that ethnographers experience as these factors coalesce" (p. 89).

Using participant observation enabled me to observe activities, behaviours of CLWHA and their peers and interactions in and out of the classroom activities, paying special attention to CLWHA in grades 4 to 7. This approach allowed me to penetrate the lives of the participants through which I was able to obtain detailed and accurate information that comprised of valuable verbal and non-verbal clues, communicated through facial expressions, body language, and verbal exchanges between CLWHA, peers and teachers. More importantly, it enhanced my understanding of the different pedagogical strategies that teachers employed to convey messages related to AIDS stigma, how the teachers engaged pupils and how pupils participated in the lessons. Emphasizing the importance of observing participants closely, DeWalt, DeWalt and

Wayland (1998, cited in Kawulich, 2005) argued that it is through observation that the researcher discovers both visible and hidden details and identifies discrepancies between what the participants say and their actual reality (p. 33).

Observing out-of-class activities, particularly during morning and lunch breaks, watching children engage in physical exercises (P.E) divulged details about CLWHA's interactions and relationships with peers, and their level of participation in extra-curricular activities. Observation helped to capture all the participants' viewpoints of AIDS stigma and discrimination as well as how CLWHA were being integrated into the school system. I also observed minute but important information posted on the classrooms notice boards, and from the murals that were painted on the outside classroom walls. Data collected through observation provided insights into the types of empowering resources that were available in the school. After each observation, I carefully documented all observed events including personal thoughts. These notes were used to supplement additional data and compare different observations in order to determine why the participants behaved in certain ways in particular situations. In order to easily access data, I kept detailed descriptive notes in order of dates and month (Creswell, 2005). This method helped me to step back occasionally in order to reflect on the different meanings of the different situations that I had encountered.

This was consistent with DeWalt, DeWalt, and Wayland's (1998, cited in Kawulich, 2005) argument that "field notes as both data and analysis,...provide an accurate description of what is observed and are the product of the observation process [since] observations are not data unless they are recorded into field notes" (p. 29).

Employing the tenets of reflexivity, I reflected on the things I had observed, learned, thought about, and experienced during the research practice. Finally, embarking on this research made me realize that each style of entrance to the research site encompasses certain problems. For example, I realized that researching vulnerable CLWHA was psychologically exhausting, tedious and time consuming in comparison with the other participants in the study. I found that conforming to the schedule at Kivuli and Karibu School programs was a challenging task; nevertheless, the rewards at the end of the study were gratifying.

Document analysis.

Because documentary data can provide a basis for an investigation in the context of the problem being studied, they are particularly useful sources of information for qualitative case studies (Merriam, 1988, p.109). "Documents are easily accessible, free, and contain information that would take an investigator enormous time and effort to gather on his or her own" (p. 108). Specific advantages of using document analysis include the absence of participants, and compared to other methods of data collection such as interviews and observation, the researcher "does not alter what is being studied by his or her presence" (Merriam, 1988, 108). Documents can also be checked several times to ensure the authenticity of the information (Robson, 2002). However, one of the limitations of using documents is that their initial purpose is not research; hence, they might not provide reliable information and their "authenticity may be difficult to determine" (Merriam, 1988, p. 109). Although these statements are refutable, documents selected for this study were relevant to the topic and provided meaningful insights.

I reviewed a range of documentary sources, which included the Kenyan HIV education policy document, books containing HIV/AIDS topics, newspaper articles and literature from the Kenya National AIDS Program (NASCOP). These documents provided both historical and local perspectives of HIV/AIDS. I also visited websites on the internet to access the current information on HIV and AIDS. In order to determine the performance of CLWHA and establish their academic trends, I analyzed their academic records. These documents supplemented the data from interviews and participant observation and offered insights on the government's response to stigma and discrimination.

Data Analysis

Glesne and Peshkin (1992) claim that data analysis is the process of organizing and storing data. It is an interactive process that starts with initial interviews, observations and reading documents (p.127). It additionally allows the researcher to establish patterns of categories, interpret themes from the patterns, and develop generalizations (Lincoln and Guba, 1985, cited in Glesne & Peshkin, 1992, p. 127). Significantly, it allows for compiling and interpreting the participants' perceptions, thereby producing rich, detailed and authentic descriptions (Glesne & Peshkin, 1992).

In this study, data from interviews and participant observations were transcribed and those scripts that were in Swahili language were translated into English. Data were hence organized and maintained. Categories and themes were developed based on the responses to the interview questions. Leininger (1985) observed that "through the process of data analysis, themes are identified by bringing together components or fragments of ideas, which are often meaningless when viewed alone" (p. 60). The emerging categories

and themes reflected the manifestations, experiences, perceptions, and attitudes of the participants with regard to HIV/AIDS stigma. During data transcriptions, I noted that the participants' reflections, remarks, and actions emphasized intended meanings, which were based on personal insights and attitudes. During the coding process I used pseudonyms to ensure confidentiality of the participants and the information provided. Charmaz (2006) emphasized the importance of coding in data analysis by arguing that:

> The first major analytic phase of the research consists of coding the data. In short, coding is the process of defining what the data are all about. Unlike quantitative coding, which means applying preconceived codes (all planned before the researcher even collects data) to the data, qualitative coding means creating the codes as you study your data (p. 37).

In this study, coding involved reading through the data, providing annotations, and identifying particular objects of interest. This is in line with Johnson-Bailey and Cervero (1996), who argue "that in an ethnographic analysis, every utterance, even repetitions and noises are regarded as part of the data to be analyzed" (p. 14). In order to include the points of view and insights of all the participants, I selected several quotes that conveyed the core themes in the study.

Ethical considerations and issues of confidentiality.

As a researcher, one of my main priorities was to ensure that the highest level of ethical practice was maintained. For this reason, I followed the ethical protocol stipulated by the University of Western Ontario and sought approval from the ethics board to conduct research. Permission to proceed was granted on September 29th 2010 (Appendix A). In addition, I sought permission from the National Council for Science and Technology (Kenya) to conduct interviews with pupils and teachers at Karibu School. This permission was granted on August, 3rd 2010 (Appendix B). The study

involved sensitive, vulnerable CLWHA, classroom teachers and the administrators from Karibu School and Kivuli Children's Home. Therefore, as a researcher, I felt obliged to protect the participants by keeping all information gained during the study confidential. In order to protect the participants and the two institutions' public identification, I assigned each a pseudonym (Cooper & Schindler, 2001). Additionally, I treated each of the participants with respect and dignity that they all deserved irrespective of age or profession.

Prior to the interviews, I provided letters of information (Appendix C) to all of the participants. Letters of information and consent forms for the parents and guardians of CLWHA and the pupils in grades 4 to 7, which I observed, were distributed by the administrator of the school. However, I ensured that all consent forms were signed and submitted to me by all the participants, parents and guardians before embarking on the interviews and observation process (Appendix D). None of the participants, parents and guardians declined to sign the consent forms. Permission to speak informally with Kivuli Children's Home personnel (Mamas and workers) was granted by the Kivuli director. The authorization permit by the National Council for Science and Technology allowed me to interview and observe teachers and pupils at Karibu School.

However, since CLWHA were minors (10-15 years old), the Kivuli Children's Home administrator signed the consent forms on their behalf. This is consistent with Newman's (1997) opinion that "it is unethical to involve 'incompetent' people in research unless a legal guardian grants written permission" (p. 451). Prior to the interview and observation process, I ensured that the participants understood that it was their right to take part in the study without feeling obliged to answer questions and had

the freedom to withdraw from the study at any time without penalty (Kawulich, 2005). I also made sure that all the participants understood their right to privacy, protection of identity, and confidentiality of all the information shared.

During the interviews, the emotional wellbeing of CLWHA remained a top priority and I ensured that the process caused them the least amount of emotional stress. At the end of each interview session, I utilized my counselling skills to empower and encourage them. The information I gathered from the participants was not passed on to the administration. All audio-recorded information was protectively stored in a personal recorder and later transferred to a personal password-protected laptop. I transcribed all the interviews and for each participant I created a file which I identified using the assigned pseudonym. All the transcripts and field notes were kept safely in my office, and will be destroyed after a period of two years as required by the ethics board.

Triangulation.

Cohen et al. (2007) define triangulation "as the use of two or more methods of data collection in the study of some aspect of human behaviour" (p. 141). It is important in providing an increased depth of understanding and investigation since perspectives other than just the researchers are presented (Berg, 2004). Berg (2004) summarized findings from several scholars who concluded that using more than one approach to investigate experiences such as those in the current study can provide a way to confirm data measurements and validate findings (p.5). In addition, Rossman and Wilson (1994) suggested the use of different sources of data to corroborate, elaborate and illuminate the topic being explored (p.304). Further, the more methods contrasted with one another, the more they hold the potential to produce different sets of data and thus the greater the

researcher's confidence in the conclusions. However, Fielding and Fielding (1986, cited in Berg, 2004) stressing the importance of applying various methods in research, stated that triangulation should not only combine different data types, but that the data should relate in order to counteract any imminent threats to validity that might be identified (p.5). This study employed structured interviews, participant observation and document analysis. The combination of the emerging information obtained from the various sources formed rich data that gave a substial picture of the realities of the participants' experiences.

Reliability and validity.

Validity in qualitative research has been addressed widely. Having summarized the work of several scholars, Thompson (2001) referred to validity as the "accuracy of the data or credibility in relation to the reports of the participants, description and interpretation, the methods used and how the conclusions of the study are drawn"(pp.78-79). While Cohen et al (2007) acknowledged that validity is a requirement for both qualitative and quantitative research, Hammersely and Atkinson (1983, cited in Cohen, 2007) argued that validity is "attached to accounts, not to data, or methods [since] it is the meaning that subjects give to data and inferences drawn from the data that are important" (p. 134). However, since the term validity is often associated with the positivist approach, Lincoln and Guba (1985, cited in Golafshani, 2003) preferred using "dependability', in qualitative research which closely corresponds to the notion of 'reliability' in quantitative research" (p. 601), while Clont (1992) and Seale (1999, cited in Golafshani, 2003) proposed "the concept of consistency or reliability in qualitative research" (ibid).

In order to enhance validity and reliability, the methodology applied in the study was carefully selected in order to sufficiently gain in-depth, rich and meaningful accounts of the participants. To ensure that validity was maintained in this study, I selected the participants using purposeful criterion sampling and employed several data collection methods, namely, structured interviews, participant observations, and document analyses. The analysis procedure employed in the study minimized bias and paid special attention to detailed accounts of the participants, which are presented in the chapters containing the findings. I also spent an elongated period of time observing the participants in different settings. Guba and Lincoln (1981, cited in Merriam, 1988) argued that "findings will be considered more valid by some [researchers] if the repeated observations in the same study or replications of the entire study have produced the same results" (p. 171).

Enhancing reliability and validity in the study

This study attempted to enhance reliability by providing a detailed description of the methodology used and illustrating its applicability in the research. Patton (2001, cited in Golafshani, 2003) argued that "validity and reliability are two factors which any qualitative researcher should be concerned about while designing a study, analysing results and judging the quality of the study" (p.601). In an attempt to enhance reliability, I used direct quotations taken verbatim from the transcriptions of the audio-taped interviews with the participants. Hence, interpretive validity was enhanced by the participants' descriptions of their experiences in their own words. A detailed description of the theoretical context of the study is provided to help other researchers understand the process involved in the interpretation of data. Furthermore, I spent a period of three months observing and member-checking with the participants to ensure consistency in the responses. I also used multiple approaches for data collection, which included in-

depth interviews, participant observations and document analysis. These strategies contributed to the understanding of the participants' perceptions and experiences, which were central to this study.

In order to ensure the accuracy of the transcriptions, I repeatedly read verbatim transcriptions of each audio taped interview. I kept a reflexive journal with records containing personal thoughts and feelings about the interviews. Additionally, during observations, I took notes of the participants' expressions, tone, change of mood and events occurring in the school. Finally numerous scholars including, Banteyerga et al (2003); Mawar et al (2005); Nwanna (2009); Stein (2003); Varas-Diaz et al (2005); Staggs (2007) and, Shott (1979) have utilized social stigma theoretical framework to investigate the experiences of stigma and social interactions among adults living with HIV/AIDS. Theoretically, validity of the current study was enhanced by utilizing this theory to investigate the experiences of AIDS stigma and discrimination of CLWHA in a Kenyan public school.

Generalizability and transferability.

"Generalizability is defined as the degree to which the findings can be generalized from the study sample to the entire population" (Polit & Hungler, 1991, p. 645). Moreover, as Robson (2002, cited in Cohen et al. 2007) remarked, "case studies opt for analytic rather than statistical generalization. That is, they develop a theory, which can help researchers to understand other similar cases, phenomena or situations" (p. 253). Transferability refers to the ability to generalize, or the extent to which the results of the research could be applied to other situations. Lincoln and Guba (1985, cited in Eisenhart, 2009) argued that "transferability of findings or results from one context to another is

possible if the contexts are sufficiently similar" (p. 56). However, the authors noted that "transferability depends on detailed knowledge of both the sending and receiving contexts" (ibid). This study is case-specific involving children living with HIV/AIDS attending the Karibu School. Although generalization of the findings in this study may be limited, its contribution and credibility can be judged using the tenets that numerous authors cited in this chapter have proposed. Basing my study on Morse et al's (2002) argument that the results of any type of research method can be applied to other situations, I argue that transferability of this study's results, the methodology and methods employed in this study can be applied in a similar context, for example, in institutions of learning where CLWHA attend school.

CHAPTER FOUR: PARTICIPANTS' PROFILES

In the section of this chapter, I provide a synopsis of the participants' profiles. Understanding their demographic and background information is important in clarifying their responses to the research questions and in illuminating their educational experiences in a public school. Utilizing specific criteria to select the participants enabled me to select a total of 22 participants comprising three different categories. The first category consisted of twelve [6 boys, 6 girls] children living with HIV/AIDS (CLWHA) from grades 4-7 aged 10 to 15 years. The second group was comprised of eight [6 females, 2 males] classroom teachers from grades 1- 8. Group three included two [1 female, 1 male] administrators from the Karibu Primary School and Kivuli Children's Home. All twelve CLWHA volunteered to participate in the study. Using purposeful sampling I selected classroom teachers because of their unique role, which permitted them to closely interact with the children. I considered the length of their teaching experience in the specific school as an important factor, and in particular, teachers who were already in the school when CLWHA were first admitted in 2004. Selecting classroom teachers was advantageous because of the unique and in-depth information they were able to provide. To ensure anonymity of the participants, any identifying information and names of persons and institutions have been replaced with pseudonyms.

HIV-Positive Children's Profiles

Participant # 1: Tindi

Tindi was a 10-year-old healthy looking young girl in grade 4 during the time of the interview. She started grade one in 2007 at Karibu Primary School. During the interview, she talked about herself and her hopes for the future. She seldom mentioned

her family and did not seem to have much information about her background. Therefore, her world revolved around Kivuli Children's Home and Karibu School.

Tindi often appeared withdrawn and did not interact much with other children particularly when at school. During the interview, she expressed feeling a sense of insecurity because she imagined that too much interaction with other children could divulge information about her or about Kivuli Children's Home. Consequently, she opted to be on her own. For example, whenever she went to pick up her lunch from the box or from the van, she walked alone and then returned to the classroom where she ate her lunch in silence. In spite of her familiarity with other children and the environment being more conducive to socialization, I observed similar behavior on several occasions. Tindi, however, was academically focused and took her work seriously as her class teacher confirmed: "Tindi is smart and well focused in her class work." During class observation, I noticed that Tindi actively participated in the lessons. Often times her hand was up ready to answer the teacher's questions. Nevertheless, Tindi did not ask any questions when I was in the class. The classroom teacher had appointed Tindi as a group leader in class 4, and although she had leadership skills, she did not have the ability to control the group. As the teacher commented, Tindi was too soft for a leadership role. Tindi however was very proud that the teacher had appointed her group leader in her class.

Participant # 2: Kakubwa

At the time of the interview, Kakubwa was 15 years old and in class 7. She was among the first children to join Karibu School in 2004. She was a healthy looking girl with no visible symptoms to suggest that she was HIV-positive. The teachers reported that Kakubwa had told her classmates that she was no longer on HIV medication. She had

a large body for her age, which made her appear more mature compared to her peers. Kakubwa had an older brother in form one who resided in a different children's home. However, she did not explain to me whether her brother was also infected with HIV. She told me her mother died when she was a baby and being younger than her brother, she could not recall details about her parents. All she could remember was that her auntie brought her to Kivuli Children's Home when her mother died.

Kakubwa was among the first children to visit relatives when Kivuli Children's Home initiated the home visit program in 2006. The visits provided her with an opportunity to spend time with her brother and visit relatives and friends, something she could not do while at Kivuli Children's Home.

According to the teachers, Kakubwa took advantage of her size to intimidate other children. She also liked to do things in her own way. However, when at Kivuli Children's Home, she was quite popular with the younger children who looked up to her as their big sister. When at school, she loved being in the company of her two close friends. Although Kakubwa was rated average academically, she aspired to become a lawyer.

Participant # 3: Kariuki

Kariuki started school at Karibu Primary School in 2006. During the time of the interview, he was in grade 5 and was 14 years old. He came to Kivuli Children's Home as a little baby after the death of his parents. Apart from this sketchy information, he did not know much about his parents although he had relatives that he visited during the vacation. Owing to prolonged ill health, Kariuki was small in stature for his age. He had a recurrent chronic chest infection, which occasionally caused him to be absent from school. At the time of research, he developed a very bad bronchial attack, which resulted

in a persistent cough that forced him to stay away from school for more than one week. I had to postpone the interview session with him until he was fully recovered. Although he had no evidence of physical symptoms of HIV, persistent coughing and general malaise made him feel constantly weak and tired most of the time. As a result, he habitually fell asleep during lessons especially in the mornings, and he blamed his behaviour on inadequate sleep because he woke up very early to come to school.

Kariuki had an extremely friendly personality and he was also very confident. His pleasant character and charm made him popular and won him numerous friends especially in school. In comparison to other children, Kariuki had more friends in school than any of the 37 children from Kivuli Children's Home. According to him, the happiest time of his life was being with friends. I noticed during observation that he was in the company of different children all of whom he introduced to me as his best friends.

However, what was unusual about Kariuki was his need for attention. During my volunteership at Kivuli Children's Home, he noticed I had a mobile phone with an inbuilt radio system. He asked me if he could use it to listen to music and this turned into a routine. Similarly, when he noticed I also had a digital camera, he asked me if he could use it to take pictures. With the two gadgets in hand, Kariuki walked around the compound listening to music while taking random pictures of the children and the buildings. He also moved from one cottage [children's houses] to another demonstrating that he was a very gifted boy. Indeed, this made him feel special and more superior to his peers. I could tell it made him feel very good about himself.

In spite of being academically weak and doing little to improve his grades including not putting an effort towards doing homework, the class teacher had made him

a class prefect, which made him very happy. The class teacher however told me that Kariuki did not participate in physical education classes or games. Kariuki was passionate about football but he accused the school boys of being too rough and was afraid of being injured a second time.

Participant # 4: Kamweru

Kamweru was a beautiful 15-year-old girl, with chocolate brown complexion and long black hair. Most teachers described her as a pleasant, and extremely well behaved young girl, who took her schoolwork seriously even though she was considered academically average. She started grade one at Karibu School in 2004 and was in grade 7 when I interviewed her. New Life, a charitable organization brought her to the Kivuli Children's Home after her mother abandoned her in one of the city's hospitals. Although she seemed well informed about her background, she was extremely concerned that she had no family she could call her own. She explained:

> Oh… I came to here when I was a baby [laugh]. But I know the hospital where I came from. [Which hospital?] City hospital [Name withheld]. I don't even know whether I have relatives [smiling].

In order to give Kamweru a sense of belonging to a family, the social worker at Kivuli Children's Home had taken her to her family home for the last two years. Similarly, friends would take her for a day out. She had two sponsors who lived in Ireland and Italy respectively and plans were underway for her to visit Italy. She deemed any place that could give her a different experience more exciting. Kamweru was optimistic that her mother was alive and if by good luck she came to learn that her daughter was alive, she would hopefully come to look for her. She wished the Kivuli Children's Home administrators would be more aggressive in the search for her mother.

Unlike the other HIV-positive children who always sought the company of their own, Kamweru interacted well with her peers in school. During the interview, she raised some issues with regard to HIV/AIDS disease, the antiretroviral drugs (ARVs), and the possibility of having children. She sought answers as to why she contracted HIV, and what would happen if she was involved in a relationship. In addition to the HIV/AIDS disease, these were some of the important challenges that Kamweru had to deal with. Like other children, she was equally optimistic that after becoming financially stable, she would financially support Kivuli Children's Home.

Participant # 5: Makena

Makena was 12 years old and in grade 4 at the time of the interview. He was a charming little boy who always had a smile on his face, hence the nickname Makena, which means "the happy one". He joined Karibu School in grade one in 2007. Makena lost his mother when he was about two years old. As a result, he lacked detailed knowledge about his parents or relatives. The reason his grandmother brought him to Kivuli Children's Home was because his aunts and uncles had persistently complained about his deteriorating condition, since he had very conspicuous HIV symptoms that were a cause of embarrassment to the entire family. The grandmother's decision to bring Makena to Kivuli Children's Home was for the boy to die elsewhere, far from home and in doing so she appeased her daughters and sons. Fortunately, Makena survived and grew to become a very handsome boy. In 2006, the Kivuli Children's Home administration contacted the family and Makena was able to visit his relatives for the first time. Unfortunately, the family visited him once and thereafter changed the phone numbers to discontinue further communication with Kivuli. In spite of the family's lack

of support, which Makena was unaware of, he still dreamt of joining his relatives in the near future.

There were three other HIV-positive children in Makena's class but he was the only boy and the two girls were extremely protective of him to the extent that they curtailed his freedom to interact with other boys. In addition, the class teacher made sure that the three children ate lunch in the classroom while she watched. Even though Makena was an innocent looking boy, he had very few friends in school. Makena actually blamed this on limited time to interact with boys his age while at school and lack of exposure to the outside world. During study observation, I noticed that the two HIV-positive girls from Kivuli Children's Home in Makena's class were too controlling, thus denying Makena a chance to mingle freely with other children. Additionally, lunch break lasted for a half hour during which the classroom teacher made the three children eat lunch in the classroom and by the time they were finished, the break was over.

Makena felt that Kivuli Children's Home was a perfect home. According to him, most of his friends were envious of this fact. He explained with a big smile on his face:

> Kivuli Children's Home is a nice place. I like being here. My friends think we are rich [Why?] Because we get everything…. When we are going for a trip we carry popcorns, crisps…. And then my friends say, "The Kivuli Children are richer" [He said smiling].

As I casually engaged the children in informal discussions, I. observed that most of the younger children shared a similar opinion.

Participant # 6: Trina

Trina was a 14 year old girl in class 5. She was always a smiling child especially when engaged in a conversation. She did not give much information about her family although she did indicate that her aunt lived in Nairobi and that she visited her during the

school holidays. It was clear from her sharing that she did not like being at her aunt's place and given a chance she would opt to stay at Kivuli Children's Home. In her view, though the aunt's place was reasonably good, it was somewhat different because it lacked the comfort and the lavishness that Kivuli provided.

At the time of the interview, she had a persistent, disturbing cough that caused her to frequently clear her throat. In spite of this symptom, she looked healthy and cheerful and had no other signs of HIV. She visited the doctor for regular check-ups since that was the routine that every CLWHA had to follow.

Trina was one of the children who had transferred two years earlier from a nearby public school. She therefore joined Karibu School in grade 4. Sharing about her old and new school, she said she found schoolwork challenging although she was working hard to catch up with the other children. During the discussion Trina expressed that she was looking forward to joining high school although she had three years before that could happen. "I want to get out of primary school. Primary is now boring." Apparently, several children shared a similar view because of the belief that high school was an avenue to the outside world.

Trina shared her experience willingly and answered all the questions satisfactorily, but there were moments of long silence, smiles, and inexplicable giggling. In order to keep her focused in the interview and to keep the discussion flowing, I had to use probes and prompts without necessarily making her feel coerced to talk. She also appeared fidgety from time to time, the reason being that she missed the company of her girl friend. She at one point asked if her friend could join the discussion and I had to explain that I wanted to hear her personal views. I knew Trina and her friend were inseparable since

they were always together at school and at home; hence, being away for as long as half an hour was definitely affecting her concentration. Trina related how happy she was with all that Kivuli Children's Home had done for her. To show gratitude she promised to support Kivuli and other orphans in the future.

Participant # 7: Gatarina

Gatarina was in grade 6 when I interviewed her and she had turned 14 years in September. Unlike other children who were orphans with no parents, Gatarina's mother was alive and everyone knew that she worked in a children's home somewhere in Nairobi and Gatarina visited her occasionally. After talking to Gatarina, I realized that she had very little information about her mother; the administrator mentioned that the mother suffered from a mental condition and could not cope with the special needs of an HIV child. As a result, her uncle brought her to Kivuli Children's Home when she was young. She did not seem to understand why the uncle had brought her to Kivuli Children's Home. She had one brother who had completed form four and was still at home looking for a job. However, Gatarina was oblivious of where and with whom her brother lived. Instead of going to stay with her mother, her uncle came to pick her up to spend the school holidays with his family.

Although she considered herself academically smart on the basis of her performance in her former school, she was stunned that her grades declined after joining Karibu. She said she used to be rank 4th, but when she moved to Karibu School she was ranked 14th. She later improved however and had attained number 7 the previous term. She admitted that competition in the class was quite stiff and generally the school was geared towards academic excellence in the final exams. Although she worked hard and

was determined to regain her class rank in the end of term exams, she alleged that her peers were smarter than she was. She told me her best subjects were Science and Christian Religious Education (CRE).

In the course of the interview, Gatarina raised some questions, which illustrated that HIV was a very significant challenge for her. She sought answers regarding HIV management, HIV cure and wanted to know whether HIV/AIDS could be cured through prayer. I guessed that the prayer idea emerged from the healing prayers that were held at the Vincentian Shrine, which the children attended from time to time. She emphasized this point as she tried to convince me that with faith and prayer HIV cure was inevitable. As we concluded our discussion, Gatarina pointed out her commitment to support Kivuli Children's Home in the near future as a way of showing her gratitude for all she had received.

Participant # 8: Kalee

Kalee was a tall 15-year-old boy in class 7. He was brought to Kivuli Children's Home at the age of 3 after the death of his parents. Even after having lived with HIV for 15 years, Kalee appeared healthy, athletically fit and very energetic. He was an exceptional footballer who liked to be challenged in the field. Every Sunday after lunch he would join other boys in a competitive match. Sometimes boys from other children's homes or nearby schools played at Kivuli Children's Home where Kalee, who acted as a team leader, bravely led his team to a captivating match that thrilled the entire population there. Outside the field, however, Kalee looked reserved, rather quiet, apprehensive and somewhat disturbed. He seldom smiled except when he was in the company of his friends.

Kalee had an older brother who had already completed high school and was looking for a job. His younger brother had died. His aunt accommodated him whenever he went home for the holidays. She had grown up children with whom Kalee spent time whenever he was at home. The break provided an ample opportunity for re-uniting with his brother and relatives. Although he was happy to be at Kivuli Children's Home, he had concerns that after entering high school, which was only two years away, he would have to leave Kivuli Children's Home and learn to be on his own. He worried about the life outside Kivuli Children's Home and how he was going to adjust once he left. With no experience of the outside world, he worried and wondered what the future had in store for him. The thought of it frightened him as he explained:

> I was told that when I finish [Primary] I have to leave Kivuli Children's Home [Why] Because now after boarding school I just go home [Is that O.K. with you?] I don't like the idea because I am used to being here.

As difficult as this decision might have been for the administrators and the children, the guidelines of the Kenyan law regarding children residing in institutions after age 18 had to be respected. However, in spite of the future being so uncertain, the idea of going to a boarding high school was fascinating. While it is possible to assume that this is contradictory, Kalee had reasons for it.

> Now I am tired…. I would like to go to another school...high school. I would like to go to a boarding school. [Is that not going to be equally difficult?]
> It is difficult but it is better because you come here [Kivuli Children's Home] you see small children playing then even you want to join them… but in the boarding school everybody is serious.

Besides wanting to become a lawyer, Kalee had no other plans.

Participant # 9: Karisa

When I interviewed Karisa he was 14 years old and in class 6. Karisa and his youngest sister had been brought to Kivuli Children's Home two years earlier from another children's home. He said he had older siblings and a grandmother but he did not elaborate much about his relationship with them. He focused more on the death of his mother and the role his maternal aunt played, which demonstrated that she remained the key person in his life because she cared for them when they visited her during the holidays. He was very well informed about the cause of death of his parents and why he and his sister were at Kivuli Children's Home. He articulately but painfully recounted how his mother became sick with HIV/AIDS and how she transmitted the virus to the father. "My mother became sick first and because she did not know what it was, she transmitted it to my father. She died first and then my father died after."

The younger sister [7 years old and in grade one] had shared in detail earlier about the family and the death of her parents. She said, "One day my mother was in the house. Then she began breathing heavily. After that she collapsed and died. Then my aunt took us to another home." According to Karisa, the aunt was prepared to take care of them but she did not have enough funds to support them so she decided to take them to a nearby children's home where she could visit them regularly. Unfortunately, there were many challenges as Karisa pointed out:

> The conditions there were very bad. The villagers insulted us and when we went to school the other children abused us because most of the people knew about our parents. It was very hard even to study.

He explained further why the aunt decided to take them to Kivuli Children's Home:

> The lady who owned the children's home mistreated us. So my aunt decided to look for another place for us because we were not getting good care. She said the

> lady was not helping us to cope with our parents' death. After that she brought us here. It is very good here.

In comparison to his former residence, Kivuli Children's Home was an ideal home where a comfortable shelter and a good education motivated him to work hard in school. He was intelligent, academically focused and showed commitment to his work as most teachers noted.

> Karisa is respectful, and an academically motivated child with strong commitment, especially when it comes to accomplishing his academic goals. He is a competitor and exceptionally studious.

Karisa was convinced that education was the only substantial gift that Kivuli Children's Home provided for the children. Education was a bridge to better things, which included improving his health. With an education, he was certain of getting a job and taking care of his needs. He said he did not want to lament over his sickness but rather devote his energies to his academic work. Unlike other children who viewed the sickness as a bad omen and were obsessed with why it had happened to them, Karisa's attitude was positive. When I asked him how he felt about the disease he responded:

> I know it is a bad disease and I can do nothing about it, but I know I can live with it and not die if I continue to take the medicine. Then I can work hard so that in future I can become a pilot…and take care of my young sister and myself and then help those in need [meaning the children at Kivuli Children's Home].

Karisa demonstrated a lot of confidence during the time of the interview. When I gave him the option to speak in Kiswahili or English, he chose the latter and spoke in fluent English.

Participant # 10: Kairu

When I interviewed Kairu he was 14 years old and in grade 6. He has been living at Kivuli Children's Home all his life because his relatives brought him there as a baby.

He was a pleasant, quiet, but a somewhat reserved teenager who did not like to be bothered. He appeared withdrawn and unenthusiastic even while interacting with his age mates, but comfortably played with the younger children. He portrayed himself as a responsible and hardworking boy because he assisted with chores in the kitchen and took part in manual work in the compound. He always delivered the food for the other children from the kitchen to the cottages, while other times he was busy working in the compound or pushing a wheelbarrow from one building to another. He was passionate about playing football especially Sundays when visiting teams came to play with the Kivuli Children's group.

Kairu started education in a nearby school but later transferred to Karibu School. Shifting to a new school did not augur well with him; hence, the lack of enthusiasm about learning. Being an active footballer, the new school fell short of his expectations because he missed having fun with his friends during games. Kairu said he missed his friends from the former school, and although he would have loved them to visit him, the rules restricted outsiders from visiting the home.

Kairu's relatives lived in the Nairobi suburbs, so Kairu visited them during the school holidays and spent adequate time with them. He mentioned that the relatives did not pick him up the previous holiday due to some financial problems. Financial problems were the reason many families had to surrender the children to Kivuli Children's Home where they could receive sufficient support. Kairu's case fell into this category of families where an additional child was considered an additional financial burden. Despite the family's grave financial situation, Kairu strongly felt that living with his family was a better option.

Like other children, Kairu had dreams for the future, in this case becoming a driver. When I asked him whether he had thought of other careers such as becoming a doctor or teacher, he said no. Although Kairu answered all the questions perfectly, his answers were dragged out and short so I had to probe until he was ready to provide a full answer. In my view, Kairu seemed to have personal issues that he was trying to deal with. After spending some time together he asked to leave so that he could join his friends in the field to play football.

Participant # 11: Beata

Beata was a shy 13-year-old girl in grade 5. She enrolled in grade one at Karibu School along with a few other children. Linda, her best friend, was not from Kivuli Children's Home and whenever she was in school, they were inseparable. School was important to her because she wished to become a teacher after graduation. Her attitude towards the teachers was somewhat mixed as she explained. "Some of the teachers are good but others are bad." It was therefore unclear whether she admired the teachers or that teaching to her was just another career.

Beata's physique was too big for her age, thus contrasting with her mannerisms, which in my view were extremely childish. Beata constantly sought the attention of adults, and was occasionally moody, but this did not cover up her charming personality, which resurfaced whenever her spirits were high. I had a hard time keeping Beata away from me since she expected me to attend to her even when I was in the company of other children. However, this attention seeking behaviour did not prevent Beata from being friendly and helpful to the younger children.

Beata was brought to Kivuli Children's Home Children's Home when she was a baby. She had no information about her family and Kivuli Children's Home was trying to get a family that could sponsor her in order to give her a family experience.

During the interview, Beata was cheerful and talked almost non-stop about everything. She was naïve to obvious things that children her age would normally be well informed about, for example, she could not provide a sufficient response to a question asking her to identify some of the things she was interested in. I attributed her ignorance to lack of exposure to whatever was happening outside the walls of Kivuli Children's Home. This was a common experience for all the children. When I spoke with Beata, she felt more privileged than other children. Given her character, of wanting to feel special, she seized the opportunity of our discussions to ask me to buy her sweets. I bought sweets for all the children but I gave her a pair of earrings which she wore every Sunday and made sure everyone saw them after church.

Participant # 12: Lekule

Lekule was 15 years at the time of the interview and was among the first HIV-positive children to join a public school in 2004. He was in grade 7. New Life, a charitable organization that cares for orphans, picked him up from the city hospital when he was a baby and brought him to Kivuli Children's Home. Therefore, he had no knowledge about his relatives despite efforts being made by the social worker to find out about his background. He shared the little information he had acquired:

> The social worker told me that my parents are alive but they don't know where they are. [Why?] You know whoever gave birth to me left me in the hospital (Coughs). So they [Parents] don't know where I am. The hospital contacted New Life and I was brought here [Coughs]. That is why I keep pressing uncle to talk to the social worker so that he can find out more about my parents. …But one day I

> got some time and I went to the social worker's office and I was shown my file and my history. I do hope some day I will be able to meet with my parents.

Lekule's "mum", the care-taker in the cottage where he was placed, gave him two names, Lekule and another name. However, his view was that he had only one name; Lekule [Christian pseudonym] but stated that he did not understand where the other name, a surname, had come from. Lekule had no relatives who could visit him at Kivuli. He therefore depended on sponsors and the caretaker in charge of the boys as he explained:

> I don't have anyone except friends and sponsors who come to visit me occasionally. But uncle [The caretaker in charge of the boys cottage] takes me to his house to spend the holidays with him.

"Uncle" and Lekule's friends lived in the outskirts of Nairobi city. Consequently, Lekule had little perception of the countryside other than what he saw once when he passed through a rural area on a school trip. He therefore yearned for someone to adopt him so that he could venture out of the confines of Kivuli Children's Home. However, he was cognizant that after attaining age 18 he would leave and settle down on his own. He indeed liked Kivuli Children's Home but having lived there for so long, it was not exciting any more. He explained:

> Here is boring…people are boring. Sometimes you don't have anything to do…just disturbing others. [Don't you play with other children?] I play but when I am tired I don't have anything to do [Coughs).

At Kivuli, Lekule was a cheerful, responsible and very hardworking boy. He helped with chores particularly in the compound and in the kitchen. He was also actively involved in church choir and played drums during the Sunday service. Teachers' view of Lekule was negative because they perceived him as undisciplined, a troublemaker, a bully and a nuisance to his classmates and to the teachers. They however commended his active participation in games.

Mrs. Mwega, the classroom teacher reported that Lekule used to exchange his lunch for Ksh.10.00, which he used to buy mandazi, a type of doughnuts. He justified his action saying that he wanted to taste other people's food. Although Lekule supported the idea of getting married, he was not prepared to raise a family. After listening to Lekule, I learned that he had adequate information about the implications of the HIV disease; hence, he was unprepared to fully commit himself to a marital relationship.

Teachers' Profiles

1. Mrs. Serare

Mrs. Serare had transferred from another school to Karibu School in 2003. The first six HIV-positive children to be admitted in the school encountered her there. She has been in the teaching profession since 1986, and had taught in several schools in Nairobi. She was the class teacher of grade one although she had taught in grade two the previous year. There were three HIV-positive children in her class, two girls and one boy. Teaching in lower primary gave her an opportunity to interact with the younger admitted HIV-positive children. She was very concerned about the children and appeared to have a deep understanding of the children's needs. I noted this concern when she said she was wondering what had happened to one of the girls who was in her class a year earlier.

She told me that the when the children reported to the school, the social worker and the child's "mum" from Kivuli Children's Home made an effort to meet with grade one teachers in order to introduce the children, to inform them about their condition and to assure them that if anything should happen to any of the children, they should contact the social worker immediately. From what I gathered from Mrs. Serare, all the teachers in

lower primary, including grade four were given the mobile phone number of Kivuli Children's Home.

Mrs. Serare was a soft-spoken person but always very cheerful. She was very articulate and humorous particularly when narrating the turn of events when CLWHA were first admitted to the school. She had a deep motherly touch and as a result the children had a special liking for her. During morning and lunch breaks, Mrs. Serare stayed in the classroom over lunch hour so that if any of the children had questions or needed to be assisted with schoolwork, she was there for them. She ate her lunch listening to the children talking, telling stories, and accusing each other of petty issues, and she cuddled those seeking attention. Her tight schedule limited her interaction with the teaching staff, since she had to mark the assignments, issue homework and prepare lessons. She was virtually absent when other teachers assembled for tea and lunch breaks.

2. Mr. Hose

Mr. Hose was the longest serving and oldest teacher in the school. He had taught for about 35 years in different schools within and outside the city. He moved to Karibu School in the 1980s. He was also the most liked and respected teacher among the staff and the pupils. According to most of the children I interviewed, he was the best mathematics teacher in the school. He was also the teacher in charge of First Aid.
Mr. Hose was endowed with HIV knowledge gained through workshops and seminars. He attended seminars on his own initiative during the school vacation because both the school and the Ministry of Education showed no commitment to empowering teachers despite the increasing number of HIV-positive children in public schools. He argued that given the presence of HIV-positive children in the school, he felt compelled to deepen his

knowledge on the subject so that he could assist the children and offer advice to the teachers. He cited a few experiences of teachers whom he thought behaved inappropriately towards the children because they had inadequate knowledge about HIV/AIDS. He expressed disappointment because the school had refused to pursue his idea of sponsoring teachers to attend HIV seminars. "I had gone for a seminar…and there was a time I tried to introduce it here [School]…to the teachers and they went…a few but there was no follow-up. It sort of died." Without giving up, he approached the administration again, though his efforts were fruitless.

> Out of one seminar I tried to sell the idea to the school of how we can go but it was not supported. The administration did not support it and I think the body that had organized it did not support it either.

In his view, HIV knowledge was critical for both teachers and pupils and for a smooth integration of HIV-positive children into the school. Besides, he envisioned knowledge for the entire Kenyan population as an essential tool in fighting HIV transmission as well as combating the related stigma and discrimination of PLWHA.

Outside his teaching career, Mr. Hose owned an elementary private school, which was managed by his wife, who was a retired teacher. He told me there were HIV-positive children in his school and had advised the teachers to maintain non-discriminatory treatment of these children. He established the school because he had been planning to retire but when the retirement age was reviewed, the Ministry of Education asked him to stay until he attained the age of 65. From my observation and encounter with Hose, it was apparent that his teaching commitment went beyond the classroom. I noted that habitually, on every lunch break, Mr. Hose sat on a bench under a tree waiting to assist grade 8 pupils with math questions. Owing to his approachable nature and the respect

they had for him, a large number of pupils came to him without reservation to ask questions about a particular subject, or to discuss personal matters.

3. Mrs. Mwega

Mrs. Mwega had been a teacher since 1981 but had only been teaching at Karibu School for about three years. She was the classroom teacher for grade seven with 62 pupils, three of them being HIV-positive children [Lekule, Kakubwa and Ritho]. In addition to her elementary teaching certificate, she had pursued a bachelor and masters degree in education and was thinking of moving to a university college to teach. Having taught for almost 30 years in a primary school, and the fact that she had better academic credentials that could earn her a better job, she was yearning for a career change. She said she felt bored doing the same thing every day and even if the Teachers' Service Commission [TSC-Teacher's employing body in Kenya] did not consider her for service benefits, such as salary increment, she wouldn't mind losing them as long she was able to find a fulfilling job.

Mrs. Mwega said she had learned about HIV-positive children from the former class teacher of grade 6 when the children moved to grade 7. I found her well informed about the HIV-positive children in her class as well as those in other classes, and she was able to point out how each of the children differed from the other. HIV/AIDS was not a problem to her because some of her family members had suffered from HIV/AIDS. She also explained that she had encounted and HIV grade 5 boy in her school. She expressed that though some CLWHA had made teaching and learning difficult for both teachers and pupils, she was determined to deal with unruly CLWHA.

4. Mrs. Siti

Mrs. Siti was the classroom teacher for grade 4. She began her teaching career in 1973 and had taught in several schools before the Teachers' Service Commission transferred her to Karibu School in 2003. Apart from the Primary Teacher Certificate [P1], she was also trained in HIV/AIDS and Community Development, Counselling and First Aid. These qualifications were an asset for the Karibu School community. Unfortunately, she was close to retirement from teaching. She was however, planning to use her skills in community work.

Children with HIV/AIDS remained close to her heart because her brother and sister-in-law had succumbed to the disease a few years ago. For this reason, Mrs. Siti made sure that the classroom environment was conducive for the three HIV-positive children. After noticing the children were not eating properly, she suggested that Kivuli deliver lunch for the children. After the school accepted her suggestion, she had to ascertain that the three HIV-positive children in her class had enough to eat before allowing them to go out to play. Mrs. Siti was convinced that no matter what the challenges of dealing with HIV-positive children were, it was their responsibility as teachers to support them.

5. Mr. Maua

Mr. Maua had taught for several years as an untrained teacher before he enrolled for an in-service teacher-training course. After completing the course, he continued to teach science in grades 7 and 8 at Karibu School. Therefore, unlike the other teachers, Karibu was the only school he knew. He was classroom teacher for grade 8, and, as a result, he only knew HIV-positive children in grade 7 since there were no HIV-positive

children in grade 8. Mr. Maua was not a sociable person and hardly interacted with the other teachers. He reported to the school very early in the morning and when his lessons were done, he left and only returned later if he had lessons. He was however more at home with Mr. Hose, with whom he discussed general issues and also shared tea break while sitting on a bench outside.

As a science teacher, he taught about HIV and delved deeper beyond the provisions of the syllabus, because he was aware that most teachers not only lacked the skills to approach HIV issues but also found teaching it appropriately challenging. He categorically stated that issues pertaining to HIV were serious and given that the HIV-positive children were becoming adolescents, there was need for the school to strategize how to reach the children with meaningful HIV information, and called on the teachers to be open minded and show willingness to challenge the pupils when teaching the subject.

6. Mrs. Kisu

Mrs. Kisu had been in the teaching profession for over 35 years and was a few years away from retirement. She had taught at Karibu School for over 10 years and was the classroom teacher for grade two. There were two HIV-positive children [boy and girl] in her classroom whom she noted were active pupils in the class. Mrs. Kisu was the class teacher for grade one when the HIV-positive children first reported to school in 2004, which means that she was well versed with details of what challenges HIV-positive children faced as they adjusted to their new environment. As a result, she could vividly narrate the educational experiences of these children as well as reactions of teachers. As many of her colleagues had expressed, Mrs. Kisu explained that having HIV-positive children in the school and in particular being the classroom teacher was very difficult

because she was psychologically unprepared, and besides she lacked skills that could help her deal with any arising eventualities. She specifically noted that in the earlier days, the HIV-positive children used to have a multitude of health problems, which declined with age.

Mrs. Kisu admitted that her class rarely participated in physical exercise (P.E.) but pointed out that whenever the trainee teachers came for teaching practice, they took the children out for P.E. and the children loved it. In order to observe how the HIV-positive children interacted with each other in grade two, Mrs. Kisu and I arranged to take the children for one of their P.E. classes. As an experienced teacher, Mrs. Kisu was cognizant of the benefits accrued from physical exercises but the demands of the teaching workload (all subjects), from 8 a.m to 5 p.m. left little time for physical education even though the lesson was a part of the time-table.

Although Mrs. Kisu was not a trained social worker, whenever she noticed a problem in one of the HIV-positive children that needed her attention, she took time to counsel the child before discussing it with the administrators. She was therefore concerned about their health and performance and ensuring that they felt at home with their peers.

7. Mrs. Were

Mrs. Were was an experienced teacher in grade 6. Having been a teacher for about 15 years in several schools, she moved to Karibu School in 2004. There was only one HIV-positive boy in her class whom she applauded as exceptionally hardworking, smart and well disciplined. Reporting to the school almost at the same time when the HIV-positive children were admitted in the school was rather challenging because it was

going to be a new experience. She recounted how she worried at the time; however, being a government employee, she had little choice. She articulately related that the other teachers' greatest concern was the impact that having HIV-positive children was going to have on the reputation and performance of the school.

Unlike most teachers, Mrs. Were had received a one-week training course in HIV/AIDS, which in her view had contributed to a change in attitude towards people infected with HIV and AIDS. She believed strongly that training or continuous education in HIV/AIDS was an important tool for empowerment that could transform certain ways of thinking and behaviour that could be harmful to HIV-positive children. Owing to her newly acquired knowledge, Mrs. Were's general view of CLWHA was extremely positive and encouraging to those she interacted with in the different classes where she taught Kiswahili (Kenya's national language), Christian Religious Education (CRE) and Science subjects.

8. Mrs. Tini

Mrs. Tini was a soft-spoken teacher who taught Christian Religious Education (CRE) in the upper classes. In addition to her primary teacher certificate, Tini was a Bachelor of Education (B.Ed) with a specialization in Special Education. She was the newest teacher in the school having reported to the school the previous year (2009), and was also the classroom teacher for grade 5. Before moving to Karibu School, she had taught in several schools in the Nairobi province. She had encountered children with HIV/AIDS in her former schools; therefore, having to deal with a new group of HIV-positive children was not a challenge. There were three HIV-positive children in her class who had adjusted quite well to the school environment and actively participated in

classroom activities. However, Mrs. Tini observed that some children had severe academic problems, which were a result of falling asleep in class and hearing problems, which she contended, affected their academic performance. Additionally, she noted that when children were new to the school they persistently talked about where they lived [Kivuli Children's Home] because they expected the teachers to treat them in a special way.

Mrs. Tini was concerned that teachers lacked the necessary communication skills to teach HIV/AIDS, yet this information was vital for children in grades 7 and 8. She counted herself lucky because her university training had equipped her with knowledge and skills, which she found exceedingly helpful in teaching the HIV/AIDS subject.

Administrator: Kivuli Children's Home

1. Mr. Chrisy

Mr. Chrisy joined Kivuli Children's Home as an employee after the construction of the home was completed in 1996. He was charged with the responsibility for designing and coordinating educational programs for the children. In the absence of HIV/AIDS treatment, and the belief that the children's lifespan was short, an intensive school curriculum was not regarded as critical since the children were perceived to be on the verge of death. However, with high-quality nutrition boosting the children's health, an intense focus on their ongoing education became a necessity. Given that AIDS disease remains an abomination to a large segment of the Kenyan society, convincing head teachers to believe otherwise was a very difficult task. Listening to Mr. Chrisy narrate his tribulations with school heads, the Ministry of Education and parents regarding the admission of HIV- positive children was heart wrenching. He pointed out how despite the

government giving an approval for the admission of children into public schools, several head teachers with the support of teachers and parents rejected the children.

Being the longest serving employee, Mr. Chrisy is the chief manager and the assistant to the director of the home. He collaborates with all the over 100 workers in the project, coordinates children's programs, keeps the children's records and together with the social worker follows up and links the children with their relatives. Above all, Mr. Chrisy is ardently concerned about the children's academic progress. As a result, he has directed the social worker to regularly visit the school in order to get information about the children's school needs and progress. He therefore ensured that support for the academically weak children was provided on a daily basis.

Having worked with the HIV-positive children for the last 15 years, Mr. Chrisy said that meeting the needs of the children is an enormous challenge; hence, his involvement in local and international fund raising, which involves a lot of travelling as well as meeting with a large number of local donors. Listening to and observing his involvement with the children and the affairs of Kivuli Children's Home, Mr. Chrisy struck me as a devoted, self-giving young man whose interest and commitment to the well-being of HIV-positive children was his number one priority. He was particularly grateful to Karibu School for opening doors for Kivuli Children's Home children to realize their educational dreams.

Adminstrator: Karibu Primary School

2. Mrs. Nuru

Mrs. Nuru was the deputy principal of Karibu School. She had been teaching at the school for over four years but had taught in other schools for about ten years. The head

teacher informed her about the HIV-positive children when she joined the school, although he was not specific about which children were HIV positive. However, as an administrator, she had to deal directly with the children and the social worker, hence the need to personally get acquainted with each one of them. It is through her office that the school maintained a genial relationship with the home, which in her view, made consultations possible whenever issues of concern pertaining to the health and learning of the children emerged.

Being an administrator of such a large school (over 1000 pupils) was very demanding. Besides her teaching load, she also coordinated all the school programs and had to ensure that learning ran smoothly. When I went to the school to conduct research, I observed how involved she was in organizing meetings with teachers in order to evaluate the school performance in the past term and to lay strategies for improvement in national examinations at the end of the year. Although her schedule was tight, her work paid off at the end of the year when the national examination results were announced. Apparently, Karibu was always among the top schools countrywide.

In her office was a list of 37 HIV-positive children. The list contained the name and grade of each child. When I questioned her about the list, she explained that the list served as a reminder that each of the children deserved adequate attention. From time to time she would call one of the children to the office just to find out how she/he was doing. She made sure the children did not have issues in the school that would interfere with their learning. Whenever a child fell ill or had problems with any of the teachers, the matter was reported to her and she in turn informed the counsellor. She commended the commitment with which Kivuli Children’s Home administrators responded to any

concerns raised by the school. According to Nuru, having HIV-positive children in school was a huge challenge, and protecting and promoting their well-being was an important task for the entire school community. Although this practice was in accord with the Ministry of Education non-discriminative policy, she also believed that it was necessary for the school to declare the school caliber and what parents should expect to find during the admission of their children. "Even writing something for the parents when they are coming in is important because this school has all types of children. Ours is an inclusive-integrated school."

Unlike other teachers who lacked HIV skills, Mrs. Nuru had been sponsored for a one-week workshop focusing on HIV/AIDS and the Most Vulnerable Children (MVC) by the Ministry of Education in order to obtain information and skills that would enable her to support the school in providing emotional and financial support to the children. She generously shared the information with other teachers upon her return and suggested that other teachers to do the same whenever they attended an educational workshop. I think she played her role well because any time I talked with the children, they quickly pointed how her kind demeanor made them feel good while at school.

CHAPTER FIVE: EXPERIENCES OF AIDS STIGMA AND DISCRIMINATION

In this chapter I present the findings of the study. During the course of the data analysis, five major themes, categories and sub-categories were developed. The themes portrayed CLWHA's positive and negative experiences while in school. The first theme described the experiences of stigma and discrimination within the school setting by children living with HIV/AIDS (CLWHA) and explored the various ways in which stigma and discrimination were manifested. Participants' descriptions of AIDS stigma involved stigmatization by parents, teachers and peers. Under this theme, experiences of received, internalized and felt stigmas were discussed. The second theme discussed the effects of stigma and discrimination. Under this theme, various strategies that CLHWA employed, and the efforts to combat stigma and discrimination are explored.

CLWHA's positive experiences were discussed in themes three, four and five. Theme three focuses on supportive and empowering experiences of CLWHA as well as that of teachers. Under this theme, CLWHA experienced various types of support from teachers and peers. Theme four explores educational resources and initiatives that were used to address the needs of CLWHA. The fifth theme describes the educational experiences of CLWHA. Information regarding CLWHAs' attitude towards learning, academic performance, career and family aspirations was gathered from CLWHA, classroom teachers and the administrators. The themes developed from the study were discussed and supported by quotations from the interviews.

Negative Experiences

Theme 1: Manifestations and experiences of AIDS stigma and discrimination.

The emerging theme focusing on the manifestations and experiences of AIDS stigma and discrimination was reflected in numerous literature studies that were specifically reviewed in chapter two and pointed to the experiences largely involving the adult populations living with HIV/AIDS (Varas-Diaz et. al., 2005; Makoae, et al., 2008). Goffman (1963) defined stigma as an attribute or quality that "significantly discredits" (p.3) an individual in the eyes of others. UNAIDS (2002) referred to stigma as a process that occurs within a particular culture or setting where certain attributes are seized upon and defined by others as discreditable or unworthy. Link and Phelan (2001) emphasized that stigma allows separation and labelling that leads to status loss or discrimination (p.367). Studies conducted by Holzemer et al (2009) and Greeff et al (2008) found that PLWHA experienced three types of stigma namely, enacted or received stigma, internal stigma and associated stigma. Similarly, Shamos et al's (2009) study involving men and women living with HIV/AIDS in Swaziland demonstrated various ways in which AIDS stigma was manifested.

In my study the manifestations of AIDS stigma were defined as negative treatment, perceived mistreatment, social isolation or exclusion and denied opportunities by teachers and peers because of the CLWHA's serostatus. In order to establish the various manifestations of AIDS stigma in the school, and to investigate CLWHA experiences of stigma and discrimination, the following questions were directed to CLWHA, classroom teachers and the two administrators. In order to understand the

participants' experiences of received stigma, questions were directed to CLWHA, classroom teachers and the administrators from Kivuli Home and Karibu School respectively. The first question required them to state whether AIDS stigma existed and to demonstrate how it was manifested in the school. The second question asked them to identify and describe incidents of HIV/AIDS stigma and discrimination they had experienced or witnessed. The responses indicated that perceptions of enacted or received stigma were comprised of negative treatment by teachers and peers. Internalized or personalized stigma was expressed as fear of disclosure, denial, withdrawal and social-isolation. CLWHA indicated that topics on HIV/AIDS and the intake of antiretroviral drugs contributed to their experience of internal stigma. Felt stigma was portrayed as imagined or perceived mistreatment or discrimination. In this study, felt stigma was characterized by the fear of peers knowing about CLWHA HIV status in case of rejection and the fear of losing supportive friends as a result of this knowledge.

Received or actual stigma.

Bond (2004) defined actual or received stigma "as the actual stigma and discrimination of others, the behavior and treatment of people in their surroundings, and how they perceived the stigmatized" (p. 40). Additionally, Brown et al (2001) stated that "enacted (actual) stigma, on the other hand, refers to the real experience of discrimination" (p. 4). The participants recounted their personal experiences and observations of received stigma. Common responses from the participants indicated that received stigma originated from parents, teachers and peers.

Stigma by Parents.

Parents of other pupils had no direct contact with CLWHA particularly while in school; nevertheless, as members of the school community, parents played a vital role in the stigmatization of CLWHA. Stigmatization by parents was manifested in the following manner: opposing the admission of CLWHA, resisting CLWHA sharing and learning in the same facility with their children, demanding CLWHA be separated from their children, engaging their children in negative discussions about CLWHA and finally withdrawing their children from Karibu School. Reports by teachers revealed that these reactions were geared towards inciting their children to reject or mistreat CLWHA. Since parents were not participating in this study, classroom teachers and the administrators articulately reported their observations and perceptions of what they considered as stigmatization of CLWHA by parents. The following quotes illustrated the parents' attitude and reaction towards CLWHA: Mrs. Tini stated:

> The parents could not understand how HIV-positive children would mix with "normal" children. But when the new head teacher came he admitted them. I don't think the new head teacher consulted the parents very much. So when some of the parents learned that these children [HIV-positive] had been admitted in the school some withdrew their children.

Mrs. Serare added:

> In the beginning some parents would complain that their children be kept off from the HIV-positive children. I think this was a concern also for teachers because when they were brought, they were sharing everything.

Likewise, teachers were equally worried after the admission of CLWHA into the school. After witnessing such strong reactions from the parents, teachers imagined them marching to the school and staging a demonstration to protest the admission of CLWHA. Rather than approaching the school administrator directly, some parents boldly went to

the director of Kivuli and demanded the immediate withdrawal of all CLWHA from the school. The director described the scenario:

> The parents came here [Kivuli] and demanded that the home withdraw children from the school. I said to them, "If we are going to withdraw the children from one school then what will happen to all the other CLWHA in other schools country-wide? Will they also be withdrawn or it is only these ones?" The parents understood what they were asking was impossible and they left.

Parental reaction resulted from fear of HIV contagion and the concern that their children would become infected. As Mrs. Siti conceded, teachers also shared similar fears: "The parents were just as fearful as the teachers." Unwarranted accusations by parents against CLWHA were reported. Mr. Chrisy described an incident where a parent accused one CLWHA of infecting her child during play. The parent said to the Kivuli administrator: "Don't you think your child has given my child HIV?" The parent demanded that the home meet the child's hospital bill and provide the child with medication for one month.

The results also showed that some parents discussed issues regarding Kivuli Children's Home and CLWHA in the presence of their children. The discussions alleged that CLWHA were a health risk to their children, thus inciting and influencing their attitudes. Ultimately, parental influence determined the treatment peers accorded to CLWHA. To attest to the impact of these discussions on their children, both the teachers and CLWHA said that after the other children heard their parents talk about the HIV-positive children, they began spreading these stories in the school. These findings are in agreement with Stadler's (2003) assertion that "rumour and gossip about the status of others was common, and has been reported in other qualitative studies as shaping folk discourse about AIDS" (p.186). Involving children in such a matter that was highly sensitive would be harmful to the social cohesion that CLWHA enjoyed while in school, and could also result in rejection. As a class teacher, Mrs. Kisu's first reaction to the

report was to protect CLWHA, and then investigate how and from where pupils had gained the information. This was necessary if progressive learning in a stigma free environment was to be guaranteed. She recounted how children learned about CLWHA from parents:

> I really wanted to find out where the stories came from and it is like one child overheard a parent talking about the Kivuli Children in relation to HIV/AIDS. And it is from there that she came to know about these children's condition. She picked it from that and she came to tell the other children.

In agreement, Mr. Maua pointed out the critical role parents played:

> In order for peers to stigmatize CLWHA, an adult had to be involved since they had little understanding about HIV/AIDS. Furthermore, HIV/AIDS and stigma are issues of concern for the adults but not for the children.

Stigma by teachers.

Stigma by teachers refers to negative treatment by a teacher, which included exclusion, name-calling or verbal abuse, prejudice and insult. Results from the data analysis revealed that most teachers and pupils maintained a genial relationship. However, reports by some CLWHA indicated that some teachers had stigmatized them. One incident that most CLWHA commented about involved one teacher who, after watching a caption of the Kenyan news on television featuring Kivuli Children's Home, shared detailed and sensitive information about CLWHA with other pupils in the grade three class. Upon hearing what the teacher said, the pupils began spreading the story to their peers. As a result, even CLWHA who heard the story from others personalized the information, and vividly described the incidence as if they were physically present when it happened. Tindi who was in the class at the time reported what the teacher said then and how she felt:

> The teacher told the whole class that Kivuli children have HIV. It made me very sad but I had just to leave it. [Would have done something about it?] I could tell

> the teacher never to do it again. Because if she says it again [Pause] then the social worker will call the police and the teacher will be caught by the police.

Makena also demonstrated how his classmates spread stories about them:

> That brown girl who sits in front [Referring to the sitting position in the class] said that children from Kivuli had HIV. [Where did she get the information from?] She said she heard it from another teacher who was talking about it. [Pause] Also some from my class were saying that we have HIV. They also said they heard from the teacher. You see…these teachers protect the other children.

Makena's statement suggested a feeling of unworthiness and being undeserving of the teacher's protection.

Another finding spelled out how some classroom teachers warned pupils to avoid sharing CLWHA food. Every lunch hour the driver from Kivuli delivered hot lunch for the CLWHA. Often times while they waited for the food they were accompanied by their friends with whom they were to share food. Thus, cautioning peers not to engage in sharing the food was envisioned as directly stigmatizing CLWHA. One mama explained:

"Mrs. "M[2]" (Teacher) cautioned other children to avoid eating food from Kivuli children because they add some medicine in the food."

Additionally, Beata who was in the class shared what transpired:

> When they were in class three she said the teacher said that Kivuli children have HIV and if you eat the food you get many disease. [I asked her, "Whom did the teacher tell?'] The whole class. [Did the teacher know Sidi was from Kivuli?] Yes. She knew. [Who told you?] Sidi told me…. She told mum and other children in the class. Sidi told all the class fours and threes (CLWHA).

In turn, CLWHA who were present in the class reported the matter to the Kivuli administrators, and to the mamas (Kivuli "mothers"). Although Kairu was not in the class, he explained d how he had learned about the incident: "I was not in the class but I heard from the other children. They said one teacher said the children from Kivuli have HIV."

[2] "M"- One of the teachers who was accused of stigmatizing CLWHA.

The teacher's insensitivity about what impact the story would have on CLWHA, had made the children feel stigmatized and betrayed.

Kivuli's policy to disclose the HIV status of the children to the teachers was to guarantee that they receive the necessary support and protection while in school. Therefore, discussing their status openly with peers was certainly a breach of confidentiality. As Tindi observed, "the teacher's behaviour was a punishable crime." The impact was emotionally and psychologically harmful to the children. During the interviews, I noticed that most CLWHA had a negative attitude toward the teacher in question and referred to her as "a bad teacher" since most of them had already concluded that the teacher disliked and insulted them. Insult in this study was likened to stigma or bad treatment. My observations confirmed that as a result of discrimination, CLWHA were extremely sensitive about what others said and how they treated them. Undeniably, teachers' prejudicial attitude had negatively influenced how peers perceived and treated CLWHA.

Generally, most CLWHA acknowledged that teachers treated them very well. However, Lekule had experienced insult and bad treatment from Mrs. "G"[3] that triggered unpleasant memories. The reminiscent remarks pointed out the difference between him and other children; being an orphan, which Lekule referred to as "loss", his HIV-positive status and the intake of ARV. He recounted how the incident ignited painful memories:

> Teachers did not treat us badly but that fat lady in the pre-unit…the plump teacher… She annoyed me. [Why?] She abused me with my mother and I was upset. She said to me, "You think I am your mother."Do you think I swallow medicine like you do?" She was telling me that in class. I was very annoyed and I told her, "Me… I swallow medicine, which keeps me healthy. So I told her, "Me I thank God because he has kept me healthy. What about you?" She told me I should not be saying such things. I told her, "All that you have said God is

[3]"G"-One of the teachers whom Lekule accused of "insulting"him.

> listening." I was very angry with her and I am still angry even now and I cannot forget.

According to the mama at Kivuli, the teachers' lack of understanding about HIV and AIDS was the reason they scrutinized CLWHA and that made them feel exceedingly sensitive about their condition. One mama (Not a participant) consenting to share information explained:

> Teachers don't seem to understand what HIV/AIDS is all about. They don't read about it and they talk carelessly. I think it is the teachers with a problem and not the children. They are the ones with a question mark. The other children don't know about who has HIV but when they talk like that about the [HIV-positive] children, then other children hear and they stigmatize.

Exonerating the teachers, Mr. Chrisy stated that they, like all the members of society, were both afraid and ill equipped to deal with the challenges that CLWHA presented. He was cognizant of the fact that AIDS stigma had remained a troublesome issue particularly in public schools. Hence, reports of stigmatization from the CLWHA did not come as a surprise since he had personally experienced stigmatization by teachers and administrators in different schools when he sought admission for CLWHA. He recounted one experience: "I remember going to Karibu School and the teachers telling us, "Please give us gloves. Suppose this child hurts herself…?" He further reported how teachers had demanded to be provided with First Aid kits and consistently service them. Finally, he commented on how one head teacher had approached him saying: "The other children will run away because your children have AIDS."

Data highlighted that teachers sought support from parents as a justification not to admit CLWHA into the public school. Additionally, stigmatization also extended to the caregivers. As Chrisy explained, when CLWHA were finally accepted into the school, the reception was very poor. He described one incident:

> We went to one school and the head teacher told the parents. Kivuli children are infected. Imagine Kivuli has brought AIDS children. Imagine our children being infected. Maybe your child leaves a pencil on the table….[Implying that HIV can be transmitted through sharing pencils] and the parents were saying: Yes. The parents said, yes. The parents were like…. yes. So we had to face it. They called for all of us to go to school, the mothers from Kivuli. The mothers went and they were heckled, they were heckled. They were told, even you have AIDS. You should not bring your victims to our school. You want our children to have AIDS. Some children were ridiculed. Some were told you have already dug your graves. You are a victim. You are a sinner because you have AIDS. So the children faced huge challenges. Their reception into the school was very bad and this affected them.

Mrs. Nuru admitted that stigmatizing attitudes were still persistent among the teachers, and she demonstrated how teachers continued to stigmatize CLWHA:

> You can know when a teacher comes to report about a child. The teacher will say, "Mrs. Nuru, I have a sick child and she is from Kivuli." This is a pointer that the teacher is not looking at the child but the status. "Mrs. Nuru I have a sick child I want you to call the parents but she is from Kivuli." They specifically point to the child's serostatus. I look at it as stigma. It has a lot of weight.

It was clear that the Ministry of Education assumed that the training that teachers had received in college adequately prepared them to capably handle illness related emergencies while in the school. On the contrary, interview reports indicated that whenever an HIV-positive child became sick, teachers would frantically avoid administering First Aid to CLWHA and would instead contact Kivuli personnel, thus confirming that CLWHA received a different treatment from other children. Chrisy explained how teachers acted when a CLWHA became sick:

> The school will call and say, your children are sick. What can we do with these children? We don't know what to do. Then I would say [If it is one child] take her to the nearest hospital.

During informal discussions, one of the mamas emphasized that discrimination of HIV-positive children was not exclusive to primary school teachers but had permeated into high schools as well. She explained: "There are issues in secondary schools where

the teacher keeps asking the child whether she has taken medicine. When one child hears that she goes on to tell others."

Stigma by peers.

Generally, the findings indicated that only a few of the CLWHA had experienced stigmatization by peers. However, five of the pioneer CLWHA spoke emphatically about a stigmatizing incident that involved teasing by peers when they first joined Karibu School. Teasing as Kalee explained resulted from writings on the school bus that conveyed information about their status, which peers in turn used to stigmatize them. Unfortunately, this experience was emotionally devastating; hence, sustaining peer trust was for him very difficult:

> We were stigmatized. It was like that before. Very bad! You know…. the bus had the name and logo written on the side and it read "Kivuli Children's Home." The other children would tease us because of that. So the writings had to be removed. That time I didn't know but I am afraid that reaction had a negative effect on me.

In affirmation, Mr. Chrisy stressed that the bus logo had to be removed because, wherever the children went out to places by bus and introduced themselves, people would insinuate as follows: "Aha! These are the AIDS children from Kivuli. We had to remove the logo… a blue line was repainted to cover the name."

It was reported that some of the peers avoided sharing food with CLWHA because they believed it had medicine added to it. Makena reported;

> Some of the children say that Kivuli children have HIV. They say that the food we get have … (Pause) and if you eat it you get many disease. Do you know Sidi? (Sidi was an HIV-positive child in the same class with Makena).

During one English lesson, a grade three boy[4] wrote the following statement in his English exercise book: "People with HIV should not mix with other people." In order to determine whether the boy fully understood what he had written, I asked him "Are you sure people with HIV should not mix with other people?" Unwavering in his belief, the boy convincingly told me that what he had written was true. To my surprise, two other boys who shared the desk with him quickly supported him. Interestingly, an HIV-positive girl with salient skin rash all over the body sat right behind the three boys. It was however indefinite to conclude whether the statement referred to this particular HIV-positive girl or to PLWHA in general. Certainly this testimony was sufficient to infer that AIDS stigma was rife in the school and a confirmation to the peer perception directed towards CLWHA. Upon raising the issue with the school administrator, Mrs. Nuru remarkably agreed and commented as follows: "Already that is stigma and you do not know how many other children think the same way. It is a sign that if they knew they will avoid the child and the child will not learn." In addition, she articulated how when CLWHA were admitted into the school, some pupils refused to share desks with them: "Some will accept but others will say, 'Teacher, I do not want to sit with so and so."

Although the school tried to protect CLWHA from peer stigmatization, reports showed that some pupils had engaged in talks that stigmatized CLWHA. Mrs. Siti said: "Here at school they don't talk about it but you can find one or two engaging in the talk." Mrs. Kisu recalled an incident where some pupils in grade two went around talking, shouting and spreading stories about CLWHA to their peers within the school:

[4] Although these boys were not participating in the research, permission to observe the class and to use their words was granted by the Ministry of Education, Science and Technology. Parent had also signed consent forms on behalf of the children.

> I had a few children who had started spreading that these children were HIV-positive. Maybe this was because I used to have two kids who were orphans and they were sick on and off, on and off.

In spite of the aforementioned incidents of stigmatization, peer relationships remained somehow intact. While this might have been true for peers, interview results and observation indicated that the incidences had deep emotional and psychological effects on CLWHA. Mrs. Serare commented about the relationship:

> Through their innocence they would just talk about CLWHA but still continue to treat them the same way they were treating them before… they did not seem to understand what that meant.

Internalized stigma.

"Internalized stigma is defined as the personalized, imagined or self-stigmatization and is the product of the internalization of shame, blame, hopelessness, guilt and fear of discrimination associated with HIV" (USAID, 2006, p.1). In order to solicit information regarding internalized stigma, I asked CLWHA the following question: "How do you feel about being HIV-positive and how often do you think about it?"

Responses to the question revealed that CLWHA viewed the disease negatively since it distinguished them from the other children. Several CLWHA said they often thought about the disease and expressed how they felt about it. The following sentiments demonstrated their experiences: Kamweru stated: "I think about it often and I feel very bad." Kalee was somehow hesitant to describe his thoughts and feelings: "Ah… yes. I think about it [being HIV-positive] and I feel very bad…. Sometimes." Gatarina described how thinking about HIV and AIDS affected her and how she reacted: "It makes me feel bad in the heart. I block the thoughts." In addition, both Kalee and Gatarina stated that being HIV-positive and coping with the disease was emotionally disturbing.

CLWHAs internalized negative feelings especially when peers and teachers talked about them in relation to their condition. I confirmed this from the way they recalled minute details about incidences as far back as seven years ago, as if they had happened yesterday. Some CLWHA described how they felt when their classmates discussed about CLWHA, Kivuli and the food. Makena shared how he felt about the talk: "It made me feel very bad because it is difficult to tell whether they are referring to your mother's HIV condition or to you."

Internalized stigma was prominent throughout the study and was characterized by denial of one's HIV status. This was despite CLWHA being fully aware of their HIV-positive status and the reason they were on antiretroviral medication. CLWHA denial verbalizations were expressed as follows: For example, Makena told his peers: "We don't have HIV." Tindi, Kairu and Sidi quoted what they told their peers: "We told them we don't have HIV."

According to Mr. Hose, denial was accompanied by a lack of acceptance of the disease, which affected mainly CLWHA from grades 5 to 7. Denial on the other hand was common among children in grades 1 to 5, who perceived HIV/AIDS as someone else's disease. Mr. Hose argued that after CLWHA assimilated the negativity that surrounded HIV/AIDS, it was difficult for them to want to be associated with the disease:

> I don't think the children accept their condition because I sometimes find them pitying themselves. You cannot pity yourself and accept yourself at the same time. I don't think they have reached a stage where they accept themselves. That is probably why they sometimes look withdrawn.

Apart from HIV being a major cause of stigma, the taking of ARV was equally a stigmatizing experience for most CLWHA. In spite of having been on HIV medication all their lives, ARV drugs are associated with HIV/AIDS, which is a highly stigmatized

disease. This is because ARV medications reminded them of the seriousness of the disease. For example, Kamweru's experience clearly demonstrated the dilemma of ARV adherence and concealing the secret from peers. She said that the school was planning to take the grades 7s for a tour to the Kenyan Coast and was looking forward to her first trip outside Kivuli. However, due to internalized fear, she was not sure whether she would take the medication during the trip or not:

> I take medicine and I am used to taking medicine. The only thing I am thinking about is what I will do when I go for the trip to Mombasa (The coastal city in Kenya). We are going for one week. We take medicine so I am wondering how I will be taking the medicine when the other children are around. I said to her, 'But the medicines are for different diseases'. But you know some friends will keep on looking into my bag. (Why should your friends get into your bag?) If you are best friends will she not look into the bag and then she will see the medicine (Laughs). There are some who know how ARVs look like. One girl in our school knows how they look like. She is called "S[5]" (Name withheld). How does she know? She has seen the tablets. I take three in the morning and three in the evening. There are others I saw and you only need to take only one.

As discussed earlier in this study, Lekule had pointed out that ARV had kept him alive; however, the reality of ARV was a painful reminder of HIV/AIDS. Physical well-being and the absence of HIV symptoms also served as a strategy for denial. Lekule, for example, said: "I look healthy." Kamweru added: "I don't feel like I am sick (Laugh) because I don't fall sick. I feel normal." Similarly, portraying the dilemma they faced as a result of ARV and the need to be perceived as normal human beings, some CLWHA lied to their friends. Mrs. Mwega described how Kakubwa had lied to her classmates: "She told the class (grade 7) that she was no longer taking medication. That she was O.K." Similar findings by Koku (2010) among immigrants of African origin living in USA revealed that PLWHA denied their status, convinced themselves they looked normal, and as a result kept their illness secret.

[5] "S"- Refers to Kamweru's friend

Internalized stigma was also expressed through questioning, which demonstrated the effect stigma had on CLWHA. Two CLWHA raised the questions "why did I" and "why did they" in particular get the disease? Although these questions were attempts to seek answers about HIV and reassurance, they permitted some of their in-depth feelings of stigma to resurface. Kamweru asked me: "Why did I get this disease? And those who do not get the disease… do they get it later …those who don't have AIDS? What about prevention?" Similarly, Gatarina who also hoped for a miracle cure questioned whether it was possible that some people got cured of HIV as she had heard from the church.

Horizons (2002) identified PLWHA's withdrawal and social isolation as a major manifestation of AIDS stigma. In this study, classroom teachers reported that several CLWHA appeared withdrawn and socially isolated. Teachers exemplified how these behaviours were manifested in the following statements: Mrs. Kisu stated: "I noted one case where the child was withdrawn." Similarly, Mrs. Serare demonstrated how one child behaved in her class:

> The only problem I have is this "R[6]". She is also a clever girl but… I don't know ….she is not free (Stressing the word free). She likes to do thing on her own [Laughs]. She is more withdrawn…. Yah…she is withdrawn, but if she could open up she could also do well like the others. She likes to do things on her own [Laughs].

Mr. Hose noted that when some children were in low spirits, they constantly talked about their HIV condition. He remarked:

> Sometimes they are down. They tell stories about themselves and you sympathize. There is this boy… brown boy (Describing his features). You can know he has a problem because he goes down sometimes. The boy gets down and starts talking about many things.

[6] "R" -A past pupil of Mrs. Serare's

Some CLWHA intentionally excluded their peers and instead associated with orphans and other HIV-positive children in the school. As an example, Mrs. Mwega described a relationship between Lekule (From Kivuli) and another HIV-positive boy named "E" (Lived with an uncle). She noted that the relationship between the two boys was exclusive since they hid in a corner by themselves and engaged in deep sharing.

> We have other children in our classes (HIV-positive). Like in my class I have Lekule and there is another one called "E[7]" [HIV-positive name withheld]. The disease is all over the skin. This one [E] is an orphan being taken care of by an uncle; the other one is from Kivuli. One from Kivuli and the other one from elsewhere…. They are different and it is like they share a lot. They share a lot.

From the teacher's observations, internal stigma was characterized by loneliness, which was common among CLWHA from grades one to three (1-3). Unlike those in upper classes (5-7) who had over the years of schooling developed strategies for managing stigma, these children were young and had numerous challenges to deal with. While commenting on the consequences of loneliness among school children, Bullock (1998, cited in Ramsey, 1991) stated:

> Children who feel lonely often experience poor peer relationships and therefore express more loneliness than peers with friends. They often feel excluded--a feeling that can be damaging to their self-esteem. In addition, they may experience feelings of sadness, malaise, boredom, and alienation. Furthermore, early childhood experiences that contribute to loneliness may predict loneliness during adulthood. Consequently, lonely children may miss out on many opportunities to interact with their peers and to learn important lifelong skills. Given the importance placed on the benefits of peer interactions and friendships to children's development, this potential lack of interaction raises many concerns for teachers who work with young children. Peer relations matter to children, and lonely children place as much importance on them as do other children (p. 1).

Most CLWHA who expressed feelings of loneliness had few or no friends among school peers except those from Kivuli Children's Home.

[7] "E" –An HIV boy –not from Kivuli Children's Home, but a friend to Lekule

During observation, I watched Tindi pick up her food from the box and then proceed to fetch drinking water from the tank. She found other children and joined the queue and stood motionless for about ten minutes with her food in hand and a bottle tucked in her armpit. While all the other children were busy chatting and playing with each other, Tindi did not talk to anyone. Finally, when she fetched the water she walked straight into the classroom where she sat in a corner and quietly ate her food.

Classroom teachers cited crying as an expression of internalized stigma. Although reports indicated that crying was perceptible among younger children particularly in grade one, because being in a new environment was challenging for them, some classroom teachers gave examples of CLWHA who cried from grades six and seven. Teachers, however, could not explain why CLWHA cried but Kisu's thoughts were as follows:

> Either they felt…. before they adapted to the environment or maybe some of them felt threatened or they were kind of afraid. It is during the adaptation process in the first term when they cry. In the second and third they get used.

Mrs. Tini exemplified how a boy in her class cried: "The boy that I taught was a tall boy. He would keep quiet and cry…cry…cry. I don't know what used to affect him."

As I observed how children interacted during lessons in different classes, I noticed one CLWHA boy in grade two crying. The class teacher was out for a staff meeting and she had asked me to take charge of the class. I decided to ask him what the problem was, but unfortunately he could not explain. I then realized that he could not do his assignment because the book was with another girl from Kivuli who was seated a few desks away from him. After talking to him he moved to sit next to the girl. This made me realize unlike other children, CLWHA were more sensitive to small things.

Avert (2010) recognized the crucial role schools play in shaping the attitudes, opinions and behaviour of young people and indicated that it is an appropriate setting for educating the young people about the biological aspects of HIV/ AIDS. Despite this fact, the results from the study indicated that during HIV/AIDS lessons CLWHA felt stigmatized. Those who reported experiencing stigma were mainly from the upper classes while those in lower grades had fewer problems. In order to establish the relationship between HIV/AIDS lessons and stigma, I asked the children the following question: "How do you feel when the HIV/AIDS lesson is being taught and do you participate in the lessons?" Before responding to the question, Trina paused for a few minutes, made a face then said:

> I answer questions but I never give examples, I only give examples in a math class. I base the question on general knowledge and not on myself. (Do you think about what the teacher is teaching?) No. Because if I think about it I will not concentrate so I don't think about it.

Though Gatarina experienced stigma during the HIV/AIDS lesson, she expressed her appreciation that HIV lessons did not target her specifically, thus enabling her not only to participate in the lessons but to also benefit from them.

> I participate in class discussions and make contribution but when the lesson is going on I feel sad [Pause]. l feel shy when the teacher is teaching. But the teachers don't single me out when teaching.

Kamweru participated actively in the lessons but when the subject had little to offer she preferred to be quiet. She responded: "Yes, I participate but sometimes when the subject is boring I don't talk." Similarly, Kalee found the lessons stigmatizing and as a result preferred not to participate in the discussions. "I feel embarrassed." I asked him, 'Do you participate in class?' "No. I don't!" While some CLWHA like Kairu stated that HIV/AIDS lessons had little effect on him, the majority of CLWHA particularly those in

grades 6 and 7 said that being in the class during HIV/AIDS lessons was extremely challenging.

Contrary to the CLWHAs' reports of stigma during HIV/AIDS lessons, observations by teachers revealed that some CLWHA, particularly those in grades 4 and 5, shared very complex information during the same lessons that other children did not have. Teachers' attributed CLWHAs' knowledge of HIV/AIDS to the sessions that were conducted at Kivuli Children's Home.

Felt stigma.

"Felt stigma refers to real or imagined fear of societal attitudes and potential discrimination arising from a particular undesirable attribute, disease (such as HIV), or association with a particular group" (Brown et al., 2001, p.4). Most often, PLWHA perceived as HIV-negative tend to conceal their serostatus because in doing so they do not experience stigma or discrimination. They also imagine that by reacting to felt stigma, they can avoid enacted stigma. In this study, CLWHA expressed fear that peers would reject them if they knew the truth about their serostatus. In order to determine whether friends' and peers' knowledge about their serostatus was a defining factor in stigmatization, I asked the following question to the participants: "How would your friends and peers treat you if they got to know about your HIV status?"

Responses indicated that experiences of felt stigma were prominent throughout the study. The fear of losing relationships and of rejection by friends and peers defined CLWHA experiences of felt stigma. The result was the attempt to conceal their true identity by making sure peers perceived them only as orphans. This is despite orphanhood being an equally stigmatized term, but compared to HIV/AIDS, it was

socially more acceptable. One mama from Kivuli confirmed: "The other people know Kivuli is a home for orphans. Even when they write their essays they write about their mum at Kivuli." During the interviews most CLWHA felt stigma as illustrated through the following quotes: Kalee stated: "If they knew [friends and peers] they would treat me badly and isolate me."

Gatarina anticipating how her friends would behave said she would leave school altogether:

> I would feel very bad because they would begin spreading that I am HIV-positive. I would feel betrayed. They would treat me badly and I would feel very bad. I would ask for a transfer to another school.

Apart from disclosing personal information to peers, details specific to Kivuli and ARV would result in peer rejection. Trina hinted:

> If they know they will go out to spread to the whole school and the school will know that we are sick. That we live in Kivuli Children's Home and that Kivuli is a home for CLWHA. And now like if they hear we take medicine they will start saying that Kivuli is like this… [Long pause]. Then they will give us sickness…now they will start saying that… and then my friends will not stick with me. (Why?) Because they will be afraid I will give them the sickness.

Kamweru stated:

> If my friends learned about my condition they would not care about me any more. They would ignore me and leave me alone… They would form their own group and that would make me feel very bad. (How would you feel about that?) I would like to stay at home than go to school [She raised her voice then laughed].

Although Kamweru acknowledged efforts by the school to ensure CLWHA felt comfortable while in school, if such daunting information leaked out she would opt to leave the school altogether:

> I would not like that to happen. Even someone can drop out of school because of that. Even in other schools some of them know that they have the disease but they don't react [Referring to other schools where other CLWHA attended]. But I am happy because Karibu School is a very special school and we learn well here.

In order to understand the CLWHA perspective of felt stigma, I asked them this question, "Do you invite your friends for a visit? Ten children said no while two said yes. Most of the children imagined if friends were allowed to visit Kivuli they would gain information that they would then share with their friends. The following illustrations explain this underlying fear as Lekule illustrated:

> I don't want to bring people here because they might go to spread news out there about medicine. (What about the medicine?) The medicine we take here 6 to 6 (What is wrong with the medicine?). Do you take the medicine when the visitors are around?] Hee… ee…hee… [Giggling] they will wonder and say, "You guys don't you get tired of taking drugs?" [He explained] In the house you have to take your visitors to the bedroom (Coughs). I don't want anyone to know that I take medicine. They will go to tell others. I don't want them to know we take medicine.

Tindi said:

> I don't invite them because they [Friends] will come and if you are here then they will say… [She made a face then said] I saw you [Whispers] …ninini…nini… [Mimicking how they would talk]. Some may come and tell you this and that then go to school and spread. Then they will go tell their parents, their parents will tell their neighbours then the neighbour will tell…then they will go and tell others and others …it will spread all over. There is a boy in our class…when we were in class two he came here and even now he is still telling…."

Some CLWHA even expressed fear that teachers might breach confidentiality by disclosing their status to their peers, especially during lessons. This fear was based on their past experience with some teachers. Trina expressed:

> If a teacher discussed about Kivuli Children's Home and about us, I would not be happy. [Why?] Because the teacher would be spreading news to others. (How would that make you feel?) I can't imagine. I would not be happy [Coughs]. If that happen I would not continue with school…I would not stay in school. I would go elsewhere.

Most CLWHA were happy that their peers lacked sufficient information about who was HIV-positive. Lack of perceptible symptoms too provided them with

reassurance since that way it was easy to conceal their status. While teachers indicated that stigmatization depended on many factors, such as individual character, they too concurred that such knowledge would result in a different treatment and eventual isolation. Mr Maua observed: "If the children knew that so and so is an HIV person they could ignore them." One mama added: "The other children do not know but if they knew they would be stigmatized."

The study further revealed that stigmatization partly depended on one's character and the experience one had with PLWHA. Mr. Hose stated:

> I think stigmatization will depend on the individual. For example, if I hear someone is HIV-positive…I will be more sensitive. But I think if the children know that so and so is an HIV person they might ignore them**.**

He also alluded to the fact that the media portrayed the severity of HIV symptoms, but the picture they depicted was contrary to what peers had observed in CLWHA; hence, the reason peers failed to stigmatize them. He explained:

> I think if they [Peers] understood about the disease they would behave differently towards them and stigmatize them [CLWHA] and maybe that would confirm what they thought about these kids. Because of the pictures we see of people living with HIV/AIDS…maybe that is the way they [peers] thought that the kids would look like.

In spite of lacking information about which of the pupils were HIV-positive, a few peers continued to demonstrate some degree of curiosity and were keen to find out which characteristics defined CLWHA. Citing an example, Mr. Kisu described how peers manifested this curiosity:

> My son is in form two. 'He asked me, Dad how do I now differentiate the ones from Kivuli and the other children? I asked him why?' We were told there are children here from Kivuli Children's Home who are sick and that we should take care when we are sharing common things and things like that.

The results indicated that although only a few incidents of stigma were reported among peers, a number of pupils already had some information regarding the HIV status of Kivuli children. However, corroborated results indicated that if peers specifically knew that a particular child was HIV-positive they would stigmatize him or her. Teachers verified why peers treated CLWHA normally. Mrs. Kisu noted that one reason was peers' lack of knowledge about their friend's disease. Mr. Hose attributed peer acceptance of CLWHA to lack of symptomatic evidence since the majority of the children had no visible signs that could be related to the disease. Additionally, Mrs. Kisu observed that peers had no clear understanding about the seriousness of the disease. Generally, reports indicated that teachers whose family members were suffering from HIV/AIDS demonstrated a positive disposition and were more considerate and supportive of HIV-positive children.

Theme 2: Consequences of stigma and discrimination on HIV-positive children.

Considerable literature indicated that an environment that facilitates stigma and discrimination has devastating consequences on PLWHA (Banteyerga et al., 2003; Nyblade & Carr, 2011). The primary aim of this study was to investigate whether stigma and discrimination affected learning and social interactions of CLWHA. Although reports by the participants offered mixed observations, there was general consensus that stigma and discrimination had negatively impacted on CLWHA's psychological well-being. Peer acceptance was positive and would have facilitated social interactions between the two groups, CLWHA experiences of internalized and felt stigmas tended to dictate their feelings and behaviour. As a result, some of the effects identified among CLWHA were denial of their HIV status, fear that peers would know their HIV status and reject them,

social isolation, and withdrawal. Additionally, the results demonstrated that some CLWHA refused to attend school, bonded together, consistently talked about the disease as a way of seeking attention and sought sympathy from teachers and peers. Some CLWHA said they felt shy, sad and embarrassed when HIV/AIDS lessons were in progress. Almost all CLWHA indicated feeling bad or unhappy whenever teachers and peers made them the target of discussion.

The sense of insecurity was strongly expressed in the reports and as a result, some CLWHA deliberately avoided sharing personal issues with peers for fear that this would result in disclosure of their HIV status. To ensure that any HIV-related information remained safe, some of CLWHA decided not to share food with friends as Tindi explained:

> Me I stopped eating in the classroom. I eat outside with my friends. I don't eat in the classroom with my friends. (Do you share food?) No. I don't share food. (Pause)… Me I hide my food. (Why?) Because some will peep or somebody will come and look at your food and go to tell others [About the food].

Attempting to explain why minimal interaction occurred between CLWHA and their peers, Mr. Hose pointed out that due to the restrictive measures Kivuli Home had designed to protect them from stigmatization, chances of socialization were limited and maintaining friendships proved more difficult. Lekule illustrated how difficult it was to gain permission to visit friends:

> It is difficult to visit because first I have to ask permission. They [Kivuli personnel] will want to know what I going to do and so on. They will ask you so many questions about where you are going…(Laughs) what time you will be back …I cannot go out with anybody unless the manager knows the person. For example, uncle [Care-taker] if he knows my friend and I tell him. Uncle might know my friend but the manager does not know. So uncle has to explain first. So if I want to go to visit my friend I have to tell uncle and then uncle will explain to the manager and if he thinks it is O.K then I can go.

However, some CLWHA expressed a longing for friends. Makena illustrated: "I have only two friends in my class and no other friends in other classes. I wish I had more." Emphasizing the importance of peer relationships, Murray and Greenberg (2006) indicated that "peer friendships and peer rejection determines children's social, emotional and academic health." (p. 222). Ladd (1990, cited in Murray & Greenberg, 2006) further pointed to the fact that "children with a larger number of classroom friends in elementary school had greater gains on measures of academic performance and school liking than did children with fewer classroom friends" (ibid). Mr. Hose provided reasons why CLWHA did not interact freely with peers:

> I have not seen them sharing with other children. I have not seen them sharing. (Are they allowed to share?) I don't know. I don't know but I have never seen them sharing. They lack the exposure.... (Pause). You know their place is so restricted. Let me say they are not set completely free by Kivuli. They are not set completely free.

I asked Mr. Hose to indicate some of the periods or times when CLWHAs socialized with peers and he responded:

> Maybe break time. Lunch time I don't think they have enough time because at lunch time they are always at this corner here [Pointing towards the corner] waiting for the vehicle to deliver the food. Sometime they come and leave the food there for them to come and pick. And when they pick, they get into a group… which means there is not actually enough time with the others because at 1.30 p.m. they are going back to class. And immediately when the bell rings in the evening the vehicle is waiting for them here so I don't think they get enough time to socialize with the others. And that makes the other kids more aware of who they are.

Study reports indicated that due to stigma, CLWHA pretended to be sick in order to avoid attending school. Although it was not a common behaviour among CLWHA, Mr. Chrisy noted that the behaviour occurred whenever a child couldn't cope with stigma in the school or when one had encountered learning problems. However, Mr Chrisy

alluded to the fact that owing to the children's poor reception in the schools, the easier option was to avoid going to school. He elucidated:

> The transition was not a good one... it was a reception with opposition. Going to school makes them remember all that … and in addition, to know that they are HIV-positive…it affects them.

In their study, Coie and Dodge, 1988, cited in Fopma-Loy, 2000) found that vulnerable children who were rejected by peers and received little support from them were also likely to receive minimal support from the teachers (p. 31). Crick and Ladd (1993, cited in Fopma-Loy, 2000) indicated that these children experience loneliness, social anxiety, and avoidance, including lack of interest in attending school (ibid). According to the participants' observations, the problem was not limited to primary school children but it also affected those in high school.

All the participants agreed that the experiences of stigma and discrimination had serious implications on CLWHA and on learning and social interactions particularly with peers. Concurring, Mrs. Nuru indicated CLWHA could not learn after experiencing rejection by peers. Additionally, most CLWHA admitted that thinking frequently about the disease, affected their level of concentration during lessons.

Mr. Chrisy cited suicidal thoughts as an effect of stigma and discrimination among CLWHA. He emphasized that when CLWHA became overwhelmed by the disease and were unable to cope with stigma and discrimination, they contemplated suicide. Though in this study there were no reports of actual suicide attempts involving CLWHA participants, suicidal attempts had been observed in other children from Kivuli. Citing a few examples, Mr. Chrisy demonstrated how one boy had believed that someone

had injected him with a virus after which he refused to take medicine. He also cited an incident where a girl from Kivuli had attempted suicide by trying to hang herself:

> One girl swallowed all the medicine at the same time saying. I am tired of taking medicine. I am going to join my [Deceased] mother. She went to the toilet and took a rope to hang herself. We took her for counselling for six months.

He referred to another child who said: "I wish I can join my father and my mother and get out of this world." Mr. Chrisy said that the challenge of living with a chronic disease and the intake of ARV, all of which were related to stigma and discrimination had deep psychological effect on CLWHA.

Emerging reports further indicated that factors other than stigma affected how CLWHAs learned. Mrs. Siti illustrated the effects of ARV on learning:

> HIV medicines do affect them. They come very early in the morning. They lie on the desk and sleep… sleep, sleep. They are three but only one is more affected than the others.

Does that affect how they learn and interact with other children?

> Yes. Sometime in the morning but not much. Because they learn and then sleep for about 20 minutes or so. But not all of them do that because they are all different. So when they see her like that maybe she has just taken medicine and she sleeps. So give her time. They [Peers] used to whisper pointing to the child sleeping. But we made them to understand that their [Kivuli] home is better than theirs [Laughs].

Mrs. Serare observed that sickness affected learning.

> Mainly in the upper there are those who get sick, sick, sick. Some sneeze all the time. "R[8]" has problems hearing.

Mrs. Mwega added:

> "P[9]" has an ear problem [Had gone through surgery]. Most of them have ear problems and many other physical conditions that are visible.

[8] "R" - An HIV-positive child who had hearing problems
[9] "P" – An HIV-positive boy who could not hear properly

Since I maintained a close encounter with all the children at Kivuli Home, I observed that most CLWHA had stuffy noses as well as chest congestion, which were typified by frequent coughs and persistently clearing of the throat. I also noticed that many of the children had hearing problems that necessitated them to use hearing aids. Surprisingly, none of the children used the hearing aid at school. The teachers reported that hearing problems affected children's learning. Teachers further observed that continuous absence from school significantly contributed to inadequate learning. Reasons cited for absenteeism were sickness and occasional visits to the doctors for check-ups.

Strategies for managing AIDS stigma and discrimination

Makoae et al's (2008) study in five African countries established that PLWHA utilized several strategies in order to cope with stigma and discrimination. In this study, coping strategies referred to the specific efforts that individuals undertake when responding to stress in positive or negative ways. Although questions with regard to coping mechanisms were discussed with CLWHA, some of the responses, which surfaced during the interviews revealed a few of the strategies they frequently utilized to manage stigma and discrimination. Teachers identified mechanisms such as seeing oneself as O.K., faith healing, denial, social isolation, talking about one's condition and clinging together.

Some classroom teachers recounted how some CLWHA constantly talked about their condition; while others sought sympathy, particularly from the teachers. Makoae et al (2008) confirmed that PLWHA who often talk about their condition do so to attract sympathy and support. Mr. Hose cited a boy who persistently told stories about himself:

> There was this boy in my class. He always told stories about himself. He did all this to seek sympathy…he seeks sympathy from time to time although not always. I noticed this when he was in class five (Now in class 7).

Some CLWHA took advantage of their condition to seek attention mainly from teachers, while others wanted to be treated in a special way by teachers. Mrs. Mwega described one case:

> Lekule said to me, "Teacher, I cannot clean the class because of my condition". I said, you cannot clean the class, bring a letter from the doctor. But I realized that most of the time all he wanted was attention.

Teachers reported that a few CLWHA engaged in disruptive behaviour, such as noise making during lessons as a way of seeking attention. One teacher described how Lekule's behaviour aggravated one teacher's asthmatic condition until she had to give up her role as the classroom teacher. Mrs. Mwega explained: "Lekule thinks he is great. When you start teaching he starts making some noises. I punish him. He has been a nuisance all through. He wants to show teachers the bad side of things." Mrs. Serare concurred: "He is the only one who had been giving problems. Teachers have been complaining about him." As if to prove that this strategy was peculiar to CLWHA, Mrs. Mwega said she had observed similar behaviours in her former school:

> In the school where I came from, there were such cases but the children were not from Kivuli. Most of them came from ordinary homes. There was this boy in class 5 was very naughty. He would say, "Teacher you know I am sick." Lekule wanted to be noticed. If you don't seem to notice him in class, he would get annoyed…very annoyed.

Intimidation and manipulation of peers were behaviours some CLWHA utilized. Mrs. Mwega confirmed that Kakubwa took advantage of her physique (big in size) to intimidate and manipulate other children. The study established that some CLWHA were older compared to their peers in the same grade.

During the interviews, every CLWHA emphasized the need for keeping one's sickness secret, which helped them cope with stigma and discrimination. As Mr. Chrisy pointed out, in order to conceal their status, some CLWHA chose to keep only a few friends. He explained: "Some children are like…(Pause) you have a few friends. You remain with a few friends. Some finish school without anyone knowing their serostatus except the head teacher. And only one person visits the school…the mum."
Another strategy that teachers identified was CLWHA's behaviour of clinging to one another. This behaviour provided CLWHA with meaningful psychological support. Several CLWHA described shunning HIV-related thoughts by blocking them, denying one's HIV status.

Consistently, reports indicated that some CLWHA believed in faith healing and consequently hoped for a miraculous cure. My assumption is that these thoughts may have been encouraged by the occasional attendance of healing services in one of the Catholic Centres in Nairobi. The aim of these spiritual engagements was to strengthen their faith rather than provide a cure. Results of studies conducted by Vyavaharkar et al (2007) and Makoae et al (2008) found that PLWHA used spiritual beliefs and practices as tools for managing the disease as well as coping with stigma and discrimination. Gaskin and Foster (2009) indicated that "spirituality was part of embracing the disease and gave them hope and strength to live their lives" (p. 1310). Faith healing provided them with needed comfort and reinforced a purpose in their lives. The following conversation with Gatarina illustrated this perception:

> Gatarina: "Can HIV be cured?
> Researcher: "It cannot be cured but it can be managed."
> Gatarina: "Are there some people who get cured?

Researcher: Yes. Not really. With prayer it can be cured. I have known people who have been cured."
Gatarina: "But can it be cured? How can it be prevented?"
Researcher: "Yes. Research has been ongoing for a long time and the good news is that there has been significant medical breakthroughs with the discovery of antiretroviral drug. This drug reduces or suppresses the viral activity in the virus in the body."
Gatarina: "The teacher does not talk about cure."

Interventions for combating stigma and discrimination.

Reports from UNESCO (2000) indicate that education has a key role in diminishing stigma and supporting the rights of all children. As an integral part of an overall AIDS response, Karibu School had designed specific strategies to challenge and reduce AIDS stigma in the school. Strategies included disclosing specific information about the status of CLWHA, education, normal treatment and involvement of CLWHA, counselling and advice to pupils.

Disclosing information to teachers about the HIV status of CLWHA and informing both teachers and pupils about their admission into the school had positively influenced the attitude of teachers and pupils. This was critically important in determining how they were accepted and treated. Furthermore, the information provided knowledge that facilitated a seamless integration of CLWHA into the school. Emphasizing why the school had to take such drastic measures, Mrs. Nuru reiterated that the purpose was to empower teachers so that they could protect CLWHA from parents' stigmatization. Information to pupils was crucial because it enabled them to adhere seriously to universal precautions. Teachers, however, pointed out that for the intervention to bear fruit, the administrator's approach had to be positive. Mr. Hose described how the headteacher disseminated the information to the school:

> After the headmaster had said they were admitting children from Kivuli Children's Home, the teachers explained to the pupils. He talked in a very positive manner. He was not negative about them. He sort of gave a general talk to everybody during the school assembly about how they should take care of their health in sharing and things like that. Then later the children came. The other children did not have a lot of problems.

Mr. Hose observed:

> When the CLWHA came he did not inform the pupils. But he had already told them that there will be many CLWHA joining the school and that they should take them like any other children but to take care of themselves…children to children. He just put it in a general manner…just general but not directing it to these children. That made it very easy for us and for the children. .

Disclosure and other information were important to teachers because psychologically they were prepared to handle CLWHA. Mrs Were added:

> We were told how to handle them. The headmaster said we were getting some children and they are HIV-positive. But when they came and the way they came… they just mingled with the other children. But we never made it public to the other children when they came.

In Kenya, as elsewhere, HIV/AIDS Education is a national AIDS intervention that is essential for equipping school children with adequate skills to enable them to make the right decisions when confronted with sex issues. Kelly (2001) and Coombe (2000) observed that education was apparently the best strategy to reduce HIV infections. According to the reports, teachers and pupils alike indicated that HIV/AIDS education was an important tool for addressing AIDS stigma. Therefore, through HIV/AIDS lessons, teachers communicated valuable and accurate information to pupils about the disease and related stigma. Mr. Maua illustrated his teaching approach:

> I teach that there are many ways of getting HIV. For example, one can get it through injections. I tell them that even our parents can get it without getting involved in sexual misconduct. Although it is just a sub-topic under health education, it mentions about the virus, what causes it, how it can be prevented and the social effects in the community. Teaching these facts prepare the pupils psychologically.

Additionally, Mr. Maua explained that the curriculum had a provision that allowed teachers to address AIDS stigma and discrimination; He explained what his teaching included:

> These people must be taken care of. I tell them about accepting others [PLWHA]. For example, HIV cannot be passed on if you shake hands, hug one another but only through other contacts such as body fluids. They should be treated exactly like any other normal person. Those who stigmatize others need counselling in order to understand that what these people need is love.

In order to capture the pupils' attention wherever they were, education had to be both formal and informal. Mr. Hose described one informal incident that involved his son: "The child was in standard three. He referred to the picture of someone with HIV. But I educated him and told him it is not all who are like that. It depends on how sick that person is."

Additionally, available resources in school, for example, pamphlets and murals contained relevant information; thus enhancing teaching and learning. To prove that education effectively addressed HIV and related stigma, CLWHA demonstrated what they had learned as Kamweru shared: "We learn that we should treat them [People with HIV/AIDS] with love. We should not ignore them [Pause]. Always to be there for them."

HIV/AIDS lessons were beneficial not only to CLWHA. Other pupils found them helpful. Kamweru observed: "The lesson is important for others because it can affect their future. They can learn about self and about HIV and how to prevent it." Kamweru went further to demonstrate how she would make use of her newly acquired knowledge: "I would use the knowledge to tell others how to prevent it, how it is caused and the precautions they should take, to take care of themselves."

Guidance and counselling and advice helped to clarify the misconceptions surrounding HIV/AIDS and stigma. Though not all the teachers had adequate counselling skills and many had to revert to skills gained during teacher training, they believed counselling was an effective method for addressing stigma and discrimination. Mr. Maua reiterated that it was extremely important to provide accurate information to the pupils by telling the truth about the disease. He explained: "We counsel them and tell them the truth. Like me I don't go about beating the bush. We tell them the truth and the outcome of it."

In this study, the teachers indicated that treating CLWHA 'normally' like all other children was an important approach in addressing stigma and discrimination in the school. In fact, all the classroom teachers agreed that treating CLWHA in an inclusive manner had significant implications on their peers' attitudes. However, as the study points out, teachers were initially uncertain how to treat CLWHA, but upon consultations with Kivuli administrators, they began involving them in all school activities including punishment. Mrs. Siti explained how they had initially treated them:

> We used to isolate the children from others like in punishment and working. But the social worker told us not to isolate them from working and beating. We said we might beat them and then make their medical condition worse. We are learning to be with them.

She however emphasized that unless one required special consideration due to his/her condition, they were all treated equally. Mrs. Were added:

> We treat them just like the other children unless there is a need. Some may look very weak and as a result we have to decide what kind of punishment to give them.

Reports by CLWHA further confirmed this treatment as Gatarina noted: "Teachers punish all of us when we make mistakes so we are not treated in a special

way." Some teachers; however, noted that many CLWHA expected teachers to accord them special treatment, but being cognizant that the treatment could trigger negative sensations among their peers. As a result, teachers avoided paying too much attention to the CLWHA. Mrs. Were observed: "In fact, we know the children are special but we do not want to show the other children that they are special. It is therefore the teacher's responsibility to decide how to treat them."

The classroom teachers confirmed that involving CLWHA in school activities and leadership positions conditioned their peers to view them normally, thus reducing the incidences of stigma and discrimination in the school. Normal treatment enhanced the confidence and self-esteem of the CLWHA, thus empowering them to deal with personal issues relating to AIDS stigma. One such school activity was the involvement in the Health Club, whose task was to educate parents, teachers and pupils on the key basics of HIV/AIDS. Key messages targeted specific audiences were expressed through drama, songs and poems. Mrs. "G[10]" expounded on how the club addresses AIDS stigma and discrimination:

> I teach the children about AIDS about how to stay with others who have AIDS etc. We have a lot of poems and dramatize things about AIDS. We did it on parent's day. But like now when we have something for the parent's day. We meet at 11.00 o'clock that is why you don't see me because I am just there with them.

Similar interventions used in Ugandan schools were reported to successfully address HIV and related stigma. These comprised of peer education and included drama and community outreach programs (Norton & Mutonyi, 2007). Mrs. Nuru concluded that although these approaches had improved the attitudes of teachers and peers, traces of stigma were still visible in the school.

[10] "G"- Teacher in charge of the Health Club

Positive Experiences

Theme 3: Supportive and empowering experiences.

This theme describes supportive and empowering experiences of CLWHA in Karibu School. Empowerment is defined as an act by another person that helps the participant to feel strengthened, feel good about him orherself, cared for and accepted. During the interview, I asked CLWHA to identify the types of support they received from the school and particularly from classroom teachers, friends and peers. Most CLWHA indicated having received support from teachers, friends and peers, which included physical, emotional and academic support. Supportive experiences were expressed as: someone being helpful, encouraging or sharing, being there for them during play or when learning or studying, and understanding them.

Academic support mainly focused on remedial work, class assignments and homework. Despite inadequate supportive programs specific to the needs of CLWHA, the few that existed in the school were essential in the learning process, in how CLWHA identified with peers and defined their identities, and in the adjustment and integration into the school. In addition to the school programs, Kivuli Home personnel also provided CLWHA with extra support.

Support from teachers.

Physical support.

To most CLWHA, food was an important component in their lives and therefore teachers' understanding and support for their nutritional needs was highly appreciated. Kivuli delivered CLWHA's food to the school daily, however, if a child failed to pack his/her lunch dish or forgot to carry snack for their break, they missed food for the day.

Whenever this happened and a teacher was notified, they would commit personal funds to buy snacks for the children since the school had no financial savings for such emergencies. Tindi, who had received a lot of support, described the form in which support was provided and received:

> One day I did not have a break ["Break' in Kiswahili meant bread to eat during morning break]. I told my classroom teacher that I did not have any break. She told me come. I went. …[Pause]. She gave me some money. Then we went to the canteen to buy chips and mandazi (A kind of doughnut). She said to me, hide. I hid the chips but ate the mandazi.

Tindi added while highlighting Mrs. Nuru's particular concern for their nutritional well-being:

> When I did not have lunch- Me, Makena and Santi… [Children from Kivuli] our class teacher went to the deputy Mrs. Siti went to the deputy [Mrs. Nuru]. She was given three mandazi (Doughnut). Then the teacher told us-Makena, Santi and Tindi . She gave each one mandazi and said, go. …Santi and Tindi, go and tell Mrs. Nuru thank you. When we ate we went. Me alone I went to thank her. So she felt for us (She was sympathetic to us). She said to her [Mrs. Nuru] that we did not have money.

Quoting another incident, she described other teachers' support particularly when the driver failed to deliver the lunch:

> The food had not come that day. There was the deputy, Mrs. Nuru who gave me a mandazi (Doughnut) then she asked me, "Are you full?" I said, " No." Then she gave me another mandazi. When I went to the class the bell rang. She is very considerate.

As the data suggest, teachers encouraged sharing food with peers; however, they were concerned that if they allowed food sharing, CLWHA would not have enough to eat. Consequently, most teachers felt compelled to ensure that they were well fed. For example, Mrs. Siti had three HIV-positive children in the class and believed that CLWHA needed adequate amounts of food to cope with their condition. In order to ensure they ate enough she supervised them while they ate in the classroom. In addition,

she had also advised CLWHA not to share their food with friends. Quoting the teachers' statement Tindi illustrated: "If anyone borrows food you come and tell me."

In my view, this action appeared to segregate CLWHA from peers and could lead to stigmatization, but apparently CLWHA perception was different and they seemed to understand and accept the teacher's decision. Makena explained: "She (Classroom teacher) wants us to eat the food until we are satisfied so that others do not borrow food from us. We can share food with other children after we have had enough." During discussion with Mrs. Siti, she pointed out that her role as a counselor obliged her to ensure CLWHA's nutritional needs were adequately met. She explained: "They used to share, eat and drink together. I explained to the class. I said; eat your food while the Kivuli children eat according to their mother's wish. I had to put it as if it came from their mothers." In order to ascertain that her action would not result in the stigmatization of CLWHA, she aptly informed the whole class that the children would eat their lunch in the classroom. Tindi (CLWHA who ate in the class) illustrated what Mrs. Siti had told the class: "Our teacher told the class that Kivuli is very rich. That at Kivuli food is tested before they eat." This contrasted with a report by one teacher, who had told the class that CLWHA's food had medicine that could cause sickness.

Although teachers were more concerned with younger CLWHA, Mrs. Mwega was equally concerned after learning that Lekule who was in grade 7 used to exchange his food for money, which he spent to buy mandazi (doughnuts). As a result she reprimanded him:

> Lekule came and said to me, 'I went out. So what I did teacher, I have not been eating my lunch'. I asked him, 'What happened?' 'I exchanged my lunch. So he was getting money from another boy. I said, 'You need the food. What will you

> buy with ten shillings? And the drugs you are taking every day. I did not want to let him know that I condone that.

Emotional and psychological support.

Given the emotional vulnerability of CLWHA, classroom teachers in this study were keen to provide emotional and psychological support. Generally, support was mainly provided when the children fell sick and when they needed reassurance and comfort. This was not a frequent occurrence because Kivuli discouraged CLWHA from attending school when they were unwell. Tindi confirmed: "If you are sick at Kivuli you stay and not go to school. If you are sick at school you go home at lunchtime." Nevertheless, whenever a child became sick at school, teachers promptly phoned Kivuli administrators asking them to pick up the child. Mrs. Kisu explained: "This boy had very bad malaria. He asked permission to go to the toilet and he fainted. I had to call home straight away."

Teachers also stated that talking with and encouraging CLWHA helped them to feel that someone cared. Mrs. Kisu explained: "I have always talked to them to make them feel at home. In case they are sick I phone the home." Similarly, emotional and psychological reassurance through words of comfort was essential for their adjustment and for coping with school exigencies. Mrs. Kisu explained how she comforted a grade two boy:

> When 'M[11]' [Name withheld] was left by the bus last time he cried… my goodness! I wanted to phone the home… but I calmed him down and he waited for the bus in the evening. I had no lunch but I gave him something to eat.

Most CLWHA who had received emotional and psychological support articulated how teachers cared and supported them when they were sick. Kairu demonstrated:

[11] "M" – An HIV-positive boy in class two.

"Teachers are helpful, for example, if you fall and hurt yourself, the teacher treats you then sends you to class." Conversely, Tindi illustrated that teachers encouraged their peers to support them:

> I was at school and I slept and when I woke up, I started feeling dizzy [Slept on the desk –there was no sick bed]. Two girls came and held me and gave me a bible. Out of the three sicknesses this was worse [She indicated having been sick twice before]. Then I fainted. Then the teacher came with four girls. One held the hand; one held the hand and one held the stomach. The teacher asked me how I was feeling and because I was feeling dizzy, I told her I see her like four people. Then she phoned and when I came here I was injected so that I don't faint again.

During observation at the school, I learned that the First Aid Kit was inadequately serviced and teachers lacked protective supplies such as gloves. As a result, teachers had to at times attend to CLWHA without any protective devices, thus putting themselves at risk. But as the findings suggested, teachers' commitment and care toward CLWHA was remarkable: Tindi affirms:

> I had a boil and now it burst. He said [The cleaner], go and fetch water. I brought the water and then I went. I said, please, wash for me this toilet. Then I went. He is coming to wash the toilet. …Then the deputy asked why he had to wash the toilet. Then I explained, I had a boil in the buttocks. The deputy asked, what happened? I went to the toilet. I bent and then it burst. Then deputy washed. She washed the dress then I went.

The majority of CLWHA were cognizant of their teachers' concern about them in particular whenever they became sick and had to be away from school. They felt it necessary for the teacher to be informed about their medical condition after returning to school. Lekule shared:

> I was sick recently. I went for treatment. I had gone but when I was going to sit for exams the eyes began disturbing me. I went to the doctor. When I came back the teacher called me. I told him I had problems with my chest. I showed him where I was injected and then I explained to the teacher that I was suffering from a certain sickness… and I told him I could not explain the nature of the sickness because it was a secret. The doctor had warned me not tell anyone. But they might think I died without them knowing. You might miss school for so long

> without the teacher knowing. You know you can die without anyone knowing. You know you can never tell. But you can die without the teacher knowing.

Guidance and counselling teachers explained how they addressed the emotional and psychological needs of CLWHA. Counselling, however, was not directed specifically to CLWHA but to the pupils in general. According to Mrs. Nuru, counselling mainly targeted pupils whose disposition towards CLWHA was negative: "For those children who have come out with these negative attitudes we tell the school counsellor." Mrs. Kisu recounted how she had counselled pupils after they began spreading rumours about CLWHA in the school. Teachers also indicated holding formal and non-formal Counselling sessions with the children who included CLWHA. Findings also showed that most of the CLWHA had never utilized counselling services at the school and gave two reasons for this. One, some CLWHA said they were unaware that such services existed. Two, CLWHA were discouraged from talking to outsiders about personal problems. Kamweru reaffirmed: "We are not encouraged to talk to our counsellor." Mrs. Nuru, however, pointed out that despite the school having two trained counsellors; the department was not very active because teacher counsellors had full teaching loads allocated to them; hence, little time was devoted to counselling.

Reports showed that Kivuli had designed a comprehensive program aimed at preparing CLWHA to adjust psychologically to public school life and to give them the necessary skills for managing stigma and discrimination. Kamweru confirmed: "There are people who come here to talk to us about HIV. Sometimes we go out and sometimes they come here. We do go for seminars." Mr. Chrisy explained how the program worked:

> Before they go to school, Sister [A Catholic nun and a nurse] has to use a child language to let them know about their status. When they hear they have "Ukimwi" (HIV/AIDS in Swahili) then they are shocked. It is very interesting

> when it dawns on them that the medicine they take is related to "Ukimwi". We have meetings with those who are already in school. We share information about medication and how to share information about their status. For some it has worked but for others it hasn't.

Although all the CLWHA admitted participating in the program offered at Kivuli, very few gave specific details regarding the benefits they gained from the program.

Academic support.

Results from the data emphasized the role of the teacher in academic support. A common observation confirmed that the participants were aware that academic support was critical for CLWHA's academic success. Classroom teachers said they provided support to CLWHA when they appointed them to leadership positions because the role was involving and they had to learn to balance academic issues and leadership. Mrs. Kisu noted, being a class prefect or group leader was academically involving; hence, the need for teachers' support: "I made Lekule a prefect in class three. I really encouraged him."

The data suggested that although teachers were willing to provide academic support to CLWHA, the majority of the teachers decried the difficulties they faced, citing the demands of the curriculum, and the heavy teaching load due to the shortage of teachers. At the time of the interviews, there were only 27 teachers serving a population of over 1000 pupils. The shortage of teachers meant that some teachers had to teach from 8.00 a.m. to 4.00 p.m. with only a 20 -minute break and a one hour lunch break. Responses from most CLWHA revealed that they had never approached any of the teachers for academic support, but noted that teachers were generally very helpful. Some described how teachers repeated previous lessons in class and encouraged them to join discussion groups. Makena illustrated: "When we miss school the teacher repeat the lesson if a child is absent during a certain lesson."

Mr. Hose confirmed:

> What I do … I repeat the work with them [children]. And with me I call them here one by one [There was a bench under a tree where he met the pupils over lunch hour]. Any of them… and that is what I do with any of the others whether they are sick or not sick.

Some CLWHA also confirmed that whenever they missed school as a result of sickness or medical check-ups, teachers encouraged them to seek help from their peers. Kariuki observed: "Teachers are helpful because they tell my friend to help me."

Although teachers acknowledged having little time to attend to the academic needs of the pupils, Mr. Hose and Mr. Maua explained that they had designed remedial programs for pupils, particularly in Mathematics and Science. However, my observation was that pupils who benefited most were from grades 6 and 7. I also observed that due to inadequate facilities in the school, teachers and pupils could not interact in the classroom, and as a result, Mr. Maua and Hose had set up a bench under a tree, where the pupils met with the teachers for academic assistance. This initiative provided pupils with a free environment thus facilitating interactive learning. I noticed that this spot had become popular with most pupils because the grade 8 national examinations were approaching. Pupils including some CLWHA brought their books as well as questions for discussion. to Mr. Hose and Mr. Maua. Attending to the academic needs of the pupils during breaks was a sacrifice the two teachers had made because there was no time left for themselves. This was indeed a demonstration of professional commitment and a sign that they were mindful of the pupils' future. CLWHA were particularly happy with the assistance teachers provided in mathematics, which most of them struggled with.

Teachers mentioned that whenever they observed any learning difficulties among CLWHAs, they addressed them promptly. They did so by approaching the child in order

to determine the problem. Mrs. Kisu explained how she had to act quickly when she noticed one CLWHA's academic performance deteriorating:

> I have noticed something with "A[12]." I noted that at the end of this term because her performance has changed. I knew she was suffering from something. She was topping the class. She was number 7 but now her performance is dropping. Probably there is something back home because here they normally don't have problems.

According to reports, relatively few CLWHA missed school as a result of sickness although they regularly went for medical checkups; hence, they did not require special academic attention. Nonetheless, they all concurred that teachers' support even in a general class environment was meaningful and encouraging. Primarily, Kivuli provided additional academic support through the homework program that took place every evening and during the weekend. Additionally, a program was in place during the school holidays where they received extra coaching.

Support from friends and peers.

Results from the study indicated that all of the CLWHA experienced some form of support from friends. Support, however, was not limited to friends in school and support from other CLWHA was equally meaningful. The majority of CLWHA, however, acknowledged having more friends at Kivuli than at school. Friendships gave them a sense of belonging and enhanced their self-esteem as Kamweru said excitedly: "Ah …(Chuckling) I have more friends here. Not so many in school." Unlike his peers, Kairu admitted having more friends in school: "I have friends here at Kivuli but most of my friends are in school." School friends and peers were important because they brought a new perspective into their lives in addition to a sense of belonging and acceptance. Association with a friend brought feelings of pride, which many enthusiastically

[12] "A"-An HIV-positive girl in class two.

gesticulated with glowing faces. To illustrate this perception, some CLWHA referred to their friends by name, while others would ask me, "Do you know so and so?" This was to ascertain that I knew exactly whom they were referring to. Some of these statements demonstrated this perception of friendship:

> Trina said smiling*:* "The whole class are my friends.
>
> Lekule added: The whole school...and all the girls are my friends" (Laughs).
>
> Gatarina enthusiastically said: My friends are good. They [Friends] fight over me to be their friend. I feel good about it.

The majority of CLWHA who had recently transferred to Karibu talked about missing their friends from their former schools. For example, Gatarina said: "I used to walk home with my friends and spent time with them."

Although Kariuki missed his friends from his former school, he explained how he tried to maintain the friendship: "When I go to the shopping centre I see them and talk to them." Visits by friends were rare but as Lekule explained, CLWHA highly appreciated whenever a friend visited: There are some friends who came here without my knowledge. My best friend came here and missed me because I had gone somewhere else.

In affirmation, Makena, full of excitement, recounted to me about his friend's visit one Saturday afternoon. Support was also conceptualized through social activities, namely playing together, staying together, eating together, sharing food, and personal items, sharing personal interests and studying together. Trina said: "We play together…we stay together. I eat with my friends at school. We pick our food and then we go and sit somewhere even in the class or outside…then eat." Tindi noted: "We can play at school and we come here (Kivuli) and continue to play."

Most CLWHA said that sharing with friends was very important although they had little to share. However, they were happy that friends were willing to share gifts with them. Kairu explained: "If they have they give me. But we are not allowed to bring anything from school." Trina added:

> If I ask them if they have a pen to share they always give me. If my friend come to me and tell me I have no pen I tell her I have only one pen and then she goes to ask another person or the teacher.

Kariuki said: "I also share pencils and other learning materials. Some they have and some don't have so I share with them."

Almost all of the CLWHA talked passionately about sharing food with friends. Food was perceived as a unifying factor. It was during sharing lunch together that CLWHA felt emotionally supported. Moreover, the fact that their friends liked their food undoubtedly gave them a sense of acceptance. Lekule explained:

> I share with my friends whatever I have [Food]. I share with whoever is near. I share bread...whoever is near is the one I share with. Most of my friends like our food I don't know why. I exchange at least to taste other people's food. Their food is tasty.

Sharing hobbies and other personal interests with friends was very important for CLWHA. These activities gave them an opportunity to discuss movies, football matches, games and other interesting activities that they had engaged in over the weekend or during the holidays. Kamweru illustrated: "We talk and share our things." Another form of support identified was through peer collaboration and encouragement in schoolwork, which enabled CLWHA to maximize on the learning benefits offered by friends. Mrs. Were described how friends and peers contributed to CLWHA learning:

> They have friends. You see without a friend you cannot interact with others. Like that boy I told you about in my class (Karisa). They are usually four boys who

> study together. Even the one I had last year was the same. He liked to study with others.

Kariuki explained: "We share about learning. …when we grow up what we shall become." Sharing with friends was a door opener to the outside world from which CLWHA were shielded. Moreover, sharing provided them with an opportunity to reflect and to dream about future aspirations.

Theme 4: Education resources and initiatives.

The study aimed at establishing the type of educational resources and initiatives that were available at Karibu School that assisted teachers and pupils in responding to the challenges of stigma and discrimination and in addressing the diverse needs of CLWHA. The participants identified the following resources: First Aid Kit, murals, wall charts, pamphlets and brochures. Financial support for orphaned and vulnerable children (OVC) was also considered an important resource. The First Aid Kit was a resource that teachers utilized regularly especially during times of emergency. A standard kit should contain some painkillers, large sterile gauze pads, adhesive tape, bandages to make a sling, adhesive bandages in assorted sizes, scissors, tweezers, safety pins, ice bag or chemical ice pack, disposable gloves, a flashlight (with extra batteries), antiseptic wipes or soap, pencil and paper, a blanket, eye patches, a thermometer, and a first aid manual. Apparently, during data collection period (September-November 2010), the kit was empty. I vividly recall one day when a grade one boy fell down during play and fractured his hand, and since the kit was almost empty, the First Aid teacher had to look for a piece of cloth to bandage the boy's hand before phoning his mother to take him to hospital. Mrs. Nuru, pointed out that despite the Ministry of Education and Technology's (MOEST) commitment to supply schools with sufficient funding for school requisites,

funds often arrived to school late. Consequently, the school was poorly prepared to handle emergencies. Mrs. Were commented:

> We have three teachers who can administer first aid. It is important to have the material because one can put him/herself in a risky situation if he/she does not know….

Financial support for the Most Vulnerable Children (MVC) was MOEST's initiative to support infected and affected children while in school. This fund benefited orphaned and children living with HIV/AIDS learning at Karibu School. Mrs. Nuru explained how the fund was spent:

> The Ministry of Education and Technology provides financial support to MVC by sending the money to the school to purchase uniforms. A committee that allocates the funds comprises a parent, myself [School administrator], two counsellors, and one teacher. We sit and identify these children. Some are HIV infected others are HIV affected. We buy uniforms, sweaters and even shoes.

Kivuli provided for all the material and medical needs of CLWHA, and as such, they did not need any financial assistance from the school. Often times, as Mrs. Were noted that the funds arrived in school late and as a result, needs of many children were not sufficiently addressed on time.

HIV/AIDS murals were part of an action plan by the MOEST that took effect in 2001 and were erected in all public schools in Kenya. Following MOEST's mandate, murals were erected outside of the classroom walls and were placed side by side to other subjects, for example, math and science. At Karibu School, murals were strategically erected so that anyone approaching the school from the gate would clearly read the message they carried. Murals contained a common theme in all the schools and in particular, informative messages that targeted parents, pupils and the general public. Teachers highlighted that murals were instrumental, educational tools, which aided them

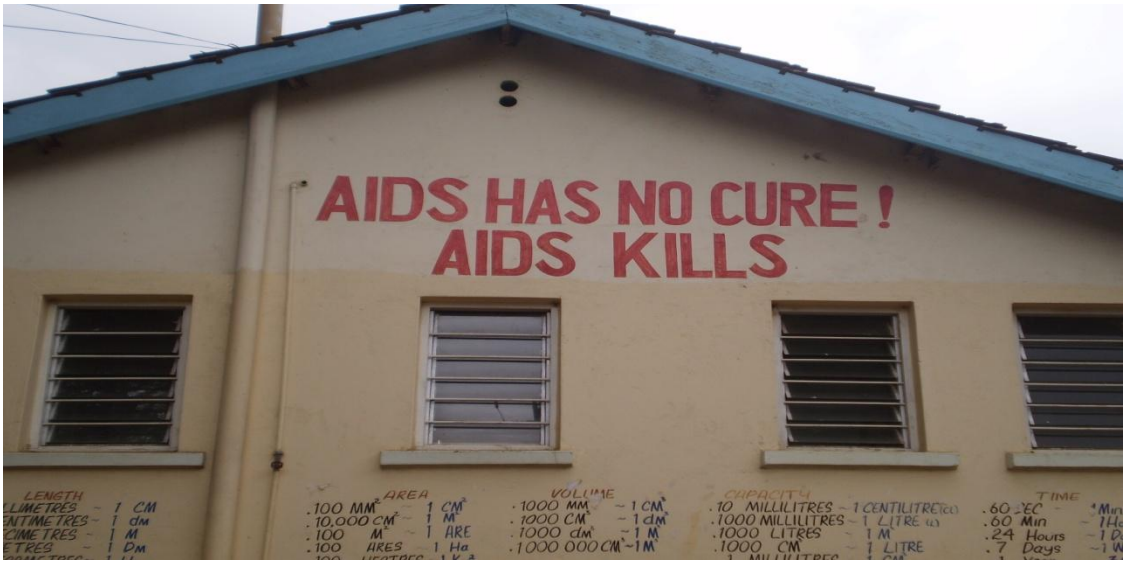
in teaching about HIV/AIDS. I wanted to establish whether murals could potentially cause the public to ask questions about the presence of CLWHA in the school. This is how Mr. Maua responded:

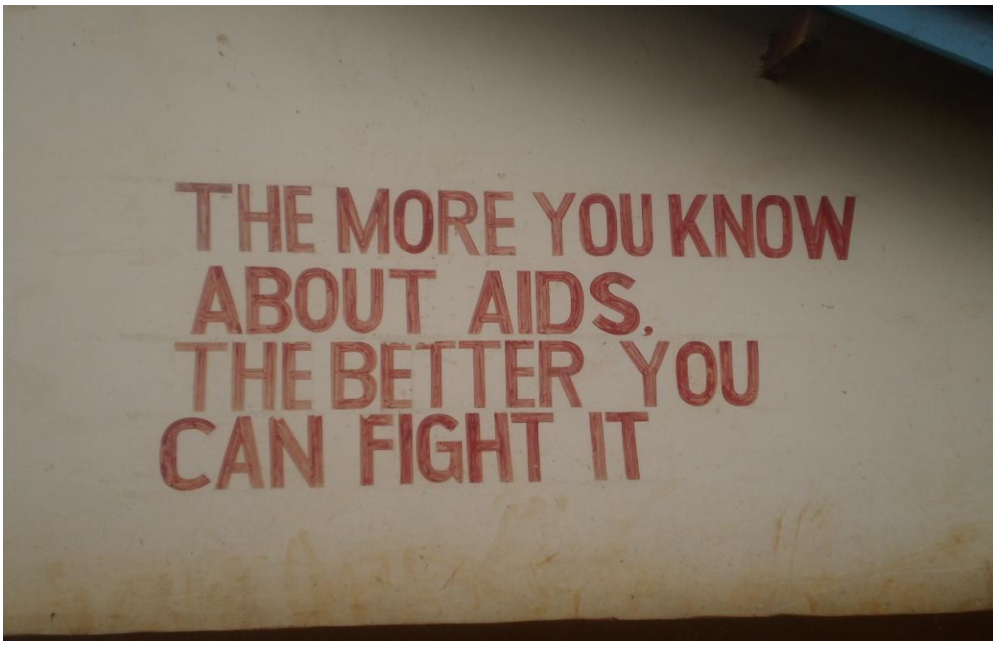
> The murals were meant for parents, for the children and for anybody coming to the school. That is why they were put in a strategic place. It is not a way of telling people that the school has HIV. They were meant to create awareness to everyone. They were supposed to be in all schools although the idea has been dying slowly.

Mrs. Mwega added:

> Murals are not only found in schools but also in other places since they are meant to enlighten the public about HIV/AIDS. These things [Murals] are all over the place. They are not for the teachers or visitors. They are for everyone.

A common observation expressed by the participants indicated that murals communicated key messages at a snap shot to a large population. Below are sample murals taken at Karibu School.





(Pictures taken at Karibu School by the researcher in October, 2010)

Wall charts were effective visual illustrations that easily communicated important messages about HIV/AIDS to pupils. Besides, they supported meaningful learning during and after the lessons. Unfortunately, during research observation, there were no wall charts in any of the classrooms and none of the teachers had access to these charts during HIV/AIDS lessons. In spite of the fact that HIV/AIDS charts were scarce, the few, which were available, were kept safely in the office for future use. Mr. Maua articulated why it was necessary to preserve the charts:

> We display some charts for HIV when we are teaching but not all of them because they will get spoiled. And maybe if one has taught that topic and might need it to teach the following year. However, some of those charts are very expensive. There are some which were laminated.

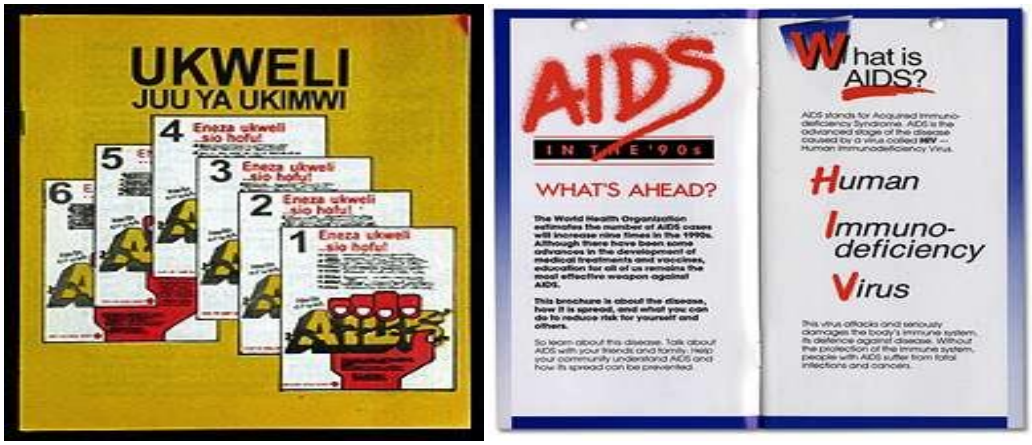
Wall charts handily conveyed basic HIV/AIDS knowledge to the pupils; however, most teachers preferred the murals because of the clearly designed graphics, as Mr. Maua observed: "Instead of the wall charts it is better to have those writings [the murals] because when the message is written or drawn on the wall it lasts longer than the charts."

It was MOEST's responsibility to supply schools with sufficient teaching materials including HIV charts, but it has been extremely slow in implementing this. Teachers further noted that despite the involvement of non-governmental organizations in HIV/AIDS interventions in the country, they too had failed to support HIV/AIDS education initiatives in public schools. Mr. Maua noted: "There is very little those organizations offer." On a similar note Mr. Hose emphasized:

> I think that the organizations that address HIV and AIDS in Kenya are more monetary minded than helping…they are money-making organizations. I have been to some of their programs just for curiosity during the holidays. I just register and attend [Pause]. Some of those have put up programs that actually should be taken to the schools but they do not go to the schools but they are there in writing. I think we need to be sensitized more.

Pamphlets and brochures provided learners with information enabling them to better comprehend issues regarding HIV/AIDS. Their content was designed specifically for a larger public audience; nevertheless, wordings and comic messages were applicable to the topics covered in the primary school curriculum. These topics included HIV transmission, prevention and awareness, HIV and sexually transmitted infections (STIs), HIV Counselling and testing, HIV medication and treatment adherence, HIV/AIDS stigma, mother to child infection, health education and needs of the Most Vulnerable Children (Orphans). Pamphlets and brochures were supplied by the Kenya Episcopal Conference of Kenya (KECK), The National AIDS/STD Control Programs (NASCOP) and non-governmental organizations such as Kenya AIDS National Council (KANCO) and were used by teachers to facilitate proper understanding of the topics. Pamphlets and brochures were distributed to the pupils during lessons on the basis of relevance to the content. The comics on these materials drove the message home and captured the

attention of pupils. The use of Swahili and English languages made information accessible to all. Below are some of the common brochures in the school:



(Sample educational brochure from the Kenya Ministry of Health: New Facts of Life)

Successful transmission of HIV information depended solely on the quality and quantity of educational materials MOEST supplied to the school. However, teachers observed that MOEST had neglected to support and provide HIV/AIDS teaching aids to the schools despite introducing the subject. Mr. Maua lamented: "The ministry should do provide teachers with charts because they introduced these topics."

HIV/AIDS lessons.

In Kenya, HIV/AIDS lessons are integrated in all teaching subjects. Regardless of CLWHA's reporting that they felt stigmatized during HIV/AIDS lessons, the study results indicated that almost all CLWHA perceived HIV/AIDS lessons positively. They emphasized the importance of HIV/AIDS lessons saying that they provided them with vital information about HIV/AIDS. The following excerpts confirmed this as Makena observed: "The teaching is important because we learn about HIV and how to avoid it." Kamweru was articulate when stating how important HIV/AIDS lessons were:

> I think teaching about HIV/AIDS is important because it educates the other children about the disease. It helps them to know about HIV/AIDS, how it is caused (transmission) and how it can be prevented.

Kamweru emphasized: “The lessons are important for other children because they teach about how to take precaution.” Makena added: “HIV/AIDS lessons teach pupils different precautions.”Tindi said: “It is O.K to learn about HIV/AIDS because it makes you know. If you don’t know … you will not know what HIV means.”

The following children explicitly stated how glad they were that HIV/AIDS lessons were not directed at them:

> Kairu illustrated: *“*We learn about HIV but not about Kivuli.”
>
> Kairu confirmed: They [Teachers] don’t bother with us. They only discuss about orphans but not about us. They talk about it in CRE.
>
> Lekule stated: There is nothing wrong teaching about HIV/AIDS. The teachers just explain but they don’t point at us, they give examples but not about Kivuli.
>
> Gatarina said: The teachers follow whatever is written in the book. They do not single me out when teaching but encourage me to participate in class discussions.

In order to prove that HIV/AIDS lessons did not stigmatize them, they illustrated how they felt about the lessons. Tindi explained:

> I don’t feel anything because everybody can get HIV but not a cow…even the president.

Some CLWHA demonstrated what they had learned from the lessons as Kariuki articulated:

> I feel good because I understand something about HIV. I learn about how to abstain, and about the dangers of sex.

He further added quoting what the teacher had taught them in the class:

> When someone is infected with HIV you are not supposed to attract some children because they will get HIV.” ([Is that true?) Yes. When you rape someone [Meaning to engage in sexual activities].

CLWHA also indicated that teachers employed useful examples during HIV/AIDS lessons. Makena cited one example to illustrate what he had learned from his science teacher:

> The teacher said that if you engage in sexual relationship with a girl who is HIV-positive you will get HIV. [So what else did the teacher say?] It was an example, but he said that we should take precaution because if we engage in sex they will give it to us.

The two statements by Kariuki and Makena are clear illustrations that teachers used general examples to teach about HIV/AIDS and did not particularly point at CLWHA in the classroom.

Kamweru added that HIV/AIDS lessons were informative and continued to describe what she had learned: "I learned that HIV kills." When I asked her whether this information affected her in any way she said no. Seemingly, discussions about imminent death resulting from HIV/AIDS were rare because what Kivuli tried to instill in the children was hope and not fear. With the kind of preparation they received at Kivuli, issues about death hardly surfaced during the discussion.

In addition to the above observations, classroom teachers reported that the lessons were important because they provided a forum in which they communicated important information to the pupils about HIV/AIDS and related stigma.

Teachers' empowerment.

The presence of HIV-positive children in public schools has remained a challenge for many teachers. Therefore, support systems for teachers that would enable them to address CLWHA's needs and to establish a safe and secure environment for learning was an important component of this study. To solicit information about the empowerment programs for teachers such as in-service training programs, I asked classroom teachers

and the administrator to identify teacher empowerment programs that were available in the school. The teachers' responses indicated that the presence of CLWHA in the school was an enormous challenge, yet empowerment programs for teachers were lacking. This resulted in limited knowledge and skills on how to handle CLWHA and about HIV/AIDS, thus obliging teachers to rely on acquired information as well as information shared by teachers who had attended HIV/AIDS seminars. Mrs. Kisu observed:

> We rely only on the information we had received…only that. Although I personally thought since we are different in the way we take things, that part of training could have been helpful. Although it depends...it depends on individuals. We might think we are handling them in the right manner while we are not. I think that type of training would have been very good.

Mrs. Kisu added:

> Teachers should be provided with information through seminars and other important information that would help us to do more than we are doing today. Because we might think we are doing our best when we are doing nothing.

Similarly, insufficient knowledge and training reinforcement led to a dilemma on how to treat CLWHA. Mr Hose echoed: "We may not be doing the right thing. Here we handle them just like the others. We don't know what to do with them [HIV-positive children]."

Owing to a lack of empowerment, teachers said they were ill prepared to teach HIV/AIDS lessons. As a result, teachers were left to use personal discretion whether to teach or avoid the subject all together. Mrs. Kisu highlighted:

> HIV has been integrated into all the lessons but it is left to the teacher to decide on the topic and when to talk about which topic. I think teachers were not prepared to teach HIV/AIDS lessons.

According to Mr. Maua, the school empowerment program for teachers was repressed by scarcity of funds. He explained how the school had spent huge amounts of money paying private groups in order to equip teachers with essential skills. This type of

empowerment was necessary because CLWHA had just been admitted to the school and the school had to devise ways of integrating them and creating an inclusive environment for them to thrive.

Reports by teachers confirmed by the school administrator indicated that prior to the introduction of free primary education (FPE) in 2003, the school had the capacity to run programs and sponsor various teachers' seminars since schools solicited levies from parents. In keeping the promise, fees and levies for tuition in primary education were abolished as the government and development partners assumed responsibility to meet the cost of basic teaching and learning materials as well as wages for critical non-teaching staff and co-curricular activities. Despite the government's effort to ensure FPE succeeds, very little had been achieved in terms of teacher empowerment, yet admissions of a vulnerable cohort that demanded additional teachers' skills were on the increase countrywide. Continuous absence of empowerment programs had implications especially for new teachers who were left on their own to develop personal mechanisms of dealing with the situation. Articulating how lack of empowerment affected teachers, Mr. Hose gave an example of a First Aid teacher who could not treat a child particularly if the child had traces of blood on the body:

> And that was the same with most of the teachers since I heard them telling others. If they were taught or given training, the situation could have been better managed. I think she was doing the correct thing not touching the blood but I think if she had been educated about it, she could have handled it in a better manner.

Mrs. Nuru blamed MOEST for being insensitive to the plight of both the teachers and pupils and for assuming that teachers had sufficient skills to address CLWHA's needs. She said: "You hear them talking in the air. The ministry has kind of neglected

this...not so much the teachers but the children." While commenting on a workshop that she had attended on HIV/AIDS and MVC, Mrs. Nuru demonstrated how teachers and pupils could benefit from such workshops:

> In the workshop that I attended, there was a man who said he has been HIV-positive for the last 30 years. Another one will say, I am a mother of 10 children...they are all in school. I cook for them and I live with them. This (Testimony) can change their [Pupil's] perspective. Then they will say, in that case my mum is also HIV positive. After that they will be able to come out. Somebody in the workshop at the end of the workshop said "Did you know from the beginning that I was HIV-positive by looking at me? Can you tell if I am HIV positive?" That is how they can learn.

As a school administrator, she was concerned that MOEST neglected pupils' needs and suggested how MOEST could respond to the needs:

> We should have personnel … at least in the schools. They [Personnel] should come and directly talk to the children. So that when we tell the children, they are able to see the reality that what is being said is true and to see for themselves.

In summary, it is crucial that teachers are furnished with adequate knowledge and skills so that they can promote positive attitudes among pupils and encourage a more inclusive education for CLWHA in public schools.

Theme 5: Educational experiences.

Attitudes towards the school and the teachers.

The rationale for CLWHA to learn in public schools was two fold. First, it provided the children with exposure to the outside world thus enabling them to socially interact with peers. Secondly, it offered them an opportunity for academic competence since Karibu School was already on the national academic map. The CLWHA's responses regarding learning at Karibu were somewhat based on similar beliefs. However, their attitude towards learning and academic performance slightly differed on the basis of which school they had enrolled in first. Records show that only seven

children had joined Karibu School in 2004 and a few more had joined in the following years. All the others had transferred from other schools citing poor performance and indiscipline as some of the reasons for the transfer. The last group to enroll at Karibu had been in the school for two years. At the time of the study, there was a total of 37 HIV-positive children learning at Karibu School from Kivuli Children's Home.

In order to gain a deeper understanding of CLWHA's educational experiences, it was necessary to explore their attitude towards the school and learning in general. I therefore asked CLWHA the following question: "Do you like school?" Most CLWHA said they particularly liked Karibu School and demonstrated a positive attitude towards learning. This was in spite of many admitting that the school was academically challenging and schoolwork was overwhelming and demanding. The rationale cited for liking the school was high discipline, good academic performance and teachers' commitment. Another motivating factor was the non-stigmatizing environment that prevailed in the school. The following statements illustrated their view of the school:

> Trina said: Karibu School is good in comparison to other schools where the Others CLWHA attend.
>
> Lekule stated: Learning is good.
>
> Karisa added: Karibu School is a very good school.

However some CLWHAs who had transferred to Karibu School faced several academic challenges as illustrated in the following interview excerpts:

> Kairu explained: In Karibu School there is too much work.
>
> Gatarina noted: There is a lot of competition in Karibu School.

Illustrating the difference between the two schools, Kairu stated: "In the former school, teachers did not give homework."

Like many Kenyan schools, Karibu School focused more on academics but failed to encourage pupils to participate in physical activities, such as games. This is in spite of study verifications regarding numerous health benefits that pupils accrue from these activities (Mahar et al., 2006). Students often look forward to the break from desk-work, considering it a high-point of their school day. For this reason, Kairu expressed his disappointment that he couldn't play soccer or have fun with his friends in the field: He said in a sulky voice:"There in Karibu they don't have games."

Reports indicated that CLWHA had a positive attitude towards teachers. Also, teachers' supportive role was emphasized in the data. They were explicit that classroom teachers and the administrator were both understanding and supportive. Although they did not use the word support per se, they used descriptive terms such as, "loving and caring teachers who are good to us." To Tindi, support was perceived as care that teachers provided. She illustrated: "Mrs. Nuru is caring". Also, in reference to her classroom teacher she said: "Mrs. Siti is a good teacher. She is very supportive and helpful". Tindi had fond memories of her former classroom teacher whom she described as follows: "Mrs. "K[13]" was a good teacher but she is not there now." Most CLWHA commended the teachers' commitment to their work. Gatarina said*: "*The teachers are good and they teach well. Kamweru added: "She [Referring to classroom teacher] is very good teacher." Kairu demonstrated appreciation for his math teacher saying: "I like her very much." For Kamweru, math was a huge challenge but that did not alter her attitude towards the teacher: Mr. "W[14]" … he is a very good teacher but math is very hard." Unlike other CLWHA, Tindi and Kariuki thought differently about some of the teachers.

[13] "K" – A former teacher of Karibu School.
[14] "W" –Refers to one of the Math teachers.

> Tindi explained: Some of the teachers are good…. But…. some are not." [I asked. Why?] She said: "Some are very tough.
> Kariuki emphasized: Yah. They are bad [Teachers]. Why? Me I don't know. but when you fail exam…(Pause). But some…some are really tough.

Upon further probing, I realized that teachers associated with stigmatization had lost credibility among the children and were often labelled as bad teachers, while those who insisted on hard work and completion of homework were perceived as tough. Additionally, another observation showed that a small cohort of CLWHA, particularly those facing problems coping with homework and general learning, expressed similar sentiments. The above statements however, clearly illustrated the difficulties CLWHA encountered when adjusting to a new academic setting where discipline and hard work were fundamental.

Learning and academic performance.

The interview reports indicated that the majority of CLWHA portrayed great enthusiasm about learning since they seemed to understood the value of education. According to the classroom teachers, CLWHA had adapted well in the school and learning was normal. Mr. Hose confirmed:

> Learning is normal and they compete well with others. However, I would say it will depend on an individual child and the way they will get sick. Because some of them are very good like we have a boy… in 6C (I don't remember his name)…very good but at times you know he gets affected. Because there was a time I was teaching them …when he has not fallen sick, he is very good in class. But then you find when he gets sick he gets really down. So he does not perform well then.

Mrs. Siti added: "They are active. They are O.K and they learn well."

Teachers also noted that most CLWHA valued education and greatly appreciated it as a special gift from Kivuli and as if to reciprocate, they worked hard in school. Mrs. Kisu observed:

> The ones I have handled it is like they understand the value of education and so they work hard. Otherwise there is one who has problems with reading. He says, "Although I am HIV, I wish I can read well." All the time he is concentrating to be better. He should be better.

In affirmation, Kalee emphasized: "I used not to work hard because I did not know. But now I know the value of education." To further illustrate, several teachers cited Karisa as the most outstanding and academically focused child from Kivuli. On his part, during the interviews Karisa acknowledged that being HIV-positive and an orphan, the only gainful gift that he would receive from Kivuli was an education. Thus, his vision for a successful future lay in his educational pursuit.

Although several CLWHA shared a similar vision, some CLWHA had learning difficulties. For example, due to poor academic background in their former schools, a good number of CLWHA admitted that learning was challenging. In particular, CLWHA in upper classes cited poor performance in math. When most of them compared their performance in their former schools with Karibu, they felt somewhat discouraged because they were used to being top of the class. To their dismay, CLWHA complained that since joining Karibu School, most teachers had consistently rated them as average. Consequently, CLWHA underrated their performance, felt incompetent and academically intimidated by their peers. In reaction, some hinted how they wished they could return to their former school. Gatarina illustrated how she felt:

> I was in "M[15]" school (Name withheld). I would like to go back there. I used to become number 4. Then what happened when you went to Karibu School? "The pupils there are cleverer.

Observations by classroom teachers indicated that the majority of CLWHA were academically average with only a few exceptions. To verify, Mr. Maua described the

[15] "M"- Refers to a school where Gatarina was attended school before she transferred to Karibu School.

performance of one CLWHA in his class: "C[16]" as average. Somebody scoring 260/500 marks is an average student. She is a hardworking girl." A study by Macharia (2005) which was conducted at Karibu School involving a similar but a different cohort, indicated that 60% of teachers rated CLWHAs as good, 10% of the teachers rated them as very good, 25% of the teachers rated them as average and 5% of the teachers rated them as poor (p. 35). Although this study found that most CLWHA were average, teachers acknowledged CLWHA's efforts to improve grades and remarked on the outstanding performance by a few children. Mrs. Were stated:

> They are trying. Like the one in my class she is trying. I have only one in my class. The child is hardworking but I cannot say anything about other children. I cannot say much about the others but I think they are average.

Mrs. Kisu added:

> There are actually some who are very good…. excellent. And then there are those in the middle and the average children. I cannot say we have very poor pupils whereby a child can do thing. The ones I have handled have been that good group and they are average. They try a lot."

Similarly, Mr. Hose commented:

> Some are very good, sometimes because there was a time I was teaching them …and there was this boy… but he does not perform well.

Mrs.Siti emphasized:

> Their performance is generally good. As I told you "D[17]" was number 4 the other time. "A[18]" was also here and she used to be number one.

For their part, CLWHAs remained enthusiastic and focused in their schoolwork.

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[16] "C"-Refers to an HIV-positive girl whose academic performance was said to be average.
[17] "D" – An HIV-positive girl who was in Mrs. Siti's class.
[18] "A" – Refers to an HIV-positive girl whose academic performance was excellent.

During the interviews, CLWHA eagerly explained about their performance and demonstrated passion for hard work. Although Lekule felt his grades were not good, he told me he was working hard to improve his class ranking:

> My number is good but I need to work hard. ..it is average and I want it to be better… I want to be at the top. I am improving. Last time I was number 50 then I became number 40. I worked hard and became number 41 and again I worked hard and I became number 40. I want to work hard and gain 10 marks to become number 30 (Smiling).

Kamweru commented:

> My best number I was 30 and above. 40's is as if I have failed. So I get between 30 and 40. This time I was number 39. Monthly I was number 42. Then mid-term I was 41. Then after that I was number 39.

Kamweru was undeterred by the academic challenges she faced and was determined to succeed. She explained: "The studies are very challenging. Not so hard. I just have to work hard. I have to really work hard."

While reports indicated that most CLWHA concentrated on their schoolwork, other data also suggested that some CLWHA were less keen. For example Kairu and Kariuki performed poorly as Kairu illustrated: "I perform poorly. Why? I sleep during the prep and I don't do homework." This was in spite of efforts by Kivuli personnel personally supervising and ensuring that CLWHA complete their school work every evening before going to bed. Kariuki on the other hand gave a different reason for his poor performance. He said as a result of rising up early to prepare for school, he often felt sleepy during the day and could not concentrate. Although most teachers concluded that sleeping in class was a side effect of ARV, Mr. Chrisy confirmed that the combined effect of waking up early and the effect of ARV impacted on the level of concentration and therefore affected CLWHA performance.

In order to gain a clear picture of CLWHA's academic performance, I asked them to specify the class ranking attained in the first and the second term exam ranking in 2010, which I later confirmed with the classroom teachers. Table 5.1 illustrates CLWHA academic rankings in terms one and two 2010 (All names are pseudonyms).

Table 5.1. Academic Ranking in 1st and 2nd Term Examination Results 2010

Name	Gender	Grade	1st Term Class Ranking	2nd Term Class Ranking
Tindi	F	4	36/60	28/60
Makena	M	4	50/60	50/60
Trina	F	5	36/60	14/60
Sidi	F	5	12/60	6/60
Kariuki	M	5	58/60	50/60
Karisa	M	6	12/60	4/60
Kairu	M	6	58/60	50/60
Gatarina	F	6	14/60	7/60
Kamweru	F	7	40/62	39/60
Kakubwa	F	7	25/62	15/60
Kalee	M	7	30/62	7/60
Lekule	M	7	50/62	40/60

The table above illustrates each child's grade at the time of the interviews and class rankings in terms one and two in 2010. According to the table above, the approximate number of pupils per class was 60. Given the large number in the classroom, academic competition was stiff. The results however revealed an improvement for each child's rankings from first to second term. Classroom teachers confirmed this observation by describing how much effort some CLWHA had put into their work. The table showed that Kalee and Trina had made remarkable improvement in term two. Kalee moved from rank 30 to 7, Trina moved from rank 36 to 14, Lekule moved from 50 to 40, and Kakubwa moved from 25 to 15. Given that most of the children had transferred from a school that was performing poorly, this academic leap portrayed in the grades was quite encouraging. These results verified that the average performance for girls was better than

that for boys. Overall, the majority of CLWHA in grade 7 showed incredible improvement. Contrary to the popular belief that HIV affects cognitive ability, this study did not correlate academic ability to the HIV disease itself, but to other factors such as continuous absenteeism due to sickness, attending doctor's appointments, and the effects of ARV.

Finally, academic enthusiasm helped CLWHA maintain optimism to gain admission in the country's top high schools. Specifically, those in grades six and seven identified high schools they anticipated attending after completing grade eight. It is every Kenyan child's dream to find admission in a top high school in the country. However, it all depends on the cut points requirement in each category of schools. Kenyan schools are classified into national, provincial and district, and each category is based on performance in national examinations and on the quota system. Working hard was hard and remaining academically focused was vital if they were to realize their academic dreams.

Hopes and Dreams

Career aspirations.

This study sought to establish whether CLWHA had defined career paths and to find out whether the HIV disease hindered their dream careers. To determine the children's career dreams, I asked them the following question: "What do you want to become when you complete school?" The findings in this study showed that CLWHA, whose ages ranged between 9 and 10 years, had clearly defined their future career plans although these could change as they became more knowledgeable, mature and exposed to the job market. This finding was supported by Auger et al (2005), who recognized career

development as a lifelong process that began in childhood and became a reality as they matured. The authors observed that the large majority of children in grade three identified career aspirations and expectations (pp.2-3).

Table 5.2 illustrated CLWHA responses regarding their career dreams. Three of the CLWHA wanted to become chefs, three wanted to become drivers, one an engineer, one a pilot, an air-traffic controller, two wanted to become lawyers, while one was not sure. In addition to becoming a chef, Tindi had ambitions of becoming a singer.

Table 5.2. HIV-Positive Children's Career Aspirations

Name	Gender	Age	Aspired Career
Tindi	F	10	Chef and Singer
Makena	M	13	Driver
Trina	F	14	Engineer
Sidi	F	13	Chef
Kariuki	M	14	Driver
Karisa	M	14	Pilot
Kairu	M	14	Driver
Gatarina	F	13	Air-traffic controller
Kamweru	F	14	Not sure
Kakubwa	F	15	Lawyer
Kalee	M	15	Lawyer
Lekule	M	14	Driver

The data in table 5.2 indicates that each of the CLWHA had distinct career plans. Also, a strong relationship between the child's grade and career aspirations was observed. The majority of those who chose high careers came from grades 5, 6 and 7. For example, Trina in grade 5 aspired to become an engineer, while Kalee and Kakubwa both in grade 7 wanted to be lawyers. Two children in grade 4 wanted to become chef and driver respectively. The study also established that learning outcomes influenced the type of career they aspired for. Most children aspiring for prestigious careers such as engineering, piloting, air-traffic control and law had the following class ranks: 4, 7, 14,

15 out of 60. Apparently, those with lower class ranking for example, Kairu and Kariuki who acquired 50 out of 60, preferred hands on jobs such drivers and chefs, which did not require high qualifications. Findings showed that age, daily interactions with the drivers, chefs and other HIV-positive children, who were already in colleges played a huge role in determining their careers of choice. Results from table 5.2 indicates clearly that apart from 13 year old Trina who aspired to become an engineer, all other children in grades 4 and 5 (ages 10-14) chose to become drivers or chefs.

The role Kivuli cooks played of providing food for the children was highly influential. As a result, cooking was considered a prestigious career. Tindi gave reasons why she wanted to become a chef:

> Me. I would like to be a chef and a singer. I am already writing my songs. Why do you want to become a chef? So I know how to cook. Do you like cooking? No. Because if you don't know how to cook… [Pause] you cannot cook a meal. …you cannot cook anything. You just go to the shop and buy anything and then you spend the money…. Then you spend evening out…everyday out…out… out.

Observations showed that Kivuli drivers were role models for a majority of CLWHA who had great admiration for them. Mr. Chrisy affirmed this by pointing out that driving and cooking careers had become a disturbing trend among the children and noted that Kivuli was trying to grapple with the problem in order to change the children's attitude. He noted that irrespective of the grades children acquired after high school, many of them had insisted on becoming either a driver or a chef. Mr. Chrisy however cited lack of consideration for prestigious careers and lack of successful career models at Kivuli Home were some of the main contributing factors. The study also confirmed that career counselling in most primary schools only targeted pupils who were completing grade 8. When I was volunteering at Kivuli, one boy graduated from the aviation college

in Nairobi. All the children and staff celebrated the graduation with a lot of excitement on a Sunday afternoon. After the Mass of Thanksgiving there was a huge party comprised of cakes, cookies, drinks and congratulatory messages from a few of the children and speeches from the director and the manager. This boy's achievement had a significant influence on CLWHAs' future careers, which encouraged them to be more focused on their academic work. For instance, Gatarina's choice of career:

> I would like to be an air-ticketer …to work with the airlines. His [Referring to the graduate] is releasing the airplanes before departure- and monitoring the weather. If the weather is bad he advises the aircrafts not to take off.

After a lengthy discussing with CLWHA regarding their career interests, one prominent thing that stood out was how inadequately versed they were about career details. Again, this was a pointer to the school's failure in showing the pupils the relationship between academic pursuit and career endeavours.

Participating in leadership and extra-curricular activities.

Classroom teachers emphasized that as part of the learning experience, involving CLWHA in school leadership and extra-curricular activities was an important venture. In order to understand the extent of their involvement in these activities, I posed a question to the classroom teachers. "Have you ever appointed any HIV-positive child to a leadership position?" Almost all the teachers responded in the affirmative. All the teachers recognized that CLWHA were highly competitive and possessed leadership qualities. Teachers emphasized the importance of giving equal opportunity to CLWHA to prove their capability. As a result, they appointed CLWHA to various leadership positions such as, class prefects or group leaders. Several CLWHA participated in extra-

curricular activities, most of which were voluntary. Teachers described in detail about the performance of those they had appointed to leadership position. Mrs. Kisu explained:

> I made Lekule a prefect in class 3. I really encouraged him. I think we should appoint them because they have all the qualities. They have all the qualities. They do participate in group leadership although there are those cases where we have chosen them as group leaders but they don't want.

Mrs. Mwega stated:

> I appointed Lekule and he was very good. Kakubwa was a prefect too. They participate very well.

Mrs. Serare remarked:

> Yes. Like "D[19]" is a very good leader. Some of them can make good leaders" There is one child in class seven or eight (Kakubwa). She is really doing very well. She is also a scout.

Mr. Hose explained:

> This boy in class 6 has been a class prefect in class 5. Then this girl in standard 7 likes being the leader…and participated in very many areas in the class. There is also a boy who is a prefect in class 5L-there is one prefect there. We don't leave them out.

Emphasizing their leadership skills and how they conducted their duties, Mr. Hose commented:

> Yes, yes… [Nodding] Very well. They do it very well.
> Mrs. Serare added: "D" is a group leader. She can make a very good leader. She is a very nice girl.

Although a few CLWHA were accorded the opportunity to participate in leadership roles and did it extremely well, one child performed poorly while others though given the chance, refrained to accept the offer. Mrs. Siti explained:

> I had tried Tindi as class prefect [Laughs] but she is too soft. Children could make noise and she could not report them. I had thought she was capable.

[19] "D"-An HIV-psoitive child who was a group leader in her class

In addition to classroom teachers appointing CLWHA as classroom prefects, peers were also given the opportunity to vote. Mrs. Were explained that rather than the classroom teacher appointing a prefect, they left it to the class to vote for a suitable candidate. Peer voting for an HIV-positive child was a proof that they not only had faith in them but also recognized fully their leadership skills. Classroom teachers highly commended these prefects saying how emphatically they worked in maintaining classroom discipline.

I asked a similar question to CLWHA regarding their participation in school leadership and extra-curricular activities. Five children said they had served or were already serving as class prefects. The children were all very proud of their leadership roles as they talked about how effectively they had executed their duties. Describing his experience as class prefect, Kariuki said he had to ensure that learning was not disrupted. He said: "I wrote their names." Additionally, Gatarina said: "I was a prefect in class 5. I used to write noisemakers" [Chuckling]. In a Kenyan classroom, the role of a class prefect is challenging since it entails maintaining discipline in the classrooms, writing down the names of noisemakers and handing them over to the class teacher for punishment. Additionally, it involves coordinating class activities, assisting the teachers in distributing and collecting books during the lessons and reporting regularly to the class teacher about the progress of the class.

CLWHA demonstrated a deep passion for extra-curricular activities. The findings showed that several children actively participated in outdoor games (Mainly football and netball) and a total of 20 (Out of 37) participated in diverse activities, which included

group leadership, music, dance, drama, scouts, health and wild life clubs (Table 5.3). Mrs. Siti pointed out:

> Kakubwa was my music leader and I was their music teacher. She is in the drama or dancing club. She does it very well.

Mrs. Serare added: There is this one in class seven ("K[20]"). She is really doing very well. She is a scout (Meaning that she is a member of the scouting club).

Other teachers acknowledged the remarkable contribution CLWHA had made in the school. Mrs. Kisu explained how children in her class presented songs and poems during the school assembly. "They do contribute a lot because they have very nice songs." Some CLWHA were also members of the health club where they had made a remarkable contribution. Commenting on their participation Mrs. "G[21]" said: "There are two CLWHA in the club. They are in class 4 and 5 and they contribute a lot...a lot." Table 5.3 summarizes the involvement of CLWHAs in leadership and extra-curricular activities.

Table 5.3. Participation in Leadership and Extra-curricular Activities

Leadership and Extracurricular Activities	**Male**	**Female**
Class prefect	3	2
Group leader	0	3
Scouting club	4	2
Bell ringer	1	0
Music and Dancing club	0	1
Health club	2	0
Wildlife club	2	0
Number of Participants	**12**	**8**

The results on table 5.3 show that a total of 12 boys and 8 girls (out of 37) actively participated in extra-curricular activities and held leadership positions. Most extra-curricular activities were scheduled after normal class hours and since CLWHA left

[20] "K" –An HIV-positive girl who performed well academically.
[21] "G"- Teacher in charge of the Health Club in the school.

for Kivuli immediately after the classes, they missed the opportunity to play and interact with peers.

Involving CLWHA in school leadership had considerable benefits. For instance, Lekule was cited as a troublemaker since he often engaged in acts of indiscipline. Several teachers said he had reformed after he was appointed a class prefect. Mrs. Nuru observed: In class six Lekule was made a class prefect and since then I have not heard much about him. This year I have not heard anything about Lekule. Another teacher remarked that since appointing Kariuki as a class prefect in grade 5, his attention seeking behaviour had changed and was more focused on leadership responsibilities.

Raising a family.

During the interviews most CLWHA, particularly those from grades 5 to 7, said they hoped to get married and raise a family. Although it is a cultural inclination for men to raise families and carry on the family tree, it was unclear whether CLWHA understood the implications of parenthood. Being HIV-positive and childless however, is also socially stigmatized, and would equally be considered an additional burden. From whichever angle one looks at it, most CLWHA were eager about having families of their own. This was contrary to the wider perception that HIV/AIDS is a death sentence for PLWHA, for CLWHA parenthood was an anticipated dream. The need for family found support in Kaida et al's (2011) study that indicated that "with the advances of antiretroviral therapy (ARV), individuals who are HIV-positive can look forward to longer, healthier lives than was previously possible…and couples infected with HIV planning their futures together can consider having a family" (p. 469).

Apart from Kairu's opinion that was somewhat different, all the other children expressed the following sentiments about raising a family.

Kalee stated: I am looking forward to raising a family.

Kamweru indicated: After I get a job I would like to marry and get children.

Karisa emphatically said: I would like to have my own family after completing school.

Similarly, Kariuki remarked: When I become an engineer then I will have a family…a wife and children.

Although Gatarina indicated that for her family was a priority, she had concerns about the disease and the effect it would have on her children. She was however aware of the medical breakthrough in HIV research, but she declined to elaborate on it. Lekule on the other hand wished to get married, but he too was concerned that it would hurt his wife, and would consider adopting a child:

> I think I will get married but I don't want to have children." Why? I asked. Ahh… [Surprised] I don't want to hurt my wife…. That struggling when she is having a child …who will take her to the hospital? I prefer to adopt a child. (Why?) Because I don't want to make her [Wife] suffer. That is a question mark But I am fifty-fifty…I am not sure. But I am still young and I am still growing and have time to make decision.

Kairu was the only one who was somehow not ready to get married or to raise a family. He stated: "I don't want to marry." (Why?) "I don't want to be a bother to people." During HIV/AIDS lessons pupils acquired basic knowledge about HIV transmission and its consequences on the human body. It is probable that Lekule's fear was based on the understanding that unprotected sex carried the risk of mother-to-child transmission. For some CLWHA, marriage and family was an important dream to be pursued. Similar outcomes relevant to this finding are reflected in a study by Kaida et al (2011) that showed a strong association between the use of ARV and childbearing intentions for

women living with HIV/AIDS. The study noted that 44% of the 674 women aged 18 to 44 years recruited in the study expressed the desire to have children. Although there are potential risks associated with fertility, particularly among PLWHA, CLWHA were undeterred.

Culturally in Kenya, being childless is considered a violation of societal norms and is an equally stigmatizing experience for both men and women. Access to ARVs is slowly changing childbearing intentions of many PLWHA, although some have to weigh the risks associated with HIV and reproduction issues.

During the interviews, none of the children in grades 4 engaged in the discussion about raising a family. My assumption was that given their young age [10 years old], family matters were not a priority. Another important observation was that boys were keener about raising a family than girls. Segurado and Paiva (2007) and Getachew et al (2010) found parenthood and reproduction intentions among Brazilians and Ethiopians respectively were culturally driven, and the desire to have children among PLWHA was more frequent among men than among women (p. 5).

Supporting the orphans and the needy.

This information was not directly solicited from the questions but emerged during the interviews when I asked: "What would you like to become after school?" The responses affirmed CLWHA's appreciation for the help Kivuli provided. As a way of reciprocating, most of them said they would support the orphans at Kivuli Home after completing school and settling down. Trina illustrated: "I will help Kivuli. The people who will be here like me the way I was. Then I will leave here when I have already planted a tree." Then Kamweru emphasized: "If I get enough money I will support

children at Kivuli." Similarly, Kariuki stressed: "After getting a job I would like to help needy people." This finding demonstrated that despite the challenges CLWHA faced as a result of the disease, they had a sense of responsibility in addition to hopes and dreams that they aspired to accomplish.

Most of the expected findings in this study found support in the literature that was reviewed in chapter two. In addition, these findings conformed to the experiences of stigma and discrimination as described in the theoretical concept of Goffman (1963). Career aspirations, raising a family and supporting the needy conformed to what Goffman (1963) termed as "positive" stigma, which demonstrates that though the experience of being stigmatized may take a toll on self-esteem, academic achievement, and other outcomes, many people with stigmatized attributes have high self-esteem, perform at high levels, are happy and appear quite resilient to their negative experiences. This theory argues that PLHWA experience a considerable amount of hopelessness as a result of stigma, which often compels them to abandon their dreams. In contrast to Goffman's (1963) observation, CLWHA portrayed an unyielding spirit of resilience and determination to succeed in their endevours. This spirit was attributed to a conducive environment as well as the overwhelming support they received from Kivuli personnel, the teachers and peers at Karibu School. Findings similar to those found in this study (Henry, 2004) illustrated factors that contributed to hopelessness or resilience in HIV-positive youth as the presence or absence of social support, stigma, peer group acceptance and appropriate coping skills.

Summary

In this chapter I presented the five themes that emerged from the study. In order to gain a deeper understanding of the issues, I involved orphaned children living with HIV/AIDS, classroom teachers, and two administrators, one from Kivuli Children's Home and the other from Karibu School. Themes one and two illustrated some negative experiences which were discussed in detail and included the manifestation of AIDS stigma and discrimination, the effects of stigma and discrimination, the coping strategies and the interventions for combating stigma and discrimination. Data revealed that each of the children had experienced at least one type of stigma and articulated how these were manifested. Each of the children had experienced both internal stigma and felt stigma. Consequently, stigma and discrimination had several implications for the CLWHA's well being or lack thereof, including social isolation, avoidance and suicide attempts. Additionally, specific strategies that CLWHA employed to cope with and confront stigma were identified.

Themes three, four and five illuminated some of the CLWHA's positive educational experiences including empowerment and supportive experiences, educational resources and initiatives. Additionally, a section on hopes and dreams focused on CLWHA's aspirations for a career, family and support for the needy. The study established that the relationship between CLWHA and teachers was cordial. The majority of CLWHA reported having received physical, emotional, psychological and academic support from teachers and peers. In addition, recognizing their skills, teachers gave CLWHA an opportunity to participate in leadership and extracurricular activities. Their involvement in these activities enhanced their self-esteem and a sense of belonging,

improved their attitude towards learning and encouraged them to compete academically. Teachers however cited lack of empowerment by the Ministry of Education and Technology especially in teaching HIV/AIDS lessons, and explained the struggles they encountered as they attempted to integrate HIV/AIDS components into the regular lessons. In spite of the numerous challenges CLWHA faced, they enthusiastically dreamed about a rewarding career, had prospects of raising a family, and the desire to support needy children as a way of reciprocating the support they had received from Kivuli Children's Home.

CHAPTER SIX: DISCUSSION, LIMITATIONS AND RECOMMENDATIONS

This study was an ethnographic qualitative investigation of HIV/AIDS stigma and discrimination in Kenyan public schools. It specifically examined the experiences of HIV-positive children from Kivuli Children's Home. In order to obtain sufficient information for the study, I designed three main research questions and three sub-questions. In-depth interviews, participant-observation and document analysis were undertaken to address these questions. The research provided insights into the various ways in which HIV/AIDS stigma and discrimination were manifested in Karibu School and demonstrated their consequences on CLWHA's well-being, social interactions and learning.

In chapter four, I presented the participant's profiles, while chapter five discussed the findings, which were situated within the reviewed literature, the theoretical framework and the methods that guided the study. This final chapter bases the discussion and interpretations of the study's findings on the research questions, reviewed literature and the theoretical framework employed in the study. In addition, the major contributions, limitations, and recommendations for future research are discussed. The structure of this chapter follows from the major questions as outlined in Chapter 1.

Q.1. In What Ways Are AIDS Stigma and Discrimination Manifested in Kenyan Public Schools.

A considerable body of research suggests that as a global phenomenon, AIDS stigma and discrimination are manifested in specific public milieus (Family Health International [FHI], 2008), operate in specific contexts of culture and power, and at multiple levels within families, communities, religious organizations, communities,

health care facilities, places of employment, in the social media, and in government policies (McNary-Keith, 1995; Manjok et al., 2009; Mahendra et al., 2006).

This study demonstrated that stigma and discrimination associated with HIV was a common occurrence in public schools. Evidence of these manifestations was illustrated by parents, teachers and peers in various schools, where parents disapproved and opposed the admission of CLWHA into public primary schools on the basis of their serostatus. Mr. Chrisy (Kivuli administrator) explained that while seeking admission to different schools, the children were met with hostility and unwarranted negative treatment by parents and teachers. This outright discrimination was in contravention of the educational policies that provide guidance on the rights to education (Human Rights Watch [HRW], 2008). Holzemer and Uys (2004 cited in UNAIDS, 2006, p. 2) maintained that PLWHA are subjected to prejudice, discrimination, abuse and hostility due to their HIV status. It is worth noting that unlike adult PLWHA who are blamed for engaging in 'bad' bahaviours that warrant mistreatment, society considers CLWHA "innocent". However, due to their serostatus, they are perceived as the product of promiscuity. Katz (1981) affirmed that in spite of their innocence, the society would still treat CLWHA in less humane ways when they grow older and attend school. In this study, manifestations of stigma and discrimination involving parents and teachers in educational institutions were discussed in the reviewed literature as well as in relevant theoretical frameworks (Conway, 2005; Thornton, 2008: Hong et al., 2008; Tavoosi et al., 2004; Macek & Matkovic, 2005; Mead & Hamilton, 2005; Pryor et al., 1999).

Q.2. In What Ways do HIV-Positive Children Experience Stigma and Discrimination in Kenyan Public Schools?

This study found that CLWHA experienced three main types of stigma; namely, enacted or actual, internalized, and felt stigma. This was consistent with Manjok et al (2009); Jones et al (1984). Stigma and discrimination involved parents, teachers and peers, who were synonymously referred to as "stigmatizers" (Jones et al., 1984). Courtesy stigma or stigma by association was directed specifically at Kivuli personnel by parents and teachers when they sought admission for CLWHA in various schools.

Enacted stigma.

Stigmatization by parents.

The study findings revealed that although CLWHA had no direct contact with parents, they had a powerful influence on school administrators' decision on whether or not to admit CLWHA into the schools. In addition, parental influence on their children determined the type of treatment pupils accorded CLWHA while at school. In this study, stigmatization by parents involved parental opposition to the admission of CLWHA in primary schools, demanding the withdrawal of CLWHA from Karibu School, and withdrawing their own children from the school. According to the study findings, parents held several misconceptions and were ignorance about HIV transmissions, which led them to question the moral character of CLWHA implying that they held them responsible for contracting the virus. Walster (1996) pointed out that when the society is confronted with a threat, it designs control measures to help control anxiety and to provide a sense of security. The reviewed literature in chapter two pointed to the critical role parents played in denying CLWHA access to education in schools (Conway, 2005;

Pryor et al., 1999; Hong et al., 2008; Mead & Hamilton, 2005; *The Times of India*, 2009; Macek & Matkovic, 2005; Thornton, 2008; Tavoosi et al., 2004).

Stigmatization by teachers.

Study findings illustrated teachers colluding with head teachers to deny CLWHA admission into primary schools until a court order compelled the Ministry of Education to authorize all the schools in Kenya to admit CLWHA without reservation (Marc, 2004). Following this mandate, lack of compliance by the head teacher of Karibu School necessitated his transfer in order to pave the way for a smooth transition and integration of CLWHA into the school. Although findings showed that most teachers cared deeply about CLWHA, interview data reports showed that CLWHA experienced stigmatization from two teachers. Stigmatization involved hurtful remarks by the teachers with reference to their deceased mothers and to the medicine they were taking. The remarks were considered insulting, painfully reminding them of the loss of dear parents and of their status as orphans.

Another finding illustrated a lack of confidentiality and insensitivity on the teachers' part when dealing with CLWHA. Some teachers' breached confidentiality by deliberately discussing Kivuli Children's Home in the classroom. The same teachers discouraged pupils from sharing food with CLWHA arguing that the food of CLWHA would make them sick. Owing to the teacher's position of authority, peers assumed it was appropriate to spread the information to other children children. This evoked a feeling of rejection by the teacher and isolation by peers. Thereafter, most of the younger CLWHA (grades 1-4) began seeking each other's company while in the classroom and outside. Levin and Laar (2004) demonstrated that utterances from individuals in authority, such as

teachers, can have dire consequences on the child and affect how they self perceive themselves.

Similarly in this study, a breach of confidentiality by teachers affected peer relations, and their interactions as well as their learning. The irony in this saga demonstrated that teachers, like all members of the society, viewed HIV/AIDS as intimidating to them as well; hence, the need for acquiring skills and relevant training so that they could be more understanding and sensitive when passing information about HIV/AIDS to the pupils. Similar findings to those in this study were reported by Cohen et al (1997) and Pryor et al (1999).

The study found that teachers deliberately distinguished between CLWHA and other pupils, particularly when reporting about a sick child from Kivuli, as the administrator demonstrated in quoting what one teacher said: "I have a sick child and he/she is from Kivuli", and when one phoned Kivuli, she/he would say, "Your child/ren are sick. What can we do with these children? We don't know what to do." The teachers' perception was consistent with UNAIDS (2006) concept of "us" and "them" distinguishing those with the attribute and those without (p. 2) The reviewed literature in this study alleged that stigmatization by teachers had similar implications on social interactions and learning (Macek & Matkovic, 2005; *The Times of India*, 2009; Thornton, 2008; Cohen et al., 1997; Ruto et al., 2009; Family Health International [FHI], 2008; Thornton, 2008).

Stigmatization by peers.

Findings in the study showed that pioneer CLWHA reported being teased by peers when they were first admitted to the school. Teasing was the result of associating a

bus logo (The bus brought CLWHA to school and picked them up every day) that protrayed the emblem of Kivuli Children's Home. Since it is common knowledge that Kivuli is a home for HIV-positive children, the pupils quickly associated the bus with the CLWHA. Another stigmatizing experience occurred when some peers began to spread rumours about their serostatus to other children in the school. These rumours originated from parents and teachers' discussions about Kivuli children. According to one CLWHA, these reactions had an effect on peer trust and peer relations.

The results indicated that pupils had stigmatizing attitudes. As a result, findings showed that some peers refused to share desks with CLWHA, resulting in a feeling of rejection. Also during class observation, I saw a statement that a boy in grade three had written in his English book, "People with AIDS should not mix with others." After insisting that what he had written was true, two boys who shared the same desk supported the statement. It was not clear whether the statement was directed at the only CLWHA in the classroom or whether he was expressing a common social belief. Future research could focus on the perceptions of peers towards their CLWHA counterparts in order to design relevant interventions. These findings were congruent with those reviewed in the literature (Link & Phelan, 2001; Baggaley et al., 1999; Huang, et al., 2005; Macek & Matkovic, 2005; Tavoosi et al., 2004; El-Gadi, 2008; Castle, 2004: TASO, 2009; Thomas et al. , 2005; Dlamini et al., 2007).

Internal stigma.

The findings in the current study revealed that internal stigma was undeniably real in the lives of CLWHA. During interviews, all CLWHA acknowledged thinking about the disease and they described how taking antiretroviral medicine was an equally

stigmatizing experience. A similar finding involving HIV children and adults living in Brazil was discussed by Abadia –Barrerro et al (2006). The expressions in this study were in response to a question I posed to each one of them during the interviews, "How often do you think about HIV/AIDS and how does that make you feel?" They all indicated frequently thinking about the disease and these thoughts triggered a negative feeling, as one girl explained: "It makes me feel bad in the heart." Evidence of internal stigma was illustrated by not accepting the disease, denying and lying that they had no HIV and were not on HIV medication. Others questioned "why me". These verbalized statements uncovered the internal resistance and anxiety that often results from living with a highly stigmatized condition. Being HIV-positive distinguished them from their counterparts. The agony of living with HIV/AIDS corresponds to Visser et al (2006) and Chapman's (2000) observation that since HIV was discovered in early 1980s, the society has associated the disease with fear, often accompanied by acts of stigmatization and discrimination against PLWHA. This fear of the disease is experienced by both those the stigmatizer and the stigmatized as well.

The findings in the study revealed some distinct behaviour patterns among CLWHA that were associated with their experiences of internalized stigma. These included social isolation and withdrawal, loneliness, crying, constantly talking about the disease, attention and recognition seeking behaviours. Although suicidal thoughts were mentioned in the study, none of the CLWHA participants had contemplated suicide. Teachers pointed out that the effects of internal stigma were more pronounced among the younger CLWHA in grades 1 to 4. However, crying was also observed among CLWHA in grades 5 to 7, although according to Mrs. Kisu, it was more common among CLWHA

in grade 1 and occurred in the first term of the school year when they were new in the school. Bullock (1998) concurs that young children adjusting to a new school often express lack of confidence and anxiety. In addition, these findings were congruent with those in the current literature and conformed to the theoretical frameworks used in this study (Anderson et al., 2004; Dorrell et al., 2008; Duffy, 2005; Gilbert & Walker, 2010; Campbell et al., 2005; Varas-Diaz et al., 2005; Abadia-Barrero et al., 2006; Monico et al, 2001; USAID, 2006).

A new finding in this study demonstrated that HIV/AIDS lessons increased CLWHA's sense of internal stigma. The sensitive nature of the subject and its relevance to their condition caused them to feel as if lessons centered on them, consequently evoking a feeling of embarrassment, sadness and shyness. Seemingly, the HIV lessons presented a different meaning for CLWHA from what was intended. In spite of HIV/AIDS being incorporated into regular teaching subjects, during class observations, none of the teachers discussed issues about HIV/AIDS during the lessons. I also did not come across any literature focusing on stigma originating from HIV/AIDS lessons. Therefore, it is important for future researchers to examine the extent to which HIV/AIDS lessons are sources of stigma for CLWHA.

Felt stigma.

Experiences of felt stigma featured prominently throughout the study. Findings illustrated CLWHA's exceptional concerns about being rejected if their peers knew their serostatus. The study showed that compared to the experiences of enacted and internal stigma, felt stigma was the most distressing. In order to understand CLWHA's experiences of felt stigma, I posed the following question: "How would your friends treat

you if they learned about your HIV status and how would that make you feel?" In response, all 12 CLWHA predicted rejection and mistreatment by peers. They anticipated that they would experience from their peers shunning, isolation, a lack of caring, dissociation out of the irrational fear they might get the disease, and, they would go about spreading information about their serostatus and HIV medicine to the entire school. Most importantly, they worried about the eventual loss of friends. Because of this anxiety and the value they attached to their friends, they avoided inviting them to Kivuli for that they might learn about the HIV medicine they were taking. Consequently, the assumption that peers were unaware of their serostatus was quite reassuring.

In response to the question, "How would that make you feel?" most CLWHA said that they would feel very bad, not happy, while some indicated they would opt to leave school, transfer to another school or stay at home. A study exploring barriers to adherence of antiretroviral drugs among HIV-positive children and adults in sub-Saharan Africa showed that stigma and fear of disclosure were key factors to adherence (Ammassari et al., 2002). Numerous studies in the current literature focusing on the experiences of felt stigma similar to those found in this study were extensively discussed (Baguma, 2008; Duffy, 2005; Schellenberg et al., 1995; Dorrell et al., 2008; Makoae et al. 2009; Yebei et al., 2008; EduSector, 2008; Gilbert & Walker, 2010).

In spite of confirmations from the medical reports showing that it is unlikely HIV could be transmitted during social interactions, some people continue to believe that it can occur in everyday contact (Dijker, 2001). It is sad that misconceptions observed among parents, teachers and a few pupils led to the stigmatization of CLWHA who otherwise deserved sympathy. Overall, these findings provided insights into how existing

social inequalities foster stigma and how stigma perpetuates existing inequalities within the context of HIV/AIDS (Deacon et al., 2005).

Peer acceptance of HIV-positive children.

Studies by Castro and Farmer (2005); Chapman (2000); Makoae et al (2009) and Staggs (2007) indicate that once the status of PLWHA became public, stigma and discrimination became imminent due to the risk factor associated with the disease. In this study, CLWHA anticipated that if their peers knew their serostatus they would ultimately stigmatize them. However, teachers cited three main reasons to illustrate why incidences of stigma and directed at CLWHA were not as many as would be expected, and the reasons why pupils generally accepted CLWHA. Peer acceptance was attributed to: (i) The absence of HIV symptoms (ii) Not knowing specifically which child was HIV-positive, and (iii) Lack of understanding of the seriousness of the disease. It is worth noting that although most CLWHA appeared normal, some had visible marks from skin rashes, persistent colds, recurrent coughs, and problems with ears and eyes. However, these symptoms totally contrasted the images often portrayed by the media about PLWHA, and for pupils without much information about HIV/AIDS, it was almost impossible to make conclusions on the basis of these observations. Related findings to those observed in this study were discussed by El-Gadi et al (2008); Cohen et al (1997); Dorrell et al (2008); Macek & Matkovic (2005); Tavoosi et al (2004); Zhang et al (2008).

Q.3. How do the Experiences of Stigma and Discrimination Affect Social Interactions and Learning of CLWHA?

Waweru et al (2008) acknowledged that children living with HIV are often predisposed to highly stressful conditions like death of a family member and the overall

stigma attached to their condition. As a result, these experiences interfere with their social and emotional behaviour. The reviewed literature in this study showed that stigma and discrimination have a range of effects on persons living with HIV/AIDS as demonstrated by the findings in this study.

In all 12 cases, CLWHA experienced three main types of stigma, namely enacted, internal and felt stigma. The effects of these stigmas resulted in self isolation and withdrawal, a sense of insecurity, crying, talking about the disease, attention and recognition seeking behaviours, seeking sympathy, feelings of sadness (depression), embarrassment and shyness, clinging together, avoidance, fear of stigmatization, refusing to take medicine, and loneliness, while some engaged in unruly behaviour. These experiences impacted on the emotional, social and psychological well-being of CLWHA since they reduced their level of interactions and sharing at a personal level, and limited their number of friends; thus minimizing their social support by peers, and increasing depression and internalized shame. In addition, the overwhelming sense of uncertainty and the attempt to conceal their real identity, to maintain relationships and to gain acceptance from peers was quite depressing. Adewuya et al's (2008) study in Nigeria showed a significant relationship between depression and quality of life in persons living with HIV in Nigeria. Similarly, literature congruent with the current findings highlighted that stigma and discrimination impacted on the emotional and mental well-being of the stigmatized by increasing internalized shame (Anderson, 2004; Banteyerga et al., 2003; Castro & Farmer, 2005; Dorrell et al., 2005; Koku, 2010; Lee et al., 2002; Thomas et al., 2005).

According to this study's findings, more boys (ages 14 and 15) than girls refused to attend school, which affected their performance. However, Mr. Chrisy clarified that children refused to go to school whenever they experienced stigmatization or encountered problems with learning. Observations by Court and Givon (2003) showed that vulnerable children who experience social rejection are likely to develop low self-esteem, refuse to attend school, which may affect academic performance and learning (p. 1)

Apart from the impact of stigma and discrimination on learning, thinking about the disease, bouts of sickness, absenteeism from school due to sickness and frequent visits to the doctor were important findings in explaining the academic performance of CLWHA. Additionally, findings indicated that HIV medicines caused some CLWHA to sleep during lessons, which affected their level of concentration and learning. Similar observations by Husstedt et al (2002); Liner et al (2008); UNAIDS (2005) showed that PLWHA including those on Highly Active Antiretrovial Therapy (HAART) often complain of mental disturbances and generalized pain in the body.

The findings also revealed that some CLWHA had hearing and vision problems that affected participation and performance. CLWHA with ear problems avoided wearing hearing aids while in school, even though they constantly used them at Kivuli. Presumably, refusing to wear hearing aids while at school reduced their chances of being stigmatized. A similar observation by Silverman and Largin (1993) indicated that hearing aids prevent children with hearing problems to look different from their peers, and because hearing aids are associated with deafness, it follows that hearing aid wearers are perceived to have a mental disability. To affirm this claim he cited Goffman (1963), who "recognised that society finds it difficult to accept 'an undesired differentness' and that a

hearing aid wearer may possess ‘a trait that can obtrude itself upon attention and turn those of us whom he meets away from him” (http://www.les-smith.com/coloured-hearing-aids/literature-review.htm).

Q.4. What Coping Strategies Do CLWHA Employ to Deal With Stigma and Discrimination in Kenyan Public Schools?

Alonzo and Reynolds (1995) argued that PLWHA constantly struggle to cope or manage AIDS stigma, while Lazarus and Folkman (1984) indicated that the coping process changed over time depending on the situation/s PLWHA found him/herself in. Findings in this study revealed that CLWHA utilized several coping strategies to deal with stigma and discrimination. Teachers reported that some CLWHA frequently talked about the disease until they were told to desist. Denial was used as a coping strategy by most CLWHA who said they felt normal. Others said they did not have HIV, while others denied taking HIV medicine. Some participants mentioned faith healing. Avoiding close encounters with peers by refusing to invite them to visit at Kivuli, self-isolation and withdrawal and banding up or clinging together while at school were also frequently noted. Folkman and Lazarus (1984) stated that employing a variety of coping styles provided the PLWHA with a feeling of comfort reducing emotional distress. Other studies with similar findings as those in this study include Coetzee et al., 2003; Dorrell et al., 2008; Makaoe et al (2008); Carr (2002); Banteyerga et al (2003); Anderson et al (2009); Koku (2010).

Q. 5. How Are Non-Infected Children Educated or Encouraged to Support Their Infected Peers?

Brown et al (2003) highlighted the difficulty of eliminating AIDS stigma and related discrimination. The indicated stigma and can be addressed by initiating a variety of interventions. The findings in this study showed that although the school had few resources that were specific to the needs of CLWHA, initiatives such as HIV/AIDS education, counselling, advice to pupils, normal treatment of CLWHA and disclosure of CLWHA's serostatus to the teachers were some of the important measures they employed to address stigma and discrimination. Normal treatment of CLWHA meant that they were not treated differently from other pupils. Teachers stated that HIV/AIDS lessons were helpful in conveying important information about HIV/AIDS and related misconceptions along with the emphasis on how PLWHA should be treated. Conway (2006) highlighted that one way of supporting CLWHA's educational and emotional needs was by creating a supportive and inclusive environment through policy and practice, which would improve their "health, well-being and opportunities" (p. 3).

Counselling and advice to pupils targeted those who were harassing CLWHA. Teachers treated CLWHA by involving them in leadership positions, extracurricular activities and classroom duties. These activities helped to enhance self-esteem, promote peer acceptance and reduce the possibility of stigma and discrimination. It was Kivuli's policy to disclose the serostatus of CLWHA to the school prior to admission. Disclosure was therefore important in preparing teachers to psychologically deal with CLWHA even in the absence of proper training to handle such a vulnerable group. Most importantly, this knowledge facilitated the integration process of CLWHA into the school.

Q.6. What Resources Exist in the School that Provide Support and/or Empower HIV-Positive Children to Deal With Stigma and Discrimination?

Supportive and empowering resources and initiatives.

This study's findings established that educational resources aimed at supporting and empowering CLWHA and other pupils were scarce. However, teachers did identify that the following resources were available, albeit in short supply: First aid kit, the murals, wall charts, HIV/AIDS pamphlets and brochures, funding for orphaned and vulnerable children (OVC), health club, counselling and HIV/AIDS lessons. These resources were not specific to the needs of PLWHA, but attended to the general needs of the pupils. They however enhanced teaching and learning about HIV/AIDS. Some CLWHA who participated in the health club found the information they obtained quite helpful. As mentioned earlier, CLWHA did not seek counselling at school. However, the administrator pointed out that the counselling department was almost non-functional, signifying that the emotional needs of the pupils were not adequately met. At the time of data collection, I observed that the First Aid Kit was empty, and as a result, children who needed treatment could not obtain the necessary assistance. Kivuli Children's Home met the school needs of CLWHA; therefore, OVC funding was used to support other orphans in the school with uniforms and books.

While collecting data, I noted that the school had several pressing needs that required urgent redress. For example, important resources such as an infirmary and a counselling office were lacking. The need for HIV-related resources was discussed by Kalichman (2003), who emphasized that HIV related resources were critical in enhancing the health and well-being of PLWHA.

The empowerment of teachers.

During the interview, I wanted to ascertain the type of empowerment teachers received to enable them deal with, or support, CLWHA. The findings showed that teachers were not fully empowered. As a result, the majority lacked the necessary skills to address CLWHA needs. They also stated that teaching about HIV/AIDS was extremely challenging. All 8 teachers attributed their incompetence to a lack of formal and informal training on issues pertaining to HIV/AIDS. This may explain why CLWHA emphasized that HIV/AIDS lessons were stigmatizing. Lack of teacher empowerment undermined their confidence and motivation to teach. This was in accord with findings in the reviewed literature (Marks & Louis, 1997; Whitman et al., 2001; Schenker, 2001). The authors consensually noted that lack of empowerment for teachers effected on teacher-pupil interactions, the quality of teaching and the general students' performance.

Attitude towards the school and the teachers.

The study found that CLWHA possessed a positive attitude towards teachers, peers and the school. Being able to attend a public school was considered advantageous. Bunch and Valeo (2004) noted that segregating children with special needs limits their opportunity to establish friendships with others which could potentially break the stereotypes that peers hold about them. Findings showed that teachers and peers made Karibu School appear special; something that I confirmed during discussions with other CLWHA attending other schools. CLWHA described teachers as good, helpful, committed to their work, and always there for them. In addition, they commended the school for creating a congenial environment for learning and for having facilitated the development of endearing relationships. Consistent with these findings, Ireson and

Hallam (2005) found a relationship between pupils' liking of school with the amount of support they received from teachers and other pupils.

Support by peers.

Peer friendship and support was a significant factor in building self-image and in promoting academic performance. All 12 CLWHA passionately spoke about their friends. Having friends helped them to feel accepted, enjoy a sense of belonging to a community, and, most importantly, develop a sense of self-worth. Goodenow (1993) acknowledged that pupils' sense of being appreciated affects their classroom experience. Findings in the current study indicated that having friends enabled CLWHA to engage in various activities such as play, food sharing and eating together, studying together, and discussing issues of interest, all of which were extremely supportive. According to Katz and Assor (2007) feelings of support by peers in improves the pupils sense of belonging. Although most CLWHA stated that socializing with friends was extremely important, time for socialization was limited to morning and lunch breaks. Several CLWHA indicated that exchanging gifts with friends was important, and although they had no gifts to share, receiving gifts from a friend was deemed a special privilege. Teachers and peers' support was fundamental, particularly during the adjustment process in the new school environment. Similarly, findings in the reviewed literature confirmed that social support for PLWHA improves mental and physical health (Darling et al., 2010; Reeves, 2001; Varas-Diaz et al., 2005).

Support by teachers.

The findings in this study indicated that CLWHA experienced physical, emotional and academic support from teachers, while material and medical needs were met by

Kivuli Children's Home. This corresponds to the findings by Hay et al (1994) that HIV-positive individuals rely entirely on formal and informal social support in order to cope with their HIV-related concerns. The majority of CLWHA acknowledged that teachers were helpful by articulately describing how they spent personal funds to provide them with food or snacks. Some alluded to the teachers' concern whenever they were ill, by pointing out how they had to use personal mobile phones to call Kivuli so they could obtain quick medical attention. Although CLWHA were discouraged from sharing personal matters with outsiders, whenever teachers noticed a problem with any of the children, they encouraged the child to seek counselling from the counsellor at Kivuli. One teacher said she talked to and encouraged CLWHA to feel at home.

This study established a significant correlation between liking of school, support, academic performance and learning. This was consistent with Goodenow (1993), who associated liking of school with achievement and academic motivation. However, the findings showed also that teachers provided minimal academic support due to teaching demands and workload pressures. Nevertheless, two male teachers said they assisted pupils mainly in grades 6, 7 and 8 with mathematics and Science subjects. As a result, CLWHA remarked that their mathematic skills had improved considerably. I asked teachers how they supported CLWHA when they missed school. In response, one teacher stated that he made sure he repeated lessons when the pupils reported back to school. CLWHA reported that teachers requested some pupils to assist them with class work. Teachers also encouraged cooperative learning and provided academic advice to weak learners. Similarly, Ryan et al (1994) observed that teachers who show interest and

support pupils' academic work by creating a positive environment helps them enjoy learning.

In order to ascertain that CLWHA participated fully in class activities, teachers said they placed CLWHA with vision and hearing problems in the front rows or desks in the class. Teachers also ensured that CLWHA shared desks, books and participated in class projects with other pupils. The teacher's intention in doing this was to encourage CLWHA to learn and interact with other pupils. CLWHA reported that learning was meaningful because none of the teachers singled them out during lessons.

Academic performance.

The findings showed that CLWHA were academically focused and passionate about learning. During class observations, I noticed that most CLWHA confidently asked and answered questions. They all demonstrated the value of education and expressed the importance of working hard in order to improve their grades. As a result, they actively participated in class and competed favourably with other pupils. Academically, most CLWHA were rated as average, while some performances according to the teacher's reports were rated excellent. For some, due to poor academic background from their former schools, learning was highly competitive and sometimes discouraging.

A strong correlation between academic performance, national examinations and admission to a high school emerged in this study. All CLWHA understood the requirements for securing a place in a good high school; hence, their determination to work hard was undeterred as illustrated in table 5.1, where class rankings according to each one's performance had improved significantly in term 2 from term 1. The performance of the girls was considerably better than that of boys, while performance in

grades seven were the most improved. Improved performance was a sign that CLWHA fully understood the quota system policy governing admission of primary school graduates into high schools. Similarly, improved grades reinforced their belief in their ability to compete and perform academically. In accord with this finding, Dweck (1999) highlighted that when the school ensures that children are secure and confident and are capable of succeeding, they are likely to put more effort in their school work.

Participating in leadership and extracurricular activities.

Leadership and extracurricular activities were identified as important learning components. Table 5.3 illustrated CLWHA participation in leadership roles. For example, 5 out of 37 CLWHA were class prefects, 3 were group leaders, while one boy was the bell ringer for the entire school. Also summarized in Table 5.3, 15 CLWHA actively participated in various extracurricular activities, such as scouting, music and dance, wildlife and health clubs. Several teachers emphasized that some CLWHA were gifted and their leadership skills were excellent. Involving CLWHA in these activities fostered their confidence in their capabilities and talent. It also promoted peer acceptance, enhanced self-esteem and encouraged social interactions. In my view, this was one of the best ways of improving peer attitudes towards CLWHA, which would consequently reduce incidences of stigma and discrimination in the school. Rosewater (2009) highlighting the importance of extracurricular activities among the youths listed substantial benefits associated with the activities. She argued engaging in activities such as sport enhanced a sense of possibility, contributed to their identity, and for marginalized children, minimized the feelings of "difference and isolation and increase[d] the likelihood of attending college" (p. 1).

In this study, several CLWHA, particularly the boys complained that while at school, they could not play soccer and have fun with friends. As I found out, apart from those in grades 1 to 3, other pupils did not participate in games and physical activities or physical exercises (P.E) at school. Yet, as Rosewater (2009) noted, "physical activity, including participation in organized sports, produces intellectual and academic benefits that may have long-term positive effects on [their] life chances" (p. 1). Unfortunately, at Karibu School this important learning component was lacking. So far, the Kenya primary school timetable allocates three periods per week per class for P.E, while games take place after school three times per week. The school however concentrated more on preparing pupils for final national examinations, thus replacing P.E and games times with remedial classes. Sifuna (1997) pointed to the effect of this practice by arguing that it negatively impacted on performance as well as teacher-pupil and pupil-pupil interactions.

Hopes and Dreams

Career aspirations.

A significant relationship between academic performance and career aspirations was observed in the study. To the majority of CLWHA, improving academics in order to match the career of choice was critical. In response to the question, "What do you want to become when you complete school?" All but one CLWHA said she was not sure of what career she would pursue in the future. As shown in Table 5:2. five out of twelve showed interest in more prestigious or high achieving careers such as law, engineering, piloting and air traffic controller, two wanted to become chefs, while four said they wished to become drivers. Seemingly, most of them lacked extensive knowledge in terms of career choice; hence, their choices were somewhat limited to their daily experiences. Unlike

their counterparts, CLWHA had little exposure to the outside world. From what I observed, television programs and movies were relied on for new ideas. Consistent with the current findings, Hayden and Otaala (2005) observed that infected children expressed interest in humanitarian service careers, such as police officers, or in order to cure people, and medical occupations (p. 17). Similar observations were made in the reviewed literature by Magnuson and Starr (2000) and Seligman et al (1991). I concur that age in career choice is an important factor; therefore, I anticipate that these career choices will change when CLWHA enter high school, where they will gain more exposure to different careers and have a chance to participate in career programs. Cochran (1983) pointed out that career aspirations became pronounced in high school, where interactive learning experience and career education programs helped the students to explore their career dreams.

Raising a family.

In response to the question, "What would you like to become when you complete school?" the majority of CLWHA indicated that after becoming financially stable they viewed themselves as being married and having a family. Those interested in raising a family were mainly from grades 5 to 7. For those below age 10, marriage and family were not a priority. One boy however, though interested in marriage, preferred to adopt a child. Boys were more keen about raising a family than the girls. Apparently, the desire to have a family is a cultural inclination where adults, particularly men are expected to keep the family lineage alive. As discussed in the literature PLWHA express similar desires to have children. Paiva et al's (2003) study revealed that men in particular wanted to have children. However, relevant literature to this finding also cautioned that

parenthood involved significant challenges, including stigma and resistance by health care providers and the general public.

Supporting the orphans and the needy.

This finding was also indentified in response to the question, "What would you like to become when you complete school?" All CLWHA passionately indicated their desire to support needy orphans. However, this would only happen after they had achieved some form of financial stability. I attributed their intention to the enormous amount of support they received from Kivuli; hence supporting the needy was their way of giving back in gratitude. People from all lifestyles visit Kivuli Children's Home bringing various donations for supporting the children. It is my assumption that this could have an influence on them. In accord with this finding, Reeves (2001) showed how PLWHA supported other individuals who encountered a similar predicament.

Most of the expected findings in this study found support in the literature that was reviewed in chapter two. In addition, these findings conformed to the experiences of stigma and discrimination as described in the theoretical concept of Goffman (1963). The findings on career aspirations, raising a family and supporting the needy conform to what Goffman (1963) refers to as "positive" stigma, which states that though the experience of being stigmatized may take a toll on self-esteem, academic achievement, and other outcomes, many people with stigmatized attributes have high self-esteem, perform at high levels, are happy and appear quite resilient to their negative experiences. This theory argues that PLHWA experience a considerable amount of hopelessness as a result of stigma, which often compels them to abandon their dreams. In contrast to Goffman's (1963) observation, CLWHA portrayed an unyielding spirit of resilience and

determination to succeed in their endevours. This spirit was attributed to a conducive environment as well as the overwhelming support they received from Kivuli personnel, the teachers and peers at Karibu School. Findings similar to those found in this study (Henry, 2004) illustrated factors that contributed to hopelessness or resilience in HIV-positive youth as the presence or absence of social support, stigma, peer group acceptance and appropriate coping skills.

Summary

In answering question 1, the study found that stigma and discrimination were manifested in the school setting and involved parents, teachers and peers. The school being central to these manifestations conformed to the range of literature reviewed in chapter two, and conformed to the theoretical concepts that were used in the study. In response to question 2, and consistent with previous literature, CLWHA experienced enacted, internalized and felt stigma. In response to question 3, the study found that stigma and discrimination affected CLWHA well-being and contributed to the level of socialization that was experienced. Other than stigma and discrimination, effects of the disease and the medicine (ARV) affected the level of concentration during lessons.

In response to question 4, findings showed that CLWHA used several coping strategies to deal with stigma and discrimination. In answer to question 5, findings revealed that teachers used HIV/AIDS lessons to clarify misconceptions about HIV/AIDS and related stigma. Disclosure of serostatus of CLWHA to the teachers, counselling, advice to pupils and normal treatment of CLWHA were important in inculcating positive messages in the pupils. Question 6 explored empowering and supportive resources. Although resources were scarce, they enhanced teaching and learning and conveyed

important HIV messages. However, teachers lacked the necessary skills and knowledge to confidently teach about HIV/AIDS. In addition, the school was strained financially, making it difficult to purchase school requisites.

Other findings showed that the educational experiences of CLWHA were extremely positive. Teachers and peers provided them with considerable support that gave them a sense of self-worth and belonging to a community. These vital factors influenced their attitudes towards teachers, peers and the school. They also motivated the pupils to learn and enhanced their social interactions. Unlike the hopelessness that most PLWHA experience, CLWHA demonstrated that HIV and related stigma did not deter their dreams of pursuing a career, raising a family and supporting the needy.

Finally, as illustrated in the discussions, these findings were consistent with the reviewed literature and conformed to the theoretical concepts that guided the study.

Contributions of the Study

This study contributes to the existing literature in providing a theoretical framework for understanding the unique experiences of children who live with HIV/AIDS, their academic success and the level of acceptance in public schools. Much of the existing literature focuses on the experiences of adults. Concurring with Shears (2002), this study gives voice to these children whose experiences would not otherwise be heard. Furthermore, using the theoretical lens, this study contributes to a greater understanding of CLWHA's experiences of various types of stigma and discrimination, etheir effects and the strategies utilized for coping. This understanding can be used to guide policy recommendations, and designing interventions and resources that will make the educational experiences of CLWHA meaningful and productive.

Limitations of the Study

This study involved a small sample comprised of 12 HIV-positive children (CLWHA) at Karibu School in grades 4 to 7. The study excluded children in grades 1 to 3 due to their vulnerability and the fact that many of them did not know their HIV/AIDS status. As a result, their views were under-represented in the study. This is a case study that involved HIV-positive children from Kivuli Children's Home. As a result, other HIV-positive children not from a residential placement such as Kivuli were excluded. Similarly, the findings in this study reflect the experiences of a select few CLWHA who were attending Karibu School. It is therefore important to note that the study results may not be applicable to CLWHA in other schools, since their experiences may be different.

The study sample included classroom teachers, HIV-positive children and both the administrators at Kivuli and Karibu School. Although the views of the participants were elaborate, perceptions of other pupils in the school who were not HIV-positive regarding CLWHA would have provided important insights. However, including peers in this study would also have exposed CLWHA to further stigmatization, which would also interfere with the depth of the data.

During the interviews, several CLWHA expressed the fear of being sent away from the home if they shared personal information with an outsider. Although I reassured them that I had full permission from the director, these concerns might have compelled them to hold back vital information. Although this might appear as a drawback, it is not believed it had an impact on the validity of the results, since the results were dependent on the level of trust between the interviewee and the interviewer that had developed over the period of three months I volunteered at the home.

The aim of using the face-to-face interview method was to provide each child with an opportunity to reflect on and share personal experiences. However, during the interviews, a number of them wanted to be interviewed along with their friends. I recognize the benefits associated with in-depth interviews, however, including a focus group discussion might have provided diverse insights.

Recommendations for Future Research

This study investigated the experiences of stigma and discrimination of HIV-positive children from Kivuli Children's Home learning in a single Kenyan public school. Although only 12 CLWHA participated in the study, Kenya has over 100,000 HIV-positive children, who are currently being integrated into public schools countrywide. The study sample focused on institutionalized HIV-positive children whose needs and challenges may ultimately differ from those of other HIV-positive children from other backgrounds, such as those coming from normal homes and those attending school in different geographical locations. In addition, Kivuli children enjoyed numerous privileges as compared to their counterparts. Investigating their unique experiences will offer important insights that will confirm the current findings.

Generally, other pupils were not fully aware of CLWHA's serostatus. However, the incidences of stigma that were reported in the school demonstrated that should their status become public, their peers would stigmatize them in some way. For example, the statement that a grade three boy wrote "people with AIDS should not mix with others", and supported by two other boys, clearly illustrated that stigma was indeed an issue in the school that required redress. Therefore, future research exploring the perceptions of non-

infected pupils towards CLWHA would clarify the magnitude of stigma and discrimination in Kenyan public schools.

Most CLWHA from grades 6 and 7 talked about feelings of embarrassment, shyness and sadness during HIV/AIDS lessons. According to Kelly (2001) HIV/AIDS lessons were aimed at equipping pupils with knowledge regarding HIV transmission and prevention, meaning that HIV/AIDS curriculum was not inclusive. Therefore the needs of the already-infected youths in schools were not addressed adequately.

It is important for future research to explore the extent to which HIV/AIDS lessons are sources of stigma in a classroom setting for CLWHA and children orphaned as a result of HIV/AIDS.

As highlighted in the study, CLWHA were gradually being integrated into the Kenyan public education system. Coming from a minority group, retaining their norms of existence and adapting to a majority culture is a challenge to their self perception. During the transition stage into adolescence in which identity exploration is critical, CLWHA are faced with what Marcia (1980) refers to as an identity crisis. It is important that future research explores the uncertainities CLWHA encounter as they construct and define their personal and social identitities.

Stigmatization is a powerful form of social control where an individual exercises power over another because he/she possesses certain traits. While there is a general consensus that power differences exist between teachers and pupils, relationships between CLWHA and their peers have not been fully explored.

General Recommendations

Most of the HIV positive children experienced stigma and discrimination by parents, teachers and peers, which impacted on their social interactions and learning. Yet, intervention strategies addressing stigma and discrimination were limited. Therefore, specific guidelines or a school-based policy specifying issues of admission and how CLWHA should be treated can effectively promote a climate of inclusiveness that is conducive to learning and socialization. Additionally, Kenya has a strong network of people living with HIV/AIDS. Involving them as guest speakers to parents and pupils during annual parents' meeting could enhance acceptability and support of, and be a source of empowerment for CLWHA.

This study indicated that teacher-counsellors had to manage a demanding teaching workload in addition to their counselling role. Given the complex nature of HIV/AIDS and challenges experienced by HIV-orphans, counsellors need to devote ample time to attend to the needs of the affected and infected pupils. The school should therefore consider reducing their teaching load. Additionally, the government should consider hiring trained counsellors, who are not necessarily teachers, as well as medical professionals, who are well versed with issues of HIV and AIDS to collaborate with teachers in addressing the psychological and simple medical needs of the affected children. The advantage of having an outsider other than a teacher is that it might encourage children to seek counselling services more regularly.

Owing to the availability of antiretroviral drugs in Kenya, the number of people living with HIV/AIDS has been increasing. As a result, almost every school in the country has a significant number of HIV infected and affected children. Considering that

these children have unique needs, it is important for the school and the ministry of education to ensure that supportive physical and human resources are adequate. For example, during the data collection period, I observed that the school lacked a counselling office and an infirmary where teachers could meet with the children in order to address their immediate psychological and emotional needs. Consequently, pupils with certain needs had to be referred to the parents or guardians. Similarly, HIV/AIDS teaching materials were scarce. Given that there are numerous non-governmental organizations working in the area of HIV/AIDS, it advisable for the schools to collaborate with these organizations in order to access teaching materials and other resources.

Most CLWHA reported that they felt stigmatized during HIV/AIDS lessons, pointing to the fact that the subject was not inclusive. Similarly, teachers' insensitivity and pedagogical approaches further excluded this specific cohort, a factor which I confirmed during class observation. Almost all the teachers used lecture method and dictation, and although learners participated actively, the methods encouraged passive learning. Based on this finding, there is need for teachers to reflect on their practice, particularly during HIV/AIDS lessons in order to ensure the participation of all learners. Reinforcing the quality of HIV/AIDS education requires enhancing instruction strategies so that the lessons become lively and more engaging. Therefore, there is need for the ministry of education to development a specific HIV/AIDS curriculum that is sensitive to the needs of CLWHA. Similarly, a review of the existing curriculum may be necessary to ensure that it is relevant to the needs of all pupils.

The findings reflected that both teachers and pupils lacked basic knowledge regarding HIV transmission. During the interviews, teachers highlighted the importance of appropriate skills and the need for empowerment in HIV/AIDS knowledge in order to be effective in the classroom. However, I observed that few teachers taught about HIV/AIDS during regular lessons. Therefore, while it is the responsibility of the Ministry of Education to design educational programs that will provide appropriate knowledge about HIV/AIDS to pupils, schools for their part should show commitment by ensuring that these programs are executed promptly.

Final Comment

As I reflect on how far I have come in my academic journey, I cannot but marvel at the incredible amount of knowledge I have gained. The conclusive years of my study have been most challenging, but also very rewarding. I am thankful that I had the opportunity to share with HIV-positive children, whose intimate stories have shaped their lives. Through them, I learned a great deal about life, about hope and resilience in the face of adversity and, above all, I learned to dream for greater things. While their voices will be contained in this document, the special gift of each one of them will always be engraved in my heart. In conclusion, "I thank my God each time I think of you, and when I pray for you, I pray with joy" (Phil, 1:3).

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APPENDIX A: ETHICS APPROVAL-UWO

Office of Research Ethics
The University of Western Ontario
Room 4180 Support Services Building, London, ON, Canada N6A 5C1
Telephone: (519) 661-3036 Fax: (519) 850-2466 Email: ethics@uwo.ca
Website: www.uwo.ca/research/ethics

Use of Human Subjects - Ethics Approval Notice

Principal Investigator: Dr. A. Varpalotai
Review Number: 17221S **Review Level:** Full Board
Review Date: September 09, 2010 **Approved Local # of Participants:** 207
Protocol Title: Investigating the Experiences of AIDS Stigma and Discrimination on Social Interactions and Learning: A Case Study of HIV-Positive Children in Kenya.
Department and Institution: Faculty of Education, University of Western Ontario
Sponsor:
Ethics Approval Date: September 24, 2010 **Expiry Date:** December 31, 2010
Documents Reviewed and Approved: UWO Protocol, Letter of Information (Principals), Letter of Information (teacher), Letter of Information (guardian), Letter of Information (parents /guardians of students in grades 4-8). Letter of Information Teachers whose classrooms are being observed), Letter of Information (HIV Positive children Grades 4-8). Consent Form, Consent Form (Parent / Guardian), Consent Form (Students).

Documents Received for Information:

This is to notify you that The University of Western Ontario Research Ethics Board for Non-Medical Research Involving Human Subjects (NMREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the applicable laws and regulations of Ontario has granted approval to the above named research study on the approval date noted above.

This approval shall remain valid until the expiry date noted above assuming timely and acceptable responses to the NMREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

During the course of the research, no deviations from, or changes to, the study or consent form may be initiated without prior written approval from the NMREB except when necessary to eliminate immediate hazards to the subject or when the change(s) involve only logistical or administrative aspects of the study (e.g. change of monitor, telephone number). Expedited review of minor change(s) in ongoing studies will be considered. Subjects must receive a copy of the signed information/consent documentation.

Investigators must promptly also report to the NMREB:

a) changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
b) all adverse and unexpected experiences or events that are both serious and unexpected;
c) new information that may adversely affect the safety of the subjects or the conduct of the study.

If these changes/adverse events require a change to the information/consent documentation, and/or recruitment advertisement, the newly revised information/consent documentation, and/or advertisement, must be submitted to this office for approval.

Members of the NMREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the NMREB.

Chair of NMREB: Dr. Riley Hinson
FDA Ref. #: IRB 00000941

Ethics Officer to Contact for Further Information			
☑ Grace Kelly (grace.kelly@uwo.ca)	☐ Janice Sutherland (jsutherl@uwo.ca)	☐ Elizabeth Wambolt (ewambolt@uwo.ca)	☐ Denise Grafton (dgrafton@uwo.ca)

cc: ORE File

This is an official document. Please retain the original in your files.

APPENDIX B-RESEARCH AUTHORIZATION-KENYA

REPUBLIC OF KENYA

NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

Telegrams: "SCIENCETECH", Nairobi
Telephone: 254-020-241349, 2213102
254-020-310571, 2213123,
Fax: 254-020-2213215, 318245, 318249
When replying please quote

P.O. Box 30623-00100
NAIROBI-KENYA
Website: www.ncst.go.ke

Our Ref: NCST/RRI/12/1/SS/696/3

Date: 3rd August, 2010

Maryanne Njeri kamau
University of Western Ontario
London, Ontario
CANADA

Dear Madam,

RE: RESEARCH AUTHORIZATION

Following your application for authority to carry out research on ***"Investigating the experience of AIDS Stigma and Discrimination on social Interactions and Learning in Public Schools: A case Study of HIV-Positive Children in Kenya"***. I am pleased to inform you that you have been authorized to undertake research in **Langata District** for a period ending ***31st December, 2010.***

You are advised to report to **District Commissioner, the District Education Officers, Langata District and the Principals of the selected Schools** before embarking on the research project.

On completion of the research, you are expected to submit two copies of the research report/thesis to our office.

DR. M. K. RUGUTT, Ph.D, HSC.
FOR: SECRETARY/CEO

Copy to:

The District Commissioner
Langata District

The District Education Officer
Langata District

APPENDIX C: LETTERS OF INFORMATION

The School Principal

Dear (Principal's name),

Re: AIDS Stigma and Discrimination in Public Schools: A Case Study of HIV-Positive Children in Kenya.

My name is Maryanne Njeri Kamau and I am a third year doctoral candidate at the Faculty of Education at the University of Western Ontario in London, Ontario, Canada. I am currently conducting research on AIDS stigma and discrimination in Kenyan public schools. I would like to invite you (principal), 8 classroom teachers (grades 4-7) and 12 HIV-positive students (grades 4-7) to participate in this research.

The aims of this research are to investigate the following: (1) how AIDS stigma and discrimination are manifested in public schools, (2) the experiences of HIV-positive children of stigma and discrimination in public schools, (3) how these experiences affect social interactions and learning, and 4) the type of support they receive from the school to cope with these experiences.

I will gather information through interviews and participant observations. This study will involve:

- 12 HIV-positive children from grades 4-7
- 8 classroom teachers (grades 4-7) or teachers who have been in the school since the first HIV-positive children were admitted in the school.
- The principal of the school
- Administrator of Kivuli Children's Home.

I will interview 8 classroom teachers who will provide information regarding their perceptions of stigma and discrimination, their personal challenges teaching HIV-positive children and the type of support they provide to these children. If you agree to participate in this study, you will be asked to share information in an interview on the challenges of admitting HIV-positive children in the school, the efforts of ensuring HIV-positive children are integrated and accepted in the school, school resources and programs that empower the school community in order to support HIV-positive children, and the changes and other improvements that are needed to create a conducive environment for social interactions and learning. I will also request you to identify and introduce me to the classroom teachers.

The Interview session will last for approximately one hour and will be audio-taped in order to have an accurate record of their information. We will agree on a suitable date, time, and place for the interviews. We will later schedule a meeting so that you can review the typed notes from the audio-taped interviews to make sure I interpreted their information correctly. You may modify or remove information that you may not feel comfortable with.

The 12 HIV-children (grades 4-7) will be identified by the administrator of Kivuli. Interviews with the children will take place at Kivuli Children's Homeso that the children are within the comfort and privacy of a familiar environment.
Data collection will also involve participant observation in the school. I will observe the following activities:
Teaching, learning and interactions in the classroom in grades 4 -8 for one hour per week per class. I will observe out-of –class activities such as games, physical exercise classes, play and interactions of students during class and lunch breaks. With the consent of the children's' guardian, I will ask you to provide me with academic records for HIV-positive children for information on performance and learning trends.

The data collected during the study will be kept confidential and used for my research purposes only. Neither your name nor information, which could identify you, will be used in any publication or presentation of the study results. No information will identify you, or the school involved in this study. Pseudonyms will be ascribed to each participant, institutions and information in order to protect their identity. All information (audio-taped information, notes from observation and transcripts) will be secured in a cabinet where I alone will have access. After a period of two years, all tapes, notes and transcripts will be destroyed.

Participation is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time with no effect on your employment status. Each of the other participants has the right to withdraw their participation at any time without penalty. Although there are no known risks to participating in this study, if you experience any form of anxiety or emotional stress, I will ensure a trained counsellor is available to provide support.

If you have any questions about this research, or any clarifications, please contact me or my thesis advisor.

Thank you.

Maryanne Njeri Kamau, PhD Candidate

Letter of Information and Permission from the Guardian

Dear Administrator (Kivuli Children's Home)

Re: AIDS Stigma and Discrimination in Public Schools: A Case Study of HIV-Positive Children in Kenya.

My name is Maryanne Njeri Kamau and I am a third year doctoral candidate at the Faculty of Education at The University of Western Ontario in London, Ontario, Canada. I am currently conducting research on AIDS stigma and discrimination in Kenyan public schools. I would like you and 10 HIV-children (grades 4-7) to participate in this study.

The aims of this research are to investigate the following: 1) how AIDS stigma and discrimination are manifested in public schools, 2) the experiences of HIV-positive children of stigma and discrimination in public schools, 3) how these experiences affect social interactions and learning, and 4) the type of support they receive from the school to cope with these experiences.

Data will be gathered through interviews and participant observations. I will conduct interviews with you and children who will meet specific criteria. Interview will last for about 30-60 minutes. However, interviews with you will be followed by subsequent informal ones throughout the research period. During the interviews, I will ask the children to share their experiences of being in a public school, incidences of harassment, bullying, labelling that can be associated to their HIV status. They will be asked to explain the coping strategies they employ, and identify the support that the school provides for them. You will be asked the number of children attending public schools, children's experiences of stigma and discrimination, the effect stigma and discriminate have on social interactions and learning, the type of supports or education children receive at Kivuli and the skills they employ to cope with incidences of harassment, bullying and labelling while in school. For privacy, confidentiality, and comfort of you and the children, I will hold interview sessions at Kivuli Children's Home so that the children are within a familiar environment. All interviews will be audio-taped in order to have an accurate record of the interviews.

I intend to spend at least three months at Kivuli Children's Home in order to familiarize myself and interact with the children. Once I am familiar with the children, I will ask for volunteers from whom I will select 10 children to participate in the research based on the criteria provided. I will also request for your consent to interview and observe the children and to gain access the children's past and current academic records. You and I will agree on a suitable date and time for the interviews. I will meet with the children in order to review typed notes from the audio-tape and make sure that I interpreted their information correctly. Any information that they will feel uncomfortable with shall be modified or removed altogether from the scripts.

The data collected during the study will be kept confidential and used for my research purposes only. Neither your name nor information, which could identify you or the institution, will be used in any publication or presentation of the study results. No information will identify the participants or institutions involved in this study. Pseudonyms will be ascribed to each participant, institutions and information in order to protect their identity. All information (audio-taped information and transcripts) will be secured in a cabinet where I alone will have access. After a period of two years, all tapes and transcripts will be destroyed.

This study involves a population that is vulnerable and extremely sensitive. Although there are no known risks to participating in this study, if participants experience any form of anxiety or emotional stress by participating in this study, I will ensure a trained counsellor is available to provide support.

Participation in this research is voluntary. You may refuse to participate and refuse to allow the children to participate, or refuse to answer any questions or withdraw from the study at any time. If you or any of the children withdraw from the study, any information he/she will have given will not be used in the study.

If you have any questions about this research, or any clarifications, please contact me or my thesis advisor.

Thank you.

Maryanne Njeri Kamau, PhD Candidate

Letter of Information to Parents/Guardians of Students in Grades 4-7

Dear Parent/Guardian,

My name is Maryanne Njeri Kamau, a student at The University of Western Ontario in Canada. I am currently doing research on AIDS stigma and discrimination in Kenyan public schools.

The aims of this study is to gain a deeper understanding of AIDS stigma and discrimination; how they are manifested in public schools; how the experiences of stigma and discrimination affect social interactions and learning; the coping skills and the type of support schools provide to children living with AIDS..

This study will involve children in grades 4-7. I am kindly asking for your permission to allow me to observe your child from September to the end of October, 2010. I will visit and observe activities in your child's classroom (grades 4-7) for one hour each week. Observations will focus on teaching and learning, learner participation, teacher-learner and learner -learner interactions, as well as observing the resources and learning materials that support learning in and outside the classroom. In addition, I will observe outdoor activities such as sports, play, and club meetings in which your child will be participating in.

The information collected during the study will be kept confidential and used for my study purposes only. Neither your actual name nor that of your child will be used in any report (publication or presentation) of the study results. In order to protect your identity, I will replace names of persons and the school with code numbers or different names.

There are no known risks to participating in this study and participation is voluntary. You may refuse your child to participate and your child is free to withdraw from the study at any time with no effect on his/her schooling. However, if your child experiences any form of anxiety or emotional stress, I will ensure that a trained counsellor is available to provide support.

Please sign the attached form if you agree to your child being observed in the classroom.
If you have questions or other concerns related to this study, please contact me or my thesis advisor.

Thank you.

Maryanne Njeri Kamau

Letter of Information to Participating Classroom Teachers

Dear Classroom Teacher,

Re: AIDS Stigma and Discrimination in Public Schools: A Case Study of HIV-Positive Children in Kenya.

My name is Maryanne Njeri Kamau and I am a third year doctoral candidate at the Faculty of Education at The University of Western Ontario in London, Ontario, Canada. I am currently conducting research on AIDS stigma and discrimination in Kenyan public schools. I would like to invite you to participate in this research.

The aim of this research is to investigate the following: 1) how AIDS stigma and discrimination are manifested in public schools, 2) the experiences of HIV-positive children of stigma and discrimination in public schools, 3) how these experiences affect social interactions and learning, 4) the type of support they receive from the school to cope with these experiences, and 5) the coping strategies children employ to cope with stigmatizing incidences.

Data for this research will be collected by means of semi-structured interviews and participant observation. If you agree to participate in this study, I will conduct interviews with you (classroom teacher) that will last for approximately one hour. During the interviews, I will ask you to provide information about your perceptions of AIDS stigma and discrimination, to identify the challenges you face teaching HIV-positive children and the type of support you provide to these children, and how you ensure that other children accept and treat them with the dignity they deserve. All interview sessions will be audio-taped in order to have an accurate record of your information. You and I will agree on a suitable date, time, and place for the interview. I will later meet with you so that we can review the typed notes from the audio-tapes to make sure I interpreted your information correctly. We shall modify or remove information that you may not feel comfortable with.

The data collected during the study will be kept confidential and used for my research purposes only. Neither your name nor information, which could identify you, will be used in any publication or presentation of the study results. Pseudonyms will be ascribed to each participant, institutions and information in order to protect their identity. The audio-taped information and transcripts will be kept in a secure place and will be accessed by myself only during this study. After the study, all tapes and transcripts will be kept securely for two years after which they will be destroyed.

There are no known risks to participating in this study. However, if you experience any form of anxiety or emotional stress, I will ensure that a trained counsellor is available to provide support. Participation in this research is voluntary. You may refuse to participate or refuse to answer any questions or withdraw from the study at any time without effect on your employment status. If you choose withdraw from the study, any information you will have given will not be used in the study. If you have any questions about this research, or any clarifications, please contact me or my thesis advisor.

Thank you

Maryanne Njeri Kamau, PhD Candidate

Letter of Information to Teachers Whose Classrooms I will Observe (Grades 4-7)

Dear Teacher,

Re: AIDS Stigma and Discrimination in Public Schools: A Case Study of HIV-Positive Children in Kenya.

My name is Maryanne Njeri Kamau and I am a third year doctoral candidate at the Faculty of Education at The University of Western Ontario in London, Ontario, Canada. I am currently conducting research on AIDS stigma and discrimination in Kenyan public schools, and would like to invite you to participate in this research.

The aims of this research are to investigate the following: 1) how AIDS stigma and discrimination are manifested in public schools, 2) the experiences of HIV-positive children of stigma and discrimination in public schools, 3) how these experiences affect social interactions and learning, 4) the type of support they receive from the school to cope with these experiences, and 5) the coping strategies children employ to cope with stigmatizing incidences.

I will collect data through observation. If you consent to my presence in your classroom, I will attend your classroom for one hour per week and one hour per week outside the classroom from August to October 2010 in order to gain insights on:
Teaching and learning strategies
The student's participation in the classroom
Teacher-student and student-student interactions
Participation of outside of classroom activities

I would like to find out the type of resources and programs teachers us to address the needs of HIV-positive children. I will send a letter requesting parents/guardians to grant me permission to observe the children in your classes (grades 4-7). Observations will allow me to interact with the students and hold informal conversations with you regarding in and out of classroom activities. I will also request access to the academic records of HIV-positive children. I will take notes during the observation sessions.

The data collected during the study will be kept confidential and used for my research purposes only. Neither your name nor information, which could identify you, will be used in any publication or presentation of the study results. Pseudonyms will be ascribed to each participant, institutions and information in order to protect their identity. The observation notes will be kept in a secure place and will be accessed by myself only during this study. After the study, these notes will be kept securely for two years after which they will be destroyed. Although there are no known risks to participating in this study, if you and the students experience any form of anxiety or emotional stress, I will ensure a trained counsellor is available to provide support. Participation in this research is voluntary. You may refuse to participate, refuse to answer any questions or choose to withdraw from the study at any time. If you choose to withdraw from the study, any information you will have given will not be used in the study. If you have any questions about this research, or any clarifications, please contact me or my thesis advisor.

Thank you.

Maryanne Njeri Kamau, PhD Candidate

Letter of Information to HIV-Positive Pupils in Grades 4-7

Dear Pupil,

My name is Maryanne Njeri Kamau and I am a student at The University of Western Ontario in Canada. I am doing a study on AIDS stigma and discrimination in Kenyan public schools. The purpose of the study is to understand how children with AIDS are treated in public schools; how their experiences affect their learning and interactions with others; and how they deal with these experiences.

I invite you to take part in this study. If you agree to participate, I will be coming in your classroom for one hour per week and outside of classroom activities for one hour per week commencing from September to October 2010. During these times, I will be interesting in your participation in the classroom, and your interactions with your classmates and teachers. I will write notes during observation. In addition, I will ask you to participate in an interview that will take about 30-60 minutes. I will use an audio-recorder to tape the interview.

I will ask your parents or guardians to be in your class and observe activities involving pupils in grades 4-7. The information I will collect from you will be kept confidential and used for my research purposes only. I will make sure your name is replaced with a code name or with another name so no one recognizes you. No information you will share or that could identify you will be used in any report (publication or presentation). All information will be kept safely in a cabinet where no one else can see it except me.

The benefit of this study will give you an opportunity to share your experience and to provide information that will guide and give practical help to administrators on how to deal with AIDS stigma and discrimination in public schools.

There are no known risks to participating in this study and participating in this study is voluntary. You may refuse to answer any questions, and/or to stop the interview or withdraw from the study at any time and your decision will have no effect on your grades. If you become anxious or upset from narrating your experiences, a trained counsellor will be available to provide support services to you.

If you have any questions, please contact me or my supervisor.

Thank you.

Maryanne Njeri Kamau, PhD Candidate

APPENDIX D: CONSENT FORMS

Re: AIDS Stigma and Discrimination in Public Schools: A Case Study of HIV-Positive Children in Kenya.

Maryanne Njeri Kamau, Ph. D. Candidate
Faculty of Education, University of Western Ontario, London, Ontario, Canada

CONSENT FORM

(Administrators: Karibu School and Kivuli Children's Home)

I have read the Letter of Information relating to the above research project, the nature of the study has been explained to me and I agree to participate. All questions have been answered to my satisfaction.

Name:……..

Signature:……

Date:…….

Name of Person Obtaining Informed Consent:

……

Signature of Person Obtaining Informed Consent:

……

Date: ……..

Re: AIDS Stigma and Discrimination in Public Schools: A Case Study of HIV-Positive Children in Kenya.

Maryanne Njeri Kamau, Ph. D. Candidate
Faculty of Education, University of Western Ontario, London, Ontario, Canada

CONSENT FORM

(Classroom teachers)

I have read the Letter of Information relating to the above research project, the nature of the study has been explained to me and I agree to participate. All questions have been answered to my satisfaction.

Name:……..

Signature:……

Date:…….

Name of Person Obtaining Informed Consent:

……

Signature of Person Obtaining Informed Consent:

……

Date: ……..

AIDS Stigma and Discrimination in Public Schools: A Case Study of HIV-Positive Children in Kenya.

Maryanne Njeri Kamau, Ph. D. Candidate
Faculty of Education, University of Western Ontario, London, Ontario, Canada

CONSENT FORM

(Parents/Guardian)

I have read the Letter of Information relating to the above research project, the nature of the study has been explained to me and I agree that my child or children to participate. All questions have been answered to my satisfaction.

Name of Student:
Name of the Parent/Guardian:……..

'Signature of the parent/guardian:

……..

Date:…….....

Name of the Person Obtaining Informed Consent:

……

Signature of Person Obtaining Informed Consent:

……

Date: ……..

CONSENT FORM

(Participating Students)

I have read the Letter of Information relating to the above research project, the nature of the study has been explained to me and I agree to participate. All questions have been answered to my satisfaction.

Name of Student:……..

Student's Signature:…….

Date:……

Name of the Person Obtaining Informed Consent:

……

Signature of Person Obtaining Informed Consent:

……

Date: ……

APPENDIX E: INTERVIEW PROTOCOL

The following semi-structured questions will guide the interviews with the participants. The questions might not follow the order in which they appear during the interviews. They may also be modified depending on the responses given by the participants.

AIDS Stigma and Discrimination in Public Schools: A Case Study of HIV-Positive Children in Kenya.

Questions for HIV-positive students

1. How long have been attending Karibu School?
2. Which year did you join this (current) school?
3. Tell me about your experience at Karibu School.
4. Describe some of the things you like most at Karibu School.
5. Tell me about friends.
6. Can you describe to me about:
   - Learning in this school-education goal-what are your future dreams
   - How you socialize with peers and teachers.
   - Leadership position/s.
   - Participation in extra-curricular activities (e.g., games, drama, clubs etc).
7. Tell me about your health status and what you think about it.
8. Do you ever discuss about your health status with other children or teachers?
9. Would you like to share how others would react if they learn about your status?
10. Are there any problems that you experienced in school due ot their condition that you would like to tell me about?
11. What do you think are the causes of these problems/challenges?
12. How do you go about solving these problems?
13. How do your class-teacher/s or the principal assist you in solving some of the problems?
14. Can you suggest in which ways you would like the school community to support you?
15. Do you know of any program/s in the school that you participate in that focuses on HIV/AIDS and related stigma and discrimination?
16. Can you remember some of the benefits of those programs you have participated in?
17. Does the school have facilities or resources that you feel are supportive of your needs?
18. Is there anything else you would like to share with me regarding yourself, school life and educational goals?

Questions for Class-room teachers

1. Can you please tell me how you feel about teaching a class with HIV-positive children?
2. How do the other pupils feel about these children and their HIV status?
3. Do you think HIV-positive children pose any challenges or risks to the school community?
4. Have you ever witnessed any negative treatment of HIV-positive children?
5. Can you describe some of these incidences and narrate how HIV-positive children experienced them?
6. Do you think these experiences have an influence on their:
   - Learning
   - Socialization with others
   - Perception of self
7. In which ways do you assist HIV-positive children and the other children to overcome the problems they face?
8. How do you ensure that other children accept HIV-positive children?
9. Do any of the HIV-positive children have a leadership role in the classroom or in the school?
10. What are some of the activities these children participate or don't participate in and why?
11. Does the school have resources or programs that address issues of HIV/AIDS and related stigma and discrimination?
12. Are there resources and programs that empower teachers and students in order to support HIV-children in their needs?
13. In your opinion, do you think the school could improve how HIV-children's needs, challenges are addressed?
14. Can you give me some suggestions on how you think the school could improve its approach to the problem of HIV/AIDS and related stigma and discrimination?
15. What do you see your role to be in making improvements to better the learning environment for HIV-positive children?
16. Is there anything else you would like to share with me relating to your role as a classroom teacher, HIV-positive children's challenges and experiences in the school or further suggestions?

Questions for the School Principal

1. Other than children from children from Kivuli Children's Home, are there other HIV-positive children in the school?
2. Describe to me the challenges of admitting HIV-positive into a public school.
3. Describe how the school ensures acceptability and integration of HIV-positive children into the school.
4. In your opinion, do you think that HIV-positive children feel accepted by the school community?
5. Can you share with me some of the experiences (positive or negative) the children have encountered since they joined this school?
6. Have you observed incidences of stigma and discrimination directed toward these children by teachers and peers?
7. In which ways do teachers and pupils support HIV-positive children in their needs including educational needs?
8. Does the school have a school-based policy to guide parents, teachers and pupils on matters relating to HIV/AIDS, stigma and discrimination?
9. What resources and programs exist in the school that empower teacher, pupils and the HIV positive to overcome or combat stigma and discrimination and to create an environment that is conducive to learning and social interaction?
10. Can you explain any significant change that has taken place since the admission of HIV-children into the school (parents, teachers and pupils)?
11. What role does the Ministry of Education play in reducing stigma and discrimination the school/s?
12. Do you think the Ministry of Education has played its role sufficiently?
13. If not, can you suggest ways in which the Ministry of Educations can make improvements that will address the children's needs effectively?
14. What do you see your role to be in making improvements to assist HIV-positive children achieve their educational goals?
15. Is there anything else you would like to share with me relating to these children's experiences, the challenges that you personally and the school encounter?

Questions for Kivuli Children's Home Administrator

1. Do you encounter problems with children's (HIV-positive) admission to public school?
2. How many children from Kivuli Children's Home attend public schools?
3. Did you disclose the HIV status of the children to school administrators and teachers?
4. Has any of the children shared some of their experiences since they joined the public schools?
5. Has any of them reported experiencing any form of stigma and discrimination by teachers or peers while in schools?
6. How do you go about solving these problems and issues of stigmatization with the school authorities and the children?
7. Do these experiences affect how they learn and socialize with peers?
8. How do they feel about peers and teachers?
9. Does Kivuli Children's Home have programs that facilitate the integration of HIV-positive children into the public school system?
10. Are you aware of any support programs in the schools that empower HIV-positive children?
11. Do you think public schools have been able to address issues of stigma and discrimination?
12. Do you have suggestions on how schools can improve learning environment, social interactions and integration and acceptability of HIV-positive children into the school?
13. Do you have additional information regarding HIV-positive children, teachers, schools, or the Ministry of Education that you would like to share with me?

CURRICULUM VITAE

Name: Maryanne Njeri Kamau

Education	**Institution**	
Ph.D Candidate	The University of Western Ontario Faculty of Education	2007-2012
M.A	University of Nairobi Department of Geography	1997-1999
B.Ed. (Hons.)	Kenyatta University School of Education	1989-1992

Employment History Teaching and Research Assistantships

The University of Western Ontario, London, Ontario, Canada	2007-2011
The Catholic College of Mandeville, Jamaica, West Indies	2001-2007
Christ the Teacher Institute of Education (CTIE), Nairobi, Kenya	2000
Teachers' Service Comission, Nairobi, Kenya	1993-1997

Honours and Awards

Graduate Thesis Research Award, University of Western Ontario	2011
Western Graduate Scholarship, University of Western Ontario	2009-2011
Margaret McNamara Memorial Fund (MMMF)	2009
Rotary International Ambassadorial Scholarship	2007-2009