Distribution Agreement

In presenting this thesis or dissertation as a partial fulfillment of the requirements for an advanced degree from Emory University, I hereby grant to Emory University and its agents the non-exclusive license to archive, make accessible, and display my thesis or dissertation in whole or in part in all forms of media, now or hereafter known, including display on the world wide web. I understand that I may select some access restrictions as part of the online submission of this thesis or dissertation. I retain all ownership rights to the copyright of the thesis or dissertation. I also retain the right to use in future works (such as articles or books) all or part of this thesis or dissertation.

Signature:

_____ _____

Bayle Conrad Date

Adolescent Program for HIV Positive Youth in Informal Settlements of Nairobi

By

Bayle Conrad
MPH

Hubert Department of Global Health

_____

Jessica McDermott Sales, PhD
Committee Chair

_____

John Blevins, ThD
Committee Member

Adolescent Program for HIV Positive Youth in Informal Settlements of Nairobi

By

Bayle Conrad

Bachelor of Arts, Anthropology and African Studies
University of Washington
2010

Thesis Committee Chair: Jessica McDermott Sales, PhD

An abstract of
A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
in partial fulfillment of the requirements for the degree of
Master of Public Health
in Global Health
2013

Abstract

Adolescent Program for HIV Positive Youth in Informal Settlements of Nairobi

By Bayle Conrad

Lea Toto, a community-based HIV/AIDS treatment and care program located in urban settlements of Nairobi, Kenya, provides comprehensive support for children infected with the disease. However, as their clients age into adolescence there are few programmatic support options available. This special studies project aims to create a feasible adolescent program plan to be implemented at Lea Toto sites in Nairobi. A needs assessment conducted at Lea Toto Kibera in the summer of 2012 provided knowledge of client needs through surveys and a focus group with adolescent clients, surveys with adolescent caregivers, and in-depth interviews with key Lea Toto staff members. Furthermore, the behavioral health theories of social support, empowerment, and stigma were utilized to better inform the structure of the program. These sources of information formed the basis of a program plan which includes suggested goals, objectives, activities, indicators, timeframe, and a monitoring and evaluation plan for an adolescent program focused on increasing social support, empowerment, and skill-building among HIV positive adolescents. This program plan is accompanied by an activities manual with ten modules and several activities to be used with adolescents at Lea Toto. This project provides insight on gaps in service provision for HIV positive adolescents while also providing Lea Toto with a flexible program to be offered to their growing population of adolescent clients.

Adolescent Program for HIV Positive Youth in Informal Settlements of Nairobi

By

Bayle Conrad

Bachelor of Arts, Anthropology and African Studies
University of Washington
2010

Thesis Committee Chair: Jessica McDermott Sales, PhD

A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
in partial fulfillment of the requirements for the degree of
Master of Public Health
in Global Health
2013

Acknowledgements

It is with immense gratitude that I acknowledge the guidance, support, and encouragement of Jessica Sales and John Blevins. Without their support, this project would not have been possible.

I would also like to acknowledge my parents for their continual support for my life ambitions, and their complete confidence in my abilities to succeed.

Finally, I am indebted to the staff, adolescent clients, and caregivers of Lea Toto Kibera for allowing my presence in their clinic for eight weeks. Without their generosity, insights, and courage, this project would not have been possible. Words cannot begin to express my appreciation and gratitude of their support.

Table of Contents

Table of Figures

Chapter I: Introduction

1.1 Introduction and Rationale

In 2010, it was estimated that 5 million young people aged 15-24 around the world were living with HIV/AIDS [1]. Of these cases, 3.8 million occurred in sub-Saharan Africa, representing 76% of the total worldwide. There were also 2.5 million children under the age of 15 living with HIV in 2010, of which 2.3 million cases occurred in sub-Saharan Africa [2]. Transmission of the virus among youth continues to occur, with 41% of new infections worldwide in the 15-24 year old age range [1]. As adolescents continue to become infected with HIV, programs need to be directed toward this population, particularly in the context of sub-Saharan Africa.

In recent years, UNAIDS has heralded the drop in HIV prevalence among youth, as it has decreased by 25% since 2000 in the top fifteen countries most affected by the epidemic [1]. While this data is encouraging, it should be paired with the understanding that as long as mother-to-child transmission of HIV occurs, the prevalence of HIV among youth will continue to be an issue as these infected children age into adolescence. On average, 390,000 children around the world are infected yearly with the disease due to mother-to-child transmission, with 350,000 of these infections occurring in sub-Saharan Africa [3]. With the advent of HIV/AIDS treatment becoming available worldwide in the past decade, children born with the disease are able to live longer, and either already have or will continue to join adolescent populations with the disease [4]. The exact number of adolescents perinatally infected with HIV worldwide is unknown, and little is known about perinatally infected children in sub-Saharan Africa past the age of five [5]. What is known is that many of these children will at some point grow into adolescence, with the

possibility of sexually transmitting the disease to others, joining the number of teenagers infected with HIV around the world.

As adolescents become infected with HIV, either perinatally or through other modes, health programs must be designed to target their needs. This is especially important in low-resource areas where teenagers may have less access to support and education. While the majority of sub-Saharan African countries have National AIDS Strategic Plans, and 98% of these plans have information on youth programs and activities, very few explicitly mention programs for those adolescents who are HIV positive, and instead focus largely on prevention strategies for the uninfected [1]. As such, HIV positive adolescents are a population largely ignored, as they no longer fit into pediatric treatment services and have yet to grow into adult clinical services. Without addressing the psychosocial needs of adolescents living with HIV in sub-Saharan Africa and providing them with supportive services which encourage healthy living, this population will continue to be ignored, with long-term repercussions on individual health as well as the continuing transmission of HIV.

1.2 Problem Statement

Kenya, like other sub-Saharan African countries, continues to cope with a generalized HIV/AIDS epidemic. In 2011, an estimated 6.2% of people aged 15-49 were living with HIV in the country, with women disproportionately affected [6]. Due to standardized age categories in data collection, it is difficult to ascertain exact figures for adolescents aged 11-19 infected with HIV in Kenya. However, a general idea of the magnitude of the epidemic can be gained by viewing infections in the under 15 age group and the 15-24 age group in the country. Perinatal infections continue to occur in Kenya, with 12,894 children infected with the disease in 2011,

through mother-to-child transmission of the virus. These cases join the estimated 180,000 children under the age of 14 infected with HIV in Kenya. Furthermore, an estimated 4.1% of females and 1.8% of males aged 15-24 are infected with the disease in Kenya [6]. The combination of these figures gives a basic idea of the number of HIV positive adolescents in the country.

Lea Toto is a community-based care program located in Nairobi, Kenya, which provides services to HIV positive children and their families in eight informal settlements of the city. The focus of the program is to provide services and support to families of children infected with HIV to prevent further orphanage. In order to improve quality of life for those infected, the organization concentrates on providing comprehensive medical care, antiretroviral medications, food security, psychosocial support, education, training, and economic empowerment to families with HIV positive children. The program currently serves over 7,500 HIV positive children, providing over 36,000 family members with the skills necessary to support and care for people living with HIV [7]. While Lea Toto has been established and providing services since 1998, it is now facing new challenges as those children perinatally infected with HIV who receive their services enter and navigate adolescence. As these children transition into their teen years, there is interest in creating a program targeting their psychosocial health and supportive needs. Currently, the organization provides several services to adolescents, although they vary in frequency and availability. These include:

- *Teen Days*: Each month, a certain date is determined as a Teen Day at Lea Toto clinics. Adolescent clients are specifically scheduled to return to the clinic for medication refills on these days. At times, scheduled events such as group counseling also occur on Teen Days, although this varies by location and month.

• *Mentorship*: This service pairs adolescents at Lea Toto with HIV positive community members, giving them one-on-one advice and support.

• *Life Skills*: One Saturday each month is designated as a Life Skills day for clients eight years and above. These days combine several activities for youth.

While still in the beginning stages of roll-out, Lea Toto hopes to incorporate these services into a teen-specific program offered consistently and frequently. The organization wants to target HIV positive youth aged 11-19 through a support program to help them successfully navigate their teenage years by increasing social networks and learning to live positively with the disease. As children continue to become infected with the virus at birth and are able to live for years on antiretroviral medication, Lea Toto acknowledges the need for a program to meet the unique needs of adolescents, as increasing numbers of their clients age out of childhood.

1.3 Purpose Statement

The purpose of this special studies project is to develop a program for HIV positive adolescents to be used at Lea Toto sites in Nairobi, Kenya, focusing on psychosocial support, empowerment, and skill-building for this population.

1.4 Objectives

Objective 1- Review existing literature to gain an understanding of the issues and needs of HIV positive youth in sub-Saharan Africa, as well as successful approaches to programmatic interventions in this population

Objective 2- Identify gaps in services provided to adolescents attending Lea Toto clinics and attitudes toward additional services through survey and focus group data collection

Objective 3- Utilize the methods of needs assessment and behavioral health theory to help inform the creation of a program framework for HIV positive adolescents

Objective 4- Create a program plan targeting HIV positive adolescents to be implemented at Lea Toto, including goals, objectives, activities, indicators, and timeframe

Objective 5- Provide a monitoring and evaluation framework to be used by Lea Toto in order to determine the effectiveness of the program and to make necessary changes

Objective 6- Create an activity manual to be included in the adolescent program at Lea Toto, with lessons on specific topics related to youth

1.5 Significance

The lack of programs available for HIV positive adolescents in sub-Saharan Africa has been widely documented [7-9]. The needs of this population are often unknown, and interventions are often combined with other programs, if available at all. This special studies project attempts to highlight some of the major issues and needs faced by HIV positive youth as well as the importance of targeting this population for interventions, specifically in the context of Kenya. This research may be particularly important for vulnerable adolescents in other low-resource areas, similar in needs to those served by Lea Toto. Additional research, intervention

development, and program implementation for this population has the potential to improve psychosocial health and quality of life for adolescents infected with HIV but often forgotten in health programming.

The introduction of a program for HIV positive adolescents at Lea Toto would fill a need for this specific population that as of yet has few targeted, consistent intervention activities. Greater support and attention given to these clients would promote better health, while also making Lea Toto more sustainable as an entity. With a cohort of HIV infected children growing into adolescence in the upcoming decade, the creation of an adolescent program at Lea Toto is necessary to continue providing high-quality supportive services to all clients. Without such a program, adolescent-aged clients may have few additional options in terms of support, remaining lost in a healthcare system that emphasizes pediatric and adult care. The creation of structured adolescent services at Lea Toto also have the potential to be used in other contexts as well, as children infected with HIV continue to age into adolescence in several sub-Saharan African countries. Overall, the creation of an adolescent health program is both necessary and lacking in many contexts, and is a vital need of both Lea Toto and other similar organizations.

1.6 Definition of Terms

- *Activity Manual*- A document containing activities, lessons, and education on specific topics, to be used by Lea Toto staff members with teenagers utilizing the adolescent program.
- *Adolescent*- A person in the process of developing from child to adult, aged 11 to 19 years.
- *Disclosure*- The process of revealing HIV status to another. In terms of children born with HIV, this can also refer to the process of revealing one's own HIV status to him/her, generally by a parent or guardian.

- *Empowerment*- The process of increasing individual capacity or providing individuals with tools to become aware of their own agency.
- *Psychosocial Health*- Psychological and social components of individual health.
- *Social Support/Network*- The social ties and support of an individual. A social network is comprised of several types of social support.
- *Youth-friendly/teen-focused services*- Services provided to clients which focus specifically on the adolescent age group. This can be distinguished from other health services which generally cater to children or adults.

Chapter II: Literature Review

2.1 Introduction

The purpose of this literature review is to gain knowledge on the experiences of HIV positive adolescents in the context of sub-Saharan Africa. The review of literature is focused on determining issues faced by HIV positive youth, as well as their unmet needs. A variety of sources were used to conduct this review, including academic journals and reports by governmental, international, and non-profit agencies. Literature searches involved databases such as PubMed, EBSCO, and JSTOR. While the focus of the literature review was on sub-Saharan Africa, generalizable data from other areas of the world was also used in certain sections. Research specific to a developed world context was only utilized when there was little published data about results in sub-Saharan Africa, and was used largely for comparison rather than to replace gaps in knowledge. Overall, the review provides a comprehensive idea of what is known about this population in the context of sub-Saharan Africa, as well as current gaps in research.

2.2 Issues Faced by HIV Positive Youth

Stigma and Discrimination

Like many populations affected by the HIV epidemic, adolescents face stigma and discrimination due of their disease status, which can lead to barriers in accessing treatment and care. Youth infected with HIV face both external stigma, which is directed to them from outside people or groups, as well as internal stigma, which includes their own self-endorsed negative beliefs about their status [2]. The impact of stigma on those with a positive diagnosis has several psychological implications which include stress, lower self-esteem, feelings of shame, emotional turmoil, and restricted social interactions [2]. With the fear of being shunned by the outside

community and even close friends and relatives, many adolescents either live with the stigma they receive or fear its occurrence. Several studies have identified fear of stigma as a major factor in disclosure status. A study among HIV positive teens in Botswana found that several choose to keep their status a secret to others. Participants saw this as a way to protect themselves against negative community opinion, and few had disclosed their status to anyone other than close family [10]. Many adolescents choose not to disclose to even close friends because of this fear of discrimination, complicating peer relationships [11, 12]. Another issue many teens face in their decision to disclose to others is the threat of stigma against entire families. By disclosing personal status, family members or sexual partners may also be implicated. For perinatally infected individuals, disclosure will most certainly implicate their mothers' disease status as well. For adolescents acquiring the disease through sexual intercourse, this may bring unwanted attention to their partners as well as the fact that they are sexually active [7].

As social stigma surrounding HIV/AIDS is still a serious problem in many sub-Saharan African countries, the perceived threat of discrimination impacts how and when adolescents choose to disclose to others. In a study involving qualitative interviews with HIV positive teenagers attending the Kalafong Hospital's Pediatric HIV Clinic in Pretoria, South Africa, one seventeen-year-old male expressed his desire to disclose his status to friends, but could not because his grandmother feared that people would burn down their house upon discovering his status [13]. Similar patterns of family anxiety over adolescent disclosure and fears of discrimination have been noted in studies throughout sub-Saharan Africa, including the Democratic Republic of Congo, Zimbabwe, and Ghana [14]. Other studies show the impact of internal stigma on adolescents whose families do not discuss their status, although it is known.

By receiving signals that their status is not to be discussed, teenagers internalize their shame and fear into negative personal feelings about themselves and their status [13, 15].

Stigma is also often cited as a barrier to accessing healthcare and treatment services. For adolescents who know their status and fear the stigma which may accompany it, provision of medication or attendance at known HIV clinics may be delayed [2]. This may be a greater concern in smaller communities or clinics which are known to treat HIV positive patients. Lack of privacy at clinics can also play a role in potentially keeping adolescents away from care [15]. This may include lack of patient confidentiality, discriminatory attitudes by health providers, or inclusion of parents in adolescent appointments, all of which may influence how and what services are received. While stigma most assuredly plays a negative role in whether care is accessed, it may also have the opposite effect. In a study among HIV positive adolescents in Botswana, stigma was found to be beneficial in accessing care. Teens in the study felt that adhering to treatment and seeking clinical care for diseases was a way to reduce the likelihood of stigma in their communities, as they would appear healthier with these medical interventions [10]. While not the case in all areas, it is important to understand the nuances in the relationship between perceived stigma and need for care. Furthermore, this shows the important role of providers in helping to reduce stigma. If these professionals can show their support for adolescents living with HIV, youth may be less worried about possible stigma and access care more frequently.

Disclosure

For adolescents living in sub-Saharan Africa perinatally infected with HIV, the process of disclosure is a complicated issue. Relatively few studies exist on the disclosure process among

adolescents and their post-disclosure experiences in resource-limited settings [7, 16]. Literature on this topic distinguishes between partial disclosure, where general information about illness is given, and full disclosure, where the adolescent becomes aware of his HIV status [2]. Most research on this topic assumes that disclosure occurs as a single event, without considering its importance as a process over time [17]. However, more recent studies have shown the importance of disclosure to perinatally infected adolescents occurring as a process rather than a one-time event, dependent on the situation and needs of the individual [2, 18]. Factors which may influence when and how a child or adolescent is told of his status include development level, health condition, home situation, and maturity level. As a result, the child can be informed about his or her status in an age-appropriate way as he or she grows into adolescence [18]. Research has also shown that this process may better equip an adolescent to deal with the knowledge of being HIV positive.

The period during which children and adolescents are disclosed to varies widely. Data from studies conducted in sub-Saharan Africa shows wide fluctuations in average age of disclosure. A study in Ghana showed that only 21% of 8-14 year olds had been disclosed to, while research in Zambia showed that 37% of 11-15 year olds had been disclosed to [14]. In Uganda, a study of 8-18 year olds showed that almost 60% had been disclosed to, and in the Democratic Republic of the Congo, the mean age of disclosure was 15 years [16, 19]. Research has also shown difference in opinions among caregivers and healthcare providers as to when disclosure should occur. In South Africa, caregivers interviewed agreed that disclosure should occur around age 11 or 12, while healthcare providers at the same clinic advocated for partial disclosure beginning at 6 years and full disclosure at age 10 [20, 21] What becomes clear when examining the available data is that no age is key to disclosing a child's HIV status. Instead, this

decision is influenced by a variety of factors which may change based on location, caregiver, health provider, and adolescent involved.

Several factors are involved in caregiver's decisions in disclosing to a child or adolescent. Common reasons for delaying disclosure include the perception that the child or adolescent is too young to understand his/her status, lack of knowledge on how to disclose, concern about the impact of disclosure on the child, parental discomfort and guilt about discussing their own status, and fear that the child will disclose their status to others [7, 14, 17]. Common reasons for deciding to disclose to a child or adolescent include health status, concerns about disease transmission, adherence concerns, age, and to help the youth understand why he/she is commonly sick [16]. Other reasons include the right of the youth to know his/her status, concern that the youth may hear of his/her status from another source, and concern that the youth will become sexually active. From this discussion, it is clear that disclosure decisions in this context are complicated and dependent on the specific individual and situation. Therefore, few conclusions can be made about how and when caregivers decide to disclose to their child, other than that the decision to do so is complex.

Reactions by the child or adolescent being disclosed to have also been reported in research on the topic. In a study in the Democratic Republic of Congo, over 70% of caregivers expected their child to react negatively to the knowledge of their status. Most commonly cited as an expected response was that the child would think of death or dying [16]. Reactions of youth in the study included physical pain and distress, thoughts of death, surprise, sorrow, and fear. However, over 70% reported that they did not feel anger or hopelessness immediately upon finding out, and 30% reported feeling relief [16]. When asked whether it was better to be informed of their status, 88% responded that it was, because they gained knowledge on their

sickness and could protect others from the illness. In a study from South Africa, similar findings occurred upon disclosure. Many youth reported feeling sad and distressed, but also relieved [7]. Furthermore, the level of support by others varied widely among studies. While youth in several studies mentioned the importance of social support and discussing their newly understood condition with other peers, many also mentioned reluctance to disclose their status to anyone, even close friends [2, 7, 15].

Several studies have also shown the link between disclosure and health. Contrary to what may be believed, disclosing to a child may actually improve overall health outcomes rather than cause extended distress and depression. In fact, studies have either shown no correlation or a positive effect between disclosure and mental health outcomes, including lower levels of stress and depression among adolescents aware of their status [7, 14]. While several of these studies were conducted outside of sub-Saharan Africa, one done in Zambia showed a similar pattern. Adolescents who had not been disclosed to were significantly more likely to suffer from emotional distress than those who were [22]. While the data indicates a strong correlation between mental health and disclosure, more studies are needed in sub-Saharan Africa before conclusions on this topic can be made, as situational determinants may play a large role in health outcomes. Furthermore, HIV positive youth attending support groups in the developing world have been shown to have fewer negative perceptions about the disease, and fewer worries about their illness [7]. This data suggests that social support in addition to disclosure may be a better measure of mental health outcomes in this context. Another factor in understanding this connection may have to do with the perceived knowledge of infection prior to disclosure. Many adolescents may already be aware of their disease status prior to official disclosure, as seen by the commonly reported feeling of relief once disclosure occurred. This may help explain the

connection between disclosure and mental health and the relief of actually knowing one's illness. Finally, connections between disclosure and adherence have also been reported. A study in Uganda reported that 75% of adolescents who knew their status reported perfect adherence to medication, while only 20% of those who had not been disclosed to reported similar adherence [23]. However, when a caregiver was the only person aware of the individual's status, he/she was three times more likely to be non-adherent. Additional studies in Uganda and Kenya also showed similar results [14]. With fewer medication regimens available to sub-Saharan Africa, it is vital to encourage disclosure if it improves adherence, as this knowledge could help prolong the lives of those infected.

Adherence

As in any HIV infected population, adherence is also an issue in adolescents living with the disease. Antiretroviral (ARV) medication regimens must be strictly adhered to in order to receive maximum health benefits and to control disease viral load. Adherence to ARVs can lower viral load, decrease transmission risk, and bolster the immune system, among other impacts [24, 25]. Literature has frequently noted that anything less than 95% adherence can be associated with negative health outcomes among HIV positive patients [26]. This can be challenging to youth for several reasons and is influenced by both situation and location. Complicating this situation is the tension between the health benefits from ARV medication and the often negative side effects of its use, which may discourage adherence. The side effects of ARV medication were noted in the literature as one factor limiting adherence among adolescents. In a study with HIV positive youth in Zambia, several acknowledged ARV side effects as a challenge to taking their medication [15]. The adolescents interviewed stated that this was a daily

challenge, and some respondents admitted to throwing away their medication because of it. Research has also shown that perinatally infected youth face particularly serious consequences from non-adherence. Because these youth are more likely to have been on ARV regimens for longer, they may be more prone to resistance against certain medication regimes [24]. Literature on the topic also makes differentiations between different types of non-adherents. Accidental non-adherers refer to patients who do not take their medication due to forgetfulness or inattentiveness, while invulnerable non-adherers are those who believe that missing doses will not affect them, and decisive non-adherers are those who understand the consequences of skipping doses but still choose to do so [7]. These categories of non-compliance emphasize the fact that adherence is a complex issue that involves several factors. Levels of non-adherence among adolescents reported in sub-Saharan Africa differ by study, and as such it is difficult to ascertain any pattern in reported literature on the youth population in this context [7, 27].

Several complex factors have been noted in the literature as reasons affecting adherence among youth. Those who attend school, drink less alcohol, and report self-efficacy are more likely adherent to their ARV regimens, along with those who had experienced more than two hospitalizations. Contrastingly, youth who had experienced a recent stressful event, display psychological distress, or have been diagnosed with depression are less likely to be adherent [16, 20, 28]. Fear of stigma or fear of others noticing medication usage are also barriers to adherence among this population [10]. Findings on age and its relation to adherence have not been consistent. For example, in one study, younger adolescents who lacked an understanding of the importance of medication were less likely to be adherent, while another showed that older youth who were less dependent on caregivers to ensure adherence were more likely to be non-compliant [7, 28]. Clearly, compliance among adolescents infected with HIV is a complex issue

with varying trends in findings based on several factors, such as location and social support. Adherence to ARVs requires a balance between disclosure among younger adolescents, so they understand the importance of compliance, as well as continued caregiver support among older adolescents, so they are able to transition into adulthood with responsible adherence habits. This transition has been cited in the literature as a critical stage in the adherence process. Older teenagers who begin to take on the responsibility for their own drug adherence must understand the consequences of non-compliance, and studies have noted late adolescence as a period where adherence levels decline [28, 29]. There seems to be a consistent relationship between decreased parental involvement in medication regimens and increased non-adherence among teenagers. While this transfer of responsibility must take place, it is integral to the health of the adolescent to ensure that adherence is continued at high levels. Healthcare providers should closely monitor adolescents during this period to make this transition as smooth as possible. Adolescent social support groups have been cited as one successful way to help manage this transition as well [15].

A final important indicator of adherence among youth, particularly those perintally infected with the disease, is caregiver relationship. Caregivers who are HIV positive themselves, have less education, or who use drugs and alcohol are more likely to have non-adherent children [7, 28, 29]. While several other factors are also involved in determining adherence status among youth living in these situations, it is important to note the impact of caregiver relationship, especially among those who have grown up with the disease. This issue needs to be explored further in the sub-Saharan African context before any conclusions can be drawn about its overall impact on adherence.

Mental Health

While physical health is often considered top priority in caring for HIV positive individuals, mental health is often just as important, particularly in terms of HIV positive adolescents. Mental health disorders affecting teenagers with HIV may include mood disturbance, anxiety, depression, social disorders, suicide attempts/contemplation, and hopelessness, among others [30]. Youth living with HIV are often subjected to more distress than their HIV-negative peers, dealing with issues such as personal illness, death of close family members, stigma, disclosure, and loneliness [2]. Coming to terms with the fact that HIV is an incurable illness, as well as the stigma and shame tied to having such a disease is an emotional burden that greatly affects infected youth [31]. This is particularly important within the context of sub-Saharan Africa, as youth constantly hear messages about the dangers of acquiring HIV, and yet must come to terms with having this disease themselves.

Recorded rates of psychological health problems in HIV infected adolescents are not consistent. While several studies have shown an association between both neurocognitive delays and prevalence of one or more mental illnesses among HIV positive youth, rates differ between studies and locations [32-34]. A meta-analysis of eight studies from developed countries attempted to capture average prevalence of psychiatric illness among HIV positive adolescents. Combined data showed an average prevalence of 24.3% for anxiety disorders and 25% for depression. However, rates between studies showed high variation. The prevalence of adolescents with at least one psychiatric disorder varied from 32%-85%, and those with clinical depression varied from 12% to 47% [32]. These data show the importance of context when discussing this issue. While almost every study showed an association between mental illness

and HIV infection among teens, it is clear that other factors such as living environment or social support may play a large role in determining the strength of this connection.

Few studies on this topic have been conducted in the sub-Saharan African context [33]. In a study with HIV positive South African teens, a focus group revealed strong negative emotions including sadness, anger, and loneliness [7]. However, in this study, these feelings rarely corresponded with mental illness diagnosis, and instead participants largely conveyed a sense of overall wellbeing. A study in Zambia found that HIV positive youth in the country had much higher emotional difficulties than age and gender-matched peers from the United Kingdom [22]. While the United Kingdom cohort was perhaps not the most appropriate comparison group, this highlights the fact that many similar studies on HIV infected adolescents and mental illness do not have a control group with which to compare findings. Finally, results from a study among HIV positive youth aged 6 to 18 in Kenya showed that 48.8% of youth in the study met the criteria for at least one type of psychiatric disorder, and 25.9% of youth in the study met the criteria for two [33]. The most common diagnoses in this study were anxiety disorders, at 32.3%, followed by depression at 17.8%. These results are similar to a study done in Uganda in which 51.2% of HIV positive adolescents had significant psychological distress and 17.1% had attempted suicide in the last year [34]. From the available data in a sub-Saharan African context, discrepancies arise when attempting to categorize psychiatric health and HIV infection. While it is clear that psychological illness is an important factor impacting HIV positive adolescents, more research in this area needs to be completed before any conclusions regarding disease status, adolescence, and mental health can be made.

Within sub-Saharan Africa, studies have provided several factors which correspond with psychological problems among positive youth. Home, school, and community challenges, along

with peer conflict, have all been associated with higher psychological stress among HIV positive adolescents. While these situations are often compounded by positive status, many may also be unrelated [11]. Specific factors found to be related to increased mental distress among HIV positive adolescents include poor ARV adherence, higher viral load, lower CD4 counts, higher rates of drug/alcohol use, and riskier sexual behaviors [7, 11]. Contrastingly, higher levels of social support, disclosure of status to family and friends, and open communication about the disease have been found to be related to lower levels of psychological distress among this population [2, 11, 31].

Finally, it is important to note how normal physical, biological, psychological, and behavioral changes which occur during adolescence may compound and be compounded by the stress of a positive status. This transitional period between childhood and adulthood is marked by puberty, development of primary and secondary sex characteristics, creation of self-image, identity formation, development of decision-making skills, increasing importance of peer groups, and development of sexual relationships [11, 31]. This period of transition is also often filled with conflict, experimentation, peer influence, and other challenges. Adolescents with HIV face a particularly difficult time as they must learn to cope with their disease while going through the challenging changes which occur during this period. Many HIV positive adolescents experience puberty later, particularly those infected at birth, which may further impact psychological and emotional problems already faced by youth [35]. Furthermore, the turmoil of teenage years may cause other issues unrelated to illness to be prominent in youth lives. In a South African study discussing youth experiences with HIV, many cited unrelated problems as integral to their lives, including trouble at home, poverty, crime, violence, drugs, problems with peers, and bullying [11]. While some of these issues could be related to disease status, others are experiences that

adolescents may have with or without the disease. A second study, also from South Africa, reported similar findings. When asked about things that made them feel badly, youth mentioned several aspects including fights with parents, ill parents, family poverty, school environment, violence, and crime [7]. In fact, only one focus group mentioned HIV at all when asked this question. These studies help demonstrate that adolescents infected with HIV face multiple issues which affect their mental health status. While the disease most likely creates stress in the lives of these youth, there are also several other stressful factors in their lives. In this sense, HIV can compound other problems they are facing, which are most likely similar to problems faced by HIV negative adolescents.

Sexual Initiation/Continuation

Sexual initiation or continuation by HIV infected youth is a common issue during adolescence. Research shows that sexual intercourse among HIV positive teens is just as common as it is among their negative counterparts. In a study conducted in Uganda with perinatally infected HIV positive youth aged 15-19, the majority stated that sexual intercourse was unavoidable in the near future [8]. These findings are similar to those found elsewhere regarding the inevitability of teenage sexual intercourse, even among those who are HIV positive [36]. Several studies worldwide have shown that horizontally infected teens continue to have sexual intercourse, and perinatally infected teens are increasingly engaging in sexual intercourse at an earlier age [7, 37]. However, policies and programs for HIV positive adolescents tend to encourage abstinence, and fail to address the issue of sexual initiation or continuation among those who are infected with HIV [36-38]. Many are reluctant to acknowledge the possibility of sexual intercourse in this population, and therefore do not address the issue with these teens.

With serious consequences of pregnancy, sexually transmitted infection acquisition, HIV re-infection, and transmission of the disease to others, there is much at stake for failure to promote more comprehensive prevention. One study in Uganda found that over 25% of HIV positive participants aged 11-21 had initiated sexual activity [39]. Several misconceptions about HIV and sexual intercourse were also present among the participants. Many girls believed they could not become pregnant due to the infection and others thought the virus was only present in the blood and not semen or vaginal fluid. These results could be partially due to the reluctance to educate HIV positive youth on sexual issues. In another study in Uganda with perinatally infected youth aged 15-19, 33% had already initiated sexual intercourse [36]. The median age at first consensual sexual intercourse was 15 years and 16 years for males and females respectively. Among those who had never had sex, 29% said they had the desire to do so, and 86% of respondents who had never had sex expected to do so in the future [36]. Condom use among this population was also measured in the study. Only 37% of respondents who had sex used a condom the first time, and only half reported currently using any contraceptive method, including condoms. While these rates are higher than the general adolescent population in Uganda, they are still low considering possible consequences of spreading the disease, and because use of condoms seems inconsistent in the population. As such, it is important to both educate HIV positive adolescents on the risks of unprotected sexual intercourse, while also encouraging the creation of a positive sense of sexuality among this population [9]. As youth will most likely initiate sex during adolescence, is it important to mitigate the impact of these decisions through positive sexual health education.

2.3 Needs of HIV Positive Youth

Adolescent-Focused Services

While literature on the subject often cites a lack of knowledge about the needs of HIV positive adolescents in sub-Saharan Africa, one commonly mentioned is a shift toward teen-focused services [9, 38]. Services for HIV positive adolescents in resource-limited countries are often underdeveloped and lack age-appropriate support for this transitional period between childhood and adulthood. Often, healthcare in sub-Saharan Africa is separated into pediatric and adult clinical support, and there is no clear space for adolescents to access healthcare [40]. Adolescent populations also have specific needs that cannot be met through child or adult clinics, a fact noted repeatedly throughout the literature [8, 11, 38]. Without creating a separate space with youth-friendly services, this already vulnerable population can get lost in current healthcare divisions which they do not fit into. Creating developmentally appropriate services for HIV positive youth will help open vital communication between youth and healthcare personnel, which may help adolescents stay engaged in care and thus facilitate positive health.

Youth-friendly programs and services are particularly important among HIV positive adolescents due to access to reproductive health services. As noted above, a large portion of the HIV positive adolescent population is engaging in sexual intercourse, or will be in the future. Without offering reproductive health services targeted at adolescents, healthcare organizations could be missing the opportunity to provide vital information and resources for this population, who may not otherwise access care. Due to this problem in division of care between children and adults, adolescents often do not receive the services they need, as they are treated in pediatric care units [36]. The child-centered focus of these clinics may not prove desirable to adolescents, who may not feel as though they can discuss teenage issues with care providers. On the provider

side, healthcare personnel may not be equipped to ask about sexual activity or discuss reproductive health if they are used to serving a younger population [36]. Potential consequences for youth include lack of knowledge on contraceptive methods, lack of ability to negotiate contraception use, hostility toward healthcare services, lack of access to prevention services, and lack of knowledge on virus transmission to sexual partners. Contrastingly, age-appropriate transitional services for adolescents have been associated with improved follow up, better disease outcomes, and improved psychological health [41]. This has been recorded in programs such as the Tuungane Youth Project in Kenya, which provides comprehensive, age-appropriate health services for youth up to age twenty-four [42]. The creation of adolescent-centered services can also be beneficial in preventing further HIV infections [24]. HIV positive adolescents provide a unique point of intervention to help prevent transmission to other partners. Creating a friendly atmosphere for discussing reproductive health and sexual intercourse would provide the catalyst to discuss preventing transmission of the virus to others, a vital need of this population. Furthermore, while reproductive health services are particularly important to offer directly to adolescents, other services such as mental health and substance abuse screening and treatment may also be useful to offer in a teen-friendly setting.

A balance needs to be established between providing HIV positive adolescents with care services that are separate enough from the general adolescent population to target their needs, while also normalizing such care so there is not stigma attached to its use [9]. While many healthcare facilities in sub-Saharan Africa are at or over capacity in terms of service provision, small adjustments to currently implemented programs can make a difference in whether HIV positive adolescents feel comfortable accessing care. As adolescent HIV populations continue to grow in sub-Saharan African countries, this will continue to be an issue. Providing youth-

friendly services can help target a vulnerable population in need of assistance to halt further disease transmission.

Adolescent Support Groups

Along with teen-focused services, support groups for HIV infected adolescents are also commonly cited in the literature as a need specific to this population. Social support by other teenagers experiencing the same issues is an important way to improve psychological health of those infected by HIV. Creating a safe space for an open dialogue with other adolescents experiencing similar issues will help teens cope with the disease as they navigate their adolescent years [11]. By providing this type of group, teenagers will be able to access support services, make social connections, and create bonds with others- all outcomes which would not be available with basic healthcare services. These groups can also help adolescents who may have few other forms of support, particularly with those of similar age [10].

Studies from developed countries show that support groups for HIV infected adolescents are linked to improved attitudes toward medication, improved feelings of support and hope for the future, increased self-esteem among participants, improved acceptance of disease status, decreased viral load, and better overall clinical outcomes [41, 43]. Differences between the context in which these studies were conducted and that of sub-Saharan Africa make it difficult to generalize these results, but it can be assumed that support groups have the capacity to improve both mental and physical health outcomes. Studies exploring the idea of social support groups in sub-Saharan Africa have also been met with positive reactions from youth. Research in South Africa and Zambia with support group components for HIV positive adolescents found many participants receptive to the idea of further group sessions [7, 11]. When asked about their

support group experiences, youth commented on the positive impact of discussing their problems and concerns with others like them. Emphasis was also placed on the importance of activities that do not specifically focus on education and learning. Other programs, such as the Tuungane Youth Project, provide support groups with facilitators who themselves are HIV positive and on medication. This project has been successful in improving mental health of participants while also providing them with education and adherence support. With 300 members and growing, the importance of such support cannot be overstated [42]. The issue of stigma and its potential attachment to the creation of such support groups is important to consider in this context as well. While some sources have cited the impact of support groups on helping youth deal with internalized stigma, the fear of external stigma and its impact on youth accessing such services must be considered prior to implementation of such groups [2].

Peer support groups can also be used as a potential arena for life skills development. Leadership training, economic empowerment, and other interventions can be utilized in this context to better prepare youth for their future [38]. This is an extremely important component for social support, particularly among resource-poor communities who may not otherwise have access to such services. A few particularly successful programs in Kenya which have focused on life skills development as part of their youth support services include the Positive Youth Initiative project, the Sunburst/FACES Project, and One-2-One Kenya [44-46]. All focus on providing both mental and emotional support for HIV positive youth, while also providing them with trainings on a variety of topics and leadership positions within the group. The Sunburst/FACES Project also trains members on how to facilitate peer support groups and educate others on HIV prevention. This model emphasizes the importance of integrating both support and life skills training for HIV positive youth, and its ability to work within the Kenyan

context. Doctors Without Borders has also created a unique program for HIV positive youth in its clinic located in Mathare, an informal settlement in Nairobi [47]. This project, incorporating several of the characteristics of the programs discussed above, allows the adolescents to develop their own newsletter. These newsletters, written and produced by the HIV positive youth of Mathare, give them the chance to create and distribute their personal stories, thoughts, and opinions to others in the area. This project allows adolescents to gain practical skills while also allowing them to connect with others in their peer group and empowering them to live with HIV. As the population of HIV positive adolescents in sub-Saharan Africa continues to grow, it is of utmost importance that unique, useful, and successful programmatic interventions such as those mentioned above continue to evolve and be made available to more HIV positive youth.

2.4 Summary and Relevance

Several conclusions can be drawn from the above literature review. First, it is clear that HIV positive adolescents in sub-Saharan Africa face a variety of difficult issues which vary based on situation and individual. Certain topics appeared from the literature review as particularly important to this population, including the issues of stigma, disclosure, adherence, mental health and reproductive health. These topics consolidated into unmet needs for this group**,** which included the need for adolescent-focused health services and teen support groups. A common theme throughout the literature review was that much about HIV positive adolescents in sub-Saharan Africa remains unknown, and more research is needed on this population. Furthermore, sub-Saharan Africa as a region is extremely diverse and it is important to note that some research presented may not be generalizable to all situations and contexts within the continent. At the same time, a basic idea of some of the concerns and complexities faced by this

population could be ascertained. Overall, this literature review accomplished the task of gaining a better understanding of HIV positive adolescent issues and needs as well as providing a basis from which to create an HIV positive adolescent program.

Chapter III: Needs Assessment Methods and Results

3.1 Introduction

As the main purpose of this special studies project is to create a program plan for use with adolescent clients at Lea Toto, two major methodologies were used to inform its creation. First, a needs assessment involving surveys with adolescent clients and their caregivers, an adolescent focus group, and interviews with key staff members was undertaken in the summer of 2012 at Lea Toto Kibera. The data gathered from this assessment helped to illuminate gaps in current adolescent services at Lea Toto while also identifying specific unmet needs of these clients. This data and the methods associated with its collection are integral in creating the topical content of the program plan. The second methodology used in the creation of this program was the utilization of behavioral health theory, including theories of social support, stigma, and empowerment, to formulate the structure and design of the program. The needs assessment and subsequent results as well as the use of specific behavioral health theories combine to inform the creation of an adolescent program to be used at Lea Toto.

3.2 Needs Assessment Methods

Study Description and Purpose

The purpose of this mixed-methods needs assessment project was threefold: to gauge adolescent client satisfaction with Lea Toto services, to identify gaps and remaining needs in currently provided adolescent services, and to assess the impact of Lea Toto's disclosure trainings. As previously discussed, while Lea Toto services have traditionally focused on children, as their clients age into adolescence there is a need for additional services for this population. In order to gauge client satisfaction, survey participants were asked what services

they used at Lea Toto, as well as how often, and their feelings regarding these services. Caregivers of adolescents were surveyed to gain their perspective on this issue as well. A focus group discussion among adolescents also provided a unique opportunity for teenagers to discuss their satisfaction with Lea Toto as a group. Gaps in services were identified through adolescent surveys, by a number of questions asking about additional desired services at the clinic. Caregivers also provided suggestions for improved service provision by Lea Toto, and the focus group discussion allowed for richer information on gaps in current services and remaining needs of adolescent clients. Key informant interviews with staff members also gave a unique perspective on this issue from the provider standpoint. Staff members identified strengths and weaknesses of currently available programs while also acknowledging needs and suggesting additional program components for adolescents. Finally, at the direction of Lea Toto administration, questions were asked of all groups regarding disclosure of HIV status. Lea Toto provides disclosure training sessions for caregivers in order to empower them to discuss HIV status with their adolescents. Questions regarding the disclosure experience (in discovering one's status) were asked among adolescent survey respondents, caregivers, and focus group participants to help assess Lea Toto's disclosure training sessions.

With several study objectives, potential research methods were discussed with Lea Toto administration, and a mixed-methods approach was chosen. With surveys providing useful quantitative data from both adolescents and their caregivers, the use of focus groups was selected to gain richer qualitative data as well as to accompany the data found in survey collection. Finally, key informant interviews with staff members were included as an integral component to the data collection, as their perspective added a needed provider-side dimension to the study. Overall, a mixed-methods approach was used to gain a more comprehensive idea of adolescent

user satisfaction, gaps in teenage services, and effectiveness of the disclosure training program at Lea Toto.

Participant Selection

All needs assessment participants were clients at the Lea Toto Kibera clinic in Nairobi, Kenya during the summer of 2012, with the exception of five adolescents who participated from the Lea Toto Kawangware location. Inclusion criteria for adolescent participants included: 1) age between 11 and 19 years and 2) current use of clinic services. If disclosure status of an adolescent was unknown, an adjusted survey was provided which had no mention of HIV/AIDS but asked questions regarding satisfaction and use of Lea Toto services. Caregivers who participated were the main guardian of adolescent-aged child who used clinic services. Both groups were selected due to their presence at the clinic or on home visits with social work staff. Focus group participants were selected based on their presence at a Teen Day event at the Kibera clinic. Key informant staff members were chosen based on their work with adolescent clients, and were all located at the Kibera clinic. Convenience sampling was the method for choosing participants in all groups.

Development of Research Instruments

The formation of questions for surveys, key informant interviews, and focus groups were completed with the assistance of administrative staff of Lea Toto. The program director approved the project and created a list of topics to include, and verified the final version of each protocol prior to implementation. The monitoring and evaluation officer for the organization helped in defining question topics, structuring questions to collect useful data, and in the overall

formatting of each instrument. Both the program director and monitoring and evaluation officer expressed strong desire to include questions on not only customer satisfaction and adolescent needs, but also disclosure experience. The researcher worked closely with staff members to ensure that sensitive questions regarding disclosure were asked in a culturally-appropriate fashion. In this way, question topics, formation, and research methods were all driven by the desires of the Lea Toto program itself and meetings were held with several staff members to ensure the instruments would gather useful information for the organization. Prior to the start of data collection the director of Lea Toto, relevant center administrators, and other colleagues examined each instrument and suggested improvements as needed. Once each instrument was finalized, data collection began.

Institutional Review Board (IRB) Approval

As this project consisted of a needs assessment at the request of Lea Toto, it was not considered human subject research, and Emory IRB approval was not required.

Adolescent Survey

The purpose of the adolescent survey was to gain specific, quantifiable information regarding the ways adolescents use Lea Toto services, their satisfaction with offered services, unmet needs, and information regarding disclosure of HIV status. Through these questions, Lea Toto staff hoped to gain a better idea of attitudes toward their services as well as how best to expand their adolescent program. The surveys themselves were two-paged, self-administered, cross-sectional data collection tools. The majority of questions had an open-ended component in order to gather the most information possible from participants. This design allowed both

quantifiable data collection but also the ability to analyze reasons why adolescents choose specific answers. This design was most helpful in the disclosure section, which allowed adolescents to discuss their experience at length if desired. By allowing this type of data collection, richer information was gained at certain points in the survey, providing valuable data for analysis.

Surveys were distributed in English to adolescents aged 11 to 19 years. These ages were pre-determined by Lea Toto staff, and the wider range provided for a variety of responses. Convenience sampling was used to gain participants, all of which attended clinic services. Surveys were largely self-administered, although a few were administered by Lea Toto staff. Because of the personal nature of certain questions, this could have biased results. Prior to approaching potential participants, their medical file was checked to ensure that disclosure of HIV status had occurred. When this could not be verified, adolescents were given an edited version of the survey, which did not include questions about disclosure or any mention of HIV/AIDS. These adolescents (n=4) were still included in order to gain information regarding client satisfaction of services by the widest group possible. For those who met the eligibility criteria, verbal consent was given after an explanation of the questionnaire's purpose and its anonymous nature. Adolescents at both Lea Toto Kibera and Kawangware were approached while waiting for services, and completed the survey at the clinic during this period of time. Overall, forty adolescents from these two sites completed surveys. See Appendix A for the full survey instrument.

Caregiver Survey

A second survey was distributed to caregivers of adolescents using Lea Toto services (Appendix B). The purpose of this survey was two-fold. First, questions were asked regarding the individual's disclosure experience to their child in order to assess Lea Toto disclosure training. Secondly, questions were asked regarding challenges of raising an HIV positive teenager and opinions on needed services for this population. This instrument was originally envisioned as a qualitative interview rather than a survey, but translation difficulties made it necessary to modify the instrument to a survey format. Overall, this instrument was created to gain a better understanding and different perspective of the challenges caregivers face in caring for HIV positive teenagers. Inclusion criteria for caregivers included: 1) caring for an adolescent-aged child, and 2) having started the disclosure process with this child. The survey itself consisted entirely of open-ended questions to gather a variety of responses. While the surveys were written in English, many caregivers did not have the ability to read and write in the language, so staff members assisted in translation and completion of the survey. Caregivers were approached at the clinic as well as on home visits and gave verbal consent prior to being asked survey questions. As adolescents often came to the clinic without their caregivers, these respondents were more difficult to find. Social work staff members agreed to collect survey information with caregivers of adolescents during home visits in order to mitigate this problem. However, as homes were often not sound-proof, and discussion of HIV-related issues was highly stigmatized in the area, few surveys were conducted in this manner (n=3) due to considerations of client privacy. These challenges made it difficult to recruit participants for the caregiver survey, explaining why only ten were conducted. However, the open-ended nature of these surveys provided a variety of responses from those who did participate.

Adolescent Focus Group

A focus group discussion guide was created in order to complement survey responses with qualitative data (Appendix C). After introductions and an explanation of the focus group, participants were asked about topics including their experience as adolescents, disclosure experience, adherence to medication, service utilization of Lea Toto, and remaining service needs. Only one focus group took place, which occurred during a Teen Day at the Kibera Lea Toto location and was integrated into other clinic activities. All adolescents who were aged 11 to 19, had been disclosed to, and attended Teen Day services were invited to join the focus group, with sixteen adolescents consenting to participate. The focus group discussion was facilitated by the Lea Toto counselor who knew the participants well and topics were discussed in both English and Swahili. The discussion was not recorded for privacy purposes; however detailed notes were taken in order to capture focus group data.

Two activities were initiated during the discussion. The first was a ranking activity, where adolescents worked in small groups to discuss and rank currently offered adolescent-targeted services at Lea Toto. These services were written on cards prior to the focus group and a set was distributed to each small group. Participants discussed their preferred services as a small group and then all respondents were brought together to discuss their answers. The second activity was a pile-sorting activity which all respondents participated in as one large group. Over twenty topics were written on note cards for participants to sort into the following piles: not needed at Lea Toto, no opinion, and needed at Lea Toto. The aim of this activity was to gain an understanding of adolescent perceptions of useful and necessary services at Lea Toto clinics. Participants were also encouraged to write their own responses on cards if topics were missing. Once the group agreed where to place all cards, a discussion of their choices occurred. The

group was asked about the placement of each card, and any disagreement was recorded. As the discussion occurred, the adolescents began to identify themes in topic placement. Detailed notes of these activities were taken and a summary report was written immediately following the discussion.

Key Informant Interviews with Lea Toto Staff

Key informant interviews were conducted with Lea Toto Kibera staff members in order to gather qualitative data on the provider side of services (Appendix D). Questions focused on the strengths and weaknesses of currently offered services and suggested additions to adolescent-targeted services at the center. Staff were selected based on how closely they worked with adolescent clients. Three social workers, one counselor, and one nurse at the Kibera center were selected as participants. All interviews were conducted in English, and participants gave verbal consent to be interviewed. All interviews were conducted in a private room in the clinic by the researcher, who knew all staff members well. No interviews were recorded due to technical error and privacy concerns by some of the respondents. However, detailed notes were taken and typed up directly after interviews were finished.

3.3 Adolescent Survey Results

Demographics

All forty adolescents participating in survey collection completed the survey between July 4, 2012 and August 21, 2012. Ages of those who participated in survey collection ranged from 12 to 18, with two participants declining to fill out their age. Participants were largely located at Lea Toto Kibera although five were from Lea Toto Kawangware. Four individuals

who completed the survey had an unknown disclosure status and were therefore given a shorter version of the instrument with no mention of HIV/AIDS.

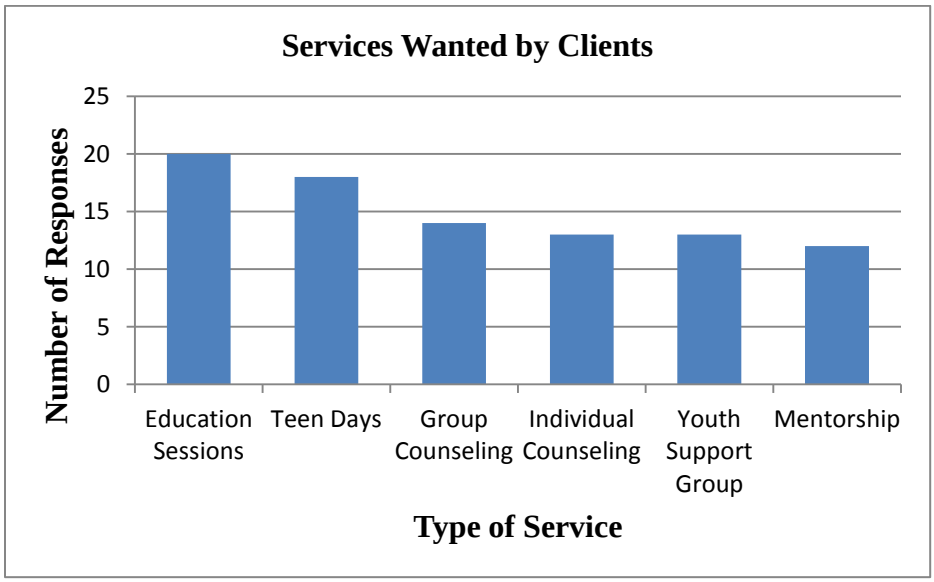
Adolescent Service Utilization

When asked about use of youth services in their community, 54.3% (n=19) of those who responded answered that they did utilize youth services, while 45.7% (n=16) answered no. Of those who did use youth services and noted where, the most frequently mentioned location was church. When asked whether they use Lea Toto youth services specifically, 65.7% (n=23) of those who responded answered yes, while 34.3% (n=12) of those who responded answered no. While this question was targeted at discovering how many adolescents used teen-specific services at Lea Toto (including Teen Days, the mentorship program, and Life Skills training), it was clear that this question was misunderstood, as several who responded "yes" mentioned treatment services as the youth-specific service they regularly used, which was not an intended response. From this, the validity of responses is uncertain. Commonly mentioned responses other than treatment included Teen Days and Life Skills sessions as most utilized by adolescents. For those few who indicated that they did not use adolescent services at Lea Toto and commented on why, most common responses were that they were busy or that they did not know of any adolescent services at Lea Toto. These responses indicate other potential problems with this question, as some participants were not aware of the adolescent services currently offered at Lea Toto.

When asked what specific services participants wanted more of, several topics were popular. The question asked participants to choose from the following topics: individual counseling, group counseling, youth support group, education sessions, mentorship, Teen Days,

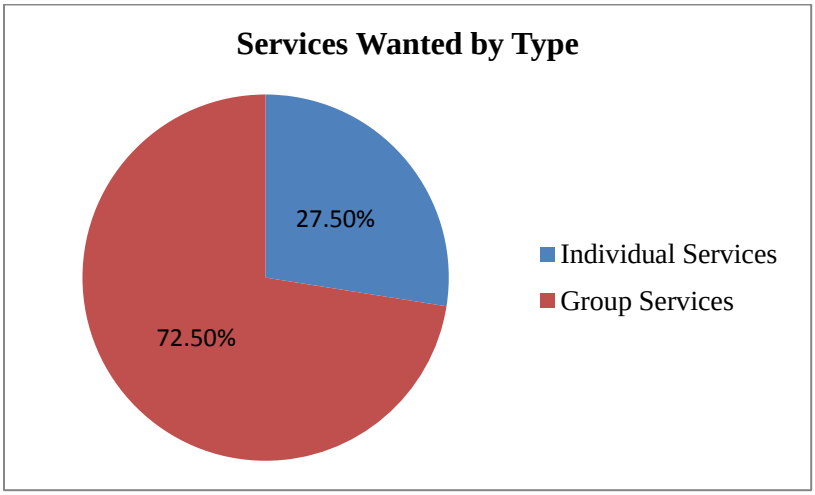
or other. Participants could choose more than one option. Figure 1 shows the most popular responses, displaying the top responses as Teen Days and education sessions, followed by the other options.

Figure 1: Services Wanted by Clients



However, when services are categorized by type, as group or individual, other trends emerge, as seen in Figure 2. For the purposes of this analysis, individual counseling and one-on-one mentorship services were categorized as individual services, and the other options were categorized as group services.

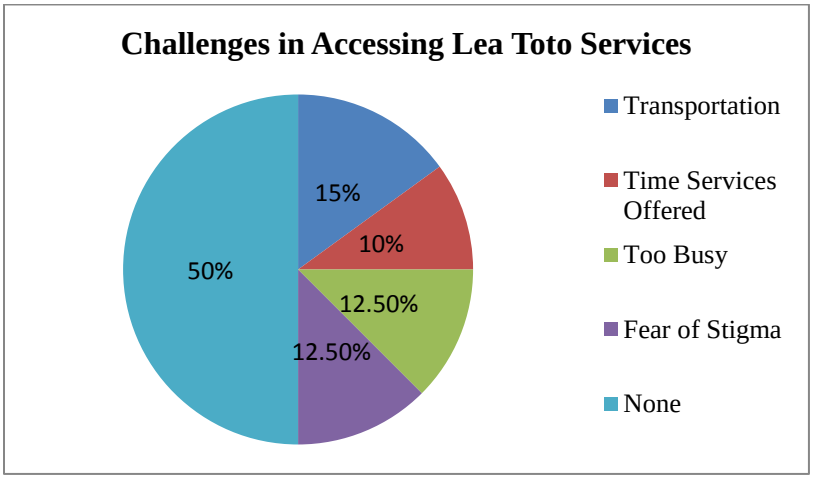
Figure 2: Services Wanted by Type



While more group services were offered as choices in this question, all respondents were able to choose multiple responses, and an "Other" category was also offered. The top three responses were all group-related activities. This is important in terms of deciding what type of services adolescents want from Lea Toto, how these services should be delivered (individual versus group activities), and therefore the design of the adolescent program. In a similar question asking respondents what they would add to Lea Toto services, the few who responded "Yes" and gave a specific answer suggested group activities, including talent shows, meetings, and a youth support group.

A final question regarding services at Lea Toto asked participants whether they faced challenges in accessing services. Half of all responses indicated that adolescents did not face any challenges in accessing Lea Toto services. Those who named challenges in service utilization indicated that transport, times services were offered, being too busy, and fear of stigma were major reasons for these challenges. Figure 3 displays these responses.

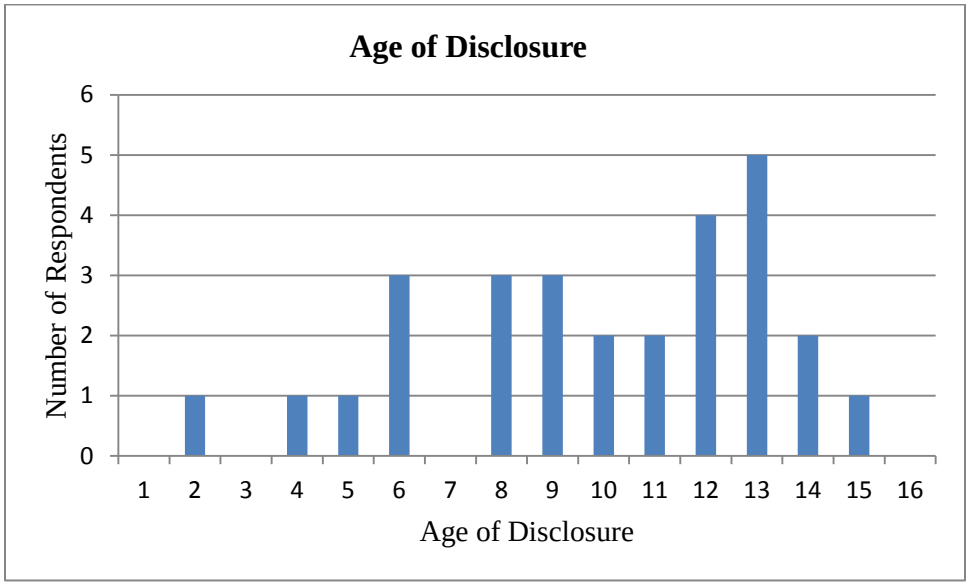
Figure 3: Challenges in Accessing Lea Toto Services



Adolescent Disclosure Experience

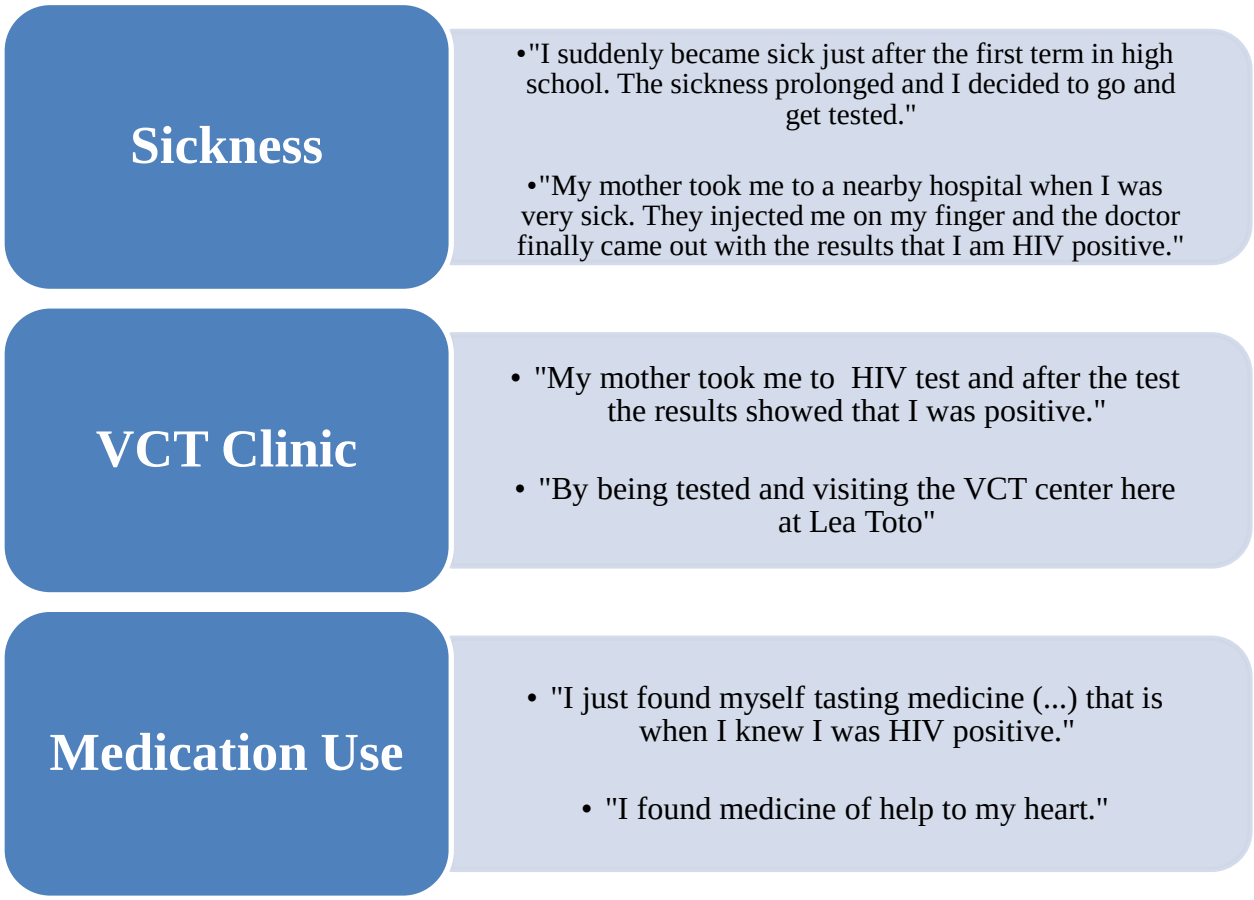
Adolescents who had been disclosed to were asked questions regarding this experience (n=36). Participants whose disclosure status was unknown (n=4) were not given this section of the survey. When asked about their disclosure experience, the majority of respondents (n=19) indicated that their experience was either positive or mostly positive, with several (n=10) indicating no opinion. Age of disclosure varied widely, as seen in Figure 4, with the peak age being early adolescence, at age 12 or 13.

Figure 4: Age of Disclosure of HIV Status



The type of disclosure method also varied widely among the respondents. Several mentioned discovering their positive status due to interaction with the medical field (n=16). Many mentioned prolonged sickness and subsequent testing as the catalyst for discovering their status. Others mentioned discovering their status because they had been receiving medication for a period of time. Several responses to this question are included in Figure 5. Respondents tended to be slightly older, between ages 10 and 15 when they discovered their status due to sickness or HIV test. From this question, it is unclear whether a parent or guardian knew or suspected HIV prior to the discovery during their adolescent years.

Figure 5: Adolescent Disclosure: Interactions with the Medical Field



Other adolescents responded learning of their status specifically due to disclosure by a parent or other family member (n=10). These respondents tended to be younger, aged 6 to 13, at the time of disclosure. These respondents largely discovered their status from parents, although the question was not detailed enough to discover how these conversations took place.

When asked to elaborate on their disclosure experience, only fourteen respondents choose to do so. Of these responses, most were positive. These responses included a discussion of support by friends, acceptance of their status, and the use of medication to help come to terms with the disease. Several responses are highlighted in Figure 6. Few respondents mentioned negative reactions. One of the few who did simply stated, “It wasn’t a happy moment.” Because

so few respondents choose to elaborate on their disclosure experience, no generalizations about this event can be made. However, it is still useful to include specific responses from those who choose to discuss their experience, to better understand the process of disclosure from these specific individuals.

Figure 6: Disclosure Experience Responses

In a question asking participants how their disclosure experience could have been improved, the majority of respondents once again mentioned positive aspects of their disclosure,

their acceptance of the disease, and their perceived support by others, rather than how their experience could have been better. Of those who did specify possible improvements to their experience, several mentioned their desire for more advice and counseling and more discussion with other teenagers during the disclosure process. Time of disclosure was also discussed; however, respondents mentioned wanting disclosure earlier as well as later and there was no clear agreement on when disclosure should occur.

A final question was asked regarding whom respondents had informed of their positive status. Of the thirty-five respondents who answered this question, 20 (57%) said that they had informed at least one other person of their status, while 15 (43%) said that they had not informed anyone else of their status. Of those who responded that they had informed others of their status, only half (n=10) had informed a person who was not a relative. Most of these respondents mentioned telling a teacher (n=7) or a close friend (n=3). These results are surprising, given that previous answers indicated that many felt supported by friends and did not fear stigma. At the same time, participants in this survey rarely disclosed their status to anyone other than close friends and family.

3.4 Caregiver Survey Results

Demographics

All participants in the caregiver survey were caregivers of adolescent-aged children who had at least partial disclosure at the time of the survey. Surveys took place between July 4, 2012 and July 28, 2012. All respondents were clients at Lea Toto Kibera and had at least one adolescent who used services at this location. Age of adolescents in their care ranged from 11 to

16, with the majority of adolescents between age 11 and 14. Ten participants completed this survey.

Disclosure Experience

Age at which disclosure to their child began varied widely in this sample. The range of responses varied from age 4 to age 12, and in several cases had only recently been initiated with their child. All respondents with the exception of one indicated that they had attended at least one Lea Toto disclosure training session. The one respondent who did not attend disclosure training indicated that the existence of these sessions was unknown at the time. When asked about the challenges faced in disclosing to their child, main responses included fear of child's reaction, worry of stigma, adherence concerns, and child's difficulty in understanding and accepting status. However, other respondents mentioned that they had few challenges, and that their child had accepted their status. When asked how their disclosure experience could have been improved, the most common response by half of respondents was more preparation and training. A minority of respondents indicated that they felt prepared for disclosure and had no suggestions for improvement. In terms of their child's reaction, participants were split on positive and negative responses. Half of respondents indicated that their child had accepted their status, while several indicated panic and stress had resulted from their disclosure discussion.

Challenges in Raising an HIV Positive Adolescent

In responding to a question regarding challenges faced when raising an adolescent with HIV, most participants named at least one challenge. Those mentioned included stigma for HIV status, concerns about adherence, sickness, and need of food. When asked about remaining

needs in relation to raising an adolescent with the disease, caregivers overwhelmingly mentioned two topics: more psychological support and more material support. Psychological support included mention of more training, support, and encouragement for both caregivers and adolescents. Material support included mention of more economic, food, and school support. While the low number of respondents make these results difficult to generalize past those who participated, these responses echo others found in both the adolescent survey and focus group results.

3.5 Focus Group Results

Demographics

One focus group discussion with adolescents occurred on July 3, 2012 at Lea Toto Kibera as part of the center's Teen Day activities. The discussion lasted approximately one hour and fifteen minutes. Participants included all adolescents who came into the clinic to receive medication, had previously been disclosed to, and stayed for the Teen Day group discussion. Of the sixteen adolescents who attended, ages ranged from 11 to 18, with most participants under age 14 (n=12). The majority of participants were male (n=12), with four females. All regularly used Lea Toto Kibera services.

Disclosure Experience

The first topic discussed during the focus group was the disclosure experience had by participants. Several participants described being sick often, taking medications, and being absent from school frequently as clues to their HIV status. Constant illness was commonly mentioned as a way participants discovered their status. Due to this, several participants

indicated they had discovered their HIV status prior to being officially disclosed to by an adult. Some mentioned learning of their HIV status on their own as early as age eight. When asked whether they would have preferred to be disclosed to by someone or to find out by themselves, participants unanimously stated that they would have preferred to have been disclosed to rather than discover their status alone. This discussion is particularly useful when addressing caregiver's disclosure concerns over fear of negative reactions.

When asked to describe their disclosure experience, participants revealed largely negative feelings, in contrast to survey respondents. Reactions mentioned included embarrassment, fear, confusion, disbelief, guilt, anger toward parents, and desire to keep status a secret. A discussion took place around the discovery that the disease was spread to the adolescents by their mothers, in which participants discussed feeling anger, hatred, and blame. Participants then continued on to discuss their understanding over time that transmitting the virus was not desired by their mothers, and the subsequent lessening of anger due to this. Respondents then discussed the lack of official disclosure by parents in terms of these negative feelings. One adolescent described the discovery of his status on his own as "It came like a dream," indicating his confusion and disbelief at learning he was HIV positive.

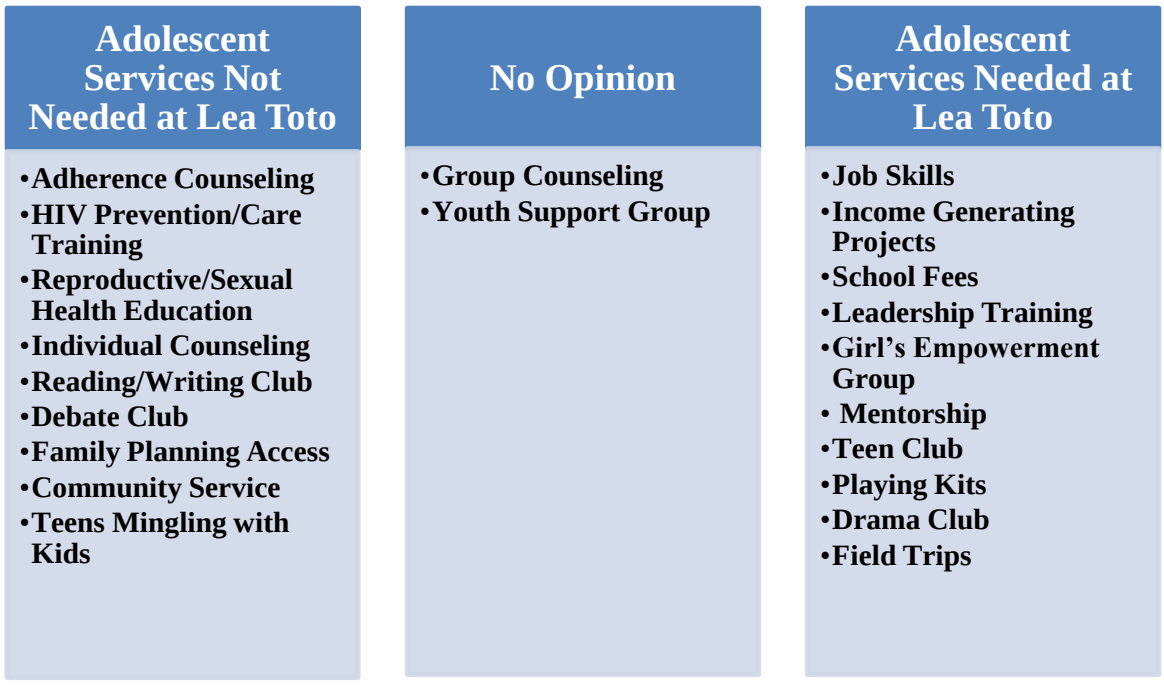
Focus Group Activities

Two additional activities took place during this focus group discussion, both of which revolved around perceptions of current Lea Toto services and remaining needs by adolescents. The first activity involved splitting the focus group into small groups of four, and asking participants to rank the following current Lea Toto services from most preferred to least preferred: Teen Days, Counseling, Mentorship, and Life Skills. After discussing their opinions

in small groups, all participants discussed their choices. The two preferred activities were the mentorship program, which was unanimously preferred by those who used it, and Teen Days. Teen Days were particularly preferred because of the group and discussion aspects of this activity. Those services which were less preferred were counseling, which was not preferred largely due to the one-on-one aspect of the activity, and Life Skills training, because it includes younger children. These results show the desire for more adolescent-only group activities among those in the focus group.

The second activity used pile-sorting to help determine the most desired activities for adolescents. Figure 7 reveals the distribution of responses and preferences by the group.

Figure 7: Pile Sorting Results



After the participants grouped the activities, a discussion of card placement occurred. For activities identified as not needed at Lea Toto, adherence counseling, HIV prevention and care training, and reproductive and sexual health education were mentioned as unnecessary because

adolescents constantly heard these messages. Participants mentioned that these activities had been repeatedly mentioned to them. While it is uncertain whether all adolescents had comprehensive knowledge of these topics, it is clear that Lea Toto's current services have succeeded in portraying these messages to clients. As discussed in the ranking activity, individual counseling was not preferred by the group due to its one-on-one aspect. As for the reading, writing and debate clubs, participants noted that these activities were too academic, and there was little interest in them due to this. Family planning access was unwanted by the group, because as one participant stated "We are not planning for a family." It is possible that the young age of participants skewed this result, the term was misunderstood, or that the topic was too taboo to discuss in a group setting. One of the additions to the activity written in by the group was "Teens Mingling with Kids." The group was adamant about wanting their own adolescent-only activities which did not include younger children, which this addition reflects. Overall, the majority of activities placed in this category were seen as repetitive, too academic, and unneeded by adolescents.

As for the "no opinion" category, there were only two items placed here. Group counseling was a topic that participants were divided on, so it was decided that it would be placed in this category. As for the youth support group, this activity may have been misunderstood by the group, as many equated the word "youth" with children, which they were clear to distinguish themselves from.

Several activities were placed in the "needed" pile. Many activities were skill-based, such as job skills, income generating projects, school fees, leadership training, girl's empowerment group, and mentorship. When discussing why they chose these activities to be placed in the "needed" pile, participants mentioned their usefulness and practical nature as

important. School fees, a girl's empowerment group, and job skills were all specifically mentioned as highly desired by the participants. The other activities in this category, including a teen club, playing kits, a drama club, and field trips, were important to the group because of their social and enjoyable nature. Participants discussed how this was important to include because they have few opportunities for socializing with each other. Important to note was that almost all activities in this category were placed quickly and agreed upon by the entire group.

3.6 Staff Key Informant Interview Results

Demographics

All five key informants were staff members at Lea Toto Kibera in the summer of 2012. Interviews with informants took place between July 1, 2012, and July 28, 2012. Key informants were chosen due to their close work with adolescents using the clinic and their knowledge of Lea Toto services. Informants included social work, counseling, and nursing staff at the center. All informants had worked with the researcher for over a month by the time interviews occurred. Interviews were conducted separately with each staff member at their convenience.

Strengths and Weaknesses of Current Adolescent Program

The first question asked of informants was useful in gaining an understanding of their perception of current adolescent services. Strengths of current services identified by respondents included: helping adolescents adapt well in society, teaching adolescents important life skills, helping adolescents cope with stigma, educating adolescents about how to live with HIV, and helping adolescents gain self-confidence. Others mentioned the ability for Lea Toto to act as a liaison to help adolescents to meet as a group as a strength of current services. One respondent

mentioned the staff's in-depth knowledge of and relationship with all adolescents in the program as a unique strength offered to Lea Toto clients. Weaknesses were also identified by the informants. The fact that services hypothetically available at Lea Toto were not consistently offered was identified by respondents as a major concern. Other weaknesses mentioned were lack of resources for teenagers, the difficulties of mobilizing adolescents to come to the clinic, lack of a teen-specific program at the center, lack of knowledge about what services adolescents are interested in, and lack of group activities where adolescents are able to connect with other teens and express themselves. More logistical concerns, mentioned by almost all respondents, included difficulty of timing activities so they do not occur during school hours, difficulty with getting certain teenagers to attend clinic activities, issues with transport, and the need of more adolescent program options to incentivize teenagers to come.

Additions to Current Services

When asked what they would add to adolescent services at Lea Toto, staff had several ideas. All informants mentioned the importance of building upon and improving existing services rather than creating an entirely new program for adolescents. This was important to staff members, as all realized how limited resources are for new services. The lack of variety of current activities was commonly mentioned as a problem. Staff members commented on the lack of structured group activities for adolescents, which they saw as a serious need. Respondents were particularly concerned with providing more enjoyable activities to attract more adolescents to use Lea Toto services. The emphasis on group activities was seen as important due to the difficulties teenagers face during adolescence, and the unique support they provide each other, particularly as teenagers living with HIV. Staff perceived this as an

important need, pointing out that peer support would be an important addition to their other counseling services. Stigma was also discussed by respondents as an issue in relation to the need for an adolescent support group or adolescent group therapy. Many teenagers prefer not to discuss their status with others due to a fear of stigma, and providing them with an outlet to gain peer support was viewed by several respondents as particularly important. Respondents also recognized that such support could ease several other issues in their clients' lives, including medication adherence, coping with their HIV status, and filling a social gap that many have. Overall, all informants commented on the need of a consistently offered adolescent program at Lea Toto in order to help adolescents live positively with the disease and gain support from each other. All staff members were clearly aware of client needs, and had several suggestions for improving services for this population at Lea Toto.

3.7 Theoretical Framework

Introduction

Along with data gathered from the needs assessment, behavioral health theories have been utilized to help inform the adolescent program creation. In order to best address the unmet needs identified in the needs assessment, the theoretical framework upon which this program is created includes theories of social support, empowerment, and stigma in order to best achieve the purpose of the program.

Theories of Social Networks and Social Support

Behavioral health theories of social networks and social support serve as a framework for understanding relationships among members of social systems. Social support specifically

provides help to individuals through social relationships and interaction, including emotional (empathy, love, trust), instrumental (tangible aid and services), informational (provision of advice and information), and appraisal support (provision of feedback useful for reevaluation/affirmation) [48]. These types of support are provided through social networks, which have a structured number of members with some degree of similarity who are connected in a certain capacity. Interventions involving this theory are generally directed toward certain types of social networks and social support. Specific types of these interventions which increase social support include: enhancing existing social network linkages, developing new social network linkages, enhancing networks through the use of community health workers, and enhancing networks at the community level through participatory problem solving. Such interventions have displayed links between social relationships and health status, and the beneficial effects of social support by peers.

In order to increase social support in HIV positive adolescents, theories of social networks and social support are important to consider. By focusing on enhancing and maintaining social networks and developing new social network linkages, adolescents gain support from peers experiencing similar issues as themselves. In Lea Toto's case, the creation of these social networks has the potential to give HIV positive adolescents the support they need to navigate adolescence and come to terms with the disease. These network linkages can be roughly measured prior to and after the program via questionnaires to evaluate how well they have improved through the creation of a support program for youth. Another aspect of social network theory involves the use of community members from the target population as role models [48]. Potentially using peer leaders, either infected or affected by HIV, can help create a sense of similarity in life experiences, which may enhance support. Overall, using these network agents

also has the potential to connect HIV positive adolescents to other networks, helping them to lead healthier lives with multiple sources of support. By utilizing interventions based on this theory, adolescents at Lea Toto will be provided with greater cognitive, emotional, and psychological support.

This behavioral health theory also reflects several findings from the needs assessment conducted at Lea Toto. Repeatedly noted throughout the results is the emphasis on the utilization of and desire for group activities by adolescents. Teen Days and the mentorship program were specifically mentioned in the results of multiple data collection tools as highly enjoyable and necessary. More specifically, the importance of social support in teenager's lives was repeatedly discussed in the data, particularly as a catalyst for helping adolescents come to terms with the disclosure of their disease status. As this period can be extremely confusing and debilitating for adolescents, many mentioned its importance in alleviating stress and negative feelings. Also noted repeatedly through open-ended survey questions was the importance of social support in living positively with HIV/AIDS. Data from caregivers echoes these sentiments, pointing to the importance of social networks and support and the need for more socialization activities for teenagers. Staff interviews had similar results, emphasizing the support teenagers can receive from their peers as a need which staff cannot fill. As a result, this theory is used in creation of the adolescent program to address the concerns, needs, and desires surrounding social support seen throughout the data collection results.

Empowerment Theory

Closely tied to social support outcomes is the idea of empowerment. Theories of empowerment utilize multiple levels, including the individual, organizational, and community, in

both process and outcome measures [48]. As a process, empowerment theory can enable individuals to gain control, with increased empowerment measured as an outcome as well. This theory has also been tied to improvements in health outcomes. At an individual level, greater empowerment can increase personal perception of control, motivation, and psychological health. At a group level, empowerment has the potential to increase understanding of group capabilities beyond just the individual level. This concept is closely related to the idea of self-efficacy, and interventions based on the combination of social support and empowerment theories have been shown to improve self-efficacy and perception of one's own capacity [48].

Certain results from the needs assessment show the importance of empowerment theory when creating an adolescent program. Similar to social support, it was noted in adolescent surveys that acceptance of status by friends helped teenagers feel more in control of their disease. However, those without such support had more negative self-images, and struggled with feeling debilitated by knowledge of their disease status. As noted above, this is closely tied to social support, which clearly helps provide adolescents with feelings of empowerment and control over their bodies and their disease. The idea of socialization as a route to empowerment was viewed in adolescent surveys, focus group, and staff interviews. Empowerment was also discussed in a much different way among focus group participants, who indicated a desire for more skill-based activities such as income-generating projects, a female empowerment group, job skills training, a more robust mentorship program, and more. These preferences indicate a second level of empowerment beyond the psychological. The repeated interest in these activities indicates a desire by adolescents for agency in their lives via skills with a long-term impact. As such, a major goal of the adolescent program is empowerment via social support as well as these activities.

While of secondary importance to social support theories, empowerment as a concept and a theory is closely tied to social support outcomes. As such, both theories are integral to an adolescent program offered by Lea Toto. As many of these teenagers struggle to overcome challenges of adolescence and to accept their disease status, the use of social support to improve group and individual empowerment is extremely beneficial.

Theories of Stigma and Discrimination

Stigmatization of those with HIV/AIDS leads to several stressors including experience of prejudice events, expectations of rejection, hiding and concealing, and stressful social interactions, among others [48]. The impact of stigma cannot be overstated, as not only does it cause negative psychological health outcomes, but can also lead to internalized stigma as an individual begins to believe in the messages of the stigmatizer. While ending stigma is extremely difficult, theories of stigma and discrimination offer certain methods of coping with such stigma, including increasing self-efficacy. As such, the use of this theory is closely related to theories of social support and empowerment. As adolescents form relationships in a peer support group, improvements in their psychological health can potentially impact their own personal self-efficacy and therefore help them cope with such stigmatization. While the creation of an adolescent program at Lea Toto will not have the capacity to eradicate community stigmatization of those who are HIV positive, by incorporating elements pointed to by theories of stigma and discrimination, it can improve personal psychological outcomes and help youth cope with stigma.

Theories of stigma and discrimination are employed for this program plan due to their relevance to needs assessment findings. In both adolescent surveys and the focus group

discussion, negative feelings about oneself (internal stigmatization) and fear of discrimination by others (external stigmatization) were major factors in how adolescents perceived themselves and their disease, as well as their likelihood to use services. While it was commonly mentioned that friends were seen as a source of support, few had actually disclosed to anyone other than close relatives. This finding points to the continued sense of isolation and fear of stigma that many adolescents have due to their status. This fear of stigma was commented on by both caregivers and staff members as well, who saw peer support as a way to potentially alleviate this issue. Clearly, theories of social support, empowerment, and stigma are all interrelated and impact each other. As the use of each stems from the needs assessment findings, they are invaluable in creating a structure for the teen program at Lea Toto.

3.8 Summary and Relevance

Combining needs assessment results with behavioral health theories forms the basis of an adolescent program plan for Lea Toto. While the needs assessment data has limitations and is not generalizable, it is valuable information, giving those adolescents who will use the program a voice in determining its components. While this information is specifically important for inclusion of topical-based components of the program plan, behavioral health theory is also useful in this context. These theories both re-emphasize the data found in the needs assessment collection while also providing needed theory behind the structure of the program itself. The combination of the data from the literature review, the needs assessment collection, and behavioral health theory will inform the creation of a useful model for adolescent-based health interventions at Lea Toto.

Chapter IV: Program Plan

4.1 Introduction

The purpose of this program plan is to outline a set of goals, objectives, activities, and indicators for an adolescent program at Lea Toto, resulting from a comprehensive literature review of the subject, needs assessment results from Lea Toto Kibera, and applicable behavioral health theories. The main goal of this program plan is to balance currently available resources at Lea Toto with adolescent client needs to create an adolescent program that can be practically implemented at Lea Toto sites in Nairobi. As such, this program plan responds to both resource limitations at Lea Toto as well as adolescent client needs in order to create the most applicable adolescent program possible. It is also intended to be flexible to allow Lea Toto to structure the program as needed; if certain activities are perceived as being less useful, staff can adjust the program as necessary.

4.2 Program Goals and Objectives

Program Goal

To improve HIV positive adolescent health and quality of life through increased social support, empowerment, and life skills education.

Program Objectives

Social Support:

- Form consistently offered psychosocial support group for HIV positive adolescents
- Increase social support network for HIV positive adolescents
- Improve or continue high medication adherence outcomes for HIV positive adolescents

- Foster mentorship among HIV positive adolescents

Empowerment:

- Increase self-esteem and personal agency of HIV positive adolescents
- Decrease internalized stigma of HIV positive adolescents

Life Skills

- Increase knowledge of secondary prevention for HIV/AIDS among HIV positive adolescents
- Increase life and job skills knowledge among HIV positive adolescents

4.3 Program Activities and Indicators

Social Support

Adolescent Support Group

The main component of the adolescent program will be an adolescent support group, offered monthly at each Lea Toto location. All other teen activities will be offered during support group meeting times. Counselors at each site will lead the support groups with the assistance of program materials, as they have in the past during Teen Days. The purpose of the support group is to provide a forum for all teen activities, provide a safe space for adolescents to gather, and to provide a peer support network for HIV positive adolescents. While incorporating other activities seen below, the support group will also include monthly discussions on topics impacting adolescents. Indicator measurements for support groups will be how often they are held, how many teens attend, and how many activities take place.

Drug Buddy Program

The issue of medication adherence will be integrated into social support by the creation of a drug buddy program. This will pair teenagers together voluntarily so each adolescent has a partner to encourage and support drug adherence. Drug buddies will meet and discuss their adherence during monthly support group meetings, and will be encouraged to meet or text outside of Lea Toto if needed. As adolescents grow into adults, they will be increasingly responsible for their own medication adherence, and this program is designed to both increase peer support while beginning steps toward independent adherence. Medication adherence is monitored in existing Lea Toto activities, and this information will be used as an indicator of program success. Furthermore, the number of drug buddy meetings will be recorded as well as client satisfaction data regarding the program in order to monitor its' success.

Mentorship Program

While Lea Toto has an existing mentorship program between adolescents and outside community members who are HIV positive, it has served few teenagers due to constraints in the number of participating community mentors. At the same time, adolescents indicated strong interest in this program. In order to meet these needs as well as increase social support and social networks, a mentorship program will be included as part of adolescent support group meetings. This will pair older (15-18 years) and younger (11-14 years) adolescents by gender to encourage support toward positive living. The aim of this activity is to give younger teens support and mentorship from an older peer, give older teens practice in a leadership role, and reduce the burden of mentorship needs on Lea Toto staff. This way, if resources allow, older adolescents will be able to participate in existing mentorship program once they reach a certain

age, allowing Lea Toto staff to pair less adolescents with outside mentors. The mentorship partners will meet regularly and participate in activities as part of the overall adolescent support group meetings. The goal of these partnerships is to increase social support and networks among adolescents and will be measured based on the number of visits as well as client feedback regarding their opinion of the program and their feelings of social support.

Empowerment

Adolescent Support Group

Closely related to social support objectives is the topic of empowerment. Objectives of increasing self-esteem/personal agency and decreasing internal stigma will be met during general support group meetings and activities. This will include group discussions on these topics and related activities, as seen in the Activities Manual. Related indicators include number of empowerment activities, baseline and endline estimations of internal stigma, and growth in self-esteem and feelings of personal agency.

Life Skills

Secondary Prevention Knowledge

As HIV positive adolescents with the capacity to transmit the disease to others, certain knowledge-related activities will be incorporated into program activities. These will include role-playing, games, and other group activities to increase knowledge of secondary prevention and its importance. As adolescents grow into adulthood, this information will be increasingly necessary as they make relationship and sexual activity choices. A survey assessing knowledge

on this topic will be distributed to adolescents to measure levels of awareness among participants prior to joining the adolescent program and then at yearly intervals.

Leadership and Jobs Skills Workshops

An important need for adolescents as they age into adulthood is the acquisition of practical skills. In order to expose teenagers to these topics, both leadership and job skill workshop activities are incorporated into the adolescent program. These include role-playing and group activities regarding leadership, as well as guest speakers by Lea Toto staff members regarding important occupational skills and experiences. Indicators for these activities include number at each site as well as client satisfaction feedback regarding their usefulness.

Figure 8: Adolescent Program: Goals, Objectives, Activities and Indicators

Goal	Objective	Activity	Indicator
To improve HIV positive adolescents' health and quality of life through increased social support	1. Form psychosocial support group among HIV+ adolescents 2. Increase social support network of HIV+ adolescents 3. Improve or continue high medication adherence outcomes for HIV+ adolescents 4. Improve mentorship capacity among adolescents	• Monthly support group for HIV+ adolescents • 'Drug Buddy' project implemented as part of support group • Mentorship project between teenagers	• Number of support groups held • Number of youth at each session • Number of drug buddy and mentorship sessions • Client satisfaction surveys • Psychosocial health survey • Individual counselor assessments of each participant (baseline/endline)
To improve HIV positive adolescents' health and quality of life through increased	1. Increase self-esteem and personal agency of HIV positive adolescents	• Monthly support group for HIV+ adolescents	• Number of support groups held • Number of youth at

empowerment	2. Decrease internalized stigma of HIV positive adolescents	• Individual and group discussion exercises • Mentorship project between teenagers	each session • Number of empowerment-related activities • Number of mentorship sessions • Client satisfaction surveys • Psychosocial health survey to assess empowerment • Individual counselor assessments of each participant (baseline/endline)
To improve HIV positive adolescents' health and quality of life through increased skills education	1. Increase knowledge of secondary prevention for HIV/AIDS among HIV positive adolescents 2. Increase leadership and job skills knowledge among HIV positive adolescents	• Education sessions/discussions on secondary prevention • Job/life skills activities • Guest speakers on occupational skills	• Number of education sessions • Number of job/life skills activities • Number of guest speakers • Knowledge assessment • Psychosocial health survey to assess feelings of preparedness

Figure 8 displays in detail the goals, objectives, activities, and indicators for the adolescent program. The topics are separated by support activities, empowerment activities, and skill-based activities. The purpose of Figure 8 is to display the number of activities and their resulting indicators.

Figure 9: Adolescent Program: Inputs, Outputs, and Outcomes

	INPUTS	**OUTPUTS**		**OUTCOMES**		
		Activities	***Measures***	***Short-Term***	***Medium***	***Long-Term***
Support	-Site counselor -Program plan and activity manual -Activities for both teen mentorship and 'drug buddy' project	-Teen support groups -'Drug buddy' sessions between teens -Mentor-ship sessions between teens	-# support groups -# teenagers attending -Client satisfaction -Psychosocial health survey and counselor assessment	-Gain immediate support circle -Inclusive social connections, safe space for discussion -Social group creation -Increased support network	-Learning to cope with HIV -Learning to live positively with disease -Learn importance of adherence	-Improved psychosocial health due to support -Stigma reduction -ART adherence
Empowerment	-Site counselor -Program plan and activity manual	-Teen support groups -Individual and group reflection exercises -Mentor-ship sessions between teens -Empower-ment exercises	-# support groups -# teenagers attending -Client satisfaction -Psychosocial health survey and counselor assessment -Feelings of self-esteem and agency	- Ability to formulate opinions on teen issues -Social networks strengthened -Improved perception of self	-Learning to cope with HIV -Learning to live positively with disease -Gain personal empowerme nt and self-agency	-Improved ability to live positively with HIV due to empower-ment -Improved personal perception due to empower-ment
Life Skills	-Education materials -Job and life skills materials	- Education sessions on secondary prevention -Job/life skills activities	-# education sessions -# job/life skills activities	-Gain awareness/ knowledge on secondary prevention -Gain knowledge on job skills and life skills via activities	-Use of knowledge to navigate relationships -Use of learned skills to plan future	-Reduction in number of transmitted infections -Use of learned skills in adulthood

Figure 9 provides a more detailed analysis of activities, indicators, and their intended short, medium, and long-term outcomes. It also provides information on necessary inputs for program success. The purpose of each program objective and activity are displayed in Figure 9.

4.4 Program Roles

As the goal of the Lea Toto adolescent program is to respond to client needs within realistic means, there are few corresponding program roles. Counselors and interns at each center will be in charge of the adolescent program and its activities, similar to their current roles in leading Teen Days. Program materials will provide them all inputs necessary to do so. As such, program materials are created to be as user-friendly as possible, with flexibility in what activities are chosen based on staff perceptions of need. The only other necessary staff for the adolescent program will be monitoring and evaluation officers. While monitoring and evaluation indicators are built into program materials, these may need to be updated and revised as implementation occurs. As monitoring and evaluation staff at Lea Toto are currently in charge of recording all activities for donors, these roles will be incorporated into their current responsibilities as the adolescent program begins.

4.5 Program Timeframe

Because formative research for this adolescent program occurred at Lea Toto Kibera, this will be the initial site for program initiation. A suggested timeframe is to begin a pilot program in Kibera, and then increase the number of Lea Toto sites participating over time. As there are few additional inputs other than the program materials created here, the actual timeline of implementation will be decided upon by Lea Toto site directors.

Figure 10: Potential Adolescent Program Implementation Timeline

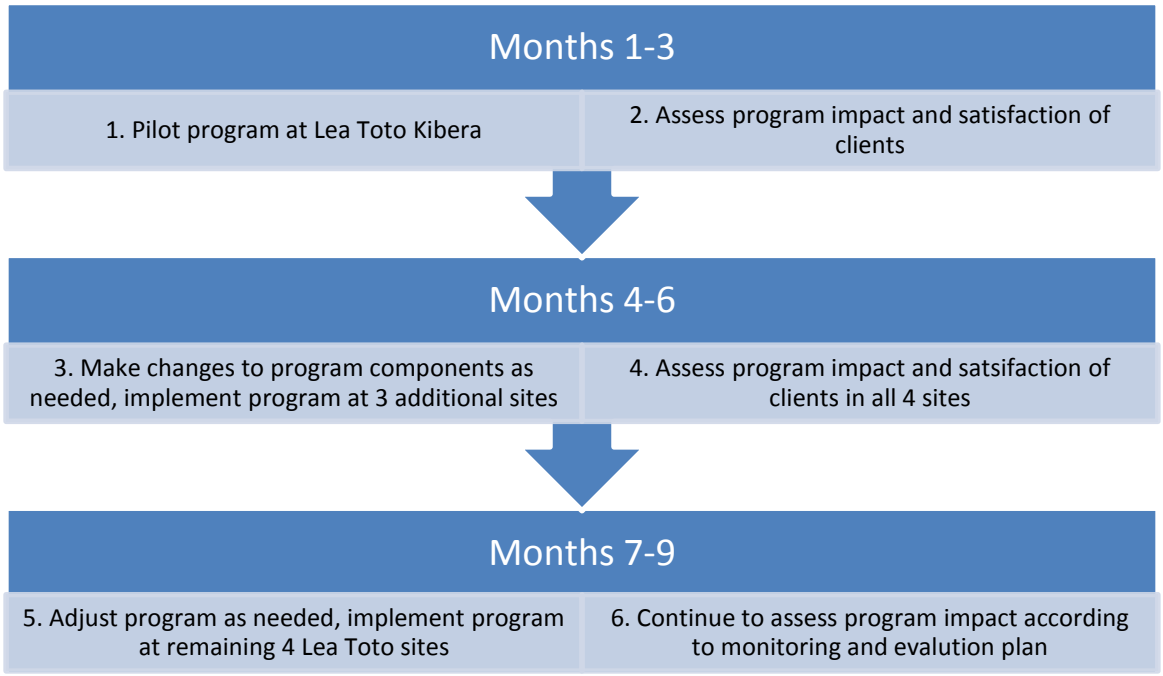


Figure 10 displays a possible timeline for program implementation with each level building off of previous accomplishments. In Months 1-3, the program will be implemented at Lea Toto Kibera, with assessments of program impact and client/staff satisfaction occurring throughout this time period. Any necessary adjustments in the program will be made as three additional Lea Toto sites implement the program in Months 4-6. During this period, program assessments will continue to be made, with adjustments made during the 7-9 Month period as the remaining four Lea Toto sites implement the program. This is only one possible implementation scenario, as site directors at Lea Toto will coordinate with the director to discuss actual program implementation. However, the constant assessment of program activities is necessary during the implementation phase in order to make adjustments to the program in initial stages as needed.

4.6 Monitoring and Evaluation

Monitoring and Evaluation Measures

Each of the above mentioned activities has several related monitoring and evaluation measures. These are listed as follows:

Adolescent Support Group

- Process Measures: Number of groups held, number of adolescents attending, number/type of activities held at each group
- Outcome Measures: Individual counseling sessions to assess psychosocial health of adolescents as well as self-efficacy/personal agency, client satisfaction surveys, psychosocial health surveys completed by adolescents to assess levels of support and empowerment

Drug Buddy Program

- Process Measures: Number of drug buddy meetings/activities, number of adolescents participating
- Outcome Measures: Recorded pill counts by Lea Toto social workers during home visits, adherence rates by Lea Toto site, client satisfaction surveys

Mentorship Program

- Process Measures: Number of mentorship meetings/activities, number of adolescents participating

- Outcome Measures: Independent counseling sessions to assess psychosocial health of adolescents, psychosocial health surveys completed by adolescents to assess levels of support and empowerment, client satisfaction surveys

Secondary Prevention Knowledge

- Process Measures: Number of education sessions, number of adolescents participating
- Outcome Measures: Knowledge surveys at baseline/endline points to assess understanding of secondary prevention

Leadership and Job Skills

- Process Measures: Number of skills sessions, number of adolescents attending, number of guest speakers
- Outcome Measures: Independent counseling sessions to assess self-efficacy/ personal agency, psychosocial health survey to assess preparedness for future, client satisfaction surveys

Each indicator will be collected at specific times throughout the program. All process indicators, including the number of support groups held, the number of adolescents attending, and the number and type of activities (ie drug buddy sessions, education sessions, mentorship sessions) will be recorded at each monthly group meeting. Outcome measures vary in frequency. Client satisfaction surveys will be recorded at each monthly meeting. Individual counseling sessions, psychosocial health surveys, and knowledge assessments will be collected at baseline and then every 6 months to one year after, depending on staff capacity for distributing these

materials. Finally, recorded pill counts will be collected quarterly by social workers, who currently check adherence to medication on home visits. Figure 11 outlines the timeframe for data collection.

Figure 11: Adolescent Program Monitoring and Evaluation Timeline

Indicator	Frequency of Measurement
Number of Support Groups Held	Monthly (at each group meeting)
Number of Adolescents Attending	Monthly (at each group meeting)
Number/Type of Activities Held	Monthly (at each group meeting)
Client Satisfaction Surveys	Monthly (at each group meeting)
Individual Counseling Sessions	Baseline, then every 6 months-1 year
Psychosocial Health Surveys	Baseline, then every 6 months- 1 year
Knowledge Assessment Survey	Baseline, then every 6 months-1 year
Recorded Pill Counts (Adherence)	Quarterly

Description of Collection Methods

The following data collection methods serve as possible ways Lea Toto can monitor and evaluate their adolescent program. These components are meant to be tools for Lea Toto staff and may not be used exactly as presented. As such, the following tools provide potential monitoring and evaluation data, but can be used flexibly by field staff as needed.

Group Meeting Records

Appendix E includes a template for recording the number of support groups, adolescents attending, and activities by type/frequency. This instrument is necessary to keep exact records of

the adolescent program and which activities occur. Its purpose is to be a useful tool in recording basic data at each session.

Client Satisfaction Survey

This instrument, found in Appendix F, asks basic questions regarding client satisfaction toward the adolescent program. It is largely quantitative in order to easily tally and view results, so that changes can be made in program design as needed. There are also open-ended questions and a section for further comments, so specific concerns can be recorded.

Counseling Session Assessment

This instrument, found in Appendix G, gives counselors a way to assess several aspects of the adolescent program, including social support, social networks, levels of self-esteem, and levels of stigma. While counselors are trained to assess their clients and may not need this tool, it provides direction in assessing specific indicators that the program is targeting. This way, it can be flexibly integrated into counselor assessment sessions as needed. A scale from 0 to 5 is used in each section, so as to easily quantify and compare adolescent scores.

Psychosocial Health Survey

This instrument, found in Appendix H, is meant to complement counseling assessments. It can either be filled out individually by adolescents, or used as part of the counselor assessment. These results should be combined with counseling assessments in order to better understand how the program has met its targets. The scoring system for this survey varies by section. For the social support/networks section, the higher the score throughout, the more perceived support by

the adolescent. For the self-perception section, the higher the score up to question 18, the more positive the self-perception. For question 18, items 2, 7, 8, and 9 need to be reverse-scored in order to appropriately measure levels of positive self-perception. In the stigma section, separate scores should be given to part A, B, and C. Part A measures the level of awareness of social stigma, with a higher score equating to a higher perception of public stigma. Part B measures the level of agreement with perceived social stigma. The higher the score, the more the adolescent agrees with public stigmatizing messages. Section C specifically measures internalized stigma. The higher the score, the more applied the stigma is to the individual adolescent. The section on future preparedness is scored similar to other sections, the higher the score, the more prepared and hopeful the adolescent is for the future. While these scoring methods are not infallible, their purpose is to attempt to measure the outcomes of this adolescent program in a quantifiable and comparable manner.

Several aspects of this survey were adapted from other sources. Sections on social support utilized an adapted form of the Medical Outcomes Study Social Support Survey as well as the Sarason and Levine Social Support Questionnaire [49, 50]. The self-perception section included adaptations of the Janis and Field Self-Esteem Scale as well as the Rosenberg Self-Esteem Scale [51]. Finally, the internalized stigma section included an adaptation of the Self-Stigma of Mental Illness Scale by Corrigan [52].

Knowledge Assessment Survey

This instrument, found in Appendix I, provides a tool to evaluate adolescent knowledge on secondary prevention. Questions can be added or changed as needed to fit staff needs. The survey is meant to be a suggested way to measure knowledge of adolescents.

4.7 Activities Manual

The purpose of the activities manual is to provide lessons and activities for Lea Toto staff to use during adolescent support group sessions in a way that requires few additional inputs from Lea Toto sites. Modules are arranged by topic and activities can be chosen and adapted by facilitators. The modules are designed to include all objectives of the adolescent program, including supportive, educational, and skill-building components. Each session is suggested to include the following components: a) introductory activity to start the session b) discussion questions about the chosen topic c) one to two activities related to the topic d) time spent with drug buddy pairs to discuss adherence concerns and e) time spent with mentorship partners to discuss mentee concerns. However, this order is only suggested. The activities manual is created with versatility in mind, and facilitators are encouraged to use it in whichever way best suits their adolescent group. For more detail, see Appendix J for the manual in its entirety.

Chapter V: Discussion and Recommendations

5.1 Introduction

In order to better understand the limitations and implications of this project, this final chapter focuses on these topics along with recommendations for future research and program implementation. In doing so, this chapter provides a roadmap for future work with HIV positive adolescent populations, both within and outside of Lea Toto.

5.2 Program Limitations and Implications

Limitations of Needs Assessment

There were several limitations of the data collection process which may impact programmatic results. With all instruments, the respondents were chosen by convenience sampling rather than a random selection of Lea Toto clients, and were largely selected at the Kibera location. This makes generalizability of results among all Lea Toto clients and locations difficult. Another limitation was the lack of pilot testing of study instruments. Some questions were misunderstood by respondents and piloting the surveys would have been useful to help revise the instrument. While adolescent surveys were self-administered due to privacy concerns and all respondents spoke English, it is clear that not all survey questions were written in a manner that was understood by respondents, and piloting may have resolved this.

The fact that the data collection was done in a busy clinic with overburdened staff created several challenges to the needs assessment. Caregivers were difficult to recruit due to language barriers and the busy nature of the clinic which made it difficult for staff members to assist with interviews. This led to low numbers of caregivers involved in the survey, giving limited information which must be noted when attempting to summarize results. The lack of multiple

focus group discussions was also due to this issue. Instead of adding additional events to the busy clinic schedule, the discussion was integrated into services already occurring at the clinic. Furthermore, dividing focus group participants by age and gender may have been beneficial in both making adolescents more comfortable as well as gaining more age- and gender-specific data. Finally, the focus group and key informant interviews were not recorded due to technical difficulty and privacy concerns. While detailed notes were taken by the researcher, word-by-word transcriptions may have resulted in better data. Although trends in the data can be identified through this needs assessment, these can only be used to discuss this specific project, and should not be generalized. At the same time, valuable information about needs of teenagers, and how to best create a program for adolescents at Lea Toto can be ascertained from the data collected.

In terms of program implementation, the limitations in data collection may have an impact on the creation of the adolescent program plan as it was based on the needs assessment results. However, careful attention was given to triangulating all sources of information including a review of the literature, adolescent surveys, caregiver surveys, Lea Toto staff interviews, an adolescent focus group, and behavioral health theory to create the most robust adolescent program plan possible, even with these limitations in data collection. Furthermore, the construction of the adolescent program plan is flexible and meant to give Lea Toto staff full authority to adjust program components when necessary. Finally, data collection was meant to be informative toward creating an adolescent program template, and the results were strong enough for this to occur. Overall, while limitations in data collection are crucial to identify, the design of the adolescent program gives staff members leverage to adapt components as needed to make up for any inaccurate data results.

Program Implications

As Lea Toto and similar organizations continue to serve children infected with HIV, there will be an increased need for targeted, supportive services as growing numbers of children age into adolescence. This project highlights a vulnerable population in need of public health interventions while also providing detailed intervention strategies in order to fill this need. At an organizational level, this program provides needed avenues of sustainability for Lea Toto, which faces a growing number of adolescent clients, particularly in the next decade. This program also contributes to a gap in knowledge regarding the needs of HIV positive adolescent populations and models for programmatic implementation, as HIV positive adolescent health programs are both necessary and lacking in many contexts. As such, it has implications both for and far beyond Lea Toto, as a potentially replicable model for similar populations in other areas.

This program also has implications at the individual level. The introduction of a program for HIV positive adolescents at Lea Toto would fill a need for this specific population that as of yet has few targeted, consistent intervention activities. For the adolescent clients which Lea Toto serves, this program has direct impacts on psychosocial, emotional, and physical health as well as ability to live positively with HIV in the future. Further implications are more indirect, with the potential to equip vulnerable adolescents with job and life skills, to reach personal goals, and to reduce further HIV transmission. Overall, the creation of this program sends a vital message to HIV positive adolescent clients: you are not alone. At a basic level, this program provides support and hope to adolescent populations living in stigmatizing conditions with few empowerment opportunities, attempting to navigate a healthcare system dichotomized into pediatric and adult care. As a result, the implications of allowing a safe space for support and reflection for such a vulnerable population cannot be understated.

5.3 Recommendations

Continued Research into HIV Positive Adolescent Needs

At an organizational level, it is recommended that Lea Toto continue research into the needs of HIV positive adolescents. As the current program plan relies heavily on feedback from Kibera adolescents and staff, the potentially different needs of adolescents at other sites should be taken into consideration when implementing the adolescent program. Also, as context changes and adolescents age, it is important to continually assess their changing needs. This research can be done via two methods. One method is to ask adolescents at various sites to complete a survey adapted from the one completed by Kibera adolescents (seen in Appendix A), and use the data results to note any differences in needs across Lea Toto sites. A second method is to implement the adolescent program and use client feedback surveys (seen in Appendix F) as a way to gauge whether needs are being met. Staff members at other Lea Toto sites can also be utilized to better understand specific needs of the adolescent clients they serve.

In terms of general research into this topic, it is clear from this project that HIV positive adolescents are in need of supportive interventions in order to successfully navigate adolescence with the disease. Further research into needs of HIV positive adolescent populations as well as programmatic recommendations in regions other than Nairobi would be useful to contribute to the growing literature on this topic. Finally, while this program model can be utilized in areas other than Nairobi, it is suggested that research specific to the replication context be completed to ensure its use is relevant and meets specific population needs.

Pilot Testing

In order to best use this programmatic framework, it is suggested that the adolescent program be piloted at a few Lea Toto sites prior to full implementation. This will ensure that any issues with the framework can be resolved prior to implementation at all sites. While the program plan has suggested goals, objectives, and activities, these components should be critiqued by Lea Toto staff and management in order to create the most relevant and feasible program design possible. By pilot testing the program and receiving client feedback about its weaknesses, Lea Toto staff will have the chance to improve necessary components prior to implementing the program at all eight sites.

Create Community Connections

This program plan was created with the knowledge of currently available resources at Lea Toto. As such, not all client suggestions from surveys and the focus group were included, due to budgetary and staffing constraints. Due to this, it may be useful for Lea Toto staff to examine those components seen in the needs assessment results which are less represented in the program plan, and research whether other organizations in the community provide these resources. Skill-based education, soccer clubs, and girl's empowerment groups are examples of some of these suggestions which Lea Toto can outsource to other organizations which may provide needed services. This knowledge can be obtained by surveying staff, community health workers, and adolescents on what opportunities are available in the informal settlement in which they live. In doing so, Lea Toto can focus on providing specific, needed services for adolescents without replicating activities which already exist in the area, and without stretching their resources to fit all suggested program components.

Emphasize Items Important to Teens

In order to engage adolescents in the Lea Toto program, it is vital to use their feedback and perceived needs to strengthen program components. By using the client satisfaction survey seen in Appendix F, these details can be gained at each monthly program session. If modules in the program plan are uninteresting or irrelevant to the adolescent population, changes can be made to better represent client needs. This can provide a consistent feedback loop in which program materials are edited in order to fit the needs and concerns of the clients Lea Toto is serving. Not only will this strengthen the adolescent program, but it will also demonstrate to the adolescents that their opinions are important to creating a successful program.

Program Ownership

While this program plan was based on extensive research both specific and non-specific to Lea Toto, the overall goal is to make a useful model for implementation at Lea Toto sites and adjustments may be needed to fit the context, resources, and mission. As such, modification and adaptation of suggested program components is encouraged. Lea Toto staff have vital knowledge about program needs and should examine the proposed program plan and discuss changes based on their experience in working closely with adolescent clients. Overall, it is hoped that this program plan can be a resource for Lea Toto staff to utilize in order to create a strong adolescent program for their clients.

5.4 Conclusions

As increasing numbers of children with HIV are surviving into adolescence, it is vital to create supportive interventions for this vulnerable population. This special studies project

attempts to identify what is currently known and provided to HIV positive adolescent populations, to analyze needs assessment results specific to Lea Toto adolescents, and to create a pragmatic model for HIV positive adolescent support, empowerment, and skill-building. In creating a flexible program plan for use at Lea Toto, the organization has the ability to both instantly implement an adolescent supportive program while also modifying its components to best fit their needs and resources. While HIV positive adolescents have several challenges in navigating their teenage years, this research provides the first step toward improving health interventions for this population. In doing so, Lea Toto will be ahead of the shifting demographic in pediatric HIV/AIDS care, continuing to provide all clients with the highest supportive services available.

References

1. UNAIDS, *Securing the Future Today: Synthesis of Strategic Information on HIV and Young People,* 2011, Joint United Nations Programme on HIV/AIDS: Geneva, Switzerland.
2. Kanesathasan, A., et al., *Equipping Parents and Health Providers to Address the Psychological and Social Challenges of Caring for Children Living With HIV in Africa,* in *AIDSTAR- One Activity Final Report* 2011, USAID's AIDS Support and Technical Assistance Resources: Arlington, VA.
3. WHO, *Global HIV/AIDS Response: Epidemic Update and Health Sector Progress Towards Universal Access*, in *Progress Report* 2011, World Health Organization: Geneva, Switzerland.
4. Shears, K.H., *HIV-Infected Youth*, in *Youth Lens on Reproductive Health and HIV/AIDS* 2009, Family Health International.
5. Gray, G.E., *Adolescent HIV—Cause for Concern in Southern Africa.* PLoS Med, 2010. 7(2): p. e1000227.
6. National AIDS Control Council and National AIDS and STI Control Programme, *The Kenyan AIDS Epidemic: Update 2011*, 2012: Nairobi, Kenya.
7. Li, R., *Growing Up on HAART : The Experiences and Needs of HIV Positive Adolescents in Care and Treatment in the Western Cape Province of South Africa.* Centre for Social Science Research, 2009.
8. Obare, F. and H. Birungi, *The Limited Effect of Knowing They are HIV-Positive on the Sexual and Reproductive Experiences and Intentions of Infected Adolescents in Uganda.* Population Studies, 2010. 64(1): p. 97-104.
9. Global Network of People Living With HIV, *Young Positives: Living Their Rights!*, in *Briefing Paper* 2009.
10. Thupayagale-Tshweneagae, G., *Behaviours Used by HIV-Positive Adolescents to Prevent Stigmatization in Botswana.* International Nursing Review, 2010. 57(2): p. 260-264.
11. Li, R.J., et al., *Positive Futures: A Qualitative Study on the Needs of Adolescents on Antiretroviral Therapy in South Africa.* AIDS Care, 2010. 22(6): p. 751-758.
12. Ayres, J., et al., *Vulnerability, Human Rights, and Comprehensive Health Care Needs of Young People Living with HIV/AIDS.* American Journal of Public Health, 2006. 96(6): p. 1001-1006.
13. Pienaar, L. and M.J. Visser, *An Exploration of the Experiences of Adolescents Living with HIV.* Vulnerable Children and Youth Studies, 2012. 7(1): p. 66-74.
14. Spiegel, H.M., *Nondisclosure of HIV status in Adolescence.* Adolescent Medicine: State of the Art Reviews, 2011. 22(2): p. 277-82.
15. Hodgson, I., et al., *Living as an Adolescent with HIV in Zambia – Lived Experiences, Sexual Health and Reproductive Needs.* AIDS Care, 2012. 24(10): p. 1204-1210.
16. Vaz, L., et al., *The Process of HIV Status Disclosure to HIV-Positive Youth in Kinshasa, Democratic Republic of the Congo.* AIDS Care, 2008. 20(7): p. 842-852.
17. Lesch, A., et al., *Paediatric HIV/AIDS Disclosure: Towards a Developmental and Process-Oriented Approach.* AIDS Care, 2007. 19(6): p. 811-6.

18. Siu, G.E., et al., *HIV Serostatus Disclosure and Lived Experiences of Adolescents at the Transition Clinic of the Infectious Diseases Clinic in Kampala, Uganda: A Qualitative Study.* AIDS Care, 2011. 24(5): p. 606-611.
19. Nabukeera-Barungi, N., et al., *Adherence to Antiretroviral Therapy in Children Attending Mulago Hospital, Kampala.* Annals of Tropical Paediatrics, 2007. 27(2): p. 123-131.
20. Moodley, K., et al., *Paediatric HIV Disclosure in South Africa -- Caregivers' Perspectives on Discussing HIV with Infected Children.* S Afr Med J, 2006. 96(3): p. 201-4.
21. Myer, L., et al., *Healthcare Providers' Perspectives on Discussing HIV Status with Infected Children.* J Trop Pediatr, 2006. 52(4): p. 293-5.
22. Menon, A., et al., *Mental Health and Disclosure of HIV Status in Zambian Adolescents With HIV Infection.* JAIDS: Journal of Acquired Immune Deficiency Syndromes, 2007. 46(3): p. 349-354.
23. Bikaako-Kajura, W., et al., *Disclosure of HIV Status and Adherence to Daily Drug Regimens Among HIV-Infected Children in Uganda.* AIDS Behav, 2006. 10(4 Suppl): p. S85-93.
24. Chandwani, S., et al., *A Multimodal Behavioral Intervention to Impact Adherence and Risk Behavior among Perinatally and Behaviorally HIV-Infected Youth: Description, Delivery, and Receptivity of Adolescent Impact.* AIDS Education and Prevention, 2011. 23(3): p. 222-35.
25. Pathfinder International, *Increasing HIV/AIDS Therapy Adherence Among Youth in Mozambique: The TAP/Pathfinder International Experience*, May 2009, Pathfinder International: Maputo, Mozambique.
26. Kobin, A.B. and N.U. Sheth, *Levels of Adherence Required for Virologic Suppression Among Newer Antiretroviral Medications.* Ann Pharmacother, 2011. 45(3): p. 372-9.
27. Arrive, E., et al., *HIV Status Disclosure and Retention in Care in HIV-Infected Adolescents on Antiretroviral Therapy (ART) in West Africa.* PLoS One, 2012. 7(3): p. e33690.
28. Naar-King, S., et al., *Allocation of Family Responsibility for Illness Management in Pediatric HIV.* J Pediatr Psychol, 2009. 34(2): p. 187-94.
29. Williams, P.L., et al., *Predictors of Adherence to Antiretroviral Medications in Children and Adolescents with HIV Infection.* Pediatrics, 2006. 118(6): p. e1745-57.
30. Lam, P.K., N.-K. Sylvie, and K. Wright, *Social Support and Disclosure as Predictors of Mental Health in HIV-Positive Youth.* AIDS Patient Care & STDs, 2007. 21(1): p. 20-29.
31. Aka Dago-Akribi, H. and M.-C. Cacou Adjoua, *Psychosexual Development among HIV-Positive Adolescents in Abidjan, Côte d'Ivoire.* Reproductive Health Matters, 2004. 12(23): p. 19-28.
32. Scharko, A.M., *DSM Psychiatric Disorders in the Context of Pediatric HIV/AIDS.* AIDS Care, 2006. 18(5): p. 441-5.
33. Judy, W.K., et al., *Psychiatric Morbidity Among HIV-Infected Children and Adolescents in a Resource-Poor Kenyan Urban Community.* AIDS Care, 2012. 24(7): p. 836.
34. Musisi, S. and E. Kinyanda, *Emotional and Behavioural Disorders in HIV Seropositive Adolescents in Urban Uganda.* East Afr Med J, 2009. 86(1): p. 16-24.
35. Majaliwa, E.S., A. Mohn, and F. Chiarelli, *Growth and Puberty in Children with HIV Infection.* J Endocrinol Invest, 2009. 32(1): p. 85-90.

36. Birungi, H., et al., *Preventive Service Needs of Young People Perinatally Infected with HIV in Uganda.* AIDS Care, 2009. 21(6): p. 725-731.
37. Obare, F., H. Birungi, and L. Kavuma, *Barriers to Sexual and Reproductive Health Programming for Adolescents Living with HIV in Uganda.* Population Research and Policy Review, 2011. 30(1): p. 151-163.
38. Population Council., *Population Brief: Studies Explore the Sexual Health Needs of HIV-Positive Adolescents*, P. Council, Editor 2010: New York.
39. Bakeera-Kitaka, S., et al., *Sexual Risk Reduction Needs of Adolescents Living with HIV in a Clinical Care Setting.* AIDS Care, 2008. 20(4): p. 426-33.
40. Birungi, H., et al., *Sexuality of Young People Perinatally Infected with HIV*, in *Informing Practice* 2007, The AIDS Support Organization.
41. Campbell, T., *"I look forward. I feel insecure but I am ok with it". The Experience of Young HIV+ People Attending Transition Preparation Events: A Qualitative Investigation.* AIDS Care, 2010. 22(2): p. 263-269.
42. Agot, K., *Youth-Friendly Services for HIV Prevention, Treatment, and Care: The Tuungane Youth Project, Kenya*, 2009, Impact Research and Development Organization: Nairobi, Kenya.
43. Funck-Brentano, I., et al., *Evaluation of a Peer Support Group Therapy for HIV-Infected Adolescents.* AIDS, 2005. 19(14): p. 1501-1508.
44. Center for Health Market Innovations. *Positive Youth Initiative*. Programs 2012 August 3, 2012 [cited 2012 September]; Available from: http://healthmarketinnovations.org/program/positive-youth-initiative.
45. One-To-One Kenya. *Youth Services*. 2012 [cited 2012 September]; Available from: http://www.one2onekenya.org/index.php?PID=11.
46. Sunburst Projects. *Kenya Program*. 2011 [cited 2012 September]; Available from: http://www.sunburstprojects.org/programs/kenya/.
47. Doctors Without Borders, *Eneza Ujumbe: The Voices of Mathare Youth*, 2010: Nairobi, Kenya.
48. Bartholomew, L.K., et al., *Planning Health Promotion Programs : An Intervention Mapping Approach*, 2011, Jossey-Bass: New York.
49. Sarason, I.G., Levine, H. M., Basham, R. B., Sarason, B.R., *Assessing Social Support: The Social Support Questionnaire.* Journal of Personality and Social Psychology, 1983. 44: p. 127-139.
50. Hays, R., Sherbourne, CD, Mazel, RM, *MOS Social Support Survey*, in *Medical Outcomes Study: Measures of Quality of Life Core Survey (MOS)* 1994, Rand Health.
51. Heatherton, T.F.a.W., Carrie L., *Assessing Self-Esteem*, in *Positive Psychological Assessment : A Handbook of Models and Measures*, S.J. Lopez and C.R. Snyder, Editors. 2003, American Psychological Association: Washington, DC.
52. Corrigan, P., *A Toolkit for Evaluating Programs Meant to Ease the Stigma of Mental Illness*, 2008, Illinois Institute of Technology.

Needs Assessment Appendices

Appendix A: Adolescent Survey Instrument

Teen Survey: *To be administered to teenagers, aged 12 and above, who are aware of their HIV status at Lea Toto Kibera and Kawangware*

Date: _____ Location: _____

Age: _____

1. Do you use youth services in your community?
   ☐ Yes
   ☐ No
   If Yes, where/what _____

2. Do you use Lea Toto's youth services?
   ☐ Yes
   ☐ No
   If Yes, which do you use? _____

   If No, why not? _____

3. What services would you like more of at Lea Toto? (Check all that apply, circle the top three choices)
   ☐ Individual Counseling
   ☐ Group Counseling
   ☐ Youth Support Group
   ☐ Education Sessions (ie sexual health)
   ☐ Mentorship
   ☐ Teen Days
   ☐ Other _____
   ☐ None

4. Are there services you would add to Lea Toto's youth programs?
   ☐ Yes
   ☐ No
   If yes, what would you add?_____

5. Do you have needs that Lea Toto is not currently meeting?
   ☐ Yes
   ☐ No
   If yes, what needs? _____

6. What challenges do you face in accessing Lea Toto's youth services?
   ☐ Transportation
   ☐ Time services are offered
   ☐ Fear of stigma
   ☐ Too busy
   ☐ Other_____
   ☐ None

Disclosure Experience

7. How did you find out you were HIV positive? How old were you?

8. How would you describe your experience of discovering you were HIV positive?
   - ☐ Mostly Positive
   - ☐ Positive
   - ☐ Negative
   - ☐ Mostly Negative
   - ☐ No opinion

If you feel comfortable elaborating on your experience, please write here.

9. What could have made your disclosure experience better?

10. Have you disclosed your status to anyone?
    - ☐ Yes
    - ☐ No

If yes, who? _____

Appendix B: Caregiver Survey Instrument

Caregiver Survey: *To be given to caregivers with children who have been disclosed to at Lea Toto Kibera and Kawangware*

1. How old was your child when you disclosed their HIV status to him/her?

2. Did you receive disclosure training services from Lea Toto prior to disclosure?

☐ Yes
☐ No

If no, why not? _____

3. What challenges did you face when disclosing to your child?

4. What could have improved your experience of disclosing to your child?

5. What was your child's reaction?

6. What challenges do you face in raising a teenager with HIV?

7. What could Lea Toto offer to help you with these challenges?

Appendix C: Adolescent Focus Group Instrument

Teen Focus Group Guide

I. Guidelines (5 minutes)
Thank you for agreeing to participate in this focus group. We are very interested to hear your valuable opinion on how Lea Toto can improve services targeted at youth.

- The purpose of this focus group is to hear teen opinions on the current services Lea Toto provides, and to better understand the challenges of being a teen with HIV. We hope to learn how Lea Toto can improve programs for their teenage clients, and how they can better support youth as they navigate adolescence.

- The information you give us is completely confidential, and we will not associate your name with anything you say in the focus group.

- You may refuse to answer any question or withdraw from the focus group at anytime.

- We understand how important it is that this information is kept private and confidential. We will ask participants to respect each other's confidentiality.

- It is important for us to hear everyone's ideas and opinions. There are no right or wrong answers to questions – all thoughts are valuable.

- It is important for us to hear all sides of an issue – both the positive and the negative.

- Only one person talks at a time.

II. Introductions (10 minutes)

Let's begin by introducing each other. Tell us your first name, your favorite color, and your favorite hobby. I will start.

Review the following:

- Who we are and what we're trying to do
- What will be done with this information
- Why we asked you to participate

Explanation of Focus Group:

- We learn from you
- Not trying to achieve consensus, gathering information
- Looking for priorities to inform services

III. Focus Group Discussion Questions (60 minutes)

1. Much of this discussion revolves around your experience as a teenager. Let's brainstorm a few ideas of what it's like to be a teenager. What are positive aspects of being a teenager? What is more negative? What are your hobbies as a teenager?

2. How do you feel about Lea Toto and using their services?

Probes: Do you ever fear stigma in using Lea Toto's services?

3. What Lea Toto services/programs do you use? What do you like about these programs?

Probes: Are there things you dislike about these programs?

Activity: After discussing this question with the group, have the teens participate in a program ranking activity. Getting into groups of two, the teenagers will discuss and rank the programs Lea Toto provides. They will then present what they discussed to the group and why they ranked the programs in the way they did.

4. How could Lea Toto better meet your needs? What services are not being provided that you would like to have?

Probes: Do you have any immediate needs that Lea Toto is not meeting?
Ask about support, education, and counseling needs.

Activity: After discussing this question with the group, have the teens participate in a pile-sorting activity. As a group, they will sort different activities into three categories: Interested, Neutral, Uninterested. Using note cards with activities written on them, the teens will then sort the activities into piles according to their interest in them. After the activity, the group will discuss why they sorted cards they ways they did.

5. What services do you use from other organizations?

Probes: What do you like/dislike about these services? What do these organizations provide that Lea Toto does not?

6. One of Lea Toto's goals is to provide youth clients with peer support. How would you rate their current support services? What could they improve upon?

Probes: Do you have support from your caregivers/family? Do you feel supported by your peers?

7. How did you feel when you learned you were HIV positive?

Did you fear stigma/discrimination? Did you feel your caregiver was appropriately prepared for disclosing to you?

8. What challenges do you face as an HIV positive teenager?

Probes: Do you feel discriminated against by your peers? Are you worried about disclosure? Do you receive enough education on the disease?

9. Who have you disclosed your status to?

Probes: Why did you choose/not choose to do so? What were your feelings when disclosing?

IV. Closing (10 minutes)

- Wrap-up of discussion
- Final thoughts
- Thank participants for coming

Appendix D: Staff Interview Instrument

Staff Survey: *To be given to social workers, counselors, and center administrators at Lea Toto Kibera and Kawangware*

1. What services does Lea Toto provide for teenagers at your center? Describe.

2. What are the strengths and weaknesses of existing services for teens at your center?

3. How can Lea Toto strengthen existing services for teens?

4. What would you add to the adolescent services offered by Lea Toto?

5. What are your thoughts on the creation of a consistently offered adolescent program? Do you see a need for this type of program?

Monitoring and Evaluation Appendices

Appendix E : Adolescent Support Group Meeting Records

Location _____ Date_____

Counselor/Facilitator _____

Number of Adolescents Attending:

Males_____ Females_____ Total _____

Discussion Topics _____

_____

Activities (Check all that occurred)

- ☐ Drug Buddy Session Number of Participants _____
- ☐ Adolescent Mentorship Number of Participants _____
- ☐ Education Session Number of Participants _____
- ☐ Leadership/Job Skills Number of Participants _____
- ☐ Empowerment/Support Number of Participants _____

Notes_____

_____

_____

_____

_____

Appendix F: Adolescent Client Satisfaction Survey

Location_____ Date_____ Age_____

Counselor/Facilitator _____

1. How useful was this support group session to you?
   - Very Useful
   - Somewhat Useful
   - Not Useful

2. Which of the following topics/activities did this support group discuss (check all that apply)?

   - Drug Buddy Session
   - Adolescent Mentorship
   - Education Session
   - Leadership/Job Skills
   - Empowerment/Social Support

3. Which of the following topics/activities did you enjoy (check all that apply)?

   - Drug Buddy Session
   - Adolescent Mentorship
   - Education Session
   - Leadership/Job Skills
   - Empowerment/Social Support

4. What did you enjoy about today's group (check all that apply)?
   - Being with other group members
   - Discussion topics
   - Group activities
   - Having peers to talk to
   - Other

5. What about today's group did you enjoy MOST?_____

6. What about today's group did you enjoy LEAST? _____

7. How many times and in what ways did you contact your drug buddy since the last Lea Toto teen meeting?_____

8. How many times and in what ways did you contact your mentor/mentee since the last Lea Toto teen meeting? _____

Appendix G: Counselor Assessment

Client Name_____ Date_____

Topic	**Assessment**
Social Support Score out of 15:_____	On a scale from 0-5 (0 being none and 5 being excellent) how much social support does the client have in each of the following categories? Peers: Family Members: Mentorship:
Support Network Score out of 5:_____	• # people in client's support network: • # people who know client's status: On a scale of 0-5 (0 being weak and 5 being excellent) how strong of a support network does the client have?
Self-Esteem Score out of 5:_____	On a scale of 0-5 (0 being none and 5 being excellent) how much confidence does client display in him/herself?

Internalized Stigma Score out of 5:_____	On a scale of 0-5 (0 being often and 5 being never) how often does client display feelings of blame, self-deprecation or negativity toward status?
Preparedness for Future Score out of 10:_____	On a scale of 0-5 (0 being none and 5 being excellent) how much confidence does client display in his/her future? On a scale of 0-5 (0 being none and 5 being excellent) how prepared does client seem for future?

Notes:

Total Score_____/40

Appendix H: Psychosocial Health Questionnaire

Section I: Social Support/Networks

How often is the following type of support available to you when needed? Please circle one number for each answer.

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Someone who will listen when you need to talk	1	2	3	4	5
Someone to give you advice about a problem	1	2	3	4	5
Someone to confide in about your problems or concerns	1	2	3	4	5
Someone whose advice you trust	1	2	3	4	5
Someone to share your most private fears and concerns with	1	2	3	4	5
Someone who shows you love and affection	1	2	3	4	5
Someone who makes you feel appreciated	1	2	3	4	5

Someone to have fun with	1	2	3	4	5

The next set of questions asks about who you can depend on for support. Please answer by writing the relationship this person has to you (for example, brother, friend, mother), and indicate the number of people you have to depend on for each question.

1. Who can you depend on to listen when you need to talk?

2. Whose lives do you feel you are an important part of?

3. Who can you depend on when you need help?

4. Who makes you feel important and appreciated?

5. Who can you be yourself around and accepts you for who you are?

6. Overall, how satisfied are you with the amount of support you have from friends, family, etc? Please circle one answer.

6-Very Satisfied	5- Fairly Satisfied	4-A Little Satisfied	3-A Little Dissatisfied	2- Fairly Dissatisfied	1-Very Dissatisfied

The next section asks you about your support network.

7. How often do you feel supported by people who know you are HIV positive?

5-Very Often	4- Fairly Often	3-Sometimes	2-Rarely	1-Never

8. How often do you feel supported by people who do NOT know you are HIV positive?

5-Very Often	4- Fairly Often	3-Sometimes	2-Rarely	1-Never

9. Do you feel like you have enough emotional support from people you know?

10. Do you feel like you are part of a group of people who are like you? If yes, where do you know these people from?

Section II: Self-Perception and Personal Agency

This section asks you to rate how you feel about yourself. Please circle one response for each answer.

11. How often do you feel inferior to most people you know?

5-Never	4- Rarely	3-Sometimes	2-Fairly Often	1-Very Often

12. How often do you feel that you cannot do anything right?

5-Never	4- Rarely	3-Sometimes	2-Fairly Often	1-Very Often

13. How often do you feel worried about what others think of you?

5-Never	4- Rarely	3-Sometimes	2-Fairly Often	1-Very Often

14. How confident do you feel that people respect and admire you?

5-Very Confident	4- Somewhat Confident	3-Confident	2- Not Very Confident	1-Not At All Confident

15. How often do you dislike yourself?

5-Never	4- Rarely	3-Sometimes	2-Fairly Often	1-Very Often

16. How often do you feel self-conscious?

5-Never	4- Rarely	3-Sometimes	2-Fairly Often	1-Very Often

17. How confident do you feel about your abilities?

5-Very Confident	4- Somewhat Confident	3-Confident	2- Not Very Confident	1-Not At All Confident

18. Please rate the following statements on a scale of 0-3.

0= Strongly Disagree 1=Disagree 2=Agree 3=Strongly Agree

I feel that I have a number of good qualities. _____

I usually feel that I am a failure. _____

I am able to do things as well as most people._____

I have much to be proud of. _____

I usually have a positive attitude toward myself. _____

I am usually satisfied with myself. _____

I wish I had more respect for myself. _____

I feel useless at times._____

Sometimes I think that I am no good at all._____

Section III: Internalized Stigma

A. The following questions ask what you think the public believes about people living with HIV/AIDS. Please use the following scale to answer each question.

1-Strongly Disagree	2- Disagree	3-Neither Agree or Disagree	4- Agree	5-Strongly Agree

The public thinks…..

19. _____Most people with HIV/AIDS cannot be trusted.
20. _____Most people with HIV/AIDS are dirty and unclean.
21. _____Most people with HIV/AIDS are to blame for their problems.
22. _____Most people with HIV/AIDS are to blame for their disease.
23. _____Most people with HIV/AIDS have below average intelligence.
24. _____Most people with HIV/AIDS are dangerous.
25. _____It is not ok to be friends with people who have HIV/AIDS.
26. _____People with HIV/AIDS should be ashamed of their illness.
27. _____People with HIV/AIDS should stay away from public places.
28. _____ People with HIV/AIDS should be avoided.

B. The following questions ask what you think about people living with HIV/AIDS.

Please use the following scale to answer each question.

1-Strongly Disagree	2- Disagree	3-Neither Agree or Disagree	4- Agree	5-Strongly Agree

I think….

29. _____Most people with HIV/AIDS cannot be trusted.

30. _____Most people with HIV/AIDS are dirty and unclean.

31. _____Most people with HIV/AIDS are to blame for their problems.

32. _____Most people with HIV/AIDS are to blame for their disease.

33. _____Most people with HIV/AIDS have below average intelligence.

34. _____Most people with HIV/AIDS are dangerous.

35. _____It is not ok to be friends with people who have HIV/AIDS.

36. _____People with HIV/AIDS should be ashamed of their illness.

37. _____People with HIV/AIDS should stay away from public places.

38. _____ People with HIV/AIDS should be avoided.

C. Now answer the following questions about yourself using the same scale.

1-Strongly Disagree	2- Disagree	3-Neither Agree or Disagree	4- Agree	5-Strongly Agree

Because I am HIV positive….

39. _____I should not be trusted.

40. _____I am dirty and unclean.

41. _____I am to blame for my problems.

42. _____I am to blame for my disease.

43. _____I have a below average intelligence.

44. _____I am dangerous.

45. _____I should not be friends with people who do not have HIV/AIDS.

46. _____I should be ashamed of my illness.

47. _____I should stay away from public places.

48. _____I should be avoided.

Section IV: Feelings about the Future

This section asks you how you feel about the future. Circle one number for each question.

	Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
I feel hopeful about my future.	1	2	3	4	5
I feel emotionally prepared for my future.	1	2	3	4	5
I am confident that I can be in control of my health in the future.	1	2	3	4	5
I have goals in life that I want to reach.	1	2	3	4	5

I believe I can meet my future goals.	1	2	3	4	5
I feel well prepared for my future.	1	2	3	4	5
I feel more ready for my future than I did last year.	1	2	3	4	5
I feel able to live positively with my disease	1	2	3	4	5
My disease won't stop me from living how I want in the future.	1	2	3	4	5
I feel that I have the skills I need for my future.	1	2	3	4	5

Appendix I: Knowledge of Secondary Prevention

True/False:

1._____A person living with HIV/AIDS can become re-infected with another strain of the virus.

2. _____If an HIV positive woman gets pregnant, it is certain the baby will be born with the disease.

3._____In a sexual relationship, one person can be HIV positive while the other is HIV negative.

4.____HIV can be spread by kissing.

5. ____Children born with HIV will not survive with the disease to become adults.

6. ____People with HIV cannot spread the disease by touching someone who is not infected.

7. Name three ways that HIV can be transmitted.

8. Which of the following methods can prevent the transmission of HIV? Check all that apply.

____Using condoms during sexual intercourse

____Abstaining from sexual intercourse

____Taking medication to prevent transmission to a child while pregnant

____Using clean needles

____No longer taking ARVs

9. You have a friend who is HIV positive. He loves his girlfriend and wants to become intimate, but he is worried he could spread the disease to her. He asks you whether he could give her HIV and what to do to protect her. What do you tell him?

_____

_____

10. You have a friend who just discovered she is HIV positive. She is scared and worried that she is going to die. What would you tell her?

_____

_____

11. You have a friend who is HIV positive and taking ARVs. He decides to stop taking them because they make him feel sick. He asks whether you think this is a good idea. What would you tell him?

_____

_____

12. What is secondary prevention and why is it important to your life?

Activities Appendix

Appendix J: Activities Manual

The purpose of this Activities Manual is to provide suggested activities to guide Lea Toto's adolescent program. Its compilation is based on topical interest seen in needs assessment data as well as organization interests in supporting adolescent clients. Facilitators are encouraged to choose activities based on feasibility, interest, and perceived benefit to the group.

I. Introduction Activities

These quick activities are meant to engage youth at the beginning of each session and help group members feel comfortable with their peers. These activities will last approximately 10 minutes and open each session. Facilitators can choose introduction activities from this list, or create their own.

Introduction Activity 1: Getting to Know the Group

Duration: 10 minutes

Materials Needed: Pens/pencils and paper

Directions: Ask group members to spend five minutes drawing a collage of items that represent themselves. These can be hobbies, images that represent their personality, or other interests. Adolescents will then be asked to present their drawings to the group. This activity will help the teenagers get to know each other and the shared interests they have with others, while also allowing them to create their own identity. This activity is ideal for a group session early in the program.

Introduction Activity 2: Learning About Each Other

Duration: 10 minutes

Materials Needed: Small toy ball or other soft item

Directions: Arrange group members in a circle. Throw a small ball or soft item to one member, have them say their name, and then throw the ball to another member, who says their name, and so on. Continue with different categories from the following list:

Name	Favorite food	Favorite sport
School	Number of siblings	Ideal job
Age	Favorite music group	Ideal vacation spot
Class level	Favorite movie	Favorite memory
Favorite hobby	Favorite color	Favorite activity

This quick activity can be used multiple times and will help adolescent group members get to know each other better.

Introduction Activity 3: Memory Name Game

Duration: 10 minutes

Materials Needed: None

Directions: Arrange group members in a circle. Start with one person and ask them to say their name and their favorite hobby. The next adolescent in the circle must repeat the first member's name and favorite hobby, and then add their own. Each member must repeat all names/hobbies named by those before them in the circle. The last person in the circle has the hardest job of

remembering all those who went before him/her. This activity is quick, can be used multiple times by the facilitator, and is a fun challenge for the adolescents.

Introduction Activity 4: Energy Hands

Duration: 10 minutes

Materials Needed: None

Directions: Ask group members to stand or sit in a circle. Have all members join hands. Start a series of "pulses" around the circle by squeezing the hands of the members next to you. Each group member will continue to pulse as it reaches them by passing it to the next person. See how long you can continue to pass the energy before the link is broken. This activity is quick, fun, and can be used multiple times in different sessions.

Introduction Activity 5: Who is the Leader?

Duration: 10 minutes

Materials Needed: None

Directions: Designate one group member to be the 'detective' and have this person leave the area for a moment. The other members of the group choose a second person to be the 'leader,' who will lead them in the game. Call the detective back to the group, and arrange members standing in a circle, with the detective in the middle. The leader will then start an action (ie clapping, grinning, touching his/her head) which all other members will follow. The leader will change the action frequently, while trying to keep the detective from guessing who they are. Once the detective has guessed the leader correctly, change roles and play the game again. This activity is quick, fun, and can be used multiple times in different sessions.

Introduction Activity 6: Left Standing

Duration: 10 minutes

Materials Needed: None

Directions: Arrange group members in a circle, sitting in chairs, with one less chair than the number of participants. Have one volunteer stand in the center of the chairs, calling out topics. For example, they could say "Everybody with a black shirt on," "Everyone who ate chapatti today", or "Everyone with a sister." All members fitting the description must stand up and switch chairs as fast as possible, without sitting back in their original chair. The volunteer will try and find a seat as well. The person left standing calls out topics for the next round of the game. This activity is quick, fun, and can be used multiple times in different sessions.

Introduction Activity 7: Telephone

Duration: 10 minutes

Materials Needed: None

Directions: Seat group members in a circle and ask for a volunteer to whisper a sentence in the ear of the person next to him/her. This person will then whisper what they heard into the next person's ear and so on. The person at the end of the circle will repeat the sentence they heard and compare it to the original whisper. This activity is quick, fun, and can be used multiple times in different sessions.

Introduction Activity 8: Two Truths and a Lie

Duration: 10 minutes

Materials Needed: None

Directions: Seat members in a circle and ask them to think of two facts about themselves that are true, and one that is false. Have a volunteer name their three facts and ask the rest of the group to guess which one is false. Continue with the next group member, and so on. This activity is quick, fun, and can be used multiple times in different sessions.

II. Discussion Questions and Activities

These modules represent the bulk of each adolescent program session and are presented here by topic, in alphabetical order. Facilitators at each site can decide how to design each session. Each module is separated into goals, discussion questions, activities, and optional media. Goals explain the purpose of each module. Discussion questions are provided in order to prompt discussion about the issue among the adolescent group. Activities are generally hands-on and provided to better illustrate the topic as well as engage adolescent group members. Optional media presents options for facilitators to add media to their discussion if proper equipment is available. Discussion and activities can be paired together by topic or selected separately based on facilitator and client preference. The purpose of these modules is to give Lea Toto staff a roadmap for potential discussion and activities, and as such they are flexible to modification as needed by each site. Prior to discussion and activities, the confidentiality of what is shared in a group setting should be emphasized by facilitators.

Module 1: Disclosure

Goals: To provide a safe setting for adolescents to discuss the challenges in accepting their HIV status, challenges of disclosing their HIV status, and to share techniques for doing so.

Discussion Questions:

- What is disclosure?
- How did you discover your HIV status? What was your response to this experience?
- How do you disclose your status to others?
- Who have you disclosed your status to?
- What was difficult about this experience? What was good about this experience?
- What is it like to tell someone your status?
- What are positive and negative reasons for disclosing to a romantic partner?

These suggested questions provide opportunities for adolescents to discuss their experience of disclosure and to share experiences with others. They also prompt thinking about secondary prevention and the potential challenges of disclosing to romantic partners. This module focuses both on how adolescents discovered they were HIV positive as well as on their own control and personal choice in disclosing to others, giving them a sense of agency over this process.

Activity 1: Before and After

Duration: 20-30 minutes

Materials Needed: Pencils/pens and paper for all adolescents

Directions: Have each adolescent draw a line across their sheet of paper. Above the line, have them write "Before" and below the line, have them write "After." Then, ask them to think about the positive and negative feelings, thoughts, and events that occurred a) before and after they were disclosed to about their status or b) before and after they disclosed their status to someone else. They can draw, write, or otherwise depict these events as they wish, and can concentrate on both their feelings and the reactions of people around them. Once the group is done creating their "Before and After" diagrams, have them discuss what they came up with. Highlight shared experiences and responses in the group, as well as both positive and negative responses. This activity will help adolescents come to terms with and reflect on their experiences while also displaying group similarities with disclosure.

Activity 2: The Power of a Secret

Duration: 15 minutes

Materials Needed: Pencils/pens and paper for all adolescents

Directions: Ask each adolescent to write down a secret on a piece of paper, and then fold it in half. Have all individuals pass their secret to the person on their left, who holds it without opening it. Ask the adolescents how they feel about another person holding their secret, and how they feel about holding someone else's secret. Highlight the importance of knowing another person's secret, as well as giving a secret to someone else. This discussion can be tied back to difficulties and fears of disclosure, while also increasing group trust. After the discussion, give each secret back to the original person who wrote it, who can then dispose of it without anyone else seeing what they wrote.

Activity 3: What Would You Do?

Duration: 15 minutes

Materials Needed: None

Directions: Read the following passages to the group and ask them how to best respond:

- Stephen and Jane are secondary school students who have been dating for two years. Stephen is HIV positive and has not told Jane. They are both considering becoming intimate, but Stephen is afraid to tell her about his status. He comes to you for advice on what to do. What do you tell him? How should he proceed?

Have the group identify Stephen's choices and discuss what he should do. After the discussion, read the next passage to them:

- Joseph and Anna are teenagers and have been dating for a year. Recently, Anna told Joseph that she is HIV positive. Joseph is worried about kissing or touching her because he does not want to get the virus, and is thinking about breaking up with her. He comes to you to ask for advice. What do you tell him? Should he break up with Anna?

Similarly to the first scenario, have the group discuss Joseph's choices and describe what they would choose to tell him. Both scenarios can start conversation about the importance of disclosure, the difficulty of disclosure, HIV stigma, and secondary prevention among the group, as well as adolescent relationships.

Optional Media

1. "Shared Hope"- Scenarios from Africa

http://www.youtube.com/watch?v=9nOvbKxi6Lw&list=PL241B41BCA3862154&index=23

'Scenarios from Africa' is an organization that produces short films based on ideas from youth in Africa, starring African actors and created by African directors. These films contain a variety of HIV/AIDS related topics and are meant to generate dialogue and discussion regarding their content. The films can be viewed in both English and Swahili. This film, "Shared Hope," contains topics related to disclosure of HIV status and living positively with the disease. Suggested questions for discussion include: How well do you think Myriam responded to Annie's despair? How did this video highlight the difficulties of disclosure and discovering one's status? What would you do if a friend like Annie came to you with this news?

2. Shuga- Episode 3: Tomorrow, http://mtvshuga.com/clips/s1e3/ (17:40-end of clip)

Created in partnership with MTV, the Government of Kenya, and PEPFAR, Shuga is a Kenyan drama focusing on sexual responsibility and choices of young people. This link can be played from the 17 minutes and 40 second mark to the end, where two young adults disclose their HIV status. Once the clip is watched, ask for adolescent reactions. How did Leo respond to the news that Virginia was born with HIV? What did you think of the radio DJ's disclosure of his status over the radio? How would people in Kenya react if this happened in the country today? This clip provides many discussion topics for adolescents.

Module 2: Future Goals

Goals: To provide adolescents with an opportunity to reflect on their personal goals and hopes for the future.

Discussion Questions:

- What are goals? What goals do you have for the future?
- What are challenges to reaching your goals?
- What are opportunities to reach your goals?
- What motivates you to reach your goals?
- Who encourages you to reach your goals?
- What is the difference between a short-term and long-term goal? Name one of each.
- How do personal choices influence your future goals?

These potential discussion questions provide an opportunity for adolescents to discuss their futures. These questions can prompt thinking about future goals and how they can be obtained by individuals. This discussion is meant to connect self-esteem, personal agency, and hope in allowing adolescents the chance to think about and voice their future goals.

Activity 1: Obstacles and Solutions

Duration: 20-30 minutes

Materials Needed: Pencils/pens and paper for all adolescents

Directions: Have each adolescent think of a goal they have for the future. Then, have them draw a vertical line down the center of their paper. On the left side, label the top as "Obstacles" and

on the right side label the top as "Solutions." Give the group time to list obstacles to reaching their goal and potential solutions to these obstacles. Then have adolescents return to the group and discuss what they came up with. Discuss what obstacles they see in reaching their goals, solutions they found, and whether any obstacles did not have solutions. The discussion will allow adolescents to identify their goals, while providing an opportunity for a practical dialogue about the challenges and opportunities for reaching them.

Activity 2: Overcoming Obstacles

Duration: 20-30 minutes

Materials Needed: Pencils/pens and paper for all adolescents

Directions: Have adolescents think of an obstacle they faced and overcame. Then, have them draw out the experience, and write words that described their feelings when faced with the obstacle and overcame it. Once they are done, have the group discuss the activity. This experience can be used to empower the adolescents and show them how they have the power to overcome obstacles in their lives.

Activity 3: Guest Speaker

Duration: 20-30 minutes

Materials Needed: None

Directions: Prior to the session, arrange for a Lea Toto staff member to talk to the adolescents about their career path and how they came to work for the organization. The adolescents will then have an opportunity to discuss their own future career goals and ask the staff member questions about their experience.

Optional Media

1. "What Would You Do if You Were President for One Day?"- Kuweni Serious

http://www.youtube.com/watch?v=6LWAsaR7JBs&feature=player_embedded

Kuweni Serious is a Kenyan blogging initiative with the goal of engaging youth in political issues. This video asks Kenyan youth the question, "What would you do if you were president for one day?" After viewing the video, adolescents can discuss the question as a group. This discussion can be related back to goals and hopes for the future for all individuals in the group.

Module 3: Health and Adherence

Goals: To provide information and discussion on the importance of healthy living and medication adherence among the adolescents.

Discussion Questions:

- Why is adherence important? What are challenges to adherence?
- What are ways to make adherence easier?
- What is health? Why is it important to be healthy?
- What are components of good health (physical, emotional, psychosocial)?
- How can your choices affect your health status?

These questions can start conversation around the challenges of adherence and living positively, and the opportunities for doing so. Personal agency and power in one's health can be emphasized as a way to display to the group how their personal choices can affect their health status.

Activity 1: Holistic Health

Duration: 20-30 minutes

Materials Needed: Pencils/pens and paper for all adolescents, large sheet of presentation paper

Directions: Divide the adolescents into five groups and give each a different health topic to discuss: general health maintenance, psychological well-being, spiritual well-being, social well-being, and physical well-being. Have each group define the topic they were given, including what adolescents need to attain a healthy lifestyle according to their topic, and challenges in

doing so, particularly for those who are HIV positive. Once the group comes back together, draw a large circle on a piece of presentation paper, divide it into five sections, and write out important components for each health topic. The discussion surrounding this can focus on the importance of a holistic health treatment plan for all adolescents.

Activity 2: Body Mapping

Duration: 20-30 minutes

Materials Needed: Large sheets of presentation paper, pencils/pens

Directions: Divide the adolescents into groups of 4-5 individuals. Ask each group to draw the outline of a body on a large sheet of presentation paper. Have some groups draw and identify regions of the body negatively affected by HIV/AIDS in a person without treatment and have others draw and identify regions of the body positively affected by a person adherent to their treatment regimen. Once groups have finished this task, discuss similarities and differences in the positive and negative health outcomes identified by each group.

Activity 3: What Would You Do?

Duration: 15 minutes

Materials Needed: None

Directions: Read the following passages to the group and ask them how to best respond:

- Sophia is a 15-year-old with HIV. Recently her medication has been changed by her doctor, and the side effects are making her very ill. Instead of continuing to adhere to her medication, she has started hiding her pills from her mother instead of taking them. She tells you it does not matter if she is adherent because she feels much better without taking

the medication. What do you tell her? Should she be concerned about not adhering to her medication?

Once this scenario is read, adolescents can respond with their advice for Sophia. Importance of adherence to health can be emphasized.

- James recently was told by his mother that he is HIV positive. He has been sick, and started on ARVs by his doctor. However, you notice he is very depressed and unhappy. He tells you it is fine because he is healthy and taking his medication. How would you respond to him? Does emotional health matter as much as physical health in his situation?

Like the first scenario, once this is read, adolescents can respond with their opinions. The importance of living positively and how emotional health connects to other areas of healthy living can be emphasized in the discussion.

Optional Media:

1. "A Love Story"- Scenarios from Africa

http://www.youtube.com/watch?v=K22kGvbjaR0&list=PL241B41BCA3862154&index=11

This 'Scenarios from Africa' video explores the challenges of adhering to ARVs and the importance of social support in doing so. Adolescents can discuss their responses to the video as well as the importance of close relationships in keeping adherence levels high.

Module 4: Leadership and Independence

Goals: To provide a forum for fostering and encouraging leadership and independence among adolescents.

Discussion Questions:

- What are qualities of a good leader?
- What characteristics do you have that make you a good leader?
- What is fun about being a leader? What is difficult about being a leader?
- What is independence? What are challenges of having more independence? What is good about having more independence?
- What responsibilities to you have now? What do you like/dislike about these responsibilities?
- What impact does increasing independence during adolescence have in terms of HIV?

These questions can be used to start conversation about qualities the group views as important to being a leader. This can create reflection about the qualities each individual has to make them a leader. Furthermore, a discussion about responsibility and independence can be linked to the challenges of being a teenager as well as the challenges of remaining healthy with HIV.

Activity 1: Deserted Island

Duration: 15 minutes

Materials Needed: None

Directions: Divide the adolescents into groups of 4-5. Describe a scenario in which the group finds themselves on a deserted island. They can only choose five items to bring with them to the island per group, which all members have to agree on. Once the groups decide on their five items, come back together as a large group and ask the adolescents how the exercise felt. Did they have to compromise on their ideas? Did one group member take control? How did they work together to decide on the five items? This exercise will display different leadership styles, and show the group the importance of decision-making as part of independence.

Activity 2: Ranking Leadership

Duration: 15 minutes

Materials Needed: Pencils/pens and paper for all adolescents, large sheet of presentation paper

Directions: Divide the adolescents into groups of 3-4 individuals. Ask them to come up with a ranked list of the top ten most important qualities for a leader to possess. Once they have completed the task, return to a large group and list all mentioned qualities on a large sheet of presentation paper. Discuss the qualities identified by the groups and ask the adolescents what they think is the most important quality. Other discussions around this topic can include asking the group what leadership qualities they have/do not have. This activity will give adolescents a chance to voice their opinions while also exploring different perceptions of what makes a good leader.

Activity 3: Different Types of Leaders

Duration: 20-30 minutes

Materials Needed: None

Directions: Divide the adolescents into three groups. Assign each group a leadership style:

- Authoritarian/Aggressive: Leaders who provide clear expectations of what should be done, and independently make decisions with little to no input from group members. Their leadership style can also be intimidating and antagonistic.
- Democratic/Participatory: This type of leader offers guidance to group members but also allows input from the group. This leadership style encourages participation, while leaving the final decision up to the leader.
- Delegate/Hands-Off: These leaders offer little or no guidance to group members and leave decision-making to the group. Expectations are often absent or unknown.

Have each group act out a situation which expresses each type of leadership style. Once all styles have been acted out, bring the group back together and ask the adolescents what they learned from the exercise, what leadership style they preferred, how they would react to the acted situations, and how the group came to decisions on what to act out. This will provide adolescents with a better idea of leadership and how several qualities define a good leader.

Activity 4: Guest Speaker

Duration: 20-30 minutes

Materials Needed: None

Directions: Prior to the session, arrange for a Lea Toto staff member to talk to the adolescents- preferably a staff member who manages or leads the team. Ask them to discuss with the adolescents what it is like to be a leader in the organization, and the parts of their job that they like and dislike. Leave time for adolescents to ask questions to the staff member as well.

Optional Media

1. "Kenyan Youth Invent Peace Application"- K24TV

   http://www.youtube.com/watch?v=_Q83991oXog

This video describes a peace application created by Kenyan youth for use on mobile phones. Once the video is played, ask the group how leadership was shown in the video. How can Kenyan youth be a force for change? What role can the adolescents play in terms of this type of leadership? Why is youth leadership important in the country?

2. "First Follower"- Derek Sivers, http://www.youtube.com/watch?v=fW8amMCVAJQ

This video describes the concept of a "first follower," the first person to join a leader allowing others to follow. Once the video is played, ask the group what they think of the first follower concept. What role does the first follower play? How important is this role? What are difficulties in being a leader? How do societal norms play a role in becoming a leader?

Module 5: Power and Self-Esteem

Goals: To help adolescents explore their own sense of power and self-esteem and what these concepts mean to them.

Discussion Questions:

- What is self-esteem? What are qualities of a person with high self-esteem? Low self-esteem?
- What impacts the self-esteem of a teenager? How is self-esteem created?
- What does personal agency mean? How much personal agency do you have?
- How can you improve self-esteem?
- How does self-esteem differ for males and females? What role do societal norms play?
- How does HIV/AIDS impact feelings of self-esteem? How does HIV/AIDS impact feelings of personal control/agency?

These questions will begin a discussion about self-esteem, and allow adolescents think critically about what this concept means to them. It will also spark discussion on where self-esteem comes from, how it is formed, and how HIV/AIDS status may or may not impact it. Furthermore, issues of personal control and agency and how this impacts self-esteem can be discussed as well.

Activity 1: Commercial Role-Play

Duration: 20 minutes

Materials Needed: None

Directions: Discuss with the group how television advertisements use positive characteristics to sell products. Have each adolescent come up with a 30 second speech to "sell" their positive characteristics. This activity will allow adolescents to think about their positive attributes while also demonstrating these to the group through a fun activity.

Activity 2: What I Like, What I'd Change

Duration: 20 minutes

Materials Needed: None

Directions: Have each adolescent come up with one characteristic about themselves they are happiest with, and one they would like to change. As individuals present their characteristics, encourage other members to emphasize the positive aspects about the characteristic they would like to change. End the activity by asking adolescents about the role of societal norms in influencing the items they want to change about themselves. This activity can be used to promote self-esteem and group trust.

Activity 3: Strength in Change

Duration: 20 minutes

Materials Needed: None

Directions: Ask adolescents to brainstorm a strength they have due to a change in their life. Examples include accepting HIV status, overcoming peer pressure, or successfully passing a class level. Ask individuals to share their experience and how the knowledge of their internal strength impacted their self-esteem. This exercise will allow adolescents to identify a time when

they had personal agency, while also reflecting on others' experiences- some of which they may also be able to identify with.

Activity 4: Automatic Negative Thoughts (ANTS)

Duration: 20 minutes

Materials Needed: None

Directions: Introduce the subject of Automatic Negative Thoughts (ANTS) to the adolescents, as thoughts individuals have without thinking which are negative, unhelpful, and hurtful toward their self-esteem. Then read the group the following scenarios and ask how the individuals could have changed their thinking into more positive thoughts:

- Kip spent his weekend relaxing and hanging out with friends. When he went to school on Monday, he realized he forgot that a large project was due the next day. Once he realized this, he thought "I'll never finish the project on time. I always fail and never do things right." How could Kip have refocused his thinking to be less critical of himself?
- Kate finally worked up the courage to ask a boy at school to hang out over the weekend. He declined her invitation, because he had to watch his younger sister all weekend while his parents were out of town. Kate's reaction was, "Of course he does not want to hang out with me. I was stupid to ask and will never have a boyfriend." How could Kate have redirected her thinking to be less negative?
- When John got home from school on Wednesday, he found his step-father in a horrible mood. John thought to himself, "It must have been something I've done. I can never be good enough for him no matter how hard I try." How could John think about the situation differently?

- Martha is nervous about an upcoming class presentation. While trying to prepare herself, she begins thinking negative thoughts, "I'm going to fail and everyone will laugh at me. I am a failure at public speaking." How might she retrain herself to think more positively?

After giving these examples, and discussing alternative ways of thinking, ask the group to think of and share other examples of automatic negative thinking. Emphasize the importance of thinking positively and being positive toward oneself, and how this will improve self-esteem.

Optional Media:

1. "Automatic Thoughts"- WellCast, http://www.youtube.com/watch?v=m2zRA5zCA6M

This animated video describes automatic thoughts and their negative impact on individuals. Once the group has seen the video, ask them what they learned from the video. What are ways to control automatic thinking? What can be gained from stopping these thoughts?

2. "Reasons for a Smile"- Scenarios from Africa
   http://www.youtube.com/watch?v=X4L6Ih1cxJg

This video describes the realization of HIV status and the decision to live positively. Once the group has viewed the video, ask them how personal choice and power played a role in the attitudes of the characters. How else could they have reacted? What are the impacts of living positively? What are difficulties of living positively? What negative thoughts were shared by the characters? How could they change these thoughts?

Module 6: Relationships and Social Support

Goals: To help adolescents understand the importance of social support and relationships and reflect on what roles this plays in their lives.

Discussion Questions:

- What types of relationships do you have with others (ie friends, family, romantic)?
- What is social support? What types of social support do you have?
- How do these types of support help you? How do you help them?
- Why is it important to have positive relationships and social support?
- What is difficult about having relationships when living with HIV?
- How do you overcome these difficulties?
- What gaps do you have in social support?

These questions will spark thinking about personal relationships and social support, and the importance of these relationships in adolescent lives. The group can reflect on what characteristics lead to positive relationships as well as any gaps they have in feeling supported.

Activity 1: Healthy Relationships

Duration: 20 minutes

Materials Needed: Pencils/pens and paper, large presentation paper

Directions: Divide the individuals into groups of 3-4. Ask each group to create a list of the ten most important characteristics to have in a healthy relationship with a friend or romantic partner. Bring the group back together and list out all items the groups brainstormed. Discuss which

characteristics the group saw as most important, and have the adolescents vote on the most important characteristic they see in a relationship. Have adolescents also think about what signs of an unhealthy relationship are. This activity will allow adolescents to give their own opinions on what creates a healthy relationship.

Activity 2: Support Network Map

Duration: 20-30 minutes

Materials Needed: Pencils/pens and paper for all adolescents

Directions: Ask each adolescent to think about their support network. Have them draw their network, detailing the types of support they receive from each person/organization listed. Once the activity has been completed, ask individuals to share their network diagrams. What components did the group have in common? Were there any common gaps in social support? How does it feel to have this support? This activity will help adolescents think through their personal relationships and the ways they are supported.

Activity 3: Trust Fall

Duration: 15 minutes

Materials Needed: None

Directions: Have individuals take turns falling backward into the arms of the group. After the activity is completed, ask adolescents how it felt to put their trust into the group to catch them, and what helped them trust the group. This discussion can be tied to the concept of trust and its importance in healthy relationships and social support.

Optional Media:

1. "Never Alone"- Scenarios from Africa, https://www.youtube.com/watch?v=ijOFV-mz1o0

This video clip explores the idea of social support in terms of HIV/AIDS. After the video is shown, have adolescents think about the importance of social support and positive relationships for Sam.

2. Shuga: Love, Sex, and Money- Episode 6, http://mtvshuga.com/clips/shuga-love-sex-money-episode-6/

Once the episode has aired, ask the group what types of relationships were portrayed in the episode. Which were positive and why? Which were negative and why? What role did social support play in these relationships? What is the message of the relationships portrayed in the episode?

Module 7: Stigma

Goals: To allow adolescents a safe space to discuss both external and internal stigma and ways to overcome them.

Discussion Questions:

- What is stigma?
- What is the difference between internal and external stigma?
- How does stigma start?
- Does anyone with HIV deserve to be stigmatized?
- How does stigma impact the person being stigmatized?
- What are ways to overcome stigma?
- What are ways that individuals, families, communities, and nations perpetuate stigma? What are examples of each of these ways?
- How do you cope as a person living with HIV/AIDS facing stigma against the disease? Does anyone want to share an experience of stigmatization that they faced?

These questions will allow adolescents to discuss the concept of stigma, how it begins, and its impact on people. The discussion will provide a safe place for the group to discuss stigma they have faced as an adolescent living with HIV/AIDS.

Activity 1: Belief Statements

Duration: 20-30 minutes

Materials Needed: Pencils/pens and paper

Directions: Using two pieces of paper, write "Agree" on one and "Disagree" on the other. Place the signs on opposite sides of the room. Read the following statements out loud and have adolescents move to stand under the sign they agree with for each:

- People with HIV deserve to be outcast because they brought the disease upon themselves.
- People with HIV should not have the same rights as those without the disease.
- People with HIV should not be able to run for government.
- People with HIV should not start a relationship with a person who does not have the disease.
- Adolescents living with HIV should have to disclose their status to their teachers.
- Adolescents living with HIV should have to disclose their status to all classmates.
- Adolescents with HIV should only be friends with others who have HIV.
- Stigmatization of HIV positive people is ok because the disease is deadly.

Facilitators and adolescents can use alternate statements as well. After each statement is read and adolescents have moved to the sign they agree with, ask the group to discuss about their opinion on the issue. This activity can stimulate discussion on stigma and rights of those living with HIV/AIDS.

Activity 2: Mapping Stigma

Duration: 20-30 minutes

Materials Needed: Pencils/pens and paper

Directions: Divide individuals into groups of 3-4. Ask each group to map their community and identify places where stigma occurs. This can be both external and internal stigma- or both

where one feels stigmatized by others and also more pressure to stigmatize themselves. After completing the activity, come together as a group and present the different community maps. Discuss why and how stigma occurs at each of the locations mentioned and techniques adolescents can use for overcoming it.

Activity 3: What Would You Do?

Duration: 15 minutes

Materials Needed: None

Directions: Read the following scenarios to the group and ask adolescents how they would respond to each:

- You are walking with two friends after school to buy chapatti and sodas. You begin to approach a local shopkeeper when one of your friends says "I'm not going there, I heard that man has HIV and I do not want to get infected." Another friend says the man should not be able to sell food if he is HIV positive. What do you tell your friends? How do you react to these statements?

This scenario will create active discussion amongst the group as in there are several forms of stigma present in this case. Individuals will have to think about their own stigmatization by friends who may not know their status, as well as that of the shopkeeper.

- You are at a dance when you notice a group of people laughing and shoving one of your classmates. "She has HIV! Gross!" yells a group of males around her. You see her looking at you for help. What do you do? Do you help her out of the situation?

Similar to the above situation, this scenario will provoke discussion about personal stigmatization as well as seeing stigma occur against another person.

- A friend who is HIV positive comes to you and tells you they feel rejected and ashamed of their status. How do you respond to this friend? What techniques would you tell her to help overcome her internal stigma?

This scenario highlights the importance of halting internal stigma against oneself, and can be emphasized in the discussion surrounding this situation.

Activity 4: Breaking Down Stigma

Duration: 20-30 minutes

Materials Needed: Paper, tape, pencils/pens

Directions: Have the group create a "wall" of stigma by writing down examples of how they have been stigmatized by others on pieces of paper. Tape these examples to a wall and read them out loud to the group, discussing their hurtful impact on individuals as well as ways to overcome this stigma. Once all have been read, have the group rip the wall down, essentially breaking down the wall of stigma. Discuss the symbolic importance of this act and its empowering effect on the group.

Optional Media:

1. "My Brother"- Scenarios from Africa, https://www.youtube.com/watch?v=p-cVDhUfKMk

After viewing the video, ask the group for reactions about its message of stigma. What role did the teacher play in reacting to this stigma? Do you have someone in your life that plays a similar role? How did the boy with stigmatizing views change after he learned more about HIV? Do you think this is a good technique for others who stigmatize about the disease? What other lessons did this video show you?

2. "HIV Stigma"- CHIVA, https://www.youtube.com/watch?v=v0QvZukMGXY

After viewing the video, ask adolescents for their reactions. Do they agree with the message of the video? What have been their experiences of stigma and disclosure? What positive messages does the video send to those individuals who might want to stigmatize against HIV positive people?

3. "Living with HIV: Stigma"- California HIV Prevention Training Center https://www.youtube.com/watch?v=7tN5vBtHdc0

After viewing the video, ask adolescents for their reactions. What was it like hearing about stigmatization from others? How does it feel to know that people living with HIV in America are stigmatized against? How did individuals describe internal stigma? Is it surprising that stigma against HIV is so strong in many parts of the world?

Module 8: Teenage Issues

Goals: To allow adolescents space to discuss the challenges and opportunities of being a teenager, and issues relating to navigating adolescence.

Discussion Questions:

- What are positive aspects of being a teenager? What are challenges of being a teenager?
- How do females and males differ during adolescence?
- How do societal norms impact teenagers during adolescence?
- What is peer pressure? What are examples of peer pressure?
- Why are individuals more inclined to take risks during adolescence?
- What are challenges in being an HIV positive teenager?
- What concerns do you have an as adolescent? What goals do you have?

These questions can be used to start a discussion among adolescents about being a teenager. This conversation can focus on normal teenage issues as well as the difficulties of being HIV positive as a teenager.

Activity 1: Body Mapping

Duration: 20-30 minutes

Materials Needed: Large sheets of presentation paper, pencils/pens

Directions: Divide the adolescents into groups of 4-5 individuals based on gender. Ask each group to draw the outline of a body on a large sheet of presentation paper. Have each group identify changes their gender experiences during adolescence. Once groups have finished this

task, discuss similarities and differences in changes identified by each group. Discuss how these changes are normal during adolescence. If the age of the group is too young to discuss these issues as a whole group, have the facilitator discuss with males and females separately.

Activity 2: Gender Boxes

Duration: 20-30 minutes

Materials Needed: Pencils/pens and paper

Directions: Divide individuals into groups based on gender, of 3-4 people each. Ask each group to draw a box on their paper and write the qualities and characteristics expected of their gender in the box. These qualities can be physical, emotional, or behavioral. Then, have the group think of characteristics that are not expected of their gender, and ask them to write these qualities outside the box. Once groups have finished their boxes, bring the group back together to compare their results. Discuss similarities and differences, as well as which qualities individuals in the group have- both in and outside the box. Have adolescents discuss where gender expectations come from and how this impacts them personality as teenagers.

Activity 3: What Would You Do?

Duration: 20 minutes

Materials Needed: None

Directions: Read the following peer pressure scenarios to the group and ask adolescents how they would respond to each:

- You are at your boyfriend's home and it is getting late. He is usually kind and gentle, but he has been taking alcohol. He suddenly becomes aggressive and tries to force you into

having sex with him. You have not had sex before and are not ready to get intimate, particularly in his condition. What do you do? How can you diffuse the situation?

- Your friend tells you a group of students are skipping school to go drink alcohol. He asks if you want to come with him and you say no. He laughs and asks if you are afraid. You have a test that day and do not want to miss school. What do you say to him? Do you decide to go with the group?
- Exams are coming up and you have been busy studying. One day, a friend comes up to you and tells you he knows someone in the Ministry and has a secret copy of the exam. He is selling copies of it and wants you to buy one. You do not want to cheat but you know you need to pass this exam. How do you respond to your friend?

These situations highlight different versions of peer pressure and mimic situations that teenagers may find themselves in. Each scenario can be given discussion time to hear what the group thinks of the situation and how they would respond.

Activity 4: Pressure Lines

Duration: 20 minutes

Materials Needed: None

Directions: Pair up adolescents in groups of two. Read each of the following "pressure lines" and ask the pairs to act out the scenario. Have one teen say the given line, and the other diffuse the situation with their own response.

- Come on, everyone is doing it!
- If you loved me, you would have sex with me.

- I know you want to, you are just scared.
- If you trusted me, you would have sex with me.
- We've already had sex before, so what is the problem with doing it again?
- If you don't have sex with me, we are over.
- If you don't have sex with me, I will find someone else.
- You won't get pregnant if you have sex for the first time!
- Aren't you curious? Just try it!

Once all pressure lines and responses have been read, discuss with the group what they thought of the activity. What did they think of the responses? Would these work in a real-life situation? How do they respond to peer pressure when they do not want to participate?

Optional Media:

1. "A Ring on Her Finger"- Scenarios from Africa

https://www.youtube.com/watch?v=6TTmTGGaKi0&list=PL241B41BCA3862154&index=15

Once adolescents have viewed the clip, have them respond by describing the peer pressure situation. What did Aliou do to try and pressure Nancy into sex? How did she resist? What did you think of her response? Is this likely to stop the advances in real life? This discussion can revolve around issues discussed in the rest of the session, including peer pressure and personal choice.

2. "Sexually Transmitted Marks"- Scenarios from Africa

https://www.youtube.com/watch?v=_4DmUjr6tio&list=PL241B41BCA3862154

Once adolescents have viewed the clip, have them respond to the video. What was the peer pressure situation, and how did the young girl stop it? Is peer pressure more difficult to resist when it comes from an adult or authority figure?

Module 9: Secondary Prevention

Goals: To discuss the topic of secondary prevention and the importance of staying healthy, avoiding sexually transmitted infections (STIs), and other HIV strains. This module will also focus on preventing transmission of HIV to others.

Discussion Questions:

- What is secondary prevention? (introduce the concept and its importance for each individual to protect themselves)
- Why is secondary prevention important for HIV positive people?
- How can HIV positive individuals protect themselves from additional infection?
- How is HIV transmitted? Why are these details important to know?
- How can you protect others from transmitting HIV to them (ie protection during sex, not sharing needles or sharps)?
- Why is secondary prevention important in terms of positive living?

This discussion can empower youth to feel in control of their disease instead of stigmatizing and shaming them into fear of HIV transmission. A frank discussion regarding the importance of individual choice and protection can occur during this session. Facilitators can highlight the importance of staying healthy, protecting oneself against STIs, and protecting oneself against other HIV strains for HIV positive individuals. This discussion can also include the importance of protecting partners against HIV transmission, by empowering adolescents to feel control over these decisions. The emphasis can be on a practical discussion of ways to keep individuals and their partners healthy.

Activity 1: HIV Transmission

Duration: 15 minutes

Materials Needed: None

Directions: Review ways that HIV can be transmitted with adolescents, asking about routes of transmission and through which bodily fluids. Conversation will include mention of:

- Sexual intercourse, blood contact, and mother-to-child transmission as routes of transmission
- Semen, vaginal fluid, blood, and breast milk as bodily fluids which can transfer HIV

Then have adolescents think of common myths of HIV transmission (ie sharing a toothbrush, hugging a person with HIV, kissing a person with HIV, shaking hands with a person with HIV) and explain why these actions cannot transmit the virus. Facilitators will ensure that all group members clearly understand the ways in which HIV can be transmitted to others in order to be aware of ways in which they could potentially transfer the virus. This discussion can be based in practical knowledge of the disease and its potential for transmission and facilitators should ensure adolescents do not feel stigmatized.

Activity 2: Belief Statements

Duration: 30-45 minutes

Materials Needed: Pencils/pens and paper

Directions: Using two pieces of paper, write "Agree" on one and "Disagree" on the other. Place the signs on opposite sides of the room. Read the following statements out loud and have adolescents move to stand under the sign they agree with for each:

1. Once a person has HIV, they cannot contract other STIs

2. If I have sex with a person who has HIV, there is no use in using protection because we are both infected
3. There is no use in trying to prevent other diseases in my body because I am already infected with HIV
4. Adherence, healthy living, and sexual protection are all important to secondary prevention
5. There is only one strain of HIV and I don't need to worry about catching another version of the virus
6. I can take steps to prevent myself from getting sicker by living a healthy lifestyle
7. I can take steps to prevent transmission of HIV to my partner
8. I do not need to be careful about adhering to HIV medication, as long as I take it somewhat well, I will stay healthy

After each statement is read and adolescents have moved to the sign they believe is correct, the facilitator can respond to any incorrect beliefs using the following information:

1. STIs can still be transmitted to HIV positive individuals, and if transmission occurs, both HIV and STI severity can increase.
2. It is possible for HIV infected individuals to acquire other strains of the virus. This can have an impact on their disease and medication regimen.
3. Having other diseases can weaken the immune system and negatively impact the status of an individual's HIV disease.
4. This statement is true- all levels of health should be promoted for secondary prevention.

5. As mentioned above, there are other strains of the virus and it is possible to acquire more than one.
6. This statement is true, and individual empowerment and choice should be emphasized in terms of keeping healthy.
7. This statement is true, and empowerment and choice should be emphasized to show the adolescents that they have control over their partner's health as well.
8. It is crucial to continue high adherence to medication in order to stop the HIV infection from worsening.

This information can provoke discussion and questions from the group about control over one's disease status and transmission. Once again, steps should be taken to ensure adolescents do not feel stigmatized or blamed through the discussion.

Activity 3: Navigating Sexual Intercourse

Duration: 20-30 minutes

Materials Needed: Large sheets of presentation paper

Directions: Using a sheet of presentation paper, draw a vertical line to create two columns labeled "Reasons For Sex" and "Reasons Against Sex." Describe a scenario in which two committed partners are in a relationship. Have the group brainstorm reasons why the partners may choose to have sex, or why they may choose to abstain. Discuss the results. What did this exercise teach the group? What are the consequences of each action? Which side had more arguments? The discussion can include mention of the complicated choices involved in sexual intercourse, even when in a committed relationship. Once this discussion is complete, draw a line vertical line on another sheet of paper to create two columns labeled "Reasons for Condom

Use" and "Reasons Against Condom Use." Tell the adolescents that the two partners have decided to have sex, but are trying to decide whether to use a condom. One partner is HIV positive. Have the group brainstorm reasons why one partner may want to use a condom and reasons why the other partner might say using a condom is not necessary. What are responses to the partner trying to avoid using condoms? Why should the partners use a condom in terms of secondary prevention? Which side had more compelling arguments? This discussion can revolve around negotiating condom use between partners, and how to decline sexual intercourse without a condom. Adolescents should be able to name several peer pressure statements against using a condom, as well as many reasons why the couple should use one to protect themselves.

Activity 4: Self-Contract

Duration: 15 minutes

Materials Needed: Pencils/pens and paper for each adolescent

Directions: An important component for secondary prevention is thinking through one's own plan for protecting themselves against ill health, and protecting others against HIV transmission. Instruct adolescents to write a "self-contract" in which they outline their plan for preventing infection and ill health in themselves, and a plan for protecting partners against HIV. The activity will emphasize empowerment and the personal agency of each teenager, and it should be made clear prior to beginning that self-contracts will not be shared with the group. A potential contact could include the following components, if adolescents need help getting started on this activity:

- Plan for healthy living and avoiding infection
- Plan for protecting oneself against STIs and HIV re-infection

- Plan for protecting others against HIV transmission via drug use or sex
- Plan for responding to peer pressure which may challenge the self-contract made by the teen

Once adolescents have finished their self-contracts, an optional group discussion may take place. Instead of asking adolescents to present their contracts, which may be personal, broader themes and ideas can be discussed.

Optional Media:

1. "Just Once"- Scenarios from Africa, https://www.youtube.com/watch?v=mgoZaAHPi9M

Once the adolescents have viewed this clip, discussion about the importance of protection can occur. Who in the film was more vocal about using condoms? How does this translate to your personal choice in protecting your partner? What did this video teach you about secondary prevention? What role did each partner play in preventing HIV transmission?

2. "Heart of the Matter"- Scenarios from Africa
   https://www.youtube.com/watch?v=dkI1ZQQ52MQ

Once the adolescents have viewed this clip, discussion about issues in disclosure and secondary prevention can occur. How and when should HIV disclosure occur to a romantic partner? What did you think about the character's choice in when he disclosed? How would you manage this situation?

Module 10: Job and Life Skills

Goals: To teach adolescents the importance of life skills and ways to acquire job skills and job opportunities.

Discussion Questions:

- What are life skills?
- Why are these important characteristics for adolescents to have?
- What are job skills?
- Why are these important skills to gain?
- How can you gain more life and job skills?
- What challenges do you face in acquiring these skills?

This discussion can center on the need for adolescents to gain practical occupational skills as well as life skills for a successful future.

Activity 1: What Skills Do I Have/Want/Need?

Duration: 20-30 minutes

Materials Needed: Pencils/pens and paper for each adolescent

Directions: For this activity, have each adolescent split their paper into three columns. Title these columns "Skills I Have," "Skills I Want," and "Skills I Need." Then have them brainstorm a list of job and life skills that fall into each category. Once they have completed this activity, bring the group back together and ask adolescents about the exercise. Were the skills they want

and need similar? What are practical ways of gaining these skills? If adolescents are stuck on knowing what skills they may need, the following list can provide guidance for this activity:

- Life Skills: decision-making, communication, social skills, personal care, independence
- Job Skills: education, computer training, critical thinking, independence, organization

These lists are not exhaustive and will change by context and future goals. Following this activity, brainstorm practical ways in which adolescents can gain these skills.

Activity 2: Practice Interview

Duration: 20-30 minutes

Materials Needed: Large sheet of presentation paper

Directions: Many of the adolescents involved in the Lea Toto program may not have opportunities to practice for job interviews. Even if the occupations they apply to work in do not require interviews, this activity is useful in having the adolescents think through their strengths and weaknesses and improve their self-esteem. Prior to the activity, write out interview questions on the presentation paper. Example questions include:

- Tell me about yourself.
- What are your career goals?
- What are your greatest strengths?
- What are your greatest weaknesses?
- What skills can you bring to this position?

Group adolescents into pairs, and have each individual perform a mock interview with their partner. Once the first interview has completed, switch roles and have the other partner interview. After the activity is finished, bring the adolescents back together and ask the group

for their response to the activity. What was difficult about the interview? What did you like? How will this help you in the future? This discussion can center on ways in which adolescents can better sell their skills to potential employers when looking for job opportunities.

Activity 3: Guest Speaker

Duration: 30 minutes

Materials Needed: None

Directions: This activity can be done using Lea Toto staff members, community business members, or both. Below, each choice is described in detail.

- *Lea Toto Staff Member:* Most Lea Toto staff members can be used as a guest speaker for this activity. Ask a staff member who is available during the adolescent meeting time to come and discuss life and job skills with the group. What skills did they need for their job? How did they gain these skills? What are more general skills that adolescents can try and gain while they are in secondary school? Allow time for adolescents to ask the staff member questions about their career path and skills.
- *Community Income-Generating Activity (IGA) Member:* The additional option for this activity is to bring the adolescent group to a community IGA group to talk with one of its members. For example, in Kibera, the adolescent group could visit the Power Women Kibera group and discuss with one of its members how the group got started, what skills were needed, and how successful the group has been. The adolescents can ask questions regarding the challenges and opportunities for starting this type of business venture.

Activity 4: Listing Opportunities

Duration: 20 minutes

Materials Needed: None

Directions: Prior to this activity, ask Lea Toto staff members about skill-building opportunities for adolescents in the area. Make a list of these to bring to the group session. When the group meets, list the potential opportunities for them, and ask them to brainstorm other opportunities in the area. Encourage adolescents to contact organizations to see if they can join these opportunities for skill-building.

Activity 5: Income-Generating Activity (IGA) for Adolescents

Duration: Varies

Materials Needed: Varies

Directions: A final optional job skills activity would involve the creation of an IGA for adolescents. This would require significant preparation which cannot be outlined in detail, as the creation of such activities would vary by site and context. However, a few introductory steps are briefly outlined below.

- *Brainstorm activities and interest:* Ask adolescents whether this idea interests them, and if so brainstorm the type of activity that can be started. The initial IGA start-up can be simple, and focused on giving the adolescents extra job skills and business training.
- *Appoint an adolescent leader:* In order to create an adolescent IGA, facilitators can appoint an adolescent leader to help design the IGA and its activities. This will also help the adolescent group gain ownership in the venture.

- *Create a plan for action:* With the adolescent group, brainstorm a plan for action in starting the IGA. What product will be created and/or sold? How will initial startup be funded? How and where will selling occur? What will revenue be spent on? This exercise will be useful for adolescents in thinking through the start-up of a business venture, and can be used in adolescent activities even if the organization cannot support an IGA for adolescents at this time.

Optional Media:

1. "Kenya Youth Business Trust Feature"- KYBT, https://www.youtube.com/watch?v=3zMuOyufqxE

After viewing the clip, ask the adolescents their opinion about the organization. What are the positive aspects of being involved? What are potential challenges? What skills are needed to join? What skills did youth learn through working with KYBT?

III. Drug Buddy Program

Once the main discussion and activities have taken place, the group can break into their drug buddy partners to discuss issues with medication adherence and encourage partners to stay adherent. Facilitators can decide how best to pair adolescents based on their knowledge of clients- either by choice or assigning partners themselves. While the structure of these drug buddy meetings is flexible and can be decided by facilitators or adolescents themselves, time should be set aside at each session for drug buddies to meet. Suggested activities for the first drug buddy meeting are highlighted below.

<u>Drug Buddy Introduction Meeting</u>

1. *Introducing the Activity:* In introducing the concept of drug buddies, the facilitator should make clear to adolescents that the purpose of this activity is to encourage adherence with the help of peers, and not to regulate or punish adolescents for lack of adherence. It should be emphasized that adherence can be difficult, and while Lea Toto staff can offer support and guidance to adolescents for ways to achieve better adherence, the drug buddy program provides a type of support which staff members cannot give- support by a peer who faces similar challenges. The goal is to empower adolescents to help each other aim for better adherence.

2. *Getting into Pairs:* As mentioned above, it is up to the discretion of each facilitator to decide how to pair up adolescents for this activity. Once adolescents are in pairs, their contact information (ie telephone number and area of residence) can be exchanged if both parties are

comfortable giving this information. This will help pairs contact each other at times other than Lea Toto program sessions.

3. *Getting to Know Each Other:* Adolescents can be given time in the first meeting to introduce themselves and discuss their interests. This discussion can also include their challenges in adherence, and tips on how to better adhere to medication.

4. *Drug Buddy "Contract":* In order to both stress the importance of the drug buddy program as well as to help adolescents make a plan for adhering well with their partner, pairs can create a 'contract' between them. The purpose of this activity is to increase the likelihood of participation in the drug buddy program, make the partnership clear to both adolescents, and increase the amount of social support each adolescent has. These contracts can be flexible and up to the judgment of each pair to decide. Suggested topics for contracts include:
    - Agreement on how often to talk via text message (ie twice a week)
    - Agreement on how often to meet up in person (ie once a week)
    - Agreement on how often each member will send text reminders, based on how much support each adolescent needs in adhering (ie daily or weekly)
    - Agreement to keep adherence concerns confidential from others

These suggested introductory components may be modified by facilitators as needed. During future sessions, adolescents will have the chance to discuss their challenges in adhering and update their drug buddy on how adherence during the previous month has been. These discussions can be brought back to a larger group setting if time permits, for all members to

discuss challenges and tips for better adherence. Adolescents should also be encouraged to contact each other outside of group meetings if needed.

Suggested Topics for Drug Buddy Sessions

While drug buddy sessions are meant to be flexible and topics discussed can be decided on by partners, it may be necessary to spark conversation via topic suggestions. The following are potential topics that can be provided to adolescents at each session:

- Challenges to adherence and ways to overcome them
- Drug regimens and side effects
- Adhering to medication without disclosing status
- Social support and adherence (ie who else gives them support to adhere)
- Adherence and its importance in preventing transmission of HIV
- Transition to adulthood and its impact on adherence (ie more responsibility on the adolescent)
- Adherence and living positively with HIV
- Adherence and fears of stigma

Each session can be started with the announced topic, to give partners a place to start their discussion. These topics will be more important to provide in early sessions when partners are still getting to know each other and may feel shy about starting conversation themselves.

IV. Mentorship Program

Similar to the drug buddy program, time should be set aside during each session for adolescents to engage with their mentorship partner. While the structure of this program is flexible, a suggested timeline of events is presented below.

1. *First Session*: During this session, facilitators can identify mentors and mentees in the group. The program can be introduced in this session, and explained to the adolescents. The existing mentorship program at Lea Toto (with outside community members as mentors for older teenagers) should still be utilized for adolescents acting as mentors, so they have the chance to be a mentee as well. Roles for both mentors and mentees within the group should be clearly explained.
    - Mentors: Facilitators can emphasize the ability for older teenagers to act as role models to the younger members of the group, as well as the chance to play the role of a leader in this program. As older teenagers having already navigated adolescence living with HIV, their experience and success in doing so can be highlighted as an asset for the younger teenagers to learn from. Expectations for this role include listening to mentee concerns, discussing issues faced by the mentee, and advising on how to best overcome challenges. Confidentiality should be emphasized as integral to the mentee-mentor relationship. Furthermore, the importance and uniqueness of the adolescent mentee-mentor relationship should be emphasized by facilitators, as a role which Lea Toto staff cannot fill without the help of older teenagers. Facilitators can also discuss opportunities for these individuals to be mentored by outside community members themselves, so they are not left out of the mentorship process.

- Mentees: As young adolescents, mentees may have questions, concerns, and anxiety about navigating adolescence, particularly with HIV/AIDS. As such, the importance and benefits of a mentoring relationship with an older adolescent should be made clear to mentees. These individuals should also be informed of the confidential nature of the mentorship program.

As with the drug buddy program, facilitators can decide how to partner mentors with mentees. Both individuals should be of the same gender in order to make the adolescents as comfortable as possible. It is suggested that adolescents aged 15 and above make up the mentors, with younger individuals as mentees. However, the composition of the group may make this difficult. As such, each mentor may be paired with a pair or group of mentees instead.

2. *Second Session:* Once the mentorship program is introduced and mentor/mentee pairs are chosen, mentorship partners will meet. This session is important in allowing partners to get to know each other better, and to begin establishing a trusting relationship between mentors and mentees. Introduction activities such as "Learning About Each Other" or "Getting to Know the Group" can be modified and utilized during this session to help adolescents learn about their partners. Contact information can be exchanged during this session, although this can be left up to each partnership to decide.

3. *Mentorship Contract:* Similar to the drug buddy contract, mentorship pairs can be given time to create a contract for their expectations of the mentoring relationship. Suggested topics to include in the contracts are as follows:
    - Agreement on whether the pairs will meet outside of Lea Toto sessions
    - Agreement on whether pairs can contact each other via text message
    - Listed expectations from both members
    - Agreement to keep concerns confidential from others

4. *Future Sessions:* As seen in the Discussion/Activities section of this manual, there are suggested topics for each group sessions. These topics can be used to prompt conversation between pairs, but overall discussion can be left to the discretion of each partnership. Mentees should be encouraged to discuss concerns and issues with their mentor during these sessions, and to use the time as best suited to their needs. The following are potential topics for mentorship discussion at each session:

- Disclosure: Ask pairs to share a time when they disclosed their status to another person, and whether it was a positive or negative experience. Ask mentors to share any disclosure tips they have with their mentees.
- Education/Job Skills: Ask partners to discuss their career goals for the future. Have mentors share their knowledge of opportunities to gain more skills before graduating secondary school (ie other organizations, teachers, workshops).
- Future Goals: Ask partners to share their future goals with each other. Mentors can use this time to advise mentees on concerns about the future.

- Health and Adherence: Ask partners to share difficulties they have experienced in staying healthy. Ask mentors to share any tips they have learned for better adherence. Have pairs discuss how personal choice can lead to ill health, or good health status.
- Leadership and Independence: Ask pairs to share a time when they were a leader and how it felt. Ask mentors to lead a discussion on positive leadership and how they have dealt with increasing independence as an older teen. This discussion can also include the increased personal choice that comes with independence.
- Power and Self-Esteem: Ask partners to share a time when they felt low self-esteem and a time they felt like they had more control or power over a situation. Ask mentors to share how they have overcome self-esteem issues during adolescence.
- Relationships and Social Support: Ask pairs to share an important person in their life who provides them social support. Positive and negative relationships can also be discussed during this session.
- Secondary Prevention: Have pairs discuss secondary prevention and its importance in romantic relationships. Disclosure and fear of stigma can be discussed in terms of this issue as well.
- Stigma: Have pairs discuss a time they felt stigmatized against, and how they reacted. Ask mentors to discuss internal stigma with their mentee, and how to decrease their own personal stigma against themselves.
- Teen Issues: Ask pairs to share the best and worst aspects of being a teenager. Insecurities, body image, and other concerns can be shared during this time as well.

Each mentorship session can be started with the announced topic, to give partners a place to start their discussion. These topics will be more important to provide in early sessions when partners are still getting to know each other and may feel shy about starting conversation themselves.

V. Optional Additional Program Components

Anonymous Question Box

In order to address questions adolescents may feel shy asking in a group setting, a folder or box can be set aside for anonymous questions. This will ensure that adolescents can get answers to questions they may have about the topic being discussed. Facilitators may want to introduce each session by addressing questions left anonymously in the previous session. This will ensure adolescents feel comfortable and not pressured to ask questions they may be nervous about in a group setting and its use can be encouraged by facilitators.

Extra Group Meetings

If there is a strong desire by the adolescent group to meet more frequently than once a month, a suggested activity is to organize other teen group sessions, either facilitated by a Lea Toto staff member or an adolescent interested in leading the group. These decisions can be determined by the group facilitator after feedback from groups is received.

Client Satisfaction Survey

As a program evaluation component, client satisfaction surveys can be given out at adolescent group sessions at the discretion of the facilitator and other Lea Toto staff. These

forms can be printed out and made available at adolescent sessions in order to better track frequency of activities and client satisfaction. See Appendix F for a sample survey template.

VI. Sources Consulted

California HIV Prevention Training Center. *HIV Stigma Video.* 2012. https://www.youtube.com/user/CaliforniaPTC.

CHIVA Association. *HIV Stigma Video.* 2012. http://www.chiva.org.uk.

German Academy for International Cooperation. *Methods Handbook for Youth Social Work.* Health, Education and Social Protection Division. Berlin.

International HIV/AIDS Alliance. *Tools Together Now! 100 Participatory Tools to Mobilize Communities for HIV/AIDS.* 2006. London.

Jonathan Morgan. *Making a Hero Book.* 2009. Regional Psychosocial Support Forum (REPSSI). Johannesburg, South Africa.

K24TV. *Kenyan Youth Invent Peace Application*. 2013. www.youtube.com/user/K24TV.

Kenya Youth Business Trust. *KYBT Video.* 2012. http://www.kybt.org/.

Kuweni Serious. *President for a Day.* 2011. www.youtube.com/user/kuweniserious.

Music Television (MTV). *Shuga Episodes.* 2011. http://mtvshuga.com/.

Peace Corps. *Life skills manual*. 2001. Publication No. M0063. Available from: http://purl.access.gpo.gov/GPO/LPS16808: Washington, D.C.

Perschy, M.K. *Helping teens work through grief.* 2004. New York: Brunner-Routledge.

Scenarios from Africa. *Various Media.* 2012. http://www.scenariosafrica.org/.

Sivers, Derek. *First Follower.* 2010. http://www.youtube.com/user/dereksivers.

Stone, H. *Group Work with HIV/AIDS Affected Children, Adolescents, and Adults: A Curriculum Guide*. 2001. Family Ties Project: Washington, D.C.

WellCast. *Automatic Thoughts*. 2012. http://www.youtube.com/watch?v=m2zRA5zCA6M