

ISSUE BRIEF

Strategies for Integrating Psychosocial Support Interventions into HIV Prevention, Care, and Treatment Services



BACKGROUND

A recent paradigm shift among institutions involved in the support and provision of HIV-related services, including the Elizabeth Glaser Pediatric AIDS Foundation (the Foundation), has resulted in a greater emphasis on the integration of health systems to support the provision of comprehensive HIV/AIDS prevention, care, and treatment services. Recognizing that the impact of HIV and AIDS is not only biological, but also psychosocial and economic, HIV programs must respond holistically to the needs and rights of people living with HIV (PLHIV).¹ A truly comprehensive approach to HIV service provision therefore involves the integration of psychosocial support (PSS) interventions within HIV prevention, care, and treatment services. This has prompted the Foundation to undertake coordinated efforts to assist countries in integrating prevention of mother-to-child transmission (PMTCT) and HIV care and treatment services, and to ensure that PSS interventions are introduced at key points along the continuum of care for women, children, and families.

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This publication is part of a series of Elizabeth Glaser Pediatric AIDS Foundation issue briefs highlighting innovative approaches to HIV/AIDS service delivery in resource-limited settings. Issue briefs highlight the work of Foundation-supported programs, as well as examples drawn from the literature, in order to provide a broader perspective on the issue being examined. The intended audience for issue briefs is HIV/AIDS program implementers, policymakers, and donors at all levels of activity.

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Cover: Participants in the Uganda Ariel Children's Camp (Credit: Elizabeth Glaser Pediatric AIDS Foundation)



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BACKGROUND... *continued*

The lack of integration of HIV services may contribute to loss to follow-up of mother-infant pairs, diminished access to antiretroviral therapy (ART) services, and other gaps in service provision.² During a recent Foundation-led technical mission to South Africa focused on strengthening linkage and integration of PMTCT and HIV care and treatment, the lack of community involvement through support groups, male involvement, or community empowerment was identified as a key factor preventing HIV program integration.

When PSS services do exist at health facilities, they may often operate as separate programs that are not fully integrated with HIV services. In addition, health-care workers (HCWs) may not systematically refer clients to PSS services or incorporate this into clinical work flows. Thus clients are denied the potential benefits of support due to the absence of linkages between HIV clinical and PSS services. At Foundation-supported sites in Uganda, however, PSS strategies are well integrated into many HIV-related services. Rather than existing as a vertical program separate from the provision of PMTCT and HIV care and treatment services, PSS is seen as a strategy to maximize uptake and retention and enhance the quality of HIV care for both adults and children.

A study by Wouters et al showed that community support initiatives significantly improved responses to ART among patients in the Free State, South Africa.³ The findings demonstrated that delayed ART initiation reduced ART effectiveness, whereas support from treatment buddies, community health workers, and support groups significantly improved treatment outcomes.

In the Free State study, characteristics associated with successful outcomes after six months of therapy were baseline CD4 cell count ($P < .001$), viral load ($P < .001$), age ($P < .01$), and community-based treatment support (compared to no such support). Support from a treatment buddy ($P < .001$) and community health worker ($P < .05$) significantly increased the chances of a patient having good immunologic and virological outcomes, as did participation in a support group ($P < .05$).³

In Nigeria, Oyeledun et al found that the creation of partnerships with local community organizations to support service delivery to clients through home-based “doorstep delivery” of HIV and AIDS services to clients enhanced linkages between facilities and community-based resources.⁴ Most of these community partners provided PSS services to clients through peer education, support groups, and clinic escort services. Their services were well integrated into clinical care, creating strong links between communities and health facilities.

The lack of integration of HIV services may contribute to loss to follow-up of mother-infant pairs, diminished access to ART services, and other gaps in service provision.



photo: Elizabeth Glaser Pediatric AIDS Foundation

INTRODUCTION

International HIV/AIDS response efforts in recent years have concentrated on the scale-up of comprehensive HIV/AIDS care and treatment services to poor and vulnerable populations, with a focus on expanding access to ART. The resulting increase in access to ART has allowed HIV-positive individuals to live longer, healthier lives, while highlighting the importance of addressing psychosocial issues in this vulnerable population. Any model for the provision of comprehensive care for PLHIV and their families must therefore ensure that clients' psychosocial needs, in addition to their medical needs, are being satisfactorily addressed.⁵

In order to better address psychosocial issues in the context of HIV, programs must increase the level of community involvement in the treatment, care, and support of PLHIV and their families. Achieving this goal will require enhancing PSS services for PLHIV and strengthening linkages between facilities, communities, and community-based care and support organizations. While numerous strategies have been implemented in high-HIV-prevalence settings to strengthen such linkages, PSS remains a significant gap in current HIV programming. Several challenges inhibit the provision of PSS services in resource-constrained settings. For example, there are often insufficient numbers of adequately trained HCWs able to provide comprehensive psychological care,⁶ meaning that PSS services are mostly provided through community-based organizations that do not always collaborate with health facilities. National departments of health must therefore train and mentor HCWs on PSS and review existing PSS guidelines, tools, and job aids to facilitate the implementation of these interventions at facilities where clients receive HIV care and treatment.

A number of PSS approaches have already been successfully integrated into clinical care services for HIV. This report will review some of these approaches in order to highlight potential best practices as well as to share knowledge and experiences accumulated from Foundation country programs and country-level experiences outside Foundation-supported sites. Specifically, several examples will be cited from a recent technical exchange visit by staff from the Foundation's South Africa country program to the Foundation's Uganda program. The visit to Uganda provided an opportunity to not only observe these best practices in action, but also to assess the potential challenges associated with the integration of PSS interventions and other community linkage activities into HIV prevention, care, and treatment services.

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photo: Jon Hrusa

STRATEGIES FOR INCREASING INTEGRATION OF PSS WITHIN HIV/AIDS SERVICES

Peer Educators

The use of peer educators in HIV programs provides an opportunity for the meaningful involvement of PLHIV in the provision of HIV services. Peer educators are usually a group of HIV-positive laypeople trained to provide various services at health facilities and within communities. At Foundation-supported sites in Uganda, peer educators support HCWs in the PMTCT programs and ART clinics. These peer educators are selected from among mothers and fathers who have graduated from the PMTCT program. They receive training and mentoring from Foundation staff and are assigned to Foundation-supported health facilities. Though their primary focus is providing PSS support to HIV-positive pregnant women, their scope of work includes counseling, escorting women to clinics for ART, record keeping, and home visits.

In Kenya, the introduction of peer educators in the antenatal care (ANC) clinic at Lumumba Health Centre, Kisumu, increased the HIV testing acceptance rate among pregnant women from 77% to 89% and reduced the time required for pre-test counseling within the clinic.⁷ Similarly, mothers2mothers (m2m), an innovative HIV and AIDS prevention and treatment support project, uses education and empowerment as tools to prevent mother-to-child transmission of HIV, combat stigma within families and communities, support a mother's adherence to medical treatment, reduce the likelihood of AIDS orphans, and support the transition to ART.⁸

Even though peer educators have been used as a strategy in several HIV programmes in developing and developed countries, the successful integration of peer education into HIV care in a clinical setting requires innovative interventions at the client, staff, and institutional level. The introduction of peer educators into clinical settings requires significant adjustments in work role expectations among staff, and clinics must be willing to spend considerable time problem-solving and developing new procedures to effectively integrate peer educators into the treatment team.⁹

Peer educators have been used in many different roles for HIV education and outreach in clinical settings, but little has been reported on their use for psychosocial and adherence support in ART programs. In Zambia, where HCWs are in short supply, one study found that the use of peer educators in treatment programs could be an innovative strategy for providing quality counseling and adherence support. The study authors recommended that peer educators be considered as an essential part of community-based HIV/AIDS clinical services.¹⁰

At Foundation-supported sites in Uganda, peer educators support HCWs in the PMTCT programs and ART clinics.

Escort Model

The Foundation's South Africa program has observed that the loss of mother-infant pairs between time of referral and actual enrollment into HIV care and treatment may be a major factor limiting access to ART outside PMTCT services in ANC. Some centers have introduced the use of escorts, who may be clinical or nonclinical staff, to accompany mothers to ART clinics and ensure that they are enrolled for further HIV care and treatment.

Pregnant mothers referred from ANC to an ART clinic may feel overwhelmed by the protocols required to enroll into an ART clinic. Many clients are also unable

At Mulago National Referral Hospital in Kampala, Uganda, peer educators escort HIV-positive pregnant women to a special PMTCT follow-up clinic separate from the ANC clinic, where they are registered for HIV care and treatment services.

or unwilling to wait for extended hours and may even be asked to return on a subsequent date just to enroll in another clinic for care. Thus, escorts provide the support such clients need to make the necessary connection between these clinics.

In HIV services, escorts are often volunteers, such as lay counselors or peer educators, and serve to facilitate increased uptake of HIV care and treatment services. In Nigeria, peer educators were successfully used to enhance community referrals to ART clinics and to accompany clients to the clinics for appointments.⁴

At Foundation-supported sites in Uganda, as soon as a pregnant woman is confirmed to be HIV-positive she is immediately assigned a peer educator, who provides individual counseling and support. At Mulago National Referral Hospital (Mulago Hospital) in Kampala, Uganda, peer educators escort HIV-positive pregnant women to a special PMTCT follow-up clinic separate from the ANC clinic, where they are registered for HIV care and treatment services. In Bugembe, a rural health center in Jinja District of Uganda, peer educators are also responsible for escorting mothers to the general ART clinic where they are registered for care and treatment.

Escorts have also been introduced in a Foundation-supported site in South Africa, the George Mukhari Hospital in Gauteng Province, using a cadre of health workers called "PMTCT supporters." These PMTCT supporters are nurses who support counseling and testing of pregnant women attending ANC. They assist the professional nurses who run these clinics with tasks within their scope of work. They are also responsible for escorting HIV-positive pregnant women who are referred to ART clinics for treatment and for ensuring that these clients are enrolled on ART. This has increased the number of HIV-positive pregnant women initiated on ART by ensuring timely enrollment into HIV treatment clinics. Due to the program's success, the use of PMTCT supporters has recently spread to other health facilities in South Africa, including Kalafong Hospital and the City of Tshwane clinics.

Mother-Infant Follow-Up Clinics

Ensuring that HIV-positive pregnant women who require ART for their own health receive timely care and treatment is a key challenge in the integration of PMTCT and HIV care and treatment services at Foundation-supported sites in South Africa. The creation of specialized ART clinics that cater to the specific needs of mother-infant pairs, rather than the inclusion of these patients at general ART clinics, is one way of addressing this challenge.

At Mulago Hospital in Uganda, peer educators escort HIV-positive pregnant women to a special PMTCT follow-up clinic where mothers and infants receive care and treatment throughout pregnancy and postnatally for six months if ART is not required, and for one year if the mother is placed on ART. Thereafter, both mother and child are referred to an ART clinic close to their residence where they can receive ongoing HIV care and treatment. Male partners are also actively encouraged to participate in the health care of their spouses and family through attending the clinics for HIV services and taking part in health promotion activities.

McCord Hospital in Durban, South Africa, has addressed the high loss to follow-up of mother-infant pairs by creating the Mamanengane Postnatal Clinic, a specialized clinic where mothers and infants receiving PMTCT services are followed up for 18 months post-delivery. The objectives of the clinic are to enhance the care of mother-infant pairs and to obtain objective data on long-term health outcomes of the program.



photo: Olivier Asselin

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Services provided to mother-infant pairs through the clinic include HIV testing for infants; health promotion services, such as growth monitoring, nutritional advice, immunizations, and cotrimoxazole prophylaxis; primary health care for infants; postnatal monitoring and care of mothers; PSS; and general and HIV-related clinical support services.

Family Support Groups

Emotional and spiritual support for PLHIV and their loved ones and care partners is an important aspect of positive living. The development of clinical care models must therefore embrace the need for such nonclinical aspects of care and ensure that HIV care is provided using a more holistic, family-centered approach.

PSS groups have been used for many years in the care of chronic illness and provide much-needed emotional and spiritual support to patients. In the context of HIV, such support groups are increasingly common and tend to cater to PLHIV, as well as their domestic partners and children; in some cases, other family members or caregivers are also involved. Groups are often based at the health facility but can also be based in the community.

At Foundation-supported sites in Uganda, PSS groups are based at the health facility and are facilitated by HCWs and peer educators. The support groups provide a forum for clients to receive health information, share experiences, receive mentorship from a peer educator, and receive counseling. Peer educators are attached to sites where support groups are held and help facilitate the groups alongside health workers.

A novel intervention from the Foundation's Uganda program is the establishment of specialized children's support groups called Ariel Children's Clubs. These clubs are specifically for HIV-positive children and are provided at select sites in larger health facilities. The clubs provide life-skills training, play therapy, and counseling services through various activities conducted by club facilitators. The clubs are mostly based at health facilities that provide ART for children, with

children generally recruited into the clubs through the ART clinics where they are receiving care; children can also enter the clubs through community referrals. An offshoot of these clubs is the Ariel Camp, an annual five-day overnight camp attended by select members of Ariel clubs. During the camp, children are taught life and leadership skills and participate in fun educational activities. They also receive additional one-on-one and group counseling. The success of these camps has been documented by the Foundation's Uganda program, and they have been shown to significantly enhance the quality of life of children and families affected by HIV and AIDS.

Invitation Letters to Male Partners

Among the greatest challenges facing providers of PMTCT services is reaching sexual partners of HIV-positive women and persuading them to receive HIV counseling and testing.¹¹ All pregnant women, and especially those living with HIV, need special care to prevent complications and to ensure that any problem is treated right away. Women often require support from their male partners to make advance preparations for childbirth, including making decisions about where they will give birth and setting aside sufficient funds for needed services. Lack of male participation is what prompted the creation of the Love Letter project in the Jinja District of Uganda, which is a program that encourages men to fully support their wives or partners during pregnancy and at the time of giving birth.¹²

The Foundation's South Africa team had the opportunity to visit Jinja and speak with the district health officer overseeing this project. The "love letter" is a special invitation letter given to all pregnant women who visit ANC before their children are born. The letters are addressed to male partners and their purpose is to encourage the men to accompany their partners when they visit ANC. When a man does accompany his partner, nurses take time to talk to him about the health of his partner and the preparations that the couple should make to ensure that both mother and baby will be healthy. The couple is also counseled about HIV and AIDS and encouraged to have an HIV test if either person is of unknown status. If the man and/or woman are found to be HIV-positive, the couple are given advice on how to protect the fetus and receive counseling geared toward giving them hope about their future and guidance on how they can access antiretroviral drugs if they need them.

Anecdotal reports from (Mulago) hospital staff indicate that use of the invitation letters has increased male participation during antenatal and postnatal care of women from the national average of 7% to 15%.

At Mulago Hospital in Uganda, all mothers visiting ANC, regardless of HIV status, are given invitation letters for their spouses. Anecdotal reports from hospital staff indicate that use of the invitation letters has increased male participation during antenatal and postnatal care of women from the national average of 7% to 15%. When women come to the ANC clinic or follow-up clinic with their male partners, they are seen by the clinician ahead of others, providing the added incentive of reduced waiting times. They are also given HIV counseling and encouraged to test for HIV.

Men's Access Clinic

A study from a rural community in Tanzania that explored the role of male participation in PMTCT programs showed that male acceptance and support facilitates PMTCT program implementation.¹⁴ Researchers explored factors that influence male participation through focus group discussions and key informant interviews and concluded that men need to be mobilized to provide community leadership and to be included in community sensitization programs. The study also found that men preferred to receive health information from other men, but that the majority of PMTCT information was entering the community through women attending ANC. Men in the study reported that they felt marginalized by inadequate access to information and the study showed that failure to involve men from the commencement of service provision exacerbated difficulties women experienced with regard to disclosure of their HIV test results and obtaining partner support for accessing PMTCT services.

Another study from Kenya identified several key barriers to utilization of PMTCT services, including both the level of male partners' involvement and women's empowerment.¹³ Delay in male involvement can therefore be detrimental to PMTCT program acceptance, a key reason why male involvement should be seen as a fundamental component of PMTCT programs.¹⁴

A study in Nairobi reported that getting men to come in for HIV counseling and testing significantly improved the uptake of specific interventions for the prevention of vertical transmission.¹⁵ Based on these findings, another study was conducted in Kenya to determine whether male partner involvement would reduce vertical transmission and improve the likelihood of HIV-free infant survival. Results of the study showed that after controlling for maternal HIV viral load and infant feeding modality, 12-month-old children of women whose male partners attended clinics were found to be much less likely to be HIV-positive. Lower rates of vertical HIV transmission were also associated with previous male partner HIV testing (adjusted hazard ratio [aHR], 2.62; 95% CI, 1.32–5.21). These findings suggest that promotion of programs aimed at increasing male partner attendance in ANC and offering greater testing and counseling services in these settings could not only improve infant health outcomes but likely have an ancillary benefit of increasing HIV testing, treatment, and prevention among high-risk discordant couples.¹⁶

At Mulago Hospital in Uganda, a specialized clinic has been established to address the low rates of male involvement in ANC. The weekly clinic, called the Men's Access Clinic, was created for male partners of pregnant women attending ANC, with men invited to attend the clinic through invitation letters sent with their spouses attending ANC. The Men's Access Clinic takes place in the evenings, a more convenient time for men who work during the day. Men receive counseling and testing services at the clinic, as well as health education on various topics. These clinics, together with the invitation letters, have significantly enhanced male participation in the care and treatment of HIV-positive mothers.



photo: Olivier Asselin

Home Visits

Home visits are a very important approach for follow-up of a couple or an entire family affected by HIV. One study conducted in a hospital in Abidjan, Côte d'Ivoire, found that home visits facilitated conflict resolution between married couples, HIV testing of the male partner, and acceptance of the HIV-positive pregnant woman at home and in her spouse's family.¹⁷ During such visits, counselors explained to the husband that his wife, though HIV-positive, could still give birth to an HIV-negative child and that the couple could continue to have sex if they practiced safer sex. From this experience, the authors recommended that national programs integrate home visits as a priority intervention for PMTCT programs.

In Uganda, home visits are conducted at both rural and urban sites as a strategy to follow up defaulters and clients lost to follow-up in PMTCT and ART clinics. These home visits involved various cadres of staff, such as peer educators, counselors, home visitors, nurses, and lab technicians. At Bugembe Health Centre IV, Jinja

The ANC clinic uses a diary system to enter the details of HIV-positive mothers and maintain an appointment system for follow-up care.

District, the home-visit team is comprised of a peer educator, nurse, and laboratory technician (since HIV testing is provided to family members of the index case at home). At Mulago Hospital in Uganda, home visits are primarily conducted by a home visitor supported by a counselor. Home visitors are trained, full-time health workers who carry out home visits.

At Foundation-supported sites in South Africa, home visits are conducted by social workers and lay counselors. Yet while the benefits of conducting home visits have been evident, implementation remains a major challenge due to a number of factors. These include the availability of transportation, the topography of the area where the site is situated, and even the policies of the local health facility regarding home visitations.

To systematically identify clients who would benefit from home visits and to ensure that clients do not miss clinic appointments, a diary and home-visit register is kept by staff at Ugandan health facilities. The ANC clinic uses a diary system to enter the details of

HIV-positive mothers and maintain an appointment system for follow-up care. This diary enables HCWs and peer educators to identify those clients who miss appointments and trace those who may be lost to follow-up. Dates for the next appointment are recorded in the diary. When a home visit is conducted by the peer educator, he or she records the interventions carried out during the visit in the visit register. Some key parameters monitored during home visits are disclosure, adherence, and HIV testing of partners and other children.

SUMMARY: PSS INTEGRATION IN THE SOUTH AFRICAN CONTEXT

Seven main strategies utilizing PSS interventions have been identified in this report. These are: use of peer educators in clinical settings, use of escorts to decrease loss to follow-up, family PSS groups, invitation letters to male partners of pregnant women, specialized clinics for male partners of pregnant women, home visits, and mother-infant follow-up clinics. HIV programs in resource-limited settings should embrace the concept of integrating HIV services at all levels, bearing in mind that PSS support is an essential core component of care for HIV-positive individuals.

The experiences cited in this report from Uganda and elsewhere demonstrate the importance and potential benefits of integrating PSS into existing HIV services. Successful implementation of PSS interventions will also require a high level of community participation and strong linkages between the health facility and the community. The Foundation's South Africa program plans to incorporate a number of the strategies cited into its service delivery model, modifying the interventions according to the specific needs and challenges at each supported site.

The South Africa program has already made progress toward achieving its goal of integrating PSS interventions into HIV prevention, care, and treatment services through the employment of several strategies. One such strategy involves the recruitment of a community linkages manager and officers to support health facilities. Their role is to facilitate the development of community initiatives integrated within clinical HIV services. The program, through the community linkages team, has also begun to train HCWs on how to establish or strengthen existing support groups for PLHIV. The team is also putting in

The South African Department of Health has commenced a 69-day training that will allow the lay counselors to transition from lay staff receiving a stipend to a permanent cadre within the department's human resources structure.

place measures to enable the establishment of child-focused support groups for children living with HIV. Ariel clubs will be launched in early 2010. This model is concurrently being adopted in other Foundation-supported countries, such as Rwanda and Tanzania.

The program has also recruited several lay counselors who support clinical staff in the provision of HIV counseling and testing services in ANC. Lay counselors are nonclinical staff who are recruited and trained for 10 days in HIV counseling and 3 days in voluntary counseling and testing. Their presence in clinics complements the role of the nursing staff while providing nurses with more time to attend to clinical aspects of care. The South African Department of Health has commenced a 69-day training that will allow the lay counselors to transition from lay staff receiving a stipend to a permanent cadre within the department's human resources structure.

As mentioned earlier, some sites in Gauteng province have another cadre, called PMTCT supporters, who assist with HIV counseling and testing in ANC, some clinical aspects of care, and the escorting of clients referred to the ART clinics. Enrolled nurses and auxiliary nurses are recruited to fill these positions and are given in-service training on PMTCT and voluntary counseling and testing to assist them with their role in ANC.

Realizing that community support and participation are critical to the success of the comprehensive care and support program for PLHIV and their families, the Foundation's South Africa program has begun a small grants program to provide more direct support to community-based organizations and faith-based organizations. This Community Awards Program will award grants to organizations with innovative projects that support HIV care, support, and treatment for PLHIV, especially women and children.

Conclusion

Experiences at Foundation-supported sites and elsewhere have shown that clinical interventions for HIV are essential but that their impact and effectiveness can be greatly enhanced by complementary services like PSS initiatives. Strengthening self-efficacy—a person's belief about his or her capacity to accomplish a task or to overcome challenges—is critical to enhancing a client's commitment and participation in lifelong management of any chronic disease, including HIV. It is believed that PSS initiatives contribute to improved self-efficacy among clients accessing HIV-related services, but further research is needed to understand the specific mechanisms by which such initiatives enhance HIV service delivery and outcomes.

In order to integrate PSS into HIV services, programs must identify existing gaps as well as opportunities to mainstream PSS initiatives. A paradigm shift from vertical programming to integrated programming is required before health services can successfully integrate PSS services. Integration often requires changes in policy, the decisions for which are enacted at various levels of health service provision. However, national policy change can be a long and arduous process and health facilities must therefore identify which changes can be made at the site level and which will require engagement and advocacy at higher levels of decision making.

PSS initiatives, just like any other program intervention, also require adequate human and financial resources. Under-resourcing is often a direct result of the lack of integration. For example, peer educators will receive allocation for stipends in an HIV program if they are included in the staffing requirements for a health clinic just like other clinical staff, but may be overlooked if seen as a separate program. The integration of PSS interventions into clinical settings also requires significant adjustments in work role expectations by other staff and clinical work flows. Clinics must be willing to spend considerable time problem-solving and developing new procedures to effectively integrate PSS interventions. By the same token, policymakers and national health program leadership should be made aware of the numerous benefits of these initiatives, so that they are no longer considered to be inferior to other more clinically focused program interventions.

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Mbabane H100, Swaziland
P: +268-404-8081
F: +268-409-0026

TANZANIA

Plots 8 & 10 Off Haile Selassie Road
P.O. Box 1628
Dar es Salaam, Tanzania
P: +255-22-260-1692/4
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UGANDA

Plot 31 Main House Nakasero Road
P.O. Box 21127
Kampala, Uganda
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ZAMBIA

Plot # 2B Zimbabwe Road
Rhodes Park
Lusaka, Zambia
P: +260-211-256-481

ZIMBABWE

143 King George Rd., Avondale
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P: +263-(0)4-302-572 or +263-(0)4-302-625
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