Knowledge is power:

Voluntary HIV counselling and testing in Uganda



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Foreword

The AIDS Information Centre (AIC) was established in February 1990 to provide anonymous, voluntary and confidential HIV testing and counselling services to the people of Uganda. The Centre operates with the understanding that knowledge of one's own HIV infection status is an important intervention in controlling HIV infection.

High public awareness of HIV and the increasing numbers of persons sick and dying with AIDS resulted in many Ugandans wanting to know their sero-status. Because there were no voluntary testing and counselling sites, people began donating blood in order to learn whether they were infected with HIV, and a few private laboratories began offering HIV testing. The private labs did not provide any counselling at all. The establishment of AIC was a response to the growing community need for knowledge of sero-status.

Since 1990, AIC has served more than 370,000 clients in Kampala and at branch offices in Jinja, Mbarara and Mbale. AIC's services include: same-day HIV testing & counselling, on-going psychosocial and medical support through the Post Test Club, counselling and treatment for sexually transmitted diseases and other medical problems, TB information and referral, training of Peer Educators, family planning services, condom distribution and community outreach programmes.

This Best Practice Collection Case Study has been prepared together with the Joint United Nations Programme on HIV/AIDS (UNAIDS) in an effort to share our experience with HIV testing, counselling and associated services at AIC in Uganda. It is our hope that this document will inform and inspire others in their AIDS prevention efforts.

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Special thanks go to the staff of AIC who have served hundreds of thousands of AIC clients with commitment and respect. We are grateful to our Board of Directors whose wisdom and guidance on all programme and policy matters has kept AIC afloat and we appreciate the collaborative and healthy working relationship that we enjoy with the Government of Uganda through the Uganda AIDS Commission and Ministry of Health. We also thank our sister agencies who complement our services, such as The AIDS Support Organisation (TASO), the Islamic Medical Association of Uganda (IMAU) and Nsambya Home Care Programme.

Additional thanks go to the donors who have enabled us to provide HIV counselling and testing services in Uganda. Over the years we have received generous support from the United States Agency for International Development (USAID), the Department for International Development, UK (DFID), the United Nations Children's Fund (UNICEF), German Development Services (DED), United Nations Fund for Population Activities (UNFPA), UNAIDS and the Government of Japan.

Finally, we thank all those who made it possible to produce this Best Practice Case Study. Over the years, AIC staff have consistently collected and analysed data that

have been an invaluable resource in analysis. Both AIC staff and clients have also participated in many helpful interviews. In closing, we thank UNAIDS for funding the preparation of this Case Study and making it possible to share the AIC experience with other people in other parts of the world.



Country Profile HIV/AIDS in Uganda

Following a lengthy period of devastation, Uganda is now rebuilding, with bealthy but fluctuating economic growth rates. The cash economy is beavily dependent on coffee, while the population is sustained mainly on subsistence agriculture. As one of the first countries in Africa where HIV was recognized, the effect of the AIDS epidemic in Uganda has been severe. AIDS was first reported in Rakai District in 1982, 180 km outside the capital city of Kampala. HIV rates increased rapidly throughout the country and by the late 1980s it appeared that Uganda had the highest rates of HIV infection in Africa, and indeed in the world.

Beginning in 1993, there have been declines in the rate of HIV infection in pregnant women and studies in other population groups have also shown lower rates of new infections and lower rates of prevalence of HIV infection. Similar declines have been observed in few other countries and, as a result, UNAIDS now estimates that many countries in eastern, central, and southern Africa now have higher rates of HIV infection than Uganda.

Total population	20.4 million	
Urban population	2.2 million	
Annual population growth rate 2.59		2.5%
HIV infection rate in	adults	9.5%
	(UNAIDS 1998	estimate)
Infant mortality rate		97
	(per 1000 liv	re births)
Life expectancy	41	years
Literacy rate	Male	68 %
	Female	: 45 %
Per capita GDP (US\$)		240
Surface area	2410	38 km²
	2110.	JO KIII

Source:Population Secretariat, Ministry of Finance, Planning & Economic Development, 1998; World Health Report, 1998; Report on the Global HIV/AIDS Epidemic, UNAIDS, 1998.





Country profile _ EDGE | S POWER

As of 1998, UNAIDS estimates that 930 000 Ugandans are living with HIV infection or AIDS. In adults, the infection rate is estimated to be 9.5%. It is estimated that 1.8 million Ugandans have already died of AIDS and there may be as many as 1.7 million children who have lost their mothers or both parents to AIDS. In 1997, it is estimated that 160 000 Ugandans died of AIDS.

In 1986 the Government of Uganda responded to the AIDS epidemic by becoming one of the first countries in Africa to collaborate with the World Health Organization to create a national AIDS control programme. The National AIDS Programme includes 13 AIDS Control Programmes operating out of 12 Government Ministries. The Uganda AIDS Commission is charged with coordinating the overall programme which has carried out extensive education campaigns aimed at preventing further spread of HIV. Strategies for HIV prevention in Uganda include: promotion of safer sexual behaviour, prevention and treatment of STDs, condom education and distribution, HIV counselling and testing, and

Global estimates of the HIV epidemic - 1997

Region	Adults and children living with HIV/AIDS
Eastern Europe & Central Asia	190 000
North Africa & Middle East	210 000
Caribbean	310 000
East Asia, Pacific & South Pacific	432 000
Western Europe	480 000
North America	860 000
Latin America	1300 000
South & Southeast Asia	5800 000
Sub-Saharan Africa	21 000 000

Source: Report on the Global HIV/AIDS Epidemic, UNAIDS, 1998.

community mobilization in support of behavioural change.

The official government policy on condoms is that of quiet promotion. While condom promotion has met resistance from certain quarters in the past, this appears to be diminishing. Large-scale importation of condoms is being undertaken with support from USAID and the Government's Sexually Transmitted Infections Project (STI).

Country profile _ EDGE | S POWER

The main mode of HIV transmission in Uganda is unprotected sexual intercourse. Education campaigns also note the dangers of unsterile skin piercing or cutting instruments. Systems, guidelines and procedures for minimizing HIV infection through blood transfusions were developed during the first years of AIDS prevention and control.

Recent declines in HIV incidence and prevalence

Beginning in 1993, rates of HIV infection in pregnant women attending antenatal clinics at selected sentinel sites began to decline. These declines have continued steadily through 1997. Particularly striking have been the declines in young pregnant women aged 15 - 19 years. Among this age group, in two large antenatal clinics in Kampala 28% were HIV infected in 1992. This rate had declined to 8% in 1997. These declines in incidence are consistent with a 50% decline in incidence of HIV infection in this age group. HIV prevalence in a different population - those seeking voluntary counselling and testing (VCT) - has declined between 1993 and 1997 from 23% to 15% among males and 35% to 28% among females.

Most public health workers believe that declining rates of HIV infection in Uganda are a result of many factors, including: the government's open and assertive response to the epidemic; education and prevention efforts implemented by government; religious groups and various community organizations; the active role played by nongovernmental organizations (NGOs) in providing care and support to persons living with AIDS (PWAs); and consistently high levels of donor support for these programmes.

Care and support

The vision of the Ministry of Health is to have PWAs cared for in the home by family members or community AIDS care providers. Several Ugandan NGOs and community-based organizations (CBOs) are intensively involved in the provision of AIDS care, such as TASO, which has eight centres in various parts of Uganda, and the mobile home care programmes operated by several mission hospitals, including Kitovu Mission Hospital in Masaka, Nsambya Hospital and Mengo Hospital in Kampala, and the Jinja Diocese. Unfortunately, the number of individuals requiring care far outnumbers the services available, particularly in the rural areas.

Education and community mobilization

Uganda is noted for the numerous agencies and institutions that have been active and effective in educating

Country profile _ EDGE S POWER



A Ugandan woman with AIDS.

the population about AIDS and how to avoid infection. These groups have also mobilized communities to support changes in social norms and practices that encourage risk reduction. For example, TASO has not only provided care and support to more than 50 000 PWAs and provided extensive AIDS education in communities, but has also trained hundreds of community workers to provide basic care and health education about AIDS. The Church of Uganda (Protestant), the Catholic Church, IMAU and other religious groups have been active in community education, have trained religious leaders and lay workers, and have encouraged changes in attitudes and behaviours.

Numerous non-sectarian agencies and CBOs, including the Young Men's Christian Association (YMCA), the Young Women's Christian Association (YWCA), the Rakai AIDS Information Network and many others have developed projects to educate special groups and to extend education efforts throughout local communities. Formal agencies and institutions, such as the Federation of Uganda Employers, local businesses, the police and the national army, have developed "AIDS in the Workplace" projects for their employees.

History of AIC

The vision was not that of any one person or group, but that of many individuals and organizations.

▲ broad range of HIV/AIDS education and awareness campaigns in Uganda since 1986 has resulted in many Ugandans asking the question Am I infected? and a growing demand for HIV testing. Before the opening of AIC, there were few HIV testing services in Uganda and almost none with associated counselling programmes. Before long, an enormous burden was placed on the national Blood Bank where many Ugandans interested in knowing their HIV status went to donate blood. The Blood Bank was not able to offer supportive counselling, and donating blood for the purpose of learning one's sero-status was an expensive misuse of blood banking services.

In response to the growing demand for testing, several organizations got together to discuss the need for anonymous and voluntary counselling and testing services in Uganda. These organizations included: the Ministry of Health's AIDS Control Programme, Nakasero Blood Bank, Uganda Virus Research Institute (UVRI), TASO, USAID, InterAid, World Learning, Inc., Uganda Red Cross, Makerere University Faculty of Social Science, and the World Health Organization (WHO). The result of these collaborative discussions was the opening of AIC, in February 1990, under the direction of the late Lydia Barugahare, a Ugandan nurse trained in the United Kingdom.

Offering Ugandans an HIV counselling and testing service distinct from the Nakasero Blood Bank (the national blood bank) had a tremendous positive impact. From 1989 to 1995 the amount of blood given by volunteer donors at Nakasero increased by over 400%, while the rate of HIV found in donations fell from 14% to 2%.

History of AIC LEDGE S POWER

In the beginning, AIC provided services Kampala, the national capital, in through a main office in a downtown office building and several satellite sites in the Kampala area. Clients received VCT over the course of two visits. receiving test results after two weeks. In its first 11 months of operation, AIC provided VCT to more than 9000 clients. This well surpassed the target of 5000 clients expected in the first year and confirmed the strong interest in VCT, which has continued up to the present. In eight years, AIC has grown from a single office with four staff into a multifaceted centre with four branches employing over 80 people. Since 1990 AIC has served over 380 000 clients.

In 1997 AIC merged its Kampala operations and opened its current headquarters in Kisenyi, an impoverished neighbourhood near the nation's largest public transportation hub and Kampala's largest outdoor market.



By 1993 district branches were opened in Jinja, the major industrial city of Uganda, Mbarara, the largest city in the western region, and Mbale, near the Kenya border. Demand rose sharply from 1990 to 1993, and fell slightly in 1994. Large client numbers early on were partly a result of the numerous satellites that AIC operated. Owing to high operational costs, satellite services were curtailed and as a result the total numbers coming to AIC declined, stabilizing at about 40 000 annually. Demand has increased in 1998.



Satellite services

In an effort to serve Ugandans living in peri-urban and rural areas, AIC began operating satellite sites in 1992. These sites were in various locations, including health centres, community centres and churches. AIC counsellors and phlebotomists traveled to these sites either once a week, bi-weekly or

History of AIC LEDGE S POWER

monthly. Blood samples were transported back to Kampala for testing with counsellors returning to the site, with test results, two to four weeks later. By 1995, 20 satellite sites were operating. Although this worked well in some areas, there were numerous problems with the approach.

Some sites had low numbers of clients with high costs of transporting staff, resulting in high expenses per person served. Overall, the problem with satellite sites was one of logistics. Blood samples were transported from a satellite site to an AIC Branch, to AIC Headquarters, then to the Blood Bank. HIV test results were then taken from the Blood Bank to Headquarters for data entry, to the AIC Branch, then back to the satellite site. Given the complexity of the routing, it was not unusual for a client to return to a satellite site only to find that their test results were not ready. Since few if any rural clients have telephones, it was not possible to notify these clients in advance. Hence, some clients took unnecessary long walks or expensive trips and were too discouraged to return a third time.

This experience demonstrated that affordable VCT for rural clients necessitated a decentralized approach with counselling and testing performed locally, with same-day results.

Increasing availability of VCT by decentralization

AIC worked with health officials in 16 districts to address the sustainability of VCT and the need for integrated services. The result was an AIC expansion strategy that included integration of VCT into existing health facilities, at the district

History of AIC LEDGE S POWER

Lessons learned in the expansion of VCT:

A lack of financial incentive for local heath personnel results in inconsistent and unreliable services.

Confidentiality is difficult to maintain in small communi-ties.

Former AIC satellite sites serve more clients and run more smoothly than sites where VCT has never been offered.

Regular and frequent supervision and monitoring is essential to maintain quality control over both counselling and laboratory testing services. level, and technical assistance and training for district personnel. In hand with this AIC introduced a pilot protocol for rapid testing with same-day results, as well as procurement and distribution of test kits, support supervision, monitoring and evaluation.

The expansion strategy required that AIC reorganize itself in order to provide adequate capacity for managing both the main branch and indirect sites. Collaboration was sought with district medical and political authorities and Memoranda of Understanding were signed. The stages of expansion included: needs assessment, site selection, personnel training, setting-up of VCT facilities (in district hospitals and health centres), assessment of performance and phase-out. By 1998, 35 VCT sites were operating at hospitals and health centres, and over 5000 clients had received VCT.



In the laboratory at AIC, Kampala

AIC Today An Overview

AIC aims to contribute to the national efforts to prevent further spread of HIV infection, to enhance the psychosocial adjustment of those already infected, and to promote the adoption of healthy lifestyles.

AIC currently offers:

- voluntary and anonymous HIV counselling and testing,
- rapid syphilis testing and on-site treatment for those testing positive,
- syndromic detection and management of other STDs,
- condom education and distribution,
- information about family planning and FP counselling and commodities,
- TB education and referral,
- psychosocial and medical services through the Post Test Club,



The AIC Jinja Drama Group

AIC TODAY VLEDGE IS POWER

- food supplementation and peer support through the Post Test Club,
- special services for discordant couples, and
- the Philly Lutaaya Initiative, with HIV-positive clients "going public" to advocate for VCT and behavioural change.

AIC also provides a number of training services to other organizations and health care providers in districts where AIC does not have a branch. AIC trains health workers in HIV test counselling, integrated HIV/STD/family planning counselling, the use of rapid tests for same-day results, and record keeping. AIC extends its monitoring and support supervision to non-AIC sites offering VCT, and supplies a limited number of test kits to selected sites. Community mobilization and referral in districts without AIC branches are supported through outreach activities such as the Philly Lutaaya Initiative.

The collection and evaluation of data, and various research projects, are an important part of AIC's activities. Hundreds of professional and international visitors come to AIC every year to learn about AIC services while AIC representatives make frequent presentations at international conferences.

AIC TODAY VLEDGE IS POWER

AIC's Objectives



- To establish facilities where the public can go for information on HIV/AIDS, counselling and testing.
- 2. To reduce transmission chains through continuous counselling.
- To promote public awareness and understanding about HIV/AIDS through diverse educational programmes.
- To collect, prepare and disseminate scientific information concerning patterns and prevalence of HIV/AIDS.
- To stimulate and assist the formation of AIC branches throughout the country.
- To decrease the number of people who go to the Blood Bank to find out their HIV status.
- To contribute to the advancement of AIDS treatment and the treatment of related infections and diseases.
- To organize and participate in educational programmes that publicize AIC activities.
- 9. To train appropriate professionals, such as medical, health and social workers, in HIV/AIDS counselling.
- To cooperate and collaborate with other national and international organizations, and government agencies, involved in the fight against AIDS.
- To ensure and maintain satisfactory standards of anonymity and confidentiality with our clients.

Geographical distribution of AIC Services



Map produced by UNICEF Uganda LP/WS – 30 June 1998 All boundaries are approximate

AIC operates main branches in Kampala, Jinja, Mbale and Mbarara. AIC is in the process of decentralizing its HIV counselling and testing services better to reach 16 districts in Uganda: Jinja, Kamuli, Kampala, Luwero, Masindi, Masaka, Rakai, Ntungamo, Mbarara, Kasese, Tororo, Kumi, Pallisa, Kapchorwa, Soroti and Mbale. Services are currently lacking in North and North-east Uganda. This has been a long-standing gap. Support from the European Development Fund (EDF) has made it possible to develop a five-year proposal to expand availability of HIV CT services in these areas.

Who comes to AIC and why?

Demographic characteristics and HIV rates in clients







Gender

In AIC's first year of operation, the gender distribution was skewed, with 66% of clients being male. With time, the number of women increased and in 1997, 49% of AIC Kampala clients were female. In sites outside Kampala the numbers remain sightly skewed, with females accounting for 44% of clients in Mbale, 45% in Jinja and 47% in Mbarara. Overall, 47% of clients are women. An eight-year trend at AIC shows that women clients are more likely to be HIV infected than male clients.







Age

About half of AIC's clients are young people between the ages of 20 and 29 years. This trend has been consistent over time, and is similar at all AIC sites. Infection rates vary considerably by age with older clients being more likely to be infected. In 1997, there was a consistent pattern that women were more likely to be infected than men in *all* age groups.



Education

AIC operates in the four main cities of Uganda, which probably contributes to the high rates of education among AIC clients.

In 1997, 57% of AIC clients had some secondary or postsecondary education; only 7% reported no education. This distribution was similar in all sites. Clients with at least secondary education ranged from a high of 63% in Mbale to a low of 46% in Mbarara. The Mbarara branch served the highest percentage of clients with no education (12%).Other sites ranged from 3% to 9% for clients with no education. A consistent pattern observed among AIC clients has been that clients with little or no education are more likely to be infected than those with more education. The lower chart presents these findings for 1997. Similar findings have been observed throughout AIC's history.



Marital status

About half of AIC clients are single, many of them coming for testing before marriage or before starting a sexual relationship with a new partner. Most single clients are also young. Single clients are much less likely to be HIV-positive than other clients. Those who are divorced, separated or widowed have higher HIVpositive rates than those who report that they are currently married.





Location where VCT was provided and HIV rates at these service sites

Clients served at health centres and hospitals are more likely to be HIV-positive because they have often been referred by their doctors for confirmation of a clinical diagnosis of AIDS.

How do clients find out about AIC?

Although many clients are referred to AIC by sister organizations such as TASO, word of mouth continues to be the way most people find out about AIC. Former clients pass the word onto friends while Post Test Club members are responsible for many referrals. Publicity in the local media about "free days" also brings in large numbers of clients.



Why do clients come?

Clients come to AIC for a wide variety of reasons. Interest in VCT is often "social", with clients showing interest in knowing their serostatus before getting married, embarking on a new relationship, or making plans for the future. Pre-marital testing has increased over time and no doubt explains the increasing percentage of couples who come together. "Medical" reasons for VCT, such as feeling ill or having symptoms of AIDS, are cited less frequently.

Although rarely mentioned in AIC's early years, 5% of AIC clients in 1997 mentioned pregnancy as a reason for requesting VCT. Some of these clients wanted to know their sero-status before becoming pregnant; others were already pregnant. Recent findings that short-course zidovudine (AZT) treatment can reduce mother-to-child



HIV transmission, and that such treatment may become available in Uganda on a wider basis, have been well reported in Uganda's press and may explain the recent increase in mentioning pregnancy when requesting VCT.

Infection rates among clients vary considerably depending on the reason for requesting VCT. Those who come for pre-marital testing have the lowest rates, at 5% for males and 7% for females. Those who want to use HIV test results to help them plan for the future have somewhat higher rates, as do those who report that they are worried or fear they have been exposed. As seen below, those who already feel ill or have HIV symptoms have very high rates of HIV infection.



HIV counselling and testing



"We bave learned bow you provide testing and counselling all in one day, so that clients get their results without waiting. The message that we bave learned from this is being taken bome to the US to try and implement."

First Lady Hillary Rodham Clinton speaking at AIC, March 28, 1997

How does it work?

A IC provides VCT to about 130 clients everyday in four sites in Uganda. More than 50% of AIC's clients are served at the main branch in Kampala.

The original AIC protocol (1990-97) involved two client visits. In the first visit, called "pretest counselling", clients received a general orientation to HIV/AIDS, HIV tests and their meaning, counselling designed to help clients decide whether or not to be tested, and counselling about how to prevent HIV transmission. At the end of pre-test counselling, clients had their blood drawn and were given an appointment to return in two weeks for test results. In the second visit, clients received "post-test counselling", learned their test results, received additional counselling and referral to other services such as the Post Test Club, TASO, and other AIDS support organizations.

On average, 25% of clients failed to receive their test results, either by not returning for the second visit or by returning but being discouraged when results were not ready. As rapid testing became more accurate, AIC decided to conduct trials to determine whether the laboratory protocol and the counselling protocol could be changed such that clients could receive counselling and HIV results all on the same day.

Trials in 1995 and 1996 showed that same-day services were desired by clients, preferred by staff, and feasible to implement, even at rural sites (Downing *et al.*, 1998; Kassler *et al.*, 1998).

As a result, the rapid testing and same-day protocol was implemented in 1997.



n. Today, clients arrive at AIC and are directed to the reception area where they are met by a receptionist. Here they help fill-out the top section of an AIC Counselling & Testing Card (see Appendix A) with brief demographic information. Each client is given a code number and information is collected such that client confidentiality is insured while at the same time impostors can be prevented from seeing client records at later dates. Information on Testing Cards helps counsellors familiarize themselves with clients and support AIC data analysis and research.

When the top section of the Testing Card is complete, the receptionist gives the client the tear-off strip at the bottom bearing the client code number and asks the client to take a seat in the waiting room until a counsellor is ready.

In the waiting room, HIV/AIDS education brochures are available for reading, health edu-



AIC Kampala waiting room.

cation posters decorate the walls, and a variety of HIV/AIDS and other locally produced health education videos are shown. In Kampala, the busiest site, clients wait an average of 20 to 30 minutes before joining a counsellor. At other sites, clients wait only a few minutes.

VCT clients participate in a four-step process: (1) test decision and orientation, (2) phlebotomy, (3) prevention counselling, and (4) test results counselling. The process includes group and/or one-on-one sessions with a counsellor. If particular clients or couples prefer not to participate in group counselling, they can request all services on a one-on-one basis. The entire process takes two to three hours, as described below.



Alice counsels a group of clients.

VCT with Alice

Alice is a typical AIC counsellor. She is a nurse who formerly worked at Makerere University Hospital. Other counsellors have backgrounds in teaching, social work and medical fields. Alice is skilled in conducting counselling sessions for individuals, groups or couples. She usually sees clients in groups of five.

Alice helps clients to:

- make an informed decision to take an HIV test, or decline to do so,
- understand test results,
- personalize risk, and
- develop a risk reduction plan based on test results.

Alice begins her day by going to the waiting room and collecting her first group of clients. If there are few clients waiting she may take clients one at a time. If she works with a group, she arranges the chairs in her counselling room in a circle.

1. <u>Test Decision and Orientation</u> (5 - 15 minutes)

Alice introduces herself and asks for each client's consent to be counselled as a group. She informs the clients that certain parts of the counselling process will be done one-on-one, such as the giving of test results. Alice explains AIC's policy of confidentiality, fee-for-service and that no certificates will be issued. She announces that test results will be ready 1.5 hours after blood is drawn and that clients can choose not to have their blood tested.

In AIC's experience, almost all people who come to AIC have already considered the advantages and disadvantages of taking an HIV test, and have firmly made up their minds to be tested. Thus, the "test decision portion of the counselling session is not lengthy.

Alice engages the group in a discussion, asking each client in turn: *Wby have you come?* and *Are you ready to receive your results?* She explains that the AIC laboratory will be testing for HIV as well as syphilis and that AIC has services to treat STDs. She also discusses AIC's family planning services, referral system and Post Test Club.



"I want my future wife to know she is getting the right person. And I want to be sure that she is right for me. We are not required to be tested. We have chosen to come. Now that we have found out that we are both HIV-negative, we can start life fresh and we can trust."

Ismail Kyondo

Each client meets with Alice, one-on-one, to fill out the middle portion of their Testing Card (Appendix A), which includes questions about the client's sexual behaviour. Answers to these questions give Alice an opportunity to learn about the client's HIV risk level. Alice explains that clients registered as couples must witness their results together and that clients registered as individuals can request to have someone else (for example, a partner or family member) witness their test results with them. After the client has signed the Client Consent Form, Alice asks: *Do you have any personal questions you would like to ask?*

2. Phlebotomy (5 minutes)

In turn, each client pays the phlebotomist a userfee and has blood drawn. Clients confirm that the number affixed to their blood sample is the same as their Client Code Number.

3. Prevention Counselling (45 minutes)

Group members convene again. Alice leads a discussion designed to educate the group about

HIV/AIDS. She alerts clients to the "window period" and the fact that negative test results may not be correct if the client has engaged in risky sex in the last three to six months. She discusses the meaning of an HIV-positive and an HIV-negative result, and AIC services such as family planning, STD management, TB referral and the Post Test Club.

Alice poses the following questions and elicits group participation:

- What is the difference between HIV and AIDS?
- How do we get HIV?
- Why do untreated STDs put us at risk of HIV infection?
- Why is it necessary to be tested again if you have recently had unprotected sex?
- If you are HIV-positive, who will you tell and what will it mean to you? What measures can you take to prolong your life and insure that you do not pass it on?

Alice gives everyone an unopened condom package and shows how to check for expiration or damage. She then uses a wooden model of an erect penis to demonstrate proper condom use. Each client takes a turn putting a condom on the wooden model. Meanwhile, the laboratory is conducting the tests. Although some clients may be distracted during the prevention counselling session owing to anxiety over learning test results, most counsellors find that clients readily participate.

When the prevention counselling session is complete, Alice has the clients wait outside her coun-

selling room as she prepares to give test results, one at a time. Alice collects the results from the lab in a closed folder, to ensure confidentiality.

4. Test Results Counselling (5 - 15 minutes) Alice meets with each client individually and gives test results. She reveals results using a professional manner, without feeling sorry or being congratulatory. She simply says: "*The virus which causes AIDS has (has not) been found in your blood.*" If a client is HIV-negative she makes sure that they understand that the result is only accurate if the client did not expose themselves to a risky situation, such as unprotected sex, unsterile injections or transfusion with untested blood in the three to six months preceding the test. If a client admits to a potential exposure, Alice encourages them to return in three to six months for another test.

Alice asks each HIV-negative client how they intend to maintain their status. If the client is interested, she gives them free condoms. Almost all clients welcome free condoms as well as advice on how to negotiate using a condom with their partner. HIV-positive and -negative clients are urged to join the Post Test Club to help them adopt and/or maintain risk reduction behaviour. Clients are urged to return for additional counselling if they feel the need, and to return for testing if they engage in risky behaviour.

During the HIV testing of blood samples, each client's blood is also tested for syphilis, using the Rapid Plasma Reagin (RPR) test. All clients who test RPR positive are offered a free penicillin injection, STD counselling and assistance with partner notification.

A Counsellor Speaks Out

Some of our most challenging cases are couples who arrive seemingly healthy and discover they are discordant — one partner is HIV-positive, the other is HIV-negative.

If the husband is positive, sometimes he will say: "I have been with my wife for a long time and she has not been infected yet. Why should we start using condoms now?" He will take the free condoms we offer and the wife will return later and tell us he is refusing to use them. We ask these women, "How much do you value your life? God has been kind to you, but for how much longer?" We help these women understand the risks. but in the end clients have to make their own choices.

Another challenge is counselling girls who come in with a "Sugar Daddy" — an older man who intends to marry them. As with all couples, we seek the couple's consent to counsel them separately. In this way, in a discussion with the girl, we often find that it is her paternal aunt who has chosen the man. The girls are usually school drop-outs. They think they will be protected from HIV if they marry. Sometimes we can convince the girl to visit us with her aunt. The men often say they are not concerned about family planing or contracting HIV after marriage.

If a client is HIV-positive, Alice reviews AIC's services and encourages them to join the Post Test Club. If a client has a cough or other symptoms suggestive of TB, she recommends that the client go for a TB test at the National TB Control Programme, and shares with them research findings that show that early treatment of TB in HIV-positive clients can improve the quality and length of life.

The above pattern of service delivery is consistent at all AIC sites. Variation between sites relates to the high volume of clients seen at the Kampala branch. Large numbers result in more group counselling sessions, more couple sessions and longer waiting periods, though efforts are made to make waiting periods as short as possible.

Special Challenges in VCT

Servicing couples

AIC clients are either served as individuals or couples. Routine data collected from clients since 1992 show an increase in the proportion of clients being served as couples, from 9% in 1992 to over 26% in 1997. AIC believes this is a positive sign. Couples are one of the most important targets for VCT, and adoption of risk reduction behaviour is often enhanced when couples receive both test results and prevention counselling together.

Analysis of HIV infection rates in couples reveals several interesting patterns. Overall, clients who come as couples have much lower rates of HIV

Alice

infection than those who come as individuals. Among couples who are already married, AIC data reveal that 18% of married couples are discordant and 15% of married couples are both HIV infected. AIC counsellors find it difficult to explain discordant results to couples who had been having unprotected sex. Counsellors also find it difficult to explain HIV-negative results to couples who are engaging in high-risk behaviour outside their marriage. In an effort to answer these perplexing questions, AIC embarked on research to learn more about discordant couples and high-risk negative couples, and how best to serve them. The 12-month research project is studying issues related to variability in transmission rates. Findings will be available in late 1999.



VCT for pregnant women

Recent research from Thailand has found that a short course of AZT during the last three weeks of pregnancy and during labour and delivery can significantly reduce the chance that a baby will become infected with HIV. These findings have been reported in Uganda's press and there is now



Drawing blood at AIC Jinja

increasing interest among pregnant women to get tested and, if positive, try to get access to AZT treatment. UNAIDS and UNICEF are now developing pilot programmes in Uganda to make AZT treatment in pregnancy available. As this is likely to affect the demand for VCT among pregnant women, AIC counsellors are now being trained in issues related to VCT during pregnancy.

The Laboratory

Up until 1997, blood was drawn from AIC clients on-site and testing was done "off-site" at the Nakasero Blood Bank (NBB). Standard ELISA tests were used with confirmation of positive test results. The entire process of sending blood samples to the NBB central laboratory, testing, recording of results, and distribution of results from NBB



to AIC's headquarters and then to AIC's four branches. took two weeks. After several trials with alternative an using system rapid HIV tests, a rapid testing and counselling approach was introduced in 1997 that made it possible to provide counselling and test results within one twohour visit.

In 1997 AIC set up simple laboratories at each of the four main branches. All HIV testing is now done "on-site" at AIC's four main branches, although 5% of samples are re-tested for quality control at NBB. In addition, selected samples, such as those which are "weakly reactive" and those which are negative but the client reports known exposure to HIV, are re-tested at the Uganda Virus Research Institute.

At the time of this study, the Capillus test (Cambridge Diagnostics) is AIC's screening test. Confirmatory testing of all positives is carried out with Serocard (Trinity Biotech). If Capillus and Serocard are discrepant, a Multispot Test (Sanofi Pasteur Diagnostics) is done.

Several problems have been observed with this algorithm and the test kits. First, the kits require refrigeration that is often unavailable at rural hospitals and health centres. Second, the packaging of these tests as part of a "kit" with 40 or 50 tests means that sites with low volume may use such small numbers of the confirmatory test that the kit expires before all tests are used. This is especially a problem with the third test, or the "tie breaker", which is very seldom used at rural sites but comes in a package of 50. A single-use kit that could be stored at room temperature would reduce waste considerably.

Research before the introduction of same-day rapid HIV testing showed that 85% of clients preferred to receive same-day results. Counsellors easily adapted to the new procedure and service delivery was improved overall. Now, the testing of samples for both HIV and syphilis occurs while the client is receiving prevention coun-
HIV counselling and testing

selling. Over 99% of clients now receive their results and post-test counselling in the same day.

Based on AIC's experience, there are few disadvantages to same-day testing. Clients not expecting to get their test results on the same day may experience stress, but most clients come to AIC expecting same-day results. Those who come unprepared to receive test results are encouraged to return another day. Counsellors occasionally experience more stress with same-day testing as there may not be time to consult with colleagues on difficult cases.

Overall, the move to same-day testing has brought advantages. All clients now receive their results and funds for testing are not wasted on clients who do not return. The possibility for engaging in risky sex, while waiting for test results has been eliminated and couples who come in for testing just days before their wedding can have their results immediately.

The effect of VCT on risk reduction

"In countries where HIV prevalence is high and where there are numerous deaths attributed to AIDS, it is common for many to develop feelings of hopelessness and a misperception that behavioural change is futile. In these settings, the power of positive behavioural change messages may be reinforced by effective HIV CT services."

> The Role of HIV Counselling and Testing in the Developing World *AIDS Education and Prevention*, Supplement B, 1997

There are many questions raised about the management, cost, and effectiveness of HIV counselling and testing programmes worldwide. An article written by staff of the US Centers for Disease Control and Prevention and AIC (Campbell et al., 1997) reviewed the broad range of ethical, social policy, technical and economic issues that cause an impact on this HIV prevention service.

Some of the barriers to VCT in the developing world are :

- Widespread fear of taking an HIV test
- Potential for increased violence, loss of security, discrimination and isolation as a result of sharing information about HIV seroposivity
- Scarce economic resources and competing priorities
- Lack of access to drug therapies, and psychosocial and clinical care.

Although these barriers are substantial, AIC experience shows that VCT plays an important role in Uganda's comprehensive HIV prevention strategy,



The effect of VCT on risk reduction

benefitting both HIV-negative and HIV-positive clients.

In 1992-93, AIC conducted an evaluation of its services. As part of this evaluation 2505 clients were followed for six months after receiving test results. Data collected during pre-test counselling sessions and three and six months afterwards showed that:

- (1) Although only 10% of HIV-positive clients reported consistent condom use before receiving test results, by six months after receiving test results condom use went up to 89% with steady, and 100% with non-steady partners. By six months, the percentage of HIV-positive clients reporting sex with nonsteady partners fell from 6% to 0.2%.
- (2) HIV-negative male clients increased their consistent use of condoms with non-steady partners from 34% to 93%, and with steady partners from 16% to 38%.
- (3) HIV-negative female clients increased their consistent use of condoms with non-steady partners from 14% to 94%, and with steady partners from 15% to 34%.
- (4) Six months after learning HIV test results, 69% of clients who had learned that they were HIV-positive were reported to be refraining from any sexual activity, compared to 45% prior to learning test results. In contrast, those who learned they were HIV-negative had increased their rates of being sexually active from 55% to 67%, but only 4% reported having "non-steady" or casual partners.

Complementary integrated services

Family planning

Family planning (FP) services began in 1993 at AIC Headquarters and have been available at all AIC branches since 1995. FP education is offered to everyone who visits for HIV testing. AIC's FP clinics have served 28846 clients and provided modern FP methods to nearly 9000 clients.

Reproductive Health Volunteers provide FP information while clients are in the waiting room. Volunteers are members of the Post Test Club and have undergone two weeks of training in integrated FP/ST/TB and HIV education. Volunteers help identify clients with particular FP needs and refer them to the appropriate nurse or counsellor.

All AIC counsellors have been trained in integrated service delivery. They educate and counsel clients, and distribute pills and condoms when needed. AIC counsellors who are also nurses provide a broader package of integrated services, including examination and provision of a number of other FP methods.



An AIC counsellor in Jinja demonstrates proper condom use.

AIC data indicate that condoms are the most popular FP method, while 28% of FP clients are using "dual methods". Condoms and Depoprovera are the most popular dual method, with condoms being used for HIV/STD prevention.

STD management

All clients who visit AIC for HIV counselling and testing also receive information and counselling on other sexually transmitted diseases and infections. As of 1998 the same sample of blood that is tested for HIV is also tested for syphilis, using the RPR test. In 1997, women clients had much higher rates of HIV infection than men while rates of syphilis among men and women were almost the same.



In 1997 most AIC Kampala clients (77%) tested negative to both HIV and syphilis; 17% were HIV-positive but were negative to syphilis, and only 2% were positive to both tests.



All clients who test positive to syphilis are offered on-site, same-day treatment with penicillin (injection) and are encouraged to bring their partners in for treatment. Unfortunately, only half of syphilis-positive clients accepted this service in 1997. In 1998 more efforts were being made to ensure that all RPR-positive clients receive same-day treatment. Clients are also offered an examination to detect other STDs that are then treated with a syndromic management approach.

In 1997, 30% of Kampala clients served by the STD clinic had syphilis and 53% had other STDs. Numbers served by the STD clinic have increased in 1998 since the introduction of a simple screening device that alerts counsellors when it is necessary to use a more aggressive approach in making a referral to the STD clinic.

Education and referral for TB

Counsellors have offered clients basic information on TB and the risks of co-infection since 1993. HIV-positive clients, especially those with TB symptoms, are encouraged to go for testing and possible treatment to any national TB control programme site.

Between 1993 and 1995, AIC was a major site for recruiting HIV-positive persons into a trial of TB preventive therapy. This was conducted at Mulago Hospital under the auspices of Makerere University and Case Western Reserve University. About 1000 clients participated in the study aimed at preventing HIV-positive clients from developing active TB.

In 1998, AIC developed a proposal to provide on-site TB preventive therapy for HIV-positive clients who are TB infected but do not have active disease. AIC hopes to implement this programme on a pilot basis at the Kampala main branch, using Post Test Club members as volunteers to ensure full compliance with courses of preventive therapy.



PTC members play chess

Post Test Club

The Post Test Club offers ongoing support to all AIC clients regardless of the results of their HIV test. PTC members enjoy each others' friendship and support as well as a variety of servic-

es including: counselling, HIV/AIDS education, medical services including family planning and management of STDs, food distribution and recreation.

The Kampala branch has 2500 PTC members. About 150 members meet every Saturday. The Saturday morning programme is dominated by food distribution for HIV-positive members and their families, sponsored by International Care and Relief. Members also enjoy board games, use the library, seek counselling, collect free condoms, and visit the Medical Booth for basic medical care.

On average 60 PTC members stay for the Saturday afternoon programme lead by the PTC Counsellor-in-Charge. Programmes include guided discussions, films, guest speakers, and drama group presentations. Similar services and programmes exist at AIC sponsored Post Test Clubs in Jinja, Mbarara and Mbale.

About 65% of PTC members are HIV-positive. Studies show that, over time, PTC members adopt and sustain risk reduction strategies appropriate to their HIV status. Their use of condoms is generally high and the PTC has become an important base for community dissemination of HIV prevention information.

My peer group was a bad influence. At age 15, we engaged in smoking, drinking and sex. My parents were worried and convinced me to attend a seminar on AIDS. I wanted to get tested, but was afraid. I went to AIC three times but couldn't find the courage to get beyond the gate. Eventually I got tested and was relieved to find out I was HIVnegative. I was eager to know everything about AIDS and the counsellor helped me feel free to ask all my questions.

I joined the Post Test Club and this changed my life. Here I have found many new friends living healthy lifestyles. Most people think PTC is only for those who are HIV-positive, but PTC gives me support to maintain my HIV-negative status. I am busy with the Drama Group and spend my free time with other members, playing board games and attending educational talks.

I will wait now to have sex until I get married. I am trying to set an example for young people in our community, and my brothers and sisters. We are 15 all together. Our community leader often asks me to tell my story at community meetings. Troubled youth seek my counsel. A lot of students in secondary school engage in high-risk behaviour, like I did. I make a special effort to reach out to these young people.



Reaching out to the community

Many Ugandans admit they are afraid to go for an HIV test. Community outreach through PTC members involved in the Drama Group, Peer Education, the Philly Lutaaya Initiative and condom social marketing has made it possible to educate communities about AIDS, safer sex and the role of AIC's counselling and testing facilities. By giving AIDS a human face, AIC's community mobilization effort helps people make decisions that safeguard their lives and the lives of their loved ones.



Drama Group

All four AIC branches have a Drama Group. The Kampala group has 25 members who meet twice a week to practice song, dance and drama. All groups perform in English and local languages, at primary and secondary schools, churches, as well as gatherings arranged by

"I joined because the group showed a lot of love and made me feel welcome. I train as well as perform. People are eager to know about AIDS. More than 600 students came to our show at Gayaza High School".

> Lestor, Kampala Drama Group

community groups. Members volunteer their time and are reimbursed for travel expenses. In 1997 AIC drama groups participated in more than 70 performances.

Peer Educators

Post Test Club members educate family members and friends about HIV prevention. Some PTC members participate in a 4-day training Reaching out to the community

course to become Peer Educators and condom distributors. Peer Educators submit monthly reports showing numbers of peers talked to, peers' choices of safer sex options, numbers of peers referred for testing, and numbers of condoms distributed. Since 1992, Peer Educators have reached 180000 people and distributed 1 200 000 condoms.



SOMARC Social Marketers

Social Marketing for Change (SOMARC), a USAID-funded programme sponsored by the Futures Group, trains PTC members AIC at branches to market Protector condoms. Social Marketers sell Protector condoms in communities, at market price, and are sometimes consulted for information on proper use. Since the programme began in 1993, PTC SOMARC Social Marketers have distributed more than 180,000 condoms.

Reaching out to the community

Philly Lutaaya Initiative

The Philly Lutaaya Initiative/People with HIV/AIDS Initiative (PLI/PWA) was founded in the memory of Philly Lutaaya, a popular Ugandan singer who "went public" with his HIVpositive status prior to his death in 1988. AIC houses the Kampala, Jinja, and Mbarara branches of PLI/PWA. AIC in Mbale does not have an official PLI/PWA branch, but trains members.

Thirty HIV-positive members of PLI/PWA are currently trained to give testimony at public events. They speak at schools and community gatherings as well as participate in radio, newspaper and television interviews. Members are provided with transportation and a small stipend for each event. Counsellors travel with PLI/PWA members to provide emotional support, particularly in cases where audience members angrily provoke speakers or members giving testimony find themselves breaking down.

As of December 1997, PLI/PWA held 3410 outreach sessions reaching approximately 102300 people in Kampala, Jinja and Mbarara. In addition to outreach sessions, PLI/PWA conducted 23 training workshops for people living with HIV/AIDS intending to go public. A total of 455 PLWH have been trained.

PLI/PWA has produced advocacy materials, including a collection of experiences of PWAs (*Stepping Out in the Open*), a compilation of most frequently asked audience questions, and a newsletter, *Today it is Me, Let It Be Nobody Tomorrow.* PLI has also produced a documentary video.

Reaching out to the community SPOVER



A member of the Philly Lutaaya Initiative tells the story.

"I was pressured by peers to have a boyfriend. He was 12 years older than me. I got pregnant at 15 and was married at 16. Two years later my busband fell sick and died. He didn't show any symptoms which is why I was shocked to find out I was HIVpositive. Our little boy is HIV-positive too.

I tell students that if I had known that someone who looked as healthy as I do could be HIV-positive that I might not be in this position. I tell them how difficult it is for an HIV-positive mother to raise a sickly child. I advise them to get tested before they get pregnant. I also tell fellow PWAs not to infect others. Coming out has made it easier for me to cope. I am not alone anymore."

PLI Member

Staff training

AIC provides training for all its counsellors, supervisors, laboratory technicians, data entrants, peer educators and reproductive health volunteers. It also collaborates with other organizations to train their clinicians in the technical skills required to offer integrated HIV counselling and testing, family planning and STD management.

Counsellor training forms the bulk of AIC's training programme. The curriculum was developed with technical assistance from the US Centers for Disease Control and Prevention to meet the special circumstances of HIV counselling and testing in Uganda. Counsellor training lasts six months, although actual time in formal training sessions is four weeks.

Counsellor training has four phases. The first phase lasts two weeks and covers HIV/AIDS/FP/STD/TB basic facts, as well as communication and counselling skills. This is followed by a four-day practical training, after which the trainee is supervised while at work for





The Luwero Health Centre serves as an indirect site for AIC couselling and testing service.

Staff training LEDGE SPOWER

a period of not less than six months. The last phase of training lasts one week and covers advanced counselling skills.

AIC has a staff development programme that offers support for outside training to certain cadres of employees, with emphasis on areas that improve staff performance.

All AIC Branch Managers and Heads of Department, including the Director, are trained HIV/AIDS counsellors. This has been helpful in planning and supervising VCT services. All staff, irrespective of their job, are given orientation in basic counselling skills to improve their client interaction. AIC refresher courses, such as integrated service delivery and rapid testing counselling protocol, are offered every six months and help counsellors renew their commitment and further VCT skills.

Financial support

IC was established in 1990 with an initial grant of US\$90000 from USAID and considerable technical assistance from USbased experts in VCT. Based on the first year of successful implementation, USAID provided an additional \$4345000 between 1991 and 1995. These funds were channeled through a US private voluntary organization, World Learning, Inc (WLI). During the period of 1991-95, WLI provided technical assistance in financial accountability, project management, grant writing, and personnel management. Beginning in 1991, the US Centers for Disease Control and Prevention (CDC) began providing technical assistance in areas such as monitoring and evaluation, counselling, training, and assessment of rapid test kits. A long-term CDC technical advisor, resident in Uganda, also provided substantial technical assistance.

As a result of AIC's institutional maturity and strength, AIC successfully negotiated a direct grant of \$3565000 from USAID in 1996. This is for the period 1996 to mid-1999. AIC also began receiving



support from the United Kingdom in the amount of UK pound sterling 615 316 (\$820 000) granted to AIC for 1996 to 2000.

Since its inception, AIC has received smaller grants from other organizations and donors, including Uganda's Ministry of Health, InterAid, DED, UNICEF, UNDP, UNFPA, Christian

Financial support EDGE SPOWER

Children's Fund, the governments of Japan and the Netherlands, and UNAIDS.

Costs of providing VCT

With technical assistance from CDC and Emory University, AIC has studied the cost of providing VCT. Between 1994 and 1996, the unit cost per client was about US\$12. Of this amount, \$5.13 was paid to the Nakasero Blood Bank. This amount included not only the costs of test kits but also personnel (both laboratory technicians and phlebotomists), supplies, equipment, technical supervision, and overhead.

Recent analysis showed that the unit cost of providing VCT services at AIC in 1997 was \$13.39, a slight increase over the 1994 figure. Of this unit cost, \$4.59 was the cost of testing, including not only test kits but lab personnel, supplies, equipment, and technical supervision. The cost of counsellor time was \$1.02. Taking into account all costs related to direct services, the variable cost per client was \$5.46 and the fixed costs for the building, administration, supervision, and monitoring was \$7.93. This compares favorably with costs recently reported for VCT Kenya (\$27) and Tanzania (\$29).

The incremental costs of adding family planning services were \$1.17 per client and for adding STD detection and treatment, \$1.76. It should be noted that these incremental costs for family planning and sexually transmitted disease management do not include the costs of drugs or commodities, but are AIC's costs in providing extra personnel and space for these services.

Financial support EDGE SPOWER



A mother visits AIC.

Costs were also calculated for the "indirect sites" such as health centres and hospitals where AIC assists. At these sites, similar categories of costs were analysed for "variable costs per client" and an average amount of \$5.32 was calculated, which includes counsellor time, test kits and technician time, and the cost of the monitoring and supervision provided by AIC. The start-up costs of training personnel for these sites averaged \$5.19 per client served in the first year after training.

History of cost sharing

When AIC opened in 1990, services were free-ofcharge. A cost-sharing experiment began in January 1994 to help sustain a programme that was proving to be expensive, even from the donor's point of view. It was agreed that client fees were also necessary as a way for clients to attach value to the service.

Experimentation with cost sharing began in Kampala with Uganda Shillings 1000 (about US\$ 1) charged per client. Up-country branches charged Uganda Shillings 500 and satellite out-reach stations charged Uganda Shillings 300. Fees have been revised upwards almost annually, following analysis of fees and service utilization. Over 80% of clients are willing and able to pay fees.

AIC routinely has "Free Days" for certain groups such as women, youth or couples. Free Days are widely publicized and the centre in Kampala can expect hundreds of clients to arrive on such a day.

Financial support EDGE SPOWER

Clients who arrive in response to a Free Days advertisement are given coupons and asked to return on a specific day. Experience shows that almost all clients with coupons return for free service. Regular free days include: World AIDS Day, Valentine's Day, International Women's Day and International Youth Day. AIC encourages couples to visit by offering two-for-one days.

AIC has a fee exemption policy for those determined unable to pay. Counsellors forward recommendations for exemption to their supervisor for approval. Only 1% of clients are exempted from paying fees, and under 20% of clients do not pay as a result of free testing days.

During the 1997-98 financial year, AIC collected Uganda Shillings 77 180 000 (about \$70 000) in user-fees. While user-fee revenue represents a modest contribution to overall programme revenues, they are an important psychological contribution. User-fees play several roles: (1) they are a move in the direction of financial sustainability; (2) they are an indicator of value of the service to the client, and (3) they are a way of discouraging inappropriate utilization.

Lessons learned

Eight years of experience at AIC has revealed some important lessons for groups interested in offering HIV counselling and testing services.

- 1. VCT should be part of a comprehensive HIV prevention programme. In settings where there is significant discrimination against persons with HIV infection, or where there are no supportive services, it may not be appropriate to offer VCT.
- 2. Anonymity and protection of confidentiality are critical to ensure public trust in, and demand for, VCT. "Anonymity" is more than just using codes instead of names. Especially when first offering VCT to the public, persons going for testing need to feel that they will not be readily identified or stigmatized for entering the VCT service site.
- 3. Integrated services for family planning, detection of and treatment for other STDs, and education and referral for TB diagnosis and treatment are feasible and well received by VCT clients. An integrated approach benefits clients and public health in general.
- 4. Effective counselling requires a client-centreed approach with good rapport between counsellor and client, based on trust. Counselling should include information sharing, risk reduction planning and demonstration of skills.
- 5. Good counsellors need basic training in one of the helping professions (social work,

Lessons learned = DGE | S POWER

teaching, nursing or medicine) intensive training in HIV/AIDS counselling, specific training in other areas such as couple counselling, sexuality, and bereavement, and periodic refresher courses. HIV/AIDS counselling is stressful and management must anticipate and address the potential for burnout. Managers who are trained as counsellors can better understand and supervise counselling services, and build team spirit.

- 6. Once VCT becomes accepted by the public, an increasing number of clients are likely to request VCT for "social" reasons such as testing before marriage or before a new relationship, and planning for the future, rather than "medical" reasons such as already having symptoms of HIV infection or AIDS. An increasing demand for VCT for social reasons is likely to increase the percentage and number of clients who come as couples rather than as individuals.
- 7. On-going support through a Post Test Club helps HIV-positive members cope with infection and helps both HIV-positive and HIV-negative members adopt and maintain effective prevention behaviour.
- 8. PTC members can contribute to overall HIV prevention through their roles as community educators and condom distributors. Participation of PWAs makes for the most effective communication strategies because community members identify themselves with PWAs. Post Test Club members also help change social norms in support of HIV risk reduction.

Lessons learned EDGE SPOWER

- 9. It is feasible to adopt cost sharing, although it is difficult to introduce fees in a service that is originally free. Fees-for-service may discourage some VCT clients, so it is important to have exemption policies as well as "free days", "two-for-one" days, or other price reductions to encourage clients.
- 10. A computerized Management Information System is critical for routine monitoring and quality control. AIC's system enables management to carefully monitor the numbers of persons served and many characteristics of AIC clients.

References

Campbell CH, Marum E, Alwano-Edyegu MG, Dillon B, Moore M, Gumisiriza E. The Role of HIV Counselling and Testing in the Developing World. *AIDS Education and Prevention*, 1997; **9** (Supplement B)

Downing RG, Otten RA, Marum E, Biryahwaho B, Alwano-Edyegu MG, Sempala SDK, Fridlund C, Dondero TJ, Campbell C, Rayfield MA. Optimizing the Delivery of HIV Counselling and Testing Services: The Uganda Experience Using Rapid HIV Antibody Test Algorithms. *Journal of Acquired Immune Deficiency Syndrome and Human Retrovirology*, 1998; **18**:384-388

Kassler WJ, Alwano-Edyegu MG, Marum E, Biryahwaho B, Kataaha P, Dillon B. Rapid testing with same-day results: a field trial in Uganda. *International Journal of STD and AIDS*, 1998; **9**: 134-138

Ministry of Health, STD/AIDS Control Programme. A report on declining trends in HIV infection rates in sentinel surveillance sites in Uganda. Entebbe, Uganda, October, 1996 Ministry of Health, STD/AIDS Control Programme. *HIV/AIDS surveillance report.* Entebbe, Uganda, March, 1998

UNAIDS. *Report on the Global HIV/AIDS Epidemic.* Geneva, UNAIDS, 1998.

Valdiserri RO. Counselling and Testing: Its Evolving Role in HIV Prevention. *AIDS Education and Prevention*, 1997; **9** (Supplement B).

Appendix A

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The Joint United Nations Programme on HIV/AIDS (UNAIDS) is the leading advocate for global action on HIV/AIDS. It brings together seven UN agencies in a common effort to fight the epidemic: the United Nations Children's Fund (UNICEF), the United Nations Development Programme (UNDP), the United Nations Population Fund (UNFPA), the United Nations International Drug Control Programme (UNDCP), the International Labour Organization (ILO), the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO) and the World Bank.

UNAIDS both mobilizes the responses to the epidemic of its eight cosponsoring organizations and supplements these efforts with special initiatives. Its purpose is to lead and assist an expansion of the international response to HIV on all fronts: medical, public health, social, economic, cultural, political and human rights. UNAIDS works with a broad range of partners – governmental and NGO, business, scientific and lay – to share knowledge, skills and best practice across boundaries.

The effect of the HIV/AIDS epidemic in Uganda has been severe. In the late 1980s, Uganda had the highest rates of HIV infection in the world. Yet, it had few HIV testing services with counselling programmes. As a result, the AIDS Information Centre (AIC) was established to provide anonymous, voluntary and confidential HIV testing and counselling services. It operates under the premise that knowing one's serostatus is an essential step towards controlling HIV infection.

This report documents the history of the AIC, its progress, and the demographic characteristics and HIV rates of its clients. It records AIC's HIV counselling and testing procedures, and its effect on risk reduction. Complementary integrated services, such as family planning, STI management and education and referral for tuberculosis, are also discussed, in addition to AIC's various efforts to reach out to the community through drama groups, peer educators and social marketers.



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